

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



Consultation on the  
Right to Control



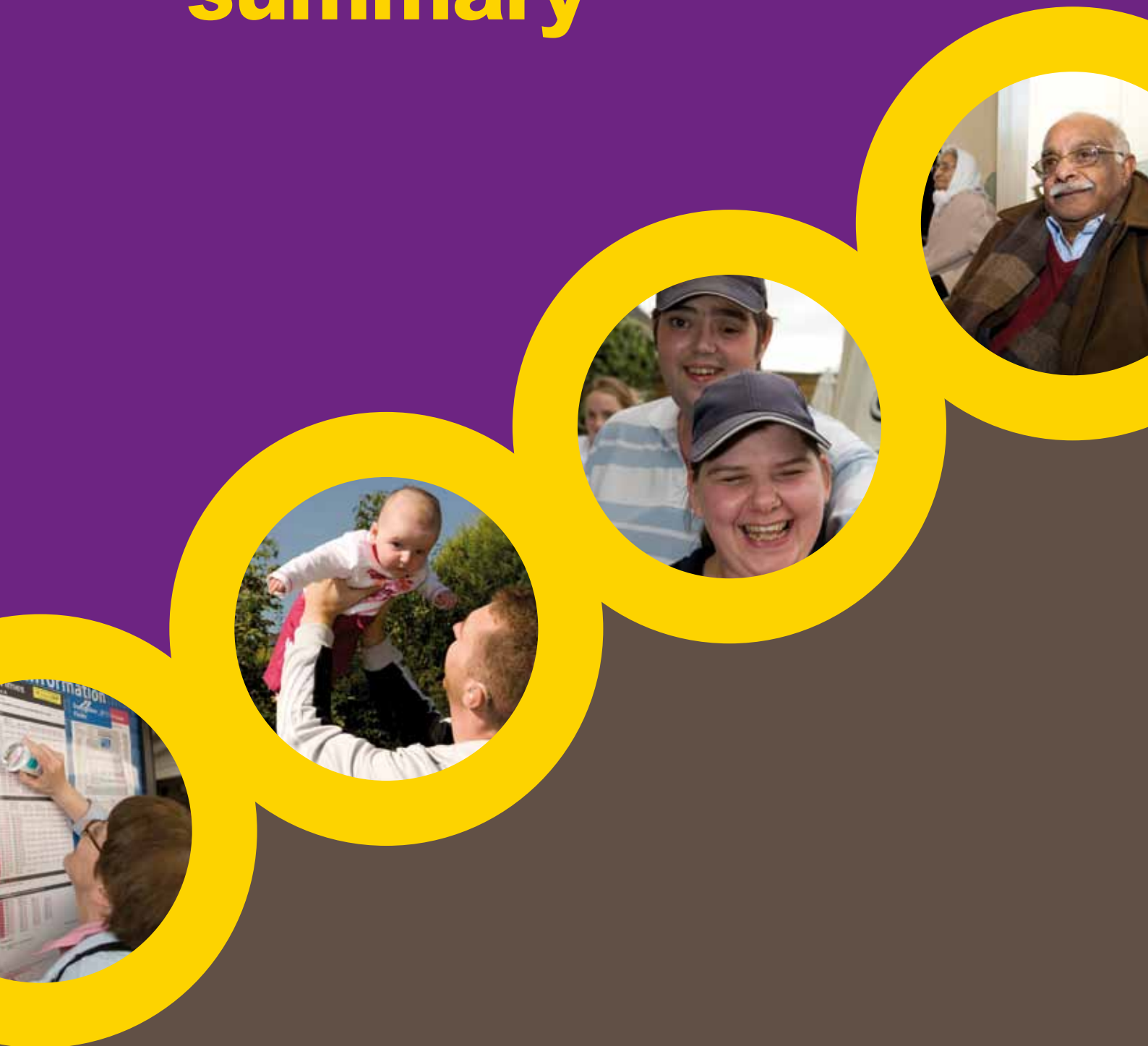
Office for Disability Issues

HM Government



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# Executive summary



# Introduction

Disabled people have told us that many of them do not have the sort of choice and control over their lives that non-disabled people take for granted. This is partly explained by the fact that their support needs are often met in ways which do not put them in charge of deciding how best to meet those needs.

This lack of choice and control is a key barrier to participating and contributing as equal citizens. The Government is committed to delivering policies that enable disabled people to have choice and control over the support needed to go about their daily lives.

We recognise that, in the course of their daily lives, many disabled people access a wide range of state funding and services. These are referred to as funding streams in this document. We are legislating to give disabled adults a right to control a range of the services to which they are entitled.

We are committed to consulting widely on the best way for disabled adults to access and exercise their new right for the services we are testing. We want to hear from as many of those who are interested or involved in receiving, delivering, commissioning and monitoring services to disabled people, as possible.

## What is the Right to Control?

The Right to Control is about disabled people having control over the support they need to live their lives.

The Government wants to shift the balance of power from the State to the individual; assisting disabled people to achieve better outcomes from the support and services they currently receive.

The Welfare Reform Bill, which is currently going through Parliament, will help to bring about this change by enabling disabled adults to access certain support and services as a single individual budget.

We are legislating to give disabled adults the power to take a range of funding streams to which they are entitled. They can choose:

- for a public body to arrange for services or equipment that they need
- to take a direct cash payment and buy services or equipment, or
- a combination of both.

## What are the Right to Control trailblazers?

From 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. These will be called trailblazer sites.

The trailblazer sites will help us decide what works and what does not work. We will evaluate whether our approach has been successful. This will help us decide what the next steps on the Right to Control should be. We only want to extend the right if we know it works for the people and services involved.

In order to make sure that we learn as much as possible from the trailblazer sites, it is important that we involve disabled people, local public bodies, service providers and relevant third sector organisations in the planning and delivery of them.

To do this, we need to design the trailblazer sites in partnership with all interested parties. This consultation is the first step in this process of working together.

The trailblazer sites will help us to find out:

- how we can make the Right to Control easy and safe for disabled people to use
- what the best ways are to deliver the Right to Control
- what the costs are, and whether and how these can be managed
- what the benefits are
- what works best for disabled people from different age and impairment groups.

We will make sure that a wide range of disabled people are involved in the trailblazer sites, including those with learning difficulties or disabilities and people with mental health support needs, to help us make decisions about implementing the Right to Control nationally.

### What are we consulting on?

There are a number of issues that we need your help with. These are:

- **Choosing the funding streams to be included in the trailblazers**

The Right to Control trailblazers will include support and services offered by different public bodies. We want to consult both on how to select these funding streams and which ones should be included.

- **Working together to support disabled people**

We want the Right to Control to be easy to understand and use. We want to consult on what things public bodies would need to do within the trailblazers, so that disabled people experience a seamless and joined-up approach to their support needs.

- **How we can overcome barriers to the Right to Control**

We want to consult on barriers that block successful delivery of the Right to Control and how to overcome them. For example, there may be occasions where the number of disabled people that are happy with the service they currently receive is too few to make that service financially viable. We want to consult on what public bodies and other service providers should do to address barriers of this kind.



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

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- **Support to exercise the Right to Control**

It is essential that all disabled people who are entitled to the Right to Control, including those with limited capacity to make decisions, have choice and control over the support they receive. We want to consult on what information and support disabled people need to be able to exercise their Right to Control.

- **Challenging a Right to Control decision**

We want disabled people to feel confident that, if they are unhappy with a decision about their access to the Right to Control, there are easily accessible ways to challenge the decision. We want to consult on how best to support disabled people who want to challenge a Right to Control decision.

- **Working together to develop the trailblazer sites**

We want disabled people and their organisations to play a full part in the trailblazers. We want to consult on what we need to do to ensure this happens.

- **Implications for service providers and commissioners**

The Right to Control will have implications for how services are delivered to disabled people. We want to consult on what systems need to be in place to ensure disabled people have genuine choices about how to use the resources available to them.



## What will happen next?

The consultation runs until 30 September 2009 – see page 42 for more information on how to get your views to us.

We have developed a toolkit for organisations who want to help disabled people participate in this consultation. The toolkit sets out ways in which organisations can run their own consultations. Please contact us if you would like a copy:

Email: [right.control@dwp.gsi.gov.uk](mailto:right.control@dwp.gsi.gov.uk)

Tel: 020 7449 5093

All the consultation responses will be posted on our website at [www.odi.gov.uk/right-to-control](http://www.odi.gov.uk/right-to-control)

We will also be publishing a formal government response and will use this to help us plan and design the trailblazer sites.



# Background



The Government is committed to delivering policies which promote full and equal citizenship for disabled people<sup>1</sup>. Following the publication of 'Improving the Life Chances of Disabled People' in 2005, the Office for Disability Issues (ODI) was set up to work with government, disabled people and others to deliver the vision that:

**By 2025, disabled people in Britain should have the same opportunities and choices as non-disabled people to improve their quality of life and be respected and included as equal members of society.**

The Right to Control is an important step on the journey towards the realisation of this aim. It is important to us that we encourage as many people as possible to respond to this consultation whether they use, provide, commission or monitor services, or have an interest in the area.

Disabled people have told us that many of them do not have the sort of choice and control over their lives that non-disabled people take for granted. This is partly explained by the fact that their support needs are often met in ways which do not put them in charge of deciding how best to meet those needs.

This lack of choice and control is a key barrier to participating and contributing as equal citizens. The Government is therefore committed to delivering policies which enable disabled people to have choice and control over the support needed to go about their daily lives.

The cross-sector concordat, Putting People First: A shared vision and commitment to the transformation of adult social care<sup>2</sup> established a framework between central government, local government and other partners in December 2007. It means transforming services to improve outcomes for people, and emphasises the need for citizens to shape their own lives, their communities and the services they need.

At its heart is a pledge to ensure that all public bodies work together towards a society that enables individuals to have maximum choice and control over their lives, and values contributions that all citizens can make, whether they need support from others now or in the future. A great deal of work has already been undertaken to implement Putting People First, and the Right to Control recognises this and seeks to build upon it.

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<sup>1</sup> [www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf](http://www.cabinetoffice.gov.uk/media/cabinetoffice/strategy/assets/disability.pdf)

<sup>2</sup> [www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_081118](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118)

As discussed in ‘The case for change – Why England needs a new care and support system’<sup>3</sup>, some of the funding streams mentioned in this consultation are part of the care and support system. Following an extensive public engagement, the forthcoming Care and Support Green Paper will consult on a range of options to reform the existing social care system and other forms of support, to create a new offer for people who need it.

There are also a range of pilots that we will learn from in developing the Right to Control. The Department of Health will shortly begin piloting personal health budgets across a range of conditions and locations and there will be an opportunity to share experiences and practical lessons between this and the Right to Control.

We will be able to learn from the Getting a Life Project pilots, which aim to provide joined-up support for people with learning disabilities and include a focus on employment and education. We will also have the opportunity of linking up with the support broker pilots which will be set up later this year, and which will test out how to enable disabled people to use their social care personal budgets, alongside appropriate disability employment funding<sup>4</sup>.

In addition, the cross-government Independent Living Strategy<sup>5</sup>, published in March 2008, set out the Government’s aim that every locality should have:

**a single community based support system which focuses on all aspects of what people need to maximise their health and wellbeing and to participate in family and community life. The right of the individual disabled person to determine the kinds of services and support that they need will be at the heart of this reformed system.**

These initiatives represent good progress in giving disabled people choice and control in different settings. We recognise, however, that many disabled people access a wide range of state funding and services in the course of their daily lives and, that, we need to do more to enable not only choice and control over such support, but also a more effective alignment or integration of different services.

The White Paper published in December 2008, 'Raising expectations and increasing support: reforming welfare for the future'<sup>6</sup> set out our commitment to a new right for disabled people, giving them greater choice and control over the public money currently spent on their behalf.

We are legislating to give disabled people a Right to Control, giving them the power to take a range of funding streams to which they are entitled as an individual budget, and we will trailblaze this approach in selected English local authority areas. There will be a full evaluation in those public authorities selected, and this will allow us to make decisions on what will happen next. The approach would need to be effective and affordable in order for it to be fully implemented across the country.

**White Paper:** a government document which says what government intends to do.

Although we will only be testing the Right to Control in England, there may be implications for all four countries in the United Kingdom (UK). For example, in the trailblazer areas we are likely to trial the inclusion of some funding streams which are available across the UK.

The devolved administrations in Northern Ireland, Scotland and Wales can tailor their policies to meet the specific needs of their countries. Following a decision on national roll out, and as we develop our proposals for testing the Right to Control, we will work closely with the devolved administrations in Northern Ireland, Scotland and Wales, recognising their particular and varying responsibilities. Each will consider the most appropriate arrangements in those areas for which they have devolved responsibility, to address the issues in ways that meet their own circumstances and needs. There is more information about this in the Important information and next steps section on page 40 in this document.

**Devolved administrations:** the countries of Scotland, Wales and Northern Ireland. These countries have some powers to decide what happens in their countries.

## What is the Right to Control?

The Right to Control is about disabled people having control over the support that they need to go about their daily lives.

The Government wants to shift the balance of power from the State to the individual; assisting disabled people to achieve better outcomes from the support and services they currently receive.

The Welfare Reform Bill, which is currently going through Parliament, will help to bring about this change by enabling disabled adults to access certain support and services as a single individual budget. This approach will be tested in selected areas of England. In doing this we hope to generate innovation and efficiencies in processes and systems that will translate to real differences in disabled people's lives. The first four case studies in Annex B (page 76) attempt to illustrate how this might happen in the future.

**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.

### **Some support available for disabled people includes:**

- support to find and maintain employment
- support to access education and training and to develop skills
- support to live independently, at home
- support with personal care
- adaptations to the home or workplace
- equipment to help at home, in the community or at work.



### What are the Right to Control trailblazers?

From 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. These will be called trailblazer sites. Our aim is to build on the approach in piloting individual budgets used by the Department of Health for adults in receipt of social care, and by the Department for Children, Schools and Families to support disabled children. Once we have reviewed the results from the trailblazers we will have a better understanding of the risks and benefits involved in the wider roll-out of the Right to Control.

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

The trailblazer sites will help us to find out:

- how to make the Right to Control easy and safe for disabled people to use
- what are the best ways to deliver the Right to Control
- what the costs are, and whether and how these can be managed
- what the benefits are
- what works best for disabled people from different impairment and age groups.

The trailblazer sites will help us to decide what works and what does not work. They will help us decide what the next steps on the Right to Control should be.

Disabled people taking part in the Right to Control trailblazers will:

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

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**Eligible:** when someone qualifies to receive a particular service.

**Public Body:** an organisation providing public services, such as a local authority or Jobcentre Plus.

The Right to Control will not change entitlement criteria for funding streams. Rather, it is about a disabled person being able to control the support they receive, and use resources more flexibly, in order to work towards outcomes agreed with the State. If a funding stream already has outcomes set out in legislation these will feature in the individual's agreed outcomes.

Disabled people taking part in the trailblazers may choose:

- for a public body to arrange for services or equipment that they need
- to take a direct cash payment and buy services or equipment and support themselves, or
- a combination of both.

We will make sure that a wide range of disabled people are involved in the trailblazer sites, including those with learning difficulties or disabilities and people with mental health support needs, to help us make decisions about implementing the Right to Control nationally.



### Why do we need to consult?

In order to make sure that we learn as much as possible from the trailblazer sites, it is important that we involve disabled people, local public bodies, service providers and relevant third sector organisations in the planning and delivery of them.

To do this we need to design the trailblazer sites in partnership with all interested parties. This consultation is the first step in this process of working together.



# What are **we** **consulting** on?



In thinking about the questions we wanted to ask we looked at how the Department of Health's Individual Budgets pilots worked.

They ran in 13 local authority areas from 2005 to 2007. Underpinning the pilots were expectations that assessments and budgets could be integrated, but this was found to be very difficult. There were legal barriers and restrictions on how people could spend the money and conflicting rules and systems. The Department of Health looked at the ways these barriers might be removed, and suggested some solutions. We want to learn from this and ensure that the way we set up the trailblazers takes into account this past experience.

There are a number of issues that we need your help with. Brief explanations of each of these issues, together with the questions arising, are set out below. We understand that you may not be able to, or want to, answer all of these questions. Please feel free to pick and choose which questions you answer.

## Considering the funding streams to be included in the trailblazers

The Right to Control trailblazers will include support and services offered by different public bodies. We want to consult both on how to select these funding streams and which ones should be included.

**Funding streams:** the money that a public body spends to deliver a service.

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Some funding streams accessed by disabled people include:	
Access to Work*	For support with getting to work and support in work
The specialist employment programmes (currently WORKSTEP and Work Preparation)*	Support with gaining skills and experience of work
The Independent Living Fund*	For support with living independently, at home
Disabled Facilities Grant	For support with carrying out adaptations to the home
Non-statutory housing related support (Supporting People)	For support with housing related needs
Disabled Students' Allowances	For support with travelling college/university and support in education
Community Care	For support with personal care and social needs

**\* Programmes administered by the Department for Work and Pensions in Great Britain.**

More information on these funding streams can be found in Annex A (page 66).

In terms of community care funding (adult social care), there is already legislation in place which means that the majority of people eligible for social care can have a cash payment to arrange their own support, instead of receiving community care services. In addition, local authorities are working towards the position that by 2011, the majority of those eligible for adult social care (except those who need help in an emergency) will have a personal budget so that they can decide how best to meet their needs.

So, although community care funding is not covered by the Right to Control legislation, these changes in the way community care funding is used are similar to what will happen under the Right to Control. The trailblazers will test the alignment between the two systems to ensure the best fit for people receiving support.

**Personal Budget:** the 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.

As a way of deciding what funding streams should be included under the Right to Control, the White Paper said that a funding stream should only be included if:

- the focus of the funding stream is to enable individuals to overcome barriers associated with illness or impairment
- the funding stream seeks 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
- inclusion of the funding is likely to have a positive impact on the lives of disabled people and will enable a more efficient delivery of services administered by public bodies.

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The White Paper says that funding streams will 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.

### Consultation question 1

What criteria should we use to select funding streams to be included in the trailblazer sites for the Right to Control?

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

We want to ask people's opinions about how funding provided by the Department for Work and Pensions (DWP), particularly Access to Work, the Independent Living Fund and the specialist disability employment programmes could be included in the trailblazers.

In addition to DWP programmes, there are other funding streams, such as Disabled Facilities Grants, and locally-administered funding such as housing-related support which could also be included or aligned within the trailblazers.

#### **Consultation question 2**

Which funding streams do you think could and should be included in the trailblazers?

## **Funding streams used by both disabled and non-disabled people**

An example of a funding stream used by both disabled and non-disabled people is:

Non-statutory housing related support (Supporting People)	This is available to disabled people, homeless people, offenders or ex-offenders, people fleeing domestic violence and vulnerable adults.
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Only disabled people will be able to access the Right to Control. However, funding streams accessed by both disabled and non-disabled people could also be included in the Right to Control trailblazers, if they are intended to support the needs of disabled people and they are not universal services.

At present, other than the above example, we have not identified any funding streams that could be included by the Right to Control trailblazers that are used by both disabled and non-disabled people. However, if we do, we would need to decide which users would be entitled to have the Right to Control in the trailblazers period.

### **Consultation question 3**

Only disabled people will be able to access the Right to Control.

Where a funding stream is used by both disabled and non-disabled people, how should we decide which users would be entitled to exercise the Right to Control?

What funding streams used by disabled and non-disabled people could be included in the Right to Control?



## Working together to support disabled people

We would like the Right to Control to:

- be easy to understand and use
- make it easy for people to manage the money that they are receiving from different funding streams
- encourage partnerships between delivery bodies and service providers to reduce the need for disabled people to give information more than once.

This means that the public bodies responsible for the funding streams will need to work together so that disabled people experience a seamless and joined-up approach to their support needs.

### Consultation question 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?

## **How we can overcome barriers to the Right to Control**

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 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. For example, we know that some disabled people are happy with the services they currently receive and that exercising the Right to Control could make it harder for some disabled people to continue to use those services, as the case study below shows.

### **Case Study 1**

Polly and Graham are two young people who both have a learning disability. They are eligible for support to assist them with getting a job. This is provided by an employment support organisation who is supporting them in work experience placements and with acquiring work-related skills.

Polly is not very happy with the support she is receiving and would like to take the money available to her as a direct payment so that she can choose a different support provider. A lot of other people who use the service would also prefer to do different things.

However, Graham is very happy at his work experience placement and with his particular support worker. If Polly and the others choose not to spend their budget with this provider there is a chance that it might have to close and Graham won't be able to choose to continue with the support he receives.

### Consultation 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?

- Should public bodies and providers continue to buy and run current services for people who want them even if much smaller numbers will use them? For example, this could be more costly and would mean that less money would be available for other people.
- How could service providers work with disabled people to make sure this type of service could still be provided?
- If a service has to close because not enough people wanted to use it, what plans should a public body make to ensure that people do not become socially isolated and still have choice and control?

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There may also be situations where services or equipment cost more when an individual uses their budget to buy them than when a service provider or public body purchases them. The case study below gives an example.

#### **Case Study 2**

Seamus has a visual impairment. He needs special equipment to help him to live his life. He is able to receive this equipment from a local public body. However, Seamus would like to receive a direct payment instead so that he can buy what he needs himself.

The public body buys equipment in large quantities and, therefore, benefits from a significant discount because of this. If the public body were to give Seamus the equivalent cost of the equipment as a direct payment it would be unlikely that Seamus could buy what he needed. However, if the public body gave Seamus the amount of money he would need to buy equipment himself, they would have to spend more and may be able to help fewer people.

### Consultation 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?

- Should they stop an individual from buying equipment himself if it means there is less money for other people?
- Should they allow him to buy equipment himself only if he can show that he needs different equipment from what the public body already offers?
- Is there anything else that an individual or the public body could do? For example:
  - Could the public body agree discounts with providers which cover purchases by local disabled people buying equipment for themselves?
  - Could disabled people with similar needs get together and negotiate a discount with the supplier themselves?

#### **Consultation 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?

The Right to Control will not change who is eligible for any of the funding streams included nor will it change the purpose of any particular funding stream.

However, local authorities taking part in the individual budget pilots led by the Department of Health said that they faced legislative and administrative barriers to, for example, putting together certain services or funding streams.

We would not wish existing legislation, or current rules, to act as a similar barrier to the Right to Control. We therefore want to know whether there is any legislation or any rules about how support is provided that may affect the Right to Control trailblazers and, if so, what steps might need to be taken to overcome these barriers. This could include rules applying to the funding streams you have suggested in your response to question 2.

#### **Case Study 3**

John took part in the Individual Budget pilot and was receiving funding from both the Independent Living Fund (ILF) and the local authority. In developing his support plan, John was encouraged to use the funding available to him in different ways. He was supported to think about what was important to him and explored new possibilities for him achieving his outcomes.

John's support plan set out transparently how he wished to use his individual budget, using both ILF and local authority funds through a direct payment. John had previously had a traditional care package.

His support plan used the same amount of funding from the local authority and the ILF within a few pounds, but with this he wanted to use the combined funding in a less traditional way to purchase gym membership, arrange grocery delivery, garden maintenance, car fuel, mobile phone costs, satellite television and Broadband in order to achieve his goals.

#### **Case Study 3 (continued)**

The local authority agreed to sign up to the support plan in line with the Direct Payments Guidance. Unfortunately, under the terms of the ILF's Trust Deed, payment could not be made for these. Reluctantly, therefore, the ILF could not agree to John's plan and, because the local authority was not contributing towards qualifying care and support, they would have had to reduce the funding they made to John by £150. As a result, John had to choose between:

- the flexibility and greater choice and control of an ILF award which gave less funding
- his traditional care package.

John decided to continue with his traditional support package.

#### **Consultation 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?



### Support to exercise the Right to Control

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 support is available if everyone entitled to a Right to Control is to be able to exercise the right. Such support may take the form of good quality information and advice, or independent advocacy, or support brokerage. We want to test out in the trailblazer sites what level and type of support is likely to be required, and which organisations or individuals are best placed to provide this.

#### Case Study 4

Jasmine is 46 years old and has autism. She has always lived at home with her mother, but three months ago her mother died and now Jasmine lives in a temporary residential placement. Jasmine would like to move back to the area where she has always lived and to get a job, but she does not know what support is available to her or what job she could do. She has never lived independently before or managed money.

Jasmine wants to have choice and control over her life but would need support in order to manage a budget and/or a direct payment.

#### Consultation question 9

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

## Consultation question 9 (continued)

### Support needs

- Who is likely to need this support, and how can they be supported to make the right choice for them?
- What types of support do you think will be needed?
- How do we ensure the inclusion of those disabled people who have, or are seen to have, limited capacity to take decisions?

### Support provision

- What is the best way of providing this support?
- What agencies are best placed to provide that support?

### Cost of support

- Should the costs of supporting people to use their budget be met from within a person's individual budget or be paid for by public bodies centrally from their overall funds available?

### Information, advice and support

- How important is **information** about the **range** of services/equipment and support in ensuring the Right to Control?
- How important is **information** about the **cost** of services/equipment and support in ensuring the Right to Control?
- How important is **advice** and **support** to disabled people in choosing and setting up support?
- What are the best ways to make sure that people know this support is available?

### Consultation 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?

## **Challenging a Right to Control decision**

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

### **Case Study 5**

Ruth is 34 and has a mental health condition. She wants to exercise her Right to Control by spending the funding available to support her in gaining employment, on a course that will teach her meditation and relaxation techniques. Her key worker does not think that this course will meet Ruth's employment needs and does not allow Ruth the right to control the budget available to her.

### **Consultation 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?

## Working together to develop the trailblazer sites

We want to develop the trailblazer sites in partnership with:

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

**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.

**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 local organisations such as Centres for Independent Living.

Disabled people will play a key role in helping us to develop the trailblazer sites in ways which deliver choice and control.

### Consultation question 12

What do we need to do to ensure that disabled people and their organisations play a full part in the trailblazers?

## Implications for service providers and commissioners

The Right to Control will have implications for service providers, third sector organisations and commissioners of services. Some of these are discussed previously – particularly the questions around affordability of the service. However, there are other issues we would like you to consider. For example:

- 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.

### Consultation 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?

### **Consultation 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?

- Who should have the lead responsibility?
- How should reviews of the support plan work?

### **Consultation question 15**

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

### **Consultation 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?

### **Consultation question 17**

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

# Important information and next steps





### **Taking part in the consultation**

This consultation is aimed at anyone who will be affected by the Right to Control. We want to hear from disabled people and their organisations, local public bodies, service providers, including individuals providing support, and relevant third sector organisations.

If you have any requirements that we must meet to enable you to comment, please let us know.

#### **Subject**

We are consulting on how we will test the Right to Control in trailblazer areas. The Executive summary on page 4 sets out the main issues.

#### **Purpose**

We want to make sure that we hear from a wide range of people, particularly disabled people, to help us make decisions about how the Right to Control trailblazer areas will work.

#### **Scope**

This consultation is about testing the Right to Control in England. The Welfare Reform Bill is reserved legislation, but the provisions on the Right to Control provide a framework for Great Britain. Although the trailblazer areas will not cover Scotland, Wales or Northern Ireland, we are working with the devolved administrations to ensure that our experiences in the trailblazer areas will help inform how the Right to Control might operate in the longer term in England and the devolved administrations.

#### **Duration**

The consultation period begins on 11 June 2009 and runs until 30 September 2009.

## Response

Please send your consultation responses to:

Right to Control Consultation Responses  
Office for Disability Issues  
Ground Floor (Room G.40)  
Caxton House  
Tothill Street  
London SW1H 9NA

**Fax:**

020 7449 5087

**Email:**

[right.control@dwp.gsi.gov.uk](mailto:right.control@dwp.gsi.gov.uk)

**Please ensure your response reaches us by  
30 September 2009.**

When responding, please state whether you are doing so as an individual or representing the views of an organisation. If you are responding on behalf of an organisation, please make it clear who the organisation represents and, where applicable, how the views of members were assembled. We will acknowledge your response.

**Queries about the content of this document**

Any queries about the subject matter of this consultation should be made to the Right to Control Team (see contact details above).

# Alternative ways of being involved in the consultation

## Attending a consultation event

To find out about regional events taking place, see our website at [www.odi.gov.uk](http://www.odi.gov.uk) or phone 020 7449 5093.

## Running your own consultation event

We have produced a toolkit for organisations who want to help disabled people become involved in this consultation. The toolkit aims to help organisations run their own Right to Control Consultation events. For a copy:

Email: [right.control@dwp.gsi.gov.uk](mailto:right.control@dwp.gsi.gov.uk)

Tel: 020 7449 5093

We have a small budget from which we are able to pay expenses for your local event. If you are interested in running your own consultation event please contact us as soon as possible, telling us how much you think the cost will be. We will let you know if we can help. We can also send a speaker along if we have sufficient notice.

## Alternative formats

Please contact us if you want to know more and/or need information in an accessible format, such as large print, Braille, audio, BSL or Easy Read – see opposite page for contact details.

The consultation can also be found on our website at [www.odi.gov.uk](http://www.odi.gov.uk)

Please do share this document with, or tell us about, anyone you think will want to be involved in this consultation.

## Freedom of information

The information you send us may be passed to colleagues within the ODI and DWP. It may be published in a summary of responses received, and referred to in the published response to consultation. Please let us know if you do not want your response published or referred to in the summary.

All information contained in your response, including personal information, may be subject to publication or disclosure if requested under the Freedom of Information Act 2000. By providing personal information for the purposes of the public consultation exercise, it is understood that you consent to its disclosure and publication. If this is not the case, you should limit any personal information which is provided, or remove it completely. If you want the information in your response to the consultation to be kept confidential, you should explain why as part of your response, although we cannot guarantee to do this. We cannot guarantee confidentiality of electronic responses even if your IT system claims it automatically.

To find out more about the general principles of Freedom of Information and how it is applied within the DWP, please contact:

Charles Cushing or Carol Smith  
Department for Work and Pensions  
Information Policy Division  
Central Freedom of Information Team  
The Adelphi  
1-11 John Adam Street  
London WC2N 6HT

Email: [charles.cushing@dwp.gsi.gov.uk](mailto:charles.cushing@dwp.gsi.gov.uk)

Email: [carol.smith14@dwp.gsi.gov.uk](mailto:carol.smith14@dwp.gsi.gov.uk)

Please note that Charles and Carol cannot advise on this particular consultation exercise, only on Freedom of Information issues.

More information about the Freedom of Information Act can be found on the Ministry of Justice website:

[www.justice.gov.uk/guidance/guidancefoi.htm](http://www.justice.gov.uk/guidance/guidancefoi.htm)

### Consultation criteria

The consultation is being conducted in line with the Government Code of Practice on Consultation – which can be found at [www.berr.gov.uk/files/file47158.pdf](http://www.berr.gov.uk/files/file47158.pdf) – and its seven consultation criteria, which are as follows:

**When to consult** – formal consultation should take place at a stage when there is scope to influence the outcome.

**Duration of consultation exercises** – consultations should normally last for at least 12 weeks, with consideration given to longer timescales where feasible and sensible.

**Clarity of scope and impact** – consultation documents should be clear about the consultation process, what is being proposed, the scope to influence, and the expected costs and benefits of the proposals.

**Accessibility of consultation exercises** – consultation exercises should be designed to be accessible to, and clearly targeted at, those people the exercise is designed to reach.

**The burden of consultation** – keeping the burden of consultation to a minimum is essential if consultations are to be effective and if consultees' buy-in to the process is to be obtained.

**Responsiveness of consultation exercises** – consultation responses should be analysed carefully and clear feedback should be provided to participants following the consultation.

**Capacity to consult** – officials running consultation exercises should seek guidance in how to run an effective consultation exercise, and share what they have learned from the experience.

#### **Feedback on this consultation**

We value your feedback on how well we consult. If you have any comments on the process of this consultation (as opposed to the issues raised) please contact our Consultation Coordinator:

Roger Pugh  
DWP Consultation Coordinator  
Room 4F, Britannia House  
2 Ferensway  
Hull HU2 8NF

Tel: 01482 609571

Fax: 01482 609658

Email: [roger.pugh@dwp.gsi.gov.uk](mailto:roger.pugh@dwp.gsi.gov.uk)

In particular, please tell us if you feel that the consultation does not satisfy the consultation criteria. Please also make any suggestions as to how the process of consultation could be improved further.

We will publish the responses to this consultation on our website as soon as possible after the end of the consultation period, and depending on the number of responses we receive, we will publish a summary of responses by the end of November.

All the consultation responses will be considered by the Right to Control Advisory Group, Ministers and policy makers across Government as we finalise the design of the trailblazers.

We will then publish a response to the consultation indicating how we have taken the information you have given us into account by the end of the year.



# Your responses

Use these pages to answer the consultation questions. Continue on a separate sheet if necessary. Remember you don't have to answer all of the questions.



Please post to:  
Right to Control  
Consultation Responses  
Office for Disability Issues  
Ground Floor, Room G.40  
Caxton House, Tothill Street  
London, SW1H 9NA



## Consultation question 1

What criteria should we use to select funding streams to be included in the trailblazer sites for the Right to Control?

Feedback:

## Consultation on the Right to Control

Which funding streams do you think could and should be included in the trailblazers?

### Consultation question 3

Only disabled people will be able to access the Right to Control.

Where a funding stream is used by both disabled and non-disabled people, how should we decide which users would be entitled to exercise the Right to Control?

## What funding streams used by disabled and non-disabled people could be included in the Right to Control?

Feedback:

## Consultation on the Right to Control

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?

- Should public bodies and providers continue to buy and run current services for people who want them even if much smaller numbers will use them? For example, this could be more costly and would mean that less money would be available for other people.
- How could service providers work with disabled people to make sure this type of service could still be provided?
- If a service has to close because not enough people wanted to use it, what plans should a public body make to ensure that people do not become socially isolated and still have choice and control?

## Consultation on the Right to Control

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?

- Feedback:

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?

## Consultation on the Right to Control

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?



### Consultation question 9

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

#### Support needs

- Who is likely to need this support, and how can they be supported to make the right choice for them?
- What types of support do you think will be needed?
- How do we ensure the inclusion of those disabled people who have, or are seen to have, limited capacity to take decisions?

#### Support provision

- What is the best way of providing this support?
- What agencies are best placed to provide that support?

#### Cost of support

- Should the costs of supporting people to use their budget be met from within a person's individual budget or be paid for by public bodies centrally from their overall funds available?

#### Information, advice and support

- How important is **information** about **range** of services/equipment and support in ensuring the Right to Control?
- How important is **information** about the **cost** of services/equipment and support in ensuring the Right to Control?
- How important is **advice** and **support** to disabled people in choosing and setting up support?
- What are the best ways to make sure that people know this support is available?

Feedback:

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## Consultation on the Right to Control

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?’



## Consultation on the Right to Control

What do we need to do to ensure that disabled people and their organisations play a full part in the trailblazers?

## Consultation 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?

Feedback:

## Consultation on the Right to Control

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?

- Feedback:

## Consultation question 15

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

Feedback:

## Consultation on the Right to Control

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?



## Consultation question 17

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

Feedback:

Thank you for taking the time to answer the questions.

The information you have provided will be used to decide how we take forward the Right to Control trailblazers.

# Annex A

## Funding streams



A summary of some of the funding streams that could be included in or aligned with the Right to Control trailblazers.

### **Access to Work<sup>7</sup>**

#### **What is it?**

Access to Work can help you if your health or disability affects the way you do your job. It gives you and your employer advice and support with extra costs which may arise because of your needs.

Access to Work might pay towards the equipment you need at work, adapting premises to meet your needs, or a support worker. It can also pay towards the cost of getting to work if you cannot use public transport or supplying a communicator at job interviews.

#### **Who can get it?**

You may be able to get Access to Work if you are:

- in a paid job
- unemployed and about to start a job
- unemployed and about to start a Work Trial
- self-employed

and your disability or health condition stops you from being able to do parts of your job.

Your disability or health condition may not have a big effect on what you do each day, but may have a long-term effect on how well you can do your job.

#### **What form does the support come in?**

The amount of help which you may receive from Access to Work will vary depending on how long you have been employed, what support you need and whether you are self-employed.

The precise level of cost sharing is agreed between your employer and the Access to Work adviser.

After between one and three years, Access to Work will review your circumstances and the support you're receiving.

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<sup>7</sup> Programmes administered by the Department for Work and Pensions in Great Britain.

## **The Independent Living Fund<sup>8</sup>**

### **What is it?**

The Independent Living Fund is designed to help you, if you are severely disabled, to live independently at home rather than in residential care. You can use payments from the fund to employ people to give you personal and domestic care in your home.

### **Who can get it?**

You can apply to the Independent Living Fund if you:

- are over 16 and under 65 when your application is received
- already get social services support to the value of at least £320 a week – this can include direct payments and/or services from your local authority, such as day-centre placement
- receive or are entitled to the care component of the Disability Living Allowance at the highest rate
- live alone or with people who cannot fully meet your care needs
- are at risk of entering residential care, or are currently in residential care and wish to leave and live independently
- are able to live independently for at least the next six months
- are in receipt of Income Support, or the Guarantee Part of State Pension Credit and have less than £23,000 in savings, or meet a similar means test
- satisfy conditions as to residence and presence in the UK.

### **What form does the support come in?**

The amount you receive is based on the cost of the care you need, worked out on an hourly or weekly basis.

The maximum available payment is £475 per week. Your savings, income and certain other benefits and expenses also affect how much you get.

Independent Living Fund payments are made directly into any account of your choice which accepts benefit payments. This might be a bank, building society, Post Office or National Savings account.

## Community Care

### What is it?

Community Care, or adult social care as it is sometimes called, is available for older people, people with learning or physical disabilities or those with a mental health condition to support them to live in the community. It is provided by local authorities. Wherever possible, this help and support is provided in people's own homes. It can also be provided in care homes and other support settings such as hostels.

There is already legislation in place which means that the majority of people eligible for social care can have a cash payment to arrange their own support. So, although community care funding is not included in the Right to Control legislation, these changes in the way community care funding is used are similar to what will happen under the Right to Control.

### Who can get it?

Eligibility for Community Care is determined by the Fair Access to Care Services (FACS) eligibility framework, which is graded into four bands (critical, substantial, moderate and low) which describe the seriousness of the risk to a person's independence or other consequences if needs are not met. Local authorities responsible for delivering Community Care have a duty to support those with critical needs, however most authorities choose to support people with lower levels of need too.

#### **What form does the support come in?**

There are many different types of services that are covered by Community Care. They include:

- home care to help people to live independently at home (for example, washing, dressing and shopping)
- meals services where hot or frozen meals are delivered to your home
- day-centre services if it is difficult to get out, meet others and take part in social activities
- short breaks away from your carer
- short-term services to help recover from things like a fall or an illness (they can be arranged to prevent a hospital admission or to provide support immediately after discharge)
- equipment and adaptations for people with serious and long-term physical disabilities, and people with visual and hearing impairments
- schemes to help disabled people and people with mental health support needs gain skills and learning so they can lead full and active lives at college, in work, at home and in the community, living as independently as possible
- care homes and care homes with nursing.

Local authorities can arrange these services on your behalf, or you can choose to take the money available as a direct payment to arrange support yourself.

Many local authorities are already working to personalise community care to give people greater choice and control over the funding available to them, and Putting People First<sup>9</sup> envisages that all local authorities will offer personal budgets by 2011.

## Disabled Facilities Grant

### What is it?

A Disabled Facilities Grant is a mandatory grant to help towards the cost of adapting your home to enable you to continue to live there. It is administered by local housing authorities, subject to a means test and a maximum limit. A grant is paid following an assessment of your needs, and that the work is reasonable and practical.

### Who can get it?

You can claim if you, or someone living in your property, is disabled and:

- you, or the person on whose behalf you are applying, are either the owner or tenant (including licensees) of the property
- you can certify that you, or the person on whose behalf you are applying, intend to occupy the property as your/their only or main residence throughout the grant period – currently five years
- you qualify for a grant following the test of financial resources.

### What form does the support come in?

A grant can be used for adaptations to give you better freedom of movement into and around your home and/or to provide essential facilities within it.

If you are disabled, acceptable types of work include:

- widening doors and installing ramps
- providing or improving access to rooms and facilities – for example, by installing a stair lift or providing a downstairs bathroom
- adapting heating or lighting controls to make them easier to use
- improving access to and movement around the home to enable you to care for another person who lives in the property, such as a child.

An occupational therapist will look at your circumstances and can recommend the type of adaptation(s) needed.

## **Non-statutory housing related support (Supporting People)**

### **What is it?**

Supporting People is a grant programme that funds housing related support services, which are administered through all 152 top tier authorities in partnership with Housing, Health, Adult Social Care Services and Probation, and is delivered largely by the third sector.

From its very beginning, Supporting People's main aim was to help end social exclusion by preventing crisis and more costly service intervention and enabling vulnerable people to live independently, both in their own home and within their community, through the provision of vital housing-related support services.

There is no statutory duty to provide Supporting People services. Decisions, about which services are provided and how, are made by the local authority based on local needs for housing related support and priorities identified within their five-year Supporting People strategies.

However in 2009, for the first time, Supporting People will be allocated to councils as a non ring-fenced grant. This removal of the ring fence provides councils with the opportunity to come up with new and innovative ways to support vulnerable people in a range of different situations.

### **Who can get it?**

The Supporting People programme helps around a million vulnerable people each year to live independently in their homes or safely within supported accommodation. It helps a wide range of people (approximately 21 different client groups) including:

- a homeless person who needs support
- a young person in need of support
- an older person in need of support
- a person fleeing domestic violence
- a person with mental health support needs
- a person with a learning disability
- an offender or ex-offender
- someone who needs support to live independently.



### **What form does the support come in?**

The types of support it provides include:

- help to develop life skills, such as understanding a tenancy agreement, budgeting or cooking, which enable vulnerable people to have an independent lifestyle
- support in accessing services and benefits, examples of this include, helping an older person to claim benefits or helping an ex-offender to register with a GP or dentist
- support in accessing training and employment, an example here would be helping a young person to find work for the first time
- support through warden and alarm services.

These services provide reassurance and a more cost-effective method of support to vulnerable groups, such as older people, domestic violence survivors and disabled people.

### **Disabled Students' Allowances**

#### **What are they?**

Disabled Students' Allowances are grants to help meet the extra course costs students can face as a direct result of a disability. They are aimed at helping disabled people to study on an equal basis with other students.

#### **Who can get them?**

You can apply if you are doing:

- a full-time course that lasts at least one year (including a distance-learning course)
- a part-time course that lasts at least one year and doesn't take more than twice as long to complete as an equivalent full-time course (including a distance-learning course).

#### **What form does the support come in?**

Disabled Students' Allowances can help pay for:

- specialist equipment you need for studying – for example, computer software
- a non-medical helper, such as a note-taker or reader
- extra travel costs you have to pay because of your disability
- other costs – for example, tapes or Braille paper.

### **Specialist disability employment programmes<sup>10</sup>**

#### **What are they?**

The specialist disability employment programmes are designed to help people whose disability may result in them facing serious and often complex barriers to finding and keeping a paid job and progressing in work. The programmes provide specialist support where mainstream provision may not be appropriate or meet the particular needs of individuals.

#### **Who can get them?**

You may benefit from the specialist disability employment programmes if you have a disability and wish to have a job where you can:

- develop and improve your job skills
- have the opportunity to develop and progress through training and support
- have the right kind of support and encouragement when you need it.

#### **What form does the support come in?**

Currently, support is available from three programmes: WORKSTEP, Work Preparation and the Job Introduction Scheme. These programmes are currently under review.

The WORKSTEP employment programme provides support to disabled people facing complex barriers to getting and keeping a job. It also offers practical assistance to employers.

You may benefit from WORKSTEP if you are disabled and wish to have a job where you can:

- develop and improve your job skills
- have the opportunity to develop and progress through training and support
- have the right kind of support and encouragement when you need it.

WORKSTEP gives you the opportunity to work in a variety of different jobs through a wide range of organisations, from small high street shops to national companies. You get the same wage as non-disabled colleagues doing the same or similar work

Work Preparation is a flexible, individually-tailored programme that can help you prepare for the return to work.

Work Preparation can help you to:

- identify the type of work most suitable for you
- gain work experience in a work environment
- learn new skills or update old ones
- build your confidence.

The programme does not last for a specific length of time. Most people who take part use it for between six and 13 weeks.

Programmes are normally available locally, either at the premises of a programme provider or a local workplace. Sometimes Work Preparation can be held at a residential centre.

The Job Introduction Scheme (JIS) is available through Jobcentre Plus. It can help you if you have an impairment that may affect the kind of work you can do. JIS pays a weekly grant to your employer for the first six weeks of your employment to help towards employment costs. In exceptional circumstances, and after agreement with your Disability Employment Advisor, this may be extended to 13 weeks.

In the future, these programmes will be combined and replaced with an integrated programme of support.

# Annex B

## Case studies



This is the start of a long and complex journey and the aspirations we have for the Right to Control will be fully realised in the longer term. Here, we set out four case studies illustrating how we hope the Right to Control could work in the future for different people, and one example illustrating what should not happen.

The case studies do not go into detail about the information channels and systems involved in enabling the Right to Control, as these are things that we want to test out in the trailblazers. Achieving the kind of seamless support set out in these case studies will not be easy and the trailblazers feedback will help us to understand what changes need to be made if the Right to Control is to work.

### **Anna wants to stay in her own home**

Anna is 80 years old and has lived in the same house for 50 years. She wants to remain living at home. Anna's husband died five years ago and, since then, Anna has lived alone. Anna knows most of her neighbours and plays an active part in the community.

Anna undertakes an assessment from her local authority. This shows that she is not eligible for adult social care, however she is eligible for assistance through the Disabled Facilities Grant for a stair lift and some changes to her kitchen units to make them more accessible to her. Anna is assessed as being eligible for up to £5,000 in total to help pay for this.

Anna has no experience of dealing with tradesmen and is not confident with managing the building work that needs to be done. A local third sector organisation helps Anna and suggests that she uses the money available to pay for help from a home improvement agency, specifically set up to help disabled and older homeowners.

The third sector organisation arranges for someone from the home improvement agency to come and help Anna organise the work that needs to be done. Anna is very happy that she has been able to make the necessary changes to her home which enable her to carry on living there.

#### **Hardeep wants to accept a new job**

Hardeep is 46 and has recently moved to a new city to live in a flat with his brother. He is deaf and communicates mainly using British Sign Language (BSL), although he can also lip-read. Hardeep has been offered a new job as an accountant for a large pharmaceutical company, which he would like to accept.

Hardeep contacts an employment adviser at his nearest Jobcentre Plus to find out what support is available for him in his new job. He answers some questions about what support he needs in order to do the job and the advisor is able to tell him how much money is available to support him – £600 a week. Hardeep must use his budget to meet the following outcomes:

- I am able to do my job.
- I am able to work towards achieving my career goals.
- I am able to develop effective working relationships with my clients and colleagues during office hours.

Hardeep's main barrier to achieving these goals is that he is unable to communicate effectively with those who do not understand BSL. Hardeep decides to use the money available to pay for someone to interpret spoken language into BSL and vice versa. He would like to employ his brother, Sadiq, to do this.

Hardeep creates a support plan setting out how many hours of support he will require and how much he intends to pay Sadiq to act as interpreter. The plan is signed-off and Hardeep receives a direct payment into his bank account to enable him to pay his brother. Receiving the money as a direct payment means that Hardeep does not have to find the money himself to pay a translator, and then reclaim the money from the public body.

Hardeep spends some of his budget on setting up a third party arrangement with a user-led organisation who are able to employ Sadiq on his behalf and sort out all the relevant paperwork (PAYE, insurance, contract, etc). Because Hardeep receives a direct payment, he is able to control how many hours Sadiq works each day, depending on what tasks he has to do. Some days Hardeep does not require Sadiq's assistance at all as he is working from home, whereas on other days he needs Sadiq to attend meetings with him all day. Hardeep likes being able to have choice and control over the support he gets to enable him to do his job.

### **Kerry wants to learn new things**

Kerry is 19 and lives at home with her parents and younger sisters in a small rural village. She enjoys mending cars and watching motor racing. Kerry has a learning disability that means she has difficulty in communicating with others and in understanding what is being asked of her. Kerry also has Crohn's disease; her health fluctuates considerably and she often needs to stay in hospital. Kerry gets very frustrated when she has to stay in hospital and is often anxious when she becomes unwell which makes her condition worse.

Kerry undertakes an assessment, with the help of an independent advocate, which shows that she is entitled to up to £450 a week to meet her eligible needs. This money is made up of funding from a range of sources, including social care and employment. Kerry must use the money to meet a range of identified goals. These are:

- I can spend time with my friends and family and make new friends.
- I am able to learn new things or get a job.
- I am able to take part in activities in my local area.

Kerry has been receiving support from her council, in the form of services, since she was a child. Now that she is older, Kerry and her parents decide that she is ready and able to have more choice and control over her life.

Currently, Kerry is dependent on her parents for any social activities she takes part in. Kerry decides that she would like to pay for her sisters to take her dancing and to the cinema. This way Kerry can meet new people and develop relationships with people her own age.

At the moment Kerry lacks the skills or the support to be able to undertake paid employment and is only able to take part in activities that her parents are able to attend with her. Kerry and her family decide to employ a personal assistant (PA) to assist her in college four days a week, where she wants to study for a BTEC in vehicle mechanics, and one day a week when she wants to volunteer to help out at her nearest go-kart track.



Kerry wants to be able to take more responsibility for managing her Crohn's disease. Currently Kerry's mum makes sure that she only eats what she is allowed. Kerry decides that what she really needs is some help with managing her health condition. She plans to use the funding available to her to pay to attend a Condition Management Course and to have all the course materials translated into an Easy Read version.

Kerry's support plan is shared with all the funding agencies for them to agree. Once this has been signed-off, Kerry and her family receive a direct payment to enable them to purchase what Kerry needs and to employ someone as Kerry's PA.

#### **Jerome wants to manage his condition**

Jerome is 23 and lives in a flat by himself which he rents from the local housing association. He has a long history of mental health issues, starting when he was very young. Jerome has a two-year-old son called Matty, who he currently sees infrequently. Jerome wants to become a self-employed joiner and to start seeing Matty more regularly.

Jerome attends a mental health day-centre. The centre staff have been trained to support people with mental health issues to exercise their Right to Control. Jerome's key worker explains to him the principles of Right to Control. They hold a series of meetings with Jerome to help him identify his needs. The key worker discusses how Jerome might realise some of these goals and explains about anger management courses.

Jerome undertakes an assessment which shows that he is entitled to up to £200 a week to meet his eligible needs. This money is made up of funding from a range of sources, including social care and employment. Jerome must use the money to meet a range of identified outcomes. These are:

- I am able to see my friends and family and maintain the relationships that are important to me.
- I am able to learn new things and gain employment.
- I am able to manage my mental health condition.



Jerome creates a support plan that considers what the barriers are to achieving these goals and sets out how he intends to use the money to overcome these.

So that Jerome can manage relationships at work, and also so that Matty's mother will agree to let Jerome see Matty, Jerome decides to use some of his budget to pay for an anger management course. Jerome also chooses to use some of the money to pay for activities that he and Matty can do together, such as going swimming or visiting the zoo, and his bus fare to and from where Matty lives.

To enable him to learn new things and to set up his own business, Jerome proposes to spend some of the available funding on tools to make it possible for him to work as a joiner. To help him manage his condition, Jerome plans to pay for music therapy sessions. He also plans to spend some of the money for a gym membership as he finds that exercise helps him to manage his depression.

All of the agencies that are providing funding for Jerome are shown a copy of Jerome's support plan and agree to the actions and activities Jerome proposes.

Jerome chooses to receive a direct payment to pay for his bus fare, his trips out with Matty and his tools, but he wants the other things in his support plan to be organised for him. Jerome knows he will find managing these changes very difficult so opts for on-going support from his key worker and the mental health day-centre, who agree to help Jerome with managing his budget and keeping records.

#### **Marius wants a joined-up system: how we don't want the Right to Control to work**

Marius is a 37-year-old wheelchair user who requires help with some physical activities. He employs a live-in PA and lives in an adapted bungalow. He receives adult social care funding and Independent Living Fund (ILF) payments and hopes to return to work which would make him eligible for Access to Work (AtW).

In order to access these funding streams he needs an annual review of his AtW and adult social care funding, and a biannual review of his ILF. This is further complicated by adult social care being paid monthly in advance, ILF being paid four weeks in arrears and AtW being paid monthly in arrears.

The three funding streams also require different financial monitoring. Adult social care requires monthly bank statements, ILF requires biannual accounts and ATW weekly timesheets. Also, ILF will only allow both adult social care and ILF to be spent on formal paid support, for example through an agency or by employing personal assistants, so Marius needs help to ensure these rules are kept.

Marius decides to use a payroll service to help him administer some of this, but ILF are not able to pay the payroll service directly, so Marius has to set up a standing order to pay the ILF to them. He asks a local advocacy service to help him with the complex record keeping required, both as an employer and to ensure he keeps to the complex individual funding stream rules.

Within the trailblazers we would try to overcome this by encouraging practices such as:

- Information being shared between public bodies to avoid the need for Marius to repeat himself.
- A joint review based on family group conferencing to ensure the funding levels are correct to meet the outcomes identified in the support plan.
- Funding streams paying money to one public body who passes the money on to Marius. This way he would only receive one payment from one organisation with one set of rules.



# Glossary



### **Aligned**

The joining up of funding available from, for example community care, with the funding available under the Right to Control.

### **Case study**

An analysis of a group or person that provides generalisations about a larger group or society.

### **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.

### **Devolved administrations**

The countries of Scotland, Wales and Northern Ireland. These countries have some powers to decide what happens in their countries.

### **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.

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#### **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.

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#### **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 the Shaw Trust, and local organisations such as Centres for Independent Living.

#### **Toolkit**

Information offering help and advice about a particular subject. In our case the Right to Control.

#### **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, BSL and Easy Read. If you would like a copy in any of these formats, please contact the Office for Disability Issues.

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We welcome feedback on this report.

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