

# Fulfilling Potential Next Steps

**Working together to enable disabled people to fulfil their potential  
and have opportunities to play a full role in society**



**This document refers to a wide variety of policies, some applicable across the whole of the UK and many to England only. The devolved administrations have their own policies with regard to devolved matters.**

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## Foreword by the Minister for Disabled People



‘Fulfilling Potential’, published in December last year, is about making the United Nations Convention on the Rights of Disabled People a living reality for disabled people in Britain. A huge thank you to the thousands of people who took part in our discussion exercise. Your involvement has been invaluable.

What was clear from these discussions is that disabled people want to live independent lives, to play a full part in society and to be able to reach their full potential like anyone else. However, society continues to put barriers in the way of disabled people. This not only limits disabled people’s choices and opportunities, it restricts the growth of our society and economy.

I am looking forward to working in partnership with disabled people and their organisations to address these challenges.

As a society, we also need a better understanding of the nature of disability in the UK today. The majority of disabled people acquire their impairments in later life – only 3 per cent of disabled people are born with their disability – meaning most of us will experience disability at some point in our lives, personally or in a caring role.

It is important that we tackle the prejudices that continue to exist and increase society’s understanding and knowledge of disability and disabled people. We need to increase disabled people’s choice and control, and increase the voice and capability of our communities, to build new partnerships that will deliver lasting change.

Much work is already progressing, as outlined in our companion document ‘Fulfilling Potential – The Discussions So Far’. The Paralympic Games have shone a light on disabled people and we are securing a strong and lasting legacy from the Games. In addition, major reforms of health and social care

services are under way, and welfare reform is critically important – to support disabled people’s rights to work and independent living, to better reflect their desire not to be labelled by a condition, and to be judged on what they can do, not what they can’t.

We are still battling with issues as fundamental as disability hate crime, and disabled people have expressed their concerns for the future, in the current economic climate and at a time of great change and reform. We need to acknowledge this as we modernise our welfare system and public services. The simple truth is that systems designed decades ago often do not fit with the approach to disability we have today.

This document outlines that new approach – one of partnership and support. It sets out the vision and principles for further reform to achieve our aims of equality and independence and increasing society’s knowledge and understanding of disability. It starts the next phase of work to find fresh, practical ideas, drawing on the three themes of ‘Fulfilling Potential’ – realising aspirations, individual control and changing attitudes and behaviours of all of us.

So this document announces the setting up of a new disability action alliance. Disabled people will be at the heart of the alliance, leading the way, to ensure the policies and actions taken forward really will make a difference to the daily lives of disabled people and increase understanding in all of us. Partners from across the private, public, voluntary and community sectors will join us.

This marks a clear commitment from this Government to collaboration and partnership, and will mark a significant step forward in our aim to change the relationship between the state and the individual and between individuals within our communities.

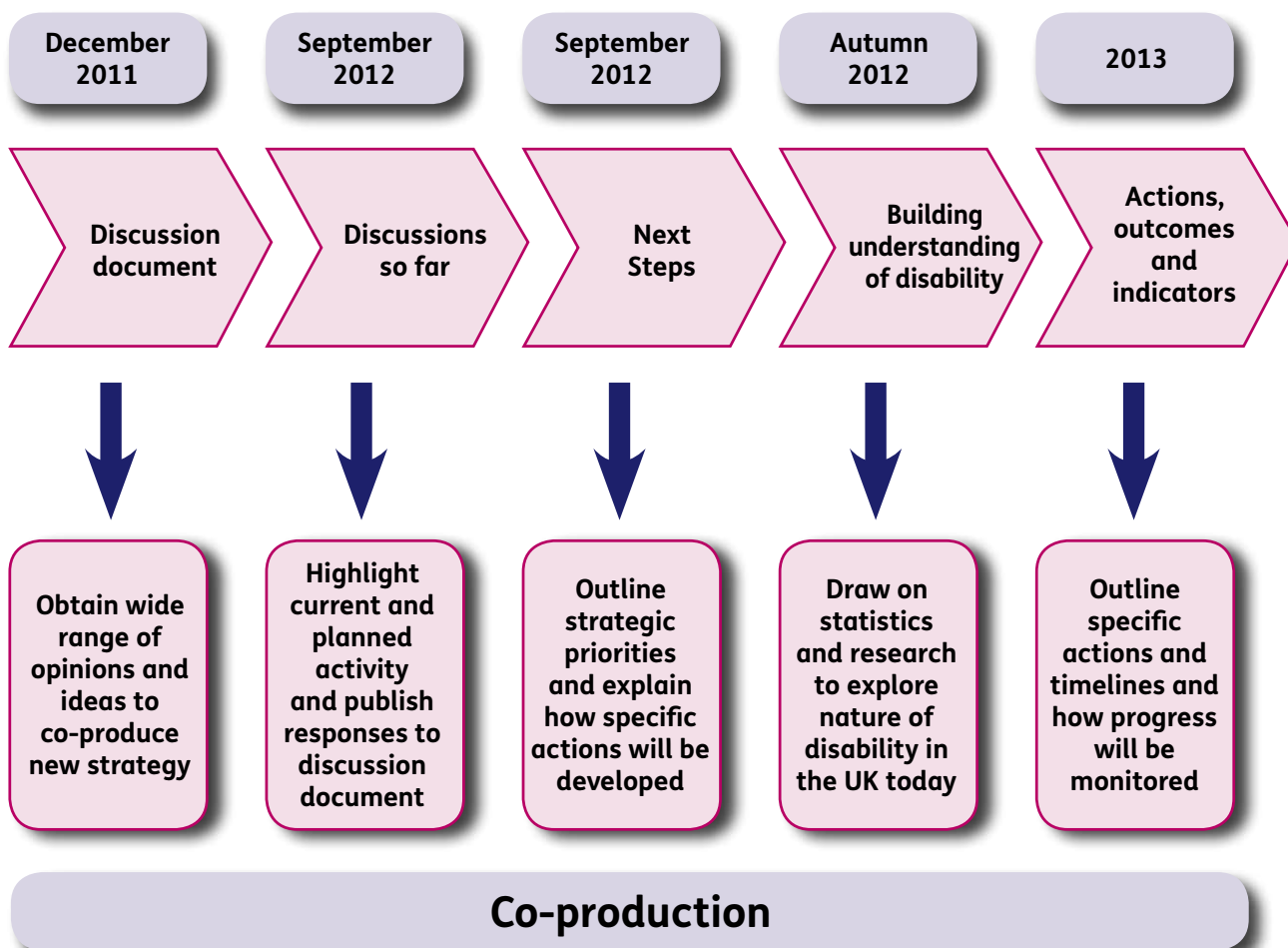


**Esther McVey MP**

Minister for Disabled People

## Fulfilling Potential Timeline

Fulfilling Potential is an ongoing activity involving Government, disabled people and their organisations and other organisations from the public, private and third sectors. It aims to find new ways to support disabled people to realise their aspirations.



## Support for the new approach

“ The United Nations Convention on the Rights of Persons with Disabilities is a major step forward in ensuring disabled people are full members of society. We are very grateful to the UK for their support in developing and implementing the Convention and for their commitment to its principles in their strategic approach. ”

**Professor Ron McCallum, Chair, United Nations Committee on the Rights of Persons with Disabilities**

“ The London 2012 Paralympic Games provide a real platform for more inclusive societies throughout the world. We welcome the UK’s commitment to the Games and to ensuring there is a strong legacy. This can include real progress in creating positive attitudes towards people with an impairment focussing on their skills and personalities. ”

**Sir Philip Craven, President, International Paralympic Committee**

“ At Disability Rights UK we are clear about what we want to achieve – independent living and disability rights in practice. We will put disabled people’s voices and experiences at the heart of the new disability action alliance. Government must work in partnership with disabled people and our organisations and we look forward to working in the alliance to achieve better outcomes for people and real improvements in services. ”

**Liz Sayce, Chief Executive, Disability Rights UK**

“ Sainsbury’s are proud to have supported the 2012 Paralympic Games and we want to help ensure that there is a strong and lasting legacy for disabled people in the UK. The new disability action alliance is a promising initiative which could make an important contribution. We are keen to explore how we might help.

”

**Justin King, Chief Executive, Sainsbury’s Supermarkets Ltd**

“ In December last year ecdp welcomed the publication of Fulfilling Potential. We strongly encouraged disabled people’s user-led organisations (DPULOs) to gather ideas and evidence from their members so that they could contribute to the discussion and shape the future of policy that affects disabled people’s lives.

We are pleased to see such a good showing of DPULOs and the lived experiences of disabled people in this document. The result is a clearer direction for the Government’s approach to ensuring that disabled people will have the equality of opportunity they need to achieve their aspirations. We look forward to seeing how this approach is made real in the future and to being closely involved in the process.

”

**Mike Adams, Chief Executive Officer, ecdp**



“ I am quite excited about the disability strategy as a whole and from what I have seen so far, the discussions that have taken place with disabled people and their organisations, have been positive. But it is true that the voices of Black and Minority Ethnic disabled people are not heard enough and their views are not represented enough. That is why I’m pleased to represent their views in the partnership going forward. ”

**Julie J Charles, Chief Executive Director, Equalities National Council**

“ We must do all we can to create more inclusive communities in which disabled people are truly able to play their part and lead satisfying lives. UKDPC aim to help bring this about. The UN Convention on the Rights of Disabled People gives us a real opportunity, which we must build on. We need to make sure that these rights are a reality for the 11 million disabled people in the UK today. ”

**Jaspal Dhani, Chief Executive Officer, United Kingdom Disabled People’s Council (UKDPC)**

“ The ambition to build inclusive communities is an important national initiative that will greatly improve the lives of disabled people, as well as older people with the inherent frailties of ageing. To achieve this ambition will require a range of organisations with different perspectives all pulling together in one direction. We study and practice inclusive design, and understand how communities and neighbourhoods can be made more accessible and inclusive by design. We are keen to be part of this initiative. ”

**Professor Jeremy Myerson, Director, Helen Hamlyn Centre for Design, Royal College of Arts**

“ Sport England is committed to increasing the sporting opportunities for and participation by disabled people and is working with disabled people’s user-led organisations (DPULOs), as part of DWP’s DPULO programme, to achieve this. We want to build on the inspiration of the London 2012 Paralympic Games and encourage wider inclusion in community life. ”

Jennie Price, Chief Executive Officer, Sport England

“ The LGA is keen to support the development of communities which are inclusive of disabled people around the country. We would be pleased to contribute to the new cross-sector alliance to help bring this about. ”

Councillor David Rogers, Chair, Community Wellbeing Board, Local Government Association (LGA)

“ We welcome the idea of a new disability action alliance and we are delighted to support the Radiate network of disabled people in senior jobs. We believe that their successes and advice could play a key role in the new alliance. ”

Tim Taylor, Manager, Diversity & Inclusion, Lloyds Banking Group

“ The Association of Chief Police Officers is committed to reducing the crime that is suffered by disabled people, particularly where it relates to disability hate crime or other targeted abuse. We are also very aware that disabled people have been less likely to be satisfied with the service they receive and we are determined to work with partners to ensure that disabled people have confidence that they will receive a quality service, should they become a victim of crime.

We will only achieve our aims if we work in partnership with government, statutory agencies, civil society groups and, most importantly disabled people themselves. We would be keen to take all opportunities to work together to ensure the safety and security of disabled people.

**Simon Cole, Chief Constable of Leicestershire Police and Disability Policy Lead for the Association of Chief Police Officers**

“ I would be delighted and pleased to be a part of the disability action alliance. The aim of cross sector work is something I totally believe in, as strength by a common approach to a wide range of issues, with a variety of people with key interests and expert knowledge, is better than specific outcome small group work, which to me, is always too much of a silo approach.

**Stephen Brookes MBE, Coordinator, Disability Hate Crime Network**

“ ADASS supports approaches which help disabled people participate fully in community life, and the development of early interventions and greater choice and control to help bring this about. Effective partnership working is crucial to success, so we would be very happy to contribute to the work of the new disability action alliance. ”

**Sarah Pickup, President, Association of Directors of Adult Social Services (ADASS)**

“ I welcome the opportunity of working with Disability Rights UK and the alliance to learn more about disabled people’s voluntary organisations and ideas on enabling smaller organisations, particularly user-led organisations, to bid for contracts. In my previous role I was Chief Executive Officer at 3SC and am interested in the opportunity for collaborative models. ”

**Michael O’Toole, Crown Representative for Voluntary, Community and Social Enterprise**

# Disability today

# 1

## The way we view disability needs to change

- 1.1 Every society needs **a way of thinking about disability** and to use that thinking to help make laws and policies which will enable its disabled citizens to flourish. Yet the very notion of disability is problematic because it affects so many of us in a very wide variety of ways.
- 1.2 There are now more than one billion disabled people in the world<sup>1</sup>. According to the World Health Organisation the **prevalence of disability** will rise due to ageing populations and the global increase in chronic health conditions such as diabetes, cancer and mental health conditions.

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1 World Health Organisation, June 2011, World Report on Disability.

- 1.3 In the UK there are now **over 11 million people**<sup>2</sup> who at any one time come within the Equality Act 2010 (the Equality Act) definition of disability<sup>3</sup> – more than one in six of the population. This is not a static group: of those disabled people who report an impairment in one year, around a third no longer report having an impairment a year later<sup>4</sup>.
- 1.4 Impairments come in a wide variety of forms and degrees of severity, and can occur at different stages of life. Only around 3 per cent of disabled people have had their impairment since birth<sup>5</sup>. It is likely that a majority of us will become disabled as we live longer lives and our bodies and minds age. More than half of all those over 70 are disabled (54 per cent)<sup>6</sup> and most of us will live beyond that age<sup>7</sup>. We are increasingly likely to live to advanced ages when we may well experience multiple impairments and disability<sup>8</sup>.
- 1.5 So it **makes little sense to think of disability in ‘us and them’ terms** or to distinguish between disabled people and non-disabled people as though these are two unchanging groups. With rapid improvements in life expectancy, and the growth in numbers of people with multiple long-term health conditions, we will increasingly need to think of being

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2 Department for Work and Pensions, June 2012, Family Resources Survey.

3 UK Government, April 2010, Equality Act 2010. In the Equality Act, a person has a disability if: they have a physical or mental impairment and the impairment has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities. For the purposes of the Act, these words have the following meanings: substantial means more than minor or trivial; long-term means that the effect of the impairment has lasted or is likely to last for at least twelve months (there are special rules covering recurring or fluctuating conditions); normal day-to-day activities include everyday things like eating, washing, walking and going shopping.

4 Office for Disability Issues, April 2012, Life Opportunities Survey Wave Two interim report 2010/11.

5 Office for Disability Issues, June 2008, Experiences and Expectations of Disabled People.

6 Department for Work and Pensions, June 2012, Family Resources Survey.

7 David A Leon, March 2011, Trends in European life expectancy: a salutary view. Average life expectancy is currently 78 for men and 82 for women, and growing.

8 According to Department of Health estimates, the number of people with three or more health conditions is currently estimated to be 2.4 million and forecast to rise to 3.2 million by 2018.

non-disabled as a temporary condition and expect other periods when we may need appropriate support and/or care. There is clearly no ‘one size fits all’ approach. We need a modern strategy that recognises not only the diversity within the population but also the diversity of disabled people’s aspirations.

- 1.6 For much of recent history a medical model of disability combined with a spirit of benevolence was the dominant intellectual model. But this combination has often led to a focus solely on impairment, and been over deterministic, too prone to think in terms of blame, cure and rehabilitation and to treat disabled people as objects of pity and charity rather than as citizens with an equal right to a full life.
- 1.7 The **United Nations Convention on the Rights of Disabled People** (the UN Convention)<sup>9</sup> – which the UK ratified in 2009 – represented years of work by disabled people and their organisations. It also represented a **fundamental shift in thinking** to recognise that disabled people have the same rights as anyone else, and should be able to claim those rights, making decisions about their own lives and playing full and active roles as members of society.
- 1.8 The **social model of disability**, which is at the heart of the UN Convention, now commands much (but not full) support amongst disability professionals and campaigners. It offers insights into the importance of attitudes, social support, and accessible information and environments in influencing the quality of life of disabled people. There is also much discussion about rights or capabilities based approaches drawing on the work of prominent thinkers like Amartya Sen and Martha Nussbaum<sup>10</sup>. These emphasise the importance of expanding freedoms and opportunities, and have, for example, influenced the recent work of the United Nations and the World Health Organisation on disability.

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9 United Nations, December 2006, United Nations Convention on the Rights of Persons with Disabilities.

10 Martha C. Nussbaum, January 2006, *Frontiers of Justice: Disability, Nationality, Species Membership*.

- 1.9 The Government’s position is clear: the social model has real value – for policy makers and service providers – as a way of thinking about how physical, social and environmental barriers can be removed so that disabled people can realise their aspirations and fulfil their potential. This is especially true when combined with the rights and capabilities approaches embedded in the UN Convention. Impairment is nonetheless an integral part of disability. The interaction between impairment and social factors is recognised in the UN Convention and the Equality Act, and we agree that it needs to be understood and acted upon.
- 1.10 We fully subscribe to the concept of **independent living** as defined by disabled people<sup>11</sup>. The Joint Committee on Human Rights has commended the fact that, “The UK has an established position as a world-leader on disability rights and in relation to independent living in particular”<sup>12</sup>. We need to build on this and strengthen our reputation.
- 1.11 It is that position, and the strong legislative and policy framework that exists to deliver disability equality, which enabled the UK to support the development of the UN Convention and to be one of the first signatories. The UK approach to disability equality is aligned with the UN Convention, focusing on **inclusion and mainstreaming**, with additional support provided where needed, and on the **involvement of disabled people in making decisions** that will affect their lives.
- 1.12 The Government’s approach to developing our new strategy is fundamentally based on the expectations of the UN Convention, recognising what has been achieved and focusing on priority areas that we have identified in discussion with disabled people. This involvement of disabled people in decisions about policies and programmes that will affect how they live their lives is itself a key principle underpinning the UN Convention.

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11 Disability Rights Commission, August 2002, Policy Statement on Social Care and Independent Living.

12 House of Lords and House of Commons Joint Committee on Human Rights, February 2012, Implementation of the Right of Disabled People to Independent Living.



## We must find new ways to include disabled people

“ Being different is a bonus to society. ”  
**Ambitious about Autism**

“ I was on a tube train at rush hour and other passengers were complaining about a wheelchair user taking up too much valuable commuter space. There was an assumption – wrongly – that the wheelchair user wasn’t employed. But they needed to get to work on time as much as anyone else. ”  
**Individual at Stakeholder meeting**

- 1.13 Disabled people are **integral to the success of our economy and society** – in terms of work, volunteering, caring and as active members of communities and families. We also know that there is still much untapped potential. For example, 35 per cent of disabled people not working want to do so.<sup>13</sup>
- 1.14 The Government’s Plan for Growth<sup>14</sup> outlines the need for the UK to become more competitive in global markets, to develop more innovative products and services, and to have a more balanced economy – so that we can afford the public services we all want, create new jobs, make education more effective, and Government spending more productive. If our country is to succeed on its path to sustainable, long-term economic growth, with new jobs and rising prosperity, we need to **harness the strengths of everyone** across all areas of society – and we need to ensure that the rewards are shared across all parts of the UK.

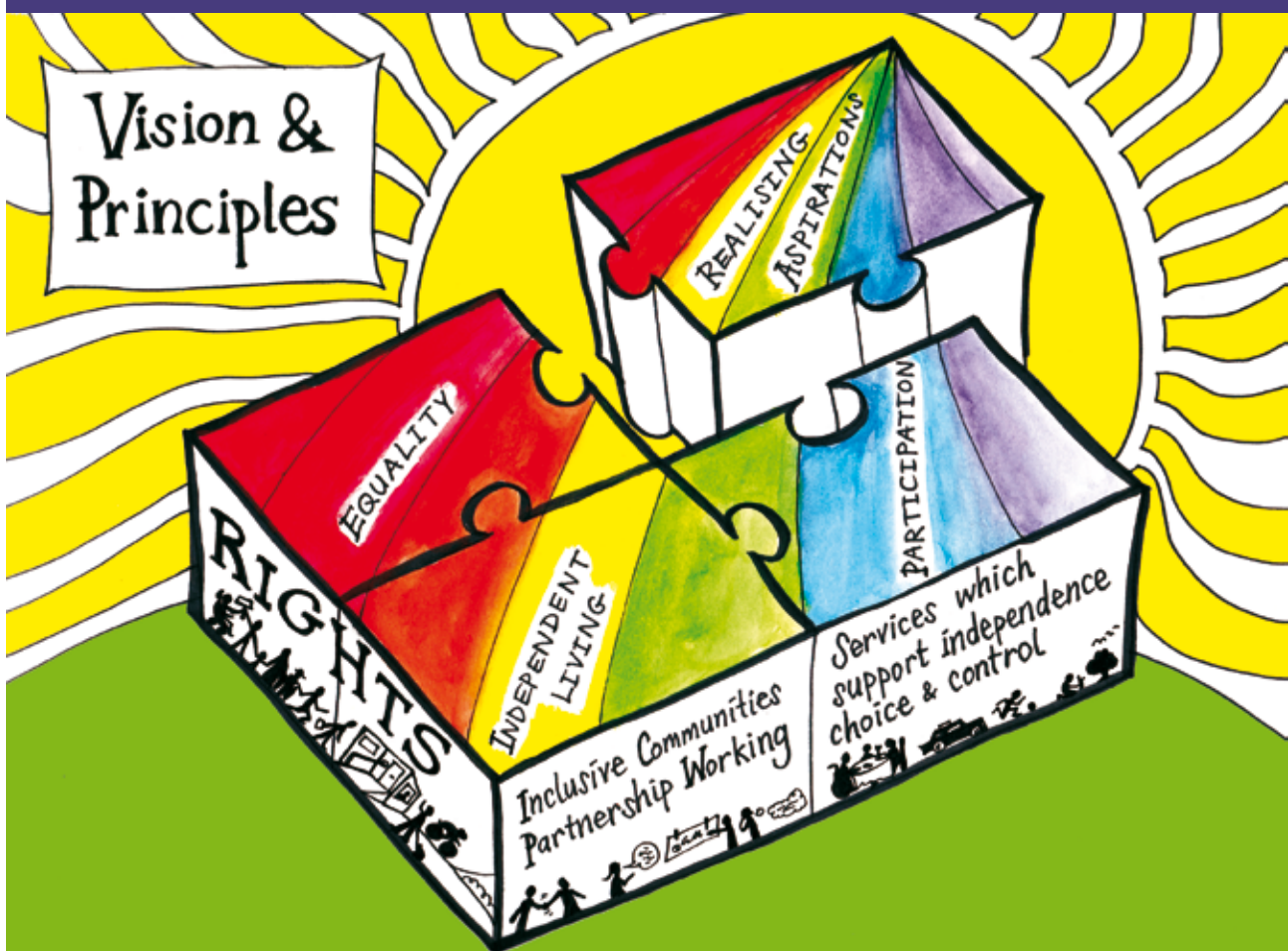
<sup>13</sup> Office for Disability Issues Indicator B9.

<sup>14</sup> HM Treasury and Department for Business, Innovation and Skills, March 2011, The Plan for Growth.

- 1.15 The Government is clear that whilst employment is not just important but good for health and well-being, and should be a realisable option for as many people as possible, at any point in time it may not be an option for some disabled citizens. Even so, **everyone makes a contribution** to their families and communities, and all citizens have a right to flourish and to live in dignity.
- 1.16 It is all the more important that the Government is clear about its principles at a time when hard economic decisions have to be made. And it is vital that assistance – whether in the form of benefits, services or legislation – commands widespread support because it is well targeted and effective. **Society has to include disabled people on an equal basis.** With very constrained public expenditure we will need to find new and innovative ways of bringing this about.

# Our vision and principles for further action

# 2



- 2.1 The Government's vision is of a society that enables disabled people to fulfil their potential and have equal opportunities to realise their aspirations – making a reality of the ambitions of the UN Convention. The 'Fulfilling Potential' discussions had three broad themes – realising aspirations, individual control and changing attitudes and behaviours – and have informed the development of key principles to guide further action.

- 2.2 We want disabled people to be able to **realise their aspirations** – for the things that matter most to them as individuals, including work, education, health, family and community life, and all facets of independent living. We will tackle the root causes of poverty and underpin our approach by adopting and pursuing the following key principles.

“ I think it should be outlined to disabled children at a primary age that you can do whatever you want! ”

**Disability Rights UK**

- 2.3 The Government has a long-term ambition of a **fair and equal society**. The aim is to create **equal opportunities** for all, devolving power to people, improving transparency, supporting social action and embedding equality.

“ I want to be treated fairly, the same as everyone else. ”

**Student at Independent Specialist College**

- 2.4 We will aim to bring about the conditions for **independent living** as defined by disabled people, i.e. “the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people ‘doing everything for themselves’, but it does mean that any practical assistance people need should be based on their own choices and aspirations”<sup>15</sup>.

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15 Disability Rights Commission, August 2002, Policy Statement on Social Care and Independent Living.

“ The support of peers with shared experiences was a key factor in being able to successfully live independently and access services and activities. ”

**AFIYA Trust**

- 2.5 This in turn will require more **inclusive local communities** where disabled people’s voices are heard and they can realise their aspirations. We will seek to ensure that communities are responsive to the needs of disabled people through stronger local accountability and increased decentralisation.

“ I would like to be more involved but there seems to be no way for me to do that. It would be nice to have a way in to influence higher decisions (so thank you for this questionnaire by the way, a way to make my voice heard!) ”

**Individual Response**

- 2.6 We will reform **public services** to **support independence and participation**, delivering the right outcomes for disabled people and those that support them. Our Right to Control trailblazers are testing radical new approaches to personalised, joined-up services, which we hope will provide a platform for further change<sup>16</sup>.

“ Individuals, carers, families and communities should be involved in the design and delivery of innovative services which maximise choice and control using a wide range of resources. ”

**Association of Directors of Adult Social Services**

<sup>16</sup> The full evaluation of the trailblazers will be published in spring 2013 and a final decision on the future of Right to Control will be taken subsequently.

- 2.7 All this will be built on a **strong and effective rights framework**. This includes the UN Convention – which sets out in one place the rights that disabled people have and should be able to enjoy in the same way as others – and the UK legislation that gives effect to those rights, including the Human Rights Act 1998<sup>17</sup> and the Equality Act.
- 2.8 We need to move beyond these rights being simply words on paper. This will involve increasing awareness of the rights, what they mean in practice, and the legislation that protects and delivers them. This awareness must be developed and shared. Service providers must be aware of and meet their legal obligations. And non-disabled people must recognise that what they take for granted for themselves must equally apply to disabled people.

“ The Equality Act provides the overall legal framework, which should enable disabled people to participate on equal terms but ongoing, in some cases systemic non-compliance undermines the Government’s wider objectives around choice and control. ”

**RNIB**

- 2.9 The ‘Fulfilling Potential’ discussions show that disabled people have a strong appetite for change and reform in public services and in wider society<sup>18</sup> (despite concerns about the difficult times we live in and the implications of some current reforms). They suggest that in order to make a reality of our vision and principles, we will need to further **reform public services** to support independence, develop a **new partnership approach** to designing and delivering change, and create a **deeper understanding of disability** in the UK today. This document outlines the actions we will take in these three areas, ensuring a strong legacy for disabled people from the 2012 Games.

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17 UK Government, November 1998, Human Rights Act 1998.

18 Written responses to the Fulfilling Potential discussion exercise held between December 2011 and March 2012 are available at [www.odi.gov.uk/fulfillingpotential](http://www.odi.gov.uk/fulfillingpotential)

## Further reform of public services to support independence

# 3

- 3.1 The ‘Fulfilling Potential’ discussions have informed a dialogue between government departments and disabled people, helping to shape the future programme of **public service reform** for disabled people. The detail is set out in our companion document ‘Fulfilling Potential – The Discussions So Far’, and key points are summarised at **Annex A**.
- 3.2 This ambitious programme will help to achieve the aims of the UN Convention and respond to the desire for modernised, personalised services with strong involvement of disabled people. **Annex A** shows how reforms will meet the demand for greater **independence, choice and control** – including through a stronger focus on early intervention – promote the development **of inclusive, accessible communities**, and ensure **truly effective rights and duties**.
- 3.3 The Government-wide programme includes a transformation of the system of care and support, reforms of our welfare benefits to support disabled people to gain and maintain independence and to support employment, and establishing Public Health England and local HealthWatch – which will improve involvement and information for disabled people. It also includes improved choice and better joining-up of services across government departments, a new Transport

Action Plan developed with disabled people, a programme of reform to improve outcomes for disabled children and those with special educational needs, and measures to tackle disability hate crime and improve participation in public life.

- 3.4 As change is taken forward, we will continue to work ever more closely in partnership with disabled people on detailed design and delivery to ensure the best outcomes are achieved.



# A new disability action alliance

# 4

“ Work across agencies and with disabled people to find solutions to local problems. ”

**Bradford Strategic Disability Partnership**

- 4.1 The ‘Fulfilling Potential’ discussions called for disabled people and disability organisations to be more involved in shaping and driving action. They highlighted how policy intent does not always match lived experience. Responses often pointed to the local nature of issues.
- 4.2 We aim to build more enabling relationships between individuals, their families and communities, and the state. To do this we will help develop **a new partnership approach**. This will recognise and support the need for local action within a broader context.

“ Engagement should take into account the diversity of disabled people and provide opportunities for disabled people from a variety of backgrounds to take part. ”

**Disability Charities Consortium**

4.3 The Office for Disability Issues will help establish and implement a new cross-sector **disability action alliance, convened by Disability Rights UK**, as the mechanism for this new approach. The alliance will aim to design and deliver innovative changes, identify and spread good practice, especially at local level, and make a real difference to the lives of disabled people by:

- putting **disabled people and their organisations** in influential roles;
- bringing together organisations from the **private, public and third sectors** who have expertise and influence;
- using networks and organisations that reach out into **local communities**, to involve those **disabled people whose voices are often less well heard**, including those in residential accommodation and from black and minority ethnic communities; and
- supporting disabled people to **understand and realise their rights**.

4.4 This approach (illustrated overleaf) will help ensure that we embrace the expectations of the UN Convention and focus on priorities which disabled people have identified. The ‘Fulfilling Potential’ discussions have suggested the alliance might address three broad areas for action, building on its three themes:

- supporting and encouraging **early intervention** and **preventative approaches** which are often critical to disabled people continuing to **realise aspirations**;
- enabling disabled people to have increased and informed **choice and control** over their lives; and
- leading the way in promoting **communities which include disabled people**, including actions which will **change attitudes and behaviours**.

“ Communities where all human diversity is valued and services build individual and collective capabilities that promote the inclusion, participation and contribution of disabled people in society. ”

From Disability Charities Consortium’s vision for disability equality



- 4.5 The 'Fulfilling Potential' discussions have brought forward a wealth of specific new ideas from disabled people and their organisations – for example a local 'red tape challenge' to tackle barriers to choice and control. Most of these ideas need a joined-up, partnership approach to design and delivery. The alliance will need to prioritise which are taken forward, how and by whom. They are summarised in an initial framework for action, attached at **Annex B**. This has been put together by the Office for Disability Issues, drawing on 'Fulfilling Potential' responses and further discussions with a range of disability organisations, to whom thanks are due.
- 4.6 A number of organisations have already expressed an interest in joining the alliance. The next steps will be to widen membership and define priorities and plans. Please contact us at [fulfilling.potential@dwp.gsi.gov.uk](mailto:fulfilling.potential@dwp.gsi.gov.uk) if you would like to be involved.

## Building a deeper understanding of disability in the UK today

# 5

“ A much better understanding of disability is needed: there needs to be more education about hidden impairments, fluctuating conditions and about the barriers that disabled people face. ”

**Disability Rights UK**

- 5.1 We need a step change in the way we view disability in the UK. Demographic trends will mean that increasingly we will all experience disability either as individuals or through our family and friends, and often in caring roles. An understanding of this should drive a change in attitudes and increased commitment to inclusion and accessibility. **The latest surveys, research and statistics** provide real opportunities for fresh insights to crystallise this story. For example, the **Life Opportunities Survey (LOS)**, a major new longitudinal survey, based on the social model of disability, is starting to inform a new understanding of the dynamic nature of the disabled population and of the barriers faced by people with impairment. Further analysis of LOS will be available from the Office for National Statistics in the autumn.

- 5.2 There are real opportunities to identify and address the key factors at play. We will work with disabled people's organisations and academics to **publish in the autumn a detailed analytical study** to inform public understanding of disability and the issues faced by disabled people. This will also inform further work by Government and non-government organisations to help disabled people to live independently and fulfil their potential. It will draw a picture of the population of disabled people in Great Britain, the demographics, how disability can develop and change over the life course, and the issues faced.
- 5.3 **Annex C** illustrates the approach we will take with some initial analysis of:
- how disability can develop over the life course;
  - the links between health conditions, impairment and disability; and
  - the trends in outcomes for disabled people and related barriers.
- 5.4 We want to take this much further – looking at the interactions of societal barriers and impairments, and understanding who has benefited, and why, from improvements in, for example educational and employment outcomes, and where more progress needs to be made. We will also look further at major transition points in the lives of disabled people, for example building on new analysis of the challenges faced in making the transition from education into work.

# Working together in the future

# 6

“ We urge the Government to consult further on their disability strategy: having a context of priorities and how they will be delivered will enable disabled people to comment constructively. We have a number of more detailed practical suggestions for the action plan and would like to work with ODI\* and other departments on this. ”

**Disability Rights UK**

\* Office for Disability Issues

6.1 The Office for Disability Issues will coordinate a work programme to take forward and monitor the actions in this document. This will include:

- helping to establish the **disability action alliance**;
- leading work on a **detailed analysis of the nature of disability in the UK today** for publication in autumn 2012; and
- working across Government to help ensure that the **reform programme** draws on the views of disabled people and those who support them.

- 6.2 In addition, we will work with disabled people on an **outcome framework** and supporting indicators to measure progress. We will use the articles of the UN Convention to guide its structure, and draw on previous Office for Disability Issues work with disabled people on outcomes and indicators.
- 6.3 The framework will also draw on:
- outcome and performance frameworks and data sources across Government, including the latest developments (such as the Public Health Outcomes Framework<sup>19</sup>). This could, for example, include employment, education, health and independent living;
  - emerging thinking from the new alliance, in particular in measuring progress with inclusive communities; and
  - combining statistical data with the lived experiences of disabled people, for example on accessibility of goods and services, the built environment, transport, and family and community life.
- 6.4 It is clear that there is an appetite for further involvement from disabled people and disabled people's organisations both to develop action, and to monitor progress. Please contact us at [fulfilling.potential@dwp.gsi.gov.uk](mailto:fulfilling.potential@dwp.gsi.gov.uk) if you would like to be involved.

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<sup>19</sup> Department of Health, January 2012, Healthy lives, health people: Improving outcomes and supporting transparency.



# Annex A

## Key public sector reforms

1. This annex summarises key reforms of services for disabled people. The full programme is set out in more detail in ‘Fulfilling Potential – The Discussions So Far’.

### Supporting independence, choice and control

“ Funded self-help is the way to go and would be far more helpful to the individual. ”

**Individual response**

2. In reforming public services used by disabled people we want to ensure that there is better support for the principle of independent living, improved availability of options to choose from, and greater opportunities to influence provision. This will include a focus on early intervention and prevention. To support **independence, choice and control we are:**

- i) Transforming the system of **care and support** to promote independence and well-being. Our White Paper, 'Caring for our Future'<sup>20</sup> sets out our plans including:
- Improving, from spring 2013, **access to information and advice** to help people organise and plan care and support. We also want to improve access to independent advice and support, for those who are eligible for support from their local authority, to help them develop their care and support plan. This will require local authorities over time to develop and commission a range of independent advice and support options. New models such as peer networks will be explored.
  - Helping disabled people who choose to remain in their own home to be better supported. The White Paper outlines plans to increase the use of assistive technology, and to tackle isolation by encouraging local authorities to build community-based support into local commissioning plans.
  - Developing, in a small number of areas, the use of **direct payments** for people who have chosen to live in **residential care** to test the costs and benefits.
  - Investing a further £100 million in 2013/14 and £200 million in 2014/15 in joint funding between the NHS and social care to support better integrated **care and support** services.
  - Changing the **charging system for residential care** from April 2013, so that the income people earn in employment is exempt from residential care charges.
  - Ensuring that local authorities bring an end to commissioning practices that risk undermining **dignity and choice**.
  - Establishing a **new capital fund**, worth £200 million over five years from 2013/14, to promote the development of **specialist housing** for older and disabled people to support their independence and well-being.

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<sup>20</sup> Department of Health, July 2012, Caring for our Future: reforming care and support.

“Central and local government should work in partnership to identify and implement strategies to remove the additional costs disabled people face. This should provide a basis for reducing expenditure on the welfare system in the long term.”

**Disability Charities Consortium**

- ii) **Reforming welfare** to support disabled people to gain and maintain independence and reduce the risk of dependency. For many this will include support to work, which is the best route out of poverty, and very often beneficial for those with long-term health conditions. But we will also provide unequivocal support for those who cannot work. Major reforms include:
- Replacing Disability Living Allowance (DLA) for 16–64 year olds with **Personal Independence Payment**, a non-means-tested and non-taxable cash benefit, to be introduced gradually from April 2013. It will provide a contribution towards extra costs arising from the impact of a disability or impairment for those disabled people who face the greatest challenges to remain independent and lead full, active and independent lives. It will be fairer, more objective and more consistent than DLA and build confidence that the right support is going to the right people.
  - Making sure work always pays, removing unhelpful distinctions between in work and out of work support and making it easier to claim all benefits that a person is entitled to, by introducing **Universal Credit** from October 2013. This will mean, for example, that people with fluctuating conditions will no longer have to wait whilst their benefits are adjusted as they move into and out of work. We will also continue to provide extra support for those disabled people who cannot work or who have limited capability for work related activity.

- iii) Building the capability of **disabled people's user-led organisations (DPULOs) by 2013/14 through DWP's DPULO programme, including using the £3 million Facilitation Fund** and by offering practical support from the National Lead and Ambassadors. Extending the programme to Scotland and Wales and increasing the number of Ambassadors.
- iv) **Removing barriers to work** by providing a more joined up and holistic approach to supporting people, helping disabled people into work, and helping them stay in work including through early interventions at the onset of impairment. From 2014, we will extend the **right to request flexible working** to all employees. We are also looking at how we can improve **Access to Work**, investing an extra £15 million, aiming to increase awareness of the scheme and build confidence amongst employers to use Access to Work to support their disabled employees.
- v) Consulting on extending the testing of the legal **Right to Control** for disabled people in seven trailblazer areas into 2013, to support delivery and choice of the joined-up services.
- vi) Setting out new duties on local authorities in the Draft Care and Support Bill to ensure that care and support is not interrupted before a reassessment, to help remove barriers to disabled people **moving to the home of their choice**.
- vii) Taking forward the proposals set out in the document, 'Support and Aspiration: A new approach to Special Educational Needs and Disability, Progress and Next Steps'<sup>21</sup>, published in 2012. This will include the introduction, by 2014, of a **single Education, Health and Care Plan** for children and young people who would currently have a statement of special educational needs or Learning Difficulty Assessment and **the option of holding a personal budget** for young people and parents of children with a Plan. This will improve personalisation and choice and control for young disabled people from birth to adulthood in education or training, and help them to be the 'authors of their own life stories'.

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21 Department for Education, May 2012, Support and Aspiration: A new approach to Special Educational Needs and Disability, Progress and Next Steps.

We will also establish a Young People’s Advisory Group to help shape the next stages of our reforms nationally and drive young people’s participation at local level.

- viii) Developing the **Long Term Conditions Outcomes Strategy**, which we aim to publish towards the end of 2012. This aims to ensure that systems exist to support people who develop long-term conditions, including disabled people, to lead an independent life for as long as possible and enhance their quality of life. It also aims to increase the focus on early intervention and prevention.
- ix) Establishing **Public Health England** in 2012/13 to ensure disabled people have information and advice on health matters, for example, through national campaigns.
- x) Establishing local **HealthWatch** in 2013 which will ensure that the views of disabled people are represented in health and social care.

## Promoting the development of inclusive, accessible communities

“ By getting out into the community and becoming involved, was felt by the people we support, the best way to change the way the general public treat disability. ”

### Dimensions

3. The ‘Fulfilling Potential’ discussions have emphasised the roles of government and others in creating the right conditions for disabled people to be able to participate in their local areas. To promote the development of **inclusive and accessible communities** we are:
  - i) Promoting the development of **lifetime neighbourhoods** which will benefit disabled people, for example through safe inclusive access to key services, strong community links and affordable housing designed to meet changing needs.

- ii) Developing a **Transport Action Plan** with disabled people, to be published in 2012, which will identify priorities to ensure a fair transport network where everyone is able to experience the same seamless journey, whether disabled or non-disabled.
- iii) Enforcing, from 1 March 2013, the European Union Regulation on the **rights of passengers in bus and coach transport**, which extends the rights of disabled passengers.
- iv) Awaiting the outcome of the Law Commission **review of legislation relating to taxi and private hire services**, including provisions relating to the safety of disabled passengers, with a view to considering their recommendations and legislating as appropriate.
- v) **Tackling hate crime** through our cross-government plan by:
  - preventing hate crime happening in the first place by challenging the attitudes and behaviours that foster hatred, and encouraging early intervention to reduce the risk of incidents escalating;
  - increasing the reporting of hate crime that occurs, by building victims' confidence to come forward and seek justice, and working with partners at national and local level to ensure the right support is available when they do; and
  - working with the agencies that make up the Criminal Justice System to improve the operational response to hate crime. We want a more effective end-to-end process, with agencies identifying hate crimes early, managing cases jointly and dealing with offenders robustly.

## Ensuring effective rights and duties

“Progress in one part of their lives can be negated by poverty and discrimination in another.”

TUC

4. **Rights and duties** are an important part of our approach. We are mindful that too many regulations focus on process rather than achieving outcomes. We will address this to ensure, where a legislative approach is best, that it achieves the required outcomes, and to use non-legislative approaches where these are appropriate. To strengthen **rights and duties** we are:
- i) Making it the default position in law that everyone, including carers, who are eligible for support should have a **personal budget** as part of their care and support plan, and a right to ask for this to be made as a **direct payment**. We will also explore how personal health budgets can be extended and integrated with this, especially for those with long-term health conditions.<sup>22</sup>
  - ii) Enacting new statutory principles which embed the **promotion of individual well-being** as the driving force behind care and support. These will be supported by duties to promote **cooperation and integration between local partners** to improve the way organisations work together.<sup>23</sup>
  - iii) Modernising the duty on local authorities to provide **information and advice**, and planning duties to make arrangements to **prevent and postpone the onset of care needs**, to **shape the market** for care and support providers and to **integrate care and support with health and housing** where appropriate to deliver better outcomes.<sup>24</sup>
  - iv) Enacting, through the Health and Social Care Act 2012<sup>25</sup>, the first ever specific **legal duties on health inequalities** for NHS commissioners and the Secretary of State for Health. These should help disabled people who may face extra barriers to accessing timely, appropriate and effective health services<sup>26</sup>. The duties include:

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22 Department of Health, July 2012, Caring for our Future: reforming care and support.

23 *ibid.*

24 *ibid.*

25 UK Government, March 2012, Health and Social Care Act 2012.

26 Eric Emerson et al., August 2011, Health Inequalities & People with Learning Disabilities in the UK: 2011.

- The NHS Commissioning Board and clinical commissioning groups are under a duty to have regard to the need to reduce inequalities in access to, and in the outcomes of, healthcare.
- The Secretary of State for Health has a wider duty, to have regard to the need to reduce inequalities relating to the health service (including both NHS and public health, and relating to all the people of England).

v) Promoting **participation in public life** by:

- introducing the Crime and Courts Bill, which will allow the principles behind the Equality Act ‘positive action’ provisions to be applied to **judicial appointments**;
- supporting the Mental Health (Discrimination) Private Member’s Bill, which proposes the **repeal of current discriminatory provisions** that exclude people with mental health conditions from acting as Members of Parliament, jurors, school governors and company directors in certain circumstances; and
- supporting disabled people seeking elected political office through the **Access to Elected Office Fund** which was launched in July 2012<sup>27</sup>.

5. We are also:

- i) reviewing the **Public Sector Equality Duty** and the specific duties that support it, to determine whether it is operating as intended, including for disabled people. The review is due to be completed in April 2013; and
- ii) conducting a **review of sentences** by March 2013 for offences motivated by hostility on the grounds of disability, sexual orientation and transgender, to consider whether there is a need for new specific offences similar to racially and religiously aggravated offences. We will consider any evidence provided by disabled people’s organisations to assess whether it provides a case for changing the law on incitement to hatred on the grounds of disability.

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<sup>27</sup> HM Government, September 2011, Access to elected office for disabled people: a response to the public consultation.



# Annex B

## Disability action alliance: framework for action

1. This framework of potential actions has been put together by the Office for Disability Issues drawing on the ‘Fulfilling Potential’ responses and working with disability organisations including Disability Rights UK. Three broad areas have been identified: early intervention and preventative approaches, increasing choice and control, and building inclusive communities. Across each of these areas the alliance will need to consider how best to support disabled people in understanding and realising their rights.

### Early intervention and preventative approaches

“ Responsive care services, early intervention and future planning are vital for people with fluctuating and degenerative conditions like MS\*. Small amounts of support at an early stage can significantly help people to manage their condition and remain independent for longer. ”

**MS Society**

\* Multiple Sclerosis

2. The alliance will work at national, and most importantly local, level. It will support and encourage approaches to **early intervention and preventative approaches** to impairment and disability whether early in childhood, when acquiring an impairment, or at other important life events. This could include:
  - i) Working with public services to develop **tools and approaches** to improve support in the early stages of impairment. The aim would be to enable people to build the lives they choose, for example by staying in education or employment, and to overcome disabling barriers at an early stage, quickly learning about independent living skills and opportunities. This would, for example, **build on new duties on local authorities** to incorporate preventative practice and early intervention into care commissioning and practice.
  - ii) Encouraging the input of disabled people into **joint planning and commissioning services**, including for disabled children and young people, and into the preparation of a local authority's local offer of services, a development signalled in 'Support and Aspiration: A new approach to Special Educational Needs and Disability, Progress and Next Steps'<sup>28</sup> and included in proposals for legislation to be introduced in 2013.
  - iii) Helping promote **public health messages** where these could have a significant impact on enhancing well-being and reducing both the risk of some health conditions, and the impact of disabling barriers. This will involve looking at ways of building on the commitment from the 2012 Games legacy to ensure more disabled people have access to sport and physical activity<sup>29</sup>.
  - iv) Feeding in promising ideas on what works best for disabled people to the Government's forthcoming **Long Term Conditions Outcomes Strategy** and helping to develop implementation plans.
  - v) Identifying best practice and promoting **peer support**, both for those experiencing the onset of impairment or a long-term condition, and for younger people with life-long impairments to offer images of possibility and raise expectations.

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28 Department for Education, May 2012, Support and Aspiration: A new approach to Special Educational Needs and Disability, Progress and Next Steps.

29 Office for Disability Issues and Department for Culture, Media and Sport, April 2011, London 2012: a legacy for disabled people.

- vi) **Building community and individual capability**, including developing disabled people's user-led organisations, and other community groups to take stronger roles in commissioned services and in particular in early intervention.

“ **Small voluntary groups (often run by disabled people for disabled people) often provide vital services and opportunities. If applying for small grants was easier, it would encourage these groups to get involved more, try out new things and provide more services.** ”

**Bradford Strategic Disability Partnership**

- vii) Exploring the potential for use of **payment by results and Social Impact Bonds**, as models that encourage innovation in early intervention and preventative methods that remove barriers and facilitate participation, as well as attracting new social investment.
- viii) **Promoting independent support, advice and advocacy** – developing standards, disseminating best practice, and working on potential new business models to grow capacity and market awareness, using the disabled people's user-led organisations' Facilitation Fund. This could also support disabled people to understand and realise their rights under the UN Convention, the Equality Act and in respect of public services and benefits.

“ **An independent advocate can be invaluable at times of transition because they help the person to identify what they really want and to identify a pathway to get there.** ”

**The REHAB Group**

- ix) Developing and building on local good practice on providing **low level support**, including Timebanks, Home Improvement Agencies, handyperson services, and volunteer services.

- x) Building on the Government's **Carers Strategy 'Recognised, valued and supported: next steps for the Carers Strategy'**<sup>30</sup> to identify and spread best practice, recognising the importance of family and social life and using a holistic approach. This will particularly recognise the critical role of carers in supporting disabled people to fulfil their potential, and of disabled people who themselves care for relatives and friends.

“ Thought must be given to providing better support for carers or family members of people with sight loss or other disabilities. ”

**Action for Blind People**

## Increasing choice and control

- 3. Disabled people and their organisations will share their experience and expertise to help develop services offering real choice and control, and to support disabled people to take more control of their employment prospects. Actions taken forward could include:
  - i) **Joint working between local disabled people's organisations and public services** to develop approaches to transforming services and their delivery. This could build on the work being done on Community Budgets and the Right to Control. It would also consider the idea of a local **'red tape challenge'** where disabled people are empowered to challenge services which do not join up or are not helping them achieve the outcomes they want, and act as a catalyst for change.

“ The idea of a 'red tape challenge', by which we mean a dialogue, really, between authorities, between individuals about the necessity of red tape that stands in the way of people exerting choice and control over their own lives. ”

**Neil Crowther Church House 22 March 2012**

<sup>30</sup> Department of Health, November 2010, Recognised, valued and supported: next steps for the Carers Strategy.

- ii) Identifying and promoting local initiatives that have worked well to grow the social care and support market, widening the **choice in service provision** available to disabled people.
- iii) Finding new opportunities to join up **assessment processes**, for example around the onset of impairment, through research with disabled people, and by building on the new duty for local organisations to work together.

“ **Person-centred planning needs to be at the heart of any assessment process for a holistic and positive transition.** ”

**Council for Disabled Children**

- iv) Working with organisations including disabled people’s organisations with an interest in employment, the Employers’ Forum on Disability, and major employers to explore how disabled people can **take more control of their employment prospects**. This would build on the Equality and Human Rights Commission (EHRC)’s research report ‘Opening up work’<sup>31</sup> which presents the views of disabled people, and involve the EHRC’s ‘working better advisory group’. This could include a focus on extending the use of apprenticeships.

“ **[M] only works a couple of hours a week at the moment. This may not seem a lot to other people but to [M] and her family this is an amazing achievement. Since starting work, [M] has become much more independent. She travels to work on the bus on her own – something which she has never done before.** ”

**United Response**

<sup>31</sup> Lorna Adams and Katie Oldfield, IFF Research Ltd and Equality and Human Rights Commission, March 2012, Opening up work: The views of disabled people and people with long-term health conditions.

- v) Working with disabled business people and entrepreneurs to maximise awareness of new opportunities for **flexible working** and to promote **self employment**.

“ Some people said that they would like to start a business, but they lack the information or confidence to enable them to do that. ”

#### Action for Blind People

## Building inclusive communities

4. These initiatives need to be set in an important context – communities need to be inclusive and accessible to disabled people to support full participation. Bringing about truly **inclusive communities** will require real knowledge and understanding of the impact of policies, services and local environmental factors on the lives of disabled people. The new alliance can play a central role in providing this expertise. Actions could include:
- i) Building on the **Lifetime Neighbourhoods**<sup>32</sup> approach to develop criteria for communities that include disabled people, both those with physical impairments and those with hidden impairments such as neuro-diverse conditions, people with a learning disability and those with mental health conditions. This might include:
- assessing engagement, accessibility, services and amenities, built and natural environments, social networks and housing;
  - exploring the option of an online assessment tool;
  - incentives for best practice; and
  - use of online mapping techniques to highlight good and bad examples of accessibility.

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32 Department for Communities and Local Government, December 2011, Lifetime Neighbourhoods.

“ Localism is good, but need to have access to good practice/ new ideas to spread innovation and find out what works in similar situations etc. ”

Kingston Mencap Carers' Group

- ii) **Working with the Local Government Association (LGA) and others** to encourage and support local authorities in further building their disability capability, particularly in respect of service commissioning. This could draw on LGA programmes and activity, including:
- using **peer reviews**, for example on how to deliver effective services at a time of financial constraints<sup>33</sup>;
  - developing a **community of practice** to spread the most effective practices;
  - using the **Equalities Framework** and **Guide for Councillors**;
  - **LGA events**;
  - developing a disability focus in programmes to **build capability** of health and wellbeing boards and local HealthWatch;
  - developing links to the **Think Local Act Personal** partnership; and/or
  - promoting the **UN Convention**.

“ There is a need to take national pride in being inclusive and proactive around disability, and to showcase good practice – the coming Paralympics could be a good opportunity for this. ”

MS Society

<sup>33</sup> Claudia Wood, Phillida Cheetham and Thomas Gregory, September 2011, Coping with the Cuts.

- iii) Developing a **programme of cultural change** which would build on the legacy of the 2012 Games to bring about **change to attitudes and behaviours**<sup>34</sup>. Working in partnership with disability organisations, trade associations, the media and others to:
- **benchmark and challenge attitudes** of the key groups where disabled people report most difficulty, including health care professionals, employers, and the general public;
  - develop an annual programme of activity to celebrate **International Day of Disabled People** on 3 December;
  - build on the **two ticks symbol** (for employers who are ‘positive about disabled people’), explore how it might have more impact, and consider whether new symbols should be developed;

“ The idea of a value-added brand like a Royal Coat of Arms to be displayed by companies and organisations that recruit, develop and promote disabled staff is an attractive proposition. ”

#### Individual Response

- encourage **positive attitudes to sport and physical activity** for all disabled people – by building on the Government’s legacy commitment from the 2012 Games and the ‘Doing Sport Differently’<sup>35</sup> guide to exercise and fitness for disabled people and people living with health conditions, and by creating a truly inclusive model for competitive sport in schools through the School Games and Change4Life Sports Clubs in schools;
- build on the positive work with the media during the 2012 Games to develop a suite of **positive stories** of change in our communities, promoting **responsible reporting of disability**; and/or

34 Office for Disability Issues and Department for Culture, Media and Sport, April 2011, London 2012: a legacy for disabled people.

35 Disability Rights UK, April 2012, Doing Sport Differently – A guide to exercise and fitness for people living with disability or health conditions.



- **identify and promote best practice**, for example in employment practices and service accessibility.
- iv) Exploring **new and innovative funding mechanisms** by bringing together social investment experts, funders, government departments and disabled people’s user-led organisations to discuss ways to access funding, and support its use across the disability sector – building on the opportunities afforded by the opening up of public services. Also exploring how community organisations can engage better with contracting and tendering processes.

“ In the shift towards levelling the playing field for different types of public service provision – see, for example, the focus on mutuals and social enterprises – we strongly feel that DPULOs\* should equally benefit from such moves, and can be ‘a part of the mix’ in the public service economy. ”

ecdp

\* Disabled people’s user-led organisations

- v) Establishing a working group on **accessibility**. This could include:
- working with leading organisations in the field of **inclusive design**;
  - a project on **accessible entertainment**, for example considering a code of practice; and/or
  - establishing local **‘accessibility champions’** who might work across planning, design and construction to help educate, inform and deliver more accessible homes, buildings and communities.

“ A small group of disabled people have been working with Bradford Theatres to improve access. The theatre is now one of the best in the Country and has won customer services awards as a result. In 2006, 186 people attended assisted performances. In 2010-11 this has risen to over 700. ”

Bradford Strategic Disability Partnership

- vi) Developing approaches to support groups with **multiple disadvantages**. For example, black and minority ethnic disabled people in socially disadvantaged areas, disabled prisoners who would benefit from education and training, homeless disabled people and lesbian, gay, bisexual, and transgender disabled people. This could include:
- drawing on recent research findings, e.g. those from Equalities National Council and Scope<sup>36</sup> identifying the need for community involvement in designing commissioning and delivering services for black and minority ethnic disabled people and improving the evidence base and communications;
  - building better linkages between government departments and agencies to work together to achieve shared objectives for disabled people facing multiple disadvantages; and/or
  - using segmentation tools to connect individuals to the most appropriate help.

“ **Recognising different cultures view disability differently and prejudices and inclusion vary widely, improving society’s understanding of inter-sectionality and issues of people who are disabled and belong to another group, and involving organisations, especially community organisations that work with different groups.** ”

**Diverse Cymru**

<sup>36</sup> Equalities National Council and Scope, March 2012, Over-looked Communities, Over-due Change: how services can better support BME disabled people.

# Annex C

## Building a deeper understanding of disability in the UK today: approach and analysis

1. This annex illustrates the approach we will take and provides some initial analysis of how disability can develop over the life course, the links between health conditions, impairment and disability, and the trends in outcomes for disabled people and related barriers.

### How disability can develop over the life course

2. We can combine new and established data sources to understand better **how disability develops over the life course**, and the different barriers faced by different age cohorts<sup>37</sup>. For example, there are now over 11 million disabled people in the UK today. This has increased steadily from 10.7 million in 2002/03. The **prevalence of disability** as a proportion of the UK population has increased from 18 per cent to 19 per cent in this time<sup>38</sup>. This is in line with worldwide rates and trends.<sup>39</sup> **Key factors** include:

37 Cabinet Office, January 2005, Improving the life chances of disabled people.

38 Department for Work and Pensions, June 2012, Family Resources Survey. Trend only available back to 2002. The General Household Survey has figures back to 1975 which show an increase in the proportion of people with a limiting long-term condition (closely related to disability) in Great Britain from 15 per cent in 1975 to 18 per cent in 2010.

39 World Health Organisation, June 2011, World Report on Disability.

- The **ageing population. Life expectancy is increasing rapidly**, especially life expectancy at 65, which has increased by almost a third since 1970<sup>40</sup>. This means that more people are living to what used to be extreme old age. Those aged 80 to 89 are the fastest-growing age cohort worldwide<sup>41</sup> and over two-thirds of people over 85 are disabled<sup>42</sup>. This means that increasingly people are more likely than not to experience a period of disability in their lives.
- The increase in the number of people with **multiple long-term health conditions** (which increase the risk of being disabled by societal barriers). For example, the number of people with three or more health conditions is currently estimated to be 2.4 million people and forecast to rise to 3.2 million by 2018<sup>43</sup>. These often emerge in middle or later life.
- Many people are **living longer as disabled people**, both those who are disabled in later life<sup>44</sup> and those who are **disabled from birth** (where life expectancy is improving). For example, half a century ago only 25 per cent of those born with congenital heart conditions survived into adulthood, whereas now 90 per cent do so. About half of those born with cystic fibrosis will live beyond 41, and a baby born today with the condition is expected to live even longer<sup>45</sup>. There is also evidence of improved survival rates for children born with cerebral palsy<sup>46</sup>. **Increasing life expectancy for those people who are disabled from birth** will also bring issues such as family carers reaching older age and managing their own impairments whilst still caring for their disabled children.

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40 Office for National Statistics, 2011, Health: Social Trends 41.

41 World Health Organisation, June 2011, World Report on Disability.

42 Department for Work and Pensions, June 2012, Family Resources Survey.

43 Department of Health estimates.

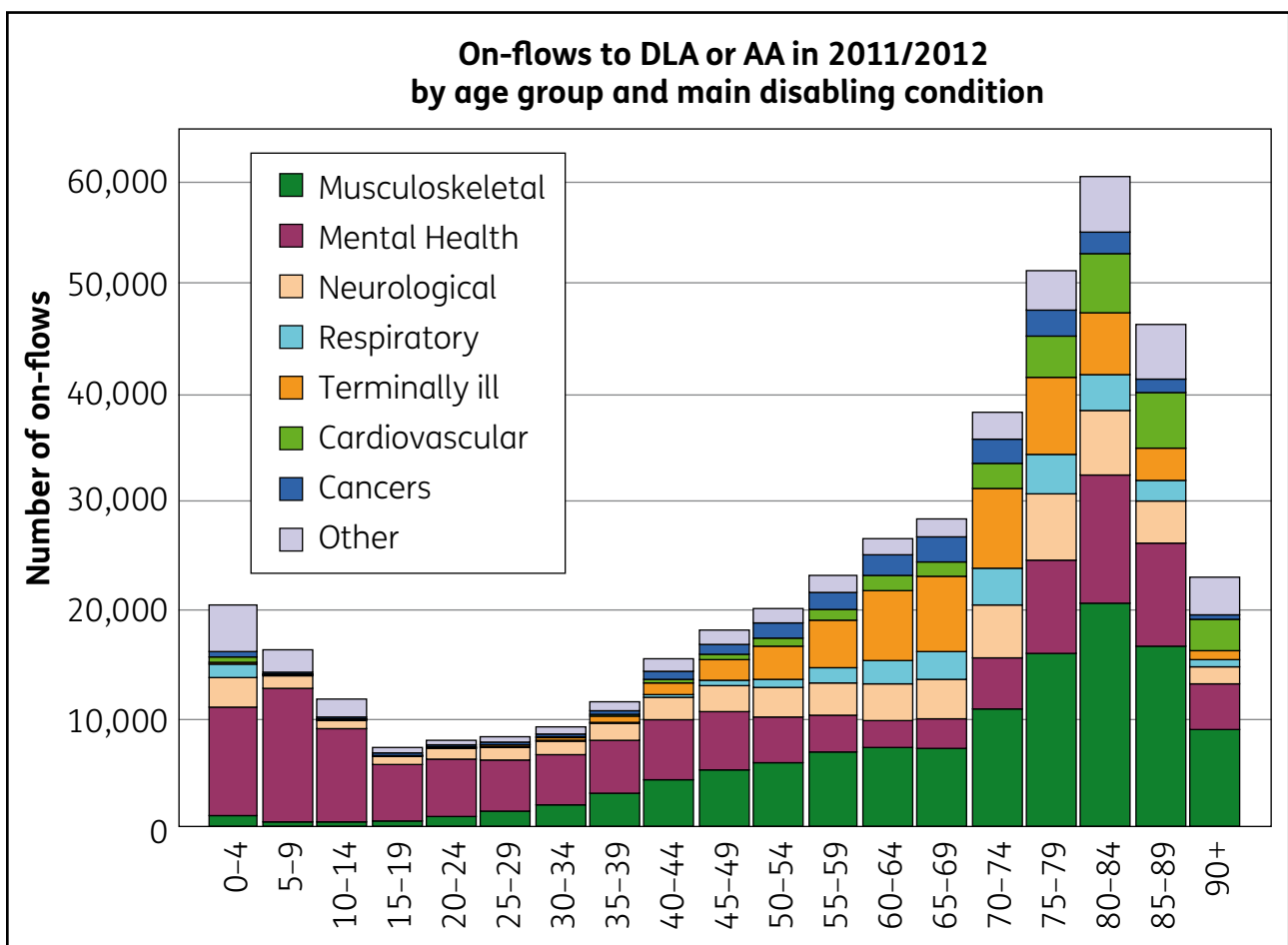
44 Life expectancy at 65 is increasing, and despite the proportion of life after 65 being lived disability free increasing, the length of time spent living with disability is also increasing slightly.

45 Together for Short Lives and Marie Curie Cancer Care, June 2012, Don't Let Me Down: Ensuring a good transition for young people with palliative care needs.

46 Strauss D, Shavelle R, Reynolds R et al., February 2007, Survival in cerebral palsy in the last 20 years: signs of improvement?

For example, Mencap estimated that there were at least 29,000 people with learning disabilities living at home with family carers over the age of 70<sup>47</sup>.

- Most disabled people are not born disabled (only 3 per cent are). Most **acquire impairments** later in life (for example, 79 per cent of disabled people over State Pension age reported that they acquired their impairment after age 50), and increasingly after retirement age (47 per cent of disabled people over State Pension age acquired their impairment after the age of 65)<sup>48</sup>. Different types of impairment tend to start or become disabling at different times in people’s lives (see Figure 1 below).



**Figure 1: Disability Living Allowance and Attendance Allowance awards by age and health condition**

47 Mencap, June 2002, The Housing Timebomb.

48 Office for Disability Issues, July 2008, Experiences and Expectations of Disabled People.

4. The chart above is based on administrative data on awards made for successful claims for Disability Living Allowance (DLA) and Attendance Allowance (AA) in the year to November 2011. The chart shows new claims by age and main disabling condition group. The bars in the chart show the total number of people in five year age-bands who were awarded DLA or AA in the year to November 2011. Each bar is subdivided to show the main disabling condition that was reported by claimants at the time of claim. In the year to November 2011 there were over 400 thousand successful new claims to DLA/AA. Other than at the start of the age distribution the number of new claims made per 5 year age band increases with age until it peaks at those aged 80–84 (which account for 14 per cent of all new claims).
5. The impairments underlying disability are very diverse, with over 900 separate conditions recorded in the Disability Living Allowance and Attendance Allowance (DLA/AA) award statistics (these are grouped into eight broad categories in Figure 1). Even so, a small number of conditions underlie over two-thirds of all awards for children (learning disability, autism and Attention deficit disorder/Attention deficit hyperactivity disorder) and older people (osteoarthritis, dementia, coronary heart disease, stroke, Chronic Obstructive Pulmonary Disease and cancers). For working age people there is more variation in conditions, with increasing prevalence in middle age of depression, anxiety and back pain and the most common conditions experienced by older people. Over three-quarters of awards of DLA and AA are to people over age 50.

6. There are also links between **age, geography and deprivation**. There are large **regional differences** in the prevalence of disability with rates being higher in Wales (24 per cent) and Northern England (20–23 per cent) than they are in London (14 per cent) and the South East (16 per cent)<sup>49</sup>. Trends over the last ten years show that these regional differences have persisted over time. The regional differences may reflect the changes in industry in Wales and Northern England resulting in a cohort effect, as prevalence in those areas is higher amongst those aged 55 or over when compared to London and the South East<sup>50</sup>. Office for National Statistics figures show that there are also regional differences in disability-free life expectancy which are strongly associated with the relative level of deprivation experienced by the area<sup>51</sup>.
7. **Age, disability and caring also interact**. For many people, especially in later life, a simple distinction between ‘carers’ and ‘cared for’ is problematic. Disabled people may be both. Many carers are disabled, and caring can have an impact on long-term health conditions. A 2011 survey found that 65 per cent of older carers said they had significant health problems or disability<sup>52</sup>. In a survey of 3,400 carers<sup>53</sup>, 83 per cent of respondents felt that caring responsibilities had a negative impact on their physical health. This included 36 per cent sustaining a physical injury such as back pain and 87 per cent who felt that caring responsibilities had a negative impact on their mental health – 53 per cent said they had depression.

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49 Department for Work and Pensions, June 2012, Family Resources Survey.

50 Office for National Statistics, July 2012, Labour Force Survey.

51 Office for National Statistics, June 2012, Disability-free life expectancy, sub-national estimates for England 2007–09.

52 The Princess Royal Trust for Carers, September 2011, Always on Call, Always Concerned: A Survey of the Experiences of Older Carers.

53 Carers UK et al., June 2012, In Sickness and in Health.

## Understanding the links between health conditions, impairments and disability

8. We can also build a better understanding of the **links between health conditions, impairments and disability**. For example:
- Around a third of the population in England (15 million) live with a **long-term health condition**<sup>54</sup>. Around 10 million of these have a **limiting long-term condition**<sup>55</sup> (this is broadly the group of those who meet the Equality Act definition of disability).
  - Strong growth is expected in the number of people living with **multiple long-term conditions**. For example, the number of people with three or more health conditions is forecast to rise by a third by 2018<sup>56</sup>. Nearly a third of people with long-term physical conditions have a concurrent mental health condition such as anxiety or depression<sup>57</sup>. People with more than one health condition are likely to be at significant risk of being disabled by the interaction of their impairments with social and environmental factors.
  - Some long-term conditions are more preventable than others. For example, coronary heart disease and chronic obstructive pulmonary disease have high prevalence and are often preventable if action is taken early. Improving **prevention** will be considered in the forthcoming Long Term Conditions Outcomes Strategy. The Office for Disability Issues will work with the Department of Health to understand how action here can help to reduce the likelihood of individuals becoming disabled.

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54 Department of Health estimates.

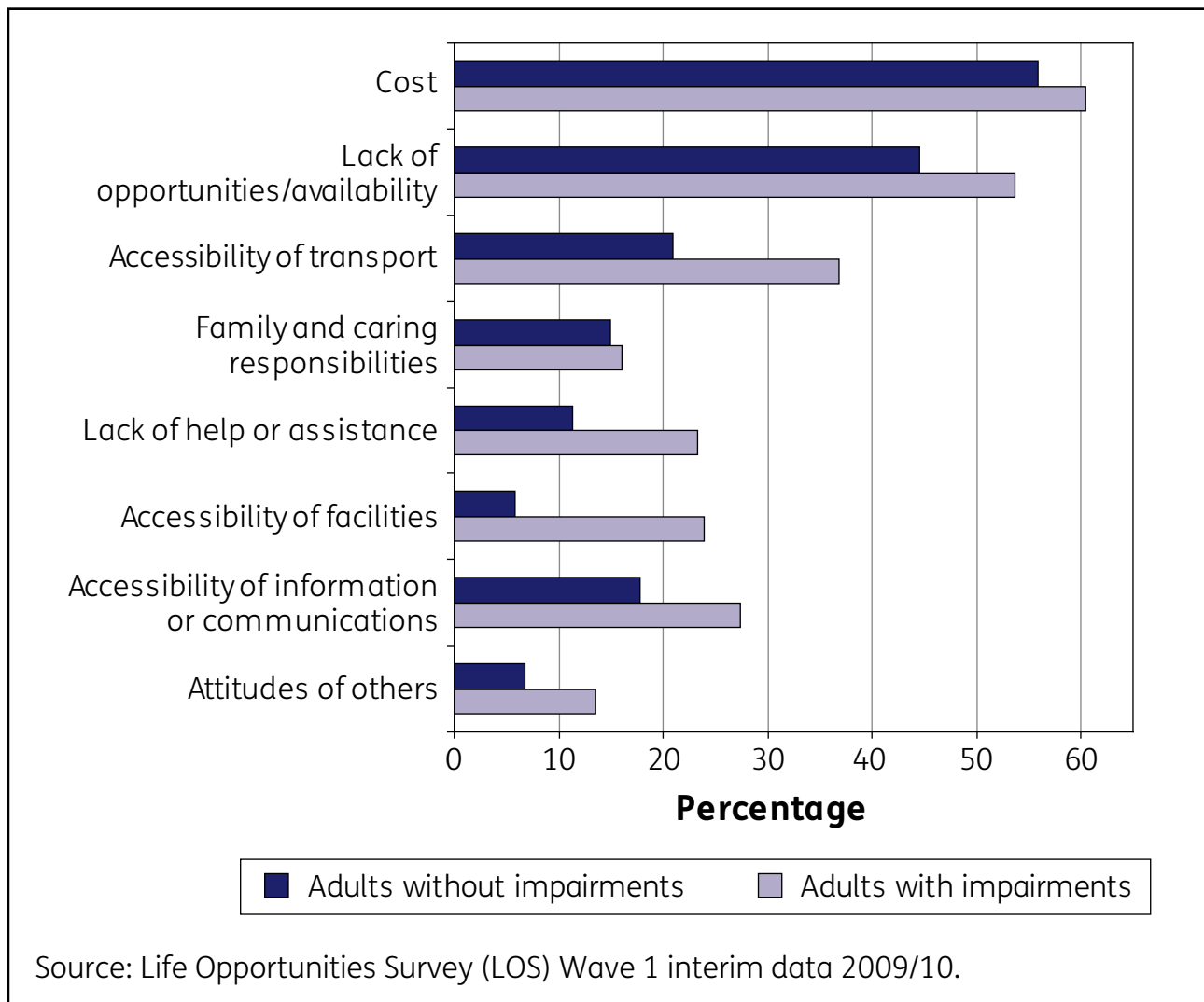
55 Department for Work and Pensions, June 2012, Family Resources Survey.

56 Department of Health estimates.

57 Naylor et al., Centre for Economic Performance, June 2012, How mental illness loses out in the NHS.



9. Understanding better the links between health conditions, impairments and disability is a priority if we are to address the impact of demographic trends, and reduce potential disabling factors. The Life Opportunities Survey<sup>58</sup> can help us to understand the factors in society that result in impairment becoming disabling (see Figure 2).



**Figure 2: Eight most common barriers to life areas by impairment status**

<sup>58</sup> Office for Disability Issues, December 2011, Life Opportunities Survey Wave One results 2009/11.

10. The Life Opportunities Survey compares the barriers experienced by those with and without impairment. Figure 2 shows that, when compared to those without impairment, the barriers that are more commonly experienced by the impaired group are:
- **accessibility of facilities** (reported by nearly a quarter of those with impairment compared with 6 per cent of those without);
  - **accessibility of transport** (reported by 37 per cent of those with impairment compared with 21 per cent of those without); and
  - **lack of help or assistance** (23 per cent of those with impairment compared with 11 per cent of those without).<sup>59</sup>
11. Experience of barriers differs by type of impairment. For example adults with a speaking or learning impairment are more likely than those with other types of impairment to experience barriers to accessing benefits and pensions services. Those with a speaking, behavioural, intellectual or memory impairment or those with a mental health condition are more likely to experience a barrier to accessing health services.

“ **Before I was disabled, I thought I was empathetic. The first time I used a wheelchair I found out how many barriers there were in society physically. I watched people’s attitudes to me change.** ”

**Individual Response**

<sup>59</sup> Office for National Statistics, 2011, Life Opportunities Survey: Analysis of barriers to participation across a range of life areas 2009/10.

## Exploring the trends in outcomes and related barriers

12. We can also explore the **trends in outcomes** for disabled people. Many have improved since baselines were set (usually in 2005, see Office for Disability Issues (ODI) Indicators on the ODI website at [www.odi.gov.uk](http://www.odi.gov.uk)). For example, there have been significant improvements in educational attainment<sup>60</sup>, in the employment rate and employment rate gap<sup>61</sup>, and in poverty rates<sup>62</sup>. There have also been improvements in other factors contributing to quality of life, for example in access to transport (22 per cent of disabled people experience difficulty accessing transport, down five percentage points since 2005)<sup>63</sup> and access to goods and services (32 per cent experience difficulty, down eight percentage points since 2005)<sup>64</sup>. Attitudes towards disabled people have also been improving in some cases. Results from the British Social Attitudes Survey<sup>65</sup> show that public attitudes towards disabled people have improved since 2005. Despite this general picture of improvement, disabled people report less choice and control over their lives than others<sup>66</sup>, and there are still significant gaps between disabled and non-disabled people's outcomes (especially in education and employment).

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60 Office for Disability Issues Indicator A5. Statistics are not collected separately for disabled pupils. Special educational needs (SEN) is used as a proxy measure. Between 2005/06 and 2010/11, the percentage of pupils at the end of Key Stage 4 achieving five or more GCSE or equivalent qualifications at grades A\*-C has increased from 19.8 per cent to 59.2 per cent for pupils with SEN without a statement and from 8.7 per cent to 24.9 per cent for pupils with SEN with a statement (compared to an increase from 66.3 per cent to 88.9 per cent for pupils without SEN).

61 Office for Disability Issues Indicator B1.

62 Office for Disability Issues Indicator C3.

63 Office for Disability Issues Indicator F2.

64 Office for Disability Issues Indicator F4.

65 Office for Disability Issues, January 2011, Public Perceptions of Disabled People: Evidence from the British Social Attitudes Survey 2009.

66 Office for Disability Issues Indicator I1.

13. As a brief illustration of some of the further analysis that might be done, we can look specifically at employment<sup>67</sup>. In **employment**, the overall trend has been an increase in the **employment rate** for disabled people (a long-term trend, now standing at 46.3 per cent – though the employment rates for people with some impairments remain consistently low. For example, people with learning difficulties or mental health conditions have employment rates of under 15 per cent) and a reduction in the **employment rate gap** (which has decreased by 5.8 percentage points since 2002 and now stands at 29.9 per cent).
14. The employment rate among people without an impairment is over 75 per cent. If it were as high among people with an impairment **an extra two million disabled people would be in work**. Detailed analysis of the Labour Force Survey shows that this shortfall is evident across the whole **range of jobs and careers**. But it is especially marked in senior management, the professions (including medicine), construction trades, engineering and IT, the arts and media, food, and hospitality. The employment gap is less wide in clerical jobs (especially in the public sector), nursing and caring, shop and sales work, and cleaning.
15. Employment trends have been largely driven by an increase in the employment rate for **disabled people over the age of 50** (from 34.9 per cent in 2001 to 41.7 per cent in 2012) as a result of more disabled people remaining in the work force. Trends in quarterly flows show that the number of people in employment aged over 50, who acquire a disability and remain in employment, has increased by 160,000 (58 per cent) since 2001. Numbers who leave work and become ‘inactive’ (that is neither employed or unemployed) have increased by less than 5,000. Maintaining and further improving retention rates for people acquiring impairments is likely to be a priority future area for policy development.

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67 Office for National Statistics, July 2012, Labour Force Surveys 2001–2012.

16. For **young disabled people**, different factors are at play. There has been the same trend towards staying on in education as for non-disabled people, but young disabled people are more likely to leave education and become unemployed than their non-disabled peers. The employment rate gap between disabled and non-disabled people increases from around the age of 21 or 22 and by 25 has reached the average level for adults<sup>68</sup>. This shows how disabled people are less likely than non-disabled people to achieve employment at these ages. However, having a degree level qualification can significantly improve employment outcomes. In 2009/10, 60 per cent of disabled graduates were in employment six months after graduating, compared to 65 per cent of non-disabled graduates<sup>69</sup>.
17. The **journey into adulthood** can be very difficult for young disabled people. Aspirations are on a par with their non-disabled peers at 16 but by 26 disabled people are likely to be less confident and more likely to agree that ‘whatever I do has no real effect on what happens to me’<sup>70</sup>. As part of ‘Fulfilling Potential’, the Office for Disability Issues (ODI) has analysed the **journeys for 12 young disabled people**<sup>71</sup>. Full details will be available on the ODI website at [www.odi.gov.uk](http://www.odi.gov.uk) in autumn 2012. They show the resilience required to persevere towards employment and point to a lack of flexibility in education, gaps in employment and other services, a lack of awareness of services, and the importance of strong family and community support. Identifying the key factors for successful transitions, and potential further actions, will be the subject of further work.
18. This annex has provided a brief overview of some of the issues that we will be exploring over the next few months. Please contact us at [fulfilling.potential@dwp.gsi.gov.uk](mailto:fulfilling.potential@dwp.gsi.gov.uk) if you have comments on any of these issues or further thoughts for our analysis.

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68 Office for National Statistics, July 2012, Labour Force Surveys 2001–2012.

69 Office for Disability Issues Indicator A12.

70 Tania Burchardt, November 2005, The education and employment of disabled young people: Frustrated ambition.

71 Department for Work and Pensions, autumn 2012, Fulfilling Potential – Journey From Education To Work.

# Notes

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This publication is available in Easy Read and Braille. A summary is available in BSL with audio voice-over and subtitles. Please contact us if you require these or other formats.

**Web:** [www.odi.gov.uk/fulfillingpotential](http://www.odi.gov.uk/fulfillingpotential)

**Post:** Office for Disability Issues, Department for Work and Pensions, Ground Floor, Caxton House, 6-12 Tothill Street, London SW1H 9NA

**Email:** [fulfilling.potential@dwp.gsi.gov.uk](mailto:fulfilling.potential@dwp.gsi.gov.uk)

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