

# Disability Rights UK



## Fulfilling Potential: Disability Strategy

### Consultation Response 9 March 2012

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#### About Disability Rights UK

We aim to be the largest national pan-disability organisation led by disabled people.<sup>1</sup> Our vision is a society where all disabled people can participate equally as full citizens and we promote:

- meaningful independent living for disabled people
- disabled people's leadership and control
- tackling disability poverty
- disabled people's equality and human rights.

#### About our response

The breadth of the scope of the discussion document makes it very difficult to respond. We decided to limit ourselves to covering the results of two brief surveys we undertook in February 2012: one general survey and a further survey aimed specifically at people with recent experience of education and training. This paper identifies the key issues, followed by our response to the consultation questions.

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<sup>1</sup> The merger of The Royal Association for Disability Rights (Radar), National Centre for Independent Living (NCIL) and Disability Alliance took place on 1 January 2012.

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.

## **Introduction**

We welcome the opportunity to respond to the Disability Strategy consultation, and we have encouraged our more than 500 membership organisations to be involved. We believe much progress has been made towards disability equality in the last 40 years but that there is a long way to go. The Disability Strategy is a real opportunity to make headway towards realising equality.

As highlighted by the recent Joint Committee on Human Rights (JCHR) report<sup>2</sup>, disabled people are already disadvantaged, are very fearful of the impact of cuts in public service and spending and the Strategy is one means to address legitimate concerns:

“We note the significant disadvantage to disabled people which persists in relation to choice and control and levels of participation in economic and social life and the impact this has on their economic and social well-being, and on what many of our witnesses considered to be their enjoyment of basic human rights. We therefore welcome the Government's recognition that more progress is required to promote disabled people's right to independent living.

The Government should continue their commitment to delivering independent living by ensuring that the forthcoming Disability Strategy sets out a clear plan of action to make progress with regard to independent living as defined by Article 19, with milestones and monitoring mechanisms. The Disability Strategy should build on and update the outcomes framework set out in the current Independent Living Strategy.”

Disabled people are disproportionately likely to require state support and a third live in poverty in the UK. Recently, the economic and political climate has changed but we do not think that this means we should lower our expectations and water down our aspirations. In former tough economic times, disabled people have fared less well than other citizens and it is important the Government outlines in more detail how it will ensure disabled people are not further disadvantaged in this period of austerity. The strategy

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<sup>2</sup> JCHR (March 2012) Implementation of the Right of Disabled People to Independent Living, 23rd Report 2010-2012, HL Paper 257/HC 1074. Available at <http://www.parliament.uk/business/committees/committees-a-z/joint-select/human-rights-committee/news/independent-living-report/>

needs to be future-proofed so that we can seize upon economic recovery to accelerate progress towards disability equality.

Disabled people are fearful of the cumulative effect of Government cuts to public services and have felt sidelined and marginalised by some 'reforms' (e.g. the replacement of Disability Living Allowance by the Personal Independent Payment for disabled people 16-64 years of age). We believe it is essential that the Disability Strategy is viewed as a means of rebuilding trust and confidence and provides a clear indication of what the Government hopes to help disabled people achieve.

We urge the Government to build on the success and progress of previous strategies – as well as reflect on why these strategies have not delivered progress as fast as we had expected, and how the Government can do better.

We strongly support the vision as set out in the Life Chances report in 2005<sup>3</sup>:

'By 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society.'

The Independent Living Strategy<sup>4</sup> was launched at the offices of NCIL in 2008 and we fully support its aims that disabled people will have greater choice and control over how support to go about their daily lives is provided, and that they will have greater access to housing, transport, health, employment, education and leisure opportunities and to participation in family and community life. The feedback to our surveys show that action in those areas remain as urgent as four years ago.

For the strategy to be effective, it needs to be informed by disabled people's views and experiences, and developed in co-production with disabled people. The fact that the Life Chances and the Independent Living strategies were developed in co-production gave disabled people a sense of shared ownership and it created a foundation for constructive dialogue.

We believe that the strategy must contain milestones and outcomes which will help disabled people and Parliament to hold Government to account and measure success.

The strategy should also set out how disabled people will be involved in the monitoring of the implementation. For instance, Equality 2025 was set up

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<sup>3</sup> [http://webarchive.nationalarchives.gov.uk/+http://www.cabinetoffice.gov.uk/strategy/work\\_areas/disability.aspx](http://webarchive.nationalarchives.gov.uk/+http://www.cabinetoffice.gov.uk/strategy/work_areas/disability.aspx)

<sup>4</sup> Office for Disability Issues (February 2008) Independent Living. A cross-government strategy about independent living for disabled people. Available at <http://odi.dwp.gov.uk/odi-projects/independent-living-strategy.php>

following a key recommendation in the Life Chances strategy and it advises the Government on their policies and progress towards disability equality. The Independent Living Scrutiny Group is an independent group of disabled people that gives their views on progress on delivery of the Independent Living Strategy.

Disability Rights UK regards this consultation as a means to help the Government determine what their priorities should be and to help inform their vision. The consultation document lacks a real vision; merely it sets out the means through which we can make 'progress'. However 'progress' is a relative word that needs to be seen in the context of desired outcomes. We urge the Government to be ambitious in the setting of their vision, and this should include full equality for disabled people, real choice and control of our lives, and the creation of a level-playing field by:

- ensuring disabled people's equality and human rights are clearly supported and enhanced
- tackling disabled people's poverty which fundamentally undermines opportunities to participate
- enhancing disabled people's independent living
- ensuring choice of education and training to gain skills and employment
- promoting disabled people's leadership and control.

## **Key Issues**

**Real steps to eliminate persistent disadvantage:** Disabled people experience persistent disadvantage in virtually all aspects of life, and a third remain living in poverty in the UK despite substantial economic growth to 2007/08. There is a need to create a level-playing field – through removing barriers where these exist, tackling prejudice and negative attitudes as well as providing support where this required. The Disability Strategy must set out what steps the Government will take to establish a level-playing field to ensure disabled people are able to enjoy the same rights and responsibilities as other citizens.

**Joined-up working by government departments:** Where support is provided it is too frequently delayed so that the individual is prevented from participating fully and to their potential for a period with long-term negative effects. This could be avoided if different government departments worked more effectively together. By putting the disabled person at the centre and ensuring all relevant agencies have policies, procedures and systems in common, the current complex and bureaucratic system would itself become less of a barrier. One student described the system as:

“Just a constant source of difficulties and pressure.”

**‘Bureaucracy of disability’:** There should be recognition of the ‘bureaucracy of disability’ by the Government and the strategy should ensure government departments, funding organisations, local authorities, health and social services departments, post 16 education establishments work together more effectively to limit stress and develop a ‘seamless’ system which places the disabled person and their support needs at the centre. One respondent said:

“Modern policies create more and more paperwork and as a blind person administration and paperwork reduce my control and independence rather than increasing it.”

The Right to Control gives disabled people control and support over resources from six different funding streams covering social care, housing support and adaptations, and employment support. It is underpinned by the principle that disabled people are experts in what barriers they face, and in how to address those barriers. It is delivered in partnership with disabled people’s organisations. It is being piloted in seven trailblazer areas and early evaluation shows positive outcomes. We urge the Government to set out in the Disability Strategy how they will use the Right to Control model across government policies and how it will be rolled out across the country.

**Effective enforcement of rights and duties:** Despite advances in the legislative framework (the former Disability Discrimination Acts and subsequent Equality Act 2010, the Human Rights Act and the UN Convention on the Rights of Persons with Disabilities), disabled people face discrimination, harassment and human rights abuses on a daily basis. For the most part this goes unchallenged. The Government needs to take real steps to strengthen the enforcement of legislation. This includes sufficient resourcing of an independent body to promote and protect equality and human rights, not reducing the ability of the Equality and Human Rights Commission to enforce legislative powers and duties. They must take and oversee systematic action towards employers, education and service providers and public bodies as well as support disabled people to access information, support and advocacy.

Reverse increase of negative attitudes to disability: our surveys confirmed existing research that prejudice, bullying and negative attitudes are increasing. We were particularly saddened by the number of disabled students who mentioned prejudice, bullying or negative attitudes to disability as affecting their ability to achieve at university or college. Around a quarter of respondents mentioned that they had personally encountered bullying or negative attitudes towards them. There was also a perception that negative attitudes were increasing and being fuelled by the media.

A third of respondents to the education survey thought that a key way to increase outcomes for disabled students was to promote positive attitudes to disability. Some suggestions put forward by respondents to both surveys were:

- start early in school by providing examples of successful disabled people and role models for all children not just disabled children
- the Government challenging negative news stories about disabled people
- tackling discrimination against disabled people being made a priority
- the Equality Act should be given 'more teeth' so a message is sent out to society that disability discrimination and hate crime will not be tolerated.

### **Recommendations:**

- all public sector staff should receive disability equality training which promotes positive attitudes to disabled people and increases their understanding of disability
- Government should do more to stamp out negative portrayals of disabled people in the media
- Government should promote positive role models of successful, educated disabled people in the media.
- Government departments should work together to make tackling disability hate crime and discrimination a priority, and publish a hate crime action plan in response to the EHRC Inquiry 'Hidden in Plain Sight' , and that builds on existing work, including Disability Rights UK's 'Let's Stop Disability Hate Crime' guidance and standards to help increase reporting.

**Assess cumulative impact of reforms and cuts on disabled people's enjoyment of rights.** The current climate of cutbacks and reform threatens to disintegrate the infrastructure of support (social, emotional, practical, financial) that enables disabled people to fulfil their potential. Disability Rights UK supports the recommendation by the Joint Committee on Human Rights (JCHR) that the Government publishes an assessment of the cumulative impact of decisions locally and nationally, to prevent the 'domino' effect that severely affects disabled people.

**Nothing About Us, Without Us: meaningful involvement of disabled people from start to end.** Good decision-making requires the involvement of disabled people, the mantra of the disability movement being: 'Nothing About Us, Without Us'. But many disabled people report that they are not being involved, nor even consulted about the impact of policy and practice.

We urge the Government to implement the recommendation by the JCHR that they involve disabled people in the development of policy, and ensure that timescales and methods are used which enable a full range of disabled people and their representative organisations to be involved. Furthermore the Government should be seen to be leading the way for other public bodies and

make involvement a key requirement of local authorities settlements and NHS bodies.

**Invest in universal design and accessible environment.** As disabled people's needs are disregarded from policymaking and service design, their reliance on 'special support' increases – often at extra cost to public services, providers or individuals. This means that the extra costs of living with a disability are rising at the same time financial support and specialist support is diminishing. We urge the Government to invest in 'universal design' in the broadest sense of the word – through encouraging timely and meaningful involvement of disabled people; building equality and access requirements into public procurement; and to invest in increasing the numbers of disabled people in public life (elected office, public appointments, volunteering).

Government procurement contracts are worth over £45bn. They are a powerful tool for government to stimulate equality, accessibility and inclusion in the voluntary and private sector. It will also help them to hold the voluntary and private sector to account on their progress. For example, funding of sports services needs to clearly state that an adequate proportion needs to be spent on disabled people's provision. At present disability provision within sports and other leisure services is seen as a charitable extra that should be supported out of benevolence. We call on the Government to include equality and accessibility as essential criteria in contracts, and to involve disabled people in the monitoring of the performance.

**The Strategy should deliver for all people living with disability or health conditions.** The Government's approach to prioritise those 'facing the greatest barriers to independent living' tends to exclude people who, with a little bit of support, can be fully equal in society. It also implies a moral and subjective judgment about 'who are truly disabled people'<sup>5</sup>. It is vital that the Disability Strategy benefits the whole disabled community, and sets out to enable full enjoyment of human rights by all disabled people.

**Government needs to win trust.** The Disability Strategy is an opportunity for the Government to win trust by disabled people, but they must show that they are genuinely committed. Sadly, most respondents to our surveys did not think the Government was serious about taking real action. That is a result of the rhetoric around the welfare reform as well as a widely perceived tokenistic consultation of disabled people on a range of reforms and a sense the Government is not thinking through the full impact of their decisions:

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<sup>5</sup> See, for example, Lord Freud's comment about an amputee climbing Mount Kenya: <http://www.publications.parliament.uk/pa/ld201011/ldhansrd/text/110511-0001.htm#11051171000240>; and our blog: <http://disabilityrightsuk.blogspot.com/2011/05/not-really-disabled.html>

“I don’t think Government wants to know about such matters let alone take any positive action.”

### **Recommendation:**

The Government needs to show understanding of the diversity amongst disabled people, involve disabled people from start to finish, and put their weight behind promotion and enforcement of equalities and human rights legislation. This should be for all disabled people, including those who feel their needs are being ignored due to their invisibility – e.g. people with mental health problems who not only have hidden impairments but also lack of voice in public debates.

Very often, people said that they could achieve their ambitions only because of determination:

“bloody mindedness and belief in myself.”

“Everything I have achieved in my life I have had to fight for, I’ve had to fight against people who have said “A disabled person can’t do that” or “A disabled person shouldn’t do that.” At the moment one of the things which really holds me back is the lack of accessible public transport in the area I live.”

Frequently people were able to get a home, job, challenge discrimination and harassment only because of the support of family and friends. Their stories show that many disabled people fulfil their potential *despite* barriers in society, not because society is equal. Disability Rights UK believes that much progress has been made in the last 40 years but that there is a long way to go. We see the Disability Strategy as a real opportunity to make headway towards realising disability equality.

## **Response to Consultation Questions**

### **Realising aspirations**

#### **1. What ideas do you have that could make a difference to you in getting an education, getting a job or being able to live independently?**

We asked respondents to highlight barriers and how these could be addressed.

Everybody talked about the need to change attitudes (which will be covered in questions 8-11). Stigma, lack of understanding and patronising behaviour hold disabled people back.

Several people said that Access to Work had helped them realise their ambitions and we strongly support the initiative being better resourced, advertised and used. Typical comments included:

“Without Access to Work it would be difficult for me to perform my current role.”

“The Government’s Access to Work programme means that I get a taxi to and from work. This means that the work I can do I can do effectively as I have not had to battle through public transport and exhausted myself.”

“Have a letter from Access to Work detailing reasonable adjustments that my organisation should put in place was a massive help in pressing sufficient pressure on [employer] to start looking at supporting disability more pro-actively”

Housing was also an important issue for many respondents:

“knowing I have (had) a secure roof over my head [has helped me].”

“There are no, or not enough, properties for disabled young people with families, they are all for [people] over 50.”

“My housing association, ..., provided an accessible application and bidding process and all the time I needed to find and move into a flat and were outstandingly helpful.”

Financial security was another lever for realising ambitions. People talked about how they cannot afford essentials like transport and how uncertainty about the future holds them back from achieving ambitions, but also how benefits are supporting them:

“The [Disability Living Allowance] has ... allowed [me] to live.”

“Getting DLA has helped me pay for things that I only have to pay out for because of my impairment such as taxi fares, equipment for the house or even more expensive LED light bulbs which are bright and instantly bright (unlike these new energy saving bulbs).”

People said how difficult, or near impossible it is, to manage a health condition and keep down a job at the same time. Health services and employers often do not provide the flexibility a disabled person needs.

Suggestions from respondents included:

- equalities legislation needs stronger promotion and enforcement. Too often employers are unwilling to make adjustments or be flexible
- more education for employers on benefits of employing disabled people
- more support from good employment advisers with a real understanding of disability and health conditions
- more promotion of flexible working and home-working
- better knowledge of what support is available and how it can be accessed
- better access to health services and better health management
- financial security, including through in and out of work support
- affordable and accessible housing. People called for specialist housing officers, a broader range of accessible housing in the social and private sector (rent/buy) and getting the right adaptations quickly

“my need as an owner occupier is to have builders compelled to build for private sale large bungalows for families with a wheelie.”

“I was mobility impaired when I moved into my flat, which unfortunately didn’t stop me being allocated a flat on the top floor of a 3-story house with no lift and no fire exit. I have found living here to be incredibly isolating.”

“moving house was a long process because it takes 12 weeks for a OT assessment before a facilities grant, the process took over 12 months before I had suitable accommodation.”

- better training about different disabilities for people on the front line and government should contract organisations with a real understanding of disability
- more disability equality training for staff at colleges and universities and for those who advise and work with disabled people such as careers advisers, local authority staff, social services and job centre staff.

As one respondent explained:

“All teaching/ health/social services staff at whatever level should be given disability awareness training so that within the classroom/clinic/ hospital/office/community they can make suitable adjustments to their methods and approach, and outside the classroom( etc) they can be part of the pressure on the system to make general adjustments within the buildings and the administration and of course to public attitudes.”

Another disabled student commented:

“Staff in further and higher education need to know more about how to support disabled students.”

**Disability Rights UK welcomes** the Government's acceptance of all the recommendations in the Sayce review to transform the Access to Work programme and the commitment to ring-fence the £300 million specialist disability employment budget. We believe that this is the best way to promote disabled people's genuine participation in the nation's workforce.

But we urge the Government to:

- demonstrate speed in implementing the recommendations – so that numbers using this essential programme can double quickly, as the Sayce review proposed; and
- ensure the rights of people working in non-viable Remploi factories are protected through financial and employment support, including support for employment, enterprise and community opportunities.

We ask the Government to publish, by summer 2012, a disability employment action plan for the next 3 years that includes joined-up action for different government departments. This should include progression from education, to training, work experience, volunteering, Internships, apprenticeships and employment as well as the role of health services and transport.

We also recommend:

- **timely and appropriate support should be put in place for disabled students by staff who really listen.**

Many respondents identified how crucial learning support was for them achieving their goals. Around a half of respondents to the education survey had issues accessing learning support. One stated:

“Full and thorough assessment should be provided by staff who understand your problems and will listen to what your saying... all the recommended support and equipment should be provided.”

Around a third of respondents said that they had received appropriate support and this had made all the difference in them achieving their ambitions.

- **colleges and universities should be made more accessible.**

Some mentioned that physical access to education establishments should be improved whilst others felt that the application process and curriculum could be made more accessible. A typical response is below:

“There needs to be more help in applying for uni and for assistance in university. There should be more accessible universities meaning structures of buildings.”

- **there should be more encouragement of young disabled people to be ambitious so they can achieve their goals.**

Many spoke of the importance of nurturing and encouraging young disabled people to achieve. The important role of teachers, disability organisations and family and friends were highlighted in encouraging disabled children and adults to achieve.

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

- **there is a need for more work experience opportunities for disabled students.**

Many disabled people mentioned that it was very difficult for them to source work experience whilst at university as employers were unable or unwilling to take on disabled students for short periods of time without support to make reasonable adjustments for them.

“My friends could all do work experience at various places throughout education and or find jobs whilst the amount of places I came across that simply did not have access was immense. Giving the Equality Act some teeth rather than the limp provisions that currently exist would be an excellent step.”

- **improving access to transport was seen as a way to enable disabled people to meet their ambitions.**

Disabled students told us about difficulties getting to college or university using public transport, issues with accessible parking at universities and also how issues around transport did not improve when considering work.

One respondent explained:

“Better services for disabled students and disabled people, regarding transport are needed. There are too many inconsistencies across the country around public transport and getting good access shouldn't depend on living in London or being under nineteen in or on what type of education you are in.”

- **funding to support advocacy and mentor schemes for disabled people.**

A mentor and advocate to follow a student from leaving school to finding work who can help them navigate the different transitions.

## **2. What would help you manage better at times of change in your life?**

People identified ‘becoming disabled’, ‘moving house’, ‘getting a job’, ‘leaving school’, ‘going to university’ as key changes in their lives. Most disabled people develop their impairment or health condition in adult life.

Moving to a new area or into a new job can be very difficult as getting information and making friends may be harder for disabled people. People find it difficult to join new groups as many community facilities are not accessible, public transport is not reliable, and people face prejudice because of their impairments and/or health conditions.

The following suggestions would make a real, positive difference with any changes in life:

- full and accessible information
- access to peer support
- more financial security.

People said that there is a real lack of accessible information to help look for a job (many job opportunities are not advertised in an accessible way, for example), get an accessible home, find out about social care and health services.

### **The importance of careers guidance**

Many respondents identified comprehensive specialist careers guidance as a key factor in enabling them to succeed. A third of respondents to the education survey identified specialist careers advice as being crucial in supporting young disabled people through changes in their lives like leaving school and finding work after attending college or university.

Our respondents had very clear ideas about what would help them better manage leaving school, embarking on further and higher education and finding work.

Better advice and guidance for disabled young people and their families which should be promoted and made more widely available.

Many told us that due to not receiving the correct advice on time or not at all, they had to change their plans or put off going to college or university.

Those who had received good, timely advice really saw the benefit of how it had allowed them to achieve their ambitions. Many were in agreement that information and advice should be provided in a way which:

- Listened to the needs and aspiration of the disabled person
- Placed the disabled person at the heart of decision making
- Had consistency and continuity - so they weren't suddenly left without support at an arbitrary age or stage in their life.

Around a half of respondents to the education survey complained about the difficulties they experienced in trying to negotiate the 'system' of transition from leaving school, to entering post 16 education and then finding work.

The sheer number of application forms, assessments and bureaucracy associated with applying for support was seen as inefficient, tiring, stressful and frustrating.

One of the most frustrating issues raised by disabled students was the lack of a 'joined up' approach between schools, local authorities, colleges and universities. This can mean that students can go through many assessments within a few years which all say the exact same thing but are for accessing different types of funding.

Many respondents admitted that they are very anxious and uncertain about how they will move on from education into work as the comments below demonstrate:

“My illness only occurred after I had started a university course. I am terrified by what the future will hold for me after my degree and for others in similar situations. I want nothing more than to be able to pursue a career and contribute towards society as well as raising my own family, but do not see how this can happen without the support of DLA and in the face of current prejudice.”

With the onset of an impairment or health condition, people need readily available support; this includes emotional support to come to terms with being a disabled person.

“the first barrier to overcome is the psychological negativity of identifying oneself as 'disabled'. [Following therapy] once I had accepted myself as a disabled human being everything was possible again.”

In relation to getting a job, people wanted help with discussing their disability with their employer. People find themselves in a catch-22 situation that they should talk to their employer about their disability or health condition so that they get the right support, but when they do, they will either not get a job or lose it. One respondent suggesting:

“on the occasions I have told people about my health problems I have not got the job. So I am in a lose-lose situation all around.”

With regards to moving to a new area, people talked about the postcode lottery in services and the difficulty of finding out about support in the new area. One person who moved from the North to the South found that the wheelchair service in the new area was far inferior to the old service, and had to buy privately. People also found huge differences between mental health

services. One suggestion was to ensure that agencies share information to ensure a smooth transition.

A major issue is that the network that holds a disabled person's life together is very fragile. Often a change in one area leads to changes in other areas – for example, if someone loses a job then they may have to move out of their privately rented house (which has been adapted) but then they cannot find affordable, accessible housing. This needs to be taken into account when making decisions that impact on disabled people.

### **3. In those situations, how are you supported or held back by other people?**

Many respondents identified negative attitudes as the key barrier to realising aspirations. Bullying was most frequently mentioned.

“I had to leave a long term employment as a result of bullying from my boss due to my disabilities.”

People also highlighted how patronising attitudes hold them back, for example from employment advisers.

“So far personally I have not found their involvement very helpful in fact I would go as far as saying their involvement and attitude has knocked my confidence.”

On the positive side, people mentioned how peer support can empower them. Peer support can be in the form of social media, staff networks, local self-help groups.

“Disabled people I've met through Twitter have been incredibly helpful and encouraged me to meet my ambitions.”

People also highlighted the difference a supportive employer could make.

Respondents to the education survey identified parents, other family and friends as the chief providers of support, advice and encouragement. They were followed closely by disabled students citing their own determination and hard work as getting them through difficult transitions in their education.

Many singled out disability organisations for praise as being sources of support and information.

Those who had positive experiences with careers guidance professionals, learning and disability support teams were very keen to acknowledge their support.

Disabled people's success in education seems to often come down to whether they have a supportive family and if they are lucky enough to come into contact with outstanding professionals. Those who do not have family to rely on or who are unable to access outstanding professionals often miss out on crucial information, advice and opportunities.

Support from family and friends was key to realising aspirations – however the impact on family should not be underestimated – one respondent said that they had not achieved their ambitions because of “being a carer”. Several respondents also said that they were on their own.

Some also highlighted the support they got from their GP.

People suggested better enforcement of equalities legislation, more guidance for disabled people and employers.

Disability Rights UK believes it is vital that the public sector Equality Duty is promoted and that government departments and other public bodies carry out timely equality impact assessments with involvement of disabled people. We agree with the Joint Committee on Human Rights that the removal of the involvement from the specific duties is a retrogressive step. Further, we are very concerned that guidance from the Home Office state that specific duties do no longer require public bodies to prepare or publish equality impact assessments (etc).<sup>6</sup> Whilst this is technically true – without equality impact assessments in particular, public bodies run a very high risk of being in breach of the public sector Equality Duty as well as discriminating against disabled people. We would strongly recommend that the Home Office commission an independent review of their guides with a view of promoting positive ways to comply with the Equality Act 2010.

## **Individual control**

### **4. What helps you to have choice and control over your day-to-day life and the support you get?**

Peer support was frequently highlighted as a key mechanism to have choice and control, with disabled people's organisations playing a key role at local and national level.

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<sup>6</sup> <http://www.homeoffice.gov.uk/publications/equalities/equality-act-publications/equality-act-guidance/specific-duties>

“My GP does not see me enough to know how my life has been affected. I need someone who knows about support, benefits, adaptations – and above all – me as a person!”

An accessible environment was a major enabler – accessible transport, accessible public venues.

Again, people talked about the need to tackle prejudice and address bullying and hate crime.

The main areas that disabled students identified as aiding them to have choice and control within education were:

- Provision of appropriate specialist advice and information so they can make informed decisions about their future
- Being listened to by professionals
- Being given control over how their support needs are met
- Providing accessible education and training buildings and transport.

## **5. What else would help you to have more choice and control over your day-to-day life and the support you get?**

People want to cut out bureaucracy and involvement of the large number of professionals:

“it is all paperwork and applying for funds here and there.”

**We recommend that** disabled people are given better information and support in all areas of life and welcome opportunities to work in partnership with Government to provide support, advice and information.

Disabled people’s organisations play a vital role in helping disabled people to exercise choice and control. They provide information, advocacy and peer support to disabled people; they can inform local authorities as well as other organisations how to build disability equality into their work and where they need to work together.

**We urge the Government to include a firm commitment in the strategy** that they will build support for DPOs into settlements with local government and into the new NHS structure as well as in the roll-out of the Right to Control.

## **6. What would help you to access services and activities which suit your needs? For example education, transport, health, social care, and sport, social and recreational**

People felt that access to information was vital for their participation, as is access to peer support and advocacy. A suggestion was to set up a database of mentors. Disability Rights UK suggests that this could potentially be operated through the network of Centres for Independent Living.

People talked about the need for an accessible environment:

- accessible transport
- accessible information
- accessible community venues
- more accessible education buildings

“I live in a market town ... there are no buses after 5pm at night. I can't afford to pay for taxis all the time. I have had to give up a language course because I could not afford to pay for the course and the £25 a lesson taxi fare!”

One person talked about how they were prevented from doing volunteering for a well-known charity because their insurance would not cover them.

People also wanted:

- more employers willing to take on disabled students for work experience
- more appropriate information provided to disabled students
- support needs being met more quickly
- less bureaucracy associated with applying for support
- frontline staff who really understand disability.

Changing the attitudes of people in service provision was a common theme; one person commented that disability equality training appears to be offered only in the areas that disabled people are considered to want to access. However, disabled people should be able to take full and equal part in all parts of society.

Disability equality training is vital to improve understanding of disability, to increase positive attitudes and to ensure that service providers comply with equalities legislation. The Government needs to promote disability equality training in all service industries including sports and leisure.

A lot of respondents talked about the need to involve disabled people in policy making and service delivery from start to end. Too often disabled people are ignored or forgotten meaning that they are excluded from using services and taking part in activities that other people take for granted:

“I would like those in government to understand an issue before they take a decision that affects us.”

**We recommend that**, for the next three years, the Government commissions independent research into the cumulative impact of their policies on disabled people's equality – in particular: the impact on poverty, independent living, progression through education and training and employment. The research should report annually, and must involve disabled people.

## **7. How can you be involved in decisions that affect your local area?**

Most respondents highlighted the benefits of involving disabled people in decision-making but they also said that this was not happening. Benefits included better policy making, better service design, greater understanding of barriers faced by disabled people, more positive attitudes.

Quite a few respondents said non-disabled people had no understanding of the different disabilities and the different barriers, and that is why it is vital to have disabled people involved at all levels of decision-making:

“until we get the disabled truly represented by the disabled themselves then nothing will change.”

Yet disabled people felt generally excluded:

“we are only ever consulted on issues that affect us, we are never the decision-makers.”

Involvement is also good for a sense of self-worth:

“I feel stronger for participating.”

There are different ways that disabled people can be involved, and they should be encouraged. Often local support groups can provide a safe environment for disabled people to speak up, yet those groups are at risk of losing funding or have lost funding.

A few people flagged up that they cannot easily leave their homes and it is vital that they are involved too – through social media, internet, telephone etc.

Effective involvement of disabled people means that they get the right information and support to participate. However people should not be penalised for active participation – with benefits rules in particular requiring sensitive implementation to prevent disincentives to community involvement.

We asked our education survey respondents to consider their involvement in college or university decision making, something which only a quarter had

been actively involved in but most of whom thought was a very worth while endeavour. As one disabled student explained:

‘I really enjoyed it. We talked about different things to help the college as a whole. We talked about changing things for the better. ... I felt it helped my confidence and speaking out in front of people.’

Most were very clear that the process would only work if they were actually listened to.

Disability Rights UK welcomes the Access to Elected Office work that is being carried out by the Home Office. We hope that support from this programme will be practical and empowering, for disabled people and for political parties. For example, Disability Rights UK provides award-winning, highly effective leadership and empowerment programmes for disabled people (some funded by the Department for Communities and Local Government), including BME young disabled people, older people living with HIV, young people with mental health issues. Our programmes are run by disabled people, and provide participants with the skills and confidence to improve their lives and make a difference to the lives of other disabled people across every sector of society. Many delegates have gone on to become more involved in their communities, including becoming councillors. We believe that our programmes provide a model for greater participation of disabled people in decision-making. One stated:

“I attended the radar disability leadership course which stimulated me into becoming a trade union activist.”

Our MPs’ Guide on Disability provides practical tips for MPs to help them interact positively with disabled people, and so better represent their disabled constituents. Furthermore our MP Disability Dialogue could provide a model to foster stronger local engagement between disabled people and elected office holders.

**We recommend** that the Government supports work to encourage more disabled people to get involved in decision-making, locally and nationally. They should also require government departments, local authorities, colleges, universities and others that they involve disabled people. We believe that the public sector equality duty and the UN Convention obligations represent significant tools in this area and we hope that the Government will set out in their strategy how they will promote these tools.

### ***Changing attitudes and behaviour***

#### **8. What works well in changing the way other people treat disabled people?**

Greater visibility of disabled people in the community and in mainstream media was considered effective, as was enforcement of equalities law.

Increasing contact between disabled and non-disabled people in all areas of life is seen as very important by disabled people:

“Meeting me and having a conversation [they] realise that I am not the stereotype they think, I am educated, articulate and constantly striving to improve my situation.”

Disabled people should steer the change in attitudes:

“I currently chair a disabled staff network and one thing we do is provide training in disability awareness and the law.”

A popular suggestion was a communications campaign, led by disabled people. Disability Rights UK would welcome working with the Government on this issue if this idea is accepted.

The general public’s attitudes towards disabled people have worsened in the last year. **We urge the Government to set out clearly** in the strategy how they will promote understanding amongst the general public of disability, and in particular with regards to people with hidden impairments or fluctuating conditions.

## **9. What else is important in changing the way other people treat disabled people?**

Virtually all respondents said that the Government needs to start with themselves, including:

- communications/messages to the public
- genuine involvement of disabled people from start to end: getting disabled people’s views before bringing in new policies
- the operation of Departments: setting standards and leading by example. More disabled people in senior positions, tackling bullying of disabled civil servants
- contracting of commercial providers, including monitoring and evaluation.

A much better understanding of disability is needed: there needs to be more education about hidden impairments, fluctuating health conditions and about the barriers that disabled people face. Stop categorising disabled people which is unhelpful and entrenches prejudice.

There must be zero-tolerance of bullying and hate crime. In February 2012, Disability Rights UK published 'Let's Stop Hate Crime' guidance<sup>7</sup>, to help disabled people report hate crime or harassment. We are grateful for the Office for Disability Issues' support on this project and we hope this kind of partnership working will continue across government.

We are developing a response to the Leveson Inquiry into the practice, culture and ethics of the press and many disabled people have highlighted their concerns to us about specific news stories contributing to discrimination and harassment disabled people experience.

Government has a significant role to play in tackling this situation, through sensitive and appropriate accurate provision of information to journalists and news outlets generally, but also through ensuring appropriate rules and a regulator is in place to monitor press coverage of relevant issues and tackle inaccurate or prejudicial articles. We will be making a separate submission to the Leveson Inquiry and will ensure a copy is sent to the Office for Disability Issues. Disability Rights UK supports the recommendation of the Work and Pensions Select Committee that the Disability Strategy contains proposals to tackle negative reporting of disability in the media and a strategy to get the message across that disabled people can and do make a positive contribution to society, very often as taxpayers.<sup>8</sup>

## **10. What can we do to make sure that everyone recognises the contribution that disabled people can make?**

Government should tell everyone about the positive side of disability equality:

“loudly and at every opportunity.”

The Government needs to avoid messages that undermine the value of disabled people as full and equal human beings. Several people commented that the Government create a false divide between disabled people as benefit recipients and 'taxpayers'. This distortion is inaccurate and also sends out a significantly negative message to the general public that disabled people somehow do not contribute.

Suggestions for more positive recognition of disabled people included:

- showing how right support and accessible environment enables disabled people to make a real contribution
- building on 'Time to Change'

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<sup>7</sup> <http://www.radar.org.uk/people-living-with-health-conditions-disability/disability-hate-crime/>

<sup>8</sup>House of Commons Work and Pensions Committee (19 February 2012) Government support towards the additional living costs of working-age disabled people, 7th Report 2010-12, HC 1493, available at <http://www.parliament.uk/business/committees/committees-a-z/commons-select/work-and-pensions-committee/publications/>

- more disabled people in government publications that are not aimed specifically at disabled people (e.g. teacher training guide, income tax leaflets)
- more disabled people in senior positions and in media/broadcasting roles.

One person commented how empowering it was to see disabled people writing in the media or having disabled people in Parliament. It is important to see disabled people leading ordinary lives, not just 'super people'. For example, we need to ensure that society's view of an active disabled person is not a Paralympian but instead is a visually impaired person using their local gym, a person with a mental health condition being a member of their Wednesday night football team or an amputee jogging down the road. More than one in five people live with a disability or health condition, and we need to celebrate the ordinary. As one person said:

“The fact that a disabled person in sport is not a survivor or an inspiration or someone exceeding beyond the odds, it is simply a disabled person doing sport.”

Several people said that they should not be made to feel guilty or penalised because of being a disabled person or claiming benefits (that they are entitled to). These people are entitled to a sense of self-worth and dignity and to respect:

“we should commend those that can and do take a full and active role in society [...] but there will always be people who CANNOT... they manage and cope in their own way ... what is best for them... and usually very successfully.”

### ***Anything else***

#### **11. Do you have any suggestions for how we should implement and monitor the Strategy once it is developed?**

People strongly agreed with our suggestion that disabled-led organisations should be involved as well as individuals – and one idea was to set up an independent, accountable and transparent monitoring board. People asked for more surveys like the one we carried out for this consultation and to ensure young disabled people and students are included. Disability Rights UK welcomes the chance to ensure disabled people's voices are heard at the heart of government by engaging our members and other individual disabled people.

The strategy needs a clear measurable action plan; one measure of success will be for more disabled people to be participating in all levels of education and work.

But disabled people also want to have a greater say in policy-making, timely and comprehensive equality impact assessments. Respondents emphasised the need for transparency of information and evidence-based government policies (not making decisions before the end of a consultation, for example with the PIP/DLA consultation being a case in point).

The strategy must set out clearly what actions the Government will be taking and each department should have their own specific actions. These must include the essential communication and co-operation required between departments on specific issues.

Disability Rights UK asked people if they agreed that the strategy should set out clearly what steps they should take in particular areas, aligned with our objectives. Many respondents felt most strongly that the Government must set out how they will:

- deliver equality and human rights
- tackle disabled people's poverty
- enhance independent living
- ensure inclusion in education, training and employment
- promote leadership and control.

There should be an annual report outlining how these areas are improving for disabled people. We welcome participating in the monitoring of, and supporting the delivery of the Government's Disability Strategy.

## **12. Is there anything else you would like to tell us?**

See key issues.

### **List of Recommendations**

#### **General**

- the Government needs to show understanding of the diversity amongst disabled people and involve disabled people from start to finish.
- the Government should set out in the Disability Strategy how they will use the Right to Control model across government policies and how it will be rolled out across the country.

#### **Promotion and enforcement of equalities and human rights legislation**

The Government should:

- put their weight behind promotion and enforcement of equalities and human rights legislation. This should be for all disabled people, including those who feel their needs are being ignored due to their disability

- include equality and accessibility as essential criteria in contracts, and to involve disabled people in the monitoring of the performance
- set out in their strategy how they will use the public sector equality duty and the UN Convention as tools to promote involvement.

The Home Office should:

- commission an independent review of their guides with a view of promoting positive ways to comply with the Equality Act 2010.

### **Promoting positive attitudes and tackling prejudice**

- the Government should set out clearly in the strategy how they will promote understanding amongst the general public of disability, and in particular with regards to people with hidden impairments or fluctuating conditions
- Disability Rights UK supports the recommendation of the Work and Pensions Select Committee that the Disability Strategy contains proposals to tackle negative reporting of disability in the media and a strategy to get the message across that disabled people can and do make a positive contribution to society, very often as taxpayers.
- government departments should work together to make tackling disability hate crime and discrimination a priority, and publish a hate crime action plan
- all public sector staff should receive disability equality training which promotes positive attitudes to disabled people and increases their understanding of disability.

### **Involvement of disabled people**

The Government should

- implement the recommendation by the JCHR that they involve disabled people in the development of policy, and ensure that timescales and methods are used which enable a full range of disabled people and their representative organisations to be involved
- require government departments, local authorities, colleges, universities and others that they involve disabled people
- be seen to be leading the way for other public bodies and make involvement a key requirement of local authorities settlements and NHS bodies
- support work to encourage more disabled people to get involved in decision-making, locally and nationally.

### **Impact assessment**

- Disability Rights UK supports the recommendation by the Joint Committee on Human Rights that the Government publishes an assessment of the cumulative impact of decisions locally and nationally

- for the next 3 years, the Government should commission independent research into the cumulative impact of their policies on disabled people's equality. The research should report annually, and must involve disabled people.

### **Employment**

- the Government should publish, by summer 2012, a disability employment action plan for the next 3 years that includes joined-up action for different government departments.

### **Education and training**

- timely and appropriate support should be put in place for disabled students by staff who really listen
- colleges and universities should be made more accessible
- more encouragement of young disabled people to be ambitious so they can achieve their goals
- more work experience opportunities for disabled students
- improve access to transport
- funding to support advocacy and mentor schemes for disabled people

### **Information and support**

- Disabled people should be given better information and support in all areas of life
- the Government should include a firm commitment in the strategy that they will build support for DPOs into settlements with local government and into the new NHS structure as well as in the roll-out of the Right to Control.

### **Implementation and monitoring of the strategy**

- the strategy needs a clear measurable action plan. 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
- the strategy must set out clearly what actions the Government will be taking and each department should have their own specific actions. It must include the essential communication and co-operation required between departments on specific issues
- the Government must set out how they will:
  - deliver equality and human rights
  - tackle disabled people's poverty
  - enhance independent living
  - ensure inclusion in education, training and employment
  - promote leadership and control.
- disabled-led organisations should be involved in the implementation and monitoring as well as individuals – and one idea was to set up an independent, accountable and transparent monitoring board

- there should be an annual report outlining how these areas are improving for disabled people.