Shaping the future of equality

discussion paper

setting the challenge
introduction by Bert Massie

When the Disability Rights Commission opened for business in April 2000 we inherited an ambitious agenda for action for disabled people contained in the report 'From Exclusion to Inclusion' produced by the Government's Disability Rights Task Force. The Disability Discrimination Amendment Act 2005 and the work the DRC is now doing in support of its implementation marks the final legislative stage in delivering that agenda. As part of our ongoing work we will turn the legislation into practical action but now we must also look forward to meet new challenges.

Ten years ago, when the Disability Discrimination Act (DDA) became law, Britain was a very different place for disabled people.

In 2005, more disabled people are in work than ever before and almost all employers now have duties under the Disability Discrimination Act (DDA). Colleges and Universities are making great strides to increase their intake of disabled students and to improve their experiences and educational outcomes. Our public transport is more accessible and there are more accessible buses and taxis on the roads and more accessible trains on the tracks. Our planning laws and regulations have been amended to ensure that access for disabled people is no longer an afterthought, but central to the way we plan and design the built environment. New housing must be built to basic standards of accessibility, increasing choice and mobility for disabled people. Legislation has been passed which emphasises the rights of disabled people to make decisions about their own lives in the form of the Scottish Adults with Incapacity Act 2000 and the Mental Capacity Act 2005. Important legal precedents have been set concerning disabled people's human rights in relation to health and social care. Hate crime against disabled people was recognised for the first time in the Criminal Justice Act 2003. More service providers are taking steps to ensure they are open for business to disabled people.

By the end of 2006, the public sector will have new duties to actively promote equality of opportunity for disabled people. In January 2005, the Prime Minister's Strategy Unit published a major strategy for Government1 aimed at promoting the life chances of disabled people, with specific measures concerning independent living, the opportunities of disabled children, young people and their families, improving employment opportunities and setting up an 'Office of Disability Issues' in central Government. The Government has recently published a five year plan for the Department for Work and Pensions, aimed at providing more disabled people with the support and opportunities to move back into work.2

Most importantly, disabled people's rights are being taken seriously and are far more widely understood and supported. New relationships have developed between disabled people, business, public bodies and Government, where previously there were none. Partnerships have been formed and people are working together for change. We have begun to build some firm foundations and disability is finally on the map.

We know from the thousands of calls we receive on our Helpline every year, from the evidence we see in research, from what disabled people tell me when I meet them all over Britain, and from my own personal day-to-day experience as a disabled person, that whilst these major steps forward are recognised and welcomed, we are still a long way from our vision of 'a society in which all disabled people can participate fully as equal citizens'.

While we should rightly celebrate the progress we have made, there should be little room for complacency. We need a fresh agenda – not simply to address the gaps in our achievements to date – but also to prepare for the future.

One almost certain facet of the future will be the emergence of a Commission for Equality and Human Rights (CEHR). The DRC will not be merged into the CEHR. The CEHR will be a new body which carries forward our responsibilities.

We want to ensure that the CEHR pushes forward the frontiers of disabled people's rights and opportunities, and continues the momentum towards a society in which disabled people live as equal citizens.

To do so, we need to articulate to the CEHR, Government and wider society an ambitious vision and we need to set out what we believe to be the necessary steps in achieving that vision, just as the Disability Rights Task Force set out for the DRC and Government back in 1999.

This agenda will only be adopted if it is informed and owned by our friends and stakeholders who, once the DRC has gone, will need to hold the CEHR and Government to account for its delivery.

This discussion paper marks the beginning of this process. We want to hear from you about your priorities, ideas and thoughts concerning a fresh agenda – one which by 2020

could truly see a Britain in which disabled people have become equal citizens – with opportunities to play an active role throughout life and in all the different ways which make life fulfilling, rich and rewarding.

We look forward to working with you to set the challenge.

Bert Massie

Chairman

1 equal citizens?

As outlined in the introduction to this paper, the last 10 years have seen major leaps forward in the rights and opportunities of disabled people. Solid foundations have been laid on which to build a new agenda to reach our goal of a society in which all disabled people can participate fully as equal citizens.3 However, major inequalities persist in British society. Many of Britain's 10 million disabled people are still denied even basic human and civil rights, whole areas of life remain off limits, and significant numbers of disabled people are left ill-equipped to participate and contribute in society.4 This exclusion is fuelled by a widespread poverty of expectation concerning what disabled people can achieve and have to offer given the right support and opportunities.

The DRC has commissioned a report to map in detail the available evidence concerning disabled people's current opportunities for equal citizenship which we will publish in September 2005. Below we summarise what we believe some of the key challenges are. These challenges are not separate from each other – resolving one depends upon resolving another. However, it might be the case that prioritising action in one area leads to significant positive change across the board.

1.1   Full membership

Recent developments include changes to our planning laws and building regulations, developments of the Disability Discrimination Act (DDA) concerning access to goods, services and transport, duties on public authorities to prevent harassment and the recognition for the first time of hate crime against disabled people in the Criminal Justice Act 2003. Together these provide us with some of the tools needed to ensure that disabled people increasingly enjoy full membership of society.

However, disabled people continue to come up against social, organisational and physical barriers which send a clear message: that they do not fully belong.

Perhaps the most profound example of such exclusion is the continued separation of some disabled people from the wider community through their involuntary placement into institutional 'care', or through policy and practice which only provides disabled people with opportunities to learn, work or enjoy leisure pursuits in separate places of education, employment or social activity. Whilst such separation has provided sanctuary for some disabled people, it has often come at the expense of basic human rights to develop relationships and participate in the life of the community.5

By placing disabled people out of sight, such policy has also placed disabled people outside of the minds of those shaping the world we live in. In a world that has been created without disabled people in mind, barriers to inclusion are far and wide. This means there are one-off costs each time an individual seeks to be included whereas the cost-effective approach is to design in access from the outset. This amplifies the cost of inclusion, and so efforts to include more disabled people in mainstream society are met with arguments concerning cost, capacity, feasibility, risk and other people's perception of what is in disabled people's best interests. We have seen this in efforts to develop a more accessible transport system, to include disabled children in mainstream education, and to provide personal assistance to disabled people in the community rather than in institutions.

The invisibility of disabled people arising from this exclusion exacerbates a poverty of expectation concerning what disabled people have to offer society.

It has also contributed to poor relations between disabled and non-disabled people within mainstream life, which for some disabled people means living in fear and social isolation.

For example, two groups significantly affected are people with learning disabilities and those with mental health conditions. Both experience marked hostility in their everyday lives. This is sometimes overt, in the form of physical or verbal abuse, harassment and bullying, or less pronounced but equally damaging in being avoided or patronised. Both these groups are also significantly less likely to be in work than disabled people generally, and experience significant health inequalities.6

Many disabled people experience discrimination and inequality in relation to other aspects of their identity, for example their age, gender, parental status, race, religion or sexuality.7

Our infrastructure – housing, the wider built environment, our transport system – continues to be out of bounds and of limited use to many disabled people, not only for reasons of physical design, but also because of the way it is organised, managed and used by the wider public. For instance, signs in hospitals to 'haematology' are of little help to people with learning disabilities seeking the blood testing clinic. This denies some disabled people the chance of leading independent lives, and the opportunity to share in the life of the wider community. The pace of technological change is often faster than the pace of accessible technological change, meaning that developments in information and communications technology can leave some disabled people behind and without access

to the means to understand and exercise their rights and obligations. The DRC's own Formal Investigation into website accessibility found that 81 per cent of websites failed to meet even the most basic accessibility standards.8 Action encouraged amongst citizens for the wider benefit of society such as using public transport instead of private vehicles, recycling waste, finding and holding down a job, parents playing an active part in their children's education or grandparents helping out with the care of their grandchildren, are rendered difficult and sometimes impossible. Through social isolation, lack of access to services and reduced opportunities to take exercise, disabled people's health suffers.

Many public services are not delivering for disabled people, and many disabled people have real difficulties accessing basic services.9 The decline of local services and amenities such as local shops, sub-post offices, small pharmacies and GP's surgeries also make access difficult as well as removing opportunities for social contact and exchange.

Unless we accept that disabled people should have full membership of society, our steps towards equal citizenship will falter. If disabled people are part of planning, equal citizenship will thrive.

1.2   Taking control

Equal citizenship rests upon all individuals enjoying the same basic rights and freedoms in their lives. Crucially, this involves having an equal right to exercise control over one's own life, without the unwelcome interference of others.

In recent years, the development of 'direct payments', and proposals for 'individualised budgets'10 aimed at providing disabled people with control over money to buy and arrange their own personal assistance has begun to transform some disabled people's lives. The Mental Capacity Act 2005 and the Scottish Adults with Incapacity Act 2000 have begun to transfer control into disabled people's hands. Both these Acts have extended the right of disabled people to make decisions for themselves, provided better access to information, and the law has begun to favour disabled people's rights to take charge of their own lives.11

However, some disabled people continue to find others appointing themselves to act in their 'best interests' and take control over their lives.

The chief reasons are twofold. Firstly, the obligations of Government and public authorities to ensure citizens enjoy basic human rights and freedoms have often extended only to avoiding actions which might breach human rights, not to taking positive action to promote the equal enjoyment of human rights. Secondly, disabled people's requests for support and personal assistance has been characterised by others as 'dependency'. This has been used to legitimise others acting on disabled people's behalf without their authority, on grounds that this 'dependency' signals a lack of competency

amongst disabled people to exercise control responsibly and in a manner consistent with their 'best interests'.

Taken together, this creates a climate in which many disabled people are denied supposedly inalienable human rights, and so equal citizenship.

Without control over their own lives, the opportunities for disabled people to realise their potential through participating and contributing in family, economic and social life is severely limited, for example:

• 'care packages' to help disabled people get up in the morning and go to bed at night which are provided only five days a week, or only available if the individual is content to go to bed at 5.30 in the afternoon
• support for disabled children in school which is not available for any extra-curricular activities or at playtimes
• involuntary placements in residential homes which prevent disabled people from going to work, or
• failure to provide communication support which effectively denies the opportunity for disabled people to express their wishes.

This compounds notions that disabled people are largely 'passive' and 'dependent' and so not 'ripe for freedom'.12

The independent living movement has sought to reshape the aims and means of delivery of services such as social care through redefining what 'independence' means. It states that some individuals require assistance and support in their lives. However, though individuals have the opportunity to take control over the way such assistance is provided, in a manner consistent with their lifestyle, aspirations and in support of their participation and contribution, the assistance they receive no longer amounts to 'dependence'. Instead it can be understood as promoting their independence, their enjoyment of the same rights, freedoms and opportunities as other citizens, and their active participation.13

Taking control is a key measure of active citizenship. Whereas previously disabled people have been cast solely as the objects of State sponsored or informal care, independent living represents disabled people playing an active part, sharing responsibility for the delivery of support with public authorities and the wider community.

Key barriers to disabled people taking control include the culture of 'risk aversion' which has become more prominent in society generally and which has considerable influence over the policies, practices and culture of the social care sector. This often limits the opportunities for disabled people to make decisions about their own lives, for fear that if something goes wrong, the service provider or statutory authority will be liable. When the 'duty of care' is exercised in this way, it denies disabled people independence by denying them the opportunity to take risks concerning their own lives.

Related to this is the English common law tradition of the law acting in an individual's 'best interests' which has in a number of cases acted to deny disabled people rights which others presume to be inalienable, for example disabled people's rights to have and bring up children, or the rights of people with a learning disability to form relationships and get married.

Disabled people's request for support in making decisions, for example when navigating complex systems such as the health service, social care or benefits, has been used to argue that disabled people are unable to make such decisions responsibly. Yet such assumptions are not applied to non-disabled individuals who, for example, seek financial advice when dealing with the complexities of buying a mortgage, arranging a pension or making some form of financial investment. The recent Mental Capacity Act 2005 makes inroads towards extending the right of disabled people to make decisions for themselves. However, unlike in Scotland where the Adults with Incapacity Act 2000 was followed by the creation of an Advocacy Safeguards Agency and the Scottish Independent Advocacy Alliance, the Mental Capacity Act has not come with a fully effective package of services to support disabled people in making decisions, leaving many disabled people without the necessary support to exert control over their own lives.

Finally, inadequate funding of services and poverty both act to restrict disabled people's opportunity to take control. Additional expenditure on services and financial entitlements has frequently been seen in isolation of any potential benefits, as an 'extra cost' of dependency. The disability movement and the Prime Minister's Strategy Unit report on Disabled People's Life Chances instead describe costs of support as an investment, helping to unlock the potential that disabled people have to offer given the opportunity.

Independent living is the major model for the delivery of assistance to disabled people consistent with achieving equal citizenship. It is in itself a form of 'active citizenship' – individuals sharing responsibility with Government and public bodies – and it is the means by which disabled people can organise their lives in order to play an active part in economic, family and community life.

1.3 Helping shape society

Creating a society in which disabled people are equal citizens requires disabled people having the opportunity to play an active part in shaping the decisions affecting both national and local life.

Disabled people and their organisations have had a significant influence in local communities and national democracy. For example, it was through the campaigning of disabled people that the Disability Discrimination Act got onto the statute book, the Disability Rights Commission was set up, and direct payments were established. The ideas generated by the independent living movement are now common currency in the thinking of central Government, not just in relation to disabled people, but in wider reforms of the welfare state.

The Westminster Government has placed considerable emphasis on engaging and involving citizens in the development and delivery of public policy. This is central to its proposed reforms of the public sector and policies to improve community life. This has included, for example, patient involvement in designing and delivering healthcare, parent involvement in school improvement and community involvement in tackling crime and anti-social behaviour.

Such reforms are seen as central to fostering a common sense of ownership amongst those in a community, promoting pride in the place where they live or work, and a sense of connection to the community because it is a place whose future they are helping to shape.

Community involvement can also provide people with the chance to acquire new skills, develop new relationships, enhance their individual sense of status and worth, and influence the way others perceive them.

However, existing initiatives to encourage involvement tend not to treat disabled people as potentially active participants. In fact, these initiatives have often reaffirmed the assumption that disabled people should only be subject to the decisions and actions of others. In a Home Office report on community self-help for example, the role of disabled people is represented as follows: "networks [linking local residents to each other] are central to: the care of children; support for old, sick, disabled and isolated people...".14 This is the only mention of disabled people in the report.

In 2004, of 15,437 public appointments in England only 545 were of people who self-defined as disabled.15 In Scotland, the figure was a broadly equivalent 3 per cent.

Disabled people experience numerous barriers to being involved in decision-making, consultation and active participation. For example, whilst all disabled adults now have a theoretical right to vote, voting in local and national elections is still inaccessible to some disabled people.16

From the DRC's own experience, many Government consultations are still not routinely offered in formats accessible to people with sight impairments, learning difficulties or who use British Sign Language.

Where consultation papers have been produced in alternative formats, they have often not been made available at the same time as print versions, and this has included consultations specifically concerning disability policy.

Consultation meetings frequently rely solely on the spoken word or printed materials, or are held in inaccessible venues.

Many disabled people are excluded deliberately or through inaccessibility from jury service – a key civic duty.

Poverty and a lack of adequate support act to prevent disabled people's participation, and the benefits system has acted as a disincentive to participation. People on Incapacity Benefit, in particular, fear that playing any form of 'active part' could raise queries concerning their entitlement to the benefit. This can further alienate them from mainstream life, denying them an opportunity to acquire new skills which might be useful in moving back to work, and locking away potential and compounding exclusion.17

Sometimes disability groups become overwhelmed by the demands of those organisations seeking their involvement. There are excellent examples of disabled people's involvement in health, education and other service design. However, local groups of disabled people are often still perceived as a cheap or free source of advice and not as a valued community asset. Sometimes the enthusiasm and energy of individuals wanes in the face of constant struggle to meet demands, secure long-term funding and feeling under-valued.18

Of people who would be covered by the DDA definition of disability, one survey found that over half do not regard themselves as disabled.19 As a result, there may be gaps between the outlook and aspirations of the 'disability movement' and the disabled population at large. This challenges us to consider who 'disabled people' are, what they want and who are the range of people best placed to represent disabled people and ensure their voices are heard.

Only through ensuring disabled people have opportunities to engage and become involved as active citizens will we reshape society in a manner which is genuinely inclusive.

1.4   Getting equipped to play a part

In a competitive economy and society, improving human capital – in particular skills and qualifications which help people get on in life – cannot be ignored. To realise opportunities, individuals need to optimise their individual skills and competencies and build their experience. This does not only concern skills for work, but also skills for everyday life, for example managing finances, a home, interpersonal skills, and the skills needed to influence local and national decision-making.

Often overlooked is the fact that many disabled people, in seeking to deal with the challenges of everyday life not encountered by non-disabled people, have developed a range of skills, competencies and experience which could be of high value to society and the economy. These include strong organisational skills, detailed knowledge of the effectiveness of the welfare system and social care practice, and expertise concerning how to make services accessible and to support those with duties under the DDA in

meeting its requirements. Disabled people possess insights which could benefit the whole of society.

It is clear though that disabled people face considerable disadvantage, in part because of a lack of formal skills. 20 The reasons for this are complex. For many young disabled people, low expectations and poor opportunities in school have thwarted educational achievement. Segregation from the wider community can impact negatively on personal development, including interpersonal skills. The incidence of impairments and long-term health conditions is greater in areas of high social and economic deprivation, and amongst older people, meaning that for some disabled people their lack of educational opportunities has played a part in their having acquired an impairment or long-term health condition, rather than their disability being a factor in not having achieved qualifications.21

Whilst the wider policy agenda on education and skills has set clear and ambitious targets to marry the interests of learners with those of employers, this has frequently, and sometimes actively omitted opportunities for disabled people. Instead, where disabled people are concerned, policy has focused heavily on methods of teaching, on meeting 'special educational needs' and on contested concepts of 'inclusion' and 'inclusive learning'. These ideas are not unwelcome, but are often detached from wider educational objectives, and do not actively help equalise opportunities between disabled and non-disabled people in relation to acquiring the skills needed to get on, for example by promoting access to apprenticeships.

Dedicated action to equip disabled people with the skills and competencies to compete and to deal with the challenges of everyday life will help prevent disabled people losing out. It is key to promoting independent living, ensuring disabled people have a say in matters affecting their lives, securing full membership of society and in enabling disabled people to make a valued contribution.

1.5   Making a valued contribution

Citizenship concerns both individual rights and the contribution individuals make.

Disabled people contribute widely across society. 50 per cent of working age disabled people are now in work. Many disabled people engage in formal and informal voluntary activity. Disabled parents and grandparents play a central role in bringing up the next generation.

In some cases an individual's access to a right is deemed by Government to be conditional upon their acceptance of certain responsibilities. This idea is at the heart of proposed reforms of Incapacity Benefit, whereby in return for income and support from the State, some individuals are expected to make efforts towards finding a job. This idea appears to be central to the opinions of the British public – that if an individual is given something by the community – then that individual should give something back.

However, disabled people continue to face dilemmas concerning the extent to which they can fairly accept the obligations associated with citizenship. On the one hand, if disabled people do not enjoy the same basic rights, entitlements and opportunities as non-disabled people, then it seems unfair to expect the same obligations and responsibilities. On the other, if disabled people are protected from holding the same responsibilities and obligations as non-disabled people, for example by not being required to seek work when able to, might this confirm the very low expectations of disabled people – on the part of Government, its agents, the wider public and disabled people themselves? Might it mean disabled people lose confidence and give up on their own possibilities? Might this approach actually entrench the lack of basic rights, entitlements and opportunities that disabled people face?

In addition to unequal opportunities, the question needs to be raised as to whether there are some disabled people who, whatever action is taken to address disabling barriers, are still likely to be reliant on the State for income and personal assistance and who do not 'contribute' in ways that are widely recognised. And if this is the case, does this mean that these disabled people cannot access full citizenship?

Current debates on the responsibilities of citizenship tend to assume that the only responsibility at issue for disabled people is that of taking up opportunities to move from receiving benefits to earning a living. As we have noted, many disabled people on Incapacity Benefit fear playing any active part which may be perceived as displaying characteristics which threaten their entitlement. There are many disabled people who could work some of the time, intermittently over their life course, or who could engage in other valuable activity if only there were greater flexibilities in our benefits system, the necessary support in place and with barriers removed.

Amongst all the government initiatives about citizenship, the Russell Commission, set up in 2004 to develop a new national framework to increase youth volunteering and civic service by young people, is unusual in its consideration of disabled people's participation.[22] However, volunteering isn't covered by the Disability Discrimination Act, and nor are schemes to provide disabled people with support in the workplace such as 'Access to Work' available for voluntary activity, meaning vital adjustments and support may not be available.

Disabled parents experience significant barriers in bringing up their children. A taskforce set up by the Joseph Rowntree Foundation found that disabled parents are undermined by poor support and the negative attitudes of staff in schools, the NHS and social services.[23]

Contribution is central to citizenship. Ensuring more disabled people can play an active part will require concerted action to remove barriers, promote opportunities, develop new flexibilities in employment and rewards in the benefits system, and strengthen the value placed on different forms of contribution.

1.6   Getting on

Being an equal citizen also means having equal chances to get on in life – to develop personally, reach one's individual potential, realise ambitions and live out dreams. It also means having a more equal stake in the economic well-being of the country.

Whilst we have noted the contributions disabled people are making to social and economic life in Britain, evidence suggests a widespread poverty of expectation concerning what disabled people can reasonably be expected to achieve in life. This is not just held by non-disabled people, but by disabled people themselves.

For example, a survey in 2002 found that many young disabled people reported being discouraged from taking GCSEs, A levels or going on to higher or further education. One in three respondents expected to be earning less than other people by the time they are aged 30.24

People's impairments and conditions are frequently seen by others as actually determining their skills and competencies. This becomes institutionalised in 'fitness criteria' and competency frameworks governing entry to vocations such as the armed forces, nursing or teaching, which screen people out on 'medical' grounds. These often have little objective relevance to a person's ability to do the job, evidenced by the anomaly that there are many people who continue working in such professions having developed an impairment or long-term condition whilst in post.

Enabling disabled people to get on in life requires that we tackle such low expectations, their causes and their manifestations.

Whilst more disabled people are in work than ever before, evidence suggests that disabled people are more likely to work in manual and lower-paid occupations, and for a lower hourly rate of pay than non-disabled people.25 Even with professional qualifications or a degree, disabled people are less likely to be in managerial positions.26 Employer discrimination persists despite the Disability Discrimination Act.

Far fewer disabled people benefit from the security offered by home ownership, with a significantly higher number of disabled people living in social housing, meaning significant inequality in relation to the security offered by asset ownership.27

Getting on in life would become significantly easier for disabled people with the basics of support in place, a climate of higher expectations and without having to face discrimination.

2 preparing for the future

A fresh agenda needs to take account of the potential challenges of the future. The DRC has commissioned research concerning the opportunities and threats presented by

potential demographic and policy trends to the year 2020. This will be published in September 2005. Below we summarise what some of the big changes might be, and potential scenarios arising from them.

2.1 The ageing population

Britain is already a 'mature society' with more people aged over 60 than under 14 and this trend is projected to grow. Whilst life expectancy is expected to increase, this may not mean a longer life free of impairments or long-term health conditions, but rather a longer life with impairments and long-term health conditions.

This could result in a 'normalisation' of disability, with increased demand and supply of accessible goods, services and infrastructure. In faster ageing societies, such as Japan, inclusive design is now more commonplace.

Related to this could be greater political pressure from the older population for the provision of social support and assistance.

However, high numbers of older economically inactive people requiring personal assistance and support (and the potential of a crisis concerning pensions) could overstretch resources and stall any developments towards independent living. The older population with impairments and conditions may not connect with the 'disability movement' and so view themselves as competitors for resources, not allies.

This scenario could also create new opportunities and threats by exerting downward pressure upon those of working age to work rather than claim benefits. On the one hand, this could lead to greater intolerance of people claiming an income from the State. On the other, it could lead employers to adopt more flexible approaches as they seek to reach out to hitherto excluded groups, and increase pressure on the education system to invest in improving disabled people's skills.

Finally, an ageing population could lead to greater support both for genetic screening (for example to make savings in order to re-direct resources from disabled children to older people) and voluntary euthanasia.

2.2 The shape of households and families

If current trends continue, by 2020 over a third of the adult population will be living alone and many people will have infrequent contact with relatives. Many older single people will require personal assistance and care.

On the one hand, this could uncover the true extent of need for assistance from the State, currently masked by the provision of unpaid care and support which disability campaigners have argued denies rights and opportunities to disabled people.

On the other, this may represent a serious mismatch between the demand for and supply of social care. This could lead to calls for a return to institutional care on grounds of cost, undermining the rights of disabled people to control and choose packages of assistance. It may also place greater emphasis on self-provision through insurance policies, charging, or seeking unpaid and voluntary sources of support.

It could spawn new technological developments aimed at promoting independence, which through high demand may become cheaper to supply.

It may also shift social care policy away from protection and risk aversion towards promoting individual responsibility and risk-taking, as is beginning to be discussed in the recent Adult Social Care Green Paper for England,28 though this could also mean greater emphasis on informal care and low levels of service availability.

2.3 The composition of the population

We will see a shift in composition of the population in terms of specific impairments and conditions, age and ethnic diversity.

Health remedies may be found for certain 'conditions' such as diabetes and cystic fibrosis. There may be significant growth in other areas including obesity, sensory impairments, impairment resulting from strokes, dementia, mental health conditions and learning disabilities including autism.

The disabled population will be proportionately older than in 2005 and more ethnically and culturally diverse.

These changes are likely to bring new perspectives, different priorities, and new challenges in promoting equal citizenship. For example, disability may increasingly be accepted as a universal issue, experienced by most of the population at some point in their lives, rather than a 'minority issue'.

The changes may mean that existing organisations of and for disabled people will, if they fail to adapt, be unrepresentative of the disabled population at large. We have already seen strong campaigns against mainstream education for children on the autistic spectrum; organisations representing black and minority ethnic disabled people have expressed alienation from areas of the mainstream disability movement; parts of the older persons' movement conceive of disability as 'frailty' and linked to morbidity and declining health.

Greater numbers of people with mental health conditions and learning disabilities may pose more complex challenges for society as these groups may exhibit behaviour which others find awkward or challenging and so easier to exclude and avoid. More emphasis may need to be placed on improving social relations, where previously heavy emphasis has been placed on the physical and organisational environment.

Society may become intolerant of people whose conditions it believes are self-inflicted or dangerous and which it believes represent a lack of personal responsibility or risk, for example people who become obese, or people with mental health conditions, and this may undermine claims to equality of opportunity for disabled people.

Our public services may be insufficiently geared towards the needs and requirements of a re-shaped disabled population.

2.4   Scientific and technological developments

The pace and scale of scientific and technological developments is ever increasing. On the one hand, science and technology could be deployed towards offering major opportunities for disabled people to live independently, access the world on more equal terms, live longer healthier lives and overcome barriers.

On the other, scientific and technological developments could be deployed in ways which might undermine equal citizenship.

Developments in genetic screening combined with influential opinion concerning the responsibilities of potential parents to avoid having disabled children could significantly undermine developments in the rights of disabled children and their families, as well as disabled people as they move into adult life.

Genetic characteristics could become a further basis for discrimination.

Technology which is perceived to be a means to break down barriers to participation could by default create a new phenomenon of technological institutionalisation. This would result where disabled people can play a part in society, but with little direct human contact or without enjoying the same opportunities as non-disabled people to access society in different ways. For example, internet shopping may allow a transaction to take place, but not any human interaction, and could further compound disabled people's invisibility.

Smart technologies have been developed which aim to promote independent living by replacing human 'monitoring' with technological monitoring, including monitoring movement, temperature, maintenance of daily routines and providing contact with call centres. Positive though many of these developments are, they could equally lead to technological institutionalisation by removing human interaction for already isolated

individuals. They could deny choice and control by requiring individuals to comply with the technology, for example by having no choice but to abide by fixed routines. This also raises serious questions concerning privacy.

2.5   The economy

The last 10 years have been a period of high economic growth. But this may not last forever, and other changes to the composition of the economy, including the sorts of jobs available, could have serious ramifications for disabled people's citizenship and opportunities.

Disabled people may be particularly vulnerable to jobs cuts where employers perceive there to be additional costs in recruiting, retaining and developing disabled people.

Disabled people have comparatively low levels of qualifications – on average well below the level of qualification the Government has set as its target for the minimum skills level needed to participate in the economy. This means many disabled people lack individual capital and competitiveness, so that where disabled people are in work, many are in low skilled, low paid jobs which may be more prone to cuts.

Increased competition from other countries, taking away entry-level, low skilled jobs could seriously affect disabled people with low or no skills.

An economic downturn could affect notions of 'reasonableness' in making adjustments to the provision of goods and services, with costs asserted as justification for poorer quality of adjustments or no adjustments at all.

It may also adversely affect the ability and willingness of Government to locate budget through taxation to pay for services and support, particularly where these are not seen as effective 'investments' or priorities.

2.6   Equality

The new Commission for Equality and Human Rights (CEHR) will bring together work on promoting equality and ending discrimination in relation to disability, race, gender, age, religion and belief and sexuality.

The CEHR could be an extremely powerful force in helping to reshape British society and address issues of multiple discrimination and disadvantage.

How the CEHR conceptualises equality, sets its aims and scope will be vital stages in ensuring that it is able to effectively advance equality for disabled people.

There is a danger that the CEHR may adopt a single definition of equality which is not grounded in the experiences of disabled people, for example by omitting to address the role of social rights in promoting human rights and independent living, by developing agendas around 'good relations' which do not take account of disabled people's experiences of living in the community, or by failing to embrace the notion of 'reasonable adjustments'. The CEHR may also define disability narrowly, failing to understand the full range of experiences of people with different long term health conditions and impairments.

There may be competing agendas within the CEHR and conflicting interests, for example around questions such as abortion.

The disability movement may be best equipped to influence the CEHR's agenda if it actively considers the wider equality agenda and represents the diversity of disabled people.

3 developing an agenda

The DRC wants to work with our friends and stakeholders to develop a fresh agenda – one which builds upon our achievements to date, addresses the gaps, and meets the potential challenges of the future.

We propose an agenda aimed at promoting equal citizenship, ensuring that by 2020 all disabled people:

• enjoy full membership of society

• have control over their own lives

• help shape the world we live in

• are equipped to play a part

• make a valued contribution

• get on in life.

This discussion paper marks the beginning of this process. Over the coming months we want to generate a national debate on the way forward, and tackle some of the tricky issues in developing an agenda of benefit to all disabled people.

We invite you to play an active part in determining the big challenges ahead and in agreeing how to tackle them.

1. What should our priorities be for a new agenda and why?

2. Are there specific issues for Scotland, Wales or England which we need to take account of?

3. What can we learn from successful action already underway in parts of Britain or abroad in addressing these priorities?

4. What new ideas do you have about how we can address these priorities?

5. What are the tricky issues and how can they be resolved?

3.1 The big questions

3.1.1 Full members of society

The DRC believes that for disabled people to enjoy equal citizenship, our communities must be ones in which disabled people fully belong, feel safe and can access basic services.

What are the chief challenges in making our communities more inclusive?

What good ideas or examples do you have of how changes can be made?

Is there ever a case for disabled people living, learning or working in places which separate them from the wider (non-disabled) community?

How can relations between disabled and non-disabled people best be improved so that disabled people feel safe and have a real sense of belonging in their community?

3.1.2 Taking control

The DRC believes that independent living is the foundation stone of equal citizenship. This means all disabled people having the same choice, control and freedom as any other citizen, with access to the practical assistance people need to exercise this right.

What are the chief challenges in seeking to ensure that all disabled people can take control over their own lives?

What good ideas or examples do you have of how this can be done?

Are there instances where some disabled people cannot exercise choice and control, even with support, and how do we ensure these people enjoy independent living?

Is the balance currently right between protecting people from risks, and giving people the independence to take risks in their lives? If not how should it be changed?

Can we reasonably expect the State to provide for all disabled people's requirements for personal assistance and support or do we need to look at how informal and voluntary activity can be commanded towards promoting independent living as well?

3.1.3 Helping shape the world we live in

The DRC believes that our society will only fully change for the better through disabled people playing an active part in shaping its future.

What are the chief challenges in ensuring that the views of all disabled people are properly represented in decisions affecting the country and local communities?

What good ideas or examples do you have of how this can be done?

How can we ensure that decision-makers are taking on board the views, wishes, aspirations and ideas of different disabled people, including those with long term health conditions, not just those who are currently part of the 'disability movement'?

How can the capacity of local disability organisations to influence decision-makers be built in cost-effective ways?

3.1.4 Getting equipped to play a part

The DRC believes there needs to be a major drive to equip disabled people with the skills to fully participate and get on in life.

What are the chief challenges in improving disabled people's 'human capital' (ie skills and experience) and equipping disabled people with the skills to participate?

What good ideas or examples do you have of how this goal can be achieved?

How important do you believe skills and qualifications are in helping disabled people get on in work and participate in the wider community?

How can we develop programmes which raise the achievement of all disabled people, without leaving anybody behind?

3.1.5 Making a valued contribution

The DRC believes that more disabled people need to be provided with the opportunities and support to contribute to family, economic and community life.

What are the chief challenges preventing disabled people from making a valued contribution?

What good ideas or examples do you have of how this goal can be achieved?

To what extent and on what conditions should disabled people accept the same obligations to work, as opposed to claim benefits, as non-disabled people?

Should disabled people have access to the same rights and level of support for contributions like volunteering and parenting, as are already beginning to be in place for paid employment?

3.1.6 Getting on in life

The DRC believes that disabled people should have equal life chances, with full opportunities to reach their individual potential, realise ambitions and acquire a more equitable stake in the economic well-being of the country.

What are the chief challenges preventing disabled people from getting on in life?

What good ideas or examples do you have of how this goal can be achieved?

Sometimes it has been argued that the DRC should not advocate aims which in practice mean some disabled people have the opportunity to get further than others, for example strategies to close the qualifications gap between disabled and non-disabled people. What are your views on this?

Should disabled people be given specific help to build up financial assets – for instance, help to buy their own home or a fund to invest for the future – rather than just benefit income?

4 join the debate!

The first part of the Disability Debate will take place between June and September 2005.

During this period we want to work with you to define the key priorities for a future agenda, and to have a serious debate about some of the tricky issues identified in this paper. Over the summer we will host a series of discussions on issues including the impact of risk on disabled people's lives, welfare and work, the role of special services, and on what the role of professionals should be in disabled people's lives. There will be further discussion papers and discussion packs on these topics which you can download from our website.

We want to make it easy for you to take part, so we are offering a number of ways for you to share your views, comments and ideas.

You can register on our interactive website and take part in on-line discussion and debate at: www.disabilitydebate.org

You can write to us or send a tape concerning your views and comments to:

The Disability Debate

Disability Rights Commission

3rd Floor, Fox Court

London WC1X 8HN

Or email your comments to us at: disabilitydebate@drc-gb.org

You can use this discussion paper to have a discussion in your local area or within your organisation and send or email us a note of the meeting.

Unfortunately, the DRC does not have the resources to send staff out to discuss the issues directly with people in their local area. However, we will be making a special effort to discuss the issues directly with 'hard to reach' groups over the coming months.

We look forward to discussing the issues with you!

Footnotes

1   Prime Minister's Strategy Unit report on improving the Life Chances of Disabled People, Stationery Office 2005 www.strategy.gov.uk

2   Department for Work and Pensions Five Year Strategy, Stationery Office 2005 www.dwp.gov.uk

3   See 'Disabled People and Citizenship', Jenny Morris 2005, DRC www.drc-gb.org

4   Disability Rights Commission Strategic Plan, DRC 2004.

5   Human rights and independent living, DRC, Parker, C 2005, DRC www.drc-gb.org

6   Hidden Lives – Improving the life chances of people with a learning disability, Turning Point 2004, Mental Health and Social Exclusion, Social Exclusion Unit 2004.

7   'Diversity and disability – exploring the interaction between disability, ethnicity, age, gender and sexuality', Grewal I et al 2003, DWP Research Report 188.

8   Formal Investigation Report: website accessibility www.drc-gb.org

9   Breaking the Cycle – taking stock of progress and priorities for the future, Social Exclusion Unit, ODPM 2004.

10   Promoting the Life Chances of Disabled People, Prime Minister's Strategy Unit 2005.

11   See, for example, Burke vs The General Medical Council www.drc-gb.org

12   Clements, L and Read, J, forthcoming: 'disabled people are not considered to be "ripe for freedom" in the same way that slaves, serfs, southern blacks and women were once not thought to be ripe for it'.

13   DRC Policy statement on Independent Living, DRC 2002 and Prime Minister's Strategy Unit report on improving the Life Chances of Disabled People, Stationery Office 2005.

14   Home Office Active Community Unit 1999, p.1.

15   Delivering Diversity Public Appointments 2004, Cabinet Office 2004.

16   Polls Apart: An evaluation of the accessibility of the 2004 European Parliamentary and Local Elections all-postal pilots, Daone, L, Morris, G and Scott, R 2004, London: Scope.

17   Equal citizenship and Incapacity Benefit Reform, Howard, M and Crowther, N 2005, DRC 2005.

18   Towards Access Standards: The Work of Local Access Groups in England and Wales, DRC 2004.

19   Disabled for Life? Attitudes towards and experiences of disability in Britain, Grewal I et al 2002, DWP.

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25   Disability Briefing December 2004, DRC 2004.

26   'Earnings and employment opportunities of disabled people', Blakabay, D et al, 1999, DfEE Research Report 133.

27   Disabled for Life, Grewal I et al, DWP 2002.

28   'Independence, well-being and choice: Our vision for the future of social care for adults in England', Department for Health 2005 www.dh.gov.uk