



# **DISABILITY 2020:**

## **Opportunities for the full and equal citizenship of disabled people in Britain in 2020**

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## **Note on the data**

This paper was written in 2005 and uses the most up-to-date information that was available at the time. Permission to publish from the Disability Rights Commission was received in 2007.

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## Executive summary

Disabled people in Britain currently have very limited opportunities to exercise full and equal citizenship, despite the progress that has been made. Both the Government and the Disability Rights Commission (DRC) agree this represents an unacceptable social injustice and have strategies designed to end this inequality. *Disability 2020* assesses key health, demographic and policy trends in order to gauge the possible circumstances and experiences of disabled people by 2020 against the ambition of full and equal citizenship for all disabled people.

### Data limitations

Given the limitations of the data, and because it would be foolish for anyone to assert that they can predict the future, this report cannot offer a definitive account of the circumstances and experiences of disabled people in 2020. Instead, the available evidence is brought together to suggest a range of possible scenarios. This analysis is intended to indicate the issues and interventions policymakers and others should prioritise in order to maximise the chances of achieving opportunities for full and equal citizenship for all disabled people by 2020.

*Disability 2020* is underpinned by an understanding of disability described in the box below:

**‘Disability’** refers to the disadvantage experienced by an individual as a result of barriers, such as physical and attitudinal barriers, that impact on people with mental or physical impairments and/or long-term ill health.

**‘Disabled people’** refers to anyone who is disadvantaged by the way in which the wider environment interacts with their impairment or long-term health problem. This may vary over time.

However, there are many other definitions of disability. For example, the Disability Discrimination Act 1995 defines a disabled person as someone with ‘a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities’. This is the definition that provides the legal basis for assessing compliance with public duties and anti-discrimination legislation.

As data about disabled people is based on a range of different definitions of disability, different surveys produce different estimates of the number of disabled people. According to the General Household Survey, there were around 11 million disabled adults in 2002. According to the Family Resources Survey, there were around 9.8 million disabled adults, and an estimated 700,000 disabled children in the UK in 2003. In order to convey a reasonable picture of possible health and demographic trends, this report uses available

data from a range of data sets.<sup>i</sup> However, it is important to note that the different sources are not necessarily compatible, and may be based on different definitions.

Even when the range of evidence available is combined, a complete picture of trends to 2020 cannot be generated. The evidence does concur in reinforcing two central points about disability. Firstly, disability cannot be regarded as a marginal issue as it directly affects at least one in five adults and one in 15 children, and many more indirectly. Secondly, disabled people experience disproportionate levels of disadvantage that prevent them from exercising full and equal citizenship.

Here we summarise the key findings from *Disability 2020* as they relate to the opportunities for disabled people across the lifecycle to exercise full and equal citizenship. In particular, we examine disabled people's likely opportunities to: take control, help shape society, make a valued contribution, get equipped to play a part and get on in Britain in 2020.

### **The best start? Children, young people and disability**

The General Household Survey estimated the number of disabled children under 16 in Britain in 2002 to be 770,000, out of a population of 11.8 million children. By 2020, the total number of children is projected to drop to 10.8 million, but it is widely anticipated that the proportion who are disabled will have increased. The drivers of the increase in disability among children and young people are not well understood but might include improved diagnosis, reduced stigma associated with reporting disability and better survival rates for pre-term infants. A better understanding of these drivers is necessary in order to improve our ability to project the future numbers of disabled children and to plan and deliver sustainable policies. It is also necessary in order to remove disabling barriers rather than just focusing on remedying the consequences of disability.

The current lack of understanding makes it impossible to accurately predict how the prevalence of disability among children and young people may change by 2020. However, we may observe that in recent years the fastest growth in the numbers of people reporting disability has been among children aged under 16, and if the same rate of increase that occurred between 1975 and 2002 were to be observed between 2002 and 2029, there would be over 1.25 million children reporting a disability by 2029. Of course, there is no evidence to suggest the same rate of increase will continue in the future so we should not hold too much store by such a figure. Nor is it clear whether or not the trend for slightly higher proportions of boys than girls to report disability will continue.

The rise in the number of children and young people reporting a disability appears to have been driven in part by a significant increase in the prevalence of particular types of impairment, namely, mental health problems, autistic spectrum disorders and emotional and behavioural disorders. It is difficult to ascertain the extent to which the increase in these impairments is down to

improved diagnosis, and the extent to which it represents an actual increase in prevalence. The number of children with complex needs also appears to have risen as a result of the increased survival rates among pre-term babies and children after severe trauma or illness. This has enabled increasing numbers of children to survive infancy and to live longer, albeit with complex needs. It is anticipated that rises in the number of children reporting these disabilities will continue. These are potentially problematic trends because people with mental health problems and more complex disabilities tend to experience particular discrimination and exclusion from full citizenship. There are also worrying increases in childhood obesity and sexually transmitted diseases among young people, both of which can lead to disability.

There is a two-way relationship between disability and poverty in childhood. Disabled children are among the most likely to experience poverty and poor children are more likely to become disabled than those who are better off. In 2002/2003, 29 per cent of people with one or more disabled children in the household lived in poverty, compared with 21 per cent of households with no disabled children. It is well established that persistent poverty during childhood has significant scarring effects on life chances but it also impacts on childhood experiences. It is particularly important to monitor the relationship between poverty and rising mental ill health among children and young people.

The extent to which full and equal citizenship for disabled people can be achieved in the future will rest partly on the extent to which mechanisms to reduce child poverty can be rooted in the fabric of British public policy now. Likewise, the successful achievement of the Government's target to end child poverty by 2020 will rest partly on sustained, targeted policies to tackle the poverty and social exclusion experienced by disabled children. For example, there is a need to ensure that Disability Living Allowance is available to and taken up by all those disabled children whose families experience extra costs as a result of disability. The level of the benefit also needs to be set at a rate that adequately covers the extra costs of disability.

There also needs to be a transformation in the quality and accessibility of key services, such as education and social care, for disabled children, young people and their families. The Government has recognised this and launched a range of initiatives but in order to be successful, the Government will have to address much more clearly how the achievement of its goals is to be resourced, managed and monitored.

It will be critical that the needs of the diverse population of disabled children and young people are built into the design of early years services, education, childhood and youth services as they undergo reform over the coming years. For example, this means ensuring there are explicit resources and processes in place so that disabled children and their families benefit from the expansion of the childcare infrastructure. This cause will be boosted if take-up of direct payments can be encouraged and if individual budgets can be developed beyond the concept stage at the earliest opportunity. This would provide disabled children and their families with the resources necessary to influence

the shape of such public services. Some helpful targets have been set: by 2010, all three- to four year-old disabled children should have access to free part-time early education and providers will have access to a fully supported early years Special Educational Needs Coordinator. By 2015 Sure Start is to ensure that all families with a disabled child under five years can access high quality, flexible childcare. However, many parents of disabled children are not in employment, and so are ineligible for working tax credits and thus may not be able to afford this childcare provision. There is also a low take-up of tax credits by parents of disabled children who are eligible. In April 2004, only 7.8 per cent of families with one disabled child received the childcare element of the Working Tax Credit, compared to 14.6 per cent of families with no disabled child. Reforms will be necessary to remedy these structural barriers, which prevent access to key services by disabled children.

A significant challenge over the next 15 years is to discredit the view that disabled children have little or nothing of value to contribute. There has been a trend towards more positive attitudes towards disabled people of all ages. As new anti-discrimination and pro-equality legislation beds in there is a good chance of this trend continuing. However, certain groups – whose numbers are expected to increase over this period – continue to face high levels of discrimination and negative attitudes. This is a particular issue for those with mental health problems.

Progress in breaking down attitudinal barriers could be undermined by advances in the use of genetics. Genetic science is underpinned by a conceptual approach that can sit in tension to the social model of disability. Genetic science could define disability in terms of biology and abnormality. So far the process of 'geneticisation', whereby social problems are redefined as genetic problems, has been countered by a strong disabled people's movement in Britain and the fact that the Government has accepted, at least in part, the social model of disability. Nevertheless, it will be important to ensure that developments that promise social benefits are not advanced at the cost of ethical principles and the erosion of the social model of disability.

Statutory levers to deliver full and equal citizenship for disabled people have been substantially strengthened by a new positive duty on all public authorities to promote the equality of disabled people. For example, this will mean that schools will have a new duty to promote the equality of disabled children. The final part of the 1995 Disability Discrimination Act also came into force in 2005, bringing colleges and universities into line with other educational establishments in having a duty to make their physical facilities accessible to disabled people.

Overall, there has been slow progress in integrating children with Special Educational Needs (SEN) into mainstream schools and children with statements of SEN are still overwhelmingly taught in segregated settings. For example, analysis of figures from 148 English local authorities between 2002 and 2004 shows that in 2004, there were still over 100,000 children with SEN being taught in segregated settings. The inclusion agenda has so far had little impact on the range of needs of pupils with statements of SEN who attend

mainstream schools. Competing policy agendas may also pose a threat to the opportunities for greater inclusion. For example, in both compulsory and post-16 education, the focus on raising standards of educational attainment and the importance ascribed to performance league tables, means that practitioners may invest their energies in this rather than in creating an inclusive environment. Although the two policy agendas are not necessarily mutually exclusive, there may be tensions. For example, the focus on attainment may create pressure towards the exclusion of children with SEN.

After leaving school, the transition to adulthood can be challenging for any young person, but disabled young people often face additional problems of low expectations, a lack of continuous service provision, unmet needs in further and higher education, and a disproportionate likelihood of not being in education, employment or training. This is a period which will continue to require particular attention especially during the planning and implementation of reforms to children's and youth services.

The social justice case for greater opportunities for full and equal citizenship for disabled children and their families is a compelling one. Policy trends would seem to acknowledge this and many point towards greater progress in improving the life chances of disabled children. However, translating ambitious proposals into practice is likely to prove challenging, both in terms of adequately meeting needs and in removing the barriers that disabled children and young people face in achieving full and equal citizenship.

### **The prime of life? People of working age and disability**

The Government Actuary's Department estimates that the working age population (from 16 to the statutory pension age) will rise from 35.78 million in 2003 to 38.8 million in 2020 (partly as a result of the increase in women's statutory pension age over this period). Our projections based on past trends in the Labour Force Survey show changes in the profile of disability in the population to 2020. These are projections only, and caution should be exercised in interpreting the figures. The projections show a moderate decrease in the prevalence of self-reported long-term health problems or disability among people in their 20s, and moderate increases among people in their 30s and 40s between 2004 and 2020. There are more significant increases in self-reported long-term health problems or disability among people in their 50s from 43 per cent in 2004 to 58 per cent in 2020.

The World Health Organisation has predicted that depression will be the leading cause of disability by 2020. The anticipated growth in the number of adults with mental health problems and learning disabilities is particularly significant because in the past these have caused people to be among the least likely to be in paid employment.

In the second half of this decade we are likely to see considerable pressures on the public finances, with the rate of increase in public expenditure slowing in all areas including health spending, and with the 2007 Comprehensive Spending Review signalling a reduced rate of growth. Achieving the full and

equal citizenship of disabled people is a social justice issue, not simply a resource issue, nor will the achievement of all measures of citizenship be contingent on public spending. However, public spending is essential in moving towards full and equal citizenship for disabled people.

One of the primary ways in which disabled people of working age will be affected by the pressures on public expenditure will be in relation to the benefits system. In 2004, almost half of all disabled people of working age were not in paid employment, and some of those disabled people who were in work received support to enable them or their employers to meet the extra costs of disability. This means that the way the benefits system works is crucial to the extent to which many disabled people are able to take control of their lives. The Department for Work and Pensions (DWP) has projected that expenditure on working age benefits for 'people with sickness or a disability' will decrease slightly from around four per cent of GDP in 2004/05 to 1.3 per cent in 2019/20 and that a lower percentage of GDP overall will be spent in 2019/20. The DWP has an objective of 'improving the rights and opportunities for disabled people in a fair and inclusive society' and estimates that it spent 2.5 per cent of GDP in meeting this objective in 2004/05, but will spend a lower proportion, 2.2 per cent, by 2019/20. These projections do not seem consistent with providing better services and maintaining relative living standards for disabled people in the context of a rising prevalence of disability.

If the overall number of disabled people continues to rise, and there are more people with mental health impairments and learning disabilities, we may see an increase in the proportion of disabled people who are out of work and claiming benefits. On the other hand, if the Government is successful in realising its objective of improving the rights and opportunities for disabled people and closing the gap between the employment rates of disabled people and the overall population, the proportion of disabled people who are out of work and claiming benefits may fall. The success of the Government's proposals to reform sickness and disability benefits and to roll out Pathways to Work, the flagship labour market programme for disabled people, will be crucial in boosting the employment rates and income levels of disabled people. We know that one of the key elements of effective support for disabled people is that it is delivered flexibly and in a way that is tailored to the needs and circumstances of the individual. This can make support more costly to deliver, but it will also make it more effective.

In 2005, the Government declared that it aspires to achieve a working age employment rate of 80 per cent. The rate in 2004 was 73 per cent, so achieving the aspiration means an extra 2.5 million people being in employment. The DWP has indicated that it believes that the achievement of an 80 per cent working age employment rate would largely offset the effects of an ageing population. This will not be simple. High levels of worklessness among disabled people have persisted during periods of economic buoyancy. This suggests that the objective barriers and constraints to taking work are likely to be complex, deep-rooted and multi-faceted.

One of the key barriers to work that disabled people face is low qualifications. In 2003, 40 per cent of disabled people of working age had no qualifications. There has been a significant increase in the demand for higher qualifications and this trend is likely to continue to 2020. The Learning and Skills Council has warned that without at least a basic grasp of Information Technology skills, people will find it increasingly difficult to find work. This poses an increasingly significant barrier to work for many disabled people. For example, of those in receipt of Disabled Living Allowance, 37 per cent have never used a computer, while only 37 per cent have used the Internet.

The other area in which the level of public expenditure is likely to have a significant impact on disabled people is in relation to health and social services. The current system of service provision is largely characterised by a lack of coordination and partnership working, and resources continue to be tied up in dependency-creating services rather than being diverted to services based on principles of independent living. Individual budgets are to be developed from 2005 but identifying appropriate resources will be essential if services are to facilitate independent living. A lack of additional resources is also likely to mean that increasing competition could emerge between different local budget holders and this poses a threat to a very promising policy development. Although the Government has acknowledged that introducing individual budgets will require a 'culture shift', it has not specified the levers by which it will deliver such a shift by 2020. This is important because policy silos have developed over many years, meaning that disabled people have had to adapt to services rather than vice versa.

Very often citizenship, and in particular opportunities to help shape society and make a valued contribution, is cast in terms of economic participation through employment. However, citizenship is equally about social, civic and political participation and disabled people of working age frequently face social as well as economic exclusion. Social and civic participation is an important expression of citizenship for disabled people, but can also play a role in dismantling disabling barriers. However, there is some evidence to suggest that there is a pattern towards an increasing class divide in patterns of social interaction and civic participation.

In order to halt this trend, national and local government consultation will need to be more imaginative to bring disabled people into political processes more fully. Formal participation as governors of public bodies, membership of panels and other modes of public involvement tend to lack involvement by disabled people. In 2004, of 15,437 public appointments in England only 545 were of people who regarded themselves as disabled; the proportion was similar in Scotland. The argument for involvement is not just rights based, but is part of a vision that 'user involvement' will improve public service delivery.

The opportunities for disabled people to exercise full and equal citizenship are diminished by the disproportionate likelihood of them living in poor or inappropriate housing and in a deprived area. The level of investment in social housing is increasing to 2007/08, but it is unclear what will happen subsequently. Even if the Government's strategies to address problems of

affordability in market housing are successful, the long-term prospects for the supply of social sector housing are likely to mean that housing need will continue to outstrip supply by a significant margin. This will mean that disabled households needing to access social housing will still face long waits, particularly in the South.

Disabled people face considerable disadvantage because the majority of the housing stock has not been designed with the needs of disabled households in mind. By 2020, Part M of the building regulations, assuming they are retained, will have applied to new dwellings for 20 years. This will mean that the proportion of dwellings meeting 'visitability' standards of access in the overall housing stock will have increased. Assuming rates of building and demolition continue at current rates, by 2020, we estimate that the proportion of housing stock in England built under the Part M standards will have reached the still-low level of 12 per cent.

Pressures to reduce the unit costs of housing in both the private and social sectors will have tended to push the space standards of dwellings towards either their regulatory minimums in the case of the social sector, or the minimum size that the market will bear in the private sector. This sits unhappily alongside studies of disabled households housing needs that have highlighted the importance of space, for example, to accommodate adaptations and the use of necessary equipment. The policy drivers to increase housing density and reduce cost may militate against the adoption of higher accessibility standards.

The problems faced by disabled people living in unsuitable housing can be exacerbated if that housing is also of a poor quality, and disabled people are more likely to live in housing that does not meet decent homes standard. By 2020, the Government should have met its target to ensure that all social housing meets a decent standard and should have made significant progress in reducing the numbers of vulnerable households, including disabled people living in non-decent homes.

Disabled people face a disproportionate likelihood of living in a deprived area. Even if the prospects for deprived areas improve, the projected increases in single households may mean that more people are vulnerable to mental ill health as a result of living alone. The most up-to-date household projections show that the number of single person households will increase by over 2.5 million between 2001 and 2021. More research is needed to understand the full social impact of the rise of single households.

People of working age are often expected to be in paid employment, to raise children and to care for older relatives as well as participate in social and civic life. Disabled people of working age have limited opportunities to exercise these aspects of their citizenship and there are considerable challenges to dismantling the barriers in the coming years. Nonetheless, there are some positive signs for the future such as the Government's ambition to increase the employment rate of disabled people, the reform of the welfare system, the

roll-out of active labour market policies for disabled people and the efforts to increase housing supply and counter area-based deprivation.

## **A good old age? Older people and disability**

An ageing population is a common trend across industrialised nations. People are living longer, and there are fewer young people as a proportion of the total population. One factor that explains the increase in the number of older disabled people is the good news of increasing life expectancy among disabled people of working age. The Personal Social Services Research Unit (PSSRU) has forecast that the number of older disabled people is likely to increase by around 40 per cent between 2002 and 2022, if age-specific disability rates remain constant.

Despite the projections, there remains considerable uncertainty about future levels of disability. There are three main theses on the future levels of disability in the population. The most optimistic one is the compression of morbidity thesis. This proposes an increase in life expectancy combined with a postponement of disability to later years. The overall result is a reduction in the proportion of time spent disabled. In contrast, the expansion of morbidity thesis suggests that people will live longer and experience more time disabled. The third hypothesis is a combination of the other two and suggests there will be an expansion in the time spent in good health as well as the time spent in disability. The analysis set out in the Treasury's review conducted by Derek Wanless in 2002 suggested there will be a fall in serious ill health, but an increase in minor health problems. In this analysis it is likely that the older people of 2022 will be healthier than the older people of 2002.

Clearly, future demand for health and social care services will be closely linked to changes in the disability profile of the population. The PSSRU has developed three scenarios about the characteristics of the disabled older population in 2022 and the consequent variance in demand for services. These are described in the box below.

### **Long-term care expenditure for older people: three scenarios by the PSSRU**

#### **1. The base case**

The model projects that, to keep pace with demographic pressures over the next 20 years, residential and nursing home places would need to expand by nearly 40 per cent and home care hours by nearly 40 per cent. As a result of the same pressures, the numbers of recipients of disability benefits (attendance allowance and the care component of the disability living allowance) are projected to increase by just under 40 per cent. The model also projects that long-term care expenditure will need to rise by around 110 per cent in real terms over the next 20 years to meet demographic pressures and to allow for likely real rises in care costs. This projection is highly sensitive to the projected growth in the numbers of older people, future dependency rates and future real rises in care costs. Looking at expenditure

as a percentage of GDP, the projected rise equates to an increase in total spending on long-term care from 1.5 per cent of GDP in 2002 to just under 1.9 per cent in 2022.

## **2. Disability scenarios: the Brookings and the half Brookings scenario**

Under the most optimistic scenario (the Brookings scenario), in which age-specific disability rates fall in line with increases in life expectancy, the numbers of disabled people are projected to increase by 23 per cent by 2022, compared with 40 per cent under the base case. Under the less optimistic, 'half-Brookings' scenario, in which disability rates fall at half the rate by which life expectancy increases per year, the numbers of disabled people are projected to rise by 32 per cent by 2022. It is particularly the numbers of severely disabled older people that rise more slowly under the two Brookings scenarios than under the base case.

As would be expected, both scenarios have a significant effect on projections of demand for informal care, formal care services and disability benefits. Between 2002 and 2022, demand for informal care is projected to increase by 33 per cent under the 'half-Brookings' scenario and 25 per cent under the 'Brookings' scenario. This compares to an increase of 40 per cent under the base case. Residential care will have to expand by 12 per cent by 2022 under the 'Brookings' scenario and by 25 per cent under the 'half-Brookings' scenario to keep pace with rises in the number of disabled older people. This compares with the 38 per cent projected increase under the base case.

A similar pattern is seen for disability benefits. Under the 'Brookings' scenario, the number of recipients is projected to rise by 15 per cent, and under the 'half-Brookings' scenario by 28 per cent, from 2002 to 2022, in comparison with 39 per cent under the base case.

Taking into account the projected expansion of the economy, under the most optimistic scenario considered here ('Brookings'), total expenditure, as a proportion of GDP, would rise gradually to reach 1.6 per cent of GDP in 2022. This is compared to the increase required under the 'half-Brookings' scenario of 1.7 per cent of GDP in 2022 and under the base case of 1.9 per cent of GDP by 2022. These results confirm the findings of other studies that projections of long-term care are highly sensitive to assumptions about future rates of disability among older people.

One factor that influences the demand for formal care is the supply of informal care. The PSSRU model suggests that there is likely to be an increase in spouse carers of disabled older people in the future. Such carers are themselves elderly, possibly in poor health and many are themselves in need of support from formal services. Any increase in spouse carers raises issues about the need for support for carers. In 2004, the majority of carers aged 65 and over reported a limiting long-standing illness. This group of disabled carers is set to become more significant, as informal care by spouses and partners may increase, whereas care by children may decrease. It is current policy to increase the amount of service support received by carers. The

PSSRU has therefore developed a 'carer-blind' scenario, which looks at the implications of increasing support for carers. The scenario focuses on increasing domiciliary services to older people with substantial needs resulting from their disability who share a household with others. It gives this group the same level of services as those living alone. The change to this situation is modelled to 2022, so that the increased probability of receipt of non-residential services by people who currently receive informal care is assumed to occur gradually. Under this scenario, it is projected that the numbers of older recipients of home care services will rise by around 55 per cent between 2002 and 2022, with overall expenditure on long-term care rising to just over 1.9 per cent of GDP in 2022, compared with just under 1.9 per cent under the base case.

Put simply, the overall increase in the numbers of older people means that there will be more disabled people and increased demand for services. However, it is important that demand and cost pressures do not become the driving force behind policy for disabled older people. A population is more than a set of numbers, and decline in functioning should not be regarded as synonymous with ageing.

There is a disparity between society's response to the physical problems of ageing and society's response to the social problems of ageing. The projections data presented here anticipates that the first trend will continue in a broadly positive direction: older people will live longer, with less likelihood of experiencing 'severe' ill health and impairment in older age and an increase in lower levels of ill health and disability. However, making equivalent projections on progress in tackling the social problems of ageing is inevitably much less certain. It is by no means inevitable that we will eliminate the social problems that are clustered around old age and disproportionately affect older disabled people. The effectiveness of the response to the ageing population in 2020 depends on choices made now.

The positive story is that in 2005 there is serious ambition to improve the lives of older disabled people. This is evident in policies being developed on independent living, aspirations for greater choice and control in public services and equal citizenship. These broad goals are likely to continue to command mainstream support. As always, the challenge is in the detail and how this vision will be delivered for all disabled older people by 2020. This means ensuring that wider policies are adapted to the particular needs of disabled people. For instance, it is necessary to ensure that disabled older people are included in efforts to improve civic participation; that their needs are recognised in strategies to promote wellbeing across the population; and that residential care does not preclude independent living. In order to guarantee independent living, the Government needs to promote a radical culture change in some social service departments.

There are other areas which have a significant impact on the lives of disabled older people, where policy goals are not being pursued so purposefully or successfully. These include tackling pensioner poverty and cumulative disadvantage, and ensuring the affordability and availability of long-term care.

The gaps in these areas raise questions about the Government's ability to realise full and equal citizenship for all older people, including disabled older people. The Government needs to re-assess whether existing policies are fully capable of securing fairness and security for all older people. There is evidence to suggest that without further action, there will remain substantial levels of poverty and social exclusion among disabled older people in 2020. The Government could take specific actions to address these issues, such as providing free personal care for older people and significantly increasing the value of the basic state pension to eradicate pensioner poverty.

Finally, it is important that these ambitions are not derailed by exaggerated and unduly pessimistic scenarios about the ageing population. While the ageing population does bring challenges for policymakers, it is important to remember that government and society has the capacity to anticipate these changes and respond in a fair, timely and effective way. By doing so, we will ensure a good old age for all disabled older people.

### **Conclusion: six key priorities**

Certain trends in health, demographics and public policy pose significant challenges to achieving the goal of full and equal citizenship for disabled people by 2020. However, the challenges are not insurmountable and there are significant opportunities to move towards a situation in 2020 where disabled people can exercise full and equal citizenship.

Six key priorities for action have emerged out of the evidence in this report. The priorities are to:

1. Develop needs-led public services to promote independent living.
2. Promote opportunities for social and civic participation by disabled people.
3. Promote employment opportunities for disabled people.
4. Boost efforts to tackle health inequalities.
5. Promote better understanding of disability.
6. Identify and allocate the necessary resources to implement the above.

#### **1. Develop needs-led public services to promote independent living**

The ongoing process of public service reform should focus on shifting services from service-led to needs-led provision. Even though approximately one third of NHS clients are disabled, the ability of health services to respond adequately to their diverse needs is patchy. This means building in the concept of independent living – rather than dependency – for disabled people into all reforms and service development.

At the local level, agencies will need to continue to develop joint working practices so that competition between budgets and poor communication are eradicated. It will also mean promoting the take-up of direct payments and the roll-out of individual budgets and ensuring that the necessary support is available for those disabled people who wish to take advantage of the opportunity to take control over their lives and the services they receive.

## **2. Promote opportunities for social and civic participation by disabled people**

The rights and responsibilities of citizenship are too often considered in terms of participation in paid employment. We need to promote a wider concept of citizenship in order to frame more imaginative policy responses that value different forms of contribution, and challenge the poverty of expectation concerning disabled people's contribution to society.

Full social rights are necessary before disabled people are able to participate as full and equal citizens. The evidence suggests that disabled people frequently do not have access to such rights. For example, disabled people are more likely than non-disabled people to live in housing that does not meet the decent homes standard and we have estimated that by 2020 only 12 per cent of properties are likely to meet the current 'visitability' standards for disabled people. Many disabled children and young people still face the possibility of segregated education. For some impairment groups, there has been an upward trend in the numbers being accommodated in residential care that too often fails to enable disabled people to live independently. Disabled people, on average, use transport one third less than non-disabled people; partly as a result of an inaccessible transport system.

As a consequence of factors such as these, disabled people have diminished opportunities for participation in social and civic life. They are under-represented in public life: for example, in 2004, 20 per cent of adults of working age were disabled, and yet only about 3.5 per cent of public appointments in England were filled by disabled people.

## **3. Promote employment opportunities for disabled people**

Despite the importance of social and civic participation, greater opportunities for participation in paid work are also rightly being demanded by many disabled people. Improving the employment rate of disabled people rests in part on the continued development of, and investment in, personalised welfare-to-work and employment support services.

The impact of low employment rates for disabled people is made worse by the inadequacy of out-of-work benefits for disabled people and the problematic structure and operation of the benefits system.

Addressing the employment of disabled people will also be essential to meeting a range of other important government targets. The realisation of the Government's aspiration of an 80 per cent working age employment rate requires an extra 2.5 million people to enter the labour market. It is highly unlikely that this can be achieved without an increase in the number of disabled people in employment. Targets to reduce regional inequalities and pensioner poverty are also implicated.

Meeting the target to end child poverty is also contingent on lifting disabled children out of poverty. Disabled children are more likely than non-disabled children to live in poverty; children with a disabled parent are also more likely to experience poverty. Tackling the poverty of disabled children and the children of disabled adults must be a top priority.

#### **4. Boost efforts to tackle health inequalities**

It is necessary to both tackle poverty and the health outcomes of poor people. The need for action is made particularly acute by the rise in mental ill health in recent years, which is closely linked to experiences of poverty and to the ageing population, as the prevalence of disability increases with age. Between 2002 and 2022, it has been estimated that there will be a 40 per cent increase in the size of the population of older disabled people. The picture is further complicated by the evidence that the fastest rate of growth in disability has been among children aged under 16. One in 15 children now reports a disability.

#### **5. Promote better understanding of disability**

The upward trend in certain disabilities is one of the most important social phenomena of modern times, and yet we understand surprisingly little about the drivers of key trends such as mental health problems. There is an ongoing need for research and better data on the drivers of disability. If policymakers have a better understanding of disability, policy responses will be more appropriate and more effective. This will also enable the perception of disability as a marginal issue to be challenged more effectively. Disability should be advanced as a cross-cutting consideration for all policy agendas.

The social model of disability has helped to combat discriminatory and negative attitudes and to provide a valuable conceptual framework for policy responses to disability. However, the articulation of the social model is an ongoing process and government and campaigners must continue to find ways of describing the process of disability in the face of possible new challenges to the social model.

Developments in genetic technology could threaten to reduce disabilities once again to medical impairments and there is a need to both embrace change that could improve quality of life while not losing sight of the need to remove disabling barriers in society. Another challenge to progress in promoting positive attitudes and better understanding of disability is the growth in mental health and behavioural problems in children that are challenging to accommodate within educational current frameworks, for example.

There is an important role for organisations run by and for disabled people to promote a more sophisticated understanding of disability. However, they face challenges if they are to be representative of an increasingly diverse disabled population. Disabled people's organisations have had a significant influence over government policies and if this influence is to further advance the

citizenship of disabled people, their ability to represent a diverse range of needs should be a priority.

## **6. Identify and allocate the necessary resources to implement the above priorities**

Although achieving full and equal citizenship for disabled people is not simply a matter of resources, they are clearly an important element of the package. It is critical that the necessary resources are made available. However, this is yet to happen. For example, although the Government acknowledged that current policy is not meeting the needs of disabled children, it failed to guarantee funding for disabled children and their families in both the 2005 Strategy Unit report and Green Paper on the future of social care. It is not enough to assume that the expansion of the childcare and early years infrastructure will reach the most disadvantaged including disabled children.

This has implications for disabled adults and older people too. The Department for Work and Pensions' spending projections to 2019/20 show a reduction in the proportion of GDP being allocated to 'improving the rights and opportunities for disabled people'. The PSSRU estimates that public spending on long-term care may need to increase by 110 per cent in real terms over the next 20 years to meet demographic pressures and likely rises in real care costs.

The successful promotion of these six priority areas would be powerful in driving forward the vision of full and equal citizenship for disabled people and would bring substantial benefits to the social justice of Britain as a whole.

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<sup>i</sup> See the glossary for a description of the definitions used in different surveys.