DISABILITY 2020:

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

A report by ippr trading ltd for the Disability Rights Commission

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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.

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.[1] 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 be 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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[1] See the glossary for a description of the definitions used in different surveys.

1. Introduction

In June 2005 the DRC launched a national ‘Disability Debate’. The debate aims to engage the widest possible range of stakeholders to help the DRC articulate an ambitious vision for the full and equal citizenship of disabled people and the necessary steps to achieving that vision. This report is intended as a contribution to that debate. In particular, it aims to make an assessment of key health, demographic and policy trends in order to gauge the possible circumstances and experiences of disabled people by 2020. This report builds on an assessment of the circumstances and experiences of disabled people in 2005 carried out as part of the research process.

The Disability Debate comes at a key point in the development of public policy affecting disabled people. For example the Commission for Equality and Human Rights (CEHR) will take forward the agenda of the DRC alongside other equalities[1] and the human rights agenda from October 2007. We have also seen the publication of a landmark report by the Prime Minister’s Strategy Unit on the life chances of disabled people (SU 2005) which heralded the creation of an Office of Disability Issues (ODI) in central government. The ODI is tasked with taking forward the vision set out in the Strategy Unit report that ‘by 2025, disabled people in Britain should have full opportunities and choices to improve their quality of life and will be respected and included as equal members of society’ (SU 2005 p.7). Similarly, the DRC has a vision of ‘a society in which all disabled people can participate as full and equal citizens’ (DRC 2005 p.3).

The Government’s vision and its implementation strategy are significant partly because they look beyond the short term and set an agenda designed to last beyond the tenure of a particular Government or political moment. However, in order to embed change for disabled people it will be crucial that public policy strategies are based on the best possible understanding of the issues that affect the lives of disabled people. This paper makes an assessment of where current policy trends may lead between 2005 and 2020 and the likelihood of their supporting the realisation of the goal of disabled people becoming full and equal citizens. This paper also considers the available evidence on patterns in health and demographic trends over the coming years and assesses how these may interact with policy trends to impact on the realisation of the vision.

The paper is divided into three core chapters each focusing on different phases of life: childhood and youth; working age; and older age. This enables us to cover a wide range of policy areas as they might actually be experienced by people. To some extent, this also reflects the way in which certain key public services are organised which enables us to make a meaningful assessment of likely progress in a given policy area. Of course, some policy developments such as the introduction of individual budgets will affect disabled people across the age range and in such cases we step back and discuss the implications for all disabled people or identify any separate age-specific issues in the different chapters. For each chapter, key health and demographic trends are highlighted, where evidence is available, and an assessment is made against the dimensions of citizenship identified by the DRC in their paper to mark the launch of the Disability Debate (DRC 2005). These dimensions are: taking control; helping shape society and making a valued contribution; getting equipped to play a part; getting on; and ‘full membership’. We take the final category ‘full membership’ as an overarching concept informing the whole. Necessarily, there are important areas that are not covered in depth or at all in this report. Instead the paper focuses on providing an assessment of certain dimensions of disabled people’s experiences of citizenship at different times of life based on what evidence is available and on where the key challenges and opportunities are likely to lie.

This report is underpinned by an understanding of disability that focuses on the interaction between a person’s impairment and their environment over time, as used in the Strategy Unit report on the life chances of disabled people (SU 2005). In this understanding, ‘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 impairments and/or ill health. The term ‘disabled people’ includes anyone who is disadvantaged by the way in which the wider environment interacts with their impairment or long term health problem and this may vary over time. These concepts show that it is important to consider both a person’s impairment or health problem and the wider environment in which they live, in seeking to promote the equal citizenship of disabled people. Also, because these concepts are accepted by Government, they are useful in establishing a shared basis for policy and practice change.

However, there are many other definitions of disability. For example, the Disability Discrimination Act (DDA) 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 definition provides the legal basis for assessing compliance with public duties and anti-discrimination legislation. However, it fails to take account of the impact of social and environmental factors on individual’s experience of disability. It is also important to note that many people who would meet the DDA definition of disability do not consider themselves to be disabled (Woodfield *et al* 2002).

In 2003, there were around 9.8 million disabled adults in the UK according to the Family Resources Survey (ONS 2003a).[2] Other surveys produce different figures. For example, the General Household Survey found that there were approximately eleven million disabled adults and 770,000 disabled children in Britain in 2002 (ONS 2004). This is equivalent to 24 per cent and seven per cent of the population respectively. In order to convey a reasonable picture of possible health and demographic trends between 2005 and 2020, this report uses the available data from a range of data sets. However, it is important to recognise that the different sources are not necessarily compatible, and may be based on different definitions of disability.

Even when the range of available evidence is combined, a complete picture of disabled people's citizenship in 2020 cannot be generated. The report incorporates new research conducted by the Personal Social Services Research Unit (PSSRU) at the London School of Economics (Malley *et al* 2005), and the work of CASS Business School at City University (Rickaysen 2005), which is based on their existing statistical models, in an attempt to plug some of the most obtrusive gaps in the data. Still there are certain areas where the lack of data is particularly acute. For example, there is a lack of understanding and data around the drivers and causes of disability, particularly among children and people of working age. This is the first significant finding of this study. The lack of understanding of the causes behind the increasing prevalence of certain impairments such as mental ill health is a substantial barrier to making an assessment of the future. This report covers England, Scotland and Wales, but again there is a variable amount and quality of data available in relation to each of the countries. We have specified which country data refers to where it does not cover the whole of Britain.

For these reasons, and also because it would be foolish for anyone to assert that they can predict the future, this report cannot offer a definitive account of what the experience of disabled people's citizenship will be in 2020. Instead, the available evidence is brought together to suggest a range of possible of scenarios. This analysis is intended to indicate the most appropriate issues and interventions public policy should consider in order to maximise the chances of moving towards full and equal citizenship for all disabled people by 2020.

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[1] The other equalities strands are: gender, race, belief, age, and sexual orientation.

2. The best start? Children, young people and disability

2.1 Introduction

Children[1] and young people have been given prominence within the Labour government's policy priorities and those of devolved administrations in Scotland and Wales. The signs are that this trend will continue at least through to the end of this decade. The Government has made a historic commitment to end child poverty by 2020 and is spending more on children than ever before.[2] This represents a significant opportunity for substantial progress in meeting the needs of disabled children and their families, not least because flagship government policies aimed at improving the outcomes of all children are, to a great extent, dependent upon meeting the needs of disabled children and their families. For example, meeting child poverty targets and raising school standards will be partly determined by how well policy is able to meet the needs of disabled children. This will mean ensuring current policy is capable of responding to the needs of disabled children but also that new policies will be required where current policy is incapable of meeting their needs.

The priority awarded to children in 2005 does not in itself mean that all children will benefit equally. Disabled children and young people, as well as their families, face specific barriers and are more likely than non-disabled people to experience disadvantages in other areas of their lives. The Strategy Unit report (SU 2005) broke new ground by acknowledging that existing policy did not meet the needs of disabled children and young people across a wide range of areas. It also proposed wide-reaching solutions and the likely success of these needs to be assessed if progress is to be made. If all children – including all disabled children - are to thrive and fulfil their potential in a just society, there is much to be done.

Childhood experiences will influence children's individual – and Britain's collective – well-being and outcomes in the future. This does not mean that poor early experiences will seal a child's fate, but it does mean that it is very important to identify the policies that can deliver better outcomes for those children experiencing disadvantage. It is also crucial to consider the possible trends in the experiences and circumstances of disabled children because there is evidence of an increasing number of children who are experiencing disability and, in particular, significant growth in the number of children diagnosed with mental health problems, autistic spectrum disorders (ASD), complex needs and emotional and behavioural problems.

Finally, it is important to note that one of the implications of an ageing population is that today's children will need to be more productive when they reach working age, as there will be fewer of them to support a larger retired population. This is a strong argument for child-centred policies that invest in children. However, public policy should also recognise the value of childhood in its own right and regard children as citizens of the present as well as of the future.

2.2 Trends

The Government Actuary's Department (GAD 2004) has projected that the total number of children aged up to fifteen will fall from 11.32 million in 2003 to 10.80 million in 2010, and that the number of children in Great Britain will remain constant at this level until 2020.[3] The General Household Survey put the number of disabled children aged under sixteen in Britain at 770,000 in 2002; this is the group in which disability is increasing at its fastest rate (ONS 2004).

Drivers of change

The drivers of the increase in disability among children are not well understood, and we need to know more in order to plan more effectively for the future. We also need this information in order to target disabling barriers. However, we do highlight some of the likely drivers below, such as improved diagnosis and better survival rates among pre-term infants. A better understanding of the drivers of disability is necessary in order to improve our ability to project the future numbers of disabled children in order to plan and deliver policies that are sustainable in the medium to long term. It is also important in order to be able to better target disabling barriers (rather than just focusing on remedying the consequences of disability).

The current lack of understanding makes it impossible to predict how the prevalence of disability among children may change by 2020. However, we may observe that if the same rate of increase that occurred between 1975 and 2002 occurred 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 higher proportions of boys than girls to report disability will continue. In 2000, 11 out of every 10,000 boys under 17 years reported a "severe" disability compared to five out of every 10,000 girls (Meltzer *et al* 2000).

Impairment trends

There has been a significant increase in the prevalence of ASD, mental health problems including emotional and behavioural disorders, and complex needs reported among children and the coming years are likely to see a continuation in these increases (DfES 2004; Audit Commission 2002; MRC 2001).

Studies over recent years have reported year on year rises in the incidence of ASD. In 2001, the Medical Research Council estimated that ASD affected approximately 60 in every 10,000 children under eight years old, and that using a more narrow definition of ASD the condition affected between ten and 30 in every 10,000 children aged eight (MRC 2001). Reasons for these increases include changes in diagnostic criteria, the development of the concept of the wide autistic spectrum, different methods used in studies, growing awareness and knowledge among parents and practitioners, the development of specialist services, as well as the possibility of true increases in prevalence (Wing and Potter 2002). A number of environmental causes for the increase have also been suggested but no conclusive evidence has been found. Although the increase in ASD cannot be robustly quantified (Charman 2003), it is clear that ASD is far more common than was previously recognised (MRC 2001). In 2004, just under one third of autistic children aged five to sixteen in Britain had another clinically recognisable mental health condition: sixteen per cent had an emotional disorder and nineteen per cent had a conduct disorder. Almost all children with ASD were reported to have Special Educational Needs (SEN) (97 per cent compared with sixteen per cent of other children) (ONS 2004a).

In 2004, one in ten children and young people aged five to sixteen in Britain had a clinically recognisable mental disorder (ONS 2004a) of whom four per cent had an emotional disorder (anxiety or depression), six per cent had a conduct disorder and two per cent had a hyperkinetic disorder. Of these children six per cent had more than one type of disorder. Boys were more likely to have a mental disorder than girls in 2004: among five to ten year olds, ten per cent of boys and five per cent of girls had a mental disorder and among eleven to sixteen year olds, the proportions were thirteen per cent for boys and ten per cent for girls (ONS 2004a).

This survey also found that the prevalence of mental conditions was greater among children and young people from poor socio-economic backgrounds and confirmed the relationship between social networks and mental health for children and young people (ONS 2004a). Among children who are in the care of a local authority, the prevalence of mental health disorders is exceptionally high and it will be crucial to ensure that the mental health of these children is better supported in the future. A study in 2003 found that 45 per cent of looked after children had a conduct or emotional disorder or hyperactivity which caused distress to the child or had a considerable impact on the child’s day to day life (ONS 2003). In addition, over three-quarters of these children had at least one physical complaint and 42 per cent had a statement of SEN.

In the past ten years, the number of children with complex needs also appears to have risen (see ONS 2003), as a result of increased survival rates among pre-term babies and children after severe trauma or illness (DoH 2004). This has enabled increasing numbers of children to survive infancy and to live longer, albeit with complex needs. However, the evidence for this increase is very sparse and there is little data to illuminate the exact level and nature of the increase in children with complex needs. In an attempt to shed some light on this issue, in their study of learning difficulties Emerson and Hatton (2005) examined administrative data from one English local authority up to 2001. They found there had been an increase in the prevalence of non-ambulant children (used to define children with ‘severe’ or ‘complex’ disability) aged five to fourteen with learning disabilities, from 0.07 per cent in 1981 to 0.11 per cent in 2001. They found no change in the prevalence of ‘severe/complex disabilities’ among young people. They predicted that the total number of fifteen to nineteen year olds who would be known to specialist learning disability services by 2021 would be 19,656 but that the true prevalence, which include those not known to specialist services, would be 77,186 young people. They concluded that this was likely to lead to increased demand for relatively high cost supports for children and possibly more young adults with severe and complex disabilities in the future.

In addition to these trends, there has also been growing concern around the rise in sexually transmitted diseases and obesity among children and young people (Bradshaw 2005). While sexually transmitted diseases and obesity may not in themselves cause a person to be disabled they both pose significant risk factors for disability in the future. For example, there has been a rise in HIV among young people. This does not necessarily constitute a disability at first but when the illness becomes symptomatic the young person will be classified as disabled under the terms of the DDA. Similarly, while obesity may not cause disability in itself, it has been identified as one of the key determinants of health (Wanless 2003), for example, bringing an increased risk of illnesses such as diabetes or heart disease which may be disabling.

In the decade to 2001, the number of new episodes of sexually transmitted infections reported at clinics rose by 143 per cent (ONS 2004). If current trends continue unabated, the sexual health of Britain’s young people will be a primary public policy concern by 2020. The explanations for this trend are far from clear and the public policy tools under-developed. Effective interventions to change sexual behaviour are neither well-established nor well-resourced. Similarly, the prevalence of obesity in children is increasing: between 1996 and 2001, the proportion of obese children rose by from 12.1 per cent to 15.6 per cent (ONS 2004). The International Obesity Taskforce has predicted, on basis of conservative estimates, that over 23 per cent of boys and 32 per cent of girls are likely to be overweight or obese by 2020, if current government policies remain unchanged (Rigby 2005). For many of these children and young people, this will have a substantial and long-term adverse effect on their ability to carry out normal day-to-day activities.

2.3 Taking control

Having the opportunity to exercise control over all aspects of life, without the unwelcome interference of others, is a key measure of active citizenship for disabled children and their families. We consider two closely related areas of life in which opportunities to take control are important: control over the economic means of securing appropriate services, and control over the nature and location of those services.

Financial control: direct payments and individual budgets

The development of direct payments in recent years has given some disabled children, young people and their families control over the resources to buy and arrange personal assistance. The Carers and Disabled Children Act (2000) made direct payments available to 16 and 17 years olds, carers and people with parental responsibility for disabled children. Since then, direct payments have begun to transform the lives of some disabled people by transferring control to the disabled person or their parent or carer (Barnes 2004).

The government intends to extend into childhood services by 2012 the concept of individual budgets that has been introduced for adults. This proposal has the potential to build on direct payments in a more holistic way, taking into account their needs across a wide range of public services. The Government believes that these budgets could meet the needs of families and enable them to live ‘ordinary’ lives. The budgets could encompass costs relating to housing, transport, equipment, childcare and support services and take into account the total impact of the child’s impairments on family life, including on siblings and parents (SU 2005).

There is evidence to suggest that these developments could have a lasting and positive impact on disabled children, young people and their families, not least because of the impetus they create towards greater personalisation of services (HM Treasury 2004). The recognition that the ‘one size fits all’ approach to public service delivery is failing disabled children and their families in a number of areas (Audit Commission 2003) means that individualised support is likely to remain high on the political agenda, even if implementation proves difficult. As the disabled population (like the non-disabled population) becomes more diverse, this will further necessitate the move towards greater personalisation within policy making and delivery (SU 2005).

Direct payments and individual budgets give disabled children and their families control over the financial means to access services, this means that they can exert considerably more control than in the past on how and what services are delivered. In 2005, there are a number of evaluations underway aimed at assessing the impact of direct payments.[4] There is a risk that should further criticism emerge of direct payments that this would force a reconsideration of the personalisation agenda in relation to services for disabled people. Such a move would undo the positive impact that direct payments have already had for many disabled people, instead of concentrating on the problems of low take-up and implementation. If this were to happen, this could have a knock-on effect on other tools that aim to give disabled people more independence, such as individual budgets.

Assuming progress continues, there is still much to be done before the potential of both direct payments and individual budgets is fully realised. In one survey, 37 per cent of families were not aware of direct payments, and more than half of those surveyed did not use them (Daycare Trust 2005).

Eligibility for, and the accessibility of, direct payments varies widely between authorities, as does the availability of services (Scope 2003; Carlin and Lenehan 2004). In 2003, Commission for Social Care Inspection in England (CSCI 2004) figures showed that only 875 parents of disabled children and 125 disabled young people aged sixteen and seventeen years were receiving direct payments. Although this was roughly four times the number of the previous year, it was still less than one per cent of disabled children (CSCI 2004). The CSCI found that the main barriers to take-up were a lack of clear information, low staff awareness, restrictive or patronising attitudes about the capabilities of potential recipients, a reluctance to devolve power, inadequate support service, overly-bureaucratic paperwork and difficulties with recruiting personal assistants.

In 2005, individual budgets are still at the design stage and it will be challenging to ensure that they are extended to disabled children and their families by 2012 as intended. It is likely to take time to investigate the mechanisms and the costs and benefits of individual budgets, and extension of the pilots is ‘subject to evidence and resources’ (SU 2005 p.89). There is also the question of whether the concept of individual budgets for adults can be extended to children in practice. The disabled child population has a different impairment profile to the adult population and budgets will have to be flexible enough to cope with the fact that disabled children’s needs are often more complex and subject to greater change than those of disabled adults. Children also have to be assessed as part of a family unit; and individual budgets would need to take into consideration additional support that parents need to carry out their parenting roles with their children, as well as the support that the disabled child needs themselves.

Although significant, it is questionable whether direct payments and individual budgets will be enough to ensure that local authorities and service providers give due consideration to the needs of disabled children and their families. For example, the ability of individual budgets to enable disabled children and their families to take control of a range of aspects of their lives, will depend on overcoming the inflexibility of service providers that prevents them integrating services effectively and working together to meet the full range of children and their families’ needs. Social workers and NHS staff, for example, have their own working practices and procedures which have developed over decades and progress in tackling this has so far proven slow (Rankin and Regan 2003).

Furthermore, there is likely to be a tightening of resources in the coming years. A reluctance to explicitly prioritise funding for disabled children and their families in both the 2005 Strategy Unit report and the 2005 Green Paper on the future of social care means there are few levers available to ensure local authorities and health services deliver improvements in service delivery. This is likely to impede the successful implementation of reforms in children’s services. The Government faces an acute dilemma here, as more targeted services for disabled children and their families will mean that spending has to increase even faster than under a policy where general needs are kept up with, but nothing extra is done for the disadvantaged. Yet, all the indications are that public spending as a share of GDP is likely to level off, if not decline, in all public services by the end of the decade (Robinson 2004; OECD 2004). In 2003, the Treasury signalled that public spending as a proportion of GDP would remain roughly constant at around 42 per cent over the period 2005-2008. Private Finance Initiatives (PFIs) and Public Private Partnerships (PPPs) do not in themselves provide extra resources for public services because they are just a different mechanism for raising the same amount of resources (ippr 2001).

While there is cause for some optimism, there is also some doubt whether the needs of disabled children and young people will be met within the planned wider reforms to children's services since both the instruments and resourced needed for this look to be more tightly constrained in the future, regardless of how the economy or public finances evolve over the next few years (Robinson 2004). This impacts considerably on the potential of planned reforms to increase the control that disabled children and their families have over their lives. These trends will mean that those children and families currently experiencing high levels of unmet needs – such as minority ethnic families, those with mental health problems and learning disabilities – may face a continuing struggle to take control of their lives in the coming years than at present.

Type of services

Control over the financial means to secure services is an important part of the picture, but it is also important that appropriate services are available and disabled children and their families can exercise choice in the services they receive.

The Audit Commission (2003a) has noted the greater likelihood of severely disabled children being in either residential care or residential education, and the importance of appropriate practical and financial support in enabling families to continue to care at home. Developments in medical technologies have already enabled some children with complex needs to be cared for at home. In general, children's use of medical technology has benefited their quality of life and health, and made the lives of their parents easier because the child's medical condition is generally more stable (Heaton *et al* 2003). Further advances could improve the quality of life for disabled children and young people in the future, and enable those who have a genetic disease or complex needs to participate in a wider range of activities, including important decisions about their lives (Shakespeare 2005).

None the less, there is still a lack of support to enable families to continue to care for disabled children at home and a significant minority of disabled children are still separated from their families and the wider community through involuntary placement in residential schools, children's homes or NHS facilities. Avoiding this segregation is a fundamental pre-requisite for achieving more control over their lives. In 2005, the Government acknowledged: 'it is possible that some disabled children and young people could avoid long-term institutionalisation if adequate and early preventative support was provided to them and their family' (SU 2005 p.115). The chances of this happening rests on disabled children's needs being *specifically* addressed within reforms to children's services.

It is unclear what levers are available to ensure that local authorities and service providers take due account of the needs of disabled children and their families. One possible future lever has emerged through recent legal judgements (see Spink family 2004 and A and B v East Sussex County Council 2004). These suggest that the duty on local authorities to adopt a person-centred approach to service delivery will be championed by the courts to give greater support to the specific needs and choices of disabled children and their families in the future. This may push local authorities further towards looking at the actual needs of individuals on a case by case basis. Another important ruling has meant that more children could be eligible for Disability Living Allowance, the benefit designed to meet the extra costs of disability, after a tribunal ruled that what matters for eligibility is a condition's effect, and not necessarily its recognition as a diagnosed disability.[5] This may set a precedent for recognising the needs of, and choices available to those with more recently diagnosable conditions, such as ASD, which are increasingly prevalent. These developments will be greatly strengthened from December 2006 by the introduction of the disability equality duty which will place a positive duty on all public bodies, including local authorities, to promote equal opportunities for disabled people.

2.4 Helping shape society and making a valued contribution

In 2005, disabled children and young people face low expectations about their potential to participate in decision-making and make a valued contribution to society. These low expectations and the low valuation of disabled children's contribution deny disabled children the right to enjoy a full and decent life, as enshrined in the United Nations Convention on the Rights of the Child. They also restrict their citizenship. Here we examine the potential for children and young people to have greater opportunities to help shape society and make a contribution that is valued by others by 2020. We consider opportunities for greater civic and social participation, and attitudinal barriers in particular, looking at the example of the potential influence of developments in genetic technology on attitudes to disability.

Greater participation

There have been a number of promising signs that there will be greater opportunities for disabled children and young people to participate in society in a meaningful way in the future. There is also a wide recognition that the involvement of children in decisions about their own welfare can improve the delivery of services for disabled children. This has been reflected in Government initiatives and the endorsement of professionals (DoH 2001; BMA 2001). The Strategy Unit has recommended that disabled young people should be included in planning that is centred on their own needs (SU 2005).

One positive example of the potential for an increasing role for disabled children in social and civic life is the report of the Russell Commission (2005) on youth volunteering which illustrated how disabled children and young people can be seen as active citizens and contributors to their communities rather than simply as 'service users' or the beneficiaries of community action. The 2005 Green Paper for youth services in England set out how the recommendations of the Russell Commission will be implemented (Russell

2005). These developments represent a promising new approach to thinking about young disabled people's citizenship; and new initiatives, such as time banks, have demonstrated a potential to increase participation among those on the very lowest incomes. For example, sixteen per cent of volunteers overall have incomes of less than £10,000 compared to 58 per cent of time bank participants (Seyfang and Smith 2002).

Creative ways of involving disabled young people have also been demonstrated by the Welsh Assembly Government. The Assembly consulted with disabled children and young people in an initiative called 'Nothing about us without us', and disabled young people have joined Assembly members in quizzing witnesses as part of the Assembly Committee inquiry into services for disabled young people. This was the first initiative where disabled young people had a direct say in shaping their future services at such a prominent level.

However, overall progress in providing opportunities for disabled children to help shape society and make a valued contribution to 2005 has been slow. Various pieces of legislation recognise the importance of inclusive participation for disabled children and young people such as the Children Act (1989), the DDA (1995), the Special Needs Education and Disability Act (2001), as well as article 31 of the UN Convention on the Rights of the Child. Yet this legislation is still not ensuring full and equal opportunities for disabled children to take control.

For example, although models of good practice exist, the involvement of disabled children in decision-making is not widespread and substantial deficits remain. In 2000, a review of young people's participation noted that there was evidence to show that disabled children were being less actively involved in decision-making than non-disabled children (Sinclair and Franklin 2000). Research also shows that social services departments frequently neglect to ascertain the wishes of disabled children regarding respite and other forms of provision (Morris 1999). In addition, the scarcity of communication aids hinders children's self-expression and limits their involvement in decision-making (Stone 2001; Rabiee *et al* 2004). Evidence published in 2004 identified gaps in the research evidence on disabled children and their participation in decision-making, and indicated that more work would have to be developed in order for disabled children and young people to be fully involved in decisions about their lives and public decisions about service development by 2020 (Mitchell and Sloper 2002).

Attitudinal barriers and genetic technology

Significant barriers to disabled children and young people having opportunities to help shape society and make a valued contribution remain, perhaps foremost among these are attitudes towards their ability to contribute. Attitudinal barriers will be the biggest barriers to overcome in order to challenge the view that disabled children have little or nothing of value to contribute (Barnes *et al* 2000). The trend to date has been towards a greater appreciation of the nature of disability and more positive attitudes, with some notable exceptions such as persistent, pervasive negative attitudes towards people with mental health problems. As anti-discrimination and pro-equality legislation beds in there is a good chance of this trend continuing. However, it is very difficult to make an assessment of the way in which attitudes may shift over the coming years.

There is one area, though, where developments to 2020 may exert a negative influence over attitudes towards disabled people; this is genetic technology. This could lead to a loss of support in wider society for the rights to equality of disabled children and their families. Clearly, developments in genetic technology are likely to impact on disabled people of all ages, not just children, but much of the emphasis is on the antenatal period, as well as genetic diseases in childhoods.

Genetic developments could pose a threat to the rights of disabled children and young people because genetic science is underpinned by a conceptual approach that sits in tension to the social model of disability. Genetic developments could define disability once more in terms of biology and abnormality (Shakespeare 2005). In the future, this re-medicalisation of disability could lead to increased discrimination against disabled children and their families.

Developments in genetics screening could create new forms of discrimination. Some people in public positions have made statements that appear to suggest that parents are irresponsible not to accept genetic screening, or not to terminate a pregnancy when a foetal abnormality has been detected.[6] The danger here is that this argument could emerge as 'common sense', not through a conscious policy direction but in a more insidious manner. King has put it this way:

> 'The danger we will need to guard against, is the development of a kind of eugenic common sense, that it is irresponsible to refuse to undergo tests, and that every child has the 'right' to a healthy genetic endowment. ... We will need to be vigilant for eugenics disguised as public health measures.' (King 1998 p.7)

This supposed 'common sense' argument runs that a child born with an impairment is inherently incompetent or at least held to be at an inherent disadvantage compared with a non-disabled child; that the barriers that they face are a consequence of their genes; and that society does not have the same obligations to uphold rights and equality for them in the same way that it does for its non-disabled peers. The progressive response should be the opposite: that if a condition is genetically determined, then there is no way the disabled individual could, or should, be held responsible for it – and hence society does have an obligation to uphold the rights and equality for that person.

Research published in 2000 found that women were not given comprehensive and balanced information about impairment and disability before making decisions about tests and terminations; doctors sometimes influenced decisions made by pregnant women; and that there was an absence of proper counselling or non-directive support (Shakespeare 2001). It is possible that people who choose to continue pregnancies affected by genetic disease could face blame for their decisions, and children who have genes predisposing them to illness may be denied certain treatments by health services (Shakespeare 2005a). The fact is that the vast majority of disability has little do with genetic problems at birth: only one to two per cent of babies born are affected by impairment (Shakespeare 2005a).

So far the process of 'geneticisation', whereby social problems are redefined as genetic problems, has been being 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. It is also worth noting that at present, technology for selecting embryos is very limited and tightly controlled. Population screening in pregnancy is restricted to a small number of genetic and developmental conditions. There remain biological and practical limits to developing screening and stem cell research (Winston 2005). The major immediate application of genetic research is diagnosis and screening, not therapy and 'cures', and successful gene therapy trials have been extremely rare (Shakespeare 2001).

Nevertheless, the pace of genetic and medical developments are widely believed to be proceeding at a pace that the rules and regulations cannot keep up with (Human Genetics Commission 2001). It is important to ensure that developments which promise social benefits are not advanced at the cost of ethical principles and the erosion of the social model of disability. The key issue when it comes to attitudes towards disabled people is the social context in which these developments are applied. Public policy needs to support disabled children and young people to achieve full and equal citizenship; if not, there is a risk that policy in this area will tackle disability by removing the potential for individuals to enter the population, rather than by removing barriers from society.

2.5 Getting equipped to play a part

It is an integral part of achieving full and equal citizenship that disabled children, young people and their families are equipped to participate in, and contribute to, society from the beginning – especially since the early years have the greatest impact on life chances. Early years and childcare services have risen up the political and public agenda in recent years, propelled by academic evidence on their significance and by women's increasing participation in the labour market. The investment made in equipping disabled children in the early years must be sustained throughout education and during the sometimes difficult transition to adulthood. We look at each of these three areas in turn.

Early years and childcare

It has been argued that the development of a comprehensive childcare and early years infrastructure in Britain should be a key focus of Government, and constitute the modern equivalent of the creation of the National Health Service in the post-war years (Pearce and Paxton 2005). The National Service Framework (NSF) for children, young people and maternity services has set out new, higher standards of care in public services for children including implementation of an improved strategy for children with Special Educational Needs (SEN) (DfES 2004c). The ten year strategy for childcare for the period 2004 to 2014 took a longer term view of the childcare infrastructure for the first time and outlined plans to enhance early years and childcare provision substantially, including proposals for ‘extended schools’ to provide ‘wraparound’ school-based childcare which will be fully accessible to families with a disabled child over five years old (HMT 2004; SU 2005). The Government intends to introduce legislation to give local authorities a new duty by 2008 to ensure there is adequate childcare provision in their area. Box 2, below, outlines some of the government’s commitments on early years and childcare provision to 2010.

Box 2.1: Early years and childcare commitments

All children:

- From April 2006 the minimum free entitlement of 12.5 hours a week will be extended from 33 to 38 weeks for all three and four year olds. From April 2007 this will be extended to fifteen hours a week for 38 weeks for some children and to all children by 2010. There is a longer term goal of 20 hours a week for 38 weeks.
- By 2010 all families in all areas will have access to a Sure Start Children’s Centre offering integrated services and providing information for parents.

Disabled children:

- 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 SEN Coordinator.
- By 2015 Sure Start is to ensure that all families with a disabled child under five years can access high quality, flexible childcare.
- The DfES is to ensure that ‘wraparound’ care is fully accessible to disabled children over five years old as it is rolled out.

These measures are likely to go some way towards addressing the lack of appropriate childcare and early education provision available to disabled children and their families (NAO 2004). For example, extended schools providing wraparound childcare are well placed to integrate early education and childcare for disabled children because many schools already have the facilities and equipment to cater for the needs of disabled children and in many cases are physically accessible.

By 2008, the Government plans to have a new reformed regulation and inspection system, underpinned by a legal framework for early education and childcare and supported by an integrated quality framework. This includes legislation requiring local authorities to have specific regard to childcare provision for low-income families and families with disabled children.

Proposals designed to streamline and simplify the regulation of early years and childcare services will mean that some childcare providers will not be legally subject to stringent regulation, but can sign up to an Ofsted-run voluntary register instead. There are considerable concerns within the childcare sector that such ‘light touch’ regulation will not ensure high quality provision. The lack of specific targets for the number of childcare places for disabled children also makes it less likely that the proposed legislation and regulation will be enough to ensure change in early years and childcare services for disabled children and their families.

All childcare settings that provide early education are already required to have a SEN Coordinator (SENCO) to coordinate and advise on SEN provision, and every local authority is required to have an area SENCO for every 20 non-maintained settings. However, in 2004, the National Audit Office reported that this target was not being met; some local authorities had only one area SENCO for every 100 settings (NAO 2004). This suggests it may be challenging to meet the target to provide every three to four year old disabled child with access to a SENCO by 2010.

There is also concern that local authorities will not have the adequate time or resources to have the planned 3,500 children’s centres in place by 2008. There is doubt as to whether the tight deadlines will enable local authorities to carry out community consultation – especially with those from the ‘hard to reach’ groups – and draw up partnership plans with health service bodies and other agencies. Research published in 2005 on behalf of the London Development Agency concluded that the timescale of 2008 for creating new childcare provision may not be realistic (Ingram and Raniwala 2005).

Play is an important way in which children learn and, of course, play opportunities also enhance childhood experiences. The Government’s aim is for £200 million of funding to reach play projects across the UK between 2006 and 2012 (Jowell 2005). This is likely to benefit disabled children because the Government’s national strategy for how the funds would be allocated paid particular attention to the needs of disabled children, although none of the funding is specifically ring-fenced for projects for disabled children (DCMS 2004). In 2005, the Government committed itself to prioritising funding for the inclusion of disabled children and young people. This is encouraging because in 2004, there was a shortage of inclusive and specialist provision for play and leisure services, with many initiatives subject to short-term or insecure funding (Sharma and Dowling 2004).

Education

Greater progress towards a high standard of educational experience is vital if all disabled children are to be socially included and able to get equipped to play a full part in society by 2020. There is already greater awareness of the need for inclusion in schools, but there is variable quality and provision of teaching of disabled pupils and those with SEN.

Some – though by no means all – disabled children will have SEN. The Government's strategy for greater inclusion of children with SEN aimed to address the variations in SEN provision in England (DfES 2004*)*. The Welsh Assembly Government has published its own code of practice. In 2005, the Assembly's Education and Lifelong Learning Committee has established a three-part investigation into SEN strategy. The aims of the strategy for England, which was designed to fit with the implementation of reforms to children's services and the NSF for children, are outlined in box 2.2.

Box 2.2: Aims of the government strategy on SEN

- Focus on early intervention to identify children's needs as soon as possible and provide the right support to help them learn.
- Personalise learning for all children and make education more responsive to their diverse needs.
- Remove barriers to learning by developing teacher skills to meet the range of needs and focus on children's progress.
- Educate more children with SEN in mainstream schools supported by special schools which will become centres of excellence.
- Ensure a clear and continuing role for designated special schools educating children with the most severe needs working closely with mainstream schools.

As we have mentioned, the role of anti-discrimination legislation has been substantially strengthened by a new positive duty on all public authorities to promote the equality of disabled people (modelled on the duty to promote racial equality enshrined in the Race Relations (Amendment) Act). This will mean that schools will have a duty to promote the equality of disabled children. This should prove beneficial as, for example, extended schools are rolled out throughout England, making childcare and more informal learning available at the schools before and after standard school opening hours. Given the challenges parents of disabled children often find in accessing appropriate care outside school hours, these developments may prove very welcome. The DfES has committed to ensuring that wraparound care is fully accessible to disabled children aged over five as it is rolled out. The final part of the 1995 DDA also came into force in 2005. This will bring colleges and universities into line with other educational establishments so they will have a duty to make their physical facilities accessible to disabled people. This supplements their pre-existing duties to make 'reasonable adjustments' to make their goods and services accessible to disabled people.

Enhanced scrutiny should also ensure greater oversight in the implementation of the strategy for improving the quality of provision in education. For example, all Ofsted inspections must now report on how schools are implementing the requirement in the national curriculum of 'providing effective learning opportunities for all pupils'. This forms a statutory baseline and, over time, with the implementation of anti-discrimination and planning duties, should bring significant improvements in access to education for disabled children. For example, in 2005, all permanent and lay inspectors employed and contracted to Estyn in Wales received practical training on legislative changes from the DRC.

Improvements in data collection and the evidence base will mean that by 2020, there will be a clearer picture of disabled student's needs (DfES 2004; Gordon *et al* 2000). One development most likely to fill the current gap in evidence and data would be the inclusion of data on disabled pupils in the national pupil database which tracks information about the attainments of individual pupils over time. At the moment this data is not collected but a change here would dramatically improve our understanding of disabled children's needs and attainment.

Other trends, however, may engender greater pessimism. If there is one lesson to be learnt since the Warnock Report of 1978 which laid the groundwork for the inclusion agenda in education, it is that inclusion policy should mean high quality provisions that ensure full integration and maximum participation across a wide range of educational experiences. However, progress in integrating disabled children into mainstream education has been slow. Analysis of figures from 148 English local authorities between 2002 and 2004 show that children with statements of SEN are still overwhelmingly being taught in segregated settings; just over 100,000 were in segregated settings in 2004 (Rustemier and Vaughan 2005). More encouragingly Local Education Authority inspection reports have shown that many are undertaking reviews of their 'special schools' and some had plans to co-locate 'special schools' on mainstream sites (Ofsted 2004). The inclusion agenda has so far had little impact on the range of needs of pupils with statements of SEN who attend mainstream schools (Ofsted 2004).

The increasing number of children with ASD and behavioural, emotional and social difficulties will pose significant challenges to plans to improve inclusion and support for disabled children (Audit Commission 2002; DfES 2004; MRC 2001). Over the last 20 years a number of non-pathological impairments, such as ASD, have been more frequently identified through improved diagnosis. This is likely to contribute to more children being identified as having SEN up to 2020.

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 professionals 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 (Singleton 2005; Miller *et al* 2005). For example, the focus on attainment may create pressure towards the exclusion of children with SEN. Exclusion figures for 2004/2005 show a six per cent increase in exclusions (ONS 2005) and policymakers need to ensure that inclusion is not just encouraged but actively followed through (Reed 2005). This is particularly important for children with SEN as they are four times more likely to be excluded from school than the population as a whole (DfES 2005a).

Children’s Trusts

By 2008, all local authority areas will have a Children’s Trust which will - in partnership with the voluntary and community sector - bring together the management and delivery of childcare, children’s education, social services, certain health services for children, young people and their families. The Trusts will run Sure Start children’s centres where a range of services will be accessible. By 2015, the Centres are expected to ensure that all families with a disabled child under five years can access high quality, flexible childcare. The aim is to deliver preventative interventions and fully integrated services for children and their families.

Sure Start children’s centres represent the rolling out of the Sure Start programme which has been piloted in some of the most disadvantaged wards across England. Great hopes and expectations have rested on Sure Start’s ability to tackle disadvantage and social exclusion. One of its characteristics is responsiveness to local community needs and a high level of involvement by local parents. The objectives of Sure Start focus on improving the outcomes of disadvantaged children and given the intersection of deprived communities and higher prevalence of disability, disabled children have been significant among those served.

Evaluation evidence to date has been mixed, with performance varying significantly between different areas. One area of concern is that tax credits which can help families to meet the costs of childcare are not available to parents who are not in paid employment. This means that many parents of disabled children, who have a lower than average rate of employment, may not be able to afford this childcare provision. There is also an important issue around the take-up of tax credits by those who are eligible. In 2004, working families with disabled children were less likely to benefit from the childcare element of the Working Tax Credit than other families: only 7.8 per cent of families with one disabled child received the childcare element, compared to 14.6 per cent of families with no disabled child (Contact a Family 2004[7]). Despite some concerns, because Sure Start aims to improve the outcomes of young children, its success will only really be measurable over a longer timescale and it would not be prudent to rush to judge Sure Start’s likely future impact.

While Sure Start has been implemented in Scotland, with a total annual spend of £52.9m in 2006, proposals for the roll out of children’s centres are still under consideration. In Wales, initiatives instigated by the Children’s Commissioner for Wales have led to the creation of a Children and Young People’s Framework and the creation of local integrated children’s centres in each of the 22 local authority areas.

As Children’s Trusts are established, all children’s services will be expected to review their impact on disabled children and their families. There are plans from 2006 for joint area reviews of children’s services, involving a number of inspectorates including Ofsted, the Healthcare Commission, the Commission for Social Care Inspection (CSCI) and the Audit Commission. The Reviews will report on the well-being of all children and young people in a local area. They will cover universal, preventative and specialist services and particular attention will be given to joint action by local services on behalf of those groups of children and young people who are vulnerable to poor outcomes.

The Early Support Programme introduced in 2002 promotes integrated services, common assessments and single care workers for disabled children and, depending on the forthcoming evaluation, the Government will decide whether or not to roll out Early Support Programmes nationally. The Government has proposed a number of further moves aimed at supporting the families of disabled children including more key workers, information about local services, children's equipment and a children's workforce capable of meeting the needs of disabled children (SU 2005). All of these reforms have the potential to make significant inroads into plugging some key gaps in provision.

However, local authorities report that there is currently a substantial shortfall in the funding being made available from central government to deliver Children's Trusts. A lack of adequate funds could also impact plans for the Children's Workforce Strategy, which lies at the heart of Government plans to improve children's services. The childcare workforce is very poorly paid as a whole, with low levels of qualifications and training, as well as high staff turnovers (Cameron 2004). This is a particular problem for children who have high levels of support needs or reduced communication, or who need trained, consistent care (Melheuish 2004); professionals are concerned that there is not enough funding to address this.

The success of these reforms also hinges to a great extent on effective partnership working to ensure that disabled children and their families experience seamless service delivery (coordinated by Children's Trusts). The difficulties of translating partnership rhetoric into effective practice have been well-documented (Pinkus 2003; Kjaer *et al* 2001) but have not yet been adequately addressed beyond the government's proposals to develop new models of effective partnership working. As progress to 2005 shows, collaborative working between different services does not happen easily. As such, joint working will be the single biggest challenge to programmes such as Early Support.

The provision of key workers will also be decisive in determining the success of children's services in catering for disabled children's needs. The Early Support Programme is funding the development of new key worker services on a range of models including the development of existing home visiting services to take on the broader responsibilities. In 2005 there is much experimentation with key workers and standards are newly developed. A number of evaluations up to 2005 have shown positive results. Families report improved relationships with service providers (Greco *et al* 2004). One study found that the impact on access to services was beneficial, but the social and emotional issues, as well as issues around funding and equipment, were still problematic (Townsley *et al* 2003). Even with all the evidence of the benefits, less than one third of families with severely disabled children have a key worker (Greco *et al* 2004) and for many Early Support funded partners, establishing new key worker services for children with complex and multiple difficulties under three, the additional resource required translates into a requirement for 1.5–2 additional full-time equivalent staff (DfES 2004c).

2.6 Getting on

Fundamental to disabled children getting on and reaching their potential, is the eradication of child poverty, a reduction in seemingly intractable health inequalities between children born into different social classes, and the success of strategies to improve children's transitions to adulthood. We discuss each of these challenges here.

Child poverty

There is a strong relationship between low income, social exclusion and disability among families who have a disabled child and many groups of families face multiple disadvantage (summarized in box 2.4 below). These families will have to be specifically targeted by government policy if the government is to achieve its goal to halve child poverty by 2010 and eradicate it by 2020. Tackling poverty among disabled children and their families will also prove important in achieving other Government aims to raise school standards and employment rates. For these reasons, improving the life chances of disabled children and their families ought to continue to feature prominently on the Government's future political agenda.

The Welsh Assembly Government has developed its own strategy to combat child poverty and has taken a decision to cease applying means testing to housing adaptations that benefit households with disabled children. In 2005, the Government has a target for 'all families with young disabled children to have the level of family support they need to enable them to function as a family and care for their disabled child' by 2014 (SU 2005 p.110). The Welsh Assembly Government has developed its own strategy to combat child poverty and has taken a decision to cease applying means testing to housing adaptations that benefit households with disabled children.

Box 2.3: Multiple disadvantage for families with a disabled child

- 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 in households with no disabled children (DWP 2004).[8]

- In 2002, 20 per cent of all lone parent families were supporting a disabled child, compared with fourteen per cent of couple families (Emerson and Hatton 2005). Lone parents were more likely to experience poverty than couple families.

- Having more than one disabled child places additional strain on the family. It is estimated that in 2004, ten per cent of families with disabled children care for more than one disabled child (Sharma and Dowling 2004).

- Those families where one or both of parents are disabled faced additional needs. Roughly two-thirds of this group are in the bottom two quintiles of income distribution (DWP 2004).

- In 2005, families from black and minority ethnic backgrounds also have a high level of unmet need (Audit Commission 2003).

- In 2003, families supporting a disabled child were 2.5 times more likely to have no parent working for more than sixteen hours per week (Emerson and Hatton 2005). Analysis of 2002 Family Fund data shows that only sixteen per cent of disabled children's mothers work full or part-time (Family Fund 2004).

Disabled children are at a high risk of poverty as a result of low household incomes. Many parents of disabled children are unable to work because of care responsibilities and the lack of, or the cost of, appropriate childcare. Work can be an important route out of poverty. Some of the wider policy measures aimed at addressing the lack of childcare have already been discussed. The Employment Act (2002) gave parents with a disabled child under eighteen the right to request flexible working arrangements which may enable more parents to more easily balance paid work and care. It is too early to assess the take-up or impact of this policy.

The extra costs associated with disability also drive high levels of poverty among disabled children and their families. The tax and benefits system does acknowledge that disabled children and their families incur additional costs, however, many have argued that it does so half-heartedly. From 2005, the childcare element of the Working Tax Credit and employer-supported childcare schemes will assist parents working at least sixteen hours a week and on low incomes with the costs of childcare. The childcare element of the Working Tax Credit will cover up to 70 per cent of the costs of registered childcare and from 2006 this has risen to 80 per cent of childcare costs. However, there is evidence to suggest that this will not benefit those families on lower incomes who live in London and the south east because childcare costs are so high in these areas (Dickens *et al* 2005).

In 2005, the level of benefits rarely meets the additional costs of families who have disabled children. The British Council for Disabled people and End Child Poverty (undated) have estimated that levels would need to increase by 30 to 50 per cent to raise disabled children out of poverty. The rates of Disability Living Allowance (DLA) in recent years have been rising at a rate of around 2.5 per cent, barely in line with inflation. In August 2004, only 271,000 children under the age of sixteen were receiving DLA (DWP 2005). Data from the

Family Fund also points to a lower rate of take-up among disabled families from minority ethnic groups (Chamba *et al* 1999).

In 2005, the DWP is improving the claims process for disability benefits and developing a new DLA form appropriate for carers of disabled children. This will be tested in 2005 in the hope that more people will claim. It is crucial that benefits such as DLA that are designed to help people meet the extra costs of disability are available and taken up by those families who they are intended to support. It is also important that the level of benefit is sufficient to fully cover the extra costs of disability.

The potential of individual budgets and direct payments to help disabled children and families living in poverty or at risk of entering into poverty has been discussed earlier but it is worth noting here that direct payments can be used to pay for early education and care services, and some parents organisations have been able to pool direct payment budgets to fund support workers (Council for Disabled Children 2003). However, 37 per cent of families in a 2005 survey were not aware of direct payments, and more than half of them did not use them (Daycare Trust 2005).

Making further progress on child poverty is likely to become increasingly challenging, requiring bolder policies. In order to halve child poverty it has been suggested that the government would need to spend an additional 1 per cent of GDP on child tax credits or achieve a substantial rise in rates of parental employment (Brewer *et al* 2004). It is clear that ending child poverty by 2020 will require specific, targeted action to address the poverty experienced by disabled children.

Health inequalities

The Government has a target to reduce health inequalities (as measured by infant mortality and life expectancy) by ten per cent and to halve child poverty by 2010. There is a strong relationship between poor health and poverty (for example, see ONS 2005), and this means that progress on both fronts will be necessary to meet the 2010 target. The target to reduce health inequalities looks set to be very challenging. While infant and child mortality declined in the UK up to 2005, the UK still has a higher infant mortality rate than most other European countries. In 2000, the UK had one of the highest proportions of low birth weight in the OECD (Bradshaw 2005). The new figures on infant mortality confirm the previously reported trend that the gap between ‘routine and manual’ groups and the whole population has widened, although there have been year-on-year fluctuations in intervening years (DoH 2005a). The latest data has shown that health inequalities continued to widen rather than narrow (DoH 2005a).

Transitions to adulthood

Any progress that is made in preventing or alleviating the effects of poverty among disabled children and their families will be lost if disabled young people’s transition through childhood and into adulthood is not supported effectively. Transitional phases can be challenging for any young person but disabled young people often face additional problems: low expectations, a lack of continuous service provision, not being in education, employment or training, and unmet needs in further and higher education.

Box 2.4: Government targets to improve transition into adulthood for disabled young people (SU 2005)

- By 2006, adult programmes are to extend self-directed control to young people when they are ready.
- From 2006 onwards, all universal services are to be assessed on meeting the needs of disabled young people and their families.
- From 2006 onwards, there is to be individualised learning and vocational pathways into employment
- By 2012, individualised budgets should support young people and their families across transition.
- By 2012, there is to be continuity in delivery from child to adult services.

The development of Children's Trusts should bring integration and coherence to the commissioning and local strategic planning of children's services. The Children Act 2004 enables Children's Trusts to focus services on disabled young people up to the age of 25 for whom the transfer to appropriate adult provision has not been adequate. The DfES is considering whether to develop a 'practice development toolkit' to evaluate and disseminate best practice models to all those working with young people on transition planning, including the Transition Information Network and the SEN regional partnerships. Although these developments are positive indications of the Government's commitment to this area, there remain significant obstacles to overcome by 2012 if disabled children and young people are to experience continuity during transition that will enable them to get on and fulfill their potential.

The impairment profile of young people is changing and increasing numbers of children with complex needs are both surviving into adulthood and experiencing increased life expectancy as adults (ONS 2003). This, along with the increases in the diagnosis of ASD and mental health problems, will present particularly challenging issues for adult services to respond to. The changing nature of impairment trends is also likely to pose a greater challenge for disabled young people's inclusion within educational settings. For example, the admission to mainstream schools of pupils with behavioural difficulties was found to be the hardest test of the inclusion framework in 2004 (Ofsted 2004). This is likely to have a knock-on effect on the prospects for inclusion in further and higher education because longitudinal studies have shown that, for many children, these conditions mark the early stages of difficulties that will continue well into adulthood.

This is likely to be compounded by the paucity of research into which models of intervention work best, for whom and in what circumstances. In 2005, there is also little cost benefit analysis of the impact of interventions with disabled young people. Relatively little work has been carried out with a holistic view of transition, which include work on young people with the most complex needs and/or from minority ethnic groups, or work which focuses on the impact of the family on disabled young people's experience of the transition towards adulthood and independence (Heslop 2002). With such a poor evidence base, future research and practice in this area will have to be initiated and piloted. This makes the 2012 target for continuous service delivery challenging.

It is unclear how continuity will be monitored, given that inspections have tended to focus either on children's services or adult services, and given that some inspection bodies lack the appropriate skills or the remit to evaluate the links between agencies that play a role in transition for disabled young people.

It is likely that the Government's aim to implement individual learning and vocational paths to employment from 2006 will be dependent largely on the success of the Learning and Skills Council (LSC) in taking a strategic lead in the provision of services for disabled learners and how this is matched in terms of workforce skills. The 2005 LSC review of this provision for those with learning difficulties and disabilities across the post-16 sector is likely to go some way towards understanding how such provision might be planned and funded within the LSC's statutory duties. One of the most significant barriers is the emphasis in Government targets on achievement of level two qualifications as the minimum required to participate in a modern economy. These fixed ways of measuring educational success are underpinned by an assumption that achievement at further education (FE) occurs by the age of nineteen, when in fact two-thirds of disabled FE students were aged 20 or over in 1997 (IES 1997). The greatest challenge for public policy up to 2020 in this area is likely to be the question of how to raise expectations in the educational sector, but also across society, so that disabled children and young people may be actively encouraged to fulfil their goals and ambitions *(*DRC 2005).

In 2005, disabled people are still more likely than non-disabled people not to be in employment, education or training (NEET), particularly from the age of 19 when many transfer out of 'special schools'. The Government has recognised that if disabled young people are to get on and realise their full rights to citizenship, meeting targets in this areas will be important. However, various targets have not delivered a focus on disabled young people up to 2005. For example, the target on the NEET group focuses on those aged between 16 and 18 which excludes many disabled young people who only become NEET on leaving 'special school' at age 19.

Employment and training programmes are often too general to provide personalized support for disabled young people (Jacobsen 2002), and programmes aimed at helping young people enter the labour market make little provision for the additional needs of disabled young people. It is vital that any broader initiatives in this area from 2006 do not continue to overlook the needs of disabled young people. In the absence of specific funding for its targets and recommendations, the Government will need to specify how it plans to tackle such barriers and ensure that disabled young people benefit from wider reforms.

2.7 Conclusion

It is well established that persistent poverty during childhood has significant scarring effects on life chances and that families with disabled children are one of the most disadvantaged groups in society. Poverty also impacts on children's experiences of childhood. The extent to which a fairer society 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. This will necessitate specific and targeted policies to tackle the poverty and social exclusion experienced by disabled children.

There also needs to be a transformation in the quality and accessibility of key services for disabled children, young people and their families. The Government has recognised many of these problems and has launched a range of initiatives. In order to be successful, Government strategy will have to address more clearly how the achievement of goals is to be resourced, managed and monitored.

The social justice case for achieving the full and equal citizenship of disabled children is a compelling one. Policy trends would seem to acknowledge this and 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.

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[1] In this chapter the term we use the term 'children' to refer children and young people up to eighteen unless otherwise specified.

[2] There has been a 53 per cent rise in real terms in child-contingent support since 1999 and this trend looks set to continue until at least 2007 (Adam and Brewer 2004; HMT 2004).

[3] A slight rise is predicted between 2020 and 2030, followed by a decline in the number of children through to 2060.

[4] For example, see the Direct Payments Survey at http://www.pssru.ac.uk/dps/dps_projects.htm.

[5] Suffolk County Council brought the case in 2005 on behalf of a fourteen year old girl who had attention deficit hyperactivity disorder.

[6] For example, the Vice Chair of the Human Genetics Commission stated that: 'parents should not bring a clearly disabled child into the world' (cited from DRC

2004). IVF pioneer, Bob Edwards, has similarly described it as a ‘sin’ to knowingly have a child who has a genetic disease (cited from DRC 2004).

[7] From analysis of Working Tax Credit Quarterly Statistics, April 2004 cited from Daycare Trust 2005.

[8] Using a standard income measure of poverty of 60 per cent below median income after housing costs.

3. The prime of life? Social and economic exclusion during working age

3.1 Introduction

In 2005, disabled people are at a high risk of social and economic exclusion. This constrains the ability of disabled people to exercise the rights and responsibilities of full citizenship. Tackling the high levels of social and economic exclusion faced by disabled people will be critical to ensuring that they can achieve full and equal citizenship in the future. This chapter examines the challenges and opportunities for disabled people's social and economic inclusion by 2020. We understand social and economic exclusion as what occurs when people face a combination of linked problems such as unemployment, discrimination, poor skills, low incomes, poor housing, bad health and family breakdown (see SEU 2004). These problems are linked and can be mutually reinforcing, creating ongoing cycles of disadvantage.

This chapter focuses on the exclusion and inclusion of adults of working age. This is a period of life when most people expect to establish their own family and home, complete their education and training, and be in paid employment. Experience of exclusion during these years will impact on a person's ability to care for their children and older relatives, as well as for themselves and their partners. In this way the exclusion of people of working age can have inter-generational impacts. Many aspects of the social and economic exclusion of disabled children and older people are explored through chapters two and four. Of course, all evidence is not based on consistent age categories and there will be some overlap in the issues discussed across all chapters. In 2020 working age is expected to be from 16 to 65 years for both men and women, following the equalisation of working age for women from 60 to 65 between 2010 and 2020.

We begin with estimates of some of the demographic trends in the population of disabled people of working age between 2005 and 2020. We then assess their opportunities for full and equal citizenship across four key dimensions of citizenship: taking control; helping shape society and making a valued contribution; getting equipped to play a part; and getting on. This highlights a number of key policy areas that are likely to be important drivers of the exclusion and inclusion of disabled people of working age in 2020. These are: employment; skills and qualifications; welfare reform; income poverty; opportunities for social and political participation in community life; and housing and the built environment.

Wherever possible, we use forward projections of current trends to estimate the nature and scale of challenges to 2020. However, this data is not always available – for example, data can be only be projected forward when comprehensive information is available at least for the current period. This is not available in relation to some policy areas, such as social and civic participation. As always it is also important to treat forward projections with caution and to regard them as only one of a wide range of possible scenarios and there is very little inevitability in any aspect of change.

3.2 Trends

The Government Actuary's Department (GAD) estimates that the working age population (aged sixteen to the statutory pension age) will rise from 35.78 million in 2003 to 38.80 million in 2020. This is partly accounted for by the increase in women's statutory pension age from 60 to 64 in the period to 2020.

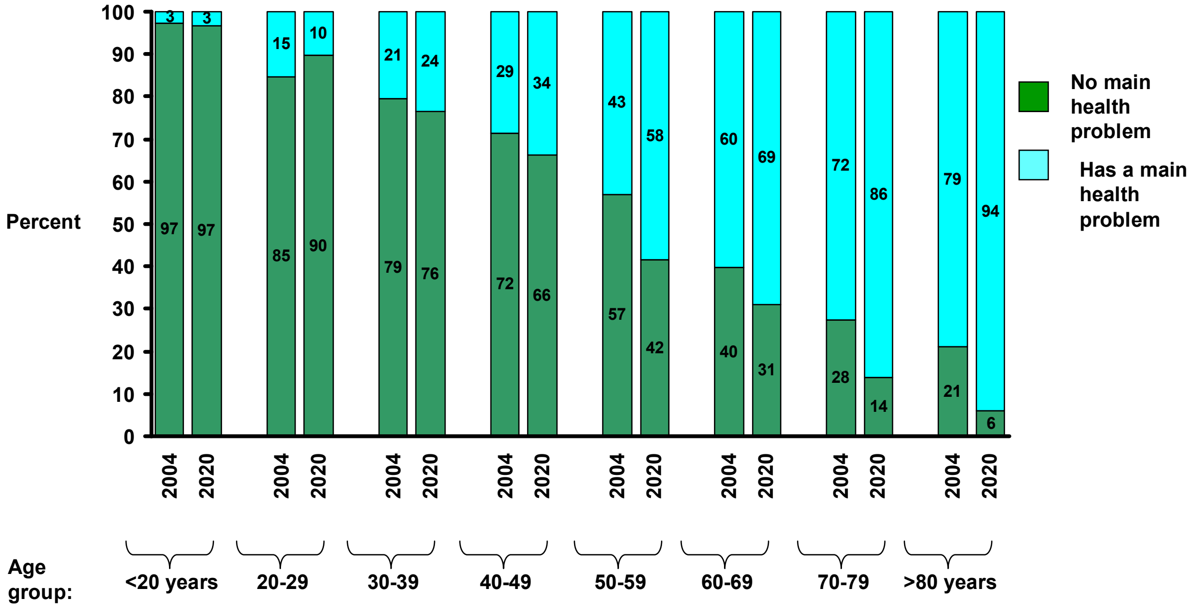
Characteristics of the working age disabled population

The Labour Force Survey, which covers the UK, provides data on the number of people who report a long term health problem or disability including those of working age (see the glossary for further details). To generate projections of the share of the population with a long term health problem or disability in 2020, we have examined the change in share of population over the period 2001/2004. This is the longest recent period for which consistent definitions covering the entire sample are available. Of course, the fact that a pattern has occurred between 2001 and 2004 is not a guide to the pattern occurring over the next four years, much less over the next 15 years. None the less, these extrapolations give at least some indication of one possible future scenario, although we cannot make any claims for its likely accuracy. The change in population share for each impairment group has been calculated as an average percentage point change per year. This annual percentage point change has been projected forward from 2004 to give projections for the share of population with each impairment group in 2020. Separate projections have been done for men and women. In cases where the projected share falls below zero, a zero share has been used.

Respondents in the Labour Force Survey are asked whether they have any long term health problems or disability, and are requested to categorise their health problem or disability into one of 17 different categories. Those who reported having a long term health problem or disability are represented in blue in figures 3.1, 3.2 and 3.3, while those who do not are represented in green.

Figure 3.1 shows a moderate decrease in the prevalence of self-reported long term health problems or disability among people in their 20s between 2004 and 2020, and moderate increases among people in their 30s and 40s. There are more significant increases in self-reported impairments among people aged over 50. The rise in self-reported impairments among people in their 50s is projected to grow from 43 per cent in 2004 to 58 per cent in 2020.

Figure 3.1: Existence of main health problems by age group, 2004-20

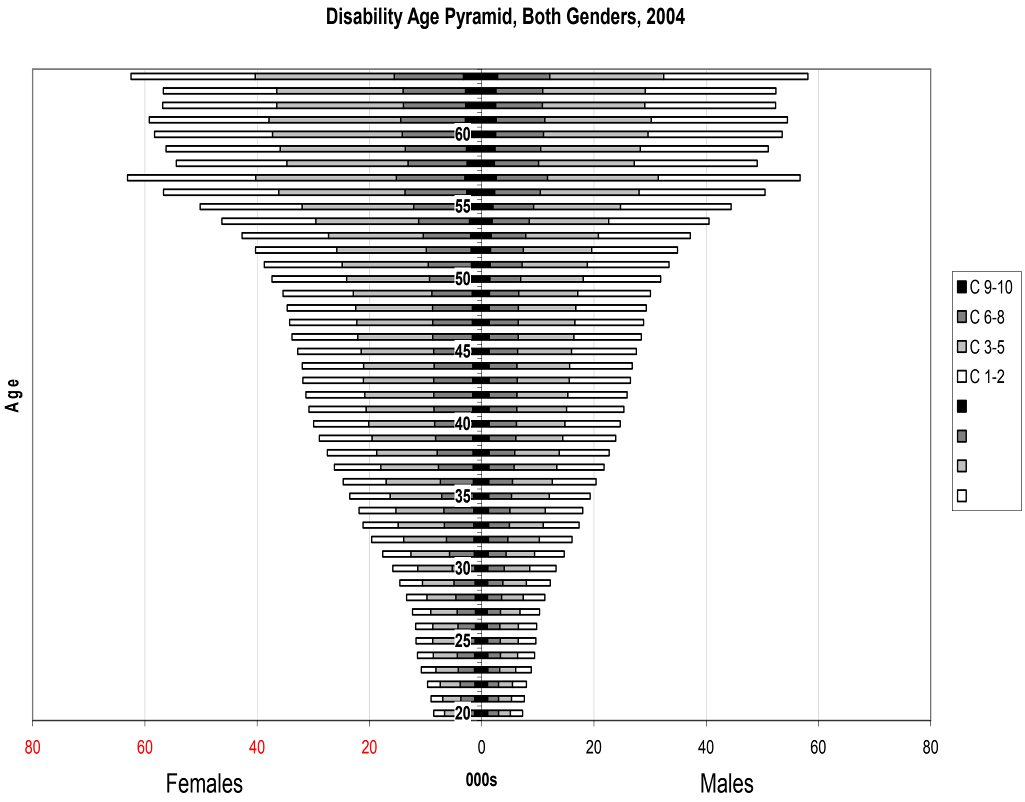


Note: Excludes those respondents who did not answer
Source: LFS, ippr projections

If this data is broken down by gender we find that that there is a projected rise in self-reported health problems and disability among men in their 30s but no rise among women the same age.

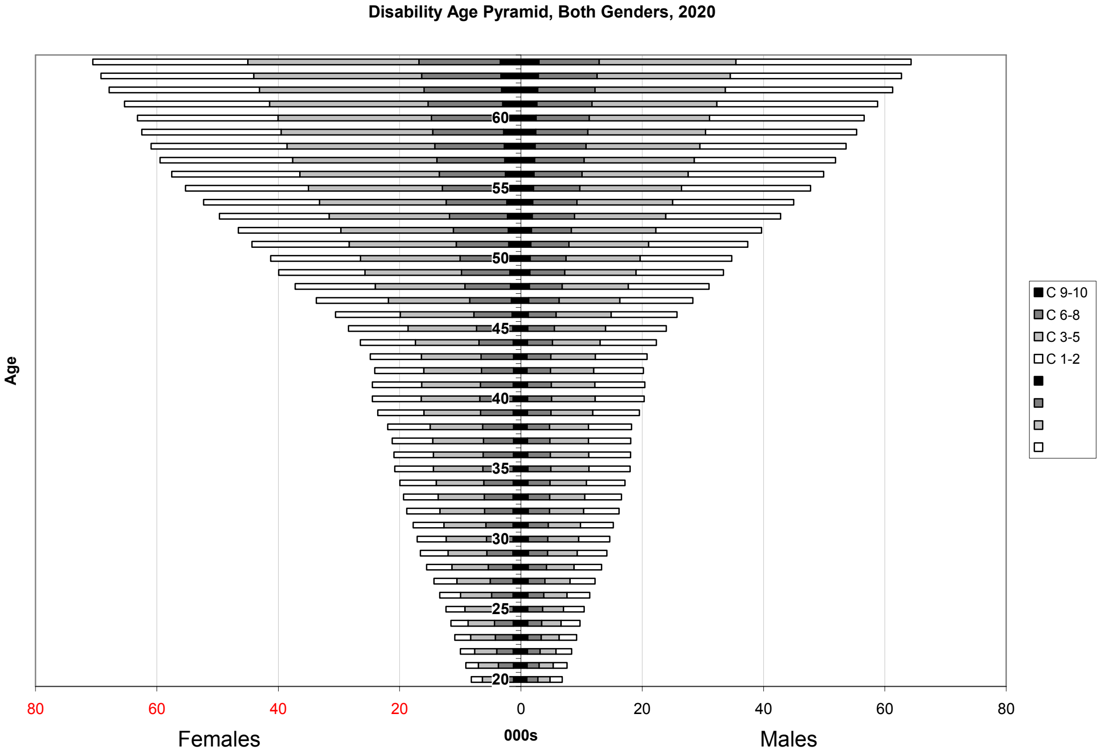
Figures 3.2 and 3.3 show the projected profile by age, gender and level of disability of people of working age reporting a long term health problem or disability in 2004 and 2020 based on data produced by Rickaysen (2005). Their projection model is based on the 1986 OCPS survey (see chapter 4 and the glossary for further details of the projection model and the OCPS survey). The level of disability is indicated by the categories identified in different shades. These categories are based on a medical definition of disability and severity which is a limitation of these projections. The age pyramids show the projected growth in the number of women and men reporting a long term health problem or disability from their late 40s.

Figure 3.2 Disability by age and gender, 2020



Source: Rickaysen 2005

Figure 3.3 Disability by age and gender, 2020

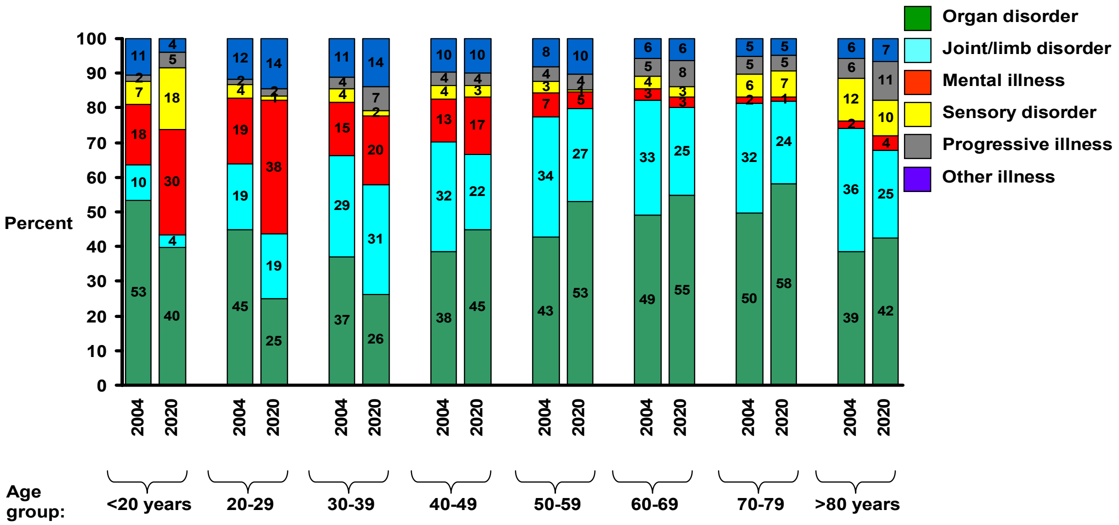


Returning to data based on the LFS, figure 3.4 shows the proportion of people with different impairments by age in 2004 and in 2020. The impairment categories are grouped into six macro categories as follows:

LFS Category	Impairment group
1 to 3	Joint/limb disorder
4 to 6	Sensory disorder
7 to 11	Organ disorder
12 to15	Mental illness
16	Progressive illness
17	Other illness

The breakdown of the main long term health problems and disabilities is then shown for 2004 and 2020. The percentages represented by each impairment group are shown in the bars. There is a notable increase in the number of people with mental health impairments across all the younger age groups and an increase in organ disorders among older groups.

Figure 3.4 Breakdown of main health problems by age group, 2004-2020
Source: LFS Spring 2004, ippr projections



Note: Excludes respondents with no health problems and those who did not answer
Source: LFS, ippr projections

This is consistent with the World Health Organisation prediction that depression will be the leading cause of disability by 2020 (WHO 2001). The growth in the number of people with mental health problems is particularly significant because they have been among the least likely to be in paid employment. Another group with similarly low employment rates has been people with learning disabilities. Researchers at the University of Lancaster have estimated that their numbers will also grow. They made estimates of the number of people aged 15 and over with learning disabilities in England by 2021 based on population projections made by the GAD, and an assumption of no change in the age-specific prevalence rates of learning disability, which they describe as an “extremely conservative assumption” (Emerson and Hatton 2004). Between 2001 and 2021, they suggest there will be a 9 per cent increase in the number of adults with learning disabilities known to services, and an 11 per cent increase in the total number of adults with learning disabilities in England. This would give a total prevalence of over one million adults aged 15 years and over in England in 2021, although they estimate that less than one quarter of these people will be known to services.

Public expenditure on working age benefits

As we have already seen in relation to children and young people, trends in public expenditure are important for the prospects of disabled people achieving full and equal citizenship. Government expenditure is required to dismantle disabling barriers in society and the economy. Many have argued that the level of this spending has been too low over many decades. The Government itself appeared to acknowledge the need for greater attention to disabled people’s circumstances and experiences, in the publication of the Strategy Unit’s report in 2005 on the life chances of disabled people (SU 2005). However, as we have already noted, the Government faces an increasingly challenging fiscal situation. In the second half of this decade we are likely to see pressure on the public finances with the rate of increase in public expenditure slowing in all areas including health where the 2007 Comprehensive Spending Review will signal a slow down. This means any assessment of the possible circumstances and experiences of disabled people in 2020 must take into consideration likely trends in public expenditure. We have focussed on early years spending in chapter two and social care spending in chapter four; here we look at another very significant area of public spending: the benefits system.

Achieving full and equal citizenship of disabled people is a social justice issue and does not simply come down to resource issues, nor will all measures of citizenship be contingent on public spending. However, it is important to make an assessment of public expenditure trends in order to understand the implications for public policy and in the interests of engendering well-informed debate about the nature and level of public spending.

As ever, there is a range of possible scenarios for the employment position of working age disabled people by 2020. If the overall number of disabled people continues to rise and the impairment profile of the disabled population changes in the ways described above so that 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 and closing the gap in 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 Department for Work and Pensions (DWP) has combined the GAD 2003-based population and benefits projections and the Treasury's long term public finance projections to help calculate a range of illustrative long term projections designed to show the overall fiscal sustainability of current benefit policy, along with any future changes to benefits that have already been decided upon, under a particular set of reasonable assumptions (DWP 2005a). A continuation of the current policy of up-rating benefits (with a few exceptions) in line with prices rather than earnings is assumed. They projected that expenditure on working age benefits for 'people with sickness or a disability' would decrease slightly from an estimated 1.4 per cent of GDP in 2004/05 to 1.3 per cent in 2019/20 (DWP 2005a). Table 3.1 below shows the projected increases in real terms spending on benefits for people of working age with sickness or disability between 2004/2005 and 2019/2020.

Table 3.1: Projected expenditure of working age benefits 2004/05 and 2019/20
Source: DWP 2005a

Real terms expenditure, £ billion, 2005/06 prices	**2004/05** (estimate)	**2019/20** (projection)
Working age benefits for people with sickness or a disability	17.3	23.3
Other principal benefits paid to people of working age:		
Disability Living Allowance	5.1	8.6
Other disability and carer benefits	2.3	2.9
TOTAL	**24.7**	**34.8**

The DWP also estimates that it spent 2.5 per cent of GDP in meeting this objective in 2004/2005 and projects it will spend a lower proportion, 2.2 per cent, by 2019/2220. It is worth noting that over this period, expenditure on benefits for disabled people is greater than spending on other working age groups such as lone parents and unemployed people combined.

On the specific target to 'improve the rights and opportunities for disabled people in a fair and inclusive society', the DWP estimates that it spent 1.3 per cent of GDP in support of achieving this objective in 2004/05. It projects that it will spend 1.2 per cent in 2019/2020. There is an overall expectation that spending on support for disabled people in relation to moving into work and supporting income levels, will increase to 2020. However, this is expected to represent a smaller share of GDP as the economy grows over this period. 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.

3.3 Taking control

Full and equal citizenship implies the ability to take control of ones own life for disabled people of all ages. We might accept though that there are certain circumstances in which children and older people with disabilities cannot take control in an absolute sense (for example, children as a result of immaturity), or do not want to take control (for example, some older people in relation to direct payments). However, there are very few circumstances in which people of working age not having control over their lives could be seen to be desirable or appropriate. Nonetheless, it is only very recently that the importance of disabled people having opportunities to take control of their lives has begun to influence policy making and the delivery of public services.

In 2004, almost half of all disabled people of working age were not in paid employment, and some of those disabled people who are 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, so firstly, we look at welfare reform. The other key dimension of taking control that we consider here is the potential for disabled people of working age to achieve independent living through exercising their rights and responsibilities as parents and access to appropriate services.

Welfare reform

Disabled people of working age will be affected by reforms to the system of out of work benefits, unlike those in other age groups. In 2005, the Government set out for the first time, a more coherent vision of how more disabled people might be supported to move off out of work benefits and into paid employment in a five year plan published by the Department for Work and Pensions (DWP 2005b). The GAD has estimated that spending on Incapacity Benefit, the main out of work benefit for disabled people, was £6.78billion in 2004/2005 and projects that it will be £8.22billion in 2020/2021 (GAD 2005)[1] which implies no rise in the number of claimants.

There are two short to medium term policy developments that could have a long term impact on disabled people when they are out of work. The first is the planned nationwide roll out of the Pathways to Work labour market programme for Incapacity Benefit beneficiaries. The second is the reform of Incapacity Benefit that the Government intends to legislate for during the 2005/2006 Parliament.

The Pathways to Work scheme is a pilot and still in its early days, but the initial findings of its evaluation have been promising. On the basis of these early results, the Government plans to expand the scheme to cover one third of the population from 2006 and has also announced its intention to roll the scheme out nationwide over time. The extension of Pathways has been broadly welcomed. Based on current costings, it would cost £500 million per year to roll the programme out nationally (Stanley with Maxwell 2004). The continued success of Pathways will be critical in ensuring that funding is allocated to labour market programmes for disabled people over the coming years. One of the key indicators that the scheme has succeeded will be employment that is also sustained – and this will only become apparent over the medium term.

The Government intends to publish a welfare reform Green paper in autumn 2005 and to legislate for the reform of Incapacity Benefit. It may also propose other changes to the benefits system. It will be important that these reforms are effective in supporting more disabled people to take control of their lives - whether or not they are able to move into paid employment. For those Incapacity Benefit claimants who could do some form and amount of work this means getting the right kind of into-work support when they need it. For those who cannot do any work – at least for a period of time – this means out of work benefits providing a decent standard of living. One welcome DWP proposal is the re-naming of Incapacity Benefit: which will help to de-couple incapacity from disability. It is not yet clear whether or not the Government's reforms will be effective in providing improved support or a decent standard of living for out of work disabled people.

Independent living

By 2008, the Government plans to pilot and develop individualised budgets for disabled adults which will bring together various sources of funding services, equipment and adaptations, (SU 2005) and direct payments are already in place. We have discussed the potential impact of the roll out of individual budgets and direct payments in relation to children, young people and older people so we will not rehearse those arguments in detail here.

However, it is important to note that the success of both these policy innovations will impact on the opportunities for disabled people of working age to take control of their lives in a similar way. It is also relevant to note that particular barriers to effective roll-out include the fact that the current system of adult service provision is largely characterised by a lack of coordination and partnership working (SSI 2004), and resources continue to be tied up in dependency-creating services rather than being diverted to services based on independent living principles. Although the Government has acknowledged that individualised budgets would require a 'culture shift', it has not specified the levers by which it will deliver such a shift by 2020. This is important because many policy silos have developed over decades meaning that disabled people have had to adapt to services rather than vice versa. We have seen this issue play out in relation to direct payments. For example, in 2005, there is confusion between health service-funded resources and social care-funded resources. Consequently, the development of the direct payments scheme is being hindered by confusion about whether or not and when health services can fund direct payments.

Individualised budgets are to be developed from 2005 to 2008 'within existing resources' (SU 2005 p.95) 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 budget holders.

One area where a new kind of support can encourage independent living is parenting (Priestley 2000; Wates 2002; Morris 2003). Disabled parents still continue to be treated as ‘incompetent’ or ‘unusual family’ members or parents (Olsen and Wates 2003). Services continue to focus on assessing the ‘capacity’ of the disabled adult to parent successfully, with little attention to the wider social contexts and the impact this has on a disabled adult’s attempts to carry out their parenting responsibilities successfully. Minimising the negative impact of parental impairment becomes the focus, rather than supporting the parent to uphold the welfare of the child. Within this frame of reference, the child is seen as the primary client within the family while the support needs of the disabled adult in relation to parenting remain unaddressed. This approach is incompatible with the need, identified by the Social Services Inspectorate (Goodinge 2000), to work from an understanding of both adult community care and children’s legislation when supporting disabled adults in their parenting role. The increase in the number of disabled parents and their relative invisibility as a sub-section of the parenting population (Olsen & Wates 2003) will make it difficult to plan and provide appropriate specialist information, health and social services to disabled adults in their parenting role in the future (Goodinge 2000).

3.4 Helping shape society and making a valued contribution

Very often citizenship, and in particular the opportunity to help shape society and make a valued contribution, is cast in terms of economic participation through employment and paying taxes. However, citizenship is equally about social, civic and political participation and disabled people of working age frequently face social as well as economic exclusion. Of course, social and economic exclusion are closely related and in this section we look first at disabled people’s prospects for helping shape society and making a valued contribution through employment. We then consider prospects in relation to social, civic and political participation.

Employment

In 2005, the Government declared that it aspired to achieving a working age employment rate of 80 per cent (DWP 2005b). The rate in 2004 was 73 per cent so achieving the aspiration means an extra 2.5 million people being in employment. This has been widely welcomed but it is merely an aspiration, not a target; and no date has been set for achieving it.

The DWP has also indicated that an 80 per cent working age employment rate would largely offset the effects of an ageing population (DWP 2005b). The key effect of an ageing population is a decline in the ratio of the working age population to the total population. This ratio is anticipated to decline over the next 45 years creating upward pressure on public spending as a share of

GDP because the per capita cost in public spending terms of a person over pension age tends to be greater than that of a person of working age.

However, analysis by John Hawksworth (2005), suggests that raising the working age employment rate to 80 per cent would offset less than half of the upward pressure on public spending as a share of GDP over the period to 2050, given certain base case assumptions.[2] On the basis of these assumptions, Hawksworth found that a working age employment rate approaching 90 per cent would be needed to stabilise public spending in 2050 at current levels of around 42 per cent of GDP, and that public spending could rise to just under 47 per cent of GDP, even if an 80 per cent employment rate were achieved.

Hawksworth concluded that the most likely scenario is that 'future governments will be faced with difficult choices between continuing with the recent direction of policy in areas like health, education and measures to tackle child and pensioner poverty, which would imply significant tax increases in the long run, and adopting a much tougher stance on public spending growth, particularly but not only, in lower priority areas' (Hawksworth 2005 p.3). Each of these specific policy areas impact directly on disabled people's opportunities for full and equal citizenship. Similarly, under these assumptions, there will be considerable pressure on the funding available for benefits granted on the grounds of disability and for active labour market programmes for disabled people.

It is highly unlikely that significant increases in the overall employment rate can be achieved without a significant increase in the employment of disabled people. One study by the OECD used a simple dynamic modelling framework to look at participation rates and labour supply in OECD countries and alternative scenarios of policy reforms (Burniaux *et al* 2004). It found that the combined effect of possible reforms targeting prime-age women, older workers and young people might stabilise the average participation rate in OECD countries over the next 25 years but not offset the drop in participation likely to be caused by demographic changes beyond 2025. This reinforces the economic arguments for looking beyond these groups and targeting reforms on supporting more disabled people into employment.

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. We know that one of the key elements of 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 (Stanley and Regan 2003). This can make support more costly to deliver but it will also make it more effective.

A further possible barrier to work may emerge as a result of genetic developments. Some fears have been expressed that, in the future, employers and insurance companies will use genetics tests and information to select candidates and/or customers. In 2005, there is no evidence that employers in the UK are systematically using genetic test results to recruit people, or using such tests as part of workplace health. However, this could change and there are precedents from the USA, where genetic testing by employers is not unusual, although it is still controversial. Perhaps the strongest indication that these fears are unfounded comes from public opinion. In 2002, there was wide public and professional support for the Government to introduce legislation to prevent discrimination in areas such as employment and insurance (Human Genetics Commission 2001). In 2000, the majority of the public surveyed were not in favour of allowing insurance companies access to genetic data and the majority were not in favour of disclosing genetic data to employers if the safety of the individual or his/her colleagues is compromised (Human Genetics Commission 2001). Future policy changes in this area would have to take such public concerns into account.

Social and civic participation

Social and civic participation is an important expression of citizenship for disabled people, but can also play a role in dismantling disabling barriers. Likewise, a lack of opportunities for such participation can exacerbate them and even contribute to mental ill health, for example. There is evidence to suggest that social isolation and socio-economic deprivation are strong aggravators of mental ill health; whereas, higher levels of social networks have been shown to reduce the likelihood of the first occurrence of mental ill health as well as improve the health of those with mental health problems. In fact, some studies have suggested that community interventions and social support networks can be more effective than medication in dealing with mental health problems (White and Angus 2003).

The evidence on current patterns of social interaction and civic participation is limited and difficult to interpret, which makes it especially difficult to assess how disabled people’s opportunities to make a valued contribution might change in the future. The 2003 Home Office citizenship survey showed that people’s sense of neighbourliness has been increasing and there are high levels of social interactions with friends and families. Other studies have shown that although neighbourhood relations continue to be significant parts of people's overall social network, the most significant ties exist outside the neighbourhood (Bridge 2002). The Department for Culture, Media and Sport has a target to increase significantly the take-up of cultural and sporting opportunities by new users including disabled people, but the participation of disabled people has not yet increased.

The number of people participating in voluntary work in the UK is high and shows no signs of declining (Grenier and Wright 2003). However, there is a range of factors that limit the ability of disabled people to participate in voluntary activity. Volunteering is not covered by the Disability Discrimination Act and so disabled people may face discrimination in accessing voluntary opportunities. ‘Access to Work’ funding - which helps employers to meet certain costs that may be associated with employing a disabled person - is not available to meet the costs of participation in voluntary work. The current structure of out of work benefits for disabled people means that many disabled people fear they will lose their benefit if they engage in voluntary activity. Formal volunteering is increasingly concentrated among higher social classes, another factor which does not bode well for volunteering rates among disabled people. Grenier and Wright (2003) argued that there is a pattern towards an increasing class divide in the patterns of social interaction and civic participation. Despite recent efforts, there is still no sign of disabled people being more fully represented in voluntary organisations. A survey by the Institute for Volunteering Research in 2004 found that disabled people were under-represented in more than half of all voluntary organisations. But, there are also some positive signs for the future. For example, the Department of Health and the Department for Culture, Media and Sport are working together to try to boost volunteering opportunities for disabled people.

We should not underplay the importance of Internet access in enabling participation. The Internet can provide information, a route to overcoming social isolation and mutual support. Enabling participation in this sense can provide a stronger voice for disabled people and should be seen as part of an emerging trend of ‘network-empowered citizens’ (Coleman 2004), using the many to many function of the Internet to create ties between individuals and to facilitate information sharing and discussion.

Concern that Internet use would limit time spent in the ‘real world’ and damage real world contacts appears unfounded (Gardner and Oswald 2001), however, evidence also shows that relationships sustained primarily over the internet are not as close as those maintained by other means (Cummings 2002). The extent to which weaker online ties can be translated into real world connections is not clear. It is yet clear as to how such initiatives could impact on disabled people although a good quality of life clearly depends on informal neighbourhood relations, as well as non-localised social networks (Anderson 2004).

While research has shown that net of any structural effects only social participation reduced the likelihood of a common mental illness (Pevalin and Rose 2003), the obstacles to disabled people taking up the opportunities offered by ‘wired’ community schemes remain. Without significant training and support mechanisms in place, the likelihood is that such schemes will only serve to widen inequalities in community participation and exacerbate existing problems.

The Government has recently expressed a commitment to neighbourhood governance, within which technology may have a significant role. It is essential those at risk of social exclusion are kept at the forefront of policy developers’ minds as they consider the level and distribution of resources for technology and training.

Technology has the potential to tackle mobility-related social exclusion by increasing ‘virtual mobility’ providing access to opportunities, services and social networks (Kenyon *et al* 2003). But levels of Internet access and home computer ownership among disabled people are currently very low and the most excluded are in danger of being left behind.

Political participation

Citizen's involvement in decision-making processes and holding power to account is essential to a fully functioning democracy. The most basic form of political participation is voting at a general election. There will be many more older voters than younger voters by 2020. Older women are the most likely to vote, with 75 per cent of those over 55 years old sure to vote. So changing demographics are likely to lead to an increase in voter turn-out, particularly if improvements continue to be made in the accessibility of voting. These changes may also impact on the issues that political parties campaign on and push issues of concern to disabled people higher up the political agenda. However, the 'disabled constituency' is extremely diverse and by no means does it have a unified agenda. For example, young disabled people may well have different concerns than the more numerous older disabled population. They report feeling alienated from government with 74 per cent believed the government rarely listens to their views (DRC 2002).

The government is seeking to promote public involvement in policy making, particularly in relation to the regeneration of deprived areas, for example through the New Deal for Communities and the Neighbourhood Renewal Fund, and this is likely to continue in the coming years. However, consultations used to assess public opinion are widely criticised for their time consuming and excluding processes and the 'tick-box' approaches of going through the motions without meaningful engagement has been widely identified across public bodies. In future, consultation will need to be more imaginative and more robust if disabled people are to be brought into these processes more fully. Techniques such as deliberative forums are slowly being accepted as useful and legitimate modes of communication between the public and policymakers.

Disabled people are less likely to enter into formal participation as governors of public bodies, membership of panels and other modes of public involvement. For example, 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 (Cabinet Office 2004). The argument for involvement is not just rights based, but is part of a vision that 'user involvement' will improve public service delivery. Disabled people are best placed to advise on services for disabled people.

3.5 Getting equipped to play a part

Before disabled people can exercise the full rights and responsibilities of citizenship, they must get equipped to play a part. This means having the personal attributes - or means of acquiring them - to fully participate in social and economic life.

In this section we examine two areas where there are significant opportunities for disabled people to get better equipped for citizenship over the next 15 years. The first of these areas is qualifications and skills which are important in enabling disabled people to play a part in both economic and social life. In particular, we discuss the potential role of information and communications technologies (ICT) in providing the means for disabled people to get equipped. The second area we consider is housing and communities. Disabled people are more likely to live in poor housing than non-disabled people, and access to appropriate, decent housing is a crucial element of getting equipped to play a part in society.

Qualifications and skills

The dynamic nature of the labour market means that the skills, qualifications and experience required of employees change over time. Of these, qualifications are easiest to measure. In recent years there has been a significant increase in the demand for higher qualifications. In 2003, 40 per cent of disabled people of working age had no qualifications at all and disabled people – on average – had lower qualifications levels than the rest of the population (DRC 2005). This is likely to have been one of the factors limiting the increase in the employment rate of disabled people, even during a period of economic stability and low unemployment. In Table 3.2 below, the possible trends in the demand for qualifications to 2020 are projected forward. These show an increase in the actual and projected demand for higher level qualifications.

Tabl3 3.2: Qualifications required in Britain between 1986 and 2001; and projected qualifications required in 2020

Source for data to 2001: Wilson *et al* 2004; 2020: ippr's calculations

Qualification level	**Highest qualifications required (per cent of workers)**			
	1986	**1997**	**2001**	**2020 (projected)**
Level 4 (higher)	20	24	29	40
Level 3	15	14	16	16
Level 2	19	21	16	13
Level 1	8	9	12	16
None	38	32	27	15

This increase is partly driven by changes in the occupational structure of employment shown in figure 3.10 below. Since 1982, there has been a substantial increase in the proportion of all people in employment in 'higher' or professional or managerial occupations. This contrasts with a substantial decline in the proportion of people in intermediate occupations and a smaller decline in the number in lower occupations. Table 3.3 shows the proportion of employment at each level in 2012 and 2020 if these trends continue at current rates. By 2020 almost half of all employment would be in higher occupations.

Table 3.3: Changes in the occupational structure of employment, 1982 – 2001, and projected for 2012 and 2020
Source for estimates to 2012 CE/IER, SOC 2000 ; 2020 ippr calculations

	per cent per cent of total employment				
Occupations	**1982**	**1992**	**2002**	**2012**	**2020**
Total 'higher occupations'	28.3	33.3	40.2	45.1	49.0
Total 'intermediate occupations'	32.5	30.4	24.6	20.5	17.3
Total 'lower occupations'	39.3	36.3	35.2	34.5	33.8

The changing nature of the demand for labour has recently seen a shift away from demand for unskilled workers. The Learning and Skills Council has warned that without at least a basic grasp of IT skills, people will find it increasingly difficult to find work (LSC 2003). Of those receiving Disabled Living Allowance, 37 per cent have never used a computer, while only 37 per cent have used the internet. ICT use is lower among people with a long term health problem or disability, even after allowing for the older age profile of this group (Coleman *et al* 2002). Given the reliance on ICT in the office environment, the Audit Commission (2004) has recommended identifying the range of physical and cognitive abilities among working age adults and current computer users, along with the types of difficulties and impairments that could potentially limit the scope of activities. This information, combined with population trends, could help to explain the impact of ageing populations, and the resulting increase in disability, on computer use. In order to prepare for 15 years, therefore, evidence on these likely trends is needed now.

More broadly, ICTs have an important role to play in bringing about opportunities for disabled people to get equipped to play a full and equal part in society in the coming years. In 2000, the European Union (EU) set out its strategy to make the EU 'the most dynamic and competitive knowledge-based economy in the world' by 2010 (European Council 2000). The strategy has four goals: to raise competitiveness, achieve full employment, strengthen social cohesion and promote sustainable development. Technology is seen as a key tool in achieving this, but Government has given little priority to considerations of how technology can help strengthen social cohesion and achieve social justice, nor how to mitigate any negative effects of ICT developments in these respects. The success of the EU's agenda depends in no small part on enabling *accessible* technological advance. But it will require, on the part of Government and business, a greater long term understanding of the emerging market demand and a more adequate response to it. It has been noted that the pace of technological change is often faster than the pace of inclusive technological change: in the case of the Internet, inclusive change is only now beginning to catch up.

Housing

Disabled people face economic (in terms of affordability) and physical (in terms of accessibility and quality) disadvantage in the housing market. In looking forward to how this may have changed by 2020, it is important to note that structural changes to the housing market can take a long time. Principally, this is because in any one year new dwellings account for less than 1 per cent of the overall housing stock.

The Government is currently looking at measures to increase the supply of housing. This, in of itself, has some potential to increase housing choices for disabled households. It is widely recognised that the housing market has passed its most recent peak and in July 2005 wages grew faster than house prices for the first time in nine years (Nationwide 2005). Historical trends would suggest that between now and 2020 it is likely that the housing market will go through one complete cycle, with affordability easing towards the end of this decade and sharpening again as we approach 2020.

The Government has already taken some steps to reduce volatility in the housing market, and is planning further action (HMT/ODPM 2005); this should mean that the affordability problems for households on moderate incomes wanting to access the housing market should not be as severe as they have been in recent years. However, many disabled people live in social housing and in 2020 it is likely that for many disabled people subsidised housing will remain the most appropriate housing option. Currently, demand for social housing outstrips supply, which means that disabled households and other people in need of social housing are not always able to access it.

The Government has significantly increased investment in social housing, such that by 2007/2008 it will have doubled since 1997/98.

However, these are increases on a low base and the growing costs of house building have meant that the output of social housing has not increased in line with investment. It is projected that by 2007/2008 social housing output will increase by 10,000 above that of current levels to 30,000 homes a year, although this is predicated on significant efficiency gains (ODPM/HMT 2005). Public expenditure plans up to the end of the decade show that spending as a proportion of GDP will not increase above the 2007/2008 level of 42 per cent and given spending commitments already made to further other policy areas, it is unclear what the investment pattern will be in housing after 2007/2008.

The Government’s current social house building plans can be compared to an independent assessment of the need for additional social housing in the population as a whole. Analysis by the Cambridge Centre for Housing and Planning Research to meet newly arising need over the period 2001 to 2011 (Holmans *et al* 2004) concluded that 667,000 additional social sector homes would be required. This translates into an annual requirement of 67,000 homes a year, more than twice the level being projected by the Government for 2007/2008 which, given public expenditure plans, is likely to be the peak of social housing output. The majority of these homes would be needed in the south of England.

These figures do not include any consideration for reducing the significant backlog of current unmet needs. On the Holmans figures, building in an allowance for reducing the backlog, brings the total social sector housing requirement up to 89,000 homes a year, nearly three times the level that social housing output is projected to reach by 2007/2008.

Overall, even if problems of affordability in market housing do ease, 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.

A significant plank of the Government's approach to increasing housing supply are its plans to develop 200,000 homes, over and above previous regional plans, between now and 2016 in four 'growth areas' in the greater south east. This is the first time that new communities will have been created on this scale since the new towns programme that began in the 1960s. The plans for the new communities in the New Towns did not make provision for disabled people (Bennett 2005). Ensuring that the new communities in the Growth Areas are inclusive and sustainable represents a significant challenge.

One of the key concerns that has emerged about the Growth Areas is around the level of funding available to support investment in necessary infrastructure (Burwood and Jess 2005). By 2008, the Office of the Deputy Prime Minister (ODPM) will have provided over £1.2 billion of specific investment in the growth areas, with a further £200 million for transport projects from the Community Infrastructure Fund. However, there are no official estimates of the level of investment infrastructure necessary to support the levels of growth that are being planned. Estimating infrastructure costs is complex and subject to significant uncertainty. The Government is currently analysing the infrastructure costs of its housing growth plans (HMT/ODPM 2005). An unofficial estimate for the infrastructure costs for the housing growth in the South East indicates that there is a shortfall in infrastructure funding of £8billion (Roger Trym and Partners 2005). This shortfall is likely to have the greatest impact on transport and affordable housing. A shortfall in the provision of affordable housing, or inadequate transport infrastructure in the Growth Areas would be likely to have the effect of excluding disabled people from the Growth Areas.

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 the current rates of building and demolition continue, by 2020, the proportion of homes in England built under the Part M standards will have reached just twelve per cent.[3] This relatively low figure highlights the limited progress in improving the accessibility of the housing stock that can be achieved solely by raising the standards of newly built dwellings.

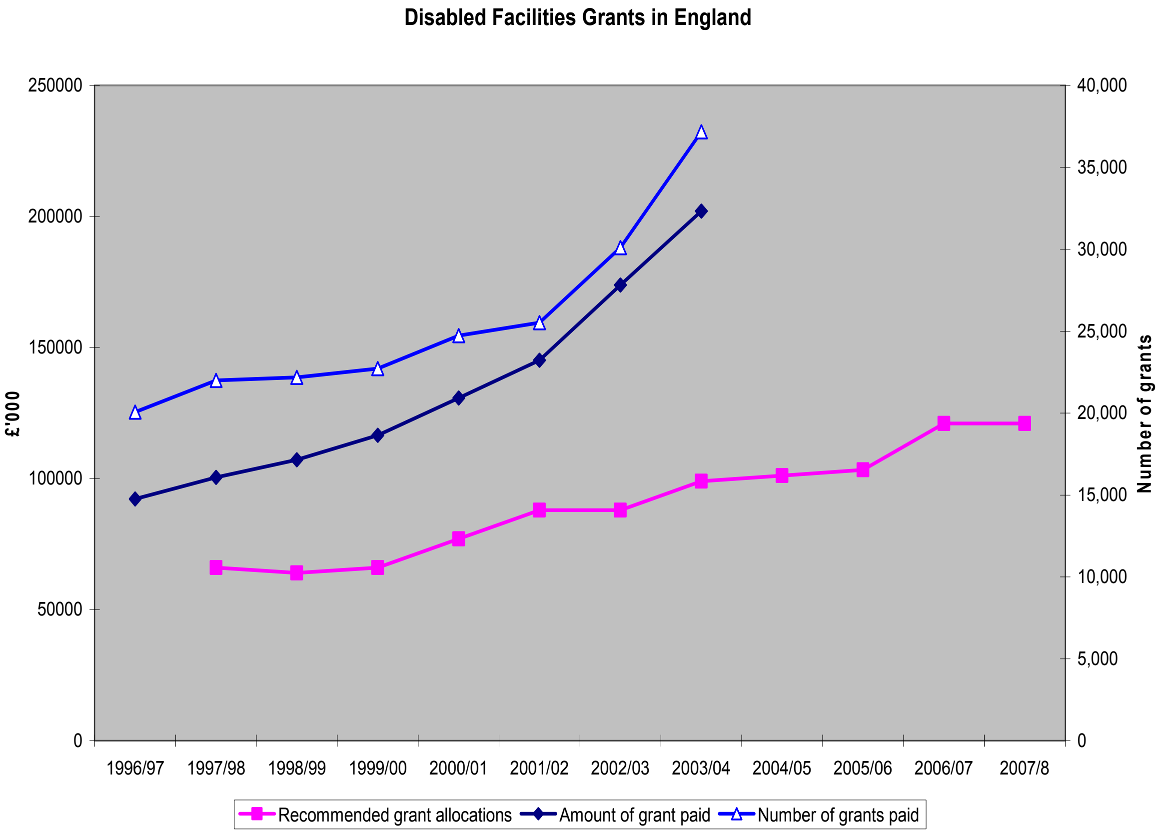
The standards required by Part M fall short of ensuring full accessibility, or even the potential for full accessibility, without very expensive adaptations. The Part M standards are currently under review so there is some prospect that a more ambitious standard, along the lines of the Lifetime Homes standard, could be adopted between now and 2020. However, a number of factors could work against further raising the accessibility standards for new homes. Recent Government policy has focused on reducing the costs of housing, both in financial and environmental terms (HMT/ODPM 2005). This has lead to planning guidance encouraging the development of housing at higher densities which has reduced the overall land-take of new housing development. In terms of financial costs, the increased funding for social housing from the 2004 Spending Review is dependent on £160million of efficiencies in social housing procurement costs (HMT 2004). In the private sector, the Government is running a competition for private house builders to gain access to develop on public land where they must provide each unit at a cost of less than £60,000 (ODPM 2005).

Building at higher densities has led to an increase in the proportion of properties being built as flats rather than houses and with a smaller number of bedrooms. In 2000/1, 34 per cent of all new homes had one or two bedrooms and 20 per cent were flats. By 2003/4, 41 per cent of all new homes had one or two bedrooms and 34 per cent were flats. Although developing at higher densities and achieving accessibility are not mutually exclusive and can be achieved through good design (Shaw *et al* 2002), there is a danger that increasing densities could make it harder subsequently to introduce higher standards requiring more space. Particularly, if at the same time, the Government is seeking to bear down on the costs of both public and private sector homes. 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 which have highlighted the importance of space, for example to accommodate adaptations and the use of necessary equipment (Oldman and Beresford 1998). However, the policy drivers to increase housing density and reduce cost may militate against the adoption of higher accessibility standards.

The lack of reliable data about both the current provision of fully wheelchair accessible housing and the overall numbers of wheelchair users makes it impossible to project what the position might be in 2020. All we can say is that currently there is a significant but unspecified shortfall. Unless a thorough assessment is made of the need for additional fully accessible homes and an investment strategy implemented to address that shortfall, between now and 2020 the position is unlikely to improve.

The provision of Disabled Facilities Grants (DFG) for households to meet the costs of adaptations to their home has been growing in recent years, although most of the resources for this growth have come from local authorities using their discretion to make grants over and above the level of recommended allocations they receive from Government.

Figure 3.5: Disabled facilities grants in England



Although the recommended allocations have grown and look set to continue to grow up to 2006/07, the capacity for local authorities to fund grants at a much higher rate is unlikely to be sustainable. As set out above, 2007/08 may represent a peak in terms of public expenditure on housing, and so central government support for the DFG may be cut beyond this point. In addition, there are a number of problems with the way the grant regime operates. This includes the overall level of funding available and also the means test that is applied to all awards. The means test for DFG has been scrapped in Wales, and in England the DFG regime is being reviewed and one of the issues they are considering is the means test. The fact that the national budget is under pressure, and that in future, sustaining the current level of resources will be difficult, would suggest that it is unlikely that the means test will also be scrapped in England.

The slow rate at which existing housing stock is replaced by new housing means that the accessibility standards for new homes only have a limited impact on the overall stock of housing. However, a number of recent policy initiatives will accelerate the rate of stock replacement, particularly in the North of England.

Under ‘the Northern Way’ (ODPM 2004) the rate of replacement of the housing stock in the Northern Regions will be accelerated. This is possible because the rate of house building in the North exceeds the rate of household formation. The objective of this housing replacement is to provide a wider choice of housing and increase the attractiveness of the North to potential investors and skilled employees. However, it would also provide an opportunity to ensure that a greater proportion of the housing stock meets higher standards of accessibility.

Previously the replacement of housing stock in the North has been poorly managed with new homes being built, offering people the opportunity to move, while older less popular homes have been left to be abandoned. This has created localised cycles of housing market decline, where poorer residents, unable to afford a move to a new home are trapped in unpopular areas which become run down. The Sustainable Communities Plan included measures to address areas affected by very low demand for housing through nine Housing Market Renewal Pathfinders in the North and Midlands with £500million of funding (ODPM 2003). Most of the resources for the pathfinders will be used to demolish, replace and refurbish the housing stock, as well as making other neighbourhood improvement, in low demand areas. The significant capital investment in providing replacement homes and major refurbishment of existing homes provides a further opportunity to improve the accessibility of the housing stock in these areas.

The problems faced by disabled people living in unsuitable housing can be exacerbated if that housing is also of a poor quality. Disabled people are more likely to live in housing that does not meet decent homes standard. By 2020, the Government will 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.

A further key element to meeting the housing needs of disabled people is the provision of housing-related support. The Supporting People programme could enable greater inclusion of disabled people. The programme was introduced in 2003 to provide revenue funding for housing-related support services which help vulnerable people live independently in their accommodation. However, the introduction of the policy has been problematic, with concerns about the growth of the budget linked to suggestions of ‘cost-shunting’ from community care budgets. This has led to a degree of uncertainty about the future of the programme and the extent to which it will be able to grow to meet unmet needs. For example, in 2004/05 and 2005/06, the Housing Corporation allocated 6.8 per cent of its rent programme for supported housing. This compared to 13.4 per cent in 2003/04. This reduction in capital investment in supported housing is due to uncertainty over the provision of revenue funding under the Supporting People regime.

In June 2005, the Government announced a further review of the Supporting People programme. This degree of uncertainty about the medium term future of housing-related support provision makes it difficult to project forward to 2020 whether or not there will be sufficient funding for housing-related support for disabled people in general needs housing, or what the long term impact might be on the supply of new specialist supported housing. Unless the ODPM can address concerns about the effective targeting of the programme and control of expenditure, it will be difficult to make the case for a higher level of resources for the programme and it will be vulnerable to further cuts.

3.6 Getting on

As we have seen, disability, poverty and social exclusion are closely related phenomena. They each also have a close geographic dimension, so that people living in certain areas are more likely to experience disability, poverty and social exclusion, than people living in other areas. Of course, this does not mean that all disabled people live in deprived communities but it does mean that they are more likely to do so. Experience of disability, poverty and social exclusion can be reinforced by living in a deprived community which can make it harder for disabled people to achieve and sustain full and equal citizenship and to get on in life, reaching their potential. In this section, we look at the prospects for improvements in deprived communities by 2020.

Deprived communities

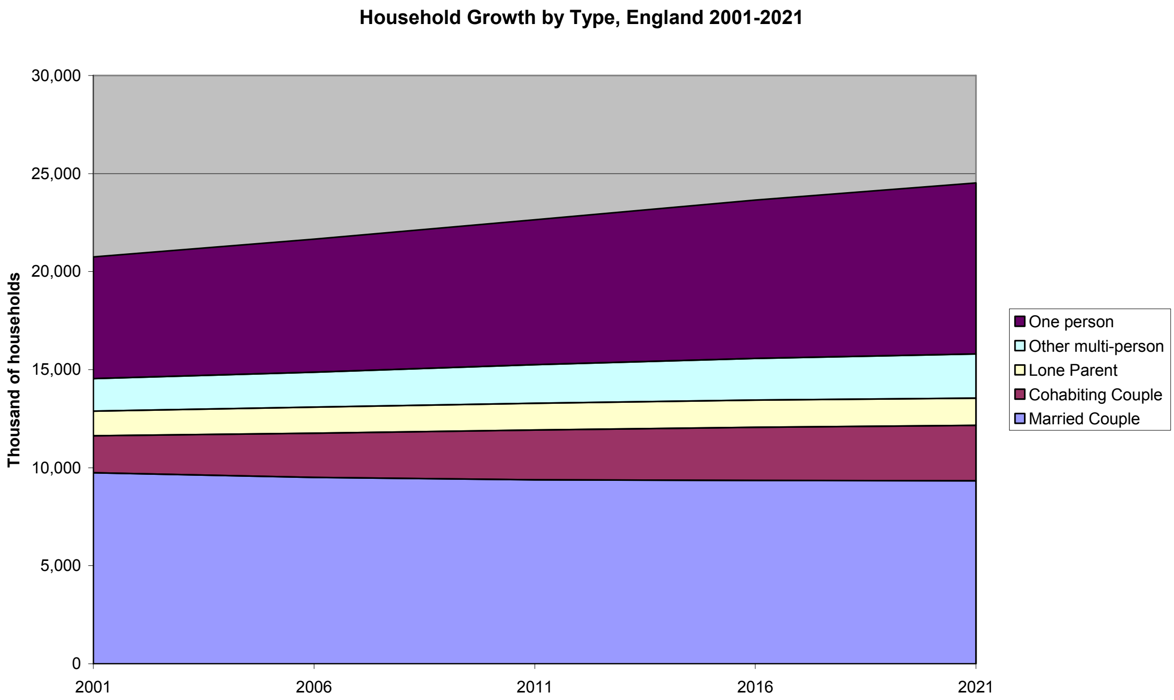
There is a strong regional distribution of disability and, at the local level, a strong association between a high prevalence of disability and areas of concentrated deprivation. In our accompanying report (Pillai *et al* 2005) we posited three possible explanations for these patterns. The first is that some post-industrial areas have high numbers of disabled residents whose disability is associated with particular industries (e.g. such as coal mining). Secondly, that the conditions of living in areas of concentrated deprivation are likely to increase health risks associated with disability. Thirdly, that the lower incomes and additional costs faced by disabled people may force them out of areas with high living costs, and particularly those areas with high housing costs. While the evidence on these factors is not exhaustive, and in the case of the third factor very limited, it is likely that all three play some role in determining the spatial distribution of disability in 2005. Looking forward to 2020, the significance of these factors is likely to change, and therefore the distribution of the disabled population may also change. For example, by 2020, the significance of an area's industrial history will have diminished, as the numbers of people in the area who were employed in those industries reduces over time. The trajectory for the other two factors will be subject to considerable variation in potential outcome dependent on the direction and delivery of public policy.

The current Government has a goal that by 2021 no one should be seriously disadvantaged by where they live (SU/ODPM 2005). To achieve this ambitious goal the Government has a number of major regeneration programmes already in train, including the National Strategy for Neighbourhood Renewal (SEU 2000) and the Housing Market Renewal Pathfinders (ODPM 2003). Further policies aimed at addressing concentrated deprivation through intensive renewal and changes to the tenure mix of social housing estates are being piloted in three areas (ODPM 2005). Overall, these policies have the potential to reduce area deprivation, although the extent to which the National Strategy for Neighbourhood Renewal has lessened the gap between deprived areas and the rest of the country is limited (SU/ODPM 2005). Closing the gap will require continuing significant levels of public investment, and regeneration and renewal will have to remain a high priority for Government up to 2021 if the target is to be achieved. This also assumes that there won't be any significant structural changes to the economy creating new areas of concentrated unemployment. Given the higher prevalence of disabilities in deprived areas, if the Government's goal is achieved it will be of significant benefit to disabled people and may even help to reduce the prevalence of disability through reductions in health inequalities and improved health outcomes.

The extent to which disabled people are forced out of areas with high living costs is an issue which should be subject to further research. The extent of differentials in housing costs in the UK housing market is in part a function of regional imbalances in the supply of and demand for housing. It is an objective of Government policy to reduce these imbalances and these issues featured large in the recent 'Review of Housing Supply' conducted by Kate Barker (Barker 2004). The Government is due to respond to this review later in 2005, although the indications are that it will implement a significant proportion of the Review's recommendations (HMT/ODPM 2005). The majority of these recommendations relate to planning reforms, with the aim of improving the supply of developable land, which was identified by the Review as the main cause of housing supply inelasticity in the UK. If the Government is successful in delivering its objective to improve the supply of housing this should have the effect of reducing price differentials in the long term, which should give disabled households a greater degree of choice over the location of housing and reduce the strength of residential sorting effects, which is the term used to describe the segregation of people in residential housing markets, in this instance by income on the basis of house price.

The possible interaction of area deprivation, weak social capital and the rise of solo living has been suggested as a possible cause for the increased prevalence of mental health problems (Pillai *et al* 2005). Even if the prospects for deprived areas do improve, the projected increase in the number of single households will mean that the number of households that are vulnerable to certain stresses as a result of their solo living may increase. The most up to date household projections show that the number of single person households will increase by over two and a half million between 2001 and 2021. More research is needed to understand the full social impact of the rise of single households.

Figure 3.6: Household growth by type, England, 2001-2021
Source: Interim Household Projections (2002 based), ODPM



3.7 Conclusion

Very often citizenship, and in particular opportunities to help shape society and make a valued contribution, are cast in terms of economic participation through employment. However, both the social and economic dimensions of citizenship are important and disabled people of working age frequently face exclusion from both full social and economic citizenship. There are prospects for improvement by 2020.

For example, the Government has declared that it aspires to achieve a working age employment rate of 80 per cent. This will not be straightforward but it will create a tremendous spur to the achievement of higher employment rates among disabled people. The reform of Incapacity Benefit and the roll out of the Pathways to Work labour market programme also represent opportunities for progress.

Social and civic participation is an important expression of citizenship for disabled people, and 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 and more robust to bring disabled people into political processes more fully. The argument for involvement is not just rights based, but is part of a vision that ‘user involvement’ will improve public service delivery. The personalisation agenda in public services, boosted by direct payments and individual budgets, is likely to enhance the opportunities for disabled people to become active service users rather than passive recipients in the future.

People of working age often expect to have opportunities 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. None the less, 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.

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[1] Based on an assumption of price (not earnings) uprating of benefits and a 1.5 per cent per annum increase in real earnings growth.

[2] Hawksworth calculates the average annual real growth in public spending per person in each age group and key spending category. It assumes real earnings growth of two per cent per annum.

[3] Based on ippr calculations assuming average house building completions of 150,000 per annum, average demolitions and other losses of stock of 20,000 per annum and a total dwelling stock 21,000,000 in 2000. Figures from ODPM dwelling stock and house building data available at http://www.odpm.gov.uk/stellent/groups/odpm_control/documents/contentservertemplate/odpm_index.hcst?n=1559&l=2.

4. A good old age? Older people and disability

4.1 Introduction

It is well known that the population is living longer; by 2020 men will have an average life expectancy at birth of 80 and women will expect to live to 84 (GAD 2003). Yet while industrialised nations such as Britain have been remarkably successful in addressing the effects of biological ageing; they have been much less successful in addressing the consequences of 'social ageing', such as age discrimination, inequality and the social exclusion of older people (Dean 2004). This is significant for any attempt to consider the citizenship status of disabled people in 2020, as the problems of social ageing weigh heavily on disabled older people, curtailing their opportunities to be full citizens. As such, any demographic analysis needs to be connected to the social and political changes that need to take place if society is to improve quality of life and citizenship rights of all disabled older citizens.

On this score, the UK has made a promising start. In 2005, the Government published the white paper, *Opportunity Age*, its strategy to manage the demographic challenges posed by an ageing population (DWP 2005). It avoided adopting the more alarmist scenarios of an ageing population characterised by dependency, doom and deficit. Instead, the White Paper emphasises active ageing, independence and citizenship. The extent to which the Government will succeed on this ambitious agenda by 2020 will be dependent on many factors. These include how far the Government changes the terms of debate on ageing, how much progress is made in tackling pensioner poverty and cumulative disadvantage, and in encouraging the take up of policies that promote independent living for older disabled people.

This last point suggests the importance of mainstreaming the disability rights agenda for older people. Traditionally, the disability rights movement has regarded itself as distinct from campaigns around older people's rights. The DRC has expressed uncertainty as to whether the older population with impairments will connect with the disability movement, it asks: will they be competitors or allies for limited public resources (DRC 2005)? But as the current disabled population grows old and the older population sees some increase in moderate levels of disability, these distinctions will become harder to sustain. Moreover, disabled adults of working age and disabled people in retirement share common goals: independence, control, and being able to determine quality of life on their own terms. The Association of Directors of Social Services (ADSS) have stated a simple but important truism: "just because we are older doesn't mean our needs fundamentally change" (ADSS and LGA 2002).

In the past, public services have been shaped by unfair and unrealistic expectations about older people, with 65 taken as an arbitrary cut-off point to 'adapt to the lifestyle of an older person' (Clark *et al* 2004). In 2005, these outdated ideas are being challenged in many spheres. Policymakers are beginning to challenge age discrimination in public services and employment (DoH 2004). Scientists have started to overturn our conventional understanding of ageing (Kirkwood 2001). Older people, both individually and collectively have contested the notion that old age and disability are synonymous with vulnerability and passivity. This work needs to continue. By 2020, we need a collective understanding of ageing, which avoids both the stereotype of the ‘old and vulnerable elder’, as well as that of the ‘heroic third ager’ in competition with the younger generation. Instead, we need a nuanced account of ageing that reflects a real understanding of the ageing process. Getting older coincides with significant turning points in people’s lives such as retirement, bereavement, and the onset of disability or chronic illness. As the Older People’s Steering Group at the Joseph Rowntree Foundation has written ‘old age is a constant (and at times quite rapid and radical) negotiation between losses, gains and quality of life’ (JRF 2004 p.3). The challenge for policymakers is developing a policy framework that supports people at key transition points in life.

As well as understanding transition points, our account of ageing also needs to acknowledge the heterogeneity of the older population. Although sometimes useful, rhetorical short-hands, such as ‘grey power’ and ‘baby boomer generation’ can mask the variations in social class, age and ethnicity among older people. The older disabled population is similarly diverse and likely to become even more so.

This chapter offers an account of the trends that are likely to affect older disabled people in 2020. This chapter and the data presented relate to people aged 65 or over unless otherwise stated. Firstly, it considers the demographic trends that will affect the size of the disabled population in 2020 and potential demand for services. Secondly, it turns to the theme of ‘taking control’, to examine the potential for older people to live independently and have greater choice over services. Thirdly, it looks at how disabled older people can help shape society and make a valued contribution through equal access to employment opportunities in later life, and through civic and social engagement, such as voting and participation in their local community. The final two sections examine what conditions need to be in place if disabled older people are to achieve independent living and equal participation. Part 4.5, ‘getting equipped to play a part’, covers the health and care settlement available to older people, including the availability of health, social care and long-term care. Part 4.6, ‘getting on’, looks at the wider factors that affect quality of life, including poverty and deprivation, lifelong learning and social engagement. Throughout, the chapter suggests potential ways of addressing the negative effects of social ageing in order to maximise the health, quality of life and security of disabled people in old age.

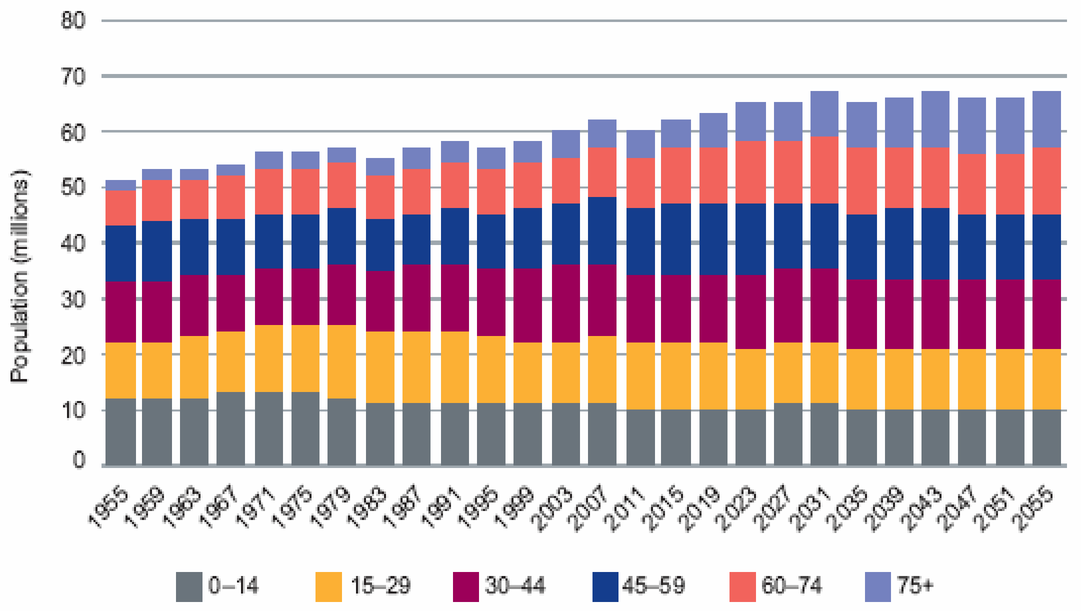
The chapter draws on original research undertaken by the Personal Social Services Research Unit (PSSRU) at the London School of Economics (Malley *et al* 2005) and the CASS Business School at City University (Rickaysen 2005) as part of this study.

4.2 Trends

The ageing population and healthy life expectancy

An ageing population is a common trend across industrialised nations. It means that people are living longer, but also that there are fewer young people as a proportion of the total population, as shown in figure 4.1 below.

Figure 4.1: Actual and projected population by age group from 1955 to 2055, UK
Source: SU 2005



Within the overall trend of an ageing population there are several important trends to note. Firstly, the ageing population means an increase in the numbers of older men. Male life expectancy is increasing at a higher rate than females, thus reducing the gender gap in life expectancies. Secondly, the ageing population means a more ethnically diverse older population. By 2016, the older ethnic minority population will have risen tenfold from 175,000 to 1.8 million (DWP 2005). Thirdly, it means an increase in the numbers of very elderly people. People aged 85 and over are the fastest growing cohort of the population. Between 2005 and 2025, there is expected to be a 183 per cent increase in the number of over 85s (Wanless Review Team 2005).

The ageing population means an increase in the size of the older disabled population. The 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 (Malley *et al* 2005). Put simply, the overall increase in the numbers of older people means that there are more disabled people and increased demand for services.

To take an example, in 2005, around one in five people over 85 has a form of dementia. It is considered unlikely we will see the development and use of new therapies to treat dementia by 2020, which means a substantial increase in demand for mental health and care services (Robinson *et al* 2005). Another factor which explains the increase of older disabled people is the good news story of an increase in life expectancy of disabled people of working age. For example, between 2001 and 2021, it is estimated that the number of adults with learning disabilities aged over 60 will increase by 36 per cent, due to a fall in mortality rates (Emerson and Hatton 2004) and this will mean additional demands. In such ways, the ageing population will have an impact on the demand for health and care 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.

Despite the projections, there remains considerable uncertainty about levels of disability. There is an ongoing debate as to whether ‘future generations will live longer but more disabled lives or increasingly healthy lives’ (Wiener 1994 cited by Malley el al 2005). There are three theses on the future health expectancy of 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 two, suggests there will be an expansion in the time spent in good health as well as the time spent in disability (Rickaysen 2005).

Data produced by CASS does not unequivocally support any of the three main theses (Rickaysen 2005). The results of statistical projections greatly depend on the definitions of illness and disability that are used in the model. If disability is defined broadly as ‘any disability’ the data is consistent with the third trend: as life expectancy increases, people will spend more time disabled and more time not disabled. However, if disability is defined as ‘severe disability’, the projections support the compression of morbidity thesis, where time spent severely disabled will reduce.[1]

CASS have used the Office of Population and Census Studies (OPCS)[2] survey of disability in Great Britain to look at the potential changes in the profile of the older disabled population (Rickaysen 2005). The OPCS categories allocate disabled people into one of ten categories, with category one being the least severe and category ten being the most severe.[3] It will be noted that this survey, and consequently the projections modelled on the survey data, uses a medical definition of disability. This clearly constitutes a major limitation in the data. It also sets ‘health’ and ‘disability’ up in opposition to one another, whereas we know, for example, that a person can be both disabled and healthy. Nonetheless, in the absence of a robust survey based on a more nuanced understanding of disability and an accompanying statistical model, the survey provides a useful guide to a range of scenarios for the future.

Box A sets out CASS's projections on levels of disability using the OPCS categories under the three different theses on health expectancy: basis N corresponds to a compression of morbidity; basis A corresponds to an expansion of morbidity, and basis O corresponds to a combination of both.

Box A: Levels of disability - three scenarios (Rickaysen 2005)

The results show that the proportion of lives expected to be spent severely disabled in each age group generally decreases as we compare the results for Bases A, O and N respectively. For example, for males aged 60 to 79 in 2004 in categories nine to ten, the respective prevalence rates are 1.9 per cent, 1.3 per cent and 1.1 per cent. This is to be expected since Bases A and N are the pessimistic and optimistic assumptions respectively, and Basis O is somewhere in between.

With Basis A, the prevalence rates for the higher disability categories increase, indicating that the position deteriorates between 2004 and 2020. For example, the proportion of females aged over 80 who are in the highest two disability categories is projected to increase from 14.7 per cent to 16.0 per cent.

With Basis O, the proportion of lives projected to be in category zero (i.e. no disability) increases from 2004 to 2020 (with a corresponding decrease in the proportion of lives expected to be disabled). This indicates that the population becomes healthier under Basis O. This is also true of Basis N, with the reduction in prevalence rates at the more severe levels of disability being more pronounced than with Basis O. For example, with females in the aged 60 to 79, the prevalence rate in categories nine to ten falls from 2.0 per cent to 1.6 per cent with Basis O but from 1.9 per cent to 1.3 per cent with Basis N.

Figures 4.2 to 4.5 below suggest how the incidence of disability in the population will change between 2004 and 2020 using Basis N, the most optimistic scenario. The key shows the colours used to represent the groups of OCPS disability categories. The graphs show that there will be an overall increase in the number of people with no disability: for men aged over 80 the number requiring no care is expected to increase from 35.6 per cent to 42.3 per cent during this period, while the proportion of women over 80 requiring no care will rise from 34 per cent to 40 per cent. The trends in moderate disability (those requiring low levels of care) varies slightly between men and women. There will be a small reduction in the number of all men over 60 who have a 'low' requirement for care; but there will be a very small increase (0.2 per cent) in the numbers of women over 80 who require a low level of care. For both men and women, it is projected that there will be a reduction in the numbers who require moderate to continuous care. The reductions are most striking at the highest levels of need, i.e. those in category 9-10. For example, among women over 80, there will be a fall from 10.5 per cent to 7.8 per cent in the numbers with a continuous requirement for care. There will be a smaller decrease in the numbers with a moderate requirement for care.

Figure 4.2: Males, incidence of disability, basis N (optimistic scenario), 2004

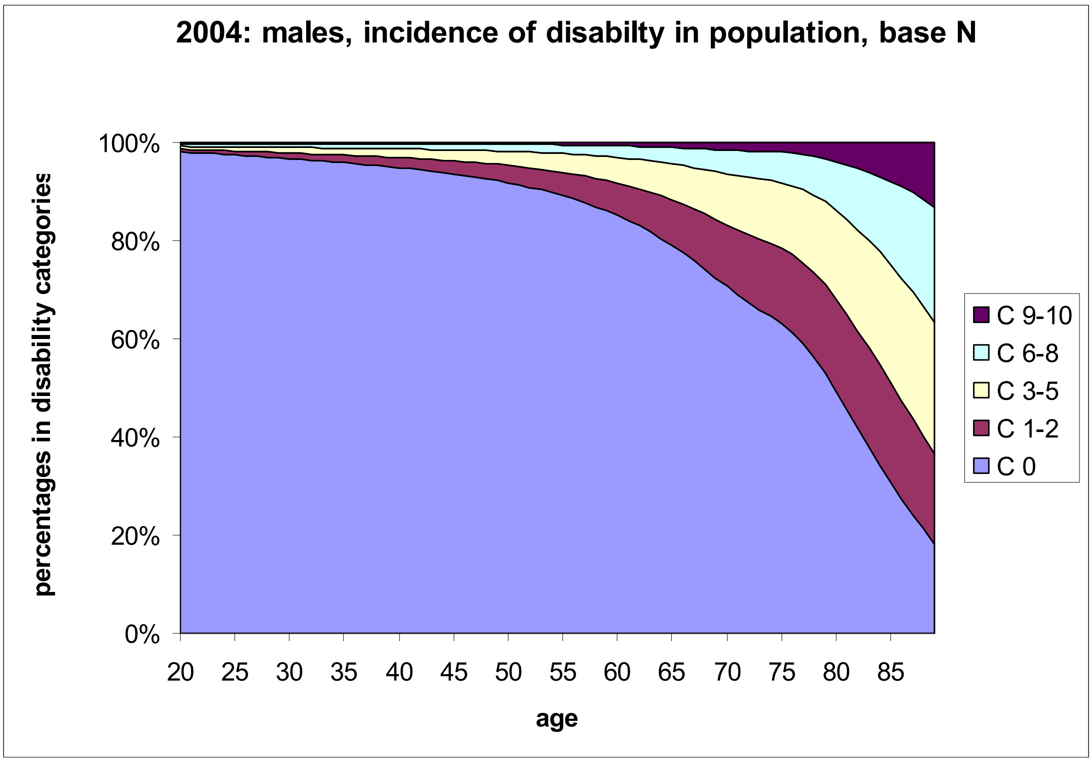


Figure 4.3: Males, incidence of disability, basis N (optimistic scenario), 2020

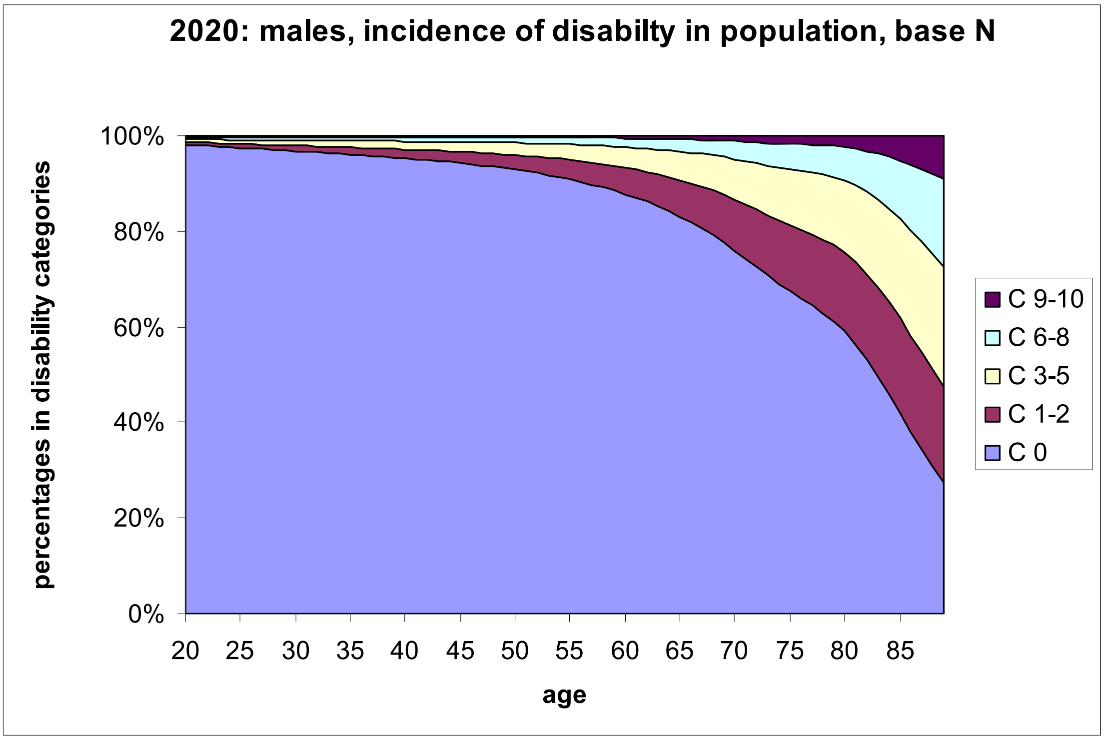


Figure 4.4: Females, incidence of disability in population, base N (optimistic scenario), 2004

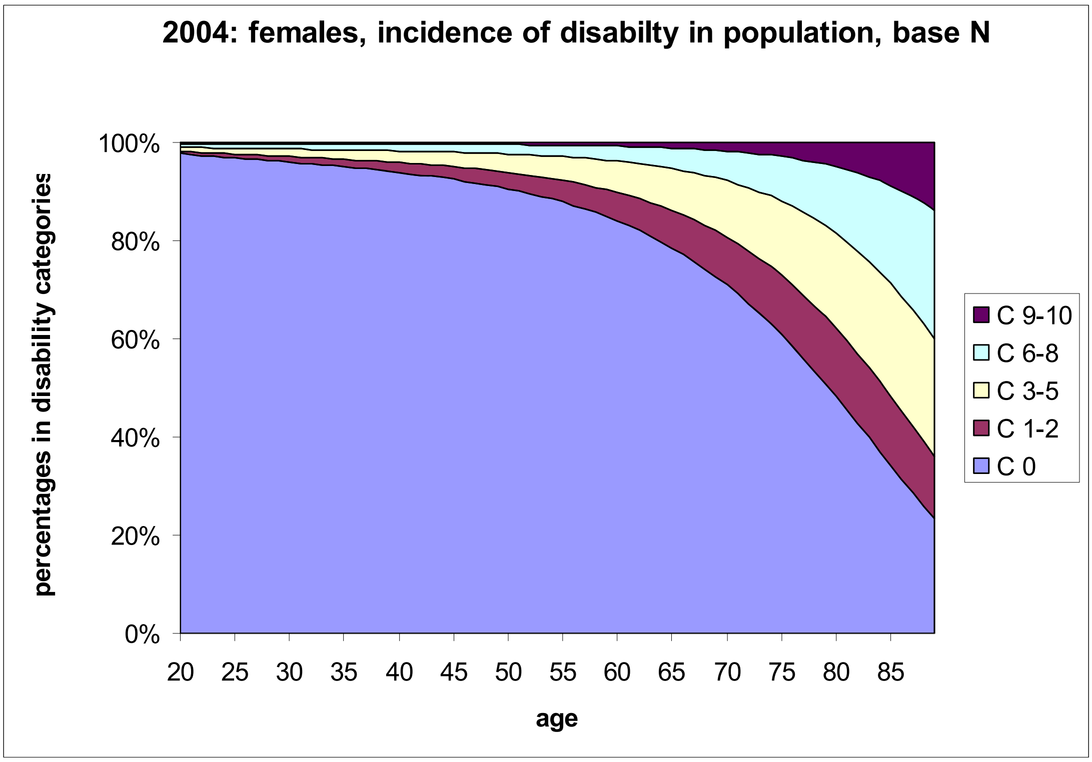
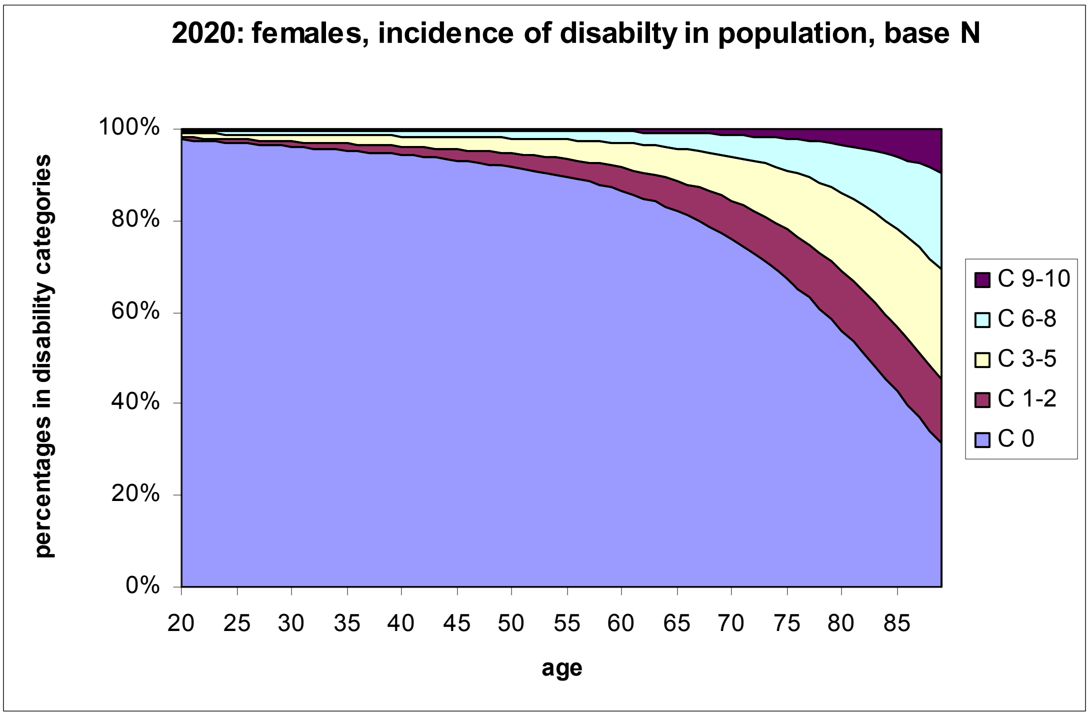


Figure 4.5: Females, incidence of disability, basis N (optimistic scenario), 2020



These trends in healthy life expectancy are congruent with the analysis set out in the Treasury's review conducted by Derek Wanless and published in 2002. This review set out to assess the financial and other resources required to ensure that the NHS can provide a publicly funded service available on the basis of clinical need rather than ability to pay (Wanless 2002). The analysis suggested there will be a fall in serious ill health, but an increase in minor health problems. It anticipates that it is likely that the older people of 2022 will be healthier than the older people of 2002.

Wanless took into account factors beyond changes in healthy life expectancy and looked at progress on a range of fronts to develop three possible scenarios for change over the next 15 years. These scenarios were characterised as ‘slow uptake’, ‘solid progress’, and ‘fully engaged’ (Wanless 2002), as described in Box B below.

Box B: The health of the nation in 2022 – the Wanless scenarios (Wanless 2002)

The Wanless Report set out three scenarios to describe possible changes in the health needs and demands of the population, technological developments and medical advance, the use of the workforce and productivity.

Slow Uptake – There is no change in the level of public engagement: life expectancy rises by the lowest amount in all three scenarios and the health status of the population is constant or deteriorates. The health service is relatively unresponsive with low rates of technology and low productivity.

Solid Progress – People become more engaged in relation to their health: life expectancy rises considerably, health status improves and people have confidence in the primary care system and use it more appropriately. The health service is responsive with high rates of technology uptake and a more efficient use of resources.

Fully Engaged – Levels of public engagement in relation to their health are high: life expectancy increases beyond current forecasts, health status improves dramatically and people are confident in the health system and demand high quality care. The health service is responsive with high rates of technology uptake, particularly in relation to disease prevention. Use of resources is more efficient.

Trends in demand for public services

Clearly, the future demand for health and social care services will interplay closely with changes in the healthy life expectancy of the population. This interplay was examined by the PSSRU (Malley *et al* 2005). They have developed three scenarios about the characteristics of the disabled older population in 2022 and the consequent variation in demand for services.

Box C summarises the three scenarios and their different impacts on the demand for health services. There is a base scenario, where age-specific disability rates remain constant and two other scenarios, where the key assumptions about the health of the population change. The first, the

‘Brookings’ scenario effectively assumes that age-specific disability rates fall in line with increases in life expectancy. So, as life expectancy rises, age-specific disability rates are shifted to higher age groups, so that an increase of one year in life expectancy would result in a shift in age-specific disability of one year. The second, the ‘half Brookings’ scenario, is a less optimistic scenario, where a life expectancy increase of three years causes age- specific disability rates to decline by one and half years (Malley *et al* 2005). The 2003-based GAD principal population projections (GAD 2005) assume that between 2002 and 2022 life expectancy at age 65 will grow by 2.9 years for men and by 2.8 years for women. In order to match this increase in life expectancy of nearly three years, disability rates by age are assumed under this scenario to decline to match, by 2022, those currently experienced by people three years younger. For example, a person aged 70 in 2022 is assumed to have roughly the same probability of being disabled of a person aged 67 years in 2002. The ‘half-Brookings’ scenario is a slightly less optimistic scenario and assumes that as life expectancy increases by three years, age-specific disability rates will decline to reach in 2022 those currently experienced by people 1.5 years younger (Malley *et al* 2005).

Box C: Long-term care expenditure for older people - three scenarios (from Malley *et al* 2005)

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 which 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 (Wiener *et al* 1994; Wittenberg *et al* 2001).

Another factor which influences the demand for formal care is the supply of informal care. Again, it is important to avoid the more alarmist scenarios, as it is unlikely there will be a collapse in informal care. Qualitative research indicates that people show broad support for the idea of a duty of care for partners and relatives (Edwards 2001). While there will be a rise in the number of people aged over 65 requiring care, the proportion of elderly people living alone is likely to fall from 43 per cent in 1996 to 38 per cent in 2031 (Pickard *et al* 2000) and the results of the PSSRU model suggest 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 often, as carers, many are themselves in need of support from formal services. Any increase in spouse carers, therefore, raises issues about the need for support for carers. In 2000, the majority of carers aged 65 and over, who spent 20 hours or more a week on caring, reported a longstanding illness (Maher and Green 2002). 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 (DoH 1999). 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 (those with two or more ADL problems) who share a household with others (see for example Wittenberg *et* *al* for further detail on this scenario). 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 (Malley *et al* 2005).

4.3 Taking control

Enabling disabled people to take control has been a key aim of the disability rights movement and is key to exercising the full rights of citizenship. It is closely bound up with the idea of independent living described in box D, which encompasses choice, freedom and equality (see Pillai *et al* 2005 for a fuller discussion of independent living). In 2005, the Government committed itself to achieving independent living for disabled people. More generally, independence, well-being and choice are central themes of the wider agenda on disability and ageing (DoH 2005a; DWP 2005; SU 2005). As these broad aspirations are now well established in principle, the key issue for 2020 is how far they will become an everyday reality for all disabled people. This shifts the focus onto the practical design and implementation of policy.

Box D: The concept of independent living

- Central to the concept of independent living is that disabled people should have the same opportunities as non-disabled people leading to people's meaningful inclusion into the mainstream of community life.
- It is underpinned by the social model of disability which identifies the barriers to participation, rather than an individual's physical or mental capacity, as the primary cause of disability.
- Advocates of independent living call for social change to facilitate disabled people's meaningful inclusion into the mainstream of community life.

Here we consider the opportunities and challenges presented by direct payments and individual budgets for older disabled people to take control. We then turn to a consideration of the likely balance between residential and community care and their implications for taking control. Finally, we consider the likely future opportunities for older disabled people to take control through 'user involvement' in public services.

Direct payments and individual budgets
First of all, it is important to understand that notions of taking control may change with age. People's perception of independence alters with age and this is especially true for disabled pensioners and those with long term health problems (Parry *et al* 2005, Godfrey *et al* 2004). Qualitative research with older people shows that independence is understood as maintaining a sense of autonomy, even when people's ability to do things on their own is compromised. Key components of independence are maintaining personal mobility, good health and social contacts and having sufficient funds to live a comfortable life (Parry *et al* 2004). For many older people, independent living remains strongly linked with being able to stay in their own home, something which has been a central aim of community care policy for the last fifteen years.

To enable people to choose to stay at home and be independent, the Government intends that 'direct payments' and 'individual budgets' will transform existing arrangements for domiciliary care. The Government has signalled expansion of individual budgets and looks to a time where people are "active consumers" rather than "passive recipients" of care (DWP 2005).

Box E: Direct payments and individual budgets

Direct payments: A direct payment is a sum of money received in lieu of directly provided social care services. Individuals often use the money to employ a personal assistant. In the UK, direct payments were introduced for adults of working age by the 1996 Community Care (Direct Payments) Act. They were extended to older people in England and Wales in 2000. In Scotland, direct payments were extended to older people in 2005.

Individual budgets: Individual budgets are an adapted form of direct payment, a 'personal bank account' that individuals manage and control in order to buy care. Under the Government's proposals for individual budgets, an individual would have control over the care money, like a bank account. Resources can be taken as a combination of cash (a direct payment); services brokered by an advisor; or council commissioned services (the current default) (DWP 2005).

But so far, the take-up of direct payments has been low, and particularly so among older people. In 2004, just 6,300 older people were recipients of direct payments although over one million received services from local authority social service departments in England (DWP 2005). This low take-up is not because direct payments are unwelcome. In fact, older people who use direct payments value the flexibility they bring to care arrangements and have reported an improved quality of life. Direct payments also have an 'added value', in that they promote a sense of emotional well-being and freedom (Clark *et al* 2004).

Early indications suggest the demand for direct payments will be stronger by 2020. The current generation of middle aged people expect to be able to have the kind of choice and flexibility that direct payments bring. A poll by Mori for the Commission for Social Care Inspection showed that three quarters of people in their 50s endorsed the concept of direct payments (CSCI 2004). Qualitative research with people in this age bracket shows that people expect a broader range of services than those that are currently on offer (Levenson *et al* 2005). This supports the extension of more flexible person-centred modes of delivery, such as direct payments and individual budgets.

However, if direct payments and individual budgets are to become widespread by 2020, Government will need to overcome particular barriers to take-up. It is likely that the model of individual budgets will encourage greater take-up than the more demanding direct payments model. It has been surmised that older people are less comfortable with the ‘hiring and firing’ model of direct payments and would prefer less onerous ways of controlling services (Glasby and Littlechild 2002). As such, the development of individual budgets is welcome.

But a move to individual budgets by itself will not necessarily lead to a critical mass of users. Central and local government will also need to tackle the cultural barriers that exist within some local authority social service departments. It should be acknowledged that these barriers are not present in all local authorities. In places where take-up of direct payments has been relatively high, it has occurred through a combination of social work enthusiasm, voluntary sector advocacy and local government drive. But these levels of support are not evident across all social service departments and it has been suggested that various barriers have combined to hinder take-up of direct payments. These include an aversion to risk-taking, lack of entrepreneurship and ‘not for our clients’ attitudes of social workers, as well as the fear among some workers that direct payments will take away public sector jobs (Riddell *et al* 2005, Carr 2004, Stainton 2002). These attitudes explain why, despite the statutory duty on all councils to offer ‘suitable’ users direct payments, many direct payment schemes remain under-publicised and unknown to potential service users (Carr 2004).

The Government will need to tackle the barriers to independent living by instituting measures to change the culture of these local authorities. This could be achieved by setting targets on the take-up of individual budgets, supporting ‘change agents’ and promoting best practice from high performing councils. Evidence from current good practice also indicates that an appropriately resourced support service is an essential pre-requisite of a successful scheme (Hasler 2003). As discussed in *Disability 2005*, the Government could consider introducing a statutory duty on local authorities to provide assistance to use direct payments and individual budgets.

Direct payments and individual budgets exist in the wider context of person-centred public services. There is a risk that an exclusive focus on individual budgets leads to the development of a ‘two-tier service’: where there are innovative services for people with the confidence and opportunity to choose and unimaginative mass-produced services for those who can’t or won’t

(CSCI 2005). Significantly, cultural barriers that hinder direct payments manifest themselves in other ways and undermine the drive towards person-centred care. For example, there is evidence that social service departments that have promoted ‘person-centred care’ were prepared to commission specific care time to support people’s morale or quality of life; whereas those that had not were reluctant to depart from care plans and would not commission time for social support purposes. Some purchasers discouraged any extra help even if there was no additional cost, for fear of departing from fixed procedures and creating new – and raised - expectations (Patmore and McNulty 2005).

Of course, direct payments and individual budgets can only ever be part of the story. If the Government is to deliver the kind of flexible services that support independent living for older people, a radical culture change will be required in some social service departments. By 2020, the goal should be to move beyond excellent exceptionalism to a situation where person-centred care is ordinary and expected. Research conducted for the Department of Work and Pensions (DWP) has set out core principles for older people’s services which would help to promote this approach, described in box F below.

Box F: Core principles for policy - promoting independence in later life (Parry *et al* 2004)

- **Joined up services and key points for intervention**
Multiple points of entry into services; service providers aware of trigger points when intervention may be required; single points of contact.

- **Equalising accessibility and targeting services**
Targeting through non-traditional routes; services that are sensitive to the needs of pensioners with mental health problems and learning disabilities, older people who have language needs and housebound pensioners with visual or hearing impairments; services prepared to carry out outreach work.

- **The need for flexibility**
Flexible ways of delivery and providers who maintain an open door approach.

- **Communication**
Provide information in different languages, including British Sign Language and different formats, Braille and type talk systems; follow up contact.

- **Advocates**
Informal and formal advocates to negotiate support.

Specifically in the NHS, policymakers are seeking to develop more person-centred approaches, such as greater choice and flexibility within services. By 2020, it is likely there will be more opportunities for disabled older people to be in control of their own health, for example, through continued development and take-up of initiatives such as the Expert Patients Programme. The Expert

Patients Programme is an NHS-based training programme that supports people with long term health problems or impairments to manage their own long term conditions by equipping them with skills and knowledge to manage their symptoms (Expert Patients 2005). This programme is based on the idea of a collaborative relationship between patients and health professionals.

Residential and community care

It is important that the principles of independence, choice and control are not forgotten when it comes to residential care. Just because people move into residential care, it does not mean that their concern with being independent disappears. Although, most surveys show that older people prefer to live in their own homes, people can and do revise their preferences on moving to residential care (Wanless Review Team 2005). For people who move into residential care, independence remains important and is increasingly measured in terms of friends, environment, security and participation in activities (Parry *et al* 2004).

In 2020, there will still be a significant residential care sector for disabled older people and it is reasonable to assume that care homes will continue to be part of the market (Laing 2005). The Government anticipates that the overall numbers in residential care may rise but the proportion of people needing residential care may fall (DH 2005a). This is a view that some providers in the care homes sector have disputed (BUPA 2005). The data in this study broadly supports the Government's more optimistic estimate that a smaller proportion of older people will require 24-hour care. However, policymakers are right to remain concerned with the quality and provision of residential care. There are several measures that need to take place in order to maximise control and independence of older people in residential care.

By 2020, there will need to be a better choice of options for housing and care.

The King's Fund inquiry into care services has recommended an expansion of different kinds of housing, such as Extra Care.[4] To address insufficient market capacity the Inquiry recommended that the Government should make available funds for capital investment in Extra Care and new care homes. These measures need to be supplemented with better information about care homes. The Office of Fair Trading has suggested an internet site supplemented by a telephone helpline or a one-stop shop. It also recognises the value of service navigators in providing information about choices (OFT 2005). To put these ideas into practice policymakers should draw on existing one-stop shops, such as Link Age.

The sector will also need to make considerable improvements to the quality of care home provision. The King's Fund inquiry found that the current care market in London failed to meet people's needs and expectations, particularly for older people from minority ethnic groups. In 2005, 55 per cent were extremely satisfied with their care homes, but older people from black and minority ethnic communities were significantly less satisfied. The wider context behind these headlines is that people from black and minority ethnic communities have continuously experienced under-provision of mainstream services and have provided their own voluntary services to fill the care gap (Patel 1999).

User involvement

Individual user choice is set to be a powerful driver for change within care and social services by 2020. However, the more formal processes of user involvement will also continue to be significant, especially in relation to collective services, such as leisure, transport and housing. The position in 2005 is that there is improved representation of older people at community and local authority level, although as with all forms of public involvement, there are problems when the good intentions behind public involvement are implemented in a tokenistic way. For example, the Commission for Social Care Inspection has highlighted a failure to evaluate user's involvement, so it runs the risk of becoming a tick box exercise. It has also been suggested that some people experience 'involvement fatigue' (Carr 2004).

Central and local government need to set standards to ensure that all service users are meaningfully engaged and involved in public services. There is already considerable guidance to draw on. The Joseph Rowntree Foundation have put forward standards about when older people are first included, how to maintain their involvement, how public involvement is resourced and clarity from the outset about the scope of involvement to influence outcomes (JRF 2004). The Audit Commission (2004) has recommended moving away from traditional consultation methods, such as the one-off meeting or event, towards longer term structures and processes. Other policy documents have also recommended that there should also be more opportunities for user feedback (CSCI 2004).

4.4 Helping shape society and making a valued contribution

Being involved in the design and delivery of public services is crucial for many disabled older people; however, the principles of collective voice and involvement currently end at services, but must extend into the wider arena of citizenship. Yet, in 2005, many older disabled people face a double bind of discrimination and are disadvantaged by both older age and disability. This constrains their ability to help shape society and make a valued contribution. Here we examine possible developments in relation to age and disability discrimination and civic and social participation.

Age and disability discrimination

Tackling age discrimination is a priority for many older people across the age spectrum (Audit Commission 2004). The disability rights movement should also play a part: just as they have successfully challenged conventional notions about disability, so they need to take on the myths around ageing. Although it is impossible to predict attitudinal change, the proposed single equalities body, the Commission for Equality and Human Rights (CEHR), would be well placed to address complex and overlapping forms of discrimination.

One area, although by no means the only area, where age discrimination has been documented is the workplace and this will need to be something the CEHR tackles. It is estimated that a quarter of disabled people experience discrimination in the labour market due to age (SU 2005). Although there are one million workers over state pension age, it is likely that more older people would like the opportunity to work. Among older people there is frustration over poor access to employment opportunities (Godfrey *et al* 2004).[5] There are policies in development to challenge age discrimination. In 2006, age discrimination legislation will be implemented to abolish the compulsory retirement age (except where this can be objectively justified).[6] The proposed CEHR would have the power to enforce these standards. In doing so, they need to ensure that disabled older people have the same opportunities to work beyond retirement age, if they are able and willing to do so. Making working later a genuine choice for disabled people will require tackling the significant barriers to disabled people's participation in employment, as discussed in chapter three.

Increasing employment rates among older adults of working age and helping people to work past the state pension age if they chose to do so, is the one means of addressing the problems posed for the pensions system by an ageing population, around which there is widespread consensus. It is expected that employment rates for women aged 60 to 64, will rise in the decade to 2020, as a result of the equalisation of the state pension age for men and women to 65, which will fully come into effect by 2020.
A number of organisations have suggested further raising the state pension age for both men and women between 2020 and 2030, as a clear signal of the desirability of working longer in the context of increased life expectancy, and to help make a more generous basic state pension affordable (see Brooks *et al* 2002).

Such a move would be very controversial. Many people do not seem to believe the predictions of significantly increased longevity – they appear to expect to become unwell and to die on a timescale that is not radically different from their parents (Robinson *et al* 2005). This creates a great challenge for the Government, which is anxious to secure a consensus on pensions reform. Any consensus would probably need to be based around the central feature of a more generous basic state pension. This is the feature that makes the UK pensions debate different from any other OECD country. Pensions reforms elsewhere have as their central objective reducing the generosity of state pensions to make them more affordable. Only in the UK is the objective of making the basic state pension more generous both desirable, as a response to problems with private and occupational pensions and as a means of sweeping away much of the complexity of the current pensions system, and feasible, as spending on pensions is not expected to rise as sharply as a proportion of GDP in the UK. A more generous pension will be a crucial means of enabling disabled older people to overcome poverty and to exercise their citizenship. If this is coupled with a raised pension age, it will increase the imperative to tackle discrimination against older and disabled workers.

Civic and social participation

Success in promoting opportunities for disabled older people to participate in society must be measured by participation in the community, as well as the workplace, as Tanner has argued: ‘the success of community care policy should be defined to the extent that care givers and receivers are enabled to achieve full citizenship’ (Tanner 2003 p.511). The Government has broad aspirations to improve the social integration of disabled people and encourage older people to get involved in volunteering (DoH 2005). However, disabled older people can be less likely to have opportunities to participate as citizens. For instance, one small study of excluded older people found that around half were excluded from civic activities, such as voting in elections, taking part in fundraising activities or writing letters to newspapers – the exception to this pattern was among people who participated in religious activities (SEU 2005b). Excluded older people may be more likely to feel a sense of powerlessness and doubt their ability to change things (Dean 2004). This suggests that policymakers need to find new ways of involving people and demonstrate that their involvement will have a positive effect on policy.

Local communities should take a lead in ensuring participation and help to develop a collective understanding of the standards society wants to promote for older people. The ADSS has recommended that local government should develop local indicators to measure older people’s quality of life. These indicators should be recognisable, easily understood and owned by the whole community (ADSS and LGA 2003). The Government has also stated they will develop new incentives for local authorities to involve older people in local decision-making (DWP 2005). In developing these measures to improve civic engagement, there is a need to ensure that all policies are inclusive of disabled older people.

4.5 Getting equipped to play a part

The opportunities for older disabled people to participate as equal citizens will also be determined by the extent to which they are enabled to play a part through the availability of high quality and affordable healthcare, social care and long-term care. Since 1997, the Government has devoted substantial time and energy to these policy issues. However, despite significant improvements and increases in public spending, in several important respects the settlement for disabled older people remains incomplete.

The future of social care

There is considerable uncertainty about the future resources that will be available for social care. The commitment to preserving the NHS as free at the point of use and funded through general taxation remains strong, but in contrast there is considerable confusion about what care services the state will provide. It is also worth noting that the rate of growth of spending on the NHS is likely to fall significantly after 2008. This will present more challenging circumstances in which to achieve public service reform goals around choice and personalisation.

Significantly, the ageing population is likely to have a more significant impact on social care than the NHS. The Wanless Report (2002) anticipated that spending on social care would increase from £6 billion in 2002 to £11.2 billion in 2022. However, in the 2004 spending review the Government decided to reduce the rate of growth of spending on social care. Between 2006/07 to 2007/08 spending on social care will rise at an annual real terms rate of 1.3 per cent, which is slower than the predicted overall rate of growth in the economy. Some have questioned whether the Government will be able to pull off this reduction in spending, something that previous governments failed to achieve (Robinson 2004). It is also necessary to ask whether an ambitious agenda for social care can be achieved on a 'cost neutral' basis - as the Government intends (DoH 2005).

To throw some light on these issues, the King's Fund have commissioned a 'Wanless' review to assess the future demand for social care and how it will be paid for (Wanless Review Team 2005). In part, the answer will depend on a collective decision about what social care is for. Is social care a safety net for those in acute need? Or does it have a broader agenda which covers tackling social exclusion and promoting quality of life?

Low-level services

The uncertainty about the scope of social care can be seen in the debate about the value of 'preventative' low-level services. Low-level services are defined as help with activities such as housework and home maintenance, and they are widely valued by older people. However, the value that policymakers attach to these services depends upon the definition of 'prevention' that is used. If a 'medical' definition of prevention is used, that is, preventing the need for acute services, then the cost effectiveness of low level services is unclear; it is not certain that low level services reduce the need for downstream care (Wanless Review Team 2005). However, if we define prevention as preventing isolation and promoting quality of life the case for low level services is more persuasive.[7] On other types of preventative interventions, the evidence is less contested. One study found that preventative home visits to older people can reduce mortality and admission to long term care, as home visitors were able to identify a large number of previously unmet health and social needs (Elkan *et al* 2001).

The erosion of low-level services is widely understood to be a consequence of the increased targeting of care. The last decade has seen increased targeting of social care services at people with higher levels of need. On the one hand, this is positive, as it marks a better use of resources and an end to the presumption that formal domiciliary services are required at age 65. However, the other side of the coin is that many people do not receive services that could benefit them (Wanless Review Team 2005). Moreover, the culture of rationing has undermined the accessibility of services and created confusion about people's entitlements to homecare (Parry *et al* 2004). Some older people are reluctant to contact social services to request more help, in case their hours are cut (Clark *et al* 2004).

In order to guarantee fairness and adequate service provision for older people in 2020, the Government needs to complete the reform of care services for older people. There are some promising signs for 2020. For the first time, the Government plans to develop an integrated home visiting service which can offer older people a full care, benefit, heating and housing check up (DWP 2005). Evidence from a pilot study in Sweden suggests that home visits of one to two hours can yield a good return in independence, identify unmet needs among older carers and improve self reported health and wellbeing. Swedish policymakers anticipate substantial future savings if the model is applied to a national level (Hellner *et al* 2005). When the UK home visiting service is rolled out, this should result in significant improvements in access to services for disabled older people and can be expected to improve health and wellbeing.

This will be a significant development, but other issues remain to be resolved. There is a need to bring greater certainty and clarity to the whole care system from long term care to domiciliary care. The projected increase in the numbers of people with moderate disabilities will make the debate over eligibility for domiciliary care and the type of services provided even more critical in the coming years. It is necessary to make decisions about what kind of social care services society wants to deliver (and pay for): whether social care should be organised to prevent secondary care admissions, or whether it should be organised to promote health, quality of life and wellbeing. The Government has already indicated that it expects social care to be part of the wider community wellbeing agenda (DoH 2005a). But this goal might entail a reversal of the targeting of homecare services and expansion of low-level preventative services in some form. There needs to be a long term financial settlement for social care, based on future demand and the anticipated cost of key objectives, to ensure the use of scarce resources in the most equitable way. There is some evidence that a new agenda for social care will lead to cost savings in the long term. For example, other countries' experience of direct payments and their equivalents supports the Government's view that direct payments can result in cost savings (Glasby and Hasler 2002; Wanless Review Team 2005). However, in the years leading up to 2020, the transition to a new kind of social care may require more resources to develop home visits and support the take-up of personal budgets. At the very least it seems unlikely that spending can grow at a slower rate than the rest of the economy.

Long term care

There is similar confusion around people's entitlements to long term care, where the funding system lacks transparency. Despite some positive developments in recent years, such as the guarantee of free nursing care, the system remains unclear and many were disappointed that the Government rejected the Royal Commission on Long Term Care's recommendation that personal care should be free. Although the implementation of this recommendation in Scotland has been widely welcomed, there remains a confusing and inequitable distinction between 'free' nursing care and charged ‘personal’ care in England. For instance, a person with cancer will receive free treatment, whereas someone with Alzheimer’s disease is liable to pay because they are deemed to be receiving ‘personal care’. Few people would understand why there should be a difference. Moreover, as care practice evolves the distinction between nursing and personal care is likely to become even more blurred (Brooks *et al* 2002). Without government action, by 2020 the UK could see serious ‘care inequalities’ between those who can pay for care and those who cannot (Best 2003) and those who receive free care and those who don’t.

However, in a departure from policy elsewhere in the UK, in 2001 the Scottish Executive announced they would introduce free personal care for older people. Interestingly, the Scottish Executive has chosen to preserve the distinction between ‘nursing care’ and ‘personal care’: in 2002 the maximum payment was £65 for nursing plus £90 for personal care (while in England the maximum was £110 for nursing care only). Thus, making personal care free in the Scottish model does not remove the difficulties of assessing individuals in relation to need (Brooks *et al* 2002).

There needs to be greater clarity and equity in arrangements for long term care. Many organisations have recommended that the Government introduces free personal care, thus ending the confusing and inequitable distinction between the diseases of acute healthcare and the diseases of long term health care (see, for example, Brooks *et al* 2002). The additional cost of free personal care would be between 0.2 per cent and 0.45 per cent of GDP by 2050. This is significant, but affordable if the Government made progressive changes to the tax system, such as aligning the upper limit of National Insurance Contributions to the higher rate of income tax (Brooks *et al* 2002).

By introducing free personal care throughout the UK and ensuring provision of low-level services (which may be provided via direct payments) the Government could complete the care settlement for older people and guarantee security and quality of life for disabled older people in 2020.

4.6 Getting on

The adequate provision of health and social services will be important for disabled older people, but these alone are not sufficient to guarantee good quality of life. There are numerous factors that influence people’s quality of life and health or disability status is not necessarily the most important determinant. Disabled older people can report good quality of life despite having a disability because they feel in control of their lives and part of their communities. Qualitative research with older people has shown that quality of life is influenced by numerous other factors aside from health and disability status, such as people’s standards of comparison, expectations, sense of optimism, social activities and safe communities (Dean 2004). As such, we need to pay attention to the Government’s goals to end pensioner poverty, promote quality of life and reduce health inequalities.

Pensioner poverty

Income poverty is both a cause and a consequence of diminished opportunities for disabled older people to ‘get on’. Tackling pensioner poverty has been a significant theme for the Labour Government, which has resulted in some bold promises. In 2002 the Chancellor Gordon Brown stated: ‘our aim is to end pensioner poverty in our country’. Yet, in comparison to the Government’s official pledge to eliminate child poverty by 2020, there is no equivalent official target to abolish pensioner poverty. So, unsurprisingly, progress has been slower. In 2003/2004, 20 per cent of pensioners lived in poverty, which is just one per cent less than in 1994/1995 (Pearce and Paxton 2005). If current levels of pensioner poverty remain constant, there could be an extra one million pensioners living in relative poverty by 2031 (SEU 2005a). Given the links between disability and poverty in working life, it is likely that disabled older people will figure significantly among this one million.

By its own account, the Government has been less successful at tackling cumulative disadvantage than pensioner poverty. Whereas government policies to tackle age-related disadvantage have had some impact (for example, the reduction of the proportion of older people on absolute low incomes) poverty and social exclusion arising from cumulative disadvantage have been much less resistant to change. In particular, along with other disadvantaged groups, disabled older people continue to experience high levels of deprivation in older age (SEU 2004). Disadvantaged older people are also less likely to claim the means tested benefits to which they are entitled (SEU 2005a).

Clearly, quality of life for disabled older people is contingent on tackling pensioner poverty. The goal of ending pensioner poverty should become an official target, an equivalent to the pledge to end child poverty. The ippr and others have recommended that the Government could achieve this goal by raising the basic state pension above the poverty line and restoring the link between pensions and earnings. In 2005 prices, this means a weekly income of £109.45 (Pearce and Paxton 2005). This would have a significant impact by guaranteeing the security and dignity of disabled retired people by 2020.

Health inequalities

Poverty and deprivation are closely linked with poor health, which requires the Government to address the health aspects of exclusion. Health inequalities persist into older age, meaning people in lower socio-economic groups effectively age faster (in a biological sense) than wealthier people in the same age bracket. The English Longitudinal Study on Ageing has found that men in routine and manual occupational classes reach poorer health one to two decades before those in professional and managerial groups. Around one third of manual male workers aged 50 to 59 report a limiting long-standing illness; in comparison, rates for professional men remain much lower than this until age 75 (Marmot *et al* 2005). The Government has committed to reduce health inequalities (as measured by life expectancy) by ten per cent by 2010. However, reaching this target will prove to be extremely challenging; the latest data shows that health inequalities are continuing to widen rather than narrow

(DoH 2005b). If all older disabled people are to make the most from their years after 65, the Government will need to devote extra attention and resources to improving the health of those at the bottom of the income scale. This may require additional targeting of resources and health promotion activity at people who are already disabled to try to ensure their impairment or health problem does not worsen (Rickaysen 2005).

The risks may be particularly acute in relation to mental ill health. There is extensive evidence that demonstrates the value of exercise, education and social engagement in maintaining health in old age: people who remain active and productive do better than those who disengage from society (Seymour and Gale 2004). Older people are aware of the importance of maintaining good health, especially mental health. Across the spectrum of old age, people value social stimulation and being able to sustain social networks (JRF 2004). Yet, although there are some innovative one-off projects, there is little evidence of a broad and inclusive approach to mental health and wellbeing in later life (Seymour and Gale 2005, Audit Commission 2004). According to a survey in 2002, over one million UK citizens over the age of 65 feel acutely isolated in their own homes (ADSS and LGA 2002). Older disabled people have a higher risk of experiencing mental health problems and feeling isolated. Mental health problems among older people, such as depression increase further down the income scale. Another risk factor for disabled older people is that they are more likely to have reduced mobility, while assistance to get out socially is not generally regarded as a need which is eligible for support from services (JRF 2004).

The Government has promised that older people will have greater access to learning and leisure activities (DWP 2005). There should be a particular focus on achieving these aspirations for disabled older people, given the barriers to participation that they face and their increased risk of problems such as isolation and depression. ‘Getting out and about’ should be recognised as an aspect of independent living and a legitimate service need. Local government should lead on co-ordinating strategies to promote older disabled people’s physical and mental well-being. For instance, older learners should be supported and encouraged to take up educational opportunities. Opportunities for learning and education bring a range of positive outcomes for older people, such as reducing loneliness, better health and mental alertness - in fact, the acquisition of knowledge is perhaps the least important benefit (Dean 2004). To enable disabled older people to take up these opportunities requires addressing transport and accessibility barriers. It would also seem to go against the grain of the Government’s learning policies, which emphasise younger people and learning for adults geared at improving their employability, rather than at the wider range of positive outcomes suggested here.

4.7 Conclusion

There is a disparity between society's response to the physical problems of ageing and society's response to the social problems of ageing (Dean 2004). The projections data presented here anticipate that the first trend will continue in a broadly positive direction: older people will live longer, with less likelihood of experiencing severe disabilities in older age combined with an increase in lower levels of 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 our response to the ageing population in 2020 depends on the collective 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 and that their needs are recognised in strategies to promote wellbeing. In order to guarantee independent living, the Government needs to promote a radical culture change in some social service departments.

But there are other areas which have 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 fully realise an ambitious agenda 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.

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[1] Severely disabled life expectancy is defined as ‘being unable to carry out some of the six ‘Activities of Daily Living’’. These are bathing, dressing, going to the toilet, transferring (to and from a bed or chair), continence or feeding.

[2] The OPCS is now known as the ONS (Office for National Statistics). See the glossary for further details.

[3] OPCS categories one to two: five hours of care per week (i.e. low requirement); categories three to five: fifteen hours per week (i.e. moderate requirement); categories six to eight: 30 hours per week (i.e. regular requirement); categories nine to ten: 45 hours per week (i.e. continuous requirement).

[4] Extra Care is not classified as residential care; older people live in their own house, which is part of a complex with an on-site care team.

[5] Equally, it is important not to overstate this case. Qualitative work by ippr shows that many people of working age do not aspire to work at later ages (Robinson *et al* 2005).

[6] This is a result of the EU Council Directive 2000/78/EC, which establishes a general framework for equal treatment in employment and vocational training and guidance. The directive is designed to outlaw discrimination at work and training on grounds of age, sexual orientation, disability and religion or belief. It is due to be implemented in October 2006.

[7] These different perspectives can be seen in different government policy documents. The DWP observes: ‘we believe that, in principle, there is a case for refocusing resources on preventative low level care over the long term… however we need to understand the costs and benefits of a preventative approach more clearly’ (DWP 2005). In contrast, the Social Exclusion Unit notes: ‘our consultation [on excluded older people] has shown overwhelmingly the importance that low level preventative services can have in improving the quality of life for excluded older people, and in preventing the need for high cost intensive care services’ (SEU 2005).

5. Conclusions

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. This will require serious commitment and action now across the full range of areas of public policy. This is no small task but the case for action is overwhelming and cannot be delayed.

Six key priorities for action have emerged out of the evidence in this report and its sister report that assessed the circumstances and experiences of disabled people in 2005. The evidence would suggest that these issues should be taken forward by policymakers and promoted by those who wish to see the full and equal citizenship of disabled people. 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.

We expand on each of these priorities below.

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. Public services from education to health to social services and housing must respond better to clients needs. This means building 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 the necessary support is available to enable all 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 to refer to participation in paid employment at the expense of consideration of other forms of contribution such as social and civic participation. 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 fail 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. This, in turn, reduces their opportunities to advocate for improved social rights for 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. Increasing the opportunities for disabled people to achieve and sustain paid employment will be essential to the achievement of the full and equal citizenship of 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. The impact of poverty on childhood experiences and life chances is well documented and tackling the poverty of disabled children and the children of disabled adults must be a top priority. Yet in 2005, the Government has not made clear just how it plans to target disabled children and the children of disabled adults who are living in poverty.

4. Boost efforts to tackle health inequalities

Despite a focus in recent years on tackling health inequalities, little progress appears to have been made. Poverty is still a driver of disability and disabled people are still more likely to be poor than non-disabled people. It is necessary both to 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 experience of poverty and by 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 report a disability.

In any study of disability it quickly becomes clear that the disadvantage experienced by disabled people is cumulative and overlapping. Consequently it is important to take action on all these fronts simultaneously in order to break the cycle of disadvantage.

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.

One example of such a challenge is genetic technology. Developments here could threaten to reduce disabilities once again to medical impairments and there is a need to both embrace change which 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 trends in children that are challenging to accommodate within educational current frameworks, for example.

There is an important role for organisations run of and for disabled people to promote a more sophisticated understanding of disability. However, they face a 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

The Government has taken a significant step in articulating a vision for "a society where all disabled people can participate fully as equal citizens". In order to realise this vision, which must begin by enacting the priorities above, it is critical that the necessary resources are made available and this is yet to happen. Three examples that affect disabled people at different ages illustrate this.

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.

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". This does not appear to be consistent with providing better services and maintaining living standards in the context of increasing numbers of disabled people over this period.

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. Of course, achieving full and equal citizenship for disabled people it is not simply a matter of resources but they are clearly an important element of the package.

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.

References

Introduction

Audit Commission (2002) *Special Educational Needs – A Mainstream Issue* Audit Commission

Department for Education and Skills (DfES) (2004) *Removing barriers to achievement: The Government's strategy for SEN* DfES

Disability Rights Commission (DRC) (2005) *Shaping the Future of Equality* DRC

Malley J, Wittenberg R, Comas-Herrera A, Pickard L and King D (2005) 'Long-term Care Expenditure for Older People Projections to 2022 for Great Britain report to ippr' *PSSRU Discussion paper 252* London School of Economics

Medical Research Council (MRC) (2001) *MRC Review of Autism Research: Epidemiology and Causes* MRC

Office for National Statistics (ONS) (2003a) *Office for National Statistics Social Survey Division and National Centre for Social Research Family Resources Survey 2002-2003* Department for Work and Pensions (DWP)

ONS (2004) *Living in Britain: Results from the 2002 General Household Survey* ONS

Pillai R, Stanley K, Bennett J, Stone L and Withers K (2005) *Disability 2005: The citizenship of disabled people in Britain* DRC

Rickaysen B (2005) *Note on CASS Projections of Trends in Healthy Life Expectancy* CASS Business School

Strategy Unit (2005) *Improving the Life Chances of Disabled People* HMSO

Woodfield K, Swales K, Lewis J, Joy S and Grewal I (2002) 'Disabled for Life? Attitudes Towards, and Experiences of Disability in Britain' *Research Report No. 173* DWP

The best start? Children, young people and disability

Adam S and Brewer M (2004) *Supporting Families: The Financial Costs and Benefits of Children since 1975* Policy Press

Audit Commission (2002) *Special Educational Needs – A Mainstream Issue* Audit Commission

Audit Commission (2003) *Services for disabled children. A review of services for disabled children and their families* Audit Commission

Audit Commission (2003a) *Too little, too late: services for disabled children and their families* Audit Commission

Barnes C (2004) 'Disability, Policy and the Way Forward' in Barnes C and Mercer G (eds) *Implementing the Social Model of Disability: Theory and Research* Disability Press

Barnes C, Corker M, Cunningham-Burley S, Davis J, Priestley M, Shakespeare T and Watson N (2000) Lives of Disabled Children *Children 5-16 ESRC Research Briefing* 8 ESRC

Beresford B (2003) *The community equipment needs of disabled children and their families* University of York

Bradshaw J (2005) *The well being of children in the UK* 2nd edition Save the Children UK

Brewer M, Goodman A, Myck M, Shaw J, Shephard A (2004) *Poverty and Inequality in Britain: 2004*, Commentary 96, London: Institute for Fiscal Studies

Brewer M (2005) 'Maintaining momentum in tackling child poverty' in Delorenzi S, Reed J and Robinson P (eds) *Maintaining momentum: Promoting social mobility and life chances from early years to adulthood* ippr

British Medical Association (2001) *Consent, rights, choices in health care for children and young people* BMJ Books

Cameron C (2004) *Building an integrated workforce for a long-term vision of universal early education and care* Daycare Trust

Carlin J and Lenehan C (2004) *Direct experience: A guide for councils on the implementation of Direct Payments in children's services* Council for Disabled Children

Chamba R, Ahmad M, Hirst D, Lawton D and Beresford B (1999) *On the edge: minority ethnic families caring for a severely disabled child* JRF

Charman T (2002) 'The prevalence of autism spectrum disorders: recent evidence and future challenges' *European Child and Adolescent Psychiatry* 11:6 pp249-256 Springer-Verlag, Berlin/Heidelberg.

Charman T (2003) 'Epidemiology and early identification of autism: research challenges and opportunities' Bock G and Goode J eds. *Autism: neural basis and treatment possibilities* Novartis Foundation Symposium 251

Commission for Social Care Inspection (2004) *Direct payment: what are the barriers?* CSCI

Council for Disabled Children (2003) *Evidence to the Work and Pensions Select Committee enquiry into childcare for working parents* Council for Disabled Children

Council for Disabled Children and End Child Poverty Campaign (undated) *Disabled children, their families and child poverty* Council for Disabled Children

Daycare Trust (2005) *Everyone Counts* Daycare Trust

Department for Culture, Media and Skills (2004) *Getting serious about play* DCMS

Department for Education and Skills (DfES) (2004) *Removing barriers to achievement: The Government's strategy for SEN* DfES

DfES (2004a) *Every Child Matters* DfES

DfES (2004b) *Five Year Strategy for Children and Learners* DfES

DfES and Department of Health (DoH) (2004c) *Early support professional guidance. Section 6: Keyworking, key workers and care co-ordination* DfES

DfES (2005) *Youth Matters* DfES

DfES (2005a) *Extended Schools Prospectus* DfES

Dickens S, Taylor J and La Valle I (2005) *Local childcare markets – a longitudinal study* National Centre for Social Research

Department for Work and Pensions (DWP) (2004) *Office for National Statistics Social Survey Division and National Centre for Social Research Family Resources Survey 2003-2004* DWP

DWP (2005) *Disability Living Allowance Quarterly Statistics: August 2004* DWP

Department of Health (DoH) (2001) *Valuing People A New Strategy for Learning Disability for the 21st Century* DoH

DoH (2001) *The expert patient: a new approach to chronic disease management for the 21st century* DoH
DoH (2002) *Listening, hearing and responding. Department of health action plan: core principles for the involvement of children and young people* DoH
DoH (2004) *National Service Framework for Children, Young People and Maternity Services* DoH
DoH (2005) *Tackling Health Inequalities – status report at the programme for action* DoH
Disability Rights Commission (DRC) (2004) *The Disability Rights Commission's response to the human Genetics Commission consultation 'Choosing the Future – genetics and reproductive decision making'* DRC
DRC (2005) *Shaping the Future of Equality* DRC
Emerson E and Hatton C (2005) *The socio-economic circumstances of families supporting a child at risk of disability in Britain 2002* Lancaster University
Family Fund (2004) *Family Fund Annual Activity Report 2003-4* Family Fund
Government Actuary's Department (2004) *Update of the Government Actuary's quinquennial review of the of the national insurance fund as at April 2000* GAD
Gordon D, Parker R and Loughran F with Heslop P (2000) *Disabled Children in Britain* The Stationery Office
Greco V, Sloper P and Barton K (2004) *Care Coordination and key worker services for disabled children in the UK* University of York
Heaton J, Noyes J, Sloper P and Shah R (2003) *Technology-dependent children and family life* University of York
Heslop P, Mallett R, Simons K and Ward L (2002) *Bridging the divide at transition: what happens to young people with learning difficulties and their families?* BILD
HM Treasury (2004) *Choice for parents, the best start for children: a ten year strategy for childcare* HMT
Human Genetics Commission (2001) *Public attitudes to human genetic information* Human Genetics Commission
Institute for Employment Studies (IES) (1997) *Mapping Provision: The Provision of and Participation in Further Education by students with Learning Difficulties and/or Disabilities* FEFC
Ingram I and Raniwala S (2005) *Neighbourhood Nurseries Initiative. Overview report and research project* LDA
ippr (2001) *Building Better Partnerships: The final report of the commission* ippr
Jacobsen, Y. (2002) *Making the Jump: Transition to work, a guide to supporting adults with learning difficulties make the jump from education to employment* National Institute of Adult Continuing Education
Jowell T (2005) *Government response to Getting serious about play* Department for Culture, Media and Sport
King D (1998) 'The Persistence of Eugenics' *GenEthics News* 22 February/March pp 6-8
Kjaer L, Abrahamson P and Raynard P (2001) *Local Partnerships in Europe – An Action Research Project* Copenhagen Centre
Medical Research Council (MRC) (2001) *MRC Review of Autism Research: Epidemiology and Causes* MRC

Melhuish E (2004) *Child benefits: The importance of investing in quality childcare* Daycare Trust
Meltzer, H. Gatward, R. and Goodman, R. (2000) *The mental health of children and adolescents in Britain* ONS
Mental Health Foundation (2005) *Up and Running* Mental Health Foundation
Miller O, Keil S and Cobb R (2005) *A review of the literature on accessible curricula, qualifications and assessment* DRC
Mitchell W and Sloper P (2002) *Quality services for disabled children* University of York
Morris J (1999) *Hurtling into a void: Transition to adulthood for young disabled people with 'complex and health support needs'* Pavilion Publishing
National Audit Office (2004) *Early years: progress in developing high quality childcare and early education accessible to all* NAO
Organisation for Economic Co-operation and Development (OECD) (2004) *OECD Economic Surveys 2004: United Kingdom* OECD
Ofsted (2004) *Special Educational Needs and Disability* Ofsted
Office for National Statistics (ONS) (2004a) *Mental health of children and young people in Great Britain* 2004 ONS
ONS (2003) *Persistence, Onset, Risk Factors and Outcomes of Childhood Mental Disorders*, *Follow-up survey to the 1999 National Survey of the Mental Health of Children and Adolescents* ONS
ONS (2004) *Living in Britain: results from the 2002 General Household Survey* ONS
ONS (2005) *Permanent and Fixed Period Exclusions from Schools and Exclusion Appeals in England 2003/04* ONS
Pearce N and Paxton W (2005) *Social Justice: Building a Fairer Britain* ippr
Pinkus S (2003) 'All talk and no Action' in *Journal of Research in Special Educational Needs* 3:2 pp115 -121 National association for Special Educational Needs
Rabiee P, Sloper T and Beresford B (2004) 'Doing research with children and young people who do not use speech for communication' in *Children & Society* John Wiley & Sons, Ltd.
Rankin J and Regan S (2003) *Meeting Complex Needs: The future of social care* ippr
Reed J (2005) *Towards zero exclusion: an action plan for teachers and policymakers* ippr
Rigby N (2005) *Seeking bold solutions to Britain's Runaway Obesity Epidemic* International Obesity Taskforce
Robinson P (2004) *Tough Choices* ippr
Russell I (2005) *A National Framework for Youth Action and Engagement* HMSO
Rustemier S and Vaughan M (2005) *Segregation trends – LEAs in England 2002-2004. Placement of pupils with statements in special schools and other segregated settings* Centre for Studies on Inclusive Segregation
Scope (2003) *The direct approach: disabled people's experiences of direct payments* Scope
Sefang G and Smith K (2002) *The time of our lives: using time banking for neighbourhood renewal and community capacity building* New Economics Foundation

Shakespeare T (2005) 'Disability, Genetics and Global Justice' in *Social Policy and Society* 4:1 pp 87-95
Shakespeare T (2005a) *Life is a Lottery*: http://www.bbc.co.uk/science/genes/who_am_i/inheriting_genes/tom_shakespeare.shtml Last accessed May 2005
Shakespeare T (2001) *Genetics: a spiralling problem* University of Newcastle
Sharma N and Dowling R (2004) *Postcards from home. The experience of disabled children in the school holidays* Barnado's
Sinclair R and Franklin A (2000) *Young People's Participation* Quality Protects Research Briefings 3 DoH
Singleton D (2005) 'A Foundation for all Children?' *Children Now* 15-21 June Haymarket
Stone E (2001) *Consulting with disabled children and young people* JRF
Strategy Unit (2005) *Improving the Life Chances of Disabled People* HMSO
Sylva K, Melhuish E, Sammons P, Siraj-Blatchford I, Taggart B and Elliot K (2003) *The Effective Provision of Pre-School Education (EPEE) Project: Findings from the Pre-School Period* Institute of Education
Townsley R, Abbott D and Watson D (2003) *Making a difference? Exploring the impact of multi-agency working on disabled children with complex health care needs, their families and the professional who support them* Norah Fry Research Centre
Wanless D (2003) *Securing Good Health for the Whole Population: Population Health Trends* HM Treasury
Wing L and Potter D (2002) 'The epidemiology of autistic spectrum disorders: is the prevalence rising?' in Mental retardation and developmental disabilities research reviews 8:3 pp151-161 Wiley-Liss
Winston R (2005) *address to the British Association's Festival Science in Dublin Ireland* on 5th September 2005

The prime of life? Poverty and social exclusion during working age

Anderson B (2004) 'Information Society Technologies, Social Capital and Quality of Life' *Chimera Working Paper 2004*-05 University of Essex
Audit Commission (2004) *Assistive Technologies: Independence and Well Being 4* Audit Commission
Barker Review of Housing Supply (2004) *Delivering stability: securing our future housing needs* HMT/ODPM
Bennett J (2005) *From New Towns to Growth Areas: learning from the past* ippr
Bridge G (2002) *The neighbourhood and social networks* ESRC
Burniaux J-M, Duval R and Jaumotte F (2004) *Coping with ageing: a dynamic approach to quantify the impact of alternative policy options on future labour supply in OECD countries* OECD
Burwood S and Jess P (2005) *Delivering in the Growth Areas: overcoming the barriers to regeneration* British Urban Regeneration Association
Cabinet Office (2004) *Delivering diversity: public appointments 2004* The Stationery Office
Coleman S (2004) *The Network-Empowered Citizen: How People Share* Civic Knowledge Online

Coleman N, Jeeawody F and Wapshott J (2002) *Electronic government at the Department for Work and Pensions. Attitudes to electronic methods of conducting benefit business* DWP Research Report 176, CDS

Cummings J, Butler B and Kraut R (2002) 'The Quality of Online Social Relationships' *Communications of the ACM* 45:7 Association for Computing Machinery

Department for Work and Pensions (2005a) *Long-term projections of benefit expenditure* DWP

Department for Work and Pensions (2005b) *Opportunity and security throughout life: five year strategy* DWP

Devins D, Darlow A, Petrie A and Burden T (2003) *Connecting Communities to the Internet: Evaluation of the Wired Up Communities Programme* Policy Internet Institute

Disability Rights Commission (DRC) (2003) *Press release: Be PM for the Day - young disabled people to get their say* DRC

DRC (2005) *Disability Briefing June 2005* DRC

Emerson E and Hatton C (2004) *Estimating future need/demand for supports for adults with learning disabilities in England* Lancaster University

European Commission (2003) *Access to Assistive Technology in the European Union* European Commission

European Council (2000) *Presidency Conclusions* Lisbon European Council

Gardner J and Oswald A (2001) 'Internet use: the digital divide' in Park A, Curtice J, Thomson K, Jarvis L, Bromley C and Stratford N (eds) *British Social Attitudes. Public Policy, Social Ties* Thousand Oaks Sage 18 pp 159-173

Government Actuary's Department (2005) *Update of the Government Actuary's Quinquennial Review of the National Insurance Fund as at April 2000* GAD

Grenier P and Wright K (2003) 'Social Capital in Britain' *CCS International Working Paper 14* LSE

Goodinge S (2000) *A Jigsaw of Services: Inspection of Services to Support Disabled Adults in their Parenting Role* Department of Health

Hawksworth J (2005) *How far can a higher employment rate offset the upward pressures on public spending as the UK population ages?* PricewaterhouseCoopers

HMT/ODPM (2005) *Housing policy: an overview* HMT

HM Treasury (2004) *2004 Spending Review – Stability, Security and Opportunity for All: investing for Britain's Long Term Future* CM6237 HMT

Holmans A, Monk S and Whitehead C (2004) *Building for the future – 2004 update* Shelter

Home Office (2003) *2003 Home Office Citizenship Survey: People, Families and Communities: Home Office Research Study 289* Home Office

Institute for Volunteering Research (2004) *Volunteering for all? Exploring the link between volunteering and social exclusion* Institute for Volunteering Research

Human Genetics Commission (2001) *Public attitudes to human genetic information* Human Genetics Commission

Kenyon S, Rafferty J and Lyons G (2003) Social exclusion and transport: a role for virtual accessibility in the alleviation of mobility-related social exclusion? in *Journal of Social Policy* 32:3 pp 317-338

Learning and Skills Council (2003) *National Employers Skills Survey 2003: Key Findings* LSC
Morris J (2003) *The right support: report of the task force on supporting disabled adults in their parenting role* JRF
Nationwide (2005) *Monthly house price index, July 2005* Nationwide Building Society
Office of the Deputy Prime Minister (ODPM) (2005) *Sustainable communities: people, places, prosperity*: *a five year plan from the Office of the Deputy Prime Minister* The Stationery Office
ODPM (2004) *Making it happen: the northern way* The Stationery Office
ODPM (2003) *Sustainable Communities: Building for the Future* The Stationery Office
Oldman C and Beresford B (1998) *Homes unfit for children: housing disabled children and their families* Policy Press
Olsen R and Wates M (2003) *Disabled parents – examining research assumptions* Research in practice
Priestley M (2000) ‘Adults only: disability, social policy and the life course’ *Journal of Social Policy* 29:3 pp. 421-439 Cambridge University Press
Roger T and Partners (2005) *The Cost and Funding Of Growth In South East England* RTP
Russell I (2005) *A National Framework for Youth Action and Engagement* HMSO
Shaw V, Baggley M and Jarvis A (2002) *Planning for disabled people in New Osbaldswick* JRF
Social Exclusion Unit (2004) *Breaking the cycle: taking stock of progress and priorities for the future* ODPM
Social Exclusion Unit (2001) *A new commitment to neighbourhood renewal National Strategy Action Plan* Cabinet Office
Social Services Inspectorate (2004) *All Our Lives – Social Care in England 2002-2003* DoH
Stanley K with Maxwell D (2003) *Fit for Purpose: the reform of Incapacity Benefit* ippr
Stanley K and Regan S (2003) *The missing million: supporting more disabled people into work* ippr
Strategy Unit/ODPM (2005) *Improving the prospects of people living in areas of multiple deprivation in England* Cabinet Office
Wates M (2002) *Supporting disabled adults in their parenting role analysis of social services department policies and protocols in relation to disabled parents* JRF
White M and Angus J (2003) *Arts and Mental Health Literature Review* Centre for Arts and Humanities in Health and Medicine
Wilson R, Homenidou K and Dickeson A (2004) *Working futures: new projections of occupational employment by sector and region, 2002 – 2012* Institute for Employment Research
World Health Organisation (2001) *Mental health: new understandings, new hope* WHO

A good old age? Older people and disability

ADSS/LGA (2002) *All Our Tomorrows:* Association of Directors of Social Services and Local Government Association
Audit Commission (2004) *Older People – Independence and Wellbeing* Audit Commission
Best R (2003) 'Meeting the growing demand for long term care' in *Tackling UK Poverty and Disadvantage in the Twenty First Century* Joseph Rowntree Foundation
Brooks R, Regan S and Robinson P (2002) *A New Contract for Retirement* ippr
BUPA (2005) *BUPA Response to the Green Paper on Adult Social Care* BUPA
Carr S (2004) *Has Service User Participation Made a Difference to Social Care Services?* Social Care Institute for Excellence
Clark H, Gough H and Macfarlane A (2004) *It Pays Dividends: Direct Payments and Older People* Joseph Rowntree Foundation and Policy Press
CSCI (2004) *What People Want from Social Care Services and Inspections as They Get Older* Commission for Social Care Inspection
Commission for Social Care Inspection (CSCI) (2005) *Response to Independence, Wellbeing and Choice* Commission for Social Care Inspection
Dean M (2004) *Growing Older in the 21st Century* ESRC
Department for Work and Pensions (2005) *Opportunity Age* DWP
Department of Health (DoH)(2004) *Better Health in Old Age* DoH
DoH (2005a) *Independence, Wellbeing and Choice* DoH
DoH (2005b) *Tackling Health Inequalities – Status Report on the Programme for Action* DoH
Disability Rights Commission (DRC) (2005) *Shaping the Future of Equality* DRC
Edwards L (2001) *Age Old Attitudes* ippr
Elkan R, Kendrick D, Dewey M Hewitt M Robinson J Blair M Williams D Brummell K and Egger M (2001) 'Effectiveness of Homes Based Support for Older People: Systematic Review and Meta Analysis' *BMJ* 323
Emerson E and Hatton C (2004) *Estimating future need/demand for supports for adults with learning disabilities in England* Lancaster University
Expert Patients (2005) http://www.expertpatients.nhs.uk/ Last accessed on September 5th 2005
Glasby J and Littlechild R (2002) *Direct Payments and Social Work* Policy Press
Government Actuary's Department (2003) *Components of Change and Summary Indicators* GAD
Godfrey M, Townsend J and Denby T (2004) *Building a Good Life for Older People in Local Communities* Joseph Rowntree Foundation
Hasler F (2003) *Clarifying the Evidence on Direct Payments into Practice* National Centre for Independent Living
Hellner B, Sahlen K and Stig K (2005) *Preventative Home Visits – A Strategy for Better Ageing* National Board of Health and Welfare
Joseph Rowntree Foundation (2004) *Older People Shaping Policy and Practice* Older People's Steering Group at the Joseph Rowntree Foundation

Kirkwood T (2001) *The End of Age – 2001 Reith Lectures:* www.bbc.co.uk/radio4/reith2001
Laing W (2005) *Trends in the London Care Market: 1994-2024* King's Fund
Levenson R, Jeyasingham M and Joule N (2005) *Looking Forward to Care in Old Age* King's Fund
Maher J, Green H (2002) *Carers 2000* The Stationery Office
Malley J, Wittenberg R, Comas-Herrera A, Pickard L and King D (2005) 'Long-term Care Expenditure for Older People Projections to 2022 for Great Britain report to ippr' *PSSRU Discussion paper 252* London School of Economics
Marmot M, Banks J, Blundell R, Lessof C and Nazroo J (eds) (2002) *Health, Wealth and Lifestyles of the Older Population in England – the 2002 English Longitudinal Study on Ageing* Institute for Fiscal Studies
Office of Fair Trading (OFT) (2005) *Care Homes for Older People in the UK- a Market Study* OFT
Parry J, Vegeris S, Hudson M, Barnes H and Taylor R (2004) *Independent Living in Later Life* DWP Research Report 216 Policy Studies Institute
Patel N (1999) 'Black and Minority Ethnic Elderly' in *With Respect to old Age – Research Volume 1* The Stationery Office
Patmore C and McNulty A (2005) *Making Home Care for Older People More Flexible and Person Centred* Social Policy Research Unit
Pearce N and Paxton W (eds) (2005) *Social Justice* ippr
Pickard L, Wittenberg R, Comas-Herrera A, Davies B and Darton R (2000) 'Relying on Informal Care in the New Century? Informal Care for Elderly People in England to 2031' in *Ageing and Society* 20:6 pp745-772 Cambridge University Press
Rickaysen B (2005) *Note on CASS Projections of Trends in Healthy Life Expectancy* CASS Business School
Riddell S, Pearson C, Jolly D, Barnes C, Priestly M and Mercer G (2005) 'The Development of Direct Payments in the UK: Implications for Social Justice' *Social Policy and Society* 4:1
Robinson J and Banks P (2005) *The Business of Caring: Kings Fund Inquiry into Care Services for Older People* Kings Fund
Robinson P (2004) *Tough Choices – the 2004 Spending Review* ippr
Seymour L and Gale E (2004) *Literature and Policy Review for the Joint Inquiry into Mental Health and Wellbeing in Later Life* Mentality and Age Concern
Social Exclusion Unit (2005a) *Excluded Older People Interim Report* ODPM
Social Exclusion Unit (2005b) *Multiple Exclusion and Quality of Life Among Excluded Older People in Disadvantaged Neighbourhoods* ODPM
Social Exclusion Unit (2004) *The Impact of Government Policy on Social Exclusion among Older People* ODPM
Stainton T (2002) 'Taking Rights Structurally: Disability, Rights and Social Work Responses to Direct Payments' in *British Journal of Social Work* 32:6 Oxford University Press
Strategy Unit (2005) *Improving the Life Chances of Disabled People* HMSO
Tanner D (2003) 'Older People and Access to Care' in *British Journal of Social Work 33* Oxford University Press
Wanless Review Team (2005*) Social Care Needs and Outcomes* The King's Fund

Wanless D (2003) *Securing Good Health for the Whole Population: Population Health Trends* HM Treasury
Wanless Review Team (2005) *Social Care Needs and Outcomes* King's Fund
Wanless D (2002) *Securing our Future Health – Taking a Long Term View* HM Treasury

Glossary of survey data

1. Labour Force Survey (LFS)

Since spring 1997, the LFS, conducted by the Office for National Statistics, has provided information about disability using the following definitions.

- **Current DDA disabled**: Includes people who define themselves as having a long term health problem or disability which has a substantial and long-term adverse effect on their ability to carry out normal day to day activities.
- **Work limiting disabled**: Includes people who define themselves as having a long-term health problem or disability which affects the kind or amount of paid work which they might do.
- **Long term disabled**: Includes people who say they meet the criteria for either (or both) of the above definitions.

Those with multiple conditions are also asked to identify their single main health problem. The seventeen categories of health problem or impairment are:

1. Problems or disabilities connected with arms or hands
2. Problems or disabilities connected with legs or feet
3. Problems or disabilities connected with back or neck
4. Difficulty in seeing (while wearing spectacles or contact lenses)
5. Difficulty in hearing
6. A speech impediment
7. Severe disfigurement, skin conditions, allergies
8. Chest or breathing problems, asthma, bronchitis
9. Heart, blood pressure or blood circulation problems
10. Stomach, liver, kidney or digestive problems
11. Diabetes
12. Depression, bad nerves or anxiety
13. Epilepsy
14. Severe or specific learning difficulties
15. Mental illness or suffer from phobia, panics or other nervous disorders
16. Progressive illness not included elsewhere (e.g. cancer, multiple sclerosis, symptomatic HIV, Parkinson’s disease, muscular dystrophy)
17. Other health problems or disabilities

2. Office for Population and Censuses (OCPS)

The OCPS is now the Office for National Statistics (ONS). The OPCS in the UK (Martin *et al* 1988) developed a measure and scale to produce age and sex specific disability prevalence rates for ten different categories of severity. The original methodology draws on the conceptual framework developed in the World Health Organization’s ‘International Classification of Impairments, Disabilities and Handicaps‘. The ICIDH identifies the following separate consequences of disease: impairment, disability and handicap.

- Impairment is defined as 'any loss or abnormality of psychological, physiological or anatomical structure or function', in other words, parts or systems of the body that do not work.

- Disability is defined as 'any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being', or things people are unable to do.
- Handicap is the relationship between impaired and/or disabled people and their surroundings and refers to 'a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role (depending on age, sex and social and cultural factors) for that individual'.

In 1985, 14,308 adults who indicated there was a disabled person at the address were interviewed. Interviewing of 3,775 disabled adults also took place in a sample of 570 institutions in 1986. The report on the survey allocates disabled people into one of ten categories with category one the least severe and category ten the most severe.

3. General Household Survey (GHS)

The GHS has provided information about disability using the following definition:
Limiting Long Standing Illness (LLSI): An illness, disability or infirmity that is longstanding (has troubled someone over a period of time or is likely to) and limits their activities in any way.

The LLSI is intended to capture the perceived disabling effects of chronic ill-health (morbidity) and physical and sensory impairments. From this, the GHS collects information on three types of health problem:

1. Acute sickness: Acute sickness is defined as restriction of the level of normal activity, because of illness or injury, at any time during the two weeks before interview. Anyone with a chronic condition that caused additional restriction during the reference period is counted among those with acute sickness.
2. Chronic sickness: Information on chronic sickness is obtained from a two-part question: the first part asks respondents to differentiate the conditions they currently have on the basis of actual or expected duration – dividing them into those they regard as ‘longstanding’ and those they consider to be temporary or short-term. This first part, generally referred to as the longstanding illness (LSI) question, is often used in surveys as a filter question that determines whether or not the second part of the question is asked; the purpose of the second part being to establish what, if any, limitations result from the condition/s. Positive responses to both parts of the question identifies individuals with LLSI.
3. Longstanding conditions and complaints: Respondents who report a longstanding illness are asked ‘What is the matter with you?’ and details of the illness or disability are recorded by the interviewers and coded into a number of broad categories. Interviewers are instructed to focus on the symptoms of the illness, rather than the cause, and code what the respondent said was currently the matter without probing for cause. This approach has been used in 1988, 1989, 1994 to 1996,

1998 and 2000 to 2003. The categories used when coding the conditions correspond broadly to the chapter headings of the International Classification of Diseases (ICD). However, the ICD is used mostly for coding conditions and diseases according to cause whereas the GHS coding is based only on the symptoms reported. This gives rise to discrepancies in some areas between the two classifications.

4. Family Resources Survey (FRS)

The FRS is carried out annually and has provided information about disability using the following definitions:

- **Work-Limiting Disability (WLD)**: A long-term health problem or disability that affects the amount or type of work a person can do.
- **Limiting Long Standing Illness (LLSI)**: An illness, disability or infirmity that is longstanding (has troubled someone over a period of time or is likely to) and limits their activities in any way.

The FRS aims to assess work-limiting disability (WLD) as defined by the respondent's perception of restriction in her or his capacity for paid work, in either the kind or amount of work they could do, or both. At it's core, the question is hypothetical in that it asks respondents to consider work they might or could do. Respondents are also asked to judge if their work capacity is causally linked to an underlying health problem (rather than to other sorts of factors such as environmental or attitudinal barriers) and to assess if this problem is enduring. The FRS assesses limited long standing illness in a similar way to the General Household Survey.

5. Health Survey for England (HSE)

The HSE has been carried out annually since 1991 and has provided information about disability using the following definitions:

- **Limiting Long Standing Illness (LLSI)**: An illness, disability or infirmity that is longstanding (has troubled someone over a period of time or is likely to) and limits their activities in any way.
- **International Classification of Impairments, Disabilities and Handicaps (ICIDH):** A restriction or lack of ability to perform normal activities which has resulted from the impairment of a structure or function of the body or mind. This definition has now been replaced by the International Classification of Functioning, Disability and Health which includes a set of environmental/ societal factors.

In the HSE, respondents who report a long-standing illness are sometimes also asked for details of the nature of their condition before the second question on limitations. Conditions are self reported and non-explicit in terms of dimensions or the type of long-term condition.

6. Census

The Census is carried out every ten years by the Office of National Statistics and has provided information about disability using the following definition:

- **Limiting Long Standing Illness (LLSI)**: An illness, disability or infirmity that is longstanding (has troubled someone over a period of time or is likely to) and limits their activities in any way.

The Census does not assess LLSI in exactly the same way as the GHS, FRS or HSE as it does not pose a two-part question. Instead, it poses the question: ‘Do you have any long-term illness, health problem or *disability* which limits your daily activities or the work you can do? Include problems which are due to old age. (Yes/No)’.