

Disability Rights Commission

Disability in Scotland: A Baseline Study

Executive Summary

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INTRODUCTION

This baseline study was commissioned by DRC from the Strathclyde Centre for Disability Research. It aims to provide an overview of policy, official statistics and research in relation to disabled people in Scotland. The timing of this review is important because it coincides with a number of major policy developments in Scotland and GB. These include the following:

The establishment of the Disability Rights Commission

The Disability Rights Commission (DRC) will play a major role in supporting disabled people through conciliation and access to legal support to bring cases to court. It is also charged with monitoring the Disability Discrimination Act 1995 (DDA) and informing government of changes which may be required to strengthen the law.

The extension of the Disability Discrimination Act

The DDA is being extended to cover a much wider range of employers and to increase the duties of those supplying goods and services to avoid discrimination against disabled people. The exemption of education from the DDA has been removed. The Human Rights Act may also have a significant effect in increasing the rights of disabled people.

The re-establishment of the Scottish Parliament

The Scottish Parliament is having an impact on the lives of people in Scotland, forging new welfare agendas. In order to ensure that the interests of disabled people are reflected in social inclusion strategies, there is a need for much better information about their experiences and needs within post-devolution Scotland.

AIMS OF THE STUDY

This study:

- Provides an overview of the Scottish legislative and policy context in which the experiences of disabled people are located.
- Presents available data on developments/trends in particular policy areas. These include education, employment, health and social care, housing, transport, access to goods and services. As well as collating data from a range of sources, gaps in available information, statistics and datasets are identified.
- Identifies the implications of the extension of disability rights in terms of the capacity of the existing infrastructure to respond.
- Makes suggestions for a future research agenda in relation to areas of Disability in Scotland social policy covered by the DDA.

Consideration is given to areas where further information is required, the form in which such information might be made available and the wider social, policy and statutory changes which may be needed to ensure that equality for disabled people is achieved.

Given the short timescale of the work, which was conducted over a two month period between February and March 2001, the review of policy, official statistics and research could not be exhaustive.

However, the study provides an overview of existing knowledge about disabled people in Scotland, the linkages between different areas of social policy and between Westminster and Holyrood Parliaments.

ESTIMATES OF THE NUMBER OF DISABLED PEOPLE IN SCOTLAND

There are no absolutely reliable estimates of the overall level of impairment in Scotland. The only primary data which are available are drawn from the Office of Population Censuses and Surveys (OPCS) studies which estimated in 1988 that there were 612,000 disabled adults in Scotland and 33,800 children (Bone and Meltzer, 1989). Since these surveys were

undertaken, there are likely to have been increases in the number of disabled people in Scotland due to the fact that the population is ageing and older people are more likely to experience impairment (see Figure 1.1).

Figure 1.1: Disabled people in particular age groups expressed as percentage Source: OPCS

The Scottish Executive Health Department, based on its own data, estimated that in 1999 there were 800,000 disabled adults in Scotland. Overall, women make up 59% of the population of disabled people because they live longer than men, but at school age twice as many boys as girls are identified as having special educational needs (SEN).

KEY DEVELOPMENTS AND AREAS FOR FUTURE RESEARCH

Education

Three per cent of children in primary schools and 4% in secondary schools have special educational needs. Two per cent of these children have Records of Needs. There is inconsistency across authorities in sue of recording. 25% of children with SEN are educated in special schools, but only three quarters of these have Records of Needs, which means that they are not entitled to a multi-disciplinary assessment and regular review.

Unlike England, parents are not allowed to appeal against Part V of the Record which sets the measures proposed by the education authority to meet the child's needs. In addition, there is no Special Educational Needs Tribunal to deal impartially with cases where parents and the education authority disagree over appropriate educational provision.

There are strong arguments for tightening up the process of assessment and recording and enhancing parents' and children's rights through the establishment of a Special Educational Needs Tribunal, which would also hear cases relating to discrimination (see below), admissions and exclusions.

The SEN and Disability Act (Part IV of the DDA) has the potential

to make school and post-16 education far more inclusive, but much will depend on the willingness of responsible bodies to plan for change and on disabled children and adults to challenge discrimination. Some policy tensions exist, for example, in both compulsory and post-16 education the focus on raising standards means that professionals may invest their energies in this direction rather than in creating an inclusive environment, although of course the two policy agendas are not necessarily mutually exclusive.

Policy makers need to ensure that inclusion is an 'incentivised' activity. In schools, because there are differences in the existing SEN frameworks within GB, there is a danger that children with SEN and their parents in Scotland may have weaker rights than their counterparts in England and Wales.

At the time of writing, planning duties do not apply in Scotland (although the Scottish Executive has promised regulations on planning in the future). Aids and adaptations are not covered by the DDA, because it was assumed that these would be addressed under the existing SEN framework. However, in Scotland not all disabled children have Records of Needs and parents cannot appeal against Part V of the Record. In Scotland appeals on grounds of discrimination will be made to the Sheriff Court, but this route is time-consuming and individuals are unlikely to qualify for legal aid.

The effectiveness of the new legislation will ultimately depend on the extent to which Scottish education authorities push schools to make changes in their practice. Education Authorities will need to give schools guidance on good practice and monitor their compliance. It will be essential to monitor the implementation of Part IV of the DDA in different parts of GB to assess the extent to which disabled people have equal access to justice.

In relation to the collation of statistical information, the Scottish Executive plans to gather individual level pupil data which will enable much more sophisticated analysis to take place. It will be important to consider carefully the criteria used to establish SEN/disability status to ensure that data are valid and comparable across authorities. Whilst information on higher education students is relatively easily available, information on further education students and those undertaking training programmes is difficult to

obtain. In order to monitor provision effectively, data are needed on all forms of post-16 education and training.

There is also a need for research which explores the experiences of disabled children, young people and adults in a range of settings to assess the extent to which institutions are adapting inclusive policies and practices.

Research is also needed on the interaction of a range of social factors (social class, gender, 'race', age, geographical location) which may influence individuals' experiences of inclusive education.

Employment

About half the disabled population of working age are unemployed and this is a key element in their social exclusion. The implementation of further DDA measures relating to employment in 2004 will be helpful in enabling disabled people to challenge discrimination in the workplace, since a much wider group of people will be covered by the law.

However, the success of the Act depends on employers acting to ensure compliance and individual disabled people bringing cases to establish precedents. Evidence from the earlier implementation phases suggests that many employers have been complacent and unwilling to improve their practice until forced to do so.

Ongoing monitoring of Part II of the DDA is needed to assess relative rates of progress in different parts of GB. This should include an assessment of disabled people's views of the effectiveness of the legislation, as well as those of the general public.

Employment Service (ES) programmes have traditionally been geared to disabled people with relatively low support needs, rather than people who require significant and ongoing support in the labour market. Current information to employers on ES programmes appeals to their goodwill as means of expanding employment opportunities for disabled people. Given the emphasis on profit-making and efficiency in modern organisations, the willingness of employers to employ more

disabled people remains to be seen and should be closely monitored.

Measures to support disabled people with higher support needs, such as supported employment programmes, are often provided by voluntary organisations on shoe-string funding. If the goals outlined in the Learning Disabilities Review are to be realised, then the funding of supported employment needs to be placed on a more secure footing.

The training programmes of Local Enterprise Companies targeted at disabled people have not been closely and routinely monitored. There is a need to set clear service standards and to review regularly disabled people's experiences of these programmes.

There are ongoing tensions between social security and employment programmes which need to be resolved. For example, a person with learning disabilities requiring housing benefit is still likely to be restricted to 'therapeutic work' with penalties for working more than 16 hours a week.

There is a need for a far more flexible relationship between employment and benefits, so that an individual may work for longer hours when they feel able without jeopardising their benefits status. These problems are recognised by Government, but are not yet resolved.

There is a need to focus not just on employment, but also on benefits. Since 50% of disabled people are forced to depend on social security, poverty will remain a problem until levels of benefits ensure that disabled people get the support they need to lead a fulfilling life.

Whilst employment and benefits policies are reserved to Westminster, research is needed to explore the ways in which these policies are experienced in Scotland. Comparisons then need to be made with the rest of the UK. Such comparative research is particularly important in the context of new programmes (e.g. the New Deal for Disabled People) and evolving services (e.g. Employment Service programmes).

Regular analysis of Labour Force Survey data is also necessary to identify labour market trends affecting disabled people in Scotland and other parts of the UK. This information will shed light on the specific conditions operating in Scotland (large rural areas and concentrations of urban poverty) and to illuminate the effectiveness of the social inclusion strategy in Scotland compared with other parts of the UK.

Very few qualitative studies have been conducted with a focus on disabled people's experiences of finding and retaining employment, as well as their experiences outwith the labour market. Such studies would be useful in shaping support within and outwith the workplace. A range of variables, including social class, 'race', gender, age and geographical location should be taken into account.

Health and social care Broad brush health and social care policy envisages a blurring of these two services which have traditionally existed separately. Health and social care services in the future, it is hoped, will deliver a seamless web of services with a focus on the well-being of people in communities rather than the treatment of illness in institutional settings.

Our review of these policies suggests that a unified system of this type has yet to be achieved. Health services continue to focus on impairment-specific populations and on treating illness. Statistics and research describe treatments and outcomes rather than service users' experiences.

There are, however, a number of interesting developments which indicate the future direction of services. For example, there are moves away from residential care (although there are some contradictory trends, e.g. a growing number of people with learning disabilities being looked after in nursing homes). Joint commissioning and funding arrangements are being put in place for certain groups of children and adults requiring a high degree of support. Community-based health services are seen as preferable for the vast majority of disabled people, although an ongoing role is envisaged for specialist services geared towards those with profound and multiple disabilities.

In terms of social care, the Scottish Executive is encouraging local authorities to develop direct payment schemes so that individuals

purchase the services they need rather than receiving standardised packages. Despite official endorsements, such schemes are in their infancy and tend not to include people who are deemed incapable of managing their own care.

There is some uncertainty about the purposes for which payments may be used. Employment Service personnel, for instance, are not always aware that direct payments may be used to help an individual at work as well as at home.

Overall, there is a need to monitor the extent to which health and social care services shift their focus towards meeting individual needs in mainstream rather than specialist settings. In addition, it will be important to monitor the way in which the NHS in Scotland and local authorities comply with the requirements of the DDA relating to employment and goods and services.

In terms of available statistics, it is evident that the Information Statistics Division of the Scottish Executive Health Department has an extensive database, but this may not be readily accessible to many people. Information on which groups of people experience specific impairing conditions is useful, but it is only part of the picture. Far more data are needed on disabled people's experiences of and access to a range of health and social care services, including direct payments. Furthermore, statistical information available needs to be collated and analysed so that specific trends in health and social care provision for disabled people may be illuminated.

Housing statistics indicate that Scotland's homes are in a poor state when measured against accessibility standards and housing stock is used inefficiently, with almost half of adapted homes occupied by people who do not require such adaptations. In both social rented and private housing sectors, there is a need for closer monitoring of housing stock, so that there is a better matching between people who need houses and available local provision.

At the moment, 60% of wheelchair accessible homes are occupied by people who are not wheelchair users. The impact of new housing regulations introduced under the DDA needs to be monitored. The model of data gathering established by the Disabled Persons Housing Service Lothian, based on the collation

and analysis of Personal Housing Plans, might be extended across the country so that there is a better understanding of need compared with provision.

Within housing policy, there has often been an unhelpful division between special needs housing, which has been seen as a community care issue, and mainstream housing, which has been largely unmonitored. There are now moves for an inclusive approach to housing policy for disabled people, with attention paid to the accessibility of all housing stock whether in the private or social rented sector. Ownership options for all disabled people are being promoted and new building regulations will apply across the board.

The new Housing (Scotland) Bill envisages a strategic role for local authorities as regulators rather than major service providers and Scottish Homes is to become an executive agency of the Scottish Executive more closely tied in with national policy objectives. Research is needed to illuminate the impact of this national policy objective on the nature and quality of housing available for disabled people.

Disabled people with high support needs experience particular problems in accessing suitable housing and in obtaining a housing benefits package which supports independence. The closure of long-stay hospitals means that new types of accommodation in the community are required which will provide support in small group or individual settings. There is evidence that some people have moved from long-stay hospitals into hostels or nursing homes which may offer few additional opportunities for independent living.

Housing benefits rules often reinforce dependence and the Government's Supporting People programme is attempting to unravel some of these unhelpful policy knots. Devolution is likely to widen existing differences in housing policy across the UK. There is therefore a need for comparative studies of the housing needs and experiences of disabled people.

Transport

Throughout the 1980s and early 1990s, Government focused on roads rather than public transport and market solutions took the place of a planned approach to transport. There is currently a

commitment to develop a planned and integrated transport system which meets the needs of minority groups, not just those with the greatest spending power. The provisions of the DDA and the Transport (Scotland) Act 2001 are intended to lead to improvements in infrastructure, and the impact of national developments on disabled people's experiences of transport need to be monitored.

The deadlines set by government for all public transport vehicles to be accessible to disabled people are far into the future and some modes of transport (ferries, aeroplanes) are not covered by the DDA. The effectiveness of the new partnership arrangements between public and private sectors in developing integrated transport systems remains to be seen. In particular, firmer legislative measures may be needed to get privatised bus and railways to prioritise accessible transport, backed up by appropriate staff training.

Much better information is needed on the accessibility of public and private transport systems for different groups of disabled people in a range of geographical locations. There is a need for research which explores the place of accessible transport in wider social inclusion strategies and cross-UK studies have a useful contribution to make here.

Access to Goods and Services

The Government has announced its intention to adhere to the timetable for the implementation of the remaining part of the DDA. From 1st October 2004, service providers will have additional duties in relation to physical features that make it impossible or unreasonably difficult for disabled people to use their service. They may have to overcome the difficulty caused by the feature by taking reasonable steps to remove, alter, avoid or make reasonable adjustments to it. As noted above, new building regulations will also be implemented in 2004. Monitoring the implementation of Part III of the DDA is required to capture differences across GB and within Scotland. This will involve charting the views of disabled people, service providers and the general public over time. It is important that the DRC is able to encourage more disabled people to bring cases, as well as provide advice and conciliation.

Future Research

To summarise, across the different policy areas discussed above, research is needed which will:

- Assess the impact of DDA and human rights legislation in Scotland
- Compare the impact of the DDA in different parts of GB and disability equality policies throughout the UK.
- Explore the treatment of disability issues within the wider social inclusion agenda in Scotland and in the wider UK context.
- Investigate the experiences of disabled people as a group, but also in relation to the specific experiences of groups such as people with mental health problems, people with learning disabilities, disabled children.
- Explore associations between disability and other social variables such as social class, 'race', gender, locality and consider how these multiple identifiers shape people's responses to policy and provision.
- Consider the way in which the modernised welfare state, emphasising flexible, person-centred services, meets the needs of disabled people in Scotland.

Future research will employ both qualitative and quantitative methods as appropriate and needs to be underpinned by a much more reliable statistical base to address information gaps. To achieve this, there is a need for the harmonisation of survey questions. There is also a need for the production of regularly updated statistical digests which summarise information on disability in specific policy areas, with signposts to data sources.

Whilst researchers need access to primary data sources, policy-makers, practitioners and activists need clear summaries of data. A Scottish information strategy on disability issues is needed to meet all these needs. Disabled people should be involved in the formulation and implementation of a future research agenda, working in conjunction with the DRC, the Scottish Executive, the

UK Government and other organisations such as the Joseph Rowntree Foundation.

CONCLUSION

The Disability Discrimination Act, now backed up by the enforcement powers of the DRC, has the potential to make a significant difference to the lives of disabled people. The existence of the legislation and the Commission conveys a strong message that a socially just society requires the full participation of disabled people.

However, barriers to overcoming discrimination remain; these include lack of local support, information and legal advice and a dearth of well qualified solicitors. In addition, the social and economic disadvantages experienced by disabled people mean that the struggle for survival may take priority over the quest for legal redress.

Knowledge is an essential element in the struggle for justice and this report is an attempt to provide an over-view of the big picture. We hope that in the future well-planned and conducted research, backed up by reliable and accessible statistics, will be used to monitor progress and identify areas for future development.

This report was produced by the Strathclyde Centre for Disability Research at the University of Glasgow for the Disability Rights Commission. The views expressed in the report are those of the authors and do not necessarily reflect the views of the DRC.

To obtain a copy of the full report see overleaf.

You can contact the DRC HELPLINE by voice, text, fax, post or email. You can speak to an operator at any time between 08:00 and 20:00, Monday to Friday.

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