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foundations

Supporting disabled children and their families in Scotland: A review of policy and research

The Joseph Rowntree Foundation has been supporting research about disabled children and their families for a number of years. An earlier **Foundations** covering the messages from these projects has already been published (1). This **Foundations** places the messages from that work into the Scottish context. It gives an overview of current policies affecting disabled children and their families in Scotland and draws on research carried out north of the border.

- There are about 33,000 disabled children in Scotland. Over 14,000 have a Record of Special Educational Needs.
- The Children and Young People's Group within the Scottish Executive Education Department now has responsibility for most matters relating to disabled children. It is less clear who is responsible for the welfare of those attending residential school.
- The Children (Scotland) Act 1995 is broadly similar to the 1989 Children Act covering England and Wales, although there are some differences. For example, children 'affected adversely by the disability of any other person in their family' are counted as 'children in need'. However, Scottish authorities are not required to provide the same range of services for children in need as English ones.
- Scotland lacks information about the experiences of disabled black children and young people. Because the number of people from ethnic minorities is relatively low, this can mean little or no action is taken to meet their particular needs.
- Authorities have a new duty to provide mainstream schooling for all children but qualifications to this requirement leave a great deal of room for interpretation.
- Looking at the Foundation's studies within the Scottish context highlights certain areas where information is hard to obtain, such as the circumstances of children at residential schools, and where there appears to be some dearth of policy initiative, for example in housing.

The background

The Scottish Parliament and The Scottish Executive

The Scottish Parliament, dissolved in 1707, was reconvened in 1999. Some of the powers devolved to Edinburgh are crucial to the welfare and interests of disabled children and their families - education, social work, housing and health. Employment, social security and legislation on disability matters remain the responsibility of Westminster.

The Social Work Services Group within the Scottish Office (now renamed The Scottish Executive), was disbanded in 1999. A new Children and Young People's Group has been set up within the Education Department, with responsibility for pre-school education, children's services and community education. A 'litmus test' of its performance will be how far it listens to and involves children and young people (2). The thinking behind this re-organisation lies in the 1999 White Paper (3). It emphasises joint working across all agencies and the role of social work in achieving social inclusion. The community care element of social work has gone to the Health Department. A new Scottish Executive Development Department includes housing, social inclusion and transport.

Number of disabled children in Scotland

There are about 33,000 disabled children in Scotland. Over 14,000 have a Record of Special Educational Needs (SEN), the equivalent of a 'statement' in England (4).

The Children (Scotland) Act 1995

Pre-dating the new Parliament, but coming six years after The Children Act in England, was the Children (Scotland) Act. This Act is broadly similar to the English one, apart from the sections relating to the Children's Hearings System, which does not exist elsewhere in the UK. There are also some differences relating to children and disability.

As in England, The Children (Scotland) Act identifies disabled children as 'children in need' and states that local authorities must provide services to support them. These services should 'be designed to minimise the effect on a disabled child ... of his disability' and enable children 'to lead lives which are as normal as possible' (s.23). In Scotland, 'children in need' also includes children 'affected adversely by the disability of any other person in their family'. This could include siblings of a disabled child, and any child whose parent is disabled, particularly 'young carers'.

The Scottish Act gives local authorities a duty to assess the needs of a disabled child, or a member of her

family, if asked to do so. However, authorities in Scotland are not required to provide the same range of services for 'children in need' as are English authorities under the 1989 Act. Only day-care, after-school care and holiday care are specified. While the English Act is accompanied by ten volumes of guidance and regulations, there are only four in Scotland. This flexibility - or vagueness - is intended to allow local authorities to be 'enabling': the danger is that it will allow some to do little or nothing.

There is no requirement on Scottish local authorities to keep registers of disabled children, as there is in England.

Like England, The Children (Scotland) Act gives local authorities corporate responsibility for children in need. In 1996 Scotland's regional councils were abolished; there are now 32 single-tier 'unitary authorities'; some have combined housing and social work, or education and social work, within joint departments. Because such a corporate structure is less common in England and Wales, Scotland seems particularly well-placed to achieve a high level of co-operation between the various partners (5).

Morris (6) has evaluated the impact of The Children Act (1989) on services to disabled children. Readers in Scotland should bear in mind the differences outlined above. However, two key issues Morris deals with - short-term breaks and children looked after away from home - are relevant to Scotland, as discussed later.

So far, no research has evaluated the implementation of The Children (Scotland) Act for disabled children, although Renfrewshire Council commissioned a study to investigate the support needs of children affected by the disability of another family member (7).

The Scottish Executive Review of Services to People with Learning Disabilities

This high-profile review of adults' and children's services, published in May 2000, was initially confined to social work and health but increasingly acknowledged the importance of education, employment, housing and other areas. Six Task Forces were set up to focus on key areas, including one for Children's Services. From a survey of users' and carers' views (8), which included four focus groups with children and young people, the main issues to emerge about children were:

- Lack of social and recreational opportunities;
- Social isolation experienced by many children and young people;
- Bullying at school and in local neighbourhoods;
- More support needed for siblings of disabled children.

Among the key recommendations of the review (9) were:

- Local authorities and health boards should draw up 'Partnership in Practice' agreements by 1 June 2000, to develop local strategy and services;
- They should appoint Local Area Co-ordinators for learning disability services: each will support about 50 individuals;
- Everyone with learning difficulties should be able to have a 'Personal Life Plan', from about the age of 14;
- Guidance on short-term care for children and adults should be reviewed, to ensure it is flexible and non-bureaucratic.

Social work and education

The Executive has emphasised that the publication of this framework document is a beginning and not an end, and that a wide range of organisations and individuals need to play their part in making the strategy a success.

Social work for children and families is now located in the Scottish Executive Education Department. Social work in Scotland is undergoing major changes. The 1999 White Paper proposed:

- A Scottish Commission for the Regulation of Care to regulate care services;
- A Scottish Social Services Council to regulate the social services workforce.

These should be in place by April 2001. Meanwhile, a National Care Standards Committee has begun to set standards for different services, starting with residential care.

In 1998, the Department of Health launched *Quality Protects*, a three-year initiative aimed at transforming services for children in need. Wales has a similar programme called *Children First*. There is no Scottish equivalent, although the Scottish Executive is developing a Strategic Framework for Children's Services (3). The framework sets out three broad aims, including 'to enrich the social and emotional development of children and families affected by disability'. Assessing need and providing 'respite services' are the two main activities proposed. The framework will not be finalised for some time: the Executive is currently considering how to take forward policy for disabled children (10).

Strategy for carers in Scotland

Scotland is included in The Carers' (Recognition and Services) Act 1995. In November 1999, the Executive

announced an extra package of measures to support carers, including:

- Promoting new and more flexible services including 'respite care' at local level;
- Introducing national standards for these;
- Monitoring health and social work's performance in supporting carers;
- Better and more targeted information for carers nationally;
- Attention to the needs of young carers.

A Carers' Legislation Working Group was set up in 1999, including representatives of users' and carers' organisations. It will come up with proposals for public consultation and a Bill should go to Parliament in Autumn 2001.

Direct payments

Direct payments are available in Scotland as they are in England, although take-up is very low (11). The Carers' and Disabled Children's Act will extend direct payments to 16- and 17-year-olds in England and to families with disabled children. The Scottish Executive has said it will also make direct payments available to these age groups and possibly to carers.

Short-term breaks

Short-break services for children are governed by The Children (Scotland) Act. As in England, where children receive 'respite' for more than 24 hours continuously in a residential or family setting, they are treated as 'looked after' and the arrangements come under the regulations for 'looked after' children.

Morris (6) found that English authorities were not fulfilling their duties under The Children Act (1989) in respect of short-term care. Prewett (12) has published research about numbers and features of shared care schemes in England and Wales, and users' views of the services. A separate study looks at ways of recruiting and supporting short-term carers for children who are 'hard to place' (13). There is no reason to think that the findings of these studies, in terms of policy, practice and users' views, differ significantly from the Scottish scene.

A national study of short-term care in Scotland commissioned by the Social Work Services Inspectorate (SWSI) (14) is now rather dated. Shared Care Scotland (15) carried out a survey similar to Prewett's first study, looking at numbers of schemes and characteristics of users: it intends to update this information next year. It estimates there are currently about 55 family-based schemes for children in Scotland, catering for around 1,350 children (10). Shared Care Scotland has a grant from the National Lottery Charities Board to investigate the costs and benefits of short breaks to the person

being cared for, and the carer, and to decide how best to measure outcomes. This study, being conducted at Aberdeen University, is focusing on five 'user groups', including children with complex needs.

Co-ordination and keyworker services

Mukherjee et al. (16) worked with a range of agencies to facilitate and evaluate a keyworker system for families with disabled children in two local authorities. Although this project took place south of the border, it has useful lessons for Scotland. As in England, there is no requirement on Scottish local authorities to provide keyworkers for families with disabled children. Indeed, many families in Scotland have little or no social work contact and, where they do, parents are often less than satisfied with the service (8). There are only two or three social work teams in Scotland dedicated to working with disabled children and their families. However, this situation looks set to change with the recommendation of the Learning Disability Review that 'local area co-ordinators should work with children and adults on an individual basis'. Keyworkers were also proposed by the Beattie Committee, set up to identify the needs of young people who require additional support to make the transition from school to further education, training or employment (17).

Families from minority ethnic communities

Chamba et al.'s study of services for minority ethnic families (18) was carried out across the UK. However, race is not 'on the agenda' in Scotland as prominently as south of the border: there is no common approach to race equality issues across Britain (19). A major difficulty in Scotland is the view that, because the number of people from ethnic minorities is relatively low, 'there is no problem'. This attitude can result in little or no action being taken to meet particular needs. For example, The National Forum on Special Educational Needs, set up this year, has 17 members, all white. This would be unthinkable south of the border.

Scotland lacks information about the views and experiences of disabled black children and young people. At least one prominent organisation of disabled people has admitted it has failed to attract members from minority ethnic communities (20).

The Guidance accompanying The Children (Scotland) Act states that, in delivering services to safeguard and promote children's welfare, local authorities must 'have regard to issues of race, language, religion and culture' (s.22) (4). Information should be available in languages other than English. However, recent research in Scotland has shown families with disabled children often feel isolated, report that interpreters are not always available, and that not enough information is translated into minority languages (8). These findings echo those of Chamba et al.

Families with two or more disabled children

Lawton (21) researched the characteristics of families with more than one disabled child across the UK. There were some regional variations across Britain in the distribution of these families, but Scotland is not identified as having either more or fewer than other areas. Follow-up work (22) looked at the experiences, needs and circumstances of 24 such families in the North of England. There is no reason to suppose that the experience of families with more than one disabled child living in Scotland will differ significantly from those of similar families elsewhere in the UK.

Disabled children living away from home

Morris (23) explored the experiences of disabled children in England living away from home. The Children (Scotland) Act and the relevant guidance in this area are very similar to that south of the border, although in Scotland there are no Independent Visitors. (Under the Children Act 1989, local authorities must appoint these volunteers to advise and befriend children and young people who are looked after and have had little or no contact with their parents for a year or more.) Morris found that information about disabled children living away from home was hard to come by and that many were becoming 'lost' in the system. The situation may be even worse in Scotland, where there has been no SWSI inspection of services to disabled children, as there has south of the border, and there are no registers. More recently, concern about the disproportionate numbers of disabled children being sent to residential schools in England prompted the JRF to commission research on this topic. Looking at 21 authorities, this research reported wide variation in the way education and social services departments were carrying out their duties in respect of these children (24).

Who Cares? Scotland has identified the lack of a coherent policy for disabled children at residential schools in Scotland (10). It is one of about 20 voluntary organisations which are coming together to discuss this issue, with a view to developing advocacy for these children. In their experience, it is difficult to get information about the numbers and whereabouts of these children, and education and social work departments often fail to work together in this area.

The Scottish Executive has no 'direct policy initiatives' in this area: at present it is not clear who should take the lead on matters relating to the welfare of disabled children at residential school (10). However, the social services legislation expected next year, following the 1999 White Paper, may strengthen social work departments' duties in this area (10).

Given the concerns outlined above, which echo the findings of the English research, these studies are likely to have useful lessons for Scotland, where there has been no research in this area.

Inclusive education

The Riddell Committee was set up to examine barriers to educational and social development affecting children with 'severe or low incidence disabilities'. Its report (25) made 22 recommendations, including:

- A harmonisation of education and social services legislation;
- Greater inclusion of children in mainstream schools;
- The setting up of a National Special Needs Advisory Forum;
- Far better inter-agency co-operation;
- More effective partnership between parents and professionals;
- Full and accurate information;
- The need to listen to children's wishes about their education.

An Advisory Forum was set up in March 2000, whose first task is to examine the Record of Needs process. An independent national SEN advice service for parents and young people, called *Enquire*, has also been established, at Children in Scotland. Other proposals have been included in The Standards in Scotland's Schools Etc. Act 2000. There was much heated debate among professionals, parents and activists concerning what this legislation should say about inclusive education. In the end, a new duty has been imposed on authorities to provide education for all children in mainstream schooling - provided this is appropriate to the needs of the child, compatible with the education of the wider class and does not involve unreasonable cost. Clearly, these qualifications leave a great deal of room for interpretation.

Housing

Beresford and Oldman (26) found that disabled children and their families in Northern England had many unmet housing needs and other difficulties arising from poor or inappropriate housing. They ran a series of workshops with practitioners from around the UK to discuss the policy and practice implications of this research (27). Guidance from The Scottish Executive on housing for 'community care groups' (28) indicates that many of the problems identified in these projects also apply to Scotland. For example, the guidance refers to 'continuing difficulties in achieving joint working across housing, health and social work', delays in supplying aids and adaptations, with some authorities taking emergency action to clear back-logs, and the need to avoid 'fragmentation of assessment processes and uncoordinated service responses'.

However, it is not clear how far families with disabled children are seen as a 'community care group'. The Executive has no policy specific to housing for disabled children and their families (10) although some broader

initiatives apply to them. For example, since 1999, all new houses funded by Scottish Homes, the national housing agency, must be barrier-free. This policy is recommended to local authorities and 'commended' to the private sector.

Beresford and Oldman (27) report a lack of information about the availability of adapted properties, particularly in the private sector, and the number of families requiring them. The Disabled Persons' Housing Service keeps a database of barrier-free houses in the Lothians and 'matches' them to individuals and families. The database is currently being extended to include private sector housing. Ownership Options helps disabled people, or households with a disabled member, overcome barriers to home ownership.

It has not been possible to find any recent or current research on housing and disabled children in Scotland. One study (29), estimating the housing needs of 'community care groups', acknowledged that issues relating to disabled children are little recognised - again echoing Beresford and Oldman.

Health

In 1993, the Scottish Office issued guidance on the care of children in hospital (30). It stated that:

- Children should only go into hospital if the care they need cannot be provided at home or on a day-care basis;
- Children should be discharged 'as soon as socially and clinically appropriate';
- Children have a right to information appropriate to their age, understanding and circumstances.

However, these principles are not always put into practice. Recent research in Scotland found two children living in learning disability hospitals: one had been there for five years (31). There are anecdotal reports of others spending long periods in children's hospitals or children's wards in general hospitals. Children are also still going into hospital for short-term care. Children with learning difficulties have mixed experiences of staying in Scottish hospitals (8).

Noyes talked to 18 young people in England who were 'ventilator dependent' (32). Their rights, under the UN Convention on the Rights of the Child and the Patients' Charter, often went unmet. Other research has looked at the numbers and needs of children who are tube-fed at home (33). There is little or no information about the experiences of similar young people in Scotland. However, a new study supported by the Joseph Rowntree Foundation is identifying the number of disabled children with complex support needs resident in healthcare settings in central Scotland and north east

England. The researchers will also talk to 24 young people about their experiences in health care settings (34).

The Foundation has also supported research about children's hospices, focusing on four units in England (35). At present, there is only one children's hospice in Scotland, Rachel House: it has also been evaluated recently (36). Some of the findings from this study are similar to those in the English research but others are very different. Overall, a much more positive picture emerges of the Scottish hospice.

Employment and social security

Employment and social security matters remain the responsibility of Westminster: there are no differences between England and Scotland in employment law or welfare benefits. Therefore the studies by Kagan et al. (37) concerning working parents of disabled children, and by Dobson and Middleton (38) about the costs of childhood disability, have equal resonance north of the border. Parents in Scotland have reported that dealings with the Benefits Agency are generally difficult, with some families feeling the long complex forms are designed to 'catch them out' (8). The Learning Disability Review recommends that the Executive considers raising certain concerns about benefits with the Department of Social Security (9).

Post-school transitions

In 1998 the Department of Enterprise and Lifelong Learning in The Scottish Executive set up The Advisory Committee on Post-School Education and Training for Young People with Special Needs, known as The Beattie Committee. Its report (17) emphasised that inclusiveness is 'the single unifying principle' behind all its recommendations. The report said that young people do not want impairment to be an unnecessary barrier to learning but nor do they want it ignored. In May 2000, a National Action Group was set up, with a remit to help young people with physical, emotional or social difficulties access post-school learning.

The Foundation has supported two pieces of work around transitions - first, Bignall and Butt (39) spoke to 44 young black disabled people about independent living. Being independent - in the sense of having choice and control over their lives - was important to all of them: some were working towards achieving their ambitions, others had met barriers. Morris (40) looked at the transition to adulthood for disabled people with complex health and support needs. It was important to these young people to have information about their condition, to be able to go out with friends and, for some, to have access to communication equipment.

They needed both health and support services to achieve a good quality life, but services often failed them.

In one small-scale study (41), six young Scots (all white) with serious medical conditions talked about their quality of life. Like their English counterparts, independence, meaning choice and control, was important to them: all felt they had achieved 'mental' and emotional independence but some remained dependent on parents for physical care. As in Morris's study, even when living with their parents, these young people felt independent because they were making their own decisions. Overall, a more positive picture emerges of the support they received, including from health services.

Research in Scotland looking at the meaning of 'the learning society' for adults with learning difficulties suggests they face particular barriers moving into adulthood (42). These include difficulty getting paid work, the benefits system and social work practices. Being treated like children, lacking financial independence and spending a lot of time in segregated social settings made it difficult for these individuals to take risks, develop their own identities and achieve 'adult status'.

Hearing the voices of disabled children

Several studies supported by the Foundation, mostly carried out in England and Wales, have shown that professionals often fail to consult with children, listen to their views or involve them in decision-making. Children with limited verbal communication are particularly likely to be overlooked. There is little reason to suppose we are doing much better in Scotland. However, there are examples of innovative practice, such as:

- The parent-led Playback project, which has produced a video of young disabled children talking about their lives and the kind of support they do - and do not - want;
- The Young People's Person Centred Advocacy Project, based at AccessAbility Lothian and funded by the National Lottery Charities Board;
- A two-year project called *Social Inclusion of Minority Ethnic Children with Special Needs* run by MELDI (Minority Ethnic Learning Disability Initiative) which aims to produce 'multi-media' information packages for families. Among other activities, this involves making videos with school children and consulting them about the editing. It is funded by the Scottish Executive Innovative Grants Programme.

Two studies have recently been completed in Scotland, looking at the everyday lives of disabled children from their perspective. Watson et al. (43), whose research was

carried out in Scotland and the North of England, observed and talked to many children in mainstream secondary or special schools north of the border. They found:

- Children often experienced social isolation and bullying;
- There was a high level of adult surveillance in these children's lives;
- Social settings and adult behaviour labelled children as 'disabled' and different in a negative way;
- The children themselves had very varying views of what disability meant.

Research by Connors and Stalker (44) involved 'guided conversations' with 26 disabled children, aged from 6 to 15, and interviews with 24 brothers and sisters and 38 parents. This research looked at the children's daily lives, their likes and dislikes, their views of professionals and services, their understanding of disability and their future aspirations.

Conclusion

Although most research supported by the Foundation about disabled children and their families has been

carried out south of the border, it has many useful lessons for Scotland. Legislative differences relating to the two Children Acts should be borne in mind when reading some studies, as should the fact that race equality issues have not been recognised to the same extent in Scotland as in England. Looking at the Foundation's studies within the Scottish context has highlighted certain areas where information about disabled children seems hard to come by, such as the numbers and circumstances of children at residential schools, and where there appears to be some dearth of policy initiative, for example in housing. Relatively little research has been conducted in Scotland about disabled children and their families: this review has indicated various topics about which we should know more.

About this review

This *Foundations* was written by Kirsten Stalker, working as an independent researcher. Dr Stalker studied relevant policy and research papers and spoke to representatives of central government, various voluntary organisations and academics.

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- JRF *Findings* and *Foundations* can be found on the JRF website, www.jrf.org.uk. If you don't have access to the Internet, you can call 01904 615905 (answerphone for publications queries only).