



Interchange 75

Children's Experiences of Disability: A Positive Outlook



Why **Interchange**?

Research cannot make the decisions for policy makers and others concerned with improving the quality of education and services for children. Nor can it by itself bring about change. However, it can create a better basis for decisions, by providing information and explanation about policy and practice and by clarifying and challenging ideas and assumptions.

It is important that every opportunity should be taken to communicate research findings, both inside and outside the Scottish Executive Education Department (SEED). Moreover, if research is to have the greatest possible impact on policy and practice, the findings need to be presented in an accessible, interesting and attractive form.

Interchange aims to further improve the Education and Young People Research Unit's dissemination of the findings of research funded by SEED. We hope you will find that **Interchange** is long enough to give the flavour of the complexities, subtleties and limitations of a research study but concise enough to give a good feeling for the findings and in some cases to encourage you to obtain the full report.

The views expressed in this **Interchange** are those of the author(s) and do not necessarily reflect those of the Scottish Executive or any other organisation(s) by whom the author(s) is/are employed.

Copyright © July 2002, Scottish Executive Education Department
ISSN 0969-613X

Interchange may be photocopied for use within your own institution.

A limited number of additional copies can be obtained by writing to the Education and Young People Research Unit Dissemination Officer at the Scottish Executive Education Department, Victoria Quay, Edinburgh EH6 6QQ. File copies for electronic downloading are available on the Scottish Executive server at <http://www.scotland.gov.uk/insight/>

Children's Experiences of Disability: A Positive Outlook

Clare Connors (University of Durham) and Kirsten Stalker (University of Stirling)

Introduction

This Interchange presents the findings of a study designed to explore disabled children's understandings of disability, and brothers' and sisters' views about having a disabled sibling. The study was part of a research programme funded by The Scottish Executive and carried out at the Social Work Research Centre at Stirling University. The research lasted two years and was completed in August 2000.

Background

The starting point for the study was the Children (Scotland) Act 1995, which requires local authorities to design services to minimise the effects of disability on children 'with' and 'affected by' disability. The latter term includes the brothers and sisters of disabled children. However, we do not know very much about the effects of disability on children, particularly from the latter's point of view. Similarly, relatively little is known about brothers' and sisters' perceptions of the impact of having a disabled sibling. A good deal of earlier research has tended to pathologise disabled children and their families, with few studies speaking directly to young people to elicit their opinions.

The aims of the study were:

- to explore disabled children's understandings of disability
- to examine the ways in which they negotiate the experience of disability in their everyday lives
- to examine disabled children's perceptions of their relationships with professionals, and their knowledge and views of service provision
- to explore their aspirations for the future and their views on the type of support which might help achieve them
- to examine siblings' perceptions of the effects on them of having a disabled brother or sister
- to identify and draw out the implications for social work and health services.

The study drew on ideas from the social model of disability: this locates disability in the material, social and attitudinal barriers faced by disabled people, rather than an individual's impairment. The research also used insights from the sociology of childhood, which views children as active agents who play a part in shaping their own lives.

Methods

Considerable difficulties were encountered in constructing a sample of disabled children. The original plan to recruit families through schools proved largely unsuccessful: approaching voluntary organisations was more effective but also met with many refusals. In all, nearly 200 letters were sent, directly or indirectly, to families, resulting in 25 positive responses (the sample included two disabled siblings).

Parents suggested various explanations for these difficulties. Some parents may not have seen any direct benefits for their children from participating in the study. Others may have wondered why there was funding for research when they had difficulty securing resources for their children. These parents often have to deal with a large amount of paperwork and may have been unwilling to reply to 'another' letter. They also have high levels of contact with professionals, which can be time consuming and tiring. The only reason given by schools for their non-co-operation was that the study's focus on disabled children was not compatible with their 'inclusion' policies. (This was despite the fact that the research was to take place within the child's home.)

Careful attention was paid throughout the study to ethical issues, such as gaining children's informed consent. Before starting data collection proper, the researchers visited each family to talk over their involvement in the research, answer any questions they might have and ensure each member was happy to take part. This was also an opportunity to gauge the disabled children's communication style.

A series of 'guided conversations' was carried out with disabled children. The interview guides for younger children (7-10 year olds) were more structured than those for older children (11-15 years) and included a number of activities and exercises to hold the child's attention. Excluding the initial family meeting, each child was visited between one and three times, usually at home. Because the children had a wide variety of communication styles, data collection methods were adapted where appropriate. Some children used British Sign Language or Makaton, others preferred written materials, while one used facilitated communication. In two cases, where children had very high support needs, we relied on parental interviews instead. The children's brothers and sisters were interviewed once, as were their parents.

The 26 disabled children comprised 15 boys and 11 girls, aged from 7 to 15. They lived in urban, rural or small town settings across central and southern Scotland. The children had a variety of impairments and attended a mix of schools: 12 were at special school, nine in mainstream and five in integrated units.

Twenty-four of these children's brothers and sisters also took part. This number included 15 girls and 9 boys, aged between 6 and 19. Thirty-eight parents were also interviewed.

Two disabled children acted as advisors to the study. They met with the researchers on three occasions to discuss and advise on the research proposal, the interview guides and recruiting samples.

Negotiating Everyday Life

In their interviews, disabled children identified at least one thing they were good at. This was usually a school subject or sport. Some could think of nothing they found difficult; others named concrete or one-off incidents as difficult. Most children reported feeling happy all or most of the time.

Happiness was linked to:

- a sense of achievement
- good relationships with family and friends
- favourite activities.

Feelings of sadness were usually linked to a particular event, such as the death of a family member or a 'falling out' with someone.

All the children made some choices for themselves and most felt they had enough say in their lives. Some of the older children were taking on more responsibility for themselves, or working to persuade their parents to allow them to.

Relationships

Most disabled children saw their parents as key figures in their lives. While some parents were seen as over-protective, others were trying to help teenage sons and daughters achieve independence. The children also felt they had good relationships with their siblings, although arguments did occur. Several children said they were bullied by their non-disabled sibling.

The majority of the children named at least one child as an important friend. However, those attending schools outwith their neighbourhood had fewer friends at home than those who went to local schools. Children at out-of-area schools also found it difficult to be involved in after school activities, due to a lack of organised transport.

School

All but three of the children interviewed were positive about school; this was not related to the type of establishment attended. Most children saw themselves as helpful classmates and enthusiastic playmates.

Children at special schools were more likely than others to talk about their impairments unprompted. In at least one such school, children were segregated and referred to by impairment group, for example, one child described herself as 'a cerebral palsy' and reported that others were called 'the wheelchairs'.

Almost half the children reported being bullied, and this occurred in all types of school setting. A few also said they had been bullied within or near their home. All of these children were attending schools outwith their local community. Most children dealt effectively with a single incident of bullying themselves but, for a few, being bullied was a daily occurrence.

Dealing with Services and Professionals

Disabled children identified a range of professionals – GPs, consultants, nurses, physiotherapists, occupational therapists, social workers, teachers and Special Needs Assistants - with whom they had contact and about whom they were mostly positive. They had a very high level of contact with health professionals, notably through hospital admissions and clinic visits, but were frequently confused about the distinction between GPs and consultants. Parents were very clear about what constituted good practice from their GP. They were appreciative of GPs who:

- built up a relationship with their child over time
- spoke directly to her/him during a consultation
- addressed the child in appropriate language
- viewed their child as an individual and not an impairment.

“She’s one of the best sisters I could ever have asked for”

– a sibling

If parents thought their GP only viewed the child through the lens of impairment, they often chose to take the child directly to a consultant instead.

Most children spoke well of educational staff. Parental views, however, were not so positive. Many parents reported long-running difficulties securing inclusive education, and/or keeping their child in a mainstream setting. There was a sense of each child having to break new ground and evidence that the inclusive policies written on paper had not been thought through and applied to every aspect of school life. Thus, a child in a wheelchair had been accepted into his local school but was then left inside the building during a fire drill because there were no procedures in place to ensure his safe exit during an emergency. The attitudes of head teachers seemed to be critical for the successful inclusion of disabled children in mainstream schools.

“(He) can be quite good to play with. He can be rubbish”

– a sibling

Several children, and some parents, were unhappy about their Special Needs Assistants. Some had an adverse effect on inclusion, for example, removing the disabled child from her/his peers at lunch and play times; others were felt to have become emotionally over-involved with the child.

Only four families involved in the study currently had a named social worker. Two of these were dissatisfied with the service. Other families chose not to have a social worker; many reported considerable difficulty securing help of any kind from social work departments.

The most valued kind of formal support for families came from voluntary organisations. These were seen as providing a valuable and reliable service across a wide range of needs.

Short Term Breaks

Half the children were receiving short breaks in a variety of settings. While the children generally enjoyed these stays (except in hospitals), there was unease among parents and siblings. Several families felt they were forced to accept inflexible and/or inappropriate arrangements because there was nothing else on offer. This frequently resulted in short breaks being stressful for children, parents and siblings.

Sisters and Brothers

Siblings generally gave positive accounts of their relationships with their disabled brothers or sisters. The disabled children were frequently described as helpful, loving and kind. There were reports of arguments and conflicts but most of these seemed to fall well within the range of 'normal' sibling conflict. There was little evidence of siblings being expected to care for their disabled sister or brother: this was viewed as the responsibility of parents. Overall, siblings' and disabled children's responses about each other were very similar.

"She's really like any other normal ten year old. I don't see her as being deaf. I just see her as a normal child"
– a sibling

Difference

Most siblings talked about their disabled brother/sister in very 'ordinary' ways and where difference was perceived, it was seldom seen as negative. Impairment was accepted as an integral part of their sibling, whom they had no desire to change. There was a strong sense of disabled children being different but equal.

Impact

Unlike the findings of much previous research (a good deal of which has not sought siblings' views directly), most of the siblings in this study did not report that having a disabled brother or sister had a significant impact on their own lives. The majority did not say it curtailed their activities, although younger children may have been more affected in this regard. Receiving less of their parents' time was not identified as an issue by most siblings.

However, for some, the presence of a disabled sister/brother resulted in their being bullied or taunted in school. Some children had told neither their parents nor their teachers about this bullying and were trying to deal with it alone.

Support

Nearly all siblings in the study worried about their disabled brothers and sisters, particularly about their health and well being. Many felt they did not have enough information about impairments or medical conditions but were reluctant to ask parents for fear of upsetting them. In several families there appeared to be a conspiracy of silence around impairment.

Siblings received little support from formal services and while some had attended siblings' groups, there were mixed views about these. Several children had gained more from talking on a one to one basis with someone of or about their own age who also had a disabled sibling.

Children's Understandings of Disability

Disabled children tended to adopt an individualistic model of disability with strong medical overtones, possibly because of their high level of contact with health professionals. Disability was seen as something belonging to them, rather than the result of society's attitudes and physical barriers. When children used the term 'disability' they were referring to their impairment, usually as they described its effects, often medical, on their lives.

However, none of the children saw having an impairment as a 'personal tragedy'. Instead, they adopted a practical and pragmatic approach to their lives. Those children who attempted to explain the cause of their impairment did so in medical terms, religious significance and/or the fact that they were 'special'. This seems to reflect information given by their parents. It was closely reflected in siblings' accounts.

"...When I see people as they two are, I think 'Gosh' and I'm like glad I can walk and people see me and I walk like this and they say 'Great she can do that and we can't.'" – a disabled girl

Difference

None of the disabled children described themselves as intrinsically 'different'; rather, they focused on the 'sameness' of their lives and on the 'here and now'. The children were generally accepting of the presence of impairment and sought to manage it in active and effective ways.

However, there were times when the management of impairment by other people, or by institutions such as schools, created difficulties. Thus, children sometimes experienced disability by being made to feel different through other people's negative reactions and/or through physical barriers. A number of children recounted distressing experiences of the ways in which adults, both known and unknown, had treated them. This included staring at them, making inappropriate comments or being overly sympathetic. Most children did have mechanisms for dealing with such situations, ranging from understanding the reasons for it to openly challenging it.

Physical Barriers

A lack of access to social facilities was widely reported by disabled children and their parents. Older children experienced difficulty accessing public transport and leisure spaces such as fast food outlets. Some of the barriers children encountered seemed to be based on the view that impairment was something that happened to adults rather than children, whose needs were often ignored. For example, one boy found his local Shopmobility had no children's wheelchairs.

The Future

Disabled children and their siblings took an optimistic and pragmatic view of the future. All but one disabled child had a clear view of what type of job they wanted as adults. Younger children did not think they would need any support when grown up: older children recognised they would need some help. Parents' views about the future varied, but were generally more qualified and, in a few cases, pessimistic.

Summary

The picture which emerges from this study is of a group of disabled children who are devoted to ‘ordinariness’. They took a pragmatic and practical approach towards the management of their impairments, strove to be helpful sisters and brothers, good friends and enthusiastic classmates. In attempting these things they were, for the most part, supported by loving parents and accepting siblings. They also seemed to be well supported by the voluntary agencies they encountered. Support from other services, however, was more patchy.

Disabled children encountered barriers in the form of other people’s attitudes towards them and the excluding practices of institutions. While it may have been possible for some children to understand or challenge the hurtful attitudes of individuals, it was much more difficult for them to address the barriers within large institutions. Nevertheless, the children maintained a positive outlook and viewed the future with great optimism.

Implications for Policy and Practice

The findings indicate a need to encourage more open communication within families about impairment and disability, to ensure that children have accurate information and reduce any anxieties. Many siblings lacked opportunities to talk to other young people who also had a disabled brother or sister. More provision for informal peer support for children, whether on a one to one or group basis, is important.

The evidence that inclusive policies had not been fully thought through by some schools has training implications for management, teaching and auxiliary staff in all settings. This also applies to those special schools which seemed to be impairment-focused.

Although all schools should have anti-bullying policies, it may be helpful to review their effectiveness. The findings indicate the need for pupils to be taught to accept and respect difference from an early age. Parents could be encouraged to tell schools if their child has a disabled brother or sister, and teachers should be aware this could be a trigger for bullying.

Families would like social work services to be much more accessible. Other research has found the key-worker system to be a valuable resource for families with disabled children.

Families want flexible, reliable, well-planned and co-ordinated short breaks, giving their children a stimulating experience in a child-centred setting. It is important that short breaks are designed in a way that suits, and in some cases includes, all the family. There is also a need for more consistency of provision nationally.

Parents’ perceptions of ‘what makes a good GP’ could usefully inform GP training in this area.

There is a need for more social and leisure opportunities for disabled children, especially those attending out of area schools, and teenagers. This finding has

“That’s it, I’m in a wheelchair so just get on with it. Just get on with what you’re doing.” – a disabled boy

implications stretching far beyond service provision, and particularly for the commercial world, since many young people wanted to be able to access the same leisure venues as their non disabled peers.

“I think it would be better if they (disabled children) could join in with everyone else because they should be treated the same as everyone else and do the same things” – a disabled teenager on youth clubs

Similarly, the research confirms the need for a public education programme to foster more enlightened, positive attitudes in the general population about disabled people. This is intended to be a key task for the Scottish Consortium for Learning Disability.

The full report, of which this Interchange is a summary, is to be published in November 2002 by Jessica Kingsley Publishers as The Views and Experiences of Disabled Children and Their Siblings: A Positive Outlook. Further details can be obtained from Dr Kirsten Stalker, Social Work Research Centre, University of Stirling, Stirling FK9 4LA.

The Interchange series

1. *Homework Policy and Practice*
2. *School to Higher Education: Bridging the Gap*
3. *Teaching, Learning and Assessment in the National Certificate*
4. *Developing School Managers*
5. *Transition from School to Adulthood of Young People with Recorded Special Educational Needs*
6. *Discipline in Scottish Schools*
7. *Training the Trainers' Programmes: Effective Management and Monitoring*
8. *Introduction of the New Further Education College Council System*
9. *Young People's Experience of National Certificate Modules*
10. *Costs and Benefits of Adult Basic Education*
11. *Performance Indicators and Examination Results*
12. *An Evaluation of the Advanced Courses Development Programme*
13. *Staying the Course*
14. *A Study of Probationer Teachers*
15. *Making School Boards Work*
16. *Professional Development through Research*
17. *Students' Views on SWAP*
18. *Specific Learning Difficulties: Policy, Practice and Provision*
19. *Foreign Languages in Primary Schools: the National Pilot Projects in Scotland*
20. *Towards More School Based Training?*
21. *Patterns of Attainment in Standard Grade Mathematics 3-6*
22. *Patterns of Attainment in Standard Grade English 3-6*
23. *Implementing 5-14: a Progress Report*
24. *Education-Business Links: Patterns of Partnership*
25. *Foreign Languages for Vocational Purposes in Further and Higher Education*
26. *School for Skills*
27. *Effective Support for Learning: Themes from the RAISE Project*
28. *Marketing Means Business*
29. *Adult Education: Participation, Guidance and Progression*
30. *Studies of Differentiation Practices in Primary and Secondary Schools*
31. *Health Education: What Do Young People Want to Know?*
32. *Social and Educational Services for Children Under Five*
33. *Issues in Teachers' Continuing Professional Development*
34. *Primary Teachers' Understanding of Concepts in Science and Technology*
35. *Putting 5-14 in Place: An Overview of the Methods and Findings of the Evaluation 1991-95*
36. *Implementing 5-14 in Primary Schools*
37. *Implementing 5-14 in Secondary Schools*
38. *Provision for Special Educational Needs*
39. *Methods of Teaching Reading*
40. *Criteria for Opening Records of Needs*
41. *Guidance in Secondary Schools*
42. *Higher Grade Examination Performance (1987-1994)*
43. *Pupils with Special Educational Needs: The Role of Speech & Language Therapists*
44. *Evaluation of the National Record of Achievement in Scotland*
45. *Part-time Higher Education in Scotland*
46. *Educational Provision for Children with Autism in Scotland*
47. *Exclusions and In-school Alternatives*
48. *Devolved School Management*
49. *Implementing 5-14 in Primary and Secondary Schools: Steady Development?*
50. *Early Intervention: Key Issues from Research*
51. *Youth Work with Vulnerable Young People*
52. *Evaluation of the Technical and Vocational Education Initiative (TVEI) Extension*
53. *Cost of Pre-School Education Provision*
54. *Managing Change in Small Primary Schools*
55. *Baseline Assessment Literature Review and Pre-School Record Keeping in Scotland*
56. *Schools and Community Education for the Learning Age*
57. *Accelerating Reading Attainment: The Effectiveness of Synthetic Phonics*
58. *Teachers' ICT Skills and Knowledge Needs*
59. *Foreign Languages in the Upper Secondary School: A Study of the Causes of Decline*
60. *Practices and Interactions in the Primary Classroom*
61. *Providing Drug Education to Meet Young People's Needs*
62. *The Attainments of Pupils Receiving Gaelic-medium Primary Education in Scotland*
63. *The Impact of Information and Communications Technology Initiatives*
64. *Parents' Demand for Childcare in Scotland*
65. *Uptake and Perceptions of Early-years' Qualifications*
66. *Developments in Inclusive Schooling*
67. *Raising Attainment of Pupils in Special Schools*
68. *All Day Provision for 3 and 4 Year Olds*
69. *Pre-School Educational Provision in Rural Areas*
70. *Gender and Pupil Performance*
71. *Early Intervention in Literacy and Numeracy*
72. *Fostering and Secure Care: An Evaluation of CAPS*
73. *Early Education and Childcare Workforce Survey*
74. *Learning Gains from Education for Work*
75. *Children's Experiences of Disability: A Positive Outlook*

If you have views on Interchange and/or wish to find out more about SEED's research programme, contact the Education and Young People Research Unit, The Scottish Executive Education Department, Room 1B Dockside, Victoria Quay, Edinburgh EH6 6QQ



ISSN 0969-613X