



Disability Rights Commission

**DRC Research Report - Experiences of
disabled students
and their families: Phase 1**

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NOTE:

Pseudonyms have been used throughout the report when referring to participants.

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GLOSSARY

ABA	Applied Behaviour Analysis
ACT	Authenticity, Credibility and Trustworthiness
ASD	Autistic Spectrum Disorder
DDA	Disability Discrimination Act
DRC	Disability Rights Commission
FE	Further Education
GP	General Practitioner
ICT	Information and Communications Technology
LEA	Local Education Authority
LSA	Learning Support Assistant
PE	Physical Education
PMLD	Profound and Multiple Learning Difficulties
RE	Religious Education
SEN	Special Educational Needs
SENCO	Special Educational Needs Co ordinator
SENDA	Special Educational Needs Disability Act
SLD	Sensory Learning Difficulties

SUMMARY

This report outlines research funded by the DRC and undertaken between August 2004 and March 2005, by a team based at the University of Birmingham. The remit was to explore the educational experiences of disabled pupils/students and their families. This encompassed identifying (broadly) their concerns and priorities but also, importantly, identifying and trialling appropriate research methodologies.

Methods

Part 1 incorporated three approaches focused on child/family oriented work in two Local Education Authorities (LEAs) in England:

- 29 children/young people (spanning disability, age (7-19 years) and special/mainstream provision) were involved in in-depth individual or small group interviews (LEA 1) with methods adjusted to meet individual needs and preferences.
- 8 families were involved in in-depth small group interviews (LEA 2).
- In addition, 8 students (age 18-30+) attending a specialist further education college were involved in in-depth small group interviews.

Part 2 focused on survey work with national e-based samples of parents/carers of disabled children/young people. The survey, made accessible to 13 web-based organisations, elicited factual information about experiences as well as ratings of perceptions about autonomy, empowerment, inclusion and identity. The survey generated replies from 157 respondents, spanning England, Wales and Scotland as well as crossing disability groupings. Given the self-selecting sample, caution is needed not to over-interpret these findings.

Issues

The following main issues emerged in relation to the substantive issues around autonomy, choice and empowerment; inclusion and support; and personal identity:

- There is considerable enthusiasm for speaking/making their views heard across all groups (children, young people and adults) and a willingness to engage.
- The 'hidden economy' and non-conventional resources (eg community-based) are important in shaping educational opportunities and experiences for disabled children and young people.
- A significant minority (in terms of voice) of parents/carers of disabled children are educating those children at home.

Methods and methodologies

- There is a need for flexibility of methods to suit individual participants (child and adult) but given this flexibility and time, a very wide range of children and young people can share their views.
- Mixed methods and methodologies have considerable value in obtaining generalisability as well as depth.
- Sensitivities around the language of disability and SEN need to be recognised; these may be particularly salient for young people in secondary, particularly mainstream, schooling and this has implications for sampling.

1. REMIT

The implementation of the Special Educational Needs Disability Act 2001, and the duties outlined in the Disability Rights Commission's (DRC) Codes of Practice for Schools and Post-16 providers of education and related services (Disability Rights Commission, 2002a, 2002b) have presented a major new opportunity to challenge prejudice and discrimination, but also to identify, develop and affirm good practice in educational settings. Reflecting this context, the University of Birmingham was commissioned by the DRC in July 2004 to carry out phase 1 of a study into the experiences of disabled pupils/students and their families. This short term project (August 04-March 05) was a follow-up to two DRC funded projects (Gray, 2002; Disability Rights Commission, 2003c). In keeping with the adoption of various policy initiatives stressing the importance of accessing users', including children's, perspectives (UNICEF 2004, Welsh Assembly 2004) the project placed the views of disabled children and young people themselves at the centre of concern.

The aims of the whole project (ie phases 1 and 2) were to inform the education work of the DRC by:

1. identifying the barriers faced by young disabled people in education, and ways of overcoming these barriers
2. examining current/recalled experiences of education provision in relation to areas covered by Part 4 of the DDA
3. providing evidence of prejudice and discrimination, as well as good practice, in education
4. ascertaining that young people and their parents or carers associate with positive experiences of educational institutions
5. ensuring that full account is taken of issues relating to ethnicity, religion, social class and gender

6. identifying issues concerning devolution in England, Scotland and Wales
7. linking the findings from the research with those from previous DRC and other relevant research

The aims and objectives of phase 1 of this project were to:

1. Test and review a variety of methods for recruiting and consulting young disabled people in education and their parents/carers
2. Identify the most appropriate methods for recruiting a representative cross-section of participants
3. Identify the most appropriate and inclusive methodologies for exploring the views of a wide range of participants
4. Identify the key concerns and priorities for young disabled people in Great Britain in relation to their experiences of education, and explore their views and experiences as outlined in the overall project objectives – to inform phase 2 and set a wider research agenda
5. Identify key issues faced by the parents or carers of young disabled people in Great Britain in relation to experiences of their child's education, and explore their views and experiences as outlined in the overall project outline.

In keeping with the original brief and in discussion with the steering group we have paid particular attention to the methodological aims (1-3 above) while the work has provided indicative foci (aims 4 and 5) for a more substantial phase 2 project taking a stronger focus on the nature of views held by disabled children, young people and their families. This is shown diagrammatically:

PHASE 1 EMPHASES	Children and young people	Parents/carers
Methodological issues	In-depth focus	In-depth focus
Findings re disability	Indicative	Indicative
BOTH >>>> implications for Phase 2		

The structure of this report continues with the context to phase 1 (referenced to a brief review of relevant background literature), followed by a discussion of phase 1 findings and their implications for phase 2 in four sections:

- Indicative findings about disability themes
- Emerging issues concerning methodologies and methods
- Key findings- methods and sampling with children/young people, and
- Key findings- methods and sampling with parents/carers
- Overall conclusions and recommendations for phase 2

The appendices contain details of samples, sampling, methods and procedures; copies of key data collection documents; and a cumulative bibliography of relevant paper and e-based resources compiled during the course of phase 1 through the research team and DRC colleagues on the steering group.

2. CONTEXT: BACKGROUND LITERATURE

This brief review of literature relevant to the research undertaken utilises material presented in the research team's original bid to the DRC. During the period in which the research was undertaken the research team, together with DRC, has collated a detailed bibliography of direct and indirect relevance to the project itself. This bibliography includes over 130 references to policy, research and practice-focused literature. This literature encompasses international as well as UK perspectives and the policy-focused material draws on publications that cut across political initiatives and the work of various government departments.

A significant amount of this material is likely to be of value to the DRC, in terms of furthering its understanding of educational issues pertaining to disability and education. It is also likely to be of direct relevance to the planning of phase 2 of the project described in this report. To emphasise this point, a very recently published report by Emerson and Hatton (2005) which describes the nature of socio-economic circumstances faced by families supporting a child with physical/sensory impairments across Britain, has a strong resonance with findings in phase 1 of the research which indicate that a significant majority of disabled children and their families are hard for researchers to reach and ascertain their views. The explanation for this may, at least in part, be due to socio-economic factors, and phase 2 research will need to take account of these.

The bibliography also lists over 20 websites relevant to both phases of the research and to research and policy development more generally.

A review of this literature could usefully inform the preparation of phase 2 of the research project, and / or be part of the phase itself. The bibliography is included in Appendix 4 of this report.

The following sections on the research context, policy and change, and moving forward: educational change and the social model disability are extracted from the original research, and have been amended minimally reflecting the continuing relevance of the material presented.

2.1 Context

Evidence regarding the extent of prejudice and discrimination experienced by disabled pupils and students in education settings is substantial (Disability Rights Commission, 2003a; Disability Rights Commission, 2003c). Furthermore, the long-term effects of this prejudice and discrimination are particularly damaging and continue to sustain patterns of social and economic exclusion (Disability Right Commission, 2003b). These patterns permeate all phases of education, and clearly arise through the negative interplay between national policies and local practices, often in spite of good intentions. The Audit Commission (2003), for example, has highlighted how poorly coordinated are a range of services for disabled pupils/students and their families in different parts of the UK, and how quickly this leads to forms of educational and social exclusion. In a review study commissioned by the Disability Rights Commission, Gray (2002) also highlights the fact that many established educational policies and practices in schools and colleges fail to take account of important conceptual understandings of disability and their practical consequences.

Disability discrimination in education becomes particularly apparent at times of transition (eg when a pupil moves from primary to secondary school, or from school to other kinds of educational provision), and frequently leads to situations where pupils and students feel that they are entering a void, with no, or very limited educational opportunities that match their own aspirations (Down's Syndrome Association, 2004a). The consequences of this are clearly harmful to the individuals, but also a matter of profound concern to families and parents. In some instances 'discriminatory transition' may also lead pupils to move, inappropriately, to special provision (Pitt and Curtin, 2004), and unnecessarily reinforce educational segregation. In other instances, educational transition may lead to placement that is impoverished or poorly monitored (eg for some pupils and students who are 'looked after' or who have significant medical or mental health needs). In a recent survey by Ofsted (2003) evidence indicates that provision for pupils with medical needs is improving, but that it is still in need of significant development, and pupils who are not in a formal placement are likely to be particularly disadvantaged. In recent years access to higher education for some

disabled young people has improved, although patterns of participation are uneven (Prospects, 2002) and too little is known about the quality of their experiences and post-graduation employment opportunities. This may also be true of extended further education and opportunities to participate in training for employment courses and in adult education.

Finally, the educational and related experiences of black and minority ethnic disabled pupils and students (Diniz, 1999; Ali et al., 2001) have not been explored in any detail. However, the Disability Rights Commission and Centre for Education in Racial Equality in Scotland (2004) does provide an agenda for future research, policy and development work in this area.

2.2 Policy and change

The implementation of the Special Educational Needs Disability Act 2001, and the duties outlined in the Disability Rights Commission's Codes of Practice for Schools and Post-16 providers of education and related services (Disability Rights Commission, 2002a, 2002b) presents a major new opportunity to challenge prejudice and discrimination, but also to identify, develop and affirm good practice. Parallel guidance on planning duties for schools and local education authorities also provides a powerful means of improving access to the curriculum, environment and information at both institutional and authority levels. Monitoring arrangements (and rights of redress) supports the acknowledgement, at policy level, of the need to address disability discrimination. These should make it increasingly difficult – but not impossible - for education providers to ignore the rights of their disabled pupils and students. Early evidence concerning the implementation of the Disability Discrimination Act in England indicates that schools are struggling to comply with both the reasonable adjustments duty and the planning duty (Ofsted, 2004). Many LEAs too, are finding it difficult to comply with new legislative requirements, and are not providing schools with the clear strategic guidance or support that legislation was intended to bring about. Whether 'non-compliance' can be attributed to an implementation gap linked to the filtering down of national initiatives to the local level, or to ineffectiveness is unclear.

A further strengthening of disability rights in general is also likely to receive political support through the introduction of more comprehensive legislation (Joint Committee of the House of Lords and House of Commons, 2004) and lead to policy development designed to improve the life chances of disabled people (Prime Minister's Strategy Unit, 2004). More comprehensive legislation and clearer policy designed to challenge the exclusion of disabled people will inevitably ask questions of education provision and its role in ensuring that the aspirations of disabled pupils and students can be more effectively integrated into mainstream policy, design and delivery. Importantly too, new legislation and policy is likely to be informed by the social model of disability, as evidenced in the report of the Joint Committee referred to above (Chapter 2 of which discusses the importance of the model explicitly).

2.3 Policy and practice

As noted above, new policy, even when it is comprehensive and 'has teeth', does not always bring about the changes required, or does so at a much slower pace than anticipated. However, notwithstanding the problems of prejudice and discrimination experienced by disabled pupils and students, positive new initiatives are taking place in the post-SENDA era, and the impact of these should be acknowledged. Some of the contextual research already referred to does provide examples of institutional good practice and of good educational experiences of pupils and students. Two specific projects in progress, and supported by the Department for Education and Skills and the Disability Rights Commission, are examining the impact of 'reasonable adjustments' and 'accessibility planning' in England and seeking to identify good practice. The Department for Educational and Skills (2004) has also published accounts of disability and special educational needs work across English regions that outline innovative approaches to including the voices of pupils and students in all matters pertaining to their educational needs. Links between these projects, both of which are due to present published findings and recommendations in April 2005, and the project described in this report are likely to warrant careful scrutiny before a phase 2 is commenced.

Innovative resources are also being introduced to schools – both early years/primary and secondary – in ways that have the potential to challenge prejudice and discrimination through awareness raising, citizenship education (Disability Equality in Education, 2004a and 2004b; Disability Rights Commission, 2004), and to enhance the knowledge, skills and understanding of educators (Down’s Syndrome Association, 2003 and 2004b). The report by the Disability Rights Commission and Centre for Education and Racial Equality in Scotland (2004) on disability and ethnicity also provides guidance that could be more directly incorporated into educational practice. Although the use of the resources and the guidance referred to here do not fall within the remit of the phase 1 research, their incidental use will be noted where it is appropriate.

2.4 Moving forward: educational change and the social model of disability

Some of the innovative work referred to in the previous section is directly informed by the social model of disability and aims to challenge approaches to education that are still impairment-focused (Finkelstein, 1980; Oliver, 1983 and 1990). At the same time, as the commentary on context makes clear, policy and practice in education is still shaped to a significant extent by views of disability that are conditioned by an individual (or medical) model, either explicitly or implicitly. The social model of disability has, however, gained momentum in recent years, and increasingly influenced social and educational policy. In its application to education, the social model has become increasingly linked to the concept of inclusive education (Oliver, 1992; 1996) and its associated policies and practices. The social model has been critically appraised in recent years (Robertson, 2001; Dewsbury et al., 2004) and has evolved to take stronger account of the subjective experience of individual disabled people as well as the relationship between this and systematic oppression experienced by disabled people as a social group (Marks, 1999). It is now clearly considered to provide a robust and analytical way of understanding prejudice and discrimination experienced by disabled people generally, and by pupils and students engaged in formal and informal education. Political moves to incorporate the social model of disability into policy design and implementation (Joint Committee of the House of Lords and House of Commons, 2004; Prime Minister’s Strategy

Unit, 2004), and so to 'mainstream' disability issues, provide further evidence of its significance.

In a recent report published by Demos, Miller et al. (2004), emphasise the importance of the integration of disability rights into the political processes of the UK, and key legislative frameworks. They go on though, to caution against assuming that developments of this kind will address all of the inequalities that disabled people experience, in education and in all other spheres of their lives. They also express legitimate concerns about disability equality issues disappearing into the 'fog of implementation' (p.71) in which bureaucratic practice serves merely to lessen, or to neutralise, equality and to reify homogeneous assumptions about disability. To resist this process, new understandings and alliances need to be established between various parties involved in the provision of services for disabled people, and disabled people themselves.

Without this next 'step change' in policy and practice, prejudice and discrimination are likely to be maintained, less visibly perhaps, but certainly in spite of legislation. Any research in this area needs to recognise these complexities, to identify the multiple perspectives brought into play by different groups of people involved and to seek common ground for social change, as well as drawing attention to inappropriate and illegal behaviour.

As a footnote to this brief review of background literature relevant to the current study, it is worth noting that the key research themes developed to provide a conceptual framework for the empirical work undertaken and the analysis of it can all be interpreted in terms of the policy and practice issues identified in this review. Wider, and perhaps deeper concerns about whether disabled children and young people are increasingly engaging with the world in ways which are characterised by the lack of choice and 'new mobility' (Urry, 2003; Hughes, Russell and Paterson, 2004) that many of their peers experience is a continuing challenge, and one that phase 2 of the research might valuably take up.

3. THEMES CONCERNING DISABILITY

Issues concerning disability are discussed under the three main themes of: autonomy, choice and empowerment; inclusion and support; and identity. These themes, which emerged as significant through the research process, were derived from a wider set of issues identified as warranting exploration by the project steering group. These focused on student experiences, and those of their parents/carers, of:

- curriculum and assessment
- policies and rules
- procedures and processes
- admissions
- choices
- aspirations
- transition and transfer.

In each of the following sub-sections, a summary discussion is given relating first to the views of children/young people and then to the views of parents/carers. Finally key conclusions and implications for phase 2 are given in each of these sub-sections.

Note - in the following sections, relating to the views of parents/carers, the responses based on a six-point scale are summed across the top two categories and bottom two categories to provide a clearer indication of the most and least frequent answers. Unless stated otherwise, the percentages quoted are based on the total sample of 157 responses. (See appendix 1 for notes on design and appendix 2 for details about samples and sampling of children/young people and parents/carers.)

3.1 Autonomy, choice and empowerment

Opportunities to act autonomously and to make choices are key to enabling children, young people and their parents/carers feel empowered and able to determine the direction of their lives. Children and young people involved in this study, regardless of the kind of educational provision they attended, recognised and articulated this. They acknowledged the difficulties and tensions that striving for greater

independence could involve, and highlighted the value of appropriate support provided within formal educational contexts.

Parents, with a few exceptions, found it extremely difficult to identify with the idea of educational choice. Instead, they described a struggle to access appropriate educational provision for their children. They also identified key barriers to accessing and sustaining this provision. Some parents 'reluctantly', had become empowered advocates for their children, usually because (reportedly) professionals had failed to take on this responsibility.

Views of children/young people

Young people attending college strongly emphasised the independence they needed to learn, and were now experiencing. Specific reference was made to the importance of, and struggle to become independent from parents:

'It wouldn't have worked [mainstream college] because I wouldn't have broken the shackles of being away from my parents.'

This transition wasn't easy, and sometimes involved young people feeling homesick, getting used to a new culture, and having to be much more independent than before, doing things like washing, things that parents used to do. However college, for both day and residential students also offered these young people opportunities to make decisions about their learning, and about their social lives. These opportunities were most positive when students received appropriate, but not overbearing support (cf 'over-parenting') from enablers, support and care workers. Support mattered.

Students leaving special schools made similar points about the independence they need to learn to 'move on' in life:

'I'm independent I can do most things myself. I like the help [at school] and I don't like the help. Because I like to do things for myself. They encourage you to be more independent at school. [I] feel different at home because people [there] they don't listen like they do here goes in one ear and out the other. Upsetting really. [I] do more things at school because I'm 18 now I'm an adult. Sometimes doesn't feel like I'm being treated like an adult at home. Here it's just better. It's harder at home. Fair enough my Mum brought me up to be independent. If it wasn't for her I wouldn't be as independent as I am now. But she still doesn't listen to me. That's mums for you!'
(Cathy, age 18, special school)

Cathy's final comment is a reminder that her views may well be echoed by many young people in her age group, regardless of whether or not they have a disability. Interestingly, Cathy's mother's comments (in a telephone interview) endorsed Cathy's view but also drew attention to how 'difficult' she had found Cathy at home. This may have reflected Cathy's acting as a carer for her mother:

'I used to do a lot at home. I'm not sure whether this is to do with what you're doing. But I used to do a lot at home. For my Mum cos my Mum's a diabetic ... She gets ill. What it was. I was so busy helping my Mum cos she's diabetic. Helping my Mum doing the housework then coming back here doing my work all the time doing same thing over and over. That made me ill. They wanted to put me on tablets. But I said no and in the end I had to talk to my Mum about it. And I said - look I can't do everything here and do everything at school at the same time. And she started getting upset with me ... When I told her. She's a brilliant mother but she didn't listen to me. I really get angry with her, shouldn't be the way. You got to say it.'
(Cathy)

Opportunities to express and carry out choices were very much in evidence, and students (in FE college) expressed the view that they made decisions about their academic and social lives, but with helpful and not oppressive guidance.

This had helped one of the students to 'come out of my shell', and develop new confidence following experiences of bullying at a mainstream school in the past, and a period of being lost 'in a hole' during an unintentional gap year. Another student, after a period of homesickness felt the college had really helped her to get her independence back. Other students too, emphasised how college had helped them to become more confident socially and academically. It felt like a friendly, supportive place, and one where students could leave behind difficult experiences and renegotiate the way in which they related to their peers and the staff who worked with and supported them. In two instances, students described how helpful it had been to have their dyslexia identified and assessed for the first time. One of these students commented:

'I think, now I know and can get dyslexia support and things then, things are a lot easier.'

Schools are being encouraged to develop school councils as a way of demonstrating respect for pupil choice, autonomy and democratic processes. However there was little support from children for, and even apathy towards, school councils and they were not mentioned by parents.

A recurrent issue in debates about inclusion concerns the likelihood that special school placement will mean longer daily travelling distances for the child between home and school. Such difficulties were mentioned frequently by children in this situation as a barrier to greater involvement with peers, a disliked experience and one over which they had little control:

'I don't mind it [coming to school by taxi] but he [taxi driver] listens to foreign music. He comes from a different culture. He speaks a foreign language... It's not good because he might be swearing... I like a bit of his music but you have to listen hard.'
(Richard, age 10, mainstream primary school).

One parent drew attention to the importance of not giving children with ASD/ autism a choice:

'If he [son with autism] is given a choice he can't cope; he has to have everything fixed ... so we [parents] have visited lots of secondary schools. Then we told him 'that's the one' when we'd decided.'

Views of parents/carers

From a total of 157 responses in the survey, 41% of parents/carers said they had little or no choice about the school/college their child attended whilst 35% said they had lots of choice on this aspect. However, indications about level of involvement in making educational decisions was higher with 46% saying they had been very involved and only 23% suggesting they were not very involved. An almost identical proportion of respondents (47% and 23%) said that they had/had not been involved in appropriate discussions about the education of their child/young person respectively. It should be noted though that combining across the two 'middle' categories and the two 'lower' categories on this question, exactly half of all respondents (50%) indicated reduced levels of involvement in discussions. It is also important to note that the sample of parents/carers responding to the survey were self-selecting. Thus, the results are indicative, rather than necessarily representative, of key issues.

Table 1 below (see appendix 3f for survey question wording) shows that parents of children in special schools felt more involved in decisions about their child's education than did parents of children in mainstream/ mix of special and mainstream provision.

Table 1: Type of current educational provision x q. 2.2 - parental feeling of involvement (3 way) Cross-tabulation
(n=143; excludes parents of children not at school/college)

		Very involved	Medium involvement	Little involvement	Total
Mainstream	Count	25	22	16	63
		39.7%	34.9%	25.4%	100.0%
Mix of special and mainstream	Count	10	8	7	25
		40.0%	32.0%	28.0%	100.0%
Specialist eg special school	Count	35	13	7	55
		63.6%	23.6%	12.7%	100.0%

In terms of whether parents/carers felt their involvement in decisions had been worthwhile 53% indicated that it had, and 22% said it had not, been worthwhile. Fewer parents/carers indicated high levels of involvement in decisions about support offered to their child/young person (36%). Again, combining across the two 'middle' and 'lower' categories a total of 60% indicated lower levels of involvement in decisions about the type of support offered to their child/young person.

Perhaps unsurprisingly, 99% of parents/carers said they should be involved in these decisions and many chose to expand on this point (86% or 135/157). Many explanations said that parents/carers needed to be included much more in all decisions concerning the education of their child/young person especially around where the child is placed and what kind of support is available:

'... We know our son better than anybody but we don't know the full range of resources available to help him.'

In open-ended comments, it was clear that some parents were frustrated by the lack of support provided by their LEA and the failure of the system to take their views and experiences seriously. Some parents/carers felt they were/had been involved in battles about decisions on educational

placement and the type/level of support offered to the child/young person, including involvement in tribunals for some:

'I should be invited to be involved with everything not have to fight to be listened to when I know him best.'

'Every meeting we have involves lip service and banging my head against a wall.'

A noticeable sub-group of these parents indicated that they had removed their son/daughter with an Autistic Spectrum Disorder from mainstream schooling because of a range of difficulties experienced. These children were now being educated at home. The strength of feeling from this group was transparent with a clear need to consider the needs of children/young people being educated at home if they have been removed from the state system:

'Why were we [parents of home educated disabled children] not included in the survey? Why did we have to unearth it ourselves? Will our views be included? Or are our children to be brushed under the carpet again?'

Parents/carers were also asked about the involvement of the child/young person in discussions and decisions about their future, as well as about people who had been particularly helpful in discussing their children's needs. 48% of parents/carers said that their child/young person had not been very involved in discussions about moving between schools compared to only 20% who indicated high involvement. Similar proportions (46% and 22% respectively) said their child/young person had not, or had, been involved in discussions about their future plans. 50% of respondents reported low satisfaction with the level of support available to help the child/young person make decisions with only 13% reporting high levels of satisfaction in this area.

Almost two-thirds (61%) of respondents said that there was a specific person/group of people who had been particularly helpful in discussing the needs of the child/young person at school/college. In the main, specific teachers were mentioned here as well as parent/charity/online

groups providing support for children/young people with specific disorders (eg National Autistic Society).

Respondents were asked whether there were any aspects about getting to/from school/college that affected the child/young person's access or involvement; 57% said 'no' and the remainder (43%) said 'yes'. In explanations, (and supporting children's views, see above) many parents/carers voiced unhappiness with their current provision of transport or the lack of it, which sometimes meant that they had to take the responsibility on themselves. Other frequent themes were the inflexibility of the timing of transport services and the lengthy, isolating nature of some journeys, which resulted in children/young people being excluded from peer groups and after school activities:

'I have to take him a long way as our local school is VERY un-inclusive – and we cannot have taxi transport as he goes to this school out of MY choice. This makes after school socialising impossible.'

'Inflexible LEA transport policy will only take children to and from school at beginning/end of school day. This effectively excludes them from taking part in after school activities.'

63% of respondents also said there were no aspects about being at school that affected their child/young person's involvement/access, whilst the remainder (37%) said that there were difficulties. Again, comments tended to reflect a lack of support available in the school environment to adequately cater for specific needs, whether in the form of appropriate understanding, resources or teaching support.

Over half (61%) of parents/carers said they were very aware of how their child/young person's progress is assessed with only 12% suggesting a low level of awareness. Whilst some parents said they received good communication from the schools about progress and assessment, others noted that formal assessment procedures seem to have limited relevance for their child/young person:

'Exams and tests are limiting and often of no real value in assessing anything worthwhile about a child's abilities or skills.'

When asked what had been most helpful in enabling their child/young person to make progress some respondents praised specific teachers or practices (eg home-school book), for example:

'Consistency of staff, staff experience in learning difficulties, small classes, intensive support. Excellent rapport with the children. Feeling included (special school).'

It was evident from comments provided that parents/carers felt that adequate support was provided in contexts in which teachers and other school-based staff were informed about individual needs and had a good understanding of the disorder or particular challenges faced:

'[Most helpful] was the school's understanding of her complex needs.'

In terms of what had been least helpful in enabling their child/young person to make progress, a few parents/carers mentioned the child/young person themselves: 'their own medical/psychological problems', but a substantial number of comments reflected a disenchantment with professionals, whether it be the LEA, educational psychologists, occupational therapists, teachers and a general lack of understanding about specific needs. Clearly, there is a large perceived gap between the 'real world' everyday understanding that parents feel they have about their own children/young people and a lack of awareness by professionals, sometimes evidenced by a reported failure to take parents' views/experiences into account:

'People ['professionals'] who think they know everything.'

'The attitude of teaching staff which ranges [with rare exceptions] from indifference to hostility'

'The communication problems. They never actually listen to what parents say.'

Finally, in 'any additional comments' at the end of the survey, there was a sense in which policies for including children with physical/sensory

impairments in mainstream schools had been unsuccessful, or were unpopular, with many parents/carers. This was again reflected in comments about lack of understanding by teachers and the 'system' in mainstream settings in relation to the needs and behaviours of children with physical/sensory impairments:

'It is ironic that while mainstream schools are being urged to specialise etc and successful schools use clandestine methods of selecting their pupils, those of us who have children in special schools are being made to feel guilty that we are segregating our children, depriving them of the experience of going to failing mainstream schools [that other kids' parents have rejected] that have surplus places and no choice let alone any expertise in meeting the needs of children with complex special needs. This is not a plea for poor special schools but a robust defence of high quality specialist special schools. Give us the choice; this is an issue of disability rights. Inclusion is not just a one size fits all.'

The large majority of respondents were from England but we did receive responses from parents in Wales (10) and Scotland (8). Given the very small comparative numbers, intra-GB comparisons can only be made very cautiously. However there are some signs that the Scotland respondents were proportionately, more involved and more likely to feel this was worthwhile. Given the different, and increasingly divergent SEN policies across these three countries, the possible differences warrant systematic investigation. The following tables illustrate the differences with reference to the extent to which parents felt involved in decisions about their child's education and how worthwhile this involvement was felt to be (note-excludes respondents who gave no, generic eg UK, or non-GB, country).

Table 2: Where do you live? Please state your country of residence x q. 2.3 - involvement in appropriate decisions (3 way) Cross-tabulation. n=148

		Very involved	Moderate involvement	Not involved	
England	Count	66	33	31	130
		50.8%	25.4%	23.8%	100.0%
Scotland	Count	5	3		8
		62.5%	37.5%		100.0%
Wales	Count	3	4	3	10
		30.0%	40.0%	30.0%	100.0%

Table 3: Where do you live? Please state your country of residence x q. 2.4 worthwhileness of involvement (3 way) Cross-tabulation n=148

		Very worthwhile	Moderately worthwhile	Not worthwhile	
England	Count	77	26	27	130
		59.2%	20.0%	20.8%	100.0%
Scotland	Count	4	3	1	8
		50.0%	37.5%	12.5%	100.0%
Wales	Count	3	3	4	10
		30.0%	30.0%	40.0%	100.0%

Parents participating in focused group discussions acknowledged the importance of helping their children to become more independent, recognised difficulties they might have in 'letting go', but also noted that future security for their children was important, and maybe more important than anything else. They emphasised how autonomy could only realistically be achieved when good support was in place, and when the school curriculum took account of the basic needs of their children.

All of the parents in the discussion group highlighted how they had to drive all decision-making processes if they were to lead to successful outcomes. Relying on professionals was characterised by concerns about how much they really cared and, how competent they were, and systemic ineffectiveness. They had learned to do things for themselves. As one mother put it:

'I've got the diagnosis for my daughter not the school not the LEA not the doctor ... I've got it done it. I knew the label would mean money to support her.'

The struggle for choices – on behalf of their children – was regarded as a battle by these parents, one they didn't enjoy, but one they were determined to fight *and* win. They recognised though, that this determination was unusual, and that a much bigger 'silent majority' of parents just took what was on offer for their children, either because they were much more accepting of service provision or because they did not have the confidence to express their concerns.

These parents, through their 'own tenaciousness', as one father put it, had found help in getting what they felt their children needed. Often, helpful support and advice came through informal networks involving family, friends and education professionals they valued (eg a SENCO, headteacher, or a teacher they liked).

Parents in the discussion group said they had experienced major problems trying to get the right choice of educational placement for their child. The situation was really one in which choice was seen to be political rhetoric as this comment emphasises:

'What's out there. Choice! There's only one place.'

Choice at a very personal level mattered to these parents, choices that their children were learning to make:

'Shaun (5 years old) has a choice about ... We always ask him if he wants to take his chest medicine.'

Bigger choices about what's the best school, or the next school for a child to move to; these choices were considered to be important, but not because choice itself was so important. What the parents wanted was good provision of a kind that could effectively address the needs of their child. The search for this involved struggle again:

'Now the cycle is starting again [looking for a secondary school] and no one is advising saying what's needed. We are doing it. Making the decision saying what's needed the transition.'

Formal LEA support, excepting some helpful advice from the *Parent Partnership Service*, was not considered to be of much use. However, these parents had developed powerful strategies for getting things done. One mother said:

'I sat in the [LEA] review and said 'I'm not leaving until you tell me which school you would send your child to' and in the end they agreed and told me the school they thought to be best.'

Another mother said that when discussions were taking place about the need for her son to be statemented she pulled out a photograph of him in the meeting and told them, 'that's the person we are talking about here', knowing it was underhand, 'but you have to do it to get the right thing done. The money you see, is the driver, not the child'.

In the context of this discussion, talking about disability rights was considered to be something that should not be necessary. Some more basic things needed sorting out.

The group felt that their children didn't always access curriculum activities, but they advocated making changes to the curriculum itself:

'The school was fantastic had a good ethos and wanted to include him. I realised he needed more not just literacy thrown at him all morning. The speech and language work was not there. It wasn't right no matter how good the school was. So I put him in a special school. He gets daily speech and language and it's going in but in mainstream it is just bang bang bang.'

They also said that joining in after school activities just wouldn't happen unless they provided the support (eg for swimming). They expected to organise and provide this, and to go into school to provide help too. One mother though, emphasised that parents do everything and should not be doing the school's/LEA's job:

'I've not gone down that route – LEAs need to do that [provide in school support]. I've put enough of my life on hold to do everything else for my children. School hours are the only ones I've got ... the LEA need to cover these. Would they ask that of a normal child ... We are filling in the education and care gaps. We are an extra resource for them and they know it. I know other parents fill in when needed. I won't do that'

3.2 Inclusion and support

Views of children/young people

Disabled children and young people are entitled to educational experiences that are inclusive, and to the kind of support that enables these experiences to be academically and socially beneficial. Children and young people in this study expressed complex perspectives on the value of inclusive educational (mainstream) placements, indicating for example, that specialist provision could enhance opportunities for long-term social and economic participation. They also highlighted how specific problems like bullying made the experience of inclusion a negative one. Children in schools, and older students attending college valued the support they received from specific members of staff, support which helped them overcome particular difficulties and which gave them confidence.

Many parents/carers were satisfied with the educational provision made for their children. They highlighted the good quality of support received from key members of staff and the welcoming ethos of particular schools. However, many others reported the significant exclusion of their children from some areas of the curriculum, and from a range of after school activities. Inclusion in some of these activities could only take place when parent/carers provided the support. Parent/carer views on the respective value of mainstream and special schools were wide ranging. A small but significant group of parents/carers were so unhappy with the educational provision available that they had decided to home educate their children, arguing that the quality and quantity of expertise and support was completely inadequate.

Particular teachers, support workers or facilitators were seen by most of the children and young people, attending mainstream or special schools, as a source of valued support:

'I do definitely like my [special needs] tutor. ... that's quite a happy thing actually because teachers are just like friends.'
(Gemma, age 11, mainstream secondary school)

However informally, schools sometimes expressed anxieties about the use of facilitators leading to a lack of 'breathing space' for children with special needs/physical/sensory impairments. Again, the contrast with established practice in the further education context is noteworthy. This issue is considered further in relation to methods of exploring the views of supported children (see 4.4, pp. 55-56).

Bullying (in and out of school) was reportedly a recurrent issue across most age groups and physical/sensory impairments; it featured in the accounts of children/young people as well as (see below) parental responses. The cause of the bullying was not explicitly related to disability:

'I do get picked on sometimes. But bullying is just like, it's just like for everyone ... it's just like, in my old school in _____. I shouldn't be speaking about _____, there was like this really nasty girl in there and she used to stand on your feet. She was very big as well and she used to be a real bully so, that's why. [Why did she pick on you? Did she pick on other people as well?] No just me because she knew that I would not have started a fight. Because I am a bit of a whinge baby. But I used to go to a teacher but she used to say, 'sorry but there's nothing to say about that' so ... didn't do anything. That's fine actually, I don't really care.'
(Gemma, age 11, mainstream secondary school)

'[Why do they bully you?] Well, it's because I fell out with my friend and now they don't want to be my friend because I fell out with her... they leave me out. And I just want it to stop. There's a girl that keeps on bullying me. She does it every time. But every time Mrs Y [headteacher] tells her off she keeps on doing it. [Tell me about the people that are bullying you.] One's a boy and some of them are girls in Year 6 or 5 girls. I talk to Mr L [teacher], I talked to Mrs G [teacher] and she didn't do anything but I think Mrs Y [headteacher] did do something about it. To sort it out. They get three warnings and if they don't stop then a letter goes home to their mums. I don't want to be their friends, I just want it to stop. Sometimes I feel sad about it. Last week I didn't want to come to school and I felt sad and I told my mum but she didn't do nothing about it because she can't take it into her own hands. She don't know what to do but she rung up. [Do you have other friends who get bullied?] No but they just look at them and say, what you hanging around her for? So they don't really get bullied; they just sometimes stick up for me.'

(Claire, age 10, mainstream primary)

More positively, as in Claire's account, the importance of friends was notable in providing a bulwark against bullies and other threats. This position was reinforced in the survey (see below). In both these areas our interviewees may have been reflecting positions no different from those of non-disabled classmates. We did not work with non-disabled child participants and it is important not to assume disabled/non-disabled differences.

In recalling experiences of mainstream education, some of the students attending the further education college commented specifically on the verbal and physical bullying they experienced:

'And I got bullied there and naturally I fell behind in my work ... because I had epileptic seizures ... this girl had hit me over the head and I went straight into a seizure.'

'[Being in mainstream] I didn't like it there. It was something I wasn't used to. I think it was because I used to get a bullied a lot.'

Other students reported better much better experiences:

'It was really good ... because the help I got was absolutely brilliant.'

A number of the special school pupils expressed misapprehensions and mixed feelings about mainstream schools as in the following extract from Cathy (age 18, attended special school, physical disability) and Tracey's (age 17, attended special school, cerebral palsy and severe speech difficulties) discussions with the researcher:

Cathy	[to researcher] Do you go to many schools where there are not disabled people?
Researcher	Yes.
Cathy	Do they say anything about disabled people?
Researcher	They say the same sorts of things as you've been saying really, that they want to be with disabled people; that they think disabled people are the same as them.
Cathy	That's sort of shocking really.
Tracey	Yes that is shocking!
Cathy	That's shocking really I think because some people [are] really nice but some people won't give you the time of day. Some people can't.
Tracey	Some people don't want to.
Researcher	But increasingly you've got children coming up through schools where there's been disabled children in their own classrooms.
Cathy	Sometimes I wonder whether I would be able to cope in a mainstream school. I think I won't [uncertainly] I won't.
Researcher	What do you think, on balance, you could or you couldn't cope?
Cathy	I think I could but I think.
Tracey	I don't know really.
Cathy	But then I think about, I worry about all the homework, because this school here didn't give me as much homework, in a mainstream school it is your homework you have to do it every time like normal. We have our study periods here, to get it in in time we don't have to do it at home, because many of the students here have difficulties in getting help, from their parents, or their

	parents can't do it because they're busy, then it's good to have the support here. Then you've got your own time and you've got the staff to help you as well and that's good
Researcher	But are you missing out on things in mainstream?
Cathy	Yes.
Tracey	I don't.
Cathy	You are really because here you can't go out. You can't, you've got to be on the school grounds. It comes to quarter past 3 and you've got to get on the bus to go home but here we've got to stay here on our breaks but in a mainstream school they can go out on their breaks and come back in but you've got to make sure you're in at a certain time and it's harder and I can understand it's harder because we're in a wheelchair and its not very ... can't get around that easy ... that's the main thing.

The views of young people attending the further education college about special and mainstream education were completely undogmatic. These views perhaps reflected the complexity of their school experiences, some of which involved moving between special and mainstream sector provision. At the same time, moving to a specialist college provision was regarded as a positive move forward and one that broadened academic and social horizons. In some instances this followed some difficult experiences at school, but also some significant problems of educational transition before re-engaging with formal education:

'I spent a year doing nothing. Then I had a job for two years working with young kids. [The] fact that my brother had started going to university ... I thought I would like to do what my brother's doing.'

'I came here, which was about three years ago now. Then I left after two weeks because I didn't like it. I just felt homesick ... I didn't have much experience of being away from home. It was then a year of doing nothing. And then I reapplied and got back here.'

Reflecting more widely on inclusion, the students highlighted the value of enabling support of a kind that impacted on all areas of life. This was something that had not always been available to them during their earlier

experiences of mainstream school. The 'politics of inclusion' were not strongly emphasised by these students. One of the group saw rights as being 'what it says on the tin', important, but not linked to his everyday educational experience which he regarded as excellent. Another student reflected that:

'Times have moved on; at that time [ten years ago] there wasn't that much disability awareness I don't think that [disability awareness] has particularly moved on in any way shape or form because people still come up to me in the street and talk over me.'

The view of the students indicated that they regarded their college experience as an inclusive one, not without its problems, but more inclusive than had been some of their other educational experiences.

Views of parents/carers

In terms of any extra support provided for the child/young person, 67% (106) of the respondents indicated that they received at least some level of extra support (note that respondents could tick more than one option in this section so the totals reported for each type of support mentioned does not equal 100%). 35% (37/106) indicated that their child/young person had a full-time helper; 38% (40/106) some part-time help and 35% (37/106) received extra support from a specialist teacher. A minority of respondents said that peers provided some in-school support (11% or 12/106). However, see below, concerning a more general question (2.14) about peer support.

Almost a third of the sample (32%) did not answer this question, possibly indicating that either the answer to the question was not known or that the child was not receiving any additional support at school/college.

The next questions in this section considered the range of activities and the support on offer both within and out of school. 59% of respondents said they were not satisfied with the range of after school or lunchtime activities on offer, with only 20% saying they were satisfied. The small number of respondents from minority ethnic groups provides some indication of possible cultural differences concerning expectations and

wishes around support. This was illustrated in a telephone interview with an Asian mother of a disabled boy. She explained that she would not use respite care facilities despite the strain which the need for constant care and vigilance placed on the family:

'He has a place here; if he is not here there is a gap in our family; he belongs here; he has his space.'

There was a higher level of satisfaction in relation to the support on offer to their child/young person if they experienced difficulties at school with 47% of parents/carers saying they were satisfied and 31% not satisfied. A higher proportion of parents/carers (61%) were less satisfied with the level of support available outside of school/college if their child/young person experienced any problems – only 11% of respondents said they were satisfied. One parent (a 66 year old father of a 19 year old young man with learning difficulties, autistic patterns of behaviour and profound deafness) gave, in a telephone interview, a particularly vivid account of his son's need for external support to sustain his autonomy and self-respect. The young man's father explained that he took his son to the discos because no one else would do this but the father felt rather conspicuous doing so and that he seriously hampered his son's ability to blend in with peers in that situation.

This account was endorsed by the high proportion of parents/carers who indicated that the level of support available to their child/young person influenced the activities in which they took part within (64%) or outside (63%) school/college. Only 18% and 20% of respondents said that level of support did not affect activities participated in both at and outside of school, respectively.

The sample was fairly evenly split between those who said their child/young person had or had not been bullied in the previous 12 months (42% and 58% respectively). The level of reported peer support was not strong in either direction with roughly a third each suggesting good (27%), medium (36%) or low (34%) support from peers. However there were some interesting relationships when we sub-divided these data by type of provision attended. There was, in parental views, more peer support for children attending mainstream compared with special settings and least

support in mixed placements (see table 4 below). It is possible that this reflected in part peer support from children in the neighbourhood (in contrast to question 1.5 which asked explicitly about additional support in school and found few reports of peer support).

Table 4: Type of current educational provision x q. 2.14 –extent child supported by friends (3 way) Cross- tabulation (n=143, excludes children not at school/college)

		Strong support	Medium support	Little support	Total
Mainstream	Count	23	25	15	63
		36.5%	39.7%	23.8%	100.0%
Mix: special and mainstream	Count	4	6	15	25
		16.0%	24.0%	60.0%	100.0%
Specialist eg special school	Count	15	22	18	55
		27.3%	40.0%	32.7%	100.0%

There was a strong association between absence of reported bullying and reported support from peers (and vice versa) providing evidence for the face validity of this survey. For example, only 14% of parents who said their child had been bullied in the previous 12 months, reported that the child had good support from friends; 46% of those parents said that support from friends was poor. Conversely for children who had not been bullied 39% had good support from friends.

Table 4: ‘Has bullying by other children/young people been an issue for your child in the last 12 months?’ X q. 2.14 – extent to which child had support from friends (3 way) Cross-tabulation. N=157

		Good support	Medium support	Low support	Total
Bullied? No	Count	35	31	25	91
		38.5%	34.1%	27.5%	100.0%
Bullied? Yes	Count	9	27	30	66
		13.6%	40.9%	45.5%	100.0%

Just over three-quarters of respondents (78%) said that there were areas of the curriculum that were harder for their child/young person to access than others. Explanations included a wide range of specific aspects of the curriculum (eg literacy, PE, RE, history) but also revealed a lack of support generally in the following areas: teachers/assistants (often due to lack of knowledge about specific disorders); specialised or relevant equipment such as ICT and visual aids; financial support from the LEA to provide adequate resources:

'Bullying and a lack of understanding by staff [even the SENCO] have been our biggest problems – and also the lack of flexibility within the school.'

'[Child] has very limited hand function so use of computers etc can be very tiring and sometimes not possible if the right equipment is not available for his use.'

A number of parents/carers also mentioned that school trips were a particular area of difficulty with not enough support available for disabled children/young people to participate along with the rest of the class:

'School trips! My daughter's school do not like to take her on them without me.'

'Every time a school trip is announced an excuse is made as to why my son cannot go on it.'

45% of respondents said that their child/young person was included in lessons, formal or informal activities at school/college compared to only 20% saying they were never or almost never included. This pattern was reversed in relation to inclusion in activities outside of school/college: 25% said their child/young person was included to a high degree but 45% indicated very low inclusion in out of school activities.

83% of parents/carers said that their child/young person had not been excluded from school, although in follow-up comments some respondents suggested there were more informal processes of exclusion occurring:

'ASD children are often excluded because the schools do not have adequate resources to help them.'

'My child was frequently excluded 'unofficially' when attending LEA maintained mainstream school. It was extremely difficult and sometimes impossible to persuade the school to include him and support him, despite a Statement giving 30 hours 1:1 LSA.'

Of the 28 parents/carers saying their child/young person had been excluded from school 10% said it was very easy to get them back into education and 32% said it had been not at all easy to do this.

The respondent sample was almost evenly split on whether they were aware of any policies at school/college about children/young people feeling included (51% aware and 49% not aware). There were many positive comments following-up this question, for example:

'I like the way this school is striving for introducing inclusion practices.'

'They are very clear and fair and place no barriers for any of the children attending the school.'

'School has an excellent ethos of treating and valuing each child as an individual instead of requiring them all to conform to particular expectations.'

However, there were parents/carers who had clearly had different, less positive experiences:

'They [inclusion policies] seem to apply to every child apart from mine.'

'They are in theory only not apparently translated into practice.'

'Inclusion can only work when teachers are fully trained – which is practically impossible.'

From the group of respondents who said they were not aware of any policies about inclusion at their child/young person's school/college a majority (89% or 75/84) said there should be rules or policies about inclusion.

When asked about awareness of rules or policies about inclusion more widely, 59% said they were not aware and 41% said they were of rules/policies on inclusion. In follow-up comments a few parents/carers mentioned the DDA explicitly:

'I know that my child has rights under the DDA which is reassuring to some extent.'

'The DDA is a bit of a 'sledge hammer'. It would be much better if there were policies for proper training for all staff in mainstream schools so that they understood autism and could provide for the needs of these children in an appropriate way.'

'Disability discrimination legislation now makes inclusion the standard way forward.'

Generally, whilst many parents were clear about the need for greater awareness and understanding about disability and inclusion, there was some scepticism about whether policies and legislation could make any real difference:

'There may be policies out in local authority schools but whether they are worth the paper they are written on is questionable.'

'Local authorities have many policies on inclusion but in practice what happens is determined by a few teachers and it is very difficult to change their decisions.'

Finally, there were many comments that suggested parents/carers were unhappy with educational provision in mainstream settings:

'I don't think it is right to think that all children could cope in a mainstream school. Autistic children for example often have no desire to be included.'

'Please don't close all the special schools; it is the only place where some people feel included.'

Not all respondents felt this way with some advocating inclusion in mainstream schools as a good way to promote a change in attitudes, although these comments were in the minority from the people who chose to include additional information at this point (42):

'Inclusion is perhaps more of a state of mind than something you can rule about. If more people went up through inclusive schools things would change much faster.'

In telephone interviews, several parents reported the need for more and better information about disability. For example, one parent (of a 10 year old) said:

'The GP just said 'he's autistic'; I did not know what that meant; just the label; I had no one to ask so when the other parents [at the school gate] asked what is wrong with him I said 'he is autistic'; I did the same wrong thing as the GP. Because I did not know what it meant, how to care for him.'

Given the more recent development of early years services and parent partnerships, such a situation is probably now less common.

Minority ethnic groups were represented in phase 1 (although not substantially). Some specific issues emerged through telephone interviews in relation to those groups. For example, one parent discussed gender issues around the need for the father rather than the mother to take a disabled boy to the mosque. However care of the boy was seen by his mother, for pragmatic and cultural reasons, to be her responsibility.

Overall, there was certainly a sizeable group of parents responding to this survey who have had/were having a very positive experience with their children/young people and the education system. These parents/carers cited the good understanding that school staff had about

their child or young person's needs/impairment/disability as a key factor in the provision of good educational support.

In contrast, there was also a sizeable group of parents/carers who expressed substantial frustration and dissatisfaction with educational provision for their child/young person and their own, as well as their child's, involvement in discussions and decisions. Amongst this group, there was a strong sense that parents felt they were not being listened to or their views taken seriously – a very 'anti-professional' view of the process for deciding where and how children are educated. Many parents voiced unhappiness about their child/young person being placed in a mainstream setting, which was often deemed inappropriate for their needs. It was noticeable that a high number of respondents were parents/carers of children/young people with ASDs. There was a strong view from many of these parents/carers that there is a substantial and widespread lack of understanding about the needs of their children/young people. In this context, the placement of children with ASDs in mainstream settings appeared particularly unpopular.

An important sub-group within the parents/carers of children with ASDs were those who were so dissatisfied with the educational provision for their child/young person that they had taken them out of school completely; choosing to educate them at home instead. For some, this was seen as the only solution to an otherwise intolerable (and distressing) situation for parents and children/young people. This is an important area for consideration for phase 2 of the project. Any future survey should aim to include the views of parents/carers who may be educating children/young people at home and include some specific questions about this experience.

Parents in the discussion group all had experience of inclusive educational provision. They regarded it as laudable in principle, and something that should be further developed to reduce barriers between children, and to reduce fears and misunderstandings about disability and SEN that could arise in the future. They did not, however, regard inclusion as an absolute necessity:

'I don't think you should have inclusion for its own sake. Children should have schools that are right for them but also have better transition when transfer from special to mainstream is the right thing.'

This view was linked by one parent to her fears about bullying in mainstream schools, particularly as her son grew older:

'I'm terrified of it happening. Children with special needs are an easy target for winding up, getting into trouble being set up. It makes you worry especially when because of their autism they interpret things so literally. It makes you worry when they are in environments you can't control.'

The parents reported high levels of inclusion in activities for their children in school, but emphasised that this was because they made it happen and frequently provide the necessary support. Participation in out of school activities was regarded as problematic, and often this was because providers of activities were constrained by 'risk procedures'. Parents didn't blame individuals concerned but were extremely frustrated at the exclusionary consequences of a risk culture. Nevertheless, parents themselves stepped in to provide support to enable their children to join in activities.

One parent in the group (an SEN governor) said that frameworks for inclusion were beginning to be put in place, and that developments in joint-service planning were beginning to emerge for young children. Others in the group felt this was too optimistic a view, and that:

'The framework isn't there. There's policy ... but it is all talk.'

'At the end of the day there are issues of training and the attitude of the head and teachers in schools. I realised with son they had had enough and decided not to waste my time there. I was doing ABA at the time ... I went round some schools and in the end found a great one. They wanted to include him and had experience of other autistic children.'

What mattered to the parents was the attitude of school staff, but also of people who worked for the LEA. They also considered expertise and

experience of working with children with complex needs to be important. Although they recognised that it was difficult for class and subject teachers to make provision for thirty pupils in a class or lesson, they also felt that the success or failure of inclusion would hinge on getting well-organised expertise in place. Key factors in making this happen, they suggested would be the introduction of better teacher training, and properly managed and organised budgets. With regard to training, they knew expertise was 'out there'. After all, they had often sought it and paid for it and ensured that it was in place. One parent outlined how she had provided her son's school with resources and training information about the education of children with Down's syndrome. No one else in the education or health service had made this information available. With regard to funding, the group expressed concerns about new funding models which were intended to operate flexibly, but which caused major problems, with support staff being withdrawn or sacked (then re-employed) because of short-term budgeting problems. This difficulty added to concerns that learning support for children with a range of special educational needs and physical/sensory impairments was becoming both fragmentary and temporary. This, the group regarded as a major problem for developing inclusive education.

Finally, for this group of parents, the lack of important services in mainstream education made a mockery of inclusion. Speech and language therapy was notable by its absence and other 'out of authority' expertise was unavailable (eg ABA and intervention schemes based on the Lovaas approach). Despite expressing these concerns, and many other reservations, the parents still saw inclusion as the way, if not the only way, to move forward:

'We totally believe in early inclusion. It will cost less in the long term.'

And:

'Through inclusion we can all learn from each other, educate others for the future.'

At the same time, they were not prepared to jeopardise their children's education by putting up with poorly planned and resourced inclusion. As one father in the group put it:

'Give me help now, not when he's 21.'

3.3 Identity

Affirmation of disability is increasingly regarded as a positive characteristic of personal and social identity. Children and young people involved in this study did not dismiss this identity, but nor did they consider it to be particularly important. Older students tended to view their identities in terms of future roles and employment aspirations, although not always realistically. Very few disabled teenagers attending mainstream schools contributed their views to this study, and this may reflect sensitivities associated with adolescence and identity formation. Other children and young people may not have identified themselves as disabled at all, a point reinforced by some parents/carers who were much more familiar with the concept of special educational needs as a marker of identity.

Some parents/carers reported different identities assumed by their children in different contexts. Sometimes, but not always, this was problematic. Other parent/carers expressed the concern that hidden disabilities were ignored or inappropriately attributed to bad behaviour.

Views of children/young people

Children and young people varied in the ways in which they talked about inclusive policies. Across all age groups, they did not express strong views about disability as a single signifier of identity. Instead, they (especially older students) focused more on the courses they were studying, what school/student life was like and – when prompted – what they would like to do in the future. This latter issue was particularly interesting, if worrying. The students expressed the vaguest of aspirations.

Perhaps because the further education college students interviewed were all following a media studies programme of some kind, they referred to future options for study or employment in the media world:

'Can't predict Well, plans, obviously for university, short term plans, to get stuff published, writing stuff ... I'd love the opportunity to go to university, that would be just great, but I can't do that. Well, anyway, I'm going to focus on creative studies. Be a journalist.'

'In the long term I would like to do something in the BBC.'

'Try and write a film and make it. Get a bit into cinema tell them what to do how to make it. Work in the media.'

'Moving back to where media stuff is happening [after college] ... the big city ... Manchester'

As well as talking about the future in very vague terms – and of course many young people might talk in this way – the groups expressed uncertainty about when their course funding would run out, and where they might be living in the future.

Some of the further education students expressed views on disability and identity, but no one saw herself or himself as being first and foremost a disabled person. Instead, as one student put it, 'I'm just ordinary':

'A normal human being. I just feel normal like everyone else.'

At the same time, the idea of being normal or disabled was understood to be something you needed to get beyond:

"There's people who come up with theories about the word [disabled] and I basically don't like it which is why I you know say I'm me, I'm Ron ...'

Interview conversations about disability and identity quickly moved to more concrete discussions about the importance of self-confidence, self-esteem and doing things with other people. The specialist college

context, suggested the students provided good opportunities to develop these dimensions of personal and social identity. It is worth noting that these students attended one specialist college and their experiences may be very different from students accessing further education in other contexts, so caution is needed to avoid over-generalising from these results.

The few mainstream secondary school pupils recruited for this project, despite strong support from the school and the SENCO for the project, was disappointing. While there were some practical reasons (the identified children were poor attenders and absent when the researcher visited the school on several occasions) and/or written parents consent forms had not been received, it is also possible that this reflected identity issues in adolescence in which young people may not want to be seen as different from peers. Conversely, reference to disability/ special needs or to the Disability Rights Commission (as funders of the project) did not, by definition, deter the people who did agree to participate.

Views of parents/carers

Almost two-thirds of respondents (63%) said they were aware of differences between how their child/young person felt at home and at school/college. For some, the structure, routine and support at school were helpful:

‘I suspect he feels better at school because there is a structured programme which he joins in – although he claims to dislike it – while at home he isolates himself.’

For others, the school setting was considered unhelpful and detrimental because of a lack of understanding of the child/young person’s specific needs, or the pressure on children/young people to behave in ‘expected’ ways at school compared to home where parents felt children/young people could be ‘themselves’:

‘At home she is a completely different person – relaxed bright and confident while at school she was shy withdrawn and scared most of the time because of the lack of interest understanding and support from

adults and children there.'

'At home she is accepted as she is. At school she is ACTING from the start of the day till she gets home. She cannot be as she is because they expect her to act 'normal' as she can.'

A majority of parents/carers (64%) also said that there were differences in the way their child/young person was treated at home and at school/college. In follow-up comments, some parents suggested that the school environment was less tolerant or understanding about the individual needs and behaviours of children/young people whilst at home 'he is free to express himself'. Generally, a main theme to emerge in further explanations from respondents was that schools were not meeting children's needs either because they did not treat children as individuals (children were expected to 'conform') or because children were treated too individually (being singled out because of their disability):

'At home we accept him as he is at college there are some expectations that he can be 'the same' as the other students whereas he has very variable social skills. This is not always apparent or catered for.'

'When my child joined the school a meeting was held [without my being invited] to reassure other parents that my child would not be a detriment to the class. He is constantly singled out as different and not allowed to do what the other children do.'

There was also some understanding that, for some children/young people, home and school offered different things but this was a positive contribution:

'We have different expectations of her; school can be stricter with higher demands whereas at home she is free er to do her own thing. It's a good balance.'

When asked about whether there were any children/young people at the school who were treated differently from others 49% responded 'yes' and 51% 'no'. The dichotomous nature of experiences was evident in further

explanations given with some parents suggesting there was no difference in treatment because schools managed equality/inclusion very well; whilst other parents/carers suggested that school was segregating and stigmatising for their child/young person.

'The school wrongly segregates all the children with learning difficulties onto one table in Year 2 which makes them a very easy target to be picked on and ridiculed. There needs to be integration made a priority at all mainstream schools.'

'All children are treated differently from every other child. All children are taught that everyone has special needs in something – even the teachers!'

This dichotomy of experience may, in part, reflect the self-selecting nature of the sample parent/carer group. That is, parents/carers with especially positive or negative educational experiences may be more motivated to complete a survey of this kind (or to participate in interviews) than are parents/carers without a strong view either way.

Some respondents noted differences in the ways children with 'hidden' physical/sensory impairments were treated, with the view that there was a certain level of discrimination for those with learning, compared with physical, disabilities:

'Visible disabilities were catered for, wheelchairs etc, or deafness. The hidden disabilities like Aspergers were ignored and they were just treated as 'difficult' children.'

'Children with physical difficulties are given a more considerate view and treated with respect because the other children can see what is wrong with them. Children with learning disability are not given the same respect.'

Parents in the discussion group confirmed many of the aforementioned points. They also described how they were trying, as sensitively as they could, to help their children understand how they were different from other children and young people. Although they felt this was very difficult

to do, they considered it to be important. One parent spoke of being inspired by a recent TV documentary about a young person with a 'facial disfigurement' who showed great determination and resilience in life. He wanted his own son to develop the same strength of character. This, he felt, would enable him to make a go of life.

3.4 Summary conclusions concerning themes associated with disability

- There are substantial issues to be addressed around the 'hidden economy' of disability/special needs encompassing both home education specifically and other parent-supplied provision. Some parents of disabled children are acting as very vigorous individual campaigners on their children's behalf. For a significant minority of parents/carers of disabled children, education at home is regarded as the only satisfactory provision at present.
- The role of voluntary groups emerged as very important in supporting, and providing information to, parents and carers (not only those parents whose views were recruited through such groups).
- Related to this, in general, there was a reported paucity of community support. An exception tended to be looked after children, whose carers often had strong and active links with a local church, and took the child to church-based activities. However as numbers of disabled looked after children were inevitably small, caution is needed about the generalisability of this finding.
- A major theme emerged around disabled children's resilience: specifically, how this is fostered or hampered across individual, school, family and community/cultural contexts. Resilience is tested and/or strengthened at times of transition so transitional experiences have a particular importance, and salience, for children/young people and their parents/carers. That salience emerged, for children and their parents, both in reported events and in hopes/fears for the future. For older students in further education settings, the availability of good quality academic and personal support seems to be particularly significant in enabling young people develop personal autonomy and 'move on' from difficulties experienced in school and in the earlier experience of post-school education.

- Thus there is a need to ascertain systematically what resources are available to disabled children and their families at times of transition. Following from this, exemplars of good practice might be identified (eg through child-based case studies) with a view to developing and implementing policy in this context.
- There may be systematic differences between parents' and carers' views but numbers were too small in phase 1 to be confident about possible differences. It was noted by some parents in the telephone interviews that looked after children benefited from additional support (eg an independent advisor) at transition, not experienced by other children.
- Differences by social class/ethnic minority may be significant. However, further work is required to test this and care is needed not to extrapolate findings from particular groups in ways that over-generalise. It may be outside the scope of phase 2 to do this unless it is an explicit and prime focus.
- While we did not explicitly compare parent and child views, these tended to complement one another (see section 7). A possible area of difference however concerned young disabled people's desire for greater independence.
- Special/mainstream schooling was not a major issue for disabled children and young people – there were more important overarching concerns such as to be well supported educationally and given opportunities for independence irrespective of educational placement. (Compare this with the views of some parents who were very clear about their preference for special rather than mainstream settings and their unhappy experiences in the latter.)
- There are some hints that there may be systematic intra-GB differences which warrant further investigation. Given possible systematic differences between England, Wales and Scotland concerning disability/SEN policy and provision, phase 2 needs to include intra-GB work including systematic surveys and case studies. One way to achieve this could be through a stratified

random sample using a combination of methods such as face-to-face and telephone interviews and paper and email/web-based questionnaires. This could be supplemented with a small number of child-based case studies in order to gain more detailed knowledge of views and experiences from particular groups (see above).

4. ISSUES CONCERNING SAMPLING AND METHODOLOGIES

4.1 Ethical issues

The project raised a number of ethical issues concerning informed consent, possible constraints on the expression of views, the need to provide feedback to research participants, and the challenge of providing appropriate support and guidance to a small minority of vulnerable participants. Most of these issues were resolved during the project, and where appropriate, some of these have been signalled as potentially significant for a phase 2 project.

The multiplicity of types of family structures in the selected areas (reflecting GB more widely) meant that for a large minority of the children, parental consent forms had to be signed by several people, possibly at different home addresses. This has repercussions for the time needed to obtain full and relevant consent from parents/carers and needs to be recognised in phase 2 planning. This also had repercussions for the schools which, in turn, had to spend extra time explaining the nature of the project to more than one parent.

There were a number of further issues around looked after children (and sometimes children living with a lone parent following an acrimonious family break up). There was, in some schools, a sensitivity about children's free use of cameras/video, reflecting worries about possible parental access issues. This also, in some instances, reflects wider concerns in education about these matters; schools feel 'at risk'.

All parents, children and young people were given information sheets (3 parallel versions, see appendix 3b). These were all in English and if the sample had included non-English speakers more time would have been needed to translate these sheets. Similarly, had Braille or taped information sheets been needed these also would have required additional preparation time. The written information sheets were developed in consultation with the DRC to ensure that they were fair, representative of the project, accurate and encouraging. Two schools modified slightly the sheet sent to parents (by playing down the 'disability' aspect). This highlights a possible tension around giving

schools control over events as much as possible to reinforce and build a genuine partnership approach to the work. However this has to be set against the need to be open and honest with parents about the nature of the project which may, in turn, require more time spent explaining the nature of the project to participating schools and other gatekeepers. The tension referred to here was not experienced in the further education context. Here, young people were free to participate in interviews on their own terms and without staff mediation of any kind.

Similar points apply to information given to participating children and young people. The research team was committed to obtaining, as much as possible, fully informed consent from the participating children/young people. They were told at the start of interviews about their right to withdraw (none did so) and promised anonymity in any written reports. When support workers were present with children/young people the researcher also stressed that confidentiality would be maintained and that the interview was a 'safe space'. One young person asked for the tape recorder to be switched off and then gave confidential information (relating to criticism of specific staff members). That information has not been used in the report but the underlying issues are discussed. In phase 2 it will be important that ground rules are again made very clear to all participants.

If taking children's views seriously then researchers need to find ways in which to give feedback to children; show how their views have, or have not, been taken on board; and the impact, if any, of their views. This highlights the importance of in-depth work in a small number of schools. Some of the young people interviewed in the further education college asked 'where the project was going' and indicated an interest to stay involved. Again, this raised concerns about research that is not iterative and not concerned with fostering partnerships with participants that are longer term and developmental.

One potential method open to children and young people was a small group interview with a friend. This was however rarely included as an option because it was only possible if the parents of all potential children had given consent. In 6/7 settings in LEA 1 individual children were identified for participation (reflecting sampling criteria at the outset) so

such open choice was not possible. There is thus a balance between sampling requirements and methods options; the tighter and more selective the sampling criteria, the more restricted are methods options involving other children unless there is whole school involvement. Further education contexts would seem to offer greater flexibility in regard to the method discussed here, because of the participants' status as 'students'. However, 'gate keeping' mechanisms not encountered in the further education college visited, could present difficulties elsewhere.

In placing access to the e-survey on open websites we were potentially triggering responses from very vulnerable or needy individuals. Around ten people contacted the research team directly, having completed the e-survey, to request support, guidance and/or information. We responded to all these individuals but have not used any of the information from those conversations in the report or analyses.

4.2 Sensitivity concerning disability labelling

The project highlighted difficulties in finding a common vocabulary that research participants, the research team and the DRC could use to enable experiences and opinions to be shared. It also highlighted possible difficulties in accessing the views of children, young people and parents/carers who simply do not identify with the term disability. These difficulties are compounded through the use of policy and practice language that downplays the use of the term disability.

The language of disability and its labelling evoked great sensitivity for some players. In some cases we suspect that this reflected uncertainty about the disability provisions of SENDA 2001. For example, question 1.3 in the survey asked parents whether the DDA definition of disability (given in full) applied to their child and over 90% affirmed this. Of those responding that the definition did not apply and giving a response elsewhere about the child's needs; these children had moderate learning difficulties (2), severe learning difficulties (1) or specific learning difficulties (7). In virtually all telephone interviews, parents were unsure or confused about the language of disability/special needs and had great difficulty in answering the questions which used these and associated terms. After two alarmed reactions to this in the telephone

interviews this question was moved to the end of the interview. The reference to mental impairment was disconcerting for some parents and reflected an unfamiliar/uncomfortable language of authority. This suggests that there may be a substantial minority of parents of disabled children who are unaware, through a misunderstanding of the language involved, about their, and their children's rights, concerning disability.

In other cases, there were possible anxieties about 'disability labelling' and uncertainties about how, if at all, this related to 'special needs' labelling (schools' more familiar linguistic environment) and consequent provision. Parents of special school children saw their children as having SEN, not necessarily disabilities.

Tensions are, possibly, exacerbated by the discourse of inclusion and its practical ramifications within LEAs in which policy shifts incorporate an apparent 'aversion' to talking about SEN (and disability?). That is, disability/SEN discourse is subsumed under a broader rhetoric/focus about inclusion as in 'everyone is unique, all are special' etc.

The sensitivities discussed here were much less apparent in the views expressed by young people attending college. These students seemed to be at ease with discussions about identities and did not see themselves as disabled young people first and foremost. Interestingly, most of this group of students had experienced complex educational careers with placements in both special and mainstream schools. Further analysis of interview transcripts may provide further insights into sensitivities surrounding definitions of disability.

4.3 Control of the research processes

The project highlighted the value that many parents/carers placed on being able to express their views. Both parents/carers and older students participating in the project also emphasised the importance of being listened to. The implication of this is that the more engaged participants are in all stages of the research process, the more likely it is that their views will be heard and responded to.

93% of survey respondents suggested that they would like to be invited to take part in future projects/surveys suggesting that there is a strong desire from this group to make sure their voices are heard ('Excellent opportunity to express views'). A comment from one respondent in particular, emphasises the importance of obtaining their views and echoes the sentiments expressed earlier about parents feeling they are not generally listened to by people in the 'system':

'I am grateful I found it [the survey] by chance but I doubt anyone will listen or care.'

On balance, the degree of choice for the interviewee about methods seems less critical than that the interviewer has in mind (and access to) a portfolio of potentially appropriate methods. The interviewer can then be flexible and responsive about using methods which seem to chime with the individual interviewee's (whether child or adult) preferences and capabilities. This has implications for the (considerable) level of knowledge and understanding required of the research staff. Such staff also need to be convincing to research partners.

Further education college students were explicitly unconcerned about methods but were concerned that their views be sought, listened to and respected. Parent/carer responses to the e-survey reflected a similar position. Perhaps unsurprisingly from an e-survey, the most popular indicated method for providing parental views was in an online survey (45%). 25% of respondents had no preference and the next most popular response was face-to-face interview (12%).

Methods of data collection with children or young people and involving technology may be skewed towards adult leadership; also, time is needed to get closer to the worthwhile/authentic. Although ICT-linked methods had been envisaged in phase 1, these were not used as considerable (not available) time would have been needed for sufficient familiarity with particular schools and pupils level of expertise and ICT resources. Similarly, other 'technologies' for exploring group interaction/activities might need extensive trialling with specific schools and/or pupils. Nevertheless, ICT-based approaches, including e-surveys, may be useful tools for including young people who might prefer a more

'distanced' approach from the research team (eg pupils at secondary schools who, as noted above, may have been less keen to participate).

It is important that DRC funded work reaches the full spectrum of disabled students and their families including those from a range of ethnic backgrounds. Conventional or paper surveys seem less likely than telephone interviews or community based projects to do this. Poor reading skills and/or lack of confidence in these may have encouraged some parents to opt for telephone rather than e-survey. Their comments about dislike of long words used by schools, 'not being clever', alarm at terminology of eg DDA question (q. 1.3), supported this suggestion. In which case, the options form could usefully have included pictorial short cuts for telephone etc. Some parents may not be as familiar with working 'online' as research communities may think, and this indicates the value of providing parallel 'paper based' or telephone survey options.

A message from phase 1 was of the need to leave room within methods for schools/others to make choices/feel they have some control. Initial briefings, engaging collaborators and then leaving them alone (except for 'health check' calls) are important. The risks involved are obvious (no time for people to do this) but without such a balance schools are likely to opt out, or not opt in, to such projects.

There is the potential for children/young people to be co-researchers in projects such as this and phase 2 might look more seriously, because of its longer duration, at including such work in data collection.

4.4 Resources: time and personnel

Findings from the project confirm that if the principles of authenticity, credibility and trustworthiness are to be adhered to in research that seeks to ascertain the views of a heterogeneous group of possible participants, then a significant level of resourcing is required. This resourcing needs to focus on the interrelated issues of researcher flexibility and time; both of which have cost implications.

It is important to recognise the considerable time demands in setting up a project such as this with multiple layers of permission needed

(particularly when liaising/working with informal groups). For example, an initial contact with a local voluntary organisation might trigger half a dozen potential new 'link' individuals and each of those trigger half a dozen possible participants but accessing those individuals might require going through several different services (eg a church group, another voluntary group and a health-related service).

Both LEA approaches were heavily dependent on goodwill so it is important that those people feel (1) it is intrinsically worthwhile; (2) they are getting something from it. In relation to both these points- in phase 1 the 'worth' issue in both LEAs was - fortunately - aligned with wider initiatives on listening to young people at the current time (this might not last); (3) children/young people get something from it; for example, as noted above, vouchers or book tokens to participants are important because they signify appreciation.

Where support workers and/or translators/signers are used/anticipated these need to be costed and used independently from school/college staff, if possible, for several reasons. First, there are confidentiality/ethical issues about what a child may feel able to reveal when adult authority figures are present. Second, 'outside' support workers may diminish staff's natural tendency to teach/intervene or 'lead' a response. Third, some schools told us that they were uneasy about involving support staff as it fostered an 'oppressive' context for the child in which the child was never separate from their own support worker. This links with issues about autonomy (see 3.1).

4.5 Summary and recommendations concerning issues about sampling and methodologies

- A nation-wide systematic sample by key demographic variables such as age, geographical location, socio-economic background and ethnicity might be accessed to collect a representative national picture of views by, for example, using brief face to face interviews with people stopped at key locations (eg shopping centres). This would have the advantage of statistical generalisability but with limited quality of responses and some sample bias.
- A national picture of views could be obtained through conventional pencil and paper questionnaires targeting, for example, a cross section of the population using recognised statistical sampling techniques. Such an approach might encompass diversity of responses but is prone to respondent bias.
- Alternatively, Phase 2 might capitalise on the experiences gained of e-survey design, development and analyses by a wider and more systematic use of an e-survey through collaborative work with a range of relevant, neutral, GB-wide groups.
- Such an e-survey would need to be supplemented with a method designed to reach parent/carer groups who do not regularly use the internet; eg via telephone interviews.
- The language of disability/SEN was found difficult or incomprehensible for a significant sub-group of parents. Phase 2 needs to bear these potential difficulties in mind and respond accordingly in planning sampling and methods.
- Phase 2 might usefully involve case studies eg a small number of children/young people in each of 4 GB regions; urban England, rural England, Wales, Scotland) to explore in-depth factors associated with resilience with disabled children/young people acting as co-researchers and 'snowballing' methods/samples (to include individual, inter personal, family and community/cultural

factors). The aim would be to both illuminate policy/provision and to provide some exemplars of effective practice.

- Individuals and groups involved in phase 1 could be explicitly involved in phase 2 in piloting and development work and/or to meet specific criteria for inclusion in phase 2 (eg looked after children). The great enthusiasm for continued involvement from virtually all phase 1 participants suggests that this would be fruitful.
- Considerable time is needed in the early stages of the project for the researcher to understand which approaches will best help the child/young person to share views in an open and comfortable way.
- This process is most meaningful, valid and ethically appropriate when disabled children and young people have continuing involvement, if possible- as co-researchers for at least part of the project, in the research process over time, in contrast to conventional 'hit and run' approaches to data collection. Close collaboration and continuing involvement of schools or voluntary groups are vital to sustain target recruitment and data collection.
- Some sub-groups (notably minority ethnic groups, looked after children, children educated at home, children in rural communities, children with mental health difficulties) were under-represented in both parts of phase 1. Phase 2 might take an explicit focus on one such sub-group.
- Modest tokens of recognition (such as book tokens) for the involvement in the project of disabled children and young people are appreciated.
- Open methods of sampling raise potentially sensitive and possibly time-consuming issues about how to respond to particularly needy or persistent individuals some of whom may be pursuing grievances against particular organisations or individuals.

5. PROCEDURES AND METHODS CONCERNING CHILDREN/YOUNG PEOPLE

The project made use of a wide range of approaches designed to elicit the views of children and young people. The strengths and weaknesses of these are summarised in section 5.2. Some of these approaches were used systematically; others were identified (eg by participants) as being of potential value in further research. Most importantly, no single approach was deemed to be the 'right one' to use. Rather, researcher flexibility was considered to be crucial. This involves working with a portfolio of approaches, responding to the preferences of research participants and where appropriate, co-constructing and using research tools.

5.1 Specific approaches

Many studies about pupil views do not go beyond conventional 1:1 interview approaches and this project has very usefully given scope for exploring methods much more fully and imaginatively. Given the focus on disabled children and young people, this is very important in maximising the range of pupils whose views might then be accessed in authentic, credible and trustworthy ways. (Note - see appendix 2a for details about samples, sampling and procedures concerning exploring the views of children and young people in this project.)

A portfolio of methods has been used (as specified in the bid) and, as well as 1:1 interviews, included: small group interviews, diamond ranking activity, cue card prompted interview, photographic trail using photos taken by the child/young person, drawings, mapping, puppets, and self-reports to video. Children were shown cards of the various activities and/or relevant objects and invited to choose their preferred approach for conveying their views; the interviewer prompted a choice if pupils found a free choice too demanding.

There was something new about some of the approaches for every school so there was also a sense that the research team were able to give something back to the schools through sharing expertise and resources in a field which was of considerable interest to these schools.

The grid (see appendix 2a, table 8) shows the range of methods planned and the ways in which they varied by key variables of initiator, mode of presenting opportunity to share views, support to communicate views, mode of child's communication and lead role in terms of adult or child.

5.1.1 Individual interviews

Conventional 1:1 individual semi-structured interviews were included in approaches with 17 children; for five of these children (see appendix 2) this required the support of a facilitator or translator. This process raises issues about the nature and role of such a supporter.

A 'long' interview schedule was developed to ensure that research priorities would be addressed. The content of this schedule was informed by the DRC's specific priorities, presented at a project steering group meeting, and by key policy initiatives, legislation and statutory/non-statutory guidance. This schedule was then refined, re-presented as an interview framework with prompts and probes for the researcher to use (see appendix 3c). This framework was transformed into a short 'user friendly' copy as an interview guide, trialled with a group of pupils, and this in turn evolved into a short thematic version (see appendix 3d). This latter version became the basis for the large majority of individual and small group interviews with children, young people and (with appropriate modification) their parents/carers. The four themes identified to elicit but not to constrain interviewees were: inclusion, empowerment, autonomy and identity. These themes were also considered to be important for all participants in the research and to address priority issues identified in the more detailed initial schedule.

5.1.2 Small group interviews

In special school 2, pupils were interviewed in small groups of 2-3 pupils. The composition of these groups was planned by the school and based on their knowledge of the pupils. It had been intended to give all pupils the option of a small group interview with a friend of their choice. However this did not happen because it would have required consent from all children potentially involved. Unless the project had been a

whole school project from the outset this would have been difficult to implement unless every child/their parents had given consent. The implications for phase 2 are considered further below.

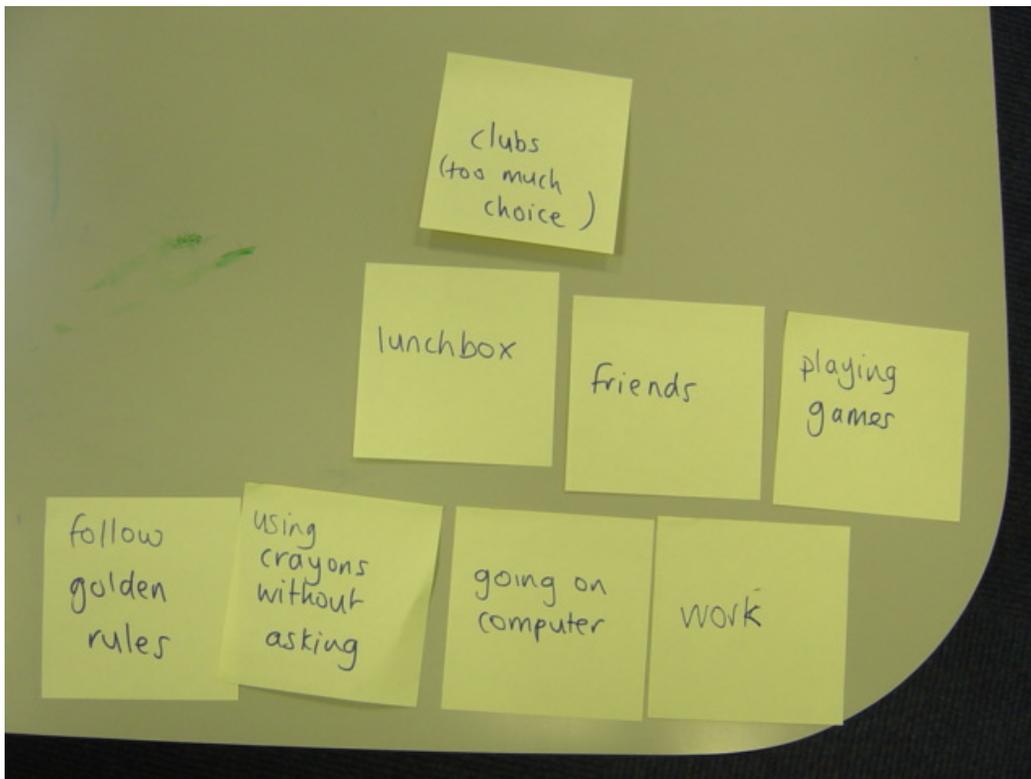
All except one of the five small group interviews (special school 2) included a pupil with severe or profound learning difficulties who was accompanied by a facilitator. The facilitator translated questions and gave specific prompts. This enabled the pupil to be involved in the project but a full contribution would have required much longer preparation with the school and facilitator, familiarisation with the pupil, and possibly ICT-supported communication aids. The short time scale of phase 1 precluded this. However the group context enabled other pupils to trigger ideas and amplification from one and justified the inclusion of this as an approach. Within the group, pupils chose their mode of response for the activities.

Interviews with young people in the further education college took place in two groups, 4 students in each, facilitated by the researcher. A college tutor had made the necessary arrangements, provided a small meeting room and made it clear that he would 'leave the group to get on'. The participants were relaxed, clearly used to engaging in discussion, but also circumspect, wanting to know if the researcher had genuinely come to listen. This point was emphasised by one student, after the formal interview discussion had ended. Care did need to be taken by the research interviewer to ensure that all members of the group could contribute on an equitable basis, and could also choose not to respond to questions. Some participants clearly wanted to respond, at length, to questions asked, and to ensure equity – with only a short amount of time available (1 hour for an interview) – their comments were curtailed by the researcher's intervention. Other participants indicated that the interview format could usefully have been enhanced through the use of activities, and opportunities to move around.

5.1.3 Diamond ranking

The diamond ranking activity (based on Thomas and O’Kane 1998) was used successfully with a diverse range of pupils. Pupils were invited to either name an aspect of school which they liked or name an aspect of school about which they had a lot of choice (the interviewer deciding which of these was likely to be more productive with individual pupils), these were followed with their opposites, then ‘in between’ responses until an array was generated. The interviewer wrote each response on a ‘post it’ note as it was given and asked the pupil to place the note on the table, slowly building up a diamond or rectangular shape of responses with the two extreme sets of responses at the top and the bottom of the shape and graded responses in between. The resultant shape became the focus for further discussion with the pupil and/or among the small group. More able pupils were asked about how aspects disliked or areas about which they had little choice could be changed and by whom.

Picture 1: Diamond ranking



Richard depicting amount of choice about things (most choice= nearest top of array; least choice= lowest part of array; words written by interviewer)

This was a particularly productive and versatile approach to exploring views with diverse groups and individuals. Pupils with severe learning difficulties were able to respond to this activity, including engaging with one another's responses. Interestingly, children with autism found this comparatively challenging; while they made interesting responses, some were overly concerned about the 'neat' placing of post-it notes. For children with speech and language or learning difficulties, or emotional needs, it enabled comparative judgments to be shown without the need to articulate these shades of difference.

5.1.4 Cue card prompted interview

The cue card prompted interview was used to explore a particular event, recalled by the pupil, in more detail; for example, a time when the pupil reported having felt left out or powerless in school. It was thus particularly useful as a follow up to wider discussion or event depicted in a free drawing. The approach stems from Fivush's script theory and aims to encourage an uninterrupted narrative from the interviewee thus removing various sources of bias introduced when a series of interview questions are presented in a dialogue (discussed in Lewis 2002, 2004). A revised set of cue cards were used (as a result of current development work in Leicester LEA) to cue recall of detail about people, actions, thoughts, feelings, speech and consequences around an event. This also provided triangulation of ideas elicited through one of the other methods used with that pupil.

The approach works best when interviewees (and interviewer) are familiar with the cue cards so a limitation here was that the interviewer needed to explain the cue on each card. However despite this deviation from an optimum presentation, the approach generated markedly more detail than was given in more open-ended approaches. Pupils responded well to the prompts and gave focused and, usually, comparatively full responses (see illustrative quotes throughout this report).

5.1.5 Puppets

The special school headteachers were keen not to anticipate pupils' limitations and so unwarrantedly exclude pupils from the project. For such pupils, with severe or profound learning difficulties, large hand puppets were used to encourage responses. Four puppet variations of gender x ethnicity were used to enable those of the pupil to match the puppet's as much as possible.

Various pupils were drawn strongly to the puppets and readily whispered (eg fears about school) to the puppet although they had been reluctant to do this in a conventional interview context. Others, with slight prompting, gave the puppet their own name and talked through the puppet. Some of these pupils wanted to play with the puppets and ideally more time was needed to get through this stage and then concentrate on talk between the pupil and the puppet 'interviewer'. Overall, their use dovetailed with approaches used in the schools and showed that many pupils who might have been excluded as unable to make a response reliably could contribute via puppets.

Picture 2: Puppets

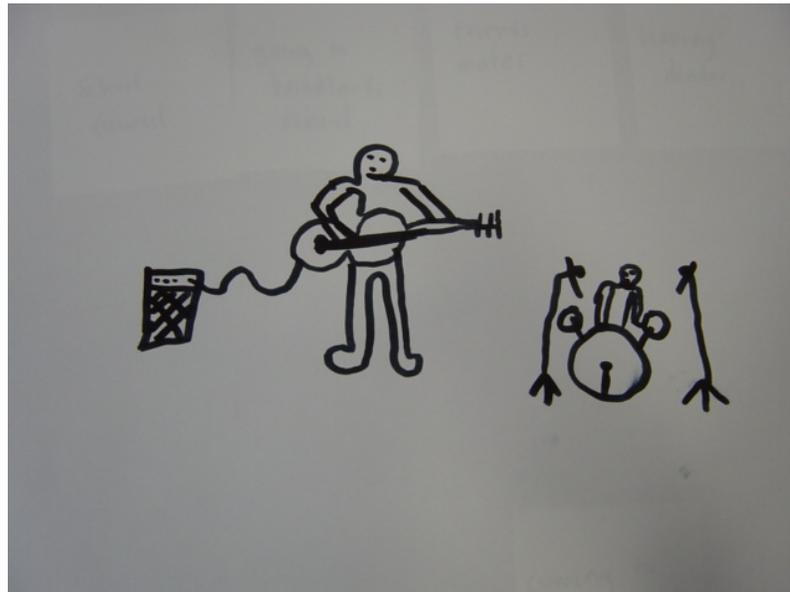


5.1.6 Drawing

Most pupils chose drawing as one means to convey their views about liked/disliked aspects of school. Exceptions were older and more articulate pupils who were happy to simply talk about their views. Given the dangers in over-interpreting children's drawings, we tended to use drawing as a prelude to, or focus for, one of the other activities.

Many of the drawings conveyed a strong sense of powerfulness, vulnerability, belonging or isolation. These were presumably particularly salient for the pupil given the initially open question which generated these responses although without knowing more about the wider context of the drawings we are cautious about over-interpreting these pictures.

Picture 3: Simon's drawing of 'a good thing' ... playing the drums; his friend on left with guitar



Although not used in this project, music or drama might similarly be used as initial stimuli.

Picture 4: Elizabeth's drawing of 'a bad thing' ... finding work hard



5.1.7 Mapping

The use of a more formal approach to mapping (Hayes, 2004), was not used in this phase of the project. However, used flexibly, but with a clearly articulated general purpose, the method would seem to offer good opportunities for children and young people in particular, to engage in activity based discussion. The approach lends itself to use alongside, or as part of small group discussions, and perhaps to uses with larger groups where 'team' activities contribute to the shaping of plenary debates and discussions.

5.1.8 Photographic trail

Staff in the two special schools felt that pupils would not be able to manipulate the controls on the disposable cameras (this required using a

manual winding on mechanism) and so taking photographs around the school was not given as an option there.

Staff in two of the other schools were apprehensive to various degrees about children taking photographs, possibly taking pictures of other children in the school. This reflected concerns about the possible repercussions of the photographs being seen elsewhere particularly in connection with parental disputes involving care of certain children (attending the school but not involved directly in this project). There was also some uncertainty by one of the schools about whether the LEA would permit such photographs to be taken. On checking with the LEA we found that the LEA had no such blanket policy so it was interesting that there had been a perception that this was the case and highlights schools' sensitivity about child care (see below).

Only one child from the remaining schools chose to use a camera in conveying her views. However on this rather limited basis, the approach was very successful. The school asked that the photographic trail be taken by the child touring the school with one of the research team, rather than leaving the camera with the child for her to take pictures in her own time. This girl (a 9 year old with autism) seemed pleased with this approach and thoughtfully took a sequence of 21 pictures during a 25 minute meander around the school building, only one photograph was unusable (thumb over lens). Invited to take pictures of things/places which made her feel good or bad she took overwhelmingly positive images (16/21 pictures). Her chosen positive images included: musical instruments, her own picture on a wall display, computer room, books, dancing (on interactive whiteboard image), tigers (in picture), serving hatch (=school dinners), lunch time tables, biblical picture, welcome poster, concept maps, flowers, school secretary and a teacher. The chosen negative images concerned untidiness or loudness, accidents (First Aid box) or a specific child. Triangulation with other methods used with the same child supported the authenticity and credibility of her choices.

We returned to the school three weeks later for her to see, and respond to, the developed pictures. There was a striking similarity in her initial commentary and her later response (about 3 weeks later as her absence or special events at the school delayed the return visit). 19/21 of the

images (all the positive and three of the negative ones) were recalled in detail and with exactly the same (and amplified) reasoning as on the first occasion. Two of the five negative images were re-interpreted positively; for example, the First Aid box was seen as being there to help children who got injured. The striking similarity in response across the two occasions and the amplification of views triggered by seeing the photographs suggests that although there may be some difficulties with schools agreeing to the approach, it has considerable potential in being authentic and trustworthy.

5.1.9 Self-reports to video

Opportunities to seek the views of young people with significant health care needs using this method were not followed up because of their reluctance to share sensitive opinions with an 'outsider'. However, the potential of this approach is one that the research team wish to pursue. Staff in a hospital school setting reported that the use of this technology was empowering, young people could 'say what they think' when they wanted to, and through the use of a popular but private media medium. Interestingly, the young people attending further education college also expressed the view that they could share ideas through contemporary media technology. This point was also emphasised by their college tutor. The potential value of video filming was also noted by parents in the discussion group.

5.2 Summary conclusions and recommendations concerning potential approaches used with children and young people

	Pros	Cons
Small group interview	Versatile Natural Supportive of quiet voices	Individual views may be lost Transcription difficult Grp composition may distort findings Equity of contributions is not easy to guarantee
Diamond ranking	Effective across wide range of children/young people Child-led	Treated rigidly by children with autism
Cue card supported interview	Effective across wide range of children/young people Versatile	Training needed with children to work at best Treated rigidly by children with autism
Puppets	Effective with pupils with SLD/PMLD May be child-led	May be distracting
Drawing	Useful stimulus	Caution needed in interpretation May be seen as childish
Mapping	Effective across wide range of children/young people May be child-led Creative (prompted by sharing ideas) Could be used as part of larger grp consultations Active (eg when compared with interviews)	Training of researchers needed if new to this
Paired interview with friend	Natural situation	Needs parental consent of all potential children/parents
Photographic trail	Child-led Requires purchase of equipment in advance	Requires confidence in child Possible sensitivity/safety issues. Parents (discussion group) thought it would work well for their children
Video to camera	May be child-led 'Sexy' eg used on TV eg Big Brother so may be particularly attractive to eg adolescents	Requires familiarity with process May need to trust researchers before being candid on camera . Parents (discussion group) thought it could be very motivating
ICT linked	Novelty May mesh with school methods Motivating Potentially private eg e-survey Can be used flexibly –in terms of time and place, but also be informal ('I'll e-mail you')	Requires familiarity with facilities in school/college

- In summary, phase 1 has shown that disabled children can be included in meaningful and valid ways in sharing their views. However one fixed approach will not work for all children and young people. It is thus crucial that researchers (or others) seeking the views of disabled children have the skills and knowledge to access a range of appropriate methods and to be able to draw on this portfolio of methods flexibly and creatively in responding to individual children and young people. Given the required skills and attitudes researchers should start from a presumption that exploring the views of disabled children/young people in authentic, credible and trustworthy ways is achievable.
- Some children and young people will need support workers to enable views to be shared. However this has to be considered sensitively and a balance struck between support and unwitting oppression; this, in turn, has implications for the selection and possible costing of such support workers within a project.
- e-surveys have the potential to reach otherwise 'hard-to access' or cautious respondents such as adolescents with physical/sensory impairments attending mainstream schools.
- Other innovative approaches to seeking views warrant serious consideration. These might include the use of photography, video, music, drama and creative work using techniques drawing on the principles of graphic facilitation.

6 PROCEDURES AND METHODS CONCERNING PARENTS/CARERS

The project made use of three approaches: telephone interviews, an e-survey, and face-to-face interviews, all of which were designed to elicit the views of parents/carers. The strengths and weaknesses of these are summarised in section 6.2. The e-survey provided, perhaps surprisingly, rich and interesting responses. It also enabled the research team to access the views of some parents/carers who feel, rightly or wrongly, that their views are excluded from most processes of consultation on education for children and young people with special educational needs and disabilities. Telephone interviews enabled the researchers to hear the views of parents/carers who may have found an e-survey or questionnaire too intimidating to complete. The face-to-face group interviews facilitated the in-depth expression of views and added authenticity to the evidence provided by the e-survey.

6.1 Specific approaches

6.1.1 e survey

The development (in consultation with DRC colleagues) of the online survey for parents/carers used the short thematic version of the interview guide for children and young people as a starting point (see appendix 3d). Thus, the themes of autonomy, empowerment, inclusion and identity formed the key substantive elements and were reflected across different sections of the survey (see appendix 3f). In addition, background information was obtained about the respondents (parents/carers) and the child/young person about whom questions were asked. Background information about parents/carers in relation to gender, age and ethnicity was, given potential sensitivities, an optional section of the survey; ie respondents could choose to omit this section if desired.

The e-survey was located within the School of Education website with a specific link that could be sent to different groups of potential participants. Before answering any questions, respondents were provided with some background information about the project, as well as

links to the DRC and the relevant group in the School of Education. Respondents were also advised of their rights of confidentiality and withdrawal and could only proceed with the survey by checking boxes to affirm that they had read and understood the available information and agreed to take part in the study.

6.1.2 Telephone interviews

The e-survey form was used as a structured interview schedule (with minor modifications) for the telephone interviews. The start of the interview included reference to the researcher's interview with the parent's child and a general positive comment about that. The child's name was used (rather than him/her) in questions to personalise the interview. Further, after two interviews in which question 1.3 'Does the child/young person have a physical or mental impairment which has a substantial (lasting more than a year) adverse effect on his/her ability to carry out day to day activities' raised concerns and confusion, it was moved towards the end of the interview. Four of the six parents who opted to be interviewed by telephone expressed worries about their understanding of words/terms used and hinted at literacy difficulties. Thus giving an explicit option of a telephone interview may have enabled us to reach a group (albeit small in numbers in phase 1) who would not have voluntarily completed e-surveys or paper questionnaires.

Data from telephone interviews (and the parallel paper questionnaire) were entered into the bank of e-survey data and are thus included in those data summaries.

6.1.3 Focus group interviews - Family groups

A parent discussion group involved talking to families about:

- Preferred methods of consultation using three questions (Which methods are best for you? Which methods do you least prefer? Which methods might be best for listening to the views of your child?)

- Their general response to the e-survey (all received online information about it and a hardcopy version)
- Emergent themes in the research, based on summary data presented under the headings of: autonomy and choice; empowerment; inclusion; identity

The views of the parents/carers have been integrated into various sections of this report. It is worth noting here that they would be prepared to sharing their experiences on a longer term basis with researchers even though they lead extraordinarily busy lives. It is also important to emphasise their concern about finding ways to help the 'silent majority' of parents of children and young people with special educational needs and/or physical/sensory impairments to express their views. Finally, parents and carers taking part in this study were a self-selecting group and so results need to be viewed within that context. A more representative sample of parents/carers would be needed to see whether the findings from the present study could be replicated more widely.

6.2 Summary conclusions: procedures and methods concerning parents/carers

	Pros	Cons
Telephone interviews	<p>Good for non readers Explore points in more depth Better re sensitive points Anonymity Not too time consuming Flexible re setting time Can ask for clarification re wording Useful to triangulate child views Good for quick fact seeking Supportive</p>	<p>Not good re very sensitive issues False support –not poss to sustain For some parents knowing and trusting the interviewer is necessary</p>
E survey	<p>Anonymity National Potential large sample Good for quick fact seeking Standardised Easy to process Serendipitous – snowball sampling which may lead to interesting and productive ‘random’ sampling Needs deliberate kick starting but then provides a potentially powerful source of data Quick and easy to complete Easy to send queries to researchers</p>	<p>Requires e-literacy No probing Needs high motivation > so may attract activists disproportionately Words may be misunderstood eg SEN labels Limited response modes Not possible to calculate respondent rates Unclear how representative are the individuals/groups reached May be under represented re minority ethnic groups Serendipitous – snowball sampling Some respondents prefer eg for access reasons, other approaches</p>
Face to face group interview	<p>Loses anonymity Good re in-depth Good re sensitive issues</p>	<p>Time consuming Can involve ‘hobby-horsing’ and domination by certain individuals Needs careful managing (not controlling) Location- may require travel Time consuming re analysis Dependent on goodwill re voluntary groups</p>

- In summary, phase 1 has shown that parents and carers of disabled children wish to have their views heard. The strength of this came through very powerfully.
- The e-survey was very effective in eliciting responses from the target groups, albeit in a relatively serendipitous way. Phase 2 might usefully capitalise on the experiences gained of e-survey design, development and analyses by a more systematic use of the e-survey through collaborative work with a range of relevant, neutral, GB wide groups.
- One fixed approach will not work for all and, as with exploring the views of disabled children and young people, researchers need to draw flexibly on a range of methods if a representative spectrum of views are to be obtained.
- Some parents and carers may need emotional support in sharing views about what may have been very difficult decisions for them and their families.
- We suspect that the three methods of recruiting parent/carers (e-survey, families recruited via informal and voluntary regional networks, and families of children identified via LEA and school routes) produced slightly different types of sample reflecting systematically different populations. Phase 2 will need to either opt for a focus on one subset or explicitly plan methods and sampling to include a cross-section.

7. CONCLUSIONS AND RECOMMENDATIONS

As noted at the beginning of this report, the context in which the research has taken place is a dynamic one in which disability equality issues are receiving a high profile. Recent developments in legislation and policy are challenging the education system at national, local and school/college levels to identify and remove barriers to learning experienced by young disabled people. New legislative requirements and innovations in policy do not however, automatically bring about positive changes in practice. This is made evident in a report by Ofsted (2004) which notes for example that, in over half of the schools visited as part of a survey focusing on the planning duty (curriculum, physical environment and written information) there were no disability access plans in place and, of those that did exist, the majority only focused on accommodation. Delays in writing these plans had in part been caused by schools waiting for LEAs to provide access audits and further support with planning. In too many cases the plans were merely paper exercises to fulfil a statutory responsibility rather than demonstrating a clear commitment to improving access (p.22, para 103).

Although difficulties of this kind might, in part, be attributable to a 'policy implementation gap', as new legislation, and associated guidance takes root, it also seems plausible that discriminatory practices are still common in many educational contexts. Findings outlined in this report indicate that this is the case, and that the texture of these practices is woven into the interrelated themes of, autonomy and choice, empowerment, inclusion and support, and personal identity.

The experiences of disabled children and young people and of parents/carers vary considerably and are both positive and negative. However, too many young people and their families need to fall back on their own resilience and resources to ensure that they can access appropriate educational provision on an equitable basis with their non-disabled peers. In some circumstances this involves battling to overcome exclusionary practices, and in others to an acceptance that exclusion is a better alternative than struggling to achieve this elusive equity. Personal resources and resilience are tested most fully at times of educational transition, and a key recommendation of this report is that a second

research phase should, through the further probing of the themes summarised below, identify barriers to, and good practice in transition. A focus on the experience of transition, rather than procedures associated with it would also illuminate earlier educational experiences and identify ways in which it could better ensure that the aspirations of disabled children and young people are recognised and met rather than immobilised (Laragy, 2004; Hughes, Russell and Paterson, 2004).

The main conclusions from our report are presented below in relation to: autonomy and choice, inclusion and support, and personal identity. The research findings also highlight specific issues concerning research sampling and methodology; these focus on ethics, sampling and approaches. This chapter concludes with consequent recommendations concerning phase 2. The basis for these highlighted conclusions, as well as wider issues, are discussed in the preceding chapters.

Autonomy and choice

- There are substantial issues to be addressed around the 'hidden economy' of disability/special needs encompassing both home education specifically and other parent-supplied provision. Some parents of disabled children are acting as very vigorous individual campaigners on their children's behalf and invest an enormous amount of time and effort in this activity. For a significant minority of parents/carers of disabled children, education at home is regarded as the only satisfactory provision at present.
- While we did not explicitly compare parent and child views, these tended to complement one another. For example, one young person recalled an incident in which she had been called to the head teacher's office after accusations, which she regarded as unfair, of bullying. The same incident, which had taken place several years earlier, was also recounted (unsolicited) by both the head teacher involved and the parent. While there were differences in terms of amount of detail given, and the interpretation of events, the similarities across the three accounts were striking (such as the exact words used by the headteacher in making the accusations). Interestingly, this consistency conflicts with findings from the

literature on child interviews (eg Ceci and Bruck 1993) which suggest that the probable recurrent retelling and 'poring over' such events would have reinforced inaccuracies.

- A possible area of difference however between parent and child views concerned young disabled people's desire for greater independence, and in some instances, the positive contribution that attending a specialist educational setting was perceived as having contributed to achieving this.

Inclusion and support

- In general, there was a reported paucity of community support. An exception tended to be looked-after children, whose parents/ carers (particularly the latter) often had strong and active links with a local church, and took the child to church-based activities. However as numbers of disabled looked-after children were inevitably small, caution is needed about the generalisability of this finding.
- The role of voluntary groups emerged as very important in supporting, and providing information to, parents and carers (not only those parents whose views were recruited through such groups).
- The small number of parents interviewed indicated that they made extensive use of informal support networks, relying on family, friends and a small number of trusted professionals. This support was regarded as essential in helping them access educational provision and resources.
- There is a need to ascertain systematically what resources are available to disabled children and their families at times of transition. Following from this, exemplars of good practice might be identified (eg through child-based case studies) with a view to developing and implementing policy in this context.

- Special/mainstream schooling was not a major issue for disabled children and young people – there were more important overarching concerns such as to be well supported educationally and given opportunities for independence irrespective of educational placement. (Compare this with the views of some parents who were very clear about their preference for special rather than mainstream settings and their unhappy experiences in the latter.)

Personal identity

- A major theme emerged around disabled children's resilience: specifically, how this is fostered or hampered across individual, inter-personal, school, college, family and community/cultural contexts. Resilience is tested and/or strengthened at times of transition (not just at the formal transition points such as those across schooling at ages 11 and 14 but also in negotiating entry to, for example, new friendship groups) so transitional experiences have a particular importance, and salience, for children/young people and their parents/carers. That salience emerged, for children, young people and their parents, both in reported events and in hopes/fears for the future.
- There was considerable sensitivity for various players- schools, parents and children in the application of the disability label at two levels: first, a lack of awareness/knowledge (for parents/ carers) about the disability provisions of SENDA (2001); and second, possible anxieties about 'disability labelling' (possibly linked with fears and/or confusions about 'SEN' compared with 'disability').

Methods and methodologies - ethics

- The considerable time demands in setting up such a project with multiple layers of permission needed (particularly when liaising/working with informal groups) needs to be recognised at the outset. Considerable time is also needed in the early stages of the project for the researcher to understand which approaches will best help the child/young person to share views in an open and comfortable way.

- Researchers need to leave room within methods for schools and others to make choices and so to feel that they have some control. After initial briefings and engaging collaborators, participants may need space to be left alone (except for 'health check' calls).
- If taking children's views seriously, researchers need to find ways to give feedback to children, and show how their views have been taken/not taken on board. In this connection, modest tokens of recognition (such as book tokens) for the involvement in the project of disabled children and young people are appreciated.
- Some children and young people will need support workers to enable views to be shared. However this has to be considered sensitively and a balance struck between support and unwitting oppression; this, in turn, has implications for the selection and possible costing of such support workers within a project. Where support workers and/or translators/signers are used/anticipated these need to be costed and used independently from school/college staff. This is so because of confidentiality/ethical issues; as well as the need to diminish a natural tendency for staff to teach, intervene or unwittingly 'lead' a response.
- Some parents and carers may need emotional support in sharing views about what may have been very difficult decisions for them and their families.

Methods and methodologies - sampling

- Procedures and methods for consulting parent/family groups were evaluated. The use of telephone interviews, an e-survey tool and face-to-face group interviews all revealed strengths and weaknesses. Most importantly, they raised significant issues about sampling (who is reached) and how (accessibility of methods) to seek the views of 'hard to reach' families and communities.

- There are some hints that there may be systematic intra-GB differences which warrant further investigation. Differences by social class/ethnic minority may also be significant. However, further work is required to test this and care is needed not to extrapolate findings from particular groups in ways that over-generalise.
- There may be systematic differences between parents' and carers' views but numbers were too small in phase 1 to be confident about possible differences. It was noted by some parents in the telephone interviews that looked-after children benefited from additional support (eg an independent advisor) at transition, not experienced by other children.
- Open methods of sampling raise potentially sensitive and possibly time-consuming issues about how to respond to particularly needy or persistent individuals some of whom may be pursuing grievances against particular organisations or individuals.

Methods and methodologies – strategies

- Phase 1 has shown that children with diverse physical/sensory impairments or special needs can be included in meaningful and valid ways in sharing their views. However one fixed approach will not work for all children and young people. It is thus crucial that researchers (or others) seeking the views of disabled children have the skills and knowledge to access a range of appropriate methods and to be able to draw on this portfolio of methods flexibly and creatively in responding to individual children and young people. Given the required skills and attitudes researchers should start from a presumption that exploring the views of disabled children/young people in authentic, credible and trustworthy ways is achievable.
- Similarly, one fixed approach (of sampling or in hearing views) will not work for all parents/carers and, as with exploring the views of disabled children and young people, researchers need to draw

flexibly on a range of methods if a representative spectrum of views are to be obtained.

Recommendations concerning Phase 2

The above conclusions, and those in the main body of the report, imply and embody many recommendations concerning the foci and methods for a possible phase 2; more specifically, the findings from phase 1 point to:

- Given possible systematic differences between England, Wales and Scotland concerning disability/SEN policy and provision, phase 2 needs to include intra-GB work including systematic scrutiny of survey and case study. An initial route in would be through (eg) surveys to relevant groups (see below) supplemented by a small number of child-based case studies.
- A nation-wide systematic sample by key demographic variables such as age, geographical location, socio-economic background and ethnicity might be accessed to collect a representative national picture of views by, for example, using brief face to face interviews with people stopped at key locations (eg shopping centres). This would have the advantage of statistical generalisability but with limited quality of responses and some sample bias.
- A national picture of views could be obtained through conventional pencil and paper questionnaires targeting, for example, a cross section of the population using recognised statistical sampling techniques. Such an approach might encompass diversity of responses but is prone to respondent bias.
- The e-survey was effective in eliciting responses from the target groups, albeit in a relatively serendipitous way. Phase 2 might usefully capitalise on the experiences gained of e-survey design, development and analyses by a wider and more systematic use of an e-survey through collaborative work with a range of relevant, neutral, GB-wide groups. This would need to be supplemented with

a method designed to reach parent/carer groups who do not regularly use the internet; eg via telephone interviews.

- We suspect that the three methods of recruiting parent/carers (e-survey, families recruited via informal and voluntary regional networks, and families of children identified via LEA and school routes) produced slightly different types of sample reflecting systematically different populations. Phase 2 will need to either opt for a focus on one subset or explicitly plan methods and sampling to include a cross-section.
- Phase 2 might usefully involve case studies (eg a small number of children/young people in each of 4 GB regions; urban England, rural England, Wales, Scotland) to explore in-depth factors associated with resilience with disabled children/young people acting as co-researchers and 'snowballing' methods/samples (to include individual, inter personal, family and community/cultural factors). The aim would be to both illuminate policy/provision and to provide some exemplars of effective practice.
- In-depth work in a few sites rather than/as well as a 'sweep' approach would enable views of non-disabled children and young people eg re choice/inclusiveness, as well as those of the disabled children and young people to be explored - so avoiding a possibly misplaced (sole) over-emphasis on disability per se; linked with a wider and deeper look at system level features (inclusion and exclusion) as well as individual perspectives.
- The language of disability/SEN was found difficult or incomprehensible for a significant sub-group of parents. Phase 2 needs to bear these potential difficulties in mind and respond accordingly in planning sampling and methods.
- Individuals and groups involved in phase 1 could be explicitly involved in phase 2 in piloting and development work and/or to meet specific criteria for inclusion in phase 2 (eg looked after children). The great enthusiasm for continued involvement from virtually all phase 1 participants suggests that this would be fruitful.

- This process is most meaningful, valid and ethically appropriate when disabled children and young people have continuing involvement, if possible - as co-researchers for at least part of the project, in the research process over time, in contrast to conventional 'hit and run' approaches to data collection. Close collaboration and continuing involvement of schools or voluntary groups are vital to sustain target recruitment and data collection. The longer-term involvement of parents would add a powerful further dimension of meaning to a second phase of research.
- If phase 2 is to involve children and young people as a reference group and/or as co-researchers, both valuable and appropriate strategies in this type of project, then this is likely to need to be set up quickly. In which case, phase 2 will need to find either a swift and appropriate method for recruiting, retaining and involving a new group or to engage known individuals. These children and young people might be through reference groups already known to the DRC and/ or through phase 1 participants.
- Some sub-groups (notably minority ethnic groups, looked after children, children educated at home, children in rural communities, children with mental health difficulties) were under-represented in both parts of phase 1. Phase 2 might take an explicit focus on one such sub-group. The likely time and budget constraints of phase 2 would preclude in-depth focus on more than one group.
- Innovative approaches to seeking views warrant serious consideration. These might include the use of photography, video, music and creative group work (such as techniques drawing on the principles of graphic facilitation). However, as above, time and budget constraints need to be recognised.

APPENDICES

Appendix 1 Notes on design

Approaches

The design of the study has involved three sets of sampling strategies: first, various purposive sampling stemming from a succession of targeted LEA contacts within one LEA and second, purposive sampling within a second LEA based on the research team's knowledge of formal and informal parent/carer/family networks concerning disabled children in that locality. A third strategy, involving e-networks has been used to provide a wider geographical sample of parent/carer views with the intention of reaching a wider group of parents/carers.

Purposive LEA-led

Selection of the two LEAs (sampling strategies 1 and 2 above) was based on: (1) consultation with the DRC in the light of regions used/not used previously, (2) the availability of diverse disabled groups including pupils and students from black and minority ethnic minorities, (3) permitted access to the Local Authority reflecting eg Ofsted Local Education Authority inspection timetables (4) geographical accessibility for the research team and (5) our previous contacts with the Authority so as to build on established relationships. The latter was particularly important for sampling strategy 2 above.

Children and young people were told about the project by parents and teachers. In one special school all relevant pupils in two transition phases (ie years 5/6 and years 12/13) were contacted by the school with letters of invitation to participate in the project; all those giving permission (N=13) were then involved. In all other schools/the college, the pupils were identified by the institution according to a series of specific criteria. This was necessary in order to ensure a sample containing looked after children, a cross section of minority ethnic children and a cross section by disability.

At the further education college, the students (selected by the college on pragmatic grounds but reflecting a cross-section by age and disability) gave their own consent. The parents/carers of the other pupils were sent letters by the schools inviting participation (see appendix 3a). The participating schools worked assiduously in chasing up delayed responses and from the outset went to considerable lengths to support the project. Only those school-age pupils whose parents/carers returned a signed consent form agreeing to their child's participation (and their own potential involvement in follow up interviews) were included. Careful attention to such ethical procedures and building of trust took considerable time.

Table 6: Successive sampling strategies within sampling strategy 1

Initial contact	2nd level gatekeepers	3rd level gatekeepers		Pupil samples
UoB> senior lead in LEA (dep director)	> named inspectors, advisors	> named headteachers, on basis of likely interest in the project, involvement with 'child voice' initiatives and relevant school populations	> 'school sweep' by age phase- invite to all parents	> all those responding positively involved
As above	As above	As above	> headteachers/ SENCO	> targeted individual children, identified by key criteria: phase transition, looked after status, ethnicity and disability to provide a cross section
As above	As above	> key individual eg Principal of national FE college	>>>>>	As above
* As above	As above	>>>>>>>	> database of children with SEN/ statements incl FE	> individual children + their parents/ carers

NOTES

- UoB = University of Birmingham research team
- 'children' = children/young people
- *italicised row*- identified as a potential approach but not used as total numbers and nature of pupils sought were met by the other strategies

Purposive researcher-led

A group of parents involved in a second LEA's consultation group on the development of a city-wide inclusion strategy was contacted through an education officer. Having been given information about the project, eight families indicated a willingness to share their experiences – independent of LEA involvement - of using educational and related services. This group discussed issues of the kind identified in the e-survey and provided opportunities for more open dialogue about educational experiences and the identification of preferred methods for consultation and involvement in the research process.

National e-based

The following 13 websites/e groups (selection of these based on the research team's knowledge of the field and discussions with DRC colleagues) were contacted:

AbilityNet

Alliance for Inclusive Education

Association for Spina Bifida and Hydrocephalus (ASBAH)

BECTA (SENCO Forum and other relevant 'SEN' forums run by them)

British Institute for Learning Disability (BILD)

Contact a Family (CAF)

Disability Equality in Education (DEE)

Home Farm Trust (Family Support Team) (HFT)

Independent Panel for Special Education Advice (IPSEA)

Mencap

National Institute for Conductive Education

Parents for Inclusion

West Midlands Regional Partnership

The nature of the project was explained and the list owner was invited to place a notice about the e-survey on their notice boards and/or e-mail message board. All agreed to do so. Some of these groups were predominantly 'direct' groups ie likely to be accessed directly by carers/parents of children with disabilities or special needs while others were predominantly indirect ie access to carers/parents of children with disabilities or special needs is likely to have been made through a message being read by a site/e group member and passed on (as invited to do). In addition, a web link was set up between the DRC site and the survey form.

APPENDIX 2 SAMPLES, SAMPLING AND PROCEDURES

a) Children and young people (including FE college)

29 disabled children/young people (as defined by the schools) were interviewed. For 19 interviewees this involved a support worker/signer. In addition, 8 young people from an FE college were interviewed and did not need additional support to participate. Six of these students were resident college students from various parts of the country (England). One lived at home and attended college on a daily basis another lived in a specialist centre but attended college on a part-time basis as a day student.

In relation to disability, children/young people interviewed included the following: 2 with dyslexia, 10 with autism/ASD, 12 with physical disabilities, 5 with sensory impairments, 5 with speech and language difficulties, 7 with severe or profound learning difficulties/disabilities, and 4 with emotional/mental health problems. NB many children/young people had multiple disabilities and so feature more than once in the above list. In relation to looked after/family status and ethnicity, children/young people interviewed included 3 looked after children (Note-many other children/young people interviewed came from disrupted family contexts) and in relation to ethnicity: 2 Black British, 1 mixed race, 2 Asian and 32 white.

In relation to age range, children/young people interviewed included the following: one under age 7, 17 age 8-11, two age 12-16, twelve age 17-19 (spanning secondary special school and FE college provision) and six age 20-35 (recruited through an FE college). The secondary school involved in the project identified six children to participate. However only one of these pupils ultimately took part as three opted out, not wishing to be identified/not seeing themselves as 'disabled, one failed to return the consent form although said his parents gave consent, and one was a persistent absentee who was not present when the researcher visited the school. Given that only one secondary school was involved it is not possible to know whether this reflects a general reluctance for similar involvement from pupils in this age band (ie 12-16 years).

Developmental work would suggest that this is a particularly sensitive period in the formation of young people's identities so being identified as different from peers (ie disabled) may be particularly delicate. Interestingly, this may be more of an issue in mainstream schools than in special schools as in the latter, a disabled identity may be nurtured and validated.

Table 7: Children and young people interviewed

SCHOOL	SEX	NAME Note re looked after status/minority ethnic group	AGE (yrs)
Sec	F	Gemma Looked after	11
Prim 1	F	Claire Afro Caribbean	10
Prim 1	M	Richard	10
Prim 1	M	Simon	10
Prim 2	M	Robert	10
Prim 2	F	Florence Mixed race	9
Prim 2	M	Mark	9
Prim 2	F	Alice Black British	6
Prim 3	F	Elizabeth	9
Prim 3	M	Symeon Asian	10
Prim 3	M	George	9
Prim 3	F	Rebecca	9
Special 1	M	Ryan	18
Special 1	M	Matthew Looked after	12
Special 1	M	Jordan	16
Special 1	F	Victoria Looked after	16
Special 1	M	Amil	15

		Asian	
Special 2	M	Jack	7
Special 2	F	Emily	10
Special 2	M	Thomas	9
Special 2	M	David	10
Special 2	F	Amy	10
Special 2	F	Sophie	10
Special 2	F	Lisa	16
Special 2	M	Michael	16
Special 2	F	Cathy	18
Special 2	F	Tracey	17
Special 2	M	William	18
Special 2	M	Ford	19
FE college	F	Jessica	21
FE college	M	Brian	20
FE college	M	Alan	19
FE college	M	John	22
FE college	F	Barbara	31 - 35
FE college	M	Ron	23
FE college	M	Kenneth	19
FE college	F	Patricia	18

NOTE: Pseudonyms given here

Procedure

Pupils were given an information sheet and/or verbal explanation outlining the nature of the project (see appendix xx) and invited to participate. The interviews were, with the explicit consent of the children/young people, audio recorded. They were told that they could ask for the audio recorder to be switched off at any point (only two pupils requested this; one towards the end of the interview when she wanted to speak 'off the record', the other when after half an hour he wanted to return to his class). Pupils were also told that they could withdraw from the activities at any point. Interviews took place in small classrooms/community rooms in the schools/college, usually near pupils' classrooms; the door of the interview room was left ajar if schools requested this. (Note - all members

of the research team hold current clearance by the CRB (Criminal Records Bureau)).

At the conclusion of the interview/activities each participant was given a £5 book token in recognition of their contribution. This was cleared with schools/college beforehand but pupils/students did not know about the tokens in advance. All were surprised and pleased with the tokens. Schools had the option of receiving the tokens for the school but all preferred that they be given to individual participants.

The same approach was adopted for interviewing young people in further education. Students were given prior notice of the interviews and the format. Interviews commenced with an introduction to the project, using a young person's information sheet, and permission to record the interviews was sought. Participants were also given book tokens and appreciated this recognition of their contribution to the discussion. During the interview/discussion, particular care was taken to ensure that all participants had the opportunity to express their views on an equitable basis. Opportunities to alter the format of the interview were offered during discussions, but participants were happy with the approach being used.

The further education college participants positively 'opted in' to the interview (in two groups). They were happy to discuss their 'disabled identity' and to relate this to earlier educational experiences in both mainstream and special school settings. They were also keen to emphasise that their identities were not solely defined by disability.

The grid below shows the range of methods planned for exploring children's views and the ways in which they varied by key variables of:

- Initiator
- mode of presenting opportunity to share views
- support to communicate views
- mode of child's communication and
- lead role in terms of adult or child.

Table 8: Variables modified in interviews

WAY OPP TO SHARE VIEWS WAS PRESENTED	NUMBER IN GROUP Child + adult *	SUPPORT/ STIMULUS TO COMMUNICATE	WAY CHILD COMMUNICATED IDEAS/FEELINGS	LEAD TAKEN BY
Talk/sign	1 + 1	Support worker as needed	Talk /sign	Adult
Talk /sign +cue cards	1 + 1	Cue cards + Support worker as needed	Talk /sign	Adult
Talk/sign	C 2-4 + 1	Small group interview + Support worker as needed	Talk /sign	Adult
Talk/sign	1+1	Puppets + Support worker as needed	Talk/sign/puppets	Variable
Talk/sign	Variable	Support worker as needed	Posters/drawing	Adult then child
Talk/sign	Variable	Support worker as needed	Mapping activity incl PATH	Adult then Child
Talk/sign	1 + 1	Support worker as needed	Diamond ranking + talk/sign	Adult
Talk/sign	1 + 0	None	Video diaries	Child
Talk/sign	Variable	None	Photographic trail	Child

* adult supporter not included in count

b) Families

- i) Linked with children/young people interviewed and recruited through LEA 1

A cross-section of parents/carers whose children were involved in interviews in LEA 1, were contacted in January 2005 and invited to take part in the next (parent-oriented) part of the project. The schools made the initial contact, by sending out letters drafted with the research team, written on school notepaper and signed jointly by the headteachers and the project team. The letters invited involvement and sought formal consent. 17 out of 18 parents approached (none from the secondary school) responded positively to these invitations. Each of these parents/carers (in one case separately as the child had concurrent visiting/residence rights with each of the separated parents) was invited by letter (including sae) to give their preferred method for sharing views (from - telephone interview, e-survey, paper survey). 13 of these 17 (76%) were followed up using their preferred method; six through telephone interviews (5 out of these 6 were parents of children at special schools), 3 through the e-survey (all were parents of primary school children) and 3 through a postal survey. Those requesting the paper survey were sent the survey form (with sae).

4 sets of parents did not respond further. These represent the most hard to reach group of parents of disabled children and we can only guess at how, if at all, their views may have differed from those of other parents. The group of parents interviewed by telephone may, as noted in the main report, have been systematically different, from e-survey respondents perhaps by internet use, culture, experiences of the system, confidence in the system, and/or reading/writing capabilities. Further, they may also have differed systematically from the parents recruited through local voluntary groups.

ii) Recruited through local support groups

As noted earlier, eight families (parent/s, children/young people) in the Birmingham area participated in focused group discussions. These families were initially contacted in writing and via follow-up telephone calls.

iii) Recruited through national e-networks

A total of 157 people responded to the survey. Approximately 30 of these either completed hard copies of the questionnaire or were interviewed over the telephone using the survey schedule. The responses of these responses were later entered into the e-survey form so that responses from all participating parents/carers could be analysed as a group.

156 respondents chose to include their background information: 133 (85%) were female, the majority (82%) aged 30-50 years, based in the UK (99%) and of white ethnic origin (97%). The geographical spread of respondents according to region was reasonably wide including South East, South West, Midlands, North East and West regions of England as well as some responses from Scotland (8 or 5%) and Wales (10 or 6%). One response was from Indiana in the United States.

The majority (85%) of respondents to the e-survey indicated that their child/young person was aged 5-11 (52%) or 11-16 (33%). 6 responses were about a child/young person aged 0-4 (4%) and 17 were in relation to young people aged 17-24 (11%). The breakdown of type of educational provision was as follows: Mainstream 40% (63); Specialist 35% (55); mix of special and mainstream 16% (25) and 9% children/young people not in school/college (14). Note that it became clear from later responses that the latter group was largely comprised of children/young people who had been withdrawn from formal schooling and were being educated at home.

143 respondents (91%) indicated that their child/young person had a mental or physical impairment which had a substantial adverse effect on his/her ability to carry out day to day activities. 47% (61) of children/young people were described as having a Specific Learning

Difficulty; 23% (30) a Moderate Learning Difficulty; 24% (31) a Severe Learning Difficulty and 6% (8) Profound and Multiple Learning Difficulty.

A range of further needs were also checked by respondents including 82% (78/95) with Behaviour, Emotional and Social Difficulty; 63% (84/134) with Autistic Spectrum Disorder; 37% (50/134) with Speech, Language and Communication Needs and 57% (25/44) with Multi-sensory Impairment. Parents/carers also indicated a range of other disabilities/conditions across the sample including epilepsy, dyspraxia, motor disabilities, food allergies and intolerances.

APPENDIX 3 RECRUITMENT AND DATA COLLECTION TOOLS

a) Letters

17 January 2005

Dear (PARENT NAME)

Experiences of pupils with special needs, and their families

Last term you kindly gave permission for your child to be involved in the above project, being carried out by the School of Education, University of Birmingham, and as you know we talked with him/ her (AS APPROPRIATE) before Christmas. We were very interested in the children's full and thoughtful responses.

The views of parents and carers are also an important part of the study. We would like to arrange to talk with you briefly by telephone about some of the issues. We are especially interested in matters concerning educational choices as well as degrees of inclusion in schools and communities.

We anticipate that the conversation will take about 10 minutes. Your responses will be confidential to the project team and no individual parent/ carer, child, teacher, school or LEA will be named in any report about the project.

A summary of the conclusions from this project will be available from our webpage from the end of April 2005. The work is funded by the Disability Rights Commission and the findings will help to shape policy concerning children with special needs or disabilities.

Please return the form below and/or contact the project administrator, Lin Walsh on 0121 414 4834 or l.j.walsh@bham.ac.uk so that we can set up a time to talk which is convenient for you. We plan to complete the telephone interviews by mid February. If you would prefer a postal or e questionnaire as a format for expressing your views please indicate this and we will then send you the appropriate survey form.

The project team is part of the School of Education at the University of Birmingham. More details about the group as well as this (and other) project(s) can be found at:

<http://www.education.bham.ac.uk/aboutus/profiles/inclusion/default.htm>

If you have any questions, or would like more details about the research project, please see our web site and/or contact Lin Walsh on 0121 414 4834 or l.j.walsh@bham.ac.uk

Yours sincerely

Professor Ann Lewis
Head of Division: Inclusion, Special Education and Educational
Psychology

Enc

Project: Experiences of pupils with special needs, and their families

YOUR NAME: _____

- I agree to take part in this study.

Please indicate your preferred way of sharing views with us

- I should prefer to share my views through a telephone interview

preferably on _____ (day(s) of the week)

at _____ (time of day approx)

telephone number _____ (work)

telephone number _____ (home)

Please give most convenient number(s) for you

OR

- I should prefer to share my views through an e survey

Please give most convenient e mail address for you

OR

- I should prefer to share my views through a postal questionnaire

Signed:

Date: _____

**Thank you for completing this form. Please return it to Lin Walsh,
School of Education, University of Birmingham, Edgbaston,
Birmingham B15 2TT**

b) Information sheets (3 parallel versions)

Project People

Ann Lewis, Christopher Robertson, Sarah Parsons and Lin Walsh are doing the project. They work at the School of Education at the University of Birmingham. The project is being carried out with the help and guidance of the Disability Rights Commission.

Lin Walsh can be contacted on:



0121 414 4834



l.j.walsh@bham.ac.uk

Project Topic

The project is looking at what young disabled people and those with Special Educational Needs like and don't like about school or college, and what they would like to change.

Other projects have suggested that many students with disabilities may be treated differently at school or college because of their disabilities. These projects have mostly asked teachers about their views.

The purpose of this project is to ask young people what they think.

Project aims

We would like to find out the best ways of helping young people to tell us what they think. There are a number of ways to do this and we hope to try different ways with different people. Some examples are: using pictures or cameras, emails and computers, talking in groups and pairs.

People can choose whether they want to take part by themselves or bring a friend or teacher with them.

Project participants

There will be a number of schools and colleges taking part, with young people of different ages and with different needs. Parents and carers of young people will also be asked to take part in the project.

Project time-scale

The project started in August 2004 and will finish by April 2005. Probably in the Autumn Term we will visit schools to see if people would like to take part and give some more information about the project. There will be a chance to ask questions about the project and people do not have to take part if they do not want to.

Project Ethics

The project will take an ethical approach, which means that it follows guidelines from different organisations about how projects should be carried out. This includes things like making sure people understand why they are doing the project and that they can stop at any time. There will be a written report about the project and people's names are never used when we do this. No-one else will know who has taken part in the project.

Information sheet:
Experiences of disabled students and their families - phase 1
Project commissioned by the Disability Rights Commission

Research team

Ann Lewis, Sarah Parsons, Christopher Robertson and Lin Walsh
School of Education, University of Birmingham.
Contact: 0121 414 4834, l.j.walsh@bham.ac.uk

Background

There is evidence from work by the Disability Rights Commission that the extent of prejudice and discrimination experienced by disabled pupils and students in education settings is substantial. The long-term effects are particularly damaging and continue to sustain patterns of social and economic exclusion.

Main aims of this project – re pupil/student views

1. Test and review a variety of methods for recruiting and consulting young disabled people in education and their parents/carers
2. Identify the most appropriate methods for recruiting a representative cross-section of participants
3. Identify the most appropriate and inclusive methodologies for exploring the views of a wide range of participants
4. (In outline) identify the key concerns and priorities for young disabled people in relation to their experiences of education

Sample – pupil/student views

10 groups (minimum of 5 children/young people per group making 50, minimum, in total) to include primary and secondary school age pupils/FE students - with learning difficulties - to include some looked after children, where possible, and to include at least 2 pupils from special/residential schools; primary and secondary school age pupils/FE students - with sensory impairments; primary and secondary school age pupils/FE students with physical disability, to include 2-3 children in hospitals; and pupils or students using mental health services.

Methods – pupil/student views

The pupils/students will be introduced to the project rationale and invited to opt for participation (with a friend if preferred) in one or more of the following strategies for exploring and expanding their views. The substantive content will relate to matters concerning experiences of disability and provision. The methods portfolio will comprise: individual interview using cue cards, e survey, posters (half to include use of disposable cameras), mapping activity, PowerPoint based interview, individual interview with peer as co-researcher, diamond ranking, small group interview, video-based techildrenique, or images.

The views of parents/carers of a sub-sample of these pupils/students will also be explored (through face to face, telephone or e-based interviews).

Time scale

This phase 1 project began in August 2004 and will be completed by 1 April 2005.

Ethical issues

The ethical codes of the Disability Rights Commission and the British Education Research Association will be followed. Informed consent will be aimed for with all participants. Participants and relevant workers will receive feedback about our findings and have the opportunity to comment on them. Direct quotes will be anonymised in related reports and publications.

Project about the experiences of disabled students and their families

Who's doing the project?

Some people from the University of Birmingham with help from the Disability Rights Commission.



Ann



Christopher



Sarah

To contact Lin Walsh (secretary):



0121 414 4834



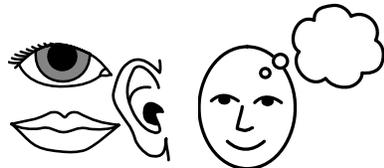
l.j.walsh@bham.ac.uk

What is the project about?

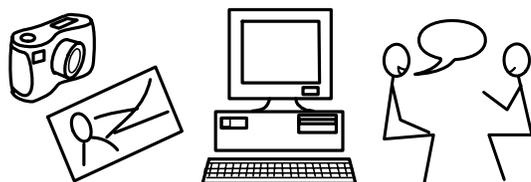
The project is looking at what young disabled people and those with Special Educational Needs like and don't like about school or college, and what they would like to change.

What do we want to know?

We want to find out the best ways of helping young people to tell us what they think.



There will be a number of ways we can try to do this, for example with pictures, a computer, cameras, talking in groups or in pairs.



People taking part in the project will be asked if they would like to have a friend with them when they tell us their views, or if they would like to do this by themselves.

Who will be asked to take part?

There will be a number of schools taking part, with young people of different ages and with different needs.

Parents and carers of young people will also be asked to take part in the project.

What happens next?

The project started in August 2004 and will finish by April 2005.

Probably in the Autumn Term, we will visit schools to see if people would like to take part and give some more information about the project. There will be a chance to ask questions about the project and people do not have to take part if they do not want to.

Ethics

There are certain ways of doing projects that makes them **ethical**. The project has to carefully consider the people taking part and includes things like making sure people understand why they are doing the project and that they can stop at any time. It also means that we will tell people about what we found out in the project when it is finished, although people's names are never used when we do this. No-one else will know who has taken part in the project.

c) Interview schedule-long version

Children and young people: Interview Frame (Schools and related provision)

<p>1.) Learning experiences</p> <p>What's it like in your class (this school)?</p>	<p>Prompts – in the classroom</p> <ul style="list-style-type: none"> • Curriculum - subjects you like or don't like? • Curriculum – are you left out of anything? • Teaching and learning - do you like the way you are taught? • Expectations – do teachers (and other staff) make you work hard enough? • Timetable - does the timetable work for you? • Grouping – what groups do you work in? • Friends - do you work with friends? • Streaming - do you work with different groups in different lessons? • Homework – do you get homework to do? • Assessments (SATs and exams) - do you do tests/exams? • Assessments (SATs and exams) – do have/need help/support with tests and exams? • Resources - do you have enough equipment to help you learn (eg ICT, special PE resources) • Space – is there enough room in the classroom(s), and can you move around it easily? <p>Prompts – around school</p> <ul style="list-style-type: none"> • Breaks and lunchtimes - what do you do at break and lunchtimes? • Friends – do you play with friends at break and lunchtimes? • Clubs and activities - do you join in with out of class activities (eg at lunchtimes and after school) • School sport – do you do and sports activities • School trips - do you join in school day and residential trips? • Space – is getting around the school easy? • Space – what are the toilets/bathrooms like, and can you use them easily? • Transport – how do you travel to and from school? • Transport – does transport cause any problems for you? <p>Probes</p> <ul style="list-style-type: none"> • How do you feel about being in this school? • Do you feel different at home? • Do other people feel differently about you <ul style="list-style-type: none"> - parent(s), carer(s) - teacher, teaching/learning assistant, SENCO - other important people • Who do you get on well with in the school? • Who supports/helps you?
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<p>2.) Policies and rules</p> <p>Are there any school policies and rules that have an effect on you?</p>	<p>Prompts</p> <ul style="list-style-type: none"> • Policy – is there a policy in your school about including disabled children and young people? • Policy – do children and young people have a say in designing a policy about including disabled children? • Policy – does the school provide information to children and young people in easy to read (accessible) formats? • Rules - are there any school rules that have an effect on things you do in the school? <p>Probes</p> <ul style="list-style-type: none"> • Should any rules be introduced to help disabled children and young people to feel included in the school? • Should any rules be changed to help disabled children and young people to feel included in the school?
<p>3.) Procedures and processes</p> <p>Are you involved in discussing your learning?</p>	<p>Prompts</p> <ul style="list-style-type: none"> • IEPs – do you have an IEP, and if so, how do you get involved with planning (what I need/want to learn), monitoring (how am I doing) and reviewing (how have I done and what do I want to do next)? • Annual reviews – do you attend these and contribute to discussions and future planning? • Other planning – did you have a say in other assessments and plans to help your learning (eg 'statutory assessment' and 'statementing') • Groups – do have opportunities to talk about your learning with other disabled children and young people? • Support – do any members of staff give you guidance about learning or other needs? <p>Probes</p> <ul style="list-style-type: none"> • What does it feel like to have an IEP/statement? • Do you have any extra learning, or other support, and if so what is it like? • What do other people (eg parent(s), carer(s), staff) think of the support you receive?

<p>4.) Choice (admissions)</p> <p>Why did you come to this school?</p> <p>Which school/college do you want to go to?</p>	<p>Prompts</p> <ul style="list-style-type: none"> • Is this the school you wanted to attend? • Where do you hope to go to next (primary > secondary, secondary > FHE, school > training or employment) <p>Probes</p> <ul style="list-style-type: none"> • Do you feel that you have had a 'real say' in choosing where you go to school? • Where did your parent(s)/carer(s) want you to go to school? • Is this the school your teachers wanted you to attend?
<p>5.) Exclusions</p> <p>Have you been excluded – formally or informally – from school?</p>	<p>Prompts</p> <ul style="list-style-type: none"> • Do you feel left out of any lessons, formal activities (eg clubs) or informal activities (eg games at break or lunchtimes) in school? • Have you (if applicable) been excluded from school, and if so has it been difficult to get back in to education? <p>Probes</p> <ul style="list-style-type: none"> • Do you feel fully included in the school? • Do your parent(s)/carer(s) think you are fully included in the school? • Have other people (eg children and young people, teachers, SENCOs, teaching or other assistants) helped you to feel included in the school?
<p>6.) Aspirations</p> <p>What are you hoping to do in the future?</p>	<p>Prompts</p> <ul style="list-style-type: none"> • What do you want to do when you leave the school (whichever phase)? • Have you thought about the next steps in education (if applicable), training or employment? • Have you received any advice about your future hopes and plans (eg from a class, pastoral teacher, careers or other adviser)? <p>Probes</p> <ul style="list-style-type: none"> • Do you feel that you will be able to do what you want in the future? • Do your parent(s)/carer(s) know what you want to do in the future, and support you? • Do teachers, or other staff know what you want to do in the future, and discuss possibilities with you in a supportive way?
<p>7.) Transfer (transitions)</p> <p>Where are you moving on to?</p>	<p>Prompts</p>

	<ul style="list-style-type: none">• What support are you getting with arrangements for transfer to the next phase of education?• Do you get advice from a specific person (eg SENCO, Connexions personal adviser)?• Have you been given the opportunity to discuss your own views on where you might continue your education (or training and employment), and have you received advice about a range of options available? <p>Probes</p> <ul style="list-style-type: none">• Are you able to say what you would really like to do next?• Do your parent(s)/carer(s) understand and support your plans?• Do your teachers and other advisers understand and support your plans?
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Children and young people: Interview Frame (Schools and related provision) 15/11/04

<p>3.) Learning experiences</p> <p>What's it like in your class (this school)?</p>	<ul style="list-style-type: none"> • Curriculum • Teaching and learning • Expectations • Timetable • Grouping • Friends • Streaming • Homework • Assessments • Resources / Space • Breaks and lunchtimes • Clubs and activities - /School sport/trips • Transport
<p>4.) Policies and rules</p> <p>Are there any school policies and rules that have an effect on you?</p>	<ul style="list-style-type: none"> • Policy • Rules
<p>3.) Procedures and processes</p> <p>Are you involved in discussing your learning?</p>	<ul style="list-style-type: none"> • IEPs • Annual reviews • Other planning • Groups • Support
<p>5.) Choice (admissions)</p> <p>Why did you come to this school? Which school/college do you want to go to?</p>	<ul style="list-style-type: none"> • Is this the school you wanted to attend? • Where do you hope to go to next (primary > secondary, secondary > FHE, school > training or employment)
<p>5.) Exclusions</p> <p>Have you been excluded – formally or informally – from school?</p>	<ul style="list-style-type: none"> • Do you feel left out of any lessons, formal activities (e.g. clubs) or informal activities (e.g. games at break or lunchtimes) in school? • Have you (if applicable) been excluded from school, and if so has it been difficult to get back in to education?
<p>8.) Aspirations</p> <p>What are you hoping to do in the future?</p>	<ul style="list-style-type: none"> • What do you want to do when you leave the school (whichever phase)? • Have you received any advice about your future hopes and plans (e.g. from a class, pastoral teacher, careers or other adviser)?
<p>9.) Transfer (transitions)</p> <p>Where are you moving on to?</p>	<ul style="list-style-type: none"> • What support are you getting with arrangements for transfer to the next phase of education? • Do you get advice from a specific person (e.g. SENCO, Connexions personal adviser)? • Have you been given the opportunity to discuss your own views on where you might continue your education (or training and employment), / received advice

d) Short interview schedule for children/young people re-organised by emerging themes

Autonomy

Choice re school/class
Choice about curric
Choice about setting/ grouping/workmates
Choices about support
Homework
After school clubs/activities

General- What can/cannot be done on own/without asking- at school/other

Views re help- who/for what/why/good-bad

Empowerment

Are you involved in discussing/choosing what work you do
Role re procedures re transition
Received advice re future?

Inclusion

Any places where people might feel left out re the school
Any places where people might feel left out re near home

Are there rules re all children feel included in this school
Should there be more rules about making all children feel included in this school

School rules/procedures- made by
School council

Identity

Do you feel different at home from at school
Treated differently at home/school/other
Any children in school who are different from others- who/why
Any disabled in school
In class
As friends
Bases for any difference

e) FE College: Group discussion/interview

How would you – as disabled students - like to be consulted about your experiences of education?

Running order

Introduction and who's who
Information about the project

Consent

Setting the scene

- ✓ Who we have met and spoken to
- ✓ How we have spoken to people (individual children in special, primary and secondary schools – using a range of approaches)
- ✓ Email survey (about to be launched)
- ✓ What will do with ideas children and young people (students) share with us > feedback to the DRC (**Check:** Do you know what the DRC is and does?)
- ✓ We want to hear from everyone in the group

Discussion framework

What is the best way of contacting/meeting students ... and listening to you?

- through college
- through an e-group or internet
- meeting offsite (eg at the university or another venue)

What sort of 'tools' should we use to help with discussion?

- interviews (individuals/groups)
- questionnaires
- discussion groups
- examples from your experience (**prompt** – video diaries?)

What are the key concerns that you have about your experience of education (here and in the past)?

Prompts

Inclusion (where education takes place) -

Empowerment (feeling in control and having options)

Autonomy (decision and choice making)

Identity (disability and identity – does it matter?)

What are your best experiences of education?

f) E survey for parents/ carers (paper version)



**Experiences of disabled students and their families:
On-line Questionnaire for parents/carers**

Dear Parent/Carer

You are being invited to take part in a new study about the experiences of disabled students/ children and their parents or carers. This is being carried out by the School of Education, University of Birmingham and aims to find out about the experiences of children and young people with disabilities at school/college. The views of parents and carers are an important part of the study and we are interested in how these views compare with the perspectives of children/young people. Your answers will feed into work by the Disability Rights Commission about raising equality for disabled people.

This part of the study involves you completing an online questionnaire. We anticipate that the questionnaire will take about 15-20 minutes to complete.

You will not be followed up in any way unless you specifically request this. The last day for completing the questionnaire online is Wednesday 23rd FEBRUARY, 2005. At the end of that day, the questionnaire will be removed from the website.

There are a number of people in the project team at the University of Birmingham: Ann Lewis, Christopher Robertson and Sarah Parsons. All have experience of working with children and young people, and their parents, in a range of settings including schools, colleges and out-of-school groups. Lin Walsh is also a part of the team and provides administrative support. The project team is part of the School of Education at the University of Birmingham. More details about the group as well as this (and other) project(s) can be found at:

<http://www.education.bham.ac.uk/aboutus/profiles/inclusion/default.htm>

A summary of the conclusions from this project will be available from the ISEEP webpage from the end of April 2005.

If you have any questions, or would like more details about the research project, please see our web site and /or contact Lin Walsh on 0121 414 4834 or l.j.walsh@bham.ac.uk

Regards
The project team

Essential information

- Your decision to take part in the study is voluntary and you can choose to withdraw from the study at any time without giving any reason.
- If you are answering this questionnaire online, your responses will be via a confidential connection which means that only the research team and the web administrator will be able to see your answers.
- All information from the questionnaires will be treated in confidence.
- All information will remain anonymous in any written reports. This means that your names (and the name of your child/young person) will not appear in our reports about the project.

Please confirm that you have read and understood this information by ticking the following box *

Please confirm that you agree to take part in this study by ticking the following box *

(Fields marked with * are mandatory and must be completed before answering the questionnaire)

**Experiences of disabled students and their families:
Online questionnaire for parents/carers**

The questionnaire is in sections. Some questions can be answered by clicking/ticking a response on a scale. Please click/tick on the box at the point in the scale which best reflects your overall judgement for example:

1 A great deal of choice	2	3	4	5	6 No choice
					

Other questions can be answered by writing responses more fully. At the end of each section there is space for you to write more about any of the questions you have been asked, so please use this if you would like to tell us more about the issues raised.

Section 1: About your child

1.1 Age of child / young person (approx) (please tick one box):

- Pre school - age 0-4+
Primary school age 5-11
Secondary school age 11+ -16
17-24
25+

1.2 Type of current educational provision (please tick one box):

- Mainstream
Specialist eg special school
Mix of special and mainstream
Child/young person has left school/ college

1.3 Does the child/young person have a physical or mental impairment which has a substantial (lasting more than a year) adverse effect on his/her ability to carry out day-to-day activities?

- Yes
No

1.4 Please indicate your child's type of special need/disability (please make up to one choice within each of the following sections; but you may respond to more than one section if appropriate):

1.4a Cognition and Learning Needs

- Specific Learning Difficulty (SpLD)
Moderate Learning Difficulty (MLD)
Severe Learning Difficulty (SLD)
Profound and Multiple Learning Difficulty (PMLD)

1.4b Behaviour, Emotional and Social Development Needs

- Behaviour, Emotional and Social Difficulty (BESD)
Specific Mental Health Needs

1.4c Communication and Interaction Needs

Speech, Language and Communication needs (SLCN)
Autistic Spectrum Disorder (ASD)

1.4d Sensory needs

Visual Impairment (VI)
Hearing Impairment (HI)
Multi-sensory Impairment (MSI)

1.4e Physical needs

Motor disability
Other physical disabilities/ conditions, including asthma, diabetes,
epilepsy and cancer (please write in)

1.4f Other (please write in)

1.5 Extra support provided for your child in school/college (if any):

Full time helper	<input type="checkbox"/>
Part time helper	<input type="checkbox"/>
Signer / facilitator as needed	<input type="checkbox"/>
Specialist teacher	<input type="checkbox"/>
Peer support	<input type="checkbox"/>

Section 2: Making decisions

2.1 To what extent do you feel that you had a choice about the school/college that your child/young person attends? (please tick a box on the scale)

1 Lots	2	3	4	5	6 None

2.2 To what extent do you feel that you have been involved in decisions about the education of your child/young person?

1 Very	2	3	4	5	6 Not

2.3 To what extent do you think you have been involved in the appropriate discussions in making decisions about the education of your child/young person?

1 Very	2	3	4	5	6 Not at all

2.4 To what extent do you feel that your involvement has been worthwhile in making decisions about the education of your child/young person?

1 Very	2	3	4	5	6 Not at all

2.5 How involved do you feel you have been in decisions about the type of support offered to your child/young person?

1 Very	2	3	4	5	6 Not at all

2.6 Do you feel that you should be involved in these decisions?

Yes

No

2.6a If so, which:

2.7 Anything you wish to add?

2.8 How do you feel about the range of after school / college or lunch time clubs / activities available for your child/young person?

1 Very satisfied	2	3	4	5	6 Not at all satisfied

2.9 How do you feel about the level of support available for your child/young person within the school / college if they have any problems/concerns/queries?

1 Very satisfied	2	3	4	5	6 Not at all satisfied

2.10 How do you feel about the level of support available for your child/young person from outside the school/ college if they have any problems/concerns/queries?

1 Very	2	3	4	5	6

satisfied					Not at all satisfied

2.11 To what extent does the amount/level of support influence the activities that your child/young person participates in at school/college?

1 Very	2	3	4	5	6 Not at all

2.12 To what extent does the amount/level of support influence the activities that your child/young person participates in outside of school/college?

1 Very	2	3	4	5	6 Not at all

2.13 Has bullying by other children/young people been an issue for your child in the last 12 months?

- Yes
 No

2.14 To what extent do you think that your child/young person is supported by his/her friends?

1 Very	2	3	4	5	6 Not at all

2.15 Are there any areas of the curriculum/course that are harder for your child/young person to access than others?

- Yes
 No

2.15a Please explain

2.16 Any comments you wish to add?

Section 3: Moving on

To what extent do you feel that your child/young person is involved in discussions about:

3.1 Moving between schools/college (transition)?

1 very involved	2	3	4	5	6 Not involved at all

3.2 Future plans (moving schools/ after school/college)?

1 very involved	2	3	4	5	6 Not involved at all

3.3 How satisfied are you with the level of support available for helping your child/young person make decisions about their future?

1 very	2	3	4	5	6 Not at all

3.4 Is there a specific person/group of people who has been particularly **helpful** in discussing the needs of your child/young person at school/college?

Yes
No

3.4a If yes, can you describe how and whom (role):

3.5 Any other comments you wish to add?

Section 4: Feeling included

4.1 Do you feel that your child/young person included in lessons, formal activities (eg clubs) or informal activities (eg at break or lunchtimes) **at school/college?**

1 Lots	2	3	4	5	6 Never

4.2 Do you feel that your child/young person is included in lessons, formal activities (eg clubs) or informal activities (eg meeting up with friends) outside of school/college?

1 Lots	2	3	4	5	6 Never

4.3 Has your child/young person been excluded from school?

- Yes
No

4.3a If yes, how easy has it been to get the child/young person back into education?

1 very easy	2	3	4	5	6 very difficult

4.4 Any comments you wish to add?

4.5 Are you aware of any **rules or policies** in your child's school/ college about all children/young people feeling included in the school/college?

Yes

No

4.6a If yes, what do you like/dislike about them?

4.6b If no, do you think there should be some **rules or policies** about all children/young people feeling included in the school/college?

Yes

No

4.7 Are you aware of any **rules or policies** more widely about all children/young people feeling included in schools/colleges and communities?

Yes

No

4.7a If yes, what do you like/dislike about them?

4.8 Any comments you wish to add?

Section 5: Identity

5.1 Are you aware of any differences between how your child/young person feels at home and at school/college?

Yes

No

5.1a Please explain

5.2 Are there any differences in the way your child/young person is treated at home and at school/college?

Yes

No

5.2a Please explain

5.3 Are there any children/young people at the school/college who are treated differently from others?

Yes

No

5.3a Please explain

Section 6: Participation and progress

6.1 Are there any aspects about **getting to/from school/college** that affect your child/young person's involvement/access?

Yes

No

6.1a Please explain

6.2 Are there any aspects about **being at school/college** that affect your child/young person's involvement/access?

Yes

No

6.2a Please explain

6.3 To what extent are you aware of how your child/young person's progress in school/college is assessed (eg exams, tests)?

1 very	2	3	4	5	6 Not at all

6.3a Any comments you wish to add about assessment?

6.4 What has been most helpful in enabling your child/young person to make progress at school/college?

6.5 What has been least helpful in enabling your child/young person to make progress at school/college?

6.6 Any further comments you wish to add? (please use this space to comment about any aspect of this questionnaire, or experiences of your child/young person at school or college)

Section 7: Methods for gaining your views

Thank you for completing the questionnaire so far. We feel that it is very important to hear the views of people like you. To help us with this in future work, please answer the following questions:

7.1 Please indicate which of the following methods you MOST prefer (choose one):

- Online survey
- Face-to-face interview
- Telephone interview
- Small group discussions
- Paper-based survey

7.2 Please indicate which of the following methods you LEAST prefer (choose one):

- Online survey
- Face-to-face interview
- Telephone interview
- Small group discussions
- Paper-based survey

7.3 How did you find out about this survey?

7.4 Would you like to be invited to participate in any further surveys/projects like this?

- Yes
- No

7.5 If yes, please indicate from the list which method of contact you would prefer:

- Email
- Telephone
- Postal address

7.6 Please provide the relevant details below

Your Background Details (optional)

These questions help us to have a context for your responses

7.7 Are you male or female?

- Male
- Female

7.8 How old are you?

- 18-24
- 25-29
- 30-34
- 35-39
- 40-44
- 45-49
- Over 50

7.9 Please state your ethnic origin or racial group, choosing from one of the following:

- | | |
|--|--|
| White <input type="checkbox"/> | Pakistani <input type="checkbox"/> |
| Black Caribbean <input type="checkbox"/> | Bangladeshi <input type="checkbox"/> |
| Black African <input type="checkbox"/> | Asian Other <input type="checkbox"/> |
| Black Other <input type="checkbox"/> | Chinese <input type="checkbox"/> |
| Indian <input type="checkbox"/> | Other origins <input type="checkbox"/> |

7.9a If other, please specify:

7.9a Where do you live? Please state your country of residence:

7.9b Please state your County/Region of residence:

Thank you very much for your time and openness in completing this questionnaire and so contributing to information that will help to improve the life chances of people with special needs or disabilities

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<http://www.ces.ed.ac.uk/Disability/Papers/PolicyRev.pdf>

<http://www.cpa.ed.ac.uk/news/research/28/1.html>

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