

**Disability
Rights
Commission**

**UNIVERSITY OF
BIRMINGHAM**

My school, my family, my life: Telling it like it is

A study detailing the experiences of disabled children, young people and their families in Great Britain in 2006

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Funded by the Disability Rights Commission

Full Final Report
(Executive Summary available separately)

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Published by the Disability Rights Commission, February 2007

Acknowledgments

Our thanks to the children and young people involved in these case studies for their enthusiastic sharing of their views. They are at the heart of this work and we hope that the report does justice to the richness and thoughtfulness of their participation. (Please note: pseudonyms have been used for children/young people and schools/colleges throughout the report.)

We are also grateful to their parents and school/college personnel who have made us very welcome and gone to considerable trouble in facilitating this work.

In addition, we have benefited from continuing discussions about this work with the core members of our advisory group: Louise Niblett and Jeremy Sharpe.

Various individuals outside the Disability Rights Commission, including Glo Potter (Scotland) and members of the Welsh Assembly Equal Opportunities Committee, have provided valuable sounding boards for emerging ideas and helpful contacts in Scotland and Wales.

Our thanks also to Dee Fellows for her careful and cheerful secretarial support.

This report focuses, in particular, on phase 2 of the Experiences project and, within this, the case studies. That work builds on, and is tightly inter-connected with, previous strands of the project. A large number of people across England, Scotland and Wales, including many colleagues at the University of Birmingham have played a vital part in the development of ideas, negotiating fieldwork and discussing preliminary analyses. We are very grateful to all those people for their time, energy and enthusiasm. While we cannot acknowledge everyone individually, this report reflects that collective input.

Finally, our thanks to the Disability Rights Commission for funding and supporting this work, without which it would not have taken place.

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Note about parent sample

Where relevant, pertinent findings from the related parent survey are referenced. These are reported in full in Lewis, Davison, Ellins, Parsons and Robertson (2006a). Where the total parent sample is referred to here, this is the same group (N=1776) as in the full report on the GB-wide parent survey.

The group of children identified as having disabilities, special needs and/or difficulties (DSD) in the full parent survey report numbered 614. Interestingly, OfSTED (July 2006) has recently used the term 'learning difficulties and disabilities' (LDD), rather than SEN, "to cross the professional boundaries between education, health and social services and to incorporate a common language for 0-19 year olds" (p 21, para 3). In keeping with this, we have used this term (learning difficulties and disabilities, LDD) to refer in this report only to those DSD group children who, using conditions or impairment as the criteria, might be considered to come under the remit of the DDA. Thus this LDD group comprised all children identified by their parents as having disabilities and/or special needs plus the majority (see explanation below) of those identified as having other difficulties.

The composition of the 'difficulties' group has been scrutinised and certain sub-groups taken out (for the purposes of identifying the LDD group) using the DDA-referenced criterion above. This has the effect of removing 51 pupils (38 whose difficulties were described as bullying only, 4 whose difficulties were described as bullying plus prejudice; 9 whose difficulties were described as 'other' (subsets referring to school induced difficulties and/or home problems only). These changes leave a total of 563 in the LDD group. The substantive findings of the full report are not altered by this modification.

Glossary

AEN	Additional Educational Needs (increasingly the preferred term in Scotland and Wales) (see Record of Need, below, regarding terminology used in Scotland)
ASD	Autistic Spectrum Disorder
CEHR	Commission for Equality and Human Rights
DDA	Disability Discrimination Act
DRC	Disability Rights Commission
FE	Further Education
LEA/LA	Local Education Authority (often referred to as Local Authority following the introduction of integrated Children's Services)
List	Term used in Scotland for pupils identified as having additional learning needs (analogous to the special needs register in England). Note that during the project, Supporting Children's Learning: Code of Practice was implemented in Scotland and this introduces significant changes in terminology
MLD	Moderate learning difficulties
Parent	The term 'parents' is used throughout to encompass parents and carers
PMLD	Profound and Multiple Learning Difficulties
Record of Need	Term used in Scotland for pupils identified as having additional learning needs requiring specialised support additional to that routinely provided by the school (analogous to the statement of SEN in England). Note that during the project, Supporting Children's Learning: Code of Practice was implemented in Scotland and this introduces significant changes in terminology. In 2005 the Additional Support for Learning (Scotland) Act introduced the removal of the Record of Needs and the introduction of

the co-ordinated support plan alongside the new concept of 'additional support needs' which is wider and more encompassing than 'special educational needs'.

Register	Term used in England for pupils identified as having special educational needs (analogous to the 'list' for special needs in Scotland); previously described as the first stage in assessing and meeting special needs
SEN	Special Educational Needs
SENDA	Special Educational Needs and Disability Act
SLD	Severe Learning Difficulties
Statement	Term used in England for pupils identified as having special educational needs requiring specialised support additional to that routinely provided by the school (analogous to the record of need in Scotland)

1. Introduction

1.1 Project aims and objectives (applying to all strands of 'Children's experiences' project)

- Identifying the key concerns and priorities for young disabled people in Great Britain (GB) in relation to their experiences of education (particularly transitions), and explore their views and experiences.
- Identifying key issues faced by the parents or carers of young disabled people in GB in relation to experiences of their child's education, and explore their views and experiences.
- Identifying the barriers faced by young disabled people in education, and ways of overcoming these barriers.
- Providing evidence of prejudice and discrimination, as well as good practice, in education.
- Ascertaining the factors that young disabled people and their parents or carers associate with positive experiences of educational institutions (and related services).
- Linking the findings from the research with those from previous DRC and other relevant research.

1.2 Main themes

- Independence and autonomy (eg role of parents/carers/teaching assistants as advocates, experience of involvement in decisions and choice)
- Ambition and aspirations (eg perceived impact of impairment and attitudes on career aspirations)
- Knowledge and assertion of rights (eg disability identity, knowledge of rights and the DDA)

- Experience of accessible/inaccessible educational services and environments (eg building design/layout, curriculum and qualifications, school travel and trips)
- Attitudes and behaviours (eg impact of attitudes to disability of parents/carers, peers, teachers and other school staff; impact of bullying).

1.3 Outline of Phases 1 and 2

The work reported here reflects four linked projects (2004-6), funded by the Disability Rights Commission and carried out by a team from the University of Birmingham, into the experiences of disabled pupils and their families (referred to, in short, as the 'Experiences' research). This series of work is summarised in table 1 below.

Phase 1 (2004-5; Lewis, Robertson and Parsons 2005) focused on piloting sampling and methods to hear the views of 37 disabled children and young people and eight families across a wide spectrum of disabilities, ages and needs. This work also provided pointers to substantive issues.

Phase 2 (2005-6) encompassed three strands. The pilot methods for accessing children's views, developed in phase 1, proved a sound and valuable basis for phase 2. Similarly, indicative findings from phase 1 were supported and amplified in phase 2.

The first strand of phase 2 was a survey of parents and carers, with particular reference to disabled children or children with special needs (1776 responses, covering six main regions of England, Scotland and Wales, of whom around 35%

were parents of children with disabilities, special educational needs or difficulties) (Lewis, Davison, Ellins, Parsons and Robertson 2006).

The second strand of phase 2 concerned the involvement of several consultation groups of disabled people who provided both formative advice about the project and feedback about emerging findings. That work, as well as the research team's other direct experiences of advisory groups involving disabled people, provided the basis for our recommendations concerning a range of flexible approaches for advisory (or 'reference') groups in such projects (Lewis, Niblett, Parsons, Robertson and Sharpe 2006).

The third strand (the main focus of this report) comprised in-depth individual (36 children/young people with disabilities and/or special needs) or group (3 groups) case studies. These case studies, from four of the six regions involved in the parent survey (phase 2, first strand), were GB-wide. Methods of data collection (building directly on approaches piloted in phase 1) included interviews with the children/young people, classroom observations, interviews with key school personnel (SENCO, class teacher, subject teacher, headteacher - as appropriate) and interviews with a sub-sample (15) of the parents/carers. The resultant rich case study data complement the parent survey (cross-referenced in this report where appropriate) and provide a sound basis for building on these findings.

See Table 1 : 'Children's Experiences" project: Summary of samples and methods in Phases 1 and 2

[see following page – landscape]

Table 1: 'Experiences' project: Summary of samples and methods in Phases 1 and 2

Main project strand	Scale and scope	Main data collection method(s)	No of respondents or participants
Phase 1 Pilot work August 04-March 05	Piloting of sampling and methods to hear the views of disabled pupils across a wide spectrum of disabilities, ages and needs; exploration of substantive issues	Case studies of pupils in 2 Local Authorities in England + family group interviews + focus group of FE students; e survey of parents/ carers of children with disabilities or special needs via parent organisations	29 children / young people ages 7-19, + 8 families, + 8 FE students (ages 18-30+); + 157 e survey respondents Full report on DRC website http://www.drc.org.uk/library/research/education/new_experiences_of_disabled_st.aspx
Phase 2: Parent Survey August 05-April 06	6 focal geographical areas in GB; spanning a range of educational settings as well as urban / rural and ethnic groups	8-page survey booklet distributed to parents via schools and colleges; key transition ages/ groups targeted (broadly, ages 9-11; 11-12; 15-16 and 16-18)	1776 valid returns; approx 35% from parents identifying their child as having a disability, SEN or other difficulties
Phase 2: Advisory groups of disabled people September 05-August 06	To advise on the progress and foci of the projects; to reflect on the process of being advisory group members in order to make recommendations for good practice.	Not applicable	2 core advisory group members plus involvement of satellite groups in England, Scotland and Wales
Phase 2: Case studies of children and young people January 06-September 06	4 focal geographical areas in GB; spanning special, specialist and mainstream settings; primary and secondary aged children and young people (aged 8-18); wide range of SEN and / or disabilities including physical, sensory, learning, behavioural, language and communication. Sub-set of parents followed-up for interview.	Individual or group interviews in school or college using a range of methods, deployed flexibly, including preference ranking, drawings and photos; within-class observation and discussion with teachers. Parents interviewed over the telephone or in person.	66 children and young people; including 36 in individual case study work and 30 in 3 group case studies. 15 parents of 13 individual case study children and young people took part in follow-up interviews.

1.4 Main findings from Phase 1

The remit of this first phase of research was to explore the educational experiences of disabled pupils/students and their families. This encompassed identifying (broadly) their concerns and priorities but focused on identifying and trialling appropriate research methodologies for a second phase of research.

- * The main issues which emerged were around autonomy; choice and empowerment; inclusion and support; and personal identity.
- * There was considerable enthusiasm for speaking/making their views heard across all groups (children, young people and adults) and a willingness to engage.
- * Issues emerged around whether and when young people identified, or were identified by the parents, as 'disabled' and/or having special educational needs.
- * A major theme emerged around disabled children's resilience: specifically, how this is fostered or hampered across individual, school, family and community/cultural contexts. Transitional experiences have a particular importance, and salience, for children/young people and their parents/carers.
- * 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 to develop personal autonomy.

For full report see: Lewis, Robertson, and Parsons (2005); also at

http://www.drc.org.uk/library/research/education/new_experiences_of_disabled_st.aspx

1.5 Main findings concerning advisory groups

The report contained a series of detailed recommendations about the involvement of disabled people in advisory groups. We repeat selected recommendations here:

1. Advisory group involvement in DRC or CEHR projects needs to be very carefully planned at the beginning with an honest appraisal made of whether (and if so how) conflicting demands, and perhaps even ethical positions can be reconciled. Larger scale and longer term projects should involve a phase of development which would enable the identification and establishment of an advisory group of the kind outlined in 1 and 2 above. This group would, if this was appropriate to the research being undertaken, be given the remit to establish an advisory or consultative network involving people with appropriate experience and knowledge.
2. This planned involvement of advisory groups from the outset would recognise the additional time needed to include an advisory group authentically. This is something that needs to be included in project remits and timelines from the start. It is a challenge to balance the need to get research done in timeframes that are related to particular policy needs/outcomes (for example) but this should not mean that advisory group

involvement is the bit that is excised because time is short. Planning ahead is essential to make sure that advisory group members can be included in DRC or CEHR projects and actual project timelines probably need to be extended (and/or more resources factored in) to accommodate this.

3. Clear agreement is needed by everyone involved (advisory group members, project team and the DRC or CEHR) about ground rules; including access, communication, foci and timings. At the same time, there needs to be enough flexibility for participants to develop these rules over time.
4. Advisory group involvement can be thought of as an 'advisory portfolio' (rather than necessarily a single group) with different sub-groups contributing in complementary ways. The nature of and relationships between these groups would vary according the kind of research being undertaken. The mediating role of such groups could be enhanced, and articulated in research specifications.
5. When recruiting advisory group members, the DRC or CEHR and researchers whom they fund, should consider what the research will give back to individual and communities involved. They should also consider how the aspirations of participants in advisory groups can be acknowledged.

For full report see: Lewis, Niblett, Parsons, Robertson and Sharpe (2006).

1.6 Extracts from the main findings of the parent survey

(See front note concerning DSD/LDD groups in the parent survey. See Table 1 for sample information.)

Disabled children, children with special needs and children with difficulties ('DSD' in short) represent overlapping groups with distinctive sub groups within them. Only 40% of parents described their child as coming into all three of these groups. One third of parents of children with special needs (35%) (including parents of pupils in special schools) described their children as having special needs but not disabilities. Therefore policy, provision and legislation aimed at a particular sub group may not be seen by parents as applicable to others.

The large majority of parents of pupils in the DSD group perceived those problems or conditions as primarily reflecting 'just the way she/he is' (63% strongly agreeing/agreeing). That is, for the most part, the child's difficulties were not being attributed to the school or other social context. (While this applied across all strata, it was strongest for the special school group.) This finding has face validity in that it is consistent with many of these parents not being aware of the DDA and the work of the DRC, both of which have drawn attention to the social contexts in which disabled people live.

Parents (particularly those of children without disabilities, special needs or difficulties) were generally well satisfied with their child's schooling. 86% of all parents surveyed were satisfied with the way

the school treated their child and under 5% were not satisfied. This finding applied across a range of satisfaction measures.

Parents of children with statements or record of needs were less likely than other DSD group parents to say that the school was the cause of difficulties (12% of parents of children with statements and 21% of those without, agreed). Similarly (using a clustered satisfaction measure) parents who perceived their child as having special needs, but did not have a statement or record of need, were less positive about their child's progress.

Nearly 60% of parents were aware of the DDA. However knowledge of the detailed impact of the DDA was lacking, even among parents of disabled children. Lack of knowledge was greatest among those in deprived communities.

Nearly 40% of parents had asked the school to make changes for their child. Parents who had heard of the DDA were more likely than were other parents to ask the school to make changes in order to help the child overcome difficulties.

Lack of awareness of the DDA and DRC may go with a more general lack of visibility about special needs and disability. A minority of parents (particularly of boys) reported not knowing their child's status in relation to SEN or disability. One might expect that parents of children on the school's SEN list or register may be comparatively unaware of their child having special needs. This was the case with nearly half (42%) of all these parents describing their child as not having special needs.

Schools were generally doing well, in parents' views, in terms of including all children in extra-curricular activities. Nearly 70% of the DSD group parents disagreed with the statement that the child's difficulties stopped the child from doing extra activities run by the school.

Almost half of the parents of pupils in the DSD group felt that these DSD would stop the child from getting a good job.

See Lewis, Davison, Ellins, Parsons, and Robertson (2006) for full report of the parent survey.

1.7 Report structure

The structure of this report follows standard report conventions. Summary and recommendations are presented at the front of the report. We then begin with the project aims and objectives and the associated main themes, as agreed with the DRC at the outset. These sections are followed by a brief summary of key background material and ideas relating, in particular, to the voice of disabled children. We move on to a brief summary of methods (more detail being supplied in the appendices). The main body of the report links findings and discussion under the five main themes (as is appropriate for rich qualitative data).

2. Background

During the course of this project, child voice has continued to be a major focus of policy and media attention (for example, Joseph Rowntree (2005) *Children's perspectives on believing and belonging*; Mayo (2005) *Shopping Generation*). The Children's Society (2005) surveyed the views of over 8000 young people concerning many aspects of their lives (family, friends, leisure, school, environment, community, money, attitudes and health). Their responses were the platform for the current (Autumn 2006) inquiry *Good childhood? A question for our times* in which adults' views are being sought about conditions for, and obstacles to, a "good childhood" (Children's Society 2006). That inquiry does not explicitly identify disabled children as a focus. It is vital that the experiences, and views, of these children are included and we hope that the views embodied in this report will be disseminated to that inquiry.

Various recent (2005-6) Local Authority projects (e.g. Coventry, Ealing) have sought to include the views of disabled children and young people in the context of local policy development and provision. This pattern of consultation, participation and involvement is particularly well established in Scotland and Wales (see for example, the work of organisations affiliated to Children in Scotland and Children in Wales) and consciously supports the inclusion of young people in transition towards adulthood.

Over time, these will contribute to a national body of understanding about disabled children's views but the varied approaches and

specifics of local contexts may limit generalisability. At the same time, as our Advisory Groups of Disabled Children and Young People report notes, the experience and expertise embedded within local and regional networks is potentially a powerful force for change.

The dearth of systematic evidence about the views of disabled children and young people was noted in the specification for this work:

A DRC review of the literature on disability discrimination in education (Gray 2002) found that there were few examples of larger scale studies of the education experiences of young disabled people and their parents or carers and that: ‘...further research is necessary to look at issues faced by disabled people (in education)...Studies need to include examples of both positive and negative experience and provide an up-to-date picture of potentially changing patterns...Greater priority should be given to listening to the voices of disabled people themselves (Gray, 2002).

A 2003 DRC research study (NFER 2003) identified some key issues for disabled pupils and students, but was not able to explore these issues in sufficient depth. Other than a survey of young disabled people, most DRC and other research on education and disability has focused on education providers, or people who have left education and are considering their experiences retrospectively. The voices of disabled students

who are currently in education need further opportunities to be heard.

Once disabled children's views have been elicited in valid ways there remain questions of what, if any, consequent action should be taken (ie implicitly, how seriously or otherwise children's views are to be taken). Some writers (eg Fielding 2004) note the variety of ways in which children's views may be subverted, ultimately merely sustaining the status quo. Such mechanisms (for example, perhaps, involving a subset of children in a school council but not linking this with any radical reappraisal of the nature of schooling) have been highlighted and challenged by some youth-run 'children's voice' groups (eg Children as Partners Alliance).

In this connection, the exploring in this research of the views and experiences of young people with disabilities or special needs in their school councils provided penetrating insights about the authentic involvement of disabled children's voices (see section 4.3.2).

Similarly, a key theme in our advisory group report (Lewis, Niblett, Parsons, Robertson, and Sharpe 2006b) was the need for research to find flexible rather than uniform ways to include disabled people at all stages of the project. This entails acknowledging that meaningful involvement can, and does, emerge over time and should not be regarded as a prerequisite (Lewis et al 2006b; Parsons et al 2004).

3. Methods

Two main approaches were taken to the inclusion of the voice of children and young people in this project. Firstly, a number of children and young people with disabilities or special needs took part as 'individual' case studies and secondly, three separate groups of young people took part in 'group' case studies. These two sets of case studies complemented the advisory group studies (Lewis et al 2006b), parent survey (Lewis et al 2006a) and, similarly, built on the related phase 1 work (Lewis et al 2005).

Individual case studies: children and young people

The individual case studies involved visiting the school or college to meet the children/young people involved; spending some time in class, as well as outside of class, observing their participation in activities. Wherever possible and appropriate, children and young people were encouraged to share their views about school in an individual session with the researcher, either by themselves (as in most cases) or with a parent, teacher, teaching assistant/ auxiliary or friend. Wherever possible, class teachers of the children/young people were also questioned about their experiences of teaching and supporting children/young people with SEN/AEN and/or disabilities in their class.

Individual case studies: parents

In addition to meeting, observing and talking with children and young people, some parents of the individual case study participants were interviewed. In two cases this took place at the child's school or college or, in two cases, at the child's home. All other parents were interviewed over the telephone after providing permission to be contacted by the research team.

Group case studies: children and young people

The group case studies involved visiting the school or college to meet with members of the existing school council (in two cases) or with a specially convened group (in one case). The two school council groups were based in special schools and the specifically convened groups were within a mainstream secondary school and a special school.

The involvement of three group case studies resulted from discussions with participating schools about how young people should and could be included in the project. One school in particular was clear that individual interviews would not be appropriate and a group approach preferred. At all times, the research team was sensitive to the wishes of the schools and the students and responded positively, and flexibly, to their suggestions. This meant that, on occasions the school, or pupils themselves, opted in to the project on their terms, and this involved the self-definition or otherwise of difficulties and disability.

The group case studies had overlaps in foci with the advisory group studies in Scotland and Wales (Lewis et al 2006b). In meetings with these satellite advisory groups, there were discussions about young people's experiences of education. These were used as soundings to see whether the perspectives presented were congruent with those identified as key themes in the research planning (and in the earlier Phase 1 work). The views of participants in these groups indicated that the research themes were appropriate and important to follow up. Members of the core advisory group concurred with these views.

3.1 Sampling and consent

Secondary 'hub' schools, and their feeder primaries, in England, Scotland and Wales (identified as part of the Parent Survey for the Phase 2 Experiences project; Lewis et al 2006a) served as the starting point for the recruitment of children and young people. The schools were located in four focal geographical regions: England (rural), England (urban), Scotland and Wales. Within these areas, special schools were also identified and contacted. Two of these areas included significant multiple deprivation (as noted in the parent survey report; see data concerning index of multiple deprivation) while one of the areas had a high proportion of diverse ethnic groups.

Head/deputy head teachers and/or SENCOs were first contacted by letter and then by a follow-up telephone call. If they agreed that children/young people from their school could take part in the case

studies, copies of information sheets and consent forms for young people and their parents/carers were sent to the school/college for distribution (see Appendix 6.2).

The continuation of methodological themes and understanding from phase 1 was important as, while hearing pupils 'voice' is now widely recognised as a goal, there are increasing signs of disquiet. Such disquiet encompasses distinct issues about means and about ends. For example, Felce (2002) raised warnings about the 'ubiquitous imperative' of hearing the views of severely or profoundly disabled children and the consequent unwarranted assumptions being made about the nature of those children's wishes. Similarly, Lewis and Porter (2004, in press) discuss a 'flexing of the boundaries' in this context with reference to what, if any, may be the limits in exploring the views of disabled children in a research context.

The aim was to recruit approximately 10 children and young people from within each of the four focal areas, across a range of school settings. In the majority of schools, two children or young people with disabilities or special needs took part. In addition, as noted above, some children and young people with disabilities or special needs were included in group case studies. The total number of participants was 66 (36 in individual case studies plus 30 in group case studies), thus considerably exceeding the target sample of 40.

We took an inclusive approach to identifying children for participation in these case studies, believing that all children can be helped to share their views in a meaningful way. This was reflected in a deliberately responsive approach to schools so that methods of

hearing children's views were tailored to school and pupil preferences.

The involvement of specific children/young people was sometimes, but not always, discussed with the researcher but the final decision about whom to include was made by the school. Inevitably, and rightly, when identification was placed in part in the hands of schools and colleges, definitional issues followed and to some extent this occurred with young people themselves (see also introduction to section 3). Schools were asked to include relevant children and young people from specific year groups i.e. those from our target pre- and post-transition groups (Years 5/6, 7, 11, 12 & 13 in England and Wales, and Years P6, P7, S1, S4, S5 and S6 in Scotland). In practice, this was not possible for all schools due to the low numbers of students with SEN/AEN or disabilities and so occasionally children were recruited from different year groups. Some children met the formal criteria for SEN/AEN but not disability.

3.2 Samples: Individual and group case studies

36 children and young people were included in individual case studies; 19 boys/young men and 17 girls/young women. These children and young people spanned a range of ages, educational settings, disabilities and geographical contexts. We obtained, through careful sampling, a balanced group in terms of these four key criteria (see table 2 for a summary of the sample for the individual and group case studies).

- As planned, the ages of the children and young people ranged from 8 to 19 years; with 14 of primary (8-11), 10 of secondary (11-16) and 12 of FE/6th form (17+) age range.
- Seven participants were from England (rural) settings and 8 from England (urban) settings; 9 were from Scotland and a further 12 were from Wales. Note: the small numbers precluded generalisations about country-specific issues. However the larger parent survey (see above) included such material and was referenced to the growing policy differences in SEN/AEN provision across England, Scotland and Wales.
- 12 children were based in mainstream primary schools; 4 in mainstream secondary schools plus 2 in mainstream secondary 6th forms; 4 from a specialist unit within a mainstream school; 10 were from special schools and 3 were at FE college. One further young person was being educated at home and, after 2 and a half years of home-education, transferred during this project to a mainstream secondary school.
- Many of our case study children and young people had more than one type of disability (see table 1). Main disabilities were autism/ASD (5); dyslexia (6); learning difficulties (12); physical disability (5); sensory needs (3); and social, emotional and behavioural difficulties (5). The overlap and co-occurrence of disabilities or special needs, the small numbers and the variation in how different authorities define, identify and

respond to these, precludes straightforward causal links between disability and school experience.

Sample: parents of individual case study children and young people

A total of 15 parents of 13 individual case study children and young people took part; in two cases, both Mum and Dad contributed; in one case it was Dad only and the remaining interviews (10) involved Mums only. Interviews spanned the four focal geographical areas and different types of provision (mainstream or special), ages of children (primary, secondary and FE) and disability (learning, physical or sensory).

It is not feasible to make reliable country-specific conclusions from the case studies owing to the small numbers of families involved. However we have extrapolated some points concerning Welsh-medium provision (see section 4.2.2). The GB-wide parent survey (phase 2, summarised above) did provide some pointers concerning country specific provision and these are discussed in the full report of that work (Lewis, Davison, Ellins, Parsons and Robertson 2006).

Table 2: Case study samples (individuals and groups)

Code no.	Area	Sex	Age	School type	Disability or SEN
Individual case studies					
1.	England (rural)	F	10	Mainstream primary	Hearing impairment; difficulties in learning and communication
2.		M	8	Mainstream primary	Learning difficulties
3.		F	11	Mainstream primary	Down Syndrome
4.		M	16	Mainstream secondary	Visual impairment
5.		M	12	Mainstream secondary	Spelling and reading difficulties
6.		F	16	Special	Learning and behavioural difficulties
7.		F	18	Special	SLD and limited verbal communication; uses a wheelchair most of the time
8.	England (urban)	M	9	Mainstream primary	PMLD and very limited understanding or use of language; uses a wheelchair
9.		F	10	Mainstream primary	Cerebral Palsy; uses a wheelchair
10.		F	10	Home-ed + mainstream secondary	Visual impairment
11.		M	17	FE college	Dyslexia
12.		M	17	FE college	Dyslexia
13.		M	18	FE college	Dyslexia
14.		F	19	Special	Athetoid cerebral palsy

15.		F	19	Special	Cerebral palsy
16.	Scotland	M	14	Specialist unit in mainstream secondary	Asperger Syndrome
17.		M	15	Specialist unit in mainstream secondary	Asperger Syndrome ADHD OCD
18.		M	18	Specialist unit in mainstream secondary	Asperger Syndrome Semantic Pragmatic Disorder Attention Deficit Disorder
19.		M	12	Specialist unit in mainstream secondary	Asperger Syndrome ADHD
20.		M	11	Mainstream primary	Asperger Syndrome and associated 'secondary' motor difficulties
21.		M	11	Mainstream primary	Behavioural and social difficulties (possibly ASD)
22.		F	12	Special	Learning difficulties
23.		M	11	Special	Cerebral palsy and learning difficulties
24.		F	17	Special	Cri-du-Chat Syndrome; physical and learning disabilities
25.	Wales	M	9	Mainstream primary	Behavioural and communication/social difficulties (possibly ASD)
26.		F	10	Mainstream primary	General learning difficulties
27.		M	10	Mainstream primary	Dyslexia

28.		M	10	Mainstream primary	Dyslexia and Dyspraxia
29.		F	9	Mainstream primary	General learning difficulties
30.		M	16	Mainstream secondary	MLD/SLD
31.		F	12	Mainstream secondary	MLD
32.		F	18	Mainstream secondary (Sixth form)	Ataxia-telangiectasia (A-T); degenerative condition which leads to physical disability; uses a wheelchair
33.		F	17	Mainstream secondary (Sixth form)	Dyslexia
34.		M	18	Special	Behavioural and learning difficulties
35.		F	15	Special	EBD
36.		F	16	Special	ADHD
Group case studies					
	England (rural)	School Council N=9	Special ages 11-18	Various including learning difficulties, autism, physical disability and emotional difficulties	
	England (urban)	School Council N=17	Special ages 9-19	Various including learning difficulties, profound and multiple learning difficulties, autism, physical disabilities and severe language/communication disorders	
	England (urban)	Group interview N=4	Mainstream secondary (with SEN unit att) ages	2 students with general learning difficulties, 1 with speech, language and communication difficulties, one with autism (ASD)	

			15-16	
(Also - closely informed by the Advisory group work, in particular the following:)				
	Scotland (urban and rural)	Group ENABLE N= 10 Ages 14-23	Mainstream and special schools, mainstream FE College, post-college provision including, NGO support organisation	Physical impairment (cerebral palsy), learning difficulties (moderate and severe), attention deficit hyperactivity disorder (ADHD), autism (ASD)
	Wales Network for Young Disabled People (Urban and rural)	Group Network N= 40 (approx) ages 14-25 (approx)	Mainstream and special schools, mainstream FE College, post-college provision, including, NGO support organisation	Physical impairment (cerebral palsy), learning difficulties (moderate and severe), attention deficit hyperactivity disorder (ADHD), autism (ASD), Tourette's syndrome, Achondroplasia

3.3 Methods for accessing views

3.3.1 Interview foci for children and young people

A semi-structured interview and observation schedule was developed with close reference to the five main themes for this project (see Appendix 6.2):

- **Independence and Autonomy:** involvement in choices and decisions; views and experiences of additional support; involvement in extra-curricular activities
- **Experience of accessible/inaccessible educational services and environments:** getting to and being at school as well as the wider community; comparisons with others
- **Knowledge and assertion of rights:** disability identity and language; fair and equal treatment
- **Attitudes and behaviours:** of other children/young people; teachers and other professionals; family; and wider community
- **Ambition and Aspirations:** feelings about school/college now and plans for the future

A shorter version was also developed for younger children or those with more limited verbal ability (see Appendix 6.2). The range and scope of questions asked in practice varied widely across children and young people depending on their verbal/cognitive ability; relevance of some of the questions/issues; level of

comfort/familiarity with the researcher and, therefore, appropriateness of asking about personal/sensitive issues (such as disabled identity, family circumstances/support).

3.3.2 Interview foci for parents of individual case study children and young people

The interview foci for case study parents followed the same five DRC themes as for the children and young people and asked similar questions (see Appendix 6.1.3 for outline). The semi-structured nature of the interview schedule allowed key questions to be asked whilst also providing space and opportunity to convey more detailed aspects of particular experiences if parents wished.

3.3.3 Procedure for children and young people: individual case studies

In most cases, either a half day or a full day was spent with each child or young person before commencing individual interviews; this facilitated a good response to the individual interview as the child/young person had become more familiar with the researcher during the day. In all cases, children and young people were very positive about spending time with the researcher and keen to share views. Where possible, the researcher spent time in the classroom observing the lesson(s) and the child's participation. This also allowed for observation of support occurring outside the main classroom setting, as well as discussion with those involved in

providing support (such as teaching assistants, specialist teachers/advisors, SENCOs).

The individual interviews with children and young people usually took place in a quiet room/area (sometimes outside) where confidentiality could be ensured, although additional, more informal, discussions sometimes took place during break and lunchtimes. Some students were taken out of class during lessons (with their and the teacher's agreement) whilst others preferred to be interviewed during break, lunch or free periods. In all cases, this was negotiated and agreed with participants during the day.

A few of the children/young people chose to be accompanied by a friend or friends whilst being interviewed, but most were happy to be interviewed alone. Two of the students – both with very limited language ability – were observed in school activities and a parent came to the school to talk to the researcher about their child's experiences and preferences. Two young people, and their parents, were interviewed in their homes, as the scheduling of the visit was only possible during the school holiday (and one of these students had been home-educated at the start of the project).

Before commencing individual interviews, children and young people were reminded about the project by showing them a copy of the child-friendly information sheet and talking them through it. They were encouraged to ask any questions and told that they could stop at any time and not answer questions if they did not want to. To help with this, children were shown the digital voice recorder and told this would be used to record the conversation and that they

could press the 'stop' button at any time (two used this option). They were told that no-one else would get to hear the conversation and their names would not be included in any reports. Finally, the children and young people were encouraged to press the 'record' button on the digital recorder when they were ready to start.

Drawing on the work completed for Phase 1 of the Experiences project, the individual interviews utilised a range of methods, deployed flexibly, to help children and young people share their views. Methods included the use of drawings, photographs, ranking/preference procedures using post-it notes, as well as 1:1 discussion (see Lewis, Robertson and Parsons, 2005 for more details about methods). The researcher did not know the children/young people whom they were meeting at the school and so needed to judge each approach carefully after arrival; being able to utilise a range of procedures depending on the age and ability of the children and young people was a real strength of the procedure.

All children and young people interviewed individually were given a voucher (£10) as a gesture of thanks for their involvement. This strategy, following from its success in phase 1, was again very well received by children and young people, their parents and the school. They had not known about the vouchers in advance and some schools made an event of this; for example, a presentation to the child in a whole school assembly. At least one child was unsure about what one did with a gift voucher. He was delighted to discover that he could spend it at JJB Sports and intended to buy himself a football with it as soon as possible.

3.3.4 Procedure for children and young people: group case studies

The approach taken by the researchers varied across the three groups depending on the context of the discussion and the expectations of participants. In all cases, the group sessions began with a reminder about the nature of the project and the kinds of things the group would be asked (eg what they liked and didn't like about school). Discussions were managed flexibly depending on the interests of the groups (some issues generated a great deal of discussion whilst others did not) with the researchers introducing new topics/issues as relevant and appropriate. Virtually all group members contributed to the discussions.

This was impressive given that in the two sets of school council meetings there was no selection of pupils to participate by the school; we talked with the established school council.

One (special school) council took part in a lengthy discussion, convened on a specific day to facilitate this, about some of the main themes of the Experiences project. The discussion had a striking impact on the pupils, triggering an immediate meeting with the headteacher and leading to direct action within the school in relation to several outstanding issues.

The second (special school) council (in a different Local Authority from the other school council observed, referred to above) was observed during two of their regular meetings. These observations

provided very useful insights into how disabled children and young people, including some with severe learning and/or communication difficulties, can be meaningfully included in decision-making processes at school. The observations highlighted how the systematic involvement of disabled children and young people can, in ways that are both explicit and implicit, model positive approaches to the development of autonomy and independence. These council processes also seemed to foster both knowledge of rights and encouragement of the assertion of these rights. Discussions outside these sessions between the researcher and the facilitator for the school council (see below 4.3.2) amplified these points.

In the group meeting in the secondary school, the researcher took advice from a senior teacher who knew the students well. She advised meeting informally in a small group and at a time that did not interrupt the flow of the students' day. The meeting took place in a lesson timetabled for citizenship. The young people who volunteered to participate wanted to know more about the project before committing to sharing their views. Having agreed to participate they also agreed to the audio-taping of the discussion. The interviewer, having introduced project themes sought verbal responses to these and members of the group were forthcoming. No specific methods were used to support the eliciting of views of the young people involved as it was felt this might unnerve members of the group, some of whom had expressed initial concern about discussing disability and special educational needs. Having got to know the young people, follow up individual interviews might have been valuable, but it was not possible to arrange these, because the

students were preparing to sit their final public examinations and then leaving school.

3.3.5 Procedure for parents of individual case study children and young people

In two cases the interview took place at the child's school or college or, in two cases, at the child's home. All other parents were interviewed over the telephone. Parents were contacted by telephone (or the timing and date of a visit arranged via the school) to determine willingness and agreement to participate and a mutually convenient time was scheduled for the interview to take place. Parents were reminded of their rights to confidentiality and withdrawal. It was not possible to interview parents of all individual case study children and young people for a number of reasons; some were difficult to contact (despite repeated attempts), others declined to be interviewed, or it was not possible to obtain contact information from schools. Some discussions were recorded in full, with permission, and others were documented through detailed notes.

3.4 Coding and analysis of data

Field notes, including observations of children and young people in school, were typed up and recorded interviews transcribed. These documents were used as the main data set for NVivo analysis – a software package designed to facilitate the storage, manipulation, categorisation and retrieval of qualitative data.

A total of 50 separate codes were developed, based closely on the main themes and questions included in the semi-structured interviews (see Appendix 6.3). Individual interviews (and observational notes) of children, as well as parental interviews, were analysed using the same set of codes (although the meaning of some of the codes differed between these groups, for example, aspects of 'Independence and Autonomy' could apply to either the child or the parent/carer in parent interviews). Inevitably with rich qualitative data there was some overlap between codes and some data were coded using more than one code. This does not affect the reporting or interpretation of the data and highlights the interrelatedness of the main themes.

4. Discussion and findings

These discussions draw primarily on individual and group case studies with disabled children and young people (including some parental interviews). In addition, this material is informed by the prior and wider parent survey (postal survey), advisory group work and phase 1 fieldwork.

Material is grouped according to the five main themes identified by the DRC for the project: independence and autonomy, experience of accessible/inaccessible educational services and environments, knowledge and assertion of rights, attitudes and behaviours and ambitions and aspirations. The views of children and young people are presented first in each section; the views of parents follow (usually more briefly as, by design, these were not the prime focus of this strand of the work; see report on the parent survey (Lewis, Davison, Ellins, Parsons and Robertson 2006a) which complemented the case studies).

4.1 Independence and autonomy

Our foci on independence and autonomy explored children's involvement in choices and decisions; their views and experiences of additional support; and involvement in extra-curricular activities, both within and outside school. Much of what children and young people in the case studies said resonated strongly with what we found in the earlier parent postal survey and advisory groups as well the pilot work in phase 1.

Discussion about independence and autonomy is sub-divided into four sub themes: self-awareness and support needs, formalities around support, support in class, and support outside school or college.

4.1.1 Self-awareness and support needs / attitudes to support

The views of disabled children and young people

Children and young people invariably expressed views showing that they were aware of their needs and wanted to be heard when they made their feelings clear. This applied to case study children across diverse disabilities and needs. Discussions with members of school councils (discussed further in 4.3.2 as a separate theme) endorsed the strong wish for involvement in decision-making by these young people.

Overall, whilst children valued independence and autonomy, and involvement in decisions about school, they also appreciated the help received both formally (inside and out of class) and more informally (from friends).

A careful balance needs to be struck between helpful, sensitive and responsive support on the one hand and encouraging an over-reliance on a sympathetic helper (especially for younger, primary age pupils) on the other hand. This is important; resources, for example, for additional support, will not necessarily in themselves increase inclusivity. This is illustrated from observations of case

study children. During observation of some younger children at school, it was apparent that there was a tendency to over-rely on the support assistant/auxiliary, to the extent that some children were reluctant to engage in tasks without their assistant/auxiliary and consequently were sometimes socially isolated from peers in class and during break times. Some young people recognised for themselves the tension between wanting, compared with needing, support (and the links with independence):

Maybe I could like have less (support) so that I don't like depend on them because when I go to (the mainstream secondary) I might depend on them.

Normally, when (my support assistant/auxiliary) is there I want her to go, but when (she) is gone I miss her!

Support to promote independence may have to focus on interrelated needs for both education and personal care. Two students with complex physical impairments made this point when discussing access to the curriculum and extra-curricular activities. They welcomed 'matter of fact' unobtrusive support which ensured that their personal care needs were met, and met in ways that enabled them to participate fully in activities. This support was characterised by good relationships between the students and their supporters, with the student knowing when to ask for assistance and their supporter knowing when to give it.

For some case study pupils, the concept of inter-dependence, rather than independence, is helpful (Robertson 2001). This connects their

growing independence with the facilitative networks of support. However developments towards independence can mask tensions and a child's different supporters may hold varying perspectives about the importance (or otherwise) of independence. Careful staff induction and continuing professional development may well help to reduce these tensions. They might also involve children and young people themselves taking on, or contributing to, training roles.

Some children commented that they found it difficult when their usual source of within-class support was unavailable. This was not necessarily a bad thing as this situation may have aided independence and autonomy by encouraging children to ask for help from others, such as their friends or the class teacher. (See above, related point concerning possible dangers of over-dependence on support.) Some pupils found this difficult and preferred to keep problems to themselves.

This suggests that children may be unsure about the response they will receive if they go to a teacher, or someone else, to ask for help. Building up trust with sympathetic adults is an important part of this process. It follows that if views are not taken seriously, then when difficulties or issues are disclosed, there is likely to be an erosion of trust in the future:

I just do things myself mostly or if it's really bad I'll go and see Mrs _____, like I had someone verbally abusing me down the corridor the other day and it was going on for ages and ages and I went to see Mrs _____ and I said I'd had enough, I'm going to call the police, and she just took it as if I was

someone stupid, there's no need to do that, it's just pathetic. But it's not because it really hurts, it's an issue for me and then nothing got done about it. But it's stopped now because I stopped it myself. I've told him, but nothing got done about it and that's bullying in school.

Some children and young people were resentful about the need to have to keep asking teachers for help, usually about the same things. Remembering individual needs was seen as an important marker that needs were being taken seriously.

Being kept informed about matters relating to school was mentioned as important by some of the young people. In some cases there were complaints by young people relating to not being told about changes or why particular courses of action were taken. One participant noted that she only found out about things that were happening at school when she went to ask one of her teachers:

They do need to tell me what's going on because sometimes someone comes to see me and I know nothing about it so I have to cope with it because nobody tells me anything unless I go up to see Miss _____ and ask her what's going on.

While the lack of information may be of concern, her preparedness to ask for clarification is a strength. It also suggests, commendably, that the school ethos was one in which she felt able to ask such questions. This shows that even if the detail of provision and processes seem to have some weaknesses, these can be

circumvented if the context is one which builds confidence in, and responsiveness to, pupils.

The views of parents of disabled children and young people

Most parents of case study pupils were satisfied with their child's current school placement and said that their children were attending the parents' preferred school:

Educationally we are more than happy with the support [he] is getting.

This endorses the findings from the parent survey in which the large majority of the LDD group parents strongly agreed (31%) or agreed (36%) that the school was doing well in helping their child. There was a similar positive pattern for the LDD parent group as a whole in terms of other satisfaction measures (although slightly lower than for non LDD group parents). For example, 29% of LDD group parents strongly agreed and 39% agreed that the school encouraged their child to aim high. The comparable figures for the non LDD group parents were 31% and 43%.

There was a marked difference within the LDD group in terms of satisfaction in relation to whether the child had, or did not have (and had never had), a statement or record of need. So, for example, asked about whether the school helped their child to aim high, 34% of parents whose child had a current statement/record of need strongly agreed that this was so. By comparison, 22% of LDD group

parents whose child did not have, and had never had, a statement disagreed that the school encouraged their child to aim high. This suggests (see parent survey report) that having a statement or record of need was associated with higher parental satisfaction. This may be linked with the earlier discussion about parents' wishes for clarity and transparency (as well, no doubt, as support).

The parent survey raised the question of whether comparatively high levels of parental satisfaction (for parents of special school pupils, in particular) were due to low expectations. We found no support for this suggestion (rather, the reverse). When asked for detail, parents gave us very full and detailed explanations for their satisfaction (or, less often, lack of it):

We looked at [the special school] because it had changed Heads and everything and there was a vacancy and we moved her here and she is one of the less able in a more able group and has come on brilliantly.

The special school has given [him] a basis for independence of thought and this is absolutely fundamental. He is more able to do things because of being at special school.

She's only really had four teachers in the whole of her time at the school, consistency is important.

[She] is an intelligent girl who does not want to feel different; the [mainstream] school has managed to give her support

without undermining her confidence. They have encouraged her ability to be autonomous; there has been no belittling of her.

Once [he] was at the [mainstream school] they did all they could for him; their attitude was 'we'll do our very best'. It's not about being an expert in disability necessarily.

Some parents mentioned aspects of previous and current placements that they wanted to see improved, reflecting frustration at dealing with an apparently unsympathetic and unresponsive educational system. In contrast, other parents felt that the school their child attended was good at keeping them informed about provision and any changes that took place.

He has a fantastic relationship with the SENCO and has done really well. To start with he was about 4 years behind his peers, now he is about 2 years behind. I feel comfortable about approaching them about things and have been kept well informed; the school has done really well. The SENCO is straight talking and really helpful. It is also a small school and so every teacher knows every pupil; there is always someone to talk to.

However for a very small minority of parents, being informed did not always mean that they had felt involved in decisions. They described experiences (not all current) of being kept at a distance from the school; either physically, through the lack of availability of

teaching staff, or communicatively, through the lack of information being provided about progress and developments.

4.1.2 Formalities concerning support

The views of disabled children and young people

Children and young people usually felt that they had had some input into choices about school, especially in relation to which school they wanted to attend. They had clear and sensible reasons for why particular schools were preferred over others, showing maturity in their judgements:

I chose to [come to this school]...we went round to different schools and I chose this school because I saw the way that the pupils were and the help they were getting and that's why. I said to my Mum and Dad, as soon as we walked out the gates, 'This is the school I want to go to because it's the only school I've seen that the school was actually getting round to helping that child'.

I had the choice of two schools. Here or [a different school]. I chose here because it was a more friendly atmosphere.

I think choices are the main thing. It's what the children want at the end of the day, it's not what the teacher's want. It's a good balance, it's not one-sided.

Many comments also implied a strong home culture in which the child's views were sought and respected:

My Mum doesn't just say you're going to do this, you're doing that she'll discuss it with me and the teacher will discuss it with me. They didn't force me or anything like that. I wouldn't let them. I said these are the subjects I want to take and I'm taking them, unless you can give me a good reason, I'm taking them.

I said this is the school I picked out and my parents agreed I could come here and by Jan 6th I started here after Christmas and it all just started being like myself like I used to [before] but as I got more independent in here.

It's been actually fun me being able to decide things by myself. My mum decides some things for me like when I go to bed and everything but I get to choose some stuff so it's really fun.

Less positively, there was a minority for whom involvement in decisions about school was not as positive:

That's where I'm wanting to go. But my Mum, no ... she wants me to go to [a different school]

Researcher: So have you been able to say to anyone that that's your first choice of school?

Ian: No, no-one's really asked me.

Two young people had been involved directly in formal procedures (or reviews) about their education. They were positive, although not always sure about the details, about this process:

Mike: They would review me as if they were reviewing any other child but they would be more understanding about [my condition] and take that into account

Researcher: So are you included in that review? Do you get to say stuff about how you think things are going?

Mike: Yes

Researcher: And is that helpful for you to be included in that and say what you think about school?

Mike: Yes

Researcher: And do you have annual reviews? Do people ask you routinely what you think or what you want to do?

Steve: Sometimes, not all the time. We have like a review with [the head teacher] every year where our parents come in

Researcher: And are you involved in that?

Steve: No it's like we get a report through and it tells you all the subjects you've done and how well you've done in them and then you get like a review date and then your parents come in and you sit with your parents...

Researcher: So you get to be a part of that meeting?

Steve: Yep, yeah

Researcher: So you get to say what you want to say about it then?

Steve: Yeah

Two other young people seemed unsure about their own involvement in more formal processes, such as these annual reviews:

Researcher: Have you managed to speak to anyone about this? Is there anyone helping you to prepare to go to (mainstream secondary)?

Greg: My Mum told me I was going to say things in this thing, I'm not sure what it was

Researcher: Like a review or a meeting?

Greg: I'm not sure what it is, I can't remember. I'm not sure if I'll do it...

I have a review with Mrs _____, my Mum, my Dad, Miss _____ and my teacher and they discuss me. Afterwards they said Claire really likes the help in class, and I thought but you didn't get my side of things!...I just feel that they are just telling me.

All four of the children who were less involved in decisions were final year primary pupils (all in mainstream schools). This suggests that it may be younger children who are less likely to be included in formal procedures, perhaps because they are not considered to be mature, or competent, enough to engage fully with decision-making processes. Note that (as our group case studies testify; see below) children and young people with profound and complex needs can be encouraged to participate in decision-making processes, given appropriate support. This series of points suggests that there is a

need for schools to be more transparent about procedures with young people and, again, to consider their contributions and perspectives as valid, worthwhile and useful.

No evidence was found of pupils more formally taking control of their personal or educational support needs. Given the emphasis on pupil participation and pupil voice in education and children's policies generally, and SEN/AEN policy more specifically, this was perhaps surprising.

The views of parents of disabled children and young people

Interestingly, some parents echoed the children's uncertainty about formal procedures. Failure to communicate fully and appropriately with parents on a regular basis, and especially around and within annual reviews, was a source of substantial frustration and anxiety. This echoed similar points made by parents in the wider parent survey about the importance of communication.

In general, parents were inclined to stress the importance of support; wanting it to be laid out clearly and systematically. Related to this, the parent survey found a higher degree of relative dissatisfaction about school provision for parents of pupils on the SEN register (England) or list (Scotland) compared with parents of mainstream pupils (whole cohorts) or parents of special school pupils. This may have been compounded by possible uncertainty about whether or not their child had special needs given that nearly

half (42%) of parents of pupils on the register/list did not consider their child to have special needs.

The procedural aspects of the reviews were also found to be alienating for some parents. The parents were often not supplied with sufficient information to be both adequately prepared, and fully informed, when discussing options:

You're supposed to have the reports a week or so before (the annual review) and that never happens. So you spend part of the meeting reading through the report and you only get about half an hour anyway and then you can't actually...I think these sort of things need more than just a one-day chit chat. It needs to be an ongoing thing. .. They (professionals) don't turn up anyway but because they are so short of staff - like speech therapists - couldn't always come because they are too busy.

These comments were made despite a positive view of the current headteacher:

Here I have a really good rapport with the Headteacher who is very accommodating, if I have a problem, he will see you quickly and I find that anything that's worrying me I can go to him and say 'Well what do you think?' I've never known a head like him.... Sometimes I've not even had, you know, 'Who would you like to come?' We've not always had that.

The disparity between the personal warmth contrasted with the unresponsiveness of the system, points to the need for a review of the associated formal procedures.

Many parents talked about the battles they had fought to obtain the educational provision they wanted for their children. In the wider parent survey 37% of the LDD group parents had made requests to the school for a change (for example, in relation to the curriculum, medical or support needs, or relationships with other children). A total of 201 parents provided written-in comments explaining why they had done so. Case study parents amplified these written-in comments. They talked about the need for constant vigilance and having to ask questions all the time. There was a frequent view that the only way things came about was to be proactive:

It is true that the most significant thing about having a learning disabled child or a child with multiple needs is just keeping tabs on things and making sure that things happen in the interests of the child.

In our experience it doesn't matter how carefully you set something up or how good it is or appears to be, it requires a huge amount of maintaining and, for the parents, continual questioning and challenging and monitoring.

One parent had been to a tribunal to fight for the provision they wanted for their daughter, Sian. The local authority told them that she should go to a special school but the parents preferred a

mainstream placement. One of the main issues for them was that the people involved in making decisions about school placement had never met Sian or seen the educational settings under discussion. Her Mum was very clear in pointing out that this was not a difficulty she had experienced with the education system alone:

It was traumatic. I found all the way through, in everything we've done, not just with education...what I've found is that the people doing the reports and assessments on the children have never met them...the educational psychologist had never actually been in and met Sian within the setting and were writing reports and that's actually why we won the appeal I think because it didn't stand up because... we asked how many times have you actually seen her and she couldn't answer that.

Other parents had also experienced, and were frustrated by, the perceived lack of knowledge (and/or lack of interest) of professionals involved in decision-making about their children:

We were saying we were interested in local primary schools and she neglected to tell us that this school had particular resources around taking disabled children even when we mentioned it as a possibility we were going to explore, she did nothing.

One aspect of particular frustration for some parents was the lack of interest and/or involvement professionals had, in their experience, in

annual reviews (see also section 4.3.4 concerning rights and inclusion). Understandably, these were seen as important occasions for parents (and children) at which to discuss their views and experiences and to make future plans. So it was not helpful when professionals, often charged with making key decisions about provision for individual children, from relevant services and agencies did not attend the meetings. Parents thought that there should be an obligation or mandate, which ensured professionals, attended annual reviews:

At annual reviews for the Statement, people (from different services) are invited to come but they don't turn up. There should be an obligation for relevant professionals to attend the meetings.

I was asking for the appropriate people to come to her review and have been asking for the last 3 or 4 years and they just don't turn up.

4.1.3 Support in class

The views of disabled children and young people

The majority of children and young people interviewed were receiving some kind of additional support within class, or had received extra support in the past. Depending on individual needs, this varied between full-time 1:1 support, to a few hours of extra help shared between different members of the class. Almost

unanimously, and wherever they went to school, children were pleased with the support they received and found it to be helpful. There was recognition of the need for support workers to know and understand children and young people's individual needs:

The teacher...she helps me and she is good...she knows how to teach me things so I don't forget

Different students do get assistance from, like, different teachers – just in case we are falling behind

She's in the class (teaching assistant), comes around, helps if you need it – it's alright

I want one to one (in class support worker) ... I'd learn more with it

There was little evidence that children and young people felt stigmatised or uncomfortable with the help received. This seemed to be an accepted normality for the pupils and the class.

Nevertheless, there were some caveats to the overall positive view about support provided within the classroom; some children felt that they would have liked more support than they were receiving. Others expressed a preference for a more flexible deployment of resources i.e. they may not have wanted or needed support for all of their formally allocated hours (so saving resources). This meant that some children and young people needed to be confident enough to state their preferences:

Sometimes in practicals in Science, it's a little bit too much help. I can do things myself but they don't realise it so I actually have to tell them all

However, in another school, the researcher noted;

Tanya worked independently on a mathematics activity and sought help from the teacher and an auxiliary on occasions. She also asked for an easy to use 'big calculator' to help check some of her answers and to do more difficult calculations. On one occasion an auxiliary told her that she should not be using a calculator and Tanya replied confidently, saying that it was OK with the teacher. In this lesson she appeared to be quietly confident and able to assert herself.

There was a clear sense that support at school was not just about the rigid application of formal hours provided on a Statement or Record of Needs. Rather, it was about asking children and young people what they would like on a regular basis; believing them when they said what they would like and including friends in the process too (both as informants and as important sources of support).

Many children and young people talked about how important support from friends was to them in relation to helping with schoolwork (see also sections 4.4.1 and 4.4.8 concerning attitudes). This more informal approach to support was valued. There was a sense, for some, that this was preferable to help from adults:

I am just really upset that we are not in the same class...sometimes I'll say to her (my best friend) oh I wish you could be in the same class... I wish (she) was in my class and you were sat on my table so if I needed any help, say if Miss _____ wasn't in the room...

For example, I was kind of falling behind, and a friend ... he helped, pushed me and I really appreciated that.

Just get on with it – help from a friend – teacher doesn't know.

The importance of peers in formal and informal processes of support was clearly articulated by a sixth-form student with dyslexia, who emphasised the valuable role that other students with disabilities or special needs could play in supporting children and young people who were only just beginning to deal with their own difficulties:

There's got to be student involvement in it, because if you have a lot of people from higher up dictating how support is going to be offered then you could end up with an unresponsive system, you could work peer mentoring into that as well, including students from the start, maybe students that have found out when they were six, and known for a lot longer...can support newly 'labelled' students into the society which dyslexic students, if they have the chance, mould themselves into, like a little protective group!

This highlights the importance of role models. Similarly, it was interesting in phase 1, to hear students at a residential further

education college talking about ambition and aspirations in relation to the experiences of brothers/sisters and to disabled peers. Clearly, these friendships/relationships encouraged the students to think about moving away from home and continuing their studies.

The views of parents of disabled children and young people

In terms of the support currently available to children and young people at school, most parents of case study pupils agreed that this was good. This resonated with the parent survey in which 70% of the LDD group parents believed that the school encouraged their child to aim high.

However case study interviews with parents showed that there was a perception that there was a great deal of luck involved in securing high quality support. The motives and intentions of support workers were viewed positively but, in part due to the low paid nature of the work, parents felt the quality of staff could not be assured. In addition, this was compounded by a perceived lack of training and support for the teaching assistants/auxiliaries within the educational system.

Other parents would tell you similar things is that one of the real dangers is the over reliance on teaching assistants and the fact that teachers can leave it to the support staff. You can have brilliant support staff but you can't guarantee it...and if you are unlucky it's not going to be sustainable.

They come from all sorts of jobs, all are really nice but they don't have the relevant training and the wages are very low. They weren't helping (our daughter), as they should have been.

In some cases, children had worked with a number of different support assistants/auxiliaries before finding one whom they liked and felt was supportive:

She was lucky that she then had a TA who could see the potential in (her) and she helped a great deal. I don't blame the school; it is the funding.

The parents of case study pupils acknowledged a challenge between the provision of support on one hand and a promotion of over-reliance on the other (noted earlier in relation to children's views, section 4.1.1). One parent of a child in a mainstream secondary school said that the school had made efforts to ensure that greater independence was encouraged:

He had NNEB support in Junior school and she transferred to (the secondary school) with (him) and this was really helpful. After the transfer, the school realised (he)...relied too much on (his TA) to 'translate' things for him. The school decided to try to maximise his independence and put in place a raft of support to encourage him to try harder. We were more than happy with that.

For parents of case study pupils, formal agreements about time and resources available for support were important; there was a feeling of needing to adhere to what had been agreed (see above, in relation to formalities). In contrast, children and young people preferred a more flexible approach to support and were happy with support not being needed at certain times (and being able to state this clearly). Children and young people were keenly aware of when they did, or did not, need extra help. Friends were also an important part of this (perhaps not recognised sufficiently by parents). Parents need to be reassured through clear communication from schools. They may also need to remember the importance of viewing support from the child's perspective.

4.1.4 Support outside school or college

The views of disabled children and young people

Additional activities, both within and outside school, were important for children and young people although these varied in nature depending on individual preferences. Many children and young people spent a lot of time at home with their families at evenings and weekends. Some also participated in more formal clubs and organised activities. Although some case study pupils said that they would have liked there to be more to do in their local areas, most had found activities that they enjoyed. The boost to self-esteem and confidence, as well as the opportunity to take a break from formal learning, were positive and welcome effects of such participation.

Some of the children and young people received additional support outside class (but still within the school/college setting). It was not always clear how this was funded or provided. There was a suggestion from some schools that they were able to 'share out' resources specifically allocated for SEN, across more children in order to maximise their use of this resource. This took a variety of forms but fell into four main areas:

1. non-curriculum pastoral support for eg behaviour, social skills, relaxation techniques and 'checking-in'
2. work-related study skills such as help with reading and spelling
3. accessing the curriculum in a different setting eg young people at special school attending GCSE or A-level classes at a local mainstream secondary school
4. community 'life skills' visits, primarily for young people at a special school as part of their weekly curriculum. For example, one observed session involved small groups of young people walking into their local town every week to learn how to buy items from shops. One of the aims of this activity was to purchase grocery items with which the class would make their lunch the following day.

Children and young people were mostly (with one exception) pleased with this kind of support or type of activity. The one child

who admitted to not liking additional support outside of the classroom was not able to amplify this or to provide a reason.

Only two young people talked about having additional support from external tutors although, of course, it is possible that other children also had external tutors but did not talk about them. Both these young people had specific learning difficulties with spelling and reading (one having a Statement for dyslexia). They said that they liked having the extra support and recognised that it helped them. Both also said that there were no real differences between the support they received in school and that given by external tutors.

Finally in this section, involvement in other activities, both in and outside school or college, was something that the majority of children and young people mentioned. Sometimes these activities were comparatively solitary in nature (such as playing computer games, especially for the boys; playing the guitar; watching TV) while at other times the activities were more formally organised team, or group-related (such as football, rounders, karate or dancing).

Monday Music at lunchtime, and after school, producing ... a bit of hip-hop, R & B, and UK Garage.

My whole week I'm doing stuff, lunchtimes and after school, English, maths DT ... you know there's no limit to what you can do, specially at lunchtime and after school.

Sign up or just turn up.

Some less formal group activities also took place, such as meeting with friends after school to go into town (although this was much less frequently mentioned) or playing football (which many of the boys noted).

A bit of football, I go the gym, do some weights, weightlifting ... xxx Road ... produce some, got a computer, program Qbase. Like Qbase, can loop a beat with another beat. It's good man.

Families played an important role for many of the children and young people, with a great deal of time in the evenings and weekends being spent with them. Indeed for some, this was the only kind of out-of-school activity in which they participated and it should be noted that this was a conscious choice for some young people:

Kelly: I don't do after school stuff...I've made the decision because I have contact with my Mum and my brothers and sisters and I want that. I think that I've got more time doing that than doing school activities. I go to the library out of school and everything and I think that's good enough for me to be honest!

Researcher: I guess it's about feeling like if you wanted to stay on you could, whether you have a choice to do that if you wanted to?

Kelly: No, I've got the choice. You have to have the choice really don't you? People can't make decisions for you so you have to have the choice

Young people in one of the groups also spoke about cooking (a theme in the whole discussion) saying that they cooked at home, making things like pork fried rice, chicken and rice, and Indian food.

Some (but not all) pupils attending specialist provision suggested that geography and transport prevented them from joining in after-school activities based in the school setting. Living some way from the school meant that it took too much time to return to the school for evening events. Accessing appropriate transport to do so was also difficult. Invariably, a family member was needed to drive the pupil or young person back to school and this placed heavy demands on everyone involved.

We found no systematic differences between special and mainstream school pupils in terms of participation in activities outside school. There were some children and young people in either context who participated in many activities (because they chose to do so) or, alternatively, spent most of their time with family and/or a small group of local friends. The main special-mainstream difference was in relation to level of additional support needs. That is, out-of-school options were restricted for pupils for whom greater support was required. This was because support or available places were limited; or participation had to be well planned in advance, so was less spontaneous. These situations created, real or perceived, barriers to participation.

Case study children and young people attending special schools appreciated the comparatively 'seamless' support available. They did not feel singled out by this and they developed independence and autonomy at their own pace. This was very noticeable for pupils who had moved to specialist provision following difficult mainstream experiences. This may be another factor behind comparative high satisfaction levels of the LDD group when split by strata (special/mainstream/register or list). (For example, with reference to the LDD group parents, 50% of parents of pupils in special schools strongly agreed that the school treated their child well; this compared with 18% of parents with children on the register/list and 27% of parents with children in mainstream schools [whole cohorts sampled]).

One of the positive effects of taking part in extra-curricular activities was the sometimes explicit, often implied, boost it provided to self-esteem and confidence. For others, there was an overt recognition of the importance of taking part in non-school/formal learning activities as a way of winding down and taking a break from the pressures of school:

I love running and biking, it's an outlet and that's one of the reasons that I think about things so much because...you can let your mind go, it's great stress relief. They are things that I've found I enjoy myself, I've done it through trial and error.

The views of parents of disabled children and young people

Some parents, also referring to additional sources of expertise, had involved professionals, external to the school and local authority, in assessments for their children when difficulties were first raised. This was because the existing system for identifying and supporting individual needs was perceived and/or experienced as slow, bureaucratic and unsympathetic (see above in relation to formalities). For some, having independent advice served as a useful lever to facilitate or fast-track responses from the school and/or education authority.

Two parents of case study pupils mentioned that they had recruited external tutors to provide additional input for their children outside of school. In both cases, parents said that their children had made substantial gains as a result and attributed this almost entirely to the input of the external tutor rather than to any extra help the school provided. However, in both cases, there was also a suggestion that knowledge of the support provided in school may not have been accurate or up-to-date.

This provides interesting detail about the sorts of strategies, alluded to in the wider parent survey, concerning responding to shortcomings in educational provision. As found in phase 1, the response seemed to be one of self-help rather than recourse to formal procedures. The immediacy and familiarity of such solutions was part of their appeal. For example, a particular home tutor was used because a friend had employed that teacher with their child. There were no comparable informal accounts about, for example, pursuing cases under the DDA.

These sets of points signal a growing privatisation of special needs provision occurring incrementally rather than by design but contributing to a fragmentation of provision. One can see both sides to this - a parent wishing for the best for their child and perceiving additional outside help as contributing to this but also concomitant difficulties for schools with (potentially) a plethora of independent freelance agencies involved with individual children, without necessarily reliable knowledge or understanding of in-school provision for the child. If parents know more about the support on offer within schools then they may be reassured and less likely to search for external options. The impact of this phenomenon on different social groups may be significant but discussion of this lies outside the remit of this project.

For parents of case study pupils, the school ethos and approach to providing a broad curriculum was important. More holistic views of support need to be adopted within the 'system'. This highlights a key aspect of satisfaction with special schooling; that is, the emphasis on wider aspects and a response to the child 'as a whole' and so greater 'all round' satisfaction. Similar points were made in the wider parent postal survey and suggest that this is an area about which mainstream schools need to review, and possibly reconsider, their priorities and communicate these to parents effectively.

One interpretation of these findings concerns the value of friendships with peers, particularly within school, in offering support and solidarity when things were difficult. It was much less clear

whether this support went beyond the school context and strikingly few of our case study children talked extensively about peer support outside school (whether through the same or different children). So what may be developing are strategies about survival, built through social skills within school, and applied more widely but with different friends outside school. Alongside this are highly family-centred and family-led support systems, possibly putting considerable strain on families, and perhaps accounting for sluggish responses to potential formal support mechanisms or challenges to the system. The family-led responses might also be very isolating and deter the development of approaches led by, or developed through, extra-family structures.

This raises a question about whether debates and discussions on inclusion should focus more strongly on aspects of community participation and the development of community based networks to foster relationships between disabled and non-disabled children and young people. In keeping with this, our advisory group report also highlighted the value of advocacy support groups and pan-disability networks in enabling disabled young people to meet together and to determine their own approaches to community participation.

These 'bonding and bridging' networks (Putnam 2000) have similarities with network theorists' examination of the 'power of weak ties' (Granovetter 1973, 1983; Barabasi 2003). In brief, weaker linkages between groups and individuals may, counter-intuitively, be more robust than strong ties because the very looseness of the group links helps them to be sustained and so influential. For disabled children and their families, who may feel very isolated,

weak ties take on a particular importance in anchoring them to wider arenas. This warrants more systematic examination and fuller investigation. (As an aside, the Experiences project is itself a good illustration of the powerful working of weak ties; the project's design and structure building on a multitude of formal and informal links epitomising such networks.)

4.1.5 Summary concerning independence and autonomy

Overall, whilst children valued independence and autonomy, and involvement in decisions about school, they also appreciated the help they received both formally (inside and out of class) and more informally (from friends). Often, children and young people were aware of their needs and wanted to be listened to when they made their feelings clear. Children need to be given opportunities to share their views and, when they do, have those views taken seriously and responded to sympathetically.

There was a clear sense that support at school was not just about the rigid application of formal hours provided on a Statement or Record of Needs. Rather, it was about asking children and young people on a regular basis what they would like; believing them when they say what they would like and including friends in the process too, both as helpful informants and important sources of support. There is a difficult balance to be struck between providing (welcome) support and promoting over reliance on additional help; fostering and encouraging independence is a challenge. Seeking to create a trusting and open environment in which children and young

people feel encouraged to participate meaningfully, and in which actions are followed through, will help them to feel confident that their views are taken seriously.

Additional activities, both within and outside of school, were important for young people too although these varied in nature depending on individual preferences. Many children and young people spent a lot of time at home with their families at evenings and weekends and some participated in more formal clubs and organised activities. Although some children said they would have liked there to be a bit more to do in their local areas, most had found activities that they enjoyed on their own terms. The boost to self-esteem and confidence, as well as the opportunity to take a break from formal learning, were positive and welcome effects of participation.

Whilst the levels of support needs may have influenced choices about involvement in out of school activities, there were (as would be true of all children) often other reasons reflected in decisions about participation. These other factors included individual choices and preferences (such as not wanting to take part, being shy or other personality factors, lacking in confidence, preferring home-based activities). For example, one pupil described how she had to stop attending an after-school club but this was because of a change in her childminder at home rather than because attendance or accessibility were problematic. This illustrates the wider danger of assuming that lack of independence or participation are necessarily directly related to disability.

For some young people with complex health and personal support needs, high dependence on other people was a matter of fact. Here the concepts of interdependence and help can be interpreted positively. More negatively, one young person who was highly dependent on other people for health and personal needs, was unlikely to be able to access appropriate education (post-19) because of an education provider's concerns about health, safety, resources and staff skills. This failure had arisen despite careful transition planning over a number of years.

There were interesting contrasts between children's and parents' views in relation to support. Children and young people seemed to be more relaxed and flexible than parents about when, and in what form, support was wanted. This chimes with the phase 1 findings in which disabled students at a specialised residential college spoke strongly about their yearning for independence while recognising their parents' possible ambivalence about this. In general, parents were inclined to stress the importance of support; wanting it to be laid out clearly and systematically.

4.2 Experience of accessible/inaccessible educational services and environments

In relation to accessible environments, we asked about young people's experiences of getting to and being at school, as well as in the wider community, and whether they felt at a disadvantage compared with others. It should be noted that only a few of the children and young people had marked or substantial physical or

mobility difficulties and so there were few comments about the physical accessibility of buildings. In addition, the issue of being different or disadvantaged in any way (especially compared to peers) is a sensitive issue that was not broached with all children, especially those with learning difficulties whom the researchers were told (by teachers) were struggling with low self-esteem.

4.2.1 Accessibility of the curriculum

The views of disabled children and young people

The accessibility of the curriculum was facilitated for some children through the use of information technology resources and this was seen as helpful, although not always straightforward or available. For example, specialist equipment (such as screen enlarging facilities) was not necessarily available in all classrooms and supplied laptop computers were sometimes not allowed in class, or were heavily constrained by tight security settings to the extent that Windows accessibility options would not operate effectively. Digital voice recorders were noted to be useful for a couple of the students although these were not without problems; for example, one school had banned the use of MP3 players at school and was reluctant to let a disabled student have a digital voice recorder over concerns of unfair treatment as well as causing her to become the unnecessary target of attention. Another student complained:

As much as your friends have accepted everything, you're sitting there with your voice recorder... and you do stand out

and sometimes the teachers do inadvertently, by accident, bring attention to it. I'm not sensitive about it but when I was in chemistry I had my voice recorder out and it was noisy outside so I couldn't hide it and she brought attention to it: '... you're making me so self-conscious with that' and I just thought hmmm!

Another student said that she had been given a laptop to use in her first year at secondary school but was not given it in her second year. She said there had been no explanation about this and that she had later seen the laptop in a teacher's room.

It was clear that some schools had made substantial investment in ICT resources not only to assist those with additional support needs but also the rest of the class (in mainstream contexts). For example, one very small primary school had interactive whiteboards in its classrooms as well as a voice amplification system to ensure that the voice of the teacher could be heard clearly. Another school used simple, recordable 'button' devices to record a verbal response which could be activated by a non-verbal student. This enabled him to be fully included in class registration (by letting the teacher know he was present). It was equally clear that there was a substantial disparity between schools in the provision of ICT resources, some were very poorly equipped in this respect having only a few shared PCs across the school.

Pupils with visual impairments were often reliant on teachers preparing work in advance, which could then be transferred to

laptops or enlarged appropriately. When the work was not available in accessible formats this created obvious difficulties. The teaching assistants/auxiliaries were essential in such circumstances as they helped pupils to access work, which would have been impossible otherwise. This was also true for teaching assistants/auxiliaries working with other pupils (ie not only those with visual impairments).

Both students interviewed with visual impairments were also keen to stress that no activities at school were off-limits to them. They both especially enjoyed PE:

I'm actually involved in the Rounders team and you would think 'a visually impaired child involved in Rounders, how can she even whack the ball?' They've got a special ball for me and in the ICT club at lunchtimes you can get on with your homework so they've got stuff like that so I can access a lot of stuff at school.

In PE it's quite hard to see some of the activities but like in Basketball, if the ball is travelling quite fast I wouldn't be able to catch it first time, but the Head of Department he includes me all the time and almost blocks out the vision and includes me and would always come up to me and ask me what colour ball would you prefer and what colour bibs would you prefer?

One student at a mainstream school, who used a wheelchair, did not like having to be taken out of classes in order to have physiotherapy. She was unhappy about the fact that she often did

not know when this was going to happen and frequently had to miss particular activities in class (which she liked) as a result. One of the teaching assistants at the school admitted to the researcher that it was difficult for the disabled pupil to be included in PE sessions due to the length of time it took for her to get changed.

Young people attending a specialist unit within a mainstream school liked the fact that the unit offered a refuge from the hectic environment of the mainstream school and also provided time and space in which homework could be completed:

I'd be very stressed with what's happening and what to do next because without (the unit) I'd just be walking around outside doing nothing.

Well, if you don't get work finished in class you can do it here (in the unit) as well.

Accessing the curriculum meant something different to two students from a special school. They were keen that a wider curriculum, including formal assessments, should be available to them:

Leanne: Science GCSE we don't do in this school which is like really stupid because that's one of the main essentials isn't it? English, Maths and Science which I'm going to try and see if I can get! We've only just started doing Maths GCSE this year
Researcher: And is Science GCSE something that you could go and do at a different school or is that not available to you?

Leanne: It's not available. For integration to go to another school, I wanted to do English last year, but apparently you have to do English literature and she (teacher at mainstream school) thought it was too hard for me but it's not because I fly through the papers in English GCSE on literature, and it's like no you're not capable of doing it and I was like I am. They just couldn't get it.

However there was a sense that how this curriculum was accessed should be flexible (either at special or mainstream school) and offer students the choice, depending on their own needs and 'comfort zone':

(It's) about having the choice...we could have a GCSE Science scheme here and one in a mainstream so some students if they wanted to go to a mainstream class they could but some who aren't sure could do GCSE science here...where they feel more comfortable and if they want to do the integration scheme when they are more comfortable then they can.

Certainly this, and other, special school(s) visited, made a great deal of effort to provide as wide and varied a curriculum as possible. This frequently meant involving many other local service providers (schools, colleges and organisations) in a range of formal and less formal curricula and activities. One of the special schools, for example, had their own – fully operational - hairdressing and beauty salons on site, which provided opportunities for students to train and obtain qualifications. The salons also had a long list of regular

clients from the local community. It should also be noted that students from local mainstream schools used the facilities for training and qualifications. There was also a café – open to the general public – at one of the special schools as well as international school exchanges, a local gardening and ‘handyman’ scheme, plus opportunities to learn car mechanics. The school had recently won a prize from the local authority for its sporting facilities and curriculum, beating all other schools in the county (including mainstream).

Pupils attending another special school made use of science facilities at a nearby High School. This was reported to have fostered good links between the two schools involved. The researcher was told by staff that some pupils with physical disabilities had missed this mainstream experience because of inaccessible transport and building facilities. The teacher describing this situation indicated that access would be radically improved as part of a redevelopment project that would co-locate the High School and special school (see also 4.2.3).

The extent to which students felt ‘included’ in different settings (when the curriculum was split across sites) was not altogether clear. There was one suggestion that this ostensible ‘integration’ was about shared space rather than shared experiences, although the former may have been more comfortable for this particular young person.

Claire: At the moment we are at [one of the local colleges] doing some tractor driving and we sometimes do a bit of composting, cutting trees and stuff...

Researcher: How do you find the attitudes of the staff and students there compared to here?

Claire: We're not actually involved with the students but some of them have been really supportive and they give you help – they are not as 'moany' as other people...they teach us stuff and it's really nice

Researcher: Would you want to be more involved with the other students or are you quite happy with the way it works at the moment?

Claire: I find it quite hard working with other kids, I'm getting better at it, slowly, and it's nice to have my friends there...the staff don't nag me, they support me...

Another student, based at a special school, was more positive about his experiences at a local mainstream secondary school:

Researcher: And what about the other kids in that class when you were joining in, and you were coming from a different school...

Steve: When I first went they asked me questions about what school I went to and I said [this one] and they were alright with it and they said 'Oh a mate of mine goes there' and 'Do you know so and so'.

Researcher: So there wasn't anything nasty about the things they said?

Steve: No, no...there's only sometimes when the teacher's away and a supply has come in and they start to muck around but that's only occasionally.

A different student, also at a special school, had mixed responses from teachers at her mainstream sessions in which she was studying for GCSE curricula, reminding us that the attitudes of the teachers in split settings are just as important as the attitudes of other pupils:

Sometimes when they give me maths homework, in the school I went to for Maths for integration, and I hadn't been able to do some of the answers and they were like well you should have got help for it. And if I can't do it I bring it back to the [special] school and then they can help me with it. Today I got told I could do Art GCSE but other teachers have told me I'm not capable of doing it so I believed other teachers thinking I'm not capable of doing Art GCSE and I go to another [mainstream] school today for integration and he says and I'm well capable and I've got to do it and I'm feeling really proud and I'm like why is everyone telling me I can't do it?

The views of parents of disabled children and young people

Case study parents noted that flexibility was important in relation to the use of ICT resources. These were considered to be helpful but their availability was considered to be lucky rather than part of a planned support strategy, and not always sufficiently individualised to best support children's needs:

(They) have acquired a laptop from another student who wasn't using it so it has been lucky... technicians have put so much security on it that she now can't use it!... There's got to be an element of trust here.

Overall, case study parents felt that schools were doing a good job of making the curriculum accessible for their children, whether it was in special or mainstream settings. The majority of parents felt that their children were happy at school (echoing the generally good levels of parent satisfaction in the parent survey, noted earlier). The small class sizes in special schools were considered to be helpful and supportive, as well as the consistency of being able to stay at the same school for longer periods of time (eg. from 5-19). This was thought to have benefits in terms of staff and students knowing each other well and being able to build trusting and sensitive relationships. Nevertheless, one Mum had some concerns about the social side of being at a special school and felt that her son had probably had a smaller social circle as a result. On balance, she felt that her son was more confident and independent because of being able to go to a special school and valued the small number of close friendships that he had made. She was aware, however, that he had intentionally excluded himself from extra-curricular activities because he still lacked confidence.

Parents of children in mainstream schools commented on a number of different aspects of the educational environment. One Mum said that teachers tried hard to find a 'handle' on a subject to motivate and interest her son; another said that the additional 'catch-up' curriculum provided at school was helpful; and another talked about

the role of serendipity in the provision of an accessible environment – the mainstream secondary she wanted her daughter to go to was moving to a more wheelchair accessible site and so she was kept down a year at primary school in order to fit with the provision timetable. Other parents were pragmatic about the accessibility of some aspects of the curriculum for their children (at a mainstream school):

Some aspects have been difficult especially with PE. He can't play Rugby because of problems with his balance as well as difficulties understanding the rules; he is unable to play football with boys of his same age

There are things like sponsored walks that (she) can't really do and when it is Sports Day, (she has) the day off, it's not fair for her to sit and watch, it really hits home to them that she is different

Chronological age in relation to year groupings was also mentioned by some of the other case study parents. A few mentioned that their children were young for their year or had been kept back a year at primary, suggesting that a more flexible approach to the year grouping of disabled children and/or children with SEN/AEN may be preferred or of benefit. This appeared to be the case for one pupil in a small, rural mainstream primary who was able to move between different classes/year groups for different aspects of the curriculum depending on her skills and ability. As her Mum said, having the smaller classes provided greater flexibility and meant that her

daughter's confidence was not knocked. Another Mum, who had tried to organise some time in mainstream school for her daughter, had been very frustrated by the inflexibility about year groupings and this had caused her to stop that particular placement:

I did ask if she could go in with a younger age group because (she) is not big in size...but they wouldn't accommodate that and she had to be with her peer group, which was Year 6 at the time. I pulled the plug on it. (She) wasn't gaining anything I felt in fact she was being totally embarrassed by the situation.

These quotes show that more ring-fenced funding or subsidies for important accessibility 'tools' such as ICT and audio books are needed. (The latter are substantially more expensive than ordinary books although this should increasingly not be the case, especially with the availability of digital downloads.) The DRC or CEHR could work more closely with publishers of all media to work towards making texts or information more available in various accessible formats.

Pupils' and parents' comments above about the importance of flexibility in relation to curricular accessibility also fit with the wider parent survey findings. There, particularly in relation to parents of pupils in special schools, flexible approaches to the child and the curriculum seemed to underlie satisfaction. The case studies provided illustrations of that valued flexibility and showed that all the

schools visited had found ways of being flexible. This was not inherently impossible in the system.

Some parents talked about their perceived differences in how people with different disabilities were supported; often the view was that other children, with other kinds of disabilities, were receiving more or better support than their children:

In other respects, you see plenty of symbols around saying they can do stuff for the deaf but you don't see anything about people with visual impairments.

The schools who have (special needs) bases have very small bases and are maybe dealing with ADHD or dyslexia or things like this, they are not really set up for children with severe and profound difficulties...(the mainstream) school next door you couldn't put anyone in a wheelchair because you couldn't get off the ground floor!

I do appreciate that there are kids who have more profound needs than us. But when I see children with less needs than mine getting more then that's hard.

In relation to formal assessments some of the children and young people were pleased to have extra time or support to complete exams (eg. having a TA who could read questions to them when needed). There was anxiety in a couple of cases around assessments, which could stem from a lack of clarity (for the young

person) about what kind of help was permissible under the circumstances:

Yeah, 'cause when I'm stuck on a word they won't be able to help me in my SATs and they'll tell me to carry on and probably that's the really key information.

The injustice of the system, for me, is the test systems. English especially I think... What are you testing us on? Are you testing us on reading abilities? Maybe I'd have to read that on my own fair enough but with writing you're not testing me on how quick I can write so why have a time limit?

4.2.2 Welsh medium

The views of disabled children and young people

Children and young people being educated in Welsh medium schools had mixed views about these schools. One found learning in Welsh much harder than in English and was happy to go to a different secondary school from her friends. The presence of cousins at the (English medium) school seemed to be reassuring:

I know I'm not going to [Welsh medium secondary] because I'm not very good at my Welsh so my Mum has told the school and everything so I might be going to x or y we don't know yet...'cause I've been doing really well in my English and I go to my English tutor and everything and she's telling me I've

come along and everything. I don't really mind [going to an English medium school] 'cause I've got cousins in both schools and if I go to the Wacky Warehouse or something I make friends like that.

Other children (with similar difficulties) did not find studying in the Welsh medium problematic:

Researcher: Do you find English easier than Welsh or harder?

Raquel: A lot harder.

Researcher: So you haven't found that being at a Welsh Medium school is difficult?

Samantha: Oh it's much better! Because there aren't as many schools in the Welsh Medium and so there's more money to go around! If you are in an English school you've got to share everything with everybody, there's not as much money in the pot. Welsh is much easier than English...it's a phonetic language so you spell it how you say it and that's much easier...plus you've got more one-to-one with Welsh 'cause there's not as many of you in the class and you're getting two languages out of it...I've always been fluent in Welsh and English.

For another child, the language was not so much of an issue compared with the presence of friends in a different school:

Researcher: And what do you feel about learning in Welsh at school? Do you find it harder than English or about the same or a bit easier?

Greg: I would like to be in [a different Welsh primary school] because some of the kids there are my penpals and I would like to see them again. I wanted to go there.

The views of parents of disabled children and young people

Parents of children being taught in Welsh medium schools had very varied views about how successful this had been. One Mum was very concerned that being taught in the Welsh medium had significantly educationally disadvantaged her child (and was now placing her in an English medium secondary school), whilst others were more positive about the benefits of this approach:

(She) is an intelligent girl who does not want to feel different; the school has managed to give her support without undermining her confidence. They have encouraged her ability to be autonomous; there has been no belittling of her. Welsh schools are generally more educationally motivated - children receive more help than they would at a comparable comprehensive...

Whilst one Mum recognised that her son had more difficulties with Welsh than English, she nevertheless remained convinced that

being taught in the Welsh medium was beneficial for wider reasons than learning a second language:

Learning in the Welsh Medium, his speaking is fine but his reading and writing are behind his English because Welsh is not his first language. It's had a positive impact really because lots of lads in the local community don't go to the same school. They tease him and (he) can wind people up too, but it helps him to say he can speak 2 languages!

4.2.3 Access to physical environment

The views of disabled children and young people

The physical accessibility of buildings was mainly an issue for those needing to use wheelchairs (five young people in total, three in mainstream settings and two in special schools) and whilst schools were making adjustments for this (one school, for example, had plans in place to install electric doors throughout the school; another had installed lifts to facilitate access between different floors) there were still some issues raised. For one special school, the cost of improving provision on the current site, or replicating provision with a move to a different site, was prohibitive. Buildings had been adapted but the changes were ad hoc and often of poor quality. At other schools, doors were heavy and difficult to push open; locks were placed too high on doors and teachers sometimes parked in front of the entrance/exit ramps near doors, making the building difficult to access. It should be noted that these issues did not always lead to an unsatisfactory outcome (for the student anyway!):

Researcher: And what's it like getting around here in your chair 'cause it's a big school isn't it?

Keira: It's OK except for when the lifts break. I can't get anywhere.

Researcher: So if the lifts break what do you do?

Keira: I don't go to my lessons! Which I like because I don't like my lessons! I don't mind missing my lessons.

The same student noted that physical accessibility outside of school was also difficult for her sometimes, especially with regard to lift access to buildings and people parking inappropriately in disabled spaces:

Researcher: How do you find it when you go out shopping with your wheelchair? Are there bits that are easier than others?

Keira: Sometimes they don't have lifts so I can't go upstairs and I don't like that.

Researcher: How does it make you feel when you can't go upstairs in those shops?

Keira: Angry.

Researcher: And have you said anything to anybody about how angry this makes you feel?

Keira: Yes... my teacher wrote a letter to the shop.

Researcher: Did you get a response?

Keira: No. When I go out shopping with my parents, everyone parks in the disabled spaces.

Researcher: How does that make you feel when that happens?

Keira: Angry.

Toilet facilities were not mentioned as particularly problematic in terms of accessibility, although one pupil did not like the fact that teachers sometimes used the disabled toilet. It was also noticeable that at one mainstream school, pupils had to take 'scheduled' toilet visits partly because of the length of time it took (eg using an electric hoist to assist with transfer; thereby taking the young person out of class for a lengthy period of time) and partly because some teachers/teaching assistants/auxiliaries were not willing to help with toileting with the result that those willing to do it needed to pair-up in order to manage this safely and effectively.

Although careful attention was given to ensuring that the physical environment in special schools was accessible, not all facilities in these schools were well developed. Staff and pupils were aware of this. One of the difficulties related to inadequate resourcing. This was also linked with a lack of foresight by local authority staff who (reportedly) did not fully understand what kind of environmental changes were required to enable good access for students, nor did they understand the costs involved. Discussions with senior staff in these schools revealed that many of their best facilities had been built with financial backing from voluntary organisations rather than with local authority or national funding. Concerns were expressed about the cost of replicating the full range of accessible facilities needed by pupils and students in 'new build' projects in the light of pressures (welcomed by staff) to co-locate with mainstream schools.

The views of parents of disabled children and young people

There were very few comments from parents about access to the physical environment suggesting that this was perhaps a lesser priority for them compared with other aspects of schooling, such as the curriculum, attitudes of others and participation in other activities:

[She] tripped over at lunch one day because they all use trays to carry their food on but when [she] uses the tray she can't see where she is going. There are glass doors as well that are not immediately obvious.

Outside the school context there was some suggestion of difficulties with the physical environment although only one parent mentioned this explicitly:

Researcher: Does the wheelchair sticker mean that it's accessible to you or not?

Parent: Not necessarily because usually ramps are not the normal entrance and... I want to walk in a building the same place as everyone else!

Another parent mentioned that some activities were likely to be inaccessible for his son in the future, and there appeared to be a pragmatic acceptance of this:

Researcher: Nothing's off limits to you?

Parent: No not really. As he gets older and bigger there are some physical activities that aren't worth it and he isn't going to enjoy because they are not accessible.

4.2.4 Travel between home and school/ college

The views of disabled children and young people

The majority of children and young people interviewed did not view getting to and from school as difficult or problematic. Some lived close enough to the school to walk in (either by themselves, with friends or siblings) and others were taken in and picked up by family members:

Researcher: So how do you get into school in the mornings?

Alex: By taxi. It started that I was on my own and then there were two other people and now it's 12 other people...it works out OK.

Researcher: I wondered whether having football after school makes it difficult for you to get home - with the taxi and everything?

Alex: No it's OK because my parents come to pick me up.

Only one student explicitly commented that he did not like using a taxi to take him home from school:

The problem about taxis is like when I'm in class like last period and they are waiting outside and I take a couple of

minutes they just expect me and some of the other students to be out straight away and sometimes I can't do it. That's the problem about it.

Some others mentioned that the taxis were sometimes late but they did not mind this very much. Another said how much she appreciated the support provided by the taxi escort:

It's OK. They have hiccups and everything, but they can be really good and there are some people in there as well so if I have a sad face on they'll be there 'spill the beans!' and they're really good as well so I've got a lot of people that help. Especially the taxis because you don't normally have that! I've been in, for four years now, going in the taxis and they've got to know me really well so yeah they are really good.

A couple of other students wanted to stop using the taxi but this was more to do with their desire for greater personal independence rather than a particular problem with using a taxi:

Mike: Transport is OK for me. I don't mind if it's late or early...Just now I am taking a taxi but after Tuesday I'll be on the bus.

Researcher: OK so how are you feeling about that?

Mike: Quite excited.

Researcher: So are you going to be coming in on the bus or going home on the bus?

Mike: It's just a trial so I'll be going home on the bus and coming in the taxi.

It is interesting that, in this case, the student associated the bus, but not the taxi, with greater personal independence. This may have been because the bus was available at regular intervals during the day and he would not have been restricted to a particular time for travelling home. More speculatively, there could also be an issue here in relation to peer comparisons. That is, using the bus, alongside many of the other students, would be one way of accessing the same services as others and so minimising perceptions of 'difference'.

At one special school, a system had been implemented to circumvent difficulties students might have in accessing extra-curricular activities because of transport issues. Transport was organised in advance by the teachers (and permission granted by parents/carers) so that students could be encouraged to participate in the range of activities on offer:

We have a Karate club, and we have a professional coming in tutoring us, there's also a football club, a homework club and when we get the computers in the café they can come in at 4.30 and they can work in the café, and also they've got transport to go home. There is a bus or the teacher will take them home...or their Mum or guardian has to sign to say they can walk home...transport is 50p.

This fits with the wider parent survey in which we found that 68 % of the LDD group parents felt that their child's difficulties did not stop them from being involved in extra curricular activities.

Although transport was not a major issue, it did cause difficulties for some children and young people in particular contexts. Difficulties arose when some students could not participate in activities with other schools (curriculum exchange) or in out of school visits (swimming; outings). This appeared to be because available transport was not properly adapted for children and young people with physical impairments. Transport may also have been a problem when it came to making choices about appropriate secondary/high schools to attend. This was because the most appropriate school for a child to attend was a long way from home and parents were concerned about transport (cost/distance). Clearly, choice and diversity in educational provision, key tenets of government policy, raise questions about the sustainability of school transport for all children. These questions are likely to be particularly salient for disabled children, young people and their families.

The views of parents of disabled children and young people

Getting children to and from school was not a major source of difficulty for most of the case study parents interviewed; some lived nearer to the school and/or were able to arrange suitable transport

for their children. There were some notable exceptions, however. One Mum was worried about the transport implications for her daughter moving from a small, rural primary school to a larger secondary school. Another Mum, who was disabled herself, found transport to and from school a particular problem:

Getting (my daughter) to and from school is one of the biggest problems because I don't drive. If (she) was Statemented we could probably get transport to the school but that is filled with its own problems...if (she) has after-school clubs that change, transport can't cope with that. There's no guarantee transport will get her in on time every day. I've been there I've done the transport bit. I had my own driver for a number of years...that was a nightmare.

Another parent refused to consider a special school (primary) placement for his son, in part, because of the transport implications of getting to and from a school that was a greater distance from their house (compared to the current school):

One of the features of special schools is that because children are not necessarily going to their local school and most children will not be local, they travel and most children go on transport provided for them...we just weren't prepared to have a 3 or 4 year old stuck in a taxi, we just wouldn't contemplate it.

We understand from DRC colleagues that transport issues for disabled children have featured prominently in enquiries from

parents to some disability-related help lines. So it is perhaps surprising that problems concerning transport were neither an overwhelming part of children and young people's experiences of school nor a major concern of case study parents. This may link with the earlier points concerning support and independence. The children and young people interviewed wanted, and felt capable with, less support and more independence. It may also be that parents had structured support concerning transport in ways which concealed from their children the extent of the 'hidden' support by parents.

4.2.5 Feeling included

The views of disabled children and young people

Most of the children and young people who were asked about feeling included at school said they felt included most of the time and the school was doing a good job with this. Some compared their present school (usually a secondary) with their previous school (usually a primary) and felt that their current experience was better than before:

Researcher: OK so do you feel like you are included in things that go on?

Mike: Yes. I do go on trips and stuff like that unlike in primary school.

Researcher: That's good. Do you feel that the teachers are also making good efforts to understand you and trying to include you in the classroom?

Mike: They are always including me. I find that maths they don't try to include anyone really, they just give out work.

Researcher: OK so you are not treated any differently to anyone else they are not including anybody?

Mike: Yes that's right.

Observations of a child within a mainstream primary also showed they were making substantial efforts to include him as much as possible. The other children in the class were very involved with Jake and very used to having him around; they were very used to the noises he makes and not bothered by them. His Dad remarked that this was actually an important characteristic of his unique personality:

I think it's part of the kids identity...we were coming into school and (he) was squealing and making noises and a voice came over the hedge 'hello Jake!'

There was also a playground rota for children to play with Jake in the morning break; this was entirely voluntary but there was never a shortage of offers. The other children in the school helped to push Jake in his wheelchair as well as do guided reading with him; a small group of children from the class sat with Jake (without a teacher being present) and read through a book together. The children sang and acted out different aspects of the book as well as engaged Jake with mini-fans (if the story mentioned wind) and a

squirty water bottle (when the story mentioned rain)! Posters and photographs showing the makaton signs most used with Jake were displayed outside the classroom (eg 'finish') and other children made efforts to use some of the signs when they could.

Nevertheless, some children's views and feelings were not as positive. They admitted to not feeling included in activities all of the time. Interestingly, it seemed to be the less structured activities (such as football, music lessons) or unstructured times, such as break and lunchtimes, about which children most often mentioned not feeling included:

It's just that when I was younger, we used to go in groups, right, choose our own groups and I'd go back and get somebody I wanted and they'd say sorry... I'm with someone else and I just feel like oh I have to put up with somebody... I just want people to include me more because I don't feel really included.

It may be argued that these problems could have been overcome by funding additional support for the young person at such times. However that is a two-edged response as support may be helpful but may also foster an over-reliance on adults.

One student's previous experience at a mainstream primary school had made him feel excluded from most things, including classroom-based activities:

They would exclude me from just about everything. I thought it was extremely unfair at the time. There was a ski trip at the end of primary 7 and I didn't get to go and throughout primary 6 & 7, I was in a cupboard, like a really small space, for one-to-one teaching. They thought it was really helpful but I found it extremely annoying.

Some of the children and young people made comparisons with others about their own abilities, suggesting they were very aware of differences either in terms of general attitudes towards them or the work provided. Despite an awareness of differences though, some young people wanted to be treated the same as others:

Yeah, they treated me differently at (my previous school) but here they treat me as normal. They just treated me as if I'm a weird girl and that, a bit of a weirdo, but here (at special school) they treat me as if I'm normal like anybody else.

I'd rather just be treated the same. I think everybody wants to be treated the same basically. It's nice to have the attention occasionally but when it comes down to it you all want to be part of a pack don't you? Give me the option whether or not I want to do the homework and whether or not I do it, in the end, is up to me. Sometimes I just physically can't do it because I get so tired.

One young woman was aware that her academic performance compared unfavourably with her friends; it was therefore important

for her that she knew there was a subject she was good at , something and could do well in (better than), compared with others:

‘cause my friends are very clever and it’s not so easy always because I’m always getting lower marks than them...you know I thought it would help them too if they beat me! I love physics, I got the highest mark in my set in physics and that was so much fun. Not everybody’s who’s academic can do physical stuff.

Having more ability than others in the class did not always confer positive effects however, as one young woman attending a special school describes:

Well, in this school, if you were higher ability you didn’t get a chance to say anything, like if you know the answer to the question and you put your hand up and they’ll go to someone else, because they know that you already know the answer...and I found that really frustrating because they go to someone who is lower ability than you because they think oh you know the answer, you don’t need to answer that and you just get left there, which was bad.

Social comparisons were very important for children and young people, particularly when this meant being seen to be ‘good’ at something; having the opportunity ‘to shine’. In line with this, parents talked about the importance of the need for more flexibility in relation to year groupings. The system needs to accommodate more flexible

approaches like this in recognition of the need to help children feel, in their own terms, confident and capable.

This links with the importance for all children of extra-curricular activities. More effort needs to be channelled into promoting wider curricula, which are not focused solely on formal attainments and standards. The special school ethos seems to be particularly important here in conveying to parents the value of this. Such an ethos can also be part of mainstream school life. In one secondary school, for example, a student spoke about being able to pursue personal interests and hobbies through extra-curricular activities (see 4.1.4).

Such flexibility is not restricted to special school provision and mainstream schools, including secondary schools, did strive to make the curriculum accessible. Within the special schools visited students were able to access good quality post-16 education. However mainstream curriculum access was more difficult and involved uncertainties for students when they were moving to further education colleges. This was illustrated strikingly by a young person who had to choose between mainstream provision and a college for the blind:

Alex: I've applied to two colleges, the _____ sixth form and the (specialist college).... I've had two visits around both. The sixth form is a bit like this school but getting the work done...I'm a bit nervous about whether they would be able to do it, but at the other college the support would always be there so it looks like more it could be the (specialist college).

Researcher: And how do you feel about going there, rather than a mainstream college? That's a difficult choice.

Alex: I don't really want to go there but if I don't then I think 2 years could be wasted.

Researcher: And what about Mum and Dad are they involved in those visits (to potential colleges)?

Alex: Yeah I think both of them would prefer me to go to the sixth form but know that it's better to go to the (specialist college)... my heart says go to the sixth form and my brain says not to.

The views of parents of disabled children and young people

Most parents believed that their children were not excluded from activities. Parents noted the importance of their children being able to take part and feel competent in activities, and the positive effect this had on self-esteem and confidence. Friends also played an important role in this.

Her friends are brighter than her but do not exclude her

Our view has been that [he] takes and goes everywhere and does everything and if he needs additional support and resources and we think it's worthwhile we'll push for it. At the moment, he goes to a mainstream play centre...on a Saturday and one evening for a couple of hours after school and he also spends a lot of the holiday time there.

The school goes to considerable lengths to make sure that 'they fit her in'.

However, for some children with social/behavioural difficulties, it was becoming more difficult for them to remain included in activities because of friction with other children and this had resulted in some feelings of being excluded:

[He] was involved in football training at school but his poor social skills led to rows.

Another parent noted that exclusion from activities was her son's decision, although this was probably related to a lack of confidence rather than a real 'choice' as well as concerns over a stigma attached to attending a special school (note that this young person did not mention this himself):

[He] excluded himself from most activities he did not want to be involved, especially now he is ready to leave. [he] does not have the confidence to get involved in things he worries that people pre-judge him when they know what school he attends; he is very sensitive about the perceptions other people have of the school.

4.2.6 Making school/ college more accessible

The views of disabled children and young people

Asking the children and young people what would help to make things more accessible for them elicited a range of responses. Some answers were focused on practical or technical improvements or tips; such as making sure a laptop could be taken to, and used in, all classes; having audio books available for use; having someone check that disabled parking spaces were not taken by people without disabled badges; and putting more lifts in where needed. Many comments alluded to the need for teachers and other adults to handle disabilities sensitively and check with individuals about their needs and preferences, rather than make assumptions:

Some of them include me in things that I'm uncomfortable in, in which case it would be helpful if they could just leave me alone until I feel confident in their class and want to actually DO the class. And the ones who don't include me at all it would be helpful if they could include me a lot more and it's always helpful if they come down and learn a bit more about it.

I think if the teachers are supportive and say look if there is anything that you don't understand just ask or maybe stay behind the lesson if you've got a question and just make it clear that they can help you with whatever you are struggling with.

Alex: On the teacher side just be aware all the time. In PE it's a big thing like in Basketball, the colour of the ball and bibs and the lighting, I need to have the lights on sometimes.

Researcher: So it's about people checking out with you and not being afraid to check with you?

Alex: Yeah, that's really important.

This linked with ideas about the need for teachers and other adults (and children) to be generally more informed and understanding about disabilities:

Rose: They (teachers) don't meet many disabled children - they just go to special schools. Maybe like introduce them to some children and the children could tell them how their life has been and maybe they could think about how they could adapt their school for them

Researcher: So it's important for you to be able to have an opportunity to tell the teachers what it's like for you?

Rose: Yeah. Gather some children with different disabilities and show them to people and the children tell them how their lives are with having a disability. It may work, it may not! Tell them how it is.

One young woman also implied that her views had not been taken seriously or listened to but now that she had gained 'higher status' she hoped that this might change. This suggests that some children and young people may feel they are not listened to because their views are not perceived as important enough:

I'm going to try to bring that up. I tried to say it before but nothing got done. But I'm Head Girl now and people might listen more. Think 'oh she knows what she's talking about'.

The views of parents of disabled children and young people

Case study parents were also asked about what they thought would help to improve access to the educational system for both themselves and their children. Some made specific suggestions regarding particular 'tools' such as audio books and ICT resources; making these more available in public arenas (such as libraries) was considered crucial. The most frequent, and surprisingly similar, response from many parents, however, was their desire to have more support with navigating the educational system, either in the form of information or (in most cases) an additional person to guide them (see also section 4.3 concerning rights).

This kind of 'independent broker' or 'liaison officer' needs to be someone who knows the young person and their family, is not 'defined' as being from one of the three major agencies (health, education or social services) but is, nevertheless, statutorily funded with a specific remit to support and signpost families with children with SEN/AEN and/or disabilities. Parents felt that they needed help to interpret and understand how legislation, rights and entitlements related to their specific circumstances. Some commented that whilst they were reasonably articulate and knowledgeable themselves, they still found it hard to do this. So other people, with less confidence, would find it even more difficult to know where to go and what/whom to ask.

Support would be better managed if it was more formalised. Personally, you can only give limited support, there needs to be someone who is designated to support the families, who

would be accountable for supporting them. The County should have a duty to provide support but this should be placed within the voluntary sector and should have two main strings: firstly, to support parents about what routes they can take in making decisions about education and secondly, to look at (and support) the child and their rights...I was able to prepare arguments and information for meetings but then I would be so close to tears having someone to say those things on your behalf would have been extremely useful.

Better communication between agencies, parents and schools (is needed)...it is a continual battle...I think for a lot of parents there needs to be somebody dedicated to doing just that, there needs to be a person that is neither school or education or charity...and I don't know how this person is fixed but there needs to be somebody who can be a central point... who knows all the people, all the schools and services, all the charities, all the contact details and holds a database of everything...

Some parents have special needs as well. Once a problem is identified there could be someone like a family liaison officer who comes to the house and explains what it all means to the family in appropriate terms, rather than having printed words all the time (some people don't take that in very well). People need someone to dissect it for them - there needs to be a more personal approach.

All I would have appreciated would have been, even when (our daughter) was 14, to say we need to do her future needs, and when you're at the future needs (review) to give you a pack or something that says this is what can happen when they turn 16. You may be entitled to income support, you may have to apply for guardianship of your child if you have to deal with any medical or legal problems, and just a few basic instructions about how you do it, where you go, who do you contact? Just basic information. For us that would be fine, but I know for other people it just gets more complicated and they can't cope with the paperwork and that sort of thing. You have to go and physically access the carers' centres and know the questions you have to ask, know what it is that you are looking for, each step of the way. An information pack would be extremely useful.

I think they moved some personnel around and seem to have adopted a different approach and suddenly people were taking the phone calls and saying yes that sounds quite reasonable and making things happen...and conducting themselves much more in the role of commissioners with the school being the provider...I think it's a very sensible and logical way of proceeding.

The Citizens Advice Bureau helped me to apply for benefits and they were also really helpful in going through his Statements - it was damn handy to have some steering through that.

(We) need to know what is reasonable to expect and ask...this info is better sooner rather than later. It should be supplied at the time of assessment/Statement. We should know our rights from the beginning... there should be a responsibility on people who are involved in this process (whether health or education) to flag up or signpost parents in the direction of information/support. Not everyone needs to be expert in this need to know where to point people.

Understandably perhaps, pupils and their parents, offered different perspectives on curricular access. For children and young people this was seen to require reasonably small (but important) adjustments to help them to access the curriculum and buildings. By comparison, parents were more concerned with being able to access, and operate within, the wider educational system. While the 'small things' were also important for parents, having more knowledge of specific entitlements was vital. This clarifies the kinds of additional information sought by parents.

A strong message from these findings, as well as the wider parent survey, is of the importance of increasing the coherence of provision for disabled children or children with special needs. Disappointingly, this message also confirms that only limited progress towards achieving greater coherence has been made since the Audit Commission (2003) highlighted major systemic failings.

Moves towards achieving better services and outcomes for disabled children or children with special needs have been made through the more recent setting up of Children's Services and Children's Trusts

plus a policy-practice focus on the five areas of the *Every Child Matters Framework*. However, the kind of enhanced multi-agency working that is demanded by *Every Child Matters* is not easy to establish and can be undermined by recurring difficulties (Young et al 2006). Concerns that the *Every Child Matters* policy has yet to address the problems of multiple disadvantage have also been expressed by a number of organisations working with disabled children and their families. These organisations have launched the *Every Disabled Child Matters* campaign to try to make sure that the policy is real rather than aspirational.

Options, rights and entitlements for individual circumstances need to be made clear within a context in which the priorities of *Every Child Matters* are more clearly targeted at the needs of disabled children and their families. This would help the broad range of parents to feel more informed about, and involved in, decision-making concerning their child.

4.2.7 Summary concerning accessible/inaccessible educational services

Overall, it was clear that many schools (both special and mainstream) were making substantial efforts to support and include children and young people in accessing the curriculum and their

environment. Practical and technical tools such as ICT and sports equipment were important for facilitating accessibility; although whilst ICT resources appeared to be useful, their deployment was sometimes inconsistent and even at odds with the individual needs of the student. A more consistent and planned approach is needed, although this has inevitable resource and funding implications, which may make it difficult for this to be achieved, by schools.

Children, mostly, felt that they were included in activities at school although this was not always the case. Participation in less structured activities appeared to be particularly problematic for some young people. This was perhaps because, unlike the classroom, participation was more linked to and dependent on friendship groups and therefore more vulnerable to the attitudes and behaviours of other children. One mainstream primary school had developed a particular strategy for helping with this by operating a playtime rota for other children to support one disabled student during break times. This worked well and children were happy and willing to spend time with the pupil.

Children and young people were sensitive to their own needs and to comparisons with others. They were also clear that teachers and other adults needed to demonstrate a greater awareness of individual needs by remembering them and actively checking with students if they were unsure. Children and young people did not expect, or want, great changes to take place in their educational environments. Rather, they wanted their views to be taken seriously and their needs to be handled with sensitivity.

Individual adjustments are likely to be highly individualised and so may not be predictable or straightforward to include within planning duties. For example, two case study pupils with visual impairments required very different forms of support (both in terms of needing someone in class with them – or not needing this and the role screen enlargement, text magnifiers played). There is, therefore, a time lag in implementation of adjustments because what they mean in practice may not be fully apparent until the child or young person attends the school. This is true for mainstream and special schools, particularly the latter as the nature of their intake increasingly shifts towards those with higher dependency needs. The implication of this is that the DDA Part 4 anticipatory duty and the duty of continuing responsibility (Disability Rights Commission 2002) need to be considered together by schools and other education providers. Making reasonable adjustments for disabled children and young people should be regarded as a continuous process, supported by active policies and practice.

4.3 Knowledge and assertion of rights

This section included asking children and young people (where possible and appropriate) about disabled identity and language, involvement in school councils as a vehicle for exercising and

understanding rights, as well as views on inclusion and comparisons between mainstream and special schools.

4.3.1 Knowledge of disability legislation and rights

The views of disabled children and young people

Nine children and young people were explicitly asked about their knowledge of disability legislation or policies. Only one had heard about the DDA and the DRC and had some very clear ideas about what the DRC should be doing in relation to messages to young people:

I think to be honest it's time to tell the truth because a lot of people you know, fair enough to the Disability Discrimination Act and everything, they are all working, but there's got to be a pamphlet out there that actually says- 'Right not everybody is gonna know what the Disability Discrimination Act is'. A lot of people are going to look at specific learning difficulties and some won't know what it is, but the majority will go to the extreme and think you can't read, you can't write and that's the truth. And it's horrible that those stereotypes exist but until we get to that point of transition, and we are still going through it, where dyslexia is not seen so much as a disability but a difficulty, then I suppose that element will always be there. I think a lot of young people need to know the truth because the DDA won't protect everybody, not a lot of people know what it is! A lot of people don't actually know that dyslexia is a

registered disability and I even think the DRC need to sit down and start telling the truth to young students with dyslexia and any disability that there will be discrimination, not so serious that you need to report it, but it's gonna happen.

We all have rights you know. Just in case we are in the wrong. We all have rights, like a Statement, to see what really happened ... cos some of us do get into fights. Like, teachers will just accuse you because you were there.

The others who were asked this question had not heard of the DDA or DRC by name. However some felt that having an organisation that supported and protected the rights of disabled people was important and valuable:

Yes it is important to me because if they weren't there I'd probably be in a mental hospital, don't really know what else to say. Just think it's great.

I haven't had much to do with the disability people but I wasn't aware of the participation of these people (the DRC) but they have helped me 'cause if I didn't have help and rights and stuff I would have had to pay for a bus to come to school.

Another student wanted to have more information about the work of the DRC available in schools but also implied that equal and fair treatment appeared to be working for him already:

Yeah I should really (have more information). I went to sixth form and they said no matter what your disability is, no matter how bad or how good, we would always try to make sure we could support you and that's what this school said as well.

Two of the students mentioned specific entitlements that they had, or thought they had, in relation to their disabilities, but did not mention the DDA or DRC directly:

This is where my (condition) comes in really handy because I've got like a special card that enables me to go to the cinema. I go discounted and I get special stuff. My (condition) can help me but I don't really like using the word disabled.

The thing is, (having this condition) you're interesting to a university anyway 'cause they're gonna get extra money! They're not doing it because they want you, they're doing it because you're (disabled) and they'll get more money! So it's a perk! It'll get you in!

Some further information about this, well-targeted at young people, might also have benefits for their parents, by being conveyed to parents directly by those disabled young people themselves. Given the apparent lack of awareness among our case study young people, this may be a fruitful way forward.

The views of parents of disabled children and young people

Very little relevant information (especially about rights and entitlements) was reportedly easily available or actively provided by organisations, agencies or local authorities to parents. Awareness of the DRC and DDA was very varied across families of case study pupils. Some parents had heard of both but did not know the detail of the legislation or the role of the DRC:

I think we are very conscious of the DRC and if you asked most people that question they wouldn't have a clue what you are on about.

You see the odd thing in the press about people complaining about the cost of having to comply with it [the DDA]...and someone had written in to complain that they had not been able to get access to a shop, but apart from that I wouldn't have known the detail of places where we are supposed to go to or the fact that they don't have to fully comply....There was nothing really that came out that would make you aware.

It is having an impact but people don't associate the DRC with all the work it does; people are well aware of gaining access to buildings and having lifts put in, but people don't know about the educational aspect [of the DRC]. I wouldn't know how to use them [DRC] or how to complain. I saw a sign in the Dr's surgery recently about a health ombudsman in Wales who can be complained to, does this cover disability too?

I work in a school so I know the system a bit and I'm still banging my head against a brick wall... 'cause I'm not sure how any of it works and I'm quite articulate but some of it is

quite difficult to understand...it's all very up in the air so I haven't got a clue what she'll be doing in 12 months time...

Of those who were aware of the DRC and DDA, the majority worked in fields related to disabilities and so had known about the legislation as part of their job. Many felt they would not have known about the DDA or DRC in their role solely as parents of disabled children. This suggests that information about rights and entitlements may not be reaching 'everyday' contexts for parents of children with disabilities. One was certain that clear and explicit information was needed:

They (the DRC) need to address this - it has to mean something for parents. We need to know exactly how the legislation affects us and information needs to be clearly laid out. If x happens then it shouldn't, like exclusion from school trips, it needs to be practical. Then you can go to the school and say this shouldn't happen.

Lack of knowledge of the DDA may have reflected wider uncertainties about formal procedures concerning special needs and disabilities (see also 4.1.2). Dissatisfaction with schools seemed to arise, in particular, when dealing with the bureaucracy of SEN/AEN procedures. This was viewed as a difficulty arising chiefly within the wider system rather than intrinsic to individual schools (see also section 4.4 concerning attitudes and behaviours).

I wrote to the head of department and I didn't actually get a letter back from him, I had a letter back from the person who

had actually said what they said, which I didn't think was right. And then I had this apology within the report, the last report, which I don't think was right.

The statementing process was unbelievably badly managed by the LEA at that time...the whole way it conducted itself beggared belief frankly...the issue for us was basically the outlook of the service and the way in which it conducted itself. It wouldn't communicate with you. They wouldn't answer the phone and if they did answer the phone they would lie about whether people were there.

I contacted the LEA and was disgusted by the response. The LEA was so unhelpful though and had a very dismissive attitude. We had to PUSH, PUSH, PUSH because it would all cost money.

It took over 12 months to get funding from the LEA to get support for [her] in school. The LEA wanted her to go to a special school this would have been inappropriate for [her] but it was a battle to convince the LEA.

That is, formal mechanisms, including the DDA, were not well understood by parents. This chimes with the widespread lack of awareness of the DDA, especially at the level of detail, found in the related parent survey. Taking the LDD parent group only: 51% were aware of the DDA, 37% knew that the DDA applied to schools and 39% had heard of the DRC. Understanding about the application of the DDA and its effects was not strong; 43% of these agreed that

they knew how the DDA helped their own child at school. The design of the Experiences project explicitly explored possible confusion about disability by, through the parent survey, exploring the distinctiveness and overlaps in parental perceptions between disability, special needs and other difficulties (such as emotional problems associated with family breakdown).

This suggests that some bridging is needed between these and the day-to-day responses of schools and communities to disabilities and special needs. The detailed concerns about SEN/AEN procedures highlight an area that requires attention, despite the otherwise generally high levels of satisfaction amongst parents (as shown in case studies as well as the wider parent survey). These case study findings also resonated with phase 1 in which a hidden economy operated and involved parents 'doing it themselves' rather than relying on guidance and support from local authority professionals. The likely stress of 'going it alone' and heavy reliance on close family support fits with a recurrent request from parents for an 'independent broker' (see sections 4.2.6 and 4.4.2).

Some case study parents made suggestions about the 'everyday' types of contexts the DRC should be targeting with information, such as supermarkets, prisons, shops, pubs and television:

Info needs to be more explicit and available in everyday contexts such as shops, supermarkets and on the television (ad breaks etc). It is difficult to distribute information via school because so much is sent home with the children - it is not always a reliable way of getting info.

Info could be available in Doctors' surgeries and hospitals, some sort of diagnosis is usually attached to Statement and so information would be useful there, as well as libraries.

Where it's not working is in prison – majority of people there have SEN; DRC needs to be 'visible' in prisons, employment services, pubs and supermarkets.

Interestingly, many of the teachers met during fieldwork in schools also had limited awareness of the DDA or DRC. Some had heard the names but were unsure of the detail or relevance to their school. The impact of the DDA (as with parents, both those involved in case studies and those in the wider parent survey) seemed not to have filtered down to a level at which it was seen to be relevant to practice.

An exception to this occurred in one special school in which pupils considered directly, issues of disability discrimination within personal, social and health education (PSHE) lessons. A teacher had identified an interesting citizenship project being rolled out nationally, as something in which her students might want to participate. They opted to do so and over a period of months undertook a survey of wheelchair accessible community based facilities (eg shops, entertainment and facilities) and produced an excellent guidebook. During the project, students were able to discuss discriminatory practices in relation to the DDA and facilities, which they either used or wanted to use.

The researchers saw very little mention of the DDA or DRC in posters or notices (eg advertising training) in staff rooms. There was a leaflet on the Disability Equality Duty (teacher union publication) posted on the notice board in one school but the teachers there did not comment on the impact of the DDA on their work. The language and experience of SEN/AEN was the most dominant, and understood, discourse in the schools visited across all the areas involved in this study.

4.3.2 School councils as a vehicle for exercising and understanding rights

Our case study pupils were not explicitly concerned with their rights. They did feel able to 'speak up' when it mattered. In certain contexts schools helped to expand their knowledge of rights and facilitated the assertion of these, through the work of School Councils. These worked particularly well when children and young people could relate rights to their personal experiences, such as being effective in changing an aspect of school policy or practice.

The effective and insightful way in which one school council involved their disabled pupils (in a special school) was noted in field notes and illustrates wider points:

The teacher-facilitator minuted the meeting and ensured that minutes would be distributed via class representatives as soon as possible following the meeting. Minutes are also posted on a School Council information board.

The meeting opened with a welcome from the Chair (a pupil) and quickly focussed on the business outlined in the agenda. The Chair of the meeting used a 'script' with words and symbols to help her manage the meeting and this appeared to be extremely successful.

Minutes of the previous meeting were read out, checked and agreed as accurate. Interaction between the chair and facilitator was excellent and the Chair was clearly placed in control of the meeting but knew that support from the facilitator was available if needed.

As the minutes were read out a student asked what a form of words meant and both the Chair and facilitator clarified the meaning.

A number of matters arising led to discussion involving many members of the School Council. Examples included:

- A student reporting on a commitment made to telling someone to carry out an agreed task.
- A pupil reporting that she had written a letter on behalf of the School Council.
- A student saying that he had forgotten to do a job. The Chair asked if someone else would be able to step in and someone volunteered.

The headteacher was given an opportunity to respond to specific requests and did so. He pointed out that funding to support the implementation of a specific recommendation made by the School Council was still not available. He also gave an update on discussions about the introduction of a school uniform indicating that a final decision had not been made yet.

Key features of successful school council work were exemplified in the meetings attended by researchers and confirmed in discussions with the teacher facilitators at two schools. Some of these features are identifiable in the characteristics of discussion referred to above. Others, with wider relevance, include:

- Developing the school council over time and making it an integral part of the way things are done in the school.
- Commitment, knowledge and experience of a teacher facilitator.
- Integrity with regard to how pupils/student should be involved, genuinely seeking ways to ensure that this involvement is meaningful/authentic.
- Good organisation (eg minuting of meetings and distribution of information).
- Representation across the school involving pupils/students of all ages and abilities.
- Regular but short meetings.
- Presenting real issues for discussion with decisions having a direct, visible and immediate impact on the life of the school.

- Allowing time for proper discussion but also focussing on actions that make a difference to pupils/students in ways that are tangible.
- A clear role for the teacher facilitator.
- A well briefed and appropriately supported chairperson.
- Strong commitment from the headteacher and a preparedness to take the School Council seriously, respecting its decisions and responding to its requests (not always positively), recommendations etc. This commitment also feeds into the work of school governors and that of the teaching (and other) staff.
- Nesting school council work in a wider school and community ethos of participation and democratic processes.

4.3.3 Disabled identity and language

The views of disabled children and young people

Views about disabled identity and language revealed a great deal of individual variation as well as ambivalence for some young people and it was mostly secondary age pupils and college students who made explicit reference to these issues. Whilst some accepted their conditions or difficulties as a fact of life:

It's a fact of life get on with it. There's no point in wallowing.

others did not consider themselves to be disabled and found the word disabled (and its implications/ramifications) unhelpful. For

example, teachers at one school talked about delaying registering one pupil as disabled over fears of the negative impact this could have on self-esteem and identity. Another pupil explained her feelings about the 'label':

I don't like it because it seems like some people can't do stuff because they are disabled and some people think they can't do stuff because they are disabled and it's just not fair. Everyone's the same, it's just because they have a little disability, it's not fair.

This emphasises the point made by others researching the lives of disabled children that they are a heterogeneous group; generalisations about views cannot be made across either disabilities as a whole or particular impairments (Barnes et al 2000, Davis et al 2000).

Field notes from the group interview in the mainstream secondary school illustrated those pupils' anxiety about disability as an explicit identity, viewing this as belonging to other students, but not themselves.

An initial conversation indicated that some members of the group were wary of been labelled 'SEN' or 'disabled'. They wanted to know if our meeting was, in some way linked to these terms. We discussed the DRC project briefly and the group seemed happy to proceed on the basis of sharing their views on their particular educational experiences in secondary school.

There are repercussions about benefits stemming from such a position. As noted by one of the DRC commentators on the draft final report:

However inclusive we are – and however much we rightly reject labels – disabled students will sooner or later have to use them. Eligibility for the Disabled Student's Allowance at university, for DLA, sometimes for additional support for leisure or other facilities may require the young person and his/her family to demonstrate 'need'.

Some children and young people interviewed thought that using the word disabled was better than other (derogatory) terms that could be used, but felt that it did not apply to themselves:

I wouldn't say I was disabled. I'd say I'm not as capable as other pupils my age should be, but I think it's a nice word to use because people use things like spastic...or they're thick, they can't walk and things, thicko, and I don't like that because it's not fair. But disabled, mostly people use that word don't they? But I wouldn't say I was disabled or anything.

I think labelling people as disabled (is wrong), if you're labelled as disabled... then (it is seen that) there is something wrong with you then you're less likely to have a social life and self-esteem in that respect.

One student talked about how using the word 'disabled' seemed to be necessary in order for individual needs to be accepted and treated with sufficient gravitas to make a difference:

I think it (disability) is more powerful than difficulty and to be honest as much as I don't agree with it being a disability, if I don't describe it as a disability, no-one would get it. It's a catch 22. I don't believe it's a disability but it does give me certain difficulties in life regardless which if I said 'I've got a learning difficulty' tends to pass by, but if I say 'I've got a learning disability' I have to use that term.

Some children and young people made clear distinctions between themselves and others on the basis of their disability, including noting differences between physically disabled and non-disabled or learning disabled students. However, in two cases, recognition of individual differences was not seen as a reason for treating people differently:

I help out with the wheelchairs and I treat them as normal kids. They're like me and I'm like them except I can walk and talk but I'm just like them. Mentally I'm 10 years old in my head. I know I'm 17 years of age but mentally I'm 10 years old and so I'm like them even though they have more disabilities than I have, it's really nice to have friends who are exactly what I'm like...mentally...it makes me feel more at home.

So we're all like one, not separate, we are all one. We're classed as one. We are all human beings at the end of the

day and should all be classed as one, not oh look at him he's in a wheelchair, we'll ignore him. In this school he's one because yes he is in a wheelchair but he's still human and you don't treat him like anything else. You treat him how you want to be treated. if you want to be respected then respect others as well.

In one case a student with physical disabilities viewed others (those with learning disabilities) as disabled, but not herself:

Researcher: How would you say going to (that club) compares to being at school? Are there things that are different about it or is it quite similar?

Keira: Quite similar although there are people with disabilities.

Researcher: Is that helpful for you to be meeting up with other people with disabilities?

Keira: I don't like seeing children like that.

Other students did not like the term 'disabled' but nevertheless thought their disability was an important part of their identity:

Yes. I'm famous for being visually impaired! People remember me for my glasses. When we had Sport Relief and we had to wear something red, I wore my glasses! If I wasn't visually impaired, my life would be so different.

Well it kind of had two kinds of effect, the label - one I'm a completely different person. Last night there was this Learning Disabilities evening, I couldn't have, a year ago, and

given a talk without notes! I was without notes, looking at everybody, talking and my confidence came from somewhere. Self belief, ability, I mean I walked into my exams this time and I was fine. I came out of them thinking that was OK.

Two of the pupils took a clear 'social model' stance towards disability; viewing it very much as a societal and attitudinal construction rather than an inherent barrier to participation and achievement:

I think schools, if you treat them like they're something else, they'll be something else. If you treat somebody like they have a disability, they'll have a disability, if you treat them normally, they'll be normal.

Yeah it's the perception of the majority which is why if you class dyslexia as a disability and you are doing a disability course then people who are external from dyslexia and who don't know people who are dyslexic are almost going to be prejudiced against them because they're not of the majority...the only real way is to label everyone as equal and to say classify like normal people as a specific thing...because it's only normal in the eyes of the Western education system, whereas there should be like almost a terminology for that, because everyone has a different learning style, a different learning system and a different way their mind works and they should almost be labelled within that.

Two other pupils, both of whom had been diagnosed with an autistic spectrum disorder, identified themselves in terms of their talents:

I used to go to art club (after school), not anymore – too easy, I can do it; it's for five year olds.

You just got it (drawing skills) ... something you are good at, you do in the future.

Both of these pupils were admired and respected for their abilities in areas of the curriculum that their peers found difficult.

Most of the primary aged children did not talk explicitly about disability and instead referred to specific difficulties or impairments that they had/experienced. This seemed to be easier to broach and discuss, suggesting that children were aware of differences and difficulties but had not yet assimilated or compared this information to notions of a more encompassing disabled identity. This point also links with younger children voicing greater uncertainty about and/or involvement in decisions about school (see section 4.1.2), suggesting that communication with young children about SEN and disability is more opaque and 'distanced' compared to older children and young people. (Note also that the researcher may have contributed to this view/approach having been unwilling to explicitly raise the issue of disabled identity for younger children where there was a known vulnerability about self-esteem and confidence.)

These points tie in with wider issues about what children (disabled or otherwise) understand about disabilities and special needs and,

from this, self and identity. It is beyond the scope of this report to explore such areas but a range of work has illustrated the cognitive complexities in explaining, for example, the nature of severe learning difficulties to children at different ages (Lewis 1995, Maras and Brown 2000, Hames 2001).

Children may hold misunderstandings about disability because they have been explicitly misinformed by adults or have picked up incorrect information. However misunderstandings may also arise just because the children are too immature, cognitively, to understand some aspects of disability. In one study, mainstream 6 and 7 year olds appeared to confound sensory needs with learning difficulties; using indicators of sensory impairments to explain the presumed cognitive needs of work partners with severe learning difficulties. So, for example, incorrect school work was attributed to presumed hearing difficulties and not having heard instructions correctly (Lewis 1995, 2002).

The views of parents of disabled children and young people

The views, of the parents of case study pupils about disabled identity were interesting. Many subscribed to a social model of disability:

Loads of people came up to me and said that and I think it is society that doesn't embrace people with a different nose or whatever it is! People do get embarrassed and don't know what to say or how to approach but if they had more

contact...it's getting a bit better because they're going out into the community more....but you still get the staunch people who just don't care at all.

If people accepted there are people that are different then I think our lives would be a heck of a lot easier...from our point of view - visual point of view - seeing has got to be the one thing that you do need because our world is driven by computers which you need to see...supermarkets are set outside towns so you need to drive to them. Pedestrian shopping centres - wonderful for pedestrians providing the pedestrians can get there!... the world is geared to seeing...if all books came out in 16 font then there wouldn't be so much of a problem...then you're not disabled.

He has the ability but the education system needs to help him show his ability.

Disability is a product of society, children should be in mainstream schools.

People's attitudes hold [him] back a lot. He is supported and recognised within his own community but when we go somewhere new people either don't bother with him or are 'overly nice'.

However, this did not mean that these parents were always comfortable with the language of disability. One parent thought that, whilst necessary, this was not always helpful:

(You) need to use this (the language of disability) in formal settings in order to get what you want; you need to use labels otherwise you struggle to get things, but it's detrimental in other settings especially when people haven't met the person and the barriers go up.

Other parents were uncomfortable with the language of disability and how it applied to their children, or talked about how parents (other than themselves) found it difficult to accept the 'label':

(He) heard people on the radio talking about disability and he said 'that's me'. I was upset, I didn't want him to feel like that.

Some people want to have a disabled badge for their car. I would love to be able to throw mine away; would give anything for (them) to be as they should be... we didn't think of her condition, just treated her as normal. You can't live life dominated by the disability and have to keep everything as normal as much as possible.

We find that some things we arrange for the school, a lot of parents won't come to events that you arrange because they really don't want to be out there and seen as having a child with a disability. They don't want to be picked out as different and therefore they don't come along. It's like having this label that you don't want to show in public.

This highlights the often challenging balance to be struck between helping children understand and deal with their difficulties whilst at the same time trying to treat them 'normally'. Children, and parents, were very aware of social comparisons around disabilities and felt it was important for people to recognise and understand what those differences were (in order to secure appropriate and sensitive support) and also maintain as much 'normality' as possible. In this sense, disability was only a part of people's identity:

She is a perfectly normal, intelligent, able-bodied child, she has this visual impairment and only has sight in one eye.

Thus there was an ambivalence from parents and their children about disability identity and language. The language of disability was not always seen as helpful; some even resented it. So there needs to be a broader approach in the language used about disability or special needs when targeting policy and legislation. This links with the current debates about the legislative definitions of disability. There is a need for DRC or CEHR to recognise this issue and to 'reach out' to young people and their families using 'everyday' language and terms. In that way information will be accessible and relevant to a diverse range of people. This will require information to be produced in a range of formats, including using different or broader (ie not disability-oriented) language.

The finding (in relation to parents' general support for the social model of disability) may, at first glance, appear to be at odds with the finding in the parent survey that a majority of parents of children in the LDD group agreed that the main source of the child's

difficulties was ‘just the way he/she is’ (ie a very within-child view). (29% of the LDD group parents strongly agreed, and 34% agreed that the child’s difficulties were ‘just the way she/he is’.) However social and medical models of disability are not necessarily dichotomous or polar constructs. We suggest that many parents have a pragmatic stance that takes into account both their experiences of different environments and the reactions/attitudes of other people, as well as the very real and everyday struggles their children were facing because of their disabilities or additional support needs. In short, there was not a straightforward adherence to a single model of disability as an explanatory concept; rather there was an acceptance that personally experienced difficulties as well as societal barriers and attitudes, contributed to lived experiences of disability.

4.3.4 Inclusion

The views of disabled children and young people

In contrast to the very varied views on disabled identity and language, children and young people were less diverse in their views about inclusion. The majority felt that having a choice of

educational setting was important; the following comment is from a student at a mainstream school:

I just think it mainly depends on how severe the learning difficulty is. It should be their choice. If they want to go to just a normal school then yeah, but if it's extremely severe then I think it's good to have an option that you can go and get additional help if you need it.

Young people at special schools took a similar view:

I think (inclusion for all) is a load of rubbish because it's not fair on the kids that have got learning difficulties, they've got disabilities, and some of the schools have got steps going upstairs, but it's not really fair on the kids like me who need to be in a special school where they can actually learn new stuff and get more supported instead of the teachers having a go at them and giving them pressure and that.

However, two mainstream students were firmly against children attending special schools and thought that everyone should be educated in mainstream settings:

I really don't like the view of segregating the people who need additional help 'cause if they do that then they're not going to be a part of society when they do leave school. They're going to be used to staying out of the way but if you include them in mainstream they get integrated into the system and more helpful for society.

Some children and young people were very well placed to comment about special and mainstream education as they had had experience of both. Having the choice between different sorts of educational provision was seen as important and, in some cases, essential to continued engagement with education:

- (a) comparing mainstream (previous) to home-education (previous)

Researcher: And how do you think it would have been if you had stayed at your primary school and not had different choices about your education?

Rose: I would seriously of hated it and I would have had to do my SATs which would be boring too....

- (b) comparing special (current) to mainstream (previous)

Well yeah. I don't think I would have been able to cope in a mainstream school 'cause it's totally different to like, they're more disciplined and things and the teachers they have different teaching styles, the teachers here are kinder, nicer, they'd expect more of you in mainstream school, so I think it's been much easier here for me to cope with...I probably would have got expelled...probably would have had to be home-schooled maybe.

It's alright (here). I haven't had a lot of problems like I used to at my old school. I used to get bullied at my old school but

here they talk to you about the problems, not actually shouting at you and giving you detention. I find it really easier to express my feelings and they take it on board.

(c) comparing specialist unit in mainstream (current) to special (previous)

Researcher: And where were you before you came here?

Andy: Just before I went to Applegrove...a special needs school.

Researcher: And what was that like when you were there?

Andy: I wasn't really having a good time there.

Researcher: And so then you came here, was it different here compared to Applegrove?

Andy: It was a lot more different being a mainstream school. There are more people my age.

Researcher: And was that a good change do you think? A change for the better?

Andy: Yeah... if I was in a special needs school I wouldn't get the right qualifications and stuff so couldn't get it all there. I suppose because if I wasn't here I would be in some special needs school and I wouldn't get the job I wanted.

Researcher: Has it been important for you to be able to come to the base here rather than spend all of your time in the mainstream school?

Steve: Yes.

Researcher: Why is that important to you?

Steve: It is important that I can come here because I can talk to my friends I have in the base because if I was in mainstream I would just be quiet all the time.

My mum was looking around schools and she applied for this because she thought it was the best thing for me and she was talking to me about it and I was like - sounds good. Because I wouldn't survive on my own, just normal, like any other pupil. I would probably be expelled by now.

(d) comparing mainstream placement (current) to special (trial period)

Researcher: So being at a mainstream school has been important for you?

Keira: It has been better for me because at (the special school) I wouldn't have been able to cope.

One pupil who had transferred from a mainstream primary school to a special school at the primary-secondary transfer stage, after experiencing bullying and isolation for a number of years, found it difficult to articulate her feelings about inclusion. When she showed the researcher her classroom it was evident that she felt that the curriculum, or timetable of lessons, was at least as challenging as that she had experienced in the mainstream school.

What she characterised as different (and better) was being in a smaller environment, with smaller classes, with staff who had time

for her and opportunities to make good friends. Over a one year period, she had reportedly 'come out of her shell', rediscovered her confidence and was happy to come to school. She could also envisage going to a mainstream school for some lessons in the future as did older students in her current school. The mainstream-special distinction for this young woman was not about polarities; it acknowledged that her needs changed over time. This perspective was also highlighted in both phase 1 and the core advisory group.

The views of parents of disabled children and young people

In-depth interviews in the case studies allowed greater exploration of parents' views concerning the strengths and weaknesses of different settings. This has helped to 'unpack' satisfaction levels.

The features of special schools which were particularly well-liked by parents of children attending special schools were: the provision of life and social skills training, small class sizes and available support for all. These were all seen as contributing to the child's building of confidence and self-esteem through a range of activities and positive social comparisons. Formal curricular aspects were much less important there.

Some case study parents were very supportive of inclusive education in mainstream settings, preferring mainstream schools for their children rather than a special school environment. This was viewed by some as within a social model approach ie as something that was not just about schooling but also had wider and lifelong ramifications for the whole community. This is illustrated in the

following quotes, both of which are from parents of children at mainstream schools (attending mainstream classes rather than accessing specialist units or provision within mainstream settings):

The reason why we wanted an inclusive education has very little to do with his childhood and it's all about his adulthood... What we are focused on is the quality of Isaac's life throughout his life and as an adult and the fact is that the quality of life for learning disabled adults is frequently crap...and the single most common reason for that is social isolation... And that's a lot about nobody knowing and not being a part of your community and not being familiar to people...The important thing is being accepted and communicated with as part of your daily life and one of the things that militates against that is going to special school. They are exclusive and out of your area and opportunities to socialise are very limited in school and outside. And all of that contributes to the fact that you grow up not knowing your peers in your local community and above all that's what it's about.

I have a very strong view that children should be able to access specialist input but shouldn't have to go to a special school for it. Some people are happier at special school because they worry about children being bullied elsewhere and all specialist services are available within the special school. But if all children went to the same schools then those services would be available and children could access whatever it is that they need.

However, whilst other parents were supportive of inclusion as an idea (and had pushed to get their children into mainstream provision), they felt that there should still be a choice for parents between types of provision. Many felt that inclusion should take into account individual needs and preferences and that it should very much be up to parents (and their children) to decide what was most appropriate for them; both of the following comments are from parents of children at special schools (one had experienced both special and mainstream contexts):

I still feel she could be included in the social aspects of school and just with that brings a better understanding from the mainstream children and that's what you need to do, you need to educate the younger ones really. All their inhibitions are coming from the parents. The four year olds at the nursery were absolutely brilliant. It's the parents that have the stigma and sort of pass it on to their children. Hopefully, the children will educate the parents! But then there are certain situations when you cannot necessarily integrate every child... I still think you're going to have to have special schools, all the therapies, you've got to have those available and you can't possibly fund every school for every therapy that the children need so you can never have full integration... I do think there is a place for special schools in some respects.

You couldn't do away with specific special needs schools because there are some children who are never going to be able to be included. They are never going to be able to participate in gym or whatever or cookery without a great deal

of support and for those children I think special education, just dealing with the day to day things, would be better...I think to do it and to do it properly, you have to make sure that that child maintains contact with the same children all the way through and that seems to be where it breaks down. You can go to primary school and be integrated but then when you move on and you're away over here and everyone else is going to the normal secondary education and you're getting shifted and having to make new friends, I just don't see the point in that.

Another parent, whilst currently acknowledging the supportive aspects of her daughter's mainstream school, questioned whether this was the right place for her education, mostly due to the importance of having expert and specialist support available in special school settings:

It (inclusion) works on one level, it is supposed to help the able-bodied to accept disability - the jury's out on that one. I do feel there is an awful lot of time spent protecting these children from the bullies and from those who are going to manipulate them...my view is that this will only get worse (the bullying)...the school has a fantastic team...but I am still not convinced that the education of kids like (my daughter) is best done in mainstream schools. I can see the advantages...in theory if everything was available and the equipment was there and we didn't have to go through this process, which is long and drawn out and can take up to six months...in specialist education, everything would be in place. The

individual attention would be there...it's not her ability to learn that is the problem it is her ability to access the curriculum in the first place....and in the mainstream system it's not simple, it all comes down to money and they are not set up for it.

4.3.5 Summary concerning knowledge/assertion of rights

Overall, this section illustrates the highly individualised nature of experiences and views of children and young people with disabilities and/or special needs. Some young people (a minority) seemed to have been empowered by accepting a disabled identity, whilst others did not feel that the words disabled and disability applied to them (including young people at special schools). Children and young people were often very aware of their difficulties and sensitive to differences between themselves and others – often viewing others as more disabled than they were. Some young people disliked the term disabled (and resented having to use it) but felt that it had to be used because it was an accepted term that carried some meaning, and therefore weight, in the wider community.

This suggests a disparity between the world of legislation and policy-speak compared to the experiences/perceptions of disability or additional support 'as lived' by some children and young people. The children and young people with whom we talked (and their families) were not engaging with formal rights-based approaches to securing improved provision. However, young people's participation in school councils was strikingly powerful and effective, thus raising awareness, confidence and knowledge about mechanisms for change, at least within the school context. The extent to which this

influence extends beyond the school context is a fruitful area for future research/consideration.

There are substantial challenges for the work of the DRC and CEHR in relation to how information and support is presented and disseminated. Whilst disability identity and language is important for some, both in terms of shaping identity and signposting information, this is not true for all; indeed some people are likely to be alienated and/or offended by the term 'disabled'. The DRC and CEHR need to find a way to reach a wide range of people who require additional support needs for a variety of reasons, perhaps by adopting a broader view on the language used and approaches taken. This also requires some critical reflection on the role (and presentation) of policy in people's everyday lives.

Similarly, whilst a few young people were against the idea of special schools, a majority was supportive of the need for choice between different forms of educational provision. This choice enabled movement between types of provision at different times during a pupil's educational career, without this giving rise to fragmentary experiences. Whilst many were happy with their current provision, they were aware that this could have been very different had they not had a choice about where and how they received their education. For some, being able to access mainstream provision was vital for self-confidence, socialisation and coping; for others, special school was an educational life raft that probably saved them from permanent educational exclusion. None of the systems was perfect but all were necessary for families negotiating a 'best fit' for their individual children.

4.4 Attitudes and behaviours

This section asked about the attitudes and behaviours of other children/young people, including friends both inside and outside of school; teachers and other professionals; family and the wider community.

4.4.1 Attitudes of friends

The views of disabled children and young people

Unsurprisingly, the majority of children talked about their friends at school as well as outside school. Whether they had a large group of friends or a smaller group, they were important to children:

I like coming to see my friends and everything...they are friendly and fun.

Disability was not really discussed between friends or, if it was, dealt with in a straightforward way:

Mike: The students here are friendlier (than at primary school). They'll talk to me and they understand a lot more about it but they are still not sure. They are not unkind but they can be a bit unsubtle at times.

Researcher: And do you think that's just the way kids are or are there some things that could help them to handle that a bit better?

Mike: It is just the way kids are. They are inquisitive and want to know more. If they want to know more they could come to (the unit) and learn about it.

Researcher: Do they ask you questions? Are they inquisitive about it in that way?

Mike: Yeah... I try to answer as if (my teacher) was answering them.

At the beginning it was like 'oh you got help!' I'm a spaz leave me alone! You just give them some random comment and they'd be like oh OK and I'd just get on with it. Because I've always had really supportive friends and it's never ever been an issue for me...as long as you just tell them straight and not make a big kafuffle about it 'cause that's when they're gonna rib you basically...just be open about it and they'll be fine.

Friends were also sensitive to young people's individual needs and tried to take an inclusive approach to the organisation of activities, for example, when special equipment or facilities were required:

Sally: My other friend... it is her birthday (soon), and she organised going ice-skating, she organised a disabled thing for me, I didn't know they had a disabled thing.

Sally's friend: It's like a wheelchair with ice skates on.

Sally: I wasn't sure I'd be able to go because I didn't know about the wheelchair thing.

Families and friends often helped parents deal with some of the frustration of dealing with difficult attitudes or experiences. Parents admitted that they were sometimes surprised by reactions:

People that you had as friends before we had her, and before she was diagnosed, you would have thought would have supported you, were the ones who didn't, they didn't know how to.

(See also section 4.4.4 concerning families.)

4.4.2 Experiences of bullying

The views of disabled children and young people

Many, but not all, of the children and young people interviewed admitted that they had experienced negative attitudes towards them from other children at school in the form of bullying. Some were reluctant to say very much about this, but others went into great detail about incidents that had happened to them.

I don't like people, rude names, talking to people... (she) talk over me, she said rude word, because is tired because people don't want to play with...(she) is not very kind. We not talking. Very nasty.

Researcher: So when you are here, is there anything that makes you feel a bit sad or that you don't like about school?

Sam: People being horrible to me.

Researcher: OK, that's not very nice. In what ways are they being horrible to you?

Sam: Some people pick on me and some people we start fighting.

Children and young people handled this differently; some went to tell the teachers and/or their parents and ask for help whilst others preferred not to say anything. Others tried to ignore what was going whilst some admitted to lashing out (verbally or physically) when things got too much for them.

We had our art exam and people said you've had the most attention in art and it's true in some ways and not true in others so when I get my exam back, and if I get a B or an A, they'll say oh well you had more help than me. And also I get 100% extra time... so there's a bit of jealousy in some ways and I just seem to block it out and get on with my work and sometimes if I have to I move away from them and let them moan to themselves.

There was a sense for some young people that their reports of bullying were not always taken seriously when they made a disclosure:

I'm not sure if it will cause trouble...I did (go and speak to the teacher) but she forgot it.

Some schools had adopted clear and explicit strategies for dealing with bullying and this was seen as helpful. For example, at a mainstream secondary there was opportunity to clearly record all incidents that took place and swift action was taken by the teachers:

Rose: There was one tiny issue on the first day...one child had a phone and was videoing me and zooming in... we had to go on the computer and they have pictures of every single student and they tried to find the student and they got punished severely.

Researcher: So they acted pretty swiftly on that, did that give you a bit of confidence?

Rose: Yeah. If any incident happens at school, anything, you write it on an internet report and tell them what happened and then that's on your file your whole time... at the moment I think I've got about 10 of them on my record.

At one special school, there was a 'buddy system' in which some of the young people had been trained as 'buddies' to help other children and young people in the school. They were clearly identified as 'buddies' through wearing a badge and all children at the school were told about the scheme:

Yeah the Buddy System... if anyone is being bullied then you go to see this specific student and they are meant to have badges on, and then like they go and talk to them.

The experience of bullying or negative attitudes from peers had changed for some young people in their present compared to previous schools. Some talked about how bad it had been at their previous school and how much better it was now:

Raquel: ...they used to say it to me at (primary school) some of the time...they were thinking that they were smarter and things like that.

Researcher: Does the same thing happen for you here or has that got better?

Raquel: Got better.

One young girl who had moved from mainstream to special school in the previous year said that the lack of bullying in the special school distinguished it from her old (mainstream) school. This was one of the main reasons why she preferred her present school.

For others, their experience of schooling had been largely positive throughout:

A woman used to come in once a week and I would go out with my friend to the lesson. 'Why are you getting help?' once came; I'm just getting help with someone. Oh alright then and that was fine, it wasn't an issue at all. We were all really good friends in that school, in that class. It wasn't a big deal.

A few young people talked about incidents that occurred outside of school also, although there were far fewer mentions of this compared with bullying in school. One incident in particular highlights another example of views and experiences not being acted upon or treated seriously:

A lad came out of nowhere and just punched me for no reason whatsoever ...we went to the police about it and they said sorry there is not a lot we can do. I thought they would have said that anyway but, that's one reason why I want to join the police force because I don't think there's much justice. I think justice is quite important.

In terms of why children and young people thought they were being bullied, only a few talked about this explicitly in relation to their disability or SEN. One young woman insisted that the bullying she had experienced was not related to her disability:

I was bullied but not because of my dyslexia.

Others interpreted children's behaviour with more innocent motives and intentions:

Sometimes they push you about and things and that's a bit annoying...'cause they bump into you when they're paying tick or something and that's annoying...I think they're just running away from the person who's 'on'.

Another child mentioned that he was a target because of his skills and strengths in a particular area:

Well, people get jealous of you drawing. There's name calling.

Only one said explicitly that the bullying she had experienced was related to her disability:

Researcher: So did they ever say anything about your visual impairment?

Rose: Yes.

Researcher: And so some of it (the bullying) was about that as well?

Rose: Yes, most of it I think. I've been bullied since I started school.

The views of parents of disabled children and young people

Some case study parents mentioned that their children had been bullied at, as well as outside of, school; all of these were parents of children who were, or had been, in mainstream settings at the time. Some noted that this had improved over time, especially with swift and supportive action from teachers.

One of the DRC reviewers of the draft final report noted the work done by the Anti-Bullying Alliance (see web reference) and their finding that parents choosing special schools or independent (non-

special) schools frequently gave size and absence of bullying as a prime reason for the move. This suggests that the sort of successful response to bullying by mainstream schools (as described by some of the case study parents) is likely to be very important in curbing (bullying-driven) changes of school.

The attitudes of most other children at school were usually referred to in positive terms and the importance of knowing children and young people over a long period of time was emphasised:

There has been a big change (over time) in the other children at school; they are being very helpful and name-calling is lessened.

Her condition has worsened but because she has always been with children who know her this has not been a problem. The difficult attitudes are always from outsiders.

(He) can be quite noisy and still can be...all of which means he is fed-up or disengaged....but the kids are just not distracted....they don't notice it. They might engage with him in an effort to reengage him or if they're too busy they'll just ignore it...

Being able to stay at the same school, from 5-19, has been important for her because she has stayed with her friends. We don't have the same aspect as mixing with her friends outside of school like (her sister) because they come from all over the city. If she was to move on elsewhere she would lose

that and wouldn't meet up with them anywhere else. I don't think that would be fair.

A sister of a young woman with learning disabilities described the reactions of her friends; she said two of them were very good and treated her sister like any other friend but some of them would not come in the house. She chooses to have her birthday parties at her Grandad's house (without her sister) so that the other children will come. She also described how her own school had done some disability awareness but only talked about people in wheelchairs and those with sensory impairments – learning disability was not mentioned. She described general awareness as an important factor in people being supportive about particular disabilities:

At my school we do all this fundraising and stuff but none of it goes to people with disabilities, it's all like breast cancer and stuff, the big ones...a girl in my class has got epilepsy and for one of our charity events she put in some information about it to see if we would do that but they just went for breast cancer...it was sad...I think it's because it's not a big charity and they don't know about it.

Children in local neighbourhoods were important also and helped children to mix socially and feel included. For one Mum of a daughter at special school this was particularly important:

Not meeting up with friends outside of school has not been a problem because she is very sociable and has made friends

around here with children. They have just included her... she's happy. She is treated like any other little brother or sister that gets in the way, they will tell her to get out of here if they don't want her around.

4.4.3 Teacher attitudes

The views of disabled children and young people

The attitudes of teachers, both at their current and previous schools, were also extremely important to children and young people: they were very sensitive to how well, or not, teachers responded to their needs or any issues arising. Helpful teachers were described as patient, kind and fun; they didn't shout or nag; were trustworthy; helped children to understand their work and asked if children and young people needed help with something.

My favourite's my Year 4 teacher... she's quite nice to me...she's quite nice and always friendly. She makes sure I understand the work properly and the work that she makes us do is quite fun.

We were in Maths and my Maths teacher was a fantastic teacher. For a couple of months he just let me be and then came up to me and said what would you like me to do to help you? I said you're doing brilliantly!

I trust the staff here, the way they act towards you. You can have a laugh with them in lessons and they don't mind you walking around with them while they are doing their duties at lunchtime, it's not like oh I can't be bothered now.

Less helpful teachers were viewed as unsympathetic; forgetful about or non-responsive to individual needs, and as shouting or nagging.

Well if you ask them something and, I wouldn't say they're busy, but they just can't help you at the minute so they should have helpers in the classroom that can help you.

His kind of teaching is if you know technology then he'll teach it you but if you don't then bugger off, that's his kind of teaching style.

Some children had experienced different or unfair treatment at school and, understandably, found this a source of frustration:

Next week we are meant to be going ice-skating, bowling and things like that and we've worked hard to do that, and go towards ice-skating and bowling...and I didn't think it was very fair that she came ice-skating with us because (she hadn't earned it)...yeah and so I went to see a teacher about it but nothing got done about it, which isn't fair because everyone was a bit miffed that she was coming next week when she hasn't been in college since September, so there are some bad issues about the school.

One student took a more stoic view about her situation, suggesting that unhelpful attitudes and judgements were a fact of life and something that had to be dealt with:

There was one case of judging me...they put me in the lowest set because (of my condition), they didn't go on my ability or anything like that because I had very good marks in my SATS in school...within three weeks I was in Set 2 and the next year I was moved to the top set and really they haven't judged me since. Really, people who do that you have to prove them wrong. You have to battle on. You're always going to meet in your life with judgements and you just have to prove everybody wrong. I mean you always get pillocks but you just get on with it.

Reassuringly, this situation seemed to have improved for many children and young people over time and, usually, with a change of school; current experiences with teachers compared favourably to some previous schools. The main source of difficulty at previous schools was to do with teachers' failure to understand the specific nature of needs or disability:

I think they tried to (be helpful) but failed miserably. I think the condition I have not many people have. I think I've only met one other child that has it.

Mike: The teachers didn't know how to deal with children with (my condition) and that's what really made it hard.

Researcher: What was it that wasn't very helpful?

Mike: It was just the way they went around things, they were dealing with me as if I was an unruly child, a bad kid.

This reflects a view from the children and young people that difficulties were at least in part related to the system. This is also reflected in parents' views (see below).

The importance of knowing about individual needs is emphasised in the following comments; both pupils mention supply teachers as a source of difficulty as they were not always informed about students' disabilities. Again, being believed when making a disclosure about disability was a recurring theme here:

Andy: The teachers are generally OK, they seem to like take an interest in the base and understand it. It's when you get a supply teacher in the school that it's a bit annoying.

Researcher: And what happens then, is it up to you to let them know or does someone else help with that?

Andy: It depends, sometimes they see me as another person in the class and I try to get on with it but sometimes they just annoy the hell out of me.

Yeah, it occurs a lot with supply teachers they just don't know. I used to have a little letter that explained my situation because sometimes a supply teacher just didn't believe me!...they obviously get a lot of jokers in their classes and I can just remember in one English lesson she gave me a sheet and I said I can't see this and she said don't be so stupid! She

walked off and I was sitting with my friend at the time and he was just laughing. I tried to explain to her and she said oh really and then just sat down so I had to get the letter out and she eventually said I'm very sorry.

The views of parents of disabled children and young people

Case study parents' experiences of the attitudes of teachers varied widely between those who were very unsympathetic and unwilling to understand, to those who had been very supportive. Many parents had had both types of experiences. The role of a 'key' staff member in supporting parents and their children was centrally important to many experiences. SENCOs were singled out for praise by some parents while others were sure that the influence of the head teacher was paramount:

And it also depends on head teachers, if a head teacher doesn't want your child in the school you might be wasting your time and if the head teacher does want the child in their school it will be quite difficult to stop it happening.

There was a widespread recognition that encountering a helpful and supportive person was often down to luck and individual personalities, rather than because these were embedded, and accepted, aspects of educational provision. In fact, whilst some parents had encountered specific problems with particular staff members, difficulties were very often attributed to the system rather than the school:

There was a lack of knowledge at the time about (her) condition but that's not the school's fault.

I don't blame the school it is the funding.

This overall lack of blaming the school was typical of the LDD parent group in the wider survey. There, 75% disagreed that the child's difficulties were due to the school. Local authorities were also not generally seen as to blame (80% disagreeing that this was the case). The case study data provide illuminating information about where schools or authorities were seen as part of the problem, just why this view was held.

4.4.4 Families

The views of disabled children and young people

Children and young people varied in the extent to which they talked about their families. In some cases young people mentioned how supportive their parents were and how important it was to be able to talk through issues and decisions with them:

But with most of my family having dyslexic traits it's like an accepted thing, get on with life, you don't really have a problem just get around it. I tend to talk to my Mum a lot about it and look at it from different perspectives and it's almost like a resolve that there isn't anything wrong and it's just the way other people look at it that puts you in a bad light.

My Mum's there with me all the time, saying I'll be there with you so it's really helpful.

In one large secondary school, students commented on the importance of having brothers and sisters in the same school. For one girl in the group it was good to know that she had a big sister in the 6th Form even if they didn't speak to each other much. For others, it was good having a younger sibling around whom they could look out for or stick together. This seemed to be to do with a sense of belonging and continuity in life. So siblings could serve an important protective function:

My brother sticks up for me and my Mum and Dad help me along the way.

In other cases, children focused on sometimes ambivalent relationships with siblings:

I've got two sisters...younger than me...I don't really get on with them very well because when we're watching things they get on my nerves and I shout at them!

The views of parents of disabled children and young people

Parents noted the importance of siblings as well as the impact of having a sibling with a disability:

Researcher: Does [she] get to see her brother and sister very much?

Parent: Yes they do, especially the younger one he's brilliant with her 'cause he's always known her to be there. The relationship with the older one is a bit different because she had to put up with her backwards and forwards to hospital when she was little so she didn't have quite as strong a bond.

Family support was noted and valued:

Family has been brilliant especially sister who has been a rock.

Great family support. In-laws were excellent. And we got a really good childminder, she was excellent. So I went back to work part-time, to keep going basically.

There is good support within the family - it is a 'Welsh mafia' family!

These were linked with the importance of understanding about disability within the family; sometimes this was difficult:

My 3 sisters all have children with problems (AS and ADHD) and they have been very supportive but it is beyond the understanding of my Mum. Mother-in-law is also overprotective and tries to over compensate.

4.4.5 External sources of support

The views of disabled children and young people

Children and young people mentioned very few other external sources of support or involvement of professionals, in addition to the supportive approaches of careers advisors included in the Ambition and Aspirations section (see section 4.5). Two young people talked about accessing specific support groups for other children with the same disability but this was not an overwhelming success:

Mike: There are groups and like clubs that I don't enjoy going to them. They are helpful for some people.

Researcher: Are they groups for people with (the same condition as you)?

Mike: I don't really feel (those groups) are necessary to me. They are for other people but not to me.

Keira: It was for a Society called _____ and teenagers with the same disability as me.

Researcher: And what did you think of it?

Keira: It was interesting.

Researcher: Do you think that's something that you'd like to do more of or do you think you get enough opportunities like that?

Keira: I think that was enough.

Another student recounted an experience, which was clearly less than satisfactory, with a counsellor in her previous mainstream secondary school:

Researcher: So did you find those sessions with the counsellor helpful?

Claire: It was alright but she kept mucking me about. She said Wed morning we'll be spending in the office but she didn't and she said oh I forgot but she didn't 'cause she had it in her diary. And also I went in there and there were other kids in there so I couldn't really tell my problems to her 'cause the other kids were in there.

By contrast, a different young woman said that the support she had received at a specialist support unit (not connected to the school) was good:

They are very understanding because they work with people and they don't judge them.

Overall, experience of meeting with other professionals or involvement in outside agencies was not discussed by many of the children. This does not mean, of course, that they did not have such contact but perhaps, because many of the questions asked related

to experiences of school, their interactions with and knowledge of professionals was less salient in this interview context.

The views of parents of disabled children and young people

Charitable and voluntary bodies are becoming increasingly prominent players in the educational landscapes of disability and special needs (signalled in both the Select Committee report on SEN [House of Commons Education and Skills Committee 2006] and the government response to that report [DFES 2006]). However they were mentioned little by the parents or young people interviewed. Interestingly, one DRC reviewer commenting on the draft final report noted that estimates suggest that no more than 30% of parents of disabled children belong to support groups. However the percentage of parents accessing disability-related information via these groups (for example, through web pages and internet searches) is likely to be considerably higher than this figure. To test this, a 'Google' search using impairment terms produced a first hit in every case of a related voluntary organisation.

It will be important for strong links to be developed and sustained between DRC and CEHR and a wide spectrum of voluntary bodies. A similar point was made in a recent research report on work experience as part of the Welsh curriculum 14-19 for young people who are blind or partially sighted (Crews 2006). A main conclusion of that report was that good links between the voluntary sector, careers advisers, specialist teachers and employer representatives are a critical factor in developing successful 14-19 provision. That

research did not mention parents in the context of fostering links with the voluntary sector.

Outside sources of support in general, including voluntary bodies, were mentioned infrequently by case study parents, suggesting (as noted earlier) that seeking of support was handled within the family and/or local community.

A few mentioned specific support groups (including online fora) or carers' organisations:

I belong to an internet forum and we swap tips and info.

Went to a family day (for other parents with children with the same condition) in May...and went to a meeting for Mums. It is useful to be able to discuss things with other people experiencing the same things - better to speak to someone who has personal experience rather than someone who has been trained to do it.

However most support mechanisms appeared to be either formal and school-related or informal and family/community related. The following comments illustrate the perceived barriers in approaching external sources of support:

The other thing is that there are quite a few different carers units within the county that I've only just started to hear about because everyone's been saying that I'm really stressed! But they are not offering, I haven't dipped into any of them, it's

very difficult because you just want an immediate answer, you don't want this rigmarole of what they seem to put you through...you just want to know...an answer to a question...nobody actually comes up with anything so I haven't bothered with any of it.

Experiences of dealing with professionals outside of school, either in the education authority, health-related settings or other agencies, were similarly varied. One LEA was described as 'second to none' by one case study parent, whilst another Mum was disgusted by the off-hand attitude she experienced in dealings with the same LEA. Parents had again experienced some fantastic support from some individuals:

The Occupational Therapist and the Physio have been great. (Her) paediatrician has been great he knows about her and is happy to carry on with her.

However this was not universal:

He says you are supposed to get a social worker to come out to see you before an appointment at the clinic is made and the diagnosis is confirmed; still to this day we have never had that social work contact.

A consultant was the worst, he is very off-hand.

4.4.6 Attitudes outside school

The views of disabled children and young people

Outside of school children and young people varied with respect to the time they spent with friends and often these were different groups of friends to those at school, usually in the local neighbourhood or a part of activities taking place in the evenings or weekends:

I've got a friend up the road and I've got a motorbike and he's got a quad bike so we go racing!

If we didn't have church I wouldn't have the friends I have now...most of my friends are at church.

The significance of support from local faith communities was noted also in the phase 1 report and warrants further scrutiny in other (ie subsequent) research projects.

Two or three of the children and young people appeared to be more socially isolated, not really meeting up with friends outside of school or finding this difficult:

Researcher: And what about friends? Do you see friends outside of school or do you tend to spend time with Mum and Dad and your brother?

Liz: I do see Clara next door of me, she's six years old

Researcher: So you don't see anyone from school?

Liz: No

This has been quite difficult in my life getting a social balance...my Mum and Dad thought it was more important for me to have a social life than to do that (study all the time) but even with that support, it's still been really difficult to keep a social life and find balance.

Children, and their families, who experienced good educational provision often saw this as compensating for a difficult world outside in which unsympathetic responses to a child's 'difference' were not uncommon. For example, a pupil with a physical impairment said that he did not do much in his immediate community because it was "rough". He felt that playing out was not safe. Instead, his parents took him to sport and swimming clubs at which he could join in and meet with children of his own age and whom he liked.

This illustrates the point that families were very important. Although children and young people did participate in their local communities, this was often through the support of specific family members. This may be common to all children and the nature of their engagement with their communities, but for some of the children interviewed this active support was key to helping them overcome social isolation. One student who was about to leave her special school (at the age of 19) was keen to stay in touch with a good friend who was also leaving. However she was resigned to not being able to meet up, because she would need to rely on someone in her family to take

her to meeting places. As the two young women lived in different parts of the city this would be difficult. Although she was supported in this way, it would not always be easy for family members to arrange this. Her difficulties in this regard were exacerbated by her high dependency on support to meet her physical and personal care needs. Meeting these needs took a considerable time and effort, and the inevitable energy expended on this decreased opportunities to go out and do other things.

In terms of attitudes in the wider community, children and young people tended to feel that these were positive towards them and/or disability more generally:

Researcher: Can you see the (your condition) being a problem in relation to that or do you feel that it's not going to get in the way of anything?

Andy: Well obviously it's going to look a bit weird but I'm hoping to get a letter of recommendation from my CO at cadets and then if they read that they would understand that it's not getting in the way of ...

Researcher: Yes, so that's really helpful. It sounds like at the cadets there are people who are being helpful and supportive, it's not like you are experiencing negative attitudes from them?

Andy: No, none of them are like that. They are all quite good.

Britain (is) very open, not that fussed about disability really. I mean at one point they might have been but we've evolved haven't we and adjusted and we're more open to disability I think now. We don't get judged as much.

Certainly in observation of some young people from a special school making a trip into their local town, for example, the shop staff members were very helpful and supportive and clearly knew the students. The importance of a local community who knew members of the group was apparent as there were welcoming and helpful responses.

However, some young people had experienced negative treatment and ignorance about disability in their local community/ies:

People didn't understand (my condition) and would shout at me all the time and it's not my fault, I can't help the way I am, but nobody understood why and it was so frustrating.

Once actually, I was trying to buy a CD and I wasn't sure which one it was so I just asked someone if they could read the back of the CD for me and they were asking why do you want that done, and in the end I had to explain why so they would do it, instead of them just doing it. It was a bit embarrassing but it was a very quiet day so that helped.

Some people will know about it and understand it more than others. Unfortunately, the greater mass of people don't understand it and they just refer to us as retards and other things along the same line... It's very stressful, I get very annoyed. I don't get angry I just walk away.

One young woman recounted an experience of exclusion on the grounds of disability but also about how important it was to challenge people's misconceptions:

Yeah, we had an issue before when we were playing football, there was a football tournament going on and our PE teacher was going to let us qualify for it and they said no sorry we don't take on disabled people because they can't do it and he said yeah they can do it, I'll prove it to you, and they thought that we couldn't do it because we were in a disabled school but we won the tournaments! We came back with six trophies and it's like 'have that'!

The views of parents of disabled children and young people

Attitudes in the wider community towards disabled children varied too; some case study parents felt attitudes had improved in the last few years whilst others recalled some shocking and painful encounters with ignorance and judgemental attitudes, including (in one case) from other parents of disabled children:

(He) loves to dance and we started to find out about dance classes as soon as disability was mentioned there was suddenly a problem with the insurance. If children are included in things from when they are small it would be normal to include people with different needs in things.

Other people make judgements: a few years ago, a woman, a complete stranger, came over and said 'my mother had 12 children and they were all normal'.

Within the space of half an hour two parents came up to (my wife) who didn't know her and said they wished their child had died. Neither of those children had anything like the level of needs that (our son) has ... in those two instances the parents were clearly more messed up than the kids were...they thought it was alright to say that to somebody that didn't know...

Reassuringly though, many parents also talked about how supportive their local communities were, in part because others knew and understood something about the children and their disabilities:

We are lucky with the community spirit here and have several friends who have reinforced (our son's) difficulties with their kids. Everyone knows and there is a level of understanding there.

Three families mentioned the importance of the church in their lives and how supportive this had been for them. This theme was noted also in the phase 1 work in this project and the place of faith communities in fostering inclusion warrants further review.

Many parents talked about how attitudes and behaviours could be better and, for most, this centred on having knowledgeable, sensitive and clearly defined support for families (this links closely with how to improve accessible environments, see section 4.2 above). Information available in everyday contexts was important as well as people who knew the families and children involved:

I think the main thing is to ask the child/young adult and the family and to have people that know that person....it would have to be the school, the teaching staff, the physio's, all the people that deal with them on a day-to-day basis - you need to ask them! Not these people who are out there and just allocated to the job and don't know the first thing about them.

It is better to speak to someone who has personal experience rather than someone who has been trained to do it.

Having somewhere to go to speak to someone at these times is much needed.

Emotional/social support needs to come from someone other than a teacher, it needs to be separate and unbiased so that people can take an all round view.

4.4.7 How to improve attitudes and behaviours

The views of disabled children and young people

Finally in this section, children and young people were asked about how other people could improve attitudes and behaviours towards those with disabilities. A few thought that the school was already doing a good job with this and there was not a lot more they could do; others emphasised the importance of listening, not only to young people but also to other teachers:

They should think about what they are doing and sometimes the teachers, everywhere, they have this very annoying habit that when I ask them to enlarge something they enlarge it up to A3 and I can't fit it on my desk. It's really annoying, they should...listen to what I need because sometimes they will enlarge stuff and it doesn't even need enlarging 'cause it's like 36 font! They don't even listen.

(Teachers should) listen to each other mainly...some teachers don't like listening to other teachers but I suppose you get that in a lot of schools, not just this one.

There was also a difficult balance to be struck between demonstrating an awareness and understanding of individual needs and, at the same time, not treating someone differently because of those individual needs:

I would prefer to be treated the same as everyone else but there are exceptions like if I'm getting completely and utterly stressed out I can come back here and they won't be like no you're staying...but most of the time I prefer to be treated like everyone else. I don't want any special treatment or anything.

Finally, as in many of the previous comments and sections, young people simply wanted to be treated with maturity and respect:

They could have treated me more, not like an adult like they do here, but treat me normal instead of saying horrible stuff and just talk to me and sit me down and politely, not rude or arrogant, saying it's her fault, she did it, we want to get rid of her.

There are many parallels here with views expressed in the advisory group report and elsewhere in this report concerning disabled pupils' involvement in school councils (section 4.3.2).

Awareness of legislation is relevant and important here. Some attitudes (eg the use of inaccessible venues) are discriminatory. They can, and should, be challenged. Clear and simple guidance on this would encourage people to challenge discrimination rather than just putting up with it.

The views of parents of disabled children and young people

Parents need to feel that professionals are sensitive to their needs and knowledgeable so that they have credibility (see also section 4.1.2 concerning the roles of professionals in formal procedures):

I think the main thing is to ask the child/young adult and the family and to have people that know that person....it would have to be the school, the teaching staff, the physio's, all the people that deal with them on a day-to-day basis - you need to ask them! Not these people who are out there and just allocated to the job and don't know the first thing about them.

Emotional/social support needs to come from someone other than a teacher, it needs to be separate and unbiased so that people can take an all round view.

It is better to speak to someone who has personal experience rather than someone who has been trained to do it.

Education and awareness raising is key but good practice (in line with the social model) goes beyond sending out information:

People should have lessons in school to accept their peers no matter what. Not everyone will read leaflets to raise awareness.

4.4.8 What helps children and young people to cope with any difficulties?

Many children and young people mentioned the support from, and attitudes of, family and friends as important in helping them cope, but also talked about developing and strengthening their intrinsic qualities such as confidence and self-esteem. For some pupils this was helped by giving or teaching them explicit strategies for coping with particular difficulties or challenges, such as relaxation techniques or anger management:

To be honest I think most of it is the support I've received and.. looking at the holistic thing, the meditation, the yoga, becoming more relaxed and kind of accepting that things are never going to be quite as easy for me as everyone else but I'm still going to get there anyway, just takes a little longer. It doesn't bother me so much anymore.

It's personality and also the way you've been brought up I think. I mean all (people with this condition) are confident in their ways really...everyone's got their own strengths and weaknesses.

For others it was more about learning to trust others and talk to them about worries and concerns:

I've learned that I can trust some people and I've learned who I can go to for help...It's the way they act towards you and you get the feeling that you can trust them. Like when you have a

conversation, it's not like yeah right ok, you get feedback off them, good conversation, and they talk back as well, it's really nice.

For other students it was also about being able to demonstrate ability in some aspect of their lives, which helped to bolster confidence:

Achieving a goal really. There was GCSE targets given out and I wanted to get them no matter what anybody said, however I got them, I wanted to get them.

Yeah and actually relaxing from it all, so I find the meditation helps a lot as well, and the running and the bike riding as well. I look forward to them and get a kick out of it...it's nothing to do with learning and it's not to do with social life either which I find challenging as well, it's just challenging and enjoyable in its own right.

It's been all of those (friends, family and teachers) because they gave me the support that I needed and it gave me a boost and made me more confident and I just got up and was jolly but when we went on an educational holiday... they got me singing which was really nice...I don't usually do singing...and they said my voice was amazing...

Overall, developing strategies and skills to foster independent coping were considered to be key in helping children and young people handle difficulties, alongside positive support and

encouragement from friends, family and teachers. Finding activities to participate in and feel good about, whether at school or outside of it, was a crucial part of this for many young people, as it enabled them to demonstrate their skills and gain positive feedback. Thus, there appeared to be a greater onus on the development of individual resilience through strengthening inner reserves and feelings, rather than an emphasis on a more interdependent style of coping through greater reliance on networks of familial and community-based support.

These two approaches can be regarded as complementary. The networks visited as part of the project's advisory group appeared to foster individual resilience through the development of self advocacy and advocacy skills in supportive group contexts.

4.4.9 What helps parents cope with any difficulties?

Finally, case study parents were asked about what helped them to cope with difficult situations throughout their experiences of raising disabled children. Close family and friends were very important in supporting families emotionally and practically, and for some, their local, including faith, communities were vitally important too. Families and friends often helped parents deal with frustration, although sometimes parents admitted they were surprised by reactions they had received:

People that you had as friends before we had her, and before she was diagnosed, you would have thought would have

supported you, were the ones who didn't, they didn't know how to.

However, many parents also talked about their own personalities and inner strength as the key factors in helping them to cope; some admitted that they tried to be strong for their families and keep the anxieties and trauma away from other family members, especially siblings:

We tried to keep it to ourselves to protect the rest of the family from the anxiety of it; we didn't want our daughters to take on the negatives of having a brother with a disability; we shielded everybody from it. It was so upsetting.

I had no time to be upset; I had 2 children with disabilities and 2 without and the 2 without can be just as hard if not harder. I can cope, you build your life around what you've got. The strength comes from myself and from my upbringing. I had a cousin with learning disabilities but there was not much contact. I felt pity for disabled people. Until it happens to you, you just don't know anything about it.

I tend to deal with things by myself, we are strong.

Myself and my husband work as a team.

Well my family are all abroad so I haven't got my family. I think having (my daughter) has made me tough because she was very sick and she shouldn't really be here and she's a real

fighter herself so it's probably just that...my husband is supportive.

It is also clear that case study parents wanted to have their views respected and taken seriously. They welcomed meaningful and informed involvement in educational provision and the related decisions/activities.

4.4.10 Summary concerning attitudes and behaviours

Overall, children and young people had experienced both positive and negative attitudes and behaviours from other people, whether it was friends, family, teachers and other staff members at school, other professionals or the wider community. Overwhelmingly, the main theme arising from this section is the importance young people attach to being treated sensitively and the same as anyone else, including being listened to and having their views and experiences treated as authentic and credible.

Supportive attitudes were considered to be honest, kind, straightforward and respectful; unhelpful attitudes were considered to be lacking in sensitivity and thoughtfulness. Children and young people did not appreciate others making assumptions about their needs and preferences without asking them directly.

It was clear from this, and other sections, that educating people about disabilities and SEN/AEN is vital and this is already happening in 'everyday' contexts for children and young people, as

they negotiate the reality and normality of their lives. For many young people, their experiences educate and challenge the peers and adults with whom they have contact. There was a general sense that understanding had improved as children and young people changed schools and matured, but there is still a long way to go before fair and respectful treatment and participation is an embedded practice in everyday life.

Overall, there was little evidence from these families that their resilience was developed and supported by a large network of familial and community support. Rather, the support circles for parents appeared to be fairly small and a more independent notion of coping was common. There are echoes here of the phase 1 report which found that some parents had no choice but to become strong for their children if those children's needs were to be met in the education system.

This highlights a key challenge for the work of the DRC and CEHR in terms of how information and support can be made available to families. There is clearly an important discrepancy between the more private inner resilience and strength within families alongside the desire for more information and support from a formally appointed 'broker' or key worker. Opening families up to an outsider, however well intentioned and committed, will be very difficult for some, partly because of a history of failed expectations and not having views and needs taken seriously. This will need to be handled carefully, and on families' own terms, in order for trusting relationships to be built. Families will need to believe that their 'broker' has the best interests of their child at heart

Different families are likely to need different avenues of support. Some are more autonomous and prefer to seek information and negotiate things for themselves. Others would like to have the option of a keyworker or broker when they feel the need for them.

It is clear that supportive and understanding attitudes towards disability/ies are still patchy and unpredictable. While discussion in the parent survey report suggested that awareness at a very general level of the DDA has improved in recent years, more needs to be done in terms of more specific awareness raising, both within schools and the wider community. Parents could be actively involved in (mandatory) training in SEN/AEN and disabilities for all teachers. Personal stories and experiences can be very powerful and insightful. The Disability Equality Duty and the development and implementation of Disability Equality Schemes involving disabled people could also be a powerful force for change/improvement.

4.5 Ambitions and aspirations

Material under this theme is examined in relation to attitudes to school/college, concerns about school transitions and longer term aspirations.

4.5.1 Attitudes to school

The views of disabled children and young people

The majority of children and young people interviewed were happy at school and liked at least some aspects of their formal education. Many were keen to remain at school and take on further study when they were older (whether at special school or mainstream setting or college):

I love school...it's not just the student's it's the teachers as well...

The good things (about coming to school) are that I have a lot of help.

It depends on GCSEs. You see, there's a certain amount of GCSEs that you need before you can think about going to 6th Form or College.

Others took a more mixed view:

Sometimes I have good days and sometimes I have bad days but most of them are bad days 'cause people take advantage.

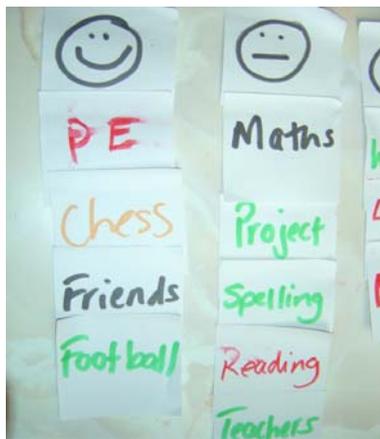
(School is) sometimes quite boring and sometimes quite fun.

In terms of specific activities or aspects of school or college that young people liked or disliked, there was a wide range of responses

(as would be expected from such a diverse group).

Methodologically, the ranking/preference procedures (building on the phase 1 development work and illustrated in Figure 1) were especially useful in eliciting information. They were particularly helpful for children and young people with limited verbal ability and children made clear choices about whether to include people and activities under the happy, OK and sad faces:

Figure 1: Examples from methods portfolio



Many children and young people mentioned practical subjects as their favourite activities at school (such as PE, art, hairdressing, computers) although some liked reading best, others preferred maths and (in one case) physics. For others, with moderate and severe learning disabilities, being with other people and enjoying the social aspects of school life were often the most rewarding features. One young man in a mainstream secondary school included many people (teachers, support assistants/auxiliaries and family) in his ranking/preference exercise; underscoring the primary importance of different people in his life. People appeared to take priority over places, subjects or material things.

The views of parents of disabled children and young people

The reliability of these findings was reinforced by parental views and classroom observations. Parents of case study pupils, talking about the experiences and preferences of their children with severe learning disabilities, also referred to the importance of the social side of school life. Endorsing this, classroom observations showed that these pupils greatly enjoyed being part of a group (in both special and mainstream settings) and that their peers were happy to include them.

Not surprisingly, the feeling of being good at something was important and motivating for many pupils:

Researcher: Are there other things at school that you really like in the same way as you like playing on the computers?

Sam: Working in class.

Researcher: What kind of things do you like doing in class?

Sam: Maths...because I got a letter from the reading rabbit for maths and I got a card that says two thousand and four hundred!

Researcher: So you'd done really well on your maths on this program on the computer. That's fantastic and how did that make you feel?

Sam: Happy.

It's been one of the best places in my life ... cos not only a place with new friends, a place where I learnt new things, an instrument – the saxophone – I achieved a lot.

Activities, or aspects of school, which were disliked produced a varied range of responses. Some children were keenly aware of the topics with which they struggled (maths, reading, spelling) because they found them difficult or boring. A few pupils mentioned teachers or assistants/auxiliaries who nagged or shouted. Some children and young people mentioned unstructured time, and spaces, at break or lunch as problematic:

It's just that the Trim Trail (in the playground) and there isn't a ramp. When Year 5 comes in there I can't get down there.

(At break times) I don't get on any of the toys because people rush out there, because I walk they should walk.

I don't like that (shows a picture of a section of corridor under a stairwell)..it's scruffy and people drop their bags down and one of them nearly hit my friend.

4.5.2 Concerns about school transitions

The views of disabled children and young people

Our case study pupils had typical concerns about formal transition (moving to a bigger school) as well as apprehensions about the support that might/not be available in these new contexts. Overall, and as found in many studies of school transition, this suggests that more needs to be done in communicating information effectively to children about the detail of new contexts. While these concerns are commonly felt by virtually all children, they are more critical for children for whom access cannot be taken for granted.

Future choices and next steps (for example moving from primary to secondary school) created some anxieties for some of the children and young people, often specifically in relation to support they may or may not receive as well as normal concerns about finding their way around a much bigger school:

I'm dreading going to University, absolutely dreading it... letting go of the support that I've got here because what I've had here is second-to-none and I'm fully aware of that.

Yeah. I'm worried, when I'm walking across and I don't know my way around and I might get into trouble for being late and I hear there's a lot of bullies and I'm afraid they'll pick on me...and I'm afraid the work is going to be too hard.

Researcher: And what about after that when you move to secondary school?

Sally: Well I'm REALLY nervous.

Researcher: Yes it's a big move.

Sally: I'll be really nervous. I know I'll still see (them) around but you get so used to seeing (my friends.)

Researcher: What do you think you're most nervous about secondary school?

Sally: Just um sort of into a timetable, it will just be a big change.

The views of parents of disabled children and young people

Some parents of case study children moving to secondary schools also voiced concerns, especially in relation to what support would be available for children and how children would cope with the increased curricular demands. They were worried about their children being bullied at bigger schools because (unlike the primary school) it could not be assumed that all the children there would know about, or understand, their children's needs. However, two parents were optimistic about the move to secondary school, seeing this as an opportunity to move on from less than satisfactory experiences at their child's current primary school.

For some families with children in mainstream schools, there was a complex (and ongoing) negotiation between schools and agencies about how to manage school placements and support, especially when a split model was preferred for the transition to secondary school (eg dividing time between special and mainstream settings). Local authorities were not felt to be supportive of this approach. However parents felt it important to keep children with some of the friends with whom they had grown up in school (via mainstream provision) as well as continuing to access important aspects of learning (such as life skills) in the special school environment (which was perceived as not otherwise available).

Case study data brought out the ways in which some parents acknowledged that the paths they were treading, the choices they were making, and the particular experiences they wanted for their children, were groundbreaking. They felt like guinea-pigs in the system but hoped that this would facilitate easier negotiations and experiences for other families in the future.

I am hoping that once (she) has gone through the school they will turn around and say yes we will take another visually impaired child we are set up and we know what we are doing...it's a huge learning curve for everybody. Every time you step into any new situation you are a guinea-pig.

That's because (he) is a bit of a guinea pig really. A child with (his) needs going to a mainstream secondary school will be without precedent and that may have been the case when he

first came to the primary school...I think that's fine. It's in our nature...

For some this was a risky strategy because it did not always work out in the way they had hoped:

It was a struggle and it was very new to the county to include and it was high priority to include so that helped but she was a bit of a guinea-pig I think and it just didn't work because it hadn't been thought through.

Parents also felt that they needed more information about school transitions and, on the whole, seemed more concerned about the future than were their children. This may have reflected greater awareness of gaps or difficulties ahead. The wider parent survey found that a substantial minority of parents of the LDD group strongly disagreed (5%) or disagreed (11%) that they had sufficient information to decide what to do next (in relation to school transitions) (conversely, allowing for neutral/non responses, 68% felt that they did have sufficient information).

Parents of pupils nearing the end of secondary age education voiced concerns and uncertainties about the options available to their son or daughter. The statutory 'grey' area between the ages of 16 to 18 was challenging and frustrating for some families in England, Wales and Scotland as children moved out of children's services but were too young to access adult services. This created particular problems for planning appropriate provision:

I haven't got any further forwards in fact I'm probably further backwards than I was when she was 14 because I've had these four years and nothing's happened and now she's into adult services and I can't get any of the resources I had in Children's (services) they won't let us in there and yet there's nothing on the other side ... this is what worries me about a lot of things - they start something and then start something else 6 months later and it's very worrying because you need to have something that you know is going to be there for a long time...it's all very up in the air so I haven't got a clue what she'll be doing in 12 months time...it makes it very difficult to plan your own life.

And also you need to have some idea of the options...you see I was told there's no point looking now because it may not be available in 4 years time...so why have a transition at 14 then? Why have a plan if what we decide now won't be there when she is 19? None of it makes any sense whatsoever and I just get so cross and frustrated.

This is our next stumbling block to be honest. The thought of losing (that service) at the end of this year, before her 17th birthday was starting to panic me a bit and when you contact them it's like 'well it's not children's services now' so you go to adult services and they say 'oh but she's not 18 yet' so there's this bit between 16 and 18 that nobody wants to take ownership of and you're left thinking 'where do I go from here?'.

Our main worries are for life beyond college. We would love (him) to have a fulfilling life but are not sure what is available for him, we would hate for him to be stuck in a Day Centre doing meaningless activities. The worst thing is that you can't plan for it; you don't know what services will be available; don't know if (he) will qualify for the Independent Living Fund. It's about picking him up on the radar. Transition... is a big problem; communication between children and adult services is very scant.

There is potentially a key role for DRC or CEHR in clarifying provision and reasonable expectations in this statutory grey area between ages 16-18. The model of the DRC or CEHR (or other agency/service) as an independent 'broker' might be a key part of this.

There were specific concerns about university options:

(We have) great concerns about the future because she is so intelligent and could get so frustrated. It is hard to get to know about University support for dyslexia; it is difficult to know how places are allocated because all is done via UCAS. This makes it difficult to plan because you don't know which Uni to target and you don't know where you'll be going until the results come through but you need longer to plan if you have a disability.

Overall, there needs to be clearer communication with parents and families around transitions and reassurance about continuance of

support in different contexts; importantly, this needs to be a long-term view (through the lifespan) rather than an ad hoc 'patchwork' of provision and support as appears to be the case for some at present. Parents noted the importance of being able to plan transitions and changes in advance but this is of limited use if services, provision and entitlement is not clear or guaranteed for the future.

4.5.3 Longer term aspirations

The views of disabled children and young people

In terms of longer-term or after-school aspirations, especially for older children, there was a reassuring sense of considered and planned approaches often based on current interests or hobbies. For example, dancing, computers, going in the army (following from current experience with army cadets), the police force, hairdressing and working with horses were all mentioned as desirable – more practically oriented - future careers. Alongside this, there was a recognition by some young people of the need to take on 'filler' jobs or activities in the meantime:

Leanne: they (the school) help me with the career I want in the army.

Researcher: Yeah what do you want to do after school?

Leanne: Well I'm getting a job at the moment doing glass collecting. It's not a very good job...but the pay is quite good,

it's like £5.70 an hour...it's just like a job so I can get some money in my pocket, just for now, it's not forever...

Well I'm working in Comet at the moment and I want to go in the police force afterwards, probably in my 20's, 'cause I know the police force need public skills so I'll probably work at Comet for three years and then leave and I'll have my public skills and also my GCSE English and Maths as well and then I'll apply for the job.

Some young people were not sure exactly what they wanted to do in terms of specific subjects or activities but were keen to stay on at school and then aim for further studies at college and University. Perhaps unsurprisingly, some of the aspirations of younger children were slightly more fanciful in nature, such as being a football coach, a basketball player, a comic book artist and riding motorbikes to do wheelies!

For some young people, their next steps were difficult decisions requiring a careful negotiation between their own preferences and the views or circumstances of their family:

That's where I'm wanting to go (a particular secondary school) but my Mum, no ... she wants me to go to (a different secondary). Looks like a prison. In the winter they make kids go out in the cold. I don't want to go there...I told me Mum. She said it's too expensive (at the school I want to go to). It's away from here...It's one of the best schools.

I don't want to move too far away from my parents because my Mum and Dad are dying really slowly 'cause my Dad has Lupus and my Mum has M and S (sic), a bad illness, and she can't walk much, is in a wheelchair, and I'm scared she might have an accident when anyone isn't there and she's on her own...it's really hard.

This emphasises the essentially pragmatic nature of decisions that many of the young people made/were making in recognition of their own difficulties and/or additional external considerations.

There was no evidence that children and young people felt they were not encouraged to aim high, or follow their own interests, or that they were being held back by their disabilities.

The two examples that follow illustrate this well; both girls had interests in different future paths but realised that their choices may be limited in some respects because of their specific disabilities:

I think it was in Year 10, I love gardening, and was there planting something and I thought what the hell am I good at? I'm no good at reading... I love science but I thought I'm crap at that as well 'cause there's a lot of reading involved and I looked down and thought 'plants!' I think (having my condition) you find it hard to read so what do you do? I never ever close my options, always keep them open. I don't think I'd ever close my options actually...if it goes tits up we'll all go in the army! So there's always a back-up plan....You have to put it (my condition) on your form (job application) or else you're

gonna get found out and you might get sacked so it is quite important...they're not supposed to judge you but you get judged no matter what, so I think job applications are an issue but they are an issue for everybody. Everybody's got their own strengths and weaknesses and sometimes you don't always get the job that you want.

I'm going to do my GCSE's and my A levels and all those sort of things and then go to University...because of my (condition) jobs are very limited. I can't be a brain surgeon unfortunately as I wanted to be a brain surgeon and I can't drive so I can't have a car and I can't drive a plane, so all the good jobs I want to do I can't. But I would like to be a big-time fashion designer like they have in America or maybe be a dancer...I want to be able to do something like be a lawyer. There's only one medical thing I can be and that's be a physiotherapist, so that's an option, but I don't know. Maybe something in design or something?

For students with complex physical and learning impairments, access to appropriate post-school or post-19 educational provision appeared to be particularly problematic. Two such students interviewed shortly before they left school faced great uncertainty about to where they would be moving next.

One young woman was starting a child care course at a local further education college after the summer holiday but she was wondering whether it might be better to go to a specialist residential college. Her teacher was concerned about this uncertainty which had arisen

only a few weeks before the end of term, feeling that it was too late to make changes in transition planning and that a residential college placement would be a better placement.

The other student faced even greater uncertainty. She said that she would be starting at college after the summer holiday, but wasn't sure what course she would be taking. Her teacher told the researcher that for a variety of reasons, one of which was related to concerns expressed by the college staff about meeting the student's complex physical and personal needs, it was unlikely that the student would be able to attend their provision for more than one day a week. Worryingly, these uncertainties had arisen despite careful and sustained transition planning over a number of years highlighting shortfalls in provision for children and young people with 'low incidence needs' of the kind noted by Gray et al (2006). Cultural factors may also have had a bearing on planning an appropriate educational placement. The student's family had expressed concerns about mixed-gender further education provision, feeling that she might be particularly vulnerable. With this in mind, both they, and the education professionals providing advice were exploring the possibility of part-time placement at a Women's Day Centre, but this too was unlikely to be set up until after the summer holiday. For this student, a combination of factors appeared to exacerbate difficulties in finding an appropriate educational placement, and her own aspirations appeared to be tempered by circumstances beyond her control.

For those young people who talked about comparisons between the choices they were making, now and in the future, and the choices

that others (without disabilities or SEN) had open to them, the majority did not think that their disabilities would be detrimental to their chances:

I think the fact that I have (my condition) doesn't really change my choices. I don't have any lower IQ than someone else, in fact I've got higher grades than anyone in my class.

I hope opportunities are open to me. Somebody said to me if there was someone (without my condition) and you apply for the same job and you were slightly better, who would get the job? I'm assuming it would be me but sometimes I'm not sure. Sometimes they always take (my condition) but you hope people would cancel it out.

I don't think it (my condition) has so much on choice because I don't see it as a disability. It shouldn't affect your choice, you can do it, it might be more difficult and you might have to go about it a different way.

Most had ambitions and aspirations beyond school and college, and these appeared to be realistically related to experience and talent. For example, the would-be Jamie Oliver said:

I've got it planned out, I'm gonna take it as a professional in a restaurant or a hotel, either one of them or both. A professional – Cooking.

Another girl made the point that she liked being different from others and feeling that she could make different choices if she wanted to; this was another way of saying that her disability or condition did not influence her choices and it was more to do with her own personality:

Well I like to be different! If some people choose things I like to be different and choose other things, I like to be my own different kind of person.

Family, friends, teachers and careers advisors were all involved in helping children and young people make decisions, and keep informed, about their next steps as well as longer-term future. For some students, Connexions had helped to sharpen thinking about what they wanted to do and to where they might move. For others, it had not produced 'the' answer, but had encouraged thinking about the future.

My Mum's there and there's a woman in the careers office who comes to the school and she is really supporting me, she phones me all the time saying I'll come with you and everything, and she's with me all the way.

Researcher: Who's spoken to you about how that (support)'s going to work (at secondary school)?

John: My Mum, because they had a meeting here with the (secondary school) special needs people and they've sorted it out that I'll go for maybe two extra lessons a week.

Researcher: OK and were you involved in that discussion?
Did you have a chance to say how you felt about things?

John: Yeah...if I didn't have those discussions I would feel very nervous and I wouldn't really want to go to (the secondary school).

Children and young people were clear about what they wanted to do; their parents were less certain what options would be available and how it would work in practice.

The views of parents of disabled children and young people

There was no evidence that parents of our case study children had low expectations of their children and young people; all aimed to secure the best, and most appropriate, support and opportunities for their children, wherever that might be available. The main difficulty was a lack of clarity about what options were or would be available at the appropriate time rather than any sense of willing acceptance of inappropriate support. Parents were often very frustrated by the lack of options open to them in their local areas:

In other areas there is better provision for people with physical disabilities; here they tend to mix people up more because of limited resources, this is not always helpful. Being with people with learning disabilities upsets (her) but there is nothing else available.

Parents were realistic and pragmatic about their children's futures and wanted them to have meaningful and fulfilling lives. The picture from the case studies, with its greater detail about parent and pupil views, suggested greater wariness from parents about change than was evident in the parent postal survey. The case studies extend the wider parent survey to comment on the expectations of parents (especially those of children attending special schools), which were realistic and appropriate.

The more personal and individualised approach of the case studies may have encouraged parents to voice fears, which they might have otherwise kept to themselves. Having an extended period of time in which to talk with an interested 'outsider' is likely to produce greater reflection and comment from interviewees. This endorses the overall research design and highlights the importance of including both quantitative and qualitative approaches:

I will always worry about (her), (she) will be what (she) will be. I think No.10 had better watch out! She has yet to accept that she can't be a brain surgeon. I know she's going to be 110% better than the sighted person sat next to her, but I know about the burnout rate too - if she has to fight too many battles of her own she will stop fighting.

We have some worries about educational attainment and whether (he) will get the job he wants but this is the same for all children. He is more able to do things because of being at special school.

(He) is a very unusual child, his capacity to learn rationally and intellectually is extremely limited, he's going to make very little progress along most conventional educational milestones...at the same time emotionally that's not necessarily true...and he does mature emotionally...and that means that we can simplify it and say our objective about education is mainly social...plus its simply about constructive engagement and we are not really interested in what he learns...that it feels meaningful to him and his peers...we think that's a very realistic outlook.

(He) has lots of expectations. We have never said he can't do those things but he is beginning to understand that he won't be able to do them.

Ideally, she would like to go and work with the animals at (a local centre), two or three mornings a week to go and clean them out, she would be in her element and we would be delighted! It's about what her capabilities are and we would like her to do something that stretches those at some point and make her try something harder and push her a bit more. I don't want her to be in the comfortable zone all the time, I want her to try...certainly from our point of view it's not been about excelling in anything or doing well at anything it's been about her getting life skills and being content...they're different expectations...it is different. We are not expecting her to go to University or get a job.

(Having a disability) must influence choices - she wanted to be a High Court Judge but couldn't have coped with the paperwork. Then she wanted to join the Police and ditto. Her memory and aptitude are fine but not her writing skills.

Parents and children were generally pragmatic about options; realistic about difficulties as well as wanting the best opportunities. We found no evidence from parents or children of settling for second best; they were 'aiming for more' but sometimes the system did not allow or provide for them well. Young people about to leave school/college faced well-founded uncertainty regarding post-school provision (although they may not have been fully aware of this) and their aspirations and, sadly, their ambitions may be tempered by the harsh realities around the available options. So, as we have noted in our other reports related to this project, widespread dissemination, in relevant formats and locations, of accessible models or examples of effective practice is vital.

4.5.4 Summary concerning ambitions and aspirations

The majority of children and young people interviewed were happy at school and liked at least some aspects of it; in fact, many were keen to remain at school and take on further study when they were older. The future plans and next steps of some of the young people were based on their current interests and hobbies and were often more practically - rather than academically - oriented career choices. Some young people wanted to go to college and/or

University and most of those who talked about their future choices did not think of their disability as an influencing or impeding factor.

Nevertheless, young people were pragmatic about their choices and realised that in some cases their preferred options may not have been realistic possibilities due, in part, to the specific nature of their disabilities. The flip side to this aspect of aspirations could be seen in the possibly unrealistic ideas of some of the younger children. Therefore, helping children to achieve their aspirations needs to be a balance between aiming high on the one hand and being realistic and pragmatic on the other. Some honesty and sensitivity is needed in this approach as children and young people become aware of the reality of their own disabilities. This should involve continuing discussions with parents, professionals as well as young people themselves (Dee, 2006). This is not the same as having low expectations of children and young people but is about an honest appraisal of strengths as well as weaknesses so that decisions about the future can be adequately informed and realistically pitched.

5. Concluding note

The focus in the case studies in phase 2 was on giving a 'voice' to children and young people across a wide range of disabilities, special educational needs, ages and backgrounds. We found that they engaged meaningfully and productively in discussions with us about their educational provision. On many occasions there was some surprise from the school at the extent to which the child was able to communicate their views and the fullness of these views. We conclude that if this is approached flexibly and sensitively, drawing on a range of sound approaches, all children can be involved in such discussions.

Recent commentators on child 'voice' have drawn attention to the temptation to invite views but then to ignore, or subvert, those voices. The thoughtfulness evident in these children's and young people's responses requires that serious consideration be given both to the processes of hearing these views and to the nature of those views.

Engaging with children and young people about their educational provision or in the context of advisory group work (or similar) requires considerable investments of time, resources and expertise. It also needs to be planned for carefully and imaginatively, recognising that considerable skill and patience is required. Reports which focus primarily on findings and discussion (as here) may give a mistaken impression that engaging authentically with children and young people in these ways can be done relatively quickly and easily.

Responses from children, young people (or advisory group members) may, if part of a trustworthy process, be challenging and uncomfortable. With that in mind specific recommendations (referenced to DRC and CEHR, policy-makers and providers/practitioners are given after the opening summary.

Recommendations for disabled children/young people or pupils with special educational needs are not included in this report. We are currently working (with core advisory group members) on producing accessible versions of key points from the Experiences project, aimed directly at disabled children, or children with special needs, and their families.

Finally, this concluding note has focused on the experiences and views of children and young people. The perspective of parents is also important and this study has attempted to reflect this. At the same time, the detailed case studies have, first and foremost been about children and young people. At times, their views have differed from those of their parents and this has raised interesting issues about the primacy of opinion (eg in relation to the use of adult support in schools), but more often points of view have complemented each other and cast a stronger light on experiences and issues. Perhaps most interestingly, many parents appear to follow the lead of children and young people and are able to identify when their experiences are good, supportive and enabling.

6. Appendices

6.1 Sample data collection materials

6.1.1 DRC main themes and foci for children and young people (Feb 06): questions for young people and observations to be made in school (short version)

Choices and Independence

- School/class/workmates/support
- Views about support and where it takes place
- Activities/clubs? How involved? Compare to 'schoolwork'?

Looking to the future

- What is school/learning like now?
- What like to do next/when older?
- Who helps to talk about/make plans?
- What helps/gets in the way?
- Choices same/different to friends?

Rights

- How are/were people treated in school?
- How describe self? (compared to friends – draw picture if you like!)
- Does the school/other people talk about how to treat people?

Getting to/moving around school and other places

- What is it like getting to school? (How? Arrive on time?)
- What is it like being at school/getting around?
- Easy/difficult compared to others?
- Who/what helps?
- Information around the school? Good/not so good?

Attitudes and behaviours

- Friends in school and outside
- Same/different to friends
- Do people say things about anyone being different?
- Family members, brothers and sisters – helpful/not helpful?
- Teachers and other adults – helpful/not helpful? (behaviour and things people say)

6.1.2 DRC main themes and foci for children and young people (Feb 06): questions for young people and observations to be made in school (long version)

(1) Independence and autonomy
Choice re school/class/workmates/type of work/support?
How did you find out about extra support (if any)?
Views about help/support – who/for what/why/what’s good/not so good? Where does ‘support’ take place (in and/or outside of school)
What can/cannot be done on own/without asking at school?
Activities/clubs at and after school? Feelings about involvement and experiences there compared to schoolwork?

Observation in school:

- Who supports/how often during day/week.

- How is support given.
- How does child/young person negotiate way around school.
- Who do they sit with during lessons.
- What happens at break times.
- What other activities are going on and who takes part in them.

(2) Ambition and aspirations
How do you feel about your school work/course now? [Happy/OK with it or would like to do something different]
What would you like to do in school/college next year ?
What would you like to do after school/college /when you are older?
Who do you talk to about this? When and where does this happen?
What might help you get where you want or get in the way ?
Are your choices different to/same as your friends? [in what ways]

Observation in school:

- Work being done/already completed.

- Any evidence of future plans/aspirations (e.g. review docs; transition plans; IEPs etc).
- Who has responsibility within the school for planning transitions.

(3) Knowledge and assertion of rights
To ask all:
Does the school say anything about how to treat people in the school? [eg about people being equal and making people feel included ?]
Does anyone else talk about these kinds of things? [eg family, social worker, ed psychs etc]
How are people treated in school ? [different – same – reasons for this]
How think of/ describe self ? [Could ask children to draw themselves to help with this?] Any differences compared to friends?
Additional questions to ask school councils:
What does the council do? How often meet? How decide who joins? Feed into other groups at or outside of school?
How do you feel about being on the council? [Important? Worthwhile?]
Has the council made a difference ? [What did it used to be like? What is it like now?]
Examples of activities/decisions
Main messages we could tell others about the school council? [Some schools may not have them and want to know why they might be good]

Observation in school:

- Documents/notices outlining school policies.
- Documents/notices in relation to disability/rights.
- Evidence of school council's role in the school and kinds of work done.

(4) Experience of accessible/inaccessible educational services and environments
What is it like getting to school?
What is it like being at school/getting around the school/playground/doors?
What things are more easy/difficult for you compared to others? [and in what ways]
Who/what helps? What's good/not so good about this?
Information around the school (e.g. posters/notices) and in class (eg when teachers give you work to do). What is good/not so good in helping you understand?

Observation in school:

- How people (including us!) get into and around school building(s)?

- What do students think of dining areas, toilets, changing rooms (eg for PE/swimming)?
- Is it more difficult for some students compared to others?
- Any plans for changing layout/accessibility?
- Have students been consulted or involved in disability planning?
- How work is explained and given to students; any differences between students in relation to this?
- What are school transport arrangements like (eg arrive/leave on time; ordinary/special)?

(5) Attitudes and behaviours
Who are your friends ? How do they help you? Do you see them outside of school? Do you have different/other friends outside of school?
Any children in school different to others? Who/why?
Do people say things to them about being different?
What about other children in school? What are they like? What do they say?
Brothers and sisters and other family members – what are they like? Who is helpful/not so helpful? Why?

Teachers and other adults in school – who/what is helpful/not so helpful? [eg ways of behaving; things that people say]. How do they make you feel?

Observation in school:

- How children/young people interact with each other and with staff?
 - What is the staff room like?
 - How 'available' are teaching and support staff during the day?
 - How is bullying dealt with/good behaviour encouraged?
 - Do children/young people have a named/key worker they can talk to about concerns?
-

6.1.3 Outline for telephone/face-to-face interviews with parents (response boxes reduced in size here)

Name of child/young person _____

Relationship to child/young person _____

Independence and autonomy

Question 1: How well do you feel the school is supporting x?

Prompts:

- Changes over time
- Differences compared to previous schools/settings
- First/preferred choice of school
- *Expectations* about support (high/low) depending on type of school
- Involvement/inclusion of parent in decisions

Question 2: Have you asked the school/LEA/wider community to change anything for x? If yes, what was the response?

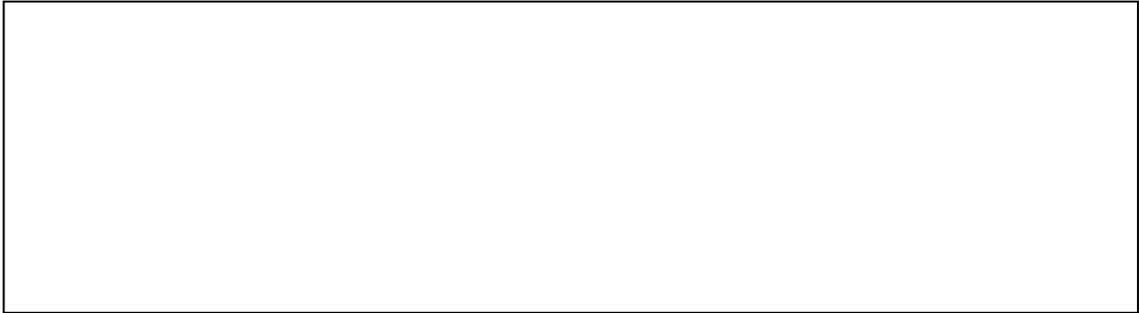
Question 3: What do you think about inclusion of children with disabilities in mainstream schools? Do you think this works differently for different children?

d

Question 4: How involved or included is x in activities at and outside of school?

Prompts:

- Lunch-time; school trips; after-school clubs
- Access to curriculum/qualifications? Differences compared to others?
- Access to activities/buildings in the wider community?



Ambition and aspirations

Question 5: In what ways does x's difficulties or disability influence their choices or chances now and in the future?

Prompts:

- Careers; choices; school/college; *especially post-school options and any worries/concerns*
- Treated differently compared to other children/young people?
- People/agencies helpful/not helpful?
- Any critical incidents - good or bad - which seem to have been very influential?

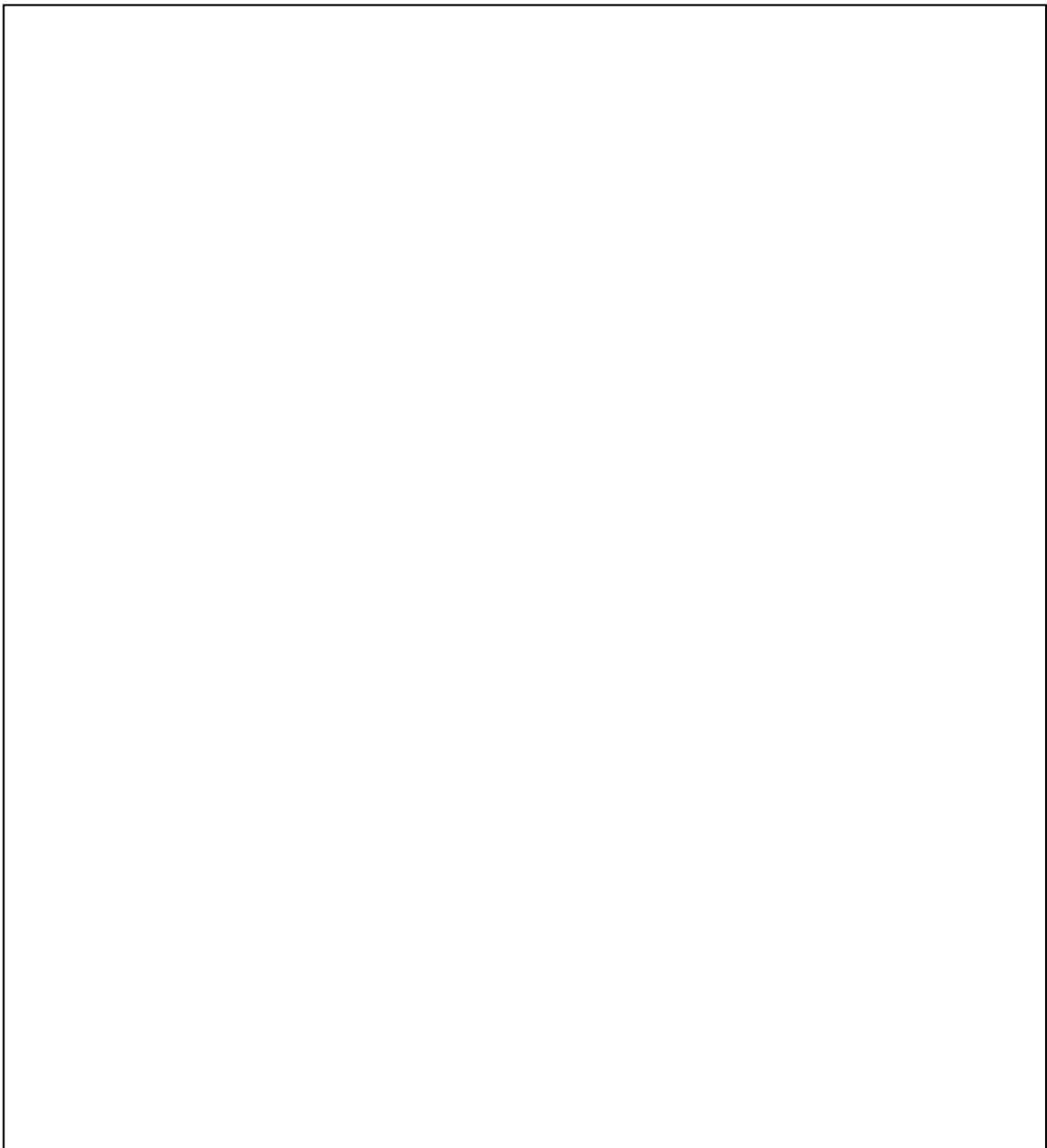


Knowledge and assertion of rights

Question 6: Do you know/have you heard about the DRC or the DDA?

Prompts:

- Making a difference?
- Main source of difficulty for x? (explore issues about medical vs. social models eg things are difficult because of disability vs. things are difficult because society is slow to adapt)?
- Involvement in any disputes/tribunals?

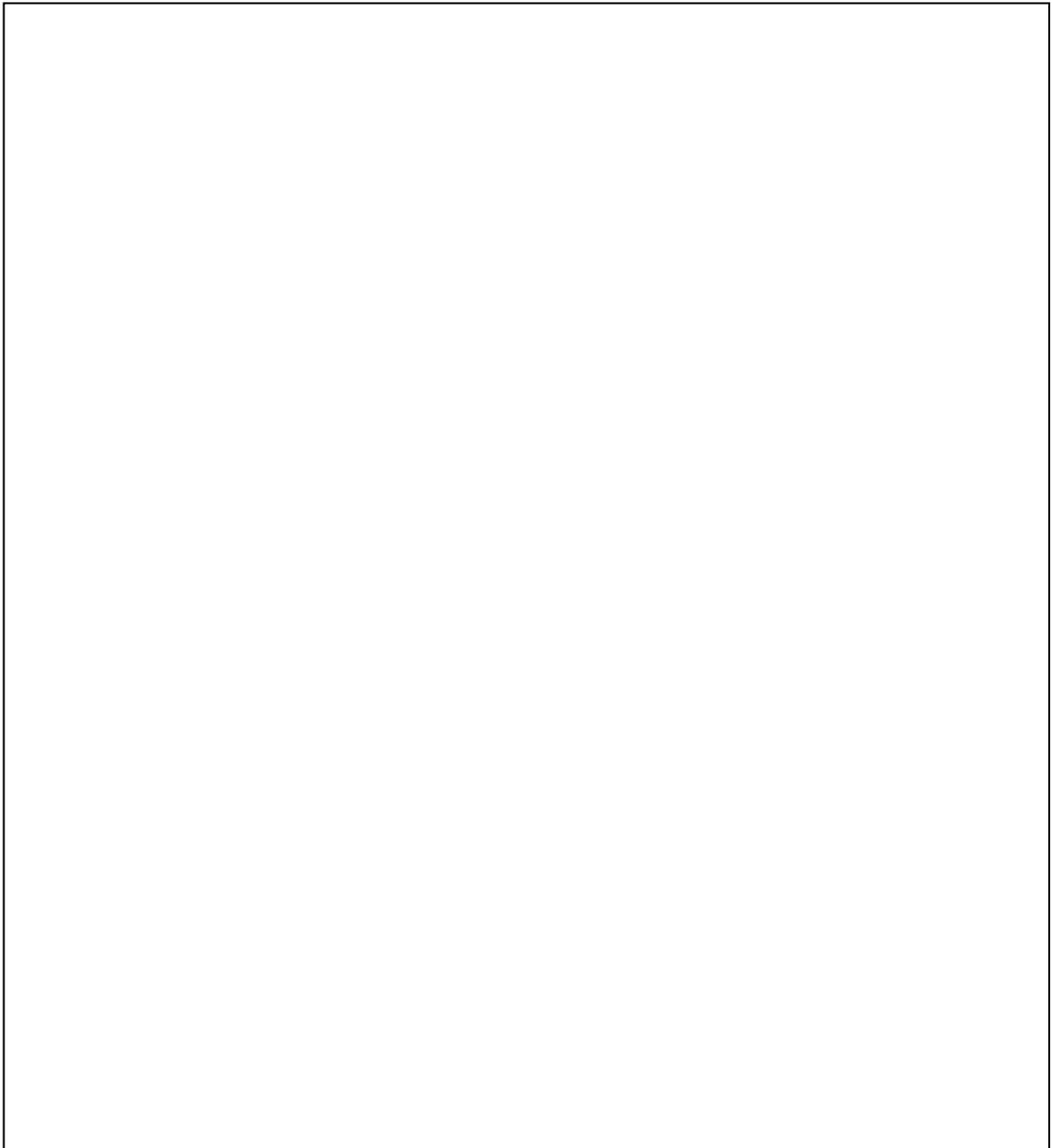


Attitudes and behaviours

Question 7: What is support like for x and you within the family and in the wider community?

Prompts:

- Siblings; grandparents; family members living locally?
- Other groups/sources of support? (incl. online groups etc)
- Attitudes of others in terms of behaviour and choices
- Experiences of dealing with teachers and other professionals?



Any further notes/reflections?

6.2 Details of coding frame

Main theme	Code name	Description	
Independence and Autonomy	1. Being informed	Ch/yp being informed about meetings, changes, provision of support etc	
	2. Asking for help	Instances where ch/yp need to ask for help or speak to a member of staff to raise awareness about something	
	3. Doing things by self	Things that ch/yp can/cannot do by themselves or choose to do by themselves	
	4. Experience of tribunals	Any comments relating to experiences of tribunals	
	5. Experiences at previous schools	Aspects of schooling in previous contexts with specific reference to support available and feelings of autonomy	
	6. Involvement in decisions at school	Involvement in decisions including choice/type of school and subjects/exams as well as involvement in annual reviews	
	7. Other activities	Choices relating to, and involvement in, extracurricular activities both at and beyond school	
	8. Support from external tutors	Involvement with private tutors outside the school setting	
	9. Support from friends at school	How friends/peers help out at school	
	10. Support inside class	Support received from teachers and auxiliaries within the classroom	
	11. Support outside class	Support received from teachers and auxiliaries outside the classroom (but within the school context)	
	12. Support unavailable	What it is like when support is unavailable for ch/yp	
	Experience of accessible/inaccessible educational services and environments	13. Assessments	How ch/yp get on in assessments and whether they receive any additional support
		14. Being at school	Experiences of being at and getting around the school
		15. Comparison with others	Are things easier or more difficult compared to other ch/yp?

	16. Feeling included	To what extent does ch/yp feel included in activities?
	17. Getting to school	What is it like getting to and from school and how does this usually happen?
	18. Outside of school	Environments outside of school such as shopping, local town etc
	19. What would help?	What kinds of things could be done to help make environments/services more accessible?
Knowledge and assertion of rights	20. Asking for change	Asking the school and/or other services to make changes to provision (and response received)
	21. Disability identity	Views about own identity in relation to difficulties or disabilities
	22. DRC/DDA	Awareness or knowledge of the DRC and/or any existing legislation/policy
	23. Rights and entitlements	Knowledge or thoughts about rights and entitlements in relation to disability (not explicitly mentioning DRC or DDA) in relation to schooling now as well as choices/options in the future
	24. Ideas about inclusion	Views about education of children with SEN or disabilities in mainstream settings or special schools
	25. Treated same or different	Whether ch/yp have received different or special treatment and how they feel about it
	26. Mainstream/special comparisons	Discussion about special or mainstream education and experiences of these, including comparisons when both types of provision have been experienced
Attitudes and behaviours	27. Bullying at school	Experience or awareness of bullying at school (to self and/or others)
	28. Bullying outside of school	Experience or awareness of bullying occurring outside of school context (to self and/or others)
	29. Reasons for bullying	Why ch/yp describe the reasons for bullying experienced
	30. Community	Attitudes and behaviours of others outside of school in the wider community (not family or friends)
	31. Family	Attitudes and behaviour of parents and other family members including siblings

	32. Friends at school	Attitudes and behaviours of friends and/or other students inside school
	33. Friends outside of school	Attitudes and behaviours of friends outside of school
	34. How better?	How could people change their attitudes and behaviours for the better?
	35. Professionals	Attitudes and behaviours of professionals (not including teachers), including LEA representatives etc
	36. Sources of support	Groups or sources of support external to school-based activities/support such as online groups and membership of organisations etc
	37. Students at previous schools	Attitudes and behaviours of ch/yp at previous schools or at other schools (e.g. taking some classes at a different school or setting)
	38. Teachers	Attitudes and behaviours of teachers, auxiliaries and other staff at school
	39. Teachers/Staff at previous schools	Attitudes and behaviours of teachers, auxiliaries and other staff at other schools
Ambition and aspirations	40. Next steps	Plans and ideas about the future
	41. Feelings about next steps	Feelings about the future and options/choices open to them
	42. Feelings about school now	What school is like now
	43. Same/different choices	Do ch/yp feel they have the same or different choices to their friends or other people?
	44. School activities like	Activities/subjects/aspects currently liked in school
	45. School activities dislike	Activities/subjects/aspects currently disliked in school
	46. Who talk to?	Who is involved in discussions about future plans and in what context(s)?
Additional codes	47. 'Guinea-pig' and challenging the system	Examples where parents describe how their children challenge and break new ground within the educational system
	48. Identification of difficulties	How difficulties were identified (at school or home; identification and awareness of own difficulties
	49. Main messages	Ch/yp's main messages that they

		would like the DRC and others to know
	50. What helps you to cope?	Main sources of support/coping mechanisms for parents and ch/yp (esp. in relation to notions of independent vs. interdependent notions of resilience)

7. Bibliography

- Anti Bullying Alliance <http://www.anti-bullyingalliance.org.uk/Page.asp>
- Audit Commission (2003) *Services for Disabled children: A review of services for disabled children* www.audit-commission.gov.uk/disabled-children/
- Barabasi, A-L (2003) *Linked : how everything is connected to everything else and what it means for business, science, and everyday life* New York: Plume
- Barnes, C (and team) (2000) *Children 5-16 Research Briefing. Lives of Disabled Children*. Leeds: Universities of Leeds and Edinburgh/ ESRC
- Children's Society (2005) *Good childhood? A question for our times* London: Children's Society
- Children's Society (2006) *The Good Childhood: A national inquiry. Launch report*. London: Children's Society
- Crews, N (2006) *Work experience as part of the Welsh Curriculum 14-19 for young people who are blind or partially sighted Research report*. London: RNIB
- Davis J, Watson N and Cunningham-Burley S (2000) *Lives of Disabled Children: A reflexive experience*; in Christiansen, P. and James, A . (eds) *Researching Childhood: Perspectives and Practices* Falmer Press: London
- Dee, L. (2006) *Improving Transition Planning for Young People with Special Educational Needs*, Maidenhead: Open University Press

- DFES (2006) *Government response to the Education and Skills Committee report on Special educational needs*. (October 2006). Cm 6940 Norwich: Stationery Office
- Disability Rights Commission (2002) *Code of Practice for Schools* London: TSO.
- Disability Rights Commission (2005) *Shaping the Future of Equality* London: DRC
- Disability Rights Commission (2006) *Delivering the Choice and Voice Agenda: The role of independent advocacy services* London: DRC www.drc-gb.org
- Disability Rights Commission, Wales (2006) Written and oral evidence (May) to Special Educational Needs Inquiry, Phase 3 – transitions. Cardiff: Welsh Assembly, Education and Lifelong Learning Committee.
- Ealing Local Authority. (2005) *Powerful Voices*, Conference report. Ealing Town Hall 1 July 05.
- Estyn (2004) *Supplementary Guidance on Listening to Learners: Further guidance for inspectors to use alongside the Common Inspection Framework and all Inspection Handbooks*. Cardiff: Estyn
- Estyn (2006) *The Annual Report of Her Majesty's Chief Inspector of Education and Training in Wales Special Schools (including independent special schools) 2004-2005*. www.estyn.gov.uk
- Every Disabled Child Matters (2006) Campaign launched by Contact a family, Council for Disabled children, Mencap and the Special Educational Consortium in September 2006. www.edcm.org.uk
- Felce, D. (2002) Gaining views from people with learning disabilities: Authenticity, validity and reliability. Paper

presented at the seminar series: Methodological issues in interviewing children and young people with learning difficulties. Funded by ESRC 2001-3, School of Education, University of Birmingham.

Fielding, M. (2004) Transformative approaches to student voice: theoretical underpinnings, recalcitrant realities. *British Educational Research Journal*, 30 2 295-311.

Gibson, S. (2006). Beyond a 'Culture of Silence': Inclusive Education and Liberation of Voice. *Disability and Society*, 21 4 315- 329.

Goodley, D and Clough, P (2004) Community projects and excluded young people: reflections on a participatory narrative research approach. *International journal of Inclusive Education*, 8 4 331-351

Granovetter, M. S (1973) The strength of weak ties *American Journal of Sociology* 78 6 1360-1380

Granovetter, M.S. (1983) The strength of weak ties: revisited *Sociological Theory* 1 201-33

Gray, P (2002) *Disability Discrimination in Education: a review of the literature on discrimination across the 0-19 age range*. London: Disability Rights Commission.

<http://www.drc.org.uk/publicationsandreports/research.asp>

Gray, P., Bullen, P., Duckett, I., Leyden, S., Pollard, I. and Skelton, R. with Leyden, G. and Fraser, K. (2006) *National Audit of Support Services and Provision for Low Incidence Needs* RR729 www.dfes.gov.uk/research

Grover, S. (2004). Why Won't They Listen to us? On Giving Power and Voice to Children Participating in Social Research. *Childhood*, 11 1 81-93.

- Grunday, A.L., McGinna, M. K., and Pollon, D. E. (2005). Striving toward inclusive research practices: the evolution of the participant-as-transcriptionist method. *Disability and Society*, 20 4 453-468.
- Hames, A. (2001) Young children's understanding of learning disability. PhD thesis. Newcastle: University of Northumbria
- Hanley, B. (2005). *Research as empowerment? Report of a series of seminars organised by the Toronto group* York: Joseph Rowntree Foundation.
- House of Commons Education and Skills Committee (2006) *Special Educational Needs*. Third Report of Session 2005-6. Volumes 1, 2 and 3. HC 478-I, 468-II, 478-III. Norwich: Stationery Office
- Joseph Rowntree Foundation (2005) *Children's perspectives on believing and belonging* York: Joseph Rowntree
- Kaplan, I., and Howes, A. (2004). 'Seeing Through Different Eyes': Exploring the Value of Participative Research using Images in Schools. *Cambridge Journal of Education*, 34 2 Online /04/020143-020113.
- Lewis A (1995) *Children's Understanding of Disability* London: Routledge
- Lewis, A. (2002) The development of children's ideas about others' difficulties in learning, *British Journal of Special Education*, 29 2 59-65
- Lewis, A. and Porter, J. (2004). Interviewing Children and Young People With Learning Disabilities: Guidelines for Researchers and Multi Professional Practice. *British Journal of Learning Disabilities*, 32 4 191-197.

- Lewis, A. and Porter, J. (in press) Research and pupil voice, 222-232 in L. Florian (ed) *The Sage Handbook of Special Education* London: Sage
- Lewis, A., Davison, I., Ellins, J., Parsons, S and Robertson, C. (2006a). *Survey of parents and carers of disabled children and young people in Great Britain*. June 2006. Research report to Disability Rights Commission. Birmingham: University of Birmingham, School of Education
- Lewis, A., Davison, I., Ellins, J., Parsons, S and Robertson, C. with Greagsby, A. (2006c). Survey of parents and carers of disabled children and young people in Great Britain (with specific reference to Wales). Written report and oral evidence (14 June) to Equal Opportunities Committee. EOC(2)-05-06 Cardiff: Welsh Assembly, Equality of Opportunity Committee.
- Lewis, A., Niblett, L., Parsons, S., Robertson, C. and Sharpe, J. (2006b) *Advisory Groups of Disabled Children and Young People with Reference to Experiences of Disabled Children and their Families (Phase 2)*. August 2006. Research report for the Disability Rights Commission: University of Birmingham, School of Education.
- Lewis, A., Robertson, C., & Parsons, S. (2005). *Experiences of Disabled Students and their Families. Phase 1*. Research report to Disability Rights Commission, June 2005. Birmingham: University of Birmingham, School of Education.
http://www.drc.org.uk/library/research/education/new_experiences_of_disabled_st.aspx
- Maras, P. and Brown, R. (2000) Effects of different forms of school contact on children's attitudes toward disabled and non-

- disabled peers *British Journal of Educational Psychology* 70
337-351
- Mayo, E. (2005) *Shopping Generation* London: National Consumer Council
- NFER (2003) *The Implementation of the Disability Discrimination Act Part 4 in educational establishments: some evidence from case studies*. London: Disability Rights Commission
<http://www.drc.org.uk/publicationsandreports/campaigndetails.asp?section=resed&id=491>
- OfSTED (2006) *Inclusion: Does it matter where pupils are taught?* London: OfSTED
- Parsons, S., Daniels, H., Porter, J. and Robertson, C. (2004) *Developing the use of ICT to Enhance Community Participation with People with Learning Disabilities*. Birmingham: School of Education, University of Birmingham.
- Porter J., Parsons, S.& Robertson C. (2006) Time for Review: Supporting the Work of an Advisory Group. *Journal of Research in Special Educational Needs*, 6, 11-16.
- Porter, J., Aspinall, A., Parsons, S., Simmonds, L., Wood, M., Culley, G. and Holroyd, A. (2005). Time to Listen. *Disability and Society*. 20, 575-585.
- Putnam, R. (2000) *Bowling Alone: The collapse and revival of American community* London: Touchstone.
- Robertson, C. (2001) Autonomy and identity: the need for new dialogues in education and welfare, *Support for Learning*, 16, 3, 122- 127.
- Save the Children. (2005). *Learning To Listen: Consulting Children and Young People With Disabilities*: Save The Children/ Hammersmith and Fulham.

- Shakespeare, T (2006) *Disability Rights and Wrongs* London: Routledge
- Shakespeare, T .and Watson, N. (2001) The Social Model of Disability: An outdated ideology? *Exploring Theories and Expanding Methodologies: Research in Social Science and Disability* 2, 9-28
- Taylor, M. (2005) Self-identity and arts education of disabled young people, *Disability and Society*, 20 7 763-778
- Turner, C (2003) *Are you Listening? What disabled children and young people in Wales think about the services they use* Cardiff: Children First/ NCH/ Barnardo's
- Walmsley, J. (2004). Inclusive learning disability research; the (non disabled) researcher's role. *British Journal of Learning Disabilities*, 32, 65-71.
- Watson N (2002) Well, I know this is going to sound very strange to you, but I don't see myself as a disabled person: Identity and Disability *Disability and Society* 17 5 509-529
- Young, A., Temple, B., Davies, L., Parkinson, G., Bolton, J., Milborrow, W., Hutcheson, G. and Davis, A. (2006) *Early Support: An evaluation of phase 3 early support* RR798. Annesley, Nottingham: DfES Publications.