

# 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

## Executive Summary

UNIVERSITY OF  
BIRMINGHAM

## **The Disability Rights Commission**

The Disability Rights Commission (DRC) is an independent body, set up by an Act of Parliament, which has the goal of creating a society where disabled people and those with long-term health conditions can participate fully as equal citizens.

We work with the voluntary sector, the business community, government and public sector agencies to achieve practical solutions which benefit disabled people and society as a whole.

There are around 10 million people with rights under the Disability Discrimination Act in Great Britain. The legal definition of disability covers people with physical, sensory, communication and intellectual impairments, and people with mental health and other long-term health conditions such as diabetes, epilepsy, cancer, multiple sclerosis, HIV and schizophrenia.

Under the Disability Discrimination Act 1995, disabled people have the legal right to fair treatment in employment, in education and as customers of services. Most duties of the Act are now in force. A new Disability Discrimination Act received royal assent in 2005. This will create a duty on public bodies to actively promote disability equality from December 2006 as well as close some of the loopholes in the previous Act.

The DRC has offices in England, Scotland and Wales and can support both those with rights and those with responsibilities under disability legislation. For further details of how we can help you please contact our Helpline – contact details can be found on the back cover.

In 2007, a new Commission for Equality and Human Rights will begin its work. This body will have responsibility for the activity currently undertaken by the DRC.

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## **‘...and the children could tell them how their life has been’**

Rose, aged 12

### **Background**

Following the introduction of the Special Education Needs and Disability Act (SENDA) in 2001, the Disability Rights Commission (DRC) commissioned a review of the literature on disability discrimination across the 0–19 age range (Gray 2002). This review 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).

The ‘voices’ of young disabled people and their parents/carers were rarely heard in the literature on disability and education, and when they were they often focused on people who had left education and were considering their experiences retrospectively. The DRC concluded that there was a need for more systematic evidence of the prevalence of prejudice and discrimination in education, the attributes of institutions associated with more positive experiences, and the impact the Disability Discrimination Act (DDA) Part 4 (Education) was having on the experiences of young disabled people and their parents or carers.

## Introduction

This report draws on the main findings and recommendations from four linked projects (2004–6), funded and published by the Disability Rights Commission (DRC) and carried out by a team from the University of Birmingham, into the experiences of disabled children, young people and their families. This report focuses mainly on the findings from the individual and group case studies of disabled children and young people which made up the fourth and final project. These case studies were gathered in England, Scotland and Wales from a range of mainstream primary and secondary schools, specialist units within mainstream schools, colleges of further education and special schools. The ages of the children/young people ranged from 9 to 19 and they had a range of impairments and health conditions including autism/ASD, dyslexia, learning difficulties, physical disabilities, sensory impairment and social/emotional/behavioural difficulties. Many of the children and young people had multiple impairments. Methods of data collection included interviews with the children and young people, classroom observations, interviews with key school personnel and with a sub-sample of the parents/carers. For an overview of all four projects and table of samples and methods see page 29.

A central aim of the research, and the case studies in particular, was to identify the key concerns and priorities for disabled children and young people in Great Britain in relation to their experiences of education (particularly transitions between phases of schooling and post-school). Following from this, the work aimed to identify the barriers faced by young disabled people in education following the implementation of the SENDA 2001, including evidence of prejudice and discrimination. Importantly, it also sought to identify ways of overcoming these barriers, to explore examples of good practice, and to investigate factors associated with positive experiences of educational institutions.

This summary, as well as the findings and discussions in the full report, are referenced to five main themes:

- independence and autonomy
- educational services and environments
- knowledge and assertion of rights
- attitudes, and
- ambitions and aspirations.

Underlying these is an emphasis on the importance and validity of hearing directly from children and young people themselves (see note below concerning terminology). Thus the work meshes closely with initiatives worldwide concerning the recognition of children's 'voice' in matters that concern them.

We are not aware of any comparable evidence which (1) focuses in-depth on a wide cross-section of pupils with disabilities or special needs and their families in the GB-wide educational context and (2) is located alongside concurrent authoritative data concerning the views of parents and carers.

This Summary Report cannot do justice to the richness, the depth and diversity of perspectives and individual stories captured in the main report. This can be downloaded from the DRC website and is fully referenced at the back of this publication.

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Note 1: Throughout this report we have used the phrase 'children and young people' to refer to the case study pupils (ie dropping adjectival references to disability, impairment, special educational need or additional support needs).

## Summary of discussion and findings

### Independence and autonomy

Our focus on independence and autonomy explored children and young people's involvement in choices and decisions; their views and experiences of additional support and involvement in extra-curricular activities, both within and outside school/college.

Children and young people valued independence and autonomy, and involvement in decisions about school, for example:

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.

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. They also appreciated the help received both formally (inside and out of class) and more informally (from friends). However, some children and young people were resentful about having to keep asking teachers for help, about the same things. Remembering individual needs was seen as an important marker that these were being taken seriously.

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

Some children and young people felt that they would have liked more support than they were receiving, whilst others expressed a preference for a more flexible deployment of resources ie they may not have wanted or needed support for all their formally allocated hours.

This underlines a flexible and pragmatic perspective to children's and young people's views about when, why and in what form they want support. Clearly, their views might conflict with those of parents or teachers in terms of whether those preferences were deemed advisable educationally. This does not negate the importance and value of children having their views heard and considered.

There were interesting contrasts between children's and parents' views in relation to support. In general, parents were inclined to stress the importance of support; wanting it to be laid out clearly and systematically. 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, even when this involved risk taking and uncertainty, while recognising their parents' possible ambivalence about this.

Some parents echoed the children's uncertainty about formal procedures. The school's or local authority's failure to communicate fully and appropriately with parents on a regular basis, and especially around and within annual reviews (associated with a Statement or Record of Need), was a source of substantial frustration and anxiety. The procedural aspects of the reviews were also found to be alienating for some parents who were often not supplied with sufficient information to be both adequately prepared and fully informed.

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.

Some parents 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 was perceived as slow, bureaucratic and unsympathetic. Parents wanted the system to adopt more holistic ways of

responding to their child's support needs. For parents who felt the system was failing them, the response often seemed to be one of self-help rather than recourse to formal procedures. These points signal a growing privatisation of special needs provision occurring incrementally rather than by design but contributing to a fragmentation in provision.

Extra curricular activities, both within and outside of school, were important for children and young people although these varied in nature depending on individual preferences.

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.

These additional activities gave a boost to children's self-esteem and confidence, as well as an opportunity to take a break from formal learning. In a highly risk-averse society, features which contribute to self-confidence and feelings of high self-esteem are vital. They matter in their own right but also because they encourage children to take risks, and so to escape from over-protection, and mature.

Many children and young people spent considerable time at home with their families at evenings and weekends although some participated in more formal clubs and organised activities. They rarely mentioned informal groups and meeting with friends outside of school, suggesting less frequent engagement in these sorts of activities compared with home and family-related leisure pursuits. Involvement in these groups was also curtailed for some young people, particularly at post-school level, by problems of access and/or support.

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: not wanting to take part, being shy, lacking in confidence, preferring home-based activities, and changes in childminder arrangements. This illustrates the wider danger of assuming that lack of

independence or participation are necessarily related directly 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 **inter**-dependence and help can be interpreted positively; that is, mutual dependence or support may, more appropriately, be seen as a positive asset rather than a problem.

The balance in the pattern of out of school activities reflects a bias (not unique to disabled children) towards an intensification of parent control/support of children in the sphere outside the home. That was supported by parents' accounts of escorting children and young people to activities, possibly essential for children with high support needs, but this necessarily curbed independence.

Extra curricular activities 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.

What was lacking, and children's and parents' reports were strongly consistent about this, was an assortment of informal activities based outside school or home with peers or other children and young people. The preponderance of transporting children to particular groups necessarily cuts down opportunities for developing inclusion, by design or chance, in the immediate community. Children were successively forming and re-forming links with a series of discrete and purpose-driven groups.

The negative repercussions of an overall lack of (particularly informal) community mechanisms or 'bonding and bridging' networks (Putnam 2000), was a theme which recurred throughout all the strands of the Experiences project. The advantages of participating in these informal community networks is the potential for increased capabilities in applying social skills across varied contexts. For disabled children and their families, who may feel very isolated, these possibly 'weaker ties' (Granovetter

1973, 1983, Barabasi 2003) take on a particular importance in anchoring them to wider networks. In brief, weaker linkages between groups and individuals may, counter-intuitively, be more robust than strong ties (formal groups) because the very looseness of the group links helps them to be sustained and therefore influential.

This raises the 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.

### **Educational services and environments**

In relation to accessible environments, we asked about children's and young people's experiences of getting to, and being at, school. We also asked about this in relation to the wider community, and whether they felt at a disadvantage compared with others. The issue of being different or disadvantaged in any way (especially compared with peers) was a potentially sensitive issue that was not broached with all children. This was particularly so for some children and young people with learning difficulties whom the researchers were told (by teachers) were struggling with low self-esteem.

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 availability was sometimes considered to be 'lucky' rather than part of a planned support strategy, and their deployment was often inconsistent and sometimes even at odds with the individual needs of the student. Discussions with senior staff in some 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.

Ring-fenced funds or subsidies for schools for important accessibility 'tools' such as ICT and audio books are needed. These funds would represent relatively small investments in children who need them but could make a substantial difference.

Within schools, curricular adjustments are likely to be highly individualised. For example, two case study pupils with visual impairments required very different forms of support (both in terms of needing [or not needing] someone in class with them; and the role played by specialist resources, such as screen enlargement and text magnifiers). This illustrates the crucial importance of flexible and imaginative responses to individual pupils; as one young person put it:

(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.

In relation to formal assessments some of the young people were pleased to have extra time or support to complete exams. However, there was also uncertainty about what adjustments were permissible:

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?

Participation in less structured activities (for example, at breaks and lunch times within school) appeared to be particularly problematic for some young people. This was perhaps because, unlike in the classroom, participation was more strongly linked to, and dependent on, friendship groups. It was therefore more vulnerable to the attitudes and behaviours of other children. The lack of informal networks in local communities (see above) will

also have meant that these children and young people may have had limited opportunities for fostering the very skills required in these informal settings.

The majority of children and young people interviewed did not view getting to and from school as difficult or problematic. This may in part stem from problems being managed by parents – and so children not recognising the ‘hidden’ support parents offered to fill gaps in the provision. However some children who used taxis felt that these sometimes curbed their independence as timings were rigid and/or because some would have preferred to use the bus with their peers.

Transport also became an issue for parents in making decisions about appropriate secondary schools to attend. Clearly, choice and diversity in educational provision, key tenets of government policy, raise questions about the sustainability of school transport for all children.

A systematic and planned approach to enabling participation of all children and young people in both school and community activities is needed. This has inevitable resource and funding implications which may make it difficult for this to be achieved by schools alone or without changes either to legislation or formal funding arrangements. Teachers also need to be provided with clear guidance about when, and how, to deploy resources. For example, pupils with dyslexia may be discouraged by a teacher from using a digital recorder in lessons; as reported by one young person:

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!

The recent Department for Education and Skills (DfES) publication 'Implementing the DDA in Schools and Early Years Settings' provides an important new training resource in this regard, but its impact must be closely monitored.

In terms of special and mainstream settings, a portfolio encompassing both special (schools/units) and mainstream contexts provides potentially flexible ways of meeting diverse individual needs. This was the perspective taken overwhelmingly by children and young people, their parents and the parents/carers surveyed more widely.

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.

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.

For some, the opportunity to access mainstream provision was vital for self-confidence, socialisation and coping; for others, special school was seen as an educational life raft that probably saved them from permanent educational exclusion. Attention to detail mattered hugely, as was evident in so much of what these children and young people told us. None of the systems were perfect but all were necessary for families negotiating a 'best fit' for their individual children.

A vital and under-developed part of an effective portfolio of special and mainstream provision is better linkage between these settings. Where provision worked well, it was described implicitly or explicitly as 'seamless' and this was an important marker of success. This 'seamlessness' needs to be addressed at the level of detail (moving beyond a token acknowledgment that each sort

of provision has strengths) and referenced directly to pupils' views. Increasing co-location of schools could be an important vehicle for analysing, fostering and disseminating this seamlessness.

### Knowledge and assertion of rights

We asked 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, and views on inclusion and comparisons between mainstream and special schools.

The highly individualised nature of experiences and views of children and young people with disabilities and/or special needs was very clear. Some young people (a minority) seemed to have been empowered by accepting a disabled identity, whilst others (including some young people at special schools) did not feel that the words disabled and disability applied to them. Members of the core advisory group, both of whom had experienced a mix of mainstream and special provision, including university education, also took strongly contrasting positions from one another about the salience for themselves of a disabled identity. Children and young people were often very aware of their own difficulties and were sensitive to differences between themselves and others; often viewing others as more disabled than they were:

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.

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 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'.

Although it was beyond the scope of this project to look at classmates' understanding of disability, there are clear links with disabled children's self-image and fostering inclusiveness in schools and communities.

Interestingly, 'disability' as a label was also downplayed in favour of 'special needs' or impairment-specific language across all strands of the work. This suggests a disparity between the disability-oriented world of legislation and 'policy-speak' compared with the experiences and perceptions of disability or additional support 'as lived' by most children and young people in schools and colleges. The children and young people with whom we talked (and their families) were not engaging with formal rights-based approaches to securing improved provision.

In contrast, one arena in which disability-related rights and awareness of such matters was apparent was school councils. Children and young people's participation in case study school councils was powerful and effective. These experiences were felt by pupils and staff to have raised considerably children's and young people's awareness, confidence and knowledge about democratic mechanisms for change, at least within the school context. Those views were borne out by observations of the councils in operation. The two school councils (both in special schools) which were included in group case studies provide useful exemplars of ways in which the rights-based aspects of disability can be grounded in a context which has meaning and impact for the children and young people involved. The inclusiveness of these school councils in giving power and responsibility to pupils having diverse needs was striking.

There are substantial challenges for the work of the DRC and Commission for Equality and Human Rights (CEHR) in relation to how information and support about disability are presented and

disseminated. Whilst disability identity and language is important for some children and their families, 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'. A key challenge is in terms of how information and support can be made available to families across diverse cultural and socio-economic backgrounds. We found strong evidence of the need to make disability-linked information much more reader friendly and to disseminate it in everyday contexts such as supermarkets, surgeries and early years settings.

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 difficult to understand.

More widely, charitable and voluntary bodies are becoming increasingly prominent players in the educational landscapes of disability and special/additional needs. However they were mentioned little by the parents or young people interviewed. It will be important for strong links to be developed and sustained between DRC and CEHR and a wide spectrum of voluntary bodies. This relates also to our points elsewhere concerning accessible formats and locations for information about disability and special needs.

### Attitudes

We were also interested in 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.

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. In the light of this, the main theme arising is the importance children and young people attach to being treated sensitively but not as 'special cases':

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.

Unhelpful attitudes were considered to be lacking in sensitivity and thoughtfulness while supportive attitudes were considered to be honest, kind, straightforward and respectful:

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'.

Many of the children and young people said that they had experienced negative attitudes towards them from other children at school in the form of bullying. Swift and supportive action from teachers was seen as important in resolving problems such as this. However there was a sense from some young people that their reports of bullying had not always been taken seriously:

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

Children and young people did not appreciate others making assumptions about their needs and preferences without asking them directly. The same sorts of helpful and unhelpful attitudes were noted in parents' views.

It seems that the views of children, young people and parents still tend to be overridden (at various levels) and may require persistence:

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.

Quotes such as this reflect the maturity of the children and young people interviewed. They also underline the importance of engaging in, and acting on, active consultation processes at family and school levels, and also more widely at authority, national and other policy levels by a wide range of bodies. A related point about authenticity of involvement was also made in connection with the role of advisory groups of disabled people.

The role of a 'key' staff member in supporting parents and their children was centrally important to many experiences. However, there was 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.

Overall, there was little evidence from 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 (see above concerning voluntary bodies). There are echoes here of the phase 1 report which also 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:

I had no time to be upset; I had two children with disabilities and two without and the two 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.

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. Families will need to believe that their 'broker' genuinely has the best interests of their child at heart. 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.

It is clear that supportive and understanding attitudes towards disability are still patchy and unpredictable. There was considerable luck involved when provision was felt to be good. So there is a great deal more work to be done in terms of general awareness raising, both within schools and the wider community.

### **Ambitions and aspirations**

Material under this theme was examined in relation to attitudes to school/college, concerns about school transitions and longer term 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 least well-provided sector was post-formal schooling for pupils with complex educational, physical and personal needs.

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.

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; it was to be lived with.

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 and young people to achieve their aspirations needs to be a balance between aiming high on the one hand and being realistic and pragmatic on the other; as this young person had already thought through:

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.

On the whole, 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.

Some honesty and sensitivity is needed as children and young people become aware of the reality of their own disabilities. 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 anticipated, adequately informed and planned for.

Organisations need to ask themselves how far their provision can, and could, rise further to meet the challenge of young

people's high aspirations. There is also a challenge for parents and children of having difficulties or differences recognised whilst at the same time being treated 'normally'. The honest awareness and acknowledgement of difficulties possibly provides a strong link to the 'just the way the child is' responses in the wider parent survey when parents were asked about perceived causes of their child's difficulties.

## Main recommendations

There is growing Government commitment to engaging children and young people in policy development, review and inspection frameworks. However, can we be fully confident that disabled children and young people will be equal players? The involvement of disabled people (including young disabled people) is also a central requirement of the new Disability Equality Duty which requires schools, local authorities and other public sector bodies to develop a Disability Equality Scheme and action plan showing how the institution will improve services and outcomes for disabled pupils/school staff and other disabled users (like parents) over time.

Children and young people across a wide range of disabilities, special educational and additional support needs, ages and backgrounds, 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 (see phase 1 report for a fuller discussion of these issues).

Responses from children, young people (and advisory group members) may, if part of a trustworthy process, be challenging and uncomfortable. With that in mind, specific recommendations (referenced to the DRC and the CEHR, policy-makers and providers/practitioners) are given below.

Recommendations for disabled children and young people are not included here. Birmingham University are currently working (with core advisory group members) on producing accessible versions of key points from this study, aimed directly at disabled children, or children with special needs, and their families.

### DRC and CEHR

1. **Information about rights and entitlements** for disabled children and their families seems not to be reaching **'everyday' contexts** for parents of disabled children or children with special needs. Consequently, such information needs to be written in very accessible ways, in varied formats and targeted at, for example, 'everyday' locations such as shops and supermarkets, doctors' surgeries, pubs, social clubs, early years settings and the media.
2. The **language of disability** is not readily understood and/or not felt to be relevant by many families of disabled children or children with special needs. Consequently, important and relevant materials about disability may reach a wider audience if they are also presented (instead or as well) in terms of maximising access/opportunities or personal development and identity. This also requires some critical reflection on the role (and presentation) of policy in people's everyday lives.
3. The increasingly prominent and varied roles of **voluntary bodies in the disability and special needs sectors** suggest two points. First, the DRC and CEHR need to work systematically and strongly with these bodies. Second, they need to seek

ways of reaching those parents who will become doubly disadvantaged if they do not access such groups.

4. Some mapping of the **roles and skills of such voluntary bodies** (possibly sub-divided by emphasis, such as disability-specific, family-oriented, rights-oriented) and conveying of this information to parents, would be valuable.
5. Information about disability-linked advocacy and support groups including **national and regional networks supporting disabled children and young people** also needs to be made more widely known.
6. There is potentially a key role for the DRC or CEHR in working with governments to clarify provision and reasonable expectations in the **statutory grey area between ages 16 and 18**. This is especially important as young disabled people aged 16 are twice as likely not to be in any form of education, employment or training as their non-disabled peers and this increases to three times as likely by the age of 19 (DfES 2005 'Youth Cohort Study'). The model of the DRC or CEHR (or other agency/service) as an independent 'broker' might be a key part of this.
7. Greater dissemination is needed concerning the **use of accessibility tools** such as ICT software and audio books, for example, through lobbying and working with key providers of these tools. The DRC or CEHR should work closely with publishers of all media to work towards making texts or information more available in various accessible formats.
8. This project has generated thought-provoking findings concerning the inclusion in their communities of families with disabled children or children with special needs. In particular, the **nature and roles of various community networks** (including 'weak ties') in which families are located (including, importantly, faith communities) warrant **systematic investigation** across Great Britain.

9. The **pattern and impact of additional parent-initiated help for their child (by socio-economic, cultural and ethnic groups)** warrants systematic scrutiny. The cross-discrimination focus of the CEHR could facilitate such enquiry.
10. It would be useful for the DRC or CEHR to work closely with umbrella organisations for **school councils** (eg School Councils UK) both to (1) promote those councils as vehicles for examining rights-based issues (2) look at the generalisability of good practice to arenas outside schools and (3) identifying and promoting examples of good practice.

### Policy-makers

1. The **Disability Equality Duty** requires that all public sector bodies (including government departments) assess the impact any new policy or initiative may have on the lives of disabled people. These **impact assessments** must consider the experiences and views of disabled children and young people across the age range and must reflect the diversity of the population.
2. A strong message from these findings is of the importance of increasing the **coherence of provision** for disabled children or children with special/additional needs. Options, rights and entitlements for individual circumstances need to be made clear. Children and young people also have views about these and should be involved in decision-making. These processes would help the broad range of parents to feel more informed about, and involved in, decision-making concerning their child.
3. The **benefits and limitations of co-location** warrant further scrutiny (including comparisons with other forms of provision) referenced to the implications for the development for provision.
4. **Shortfalls in post-school and post-college provision for students with complex learning, physical and personal needs** should be addressed through partnerships between relevant Government Departments and public bodies.

5. **Greater clarity and communication is needed between key partners** in relation to both children's and parents' voices in formal SEN/ASN (Additional Support Needs – Scotland) or disability-linked procedures.
6. This may be helped by the identification of **independent key workers** for families with a disabled child. A key worker/key professional system (well established as part of the Common Assessment and Every Child Matters frameworks) and the role of mentoring and peer group support should all be considered by Governments and local authorities as a way to help ensure informed continuity at all levels.
7. Greater **openness is needed between schools and parents** concerning additional help being provided for the child via the home and/or community. Schools and local authorities need to establish procedures which facilitate home–school exchanges about such information and how it meshes with school-based provision.
8. The **pattern and impact of additional parent-initiated help for their child (by socio-economic, cultural and ethnic groups)** warrants systematic scrutiny.
9. There needs to be **clearer communication with parents and families around transitions** and reassurance about continuation 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. These need to build on the generally high aspirations of disabled children and young people.
10. Government has promised a major expansion of **after-school/extended school activities**. Disabled children and young people must be able to access these services and they must be affordable to parents. They will need to monitor the effectiveness and 'impact' of these new initiatives as part of the Disability Equality Duty.

11. An **audit of community-based provision** (eg clubs/interest groups, sports groups) would be valuable to show how far and in what ways inclusion can extend beyond the school gates. This could mesh with a review of schools' ethos in terms of concern for the individual as a whole person and hence their promotion of access to community-based provision moving out from the school.
12. **Direct Payments** (a social care initiative, where disabled people and parents of disabled children are in control of purchasing support services) should help facilitate more spontaneous and informal involvement in after school activities. Government departments should closely monitor the impact and take up of these.
13. A school's review of special educational or additional support (for example, through a statement) might usefully and explicitly **refer to support needs and educational aims beyond a narrow conception of academic/curriculum help** within the classroom. This would lead the school to consider both within-school strategies to address these (eg a school ethos emphasising broad educational goals) and also the child or young person's needs, referenced to the wider community (eg help with accessing youth groups).

### **Providers and practitioners**

1. Authentic hearing of children's voices requires that schools and colleges think through carefully and systematically **the ways, and frequency with which, they hear those views and how they then respond**. These might be linked with 'advocacy' movements.
2. Children, young people, parents and school/college staff should **discuss, on a regular basis, the use of additional staff support** with a view to ensuring that it continues to work effectively for everyone involved.
3. **Greater openness is needed between schools and parents concerning additional help** being provided for the child via

the home and/or community. Schools need to establish procedures which facilitate home–school exchanges about such information and how it meshes with school-based provision. Information about successful approaches could be shared through professional networks and magazines.

4. Schools and other providers need to ensure that good communication systems are in place in relation to passing on **information to temporary staff**, for example, supply teachers, about individual children’s needs, adjustments and preferences.
5. **Information about disability-linked advocacy and support groups** needs to be conveyed in a variety of accessible forms to disabled children and young people, particularly when they are about to leave formal schooling.
6. Parents could be actively involved in (mandatory) disability equality **training in SEN/ASN and disability for all teachers**, drawing on their potentially very powerful and insightful personal stories and experiences. 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 in this connection.
7. Good **role models** are vital in sustaining aspirations. Schools and community groups need to identify, support and promote such role models. Within schools, this may link with the celebration of successful buddy or support strategies. One specific context for this is the work of school councils involving disabled pupils.
8. A school’s review of special educational or additional support (for example, through a Statement) might usefully and explicitly **refer to support needs and educational aims beyond a narrow conception of academic/curriculum help** within the classroom. This would lead the school to consider both within-school strategies to address these (eg a school ethos emphasising broad educational goals) and also the child or young person’s needs, referenced to the wider community (eg help with accessing youth groups).

## Further background to the project

### Overview and references for all projects in phases 1 and 2

**Phase 1** (2004–05) 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.

(Lewis, A., Robertson, C., and Parsons, S. (2005). **Experiences of Disabled Students and their Families. (Phase 1)**. Birmingham: University of Birmingham, School of Education and the Disability Rights Commission).

**Phase 2** (2005–06) encompassed three strands. The pilot methods for accessing children's views, developed in phase 1, proved a 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 per cent were parents of children with disabilities, special educational needs or difficulties).  
(Lewis, A., Davison, I., Ellins, J., Parsons, S and Robertson, C. (2006). **Survey of parents and carers of disabled children and young people in Great Britain**. Birmingham: University of Birmingham, School of Education and the Disability Rights Commission).
- 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, A., Niblett, L., Parsons, S., Robertson, C. and Sharpe, J. (2006) **Advisory Groups of Disabled Children and Young People with Reference to Experiences of Disabled Children and their Families (Phase 2)**. Birmingham: University of Birmingham, School of Education and the Disability Rights Commission).

- The third strand of phase 2 (the main focus of this report) comprised in-depth individual (36 children/young people with disabilities and/or special needs) or group (three 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 on approaches piloted in phase 1) included interviews with the children/young people (using a range of support strategies and techniques), 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. Many of the children/young people had more than one type of disability. Main disabilities were autism/ASD, dyslexia, learning difficulties, physical disability, sensory impairment and social, emotional and behavioural difficulties. The resultant rich case study data complements the parent survey (cross-referenced in this report where appropriate) and provides a sound basis for building on these findings.

(Lewis, A., Parsons, S. and Robertson, C. (2007). **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**. Birmingham: University of Birmingham, School of Education and the Disability Rights Commission).

| Table of samples and methods in phases 1 and 2            |                                                                                                                                                                  |                                                                                                                                                                                                                      |                                                                                                                                                                                        |  |
|-----------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|
| Main project strand                                       | Scale and scope                                                                                                                                                  | Main data collection method(s)                                                                                                                                                                                       | Number of respondents or participants                                                                                                                                                  |  |
| <b>Phase 1</b><br>Pilot work<br>August 04–<br>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 two 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 aged 7–19, 8 families, 8 FE students (ages 18–30+), and 157 e-survey respondents.<br><br>Full report on the <a href="#">DRC website</a> .                     |  |
| <b>Phase 2</b><br>Parent survey<br>August 05–<br>April 06 | Six focal geographical areas in GB; spanning a range of educational settings as well as urban/rural and ethnic groups.                                           | Eight-page survey booklet distributed to parents via schools and colleges;<br>key transition ages/ groups targeted (broadly, ages 9–11; 11–12; 15–16 and 16–18).                                                     | 1776 valid returns; approx 35 per cent from parents identifying their child as having a disability, SEN or other difficulties.<br><br>Full report on the <a href="#">DRC website</a> . |  |

| Table of samples and methods in phases 1 and 2 (continued)                         |                                                                                                                                                                   |                                |                                                                                                      |
|------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------|------------------------------------------------------------------------------------------------------|
| Main project strand                                                                | Scale and scope                                                                                                                                                   | Main data collection method(s) | Number of respondents or participants                                                                |
| <b>Phase 2</b><br>Advisory groups of disabled people<br>September 05–<br>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.                | Two core advisory group members plus involvement of satellite groups in England, Scotland and Wales. |

| Table of samples and methods in phases 1 and 2 (continued)                             |                                                                                                                                                                                                                                                                                                                                     |                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                     |
|----------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Main project strand                                                                    | Scale and scope                                                                                                                                                                                                                                                                                                                     | Main data collection method(s)                                                                                                                                                                                                                                  | Number of respondents or participants                                                                                                                                                                                                               |
| <b>Phase 2</b><br>Case studies of children and young people<br>January 06–September 06 | Four 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.<br>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.<br><br>Full report on the DRC website. |

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