Research Report DCSF-RR062

Disability Data Collection for Children's Services

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Executive Summary

Introduction

Public authorities are required under the Disability Discrimination Act (DDA) (2005) to measure performance in delivering improved outcomes for disabled children and young people. Local authorities and schools do not routinely collect data on disabled children, only on those with a special educational need (SEN). The purpose of this research was to develop tools to identify children and young people with a disability.

Key Findings

- Disability cannot be identified without reference to impact and therefore requires data collected from both parents and children ;
- 42% of parents returned the questionnaire and this figure was as high as 80% in some primary and secondary schools.13% of parents indicated their child meets the DDA criteria ;
- Disability and special educational needs (SEN) are not interchangeable terms;
- A quarter of identified children did not have a SEN and in all mainstream schools visited as part of the project there were children with a disability about whom schools and local authorities had no knowledge;
- Conversely over half the children with SEN in mainstream schools were not identified by their parents as meeting the DDA criteria;
- Data collected from children suggested that there are a considerable number (including those with a difficulty, medical condition or mental health problem) struggling with aspects of school life with 16% who completed the online questionnaire reporting that their difficulties had gone on for more than a year;
- Children found peer support particularly helpful but also wanted further teacher input including good explanations and instructions for the whole class as well as individual support and extra lessons;
- Parents also suggested the importance of individual or small group teaching;
- Analysis of pupil attainment using the National Pupil Database suggested that the presence or absence of SEN was unsurprisingly the best determiner of pupil performance and children with a disability and no SEN are in general achieving at a level commensurate with their peers although there are individuals within the group who are under-achieving. Measures available for monitoring progress for children in special schools were limited in their usefulness.

Background

Currently schools in England are required to collect data on children with Special Educational Need (SEN) only. This does not capture information about all disabled children; it excludes some pupils with a current medical condition or one that is in remission, and some children with a mental health problem. It also excludes children who might not readily be considered disabled such as those children with cancer, HIV or physical disfigurement.

Aim

The aim of the project was to develop a basic data collection tool for use with pupils and parents to inform planning and monitoring of the Disability Equality Duty (DED) by schools, social services, LA and central government, employing user friendly approaches to establish:

Does the pupil have a disability- in line with DDA definition?
What type of disability do they have?
What support needs do they have?

Methodology

This was a three phase enquiry involving

- a scoping study to analyse the strengths and limitations of different indicators used to identify disability;
- a development phase to pilot parent questionnaires and develop tools to collect data from children on the barriers and supports to learning with 11 schools;
- a national trial of a parent questionnaire and a range of flexible tools to collect data from children in years R, 4 and 8 with 74 schools.

Findings

The scoping study revealed the advantages in using mixed descriptors of disability, incorporating the use of the term difficulty as well as disability. Data on disability is seldom collected from children themselves yet pupil views are vital in understanding the barriers and supports that they encounter.

The pilot confirmed the importance of using multiple indicators of disability and including reference to difficulties alongside disability. Development work in schools revealed the challenge to provide guidance to staff that will encourage children to reflect more deeply and not constrain or pre-empt their responses.

National Trial

Parent Questionnaire

The overall return rate for the project was 42% (2895) with 2% returned online. Some schools achieved returns from over three quarters of parents.

Children who meet the DDA criteria

13% (390) of parents indicated their child meets the DDA definition; a figure that is higher than the 7% quoted by the DfES/DRC (2006) and possibly indicates that these parents were more likely to return the questionnaire.

- Just under a quarter described the impact as severe or profound having a frequent and significant impact on daily activities.
- Over a third reported that the difficulty sometimes leads to an absence from school.
- Around three quarters experience difficulties in school and just under half experience difficulties at home.
- Asthma and Autistic Spectrum Disorder are the two most reported conditions.

Children who meet the DDA criteria without SEN

In primary schools, 32% of these pupils and 41% in secondary were identified by their parents as having health, medical or mental health needs but not SEN. Their disability is more likely to interfere with “other school activities” than classroom learning and for just under half it results in absences from schools. The majority describe the impact as mild.

Children with SEN who do not meet the DDA criteria

A substantial proportion of children whose parents identified them as having SEN did not meet the DDA criteria, either because parents did not see their difficulties as longstanding and/or they had no impact on daily life. 60% of pupils in primary schools with SEN and 54% of pupils with SEN in secondary schools did not meet the DDA criteria on the basis of parent judgements. This figure was lower for children in special schools where 24% were not identified by their parents as meeting the DDA criteria.

Support that the parents of children who meet the DDA criteria find helpful

Parents described the support their child found helpful to include one to one (or individual) support, small groups or classes. Where parents referred to particular lessons it was more likely to be reading and writing. Some stressed above all the need for a positive and understanding attitude.

Children's Views on Barriers and Supports to Learning

In total 45 schools used at least one version of the flexible tools providing data from over 2714 children on the barriers and supports to learning. To some extent the richness of the data reflected the interest and commitment of schools as these were tools that needed embedding in meaningful activities and some personalisation to meet the needs of children who experience difficulties in communicating their views. Schools largely opted to use either the symbol or online questionnaire or the interview schedule, with few choosing to use more individualised approaches.

Data from the online questionnaire revealed 22% (359) of children stating they had a disability or difficulty and 16% (258) stating that it had been present for some time. These children found peer support particularly helpful but also wanted further teacher input. Their comments suggested that they welcomed good explanations and instructions for the whole class as well as individual support and extra lessons. The main aspects of the environment which were viewed as important were the level of noise and distractions, and the general atmosphere created by the teacher in charge. Aspects of this resonate well with the parent comments on support, although parents' descriptions underplayed the vital role of friends.

Stakeholder Feedback

Parents

The number of parents identifying issues of concern or offering suggestions was small, making it difficult to gauge how much weight to place on individual comments. There were individual cases of uncertainty over meeting the DDA definition and the relevance of this form for particular children. The difficulty in constructing a list of categories that fits all cases is highlighted by the contradictory calls for such descriptors to be both 'more specific' and 'more flexible'.

Schools

Follow-up validation visits were made to eight mainstream and four special schools and in all eight mainstream schools indicated that there were pupils with a disability who were unknown to them. Staff felt that the information received raised their (teachers') awareness, and were particularly interested to read about parents' views of the impact of their children's difficulties/disabilities although felt there was some surprising under-reporting with respect to whether the disability was longstanding and felt that some parents under-rated the impact of the child's difficulty. Some concerns were raised about parents' ease of understanding the questionnaire given poor literacy skills or English as an additional language.

Schools reported using a variety of strategies to increase returns e.g. explaining the survey to children; giving tutor groups incentives to have the highest return rate; mentioning the questionnaire in newsletters and during morning assemblies; inviting parents in to a coffee morning to discuss the questionnaire; and asking a home-school link worker to liaise with parents. A number of schools reported that they offered support for parents to complete the form, but that this was not taken up.

Local Authority Perspectives

Most local authority staff strongly welcomed the availability of the data as the parental questionnaire provided a richer picture than the data currently collected. The inclusion of parental perceptions of impact were welcomed, as it was noted that these may well differ from school perceptions. Despite the amalgamation of children's services, there remained some concern about a lack of sharing of information at the ground level between professionals working with families.

Using the Data to Monitor Progress

In order to examine how well the data enabled monitoring of the DED against existing indicators of attainment the survey data were matched to the National Pupil Database (NPD). Attainment data for children at KS1 revealed that children who met the DDA with no SEN achieved level 2 in reading, writing, maths and science. In contrast, fewer of those with SEN achieved as well, particularly in reading and writing where only 65% and 57% respectively achieved level 2. The KS2 data provided a similar profile.

In order to analyse progress between KS1 and 2, value added comparisons were made. Those who meet the DDA definition without an SEN are, as a group, largely progressing in line with expectations, but this picture obscures the profile of children who are underachieving, including those who are achieving at level 4 but whose anticipated achievement is higher. This is also true for some nondisabled pupils.

Contextual value added data also revealed that children who meet the DDA definition but who don’t have SEN are generally making expected progress. There are however some who are not doing as well as anticipated and these are largely children who are performing above level 4 and whose under-achievement may go unnoticed.

The analysis of performance of children in special schools revealed that the majority are performing well below the expected level at KS2, with scores of 15 or below the level assessed by the test. Contextual value added data suggested that children were generally performing below that expected on the basis of KS1 scores but with wide variation amongst the group. Pupils in special schools are likely to have multiple difficulties and it may not be possible to identify what constitutes a primary or secondary need, making contextual adjustments on the basis of SEN less certain.

Conclusions and Implications

Collecting this data from parents is achievable, and if schools are committed to getting a high return rate there are some useful additional strategies that will help them to achieve this. The current methodology will require some adjusting to meet the needs of parents whose first language is not English and those with poor literacy skills.

While it is possible to provide “off the shelf” tools to collect children’s views their use will require some preparation and time to ensure that they are suitable for eliciting the insights of *all* children. It is important to embed the use of these tools in meaningful activities that are given the appropriate gravitas to ensure that they promote self-reflection on learning and a positive ethos towards children encountering difficulties.

Many schools and local authorities suggested the data were collected from parents on admission. This timing has a number of advantages as nearly all schools reported meeting face to face with parents enabling disability data to be collected alongside other personal data. Parents may however feel reluctant to provide information that would lead schools to anticipate difficulties and may be concerned that their child could be denied a place if they are seen to experience “problems”. These disadvantages need therefore to be set against the greater potential for returns from all parents, and the possibility of getting parents to provide this data online with or without support from a member of staff. Familiarity with the form would facilitate annual or bi-annual follow –ups.

If schools are to be autonomous in the collection of this data they will, as local authorities suggested, need some training. The provision of a common questionnaire with data confidentially downloadable by individual schools has many merits. The development of a user-friendly IT system that provided schools with easily accessible analysis would enable them to use the information to enhance provision as well as make returns to local authorities.

As a result of these findings a number of important policy implications are discussed. These would support the use of common methods to facilitate communication between schools and families and create a culture in which it is safe to disclose information concerning disability and difficulties.

Chapter 1: Introduction

1.1 Disability Discrimination Act

The Disability Discrimination Act (2005) came in to effect in December 2006 placing a duty on all public sector authorities to ensure that disabled people are treated fairly (Disability Equality Duty). It extended earlier legislation of the SEN and Disability Act of 2001 which in turn extended the 1995 Disability Discrimination Act. Together they provide a definition of disability and a statutory framework to ensure equality of opportunity for disabled people.

Appendix B of the statutory code defines the meaning of disability:

> *"A person is disabled if they have a physical or mental impairment which has a substantial [going beyond normal differences in ability] and long-term [more than 12 months] adverse effect on their ability to carry out normal day-to-day activities,"* DRC 2005 p120.

Extensions to the definition have been made to include people with certain medical conditions (Cancer, HIV and multiple sclerosis) within the definition and to remove the requirement for clinical diagnosis with respect to mental illness. In order to fulfil their duty public sector authorities are required to be proactive in eliminating discrimination and assessing the impact of their activities on disabled people. Secondary schools were required to develop a Disability Equality Scheme by December 2006 and primary and special schools by December 2007.

This Act requires public authorities to measure performance in delivering improved outcomes for disabled children and young people. As recommended in a DRC report (Miller et al 2006) the development of a robust data collection system is vital in firstly monitoring whether disabled children and young people are realizing their potential and secondly measuring the impact of enhanced services. A number of reports have detailed the multiple disadvantages that may have an impact on children with disability (Audit Commission 2003; Strategy Unit Report 2005; Gray et al 2006; Select Committee 2006.) Although the Every Child Matters policy has focussed on universal services there is concern that, without this more targeted approach, disabled children will be denied the opportunity to reach their full potential.

1.2 Existing data collection

Currently schools in England are required to collect data on children with Special Educational Need (SEN) only. From 2006 these data have been collected through School Census including information on the type of primary SEN (and if appropriate secondary) for pupils who are statemented and for those on the School Action Plus stage of the Code of Practice (DfES 2000). Placement information in relation to special school, unit, class or resourced provision has been collected from 2006 to enable comparisons using achievement data on national tests. Data on the achievement of some of these pupils are recorded against performance on the P levels, their progress towards level 1 of the National Curriculum. Schools were invited to report attainment for pupils using these scales from 2005 and in 2007 this became mandatory.

The School Census does not capture information about all disabled children. For example it excludes pupils who are on the earlier stages identified in the Code of Practice of School Action, those who have a current medical condition or one that is in remission, and children with a mental health problem. It does not easily capture information concerning children in secure units where the statement does not follow the child. It is also limited in the extent to which it may reflect the complexity of pupil needs. This was highlighted in a recent audit of 1300 children attending special schools which found a significant number of pupils had two, three or four disabling conditions (Porter & Lacey 2008).

1.3 Issues in the definition and description of disability

The description and categorisation of disability, like that of SEN is not unproblematic. Descriptions and categorisations are often highly situated depending on the context and impact, as well as other factors. This is well exemplified in medical conditions where the same condition can lead to different experiences, dependent in part on its severity and the school response. Closs (2000) notes the overlap between medical conditions and disability and in particular the grey area between the two, in which many children may not be really ill or really well. She lists the following possible disabling factors which may result in under-achieving through: feeling under-par; being absent from school; requiring treatment or medication in a way that disrupts the school day; feeling anxious and uncertain about the prognosis or course of the condition; feeling different from others because of the treatment or the condition itself.

A cabinet office report published last year entitled “Improving the Life chances of Disabled people” set out a vision for disabled people for 2025, stressing the importance of adopting a social model of disability. This model seeks to explain disability through reference to the barriers that society erects and the consequent oppression experienced. Despite its many strengths, this approach is not unproblematic and increasingly it is recognized that the social model often fails to reflect the heterogeneity of personal experience (Shakespeare 2005) and underplays the experience of physical symptoms including pain and fatigue. The adoption of a more transactional perspective would mean that need would be identified in the context of readily available environmental supports (not unlike arguments that have been made in the past with respect to special educational needs, Wedell 2003). As Shakespeare and Watson (2001) have stated: “Disability is an interaction between impaired bodies and excluding environments.”

In a school context an interactional perspective places emphasis on the identification of the support needed to eliminate discrimination. This approach is well illustrated in the framework for intervention developed in Birmingham and now used across the UK (Cole, Visser & Daniels 2000). Such approaches need to reflect the full range of ways in which pupils are supported e.g. CCTV to access lesson from another room, opportunities for practical experience, providing positive role models, self-esteem/emotional well-being activities. There are two particular issues to bear in mind. Firstly the mixed feelings that disabled pupils may have about receiving support and secondly that the identification of support needs (*as distinct from provision*) depends on knowledge about the full range of resources available (Miller et al 2005).

Despite the clarity of the DDA definition, disabilities are often hidden, either from schools, peers, parents or the child themselves. A DRC project (Lewis et al 2005) found some schools unaware that they had disabled children, and some parents who were uncertain about their child’s disability.

1.4 Aims and objectives

Within this context the aim of this research was to:

- develop a basic data collection tool for use with pupils and parents to inform planning and monitoring of the Disability Equality Duty by schools, social services, local authorities, and central government, employing user friendly approaches to establish:
  Does the pupil have a disability- in line with DDA definition?
  What type of disability do they have?
  What support needs do they have?

More specifically three objectives were identified:

1. Drawing on an evaluation of existing (good) practice develop and pilot a range of examples collecting pupil and stakeholder feedback;
2. Following further refinement of the data collection tools and the development of accompanying materials and guidance, evaluate their use/usefulness in a wide sample of representative schools;
3. Validate the utility of the data with reference to existing local authority data and the National Pupil Database.

1.5 Phases of the project

Three phases of the project can be identified:
Phase 1: A scoping study
Phase 2: A development phase involving pilot work in school
Phase 3: A national trial
This report starts therefore with an overview of the outcomes of the scoping exercise undertaken to identify examples of good practice.

Chapter 2: Scoping Study

2.1 Methodology

The scoping study set out to locate and evaluate existing practice in disability data collection by examining proformas used nationally and internationally and the literature that supported their development and use. In order to understand further the current English context we also gathered information through email and telephone interviews with over a hundred professionals working in the field. The interview schedule drew on guidance provided by the Advisory Committee on Australian and International Disability Data (2005) and this together with other details of the methodology are provided in Appendix A

2.2 Findings

Disability is a sensitive and complex area with no single recommended “gold standard” approach to data collection (Scottish Council Foundation 2005; Whitfield 2007). Different approaches have been developed in the global search for a common screening measure sponsored by international organisations (e.g. UNESCO, OECD, Worldbank). There are a number of UK panel and cohort studies that have collected disability data producing prevalence figures that vary more than 10%. This variation is in part due to using slightly different definitions, sampling methods and populations (see Read et al 2007 for a detailed comparison).

Disability is an area where lay knowledge and understanding could best be described as partial, dominated by four beliefs: that disability is primarily a physical impairment (as reflected in the wheelchair logo); that the differences between disabled and nondisabled people are clearly visible; that disability is a permanent and unchanging condition; and that it causes incapacity (Bajekal et al 2004). Research undertaken in Canada indicated that negative sounding terminology (such as long standing, person limiting) were the main reasons for non-reporting in adults. There are also age related factors that contribute to perceptions and awareness. For example there may be uncertainty about the trajectory of development in younger children and a reluctance to assign a descriptor to a child that pre-judges the longer term consequences. For older children there may be important issues and sensitivities around self-image and self-esteem as well as confusion over the term disability (Lewis et al 2005). As a consequence any survey device has an important educative function and must be sensitive to the emotional consequences of asking people to reflect on personally experienced difficulties.

An evaluation of different approaches must rest on an appreciation of the different purposes of data collection and the ways in which definitions are embedded in criteria. The DDA foregrounds four important aspects to the definition: that it arises from an impairment, that the condition is one that has lasted a year or more (or is expected to); that it has an impact on everyday activities and that the effect is substantial (i.e. not trivial) (see DfES/DRC 2006 for more discussion). This goes beyond a simple medical definition in that it places emphasis on the experience of an impairment and makes it important that the information is not provided by a professional or third-party. The use of an interactional model suggests going beyond the approach commonly adopted in national census data that focuses on health related aspects (Bajekal et al 2004), to recognize the ways in which environmental circumstances serve as mitigating factors in the experience of every-day life.

The focus of this research is children’s experience and school is an important part of daily life. In general the starting place for the majority of survey instruments has been the development of adult proformas with only subsequent recognition of their inadequacies for collecting data in relation to the daily life of children. This is well evidenced in the 1990s by the development of the World Health Organisation International Classification System (ICIDH) of a biopsychosocial model incorporating body structures and functions, activity limitations and participation and environmental factors (WHO 2002). This lacked appropriate content in relation to the young child (Florian et al 2006). A separate child and youth classification was later developed and launched during the time of this project in 2007.

Keeping these factors in mind a working taxonomy was developed to interrogate eighteen examples of practice and the literature that reported on these. Definitions, content, formats and systems of administration were examined. The results of this can be found in appendix B. The analysis highlighted the strengths and limitations of different forms of questioning.

2.2.1 Different question types

DDA type questions of the type used in census and cohort studies: e.g. *Does [child's name] have any longstanding illness or disability? By longstanding I mean anything that has troubled [child's name] over a period of time or that is likely to affect [child's name over a period of time.* (Family and Children Survey 2006 DWP).
These are amongst the least consistent and are particularly sensitive to question order effects, including whether a checklist of types of impairment is presented first or second (Bakjekal 2004). People are unclear about whether a condition is severe enough to count as a disability. The addition of a "limiting and longstanding" question has been seen to reduce self-reported prevalence (Read et al 2007).Research funded by the DRC suggests that because parents, carers and children may not identify with the term disability, there is much to be gained by asking about difficulties (Lewis et al 2005; 2006)

Including lists of impairments**:** These may include lists of specific conditions e.g. diabetes, asthma and/or outcomes of conditions e.g. difficulty in hearing, problems with legs, arms, neck, thereby mixing the medical with the functional. Unless the list is very long, these questions are unlikely to be truly inclusive. Additionally, only around 54% of disabilities have a medical diagnosis (Hutchinson & Gordon 2005). One of the largest discrepancies is in relation to reporting sensory impairment, indicating the importance of functional rather than medical data. Question should not ignore the contextual and societal influences on functioning in every-day life.

Asking Questions about (Developmental) Functioning- e.g. *Compared with other children, did the child have any serious delay in sitting, standing or walking?* This question is taken from "The Ten Questions Screen" originating with work funded by the OECD and developed as an international instrument for identifying children "in any culture (Robson & Evans undated; Durkin et al 1994). These questions tend to under-identify disabled children and used on their own are not sensitive enough (Mung'ala-Odera et al 2004, Westbrook et al 1998). They assume knowledge of the range of developmental norms and make no distinction with delayed development.

Asking about Activities & Participation: e.g. *Last week.. I put toothpaste on my toothbrush then brushed my teeth by myself* (Young et al 1996). This illustrates the need for questions to distinguish capacity (could they do) and performance (do they do). The former tends to exceed the latter, and reflects the fact that performance measures are a more sensitive measure of changes to the environment and circumstances in which an activity takes place (Young et al 1996). In adult populations, the more activities included the more people are identified (Gudex 2000). However this may not be true for children who may have access to additional activities (e.g. horse-riding). This suggests that a more open question may be better than listing activities.

Asking about Barriers & Support: These questions do not typically feature in disability data collection which focuses on the individual, but are more likely to be included in organisation level audits (e.g. Index for Inclusion Booth and Ainscow 2002). Riddell & Banks (2001) suggest the following approach to questioning reflects a social model of disability although the focus here is on adult populations and requires some translation for children***:***

As a result of a physical or mental impairment, have you been stopped from doing anything, or going anywhere, or achieving any goal, by:

1) *The attitude of any person or group?*
2) *The design or operation of any thing or object?*
3) *The rules or procedures of any organisation or body?*
4) *The structure or process of any organisational system?"*

In summary it can be seen that there are shortcomings with each approach and an advantage in using mixed descriptors to offset the limitations of each one. As Rose (2006) has pointed out it is clearly not sufficient to put a single question on a form. The ICIDH recommends using more than one definition. Studies comparing questions concerning functional limitations, dependence on assistance/aids/medication, or service use found that only 20% of children were identified by all three categories (Westbrook et al 1998). Children with sensory impairment were more often identified through functional limitations, children with BESD through service use or functional definitions.

Although there are concerns about the standard "long standing life limiting" question used in national household surveys, its inclusion facilitates comparisons and judgements about the ways in which children are identified or excluded through different question types.

2.2.2 Staged approaches to questioning

Using mixed descriptors one can identify the role of a staged approach. The Australian Bureau of Statistics (2005) provide an example of a 2 stage question approach with a Yes or no answer required for Question 1-

> *Does the person have difficulty doing everyday activities such as eating, showering or dressing etc?*

Where Question 2 seeks views on causation:

What causes the difficulty shown in question 1- short-term health lasting less than 6 months etc, long-term health, disability, Difficulty with English language, Age, Other

The Family Resources Survey 2004/5 used a four stage approach:

"Any illness, disability or infirmity? By longstanding…anything that has troubled [the child] over a period of time or is likely to affect him/her over a period of time?

With a follow-up to ask whether the
"physical or mental illness or disability limits [the child] in any way?

They are then asked whether they had

> *significant difficulties with any of these areas of his/her life?*

And whether they

> *took medication without which their health problems would significantly affect their lives..."*

Where disabilities in children are cyclical or variable there may be uncertainty as to how to respond to questions that require a simple yes/no response. There are additional issues with respect to reporting on children where their functioning and learning may be constantly changing (Langlois 2002). This suggests that there must be opportunity to answer more fully than yes/no and include an option of "sometimes" and the opportunity to clarify through open questions.

The function of multi-stage questions is to ensure there is not over or under-representation of particular groups. Previous surveys have under-represented some groups such as those whose difficulties are manifested later in childhood. For example figures for children with mental health problems found in the Mental Health survey (9.6%) exceed those quoted for all children with a disability. Children with acquired brain injury are also under-represented as although most of experience difficulties with learning, behaviour and emotional difficulties they may be unrecognized by the school (Rees 2007). Both groups must be overtly included in the survey.

Given the inclusion of the term substantial in the DDA definition it is also important to include questions concerning the degree to which a condition impacts on child's activities. No survey has looked at the extent of the limitation although the Office for National Statistics General Household Survey (2004-5) does ask if children's activities are "limited" or "strongly limited" as the result of an illness of disability. These questions help to validate whether the child's difficulties meet the definition set out by the DDA.

A further approach to validation concerns the child's impairment although as we have reported not all children will have received a diagnosis for their difficulties. For a variety of reasons parents may not know or remember the medical words used to describe their child's condition. Diagnosis may provide only partial validation. The Scottish system circumvents this in part by asking whether a child has been seen by a professional without the need to confirm the cause of the disability (Scottish Executive 2004).

2.2.3 Purposes of data collection

Data on disability has usually been collected by local authorities in relation to different services (health, social, education) with criteria dependent on the way provision is allocation. This has caused problems in aggregating the data into a joint data base (Parker et al 2003; Blackburn et al 2006). Knowledge and ownership resides at different levels (Parker et al 2003) and with the development of Children's Services these shortcomings are very apparent. (For further discussion of local authority disability databases see Mooney et al 2008). The prime purpose of this research is to support the obligations of public authorities under the DDA by promoting equality of opportunity together with positive attitudes towards disability (Purdan et al 2008). Arguably the data collection is not linked to the development of specialist services but to monitoring the adequacy of generic services in meeting the needs of all children. The data collected in this study need to support the work of schools, local authorities and central government all of whom will have slightly different requirements in meeting their duties.

The scoping study revealed that local authority personnel perceived a number of purposes for collecting disability data:

- to identify areas of unmet or rising need in particular areas (for example increasing numbers of children with ASD);

- to use the statistics to prove which provision was best for which child;
- to advise parents about the strengths of different schools;
- to monitor whether schools are doing the best for their disabled pupils;
- to find out which schools need additional support.

Local authorities have expressed particular interest in using the data to identify provision which best matches the needs of particular groups of pupils and to use this information to advise parents and provide further support to schools. Local authorities also expressed interest in identifying areas of rising need using categories in the Code of Practice.

Follow up interviews also revealed the tension between the need for individual pupil level and school level data. This is partly a reflection of the extent to which schools adopt a social model of special needs which places an emphasis on environment and organisational barriers. Schools need to feel confident that the tools will uncover new information but also that they will be able to support any additional needs that the survey uncovers by making adjustments at both individual and whole school level.

2.2.4 Motivation

Motivation to administer the survey device is a key issue and schools and local authorities raised a number of concerns with respect to raising expectations of parents and demands for additional support for their children. The usefulness of the data depends on high return rates. There is a tension between the voluntary nature of disclosure and the need for a representative sample. Research indicates that, in the adult population, ethnic minority groups are under-represented (Purdan et al 2008).

There is evidence suggesting sensitivity to the format of the survey tool including the deterrent effect of an official looking document (Rees H. 2007). Higher return rates are more likely if the questionnaire is kept as short as possible. This is sensitive information which necessitates explicit statements with respect to confidentiality (Rose 2006) and clear information on the reason why the data is collected which, given the resource concerns of schools, requires careful phrasing.

Experience with local authority disability registers suggests that without a number of concerted strategies including developing publicity and making clear the benefits, there will be low levels of uptake (Parker et al 2003).

2.2.5 Approaches to collecting data from children

This is new ground for census data. Data on disability is seldom collected from children themselves, although two notable examples are the Mental Health Survey (Green et al 2005) and the Activity Scale for Kids (Young et al 1996). Data is more typically collected by proxy, despite strong arguments for adopting a social model. Pupil views are a vital component in understanding the barriers and supports that they face and consultation with children is an important element of putting together a Disability Equality Scheme. As the DRC state:

> Involving disabled people increases the likelihood of success, thus increasing your chances of reaching your strategic objectives. (DRC 2005)

This is essential in the current project especially given the language sensitivities around labelling, particularly for children in secondary mainstream settings (Lewis et al 05) and the importance of not portraying disability as a “single signifier of identity”.

Recent guidelines on eliciting the views of children and young people raise a number of methodological and ethical issues which are pursued in depth elsewhere (Porter & Lewis 2004; Lewis & Porter 2007). Importantly research has indicated that asking questions is not always the best approach to eliciting information. It is important to draw on the expertise developed by researchers, teachers and other professionals including exploring the potential of innovative methods to enable all children to have a voice (Porter & Lacey 2005).

One conclusion of the DRC study (Lewis et al 2005) on collecting pupil views was that

> “Children with diverse physical/sensory impairments or special needs can be included in meaningful and valid ways in sharing their views. However one fixed approach will not work for all children and young people…” pg 73.

The study also suggested that there is a need to leave room within methods for schools and others to make choices. The importance of this is further reflected by studies of teachers’ confidence in involving all children including those with little or no verbal communication in their education (Watson, Tarleton and Feiler 2006).

A small scale study by Connors and Stalker (2002) found that children referred to their own impairment rather than to the barriers they faced. The same research suggests that children may find it hard to talk in general about difficulties but instead can identify discrete concrete examples. This reinforces the importance of developing materials that can be customised to meet the child's needs.

These tools should be appropriate for both disabled and non-disabled children. A flexible pupil driven approach is also an important part of supporting schools in developing a positive ethos towards disability, which will in turn impact on the willingness of parents to disclose sensitive information. The activities must therefore reflect the range of different contexts for collecting this data. Guidance must facilitate school and pupil choice in accessing a group or individual activity and in the latter case one which can also be confidentially completed in an electronic form.

Chapter 3: Development of the Parent Questionnaire

3.1 Key questions for the development phase

The focus of this phase was developing and evaluating the adequacy of the data collection tools. The following questions were asked with respect to the parent questionnaire:

- How well do these structured tools identify individuals with a disability?
- Are parents willing and easily able to complete them?
- How well does the information meet stakeholder needs?
- What system of administration is best suited to school needs?

3.2 Methodology

Three alternative questionnaires were developed for testing in school. Two of these contained the frequently used disability question:

Does your child have a longstanding illness, medical condition or disability? By long standing we mean anything that has troubled them over a period of a year or more, or that is likely to affect them over this period of time?

One included the question at the beginning of the questionnaire (proforma 1) and the other at the end (proforma 2). In addition proforma 2 asked an initial question:

“Does your child have a disability or difficulty such as: arthritis, asthma, epilepsy, hearing impairment, mental health difficulty, anxiety or depression, mobility problems, learning difficulty, ME, diabetes, visual impairment?”

In this way one of the questionnaires used a 2 stage approach as seen in some of the literature. It also combined the use of the term disability with difficulty recognizing that some parents may find the term disability problematic (Lewis et al 2006).

These questions however do not take into account the impact of the disability so in addition both questionnaires specifically sought information on whether the child experienced *difficulties in school, in the classroom* or *out of school* and what kind of support the child found helpful. The aim was to identify children whose parents might not have described as having a disability but who encountered difficulties to a substantial degree. Parents were also asked to rate the extent of the difficulty from occasional interference with everyday activities and only in a minor way through to preventing a number of activities. They were asked whether *the difficulty or disability interfered with attendance at school* thus giving us an additional measure of impact. Parents were specifically asked *whether the child had experienced a major accident or trauma in the previous 5 years*.

The third questionnaire (proforma 3) was devised to more closely follow the questions used in the DDA guideline materials “Is Tom Disabled” (DfES/DRC 2006). Of the type:

“Does your child have a difficulty, condition or disability that affects their participation in school activities “

“If your child has a difficulty does it affect any of the following day-to-day activities? This then listed the areas in the *‘Is Tom Disabled’* guidance of the areas to be taken into account when determining whether the child has a disability or not*: mobility, manual skills, physical co-ordination, lifting, carrying, continence speech, hearing eyesight, memory or ability to concentrate, recognize danger. “*

The emphasis in this third questionnaire proforma was therefore on functioning. It resulted in a format that was felt to be largely unsuitable for some groups of parents, namely those whose child had a significant disability (as inevitably they would tick every box) and those with younger children where differences in development may be less easy to identify. The project team were concerned about the focus on impairment but it was provided without comment as a choice for four schools. Each preferred the alternative version- whether proforma 1 or 2.

A question was included on who the information could be shared with and enquired whether they would like the opportunity to discuss any of the issues raised by the questionnaire with a member of staff. Parent’s comments on the questionnaire format were also solicited.

All questionnaires were made available in both electronic and hard copy version. Each school was provided with their own URL and given a choice of how they would like to be supported in the administration of the questionnaire.

Collecting stakeholder views

Data from the parental questionnaire was returned to headteachers and local authorities (omitting children for whom parents had requested confidentiality) and each was interviewed to collect their views on its use and usefulness. We also collected their views on the administration of this process and their thoughts on future disability data collection procedures.

Sample

Schools were initially nominated through the LA and then contacted directly to clarify details of the project and invite their involvement. Additional schools were approached directly to offset gaps in the sample**.** The target pupil groups were years R, 3 and 7. The final sample comprised: one First School, four Primary Schools, one City Academy, one High School, one Community Technical College, one Primary School for Children with Behavioural, Emotional and Social Difficulties (BESD), one Secondary BESD School, and one School for Children with Learning Difficulties (LD).

Table 3.1: Numbers of parents receiving the questionnaire by school and proforma.

	Proforma 1	**Proforma 2**	**Totals**
Primary/First Schools	273	290	563
Secondary Schools/College	395	209	606
Special Schools	23	65	88
Totals	691 (55%)	564 (45%)	1257

In total 1257 parents received the pilot questionnaires with 46% having children in primary/first schools, 48% in secondary and 7% in special schools. Distribution of questionnaire proformas 1 and 2 across types of school became skewed when one special school distributed the questionnaire to all pupils irrespective of age, resulting in 55% of the sample received proforma1 and 45% of the sample received proforma 2.

3.3 Findings

3.3.1 Questionnaire returns

Response rates varied from 60% of the year R and 3 children in a First school to a low of 10% in a City Academy. In general primary schools had better return rates than secondary schools, averaging 44% and 17% respectively.

Schools selected their own package of support for distributing the questionnaire, some electing for the researchers to take over all aspects, providing the school with stamped envelopes containing questionnaire and cover-letter and return stamped envelope addressed to the university. Others elected to add their own cover letter, and make separate arrangements for sending out the forms and arranging for their return (see Appendix C for more information). There was no clear discernible relationship between the use of this package and return rates. However the more personal the approach and the use of more than one form of communication generated higher return rates. Higher returns are noticeably from schools who included information in their newsletter, spoke directly to parents, sent out reminder letters, or invited parents into school. The use of these strategies is more likely to be used by schools with a stronger commitment to the project and a more positive school ethos around issues of disability and difference.

It was important that the questionnaire was returned by all parents, not just the parents of children experiencing difficulties, and the return rates show this was the case. Excluding the special schools between 13- 38% of the respondents ticked yes to a disability question. Over 60% of the returns were therefore from parents of children without a disability, indeed for some schools this figure was as large as 82%.

3.3.2 Children identified with a disability

The questionnaires gathered data in slightly different ways. Questionnaire 1 used the longstanding question at the outset to the questionnaire:
Would you describe your child as having a longstanding illness, medical condition or disability? By long standing we mean anything that has troubled them over a period of a year or more, or that is likely to affect them over this period of time?

Questionnaire 2 included two questions, the first at the beginning of the questionnaire asked:
Does your child have a disability or difficulty such as: arthritis, asthma, epilepsy, hearing impairment, mental health difficulty, anxiety or depression, mobility problems, learning difficulty, ME, diabetes, and visual impairment?

And the longstanding question followed questions asking about any difficulties the child experienced.

Looking across the 11 schools, the longstanding question identified between 13% and 83% of children with no discernible differences between questionnaire 1 and 2. The sample size was not large enough to make statistical comparisons between them. The average for the primary/first schools was 21% and for the secondary schools was 22%. Not all parents of children in special schools answered yes to this question giving an average of 79%.

Significantly for this study the use of two questions provided some interesting differences with some parents answering yes to both questions, some saying yes to the disability question but no to the longstanding and a few parents who answered no to the disability question and yes to the longstanding. This is consistent with the literature (Bakejekal 2004; Read et al 2007). Table 3.2 reveals that more parents answered yes to the disability question than to the longstanding question and once those two categories are used together i.e. yes the child had a disability and yes it was longstanding slightly fewer children are identified. However there are additional children identified only through the longstanding question which suggests that some parents may include their children in this category only when a specific reference is made to “illness” or medical condition”. The future use of a two question approach has distinct merits.

Table 3.2: Combinations of responses to the disability and longstanding questions

School	**Type**	**Proforma**	**Yes to Disability Question**	**Yes to Long-Standing Question**	**Yes to Disability *and* Longstanding**	**No to Disability but Yes to Longstanding**	**Child identified as having a disability but not Longstanding**
1	Sec m/s	2	14 (33%)	9 (21%)	7	2	6
2	Prim m/s	2	13 (16%)	11 (13%)	9	2	4
3	Prim m/s	2	13 (32%)	9 (22%)	8	1	5
4	Prim BESD	2	11 (92%)	10 (83%)	10	0	1
5	All age LD	2	6 (100%)	5 (83%)	5	0	1

Taking the continuum of identifiers, the disability/longstanding questions identified children well. Few children were *additionally* identified through SEN categories consistent with the view that many but not all children with a special educational need have a disability. If these children are removed from the sample together with those whose parents indicated they had a disability (whether or not it was long-standing) some children were identified as experiencing difficulties in schools and a *few additional* children had seen professionals. It is important to continue to include these broader questions as, although on their own they do not identify children who meet the DDA definition, they do provide important further information about the target group.

Table 3.3: Numbers of *additional* children identified through questions relating to the category of need, professional consultation, and difficulties experienced in school?

School Type	**Total Sample**	**Child identified as having SEN but no disability**	**Yes to has your child seen a professional But no to disability or SEN**	**Yes only to Questions about Difficulties In school**
Special	88	2	1	1
Secondary	606	9	5	9
Primary	563	6	3	9
Totals	1257	17	9	19

Of importance for this project is the question of whether children are identified who have a disability that does not lead to a special educational need. The analysis suggests that 30% of the parents who answered yes to a disability question described their child's' needs with reference to the categories health/medical and/or mental health needs *only*. Tentatively this suggests that the tool is accessing new information.

The majority of parents (79%) who answered yes to a disability/longstanding question indicated that their child had seen a professional about the child's disability and 77% of parents (questionnaire 1 only) said a diagnosis had been made. Again this supports the literature (Hutchinson & Gordon 2005) suggesting that not all parents have a diagnosis for their child's difficulty.

The largest category of difficulty, unsurprisingly, was in relation to classroom learning although a number of children's difficulties included relationships with peers which in some instances impacted on their participation in both school and out of school activities. In 34% of cases parents reported that their difficulty/disability impacted on school attendance.

Table 3.4: Profile of children identified through the disability/longstanding question

	Secondary School N= 28	**Primary/First N= 57**	**Special N= 22**	**Percentage Overall**
Needs don't include a SEN	9	23	0	30%
Needs include a SEN	15	26	22	59%
Seen a Professional	18	44	22	79%
Given a Diagnosis*	9	23	3	77%
Experienced Difficulties With Classroom learning	14	28	20	67%
Experienced Difficulties With relationships	10	19	20	46%
Experienced Difficulties with school activities	15	17	16	45%
Absent From School because of their Disability	8	20	8	34%
Experienced Trauma	0	1	4	5%

*diagnosis was only sought in questionnaire 1

Integral to the DDA definition is that the disability has a substantial impact on everyday activities. Parents were invited to indicate the impact of the difficulties the child experienced using the following descriptors:
No real difficulty;
Mild- occasionally interferes with everyday activities and only in a minor way;
Moderate- intermittent but regular limitation of normal activities;
Severe- frequent and significant impact on daily activities;
Profound- unable to take part in a number of activities.

For three quarters of the sample of children whose parents indicated they had a disability there was some impact although almost half of the parents described this as mild (47%), just over 40% describe the impact as moderate. Taking the word *substantial* as key, only 12% of parents rated the impact as severe and less than 1% profound.

3.3.3 Identifying children who meet the DDA definition

Analysis of the disaggregated data revealed the complexity of providing a definitive profile of responses that lead with absolute certainty to the identification of a child with a disability. The following is taken from an analysis of the returns of questionnaire 2 from a secondary mainstream school:

Who meets the DDA criteria in a mainstream secondary school?
Of the seven children whose parents answered yes to the disability and longstanding questions, four were identified as having SEN but three not, they had medical needs and one also had a mental illness. The three returns from pupils with no SEN were looked at more closely.
Pupil 1: His particular needs are described as medical and mental health. He has seen a professional. The impact is described by his parent as mild. The disability sometimes impacts on school activities and classroom learning and leads him to be absent from school on occasion. The parent reports that their son requires (and receives) counselling support and people that make him feel safe.

It is possible that this child would meet the DDA definition and would not be picked up on the school SEN register.

Pupil 2: This child's needs are described as medical. They sometimes impact on classroom learning and taking part in school activities. The disability prevents him from playing football with his friend. The parent describes the impact of the difficulty as mild (it occasionally interferes with everyday activities and only in a minor way). No professional has been seen.

On the basis of this information alone the child would probably not fall within the DDA definition.

Pupil 3: This child has chronic fatigue syndrome and has seen a professional. It affects taking part in school activities, and sometimes impacts on classroom learning, his relationship with his peers. It limits out of school activities such as sport. It means that he is absent from school on occasion. The kind of support required includes being allowed to start school late, and having access to a lift and a first floor locker (which he hasn't). The impact is described as moderate.

It is possible that this condition meets the DDA definition and would not be picked up on the school register

The returns from special schools equally demonstrated the complexity of making judgements, and below is an analysis of the returns from three children at the primary BESD school, an area where the relationship between SEN and disability is particularly unclear.

Who meets the DDA criteria in this primary BESD school?

Taking three children of parents who answered yes to both disability and longstanding questions, all three children had two or more areas of need and their parents describe the impact of the disability as moderate, severe or profound. As the following shows there are no clear aspects which differentiate between children and predict the impact of their disability.

Pupil 1 with Profound Impact: The parents report that in addition to BESD he has learning needs and speech, language communication and interaction needs. He experiences difficulties in classroom learning, relationships with peers, and other school activities as well as in out of school activities. In common with the other children, he has seen a professional about his disability.

Given that profound impact is described as affecting all areas of activity it would appear he meets the DDA definition

.

***Pupil 2 with Severe Impact**:* He is reported by his parents to have BESD, learning needs and dyslexia and these impact on classroom learning, school activities and sometimes on relationships with peers. No additional information is provided about the effect on out of school activities and in consequence *it is not totally clear whether he falls within the DDA definition but given the tick of the severe impact box probably does*.

***Pupil 3 with Moderate Impact**:* This child is described by his parents as having learning needs, sensory impairment, BESD and some physical difficulties. These impact on classroom learning, sometimes on school activities and relationships with peers. It does not however impact on out of school activities.

This is ambiguous given that the descriptor for moderate impact is "intermittent but regular limitation of normal activities" as it appears that his difficulties may be limited to school. However given that he has four identified areas of need it suggests that he meets the DDA definition

This analysis drew attention to the fact that the focus of the difficulties question had been on the school with only one question that made reference to out of school activities. The analysis suggested the need to collect more information on this aspect.

Analysis of special school data also served to highlight that parental responses are culturally or contextually situated. The difficulties experienced and their impact depend on the expectations and environmental support. While impact data forms a vital part of the identification process, it needs to be taken in conjunction with other information on the questionnaire. The data suggested that there is much merit to using multiple indicators rather than adopting a single longstanding or disability question. It is by looking at the combination of indicators that we can start to identify children who are likely to meet the DDA definition.

3.3.4 Parent feedback

Fifty three parents (15% of the entire sample) provided specific feedback about the questionnaire. Their comments were overwhelmingly positive with 62% specifically saying they found the form easy and straightforward to use. This included feedback from parents who had a child with a disability and those who didn't. The following provides a snapshot of the positive comments.

- *The form was very easy to follow. I don't think my child has any difficulties but would welcome any help if someone found different, so feel a form like this may help me to seek any help I may need if the case may be.*
- *This form is fine how it is. Easy to fill out and the questions straight forward.*
- *Useful - especially if it is followed up and enables T to have more support.*

However some comments (10) expressed concerns about the questionnaire. One particular area is in relation to parents who don't feel that the form is appropriate to their child:

- *If you answer 'no' to the first question there is no point in answering any other question.*
- *Inappropriate as my child has no disabilities but could be important to members of staff who may need to know about other children who have some form of disability*

Given that the form was returned from a large number of parents of children without a disability or difficulty this suggests that parents were still prepared to complete it. Clearer explanations are required for why returns from all parents are important.

Some comments also reflected the complexity of collecting disability data:

- *difficult to describe T's minor anxiety problems in the context of long term mental health issues - not sure they really fit and feels like over medicalising it*

There is also a question of how accessible the questionnaire was with two comments expressing some concerns about the language used. This has implications for providing translations and the possibility of providing a simple language form recognizing that where this is used the data gathered may be more limited.

Finally a number of parents (14) made some useful suggestions by way of developing the form. A number of these were suggestions of further information to collect:

- *The opportunity to elaborate on specific difficulties and provide detailed accounts of difficulties encountered may be useful.*
- *There should be a question(s) about listing present support and what other support can be available depending on the child's needs. Also there should be a chance for parents to describe unhelpful support and give any suggestions. (parent of a child with no difficulties)*

One of the challenges to designing the questionnaire is to encourage people to reflect on the experiences of their child and, for those parents who are not happy with the descriptor disability, to continue to report any difficulties the child experiences. A short cut through the questionnaire could remove this necessity. Keeping the questionnaire brief and strengthening the rationale would be a better safeguard to encouraging responses.

3.3.5 Feedback from validation visits

Follow-up visits were made to validate the data in four of the schools; two primary one special (BESD) and one secondary school. Schools were presented with summary data from the questionnaire indicating which parents had ticked the disability and or longstanding question, what needs they had identified and the impact of the child’s difficulty. In all three of the mainstream schools that took part in the validation exercise between three and five children were identified through the questionnaire who schools did not know about. For the BESD primary school all children were known to the school and all had statements of special educational need.

One might predict that as the questionnaire identified several children in mainstream schools whose disability was unknown to the school but revealed no new data to the special school that this would be reflected in their relative perceptions of how useful the exercise had been. In fact the special school felt it was worthwhile and that they embraced any opportunity to get the parents (and the children’s) points of view in order to make adjustments to provision. Among the three mainstream schools there were mixed perceptions. One of the primary schools felt that it was the parents who they knew well who on the whole completed the questionnaire, and in the second primary school the head felt that it had not revealed much that she did not know already given the effort that it involved. Schools made a number of suggestions for improving the questionnaire including; clearer explanation of why schools want this information; easier language in the questionnaire and translations; schools to add a covering letter of their own/ a shorter and simpler letter to accompany the form; distributing the form through tutor groups; and giving stickers to children who brought back the questionnaire.

3.3.6 Local authority feedback

Summary data was provided for four local authorities and representatives interviewed about its usefulness. There was positive feedback about using multiple indicators of disability recognizing that this lengthened the form but resulted in more information being passed to the local authority. The simpler the questions the easier it was felt to embed this data within existing systems.

In particular it was noted that the data had revealed additional children - those with medical needs for example that they would not identify unless they required particular support. One LA representative wanted autism to be identified separately; another wanted the identification of the child's *primary* difficulty/disability. Another wanted a question on what services the children received. This latter suggestion was made by a Strategic Manager for Disability Services who felt that the questionnaire was overly focused on schools. However he also identified the place for this questionnaire to act as a filter or screening device to identify children for follow-up.

The responses of parents from the BESD special school raised comment as the returns included a parent who did not indicate that their child had behavioural, emotional, or social difficulties despite the fact they were statemented. The representative of another LA asked how parents indicate that the reason for their child's needs may be because they are looked-after and have had a disrupted education. One LA officer also asked whether parents would know that they were being seen by a professional in school.

3.3.7 Systems of administration

The only LA representative to identify the preferred timing for this questionnaire suggested that the information could be collected as part of the admissions process.

A number of schools also mentioned collecting this data at admissions/ at reception. This may be because that is a time when they see all parents face-to-face. At this point however parents have not built a relationship with the school and could feel that it jeopardizes their child's place. Additionally, some disabilities may manifest themselves after arrival at the school.

Schools cited a number of ways to maximize return rates including using events such as parents evening or special school events when higher numbers of parents are likely to visit the school. This suggests that if there were to be a common census date, schools need some flexibility about when to collect the data within the year.

No clear evidence was found of differences in return rate between the administrative systems used on the project. Costings from a primary school indicated that some 4 hours was spent on compiling and distributing the questionnaires. Additionally the head-teacher spent 1.5 hours opening the questionnaires and recording responses. Other schools chose to cut these cost implications by asking the research team to carry them out. Only a limited number of parents chose to enter the data on-line.

Chapter 4: Collecting Data From Children

4.1 Methodology

Guidance on the use of five flexible tools was developed to collect data on pupil views of the barriers and supports to participation in school activities.
The tools were designed with a range of communication needs and ages in mind together with a concern to produce activities that could be accessed in a group, in pairs or individually. The aim in producing the guidelines was for schools to customise these and, if willing, provide vignette material to illustrate their use in practice for the next phase of the study. They included:

1. Online Child Questionnaire: This invited pupils to rate their experiences in school, in the classroom in different types of lesson, and around the school. It asked pupils what helps in those activities and what makes them more difficult. It also asked them if they have any disability or difficulty. A hard copy of this questionnaire was also made available.

2. Nominal Group Technique: This structured method for group "thought showering" encouraged contributions from everyone which through discussion were narrowed down. Every member of the group then ranked them through a voting system. Suggested questions around which to discuss: *What gets in the way to getting on well in school? What support would help to get around these barriers?*

3. Younger Child Interview Schedule. This was designed to be undertaken either individually or in a small group and explores children's favourite things about school as well as those aspects they don't like doing and asks what would make these activities easier.

4. Point to Point: This tool was based around counselling techniques and provided a concrete approach focusing on specific events that the child identifies as good or bad. With the help of a facilitator pupils represent these events with a mark on paper to locate when they felt best and when they felt worst. They then position themselves on a line between the best and worst indicating how they feel today. This activity provides a vehicle for exploring the barriers that contributed to the worst and the positive supports that contributed to the best experiences.

5. Good and Bad Things About School: This was based on the approach adopted by Talking Mats (Cameron & Murphy 2002) that uses a simple symbol array to enable young people to record the barriers/things that make school difficult and the things that help them in school by placing pictures of activities, people and places alongside a symbol that best represents their feeling.

Teachers in the nominated age groups (years R, 3 and 7) in each of the pilot 11 schools were invited to select and try out the use of one or two flexible tools with between four and six children (or more if they wished), including one or more children with a disability. Where possible a member of the research team joined in and observed the use of the flexible tool and noted the adaptations made. Where schools had their own similar tools in use observations were made of these. Validating observations were carried out of a small sample of children (where possible one or two children in each setting) to investigate the barriers and supports available to them in their daily school activities.

4.2 Findings

In total 10/11 schools used their chosen forms of the flexible tools, providing data from some 350 children. Over half the schools tried out more than one type of data collection material, in some cases as many as three. With the exception of special schools the tools were used to collect data from children both with and without a disability, reflecting schools' concerns to identify and remove barriers to learning for all children. Unsurprisingly schools varied in their commitment to these activities, in part dependent on the understanding of individual members of staff of the ethos of the project but also on pressures on them at the end of the school year. The success of the tools reflected to some degree the extent to which they prepared for the activity and to the experience of the person carrying them out.

Collecting data on the barriers children face and what supports them is not easy and there are gradations in the amount of information collected that depend on the level of communication and age of the child. It would seem relatively easy to gather superficial information on likes and dislikes with children in years R, 3 and 7. The challenge is to provide guidance to staff that will enable them to promote a deeper level of reflection and support children that experience difficulties in communicating in a way that does not constrain or pre-empt their responses. The following sections describe the findings from using each of the flexible tools.

4.2.1. Online (older child) questionnaire

This was used in two secondary schools, one as an online survey with 58 year 7 pupils and the other in hard form with 142 pupils. Additionally it was chosen to be used with year 3 pupils in the BESD School by reading aloud the questions and entering it on-line. In the latter case this was done as a 1:1 activity.

Of the online returns children spent between 5 and 29 minutes completing it with a mean of 14 minutes 45 seconds. In part these differences reflect the extent to which pupils answered all questions. Looking at the two questionnaires from mainstream schools, unsurprisingly qualitative questions were more likely to be skipped than those requiring a simple click to respond. Between 8-9% of children at most skipped a simple rating question, suggesting that these were a preferred format to the open questions. The exception to this was the disability question where rates of skipping increased; 15% of children skipped it in the online version and 13% in the hardcopy version. This tentatively suggests that children may have been unsure about this question. Of those who did answer, the majority responded no, but in both settings the number of children saying yes was unexpectedly high. In the online school 31% of children answered yes they had a disability or difficulty and of these over two thirds (70%) indicated it had gone on a long time. In the offline sample 19% said yes and around half of these children reported it had gone on a long time. The question must be asked whether the online version leads to over-reporting of difficulties or whether it provides a safe context in which to disclose difficulties. Notably it provided a forum for children to share anxieties and depression and to describe the bullying they experienced. Analysis suggested that in the online version at least, pupils who said yes to the Disability Question rarely skipped questions, and added written comments more often than other pupils – suggesting they were motivated to respond to this questionnaire – i.e. it was providing them with a voice.

Observations of sessions and feedback from staff suggested that the tool worked on two levels – as an opportunity for all children to express their views about different aspects of school life, and as a way of finding out whether children with disabilities face specific barriers or find particular things helpful. Staff felt that an on-line questionnaire would provide information about general and individual needs which they would otherwise be unlikely to access. It was seen as an appropriate tool for the majority of pupils, which could be supplemented with the other tools for pupils with communication difficulties or where more in-depth and personalised information was desirable.

The profile of the distribution of responses for individual questions was felt to be informative, both to show where and when pupils in general felt good or bad at school, and which pupils felt differently form the general trend. This profiling has the potential to pick up pupils whom are struggling with (aspects of) school life. The written comments often reveal barriers – such as the need to care for sick mother, struggling with feelings of sadness and trying to cope with being called names, which might not have emerged in other contexts.

Pupils were generally positive in their comments written at the end of the questionnaire, with a small number of students commenting that they appreciated being able to 'express their feelings anonymously'. While the questionnaire matched the reading ability of the majority of pupils, some found it difficult – either because of specific reading difficulties or because of difficulties with reading and/or speaking English. There were some criticisms and suggestions from students, mainly about the questionnaire being too long/boring/complicated. Although some questions produced focused responses, pupils tended to make similar comments to some of the questions and this may have contributed to comments that the questionnaire was repetitive. They generally liked the smiley faces used as a rating scale. Some pupils found the choice of six response options confusing. This range of options enabled easy visual comparison of responses patterns across questions and made it possible to identify when individuals' responses differed from the general trend.

Some verbal comments (overheard by the researcher) suggested that the title with the word 'disability' had strong negative connotations for some pupils which interfered with their capacity to engage with the activity.

4.2.2 Nominal group

This activity was carried out with two groups of yr 7 pupils in a secondary school both supported and observed by a member of the research team. Each session lasted 35 minutes. The first group addressed the question *What gets in the way of getting on in school?* The 'getting on' phrase clearly triggered responses referenced to social life in school. (The school were certain that the term 'barriers' would not be understood.) The top five responses included: *bunking off, stealing, blackmail, fighting timewasters, forgetting equipment*. For the second group a slightly different question was used: *What do you find difficult in school?* This group were more responsive and the question elicited more concern with teachers and teaching. They also did not feel that the term barriers would be useful in future. The top five responses included: *teachers not being fair, teachers not listening, bullying, teachers pick on you and long lessons*.

The school found it useful and an interesting activity and plan to adapt it to carry it out again. These were however not easy activities to carry out and the group needed careful handling to keep it focussed yet at the same time welcoming diverse views and discussion. This is not an activity for an inexperienced member of staff. One group was more responsive than the other in part due to the late arrival of a pupil from a difficult previous session. The groups revealed how difficult it can be to tap into academic aspects as the social world of schooling dominated discussion. In both groups the girls were less forthcoming than the boys with ideas. Children who experienced difficulty in reading needed support.

4.2.3 Younger children interview schedule

This was tested out in six settings (making it the most popular choice of activity) again as either an individual, paired or group activity, in primary and special school settings. Some schools used their own version; others added supportive materials such as photographs or symbols.

Schools are more familiar with the notion of interviewing and asking children questions. Some felt they would not find out more than they already knew possibly constraining their questioning and leading to a self fulfilling prophecy. Observations of the sessions suggested that the activity needed relatively little preparation or customisation for individual children but how the activity was introduced was important. Visual cues acted as a support but should not distract or constrain discussion. Responses can be pre-empted through concretising general questions for children with the most specific needs. In some instances schools needed support to enable them to probe and go beyond the superficial.

4.2.4 Point to point

This activity was used in just two settings, in a primary setting with pairs of year 3 children and as a group activity involving all children in a primary BESD school. In the latter case there was some overlap with the techniques used for the nominal group work. This was a new tool for schools and its potential was well recognised for those children with BESD providing new insights for teachers.

Observations and feedback from staff revealed that the importance of providing ground rules for the whole class to ensure honest responses and to dissuade children from copying one another. Clarity was needed on the scope of the responses, that this is about school and learning. There was a danger of placing too much emphasis on drawing – children might decide on things that are easy to draw or that they enjoyed drawing. At the same time this part of the activity serves to focus attention in a way that just talking would not do. The activity takes time and some staff did not get to the issue of barriers and supports.

4.2.5 Good and bad things about school

This was tried out in five schools including primary, special and secondary schools. Schools either used it individually (in the special school with children who were non-verbal) in pairs (in a primary school with reception aged children) or as a whole group activity (in the secondary school). This was a new method for many schools and teachers, with clear potential for those children with more limited communication. Inevitably eliciting their views is more time intensive, requires some creativity as well as good knowledge about the child. With older pupils it was particularly appropriate to stress the importance of being honest and to be careful of providing examples that could give a steer. The activity often needed individualising, both with respect to response option and stimulus material and therefore the activity took time to prepare. It is not always easy to find a visual representation for some “barriers” and supports. A staged approach to presentation had merits, introducing in turn: lessons, places, and people. Questions about dislike were more difficult to explore and staff were reluctant to ask about liking/disliking other members of staff. It was more difficult to elicit the views of some children (for example those with autism) where communication is typically embedded within a routine that leads to a particular outcome.

4.3 Relationship between the data from the flexible tools and parent survey

The most extensive information was collected through the online questionnaires, however because these were completed anonymously it was not easy to make comparisons with the information provided in the parents’ questionnaires. Of the 25 pupils in one secondary school who gave their names, five of their parents returned the questionnaire and commented that they had difficulties. The parents' categorisation in each case matched that of the child. None of the parents returned the questionnaire for the 12 pupils who gave their names in the other secondary school.

The flexible tools provided additional information to that given by parents particularly that collected through the anonymous online questionnaire where the majority of children answered most of the questions. This was particularly true for children who identified their disability/difficulty and who described in more detail the barriers and supports they encountered.

Chapter 5: The National Trial of the Parent Questionnaire

The National trial provided an opportunity to further address the questions set out in the development phase and to look more closely at the usefulness of the data in meeting the obligations of public authorities with respect to the DDA. As before data was collected through a survey of parents (described in this chapter) and subsequently matched with the National Pupil Database to determine its usefulness in monitoring the outcomes for disabled children (described in chapter 6). Data was also collected from children on their experiences of the barriers and supports in school (described in chapter 7).

5.1 Methodology

5.1.1 Development of questionnaire

A single version of the questionnaire was developed using the best elements from proforma 1 and 2 to identify 10 key questions (see appendix D for a copy of the questionnaire). A number of steps were taken to promote parental reflection on children's experiences of school and home. The starting point for the questionnaire was to consider if their child experienced difficulties in any aspect of schooling. Additional information was sought on limitations to participation in activities at home. Each question was examined to ensure there was a clear response option for *all* parents, including those whose children experienced no difficulties or disabilities. The strap line of the questionnaire was changed to provide a more inclusive heading "Making Schools Better Places for Learning". Information was provided about how the responses would be used and who would have access to it. Parents were asked to state if there was anybody they would not like to access the information.

The work in the development phase suggested retaining both disability and longstanding questions and continuing to use multiple indicators. Overall seven questions were closed and required a simple tick response. Parents were also given the opportunity to describe in their own words the difficulties their child experienced, the diagnosis given and the type of support required. As before the form provided an opportunity for parents to indicate if they wished to speak to a member of school staff, and to provide feedback on how they found the form.

A simple, easy to read version of the covering letter invited parents to contact the school if they required help in completing the form and informed about the ease of using the school specific electronic version.

5.1.2 Refinement of flexible tools

The development phase had indicated the importance of providing schools with more structure and guidance to using the materials. An overview of the tools was provided to enable school staff to identify the particular strengths of each tool while also giving indicators of the time spent on preparation as well as on carrying out the activity. In addition to this overall information the guidance on each tool was revisited to provide:

- a description of the activity;
- guidance on the role of the facilitator;
- a list of resources;
- a script for introducing the activity to pupils;
- example vignettes of how schools in the development phase had used/adapted the activity;
- sample teacher recording sheet.

More explicit changes were made to the online pupil questionnaire to improve the layout of the six response options and cut questions that were rather too subtle and which had seemed repetitive to pupils.

Recognizing the attractiveness of questionnaires for both pupils and teachers a short symbol questionnaire was devised which was available in hard form. This had 11 closed questions exploring good and bad things about school. It included a disability question and asked if the child experienced difficulties. Children were also asked what would make school better and whether they had enjoyed completing the questionnaire. As with all the other tools this was an activity that could be undertaken in a group or individually, with or without support.

5.1.3 Procedures for implementation

A cascade approach to recruitment was adopted with 10 local authorities from across the country taking part in the project and nominating between 5-10 schools. Schools were sent a pack with an open envelope for each parent containing the questionnaire, cover letter and return-to-school envelope. In addition schools were provided with reminder letters to be sent out one week after the questionnaires were dispatched with a closing date set for the end of that week. Translations were made in eight languages and sent to schools. Link researchers kept in contact with the schools during this two week period and the subsequent three weeks which had been set aside for carrying out the flexible tools.

Two meetings with schools were set up in each of the local authorities, the first to brief schools and the second to feedback data to the school and receive evaluations. Each school received three evaluation forms; one asking for feedback about the questionnaire process and what system of administration best met their needs; one asking for feedback and a rating on each of the flexible tools; and one that provided guidance on making use of the questionnaire data and invited feedback.

Twelve schools, representing those with high and low return rates were visited to make a more careful validation of the data collected.

In addition telephone interviews were carried out with local authority representatives to ask about the way in which the data added to what was already collected and what system of administration they favoured.

5.2 Results of the national trial

5.2.1 Description of sample

Ten local authorities nominated a total of 74 schools, all of which returned data from the child questionnaires. The profile of the 10 authorities with respect to provision for pupils with SEN varied with levels of statementing between 2.0% and 3.8%. The percentage of pupils with special educational needs in primary schools varied from a low of 14.0% to a high of 22% and in secondary schools from 11.5% to 23.4%. The proportion of pupils with statements placed in mainstream varied between 34% and 58%.

Authorities were located in Yorkshire and Humberside (1) West Midlands (5), Outer London (2) and South West (2). They included representatives from unitary authorities, areas of high social deprivation, an authority with a high level of private schooling and authorities with high levels of children with English as a second or additional language.

Table 5.1 Number of schools by phase in the national trial

	Primary	Secondary	Special	Grand Total
Schools	46	13	15	74

Table 5.2 Numbers of pupils by phase in the national trial

	Primary	Secondary	Special	Total
Pupils Total	4288	2347	359	6994

5.2.2 Return rates

A total of 6,994 questionnaires were distributed with an overall return rate of 42% Returns at an authority level varied between 34% (in the most deprived area) to 49% (the most affluent authority). These differences may be explained by levels of literacy and by the lower returns from parents whose first language is not English. Variation was greater at school level with return rates ranging from 10% to 80%. Surprisingly (given the results of the Development Phase) there was relatively little difference overall between primary and secondary schools. Secondary school returns ranged from 14% to 80% with an average return of 39%. Primary school return rates ranged from 10% to 78% with an average of 42% and special school returns ranged from 29 to 78% with an average of 46%.

Turning to pupil level data, 2895 questionnaires were completed, of these only 2% were completed online. The sample was virtually equally balanced across gender (50.3 % boys to 49.4% girls). Table 5.3 shows the distribution of returns across year group with a largely equal number across the 3 designated years.

Table 5.3 Returns by age and phase

Year group	Primary	Sec	Special	Grand Total
Reception	915		29	944 (33%)
year 4	896		51	947 (33%)
year 8		922	78	1000 (35%)
Blanks	2	1	1	4
Grand Total	1813	923	159	2895

5.3 Disability data

5.3.1 Parents' response to the disability questions

As with the development study three groups of parents were identified:

- those who replied yes to the disability question only;
- those who replied yes to the disability and longstanding question;
- and those who replied yes to the longstanding question only.

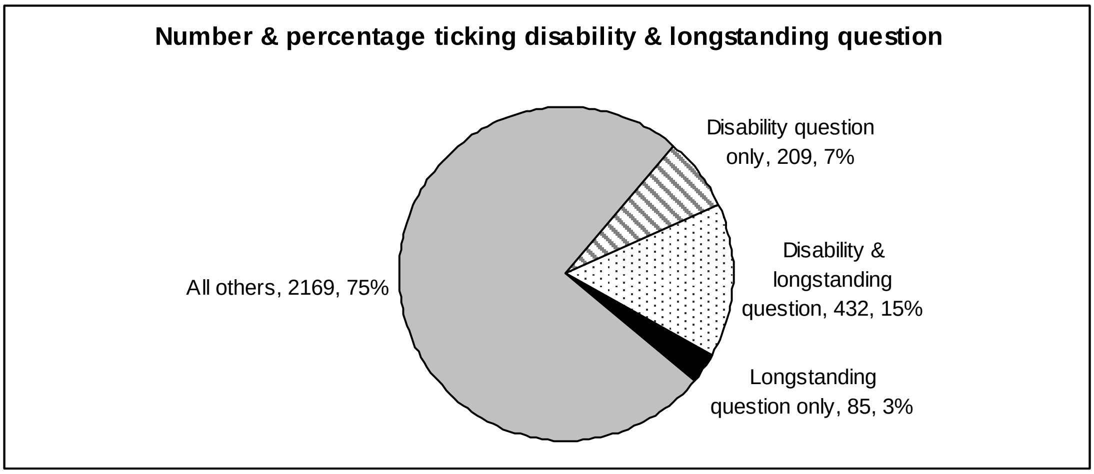
In total 640 parents (22% of the sample) ticked yes to the disability question, with fewer parents of children in the youngest age group; (271 children in year 8, 220 in year 4 & 148 children in year R with one blank return). This sample is refined further by looking only at those parents who *also* ticked the longstanding question and 431 of the 640 also ticked yes to the longstanding question, 15% of the entire sample. The third group, those who ticked yes to the longstanding question only, formed the smallest sub-group, just 3% of the total sample. Table 5.4 shows the percentage of children in each school type. This reveals similar percentages of children in mainstream primary and secondary schools across all three sub-groups. In special schools the majority of parents indicated their child had a disability which was longstanding but a proportion (13%) indicated they had a disability but not that it was longstanding. This was also a finding of the development phase, where the largest group of children with SEN were from BESD schools and highlights the importance of recognizing that although children may have a statement of SEN they are not necessarily seen as having a longstanding disability.

Table 5.4 Parents responses to the disability questions by phase

Phase	Numbers Ticking the Disability Question Only	Numbers Ticking the Longstanding Question Only	Numbers ticking the Disability & longstanding Question	Total returns
Primary	113 (6%)	54 (3%)	179 (10%)	1813
Secondary	75 (8%)	27 (3%)	122 (13%)	923
Special	21 (13%)	4 (3%)	131 (82%)	159
Total	209 (7%)	85 (3%)	432 (15%)	2895

The distribution of the groups is represented in Figure 1.

Figure 5.1: Proportion of parents ticking the disability and/or longstanding questions



5.3.2 Children who meet the DDA criteria

Looking more specifically at those who would potentially meet the DDA definition i.e. those parents who responded yes to disability, yes to longstanding, and noted some impact, 360 children who meet the criteria (52 parents describe their child as experiencing no difficulty and a further 20 parents left this question blank) . There are an additional 85 parents (shown in table 5.4) who ticked the longstanding box only and for 30 of these children the disability had an impact. Taking these two groups together forms a total of 390 children whose parents indicate they meet the DDA definition - 14% of the children whose parents returned the questionnaire.

Table 5.5: DDA recognized group by year as a percentage of returns from that year group.

Year group	Primary	Secondary	Special
Reception	6%		76%
year 4	11%		86%
year 8		12%	73%
Overall	9%	12%	78%

Schools varied in the proportion of children identified as meeting the DDA. Table 5.5 shows the average by school type. (A full list by school and response rate is shown in Appendix E. Again it reveals that not all parents of children in special schools see their child as having a disability and the lowest rate of 50% is based on returns from a school for children with moderate learning difficulties. Additionally it should be noted that 60% of pupils in primary schools with SEN and 54% of pupils with SEN in secondary schools did not meet the DDA criteria on the basis of parent judgements.)

In primary schools there were fewer children at reception than year 4 who meet the DDA definition but little difference in percentage of year 4 with year 8. Research suggests that the peak of statementing is year 4 (Daniels and Porter 2007) and this might account for the similarity in numbers. Equally some children may have grown out of medical conditions while for others disabilities become apparent in adolescence. In special schools also there is a peak in year 4. One of the implications of this data is the necessity for schools to update data collected at admissions.

Predictably more boys that girls met the DDA definition although this skewing was more apparent in some settings than others with the smallest differential being in primary schools where 84 of 158 children (53%) were boys. In secondary schools boys formed 62% of children who met the DDA definition and in special schools this proportion rose again to 71%.

5.3.4 Parents' description of their child's needs

Parents were asked to describe their child's additional needs against descriptors including the Code of Practice categories of SEN. Overall parents of 76% (295) of this DDA group indicated their child's SEN with some differences in the proportion across settings. 68% of parents (107) in primary settings, 59% (64) of parents in secondary settings and 100% (124) of parents in special schools indicated that their child had special educational needs.

In addition parents were asked to indicate if their child had medical or health needs or mental health needs. 147 (37%) of the DDA group had additional health needs and 64 (16%) had additional mental health needs, 21 of these children (5% of the DDA group) had both health and mental health needs. Of particular interest to the project are children who have medical and mental health needs but no SEN. There were 95 children in this group who will be considered in more detail later in the report.

Parents were asked if their child had an accident or trauma in the previous 5 years as some pupils may have an acquired disability that was not readily recognized (Rees

2007) In total 28 of the DDA sample (7%) were reported to have experienced an accident or trauma in the previous 5 years with no differences across phase. This compares to 2% in the remainder of the sample.

5.3.5 Seeing a professional

Parents were asked whether their child had seen a professional and what diagnosis had been made. In the DDA recognised group, the vast majority of parents, 94% (366/390) reported that they had seen a professional. This figure compares to 9% in the non-DDA recognized group who had seen a professional.

Table 5.6 Percentage of children to have seen a professional because of a disability by phase

DDA	Professional seen because of difficulty	Primary	Secondary	Special	Grand Total
Yes	Yes	144 (91%)	103 (95%)	119 (96%)	366 (94%)
Total		158	108	124	390

Turning to consider whether children had a diagnosis, 332 (85%) of the DDA parents indicated their child's diagnosis. In many cases there were multiple contributors to the child's disability. Overall one of the most common conditions was, unsurprisingly, asthma**.** 15% **(**59) of children in the DDA group had a diagnosis of asthma that led to their meeting the DDA criteria, including 12 children who had asthma as one of the conditions. Overall 4% of children in mainstream schools had asthma. The second largest group were children whose diagnosis included autism/Asperger/ASD with 14% of the 332 parents listing this. The difficulty of diagnosis is well represented by the parent who wrote

"It has varied. Speech and Language impairment, social communication difficulties and Asperger Syndrome have all been mentioned but no definitive label attributed."

5.3.6 Impact of the disability for the DDA children

Parents were asked whether their child experienced difficulties with classroom learning, relationships with peers or other school activities. They were also asked if the disability limited activities at home. Data in Table 5.7 suggests that children are more likely to experience difficulties in school than at home and these are most likely to affect classroom learning.

Table 5.7 Impact of the disability for the DDA children on aspects of their life

DDA	Primary	Secondary	Special	Overall percentage
Classroom Learning	62%	61%	95%	72%
Relationships with peers	47%	44%	84%	58%
Other school activities	52%	56%	85%	64%
Limits activities at home	35%	31%	77%	47%

Parents were asked what level of impact was experienced. For just under half the pupils, (47%) the impact was considered to be mild, occasionally interfering with everyday activities. For 110 children (28%) it was described as moderate with a regular limitation of everyday activities and for 69 (18%) the impact was described as frequent and significant. Finally for 7% of the sample the disability meant they were unable to take part in a number of activities.

Table 5.8 Level of impact experienced by the DDA group

Impact type	Primary	Secondary	Special	Grand Total
Mild	98 (62%)	68 (63%)	18 (15%)	184 (47%)
Moderate	41(26%)	26 (24%)	43 (35%)	110 (28%)
Severe	18 (11%)	13 (12%)	38 (31%)	69 (18%)
Profound	1 (>1%)	1(1%)	25 (20%)	27 (7%)
Total	158	108	124	390

5.3.7 Absence

Absence is one important reason why a child with a disability might do more poorly in school compared to other children. Looking specifically at the children who meet the DDA definition, 144 (37%) parents reported that the difficulty sometimes leads to an absence. This includes 59 (37%) of children in primary, 40 (73%) in secondary and 45 (36%) in special schools.

5.3.8 Children who meet the DDA criteria without SEN

Ninety-five children who meet the DDA definition were not identified by their parents as having SEN, 51 of whom were in primary schools and 44 in secondary schools. 85

(89%) of these children had health, medical or mental health needs. The majority of additional needs were health or medical with only 8 (8%) parents indicating their child had mental health needs. This is an important group of children. They are likely to include children whom schools are unaware have a disability.

Twenty-one (22%) of these parents stated that the difficulty limits activities at home and two thirds of these specifically mention asthma as one of the sources of the difficulty. Turning to look at school activities, the greatest impact is on “other school activities” rather than classroom learning per se which is consistent with a disability that does not result in SEN.

Table 5.9: Experiences of difficulty of the non-SEN group (N=95)

	Yes	**Sometimes**	**Total**
Classroom Learning	2 (2%)	17 (18%)	19 (20%)
Relationships with peers	1 (1%)	12 (13%)	13 (14%)
Other school activities	28 (29%)	8 (8%)	36 (38%)
Limits Activities at Home	21 (22%)	0	21 (22%)
Results in Absence from School	43 (45%)	-	43 (45%)

For the majority of this group (88%) parents described the impact as mild, but for nine the impact was moderate and for two severe. Seven parents indicated their child had NOT seen a professional including two parents who describe the impact of the disability as moderate. Both children are in secondary school and parents describe them as having mental health needs. These are children whose disability may not be recorded by the school and yet are vulnerable to under-achievement. A higher proportion of them (45%) are reported as absent from school on occasion suggesting that almost half are missing out on schooling because of their disability.

5.3.9 Support identified by parents as helpful

Almost three quarters (286) of parents of children who met the DDA criteria provided qualitative information on the support needs of their child, 116 parents of children in primary schools, 80 in secondary schools and 90 in special schools. The focus of the majority of parents was on *school* support and relatively few parents (15) made reference to outside support or support that they provided in the home.

Many parents made reference to the need for encouragement and support. Indeed if one type of support surfaced as particularly pertinent this is one: 49 (17%) parents explicitly made reference to the need for a particular attitude in supporting their child with key words including encouragement, reassurance, sympathetic, patient, listening, giving confidence. Parents wanted their child to be treated with understanding and staff who were able to give reassurance as well as encouragement to the child:

The main people who have helped T have been the ones who care for him as T. They have been the positive ones who see the real T not the annoying, naughty T. These have been people who have seen him throughout his life - family, friends, Sunday School.

Non intrusive support, so that he has a person he can 'run' to when he is likely to lose control. He responds well to encouragement, boosting his self esteem which otherwise is very low, therefore he needs support that provides this positive feedback.

When parents spoke about their child’s needs they were often clear about the type of responses that were helpful:

K finds it helpful to have regular routines - and if things are changing to have it explained beforehand. Also, anything that helps K to keep focussed and remind him of the job in hand helps. Any one-to-one that he has helps him considerably.

Educational Support

Given the importance of providing a positive emotional climate for the child it is perhaps unsurprising that access to people feature largely in parents responses and one of the main ways of providing this through one to one or individual support, small groups or classes with 64 (22%) parents referring specifically to this very visible aspect of provision. The links are clear in the following quote

Constant reassurance one to one assistance & guidance

For ten parents this was the only comment made in this section of the questionnaire and for one it was the reason for their child to receive a statement. In the main the provider of the one to one support was not identified but in other responses therapists featured with18 references from parents to speech therapy, and 24 parents referring to physiotherapy or occupational therapy.

The “what” of teaching appeared to be less of an issue but where parents did refer to the content of the learning, reading and writing were more likely to be mentioned as we can see from the table below 18 (6%) parents mentioned it.

Table 5.10 Parental views and the focus of learning

Games, PE sport	4
Reading, writing, literacy, spelling	18
social skills	6
Art, drawing, music	3
Speech communication and language skills	8
Fine, gross motor and co-ordination skills	4
Self-help skills, toileting washing dressing	6

Parents varied in their awareness of what “special” practices were employed but those who were able to describe them often clearly had knowledge and understanding of what was helpful:

The smaller groups and structured environment and makaton and picture exchange is helpful

Visual timetable; calm environment; consistency; understanding of sensory modulation dysfunction; self-calming strategies; confidence and self-esteem-building strategies

While some of the descriptions concerned strategies to facilitate new learning others were designed to help the child manage their disability in school:

J has a white card allowing him access to water and the toilet at any time

B has a passout card that when she needs to she may prepare to leave the school site at the end of the afternoon a little earlier than her peers to avoid being jostled, this has been most appreciated by B when her joints have been painful ..

Perhaps surprisingly only two parents mentioned the need for specialist teachers.

Seventeen parents commented on providing the right environment. A key point raised was the child's position in the class with 9 (3%) parents saying how important it was for their child to sit in the front of the class. Two other parents spoke of the need for a quiet or distraction free environment. One parent spoke of the importance of the temperature of the room:

My child suffers from eczema and as a result finds it difficult to learn if the heating arrangements in the classroom are too high. Extremes of heat and cold cause great irritation, and therefore, distract. Keeping the environment (room) at an even temperature.

Medical Support

Some parents wrote fairly exclusively about the medical needs of their child with 40 parents providing an outline of their child's medical support. Twenty five of these parents gave specific reference to asthmas/use of inhalers:

L carries her inhaler with her all the time. If she gets slightly out of breath or wheezy she takes a puff or two of the inhaler.

Here again however parents also respond to the importance of having support from those around them:

O needs to be taken seriously when she feels asthmatic or is having an allergic reaction, rather than as on one occasion she was told "there is nothing wrong with you, go back to class". She does not "play" on these difficulties ….

What I don't find helpful is a head teacher sending a letter to us about bad attendance when she is ill and advised by a doctor not to attend school.

Despite the emphasis placed on the social aspects of schooling and providing a positive emotional climate that, few parents (9) made explicit reference to the child's peers or friends. Instead the focus was on the adults to provide support and encouragement.

Finally there were 11 responses from parents stating in different ways that they have not received any support and a further three responses about what they themselves provide at home:

Any help as a parent which we can give is important to him e.g. explaining carefully and slowly anything which is giving him anxiety or upsetting his routines (reassure him at all times) Raised voices only upset any situation.

He has had no support at all. The people we have seen don't seem interested at anything I say. Apart from a paediatrician who diagnosed him with ADHD and I have seen two people since who have been no help at all

These final comments give a picture of the mixed expectations that parents have of available provision as well as the difficulty with which some access help.

5.4 Checking for false negatives

In order to check whether any children had been falsely excluded, data from 209 children who did not meet the DDA definition because their parents had not ticked the longstanding question was examined. Eighty- nine had seen a professional and of this subgroup 49 reported an impact. This suggested that potentially there were children in this group who had a significant difficulty although their parents did not describe it as longstanding. Diagnoses were therefore examined for each child with descriptors including speech and language difficulties or delay (3), asthma (11) investigations of ADHD (2), cerebral palsy (1), and moderate learning difficulties (1). All of these might not be seen as longstanding. However the list also includes one parent of a child with a cancer and 5 with ASD, both diagnoses that would normally be identified as a longstanding disability. It would appear that six of the “disability only” group were indeed false negatives. This constitutes .002% of the non DDA sample.

5.5 Validating data

Relevant data was received from 25 schools (17 primaries, 4 secondary and 4 specials) who returned their own analysis on the results of the parent questionnaire using a nudge sheet to guide them. Three of the four secondary schools indicated that there was at least one child whose parent had ticked the disability and longstanding question whose needs were previous unknown to them. In the 17 primary schools, six of them indicated that this was also true for them. As all children in special schools were statemented all pupils were known to the school and one of the 2 schools commented on the surprising accuracy of the parent responses.

School visits

Visits were made to four special, four primary and four secondary schools across seven local authorities. All eight mainstream schools indicated that there were pupils who were unknown to them whose parents had indicated that they had a disability, and some of these would meet the DDA definition. This mirrored the findings of the development phase.

Schools also suggested that parents had under reported the impact of the disability. In one secondary schools returns from four parents did not identify their child's disability (which in the schools view reflected a desire to avoid labelling their child or being seen by a professional). In the MLD special schools returns from eight parents did not indicated that the disability was longstanding and in the SLD school there was also some under-rating in the schools view of the impact of the child's difficulty.

5.6 Stakeholder feedback

Parent feedback

Six percent of parents (167) added comments in the box asking about improvements to the form (a lower percentage than the developmental phase), almost equally divided between parents with and without a child with a disability. The number making comments about particular issues was often very small and sometimes from just one parent, making it difficult to know how much weight to place on individual comments. Parents also took the opportunity to give more information about their child's difficulties, to praise or criticise their school or to offer suggestions for how to improve provision for pupils with difficulties. The range of types of comments is illustrated in the table 5.11.

There were 17 comments expressing approval, which ranged from general approval of the form and/or the project (8) to positive comments about coverage (6) and clarity (5), for example

The form is fine. Easy to read, clear and precise and more importantly, not too long.

The form covers everything and gives opportunity for us to advise you of her problems.

Table 5.11 Parental feedback on the questionnaire

	Disability Yes	Disability No/Blank	Total
Comments about form			
“No comments’	2	2	4
Approval – no problems	8	9	17
Problems	27	17	44
Suggestions	20	33	54
Total form comments	60	58	119
Other Comments	48	47	94
Total number of parents using this box to comment	81	86	167

Forty four (26% of respondents) parents identified problems, which were concerned with the format, the categories used and whether these included their child, the clarity of the wording, the purpose of collecting the data and concerns about providing personal details. Fifty-four (32%) parents suggested improvements to the format, wording and categories, as well as suggesting additional questions and areas where they would have appreciated the opportunity/space to provide more information.

Problems with the format were concerned with a range of aspects of the structure and presentation of the form, with no particular aspect dominating. This included enabling parents who considered that their children were not disabled to “fast-track” through to the end (only 2 comments). Other parents who were at the beginning of a process towards diagnosis wanted to be able to add a comment about difficulties not yet diagnosed. Also of concern were the limitations of yes/no questions (four comments), the uncertainty of how often was ‘sometimes` (1) and how to fill in the form about more than one difficulty (1). Several comments suggested ways to make the form more accessible (larger print, coloured paper, other languages, simpler, more interesting, less remote – all single comments). However, although these comments offered useful suggestions about how to improve individual questions and the overall structure, they did not produce a clear message about difficulties with any one aspects of the form.

Problems with categories and suggestions to amend them highlighted individual cases of uncertainty over meeting the DDA definition and the relevance of this form for particular children. Some of these referred to difficulties which might be considered borderline (e.g. food allergies, dyspraxia, and asthma) and others referred to past/enduring conditions not currently causing difficulties, as well as specific health/medical conditions not explicitly included in the lists on the form. The difficulty in constructing a list of categories that fits all cases is highlighted by the contradictory calls for categories to be ‘more specific’ and ‘more flexible’.

There were some parents (10) who had problems with the whole research project or with providing personal details (5) These included two comments that this information was already available in school (for children with disabilities/difficulties) two that the form represented unnecessary paperwork, four suggested that more detailed information would be required to improve provision.

Finally, parents made suggestions for additional questions. These were concerned with parents’ satisfaction with support provided, opportunities to record specific conditions or illnesses, or to raise other school issues. Three parents also suggested asking about pupils’ experience of disability within the family as this could also affect non-disabled siblings.

School feedback

Feedback from schools on the parents’ questionnaire was collected during the regional evaluation meeting and 12 validation visits. Despite the tight deadline schools gave some positive feedback on the experience:

‘First time we have done questionnaire on disability but would like to continue this with every Year 4 intake every year.’

Thought this was a very daunting task at first, but the reality was fine.’

Easy to fill in and didn’t require them [teachers] to look anything up.

Three visited schools commented with surprise on their high return rates but some noted some bias in who replied. For example one school noted that apart from children experiencing difficulties it was the “express” stream, children who were doing well, whose parents had responded. At the same time one school were disappointed that only one in three of parents of pupils registered as having SEN returned the questionnaire, and noted low return rates from parents for whom English was a second language despite sending out translations, and from parents who may have experienced difficulties reading/completing the form.

Schools used a variety of strategies to make an impact with parents when the questionnaire was sent out, for example explaining it to children; mentioning the questionnaire in the school newsletter and during morning assemblies; inviting parents in to a coffee morning; asking a home-school link worker to liaise with parents. A number of schools reported that they offered support for parents to complete the form, but that this was not taken up. Schools also used a range of strategies for ‘chasing’ parents: reminder letters with children (provided by the project team); reminding parents in a newsletter and during an assembly; reminding children (to remind parents); and offering an inducement to children whose parents complied (additional ‘house’ points).

Schools described how the process had impacted on their activities and raised their (teachers’) awareness. For example one school used the information in the questionnaire to help write the school’s Disability Discrimination Act Action Plan. Another was prompted to arrange a lunch for pupils with physical impairments, and to ask their views about access arrangements at the school. Across all school types staff were particularly interested to read about parents’ views of the impact of their children’s difficulties/disabilities and special school staff commented on the importance of knowing about the discrepancy between parents’ and staff views.

Local authority feedback

Most local authority staff strongly welcomed the availability of the data – the parental questionnaire data provided a richer picture than the data currently collected.
One representative emphasised that a breakdown of such information for *all* schools (including post-16) and for *all* parents would be very illuminating for the local authority (with a preference for electronic data being entered at school level). Another anticipated that the data would be very useful for strategic planning. If for example a substantial proportion of disabled pupils are on the autistic spectrum then the

provision of distraction-free learning environments may be viewed as a higher priority than funding ramps in every school. It was underlined that schools tend to find it difficult to make reasonable adjustments without full data returns although they also recognized of the importance of this sort of data for schools for access planning and general school improvement planning.

Local authorities differed with regard to preferred future arrangements; whether the local authority or school should take responsibility for collecting disability data. Some representatives anticipated that local authority staff would take this on, while others indicated that schools would take a lead but would need training/support from the local authority (backed up by guidance/support materials from the DCSF). Cost estimates varied greatly between local authorities – from no costs, to funding for two or three full-time staff over 6 months (when training for schools was included).

One representative felt that this data should be collected at school entry (as this would mesh in with current data collection arrangements). However another emphasised that children’s needs change over time and a one-off data collection procedure (e.g. at school entry) would not suffice. A further suggestion was for a data collection system linked to admission and transition between schools and between Key Stages.

Despite the amalgamation of Children’s Services there remained some concern about a lack of sharing of information at the ground level between professionals working with families.

Chapter 6: Monitoring Using the National Pupil Database

6.1 Matching the data to the National Pupil Database

The survey data were matched to the National Pupil Database (NPD) with an overall match of 80%. Higher rates were achieved for year 4 and year 8 with over 90% matched but with a lower proportion (50%) for reception age pupils. This may reflect the (January) timing of the match process. The equal split in gender in the survey data was retained in the matched data and figures for Free School Meals are comparable with national averages (13.3% of pupils in primary schools, 14% in secondary and 31% in special schools) (DCFS 2007). There was a slightly higher return rate of 10% from parents of children who fall under the category Asian or British Asian compared to a national average of 8.4%, and slightly lower returns from parents of children described by the School Census data as white British/Irish/Any other white, with survey returns of 78% compared to a national average of 80.7% (DCFS 2007). These slight differences reflect regional variations in the sampling. More details of the ethnic breakdown are in Appendix F.

Disability and Special Educational Needs

A good proportion of pupils identified through the DDA criteria were matched across the three school phases as Table 6.1 shows.

Table 6.1 Match of DDA pupils to the National Pupil Database

Phase	Number of DDA pupils identified in survey	Number matched to NPD	% matched to NPD
Primary	158	127	80%
Sec	108	103	95%
Special	124	112	90%
Total	390	342	88%

Table 6.2 highlights the number of pupils by phase that the survey identifies as DDA showing whether they have been identified as SEN. It revealed that there were 35 children in primary and 35 in secondary who met the DDA definition but who were *not* recorded as SEN as their disability arises from health or mental health needs. In addition to these there were 31 children in primary and 9 in secondary schools who met the DDA requirements whose parents considered them to have needs consistent

with a SEN but who were *not* recorded as such on the School Census data. It also reveals that there is a small group of children, three in primary and eight in secondary who are entered in School Census as having SEN but whose parents did not indicate this on the forms. Significantly none of these are statemented pupils, ten are on school action and one on school action plus stage of the Code of Practice.

Table 6.2 Identification of SEN in the pupils who meet the DDA criteria

Phase	DDA + No SEN in School Census + No SEN Survey	DDA + SEN in School Census + SEN Survey	DDA + SEN in Survey only	DDA + SEN in School Census only	Total DDA
Primary	35	58	31	3	127
Secondary	35	51	9	8	103
Special		112			112

Given that the aim of the survey was to collect parental views, the SEN survey only group are collapsed with those recorded in the School Census data but singled out for further analysis in Section 6.5

6.2 Pupil attainment analysis

A key issue for this report is the scrutiny of attainment of pupils who meet the DDA criteria and to compare their performance with their peers. It is particularly important to track the progress of those children who meet the DDA criteria but are not identified by schools as having SEN. The analysis in this section places the pupils into four groups distinguishing children on the basis of whether or not they meet the DDA criteria and whether or not they have SEN:

- DDA and no SEN
- DDA + SEN
- Not DDA + SEN
- Not DDA + No SEN

There are several approaches to considering pupil performance. Attainment can be compared at each key stage in absolute terms. Alternatively a more refined approach is to examine the progress children make between key stages with two methodologies for making this value added analysis. One is purely a prediction based on prior attainment and the other adjusts the predicted scores/levels of the children to take account of contextual factors. For special schools and those children in mainstream whose attainments are described as below level 1 of the National Curriculum measuring performance is more problematic. The data file containing P Scale information, at the time of writing this report, does not include pupil level identifiers to match the survey pupil level data.

A second limitation for the purpose of this study was that only 50% of reception pupils were successfully matched to School Census data. Furthermore of the 82 pupils with Foundation Stage Profile data records (a 1 in 10 survey), only two records concerned pupils currently in year R and therefore little can be said about the year R pupils at this point in time.

The year 4 and year 8 mainstream and special school cohorts were however matched to their Key Stage1 and where appropriate KS2 data records. Counts of pupils from the survey successfully matched to attainment by phase are shown in Table 6.3.

Table 6.3 Pupils matched by key stage

	Primary Yr4 pupils	Secondary Yr8 pupils	Special school pupils	Total
KS1	812	845 (also matched to KS2)	106	1763
KS2		847	62	909

KS1 attainment for Year 4 cohort in primary schools

This section refers to an analysis of attainment at KS1 of the year 4 cohort in primary schools in terms of the level achieved in writing, reading, maths & science. The pupils were allocated to the four groups according to DDA and SEN criteria.

Table 6.4 Percentage of KS1 pupils identified by disability and SEN

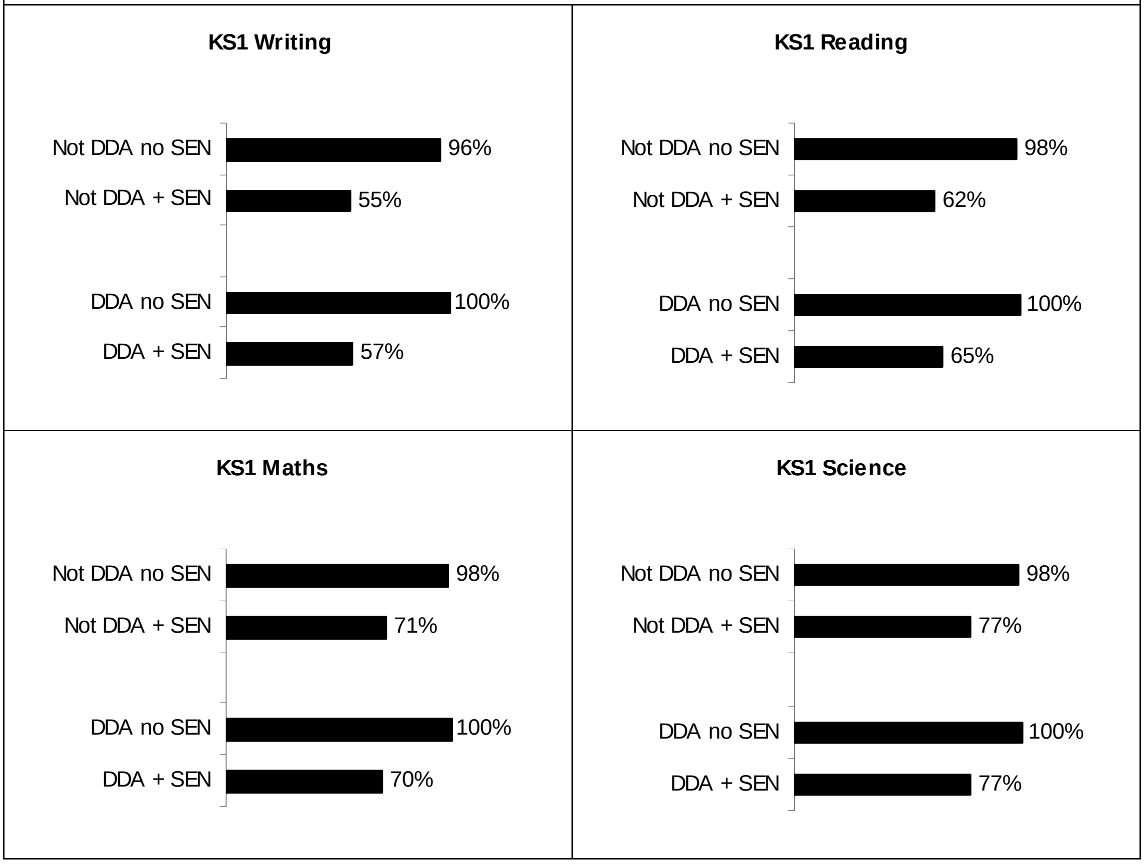
KS1 Year 4 Primary pupils	DDA + SEN	DDA no SEN	Not DDA + SEN	Not DDA no SEN	Total
number of pupils	69	23	150	570	812
% of pupils	8%	3%	18%	70%	100%

Noting the small number of pupils (23) in the group DDA + no SEN, the charts below show that they were doing as well as (or better than) other children with 100% achieving level 2 or above in reading, writing, maths and science. Looking at children with SEN, a considerably smaller percentage of pupils (whether or not identified through the DDA criteria) achieved level 2 at KS1 in all four subjects. The difference is more marked for writing & reading.

Figure 6.1 KS1 Pupils achieving level 2 or above in core areas of the curriculum

KS1 Curriculum Areas by DDA & SEN

Percentages achieving level 2 or above (expected level) in KS1



KS2 attainment for Year 8 cohort in secondary schools

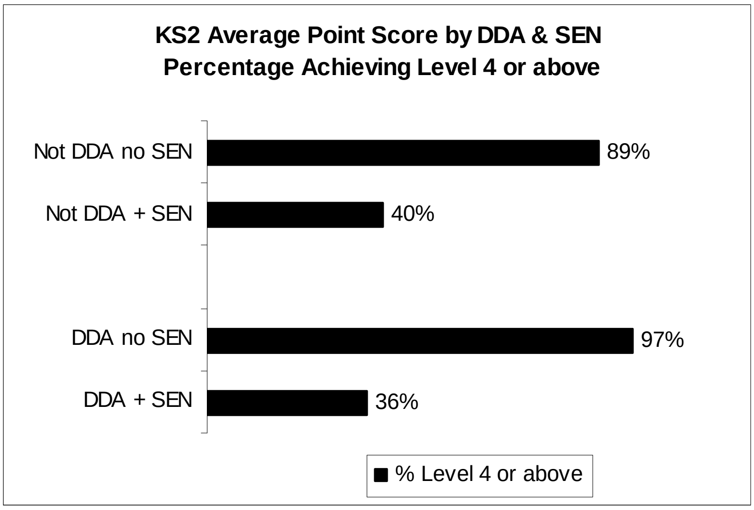
This section refers to an analysis of the year 8 cohort on prior attainment at KS2 in terms of the average points score achieved. The pupils were again allocated to four groups according to DDA and SEN criterion and the numbers in each group are presented in Table 6.5.

Table 6.5 Percentage of KS2 pupils identified by disability and SEN

KS2 Year 8 Secondary pupils	DDA + SEN	DDA no SEN	Not DDA + SEN	Not DDA no SEN	Total
number of pupils	66	33	142	606	847
% of pupils	8%	4%	17%	72%	100%

As with the KS1 analysis, we have analysed performance for KS2 separately for the target groups (as defined by SEN and DDA criteria). Figure 6.2 shows that the DDA no SEN group (although small numbers of just 33 pupils) perform as well or better on average as the Not DDA no SEN group, with 97% achieving level 4 or above as an average point score at KS2 compared with 89%. As with the KS1 analysis, a markedly lower percentage of children with SEN (whether or not identified through the DDA criteria) achieved this expected level.

Figure 6.2 KS2 pupils achieving level 4 or above- Average Point Score by Disability and SEN



6.3 Value added comparisons

For the year 8 pupils in secondary schools matched Key Stage 1 attainment was available enabling an analysis of the (value added) progress made by these pupils. The KS2 results achieved in Year 6 was compared against a pupil's starting point (or prior attainment), the results of Key Stage 1 assessments in Year 2. Pupils are analysed in the same four groups as previously, according to whether or not they meet the DDA criteria and have SEN with small numbers in the DDA no SEN group - 33 pupils. Level 4 is taken as the expected achievement at KS2, equivalent to 27 points. Level 3 is 21 points and level 5 is 33 points.

Table 6.6 shows that the predicted scores for the DDA no SEN group range from 25 points to 33, mostly higher than level 4. This compares to the larger range of scores predicted for the DDA and SEN group (from 17 points to 33) with only 35% of such pupils with a predicted score of level 4 or above. Figure 6.3 shows that this predicted clustering is reflected in the actual scores. i.e. DDA no SEN pupils centred in top right hand side of chart & DDA plus SEN in the bottom left hand side.

Table 6.6 Value added predicted scores summary by disability and SEN

	No. of pupils in Value Added analysis	Predicted KS2 Average Points Score		
		Minimum	Maximum	% of pupils level 4 or above (27 points or more)
DDA no SEN	33	25	33	97%
DDA + SEN	65	17	33	35%

Figure 6.3 reveals that the pupils who meet the DDA criteria who have SEN are performing less well as a group in VA terms than those pupils with no SEN. Indeed, as shown in Table 6.7, all of the other 3 groups performance in VA terms is similar and better than the group of pupils with SEN who meet the DDA criteria. Naturally there are exceptions and some pupils within all four groups perform particularly well and others below expectations.

Figure 6.3 Value added data for year 8 pupils with a disability

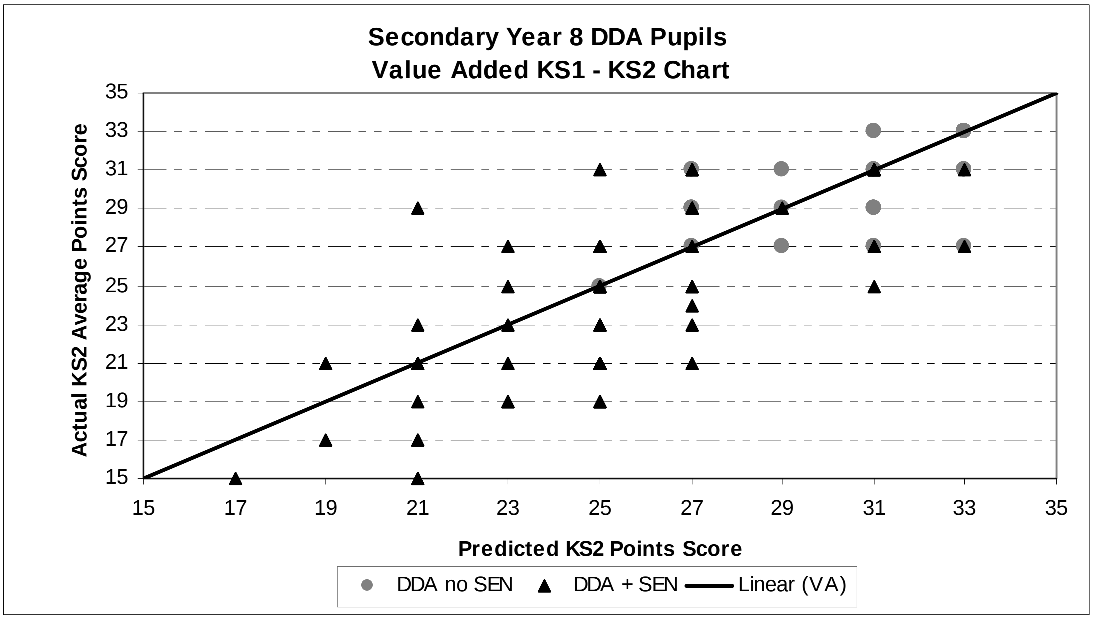


Table 6.7 Value added summary by disability and SEN

	Total matched to KS1 – KS2 results	No. of pupils more than 2 points below predicted score	% of pupils more than 2 points below predicted score
DDA no SEN	33	3	9%
DDA + SEN	65	23	36%
Not DDA no SEN	605	73	12%
Not DDA + SEN	142	26	18%

6.4 Contextual value added analysis

Given the potential contribution of gender and the predictor of eligibility for free school means as well as SEN it was considered important to also look at Contextual Value Added (CVA) measures. This methodology calculates the progress from Key Stage 1 to Key Stage 2 after adjustments are made to take account of a number of external factors including; gender, special educational needs, ethnicity, FSM, first language, age, movement between schools, and family circumstances. CVA could therefore be seen as a more useful tool in assessing the attainment of pupils with and without SEN who meet the DDA criteria. There are more points plotted in this analysis because fine grading of the average points score is used therefore the pupils are more scattered. Figure 6.4 shows two distinct clusters – with the DDA no SEN pupils having generally higher scores both projected and achieved.

Figure 6.4 Contextual value added data for year 8 pupils with a disability

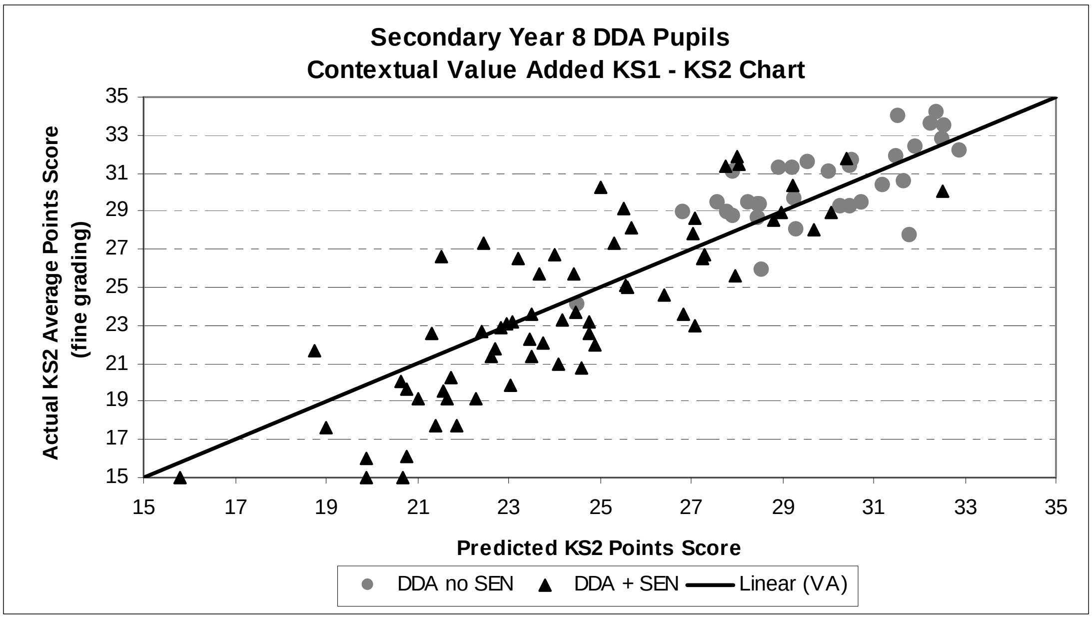
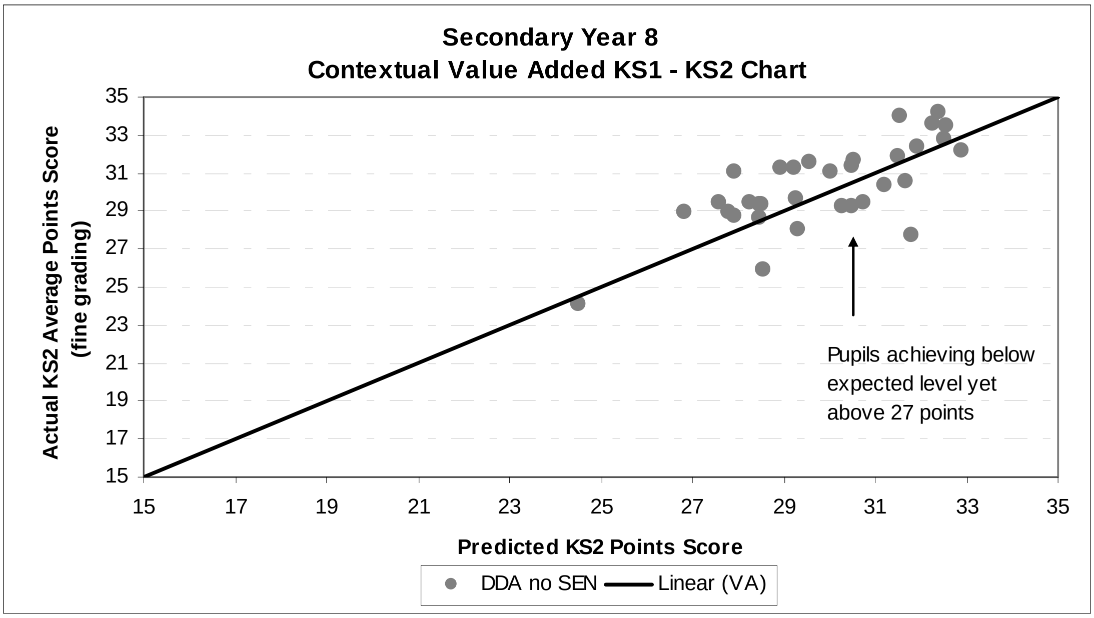


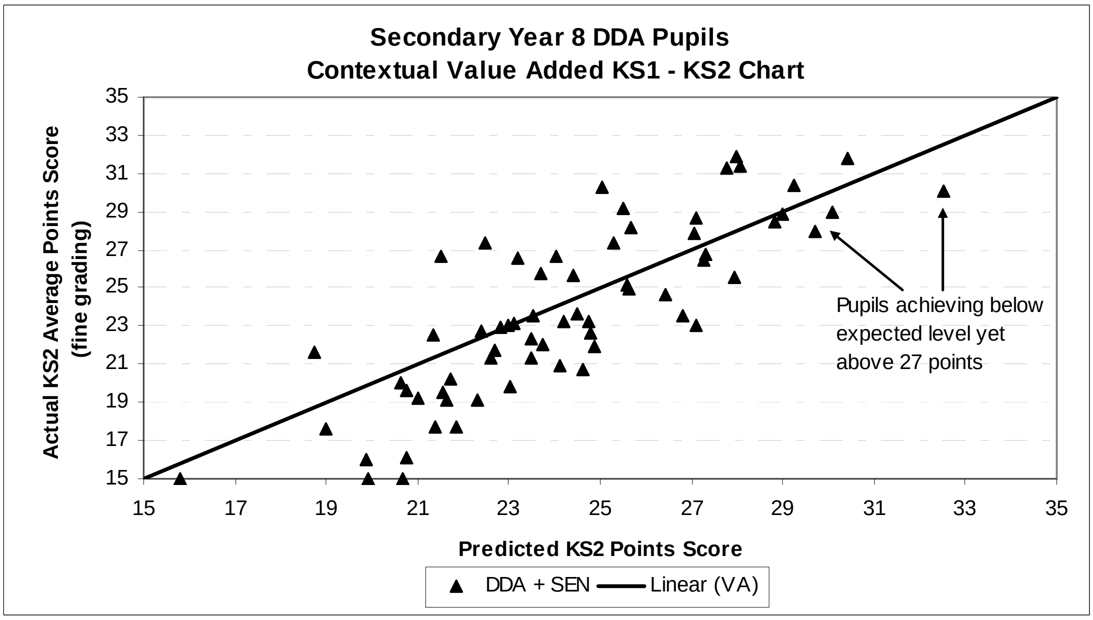
Figure 6.5 shows as expected that those children without SEN who meet the DDA requirement generally make progress as expected but there are a group of children who do not do as well as projected. These are largely children who are performing above level 4 (27 points) and for whom schools may therefore be satisfied with their attainment and whose under-achievement may go unnoticed.

Figure 6.5 Contextual value added data for year 8 pupils with a disability and no SEN



A similar analysis can be made for those children with SEN and Figure 6.6 indicates that many are making less than expected progress including some whose performance is above level 4 and whose under-achievement may again go unnoticed.

Figure 6.6 Contextual value added data for year 8 pupils with a disability and SEN



6.5 Monitoring the performance of vulnerable groups

Given that the impact of a disability will vary with the availability of environmental supports it is important for schools and local authorities to be able to look in detail at the performance of individuals and groups who are vulnerable to under-achievement. This section provides examples of the types of analysis that could be undertaken. Using value added data on this sample at KS2, a group of the outliers who met the DDA criteria were investigated further taking children who were performing better than expected and also those who were under-achieving .These are briefly described in Table 6.8 and include children with and without SEN.

Table 6.8 Information on the pupils who achieved well above or below the expected

Meeting DDA criteria	SEN	KS2 predicted score	KS2 actual score	VA score	Further information
Yes	yes	21	15	- 6	5 pupils all with School Census SEN statement & primary needs as ASD (*2), MLD, SPLD, SLD.
Yes	yes	21	29	+8	Pupil with School Census School Action and medical diagnosis.
Yes	no	27	31	+4	2 pupils: pupil with asthma having a mild impact & another with mental health needs & moderate impact. Neither recorded as SEN in School Census or survey
Yes	no	33	27	-6	Pupil with egg allergy, IBS, Asthma & mild impact

This type of investigation is an example of an analysis that could be undertaken at school level to track the progress of pupils in VA terms, with a particular focus on those displaying particularly poor and good progress. Although no particular profile is identified in this data the information would enable schools and Local Authorities to identify groups of children with a common need who are under-performing and enable them to re-consider and refine formulations for provision

Another vulnerable group are those identified by the parent survey as having special educational needs which were not recorded in School Census as SEN pupils. Data from these children are analysed as a group, providing a national picture of their performance. Table 6.9 shows the numbers available with matched KS1 – KS2 VA data and suggests that the following charts should be analysed cautiously.

Table 6.9 Sample of year 8 pupils identified by parents only as having SEN

Pupils identified by survey but not identified as SEN in School Census	Total in survey	Total matched to KS1 – KS2 results
DDA , yes SEN survey only	9	9
Not DDA, yes SEN survey only	25	22
Total	69	65

Those children who meet the DDA criteria and for whom parents expressed a concern for their educational needs are depicted by a cross in Figure 6.7 and are largely doing better than projected but not in all cases; three of the nine such pupils have achieved below the expected score, 2 of which are more than 2 points lower. The picture is similar for those children who do not meet the DDA criteria but have been identified as SEN in the survey and are shown by a diamond shape in Figure 6.7. The majority of this group perform as expected or better however the performance of 9 of the 22 pupils who perform below the predicted scores requires attention; particularly the three pupils who fall more than 2 points below.

Figure 6.7 Value added data for year 8 pupils identified by parents only to have SEN

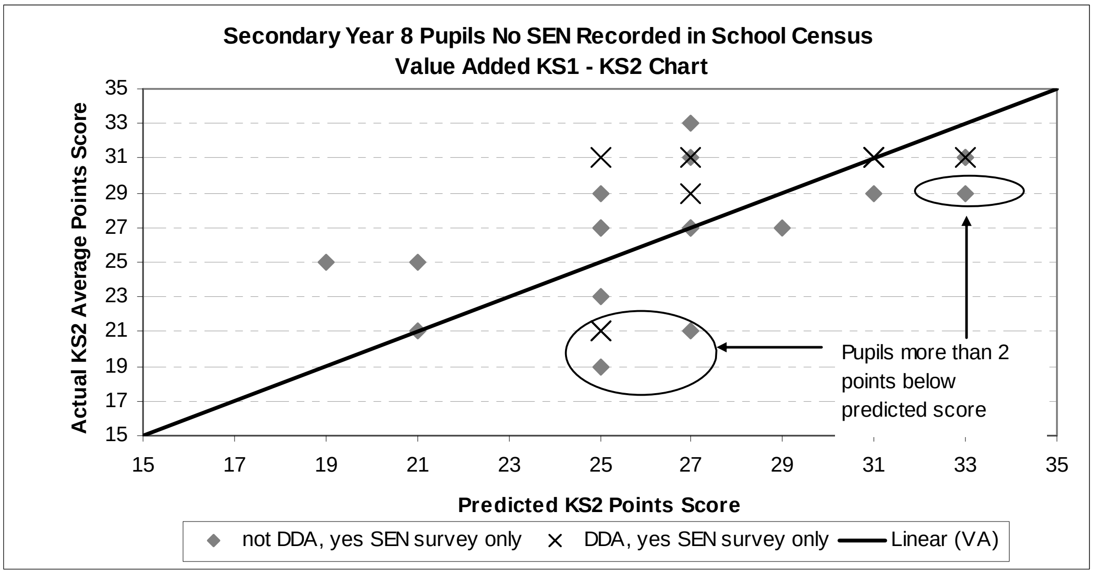


Table 6.10 Value added summary of pupils identified by parents only to have SEN

Pupils identified by survey but not identified as SEN in School Census	Total matched to KS1 – KS2 results	No. of pupils more than 2 points below predicted score
DDA , yes SEN survey only	9	2
Not DDA, yes SEN survey only	22	3

Data in Table 6.11 and Figure 6.8 also suggests that on the whole the group identified by their parents only are doing better than those children who are formally recorded as having SEN. This would be expected given that schools have yet to recognize their special educational needs.

Figure 6.8 Value added data for year 8 pupils with a disability and SEN

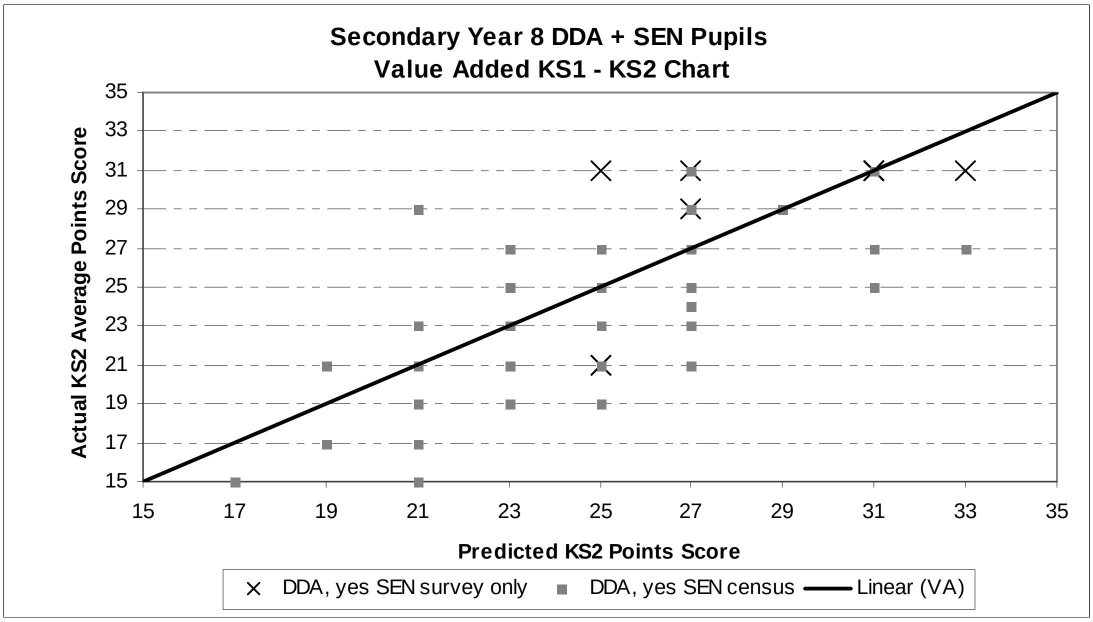


Table 6.11 Value added summary of pupils identified as having SEN any source

Pupils identified by survey but not identified as SEN in School Census	Total matched to KS1 – KS2 results	No. of pupils more than 2 points below predicted score
DDA , yes SEN survey only	9	2
DDA, yes SEN census	56	21

Again it is worth noting the profile of outliers and some pupils with SEN exceed expectations. One pupil who was identified as SEN in School Census only, with a complex medical diagnosis had a predicted score of 21 and achieved an average point score of 29. Another pupil with dyslexia who was identified with SEN in the survey only achieved 31 points, some 6 points higher than the predicted score.

Although the numbers of children identified may be small, arguably it is important for schools to be able to identify these children and to investigate the barriers they are encountering and the supports that could be put in place. The school level example in Figure 6.9 suggests that the attainments of those children who meet the DDA and have no SEN are at the predicted level or higher but those children who meet the DDA and who have a SEN are making less progress than expected compared with other groups (see Table 6.19). Given that contextual data of this type corrects for the effect of SEN the school might look more closely at these children to explore why this is the case. This is a school that recently had a good Ofsted.

Figure 6.9 Contextual value added data for year 8 pupils by disability and SEN

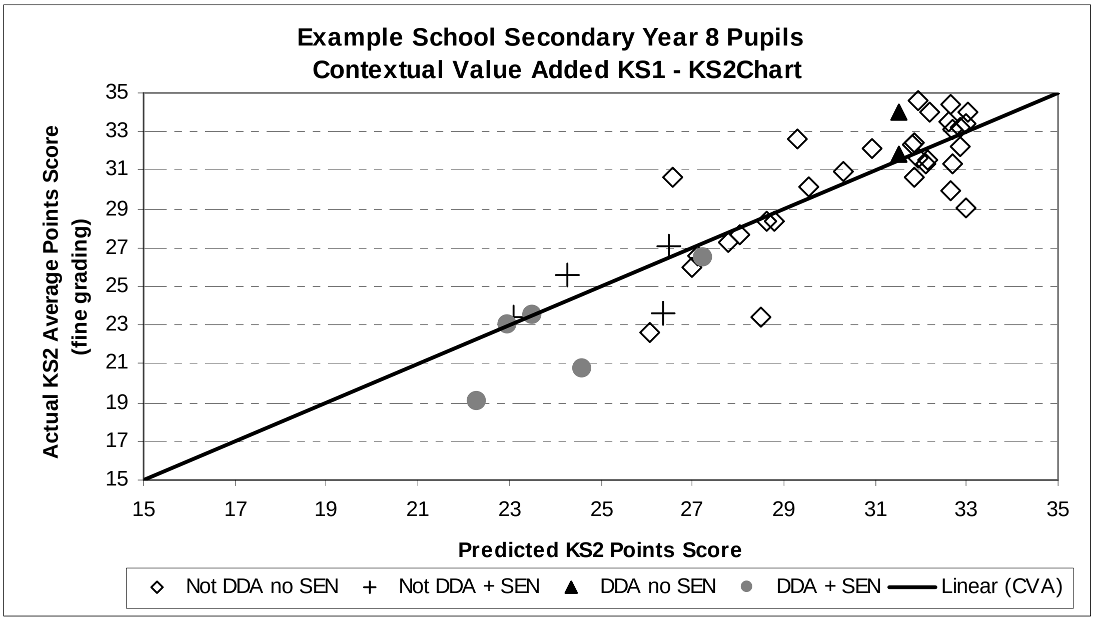


Table 6.12 Value added summary of pupils at example school

Example school	Total matched to KS1 – KS2 results	No. of pupils more than 2 points below predicted score
Not DDA no SEN	31	3
Not DDA + SEN	4	1
DDA no SEN	2	0
DDA + SEN	5	2

A second school example is in Appendix G.

6.6 Special school data

It has already been noted that, at the time of writing the report, it was not possible to provide matched P level data with which to consider the attainment of pupils who are performing below level 1 of the National Curriculum. Arguably given the multiplicity of identified needs it is much harder to be confident in making predictions of progress in this pupil group. It is however possible to track pupils in special schools and data in

Table 6.13 reveals that the majority are performing well below the expected level (27 points). The majority have scores of 15 points or below, that is below the level assessed by the test, one pupil however is performing at level 4 .

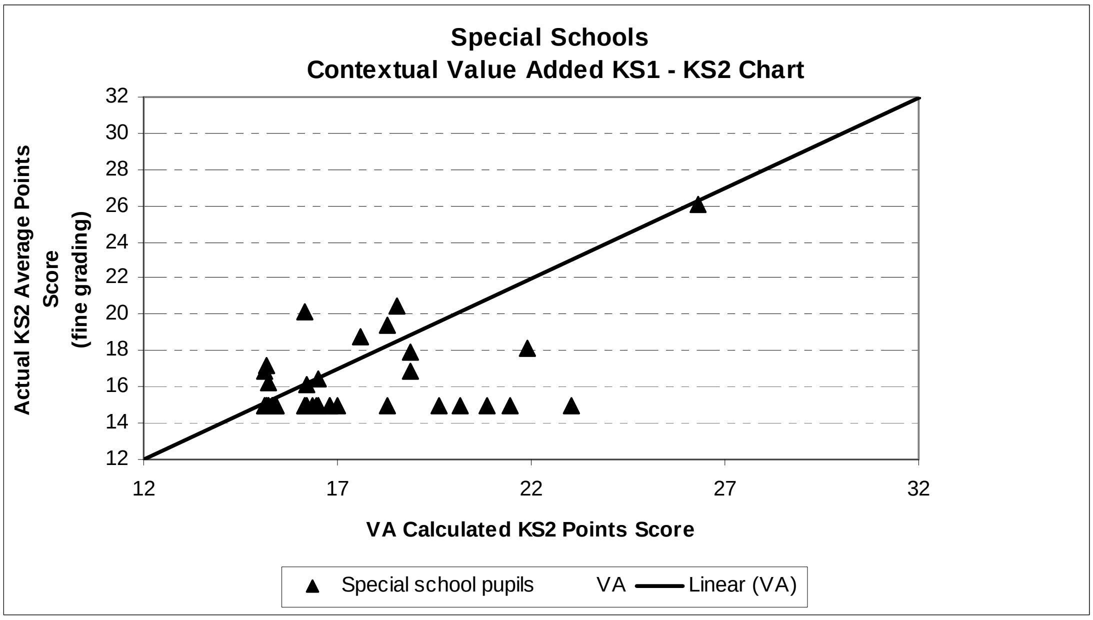
Table 6.13 Achievement at KS2 of year 8 pupils in special schools

Special School Pupils: KS2 Average Points Score

	15 points	17 points	19 points	27 points	Total
no to DDA	11 (69%)	4 (25%)	1 (6%)		16 (100%)
yes to DDA	37 (82%)	2 (4)	5 (11%)	1 (2%)	45 (100%)
Total	48 (79%)	6 (10%)	6 (10%)	1 (2%)	61 (100%)

As with children in mainstream settings it is possible to look at the contextual value added to identify whether children are making the expected progress. Examining data for 61 children at KS 2, the majority of children performed below the expected with a mean of -.9 and a median score of -.4. These are children represented in Figure 6.10 below the line. There is however considerable variation with a maximum score of 4.0 and a minimum of -8.0. Many pupils continue to score 15 despite expectations of higher scores. The majority of pupils make less than expected progress. This raises an important question as to how the adjustments are made to take into account the very diverse nature of a pupils special educational needs and the obdurate difficulty of distinguishing between primary and secondary needs.

Figure 6.10 Progress of year 8 pupils in special schools using contextual value added data



As with mainstream schools, special schools can also look at pupil level data to identify whether there are particular groups of children who are under-achieving and make appropriate adjustments and closely track the progress for individuals or defined groups.

Chapter 7: Collecting Children's Views Using the Flexible Tools

7.1 General overview

In total 45 schools used at least one version of the flexible tools with the target year groups, providing data from over 2714 children. 40% schools tried out more than one type of tool for data collection, with some schools using four different tools. A greater range of tools was employed in the primary and special schools, where there was a much wider range of communication needs than in the single year group of the secondary schools. With the exception of special schools, the tools were used to collect data from children both with and without a disability. (Examples of the tools can be found on www.bath.ac.uk/research/pdes) Table 7.1 shows the usage of the six tools across the three sectors, with much higher usage of those tools which required relatively little preparation.

Table 7.1 School use of the flexible tools

	Primary	Secondary	Special	Total
Talking Mats -				
Number of Schools	8	0	1	9
N(pupils participating)	(238)		(2)	(240)
Symbol Questionnaire				
Number of Schools	8	1	11	20
N(pupils participating)	(124)	(15)	(158)	(297)
Online Questionnaire				
Number of Schools	16	8	1	25
N(pupils participating)	(832)	(849)	(7)	(1688)
Interview schedule				
Number of Schools	9	2	5	16
N(pupils participating)	(259)	(128)	(30)	(417)
Focus group				
Number of Schools	4	0	0	4
N(pupils participating)	(131)			(131)
Point to point				
Number of Schools	2	0	0	2
N(pupils participating)	(6)			(6)
Total schools using at least one flexible tool	24	9	12	**45**
(no. using 2+ tools)	(12)	(1)	(5)	**(18)**
Total pupils participating	1529	992	197	**2774**

The online questionnaire proved particularly popular, and the symbol questionnaire also had immediate appeal to staff taking part in the project. After using the tools, teachers commented in feedback meetings that they were aware of the potential of other tools but chose the ones which were relatively easy to set up, because of pressures of time and other commitments. The appeal of these “off-the-shelf” tools led to some surprising combinations of age-group and tool (such as the online questionnaire tool designed for secondary schools being used with reception class pupils) and afterwards teachers’ comments often reflected this mismatch. However, it sometimes led to successful if unpredicted outcomes, such the use of the young children’s interview schedule as a written questionnaire for year 8 pupils in a special school.

The quality and usefulness of the data collected using different tools varied both with the level of communication of the child and the flexibility of the data collection tool. The interview schedule proved to be the most adaptable and schools were generally able to use it - or see how it could be used – to consult pupils with a wide range of ages and communication needs. The anonymous online questionnaire provided detailed information without the concerns about the need to please the interviewer; it did, however, rely on the pupils being able to read the questions. Although the symbol questionnaire was simple, attractive and popular, its lack of adaptability to individual communication needs limited the kind of data which it produced.

Discussing possible refinements and future plans with teachers sometimes revealed a developing understanding that accommodating the full range of communication needs entails customisation, and that a range of tools might be required to access the views of all pupils about what help or hinders their learning. However, there was also evidence that some schools were more concerned with ease of preparation and administration and this suggests that, if consultation of pupils about barriers and supports is to become more than a largely superficial exercise, it needs to be seen as part of a wider move towards more personalised learning.

The following sections outline the usefulness of the six different tools, looking first at those tools which used methods which staff already understood, that is, the two questionnaires and interview schedule, followed by the three tools which introduced new methods – talking mats, point to point and the structured focus group.

7.2 Interview schedule

This tool was the easiest to understand and easiest to adapt to individual school situations. It was well suited for use with whole classes to elicit views about school in general but was also designed so that disabled pupils or pupils who were experiencing difficulties had opportunities to talk about things that helped and things that made their life more difficult. The tool therefore fitted into existing school programmes for accessing pupil voice (e.g. circle time, PSHE, Data handling in Maths) and so was used in different ways across the whole age range and in both mainstream and special schools, with different methods of presentation and different prompts and supports.

It was used successfully in secondary schools as a written questionnaire, completed on the computer or on paper. Some schools used it as starting point for devising their own questions and introduced features of other tools to suit the pupils whom they wished to consult, so that in one school, for example, it was used with all four reception classes as part of a themed "Happy Week". Because of the wide variation in ways of using the questionnaire, the length of time needed for the activity also varied widely from 15 minutes to a whole week (in the case of the themed "Happy Week").

Stakeholder feedback

Schools reported that pupils enjoyed activities using the Interview Schedule, but two schools thought that quieter children found it hard to express their opinions in group discussions. Staff found the interview schedule either quite or very useful, with those who were less enthusiastic expressing reservations about its use with reception class pupils, particularly how their willingness to please might affect the usefulness of their answers, as well as their being generally quiet and more timid. Elsewhere, however, teachers who used it with reception class children reported that "all pupils engaged with the activity. Children were very honest about their opinions".

Schools reported that the activities had revealed aspects of pupils' response to school that surprised them, and that the experience of trying out this activity had revealed ways in which they might want to adapt it for future use. It had also showed that more work was needed with some children to help them to become more confident with expressing their own opinions.

The overall impression from schools was therefore positive, and led staff to making changes in their practice

> *I have adapted my 'Book session' activity based on children's thoughts about their ideas and make it more fun and interesting*
>
> *[We shall now] be aware of areas that children worry about for future intakes*

Views elicited using the interview schedule

The interview schedule proved very effective in revealing pupils’ feelings about parts of the school building, particular people in school as well as particular events. The older pupils were also able to give reasons why they felt this, or what it was about the things they liked or disliked which made being at school better or more difficult, and these responses offered starting points for discussion about supports and barriers to learning. It also encouraged children to identify their own strengths and weaknesses, recognise the progress they had made, and so help them to understand how they might overcome difficulties in the future.

> *Maths - changed to lower group which is much better but can do work now, before it was too hard (Yr4 pupil, Primary school)*
>
> *It is good that I can find words in a dictionary at home. And now that I can move myself from one lesson to another. I dislike the shouting/rudeness and swearing comments (yr 8, pupil, special school)*

The Year 8 pupils who filled the interview schedule in on the computer produced a similar range of responses to those produced with the online questionnaire (see following section below). Some pupils found typing answers to the Interview Schedule rather long and laborious and some started to question the content (specifically the question about favourite books etc included for younger pupils to end the interview on a positive note). However, it produced a wealth of useful data about the niggles of school life and some more concerning difficulties which some pupils faced through name-calling and bullying. It provided pupils with the opportunity to reflect on their strengths and weaknesses, which could provide useful starting points for annual reviews.

7.3 Online questionnaire

This tool was simplified from the version used in the development phase, to make it shorter and to avoid questions which seem to produce the similar kinds of reply, but with an extra "wild card" question ("If you had a magic wand what would you change about the school?") to allow pupils to raise issues not raised elsewhere in the questionnaire. Schools commented that this turned out to be the most useful question to reveal what pupils were really concerned about.

Twenty-five schools used the online questionnaire, 16 primary schools (mainly with year 4), 8 secondary schools and one special school. Out of the 1624 pupils who registered responses online, 359 (22%) indicated they had a difficulty or disability and for 258 of these (16%) it had gone on for a year or more. Some schools tried out the tool with all children in a class or in a year group and others with a selected group of pupils resulting in a broad range of 6%-56% of pupils found in mainstream schools.

Stakeholder feedback

Schools were enthusiastic about this tool in spite of some technical difficulties including arranging access to computers for whole classes. Several schools suggested that this activity could be spread across the year or set up for pupils to access in their own time.

Schools reported that the questionnaire had raised specific issues, some of which confirmed things they all ready knew and some of which were surprises, and this had led to further consultation with pupils to improve aspects of school life. For example, in one secondary school, the discovery of problems in the lunch queues prompted staff to arrange a lunch for pupils with physical impairments, and to ask their views about access/arrangements at school in general. Another school commented that it was useful to see the extent to which pupils looked to their friends for support, and this could inform development of the school's "buddy" system. This school also noted that the questionnaire revealed that some students held stereotypical or negative views, and this gave them an indication of an area which needed further work, especially as the school was co-located with a special school.

The issue of confidentiality was also raised; one of the most important features of the tool was that it was the only one which allowed pupils to express their views anonymously. Staff felt however that they would liked to have been able to follow up comments but the rubric on the form promised pupils they would not be identified by their comments, unless they requested further support and volunteered their name. Pupils could have been given the option of several levels of disclosure between complete anonymity and disclosure of name in a request to discuss issues further. In feedback meetings staff did comment that this should be approached cautiously as pupils tend to see “name” and just fill it in without thinking, but this could easily be introduced into the discussion before the questionnaire was carried out. Another school commented on the importance of setting the scene, to give the form the necessary gravitas, and emphasise that it was not just a fill-in activity.

Views elicited using the online questionnaire

The smiley/sad face symbol ratings gave indications of which times/ places /lesson types were most liked by the pupils groups in general and by individual pupil and groups of pupils in particular, and this overview provided a useful starting point for schools and revealed immediately where pupils were les comfortable. It was however the open questions which provided the most insight into specific barriers and supports, and this was enhanced by the capacity to analyse the views of the pupils who answer yes to the disability/longstanding question separately from the other pupils. This analysis enables comparisons of those aspects which might help specific pupils and adjustments that might be of benefit to all the pupils.

Analysis of the large data set generated by this tool is still continuing, but the evidence so far supports the conclusion that the online questionnaire does indeed encourage pupils to identify supports for and barriers to school in general and to learning in particular. The overwhelming message from the questions about what helps pupils in school in general was the importance of peer support and this also emerged as important in response to questions targeting supports and barriers for learning.

The issue that came up most frequently as supporting (when it was there) and as a barrier (when not available) was help from teachers and sometimes from other staff. This ranged from individual support during class and extra lessons, to the provision of good explanations and instructions for the whole class. Most of the comments which went beyond just a general enthusiasm for help mentioned the availability of the teacher for further explanation, either when the pupils requested it or unsolicited. The impression left by these comments is of pupils wanting further teacher input. This suggests the kind of investigation which schools could pursue; for example they could check whether, as the initial analyses of the whole data set appear to indicate, data from the pupils who did not say yes to the disability question demonstrate a different pattern of results, with fewer comments about help and more comments about lesson content. Appendix H shows samples of responses that pupils who answered yes to the disability question gave in response to questions about what helps and what makes things more difficult in during lessons.

The positive comments about how friends help and the preference for working in pairs and groups are echoed in those responses that showed a dislike of working alone. Comments about friends refer both to companionship and the pragmatic support they might provide through being able to answer questions during tasks. However, some pupils found working alone helpful and group-working difficult, especially when expected to work with pupils they disliked. Given the difficulty for teachers in knowing who are currently friends with whom, pupils suggest a safe option of allowing them to choose their own partners/working groups.

The main aspects of the environment which were cited were the level of noise and distractions, and the general atmosphere created by the teacher in charge. The effect of other pupils, who distracted or ridiculed those who wanted to work, was also a frequent issue:

> *60% of class don't want to learn when i do*
>
> *[what makes it more difficult is] when i work in a group who ignore me and make fun of me for knowing answers to difficult questions.*

Unlike parents’ comments about support there were almost no explicit references to the need for awareness of pupils’ difficulties, except for comments about unhelpful attitudes from other pupils. All the comments about staff with unhelpful attitudes, however, referred to their general demeanour, not to a specific concern over the way they treated pupils with difficulties.

Also in contrast to parents’ comments, pupils made many references to the content of lessons and other activities like homework. These indicated preferences for practical lessons, sport and things that were fun/interesting (with corresponding antipathy to anything boring or hard). Comments about lesson content included enthusiasm for demonstrations and examples, and a dislike of too much writing.

Some pupils commented on things which they themselves could do that might help in lessons, such as listening, practising and trying hard, and barriers often revealed more individual needs, including difficulty with understanding, hearing, walking, concentrating and controlling their temper.

Although the presence of certain resources was mentioned as being beneficial, with the interactive white board being the most frequently quoted item, the absence of resources was not recorded as a barrier to learning.

7.4 Symbol questionnaire

This was used by eight primary schools, both with year 4 and reception children, and 11 special schools across the age range, and by one secondary school.

Stakeholder feedback

It produced a wide range of feedback from staff, with some rating it ‘not that useful’ and two ‘very useful’. It also took a wide range of time to carry out – between 5 and 45 minutes per pupil, both with reception aged pupils. Some pupils enjoyed it, some struggled to engage with it as an activity and one secondary pupil declared it was too baby-ish until he was offered the Online Children’s Questionnaire instead, when he decided it was a better option.

It was not the use of symbols themselves which made the tool difficult, but the questions which were asked. Negative questions of the form “at school I don’t like ..” were difficult for pupils in two special schools to understand. One teacher suggested that parents could have a pack of symbols to enable them to involve their child and this could form a useful addition to the annual review process.

The two primary schools who found it useful had selected it to try with reception class pupils, and were able to use it or see how it could be used in conjunction with other activities to promote equality

> *“we could use them during our Equality Week for information gathering”*

They were surprised by some of the responses, such as confident children who found it difficult to make friends, and pupils with obvious medical conditions who did not think they were disabled. It gave them insights into the sort of things their reception classes needed to be working on, and what they were already doing well. The special school who found it useful matched pupils with flexible tools using reading level, and it was mainly year 4 pupils who had moderate learning difficulties and/or ASD who used the symbol questionnaire.

Views elicited using the symbol questionnaire

Several schools (four primary, one secondary and eight special schools) retuned their questionnaires to us for analysis and this offers some insight into pupils’ response, and shows that the questions did enable pupils to express views about what they liked and disliked about school, although most children (both from mainstream and special schools) seem to like most things and dislike very few things. This did, however, make the occasional “don’t like” response stand out and suggest areas which schools might want to investigate further. Circle time in the secondary school, for example, was disliked by 10 out the 15 pupils, making it more unpopular than any other lesson. Different pupils disliked or liked different things, and some of the patterns of response around creative, sporting and practical activities were similar to those from the online questionnaire at the same school. However, it did not give much scope for comments.

The questionnaire did, however, ask pupils whether or not they saw themselves as like the other pupils, or disabled, or whether they found things difficult. Very few pupils opted for responses using the term ‘disabled” (17/274 or 6%), which is much lower than the proportions found with the online questionnaire, despite the higher proportion of special school pupils responding to the symbol questionnaire. 16% pupils, however, opted to say they found things difficult, suggesting that the term ‘disabled’ was perhaps not well understood or liked by pupils completing the symbol questionnaire. 19% of pupils from special schools did not give any response to this question at all, which echoes the comments from special schools that pupils found this question particularly difficult to understand.

7.5 Talking Mats

For many schools, Talking Mats was a new technique for asking pupils to think about what they liked and didn’t like and only nine schools (eight primary and one special school, from seven different local authorities) reported trying this tool out. Other schools, however, used elements of the approach (sad/happy face symbols and photographs) in conjunction with other tools, notably the Interview Schedule.

Stakeholder feedback

Where information was returned about usefulness, staff found it either quite useful or very useful. The activity was lead by a teacher in six out of the eight schools, by a teaching assistant in one school and jointly by teacher and teaching assistant in the remaining school. Some schools used it as a whole class activity, some as a small group and some as a one-to-one activity. Time taken to carry out the activity varied between 5 minutes per child (reception class) in one school and 20 minutes per child in year 4 in another school, with whole class activities taking between 30 minutes and an hour.

All schools reported that pupils engaged well with the activity, and that it encouraged them to talk about their feelings about school. Different schools used different prompts and supports - symbols, pictures and photographs – and reported that these were useful in enabling children who were less confident to give their opinions. Suggested amendments ranged from making the question more specific (with year 4 pupils), using boxes to post likes/dislikes (with autistic pupils, working with small groups over a longer period, and following up individual activities with a whole class discussion (and vice versa).

One school developed their own version for use with their reception class children which combined Talking Mats with some features of a questionnaire and the interview schedule. First children were asked questions which they rated using happy/sad/unsure faces, and then they were asked about photographs of people and places in the school. Their responses were recorded individually providing useful summaries of what children liked and disliked about school, and some of the things that worried them. Because of the range of ways of responding and the provision of verbal and visual prompts, this activity covered a wide range of communication needs of a reception class in their first term at school.

Specific difficulties arose in one school with younger children for whom English was an additional language, or whose responses were perhaps coloured by their willingness to please; scheduling the activity later in the school year when reception class children had gained more confidence might yield more genuine responses. In another school, finding space to carry out the activity was a problem, together with ensuring that staff carrying out the activity had a firm understanding of its purpose.

Views elicited using talking mats

For the most part, the barriers revealed by the Talking Mats activity were concerned with the practical side of attending school, rather than specific problems about learning. These practical barriers included things that were uncomfortable (assemblies too hot, too crowded, and too long) and which impinged particularly on children with disabilities; children in wheelchairs got an even longer dose than their classmates because they were wheeled in first and had to wait until last to leave. Play time was also problematic for some children, because of fear (well-founded, as it turned out) of getting knocked over by bigger children or, in the case of other children with BESD, a preference for staying inside by choice (instead of being sent there after having misbehaved outside). The canteen/lunchtimes and the school toilets also emerged as areas that were disliked by some children, because of noise and doors that bang.

In one school, where the activity was carried out with year 4 pupils, staff also found out about barriers which were more closely related to learning; pupils didn't like it when staff finished their work for them, they didn't like topic work because of the extra reading and writing, and they were worried about aspects of English and Maths. In two other schools it emerged that individual pupils wanted help to learn to talk to and play with other children; the activity had encouraged a girl with Down syndrome to raise issues about her problems with getting other children to understand her and knowing how to join in conversations. These discoveries provided staff with clear indications about areas to work on.

7.6 Point to point

This tool was used by just two primary schools and with just six pupils. However other schools saw its potential and have plans to include it in individual interviews with disaffected pupils and in consultation with individual children. One of the two schools who used it also agreed it worked better when carried out one to one, but the second school found it worked well with groups of four yr 4 pupils with SEN, when it took about 20 minutes to carry out. They were also considering how they might carry it out with the whole class.

Both school reported that children enjoyed this activity, one saying that most answers were as expected - children appreciate the support given, and enjoy practical activities, while the other school reported that it had identified things that they did not know before, and they would use it again.

7.7 Structured focus group

Four primary schools used a focus group technique with both reception and year 4 pupils, although one of these based it around the interview schedule and did not carry out the voting procedures. Two of the four found using the full technique very useful, but made some modifications to suit their facilities. The interactive whiteboards worked well to collate and present responses with reception pupils, and staff reported

> *that even young pupils have their own definite opinions and are not swayed by their friends'/peers*

Another primary school who used it with a group of year 4 pupils found that it fitted in well with Social Emotional Aspects of Learning, Personal Social and Health Education, and circle time. The session revealed that fear of bullying, theft, security were issues which pupils found difficult in school. A follow up question “What would help you to do better” provided some insights into ways in which these concerns could be met.

7.8 Summary

As in the development phase, the usefulness of the activities to a certain extent reflected both the commitment and the interest of the schools involved, together with the amount of thought they were able to give to matching the tools to the pupils whom they wished to consult.

Several schools used the result of these actives to report back to governors and to inform the development of DES, with one school asking the governors to try out the tools themselves.

In some local authorities the interest in the flexible tools was such they would have appreciated more opportunities to try them out and they have plans to use them more widely in the future.

Chapter 8: Conclusions and Implications of the Study

Collecting disability data from parents and children demands time and energy from all those involved in the process. It is therefore important to ensure that the data collected is robust and results in additional knowledge. In the final section these points are directly addressed through providing an overview and drawing out policy implications.

8.1 The validity of the data

A number of measures were taken to encourage parents to disclose their child's disabilities, including adopting a more inclusive approach, using the term difficulty in addition to disability, adopting multiple indicators, having a two stage approach to questioning, providing “sometimes” as alternatives to yes/no answers and encouraging all parents to see the relevance of the questionnaire to “making schools better places for learning”. This together with other measures increased the return rates achieved. Arguably, it could have resulted in over- reporting of children's difficulties. To counteract this, parents were asked whether their child had seen a professionals and if this had resulted in a diagnosis and were invited to give qualitative descriptions of their child's difficulties. Parents were also asked about the impact of the difficulty and this together with answer to the longstanding question was given priority in establishing whether or not the child met the DDA criteria. Analysis of the profile of children who did not fulfil all these criteria provided a conservative estimate that less than 1% was excluded as their parents did not complete the longstanding question.

Few parents failed to make reference to needs consistent with their child's SEN and when this under-reporting was individually checked it was revealed that they were on school action or school action plus. Conversely a larger proportion of parents identified needs consistent with a SEN who were not identified in School Census data. The majority of these were children in primary schools with very few children identified in secondary schools suggesting that these were children for whom schools had yet to make a formal response. Given that these were sometimes children for whom schools had no knowledge, only a follow-up dialogue with parents and further investigation will reveal whether the parents concerns are valid.

Where schools disagreed with the impact descriptors in almost all cases this was seen as under-estimation.

It is likely that there is still under-reporting of mental health issues. National census rates place this at around 9.4% for the clinically diagnosed (Green et al 2005). In the development phase parents of children with BESD were more likely to see these difficulties as transient and not tick the longstanding box and it is possible this was true of parents of other children with emotional difficulties. The higher (anonymous) self-reporting of children suggests that there are a body of children who are struggling with aspects of school life. Until a culture is created in which it is safe to disclose these needs it is likely that the true scale of these difficulties will remain unclear. The continued use of both parental and child measures are important steps in developing a positive ethos/climate and providing opportunities to communicate this information.

8.2 Additions to what is currently known

Local authority officers confirmed what the scoping study had suggested that this data was not currently collected. Parent returns identified children who are not currently on the SEN register including children with health, medical and mental health problems suggesting that as the scoping study had highlighted, there was a lack of communication between services. About a quarter (24%) of the children who did meet the DDA definition did not have a SEN. Unsurprising therefore all 11 mainstream schools that received validation visits during the course of the project found children identified through the questionnaire who they were unaware had a disability.

Given that consistently across both phases over a third of parents report that the disability leads to absences from school then children with a disability are particularly vulnerable to under achievement.

Census data has not characteristically collected the views of children and young people about their disabilities. 16% of the 2774 children who completed the online child questionnaire indicated that they had a disability or difficulty that had gone on for a year or more.

Using the NPD to match the survey data revealed that the attainment of those children who meet the DDA and who are not identified as having SEN are achieving as well as their peers at KS1 and 2. Analysis of value added data reveals that on average the children without SEN are making progress as well as their peers. There are however a group of children who do not do as well as projected, many of whom are performing above level 4 and whose under-achievement may go unnoticed.

Children who meet the DDA criteria with SEN in mainstream at KS1 are performing below the expected especially with respect to reading and writing where between 55% and 62% achieve level 2 or above. At KS2 36% achieve level 4 or above. The presence of SEN is therefore a big determiner of attainment.

This data enables schools to identify “outliers”, children with and without a SEN who meet the DDA who are *making less than expected progress*. At a local authority level this data can be aggregated to re-consider the availability of provision for children with particular needs.

There are limitations in the data for monitoring the progress of pupils in special schools. These pupils are likely to have multiple difficulties and it may be hard to identify what constitutes a primary or secondary need (Porter & Lacey 2008; Florian et al 2004). Corrections for the presence of SEN in CVA data are arguably therefore less robust than that of gender or FSM. The majority of these pupils were recorded as being below the level assessed by the test. These factors contribute to making it harder to ensure that these pupils are making the expected progress.

The flexible tools provided important insights into the barriers and support that children encounter in school. This builds on and extends the work undertaken by schools as part of their DES. Schools reported how they had used this additional information including reporting to governors, setting up special meetings with disabled children, changed their practice in specific activities and used it to set up a buddy system.

8.3 The practicalities of collecting disability data

The research team were pleased by a 50% over-recruitment of schools especially given the short time-scale of the project. The average return rates for all 74 schools was 42%

with some schools achieving an impressive 80% response rate within the two week period set aside. While a few schools were disappointed by their returns equally many felt they had been better than expected. If schools are committed there are some useful additional strategies that will help them to achieve a higher return rate.

However schools were well supported by the project team with all materials supplied ready for distribution. Furthermore the data entry was carried out by the team and the subsequent analysis fed-back in a user friendly form.

The current methodology needs some development for parents whose first language is not English. The poor return of translated forms suggested that parents either used these but returned a conventional form or found local support with English if needed. These needs would be offset to some extent through the development of a simple language version. The complexity of translation should also be noted. A number of conditions do not exist in other countries/cultures and there is no language therefore to refer to them.

It would seem important to recognize that this information is a first level screening for disability data. The information produced by the form enabled schools to identify new children with disability for follow-up with a more individualised personal approach.

It should also be noted that the task appeared manageable because it incorporated an important element of collecting pupil views. It therefore enabled schools to meet their DED in two distinct ways, consulting with children as well as parents. Although not all schools within the time-frame were able to carry out the flexible tool activities, they were positive about the place of these and the potential insights that would arise. It also enabled them to comply with external demands and to contribute evidence to their “Self-Evaluation Forms”.

While it is possible to provide “off the shelf” tools for eliciting the views of children, their use will require some preparation and time to ensure that they collect the insights of children with communication difficulties and those who may be more reticent to give their own views. It is important to embed the use of these tools in meaningful activities that are given the appropriate gravitas to ensure that they promote self- reflection on learning and a positive ethos towards children encountering difficulties.

At the same time as these benefits were noted schools and local authorities raised concerns about possible resource implications including being asked to support applications for Disabled Living Allowance.

Little data was directly produced on the cost of the method for schools. To develop a system for future use is likely to incur start-up costs. Many local authorities saw their own involvement as fairly minimal and, without exception expressed a lack of spare capacity to take on additional work. If local authorities were responsible for training in schools then, depending on the size of the local authority, this would entail funding staff time.

8.4 The fit with existing systems

Many schools commented on their current data collection systems for parents at admission and nearly all schools reported meeting face to face with parents. This would enable disability data to be collected alongside other personal data. Schools also reflected on the importance of having an ethos where parents feel confident in disclosing information and in these early stages it is less likely that new parents have built a relationship with the school. Parents may also feel reluctant to provide information that would lead schools to predict that their child would encounter difficulties; in the case of a primary school because of the age of the child making it harder to determine normal variation, and in the case of a secondary school to enable the child to make a “fresh start”. At both stages parents may be concerned that their child could be denied a place if they are seen to experience “problems”. The potential disadvantages of collecting data on admission need therefore to be set against the greater potential of returns from all parents through face to face contact when parents could be given the option of completing this data online in school with or without support from a member of staff. Familiarity with the form might then facilitate annual or bi-annual follow–ups.

If schools are to be autonomous in the collection of this data they will, as local authorities suggested, need some training. The provision of a common questionnaire with data confidentially downloadable by individual schools has many merits. The development of a user friendly IT system that provided schools with easily accessible analysis would enable them to use the information to monitor and improve provision. It would also provide data which could form the basis of returns to local authorities and to DCSF who in turn could monitor the impact of their policies regionally and nationally.

8.5 Policy implications

Finally, there are a number of important policy suggestions which will support the success of these measures:

All schools need to be encouraged and supported to have learning conversations about disability with *all* children. This study suggests that these conversations are fundamental to encouraging a positive ethos to disability and difficulties. The collection of data from children on the barriers and supports to learning facilitates the development of provision which helps young people with mental health and other needs. Schools however need support in order to develop approaches that can be individualised with those children who find communication difficult. Off the peg systems may enable the views of many children to be collected but can marginalize the views of others.

All schools need to be encouraged and supported to open dialogues with all parents about difficulties and disabilities and schooling. The proformas developed in this study opened a new dialogue with parents, providing schools with information that supplemented and enhanced existing records. It is essential that this dialogue takes place with all parents and is seen as on-going.

A national system of data collection developed in partnership with local authorities and schools would reduce local variation

For the data to be useful to schools, local authorities and the DCSF it requires a national system of data collection as they meet their respective obligations under the DDA. A national system would also reduce local variation in operational definition of disability and become an important move in establishing equity of provision. This system should serve to integrate the record of children with SEN and disability and would make this information more readily available across all areas of Children’s Services.

Ethical Standards in Information Systems require close scrutiny

The study highlighted the tensions in sharing sensitive data. They rely on the trust of parents that the information will be used to the benefit of their child. They also rely on appropriate procedures to protect confidentiality. This is true also for information collected directly from children. While for the purposes of this study children were able to remain anonymous, schools will have to weigh up the advantages of adopting this code for their own data collection. It is important that the systems that are developed for both children and parents are clear and transparent with appropriate checking mechanisms to ensure that respondent's requests for confidentiality are safeguarded.

Schools and local authorities require supporting to develop ways of interpreting and using the data to inform the strategic development of provision in which barriers to progress are minimized. The development of a central system could provide a user friendly system to produce the data to enable them to look specifically at the progress of children who meet the DDA, both with respect to value added and contextual value added data. Building on the good guidance currently available to schools on implementing the DDA (DfES 2006) would enable them to use the data to monitor progress, and look at the impact of activity.

As well as school level monitoring, routine aggregation of data by local authorities will enable them to re-consider the availability of provision for children with particular needs and identify good practice in schools.

Information systems are required that reflect the complexity of many children's needs and enable schools and local authorities to respond appropriately. The majority of pupils with a disability have special educational needs. Current systems of recording and monitoring progress at a national level are not sufficiently sensitive to monitor the impact of activities on all their achievements. The further development and refinement of the P scale data or similar would provide a more refined measure with which to monitor progress.

A more sensitive approach to collecting absence data is required which recognizes that for some children their disability leads them on occasion to be unable to attend school. This suggests the need for a more careful system for recording reasons for absence.

8.6 Conclusions

This survey has provided an example of a data collection method that can support schools, local authorities and the DCSF in meeting their duties under the Disability Discrimination Act. It used a twin approach collecting data from both parents and children thereby adding to schools knowledge and awareness of children with disabilities and their support need. The report illustrates that it is possible to identify and monitor these children both at national and local level in order that provision can be enhanced where appropriate. There are however uncertainties about the extent to which it is possible to identify and therefore safeguard under-achievement in children with special needs who are performing at levels below that assessed by the KS tests. The report also raises concerns that children with mental health difficulties are under-identified. The higher (anonymous) self-reporting of children suggests that there are a body of children who are struggling with aspects of school life. Until a culture in which it is safe to disclose these needs has been created it is likely that the true scale of these difficulties will remain unclear. The continued use of both parental and child measures are important steps to developing a positive ethos whereby it becomes easier to communicate this vital information.

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Appendix A: Methodology for the scoping study

A broad approach was adopted to locate examples of good practice: at the level of a single organisation, (e.g. schools and Further Education colleges); at the level of a service (e.g. Speech and Language Services, Under Five) and local authority (e.g. Children Services), drawing on a range of sources including:

i) Government agencies across the UK including the Welsh and Scottish assemblies e.g. DRC; Ofsted;
ii) (SEN) regional partnerships;
iii) non-government organisations who represent parental interests e.g. Council for disabled children Mencap, Mind, BESDA, RNIB, RNID, SENSE, Epilepsy Action;
iv) researchers engaged in collecting the views of children and young people including those with a disability;
v) Web forums to access relevant practitioner activities: e.g. Teacher Net, Senco forum, SLD forum;
vi) Other relevant literature and policy documents

In addition to the literature and web-based searches we gathered additional information directly from 21 local authority officers, approached 29 people involved in regional partnerships,13 voluntary organisations; 5 professional organisations, 5 schools, 5 FE colleges, 5 researchers & 1 independent/commercial company. On the basis of this information full interviews were carried out with 20 people; 4 school heads/teachers, 1 FE provider, 2 voluntary service providers; 1 Independent company, 6 Local Authority Education Service Officers, 1 LA Health Service, 4 Children's Services ,1 LA Early Years Provider. Additional case study material was collected from 1 FE, 1 Children's Services, 1 Commerical Data Collector. The interview schedule drew on guidance provided by the Advisory Committee on Australian and International Disability Data (2005) and included the following questions as prompts:

1. What do they use the information for ? and how is the data used ?
2. What specifically do they need to know from the data ?
3. How often is the data collected ?
4. Who uses the data ?
5. How is the data collated and analysed ?
6. About whom exactly do they collect data ? (including age, is it everyone, or targeted groups).
7. How do they tell people about the purposes and uses of the collection, how do they gain consent, how do they give people confidence in access to information / storage of this information ?
8. What triggers the collection of the data (time, event etc)
9. What medium is used to collect data, ask questions ?
10. Who provides the answers ?
11. What resources are needed to collect the data- time, people etc.
12. What gaps are there in their current system ?
13. How have they piloted/refined it over time, drawn on previous measures ?
14. What for them are the strengths and limitations of the measures, including any feedback from other stakeholders ?

Appendix B: Taxonomy of questionnaires

Access ***Reference + contact details***	**Definition of disability-** ***Consistent with DDA? Linked to adjustments/ Barriers?***	**How is disclosure encouraged**? ***Rationale for data collection? Measures for confidentiality?***	**Target Group of data collection**? **Provider of data** ?	**Systems/ Structures** ***Who administers ? What triggers ? How collated ?***	**Format of data collection** ***Interview/ questionnaire***	**Special Features** ***e.g. vignettes**, **staged, e, statements ?***
D4 Model [DfES] form for the recording of disability data www.dfes.gov.uk/consultations/ downloadable Docs/ **D4**%20**Model**%20Disability%20data%20**form**.doc	No definition given but consistent Focus on impairment	Rationale by way of reference to law END provides note on confidentiality and use of data	Children 11-15 could fill it in on own, aged 16+ make their own decision, otherwise parents	No guidance provided	Unclear but probably questionnaire	
Plymouth City Council data collection form for children and young adults http://www.plymouth.gov.uk/spin_questionnaire2.pdf	No definition, but mentions 'needs more care than children of same age'. Broadly consistent	Introduction mentions why data needed (law, information for local services) and confidentiality explained at the end	young person themselves (age not specified) or parent/carer, but also mentions involving child/young person	not mentioned but section included on which of range of people might have helped to complete form	questionnaire	Rather long (36 pages) and wordy because headings often accompanied by explanations. designed for use with children/young people from 0 to 25 years. Some pictures but used decoratively rather than to inform
epilepsyaction_schools_policy.pdf p16 - form A From http://www.epilepsy.org.uk/info/ education/ index.html	Clear section on why schools need Epilepsy policy, referring to DDA and Health & Safety legislation	Rationale clear (to support children during seizures) Confidentiality not mentioned	Parents with Headteacher and where possible child	Not mentioned but implied that Headteacher will ask parents to fill in questionnaire when school becomes aware of child's condition	questionnaire	Appears in the context of document to develop school policy on epilepsy
DRC 2006 Lewis et al survey	3 aspects disability consistent with DDA, SEN and difficulties. looks at what supports required	clear rationale in covering letter	parents of children in years 5 and 6	survey therefore triggered by school Unclear how electronic version was triggered	questionnaire	Useful model/ starting point- entire questionnaire long but this section is not. Includes interesting discussion of why not translated into Urdu etc-

Access ***Reference + contact details***	**Definition of disability-** ***Consistent with DDA?*** ***Linked to adjustments/ Barriers?***	**How is disclosure encouraged**? ***Rationale for data collection?*** ***Measures for confidentiality?***	**Target Group of data collection**? **Provider of data** ?	**Systems/ Structures** ***Who administers ?*** ***What triggers ?*** ***How collated ?***	**Format of data collection** ***Interview/ questionnaire***	**Special Features** ***e.g. vignettes***, ***staged, e, statements ?***
						technical nature of language. Designed to be inclusive of those parents who did not consider their child had a disability- hence 'difficulties' included.
Scottish Pupil and School Census 2006 https://www.scotxed.net/jahia/ webdav/site/ myjahiasite/shared/ ScotXed/Data%20Exchanges/2006/School%20Pupil/School%20Pupil%20Census%20Guidance%20Notes%202006%20Uplift%2029%20Mar%202006%20v3.0.doc (or advanced Google)	Consistent with DDA- physical or mental impairment	school census	Headteacher	particular week of the year	unclear if form but gives details of the information to be given against each child	checks whether assessed by professional + asks for information against curriculum adaptations, physical adaptations, communication needs
OCPS survey 1995/8	focus is long term health problems or disability	?	household survey assumer therefore adult completion on behalf of others	ad-hoc survey	face 2 face interview	critiqued by Abberley - questions focus on difficulties, which is subjective e.g. going outside home, lack of bladder control, fits and depression. for child questionnaire is are they unable to do things children of same age could do, need more help with self care activities, attends special school etc,
Health Survey for England 2001 http://www.archive2.official-documents.co.uk/document/deps/ doh/survey01/disa/disa01.htm	has module on disability as part of health has 5	?	household survey based on postcodes and random addresses		face to face + samples (!) from visiting nurse	communication questions

Access ***Reference + contact details***	**Definition of disability-** ***Consistent with DDA?*** ***Linked to adjustments/ Barriers?***	**How is disclosure encouraged**? ***Rationale for data collection?*** ***Measures for confidentiality?***	**Target Group of data collection**? **Provider of data** ?	**Systems/ Structures** ***Who administers ?*** ***What triggers ?*** ***How collated ?***	**Format of data collection** ***Interview/ questionnaire***	**Special Features** ***e.g. vignettes***, ***staged, e, statements ?***
	domains, does not include mental health- function imapirment- self help, mobility, sight, hearing, communicating		All ages questions asked for 10+ but have to read cards			
Family and Children Study 2006 Wave 8 DWP http://www.dwp.gov.uk/asd/ asd5/facs/ facs_questions.asp	consistent with DDA with impairment (what kind of disability/illness) and functioning (significant difficulties with mobility etc) questions about type of school and exclusion nothing about supports	?	households		face to face	has also child questionnaire whizzy self-completion- nothing on disability but worth a look for format including clear context of questions
General Household Survey 2005	consistent with DDA longstanding illness, disability or infirmity (!) limit activities, last 2 weeks in relation to health	?	households	survey	face to face proxy under 16	government inter-departmental- policy, planning and monitoring
Family Resources Survey 2000/1	DDA definition used followed up by do they limit your activities in any way	?	focus 16+	ad hoc survey	face-to-face	focus is ability to work
Child health at School Entry (CHASE project) ?2003 http://www.ingentaconnect.com/	not linked to DDA	"data have the potential to inform interventions and	children on school entry - parents to provide info	parents and school nurse	two separate questionnaires. Details about how	developed to capture the multiple dimensions of the health of children in their first

Access ***Reference + contact details***	**Definition of disability-** ***Consistent with DDA?*** ***Linked to adjustments/ Barriers?***	**How is disclosure encouraged**? ***Rationale for data collection?*** ***Measures for confidentiality?***	**Target Group of data collection**? **Provider of data** ?	**Systems/ Structures** ***Who administers ?*** ***What triggers ?*** ***How collated ?***	**Format of data collection** ***Interview/ questionnaire***	**Special Features** ***e.g. vignettes**, **staged, e, statements ?***
content/ bsc/cchd/2005/ 000031/00000002/art00003;jsessionid =16oqapcqmb0fs.alice (downloaded as 15683837.pdf, saved as CHASE)		service provision at school & Borough level"			these were developed and piloted.	year at school
Family Pack to support Framework for the Assessment of Children in Need and their Families (2000)http://216.239.59.104/search?q=cache:iGXZ3aXG4QIJ: www.asylumsupport.info/ publications/doh/questionaires.pdf + Cox+bentovim+family +pack&hl=en&c t=clnk&cd=3&gl=uk	not linked to DDA	data to support work with families. confidentiality negotiated in individual circumstances	carer completes questionnaires /scales	designed to be administered by practitioners working with families in need	questionnaire	8 separate Questionnaires/scales Strengths and Difficulties Questionnaires The Parenting Daily Hassle Scale Home Conditions Scale Adult Wellbeing Scale The Adolescent Wellbeing Scale The Recent Life Events Questionnaire The Family Activity Scale The Alcohol Scale
Activities Scale for Kids (2000) Young et al J.Clin Epidemiol. 53 (2) 125-137	measure of disability based on functioning of everyday activities	No details of content although explanation given of 2 questionnaires and why answers may be different	children aged 5-15 with parents reading out questions to those below 9. Additional Questions" to parents in order to "minimize their desire to change the children's answers	Canadian survey through clinics	self-report	measure of childhood physical disability

Access ***Reference + contact details***	**Definition of disability-** ***Consistent with DDA? Linked to adjustments/ Barriers?***	**How is disclosure encouraged**? ***Rationale for data collection? Measures for confidentiality?***	**Target Group of data collection**? **Provider of data** ?	**Systems/ Structures** ***Who administers ? What triggers ? How collated ?***	**Format of data collection** ***Interview/ questionnaire***	**Special Features** ***e.g. vignettes**, **staged, e, statements ?***
Canadian example- PALS http://www.cdc.gov/nchs/about/otheract/citygroup/products/langlois.htm	measure of disability based on activity/participation "Under PALS, persons with disabilities are those who report difficulty with daily living activities, or who indicate that a physical or mental condition or a health problem reduces the kind or amount of activity they can do."		parents/carers answer questions	census	? face to face	part of a article reviewing development of global measures including difficulties for child measures critiqued by nisra for false negative rate
Common Assessment Framework http://www.everychildmatters.gov.uk/resources-and-practice/TP00004/	"The CAF is a standardised approach to conducting an assessment of a child's additional needs and deciding how those needs should be met. It is intended to provide a simple process for a holistic assessment of a child's needs and strengths, taking account of the role of parents, carers and environmental factors on their development"	leaflets provided for children & parents explaining why CAF used and how & when information is shared	children at risk of not progressing along the five ECM strands but not used if in immediate danger of harm. data provided by practitioners,	triggered by practitioner's concern collated and shared between agencies	built up through contact with family and through information from different agencies	completion requires considerable knowledge and experience from practitioners; categories are general rather than detailed

Access ***Reference + contact details***	**Definition of disability-** ***Consistent with DDA?*** ***Linked to adjustments/ Barriers?***	**How is disclosure encouraged**? ***Rationale for data collection?*** ***Measures for confidentiality?***	**Target Group of data collection**? **Provider of data** ?	**Systems/ Structures** ***Who administers ?*** ***What triggers ?*** ***How collated ?***	**Format of data collection** ***Interview/ questionnaire***	**Special Features** ***e.g. vignettes***, ***staged, e, statements ?***
MICS 3- Unicef data collection tool http://www.childinfo.org/ **mics/ mics3/index.php**	definition based on functioning		focus of unit on child under 5			Unicef's option module on disability as part of household survey
Millennium Cohort Study 2006	DDA – "longstanding illness, disability or infirmity?" then question to identify impairment /illness (plus tests)		relevant aspects focus on worries and health and development	random sample of over 18.800 children born in UK in year 2000-1	5 yr old –CAPI (computer-aided personal interview) with parent or guardian + child tests of cognition & physical	no key word search on disability i.e. inferred from information. survey 9 months, 3 5 7 etc includes question about school and support
Mental Health Survey 2004	Based on ICD-10 to look at mental /emotional/ conduct & hyperactivity disorders	inform policy decisions about need for child and adolescent mental health services		sample drawn from child benefit records 5-16 in private households	parent interview teacher questionnaire (83% returns) child interviews 11-16 (93%)	provides an indication of children without special needs who have a mental health disability as defined in the survey. However follow-up at 6 moths also indicates improvement in the disorder in some but in no case had it disappeared. 6 month follow up includes a global question.

Appendix C: Pilot study data on the parent questionnaire

Table C.1: Returns from primary schools

School	**Proforma**	**Number returned**	**Response Rate**	**Distribution Methods and follow up**
Primary	2	82	48%	Questionnaires distributed by and returned to the school. They wrote their own cover letter. TAs handed out questionnaires (only to R parents) and reminded them to return them
Primary	2	41	40%	Questionnaires distributed by and returned to school with their own cover letter in addition to ours.
Primary	1	52	48%	Head invited parents of year R in (only 12 turned up) others distributed by the school and returned to the school
First	1	39	60%	Questionnaires were distributed by and returned to school using our cover letter but with information in the school newsletter. Additionally a reminder letter was sent out.
Primary	1	26	26%	Questionnaires posted out to parents and returned to the university. Cover letter was written collaboratively.
Totals		240	44%	

TableC.2 Returns from secondary schools

School	**Proforma**	**Number returned**	**Response Rate**	**Distribution Methods and follow up**
Secondary	2	42	20%	Questionnaires posted directly to the home but returned to school using our easy cover letter and one from the school.
Academy	1	21	10%	Questionnaires distributed and returned to school (originally with a plan to be completed during open evening).
College	1	35	21%	Questionnaires distributed by the school supplied by us with a covering letter (during the floods).
Totals		98	17%	

Table C.3 Returns from special schools

School	Proforma	Number returned	Response Rate	Distribution Methods and follow up
Primary school for children with BESD	2	12	22%	Questionnaire posted out and returned to school
All age School for Children with Learning Difficulties	2	6	55%	Questionnaires produced and distributed and returned by school.
Primary and Secondary school for children with BESD	1	7	30%	School produced, distributed and collected responses.
		25	36%	

Appendix D: Questionnaire used in the national trial

Making Schools Better Places for Learning

Please help us find out about any difficulty or disability that may affect your child's learning so that the right support and help is provided. We want all children to get the best from their education. You may find it helpful to ask your child some of these questions to find out what they think.

Please take the time to answer ***all*** questions and return the form whether or not your child has any difficulties.

Child's Surname / family name ………………………………………………………………………

Child's first name ………………………………………………………………………

Child's Other names …………………………………………………………

Date of Birth (dd/mm/yy) ../ .. / ..

Year group (please circle): Reception Year 4 Year 8

Gender (please circle): Boy Girl

A quick electronic version of this form is available at:
www…………………………………………………….

If you need help to fill in this questionnaire please let your school know.

1. Does your child have any difficulty that interferes with his or her:

	Yes	**Sometimes**	**No**
a) Classroom learning?	☐	☐	☐
b) Relationships with his or her classmates / peers?	☐	☐	☐
c) Other school activities?	☐	☐	☐

2. Does your child have a disability or difficulty such as: anxiety or depression, arthritis, asthma, autism, cancer, diabetes, epilepsy, hearing or visual impairment, ME, MS, mental health difficulty, mobility problems, learning difficulty, physical difficulties or severe disfigurement?

☐ Yes ☐ No

3. Does your child have a difficulty or disability which means that they are sometimes absent from school?

☐ Yes ☐ No

4. Does your child have a difficulty that limits activities at home?

☐ Yes ☐ No

If yes please tell us about these difficulties:

5. Overall how would you describe the impact of the difficulty (or difficulties)?

No difficulty	☐
Mild – *occasionally* interferes with everyday activities and only in a *minor* way	☐
Moderate – *intermittent* but *regular limitation* of normal activities	☐
Severe – *frequent* and *significant* impact on daily activities	☐
Profound – unable to take part in a number of activities	☐

6. Has your child seen a professional because of a difficulty?

☐ Yes ☐ No

If yes **please circle** who you have seen:
educational psychologist / doctor / counsellor / paediatrician / therapist
other (please specify):

If yes what was the medical diagnosis:

7. Has your child had an accident or trauma in the last 5 years that has significantly limited their activities?

☐ Yes ☐ No

8. If you have answered yes to any of the questions above please describe the support that your child finds particularly helpful to overcome his / her difficulties:

9. Does your child have a <u>longstanding</u> illness, medical condition, difficulty or disability? By longstanding we mean anything that has troubled them over a period of a year or more, or that is likely to affect them over this period of time?

☐ Yes ☐ No

10. How would you describe their particular needs? Please tick where appropriate, this may be more than one box.

No additional needs	☐
Health or medical needs e.g. allergies, asthma, blood pressure, cancer, circulation, diabetes, epilepsy, HIV, ME, MS etc	☐
Cognitive or learning needs e.g. dyslexia, moderate learning difficulty, profound and multiple learning difficulty, severe learning difficulty, specific learning difficulty	☐
Mental health difficulties e.g. anxiety, depression, eating disorder, phobias	☐
Sensory Impairment e.g. blind or multisensory impairment, deaf, hearing impairment, visual impairment	☐
Speech language, communication or interaction needs and difficulties; speech and language difficulties	☐
Autistic spectrum disorder, eg. Asperger's syndrome, autism	☐
Physical needs and difficulties e.g. arthritis, cerebral palsy, rheumatism, stroke	☐
Behaviour, emotion and social development needs e.g. attention deficit (hyperactivity) disorder, conduct disorder, emotional and behavioural difficulties	☐
Other (please specify):	

11. Would you like the opportunity to talk about any of these issues with a member of school staff?

☐ Yes ☐ No

Have you any comments about how we can improve this form?

The information will be used by the project team on behalf of The Department for Children, Schools and Families for educational research purposes. No information will be published that would identify your child or school. Information will be shared with those staff in the school and in the Local Authority who support your child. By returning this form you are agreeing that the information can be used in this way.

We will treat what you have told us here sensitively. None of the views on your child will be shared with other parents and pupils.

If there is anybody in the school or Local Authority staff who you would **not like** to share this information with please name them below:

…………………………………………………………………………………………….

On behalf of The Department for Children, Schools and Families project team:
Dr Jill Porter, University of Bath (email: j.porter@bath.ac.uk tel: 01225 386857)

Please return the completed form to your school by Thursday 15th November

Many thanks for taking the time to complete this form. Having your views is an important step towards making schools better places for learning.

Appendix E: Data from the parental questionnaires in the national trial

Table E.1 Percentage of children identified as meeting the DDA criteria by school

Primary	DDA	not DDA	Total	% DDA	Return Rate
1		22	22	0%	49%
2	1	50	51	2%	52%
3	1	31	32	3%	58%
4	1	31	32	3%	36%
5	1	30	31	3%	29%
6	2	58	60	3%	29%
7	2	52	54	4%	15%
8	2	51	53	4%	39%
9	2	44	46	4%	40%
10	2	42	44	5%	41%
11	4	81	85	5%	74%
12	3	58	61	5%	51%
13	1	18	19	5%	42%
14	1	17	18	6%	10%
15	2	33	35	6%	37%
16	2	33	35	6%	45%
17	5	81	86	6%	25%
18	5	69	74	7%	52%
19	3	39	42	7%	33%
20	2	25	27	7%	37%
21	3	37	40	8%	63%
22	1	12	13	8%	30%
23	1	11	12	8%	41%
24	3	33	36	8%	58%
25	6	63	69	9%	48%
26	2	20	22	9%	42%
27	5	48	53	9%	52%
28	5	48	53	9%	47%
29	2	18	20	10%	43%
30	3	26	29	10%	56%
31	7	60	67	10%	43%
32	2	17	19	11%	35%
33	3	23	26	12%	40%
34	5	38	43	12%	67%
35	6	44	50	12%	46%
36	6	40	46	13%	52%
37	4	24	28	14%	44%
38	4	23	27	15%	42%
39	6	34	40	15%	35%
40	3	15	18	17%	35%
41	12	57	69	17%	55%
42	3	14	17	18%	28%
43	9	38	47	19%	50%
44	3	11	14	21%	45%
45	6	22	28	21%	58%
46	6	14	20	30%	23%
Primary Total	158	1655	1813	9%	

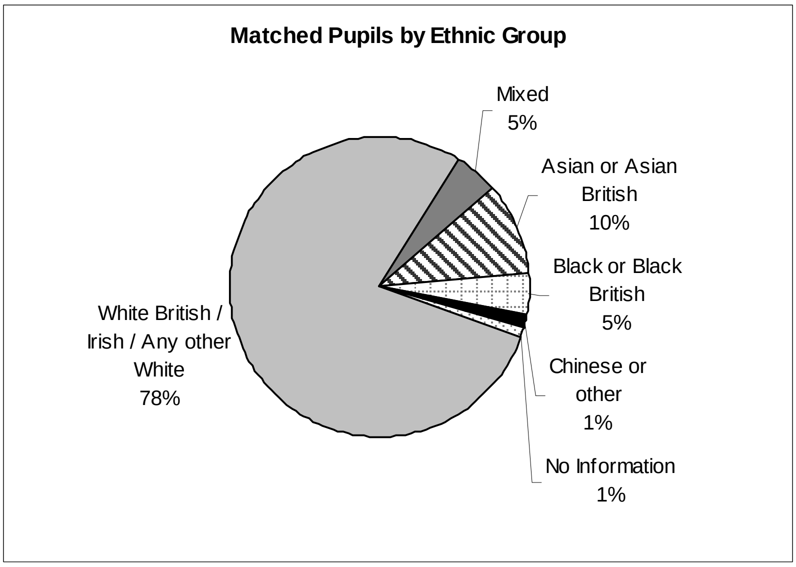
	DDA	not DDA	Total	% DDA	Return Rate
Secondary					
1	10	123	133	8%	35%
2	4	44	48	8%	51%
3	6	60	66	9%	39%
4	2	19	21	10%	80%
5	9	84	93	10%	50%
6	12	107	119	10%	57%
7	8	68	76	11%	44%
8	3	23	26	12%	23%
9	14	107	121	12%	35%
10	11	74	85	13%	14%
11	7	44	51	14%	31%
12	9	26	35	26%	44%
13	13	36	49	27%	38%
Sec Total	108	815	923	12%	
Special					
1	4	4	8	50%	35%
2	17	10	27	63%	54%
3	11	5	16	69%	49%
4	9	4	13	69%	52%
5	8	3	11	73%	40%
6	10	3	13	77%	52%
7	4	1	5	80%	38%
8	8	2	10	80%	78%
9	15	3	18	83%	50%
10	6		6	100%	49%
11	7		7	100%	52%
12	7		7	100%	14%
13	5		5	100%	46%
14	5		5	100%	26%
15	8		8	100%	44%
Special Total	124	35	159	78%	
Grand Total of Primary. Secondary and Special	390	2505	2895	13%	

Appendix F: Matched NPD data

Table F.1 Distribution of ethnic minorities in matched NPD sample

Matched Pupils by Ethnic Group	Count
African	38
Any Other Asian Background	37
Any Other Black Background	12
Any Other Ethnic Group	22
Any Other Mixed Background	33
Any Other White Background	56
Bangladeshi	28
Caribbean	54
Chinese	6
Gypsy / Romany	2
Indian	89
Information Not Obtained	8
Irish	9
Pakistani	76
Refused	6
White and Asian	22
White and Black African	7
White and Black Caribbean	42
White British	1729
(blank)	12
Grand Total	2288

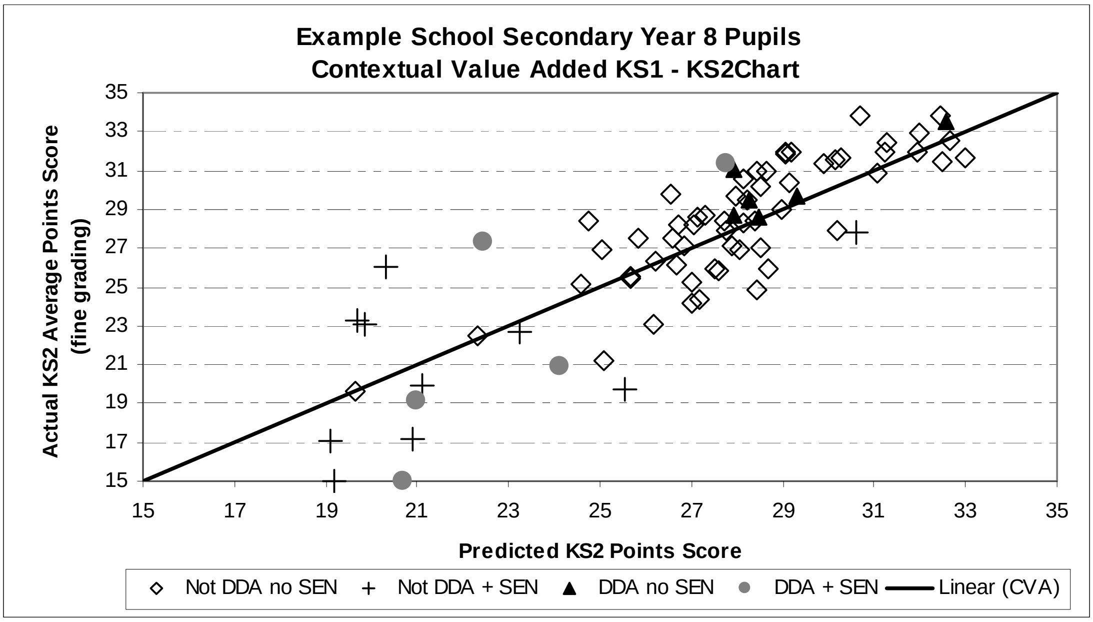
Figure F.1 Proportions of pupils by ethnic group



Appendix G: School level monitoring of vulnerable groups

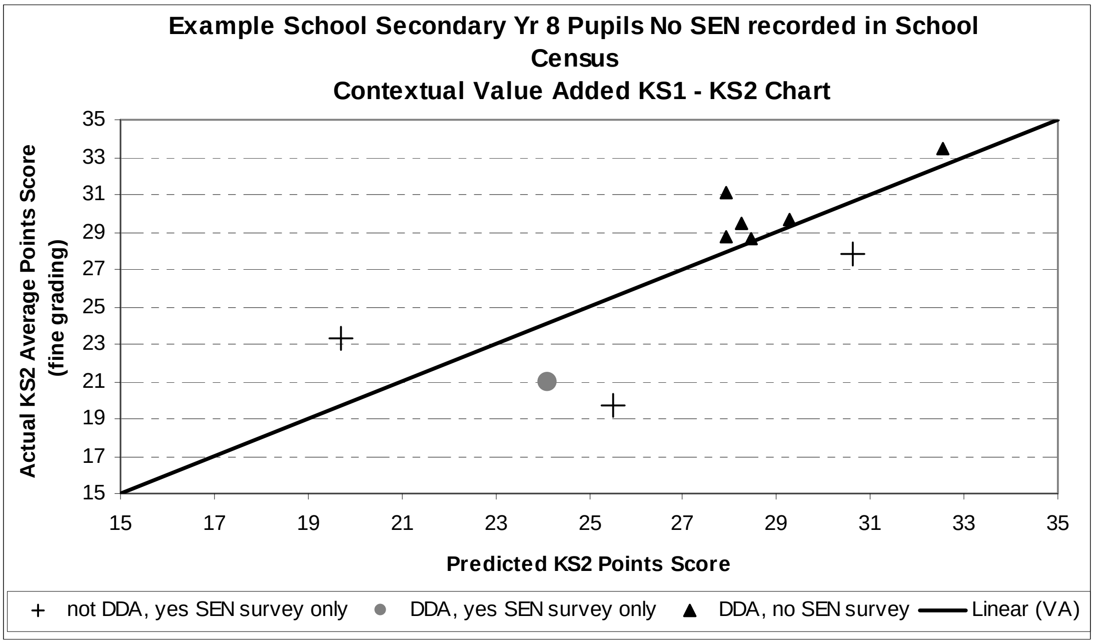
Below is a second school example based on the returns from a secondary school which despite a low return rate revealed examples of all target groups. The overall profile is again of children who meet the DDA and without a SEN largely performing as expected or better and children with a SEN largely performing less well than expected. Children for whom the school may have lower expectations may be particularly vulnerable.

Figure G.1 Example school contextual value added data for year 8 pupils



In Figure G.2 a distinction is made between those children who are formally recorded as having a special educational need and those who are not. The school may wish to explore further the case of those children whose parents indicate they have a SEN and who are performing less well than expected.

Figure G.2 Example school contextual value added year 8 pupils by disability and SEN



Appendix H: Data from the online questionnaire

Table H.1 Supports for children with disabilities in their lessons

Q15. Can you tell me a bit more about lessons? What helps? (319 comments in total from the 359 pupils who ticked yes to the disability question)		
Type of comment	**Number of comments**	**Example of comment**
Being with friends/ working with others	Working with others - 29	sitting next to friends and working with them
	Friends - 39	when I am working with a partner particularly at maths because I have someone to express my ideas with and I feel more confident.
Access to help	106	Getting my own LSA (Learning Support Assistant)
		It helps when the teacher explains really well on what you have to do
		teachers helping you individually.
		teachers who help you instead of walking off somewhere else
The right environment	36	People not talking or being silly.
		It helps when other students don't disturb or distract you when you are trying to working
		people not moving in lessons when I am working
		When it's quiet and there's less children in the classroom.
		well support from people not putting me down like some people in my class.
Lesson content	73	The exapels in a lessons are very help me.
		when we do practicals and do fun things were you use your hands and stuff
		i think aswell a lot of moving about instead of just writing. Practicals and stguff is cool!!!
		Doing P.E. when I do really good work so I feel proud.
Individual/personal strategies	18	I can also work alone because i sometimes find it easier to put my ideas down on paper.
		Trying your hardest really helps achieve things. When you do you are on cloud 9. You also get meanigful rewards.
Resources	18	dictionaries for spellings
		pictures; practicals e.g. in science etc
		when the teacher or someone does a demonstration
		interactive white boards

Appendix I: Glossary

BESD	Behavioural, Emotional and Social Difficulties
CVA	Contextual Value Added measure of progress
DDA	Disability Discrimination Act
DES	Disability Equality Scheme
DRC	Disability Rights Commission
LA	Local authority
NPD	National Pupil Database
OECD	Organisation for Economic Co-operation and Development
PSHE	Personal, Social and Health Education
SEAL	Social and Emotional Aspects of Learning
SEN	Special Educational Needs
UNESCO	United Nations Educational Scientific and Cultural Organisation
VA	Value Added measure of progress

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