Research Report DFE-RR025

Testing of Disability Identification Tool for Schools

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Department for Education

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Executive Summary

Introduction

There has been an ongoing concern about the lack of reliable data on disabled children in schools. To date there has been no consistent way of identifying and categorising disabilities. Schools in England are currently required to collect data on children with Special Educational Need (SEN), but this does not capture information about all disabled children. The lack of this information may seriously restrict capacity at all levels of policy and practice to understand and respond to the needs of disabled children and their families in line with Disability Discrimination Act (2005) and the single Equality Act (2010).

Key Findings

- 42% of parents returned the questionnaire providing information on their child in relation to any difficulties, physical or mental health conditions or impairments; School level return rates ranged from 5% to 80% with the largest range from secondary schools;
- 270 children were identified as meeting the criteria for disability set out in the Equality Act 2010, around 11% of the returns;
- Impact is pivotal in the identification of children who are disabled although for some children the condition is controlled through treatment;
- Parents reported that they found the questionnaire very useable and clear;
- The questionnaire revealed children where the disability was invisible to some schools;
- Schools valued having explicit directions to guide their analysis of the returns although not every school followed them and there appeared to be some misunderstanding about the role of impact in identifying disability;
- There was therefore some inconsistency in recording and reporting this information;
- Almost half of the schools reported taking actions as a result of the data, reporting that this new information provided more detail to that which is currently collected;
- Schools required a different time-scale for collecting pupil views to complement and enhance these data.

Background

The DCSF commissioned research in 2008 to develop a basic data collection tool to help schools identify:

- Whether a child has a disability – in line with the Disability Discrimination Act (2005) definition
- The nature of the child's disability
- The child's support needs

This research confirmed the importance of gathering data on disability with explicit reference to impact, which requires data collection from both parents and children. A toolkit was designed that incorporates a national questionnaire for use with parents and a suite of five flexible tools for use with children.

Aim

The aim of the project was to test the draft tools for identifying disability and accompanying guidance in a sample of all types of maintained schools in order to assess their usability and reliability and whether they resulted in the generation of robust and consistent data that could reliably inform school returns for the annual School Census.

Methodology

A national survey was conducted involving:

- testing the parent questionnaire and methods for collecting pupil views on the barriers and support to learning in 50 schools;
- completion by schools of an online summary form identifying children who, on the basis of parental returns are disabled, following an algorithm provided by the research team;
- telephone interviews with 25 parents who completed the questionnaire
- observation of 37 pupils in class;
- interviews with staff in 45 schools about the use and usability of the tools and the resulting data.

Findings

Parent questionnaire

The overall return rate for the project was 42% with 3% returned online. School level returns ranged from 5% to 80% with the largest range from secondary schools. Schools used a number of strategies to increase return rates, one of the most efficient being text messaging. However socio-economic factors appeared to contribute highly to return rates.

Children identified as disabled

Taking impact as the starting point for identifying disability: 270 children were identified, around 11% of the returns. This included 78% of children in special schools. In part this reinforces previous research findings that not all children with special educational needs are disabled. It is likely however that this also reflects the adjustments and adaptations made by both home and school that enable children with multiple areas of need to participate in activities. A higher than expected proportion of the sample in mainstream primary schools, were male. This may reflect the high numbers of children identified with ASD.

The impact question falsely excluded some children for whom treatment offsets the condition including deaf children and those with epilepsy suggesting some adjustments are needed to the wording and ordering of the impact question.

Observational Data

Observations were carried out to validate the questionnaire data and investigate further children for whom parental responses were a surprise for schools. These included a measure to indicate how well engaged in the lesson the pupil was and therefore whether or not schools might have concerns because the level of involvement was very low or whether they would be assured by high levels of participation.

Overall the data suggest that schools are aware of difficulties that give rise to problems with participation in class. However the parental questionnaire revealed experienced difficulties that remain invisible to the school and have hitherto been unreported raising the need to reinstate a questionnaire item which probes impact of a disability on school attendance. The observations also revealed cases where there was no difficulty experienced outside the school.

Gathering Children’s Views on the Barriers and Supports to Learning

Twenty schools planned to use the flexible tools during the trial period, but in the event only 13 schools collected children’s views. Two schools out of the 13 chose to use their own symbol questionnaire. Low uptake was reported to be due to insufficient time to administer both flexible tools and parents’ questionnaire and to lack of confidence. Several schools indicated that they would use them at a later date. Compared to previous studies, schools were more inclined to select tools designed with the needs of their particular pupils in mind but as before, the online questionnaire proved to be the most popular. For some pupils, it was necessary to experiment with more than one tool to find out which offered the pupil the most appropriate means to express their views about what helps or hinders them in school.

Schools Analysis of the Data

There was not a perfect match between those children identified by the research team and those recorded by schools in the online summary census despite using the same algorithm. The school entries included 104 children not identified by the research team, all but three of whom experienced no impact in relation to their impairments. Five schools (three primary, and two secondary) accounted for 84 (81%) of the additional children indicating the importance of schools understanding the role of impact.

Stakeholder Feedback

Parents

Twenty five parents were interviewed, all but two had children that experienced difficulties in some area of life and eleven met the criteria for disability. Parents reported that they found the questionnaire very usable and clear. They raised no concerns or qualms about their involvement or their child’s involvement, or the questionnaire. While the parent interviews were primarily to test the usability and the clarity of the questionnaire, interviews with parents about the process of completing the questionnaire (which included validation of the responses), did not reveal further (significant) information suggesting that the questionnaire provides appropriately detailed information and parents are able to make a consistent decision in response to items.

Schools

Completed interview and evaluation forms were received from 45 schools (90% of the sample) and their reaction towards the process of sifting through the questionnaires and identifying students judged by parents to have disabilities was overwhelmingly positive. Thirty three (of the 45 schools that returned questionnaires) found the process undemanding. Feedback included, “Easy”, “Very straightforward” and most schools found the process of distributing and gathering data from parents unproblematic. Almost half the schools (20 out of 45) opted to alert parents before sending out the questionnaire.

Twenty schools (out of 45) indicated that they would take some action as a result of the data collected from the parental questionnaire including:

- identifying students’ difficulties, for example “to highlight any undiscovered issues mentioned by parents”
- using the survey information to liaise with other professionals about health problems;
- updating information without targeting students suspected of being disabled;
- informing pastoral and SEN planning;
- contributing to the School Development Plan and Disability Scheme;
- informing possible Continuing Professional Development events;
- using the information to review and update information on students’ statements.

The data added to the ‘whole picture’ by increasing specific knowledge of students’ difficulties, and helping schools improve their response to diverse needs.

It was recognized that the process provides more detailed information for the school, particularly in relation to impact, and ‘about *what* the disability is’, and was therefore much more detailed than current SIMS data.

Main Recommendations

The parent questionnaire had provided robust information about a defining aspect of disability, namely the impact, providing schools with additional and sometimes surprising data. Some schools appeared to use impairment rather than impact for the starting point to identify disabled children thereby including children not covered by the Equality Act 2010. Further guidance and support is therefore needed to ensure that the data that are collected reliably inform recording and reporting. The inclusion of a question concerning absence as a result of a medical condition or difficulty would enable schools to recognize an impairment or health condition which is not manifested in school. The impact question requires some alteration to differentiate between individuals where, without treatment, the condition would have a substantial impact on daily life, and those for whom the impact is minor or trivial without the use of medication, aids and equipment.

Some schools, collected data from over three-quarters of their target group. There is however a challenge for schools in some of the most deprived areas to gain high return rates and this suggests that the timing of the data collection needs to coincide with times when schools routinely see all parents i.e. at admission. Data will require refreshing during a child's school career. The study has indicated that there are a small group of children who, whilst not currently meeting criteria for disability, schools may wish to follow up or have a “watching brief”. The development of an online questionnaire that schools can complete with parents has the advantage of entering data directly into a data base and a simple formula can be used to inform reports on the Annual school census.

Views gathered from children on the barriers and supports to their life in school make an important contribution to these data. While many schools are confident in the selection and use of appropriate tools, others will require encouragement and support to realise the particular benefits and ensure that this is carried out as a meaningful activity which informs the adjustments they make to enhance provision for disabled children.

1.0 Background

There has been an ongoing concern about the lack of reliable data on disabled children in schools. Schools in England are currently required to collect data on children with Special Educational Need (SEN), but this does not capture information about all disabled children. Previous research has pointed to the way in which schools and Local Authorities conflate disability and SEN (Mooney et al, 2008). While these form overlapping groups there are substantial differences: Grant et al., (2005) found that 52% of their sample of children who met the Disability Discrimination Act (2005) criteria did not have SEN and Porter et al. (2009) that around half the sample of children with SEN did not have a disability.

To date there has been no consistent way of identifying and categorising disabilities. The lack of this information may seriously restrict capacity at all levels of policy and practice to understand and respond to the needs of disabled children and their families in line with the Disability Equality Duty (DED).

The Disability Discrimination Act (DDA) (2005) and yet to be enforced Equality Act 2010 widen the meaning of disability far beyond definitions previously used within the general population and to some extent by professionals in welfare services. This new definition includes individuals with impairment where the difficulty may be largely invisible to schools (e.g. mental health difficulties or medical conditions where the treatment is effective in offsetting the impact of the condition in the school setting). Schools are therefore not in a position to validate, first hand, the presence or incidence of disability. However they do have an important role to play given their knowledge of children who experience difficulties in the particular context of school.

A central element of the DDA definition concerns the impact of disability, foregrounding the importance of the subjective experience of the child and his or her family. The extension by the DDA definition to include issues of mental health and medical conditions such as HIV and facial disfigurements highlights the importance of recognizing that “impairment” can only be viewed within the context of its impact. It therefore recognizes the contribution played by the supports that are in place.

In response to these challenges, the DCSF commissioned research in 2008 to develop a basic data collection tool to help schools identify:

- Whether a child has a disability – in line with the DDA definition
- The nature of the child’s disability
- The child’s support needs

This research confirmed the importance of gathering data on disability with explicit reference to impact, the experience of a substantial adverse effect on everyday activities which requires data collection from both parents and children. A toolkit was designed that incorporates a national questionnaire for use with parents and a suite of five flexible tools for use with children. The current project relates to a requirement to test the usability and reliability of the draft toolkit with a sample of schools nationally. Outputs from the project will be a revised toolkit in line with findings about usability and a research report setting out methodology, key findings and recommendations for usage of the tools.

1.1 Project Aim

The aim of the project is to test the draft tools for identifying disability and accompanying guidance in a sample of all types of maintained schools in order to assess whether they result in the generation of robust and consistent data that could reliably inform school returns for the annual School Census.

1.2 Project Objectives

- To assess the usability of a parental questionnaire and flexible tools across different types of maintained schools;
- To assess the validity of the data generated by the tools across schools and types and levels of disability;
- To assess the reliability of schools' use of the data in responding to proposed disability questions in the School Census;
- To explore schools' proposed use of the data with particular regard to the DED;
- To identify good practice in the use of the tools;
- To consider the implications in relation to the form and format of the tools, the accompanying guidance and the training needs of staff;
- To refine the tools and guidance on the basis of these empirical data.

1.3 Issues for the Methodology

Disability is a complex area. Validation is not simply about confirming the presence of a longstanding impairment as it is the impact of impairment which forms a pivotal part of the designation. Validation methods need to reflect the cultural and other differences between families, schools and communities that mediate the experience of that impairment. Routines and favoured activities vary between families. Parents have varied expectations of their children and of family life, and the presence of impairment can make a differential impact on daily life. Parents can therefore be differently placed to make adaptations and accommodations. This can bring perceived disparity between the judgements of impact by parents of children with identical impairments and in consequence whether or not they meet the DDA definition. Notably therefore it was decided that the researchers would not simply ask schools to confirm the presence or absence of disability (thereby negating the purpose of having a parental questionnaire) but would investigate returns that were surprising to schools and scrutinise these more closely. This scrutiny included an analysis of the barriers and supports that are existent in school and that may be present or lacking at home, and observations of pupils' engagement in school.

It was also considered important to gain the views of a sample of parents on the process of completing the questionnaire and to explore any uncertainties that existed for them in completing the form and providing valid data. One challenge was to gain a representative sample as parents self-nominate for follow-up.

Use and usability of the process were also viewed as important areas for study and these needed to be considered in the light of the different engagement levels of schools and their previous experience of collecting disability data. Key questions included whether the process was manageable and the guidance transparent and easy to follow. It was recognised that this would depend on the number of questionnaires returned. We anticipated that there would be differences between primary, secondary and special. Previous research has illustrated variation in the way schools interpret and record SEN data and therefore a further element of usability concerns the consistency with which schools would interpret and report on children identified as disabled.

2.0 Procedures

2.1 Sample Identification

Local Authorities were contacted (some through the Regional Partnership Leaders) with information about the project and invited to nominate between 5-10 schools. Additionally information was included in the LA Bulletin sent out by the DCSF and on the TeacherNet website. Some 22 authorities expressed an interest of which 11 were able to identify schools within the available time-frame (one month) and additionally one special school sought to be included despite the authority not being able to take part. Levels of initial interest did not necessarily predict numbers of schools recruited and a number of different approaches were adopted: some authorities approached particular schools; some put out a general call for responses; and one authority nominated schools without their prior notification. Schools therefore entered the project under different conditions. They were recruited in two waves enabling comparisons of working under slightly different time-scales and providing differential opportunities for follow-up visits.

Schools were briefed through a combination of processes. They all received a full information pack and those who opted into the project early were invited to a briefing meeting, set up in 6 Local Authorities. A podcast was made for schools where staff were unable to attend and posted on the project website. Schools were invited to provide information that would enable their materials to be individualised through the inclusion of the head teachers name on the letter to schools and the name of the person who would be receiving the questionnaires and providing confidentiality for the responses.

In order to lessen the administrative load, schools were offered different levels of involvement to match their capability to meet the time constraints. Schools chose the target year group(s) and which (if any) of the flexible tools to use (but with the proviso that work was carried out with a sample of the children for whom parental returns had been received). Schools were supplied with all materials (questionnaires, personalised covering letters, additional information for parents, reminder letters, and return envelopes) and given a 2-week (wave 2) or 3-week (wave 1) timeframe to encourage returns. In this way we involved schools with differing levels of engagement in the project.

2.2 Parent Questionnaire Returns

Schools were asked to review their returns following a simple sifting process and guidance to identify pupils who met the DDA definition and to complete a simple online form ONLY entering data about those pupils who meet the DDA criteria.

There was the potential to identify three groups of children who met the DDA requirement:

Group 1: Children whose parents answered yes to their having a physical or mental health condition, impairment or difficulty which had persisted for a year of more and which had a substantial impact on daily life.
(Q4i), 4ii) and 6c), d) or e)

Group 2: Children who were not included in group 1 but who had a significant trauma or accident that continued to impact on daily life more than a year after the event.
Q3 and 6c), d) or e)

Group 3: Children who had a diagnosed longstanding impairment or medical condition, had seen a professional about this and it had a substantial impact on their daily life but parents had left parts of Q4 blank or indicated they were unsure.
Q5 & and 6c), d) or e)

Schools were asked to return all completed questionnaires (using prepaid and addressed envelopes) to the research team for the data to be entered online for analysis by the research team, testing the algorithm for identifying disabled pupils against those entered by the schools and identifying internal discrepancies.

Schools will be given a data base of these returns and Local Authorities provided with an overview of schools' involvement in the project.

2.3 Follow Up Visits

Validation visits were made to 31 schools: 12 secondary, 13 primary and 6 special. Staff responsible for collating the returned questionnaires were interviewed about the use and usability of the questionnaire. The interview included questions about process of gathering data, the sifting and recording of the data, the use and usefulness of the data it generated, how the process compared with their existing systems of gathering disability data and their views on systems and structures for the future, given the intention to include a disability question in the annual School Census. A short paper version of this interview schedule was also sent for completion to schools that were not visited.

Where possible during the school visits the research team also observed 1-6 children of parents who had returned the questionnaire including those who provided information that was a surprise to schools. Researchers carried out short narrative observations of 1-2 activities over a 40 minute period, noting in particular the level of participation and engagement of the pupil (adapted from Laevers et al 2002)[1], any barriers and supports to learning and any areas of need that were noticeable during the session.

A final element of the school visit was to interview any member of staff who had used one of the flexible tools to collect children's views, again exploring the use and usefulness of the data gathered. In a few instances researchers were able to observe the flexible tools being used. Schools that had used one of the flexible tools but had not been visited received an evaluation form and asked to rate how useful they found the tool they had used.

2.4 Parent Interviews

Parents were invited to give their contact details if they were willing to talk with the research team about their experience of completing the questionnaire and any uncertainties or confusions they encountered. Twenty-five parents were interviewed, sampling across categories of children who met the DDA criteria and different levels of impact, as well as who had entered data on other areas of the form.

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[1] We adapted a scale for monitoring involvement and engagement in lessons put forward in the following text: Laevers F., Vandebussche E., Kog M., Depondt L. (2002) A process-oriented child monitoring system for young children. Centre for Experiential Education

3.0 Results

3.1 Schools and LAs

Twelve Local Authorities were represented in the project, including unitary, county, metropolitan and Greater London Authority districts situated in inner city, urban and rural locations. Table 1 shows how these were distributed.

Local Authority	Region	Designation of LA	Urban / Rural / Inner city	Number of schools in project at start
1	South	Unitary	Urban	2
2	South West	Unitary	Urban	2
3	London	Greater London Authority (outer)	Urban	1
4	Midlands	Unitary	Urban	1
5	London	Greater London Authority (inner)	Urban	8
6	North East	Metropolitan district	Urban	2
7	West Midlands	Metropolitan district	Urban	4
8	South West	County	Rural	6
9	South	Unitary	Urban	1
10	North West	Metropolitan district	Urban	7
11	South	County	Rural	10
12	West Midlands	County	Rural	8
	Total			52

Table 1: Type of Local Authority.
Source : www.communities.gov.uk/documents/statistics/pdf/1311207.pdf

In order to explore how the sample of Local Authorities responded to pupil need we examined the proportion of children who received a statement and the proportion of those educated in mainstream schools. This analysis revealed a range (in project LAs) of 0.9%- 3.5% of children receiving a statement with between 38%-51% of those children attending mainstream provision. The participation of a highly inclusive authority, with only one special school and very low rates of statementing, ensured that children with the range of SEN were included in the sample. Statementing percentages across participating Local Authorities are presented in Table 2.

Region	Met / uni	Percentage of pupils with Statements of SEN (proportion in m/s)
South	Unitary	2.2 (40%)
South West	Unitary	3.1 (43%)
London	Greater London Authority (outer)	3.3 (51%)
Midlands	Unitary	3.1 (37%)
London	Greater London Authority (inner)	0.9 (58%)
North East	Metropolitan district	3.5 (42%)
West Midlands	Metropolitan district	2.8 (39%)
South West	County	1.6 (38%)
South	Unitary	2.1 (28%)
North West	Metropolitan district	3.0 (53%)
South	County	2.3 (36%)
West Midlands	County	3.0 (44%)
Average for England		2.7 (47%)

Table 2: Local Authorities and Special Educational Needs
Source: DCSF: Special Educational Needs in England: January 2009

In total 52 schools were recruited: 48% of these are primary schools (including one infant and 1 middle school, 35% secondary and 17% special. Table 3 below sets out the distribution across wave and Local Authority.

Wave	**Primary**	**Secondary**	**Special**	**Total**
Wave 1	14	8	5	27
Wave 2	11	10	4	25
Total	25	18	9	52
	(48%)	(35%)	(17%)	(100%)

Table 3: Distribution of Schools By Phase and Wave

The nine special schools included one school for pupils with Behaviour, Emotional and Social Difficulties (BESD), two schools that were designated Moderate Learning Difficulties (MLD) and six that were designated Severe Learning Difficulties (SLD). However, as Appendix C reveals the special schools often had a range of pupils outside of their specific designation, most notably all but one explicitly also provide for pupils with ASD. In addition to these schools the sample also included a range of resourced mainstream provision, including one primary school with a unit for children with a hearing impairment, another with provision for children with ASD, and a third for severe Language and Communication Difficulties. Three secondary schools also have additional special provision, one with a unit for pupils with PMLD, one resource provision for pupils with Specific Learning Difficulties (SpLD) and a third with integrated MLD and SLD provision

3. 2 Pupils

In terms of numbers of pupils, schools specified a total of 6,208 to receive the parent questionnaire (2382 primary, 3426 primary and 400 special). Subsequently two secondary schools failed to return any data to the project team and were deemed to have withdrawn from the project leaving a final sample of 50 schools. Despite the loss of two schools final numbers slightly over-represent mainstream secondary school-aged pupils (in contrast to previous trials) as shown in Table 4.

Phase by Pupil Numbers			
Primary	Secondary	Special	Total
2382	3426	400	6208
38%	55%	6%	

Table 4: Distributed Questionnaires, Pupil Numbers and Percentage by Phase

3.3 Levels of Engagement

Of the 25 primary schools, three schools opted to collect data for all year groups, 16 selected a single year group (the most favoured being Year 3) and six schools chose two year groups. The secondary schools all chose a single year group (Year 7 being the most favoured) and one school elected to survey a single tutor group. The special schools mirrored the primary schools in that three chose to survey the whole school, one chose two year groups and the remaining five schools selected single year groups.

Planned flexible tool use was variable with 13 of the schools not intending to use the tools and a further 19 being unsure. A larger proportion of primary and special schools planned to use one of the flexible tools compared to the secondary schools.

	No	Unsure	Yes	Total
Primary	5	8	12	25
Special	3	1	5	9
Secondary	5	8	3	16
Totals	13	17	20	50

Table 5: Plans for Use of the Flexible Tools

Schools that were recruited during wave 1 were much more likely to indicate they intended to use the flexible tools than schools who entered the project in wave 2, (65% and 13% respectively said yes).

4.0 Is the Data Collectable?

2537 questionnaires were returned to schools, 72 of them online. Table 6 shows the split by gender (where known) and by phase of schools of the responses.

Phase	Boy	Girl
Primary	(52%	(48%)
Secondary	(48%)	(52%)
Special	(71%)	(29%)
Total	(52%)	(48%)

Table 6: Pupils by Phase and Gender

Boys were slightly over-represented in the returns and this was particularly true of those from special schools.

4.1 Return Rates

The overall return rate was 42%, which despite the tighter time scale was exactly comparable to previous phases of the project (Porter et al 2008). As with the previous phase secondary schools provided both the highest and lowest response rate. Notably the school with the lowest rate was recruited by being nominated by their local authority and received briefing through the post only. This school had no time to brief parents before the questionnaires were sent out but did issue reminder letters.

Phase	Average Return rates	Minimum return rate	Maximum return rate
Primary	51%	27%	71%
Secondary	35%	5%	83%
Special	49%	31%	75%

Table 7: Return Rates by Phase

Twenty seven of the 49 schools who returned questionnaires (15 primary schools, 10secondary and 2 special) received online responses but this represented less than 2% of their total for the majority of schools.

There was no clear relationship between return rates and when schools entered the project, i.e. whether they were wave 1 or wave 2 schools. Graphs can be found in Appendix D.

Return rates from primary schools were slightly higher than in the previous phase (51% rather than 42%) as were those from special schools (49% rather than 46%) but marginally lower on average in secondary schools (34% rather than 39%).

5.0 Who Met the DDA Criteria?

In total 270 children were identified through the algorithm to meet the criteria set out in the DDA and explained below. Data are set out by phase in table 8. The gender divide In primary schools was more uneven (72% boys and 38% girls) than secondary schools (46% boys and 54% girls). Special schools were divided 71% boys again reflecting the total sample. It is unclear why prevalence rates for boys are higher in primary schools. National figures for disability are generally only slightly higher for mild disability in boys although substantially higher for severe disability (ONS 2004)

Phase	Group1	Group 2	Group3	Total
Primary	53	1	5	59
Secondary	45	4	5	54
Special	153		4	157
Total	251	5	14	270

Table 8: Children who meet the DDA criteria

When findings from the previous phase of the project are considered, differences emerge in the proportion of returns for children in mainstream but not special schools. The 2008 study found 9% of the returns from primary schools met the DDA criteria and 12% of those from secondary schools. This may simply reflect differences in who returned the questionnaire or that the improved format of the key question differentiated better between children. The proportion of pupils identified in special schools was identical to the 2008 study.

One of the most prevalent diagnoses was being on the autistic spectrum. This accounted for some or all of the difficulties experienced by 40% of the children and a further 11% of children had asthma. The previous study also found that ASD and asthma were the two most prevalent conditions although figures for ASD are notably higher here. This may reflect some skewing of the sample as all specialist forms of provision explicitly also catered for pupils with ASD and also ASD specialist resourced mainstream provision was included in the sample.

5.1 Group 1 Children with a Longstanding Health Condition

The first group of children who met the DDA criteria were children whose parents had indicated that they had a physical or mental health condition, impairment or difficulty, that had lasted for a year or more (or was likely to) and affected their child in their daily life. 251 parents indicated their child met these criteria. These formed 10% of the returns. Unsurprisingly the highest proportion of the sample population was in special school settings with 78% of parents reporting their child met these specific DDA criteria. In primary schools the proportion was 4% and in secondary schools 4%.

Phase	No	Yes	Total
Primary	1169	53	1222
Secondary	1074	45	1119
Special	43	153	196
Total	2286	251	2537

Table 9: Pupils in Group 1

5.1.1 Did Parents Record Having Seen a Professional?

The majority (98%) of parents with children who met the Group 1 criteria reported that they had seen a professional. Of the six parents who said they hadn't four were in special schools and it is therefore highly probable that they would have seen a professional prior to entry.

	Parents in Group 1 whose child had seen a professional		Total
Phase	No	Yes	
Primary	1	52	53
Secondary	1	44	45
Special	4	149	153
Total	6	245	251

Table 10: Group 1 and professionals

5.1.2 Did Parents Provide a Diagnosis?

233 (93%) of Group 1 parents provided information in relation to a diagnosis. One of the most prevalent diagnoses was being on the autistic spectrum: 108 children had this diagnosis although in many cases it was one of several. 29 children were diagnosed as having ADHD, 29 asthma, 19 epilepsy, 13 cerebral palsy and 11 Down syndrome. Generic terms were used frequently to describe the diagnosis the most commonly used was global developmental delay (24 children). For seven pupils the assessment process was ongoing and for a further five the diagnoses were uncertain, with one parent stating they could not remember and another that the diagnosis was private.

	Parents in Group 1 providing a diagnosis for their Child		Total
Phase	No	Yes	
Primary	3	50	53
Secondary	1	44	45
Special	14	139	153
Total	18	233	251

Table 11: Group 1 and Diagnosis

5.1.3 What was the Impact on Daily Life?

A significant aspect of the criteria for inclusion within Group 1 is that the impairment or medical condition has a substantial (i.e. not trivial) impact on daily life. In some cases the impact was felt on almost all activities. This included 45% of the pupils who met the definition in special schools, 11% for secondary schools and 28% for primary schools.

Phase	**Group 1: Level of Impact on every day life**	**No of pupils**	**% of pupils**
Primary	c) There are particular times and situations when activities are regularly stopped or limited because of the difficulty	20	38%
	d) It frequently affects a number of daily activities	18	34%
	e) The impact is felt on almost all activities every day	15	28%
Primary Total		53	100%
Secondary	c) There are particular times and situations when activities are regularly stopped or limited because of the difficulty	28	62%
	d) It frequently affects a number of daily activities	12	27%
	e) The impact is felt on almost all activities every day	5	11%
Secondary Total		45	100%
Special	c) There are particular times and situations when activities are regularly stopped or limited because of the difficulty	48	31%
	d) It frequently affects a number of daily activities	36	24%
	e) The impact is felt on almost all activities every day	69	45%
Special Total		153	100%
Overall Total		251	

Table 12: Group 1 and Impact

In primary and secondary schools the impact was more likely to occur at particular times and situations, although notably the distribution across categories of impact was more evenly spread in the primary school. For almost half the pupils in special schools the impact was experienced on almost all activities every day.

	blank	Don't know	No	Sometimes	Yes	Total
Classroom Learning	4	7	17	41	182	251
Interactions with his or her peers	5	9	36	49	152	251
Joining in Other school activities	5	12	34	66	134	251
Daily Activities at home			38	66	147	251
Taking a full part in activities at home			42	79	130	251
Taking part in activities outside the home	1		28	70	152	251

Table 13: Group 1 Impact on Activities at School and at Home

The impact for all but seven pupils was captured by questions 1 and 2 that addressed activities at home and in school. The exceptions are seven pupils, six of whom had asthma and one severe migraine. The parent interviews shed further light on how difficult it was to respond where a health condition occurred irregularly.

5.1.4 How Do Parents Describe Their Needs (Children in Need Category)?

Perhaps unsurprisingly the largest category of need was in the area of learning followed (in order of size) by communication, behaviour and personal care.

How is the child affected?	No. in Grp 1	% of Grp 1
a) Mobility: getting around in or outside the home	105	42%
b) Hand function: holding and touching	71	28%
c) Personal care: has difficulty washing, going to the toilet, dressing	134	53%
d) Eating and drinking: has difficulty eating or drinking by themselves or sickness or lack of appetite	78	31%
e) Incontinence: has difficulty controlling the passage of urine and/or faeces	77	31%
f) Communication: speaking and/or understanding others	185	74%
g) Learning: has special educational needs	202	80%
h) Hearing	29	12%
i) Vision	48	19%
j) Behaviour: has a condition that leads to the child being hyperactive or having a short attention span or getting frustrated or behaving in a socially unacceptable manner	158	63%
k) Consciousness: has fits or seizures	34	14%
l) Diagnosed with Autism, Asperger Syndrome or Autistic Spectrum Disorder (ASD)	104	41%
m) Palliative care needs	5	2%
n) Mental health needs e.g. depression, anxiety	52	21%

Table 14: Group 1 and CIN category (N=238)

Additionally it is important to look at the numbers of children with multiple areas of need. As might be expected pupils in special schools were more likely to have multiple needs and pupils in mainstream in Group 1 having a markedly higher proportion of children with a single area of need.

Parents had the opportunity to add comments in an “other” category and ten of the 13 who did not tick a category provided additional information. These referred to breathlessness and difficulty doing sport and to issues of safety.

In order to examine whether additional categories of response were needed for this question, all entries under “other” were examined. 53 parents provided additional information. There were a number of reoccurring themes of which lack of awareness of danger was cited by seven parents, breathing difficulties generally (4) or in the context of sport (5) was another and health, particularly pain, nausea, tiredness, infections (5) and absence from school (2) was noted. Other parental comments largely added clarification and illustration to the categories they had already ticked.

	Total Number of Areas of Needs (excluding other)													
	0	1	2	3	4	5	6	7	8	9	10	11	12	Total
Primary	3	9		8	4	8	5	6	5	1	1	3		53
Secondary	10	11	6	6	5	3	1	1	1			1		45
Special		1	9	15	22	23	19	17	18	18	7	4		153
Total	13	21	15	29	31	34	25	24	24	19	8	8		251

Table 15: Number of Areas of Need by Phase for Group 1

5.2 Group 2: Children Who Had Experienced a Significant Accident or Trauma

Parents of 105 children indicated on their forms that their child had an accident or trauma, but only 34 were reported to experience a continued impact on daily life and all but five of the children had already been included in Group 1 above. These included four girls and a boy, all of whom had seen a professional and been given a diagnosis. Four of these children are in secondary schools and one in primary. Parents of three children reported a mental health disorder arising from the incident; and two had mobility problems as a result of the accident. All parents in Group 2 provided a diagnosis for their child. One was in the primary phase and four were in secondary school.

The impact of the trauma on everyday life varied from regularly stopping or limiting activities at particular times (2 pupils) to frequently affecting daily activities (1 pupil) and in two cases having an impact on almost all activities everyday.

Parents in Group 2 responses to Q6 How does it affect your child in their daily life?	Yes
c) There are particular times and situations when activities are regularly stopped or limited because of the difficulty	2
d) It frequently affects a number of daily activities	1
e) The impact is felt on almost all activities every day	2
Total	5

Table 16: Group 2 by Impact

5.3 Group 3 Children Who Had a Diagnosis Which Impacted on Daily Life

The literature suggests that parents may be reluctant to indicate that their child has a longstanding condition. Instead of simply relying on responses to question 4 we looked for any additional information that indicated some pupils may be falsely excluded through the algorithm.

This group comprise children who are *not* already included in the previous categories whose parents report an impact and provide a diagnosis that is longstanding even though they do not tick the disability and longstanding question.

Nineteen parents entered information under these categories and these data were examined more closely. All but one had seen a professional (the exception was a parent who indicated their child had dyslexia -because there is no indication that the diagnosis was a result of a professional consultation this pupil needs to be the subject of further discussion with the parent in the light of he recorded impact, category 6c) i.e. particular times and places). A further four did not identify a confirmed diagnosis, usually because it was on-going and they will be included in a “follow-up” group (discussed below). Impact data are provided for the remaining 14 in Table 17.

Diagnosis and Impact	Group 3
Q6 Affect your child in their daily life?	Yes
c) There are particular times and situations when activities are regularly stopped or limited because of the difficulty	6
d) It frequently affects a number of daily activities	5
e) The impact is felt on almost all activities every day	3
Total	14

Table 17: Group 3 by Impact

Of the 14 children in Group 3, five were in primary school, five in secondary and four in special schools.

5.4 Follow-up for dialogue

We now consider the responses of parents whose returns suggested that they were unsure how to respond to items on the questionnaire, including those who left particular key questions blank. These include parents who either indicated they were unsure or left either question 4i) or 4ii) or both blank and yet elsewhere on the form indicated their child had a difficulty that impacted on daily life. Blank responses may indicate that the parent forgot to put a mark against that question or that they were considering how to respond, perhaps with the intention of coming back to it or indeed that they hadn’t read the question. All possibilities suggest that it is important to check through other elements of the questionnaire to see whether they should be included under the DDA definition. In fact only seven parents provided partial data that indicated their child may in the future be viewed as being disabled, five in primary school and two in secondary.

	Follow Up Group
Phase	No of pupils
Primary	5
Secondary	3
Special	
Total	8

Table 18: Follow Up Group by Phase

All of these parents said their child's difficulties impact on daily life, indeed for one young person it impacted on almost all activities. Moreover all indicated one or more category in which their child had particular needs. Yet not all parents indicated that their child had seen a professional (5). In three cases parents were awaiting a diagnosis and in the case of a further pupil the difficulty had only recently appeared. In the light of this data it is unsurprising that parents were uncertain in some of their responses. Perhaps notably two of the pupils had mental health difficulties.

	Follow Up Group
Q6 Affect your child in their daily life?	No. of pupils
d) It frequently affects a number of daily activities	4
c) There are particular times and situations when activities are regularly stopped or limited because of the difficulty	3
e) The impact is felt on almost all activities every day	1
Total	8

Table 19: Follow Up by Impact

The small size of this Follow-Up group suggests that while some parents may have been uncertain about particular questions they felt able to respond to most of the items. Although this group may fall into the disabled category at some point, notably two parents did not want to discuss the issues with teachers and therefore conversations need to be handled sensitively.

5.5 Impact and Medication

The analysis to this point has taken impact as pivotal but the DDA also states that the effect of the impairment has to be considered ignoring all treatments. It is therefore possible that some children had been excluded as their parents had indicated they felt no impact and this may have been because they received medication, special aids or equipment or diet. To investigate this issue the responses were examined concerning children whose parents had indicated they had a longstanding disability, received (medical) treatment of some form, and whose parents had stated "No difficulty. medication/aids/equipment allow my child to take a full part in home, community and school activities". Ninety three children fell into this category for whom diagnoses were provided for 85. The majority of these children (68 or 80%) were asthmatic with parents often indicating that it was mild e.g. "uses an inhaler on rare occasions", "Little bit of asthma". The question wording does not fully discriminate between those who, without such treatment, would experience a substantial impact on daily life and those for whom the effect would be minor or trivial. Also included within this combination of responses are six children with epilepsy who were on medication and therefore would likely meet the DDA definition and seven children with a hearing loss, six of whom have a hearing aid and one who is waiting for the delivery of such a device. These are also children who would probably be covered by the DDA[2]. There were also six pupils with hearing loss whose parents indicated they had physical aids but who referred to the disability having an occasional impact that was trivial or small. Taken together this suggests that the algorithm needs amending together with some re-wording of the impact question to ensure that these children are not falsely excluded.

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[2] Guidelines from the Equality and Human Rights Commission state: if a person with a hearing impairment wears a hearing aid the question as to whether his or her impairment has a substantial adverse effect is to be decided by reference to what the hearing level would be without the hearing aid. http://www.equalityhumanrights.com/uploaded_files/guidance_on_matters_to_be_taken_into_account_in_determining_questions_relating_to_the_definition_of_disability.pdf

5.6 In Summary

The data had therefore revealed three groups of pupils identified through the questionnaire that met the DDA criteria, and a fourth group for whom some adjustments to question order and phrasing are required to identify those whose condition is controlled through medical treatment and as a consequence are not affected in their daily life.

Later in the report we investigate whether these are the children entered by schools in the online census form.

6.0 Parent Feedback about the Form

Given the presence of “unsure responses” and of questions left blank it is important to consider the views of parents in completing the form. Twenty five parents were interviewed. Twenty one of the 25 parents had entered details of a diagnosis and eight of these reported an impact. A further two had reported an impact and provided no diagnosis although one child was seeing a professional. One parent had replied no to every question and two had identified single elements of difficulty in the opening questions. In terms of our groupings seven fell into Group 1, one in Group 2 and one in Group 3 leaving fourteen of the sample not meeting the DDA criteria.

Parents found the questionnaire very usable and clear. They raised no concerns or qualms about their involvement, their child’s involvement, the questionnaire or the interview, although one parent was confused as to the origin of the questionnaire. Two parents commented that the questionnaire was difficult to complete when their child was affected by more than one condition and one said that their tendency was to complete the questionnaire for only one of the conditions as it was difficult to keep both in mind while answering the questions. Interestingly by way of contrast, one parent of a multiple-disabled child did not make this observation. Thus, it may depend on how distinct the conditions are. One parent suggested separate questionnaires for physical and mental conditions, although for some children the distinction might not be so clear. The following issues were raised by individual parents: one parent commented on the advantage that the online version of the questionnaire had in filtering the questions for the parent i.e. they didn’t have to sift through what was/ was not applicable themselves; one parent wasn’t sure if completion of the questionnaire was compulsory or voluntary but felt that it was compulsory; one parent said that they had found the questionnaire daunting initially, before starting, but then found it ok once they had started; and one parent found the process of completing the questionnaire upsetting.

Figure 1 provides details of comments in relation to specific questions and provides important feedback for further refining of the presentation and wording of the questions. It draws attention to the challenge of enabling parents to indicate that their child has a psychological or mental health difficulty.

Qn	Comments
1	Some parents said they couldn't comment on difficulties in school activities as they weren't party to them. One parent thought this question was more to do with learning difficulties than anything else. One parent thought this was difficult to answer in terms of distinguishing between what was a 'classroom learning' difficulty and what was a 'day to day' difficulty.
2	One parent found this difficult to answer in relation to their child's difficulty (asthma) when a problem only occurred 'once in a blue moon'
3	One parent wasn't sure what traumas were relevant and this is further indicated in the comment that; One parent thought this question should cover psychological aspects
4i	The list of conditions was seen to be helpful and problematic (but not for the same person). One parent missed 'learning difficulty' in what they thought was a long list and one which should have specified conditions more specifically e.g. including dyslexia and dyspraxia (i.e. they were looking for named conditions rather than 'learning difficulty'); 'It would be better to ask what disability/special need a child has rather than present a big list which makes you switch off (and is less polite)'. 'Eating disorders aren't mentioned – should they be?' 'Should there be an 'other' category'? 'There should be more options for anxiety'.
4ii	Doesn't cater for the severity of conditions; suggestion of a further clarification 'is someone on medication all the time or not?' 'Seems a pointless question if the condition is for life'.
6	One parent said they found it difficult to know which to tick for a complex condition and didn't know what they were supposed to be comparing with – relative to life without a disabled child?
7	One parent didn't know whether to tick or not – their child has a mental disability but was not depressed

Figure 1: Parental Responses Concerning Specific Questions

Clarity of questionnaire
The great majority of parents commented that the questions themselves were clear with just one parent finding some of the questions confusing (Q1, Q2, Q4i, Q4ii). No detail was supplied on the specific problems. The name suggests this may have been a parent for whom English was not their first language.

One parent felt that the questionnaire repeated itself as they repeated the same information for different responses. However, this was possibly because they included more than the question needed – the information repeated was about their child's medication.

Pertinence of questionnaire
Two parents thought that the questionnaire/questions weren't relevant for them as their child was already 'in the system' i.e. in a special school and that their needs were being (better) catered for. One of these parents said that their responses would have been different had their child still been in mainstream provision.

While the parent interviews were primarily to test the usability and the clarity of the questionnaire, interviews with parents about the process of completing the questionnaire (which included validation of the responses), did not reveal further (significant) information. That is, the questionnaire in itself provided full and sufficient responses. However as the previous phase identified there is a challenge to providing a definitive list of impairments in question 4i).

7.0 Observational Data

A further source of evidence is provided through our observations of 42 children in school. These included three children for whom there was no returned parent questionnaire, one with the wrong name and one for whom we had no surname and were therefore unable to match them with confidence to the database.

Phase	Group1	Group 2	Group3	Follow Up Group	Others	Total
Primary	10			2	3	15
Secondary	8	1	1		4	14
Special	4				4	8
Total	22	1	1	2	11	37

Table 20: Observed Children by Group

It was not possible to observe pupils in every visited school and some pupils that schools suggested we observe were absent on the day of the visit. The majority (59%) of the observed children fell in our designated group 1.

Of the 42 observations that were carried out there were 13 cases where the response to the parental questionnaire surprised the school and data concerning these pupils were given particular scrutiny. In particular we looked at the levels of participation assigned by the researcher on a scale from 1 (shows little or no involvement or activity) to 5 (shows high and sustained involvement) during the observed lessons. Although this was an approximate measure it served to indicate how well engaged in the lesson the pupil was and therefore whether or not schools might have concerns because the level of involvement was very low or whether they would be assured by high levels of participation.

7.1. Case Studies where the response to the parental questionnaire surprised the school

a. Children who were observed to be a concern with respect to participation in class

Of the13 "surprise children" there were five children whose class participation could be judged to be problematic. They were scored as 1 or 2 on a five point scale, that is they were not participating in an activity showing little awareness of what was going on in the classroom, little receptivity to the learning opportunities on offer or they showed small fleeting moments of involvement or participation. Of these five there four cases where the school was surprised that the parents did not report the same order of difficulty observed in school.

Child KC attends a mainstream secondary school. She did not speak in school but did at home. The staff were aware of the child's difficulties and had been specifically asked not to put pressure on her to speak. In the classroom she did not engage with the primary task, which was a maths test, and she spent much of her time looking around the room in a distracted and 'dreamy' fashion. Her teacher said that she was often like this in class. Her parents answered that her condition was longstanding on the questionnaire although they did not consider that it had an impact on her daily life. They did feel that she experienced difficulty interacting with classmates and with speaking and understanding others. The young person had been seen by a hypnotist and a doctor.

The fifth child was a case where the school was surprised and had not recognised the barriers to progress. The child, XY, had Spina Bifida which was unknown to the school. As we can see from the details below parents had important information to share with the school.

On the questionnaire his parents indicated that his condition was long standing and that it frequently gave rise to difficulties in participating in activities outside the classroom in school and outside the home.

> *'He finds it hard to walk effectively. He has numb feet and ankles and constant foot ulcers and trauma to his feet. His poor circulation causes slow healing'*

They stated that he had no support in school and that he is unable to do contact sports such as rugby, football or running because of the risk of trauma to his feet & ankles & his extremely delicate spine. They wrote that he has to stand or sit and watch, and isn't given alternative activities. The young person had been seen by a doctor, a paediatrician, a neurosurgeon and a physiotherapist.

His observed engagement in class was problematic. He was intermittently engaged in the classroom tasks and appeared to have difficulty in discerning exactly what it was he was supposed to be doing. His teacher suggested that he was easily distracted and that he could frustrated and behave in an erratic manner. He has a record of poor attendance.

The school were aware that he was experiencing difficulties but were not all staff were aware of the exact cause. The school's 'Specific Medical Difficulties' sheet has now been updated by the Matron and re-published to staff.

b. Children who were observed not to be a concern with respect to participation in class.

Observations on the remaining eight surprise children suggested that they were engaged in class activities. Seven of the eight showed good levels of involvement, the activity appeared to have meaning for them and they were engaged, sometimes intensely so. The eighth child showed more or less sustained activity (although it lacked intensity). These then were children who, at least on casual observation, would not be a cause for concern. Interestingly this included cases where the condition had no impact at home, only at school and indeed on short observation it appeared not to be the cause of problems at school i.e. the school had successfully made the necessary adaptations. However there were two cases where schools would have benefitted from more information as both led to absences at school.

- Child RD where the impact of asthma caused school attendance difficulties
- Child JK whose migraine attacks caused school attendance difficulties

These data suggest the need for a question which probes impact of a disability on school attendance.

7.2 Case studies where the response to the parental questionnaire had not surprised the school

There were 29 observations of children whose parents reports on the questionnaire did not surprise the school. Of these, five were children whose class participation was judged to be problematic (scored as 1 or 2 the five point scale). All of these were cases where very visible conditions were reported e.g. ADHD, SLD/PMLD, ADD and ASD, one in special school and the others in primary schools. The remaining pupils were however showing good levels of participation in the learning opportunities offered to them.

Conclusion

Overall the data suggest that schools are aware of difficulties that give rise to problems with participation in class. However the parental questionnaire surfaced experienced difficulties that remain invisible to the school and have hitherto been unreported. They also revealed cases where there was no difficulty experienced outside the school.

8.0 Reliability in the Use of the Data

An important element of reporting on disability is to facilitate consistent interpretation of the returns across schools. To this end schools were provided with guidance on how to identify pupils that meet the DDA criteria by considering responses to combinations of questions. Thirty six schools completed the online summary census form and also returned their questionnaires, providing data drawn from a sample of 1,632 pupils.

Phase	Number of Schools Entering Data in Online Census	Number of Pupils in the Schools Participating in the Survey
Primary	21	979
Secondary	8	501
Special	7	185
Total	36	1665

Table 21: School Completion of the Online Census Summary

8.1 Online Census Data

Thirty six schools entered data in the online summary census. They identified a total of 318 pupils, including 104 children not identified by the research team using the algorithm. Notably only three of the additional children had a reported impact, suggesting that schools had not taken impact as pivotal in meeting the DDA criteria. In many cases it is not clear why schools included those additional children. For example not all the additional children had parental records of difficulties experienced at school, nor of difficulties in learning and/or behaviour so it is unclear that schools characteristically used their own knowledge to enter these pupils. One explanation is that schools included children who were already on their own register- for example because they had asthma or another medical condition irrespective of whether the parents reported an impact. Appendix E contains a list of the diagnoses.

Of the 36 schools included in this part of the sample 16 had reported differences, but in the majority of cases these were limited to four children or less. Closer scrutiny revealed that five schools (three primary, and two secondary) accounted for 84 (81%) of the additional children.

	Number of pupils identified in the school online census
Phase	
Primary	114
Secondary	58
Special	146
Total	318

Table 22: Number Of Pupils Entered in the Online Summary Census

There were additional mismatches: twelve of the children identified as belonging to Group 1 (three primary, three secondary and six special school pupils) were not entered on the online census, nor were two in Group 3 (both in secondary schools). Conversely all but two of the "follow up" group were included. Further scrutiny of the Group 1 children who were not entered revealed that five of the parents had returned the data on the web and although copies of these questionnaires were sent to schools it is possible that they were not to hand when the data were entered in the census summary. In fact none of the additional 104 children had parental returns online but as these were a small percentage of returns this may not be significant.

"Allen" secondary school entered data from 24 of the 110 returned questionnaires in the school census. Three of these pupils matched the criteria for inclusion in group 1. There were an additional twenty one children entered none of whom were reported to experience a substantial impact. Eleven parents had ticked yes to question 4i)& ii) i.e. having a physical or mental health condition, impairment or difficulty, that had gone on for a long time, and a further parent was unsure. Two further children had experienced an accident or trauma, one of whom was too recent to fulfil the long-term element of the DDA criteria and as with all these additional children none reported an impact.

On the one hand the degree of difference between schools' entries on the census and that of the research team is surprising especially given that schools reported the sifting to be an easy and straightforward process (see below). However four of the five schools with the greatest disparity were not able to attend briefing meetings and may therefore have been unclear about the rational for entering data only from children that met the DDA criteria or perhaps more likely, that despite the algorithm they were unclear about the pivotal role of impact and which children met the DDA criteria.

"Morris" primary school had returns from 123 children, they entered 24 children in the online census of which 23 did not match the algorithm for inclusion in Group 1,2 or 3. None of these additional children were reported by their parents to experience an impact although seven parents reported "occasionally it interferes with everyday activities, but only in a minor way". Sixteen answered yes to question 4i) but did not fulfil any of the additional criteria, 17 had seen a professional and 20 provided a diagnosis. Only six of these additions had been entered under CIN categories. There appeared to be no consistent pattern to explain why these children were viewed as meeting the DDA criteria.

9.0 Usability

Our analysis investigated the use and usefulness of the data collection process. In addition to collecting data from parents we carried out interviews with key staff as part of our field work in schools and we invited schools to return evaluation forms. Interviews and evaluation forms were completed for a total of 45 schools (90% of the sample) and the following commentary is based on feedback from this group.

9.1 What is the feedback from schools on the sifting process?

The reaction from schools about the process of sifting through the questionnaires and identifying students judged by parents to have disabilities was overwhelmingly positive. 33 (of the 45 schools that returned questionnaires) found the process undemanding and feedback included, "Easy", "Very straightforward – really liked the guidelines", "Fine, no problems." The only concern raised by schools related to time demands: five schools (out of the 45) commented on this, e.g. "Time consuming but interesting", "… lengthy process."

9.2 Are the data collectable?

Most schools found the process of distributing and gathering data from parents unproblematic. Almost half the schools (20 out of 45) opted to alert parents before sending out the questionnaire. Of these, most sent parents a briefing letter or included information about the questionnaire in a school newsletter (13 schools). Other briefing/preparation methods included mentioning the questionnaire in a school assembly, and displaying the questionnaire at a parents' evening.

The great majority of schools distributed the questionnaire to parents by sending it home with students (35 out of 45 schools). Two schools handed the questionnaire to parents personally, and one school did both (sent it via students and handed it to parents personally). Schools went to considerable lengths to ensure a good return: 31 schools chased up parents by sending a reminder letter home with students; and other schools used a variety of creative methods to remind parents, e.g. using a text messaging system, and posting up reminders on a daily bulletin board in the playground.
Few schools (eight) judged it necessary to offer support to parents. However, one school commented that although no parents asked for help, it would have been better to have informed parents that they could contact the school's parent adviser if help with completing the questionnaire was needed. Furthermore, four schools indicated that translations would have been useful (three of these mentioned the need for Polish translations).

9.3 How will schools use the data?

Twenty schools (out of 45) indicated that they would take some action as a result of the data collected from the parental questionnaire. Five schools anticipated using the data as an additional check (e.g. to ensure that the schools' current records – including medical records - are comprehensive); five schools will use the data to inform plans for targeting or monitoring support for students; and four schools planned to contact parents to follow-up issues they had mentioned. Two schools commented that this exercise would contribute to better data collection in future: “This needs to be included in what we are already doing”; and “We will improve our data collection as a result of this survey.” Another two schools commented that the data would help identify students’ difficulties, for example, “… to highlight any undiscovered issues mentioned by parents.” Other matters raised by schools included using the survey information to liaise with other professionals about health problems; to update information without targeting students suspected of having DDA status; to inform pastoral/SEN planning; to contribute to the School Development Plan and Disability Scheme; to inform possible CPD events; and using the information to review and update information on students’ Statements. A member of staff in one school considered that the data added to the “whole picture” by increasing specific knowledge of students’ difficulties, and in similar vein, another member of staff commented, “It will help the school to improve [our] response to diverse needs.”

9.4 How did this add to the data collected by schools in the past?

Eleven schools indicated that the data from the parental questionnaire did not add new information. However, responses from 20 schools (out of 45) indicated that a range of benefits emerged from conducting this survey. Interestingly, this number included four of the seven special schools (where it might be anticipated that staff would be knowledgeable about the range and impacts of children’s difficulties), one of whom commented, “We get a lot of information from Statements … but this is much more detailed than current SIMS data.”

As with the above item (*How will schools use the data?)* schools felt that the parental questionnaire provides a useful additional check to current records. Other comments about positive benefits included the following:

- The questionnaire provided opportunities for parents to voice their views/concerns about their child’s difficulties.
- The process provides more detailed information for the school, e.g. about impact, and “about what the disability is.”
- Current documentation relies on information gained from the primary transfer process and from parents’ evenings (the implication being that these sources may not provide sufficiently detailed information).
- A reminder that information about accidents or traumas needs to be included in the school’s records.
- The data highlight the needs of students who have recently been admitted and/or who are mid-phase entrants.
- A useful exercise “… to get people to think more deeply about the DDA definition of disability.”

9.5 Are the data worth collecting?

It is imperative to explore the extent to which the parental questionnaire reveals new information for schools, particularly whether or not the returns identify students with disabilities not previously known to the school. Overall, about one third of schools recorded unanticipated findings from the parental questionnaire (“surprises”). The numbers of surprises were distributed fairly evenly across the three types of school: four out of 14 secondary schools reported surprises; eight of the 23 primary schools; and three of the eight special schools. Most of the surprises related to students who were identified as disabled by parents but whose difficulties were not recorded in this way by schools; and these difficulties tended to be health related (e.g. difficulties associated with asthma). The exception was in special schools, where two of the three surprises related to parents’ judgments that their child’s difficulties did not meet disability criteria, which was in contrast to the schools’ views.

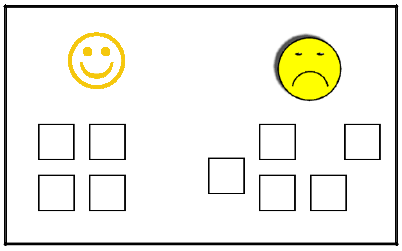
Unsurprisingly, the number of surprises per school was relatively low - most schools that reported surprises identified one or two students in this category. However, one secondary school reported a comparatively high number (12) of such cases: six students identified by parents who were not listed by the school as disabled (though two were known to the school nurse); and conversely, six students identified as disabled by the school who were not rated as such by parents.

Although information about surprises is important when evaluating whether or not the data are worth collecting, it is also important to consider other benefits that accrued from the survey. As discussed above, a significant number of schools indicated that they found the data useful: about two thirds of the schools (30 out of 45) indicated that they intended acting on the information that emerged from the survey or that the survey added to data already collected.

10.0 Flexible Tools

Six flexible tools had been developed to collect data on pupil views on the barriers and supports to participation in school activities as part of the previous phase (Porter et al 2008). These 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.

1. 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. The diagram below provides an indication although all aspects of the symbols can be personalised and where appropriate replaced by objects of reference.



2. Symbol questionnaire: 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. This was an activity that could be undertaken in a group or individually, with or without support.

3. Younger Child Interview Schedule. This was designed to be undertaken either individually or in a small group and explored 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 is based around counselling techniques and provides 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. Online Child Questionnaire: This invites pupils to rate their experiences in school, in the classroom, in different types of lesson, and around the school. It asks pupils what helps in those activities and what makes them more difficult. It also asks them if they have any disability or difficulty. A hard copy of this questionnaire was also made available.

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

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. Our aim in producing the guidelines was for schools to select and customise the tools to suit the children who would be taking part.

These tools and accompanying guidance material were further refined in response to comments from a virtual reference group set up by Capita, and from the research teams' experience of using the tools in the earlier trial. The symbol questionnaire was extensively revised to make it adaptable to suit the interests and experiences of individual pupils.

Teachers in the schools participating in the National Trial in 2010 were invited to select and try out one or two flexible tools with children with and without a disability. They were then asked to record their experiences on a feedback form, or were interviewed by researchers during the school visit following up the use of the parent questionnaire. In a small number of cases it was possible to observe the tools in use, but in general this was too difficult to organise in the short time scale.

10.1 Use of the Flexible Tools in previous phase.

61% (45) of schools in the national trial in 2008 had used at least one version of the flexible tools providing insights into the barriers and supports encountered by children. These included people, places and particular events or practices. It emerged that the tools needed embedding in meaningful activities and some personalisation to meet the needs of children who experience difficulties in communicating their views, and to some extent the richness of the data reflected the interest and commitment of schools to match the activity to the pupil. The most popular of the Flexible Tools was an online questionnaire; 22% (359) of children completing this said they had a disability or difficulty and 16% (258) said that it had gone on 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 important were the level of noise and distractions, and the general atmosphere created by the teacher in charge.

10.2 Use of the Flexible Tools in current National Trial

Twenty out of 52 schools planned to use the flexible tools during the trial period, but in the event only 13 schools used at least one of the flexible tools, with two schools using two different flexible tools. Two schools out of the 13 chose to use their own symbol questionnaire. When asked about why they had not used the tools, schools told us that they did not use the flexible tools as there was not enough time to administer both flexible tools and parents' questionnaire. Some schools felt that they had agreed to sending out the parents' questionnaire but despite the briefing were surprised that we wanted to observe children and the use of flexible tools; they hadn't "signed up for that". In part this probably reflects the recruitment messages from LAs.

In the 2010 National Trial, schools had also more responsibilities during the narrow time window, to collect in, sort and sift the questionnaires (during the previous study the research team carried out the analysis). This meant there was even less time to spend on the flexible tools. Several schools added that they thought the tools looked useful and that they might try them out at a later date and one school said they might have felt more confident about using the tools had they managed to attend the briefing

Schools did not take up the option of using the tools when given an extra month to do so. This period was a busy half term for many classes with exams and transitional arrangements to prepare.

The actual and intended use of different tools by primary, special and secondary schools is shown in Table 23.

	Primary	Secondary	Special	Total
Talking mats	3		1	4
Symbol Questionnaire			2	2
Point2point	1			1
Interview /written questionnaire	1		2	3
Focus group		1		1
Online Q	2	4		6
Total no of schools using flexible tool(s)	5	5	3	13
(total number of schools who had planned to use flexible tools)	(11)	(3)	(5)	(20)

Table 23: Schools Use Of Flexible Tools (including own versions of written and symbol questionnaires)

It is difficult to draw strong conclusions from the small data set, but it would appear that schools were more inclined to select tools which were originally designed with the needs of their particular pupils in mind; special and primary schools selected talking mats and secondary schools selected focus group and the online questionnaire. However, as before, the online questionnaire proved to be the most popular, and was used by a wide age range, from Year 4 through to Year 10.

10.3 Experience of using flexible tools in the current study

Talking mats

One special school described how staff routinely use talking mats to communicate with pupils about their needs and preferences. One primary school used talking mats as part of a range of techniques matched to the needs of individual children in Year 3. Children used happy and sad faces to respond to photographs. Another primary school tried out talking mats successfully with Year 1 pupils and now plans to use it with Foundation Stage pupils. The third primary school developed an activity for one pupil based on talking mats using smiley faces and using language pitched at an appropriate level.

Symbol Questionnaire
We had commissioned a flexible version of the symbol questionnaire but, in the event and in contrast to the previous National Trial, no schools opted to use our symbol questionnaire. Two schools, however, used their own symbol questionnaires which were developed to meet the specific needs of their pupils. One primary school used their own symbol questionnaire which they had developed after taking part in the previous national trial, and which was modelled on questions from the project's interview schedule. Another special school shared their own symbol questionnaire with us which they have developed to find out about pupils' experience of school.

Point2point
This was used by one primary school with one child with ASD, but it did not suit that child's communication needs as he found it difficult to think beyond the present day and compare this with past events. In the previous phases of the project this method was used enthusiastically throughout a primary school for children described as having BESB and a mainstream secondary school used it after the project with all pupils with SEN. Feedback suggests that it is difficult to find methods that form a single event that are appropriate for pupils with ASD.

Interview /written questionnaire
This was used by three primary classes as a whole class written activity (Year 4), supported by teaching assistants for those who needed help to record. Teachers who used the interview reported that the pupils were initially enthusiastic but their interest waned and the schedule was therefore too long for this mode of delivery with this age group. The teachers were also concerned that pupils had responded about aspects of the behaviour and attitudes of other pupils, instead of what they considered more relevant more structural issues (like being able to turn on taps). This implies that the guidance for teachers needs to include consideration that barriers might well be something to do with people (adults or pupils) as well as structural problems.

Focus group
This was used by one secondary school with a small group of Year 9 pupils. The teacher followed the procedure carefully and managed the process well, giving all boys the opportunity to contribute and work together to reach a consensus about "what stops you doing well at school".

Online Questionnaire.
Three schools completed this online, while the others used paper copies. It is apparent from the online responses that this tool offered all pupils, as before, the opportunity to express anonymously their views about different aspects of school life. When used with whole year groups, it also offered an opportunity to reach those pupils whose parents had not returned the questionnaire. As before, the majority of comments about what helps and what hinders were about other people, both children and staff. Both younger and older pupils reported that support from teachers helped them;

[what helps is] *when i have soporet in my lessons by different adults at different times* (Year 6 primary school pupil)

and pupils valued help from peers;

[it makes it difficult] *sometimes working by your self when work is hard. .. Just really working together sometimes helps* (Year 9 secondary pupil)

Pupils reported finding lessons difficult because they were distracted by other pupils, and in some cases this revealed that issues around inclusion perhaps needed to be explored;

I think it would be easier if people with difficulties would have their seperate class room… Things that are difficult is when people that have problems, [..] they get really worked up and then we have to just listen to screaming and when people run out the class we have to wait until Miss comes back in to teach us (Year 6 primary pupil)

In one secondary school using the paper version of this questionnaire, new issues emerged such as the start time of schools, whether pupils had had breakfast and how ready they felt for lessons.

10.4 How useful did schools find them?

Where schools had had some opportunity to look at the results, there were different ratings of the usefulness of the tools. Talking mats were rated very, quite and not that useful by the three schools trying them for the first time, while the online questionnaire was found to be very useful by three schools, quite useful by one school and not that useful by one school. Schools which rated tools as not that useful commented that this was because they already had mechanisms in place to collect this kind of information and so did not learn anything new, or that they had just selected the tool which seemed least onerous (Online pupil questionnaire). A third school (using point2point) found the technique unsuitable for communication needs of the pupil with ASD who had used it, This echoes findings from the first National Trial, which highlighted the importance of matching tool to pupil. Clearly for some pupils, it might be necessary to experiment with more than one tool to find out which offered the pupil the most appropriate means to express their views about what helps or hinders them in school.

11.0 Further Discussion

On the basis of parental responses we distinguished between three groups of children, the largest of which based on parental responses to being asked whether the child had a physical or mental health condition, impairment of difficulty. The removal of reference to disability from this question helps to ensure that parents are not deterred from answering. In contrast to the previous phase, there was no large group of parents who ticked yes to this question but did not see it as longstanding. In order to check this Group 3 included children excluded from Group 1 whose diagnosis indicated they had a longstanding impairment and parents reported a substantial impact on daily life. The high numbers of children who have experienced a serious accident or trauma suggest that Group 2 is also an important group to continue to include, not least because it includes children with a mental health difficulty. These two additional groups were small by comparison but included children who would have been excluded by the use of the impairment and longstanding questions only. The phrasing of the impact question did not able us to clearly identity a fourth group of children, those who experienced no impact due to medication or treatment. Additional scrutiny of the questionnaires enabled us to identify a small further group, those for whom schools may wish to keep a watching brief.

A smaller proportion of pupils have been identified as meeting the DDA criteria than in the previous study. On the one hand improved phrasing and ordering of the questions may have resulted in a more sensitive instrument, on the other hand it may have inadvertently excluded a small number of children who would have experienced a substantial impact but medication and treatment effectively controlled their condition. This included a small number of children who were deaf and a small number with epilepsy. It is unclear how many of the children with asthma would be included here, given that many reported it to be mild.

11.1 Reflections on the Algorithm

In addition to looking specifically at the mismatch of some of our groupings and those of schools we examined the data for evidence that our algorithm had falsely excluded children. Impact was taken as a pivotal element in this study, recognizing that pupils with physical or mental health conditions are ‘disabled’ when faced with barriers that restrict their participation in different areas of life or experience discrimination. Pupils in highly supportive environments including those for whom schools (and parents) have made reasonable adjustments are therefore less likely to be disabled.

The following section looks more closely at the question of impact and to responses to question 7 that asked how the child was affected. Fourteen areas of need were outlined, drawn from the Children in Need categories. Recognizing that the parents of one nine year old pupil had identified 12 areas of need yet had indicated that the condition only occasionally interfered with daily life we looked to see how frequent an occurrence this was.

Number of Areas Affected	Number of Children	Reported Impact	School	Entered in Census
12	1	Occasional	Special	No
9	1	No difficulty	Special	No
8	1	Occasional	Special	No
7	1	Occasional	Primary	No
7	1	Occasional	Special	No
6	1	Occasional	Primary	No
6	1	Occasional	Primary	Yes
6	1	Occasional	Special	No
5	1	Blank	Special	Yes
5	1	No difficulty	Special	No
5	1	Occasional	Special	No

Table 24: Impact and Children in Need Categories

Eleven pupils had five or more areas of need, three of them were placed in primary schools but the majority were in special schools. Their parents had either reported that the impact was trivial or small (8 instances) or that there was no difficulty (2) or left the question blank (1). Given that the DDA definition refers to a substantial impact, these children could not on the basis of parental returns been judged as meeting the DDA criteria. All 11 pupils were reported to have an impairment (Q4i) although for two children it was not seen as longstanding (Q4ii). In two instances schools entered them into the census, indeed one school had differentiated between two children, entering one (impact left blank) and not the other (no difficulty reported). Clearly there is not a simple equation between numbers of areas of need and impact on the child. This is well illustrated by the following quote from a parent whose child is represented in Table 24:

He has a brilliant support team at his school. This enables him to participate in all subjects. We continue to work at home via interaction from school.

It is important that guidance addresses this complex issue so that schools are clear about whether or not to enter children in the annual School Census.

Do these anomalies explain schools additional inclusions on the census? Taking those children for whom there was “No difficulty: Medication/aids/equipment allows my child to take a full part in home, community and school activities”, thirteen of the 68 children with asthma were included in the census summary and 1 of the seven children with hearing impairment. As we have seen, looking at children with multiple needs recorded in question 7 few of these were included in the census. They did not therefore fully explain anomalies in the census summaries.

Feedback from parents also suggested the need for further strengthening of the inclusion of mental health difficulties in the survey. It is difficult to make judgements about the extent to which the instrument is sufficiently sensitive to collecting information about pupils with mental health needs, despite explicit reference to them in the opening phrasing of all relevant questions. Eight pupils were recorded as having mental health needs only in Q7 with a further 60 having those needs in combination with others and all but ten of these 68 children had a reported impact to their difficulties. This is difficult data to evaluate. Green et al (2005) report an overall incidence of clinical mental health difficulties in children 5-16 to be 9.6% but this includes children with conduct disorders who would be represented elsewhere in our survey. Looking just at emotional disorders the prevalence is 3.7% with a slightly higher incidence in girls. Pupils identified in this survey in relation to Q7 constituted just 2.7% of the population (suggesting as parents also indicated) that further exemplification could be given in the question.

11.2 Special Schools

Previous research has indicated that although disability and SEN form overlapping categories, a sizable proportion of children belong to one or other group (Grant et al, undated; Porter et al 2009). We have less data in this project to pursue this line of analysis but notably 153 of the 196 special school returns matched criteria for Group 1 and four matched the criteria for Group 3, there were no special school children in Group 2 or in the follow-up group. Consequently 20% of the special school returns did not meet the DDA criteria. These children were placed in the whole range of special schools. Some of these responses were a surprise to schools including one child who formed part of our observation sample who has multiple difficulties whose level of participation in the lesson was sporadic. A brief observation suggested that although the pupil was communicative that the impact was more than occasional in the school setting. The mismatch between school and parent views was evident.

Interestingly two of the three parents who were telephoned whose children were in special schools commented that they did not see the questions as relevant to them as they were already “in the system”. However four of the seven special schools felt that there had been benefits from undertaking the survey and that although they received a lot of information from statements that this survey provided more detailed information than current SIM data. It would seem therefore that if the data is collected on admissions that special schools should continue to collect this additional detailed information.

Decisions here must be taken in the light of the purpose of the DDA as well as the criteria. In the context of the school, the central purpose is to promote disability equality and eliminate discrimination. Schools are called on to remove barriers to participation in school life and make reasonable adjustments. Guidance to schools has put together SEN legislation with that of Disability (DES 2006) . The duties to protect people from discrimination have been strengthened in the Equality Act 2010 although it is unclear when it will come into force, the definition of disability remains unchanged. Guidance therefore needs to reflect the ways in which the data will be used for monitoring any adverse outcomes of schools/LAs or governments activities and whether this will be undertaken for pupils with disability and SEN or disability and not SEN.

11.3 Schools Engagement with the Data Collection

A key question for the study concerns whether schools will find that these data are collectable. As discussed earlier, schools were given the option for different levels of engagement with the project. Despite the very tight time schedules the returns from this phase have in many ways been comparable to that of earlier phases (see Porter et al 2009). The overall return rates were identical and the minimum and maximum by phase very similar to that of the slightly lengthier previous study. However it appeared that the timescale impacted differentially on the tasks involved. Wave 1 schools had more time and seven schools (three special and four primary) opted to send the questionnaire out to all pupils. None of wave 2 schools decided to do this. Overall there was little difference in return rates for wave 1 and 2 schools. Most schools found the process of distributing and gathering data from parents unproblematic. Twenty of the 50 schools did not manage to brief parents before hand, a strategy that research suggests increases return rates (Heberlein & Baumgartner 1978). A number of schools said that there was no time for this and in one instance that they had no mechanism for doing so. Schools went to different lengths to remind parents with all but five schools sending out the provided reminder letters but one school used text messaging systems instead, a more efficient system for contacting parents. As before secondary schools represented the highest and the lowest return rates. Our analysis however found no discernible pattern between the use of strategies and actual return rates. It is likely that there is a more complex set of predictors. Taking the schools with the lowest rates these were over-represented by schools in areas of deprivation and higher rates of children eligible for free school meals. This is a particular concern given the two way relationship between poverty and disability in children “with a close geographical dimension” (IPPR 2007) so that children who are particularly disadvantaged may be under-represented in Local Authority and government statistics through low return rates. This indicates how vital it is to collect this data from parents at the point at which they are most likely to be in contact with the school, namely at admission.

As before we were disappointed by the take-up of the online version of the parent questionnaire, especially given the comment from a parent who stated how much quicker it was to complete. The entry of information directly into a data base is also advantageous for schools. In the previous study we recommended that schools could encourage parents to complete the survey online as part of the admissions process, thereby providing familiarity with the content and increasing the likelihood of them using the same format to update this information. The project used a survey provider to support this format. It is unclear whether schools will have this facility and whether LAs would support them in achieving this.

Around a third of schools recorded unanticipated findings from the returned data and our observational data highlighted the contextual nature of some pupils' difficulties. Consequently some children experienced the impact only in the home setting and were well engaged in school with the reverse true for others. Schools were unaware of the reason for some absences that would alert them to the child's difficulties. Repeated absences may make the child particularly vulnerable to under achievement.

A notable finding of the project was however the lack of reliability with which schools followed the algorithm and recorded data on the census. It appeared that they failed to take impact as pivotal and in consequence included children who would not meet the criteria. Schools who did not attend a face-to-face briefing were overrepresented in the group of schools who entered large numbers of additional children. This suggests the need for enhanced briefing and improved understanding of disability as distinct from impairment.

Timescales have impacted on the uptake of the flexible tools but although the feedback was limited it could be compared to that arising from more wide-spread use in previous phases of the research. Notably schools signalled their intention to use the tools in the future or indicated that they already used similar methods. However in a couple of instances staff said they felt unconfident and had not been able to attend their regional briefing session. Conversely it was also clear that a number of schools had already taken the initiative to collect this data from children. Indeed one school was using an earlier version of one of the tools developed by the project team. There is however a sense of a divide between those schools who routinely collect data from children on the barriers and support to learning and those schools who either feel unconfident or don't recognize the benefits of doing so. It is important therefore that these schools are supported to realise the importance and gain the confidence and expertise to access pupil views. Our data illustrated how staff and pupils can often view very different elements to act as supports and that schools can forget the centralality of social support from peers and the importance of enabling this to be accessed.

12.0 Implications and recommendations

12.1 Questionnaire Content

Analysis of the questionnaire responses has underscored the importance of using multiple indicators and the complexity of identifying a simple set of algorithms to aid schools in assessing whether the child meets the DDA criteria. Taking impact as pivotal in the definition, three groups of children could be identified with relative ease but this falsely excluded children for whom treatment (either through medicine/aids/equipment or diet) satisfactorily controls the effects of the condition. The majority of children in this group had asthma but it also included a small group of children with epilepsy and those who were deaf.

There were some additional children whose parent judged there to be no substantial impact at this point in time and who were excluded despite having a number of areas of need, and/or experiencing the effect of the difficulty at home or at school. The adjustments that both schools and parents are making are enabling children to participate. However schools may wish to keep a “watching brief” to monitor whether experiences change over time and judgements are later made that the child is disabled.

The Office for Disability suggests asking whether the child receives “medication or treatment without which their health problems (when taken together), would substantially affect their life” which we would suggest informs the phrasing of a revision to the impact question.

A number of smaller revisions were suggested by our data analysis and from feedback from parents. The attendance question had been removed in this phase on the suggestion that schools knew whether children were absent or not, however the data suggests that it provides a useful source of information, not least in the context of children whose difficulties were unknown to schools and therefore should be included. A number of children had received multiple traumas and the format of this question requires small revisions to enable them to indicate more clearly the date of each one. Exemplification of the way that mental health difficulties may manifest themselves should also be provided. The questionnaire needs to be more explicit that all questions require a response and an invitation to check before returning it to school

12.2 Guidance for Schools

Schools in this project had access to a range of formats to guide them: schools were briefed in regional meetings; they were sent written material in the form of guidance and a checklist; and they could watch a podcast. Schools reported that they found the “checklist” particularly useful – this distilled what they had to do but gave relatively little by way of explanation which was provided in more detail in the Guidance. They also reported that they found the sifting easy and straightforward but for at least four schools this did not guide their actions. It is important that the checklist and guidance are amalgamated retaining the accessibility of the checklist information. It is quite possible that the task was delegated, a number of schools have data managers and this has implications for the briefing process, and for confidentiality.

The procedures adopted in this project underscored the importance of assuring parents of the confidentiality of these data and it is important that schools in the future adopt practices in line with these. Feedback from one parent revealed a bad previous experience that had impacted on their willingness to disclose personal information in the future. The assignment of a named person to collect and analyse the data helps to offset this and also provides parents with a point of contact for raising issues and concerns.

Schools had a number of strategies for increasing response rates that can be illustrated in the guidance. Many of these however were time intensive and involved “chasing” particular parents. Conversely, the use of texting parents appeared to be a particularly useful strategy in ensuring that parents knew about the questionnaire and were not reliant on pupils as messengers.

A small number of additional points arose with respect to administering the questionnaire to be addressed in the guidance.

- Some parents used one form for two or even three children and in the event that schools collect data across year groups this needs to be addressed.
- There is some uncertainty about whether the completion of the form is voluntary or compulsory.
- One parent did not want pupil details (name etc) entered.
- Five parents entered more than one tick against impact and schools will need guidance about how to respond to these instances.
- There is an on going issue of ensuring that parents with literacy difficulties and those for whom English is a 2nd language are provided with support to complete the form

As already indicated schools will need more guidance on the pivotal role of impact in their analysis of the questionnaire returns. In part the accuracy of the sifting and reporting depend on schools motivation and interest in the findings and information from this study in relation to unanticipated findings and use of the information will be useful inclusions to the Guidance. This is especially timely given the Equality Act 2010.

12.3 Using the Flexible Tools

In response to discussion with teachers and observation of tools in use, modifications can be made to the guidance for staff intending to use the flexible tools. In the introductory guidance to the whole set of tools, more emphasis should be placed on the importance of preparation and the need to match tool to child's communication needs and their capacity to handle key concepts. In particular, attention can be drawn to the fact that some tools rely on children being able to think about things beyond the here and now, and teachers will need to judge whether these are the most appropriate for all the pupils in their class. Sections on using the Symbol Questionnaire should be placed together with suggestions that there is a need for schools to customize the popular Online Children's Questionnaire to accommodate the wide age range over which it has been pressed into use. Some specific suggestions can be offered when using the Interview Schedule as a written exercise. In addition, the data revealed that staff were sometimes steering children away from talking about problems with their classmates and focussing their responses instead on aspects of the environment like the width of doorways. This is a matter for all the guidance by clarifying that barriers and supports include the effects of social relationships as well as aspects of the schools' organisation and the physical environment.

12.4 The Process for Collecting Data.

As schools already collect data from all parents on admissions this timing serves to offset the disparity across schools with respect to return rates. However, as noted in the previous study (Porter et al 2008) it should be recognized that parents may feel less confident in talking about their child's difficulties before they have built a relationship with the school. They may in particular not wish to create a self fulfilling prophecy nor put their child's place in jeopardy. This issue therefore needs to be handled with sensitivity. We also recommend that the data is "refreshed" during the course of attendance at that school. Schools routinely ask parents to let them know about changes in address, contact details and medication. However asking about disability requires more precision and analysis of the responses. Where schools are relying on data managers they need to ensure that they have appropriate briefing and are aware of the confidential nature of the information.

The online version of the questionnaire may be a useful format for schools to complete with parents on admissions. However in this project few parents returned questionnaires online. One family completed both online and hard copy with more text in the online version. The development of an online version has the potential to provide schools not only with the information entered into the database, but also the potential for the algorithm to be built in the system thus obviating the need for manual sifting and avoiding human error.

12. 5 Main Recommendations in Summary

1. Retain all three groups identified in the questionnaire but amend the algorithm to include children whose treatment offsets the impact of an impairment
2. Adjust the question order and impact question to ask parents directly if without medication, aids or equipment the child's health problems (when taken together) would substantially affect their life, to form a fourth group.
3. Suggest that schools keep a "watching brief " on children whose parents report no impact despite the presence of multiple disabilities
4. Add in a question asking about whether the child's health problems lead to absence from school to enable schools to be more alert to the ways in which some disabilities are "hidden".
5. Strengthen the significance of impact in the Guidance
6. Give further illustration on the contribution of this data to school development in the Guidance.
7. Schools to collect disability data routinely as part of admissions to primary and secondary phases of education and to actively refresh the data during the course of attendance at school.
8. Consider in the long term making software available to support schools in collecting this data online and in making the analysis of which conditions/difficulties meet the Equality Act 2010 criteria.
9. Make briefing materials available in a variety of formats recognising that it may be data management personnel that are given responsibility for some elements of the task.
10. Strengthen the importance of pupils' views in developing reasonable adjustments to the barriers and supports to learning.

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Appendix A- Field Work Tools

INTERVIEW SCHEDULE FORMAT

Disability Data Collection

Parent Questionnaire School Evaluation AND Questions for Staff about Identifying Children with a Disability that Meets the DDA

I’d like to ask you some questions about how useful and usable you found the parent questionnaire. You may have already completed an Evaluation Form (please show them a copy), if you have we can skip some of these questions (those marked with an asterisk).

School Name:	Year Groups Involved in Project:
Local Authority:	
Name and Position of Person interviewed	
*1. The first questions ask for comments about sending out the PROJECT questionnaires	
Were you able to brief parents and if so how?	
*How was the questionnaire delivered to parents? (please tick) ☐ Sent home with children ☐ Handed to parents/carers personally ☐ Given out at parents’ evening? ☐ Other (please specify)	
*How did you “chase” responses? (please tick) ☐ Sent reminder letter home with children ☐ Handed 2nd copy to parents/carers personally ☐ Gave out at parents evening ☐ Other (please specify)	
Have you any particular issues with the process? - How do you feel about the time allowed for sending out the questionnaires? - How are you dealing with issues of confidentiality?	
Did you offer/need to provide any support to parents? Yes No Please specify and also comment on the need for translations or other accessible formats?	
*2. The next set of questions are about using the PROJECT questionnaire	

to identify children who met the DDA criteria
How many of the pupils identified as disabled by their parents were on the school records as having a disability?
*Were there any surprises? e.g. children who were not identified as disabled which you expected to be or the converse ?
*How did you find the "sifting" process; deciding which questionnaires to look at more closely?
*How did you find completing the summary census form?
In addition to the school census how will you use this additional information on these pupils? How will you use the data with particular regard to the DED (Disability Equality Duty); How would you improve on the questionnaire's usefulness?
*3. Now for some general comments about PROJECT QUESTIONNAIRE

Were there any particular issues and comments from parents / carers?

*In what ways does this method add to the data you currently collect?

4. looking back to what you have done in the past- How and when do you usually collect this kind of information?

How often is the data collected and who has access to it?

What triggers the collection of the data (time, event etc)

About whom exactly do you collect data? (including age, is it everyone, or targeted groups)

What resources are needed- people, time etc

How and when do you update this information?

How do you tell people about the purposes and uses of the collection, how do you gain consent, how do you give people confidence in access to information / storage of this information?

What medium is used to collect data, ask questions? Who provides the answers?

How is the data collated and analysed?

What gaps are there in their current system? Are these also gaps of the new system?

How have you piloted/refined it over time, drawn on previous measures?

What for them are the strengths and limitations of what you usually use to collect his information, including any feedback from other stakeholders?

The Future

Now looking towards the future. This project will advise the Government about how they introduce the roll-out of the disability questions in the school census.

1. Do you feel the census should include all the year groups right from the start or be introduced in phases?

2. What do you feel about collecting data on admission?

3. One option is for a rolling programme so that data is initially gathered for example on admission at the beginning of the next key stage so that in successive years so that in a few years you have data on all the school? Is this a reasonable option?

4. Do you have any other suggestions for the roll-out?

5. What preparation do you feel is needed for schools for the next Census, if any?

Any other comments?

Thank you for your thoughts on this process! We will use this information to provide feedback and make recommendations to the DCSF. Researchers please return a copy of this form to: Dr Jill Porter, Department of Education, University of Bath, BA2 7LU in the SAE provided.

NUDGE SHEET - OBSERVATION OF THE FLEXIBLE TOOLS

School Name:
Date:
Researcher Name:
Type of Tool: Talking Mats/ symbol questionnaire/ point2point/interview/focus group/online questionnaire (please circle)

Where: Describe Setting classroom/hall/IT room etc	
Timing: in lesson/tutor group time? Length of observation?	
Staff: Numbers and role(s)	
Group: Size, Composition and Choice	
Introduction: Describe Purposes and Outcomes Are these shared with the pupils? How do they show that diversity is valued? That having difficulties are OK What examples given:	
Development of session: How does the activity develop?	
Participation/engagement What got pupil interest	
Responses required and provided by all/some	
How is activity **concluded**	

Do they keep a record of children's responses? Who does this? How do they do it? What do they record? ,	
Interview with member of staff who planned the activity: name:	
What **motivated you** to carry out the activity? i.e. why are they doing it?	
Decision-making How did you choose which tool to use? How did you choose who to take part?	
Where do you see this activity going? What will you do by way of a **follow-up?**	
Overall how useful did you find the activity and the data gained from it?	Very Useful ☐ Quite Useful ☐ not Useful ☐ Not useful at all ☐
How helpful did you find the guidance materials?	
Is there additional guidance you would have liked to have been given?	

Validating the Parent Questionnaire Through Classroom Observation

NB direct observation may not be possible in all schools but gather data as indicated from the teacher

Purpose: To explore the validity of the data generated by the parent questionnaire
Who: 2-3 children including one whose parents' returns were a surprise to the school and one child where the parent returns were not a surprise to schools

Where:
Contexts: 1 or more of the following, unsupervised, lunch or snack time and 1 or more learning situations: classroom learning, other school activities

Duration 15-20 mins in each context and approx 40 mins/child

Ask the class teacher/head of year group or someone who knows the child well

1. Does the child have a physical or mental health condition?

Do you know what the child's diagnosis is? Do you view this as a long term condition? (Y/N/Unsure).

Is English the first language of the child?

2. What difficulties (if any) does the child experience in school?

3. What supports are in place that meliorate the child's' difficulties, e.g. people (assistants, 1:1 supports), aids and equipment, pedagogic/behaviour management; environment, structures (routines etc)

4. Do you know if these kinds of supports are present in the home?

5. Does the child have any additional needs that are not easily met in school (i.e. the barriers?)

6. Do you know, how does the home meet these additional needs?

Name: **Context: Lesson/staffing/Organisation and Grouping of Pupils**
Narrative Observation of Pupil Participation and Impact of any difficulties

Pupil Participation Summary

Level 1: *Little or no involvement or activity*: Does not participate in activity, e.g. staring idly, absent-minded, little awareness of what is going on in the classroom, little receptivity to the learning opportunities on offer.

Level 2: *Moments of sporadic activity or involvement.* These are fleeting so only occasionally are they occupied with the learning activity

Level 3: *More or less sustained activity but it lacks intensity,* they are doing something but they are not often really engaged or fully attentive to the task

Level 4: *Good levels of involvement*. The activity has meaning for them and they are engaged and sometimes intensely so.

Level 5: ***High and Sustained Involvement*** The activity has intrinsic meaning and they are intensely involved putting a lot of effort and concentration into it. They show signs of persistence.

Please comment briefly on
Barriers:
Supports offered:

Is there observational or other evidence of the following difficulties?

Mobility: getting around in or outside the school	☐
Hand function: holding and touching	☐
Personal care- washing, going to the toilet, dressing	☐
Eating and Drinking: has difficulty eating or drinking by themselves or sickness or lack of appetite	☐
Incontinence: controlling the passage of urine and/or faeces	☐
Communication- speaking and/or understanding others	☐
Learning or special educational needs	☐
Hearing	☐
Vision	☐
Behaviour- a condition that leads to the child being hyperactive or having a short attention span or getting frustrated or behaving in a socially unacceptable manner	☐
Consciousness- fits or seizures	☐
Autism, Asperger Syndrome or Autistic Spectrum Disorder (ASD)	☐
Palliative Care needs	☐
Mental health needs e.g. depression, anxiety	☐

Appendix B- School Evaluation Forms- Schools that are not visited

Parent Questionnaire
School Evaluation

Disability Data Collection

School Name:	Year Groups Involved in Project:
Local Authority:	
1. Comments about sending out the questionnaires	
Were you able to brief parents and if so how?	
How was the questionnaire delivered to parents? (please tick) ☐ Sent home with children ☐ Handed to parents/carers personally ☐ Given out at parents' evening? ☐ Other (please specify)	
Did you offer/need to provide any support to parents? Yes No Please specify and also comment on the need for translations or other accessible formats?	
How did you "chase" responses? (please tick) ☐ Sent reminder letter home with children ☐ Handed 2nd copy to parents/carers personally ☐ Gave out at parents evening ☐ Other (please specify)	
Have you any particular issues with the process?	
2. Using the questionnaire to identify children who met the DDA criteria	
How many of the pupils identified as disabled by their parents were on the school records as having a disability?	
Were there any surprises? e.g. children who were not identified	

as disabled which you expected to be or the converse ?

How did you find the "sifting" process; deciding which questionnaires to look at more closely?

How did you find completing the summary census form?

In addition to the school census how will you use this additional information on these pupils?

3. General comments

Were there any particular issues and comments from parents / carers?

In what ways does this method add to the data you currently collect?

How and when do you usually collect this kind of information? e.g. admissions information, school nurse etc.

How and when do you update this information?

Thank you for your thoughts on this process! We will use this information to provide feedback and make recommendations to the DCSF.

Please return a copy of this form to: Dr Jill Porter, Department of Education, University of Bath, BA2 7LU by 26th March 2010

## School Evaluation of Tools [Please complete one form for each activity and for each year group]	

School Name:	Activity – please tick one of the following (please complete one form for each activity and for each year group): ☐ Talking Mats ☐ Point-to-Point ☐ Children's Interview ☐ Structured Focus Group ☐ Online pupil Questionnaire ☐ Symbol Questionnaire
Local Authority:	
Year Group:	Number of pupils participating in activity? Overall number of pupils in this year group?
Name of person leading activity: Role of Activity leader: Teacher ☐ Teaching Assistant ☐ Other ☐ (please specify)	Did you fit this into a particular lesson? If so, which?
Phone number: Email: (both unlikely to be used)	How long did it take?

Process
How was the activity introduced to the children?
How well did pupils engage with the activity? What did they find most stimulating?
Did you adapt anything – if so, what?
What were the best prompts and supports?
How might this process be adapted or extended in the future?

What advice/tips would you pass on to others?

Outcomes

What did you find out?

What barriers to participation were identified - were these linked to a specific context?

What supports were identified - were these linked to a specific context?

Any other record kept (interview notes, response sheet)? (Can we have a copy?)

How will you provide feedback for the children?

Taking children's views forward

What have you learned from the pupils that you can take forward?

Any surprises or any particular challenges?

How will you use this information?

What follow-up will there be?

Description of activity

Our aim is to find out overall how useful you found this activity and the data you gained from it – please circle:

Very Useful	Quite Useful	Not that Useful	No use at all
☐	☐	☐	☐

Other comments

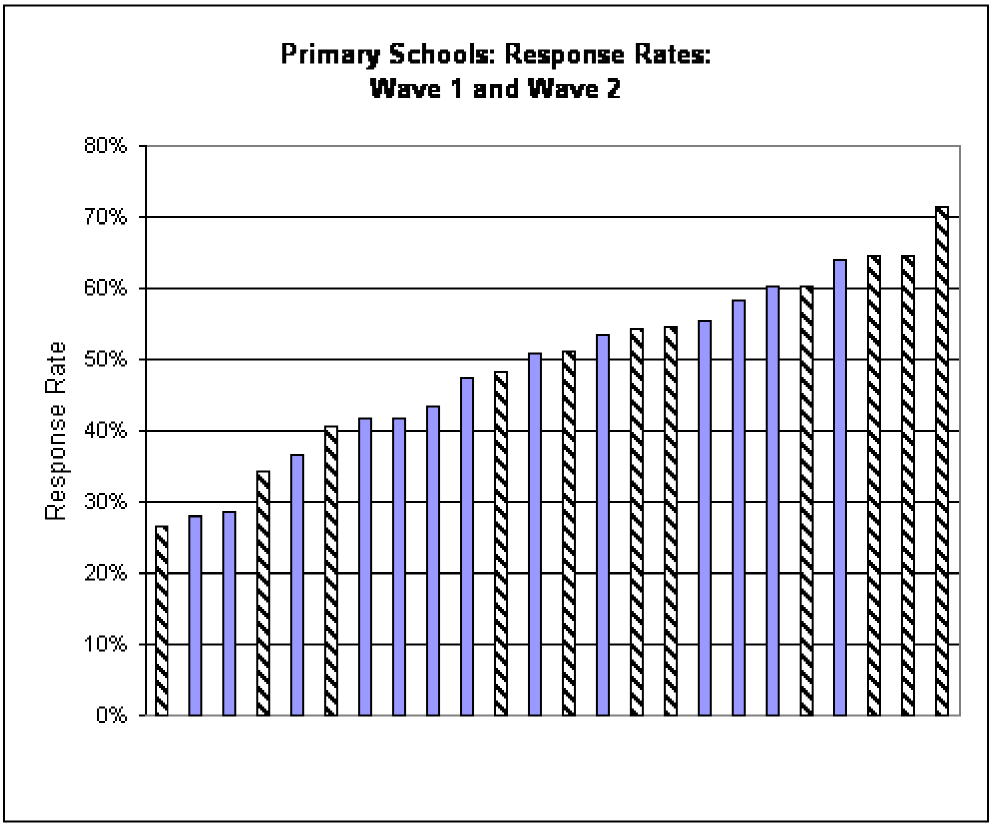
Please return a copy of this form to: Dr Jill Porter, Department of Education, University of Bath, BA2 7LU by 26th `March 2010`

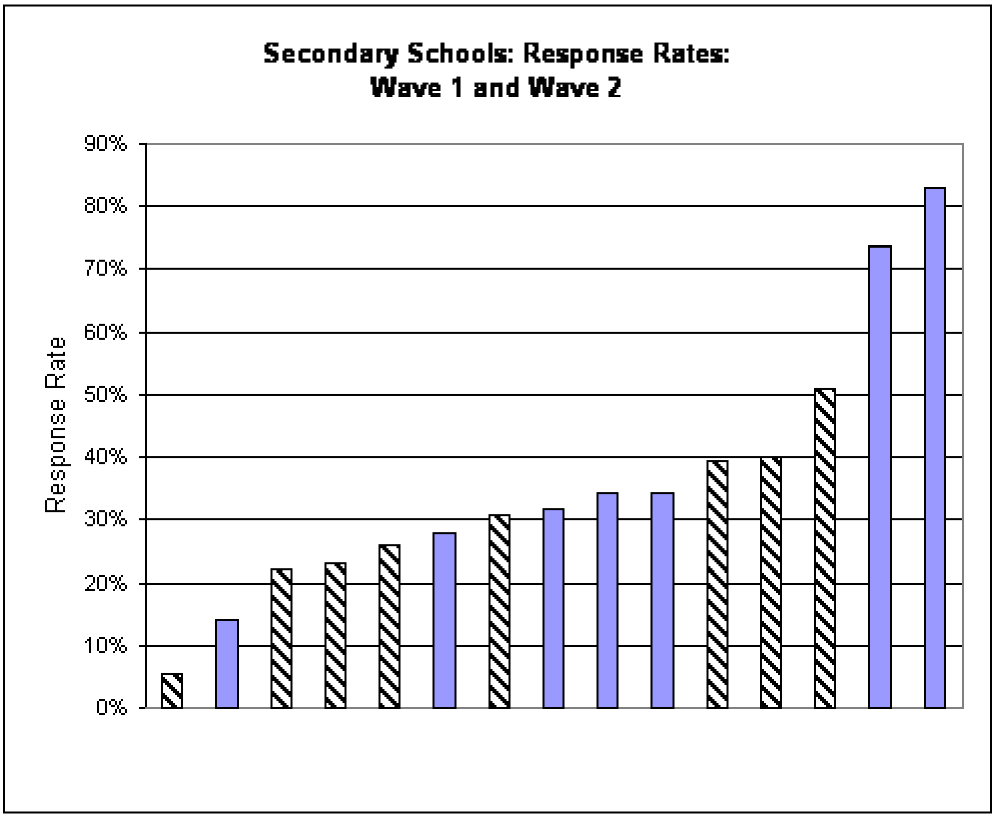
Appendix C – Descriptions of Special Schools in the Sample

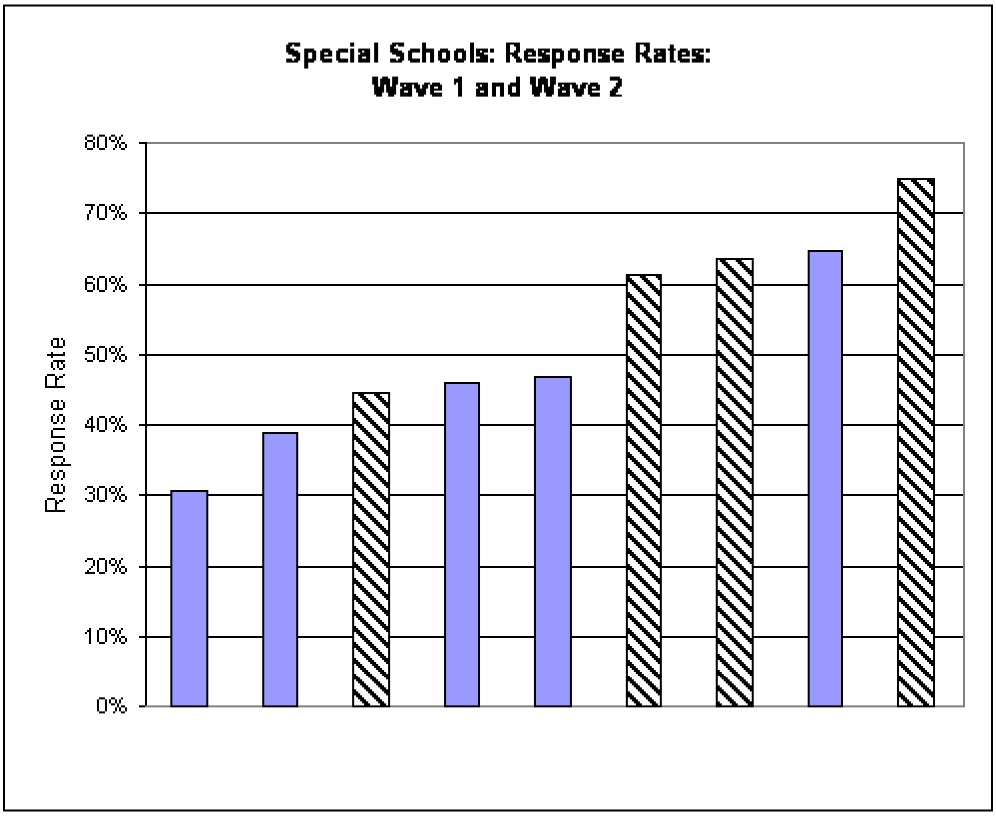
Special	2-19	Mixed	Community Special School	The school provides for learners who have statements of special educational need for their severe, profound and complex learning difficulties, including autistic spectrum disorders (ASD). In addition, many learners have complex medical needs
Special	4-19	Mixed	Community Special School	School educates pupils with a range of severe learning difficulties, including those children with visual and multi-sensory impairments. Some children also have an autistic spectrum disorder. A number of pupils also have complex medical needs.
Special	11-16	Mixed	Community Special School	School caters for pupils with moderate learning difficulties, complex learning needs, and autistic spectrum disorders, all of whom have a statement of special educational need. It offers residential accommodation for up to 24 boarders. The school has opened a new unit. This accepts up to 30 pupils with autism.
Special	4 - 19	Mixed	Community Special School	Designated for severe learning difficulties (SLD), it also provides for pupils with moderate learning difficulties (MLD) and additional complex needs including autism (ASD), profound and multiple learning difficulties (PMLD) and behaviour, emotional and social difficulties (BESD
Special	2 - 19	Mixed	Community Special School	The school provides for pupils with a statement of special educational needs, which identify a wide range of learning difficulties and/or disabilities. The main groups are pupils with moderate learning difficulties, severe learning difficulties and autism spectrum disorders. In addition, a few pupils have: behavioural, emotional and social difficulties, a sensory impairment, or profound and multiple learning difficulties.
Special	11 – 19	Mixed	Community Special School	School is a special school providing education for pupils with severe learning difficulties, profound and multiple learning difficulties, autistic spectrum disorder and behavioural and emotional difficulties. In recent years it has admitted an increased number of pupils from mainstream schools with challenging behaviours who are at risk of permanent inclusion.
Special	11 - 16	Boys	Community Special School	The School provides education for boys aged 11 to 16 who have a statement of special educational need (SEN) related to behavioural, emotional and social difficulties. Nearly all have additional learning or medical needs. Nearly half the pupils are known to the Youth Offending Team and a few are Looked After Children.

Special	2-19	mixed	Community Special School	This school provides for pupils with severe learning difficulties (SLD), autistic spectrum disorders and profound and multiple learning difficulties (PMLD). A significant number of pupils have additional medical needs.
Special	5-18	mixed	Community Special School	This is a special school for students with moderate learning difficulties (MLD).. All students have a statement of special educational need for MLD and an increasing number have a wide range of additional difficulties, including autistic spectrum disorders and more complex learning difficulties.

Appendix D Response Rates by Wave
(block is wave 1, striped wave 2)






Special Schools: Response Rates:
Wave 1 and Wave 2
Response Rate
80%
70%
60%
50%
40%
30%
20%
10%
0%

Appendix E – Diagnosis of Additional Census Children

	Q5iii What was the condition identified / diagnosed?	impact	No	Total
Primary	Blank	2	25	27
Secondary	Blank		17	17
Special	Blank	1	1	2
		3	43	46
Primary	- Slight asthmatic condition - Eosinophilic Oesophagitis - Multiple Allorgios		1	1
	A.M.L. Been in remission for 10 years, regular checks and heart echoes.		1	1
	ADHD		1	1
	Asthma		15	15
	Asthma.		1	1
	at the age of 3.		1	1
	Autism		1	1
	Awaiting results		1	1
	Broke right arm (He is right handed)		1	1
	C was born with a cleft lip (Not Palate) On going seeing paediatrician until age of 20 years.		1	1
	Cystinosis.		1	1
	Destrusor instability - (bladder spasms)		1	1
	Dyslexia		1	1
	Glue ear and hearing - Gromits - Now out.		1	1
	Half language, half understanding.		1	1
	He was upset because he witnessed his grandfather have a heart attack.		1	1
	Hearing impairment		1	1
	Hearing loss in left ear		1	1
	Hearing problems, had an operation Dec 2008. This had put been back, ie. could not hear so speech delayed. Bowel problems.		1	1
	Heart Murmour		1	1
	Histicytosis (neck)		1	1
	Little bit of asthma		1	1
	on the autistic spectrum		1	1
	Poor eye sight.		1	1
	possible dyslexia		1	1
	Short sighted (severely)		1	1
	Unable to sound out and recognise some phonics.		1	1
Secondary	Achilles tendinitis		1	1
	ADD (Attention Deficit Disorder)		1	1
	Aspergers		1	1
	Asthma		2	2
	Asthma - mild.		1	1
	Asthma since early childhood, and OCD diagnosed January 2010.		1	1
	Asthma, Anger Management counselling (had a few sessions)		1	1
	Blockage in Bowel		1	1
	Don't know yet.		1	1
	Dyslexia		1	1

	Dyslexia; mild ADD/ADHD (predominantly inattentive type); asthma.		1	1
	Glasses for short-sightedness, when reading board.		1	1
	Hormonal Problems		1	1
	J has mild co-ordination problems and has just completed a speed up exercise to help with his writing skills and tasks such as fastening buttons and shoe laces etc.		1	1
Special	Cranisynostosis, which cause bilateral sensor, hearing loss		1	1
	None identified		1	1
			58	58
		3	101	104

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