

---

## DISABILITY DATA COLLECTION FOR CHILDREN'S SERVICES

---

*Jill Porter, Harry Daniels, Jan Georgeson, Jayne Hacker and Vicky Gallop  
University of Bath*

*Antony Feiler, Beth Tarleton and Debby Watson  
University of Bristol*

### Introduction

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

### Key Findings

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

## Background

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

## Aim

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

*Does the pupil have a disability- in line with DDA definition?*

*What type of disability do they have?*

*What support needs do they have?*

## Methodology

This was a three phase enquiry involving

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

## Findings

### Scoping Study

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

### Pilot Phase

The pilot of the parent questionnaire confirmed the importance of using open and closed questions probing multiple indicators of disability

and including reference to difficulties alongside disability. Development work in schools of tools to use with children revealed the challenge to provide guidance to staff that will enable them to encourage children to reflect more deeply without constraining or pre-empting children's responses.

### National Trial

#### **Parent Questionnaire**

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

#### **Children who meet the DDA criteria**

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

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

#### **Children who meet the DDA criteria without SEN**

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

#### **Children with SEN who do not meet the DDA criteria**

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

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

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

### ***Children's Views on Barriers and Supports to Learning***

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

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

### **Stakeholder Feedback**

#### ***Parents***

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

### **Schools**

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

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

### ***Local Authority Perspectives***

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

### **Using the Data to Monitor Progress – NPD Matching**

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

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

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

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

## Conclusions and Implications

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

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

Many schools and local authorities suggested the data were collected from parents on admission. This timing has a number of advantages as nearly all schools reported meeting face to face with parents enabling

disability data to be collected alongside other personal data. Parents may however feel reluctant to provide information that would lead schools to anticipate difficulties and may be concerned that their child could be denied a place if they are seen to experience "problems". These disadvantages need therefore to be set against the greater potential for returns from all parents, and the possibility of getting parents to provide this data online with or without support from a member of staff. Familiarity with the form would facilitate annual or bi-annual follow-ups.

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

The research highlights the need for policies which strengthen an expectation that schools will have learning conversations with *all* children about the barriers and supports to learning and similarly open dialogues with *all* parents about the difficulties their children encounter. The continued use of both parent and child measures are important steps to developing a positive ethos whereby it becomes easier to report this vital information

## Additional Information

Copies of the full report (DCSF-RR062) are available by phoning the DCSF Publications Orderline on 0845 60 222 60. Reports are priced at £4.95.

This research brief and the full report can also be accessed at [www.dcsf.gov.uk/research/](http://www.dcsf.gov.uk/research/)

Further information about this research can be obtained from Nigel Gee, Floor 4, DCSF, Sanctuary Buildings, Great Smith Street, London SW1P 3BT.

Email: [nigel.gee@dcsf.gsi.gov.uk](mailto:nigel.gee@dcsf.gsi.gov.uk)

*The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Children, Schools and Families.*