

Disabled Children: Numbers, Characteristics and Local Service Provision

Introduction

There is a lack of data, both nationally and locally, on the numbers and characteristics of disabled children and their use of local service provision. Yet, such data is a prerequisite to the planning and delivery of effective services. The Thomas Coram Research Unit was commissioned to undertake a survey of all Directors of Children's Services in England to collect and analyse data on the numbers and characteristics of disabled children and the services provided to them.

Key Findings

- Respondents made considerable efforts to collate the data available to them in the time available and the survey achieved a high response rate (77%). However, the survey information did not provide a reliable figure for the number of disabled children for each local authority. This was due to the difficulties local authorities had in identifying and counting disabled children and the different definitions of disability applied.
- Varying sources of data available to local authorities, the lack of a consistent definition of disability, and the different categorisations and interpretations of service provision, currently make it impossible to assess accurately the level of health and social care services provided for disabled children and their families, nor the variation in services between local authorities.
- Comparisons have however been drawn using published figures. Analysis of these figures makes it possible to put a lower and upper bound on the number of disabled children in each local authority, based on the number of children with a statement of Special Educational Needs and in receipt of Disability Living Allowance (DLA). On this basis the number of disabled children in England is estimated to be between 288,000 and 513,000. The mean percentage of disabled children in English local authorities is likewise estimated to be between 3.0% and 5.4%.
- Most local authorities experienced difficulties in providing information on disabled children. Most recognised the need for improved data to inform their work and deliver effective services, but many were struggling with the difficulties in collecting and collating data on disabled children.
- Without comprehensive and comparable data it is difficult for both local and central government to assess how well the needs of disabled children are being met.
- The need for agreement on definitions of disability, a single database or shared, compatible databases, good communication between agencies, adequate resourcing and more guidance from central government are all important in helping to improve data on disabled children.

Background

With the publication of the report, *Aiming High for Disabled Children: Better Support for Families*¹, the government has pledged to improve outcomes for disabled children and their families identifying three priority areas: access and empowerment; responsive services and timely support; and improving quality and capacity. In order to plan and deliver effective services, local authorities require good information about the numbers and needs of disabled children, and about the support they receive. Such data are also needed by central government to support policy development and monitor progress in improving outcomes. The limitations of national data on the prevalence and type of disability among children have been widely recognised. Sources of local data, such as the Children Act Register, the Children in Need (CIN) Census, or data on children with special educational needs (SEN) are also unable to provide comprehensive information on the prevalence of children with a disability.

Aims

The study had three specific aims:

1. to design and administer a survey of all 150 Directors of Children's Services in England likely to achieve a high response rate.
2. to analyse and report on how disability is defined and recorded; the prevalence, and characteristics, of children with disabilities; the services that are provided to them and the robustness of these data.
3. to critically examine the difficulties that local authorities might encounter in providing these data and what may be done to resolve these difficulties.

¹ HM Treasury and Department for Education and Skills 2007

Methodology

A scoping phase informed design of the survey, exploring with four local authorities a range of issues including definitions of disability, data collection and management (including what information was available from partner agencies), and the kinds of questions that could feasibly be asked in a survey about the provision and delivery of services.

Following piloting, the survey was sent electronically in January 2008 to all 150 Directors of Children's Services and copied to the person most likely to complete it. Altogether, 115 questionnaires were returned - a response rate of 77 percent. Telephone calls were made to ten of the 35 non-responding authorities to elicit the reasons why they had been unable to complete a return.

Findings

Estimating the numbers of disabled children

Given the variation in definitions of disability the survey could not provide definitive figures for the numbers of disabled children for each local authority. However, comparisons were drawn based on five different sources of data: the total number of children with SEN statements; the total number of children with SEN (both with and without statements); the 2001 Census figure for the number of children with limiting long-term illness (LLI); the number of children in receipt of Disability Living Allowance (DLA); and the number of disabled children recorded in the CIN Census; and with figures based on the Office of Population Censuses and Surveys (OPCS), which may now be outdated, and FRS estimates.

Based on their analyses of published figures, the authors propose that it would be possible to put a lower and upper bound on the number of disabled children in each local authority based on the number of children with a SEN statement and the number of children in receipt of

DLA. Since it was widely agreed by local authorities that children in either of these categories would be counted as having a disability, a lower bound could be taken as the larger of these two and an upper bound as the sum of those two. The most likely figure would be somewhere between these two, its exact position depending on the degree of overlap between the two sources. It will also depend on the definition of disability applied. A narrow definition would tend towards the lower bound, whereas a broader definition might produce a figure even above the upper bound. Figures for each local authority, and for England as a whole, have been calculated based on this model and are included in an appendix to the report.

Characteristics of disabled children

According to the survey, boys are twice as likely as girls to be categorised as disabled, which is consistent with the 2005 Children in Need Census and the 2007 SEN statement figures. Compared to the 2001 Census, children under five are less likely to be known to be disabled, which is also consistent with CIN and SEN figures. However, the survey found, on average, equal numbers of disabled young people in the age range 5-11 and the range 12-18: this is consistent with the 2001 Census, but the CIN and SEN figures both show higher numbers in the oldest age group.

Due to a lack of comparable data on numbers of children with different types of disability the survey findings cannot be regarded as clear indicators of the prevalence of different types of disability. Furthermore, categorising by disability is not necessarily the best way of collecting information to inform service planning, and more useful information could be gathered by asking about function and need for support.

Use of local service provision

Despite careful piloting and the best efforts of survey respondents, the information collected by the survey on local service provision for disabled

children does not provide a strong basis for making judgements about the overall level of health and social care provision, nor of variation between local authorities in the services available. Substantial variation may well exist, but this could only be safely concluded on the basis of figures that are comparing like with like. The varying sources of data available to the local authorities responding to our survey, the different categorisations and interpretations of service provision and the lack of a consistent definition of disability, all mean that such comparisons cannot yet usefully be made.

Providing information on disabled children

Most authorities experienced difficulties in providing information for the survey. This was because Social Care, Education and Health differed in their definitions and criteria for categorising disability. An agreed definition and a single shared database, or databases that were compatible, were considered essential for improving data on disabled children. Integrated children's services and joint funding and commissioning may help to drive improvements, but more guidance from central government about what data to collect and protocols for data sharing would be helpful. Adequate resourcing for data collection and management, and good communication between agencies were important too. Those advocating that Children Act Registers played an important role suggested that adequate investment was needed, alongside strengthening its reach for example by providing incentives for parents to register their children or even making registration mandatory.

Conclusions

Planning and improving services for disabled children requires accurate, comprehensive data on numbers of disabled children in the population, together with the characteristics and use of local service provision. Improving services for disabled children will be significantly hindered without these data.

The survey shows that whilst local authorities recognise the need for such data to inform and improve their work, and whilst some are working towards improving their data systems, most are struggling with the difficulties associated with collecting and managing these data. The survey results indicate that no authority has found all the 'answers' and authorities are at different stages in the process of improving their data with some further along than others.

Implications for policy

In developing a strategy to meet the commitment outlined in *Aiming High for Disabled Children* for 'better local level data on disabled children and regular monitoring of the progress made on improving outcomes for disabled children, with much greater use of comparisons across the country to judge how different local areas are performing', these findings have implications for policy.

Currently, it is impossible to compare local authorities on their numbers of disabled children, because they do not use a consistent definition of disability. Whilst there is no single 'correct' definition, it is important that DCSF provides a common definition for the collection of a comparable dataset. The information currently collected on children with special educational needs is relatively comprehensive because there is a standardised format; local authorities know which data they are required to collect for the annual return and in turn have developed databases that will provide the relevant information. If local authorities knew which data they should be collecting on disabled children, and a similar reporting requirement was introduced, improved data collection and better databases would result.

Without data on disabled children collected by local authorities on a consistent basis, it is impossible to compare the services that are provided, as like is not being compared with like. In order to make any progress on assessing service delivery, a prerequisite is that

statistics are collected using a common definition. In developing that definition consideration should be given to categorising disability in ways which best inform service planning.

The findings support the need for central government to develop guidance to promote better practice in collating robust data. Data sharing and data protection are real issues faced by local authorities and their partners as they move towards a better database and such guidance could usefully include data sharing protocols.

Providing robust data on disabled children requires investing in the necessary resources to make this happen. The resources that local authorities currently allocate for collecting and collating information about disabled children appear to vary considerably.

It will take time for local authorities and their partners to develop the databases necessary to provide better data on disabled children, but the TCRU survey suggests that local authorities in general are keen to move towards this position, even though the process may be difficult. A step has already been taken to address the need for guidance on how to collect robust and comparable data, with the recent establishment of a joint DH/DCSF working group. This group is considering how effective systems can be developed for data collection and the use of data in the local planning and delivery of services, and what central government can do to remove obstacles that act as a barrier to joint commissioning and joint activities. With a greater commitment to improvement in data collection, it is to be hoped that associated improvements in services for disabled children will be realised.