

## Trajectories and transitions of disabled children and young people

### Research summary one: Child disability

# What is the prevalence of child disability?

## Evidence from two cohort studies of children and young people

### Introduction

Children are less widely surveyed than adults and there is substantially less consistent, nationally representative evidence on the rates and experience of disability in childhood. Different measures of disability are often used in research, and estimates of disability prevalence vary.

This research summary outlines the measures of disability used in two cohort studies of children and young people, the Millennium Cohort Study and the Longitudinal Study of Young People in England, and shows how they overlap. It identifies rates of disability at different ages in childhood and the extent to which disability is long-term.

This work is part of a broader research project, *Trajectories and transitions of disabled children and young people*, which aims to enhance our understanding of disabled children's early development and their subsequent educational transitions.

### KEY FINDINGS

- Multi-purpose surveys can be used to identify the prevalence of disability in childhood, using different measures. Longitudinal studies, which follow the same children over time, offer particular advantages for this.
- The prevalence of disability varies according to the measure used. Estimates suggest that 11 to 17 per cent of seven-year-olds have experienced disability, and 7 to 10 per cent of young people.
- There is little overlap across different measures of disability. Only 1 per cent of seven-year-olds have experienced disability according to all three measures outlined in this research: developmental delay, long-standing limiting illness, and Special Educational Needs.
- Different measures capture different aspects of disability. It may be important to use all of them to fully understand the impact of disability on children's lives.

### Defining disability

Official definitions of disability encompass both physical and learning disabilities, and physical and mental illnesses. The social model of disability identifies disability not with particular health conditions or impairments but in terms of the limitations experienced by individuals in society as a result of these conditions or impairments. This is the model of disability that is now in most common use and which has been explicitly recognised in legislation.

Since the implementation of the Disability Discrimination Act (DDA) in 1995, standardised questions have been used in surveys. The DDA defines a disabled person, reiterated in the 2010 Equality Act, as someone who has 'a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities' (part 1, paragraph 1). Survey questions which capture 'long term' and 'day-to-day' limitations have enabled researchers to estimate disability prevalence and explore how disability is associated with economic and social disadvantages.

However, the definition used in population surveys remains contested and estimates of prevalence vary across sources.

### Previous research

The Life Opportunities Survey covers children aged 11-15 and, distinguishing between impairment and disability as defined in legislation, estimated in 2009 that nine per cent of children were disabled<sup>1</sup>. However, this is a specialist survey, and much less information is available about younger children.

For children of school age, much research has focused on Special Educational Needs (SEN) as a proxy for child disability. Annual data indicate the range and variety of SEN, and rates are much higher than those for disability measured in other ways, at around 20 per cent of school age children<sup>2</sup>. However, SEN assessment may not fully capture the experience of child disability. While the extent of overlap between disability, as defined under the DDA and the Equality Act, and SEN has been estimated at 75 per cent (i.e. 75 per cent<sup>3</sup> of those identified as DDA disabled also have SEN), it is not clear that this estimate of overlap can be generalised. Moreover, assessments and trends in SEN may reflect changes in policy, as well as changes in the prevalence of disability.

## The studies

### The Millennium Cohort Study (MCS)

The MCS is a study of more than 19,000 children born in 2000-2001. The children have been surveyed five times so far: at 9 months, and ages 3, 5, 7 and 11 years. The age 11 survey was completed in 2013 and data will be available in early 2014. The study collects a rich array of information on different aspects of the children's lives, including socio-economic background, health and disability, and behavioural and cognitive outcomes.

In order to explore the experience of the children over time using consistent measures of disability, this research focuses only on children who were present at each of the first four surveys. For comparison with the LSYPE,

we concentrate on those living in England, providing a sample of 7,342 children.

### The Longitudinal Study of Young People in England (LSYPE)

The LSYPE is a large scale, representative study of nearly 16,000 young people born in the early 1990s. They were first surveyed when they were in year 9 (aged 13/14) and followed up annually for seven years. The study contains a wealth of data relating to the young people's educational experiences, occupational and educational aspirations, and personal and family characteristics. This research concentrates on those who were present at each survey, providing a sample of 8,115 young people.

1 Office for National Statistics (2009) Life Opportunities Survey: Interim Results, 2009/10.

2 Lewis, J., Mooney, A., Brady, L., Gill, C., Henshall, A., Willmott, N., Owen, C., Evans, K. and Statham, J. (2010) Special Educational Needs and Disability: Understanding Local Variation in Prevalence, Service Provision and Support. London: Department for Education.

3 Porter, J and others (2008) Disability Data Collection for Children's Services Research Report DCSF-RR062.

## Measures of disability: MCS

The MCS includes a range of measures of health problems and disability that have been collected at different points in the study.

These can be used to look at specific conditions, such as visual impairment<sup>4</sup> or ADHD<sup>5</sup>, that are of interest to those concerned with particular health problems, but also have the potential to estimate overall disability among the age group. This research focuses, therefore, on three, broader measures of disability:

- Developmental delay, measured at age 9 months
- Long-standing limiting illness, measured at age 3, 5 and 7
- Special Educational Needs (SEN), measured at age 7.

### Developmental delay

Developmental delay was tested at 9 months by assessing motor coordination and early communicative gestures.

Of the sample of 7,342 children, 88 per cent (6,434) had no delay, and 12 per cent (903) had either mild (10 per cent) or severe (2 per cent) developmental delay.

### Long-standing limiting illness

Long-standing illness, and whether or not it limited daily activities, was measured in the surveys at ages 3, 5 and 7. In line with the legislative definition, we considered as disabled children who had a long-standing illness which limited day-to-day activity at any of the three surveys, even if they ceased to be defined in this way at a later survey. Examples of long-standing limiting illness include long-term health conditions such as type 1 diabetes or asthma; mental health problems; and impairments such as a missing limb or partial sight.

By this measure, 773 children, or 11 per cent of the sample, had a long-standing limiting illness at one or more of the surveys, including 3 per cent who had a long-standing limiting illness at two or three surveys.

### Special Educational Needs (SEN)

We included children who were considered to have special educational needs by either their parent or their teacher or both. SEN covers health conditions or impairments that may inhibit learning, such as hearing loss; behavioural difficulties such as ADHD;

learning-related conditions such as dyslexia; and learning disabilities.

Overall, 13 per cent of children had SEN and a further 4 per cent had a Statement of Needs, equalling 17 per cent in total. A Statement outlines the additional support for a child with needs that cannot be met within the school's existing resources. This SEN rate is slightly lower than the rate for school age children as a whole, as suggested by Department for Education statistics (i.e. 20 per cent); however, rates of SEN tend to be lower in very young children, which may account for the difference.

4 Harris, J., Keil, S., Lord, C. and McManus, S. (2012) Sight impaired at age seven: Secondary analysis of the Millennium Cohort Study. London: RLSB, RNIB and NatCen Social Research.

5 Russell, G., Rodgers, L.R., Ukoumunne, O.C. and Ford, T. (2013) Prevalence of parent-reported ASD and ADHD in the UK: Findings from the Millennium Cohort Study. *Journal of Autism and Developmental Disorder*. DOI 10.1007/s10803-013-1849-0.

## Findings: MCS

- 2,294 children, or 31 per cent, were disabled by one or more of the three measures.
- However, only 94 children, or 1 per cent, were disabled under all three definitions (Figure 1).
- 228 (25 per cent) of children with developmental delay at 9 months were defined as SEN by age 7, and 152 (17 per cent) had a long-standing limiting illness.
- Of those with a long-standing illness, 292 (38 per cent) also had SEN.

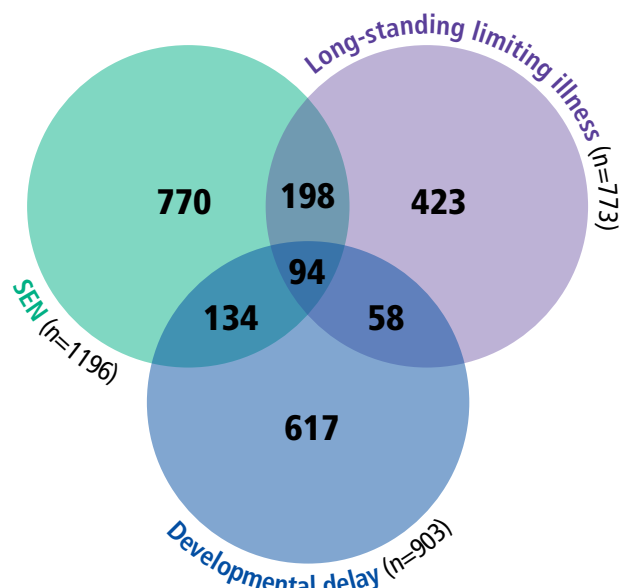
These findings show that, among young children, different measures are capturing different aspects of disability experience.

Developmental delay is not a strong predictor of either long-standing illness or SEN, but a higher proportion of those with developmental delay than those without end up so classified. Seventeen per cent of those with developmental delay are classified as having a long-standing illness and 25 per cent as having SEN. This compares to 9.5 per cent and 15 per cent, respectively, among those without developmental delay.

At the same time, SEN captures the experience of only half of all those who might be considered disabled, and it is not clear that the experience of those with SEN is typical of the wider disabled group. This is a question we explore in following summaries.

FIGURE 1

### Relationship between disability measurements in MCS



## Measures of disability: LSYPE

### Long-standing illness

Young people were asked about long-standing illness in the fourth LSYPE survey (age 16/17), and their parents were asked in the first survey (age 13/14).

We defined as disabled those who had a limiting long-standing illness at either (or both) of these surveys, as well as young people with a long-standing illness that did not limit activity as long as it was reported at both surveys. Young people under this combined definition experienced similar levels of disadvantage.

In total, 571 young people, or 7 per cent of the total sample, fell into this category.

### Special Educational Needs

We included young people who were identified by their parents as having SEN in either of the first two LSYPE surveys. In total, 775 (9.6 per cent) young people were defined as having SEN.

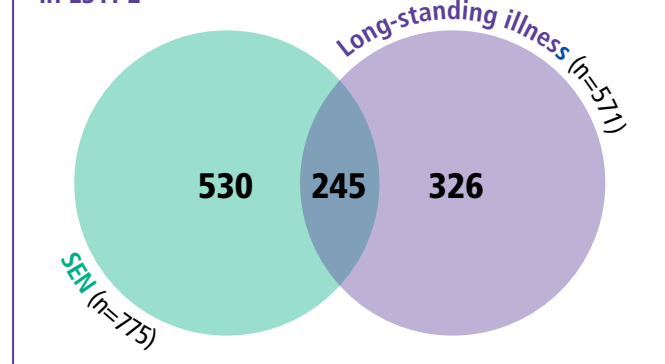
## Findings: LSYPE

- 1,101 young people, or 14 per cent of the total sample, were disabled under one or both measures.
- This comprised 530 who were SEN only, 326 who had a long-standing illness only, and 245 (or 20 per cent) who were both (Figure 2).

The level of overlap is greater for the young people in the LSYPE than for the MCS children. The rate of SEN among those with long-standing illness (43 per cent) is substantially higher than the rate among those without a long-standing illness (seven per cent); and the rate of long-standing illness among those with SEN (32 per cent) is also substantially higher than among those not defined as having SEN. However, it is striking that the overlap is still relatively minor. It leaves a large proportion of children who are disabled but do not have SEN: a group about whose experience, and how well it is catered for, we know relatively little.

FIGURE 2

### Relationship between disability measurements in LSYPE



## Conclusion

The two cohorts highlight a wider group of disabled children whose experiences may differ from those who have been the focus of extensive investigation into SEN. Both SEN and other disabled children are highly diverse groups and the next stages of this research will enable us to explore their experience and levels of disadvantage in more detail, and look at how they fare over time.

## About this study

*Trajectories and Transitions of Disabled Children and Young People* is a joint project between the Centre for Longitudinal Studies (CLS), the National Children's Bureau (NCB), and the NCB's Council for Disabled Children (CDC).

Research is being carried out by Lucinda Platt, Sam Parsons and Stella Chatzitheochari from CLS; Becky Fauth and Helena Jelcic from NCB; and Philippa Stobbs and Lucia Winters from CDC.

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This summary is the first in a series that will be produced to reflect the different stages of the project. Summary 2 covers the socio-demographic circumstances of disabled children.