

Understanding the needs of disabled children with complex needs or life-limiting conditions

WHAT CAN WE LEARN FROM NATIONAL DATA?



Exploratory analysis commissioned
by the Council for Disabled Children
and the True Colours Trust.

by Anne Pinney

Foreword

The data challenge: how can we plan to meet people's needs if we don't know what they are?

There are growing numbers of disabled children and young people with complex needs and/or life-limiting conditions in the UK. These children, and their families, need support from statutory services in health, education and social care: but there is a data challenge. Local authorities and providers do not have the data that allows them to adequately plan and commission services for these children and young people.

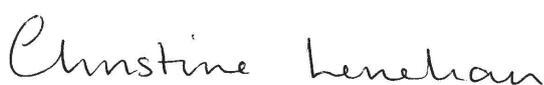
The national data set on disabled children is inadequate: it has gaps, anomalies and inconsistencies. It is unfit for purpose. There is growing acceptance of the need to integrate and plan holistically for children and young people's needs. But there is a lack of coherence across services on terminology and what data to collect. Even when data is collected it is not always as helpful for other agencies and services as it could be, as data is collected on children separately by different agencies using different systems making it difficult for services to be commissioned and planned in an intelligent and efficient way.

There have been a number of useful and significant recent initiatives to improve the health data on children which are highlighted in this report, however, there is still much to be done.

We commissioned this piece of research because we wanted a definitive picture of the type of data that is available; to understand what this data tells us about the population and whether it shows us anything useful in terms of developments and/or changes in the population; to identify gaps in current data collection; and to develop an action plan with key stakeholders to drive forward improvements.

We would like to thank Anne Pinney for her work and commitment to this piece of work; all those who assisted Anne; and all the participants at the Expert Workshop (listed in Annex B) who helped identify solutions to the challenges we currently face and who have made personal and institutional commitments to meet the data challenge.

We believe that disabled children and young people with complex needs and/or life-limiting conditions deserve better support than they currently receive. The Council for Disabled Children and the True Colours Trust are committed to improving the national data on these children because, without robust and accurate data, it is impossible to commission and provide services which meet their needs and enable them to live full lives. This report is a first, important step, in meeting the data challenge.



Dame Christine Lenahan
Director, The Council for Disabled Children



Lucy Sainsbury
Chair of Trustees, The True Colours Trust

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Executive summary of key messages from this analysis

There are rising numbers of disabled children with complex needs and/or life-limiting conditions, who, with their families, are likely to need support from health, education and social care continuously or at times throughout their life.

More than a decade ago, the National Service Framework (Standard 8: Disabled Children and Young People and those with Complex Health Needs) noted:

In the past ten years, the prevalence of severe disability and complex needs has risen. This is due to a number of factors, including increased survival of preterm babies and increased survival of children after severe trauma or illness. There are up to 6,000 children living at home who are dependent on assistive technology. Children and young people with life-limiting conditions, such as cystic fibrosis, have better life expectancy.¹

Three years later, Aiming High for Disabled Children: Better Support for Families (DfES, 2007) estimated that around 100,000 disabled children had complex care needs.²

Similarly, Better Care, Better Lives (DH, 2008), informed by the Independent Review of Children's Palliative Care Services, noted the challenge faced by service providers and commissioners due to: 'the change in the profile of children with life-limiting or life-threatening conditions over the last 20 years due to technological advances and increased survival rates of low-birthweight babies.'³

These seminal policy documents are still highly relevant today, but over the past decade, policy attention has shifted to other vulnerable groups (e.g. looked after children, troubled families) while budget cuts have eroded local services.

Our analysis suggests that there is an urgent need to sharpen the focus on disabled children and young people, in particular, the rising number of children with complex needs and life-limiting conditions. We need to know more about the numbers and needs of this cohort, how this is changing over time and what this may mean in terms of future demand for specialist services.

What can we learn from national data (education, social care and health) about these trends?

School Census data shine some light on these trends. The School Census collects detailed data on the great majority of school children in England, including information on their special educational needs (SEN) using a standard list of terms (Annex C). Usually only a child's 'primary need' is reported.⁴

Some primary needs are associated with complexity: on average, children with these needs are most likely to attend special schools and most likely to receive specialist support provided through an Education, Health and Care (EHC) plan or a statement.⁵ Based on this approach, a narrow estimate of the number of school children (broadly, aged 5-16 years) with complex needs is 73,000, made up of:⁶

- 10,900 children with profound and multiple learning difficulties
- 32,300 children with severe learning difficulties
- 27,500 children with autistic spectrum disorders in special schools⁷
- 2,300 children with multi-sensory impairments.⁸

The equivalent figure in 2004 was 49,300. This suggests that the number of school children with complex needs in schools in England may have risen by nearly 50 per cent in just over a decade.

The actual number is higher, as children with other primary needs may have complex

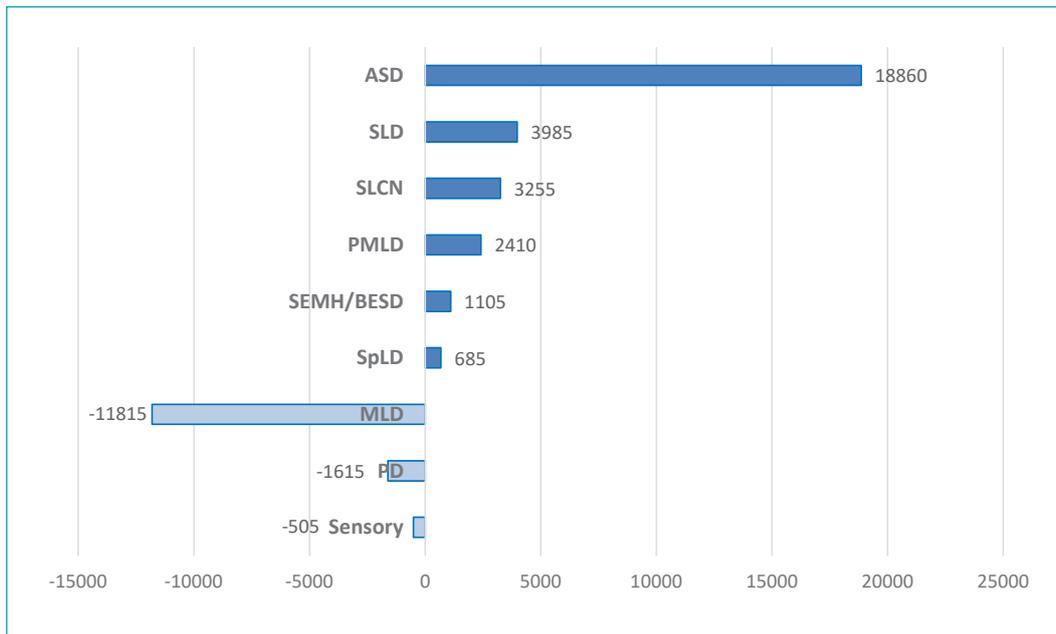
needs and because there are some important gaps in School Census data. Notably:

- 13,500 children with statements/EHC plans placed in independent schools, which provide some of the most specialist placements⁹
- 23,100 more young people aged 16-25 years with statements or EHC plans who are not included in School Census data, including over 1,000 aged 20-25 years.¹⁰

Another way of estimating the number of children and young people with complex needs is to look at the size of the special school population (acknowledging the great variation in placements at local level¹¹). Nearly **118,000** children and young people with statements or EHC plans are placed in specialist schools and colleges.¹² Special schools now cater for many more children with complex needs than in 2004 (Chart 1). The number of children with complex needs in mainstream schools has also risen over the same period.¹³

These trends are not evident in the social care data, partly because so few disabled children are assessed as children in need (0.4 per cent of all 0-17 year olds) or looked after under the Children Act 1989 (with only 2,250 children nationally whose main reason for being looked after is disability).¹⁴ It is clear from the data analysed that thresholds for support from social services for disabled children and their families are high and vary widely from area to area. This may reflect tight local authority budgets and more positively, the roll-out of Early Support.¹⁵

Chart 1: Change in the primary needs of children in special schools between 2004 and 2016 (increases on right, decreases on left)



Source/notes: SFR 29-2016 national tables (table 8) compared to SFR 44-2004 (table 9). School Census data, excludes children in independent schools. Figures rounded to nearest 5. Categories 'other difficulty/disability' and 'no specialist assessment' excluded. Hearing impairment, visual impairment and multi-sensory impairments aggregated into 'sensory' category. See Annex C for glossary of acronyms.

Major efforts are being made to improve health data on children, with the introduction of a standard approach to recording childhood disabling conditions and the support needs of children, young people and families, as part of the mandated Children and Young People's Health Services data set (CYPHS).¹⁶ Work is also underway to develop a small national data set on children and young people with life-limiting or life-threatening conditions.¹⁷ However, at present there appears to be no routinely published national health data on disabled children.¹⁸

In the search for health data on disabled children with complex needs or life-limiting conditions, we spoke to senior officials and data experts in the Department of Health, NHS England and Public Health England, as

well as several academics. Two key trends were highlighted repeatedly, both contributing to rising numbers of disabled children with complex needs or life-limiting conditions:

- improved survival rates of preterm babies and babies with congenital conditions
- increased life expectancy for children with complex disabilities, including children with severe cerebral palsy, cystic fibrosis and Duchenne muscular dystrophy.

These perceptions are consistent with academic evidence,¹⁹ but hard to discern from national data. This contributes to a widespread lack of awareness and policy attention, locally and nationally, on the rising numbers of disabled children with complex needs and life-limiting conditions.

This matters, because many local authorities and clinical commissioning groups (CCGs) have an incomplete and out-of-date picture of disabled children and young people in their area, undermining the potential for forward planning and intelligent commissioning of specialist provision. Poor data has been highlighted as a challenge for local areas in inspection reports.²⁰

Yet disabled children with complex needs and life-limiting conditions may be known to health services from birth. They are known to the education service throughout their school years and increasingly into early adulthood. They and their families are also likely to be known to social care, although it is clear from the data that thresholds for formal assessment are very high. Over the last decade, there has been a drive to improve our knowledge of looked after children and accountability for improving their outcomes. This has included developing integrated statistical bulletins which include social care data and key health and education indicators, and using data-matching to provide a fuller

picture of looked after children's experiences of services and outcomes.²¹

Disabled children with complex needs and life-limiting conditions are a larger, more costly and equally vulnerable group. We know very little about their outcomes, but successive studies involving research with their families give cause for concern.²²

As a nation, we urgently need a much clearer picture of the number and needs of this growing cohort. We need to work with them and their families to understand the services they require to achieve the best outcomes possible. We need to plan ahead to meet their needs, supporting children and families before they reach crisis point, where a residential placement or admission to a mental health inpatient unit becomes the only option or they are denied a dignified death in the place of their choosing.

This requires vision and leadership at national and local level, underpinned by robust data to drive improvements in policy and practice.



Section One: Introduction

Purpose of this research

This paper shares the findings of a data analysis carried out between August and October 2016. The main aim of the project was to explore what national data reported by health, education and social services tell us about disabled children and young people with complex needs or life-limiting conditions. We wanted to put together as full a picture as possible of this cohort using national data, to inform improvements in planning, commissioning and policy development, both locally and nationally.

This was a short, exploratory project, perhaps best characterised as a big, messy jigsaw with some of the most important pieces missing! We knew from the outset that the analysis would raise more questions than it could answer, indeed, understanding the gaps in the data picture and the barriers to making use of the available data was integral to the project's aims. Equally, we wanted to identify how to make progress and to identify some practical recommendations to that end.

We did not know if we would publish a report. However we believe that the messages emerging from this analysis, summarised in this paper and the accompanying data bulletins, have some important implications which need to be grasped by policy makers and service commissioners at the local and national level.

This paper was initially prepared for discussion at an expert workshop in November 2016, involving senior officials from the Department for Education, Department of Health, Public Health England, NHS Digital and voluntary sector partners (a list of attendees can be found in Appendix B). The conclusions and recommendations reflect the suggestions and commitments made at that workshop.

Grateful thanks are due to the many people who contributed their time and ideas, not least to DfE and NHS Digital analysts for their patience and support in meeting our data requests; colleagues at CDC and the True Colours Trust for their support and encouragement throughout; and to a wide range of people who shared their expert knowledge and insights.

Project scope and definitions

This analysis focussed on disabled children and young people aged 0-19 years in England, who have complex needs and/or life-limiting conditions.

Definitions are a challenge. The project specification offered the following definition of this cohort: Around 2% (rough estimate) of children and young people whose disabilities have a significant and enduring impact on their life and who are likely to need specialist support from education, health and/or social care at times or throughout their childhood and adolescence. In service delivery terms, it is likely that these children:

- are known to Child Development Teams (health-led)
- are known to Disabled Children Teams (social services)
- have an EHC plan (or statement or Learning Difficulty Assessment).

Each sector uses a different set of definitions for disability, tailored to reflect their own priorities. So for example, some health data is based on medical diagnoses; education data focusses on children's primary 'special educational needs' as reported by school special educational needs coordinators (SENCOs); social care uses another list of definitions, which include terms such as 'hand function' and 'consciousness' (for epilepsy). Education data use the term learning difficulties, while health and social care use the broader term learning disabilities. Annex C provides a list of terms used to describe children's needs and disabilities, descriptions and a glossary of the many acronyms used in this report.

We tried to take a pragmatic approach to definitions, looking at data on disabled children broadly and drilling down in more detailed analyses where definitions (such as profound and multiple learning difficulties and severe learning difficulties) could be associated with complexity.



Data sources

The data sources interrogated for this analysis included national data reported by education, health and social services on disabled children and young people:

- Education data on children and young people with special educational needs (SEN)
- Social care data on disabled looked after children and children in need with a disability
- Mental health data on inpatients and referrals for children and young people with learning disabilities and/or autistic spectrum disorders.

Published data tables were supplemented by requests to DfE and NHS Digital to provide different breakdowns (e.g. a wider age range) and because some data collected on disabled children and young people are not published; DfE data on residential placements of children with SEN is a good example. So there are potentially some 'easy wins' for Government departments, if they want to improve the evidence base on this cohort, simply by making fuller use of data already collected.

Surprisingly no national health data on disabled children and young people are currently published, although major efforts are underway to remedy this, including the introduction of a standard approach to recording childhood disabling conditions, issues and the support needs of children and families, as part of the mandated Children and Young People's Health Services data set (CYPHS²³). If successful (there are significant cultural and technological challenges), it has the potential to yield rich insights on the numbers and needs of this cohort and their families in future.

Section Two: What do national data tell us about disabled children and young people with complex needs or life-limiting conditions? Headline findings from the data analysis

The main audiences for this analysis are those responsible for planning and providing services for disabled children and young people and their families, at local and national level – in health, education and social care. Accordingly, the key data sets we focussed on were those collected at the national level by these services:

1. Education data on children and young people with special educational needs (SEN)
2. Social care data on disabled children who are looked after and on children in need with a disability
3. Mental health data on children and young people with learning disabilities and/or autistic spectrum disorders in inpatient care and referrals for this cohort.

This section shares headline findings from our analyses of the data. The full data analysis is available at www.councilfordisabledchildren.org.uk/help-resources/resources/data-report

Children and young people with special educational needs (SEN)²⁴

The number of children with SEN in schools in England has fallen by one fifth in the last decade, to 1.23 million in January 2016 (driven by recent reforms and criticism by Ofsted that schools were identifying too many children as having SEN²⁵). Over the same period, the proportion of school children with more significant SEN, requiring specialist support provided through a statement or an Education, Health and Care (EHC) plan remained steady at 2.8 per cent, or 237,000 children in 2016.

Across all children with statements/EHC plans, 73% are boys and 27% are girls (a more pronounced gender gap than in the UK Census, social care or mental health data). The number of school children with statements or EHC plans increases with age, peaking at 15 years.

Autistic spectrum disorder (ASD) is the most common primary need amongst children with statements or EHC plans. 57,200 children have a statement/EHC plan for ASD, just over one quarter (26%) of all children with statements/EHC plans. The great

increase in the number of children with ASD is the clearest trend in the education data, across both mainstream and special schools. This trend is also evident in our analysis of disabled children in need.

Children with statements or EHC plans are now more likely to attend a special school than a mainstream school. Our analysis suggests that this mainly reflects rising numbers of children with complex needs over the past decade, rather than a drift away from inclusion, as:

- Special schools are working with a cohort of children whose needs are more complex than a decade ago
- The number of children with complex needs in mainstream schools has also risen.

The opportunity for children with complex needs to choose to attend a special or mainstream school varies greatly depending on where they live. Many more are included in primary schools than secondary schools. The great majority of those in mainstream schools are learning alongside their peers, rather than in separate units or specially resourced provision.

A very narrow estimate of the number of children with complex needs in schools in England in 2016 is **73,000**, made up of:

- 10,900 children with profound and multiple learning difficulties (PMLD)
- 32,300 children with severe learning difficulties (SLD)
- 27,500 children with autistic spectrum disorder (ASD) attending special schools

- 2,300 children with multi-sensory impairments.

The equivalent figure in 2004 was 49,300. This suggests that the number of school children with complex needs (narrowly defined, as above) in England has risen by nearly 50 per cent since then.

The actual number is certainly higher, as children with other primary needs may have complex needs and because there are some important gaps in School Census data (the fullest data set available on children with SEN). Notably:

- 13,500 children with statements/EHC plans in independent schools, many with complex needs as this sector provides some of the most specialist placements
- 23,100 more young people aged 16-25 years with statements or EHC plans who are not included in School Census data, including over 1000 aged 20-25 years. It is likely that most of these young adults have complex needs.²⁶



Another way of estimating the number of disabled children and young people with complex needs is to look at the number of children and young people with statements/EHC plans in specialist placements. In 2016, a total of **117,900** children and young people with statements or EHC plans were placed in special schools or specialist colleges, with a small number in hospital schools.²⁷

Over 5,200 children with the most complex needs live away from home in residential special schools.²⁸ A recent survey suggests that this includes over 1,100 in full-time '52-week' placements.²⁹

Children in need (CiN) with a disability³⁰

There were 50,800 children in need (CiN) with a disability or illness in March 2015, 13% of all children in need. The proportion of children in need with a disability has fallen in each of the past five years (since 2011) while the number of children in need has risen overall. This suggests that thresholds for assessing disabled children have been rising.

Children in need with a disability represent 0.4% of the 0-17 year old population in England.

Disabled children in need are most likely to be boys and of secondary school age. Disability/illness was the main social care need for the majority (63%) of children in need who had a disability recorded. The other main reasons for needing support were:

- Abuse or neglect, for nearly one in five (18%, 9,190) children in need with a disability
- Family difficulties for 13%, because of acute family stress or family dysfunction.

There is great variation at local authority level in the number of children in need with a disability and in the disabilities recorded. Six of the largest authorities have over 1,000 CiN with a disability, while seven authorities have less than 100 (with a median of 260). It is likely that these wide variations reflect local eligibility criteria and the way services are organised (e.g. availability of Early Support) rather than variations in the number and needs of disabled children in each area.

Learning (broadly defined as having SEN) is the most common disability recorded, for 46% of children in need with a disability. Autism/Asperger syndrome is the second most common, for 31% of this cohort. The next most common disabilities are communication (24%), behaviour (23%) and mobility (22%).

The proportion of children in need with a disability with autism/Asperger syndrome has risen most over the last five years (from 26% of the cohort to 31%), echoing the clearest trend in the SEN data.

For over half (56%) of disabled children in need, only one disability is recorded and for almost three quarters (73%) only one or two disabilities are recorded. This suggests that relatively few children with complex disabilities and their families are supported as children in need, perhaps because they are supported by other services – local research is required to understand this.

Children who are looked after under the Children Act 1989 due to their disability³¹

2,250 children and young people were looked after due to their disability at March 2015 or 3 per cent of looked after children, the same proportion in each of the last 5 years. The actual number of disabled looked after children is higher, but if abuse or neglect is involved, that would almost always be recorded as a child's primary need, instead of disability.

At local authority level, numbers are low, typically between just 1-24 disabled looked after children. Most children looked after due to their disability are boys and most are secondary school age.

Over two-thirds (68%) are looked after on a voluntary basis (section 20 of the Children Act), often used for children in full-time residential placements.

Disabled looked after children are nearly five times as likely to be in a residential placement, compared to all looked after children (59% vs 12%), the great majority of them in children's homes and residential special schools. They are also more likely to be placed 'out of area' than others.

Disabled care leavers are more likely to be in education, employment or training at age 19 years than all care leavers (60% vs 53%) but slightly less likely by 21 years (40% vs 42%).

At age 19, 40% of care leavers whose main need was disability were living in community homes, ten times the proportion across all

care leavers (4%). Just over one in ten (11%) were living independently, compared to one third (32%) of care leavers overall. By age 21, the proportion of disabled care leavers living independently has fallen to 10%, compared to 45% of care leavers overall. This suggests that this cohort includes many young people with complex needs.

Children and young people with learning disabilities and autistic spectrum disorders in mental health inpatient facilities and specialist referrals³²

In 2011, the Panorama programme uncovered horrific abuse of patients with learning disabilities at the Winterbourne View Hospital. This prompted an ambitious cross-Government programme of action known as Transforming Care³³ to reduce to a minimum people with learning disabilities and autistic spectrum disorders (ASD) living in mental health inpatient units for assessment and treatment. Improving national data on this cohort has been central to this reform agenda, to inform and drive progress in all areas. At the end of February 2016, there were 170 mental health inpatients with learning disabilities and/or autistic spectrum disorders aged under 18 years and 635 aged 18-25 years. The number of under-18s who received inpatient care at some point in the year (to February 2016) was much higher, at 430. (Equivalent figure not available for young adults.)

The gender split was fairly even among under-18 inpatients with 49% girls: 51% boys. Among young adults aged 18-25 years, 76%

were male, 24% were female, consistent with the wider inpatient population.

Children are more likely to be treated further away from home than other inpatients. Under 18s were admitted to inpatient units on average 79km from home, with roughly one quarter placed between 50-100km away and one quarter more than 100km away.

Nearly one third (31%) of under-18s were admitted to inpatient care informally, compared to 9% of young adults and 11% of the inpatient population overall. Nearly two-thirds (62%) of under-18s were admitted for assessment and treatment (part 2 admissions³⁴).

For young adults aged 18-25 years, 59% were subject to part 2 while 17% were detained under part 3 (no restrictions) and 14% with restrictions. Young inpatients (<18 years) at the end of February 2016 had on average been in hospital for 285 days or around 9 months - ten times longer than the 28 day limit for section 2 admissions for assessment. Around one third stayed for a year or more, with 10 children who were inpatients for 2-5 years.

Care and Treatment Reviews (CTRs³⁵) were developed to avoid unnecessary admissions and to plan towards discharge (or transfer) as soon as possible. CTRs should take place soon after admission, then every six months. 100 (60%) of the 170 inpatients under 18 years had not had a CTR and 105 (61%) children still had no scheduled CTR, worse than for other age groups. Only 35 (21%) of the 170 children in inpatient care

had a planned transfer date, a much lower proportion than across all inpatients (32%) or 18-25 year olds (30%).

The Learning Disability Census collected information on inpatients' experience of care (there are concerns that these data on children and young people may no longer be regularly collected). 'Adverse experiences' include self-harm, accidents or physical assault; 'restrictive measures' include use of hands-on restraint and seclusion. The last Census showed that under-18s were by far the most likely age group to have experienced both adverse experiences and restrictive measures during the last three months. Among under-18s:

- 70 (41%) experienced both adverse experiences and restrictive measures
- 20 (12%) had adverse experiences only
- 25 (15%) experienced restrictive measures only
- 55 (33%) experienced neither.



Nearly two-thirds of children and young people (105) had been given anti-psychotic medication regularly in the last 28 days. 45 children and young people (27%) had rapid tranquilisation medication given to them, more than twice the proportion for all inpatients. There are serious concerns about the appropriate use of such medication.³⁶

The average weekly charge across all inpatients was just over £3,500, ranging from up to £1,500 to over £6,500. Most children are in higher cost placements of more than £4,500 per week.³⁷

In June 2016 (latest monthly data at time of writing), 41,500 children and young people with a learning disability or autism were waiting to see a mental health specialist (open referrals). This included:

- 15,015 children aged under-18 years
- 26,550 young adults aged 18-25 years inclusive.

This is indicative of high levels of unmet need, consistent with recent research³⁸ and widespread anecdotal evidence from other services and families of disabled children and young people.

Section Three: Key gaps in the data picture and challenges in using national data on disabled children

This section reflects on gaps in the data on this cohort and challenges in using the data. This is summarised under five themes:

i Lack of evidence on some of the most important trends

ii Using one-dimensional data to understand children with complex needs

iii Missing pieces in the jigsaw

iv Difficulties in accessing and interpreting the data

v Lack of policy focus and accountability: policy levers

i. Lack of evidence on some of the most important trends

The headline message from this analysis is that there are rising numbers of disabled children and young people with complex needs and life-limiting conditions, who will, with their families, need support from health, social care and education at times throughout their lives. This trend is driven primarily by advances in healthcare, notably improved survival rates of preterm babies and increased life expectancy for children and young people with congenital conditions.

This is a hugely important trend which is hard to discern from national data, readily accessible to local commissioners. The clearest evidence emerged from our analysis of SEN data, but locating, compiling and analysing the data is not a quick or easy task and national data bulletins have not, as far as we are aware, drawn attention to this trend.

Although health experts (in government and academia) repeatedly referred to the rising number of children with complex healthcare needs, including children who rely on technology to help them breathe, eat or communicate, we struggled to find national data to substantiate their perceptions.

Key policy documents are remarkably data-free when it comes to quantifying the size and needs of this cohort. For example, the National Framework for Children and Young People's Continuing Care (DH, 2010, updated 2016³⁹) sets out a process for agreeing continuing care packages for children whose needs cannot be met by existing universal and specialist services, needs which 'generally arise from congenital conditions, long-term deteriorating conditions, accidents or the after effects of serious illness or injury'.

Although this guidance makes reference to a pilot study which included estimates of '5,000-6,000 assessments nationally per year',

there is no attempt to project demand for continuing care packages or reference to data which might help local commissioners in this task.

Evidence and awareness of the rising number of children and young people with life-limiting conditions is somewhat better, but again, not visible in routinely published national data. The Department of Health published a detailed analysis of this cohort in 2007⁴⁰ which estimated that approximately 20,100 children and young people aged 0-19 were likely to require palliative care services annually in England, or 16 in every 10,000 children and young people.

Since then, academic studies in partnership with charities working in this field suggest a doubling in the prevalence of children with

life-limiting conditions, from 16 to 32 in 10,000 or over 40,000 children and young people likely to require specialist paediatric palliative care, with important variations associated with ethnicity and deprivation.⁴¹

National data, accessible to local commissioners and policy makers, tell us little about these important trends. Many pieces of the jigsaw are available from research (Text box 1) but this is often not readily accessible to commissioners and policy makers and it can be difficult to make robust projections of future demands on specialist services, on the basis of such evidence.

ii. Using one-dimensional data to understand children with complex needs

Part of the challenge in using national data to understand the number and needs

Text box 1: Selected studies which provide evidence of the rising number of disabled children and young people with complex needs and/or life-limiting conditions

The EPiCure Study – major cohort study of outcomes for very preterm babies
<http://www.epicure.ac.uk/epicure-1995/epicure-at-eleven-years/findings/>

Fraser L., Miller M. et al (2012) Rising National Prevalence of Life-Limiting Conditions in Children in England, PEDIATRICS Volume 129, Number 4, April 2012
<http://pediatrics.aappublications.org/content/129/4/e923>

Emerson E., (2008) Estimating future numbers of adults with PMLD in England, CeDR
http://eprints.lancs.ac.uk/21049/1/CeDR_2008-6_Estimating_Future_Needs_for_Adult_Social_Care_Services_for_People_with_Learning_Disabilities_in_England.pdf

Cochrane H., Liyange S., Nantambi R. (2007) Palliative Care Statistics for Children and Young Adults, DH (rich in data and includes an overview of studies at the time showing increased life expectancy for key congenital conditions, p.10-11)
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_074699.pdf

of disabled children with complex needs, is that national data sets tend to be one-dimensional.

SEN data are currently the most useful for understanding this cohort, but they focus on children's primary needs. Secondary needs may be reported but these data are very incomplete⁴² so may not present a valid picture. Some primary needs are associated with complexity – notably profound and multiple learning difficulties, severe learning difficulties and multi-sensory impairment. But for most types of SEN, there is no way of gauging severity or complexity. Given great variations in the use of statements and EHC plans across local areas, and in the use of specialist placements, these too have their limitations as a proxy for severity/complexity.⁴³

The Children in Need Census allows for many disabilities to be reported for individual children, but these data are not analysed in a way which sheds light on complexity (i.e. several needs occurring together) and in most cases (56%) only one disability is reported, similar to the SEN data.

National data sets tend also to be one-dimensional in their service focus. For example, the Looked After Children data set allows for one category of need to be recorded. If a disabled child experiences abuse or neglect, this will almost certainly be reported as their primary need, so they would not be counted in the data on disabled looked after children. Yet children in need data suggest that around one fifth of disabled children are abused or neglected.⁴⁴

This point is well illustrated by the challenges of finding out how many disabled children are in full-time residential placements. Settings which provide 52-week residential placements are dual-registered as schools and as children's homes. When a looked after child is placed in a dual-registered setting, this is reported in the looked after children data set as a placement in a children's home⁴⁵. However, as some children in such placements are not looked after, they will not be included in this data set. In the School Census, children in full-time residential placements are reported as boarding in residential special schools. However, as the majority of dual registered settings are in the private sector, they are not included in the pupil level School Census, meaning it is currently impossible to collate comprehensive data on disabled children and young people in full-time residential placements.

Data-matching or unique identifying numbers can help to shed light on disabled children's pathways through local services and their outcomes. For example, the Narey Review of Children's Residential



Care⁴⁶ reported (based on matched looked after children outcomes data) that 53% of children in children's homes have a statement of SEN or EHC plan at March 2015, an important statistic that is not available from SEN data or looked after children data alone.

Government departments could generate a much richer and more robust data picture of this cohort by using data-matching more extensively and by introducing a unique identifying number for each child, across education, health and social care (and data sets). Lessons may be learnt from experience in Scotland, where unique Community Health Index (CHI) numbers have enabled integrated data to be developed.⁴⁷

iii. Missing pieces in the jigsaw

As noted, national data do not tell us a great deal about the rising number of disabled children with complex needs and life-limiting conditions. Academic research provides some of the missing pieces in this jigsaw, but is not always easy to access or translate into local service implications.

There are also important gaps in the available data, in relation to key stages in these children's development and key sectors catering for their needs. These include:

- **The early years, a critical stage for early intervention and family support.** Education and social care data on disabled children indicate low service involvement in the early years and/or low reporting. Disabled children with complex needs are most in contact with health services in the early years, but at

present, national data are not available.

- **Post-16 in the education data**, when the numbers in School Census data fall steeply, despite this being the fastest growing age group for EHC plans.⁴⁸
- **Post-19 in all the data sets**, except outcomes for looked after children data.⁴⁹ This is a critical stage of transition for young people with complex needs but data to inform much needed improvements in planning (e.g. to project demand for adult social care and specialist services) are currently lacking.
- **Residential placements.** Thousands of disabled children and young people are in residential placements, often far from the family home. This includes placements in residential special schools, children's homes, specialist colleges, care homes and mental health inpatient units. These are high cost placements which may be maintained for years. Robust data on the number of children in such placements, costs and outcomes is lacking.⁵⁰
- **Independent sector provision.** 13,500 children with statements or EHC plans are placed in independent schools approved for SEN, funded by local authorities. Independent schools do not report pupil level data, so we have no information on, for example, their needs, outcomes, exclusions, attendance or looked after status. This is a growing sector, providing specialist placements for children with the most complex needs, including a majority of those in 52-week residential placements.⁵¹

iv. Difficulties in accessing and interpreting the data

This analysis endeavoured to locate and analyse all relevant national data published

by education, health and social care on disabled children with complex needs and life-limiting conditions. Much of the data on disabled children and young people that is collected, is not routinely analysed and published. For example, much of the social care data used in this analysis needed to be requested from DfE; and SEN data bulletins say nothing about residential placements.

Equally, much of the data requires a degree of expert knowledge to interpret it. For example, social care data at present suggest that very few looked after children are in residential special schools, but this is because placements in dual-registered institutions (i.e. special schools and children's homes) tend to be recorded as children's home placements. Recent changes should provide a clearer picture of the breakdown of these placements in future.⁵²

This matters, because it can lead to misleading conclusions. For example, a recent draft report shared with the author from an influential health body commented on falling numbers of disabled children in England, due to a decrease in the number of children on SEN support.⁵³ Our analysis of SEN data leads us to a very different conclusion: there are rising numbers of disabled children in England, especially those with the most complex needs.

There are some valuable data portals (see Annex A) which bring together data on disabled children and those with SEN (SEND), with in some cases, insights from research to help local commissioners and policy makers to interpret the data. However, we found no

examples of a focus on disabled children with complex needs or life-limiting conditions or commentary on the rising number of children and young people with such needs.

v. Good intentions but a lack of progress

A succession of reports and policy documents have highlighted local areas' inability to map the number and needs of disabled children and young people in their area, reflecting shortcomings in both local and national data. To cite a few examples:

- Academics at the Thomas Coram Research Unit were commissioned by DfES in 2007/08 to conduct a survey of Directors of Children's Services in England, to collect data on the number and characteristics of disabled children in their area. Despite a high response rate 'the survey information did not provide a reliable figure for the number of disabled children for each local authority... due to the difficulties local authorities had in identifying and counting disabled children and the different definitions of disability applied.' Disabled Children Registers did not yield adequate data on this cohort, often reflecting high service thresholds. In the end, the study estimated the number of disabled children using SEN data and data on disability benefits recipients, providing a range for each local area. These ranges are still widely used, as they provide the basis for estimating the number of disabled children in the local area profiles developed by ChiMat.^{54 55}
- *Better Care, Better Lives* (DH, 2008) which set out the Government strategy for improving children's palliative care

services noted that: 'One of the biggest challenges facing children's palliative care commissioners, providers and service users is a lack of uniform, regular and accurate information about the nature of life-limiting conditions and the services available to support them. This means that it is difficult to effectively plan, commission and deliver services to children and families where they are most needed...it is impossible to predict need, track prevalence or spot trends.'⁵⁶

- Professor Sir Ian Kennedy's review of health services for children and young people in 2010 found: 'Data in many areas of health and healthcare for children and young people is poor or non-existent... there appears to be only limited recognition that one of the consequences of extraordinary advances in care is the growing number of disabled children and young people who have very complex needs... Their needs must be factored into the calculation of priorities, as must the fact that they will now progress to adulthood.'⁵⁷
- A recent review (2016) of Local Safeguarding Children Boards' (LSCB) role in protecting disabled children found that 'many LSCBs are not systematically gathering and evaluating information on disabled children.'⁵⁸

Yet there are clear requirements on local authorities and health commissioners to collect information on disabled children in their area, including the statutory requirement in the Children Act 1989 to maintain a Disabled Children's Register and guidance expecting that information on disabled children should be included in Joint Strategic Needs Assessments.⁵⁹

Local area inspections, following the recent SEND reforms,⁶⁰ are providing some momentum to improve practice on this front, looking at amongst other things, how effectively local areas identify children and young people who have SEN and/or disabilities and how far identification and assessment information is used to inform joint commissioning.

A decade ago (2007), Aiming High for Disabled Children: Better support for families⁶¹ made clear commitments to improve data on disabled children and young people, through action at the local and national levels:

'To allow Local Authorities and PCTs to plan and provide for their population, Government will look to all Local Authorities and PCTs to collect data on:

- the number of disabled children in their area, where possible classified by type of disability; and
- the percentage of this disabled children population accessing both universal and specialist services, such as short breaks or therapy services.'

'The Government will...take forward further work to develop more consistent, compatible and comparable data on disability on which to base service planning, commissioning and provision at both a local and national level.'

The policy intention was absolutely right and the imperative remains, but there is still far to go in meeting these commitments.

Section four: Conclusions and recommendations

As a nation, we urgently need to develop a clearer picture of the number of disabled children and young people with complex needs and life-limiting illnesses, and how this is changing over time. We need to raise awareness of these important trends and ensure that local areas have access to robust data to help project future demand for specialist services.

Our 12 recommendations are grouped into four themes arising from this analysis, consultation, feedback and discussion at the expert workshop in November 2016. A list of workshop attendees can be found in Appendix B

Filling the gaps

Department of Health

1. Actively support and incentivise the reporting of data on childhood disabling conditions and associated support needs, within the Children and Young People's Health Services Data Set. This should include:
 - a. Introducing incentives and penalties to strongly encourage data returns, for example, requiring data returns as an integral part of contractual arrangements and linking data returns to payments.
 - b. Developing a web-based interface to facilitate data collection.

Department for Education

2. Require independent schools to report School Census pupil level data on children with statements/EHC plans, in line with requirements on non-maintained special schools. This has the support of the sector organisation, The National Association of Independent Schools & Non-Maintained Special Schools, and the Council for Disabled Children.
3. Improve disability social care data by:
 - a. Introducing a code for disability in the Looked After Children data set so that disability is recorded, even if it is not the main reason for being looked after.
 - b. Include all children with a disability in children in need census analyses on this cohort, not just children who have disability as their primary need.
 - c. Introduce a national data set for children and young people receiving support through early help, linked to children in need census data.

NHS Digital

4. Ensure the continued collection of key data on young inpatients' experiences of care, formerly gathered in the Learning Disability Census, including: adverse experiences, incidents, use of rapid tranquilisation and anti-psychotic medication, distance from home and length of stay.
5. Break down mental health inpatient data to focus on young adults (aged 18-25 years) as a key phase of transition when inpatient episodes rise.

Making better use of data already collected

Department for Education

6. Ensure available data has a clearer focus on disabled children and young people in routine national data bulletins and statistical first releases, highlighting key trends, for example:
 - a. Analyses of children in need and looked after children data should include tables and commentary focussed on disabled children and young people
 - b. SEN data bulletins should include a section on children and young people with complex needs, including those in residential placements and those placed out of authority in independent and non-maintained special schools.

NHS Digital

7. Develop an accessible, integrated data set/portal (or 'data cube') drawing together relevant health data on disabled children and young people.

Towards an integrated data picture

Department of Health, Department for Education and NHS Digital

8. As an early priority, develop an integrated data picture on disabled children and young people in residential placements (including residential special schools, specialist colleges, children's homes, care homes and assessment and treatment units). This should be accelerated to inform the Lenehan Review of specialist residential placements.

9. Building on this initial work, further develop an integrated data set on disabled children and young people, similar to data currently published on outcomes for looked after children. This should involve:
 - a. Using data-matching to explore numbers, needs, pathways and outcomes
 - b. Piloting unique identifying numbers, learning from the experience of Scotland, where Community Health Index numbers are used.

Raise awareness of these trends and generate robust local data

Ofsted and Care Quality Commission

10. Reinforce the importance of robust, integrated data on disabled children and young people in local area inspections, identify and promote best practice on this front, in particular demonstrating the link between data and excellence in commissioning.

Department of Education, Public Health England with ChiMat and the Local Government Association

11. Sharpen the focus on disabled children with complex needs and life-limiting conditions in local area reports generated by data portals (LAIT, LG Inform and ChiMat, see Annex A), drawing attention to key trends in national data, together with accessible research summaries.
12. Identify local areas that have developed robust local data on disabled children and young people and disseminate their learning and experience to help other areas to make progress and support improved commissioning processes.

Section five: Annexes

Annex A: Data sources on the number and needs of disabled children in England

This annex briefly describes and provides links to a variety of accessible data sources on disabled children and young people, including several which provide local area breakdowns (listed first).

UK Census

The most widely cited estimates on disabled children come from the UK Census, a survey of all households in the United Kingdom, last carried out in 2011. This included the question:

Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months? Respondents were able to reply:

Yes, limited a lot / Yes, limited a little / No.

Census 2011 data indicate that overall **4%** (511,600) children and young people aged 0-19 years in England are disabled:

- **1.6%** whose day to day activities are limited a lot (**206,400** children and young people)
- **2.4%** whose activities are limited a little (305,100) children and young people).⁶²

Although now rather out of date, the Census 2011 figure, which can be broken down to the local level (and cross-tabulated with other Census data)

provides a useful starting point for areas to explore their population of children and young people with complex needs and life-limiting conditions.

<https://www.nomisweb.co.uk/census/2011>

SEN & disability data portals

There are several data portals designed to help local authorities and CCGs to map out the number and needs of children with special educational needs and disabilities in their area. The key ones are:

- **ChiMat online tools and resources** on children with disabilities, published by the National Child and Maternal Health Intelligence Network (ChiMat).
http://www.chimat.org.uk/resource/view.aspx?QN=DISABILITY_CHIMATTOOLS
- **Local Authority Interactive Tool (LAIT)** published online by DfE, enabling local authorities to make comparisons across a range of education and children's services' data.
<https://www.gov.uk/government/publications/local-authority-interactive-tool-lait>
- **LG Inform** hosted by the Local Government Association with support

from DfE, which includes a local area SEND comparison tool.

http://lginform.local.gov.uk/reports/view/send-research/local-area-send-report?mod-area=E92000001&mod-group=AllLainCountry_England

Department of Work and Pensions data on disability benefits

Another source which can be broken down to the local level and downloaded, are the data collected by the Department of Work and Pensions (DWP) on disability benefits recipients.

The Disability Living Allowance (DLA) for children may help with the extra costs of looking after a child who is under 16 and has difficulty walking or needs more care than a child of the same age who doesn't have a disability. There are two components: care and mobility, each with two to three different rates reflecting the level of support required day-to-day.⁶³

Data on the number of children receiving DLA at different rates, broken down by age, type of impairment and other variables is easy to select and download using the DWP data portal, NOMIS.⁶⁴

<https://www.nomisweb.co.uk/>

Family Resources Survey (national and regional statistics)

A national (and regional) source of disability statistics is the Family Resources Survey (FRS), a major annual survey commissioned by DWP to provide evidence on the incomes and circumstances of UK households. Like the UK Census, this uses the Equality Act

2010 definition of disability.⁶⁵ The latest FRS (2014/15) indicates that **7%** of children in the UK have a disability, a much higher figure than Census 2011. The FRS also provides a breakdown by type of impairment against a list of definitions, with individuals self-reporting as many impairments as relevant, as well as information on household composition and benefits received.

<https://www.gov.uk/government/statistics/family-resources-survey-financial-year-201415> (See main report. Scroll down for disability data tables, although these are only broken down to the regional level. More detailed data for research may be accessed via the UK Data Service.)

Health Survey for England

Another major household survey which includes data on disability and ill-health among children and young people is the Health Survey for England. This aims to provide information on changes in health and lifestyles. Around 8,000 adults and 2,000 children take part in the survey each year, through an interview and if participants agree, a visit from a nurse. It includes data on children aged 2-15 years. Young people aged 16 and above are counted as adults, in line with most health data.

The latest survey (2015) found that **just under 8% of children** (9% of boys and 6.5% of girls) have a 'limiting longstanding illness', reducing their ability to carry out day-to-day activities. <http://www.content.digital.nhs.uk/catalogue/PUB22616> (Scroll down for trend data etc. More detailed data may be accessed via the UK Data Service, via the webpage.)

Annex B: Expert advisors

This report would not have been possible without the help and support of those listed below who either shared their expert knowledge and insights during the initial development of the report or at the Expert Workshop, held in November 2016, and in some cases did both.

Amanda Allard, Council for Disabled Children

Becky Benwell, 0-25 Special Educational Needs and Disability Unit, Department for Education

Lizzie Chambers, Together for Short Lives

Gemma Coleman, Department for Education

Dr Jacqueline Cornish, NHS England

Martin Cunnington, South East Commissioning Support Unit

Sarah Day, Personal Health Budgets & Integrated Personal Commissioning Team, NHS England

Dr Helen Duncan, Public Health England

Professor Eric Emerson, Lancaster University & University of Sydney

Jo Ecclestone Ford, The True Colours Trust

Kevin Elliot, Transforming Care Programme, NHS England

Andrew Fellowes, Council for Disabled Children

Dr Lorna Fraser, Department of Health Sciences, The University of York

Helen Harger, NHS Digital Child Health

Roz Harper, Department for Education

Dr Karen Horridge, British Academy of Childhood Disability

Christine Lenehan, Council for Disabled Children

Rory McErlean, 0-25 Special Educational Needs and Disability Unit, Department for Education

Stuart Miller, 0-25 Special Educational Needs and Disability Unit, Department for Education

Megan Moore, NHS England

Lorraine Mulroney, NHS England

Sue North, NHS England

Nicholas Richman, NHS Digital

Lucy Sainsbury, The True Colours Trust

Kate Thurland, Public Health England

Annex C: Glossary of terms, definitions and acronyms

'SEN type' – Codes and descriptions used in School Census reporting⁶⁶

SpLD	Specific learning difficulty (e.g. Dyslexia, dyspraxia)
MLD	Moderate learning difficulty
SLD	Severe learning difficulty
PMLD	Profound & multiple learning difficulty
SEMH	Social, emotional and mental health
SLCN	Speech, language and communication needs
HI	Hearing impairment
VI	Visual impairment
MSI	Multi-sensory impairment
PD	Physical disability
ASD	Autistic spectrum disorder (includes Aspergers syndrome).

Children in Need Census disability terms and descriptions (guidance 2015-16)

Mobility	Getting about the house and beyond
Hand function	Holding and touching
Personal care	Eating, washing, going to the toilet, dressing, etc.
Incontinence	Controlling the passage of urine or faeces
Communication	Speaking and/or understanding others
Learning	Having special educational needs, etc.
Hearing/Vision	
Behaviour	A condition entailing behavioural difficulties, includes attention deficit hyperactivity disorder (ADHD)

Consciousness	Seizures
ASD	Diagnosed by a qualified medical practitioner as having classical autism or Asperger syndrome
Other DDA	One or more of the child's disabilities under the Disability Discrimination Act 2005 does not fall into above categories.

Health terms and definitions for the Children and Young People's Health Services data set

Glossary for reporting in the Children and Young People's Health Services data set, with some detailed descriptions and helpful cross-referencing to terms used by other services, available at: www.bacdis.org.uk/policy/documents/ExplanatoryGlossaryofTerms.pdf

Other acronyms and possibly unfamiliar terms used in this report (a-z)

Aspergers	An autistic spectrum disorder, sometimes called 'high-functioning' ASD as intelligence is not impaired
ATU	Assessment and treatment unit i.e. a mental health inpatient unit
CCG	Clinical commissioning group (local area health commissioners)
ChiMat	National Child and Maternal Health Intelligence Network, Public Health England
CiN	Assessed as a Child in Need of support from social care, under the Children Act 1989
CQC	Care Quality Commission (health inspectorate)
DCSF	Department for Children, Schools and Families (now DfE)
DfE	Department for Education
DfES	Department for Education and Skills.
DH	Department of Health
DWP	Department for Work and Pensions
Early Support	Widely used model for early intervention, providing support to children and families without needing to go through a formal assessment process
EHC plan	Education, Health and Care plan based on a multi-disciplinary assessment, replacing statements of SEN
FRS	Family Resources Survey

HMT	Her Majesty's Treasury
JSNA	Joint strategic needs assessments to identify local areas' health and well-being needs and to inform service planning
LAC	Looked after child. Looked after by the local authority under the Children Act 1989
LAIT	Local authority interactive tool, produced by DfE, bringing together key data on education and children's services & enabling comparisons to be made.
LG Inform	Data portal from the Local Government Association. Includes a local area SEND comparison tool
LLC	Life-limiting condition
LLI	Life-limiting illness
LSCB	Local Safeguarding Children Board
NSF	National Service Framework: DH guidance setting out standards and pathways for health services
Ofsted	Office for Standards in Education, Children's Services and Skills (inspectorate)
PCT	Primary care trusts – responsible for commissioning health services and delivering community health services until 2013
SEN	Special educational needs
SEN support	School-based support for children with SEN, without needing a statement or EHC plan
SEND	Special educational needs and disabilities
SFR	Statistical first release – regular Government statistics bulletins.



References

- 1 DH, DfES, (2004), National Service Framework for Children, Young People and Maternity Services. Standard 8: Disabled Children and Young People and those with Complex Health Needs
- 2 DfES and HMT (2007) Aiming high for disabled children: better support for families
- 3 DH (2008) Better Care, Better Lives: Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions
- 4 Secondary needs may also be reported but usually are not. See SEN data bulletin, section 2.
- 5 Acknowledging significant variations in local practice, see SEN data bulletin, section 1 (statements/EHCPs) and section 3 (type of school). The Children and Families Act 2014 replaced statements of SEN with EHC plans.
- 6 Includes all children with primary needs most associated with complexity (SLD, PMLD, MSI) plus those with ASD in special schools. Source: SFR 29-2016 (table 8) rounded to nearest 100.
- 7 ASD is a broad spectrum. As there is no marker for severity or complexity in the School Census, we used being in special school as proxy.
- 8 Although children with MSI are less likely to attend special schools, multi-sensory impairment implies complexity.
- 9 Independent schools provide 36% of residential special school placements including around two-thirds of 52-week placements. See SEN data bulletin, end of section 3.
- 10 Difference between School Census total for young people aged 16-25 years with statements / EHC plans (N=19,230) and LA data on statements/EHC plans for 41,300 16-19 year olds and 1,065 20-25 year olds, at Jan 2016. Source: SFR 17-2017 (table 1) and SFR 29-2016 (table 3) rounded to nearest 100.
- 11 Many children with complex needs attend mainstream schools, especially in primary education. See SEN data bulletin, section 3.
- 12 Includes all special schools (maintained, non-maintained, academies, independent), specialist post-16 institutions, children with statements/EHC plans placed in independent schools and a small number of children in hospital schools. Source: SFR 17-2016, table 1.
- 13 See SEN data section for full references and analysis of these trends, section 3.
- 14 At March 2015. See CiN and LAC data bulletins for full analysis and references.
- 15 See <https://councilfordisabledchildren.org.uk/our-work/whole-child/practice/early-support-integrated-and-person-centered-approach>
- 16 See <http://content.digital.nhs.uk/maternityandchildren/CYPHS>
- 17 Correspondence with the charity Together for Short Lives, which is involved in this development.
- 18 Some detailed health data are available by request or online e.g. HES (hospital episode statistics) or the Secondary Uses Service (<http://content.digital.nhs.uk/sus>), but require some expert knowledge to use.
- 19 Examples are provided in Text box 1.
- 20 e.g. CQC (2012) Healthcare for disabled children and young people (p.29)
- 21 See <https://www.gov.uk/government/statistics/outcomes-for-children-looked-after-by-las-31-march-2015>
- 22 e.g. JRF (1995) The needs of disabled children and their families; Audit Commission (2003) Services for disabled children; CQC (2012) Healthcare for disabled children and young people
- 23 See <http://content.digital.nhs.uk/maternityandchildren/CYPHS>
- 24 Statistics rounded to the nearest 100 or whole percentage point. Source: School Census data for January 2016, unless another reference is provided. See SEN data bulletin for further detail and full references.
- 25 The SEND Code of Practice 2015 replaced 'School Action' and 'School Action Plus' with single category of 'SEN Support'. Ofsted in 2010 criticised schools for inappropriately identifying so many children as having SEN (Ofsted, 2010, SEND Review: a statement is not enough).
- 26 Difference at Jan 2016 between School Census total for young people aged 16-25 years with statements/ EHC plans (N=19,230) and local authority data on statements/ EHC plans for 41,300 16-19 year olds and 1,065 20-25 year olds, published in SFR 17-2017 (table 1) and SFR 29-2016 (table 3) rounded to nearest 100.
- 27 Local authority data (SEN2) on placements of children with statements/EHC plans in special schools (maintained, non-maintained, academies, independent), hospital schools and specialist post-16 institutions. SFR 17-2016, table 1. Structural

changes make it impossible to produce valid time comparison.

28 Special request to DfE, data for Jan 2016.

29 Soon-to-be published data collected by the Transforming Care Programme (SEN bulletin, end of section 3).

30 Data rounded to nearest 10 or whole percentage point. Source: SFR41-2015. Children in Need Census data, 31 March 2015 on Children in Need with a disability aged 0-17 years in England and previous annual bulletins. Some data provided by special request to DfE. See CiN data bulletin for full references.

31 Data rounded to nearest 10 or whole percentage point. Source: SFR34-2015 supplemented by special request to DfE. Full references provided in LAC data bulletin.

32 Data rounded to the nearest 10 or whole percentage point. Sources: Learning Disability Statistics annual overview 2015-16 (end Feb 2016); Learning Disability Census data for September 2015; Mental health services data set (MHSDS) on referrals for patients with a learning disability or autistic spectrum disorder in June 2016. Data on young adults aged 18-25 years through a special request to NHS digital. Full references in the mental health data bulletin.

33 Transforming Care: A national response to Winterbourne View Hospital: www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response

34 Implications of Mental Health Act 1983 are explained in the Code of Practice

35 <https://www.england.nhs.uk/learningdisabilities/ctr/>

36 For example, see research cited in the LD Census Sept 2013 Report: Further Analysis (p.15-16). <http://content.digital.nhs.uk/catalogue/PUB14046/ld-census-further-sep13-repv2.pdf>

37 Based on analysis of previous LD Census data. See HSCIC (April 2014), LD Census Report -Further Analysis. Table 6A of the accompanying data tables.

38 For example, Office of the Children’s Commissioner (May 2016) Lightning review: Access to Child and Adolescent Mental Health Services

39 <https://www.gov.uk/government/publications/children-and-young-peoples-continuing-care-national-framework>

40 Cochrane, Liyanage and Nantambi (2007) Palliative Care Statistics for Children and Young Adults, Department of Health

41 Fraser L., Miller M. et al (2012) Rising National Prevalence of Life-Limiting Conditions in Children in England, PEDIATRICS Volume 129, Number 4 <http://pediatrics.aappublications.org/content/129/4/e923>

42 57% of children with statements/EHC plans do not have a secondary need reported and 83% of children on SEN support. See SEN data bulletin, section 2. January 2016.

43 See SEN data bulletin, sections 1 and 3 (respectively, variations in statements/EHC plans and local provision)

44 See CiN data bulletin. 18% of CiN with a disability experienced abuse or neglect (March 2015).

45 From 2016, unique provider reference numbers should lead to a clearer picture of type of provision (correspondence with DfE analysts).

46 <https://www.gov.uk/government/publications/childrens-residential-care-in-england>

47 Suggested by delegates attending our workshop.

48 Following changes introduced under the Education & Families Act 2014. See SEN data bulletin, section 2.

49 See LAC data bulletin, section on Care Leavers.

50 It is hoped that the forthcoming (2017) Lenehan Review of specialist residential placements will lead to improvements on this front.

51 See SEN bulletin, section 3 (‘What type of school’? And ‘Residential placements’ headings)

52 From 2016 unique provider reference numbers will enable DfE analysts to validate type of provision (source: correspondence with DfE analysts).

53 This decrease reflects changes under the SEND Code of Practice 2015, replacing ‘School Action’ and ‘School Action Plus’ with single category of ‘SEN Support’; and by criticisms made by Ofsted that too many children were being identified by schools as having SEN (Ofsted, 2010, SEND Review: a statement is not enough).

54 Mooney A, Owen C, Statham J (2008) Disabled Children: Numbers, Characteristics and Local Service Provision: Final Report to DCSF, Thomas Coram Research Unit (Institute of Education) young people who have left school, potentially up to the age of 25. See SEND Code of Practice 2015 (summary at pages 13-14) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf

55 <http://atlas.chimat.org.uk/IAS/profiles/profile?profileId=46&geoTypeId=#iasProfileSection4>

56 DH (2008) Better Care, Better Lives: Improving outcomes and experiences for children, young people and their families living with life-limiting and life-threatening conditions, page 23

57 Sir Ian Kennedy (2010) Getting it right for children and young people, COI

58 Safeguarding Disabled Children in England. How Local Safeguarding Children Boards are delivering against Ofsted requirements to protect disabled children: findings from a national survey. A report of the National Working Group on Safeguarding Disabled Children July 2016 <http://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/safeguarding-disabled-children-england.pdf>

- 59 The Children and Young People’s Health Outcomes Strategy (2012) recommended: “Directors of Public Health, through their health and wellbeing board, should ensure that they include comprehensive data for all children and young people within their Joint Strategic Needs Assessment incl. those requiring tailored provision, such as those who are looked after, those with disabilities and long term conditions...”
- 60 Local areas (including the local authority, CCGs, public health, NHS England and local providers) are to be inspected by Ofsted and CQC every 5 years to assess how well they are implementing their duties under the Children and Families Act 2014 and the 2015 SEND Code of Practice.
- 61 DfE and HMT (2007) Aiming high for disabled children: better support for families
- 62 Rounded to nearest 100.
- 63 See <https://www.gov.uk/disability-living-allowance-children/overview> for fuller explanation
- 64 At the time of writing, this could be done by selecting the ‘query data’ link, then ‘DWP benefits’, then one of the DLA options. Local area breakdowns can be selected, some right down to ‘lower super output area’ level (very fine-grained).
- 65 A person is disabled under the Equality Act 2010 if he or she has a ‘physical or mental impairment’ that has a ‘substantial and long-term adverse effect’ on their ability to do normal activities.
- 66 DfE (Jan 2016) School census 2015 to 2016 Guide (version 2.5) https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/495464/2015_to_2016_School_Census_Guide_V_2_5.pdf



About the Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector with a membership of over 200 voluntary and community organisations and an active network of practitioners and policy-makers that spans education, health and social care. Their aim is to see a fully-inclusive society where disabled children and young people and those with special educational needs can lead full and happy childhoods and rewarding adult lives. They do this by working with the sector to find out what is and isn't working on the ground and use what they learn to influence policy and improve practice.

CDC hosts the following networks and projects:

Independent Support

IASS Network

Making Ourselves Heard

Special Educational Consortium

Transition Information Network

CDC is proud to be part of the National Children's Bureau (NCB), a leading children's charity working to build a better childhood for every child.

More information about CDC can be found at www.councilfordisabledchildren.org.uk

About the True Colours Trust

The True Colours Trust is passionate about making a difference to the lives of disabled children and their families and supporting people with life-limiting and/or life-threatening illnesses. The Trust was established in 2001 and works in the UK and Africa.

True Colours has developed a framework of grant-making which enables it to effect change in the short, medium and long-term. This is done through small grants to local initiatives; multi-year grants to build sustainable organisations and sectors; commissioning research to gather information and identify solutions to complex issues; and, making long-term investments towards advocacy and policy change. The Trust's framework enables it to make positive change today, tomorrow and in the future. The Trust is proud to be a long-term supporter of the work of the Council for Disabled Children.

More information about the True Colours Trust can be found at www.truecolourstrust.org.uk