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getting young voices heard

Disability, disparity and demand:

Analysis of the numbers and
experiences of children in care and
care leavers with a disability or
long- term health condition

Summary report

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Summary

Overview

This insight paper looks at what we do, and importantly do not know about children in and leaving care with a disability or long-term health condition in England.

It brings together findings from:

1. a Freedom of Information (FOI) request to local authorities,
2. learning on disability from the Bright Spots Programme including surveys with over 8,000 young people in and leaving care and
3. workshops with young people and leaving care professionals

The report identifies and illuminates key disparities in understanding, measuring and recognition of disability as well as significant local variations.

The Bright Spots Programme, developed by Coram Voice in partnership with Professor Julie Selwyn, has been working with children in care since 2013, and care leavers from 2017, to understand what needs to be in place to enable these children and young people to flourish. The Programme helps local authorities to systematically gather the views of their children and young people. Findings are used to influence practice, service development and strategic thinking, which is essential in ensuring that children's well-being is at the heart of delivering high-quality services. The Programme uses four online surveys of well-being to capture the views of children and young people in care (a survey for each of the ages 4-7 years, 8-10 years and 11-17 years), and care leavers. To date, the Bright Spots surveys have been completed by over 25,000 children and young people from 80+ local authorities in England, Wales and Scotland.

Understanding disability?

Defining 'disability' is not a simple thing. It includes impairments, but also effects from social, cultural, economic and physical environments.

Under the Equality Act (2010) definition you're disabled if you have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on your ability to do normal daily activities.

To understand more fully disabled children and young people's experiences and needs, and to ensure their rights are upheld we need good quality statistics and information about their experiences.

Government national statistics do not tell us how many children in care and care leavers have a disability or long-term health condition and young people's views on disability tended not to be recorded or sought.

To address this gap, we sent an FOI request to all local authorities (LAs) in England.

We also asked care experienced young people and professionals who support them their views about 'disability.' They reflected that disability could include lots of things: some disabilities are 'easier to define', not all are visible or well-understood.

Together these approaches reveal significant variation across service definitions and eligibility criteria for support and an urgent need to address the issues identified.

Key Findings

This report provides an important new analysis of the numbers of children and young people in and leaving care living with a disability or long-term health condition and the disparity between the support needs and those recognised or supported by local authorities.

The data we received means that, for the first time, we can report:

- **11% of 76,528 children in care** were recorded as having a disability – this is the same proportion as children in the general population (11%)
- **13% of 55,222 of care leavers** were recorded as having a disability – this is lower than young people aged 16-24 in the general population (15.6%)

However, there was wide variation in the proportion of children in care and care leavers with a disability recorded by local authorities:

- For children in care with a disability this ranged from 3% to 32%
- For care leavers with a disability this ranged from 1% to 36%

Guidance to local authorities on collecting disability data instructs them to record 'type of disability'. Our analysis shows that for both children in care and care leavers the most common types of disabilities were 'learning', 'autism' and 'behaviour' (e.g. ADHD).

When care leavers were asked directly (via the Bright Spots Programme) if they had a disability or long-term health problem, we found that just over a quarter self-reported disability.

- This is a stark difference compared to the proportion recorded by professionals in local authorities (27% vs. 13%).
- In addition, the proportion of care leavers self-reporting disability in the Bright Spots Programme has increased over time (22% in 2017 vs. 32% in 2023).

To help to understand this, a new question has been introduced to the Bright Spots care leaver survey.

This means that, when a care leaver answers, 'yes', they have a disability or long-term health condition, they are additionally asked: 'If you want to, please tell us more about your disability or long-term health problem'.

Analysis of the responses of nearly 300 young people shows many disabilities co-exist - it was rare for a young person to write just one disability or health problem.

- The top 3 disabilities recorded by young people were: autism, mental health conditions and ADHD.
- Care leavers often highlighted mental health conditions, e.g. depression, anxiety and PTSD (Post-Traumatic Stress Disorder) – these are not a specific 'type of disability code' in the data recorded by local authorities.

Care experienced young people need their workers to be curious about disability and to have conversations with them to hear their views and experiences.

Whichever way 'disability' is measured there is a significant group of children in care and care leavers affected, yet we know very little about how they are doing.

Existing Research

Existing research shows:

- Children and young people with a disability are at an increased risk of harm and abuse than non-disabled children. Children with a disability may be more likely to be looked after than non-disabled children.
- Children in care with a disability can have different 'pathways' through the care system e.g. more likely than other children in care to live in residential care; to live 'out of area'; wait longer than others to be adopted; less likely to go home to their family and more likely to experience multiple moves or live in inappropriate placements.
- They may not always be supported to stay connected to the people who are important to them. Their views and perspectives may not be routinely sought in matters that affect them.
- There can be limited options and choice in employment and housing for care leavers with a disability or long-term health condition.

Bright Spots data shows care leavers with a disability or long-term health problem reported lower well-being on a range of measures compared to other care leavers e.g. they felt lonelier, less likely to feel safe or settled where they lived and more likely to report difficulties coping financially.

Law and guidance are designed to ensure children in care with disabilities experience a well-planned, smooth transition from care. . It is clear that not all young people do.

Advocacy case studies and learning from serious incidents shows evidence of poor processes, non-person-centred approaches, limited recognition of young people's rights, failure of services to work together and funding issues.

Recommendations: from knowledge to action

Our work for this insight paper has exposed how little information is currently available to plan and monitor the effectiveness of support to children in care and care leavers with disabilities.

We need urgent action to redress these stark omissions.

Our recommendations for improvements are in two main areas:

1. improve data collected on disability for children in care and care leavers and
2. improve policy and practice with children in care and care leavers with a disability

We make 19 specific recommendations for government, local authorities and ourselves here at Coram Voice [see main report for details].

For a more visual summary please also see our accompanying slides:

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