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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

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Dr Claire Baker
and Linda Briheim-Crookall

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‘Be more curious about ‘diagnosis’ on file when they transition. What does that mean for the young person, how does that impact them and how do they feel about it?’

Professional working with care leave

Acknowledgements

We would like to thank the young people and professionals who contributed their views to this research. We are also grateful to Emma Robinson, Specialist Advocate for Disabilities for contributing insights from Coram Voice advocacy work with disabled children. In addition, we would like to acknowledge all the local authorities who responded to our enquiries.

Authors

Dr Claire Baker and Linda Briheim-Crookall, Voices Improving Care team, Coram Voice.

About us

This report was written as part of the Bright Spots Programme at Coram Voice and published by the Coram Institute for Children, the dedicated research and development organisation for children at the heart of the Coram Group.

Bright Spots Programme

The Bright Spots Programme has been working with children in care and care leavers for over a decade to understand what they feel is important to have a good life. The Bright Spots Programme was developed by Coram Voice together with Professor Julie Selwyn at the Rees Centre, Department of Education, University of Oxford, funded by the Hadley Trust.

Coram Voice

Founded 50 years ago as A Voice of the Child in Care and now part of the Coram group, Coram Voice champions the rights of children by getting young voices heard in decisions that matter to them and working to improve the lives of children in care, care leavers and others who depend upon the help of the state.

Coram & the Coram Institute

Coram's vision for children is a society where every child has the best possible chance in life, regardless of their background or circumstances.

Building on our legacy as the first and longest continuing children's charity, the new Coram Institute for Children is instrumental in realising this vision by acting as a catalyst for change and collaboration, seeking evidence-based solutions to the challenges facing children in the 21st century in policy, law and practice.

The Coram Institute for Children is the research, policy and practice think tank dedicated to the future of children, working with partners and young people to learn from the past, examine current needs, improve practice and create better chances for the next generation.

More information about Coram and the work of the Institute can be found here: www.coram.org.uk

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 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:

- improve data collected on disability for children in care and care leavers and
- 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 page 37].

For a shorter, more visual summary please also see our accompanying slides: www.coramvoice.org.uk

What do we mean by 'disability'?

'Disability' results from the interaction between a person's impairment(s) / health condition and factors within their environment¹ (negative attitudes, inaccessible transport, limited support etc).

Government guidance² on writing about disability advises to avoid medical labels as these say little about people as individuals and tend to reinforce stereotypes of disabled people.

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

Disability viewed primarily through a 'Medical model' lens – tends to focus on 'what's wrong with the person and how do we fix it'.

Disability viewed primarily through a 'Social model' lens – tends to focus on 'what's wrong with society and how do we promote social justice'. The social model recognises that people are disabled by barriers (e.g. physical; attitudinal) that can make their lives harder. Removing those barriers can create equality and offer disabled people more choice and control in their lives.

The Equality Act (2010) protects people from discrimination in the workplace and in wider society.

You are disabled under the Equality Act 2010 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 (Equality Act, 2010)³

In the Equality Act definition, disability can arise from a wide range of impairments. It is inclusive of sensory impairments, impairments with fluctuating or recurring effects, progressive or auto-immune conditions, developmental impairments such as autistic spectrum disorders (ASD), learning disabilities, mental health conditions (with symptoms such as anxiety, bipolar, post-traumatic stress disorders etc.) and mental illness (such as depression)⁴.

Whether a person is disabled for the purposes of the Act is generally determined by the effect that an impairment has on that person's ability to carry out normal day-to-day activities (Equality Act, 2010).



¹ https://www.who.int/health-topics/disability#tab=tab_1

² <https://www.gov.uk/government/publications/inclusive-communication/inclusive-language-words-to-use-and-avoid-when-writing-about-disability>

³ <https://www.gov.uk/definition-of-disability-under-equality-act-2010#:~:text=You're%20disabled%20under%20the,to%20do%20normal%20daily%20activities>

⁴ <https://www.gov.uk/government/publications/equality-act-guidance/disability-equality-act-2010-guidance-on-matters-to-be-taken-into-account-in-determining-questions-relating-to-the-definition-of-disability-html>

UK Government: Measuring prevalence of disability⁵

Estimates of the number of disabled people in the UK can vary depending on definitions, context and source of information.

To ensure consistency, most official statistics use a definition of disability that is consistent with the Government Statistical Service (GSS)'s harmonised definition. The GSS definition is designed to reflect the core definition of disability that appears in the Equality Act 2010⁶, and the definition that appears in the Disability Discrimination Act 1995⁷, which applies in Northern Ireland.

To measure disability based on this definition, survey respondents are asked whether they have a physical or mental health condition or illness that has lasted or is expected to last 12 months or more, and whether the condition and/ or illness reduces their ability to carry out day-to-day activities. A person who answers yes to both questions is considered disabled.⁸

NB: This harmonised measure does not capture everyone who is legally disabled under the Equality Act, for example people with a long-standing illness or condition which is not currently affecting their day-to-day activities.

A note on language

There are differing views on whether person-first⁹ ('children and young people with a disability or long-term health condition') or identity-first¹⁰ ('disabled child') language should be used. In this paper we have mirrored whatever terminology the author/ source has used.

We acknowledge that not all children and young people who meet the legal definition of being disabled will identify as 'disabled', and conversely some will self-identify as disabled but not meet official definitions of disability.

Ultimately, we believe that individual preferences around language should be respected: as such we have not changed or edited the words used by those who shared their experiences and views with us.

⁵ CBP-9602.pdf (parliament.uk)

⁶ Equality Act 2010 (legislation.gov.uk)

⁷ Disability Discrimination Act 1995 (legislation.gov.uk)

⁸ Measuring disability for the Equality Act 2010 harmonisation guidance – Government Analysis Function (civilservice.gov.uk)

⁹ <https://hubnanog.ie/wp-content/uploads/2024/06/20240530-FINAL-Literature-Review-Inclusion-of-Disabled-Children-and-Young-People-in-Participation.pdf>

¹⁰ <https://www.disabilityrightsuk.org/social-model-disability-language>

¹¹ Coram Voice, along with 3 care experienced consultants, facilitated a workshop at the Amplify event in October 2023 see: <https://coramvoice.org.uk/wp-content/uploads/2023/12/Page-3-report-link-Session-5-Embracing-Diversity-A-workshop-on-disability-and-inclusion-3.pdf>

What does 'disability' mean to you?



Figure 1
Photograph from care experienced young people's workshop

Children and young people's views

Missing from much of the work on disability are the views of children in care and care leavers. We held a workshop¹¹ with 18 care experienced young people to discuss, 'What does 'disability' mean to you?'

How care-experienced young people view disability – key themes

- Disability is something which affects your life – it may be long-term.
- Disability can include lots of things including neurodiversity.
- Not all disabilities are visible – some are hidden.
- Everyone has needs of some kind - no one is 'normal'.
- Sometimes it can be good to have a diagnosis – so people know how to manage their needs (but sometimes there can be 'mis-diagnosis').
- There can be a stigma associated with disability.
- Getting help with disability can be difficult – professionals may pass young people onto other workers – sometimes these services can't provide what is needed and young people are told they "don't meet thresholds."
- Things in day-to-day life can make life with a disability more difficult – like access to transport or finding an accessible toilet.
- Sometimes having a disability means you get additional financial support.

Care experienced young people said:

‘We would like to normalise disability and make society more aware of the difficulties’

(Care experienced young person)

‘When someone tells you an illness is impacting their life, listen and fully explore’

(Care experienced young person)

Leaving care professionals' views

To inform our work we held a workshop¹² with over 100 practitioners and managers who work with care experienced young people to discuss: 'What does 'disability' and long-term health condition mean to you?'; participants considered this both in relation to their own views as well as what it means in terms of service delivery.

‘No idea where in our records we could pull disability data if asked’

‘Not recorded in plans’

(Professional working with care leavers)

‘We worry it's focused on the wrong thing – physical disability will always be clear cut – neurodiversity is so much harder’

(Professional working with care leavers)

How leaving care professionals' view disability – key themes

- Some 'disabilities' are more 'clear-cut' or 'easier to define' – as a result work around 'disability' tends to mainly focus on physical health or learning
- impairments where the need for ongoing support or adaptations may appear more obvious.
- Some disabilities are not always visible. Some are less understood. For example, practitioners and managers in the workshop sometimes felt less confident in their understanding of certain things e.g. neurodiversity.¹³
- It was acknowledged that a 'label' or 'diagnosis' may not tell you very much as people can experience the same thing differently compared to others. Whilst a diagnosis can be useful in terms of access to services, it may also be experienced as stigmatising.
- Some professionals reflected on the association between **experience of trauma and disability / long-term health conditions**.^{14 15}
- Many felt that **disability was not always well understood in leaving care** – there were gaps in knowledge, a lack of confidence in some areas and uncertainty about referral pathways and systems.
- Overall, people reported there was **limited data and information on disability** in leaving care services.
- There was acknowledgement that services **didn't tend to record or ask young people their views on disability**.
- How disability was defined in local authorities was **inconsistent** – there were different definitions used in different local authorities and by different partner agencies.
- Eligibility and threshold criteria for services were discussed. Many in the workshop spoke about the separation and **disconnect between children's services and adult services**. Some reflected that **eligibility for these services could be 'unclear and fluid'** – with some care experienced children accepted and others unable to access support.
- Professionals shared experiences of working with care experienced young people who were **mis-diagnosed or undiagnosed but who still had support needs and were impacted by their disability or long-term health condition**.
- **'Everything is a fight'** – it could be difficult for leaving care services to get the right support needed for their young people. There was a lack of resources which led to rationing –some care experienced young people were **'not disabled enough'** – commissioning and provision tended to be resource-led rather than needs-led.
- Those taking part in the workshop felt there was a **need for services to flex more** rather than simply expecting young people to fit in. To **improve inclusivity**, it was important to make sure **plans were person-centred and individualised**.



¹³ See also for a discussion of social workers' perceptions on neurodevelopmental conditions. <https://cronfa.swan.ac.uk/Record/cronfa59956>

¹⁴ The context of maltreatment and trauma exposure may contribute to the development of an emotional disability, such as an adjustment disorder or anxiety disorder such as posttraumatic stress disorder. <https://www.sciencedirect.com/science/article/abs/pii/S0190740918303591>

¹⁵ <https://www.ticservicesltd.com/2024/05/31/interwoven-paths-exploring-the-complex-relationship-between-trauma-and-chronic-pain/>

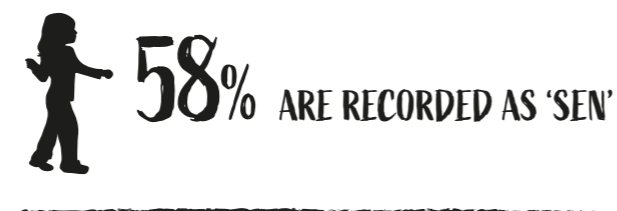
¹² Workshop held at the National Leaving Care Benchmarking forum in November 2023; 69 leaving care managers/ practitioners attended in person and 37 joined online – they were from 71 local authorities in England - workshop facilitated by Coram Voice

How many children in care and care leavers are 'disabled'?

In England, national data on disability or long-term health condition(s) for children in care or care leavers are not routinely published¹⁶.

- One of the reasons for the lack of information is uncertainty over the definition and measurement of 'disability'.
- Different services (e.g. education; social care; health; welfare benefits departments) have different definitions.
- Different definitions produce different numbers.
- The number of young people recorded as disabled is likely to be dependent on who you ask – it is often professional perspectives (e.g. from social care or school settings) that are recorded rather than the young person's own views.
- Definitions of disability can be a fallible guide to the experiences of individuals, and the label may be rejected by young people.

Outcome data for looked after children does include information on special education needs. Of children looked after for at least 12 months, 58% are recorded as 'SEN' with 27% receiving SEN support. Data highlights the primary types of special education needs: 53% recorded 'social, emotional and mental health' needs; 15% 'moderate learning disability'; 13% speech, language communication; 8% specific learning difficulty and 2% autism spectrum disorder.



‘Having an Education Health Care Plan does not mean you are disabled: outside the school context, a child may experience no impairment and could be surprised or unhappy to hear themselves described as disabled. Government guidance for organisations supporting children with special educational needs or disabilities explains that, though children with disabilities under the Equality Act definition do not necessarily have SEN (Special Education Needs), there is a ‘significant overlap’ between disabled children and children with SEN.’

‘We all have a voice’: Disabled children’s vision for change, Children’s Commissioner for England (2023)

¹⁶ SSDA903 Government statistics on children in care and care leavers do not include information on disability <https://www.gov.uk/government/statistics/children-looked-after-in-england-including-adoption-2022-to-2023>
<https://explore-education-statistics.service.gov.uk/find-statistics/outcomes-for-children-in-need-including-children-looked-after-by-local-authorities-in-england>

Freedom of Information request findings: Local authority data

Children in care and care leavers with a disability or long-term health condition are not easily visible in children’s social care data, leading to their experience potentially being overlooked.¹⁷ To address this gap in knowledge we sent a Freedom of Information (FOI) request¹⁸ to all 153 English local authorities and asked them to tell us more about what was recorded on their Children Social Care management information systems, specifically:

1. How many looked after children have a disability?

- TOTAL - total number of looked after children.
- YES - number of looked after children with a disability.
- NO - number of looked after children who do not have a disability.
- UNKNOWN - number of looked after children where disability status unknown.

2. The number of looked after children with different types of disability as recorded on the Children Social Care management information system.

- Answer options - number of looked after children recorded as: mobility; hand function; personal care; incontinence; communication; learning; hearing; vision; behaviour; consciousness; diagnosed with autism or Asperger¹⁹ syndrome; other DDA²⁰

3. How many care leavers²¹ have a disability?

- TOTAL – total number of care leavers.
- YES – number of care leavers with a disability
- NO – number of care leavers who do not have a disability.
- UNKNOWN – number of care where disability status unknown

4. The number of care leavers with different types of disability as recorded on the Children Social Care management information system.

- Answer options - number of care leavers recorded as: mobility; hand function; personal care; incontinence; communication; learning; hearing; vision; behaviour; consciousness; diagnosed with autism or Asperger syndrome; other DDA.

We were confident that local authorities would be able to source this information i.e. through (1) the Children in Need census which instructs local authorities (LAs) to collect information on disability for all children in need and looked after children and/or (2) Ofsted inspection of local authority children’s services Annex A child-level data list 9²² which asks local authorities to record whether a child is disabled. Data from these sources are not currently published in a way which allows identification of disability in relation to looked after children or care leavers.

We received responses from 133 of 153 local authorities (87%)²³. Local authorities reported information on 76,528 looked after children and 55,222 care leavers.

Most LAs could provide the information but for a small proportion the information was recorded as ‘unknown’ (e.g. this data was not available for around 1 in 20 care leavers).

87% WE RECEIVED RESPONSES FROM 133 OF 153 LOCAL AUTHORITIES

¹⁷ Hill et. all (2015) <https://pureportal.strath.ac.uk/en/publications/being-counted-examining-the-prevalence-of-looked-after-disabled-c>

¹⁸ The Freedom of Information Act, 2000, in the UK provides members of the public with the right to request access to information held by public authorities <https://www.gov.uk/make-a-freedom-of-information-request>

¹⁹ NB: language used in Children in Need guidance - this is despite advice from National Autistic Society (and others) to no longer use this term <https://www.autism.org.uk/advice-and-guidance/what-is-autism/the-history-of-autism/asperger-syndrome>

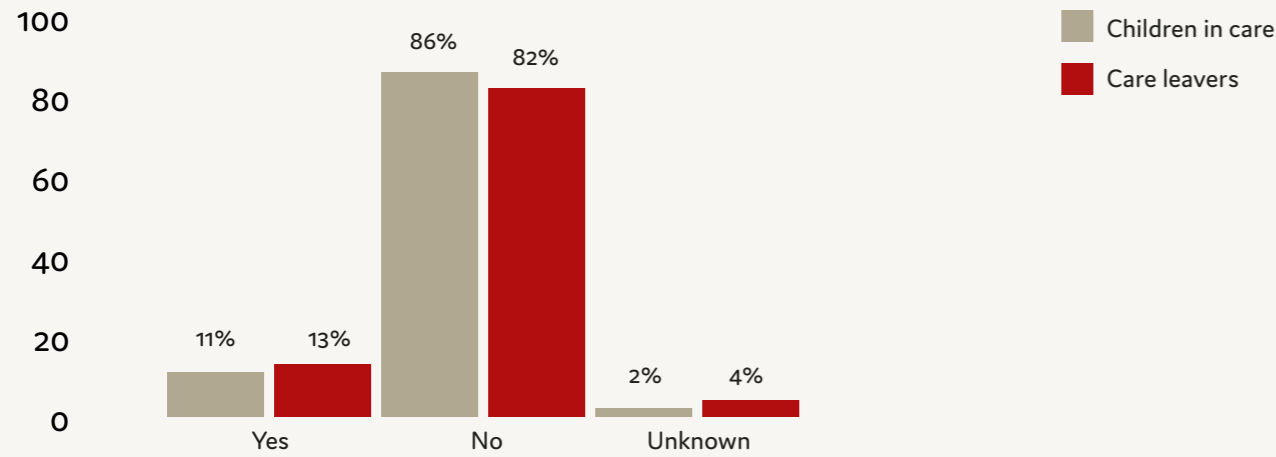
²⁰ Type of disability categories from Children in Need guidance page31/32: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1025195/Children_in_need_census_2022_to_2023_guide.pdf

²¹ Care leaver definition supplied in FOI: “Annex A child-level data list 9 for inspection of local authority children’s services (ILCAS) defines care leavers as: All those who have reached the threshold for receiving leaving care services at the point of inspection includes: relevant children; former relevant children; qualifying care leaver (only those requesting and receiving a service from the local authority). Please exclude eligible care leavers as they will appear in the looked after numbers”.

²² <https://www.gov.uk/government/publications/inspecting-local-authority-childrens-services-from-2018>

²³ Between October and November 2023 FOI requests were sent by email to all English local authorities. A spreadsheet template for responses was supplied. If no reply had been received a follow up email was sent.

Figure 2 Percentage of children in care and care leavers recorded by local authority to have a disability



11% OF CHILDREN IN CARE WERE RECORDED AS HAVING A DISABILITY – THIS IS THE SAME PROPORTION AS CHILDREN IN THE GENERAL POPULATION (11%)²⁴



There was variation across local authorities:

- The lowest proportion of disabled children in care recorded was 3% and the highest was 32%.
- The lowest proportion of disabled care leavers recorded was 1% and the highest was 36%.

Data on 'type of disability' is available via the Children in Need census. Guidance²⁶ details the following different 'disability codes' and instructs LAs to record all relevant disabilities that have affected the child i.e. children can have multiple disabilities so more than one category from the below list can be selected for an individual child.

Code	Description
Mobility	Getting about the house and beyond
Hand function	Holding and touching
Personal Care	E.g. eating, washing, going to the toilet, dressing
Incontinence	Controlling the passage of urine or faeces
Communication	Speaking and/ or understanding others
Learning	E.g. having special educational needs
Hearing	-
Vision	-
Behaviour	A condition entailing behavioural difficulties, includes Attention Deficit Hyperactivity Disorder (ADHD)
Consciousness	Seizures
Autism	Diagnosed with Autism or Asperger syndrome – diagnosed by a qualified medical practitioner as having classical autism or Asperger syndrome. Do not include children who have merely been identified as having an autistic spectrum disorder (ASD), e.g. by their school. This can be associated with the behaviour and learning categories above
DDA	Other DDA – one or more of the child's disabilities under the Disability Discrimination Act 2005 (DDA) does not fall into any of the above categories

The 'types of disabilities' categories that local authorities use do not explicitly include 'mental health condition(s)' – this is different to the definition of disability in Government legislation e.g. Equality Act 2010

Local authorities reported to us information on the number of children in care and care leavers recorded within each type of disability – as many individuals had more than one type of impairment the overall total exceeds 100%²⁷.

NB: the figures recorded on children's social care systems are based on professionals' view using categories which refer explicitly to presence of medical diagnosis, and they do not include a specific 'mental health condition' category.

13% OF CARE LEAVERS WERE RECORDED AS HAVING A DISABILITY – THIS IS LOWER THAN YOUNG PEOPLE AGED 16-24 IN THE GENERAL POPULATION (15.6%)²⁵



²⁴ The Family Resources Survey is the most used measure of disability prevalence in the UK. In the general population (in 2021-22) around 1 in 10 (11%) of children in the UK were recorded as disabled - this has almost doubled in the last decade (from 6% in 2011-12). Growth in disability prevalence appears to be driven by an increase in mental health and behavioural conditions (e.g. ADHD) among children. Half (50%) of disabled children reported a social or behavioural impairment, followed by mental health (30%) and learning impairments (26%). CBP-9602.pdf (parliament.uk) The survey uses a harmonized definition of disability i.e. respondents are asked whether they have a physical or mental health condition or illness that has lasted or is expected to last 12 months or more, and whether the condition and/or illness reduces their ability to carry out day-to-day activities. A person who answers 'yes' to both questions is considered disabled. Official statistics on disability are primarily collected through surveys, which means that disability tends to be self-reported.

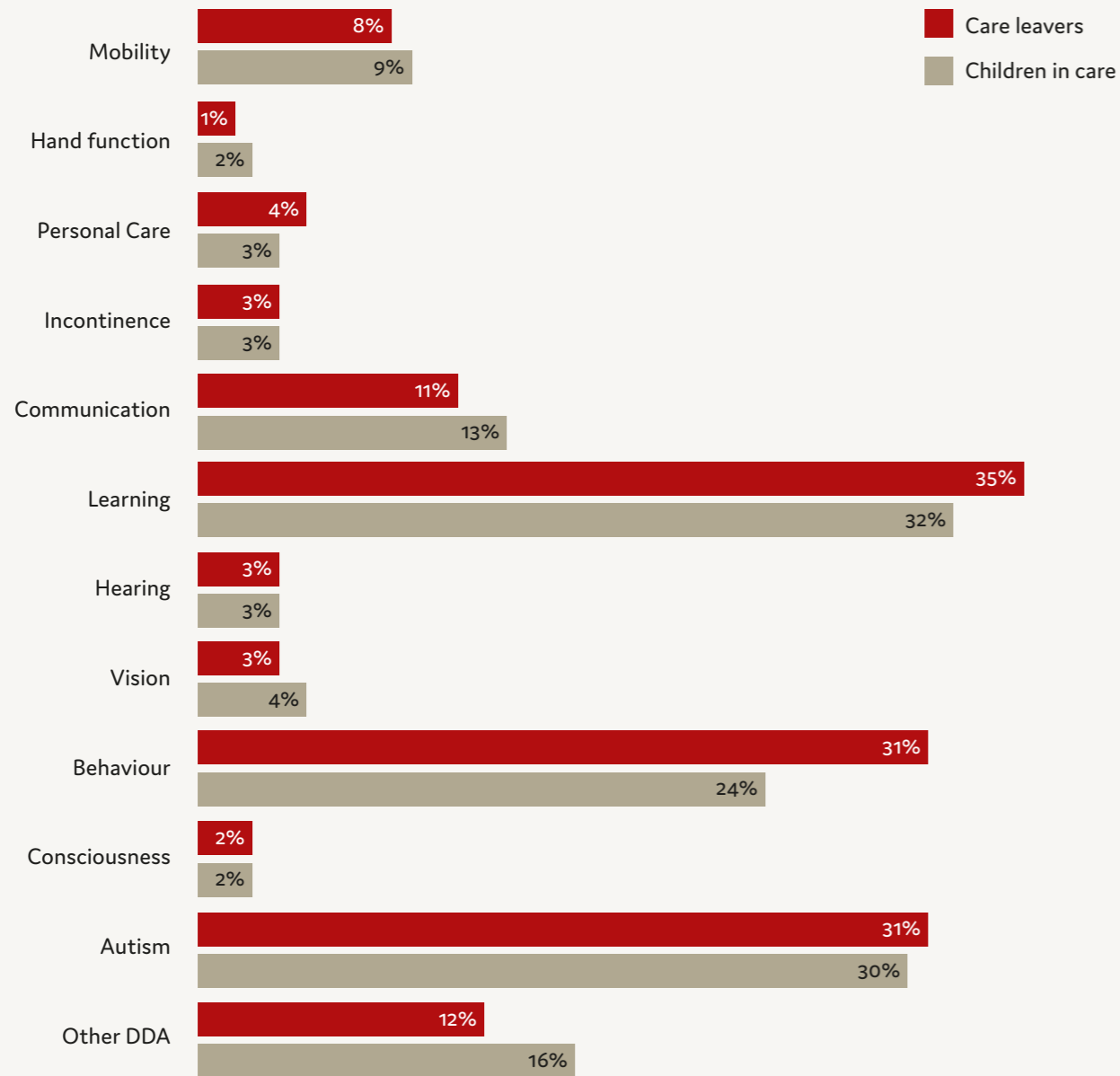
²⁵ In the general population (2020) 15.6% (16%) of young people aged 16-24 were reported to have a disability. The definition of disability used is consistent with the core definition of disability under the Equality Act 2010. A person is considered to have a disability if they have a long-standing illness, disability or impairment which causes difficulty with day-to-day activities. The questions are asked of the respondent in the survey, meaning that disability status is self-identified. There has been an increase over time in the proportion of young people in the general population reporting disability (9% in 2013 and 15.6% in 2020) <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/datasets/youngpeopleswellbeingmeasures>

²⁶ https://assets.publishing.service.gov.uk/media/65256511244f8e000d8e734e/Children_in_need_census_2024_to_2025_guide_V1.1.pdf Definition cited in guidance: The Disability Discrimination Act 2005 (DDA) defines a disabled person as a person with a physical or mental impairment which has a substantial and long-term adverse effect on his/her ability to carry out normal day-to-day activities. The condition must have lasted or be likely to last at least 12 months to be counted as a disability.



²⁷ For example, 7399 care leavers were reported to have a disability, of these 600 were recorded with a mobility disability ('MOB') [600/7399=0.081=8%]

Figure 3 Children in care and care leavers recorded by local authorities with a disability - by types of disability



The most recorded types of disability were 'Learning', 'Autism', and 'Behaviour' (e.g. ADHD)

Looking at the data for both children in care and care leavers we can see that the most recorded disabilities were 'Learning' and 'Autism' followed by 'Behaviour' (e.g. ADHD)²⁸. Less common types of disabilities recorded were: 'Incontinence', 'Hearing', 'Personal Care', 'Consciousness' and 'Hand function'.

For the first time we can see the data local authorities record about disability and children in care and care leavers. Unlike the data on the general population, which is self-reported, the data from local authorities is based on professionals' recording, not the views of young people themselves.

Next, we look at care leavers' own views.

²⁸ One review (Heady, 2023) estimated the prevalence of neurodevelopmental disorders (NDDs) such as autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD), it found children in care have much higher rates of neurodiversity <https://cronfa.swan.ac.uk/Record/cronfa63857>

Bright Spots findings: asking care leavers directly about disability

The Bright Spots Programme²⁹ asks care leavers: **Do you have a long-term health problem or disability that limits your day-to-day activities? (By 'long-term' we mean lasting at least 12 months).**

Based on over 8,000 responses we found that just over a quarter (27%) of care leavers self-reported that 'yes', they did have a disability/long-term health condition; about two-thirds (67%) said 'no' and a small proportion (7%) answered 'prefer not to say'.

Over a quarter of care leavers (27%) self-report that they have a disability or long-term health problem.

The proportion of care leavers self-reporting disability has increased over time: when the survey started around a fifth (22%) of care leavers answered they had a disability, but the latest figures suggest it is now nearly a third (32%)



²⁹ The Bright Spots Programme 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.

NB: Disability and long-term health condition question is only asked to care leavers via the Your Life Beyond Care survey – children aged 17 and under still in care are not asked about disability <https://coramvoice.org.uk/for-professionals/bright-spots-programme>

Table 1 Proportion of care leavers self-reporting long-term health problem or disability by Bright Spots survey year

Bright Spots survey Year	Yes 'disability' or long-term health condition		No		Prefer not to say		Total
	Number	%	Number	%	Number	%	
2017-2018	52	22	179	75	9	4	240
2018-2019	217	22	703	72	55	6	975
2019-2020	438	26	1157	68	109	6	1704
2020-2021	420	25	1132	68	115	7	1667
2021-2022	631	27	1478	64	186	8	2295
2022-2023	196	31	402	64	33	5	631
2023-2024**	237	32	444	61	52	7	733
Total	2191	27%	5495	67	559	7	8245*

* Data drawn from 83 Your Life Beyond Care surveys conducted in 48 local authorities in England, Scotland and Wales
 ** not all data from 2023-2024 included – at time of writing some local authority surveys were still open and receiving data

A higher percentage of care leavers (27%) self-report a disability or long-term health condition than their peers in the general population (15.6%)³⁰

A higher percentage of care leavers (27%) self-report a disability or long-term health condition than the proportion recorded by professionals on children’s social system (13%)

Looking across the different LAs there was variation in the proportion of care leavers self-reporting disability – the average was 27%; the lowest 12% and the highest was 51%.

To support our work on disability and care experience we introduced a new question to the Bright Spots care leaver survey in 2023-2024. Now, for the first time, when a care leaver taking part in the survey person 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 health problem'.

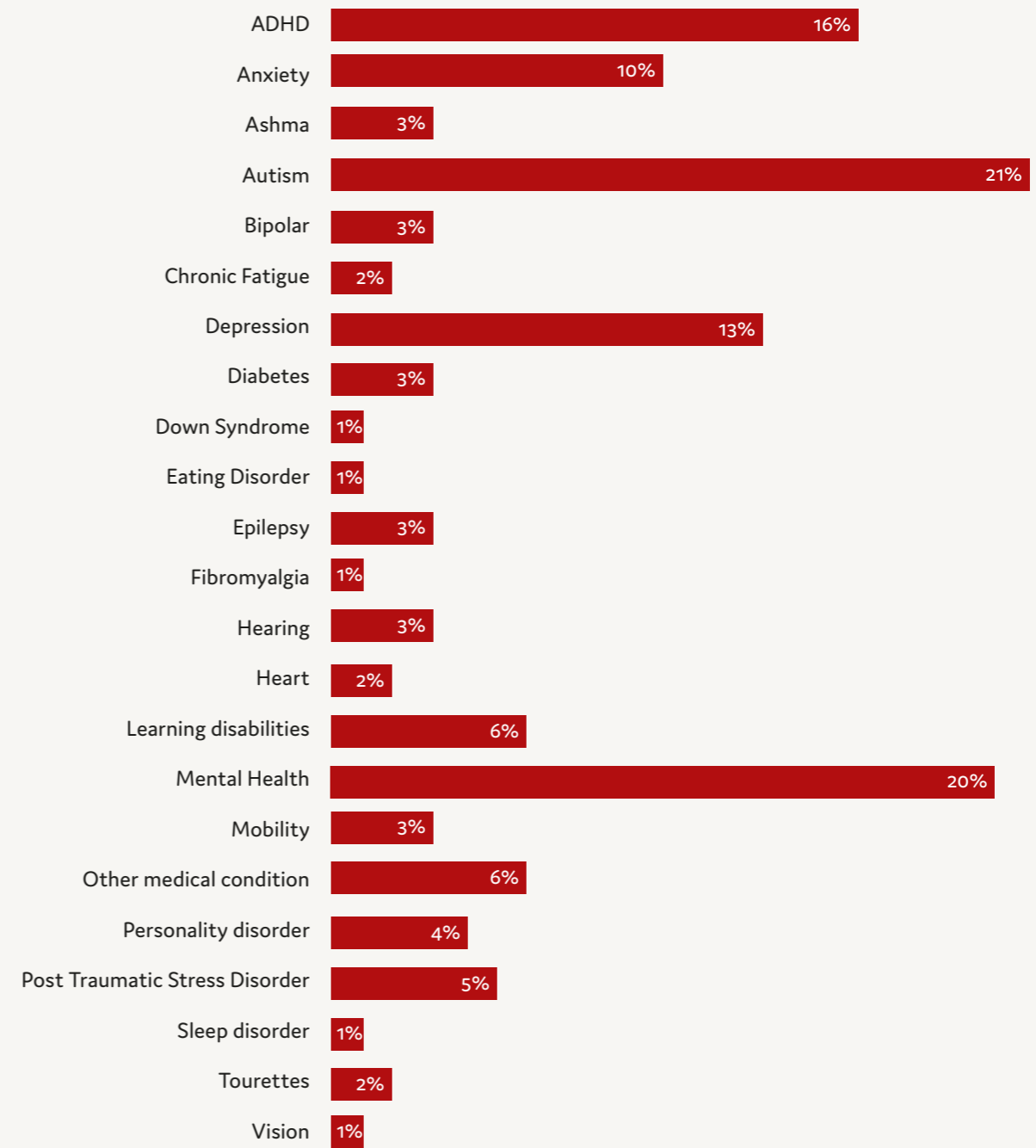
We analysed responses from surveys in 10 local authorities. Nearly 300 (n=270) young people shared their thoughts and feelings on their disability or long-term health problem (See Appendix 1 for further detail). As we saw in the LA data many impairments coexist, similarly in care leavers’ self-report responses it was rare for someone to just write one thing; many noted several disabilities and conditions.

Below (see Figure 4) we list the main disabilities and long-term health conditions.

Whilst some of the most common types of disabilities/long-term health conditions reported by young people appear similar to those recorded by LAs (e.g. autism³¹, ADHD), the language care leavers use is different. Rather than 'behaviour' care leavers wrote things such as: ADHD. Learning disabilities were less frequently reported by young people, which may be because young people with more severe learning disabilities and communication problems may not be included in the Bright Spots sample³².

Through the Bright Spots Programme survey care leavers often wrote about mental health conditions or issues, e.g. depression, anxiety and PTSD (Post-Traumatic Stress Disorder) – these are not 'disability codes' in the data recorded by local authorities (i.e. not included in the Children in Need guidance).

Figure 4 Different type of disabilities written about in Bright Spots survey by care leavers who self reported a disability/ long-term health condition



30 Young people’s well-being measures - Office for National Statistics (ons.gov.uk) The question asks (1) Do you have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more? And (2) Does your condition or illness do any of your conditions or illnesses reduce your ability to carry-out day-to-day activities? (Yes, a lot) (Yes, a little) – A person is not considered disabled if they say “yes”, they have a physical or mental health condition or illness lasting or expected to last for 12 months or more, but it does not restrict their activities.
 Measuring disability for the Equality Act 2010 harmonisation guidance – Government Analysis Function (civilservice.gov.uk).
 NB: Unlike the harmonized question the Bright Spots disability question is not split into two parts
 31 See past work to measure proportion of looked after children with autism https://eprints.soton.ac.uk/424181/2/Parsons_et_al_2019_British_Educational_Research_Journal.pdf

32 Bright Spots responses are self-selected rather than systematically sampled. At present there is not an adapted version of the Bright Spots survey for children and young people with different cognitive abilities. Nor is there an adapted version for children and young people who use alternative communication techniques. The survey is distributed via a 'trusted adult model'; whereby someone who knows the child well (not their carer or social worker) is asked to introduce the survey to the child, to explain more about it and invite them to take part. The trusted adult should be available to provide additional support to take part as needed e.g. reading the questions; explaining the information etc. The Bright Spots team encourage LAs to invite as many of their children and care leavers to take part as possible, considering how children with a disability can take part is part of the working group discussion. For example, one local authority made efforts to ensure disabled children in different settings, such as residential special schools, were supported to take part if they chose and created alternative feedback (e.g. use of picture cards with photo of social worker; observations of child’s behaviour when asked about question area rather than answering the question per se)

Examples of what care experienced young people wrote:

‘ASD; Depression; Anxiety. I am not able or barely able to leave the home (mentally)’

(Care leaver, Bright Spots survey)

‘I have epilepsy and Autism, and this can prevent me from some daily tasks’

(Care leaver, Bright Spots survey)

‘I have severe mental health issues and some physical disabilities’

(Care leaver, Bright Spots survey)

‘Just feel foggy daily, been struggling a bit lately as well, just want to be normal and I try reach out but there’s never anyone there’

(Care leaver, Bright Spots survey)

‘I have autism, this impacts my emotional regulation, social capabilities, daily activities, motor skills and cognitive function’

(Care leaver, Bright Spots survey)

‘I’m mentally ill and it deeply effects my ability to take care of myself’

(Care leaver, Bright Spots survey)

‘I have PTSD which makes my day-to-day life a real struggle dealing with voices and flashbacks’

(Care leaver, Bright Spots survey)

‘I have fibromyalgia and chronic fatigue syndrome’

(Care leaver, Bright Spots survey)

‘I was diagnosed with ADHD and ASD along with depression and anxiety while not your standard or most obvious disability it is defined as such and does affect my day-to-day life’

(Care leaver, Bright Spots survey)

Looking across the sources of information there are differences in the proportion of children in care and care leavers recorded with a disability or long-term health condition.

	% recorded by LA ³³	Bright Spots self-report via survey		General Population
Children in care	11%	n/a	Children	13% ³⁴
Care leavers	13%	27%	Young people	15.6% ³⁵

³³ Based on FOI data which is professionals’ view based on Children in Need categories

³⁴ UK disability statistics: prevalence and life experience (2023) <https://commonslibrary.parliament.uk/research-briefings/cbp-9602/>

³⁵ ONS Young People’s well-being measures (2020) <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/datasets/youngpeopleswellbeingmeasures>

How disability impacts on children in care and care leavers

Whatever way ‘disability’ is measured and recorded there appears to be many children in care and care leavers with a ‘disability or long-term health condition’. Despite this there is limited evidence about how these children and young people are doing, although existing research provides some insights.³⁶



³⁶ NB: Research doesn’t always differentiate between ‘type of disability’ and the experiences of ‘different groups’ of disabled children and young people may vary

Children in care

Research exploring the experiences of children in care with a disability has found:

- Children and young people with a disability are at an increased risk of experiencing abuse compared to children without disability.^{37,38}
- Some disabilities are directly linked to early experiences of physical or psychological maltreatment and trauma.
- Children with disabilities are more likely to be looked after than non-disabled children.
- Disabled children can have different 'pathways' through care e.g. they may be more likely than other children in care to live in residential care; more likely to live 'out of area'; wait longer than others to be adopted (and those with intellectual disabilities may be less likely to be adopted); they may be less
- likely to go home to their family and more likely to experience multiple moves or live in inappropriate placements.³⁹
- Disabled children may be more likely to stay in care for longer and become 'care leavers'.⁴⁰
- Whilst in care disabled children may not always be supported to stay connected to the people who are important to them (there is some evidence they have lower levels of 'contact').⁴¹
- Disabled children and young people's views and perspectives may not be routinely sought in matters that affect them.

Care leavers

Findings from research focused on disabled care leavers include:

- Concern that many young people, e.g. those with 'borderline impairments', are not getting the support they need and fall through the gap between mainstream services and disability services.⁴²
- Gaps in support and service delivery when moving from child to adult services even when disabled young people do meet 'eligibility criteria'.
- Worries about the degree to which care leavers are involved in decision-making, and whether pathway planning is done to, rather than with, young people with disabilities.⁴³
- Concerns that disabled young people leaving care can face unsatisfactory support (personal advisers not always allocated, lack of planning, inadequate information and consultation with young people and restricted housing and employment options).⁴⁴



37 <https://www.communitycare.co.uk/2015/08/14/protection-disabled-children-latest-research-tells-us/>

38 See: national review into safeguarding children with disabilities and complex health needs which revealed serious failures at 3 residential special schools registered as children's homes <https://www.gov.uk/government/news/urgent-action-to-protect-children-with-disabilities-from-abuse>

39 Permanence for disabled children and young people through foster care and adoption: a selective review of international literature – University of Strathclyde

40 <https://academic.oup.com/bjsw/article/37/7/1173/1641239>

41 <https://journals.sagepub.com/doi/abs/10.1177/030857590603000204>

42 <https://research.hscni.net/sites/default/files/YOLO%20Final%20Report.pdf>

43 <https://disability-studies.leeds.ac.uk/wp-content/uploads/sites/40/2011/10/finalreport1.pdf>

44 <http://www.csdg.org.uk/2020/02/26/destination-unknown-improving-transitions-for-care-leavers-andyoung-people-with-send/>

Bright Spots Programme findings: how are disabled care leavers doing?

‘My rights are often ignored because I am very disabled, [I’m] expected to fit into a system that I can’t fit into’

(Care leaver, Bright Spots survey)

‘In relation to housing, I feel that I can receive unfair treatment as a care leaver, its better as a disabled young person’

Care leaver, Bright Spots survey)

‘I was moved to semi-independent living without knowing. Being a care Leaver especially with no family support is 5x harder than an average young person. It’s even more harder if you suffer from a disability. I would never recommend care to anyone. This care system needs to improve otherwise within a few years, care leavers will end up exhausted of life at only 16 or 18 or younger’

(Care leaver, Bright Spots survey)

‘Hard to manage due to disability, bad memory but PA [Personal Adviser] helps and other people around me’

(Care leaver, Bright Spots survey)

‘I don’t feel Mental Health recognise that I need help support with thoughts and feelings. They diminish what I feel, and this makes me angry and depressed’

(Care leaver, Bright Spots survey)

‘My mental health prevents me going out due to my social anxiety and I can’t access counselling due to long waiting lists’

(Care leaver, Bright Spots survey)

‘I suffer with depression and anxiety. I have found there is no support. I have tried seeking help, but they all come back saying they can’t help. I am trying to help myself, but I need professional help. I think there should be more support around mental health for care leavers because we didn’t ask to have the childhood we had. You leave care at the age of 21 but we’re still battling with ourselves to try and understand what has happened to us’

(Care leaver, Bright Spots survey)

In the Bright Spots surveys, care leavers with a disability or long-term health problem reported lower well-being on a range of measures compared with other care leavers

The Bright Spots Programme offers some insights into how young people themselves feel they are doing. Analysis of the responses^{45,46} from care leavers who reported a disability or long-term health condition were compared with other care leavers.

45 <https://coramvoice.org.uk/wp-content/uploads/2020/11/1883-CV-What-Makes-Life-Good-Report-final.pdf> Data based on 21 Local authorities, n=1804 care leavers

46 <https://www.sciencedirect.com/science/article/pii/S0190740924000343?via%3Dihub>

Table 2 Bright Spots Programme: Comparison of care leavers with a disability and all other care leavers*

	Care leavers reporting a disability or long-term health problem	All other care leavers
Hardly ever / never feel safe in my home	12%	6%
Hardly ever / never feel safe in my neighbourhood	16%	8%
Hardly ever / never feel settled in my home	19%	13%
Unemployment	59%	43%
Finding it difficult to cope financially	29%	18%
Two or more leaving care workers in the previous 12 months	44%	35%
Limited involvement in the pathway programme (feel involved some or none of the time)	43%	36%
Not have a good friend	21%	12%
Unhappy with appearance	41%	22%
Always or often feel lonely	35%	16%
Low well-being	42%	24%

*Data drawn from 21 local authorities (n=1,804) in England as reported in 'What Makes Life Good? Care leavers' views on their well-being' (2020).

Research has not always paid attention to the intersection of care experience and disability— in much of the (limited) information in this area the voice of young people themselves is missing.⁴⁷ One recent exception to this is the project:

Headphones, Odd Shoes & A Second Chance at Life: An Exploration of the Experience of Children in Care & Care-leavers with Disabilities⁴⁸ (2023)

This study, commissioned by EPIC (Empowering People in Care) Ireland, was inspired by a webinar on Disability & the Care System as part of Care Day 2021 events.⁴⁹ The research asked:

- What are the experiences of children and young people with disabilities while they are in care and aftercare?
- What do EPIC youth understand as their rights under the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and does their care experience match with these rights?
- A youth advisory group was established to advise on design, delivery & data interpretation. In total 8 disabled young people in and leaving care participated in 2 online focus groups. Young people had a range of care experiences and disabilities (physical, intellectual & invisible disabilities).
- Session 1 focused on areas of positive practice, challenges or gaps in provision in the care experience and in terms of disability.
- Session 2 explored the rights of care-experienced children and young people in relation to the UNCRPD.

Disabled children and care leavers reported some positive experiences: e.g. the importance of significant people in their lives (foster or kin carers, social workers, advocates) or specific 'interventions' that had been helpful. Some

of the challenges presented involved the attitudes or awareness of others (false perceptions, lack of recognition of specific needs related to disabilities). Other challenges linked to navigating relationships, vulnerability to bullying, missing out on 'normal' teenage experiences and complicated dynamics with family members.

Several felt they had not been provided with information about their rights. Whilst some struggled with the terminology, all had a strong sense of fairness & many were articulate about the right to have a say & importance of being heard.

Some of the young people's ideas for change included:

- Improving relationships with professionals – more emphasis on listening, explaining what is happening and follow through.
- Structural issues in the care system - effective linking and signposting to services/supports, continuity, delivering on implementation.
- Improved capacity in relation to disability – information and training for professionals and foster carers, more information about specific hidden disabilities, accessibility improvements, responsiveness to specific disability needs.

The research highlighted that the ways in which young people in care and care leavers are often labelled or described does not tell the whole story of their lives. Young people wanted to emphasise that they are 'not marginal', rather it is they who have been marginalised by the obstacles placed in the way of their meaningful inclusion and participation. The onus needed to be on relevant statutory agencies to deliver on their responsibilities as the Corporate Parent and to do so in a way that recognises the intersectionality of care and disability.



47 Important blog on the intersection of care experience, disability and neurodiversity <https://diversityandability.com/blog/a-hidden-intersectionality-care-experience-disability-and-neurodiversity/>

48 <https://www.epiconline.ie/headphones-odd-shoes-a-second-chance-at-life/>

49 <https://www.youtube.com/watch?v=ZUgk4Kz4p04&t=4>

Support for children and young people with disabilities as they grow older

As disabled children in care grow older there can be lots of changes (or 'transitions') – two of the main ones that services focus on are:

1. The transition from being in care to becoming a care leaver.
2. Transition from receiving services and support funded by children's social care to receiving services from adult social care.

But alongside this there may also be lots of other changes happening around the same time:

- Moving to different accommodation⁵⁰
- Moving from school to college
- Moving from education to employment, volunteering or other programme of activities
- Moving from one social care worker / team to another (e.g. looked after children team to transition team or disability team and leaving care team)
- Moving from one assessment process to another (e.g. from looked after child plan to Care Act assessment/ support plan and/or Pathway Plan).

Coram Voice have mapped out 'the ideal transition from care' for disabled young people⁵¹, which would include:

- Discussions about transition starting early/from year 9.
- Different agencies/organisations working jointly together and with the young person/family or carer to ensure a smooth transition.
- If a child is likely to need care and support from adult services after turning 18, a transition assessment should be completed within a reasonable timescale, and at a point in time when it is most likely to benefit the young person and carer.
- A lead professional to coordinate the transition process.
- The child or young person should be involved in planning for the future, and their wishes and feelings should be listened to
- Written assessments should be kept up to date and the young person and/ or carer(s) should be involved in reviewing them.
- A situation should not arise where children's services stop funding support, but adult services haven't taken over yet: there should never be a gap in services.
- If a disabled young adult is also a care leaver, they will be entitled to leaving care support such as a Personal Adviser, Pathway Plan and Setting Up Home Allowance (and they are entitled to this regardless of whether an adult social worker is also involved).

Common barriers and challenges in transition from care for disabled young people

The law and accompanying guidance are designed to stop children and young people with disabilities slipping through the net as they grow older, become adults and care leavers (see Appendix 2 for detail of some of the key legislation). But despite the expectation that disabled children in care should experience a well-planned, smooth transition, for some young people this is not the case.⁵²

As children in care with disabilities grow older, they do not always get the support they need due to poor processes or a non-person-centred approach, a lack of recognition of young people's rights, failure of services to work together and funding issues.

Coram Voice's specialist disability advocate⁵³ has collated some of the most common issues disabled young people face as they grow older. These include:

Process issues

Lack of planning or failure to plan at all until it's too late e.g. Care Act Assessments, Pathway plans, Mental Capacity Assessments and Education, Health and Care plans not completed lawfully or in a timely fashion

Drift: decisions have been made about future planning, but they have not been acted upon

Failure to work together

- Failure to communicate between agencies
- Disagreements between professionals, carers and social workers about what is in a young person's best interests

Rights based issues

- Lack of recognition that disabled adults can also be care leavers/entitled to care leaver support
- Disputes about how much capacity a young person has
- Refusal to assess and/or such rigid criteria that individual needs are not considered
- Failure to convene meetings or refer to court when disputes arise

Non-person-centred approach

- Failure to listen to young people about their wishes with regards to transition planning, especially if they lack capacity in some areas
- Lack of appropriate communication with the young people themselves about complex issues
- Frequent changes of staff/no allocated worker who knows the young person and understands them and their needs
- Failure to prepare young people or recognise the emotional impact of transition: the need for planned endings/life story work, therapy etc

Funding

- Disputes between different agencies about which service funds what e.g. health, social care and education (especially if a young person was/is looked after by one LA but lives in another)
- Difficulties with identifying suitable provisions, placements, educational options etc. especially for young people 'with complex needs'
- Disputes about whether high-cost placements are justified



⁵⁰ For example, Shared Lives Plus – this option is currently expanding via a new Care Leaver Programme which aims to support local authorities and local partners in the NHS, voluntary sector and housing sector to develop Shared Lives for care experienced young people with learning disabilities and mental ill-health. <https://sharedlivesplus.org.uk/our-work-and-campaigns/our-shared-lives-programmes/young-people/>

⁵¹ https://coramvoice.org.uk/wp-content/uploads/2019/08/transition_toolkit.pdf

⁵² For example, this Ofsted report highlighted: "For some disabled care-experienced young people, personal advisers are unable to demonstrate an understanding of their needs and they do not visit these young people regularly. Vulnerable young people told inspectors that personal advisers used their involvement with adult services as an excuse not to help them, and that this affected the level of trust and confidence they had in them". <https://files.ofsted.gov.uk/v1/file/50239562>

⁵³ FAQ's for care leavers with disabilities - Coram Voice

Advocacy case studies and learning from serious incidents

When we do not get things right for children and young people in and leaving care with disabilities the consequences are serious. Not only is there a risk of young people not thriving, but for some it can lead to even more tragic outcomes as illustrated by the serious incident below.

Learning from serious incidents

In 2019, an 18-year-old care leaver with type 1 diabetes and learning disabilities died during a visit home. A coroner's inquest in 2024 found neglect by the authorities contributed to his death. The Action to Prevent Future⁵⁴ death report listed several failings from the Children's Services care leavers team, including:

- Failure to obtain information about the risks posed by type 1 diabetes from specialist diabetic service.
 - Failure to obtain information about the young person's cognitive ability and how it impacted on their ability to manage diabetes independently.
 - Failure to undertake a risk assessment.
 - Failure to create an adequate pathway plan which included a proper evaluation of what support was needed for the young person to have contact with their family.
 - Failure to co-ordinate agencies providing support to inform the pathway plan.
 - Failure to hold properly minuted and informed meetings prior to deciding that the young person could have unsupported contact.
 - Failure to inform the young person of the risks of going home unsupported and suggesting ways to mitigate the risks.
 - Failure to identify that had the young person been made aware of the risks and insisted on going home unsupported, a capacity assessment would be required.
- "A referral was made to the local authority Transitions Team for an assessment of [the young person's] care needs. The entry requirement for that team required an evidenced diagnosis of learning disability. The report containing the original diagnosis had been lost. Children's Services were unable to obtain an up-to-date diagnosis of learning disabilities. [Name] was assessed not to meet the threshold for the transitions team. He did not have the support of an adult social work team. This outcome was being challenged when he died."

The report details systematic failings on the part of the local authority to adequately train and oversee Personal Advisers in relation to their legal obligations in preparing Pathway Plans.

The coroner recorded that they were not satisfied that in the years since the young person's death there had been sufficient action to prevent future deaths. Outstanding matters of concern included:

- Inadequacy of pathway planning – training for PAs was not mandatory and only just being rolled out.
- The process by which diagnoses of learning disabilities can be obtained remains opaque. There is no protocol in relation to this. The current situation leaves those making decisions in relation to young people struggling to obtain this vital information.
- The issue of how the numerous adult social care teams are accessed to obtain adult social care assessment for care leavers leads to confusion and delays. Vulnerable care leavers are at risk of being denied necessary support.
- How internal meetings and formal review meetings with other interested parties are informed and recorded is not subject to a protocol and the risk remains that decisions will be taken without adequate information and inquiry as to the risks inherent in those decisions.
- Practice standards have not been put in place in relation to risk assessments of care leavers to inform their needs.
- Mental Capacity Act training is not mandatory in children's services and the adult services have no audit of the effectiveness of the mandatory training provided and how it is being used in practice. There is therefore a risk that erroneous assumptions as to capacity will continue to be made.

Advocacy (including non-instructed advocacy) is an important part of ensuring children in care and care leavers' voices (including those with disabilities) are heard in matters that affect them and that their rights are upheld as illustrated by the below case studies.

Maddie was 6 years old and had autism. She has been in care for several years and had been in her current foster placement for a year when she accessed advocacy. Maddie's foster carer asked for an uplift in her fee because of Maddie's disability.

The social work team then said they wished to move Maddie to a different placement. This placement was with a single carer who worked full time, was out of area, would necessitate a school move and there were real concerns it would not meet her needs.

A referral was made for an advocate from the charity commissioned by Maddie's local authority. Maddie is verbal but due to her disability and age she worked with

an advocate on a semi non-instructed basis.

The advocate met with Maddie who was clear she wanted to stay where she was. The advocate also obtained the views of those close to her, including her birth family and current carers. The advocate challenged the move.

The advocate also escalated concerns to the Children's Commissioner's Office and instructed a solicitor on Maddie's behalf.

As a result, the local authority employed a clinical psychologist to review the care plan. The decision to move Maddie was reversed and she remained in her foster home.⁵⁵

Alison⁵⁶ was a 17-year-old looked after child when she was referred to the Coram Voice disability advocacy service. At this time, she was

living in a specialist children's home in the north of England. Alison has autism and a learning disability.

Alison's support workers referred her to an advocate five months before her 18th birthday, as there had been no discussions about her transition to adulthood. Alison was expressing anxieties about where she would live as an adult, and who would help her with things. Alison spoke to her social worker in Children's Services who agreed to follow this up, but the plans remained unclear.

An advocate met with Alison and discussed her worries about the future. She also advised Alison of her rights. The advocate explained that a transition assessment should have been undertaken, so that a plan could be made for when Alison turns 18. The advocate wrote to Alison's social worker's manager. As a result of this, a referral was made for a transition social worker, who completed an assessment. Alison then visited some supported living providers, and a new home was identified.

Alison moved into her new home and began to settle in. By this time, she was 18 and a care leaver. However, she still did not have all the support she needed. Although Alison had a social worker with Adult Services, she had no allocated Personal Adviser (PA) in the Leaving Care Team. She also had difficulty understanding and managing money, because of her learning disability. No one had helped her to make a welfare benefit claim or access her setting up home allowance. The advocate supported Alison to make a complaint. As a result, a leaving care PA was allocated, who met with Alison to complete a pathway plan. The PA also supported Alison to make a benefits claim, and adult

social care completed a mental capacity assessment regarding finances. Following this and another meeting, an appointee was arranged to support Alison in managing her money.

Alison is now enjoying life in her new home. She has been supported to purchase some items for her bedroom, using her setting up home allowance. Alison's PA is now focusing on supporting Alison with her education, by helping her to apply for a college course for the next academic year. Alison is now feeling positive about the future and gaining skills for independence. She has a social worker and PA, as well as the staff at her home, who make sure she has access to support.

55 'We all have a voice': Disabled children's vision for change | Children's Commissioner for England (childrenscommissioner.gov.uk)

56 This is an anonymised case study based on Coram Voice's advocacy work: any identifying details such as the young person's name have been changed

Conclusions

The collection of good quality data is critical to understanding the needs of disabled children in and leaving care. But our work clearly shows worrying gaps in information. We used FOI requests to obtain data to find out more. We achieved a high response rate. We have, for the first time, provided a systematic snapshot of the proportion

of children in care and care leavers in England (as recorded by local authorities) with a disability or long-term health condition; 11% for children in care and 13% for care leavers.

In stark contrast to the figure recorded by local authorities our analysis shows that when you ask care leavers directly more than a quarter (27%) self-identify as having a disability or long-term health problem. The proportion has increased over time.⁵⁷

Further exploration of how care leavers with a disability or long-term health condition feel life is going shows that many are struggling with loneliness, low well-being and issues such as feeling unsafe at home.

It's likely some care leavers who identify as disabled or with long-term health issues do not receive support from adult services. Professionals who support these young people are concerned that many can miss out on the support they need. They would like to see improvements to their own knowledge and skills in this area and more flexible services.

Our work exposes how invisible disabled children in care and care leavers are in our national statistics – underestimation and under-recording of disability means that individual and collective needs and experiences of disabled children in care and care leavers are not fully understood. Currently there is little information available to plan and monitor the effectiveness of support. We need urgent action to redress these stark omissions - we make recommendations for improvements in two areas:

(1) improve data collection on disability for children in care and care leavers and (2) improve policy and practice. We detail 19 specific recommendations for government and local authorities.



⁵⁷ This echoes the general population which has seen an increase in the number of children receiving disability benefits amid a rise in learning difficulties, ADHD, autism Number of children claiming disability benefits doubles in a decade (telegraph.co.uk)

Recommendations: from knowledge to action

‘No idea where in our records we could pull disability data if asked. Not recorded in plans.’

(Professional working with care leavers)

‘Not all disabilities need a diagnosis and are visible.’

(Care experienced young person)

To be sure the rights of disabled children and care leavers are upheld, we must know who they are and when they do not get the support they are entitled to. The absence of accurate information impacts on the development of services to effectively meet the needs of children and young people.⁵⁸



⁵⁸ <https://onlinelibrary.wiley.com/doi/10.1111/cfs.12239>

Improve data collected on disability for children in care and care leavers

I. Use existing data better

Identifying and recording a child's disability enables services to better understand the child, make reasonable adjustments, provide suitable support and deliver on their Equality Act 2010 duties.⁵⁹ Our FOI request showed that local authorities do collect data on 'disability status' and children in care/ care leavers (e.g. via the Children in Need census) - but not everyone in the local authority knows about the data or uses it. On a national level, the Department for Education (DfE) do not publish data on disability of children in care and care leavers, yet aggregating, linking and analysing existing data can provide useful insights.⁶⁰

Recommendations

1. Local authority leaders should collate and review disability data regularly to effectively plan and monitor service delivery for children in care and care leavers.
2. Team managers and practitioners should have access to and utilise existing data to inform planning (e.g. ensure recorded disabilities inform care and pathway plans).
3. Department for Education should publish disability data already collected as part of the Child in Need (CIN) Census in the annual looked after and care leavers statistics (looked after data would need to be matched to the CIN census data).
4. Department for Education should include 'disability' as a category (in the same ways as ethnicity, age and gender are included) in all their statistical tables that are available through the explore education statistics site - including the data on care leavers (<https://explore-education-statistics.service.gov.uk/>).
5. Department for Education should publish ad hoc statistic or a deep dive one-off 'data pack'⁶¹ 62 on disability and children in care / care leavers.

⁵⁹ <https://www.celcis.org/news/news-pages/new-analysis-shows-disparity-statistics-collected-about-disabled-children-scotland>

⁶⁰ The CIN census guidance states this is possible: "Linking to the children looked after data allows, for example, the analysis of the proportion of looked after children who are disabled and analysis of the original reasons for the child being identified as being in need" (page 13 CIN census guide 2024 to 2025)

⁶¹ For example, at times government produce ad hoc statistics to understand issues further e.g. experiences of 16-17 year olds in supported accommodation <https://explore-education-statistics.service.gov.uk/find-statistics/looked-after-children-aged-16-to-17-in-independent-or-semi-independent-placements>

II. Improve data and knowledge

The 'disability codes' used in data have not changed for many years and do not reflect the lived experience of children and young people. When young people describe disabilities and long-term health conditions, they include mental health, PTSD, anxiety and other disabilities, many of which are not currently included in the current Children in Need Census data.

Adding self-report questions to assessments, plans and children's records would provide important insights into children and young people's needs both individually and collectively, especially if this triggers a discussion about how they could best be supported.⁶³

Whilst this insight paper has addressed some gaps in our knowledge, there is still too little understanding of the experience of children in care and care leavers with disabilities and what services and support would best meet their needs. The variation in the proportion of children in care and care leavers recorded as disabled by different local authorities warrant further exploration to understand reasons and implications for the differences. Research that incorporates youth voice and participatory research methods could help us understand the impact that impairments have on care experienced children and young people's lives.

Recommendations

6. Department for Education should review the 'type of disabilities' codes used in the Children in Need census guidance with young people and local authorities to ensure language and content reflect young people's lived experiences.
7. Local authorities should record children and young people's self-reported experiences of disability and long-term health conditions and use this to inform individual care plans and collective service development.
8. Coram Voice should collate and promote the different ways the views of disabled children are captured when local authorities participate in the Bright Spots programme, e.g. through visual cues.⁶⁴
9. Coram Voice should seek funding to work with young people and disability specialists to develop tools to capture the well-being of a wider range of children and young people with disabilities in the Bright Spots Programme.
10. Government and research funding bodies should commission further research to better understand the experience of children in care and care leavers with disabilities, how these are identified and addressed and what works in supporting them to inform policy and practice.

Improve policy and practice

III. Listen and respond to disabled children in care and care leavers

‘Be more curious about ‘diagnosis’ on file when they transition. What does that mean for the young person, how does that impact them and how do they feel about it?’

(Professional working with care leavers)

‘When someone tells you an illness is impacting their life, listen and fully explore.’

(Care experienced young person)

Our work showed higher rates of young people self-reporting disability compared to the data collected by local authorities. Young people urged their workers to be curious about disability and to have conversations with them to hear their views and experiences - shifting away from an absolute focus on diagnosis and service eligibility criteria.

Young people can help professionals understand their experiences by voicing what the impact of their disabilities or conditions are, what they struggle with, and feel may help. To do this, however, requires worker confidence and awareness of how to communicate with children and young people in ways that works for them.⁶⁵

Advocacy services, including non-instructed advocacy, can help ensure that children and young people's voices are heard in the decisions that are important to them.

Accessible youth and influence groups can capture children and young people's collective voice and help improve services – it is important that these are inclusive and accessible to the needs of all children in care and care leavers.⁶⁶

⁶³ E.g. during pathway planning asking and recording responses to: do you feel you have a disability / long-term health condition? If yes, how does this affect you day to day? What can we do to help with this?

⁶⁴ Example from West Sussex <https://coramvoice.org.uk/for-professionals/bright-spots/resource-bank/finding-the-way-that-works/>

⁶⁵ Coram Voice, and others, offer training to support this <https://coramvoice.org.uk/for-professionals/specialist-advocacy-service/specialist-advocacy-service-training/meaningful-communication-advocating-for-the-wishes-and-feelings-of-young-people-with-disabilities/> and see also: National Autistic Society, Mencap, Scope, Mind etc.

⁶⁶ Examples of voice and influence projects: Work in Leeds led by young people to raise awareness of disability <https://wearechildfriendlyleeds.com/raising-awareness-of-disabilities/> Fostering network project in Scotland (Walking Tall) to discover if the voice of children and young people with complex disabilities were being heard; explore how foster carers are supported to look after children with complex disabilities and produce some guidance to support foster carers working with children with complex disabilities [walkingtall-disabilityinclusionmarch2019.pdf](https://walkingtall.org.uk/wp-content/uploads/2019/03/walkingtall-disabilityinclusionmarch2019.pdf) (thefosteringnetwork.org.uk)

⁶⁷ https://participationpeople.com/wp-content/uploads/2020/11/Compressed-PP-_-Lundy-Model-Explained-2.pdf

Recommendations

11. Professionals working with care experienced children and young people (e.g. social workers, PAs, carers, supported accommodation staff) should create space for meaningful conversations about disability and long-term health conditions with young people to inform their day-to-day care by:
 - a. Creating supportive and inclusive environments where children's voices are heard, and experiences are validated.
 - b. Responding to children and young people's communication needs.
12. Local authorities should provide access to advocacy to safeguard the rights of children and young people with disabilities:
 - a. Commission high quality independent advocacy including non- instructed advocacy for children in care and care leavers.
 - b. Ensure advocates have received specialist training to meet children's needs.
 - c. Ensure children in care and care leavers are aware of their right to advocacy to make sure their voice is heard in matters that affect them.
13. Local authorities should provide accessible opportunities for care experienced children and young people with disabilities to collectively influence service improvement – following the Lundy model to ensure space, voice, audience and impact.⁶⁷

IV. Build staff confidence, skills and understanding

‘Professionals pass us to other workers who can’t provide us with the necessary services.’

(Care experienced young person)

‘The separation of disabled children’s teams and the disconnect with adults’ services – eligibility for either is unclear and fluid. Why are some children looked after able to go to disabled children’s teams and others don’t?’

(Professional working with care leavers)

‘Take away ‘tick-boxes’ and be needs led – confidence in moving away from tick boxes.’

(Professional working with care leavers)

The way we respond to children and young people is grounded in our understanding and assumptions about disability and long-term health conditions, yet professionals did not always feel confident in understanding or responding to these needs.

Using a narrow medical lens when interpreting disability, can limit our understanding of children and young people’s experiences. Professionals also need to incorporate a social lens to understand how disabilities can impact on children and young people’s lives, the services and systems available to support them and where to access further advice and support.⁶⁸ Autism⁶⁹, learning disabilities and ADHD were commonly reported and could provide a focus for training. Workshop participants also suggested that mental health first aid; neurodiversity; mental capacity assessments and meaningful communication would be helpful training areas.

Recommendations

14. Local authorities should support professionals (e.g. social workers, PAs, carers, supported accommodation staff) to develop confidence, skills and knowledge of disability and long-term health conditions including:
 - a. Identify staff skill gaps by exploring the additional support/training they would find helpful and taking action to address the gaps identified.
 - b. Provide information, tools and access to specialist advice⁷⁰ for professionals.
 - c. Create opportunities for professionals to reflect on their understanding and assumptions about disability, e.g. in group supervision.

V. Improve existing services

Assessment, diagnosis and eligibility is important to access disability and health services. Some young people with ongoing care needs are not identified and struggle with the transition to adult services. There is another group of young people who do not meet thresholds, but whose additional support needs are not being met by current services. Leaving care services can struggle to meet the needs of both groups.

If we make better use of data and improve the information we hold on children and young people’s needs, this can inform the services that are provided and how

resources are best utilised to meet needs. Awareness of ongoing disabilities and long-term health conditions can trigger interventions and early planning for transitions

to adult services. It can help managers make sure that policies and practice align and are accessible and supportive. Guidance outlines that policies and protocols should be in place for care leavers with disabilities age 16+ and should cover young people placed in other authorities.⁷¹ Protocols should include ways to escalate and

resolve problems if there are delays or barriers to accessing support for care leavers.⁷² Evidence from advocacy and serious incidents shows that transition to adulthood is not always working well for young people.

Recommendations

15. Local authorities should improve referral pathways for disabled children in care to disability services i.e.
 - a. Review pathways for children in care that are likely to need care and support from adult disability and mental health services after turning 18⁷³ to ensure referrals to conduct Care Act Assessments are made and that joint working is in place to establish how on-going support needs will be met.⁷⁴
 - b. Use disability data to audit whether all children in care and care leavers with disability or long-term health needs are receiving the full range of leaving care, mental health and/or disability support they are entitled to.
16. Local authorities should ensure that services for children in care and care leavers are accessible and supportive of children and young people with disabilities, including:
 - a. Ensure policies explicitly include reference to disability and long-term health conditions (in line with the range of self-reported disabilities).
 - b. Work with young people to review the accessibility of care planning, health plans, pathway plans, the care leaver local offer etc. and improve where necessary.
 - c. Review whether children and young people with disabilities access advocacy services and improve accessibility if needed.
 - d. Review whether children and young people with disabilities have opportunities to participate in voice and influence groups and improve accessibility if needed.

⁷¹ See Annex F (page 109): https://assets.publishing.service.gov.uk/media/61f81624d3bf7f78df30b359/CA1989_Transitions_Guidance.pdf

⁷² See Chapter 6: https://assets.publishing.service.gov.uk/media/61f81624d3bf7f78df30b359/CA1989_Transitions_Guidance.pdf

⁷³ <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>

⁷⁴ The Wandsworth example of a specialist Transitions team/social worker role based in leaving care teams to support completion of Care Act Assessments and support leaving care team colleagues can provide a model to improve referral pathways <https://coramvoice.org.uk/for-professionals/bright-spots/resource-bank/transition-social-worker/> ⁷¹ See Annex F (page 109): https://assets.publishing.service.gov.uk/media/61f81624d3bf7f78df30b359/CA1989_Transitions_Guidance.pdf

⁶⁸ Coram Voice toolkit on the rights of disabled young people in the transitions planning process https://coramvoice.org.uk/wp-content/uploads/2019/08/transition_toolkit.pdf; FAQ for care leavers with disabilities <https://coramvoice.org.uk/myrights/my-rights-when-i-am-leaving-care/faqs-for-care-leavers-with-disabilities/>

⁶⁹ <https://www.theguardian.com/society/article/2024/jun/01/the-truth-about-adhd-and-autism-how-many-people-have-it-what-causes-it-and-why-are-diagnoses-soaring>

⁷⁰ <https://coramvoice.org.uk/for-professionals/specialist-advocacy-service/specialist-advocacy-advice-consultation-form/>

VI. Address gaps in service provision

There is a significant group of young people who self-report disabilities, who struggle and who have lower well-being than other care leavers. They have a range of additional support needs, but do not meet thresholds for individual adult services. Existing guidance on leaving care support stresses that local authorities should ensure these young people are well supported.⁷⁵

Care leavers need more flexible services that respond to young people's presenting needs rather than diagnoses. For care leavers who do not meet the criteria for support by adult services, the Personal Adviser (PAs) will be pivotal in making sure support needs are identified and addressed⁷⁶, but they will not always be equipped to respond on their own.

There is a need to move towards more relational public services⁷⁷ that focus on understanding children and young people's lived experience and responding to need rather than just assessing eligibility. Local solutions may take different forms from flexible transitions services⁷⁸, dedicated mental health or disability workers in leaving care teams⁷⁹ or commissioning specialist support.⁸⁰

Recommendations

17. Local authorities and their partners should use the data collected on, and from, children in care and care leavers with disabilities to commission services for those young people whose needs cannot be met by existing services.
18. Local authorities should appraise whether Pathway planning is sufficiently robust for these young people.
19. Department for Education should establish a way to collate promising practice and a programme to test models of effective support for disabled children leaving care.

Appendices

Appendix 1

Types of disabilities self-reported by care leavers

Types of disabilities reported by care leavers answering the Your Life Beyond Care survey (information from 10 local authorities).

Disability or long-term health problem	Of those who reported 'yes' have disability number of care leavers who reported specific disability	Percentage of care leavers who reported
Autism	56	21%
Mental Health	55	20%
ADHD	44	16%
Depression	36	13%
Anxiety	27	10%
Other medical condition	17	6%
Learning disabilities	17	6%
PTSD	14	5%
Personality disorders	10	4%
Diabetes	9	3%
Asthma	9	3%
Hearing	9	3%
Mobility	8	3%
Bipolar	8	3%
Epilepsy	7	3%
Heart	5	2%
Chronic fatigue	5	2%
Tourette's	5	2%
Eating disorder	4	1%
Fibromyalgia	3	1%
Down syndrome	2	1%
Vision	2	1%
Sleep disorder	2	1%

⁷⁵ "Some care leavers will need support as part of the transition planning. These include: young people with emerging mental illness and personality disorder; young people (perhaps with mild to moderate learning difficulties or disabilities) who will not require specialist services but who will need a pathway planning package to reflect their delayed maturation" page 99-100 https://assets.publishing.service.gov.uk/media/61f81624d3bf7f78df30b359/CA1989_Transitions_Guidance.pdf

⁷⁶ https://assets.publishing.service.gov.uk/media/630623bdd3bf7f3660de63da/Promoting_the_health_and_well-being_of_looked-after_children_August_2022_update.pdf (page 31)

⁷⁷ <https://www.jrf.org.uk/neighbourhoods-and-communities/relational-public-service-can-tackle-hardship-in-neighbourhoods>

⁷⁸ https://www.birmingham.gov.uk/info/50287/other_adult_care_services_and_support/1400/preparation_for_adulthood/3

⁷⁹ For example: see work in Wandsworth <https://coramvoice.org.uk/for-professionals/bright-spots/resource-bank/specialist-emotional-health-workers/>

Appendix 2

Selected Law and Guidance

The Children Act 1989, regulations and guidance - Volume 3: planning transition to adulthood for care leavers

‘The responsibilities of local authorities to prepare pathway plans and support care leavers as they make the transition to adulthood apply irrespective of any other services being provided for them, for example, because they are disabled’⁸⁰

(Vol 3: planning transitions to adulthood for care leavers)

- Local authorities’ responsibilities towards disabled care leavers are the same as for all other care leavers.
- Because of their additional needs, some young people may draw on several services, receive support from several professionals and have multiple plans. The local authority must ensure that these processes are streamlined as much as possible, and roles and responsibilities discussed with the young person and their carer(s).
- Each disabled young person will have their own individual aspirations, hopes, needs and wants. Whilst different services will have their own eligibility and access criteria, they must work together to adopt a holistic approach based on assessment of individual needs informed by each young person’s wishes and feelings.

The Care Act (2014) and Care Act statutory guidance

The Care Act 2014 and the Care Act Guidance⁸¹ applies to care for disabled adults, but it also contains provisions to help ensure that a disabled young person’s transition from children to adult’s social care services goes smoothly. Although support under the Care Act 2014 is not granted until a person turns 18, the local authority will need to assess in advance of this date, whether a disabled young person in transition to adulthood is likely to have needs for care and support (‘eligible needs’: arising from a physical/mental disability or illness meaning they are unable to achieve 2 or more specified outcomes and consequently there is an impact on their well-being) after becoming 18 and, if so, what those needs are likely to be.

The Act does not specify an age when this should take place, but guidance says that transition assessments should be carried out in a reasonable timescale and local authorities should keep the young person informed.

There is a duty on local authorities to provide an independent advocate to facilitate the involvement in the transition assessment where the person in question would experience substantial difficulty in understanding the necessary information or in communicating their views, wishes and feelings – and if there is nobody else appropriate to act on their behalf.

Local authorities must not allow a gap in care and support when young people move from children to adult services.

Paragraph 12 of Chapter 16 says that for care leavers, local authorities should consider using the statutory pathway planning process as the opportunity to carry out a transition assessment where appropriate.

Special Educational needs and Disability code of practice 0-25 years (2015)

The Special educational needs and disability code of practice 0 to 25 states⁸² that for young people with an education, health and care (EHC) plan the local authority should ensure the transition to adult care and support is well planned. Local authorities must ensure that the EHC plan review at Year 9, and every review, thereafter, includes a focus on preparing for adulthood.


⁸⁰ <https://www.gov.uk/government/publications/children-act-1989-transition-to-adulthood-for-care-leavers>


⁸¹ <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>


⁸² <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>








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Coram Campus
41 Brunswick Square
London WC1N 1AZ
Tel: 020 7833 5792

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