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getting young voices heard



Disability, Disparity & Demand

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

**Dr Claire Baker & Linda Briheim-Crookall
October 2024**



In Brief

Findings in brief

- Local authorities record that 11% of children in care and 13% of care leavers have a disability, but there is lots of variation between local authorities.
- When you ask care leavers direct 27% say they have a disability or long-term health condition and the percentage is increasing.
- Both professionals and young people think that disabilities come in many forms and not all young people get the help they need.

Recommendations in brief

- Make better use of and improve the data held on children in care and care leavers with disabilities.
- Be curious and listen to children and young people about their disabilities and how they affect them.
- Use the data and what children and young people report to design services that are better able to meet their needs, including building staff confidence, skills and understanding of disabilities and long-term health conditions.



Introduction

Good quality data can help us understand the needs of disabled children in and leaving care. Yet it can be hard to find.

This insight paper

Summarises what we found from



Freedom of Information request sent to all local authorities in England.



The views of young people and leaving care professionals views.

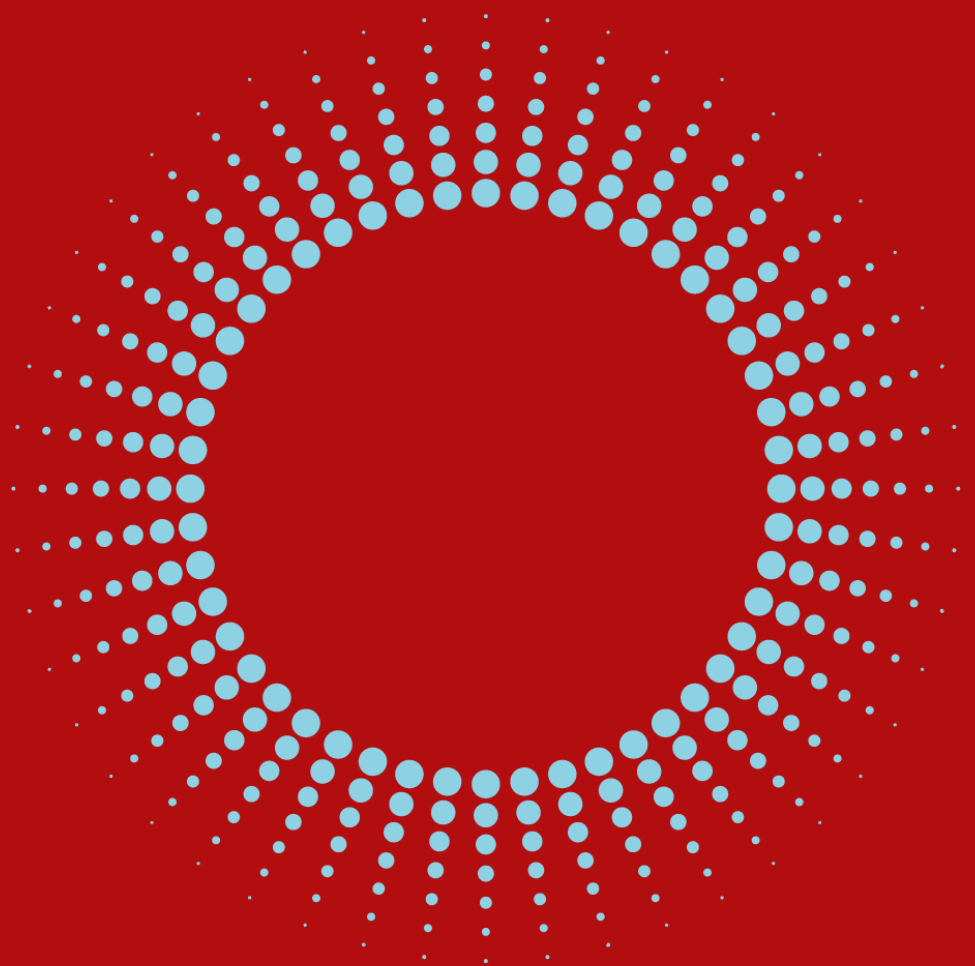


The learning from Coram Voice [Bright Spots Programme](#) and advocacy services.

Discusses

What we do, and importantly do not, know about disabled children in and leaving care, exploring:

1. What does 'disability' mean to children, young people and professionals.
2. Numbers of children in care and care leavers who are 'disabled'.
3. Experiences of disabled children in care & care leavers.



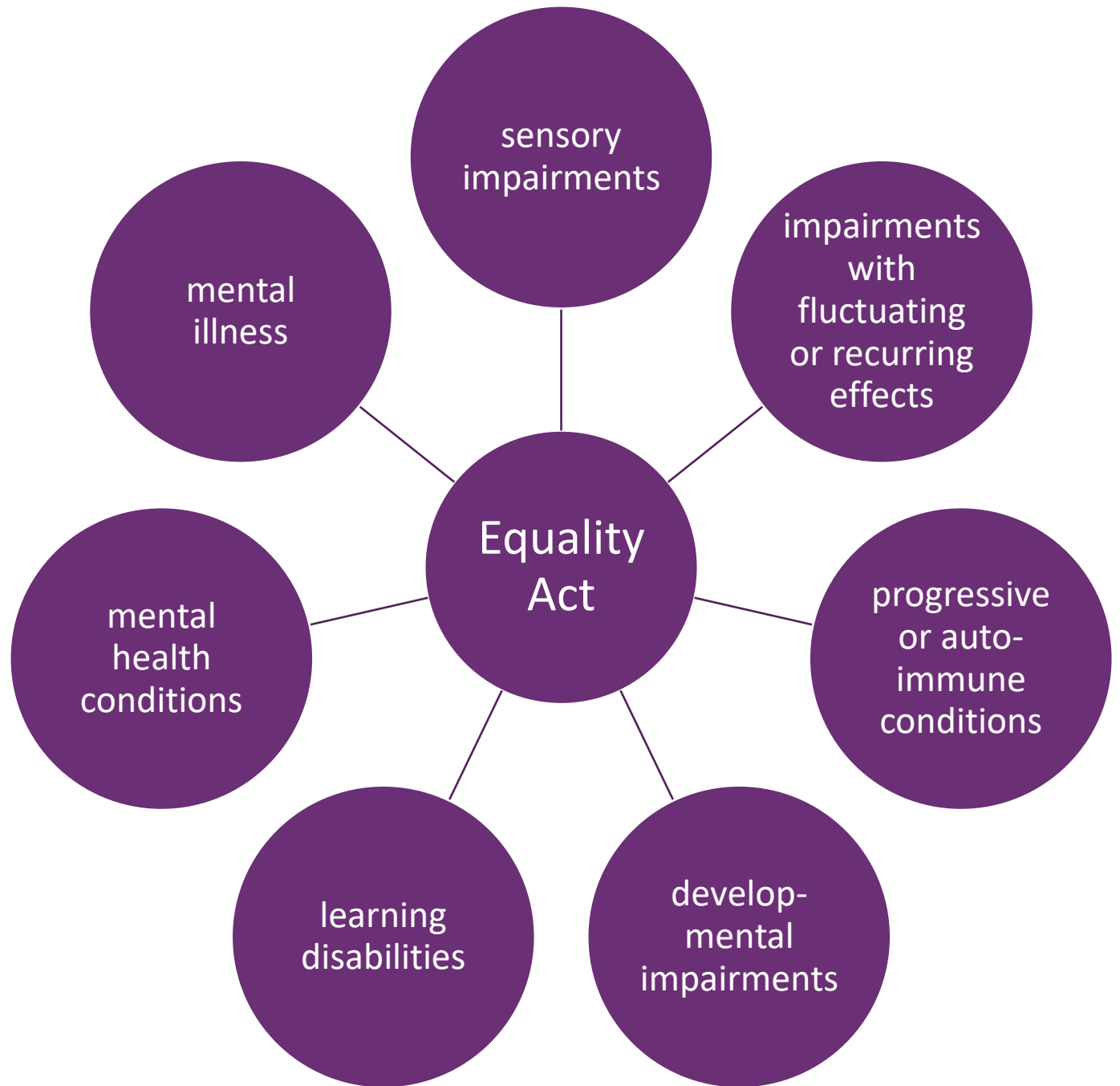
Defining 'disability' is not simple. It includes impairments, but also effects from social, cultural, economic and physical environments.

We found that there are often similarities in the challenges highlighted by young people and professionals, but also that different services and people talk about disability in different ways.

Some approaches focus more on what's wrong with the person and how to fix it (medical model), others on what's wrong with society, e.g. how attitudes and physical barriers disable people (social model).



You are disabled under the Equality Act 2010ⁱ 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.



What does 'disability' mean to you?

How care-experienced young people view disability

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.

Things in day-to-day life can make the disability more difficult – like access to transport or finding an accessible toilet.

Everyone has needs of some kind - no one is 'normal.'

We held a workshop with 18 care experienced young people to discuss

'What does 'disability' mean to you?'

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.*"

Sometimes having a disability means you get additional financial support.

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.

Professionals' views on disability

Defining disability

We held a workshop with over 100 practitioners and managers who work with care experienced young people to discuss: *'what does 'disability' and 'long-term health problem' mean to you / your service?'*



- **Some 'disabilities' are more 'clear-cut' or 'easier to define'** – so work tended to focus on physical health or learning impairments where the need for ongoing support or adaptations appeared more obvious.
- Some disabilities are **not always visible**. Some less understood e.g. neurodiversity.
- Some professionals reflected on the association between **experience of trauma and disability**.
- A **'label' or 'diagnosis' may not tell you very much**
- How disability was defined in local authorities is inconsistent

Professionals' views on disability

Lack of information and knowledge

- Many felt that **disability was often not a specialism in leaving care** – gaps in knowledge, lack of confidence.
- There is **limited data and information on disability** in leaving care services.
- Services **don't tend to record or ask young people their views** on disability.



We don't have a good understanding of neurodiversity or how our services need to be shaped to support young people to thrive.

(Professional working with care leavers)

No idea where in our records we could pull disability data if asked. Not recorded in plans (Professional working with care leavers)

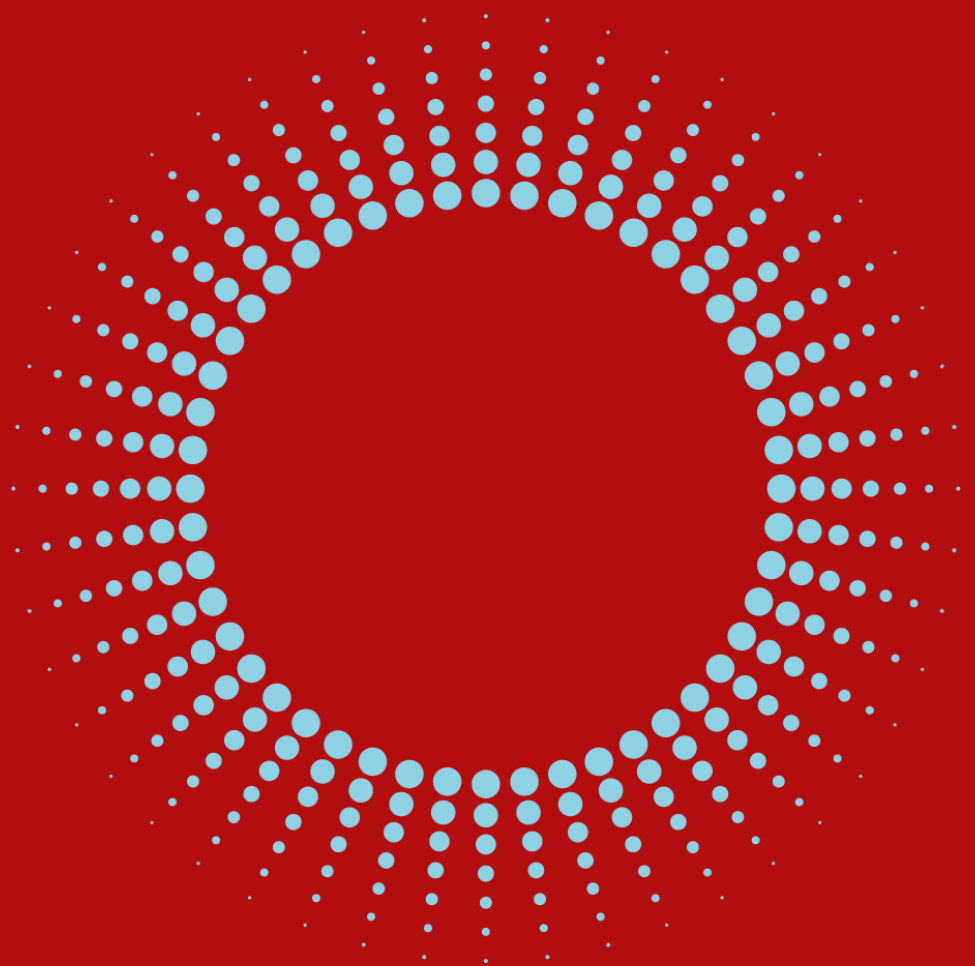
Professionals' views on disability

Addressing the needs of disabled care leavers

- There is a **disconnect between children's services and adult services** - eligibility for these services could be 'unclear and fluid' with some care experienced children accepted and others unable to access support.
- **'Everything is a fight'** – it could be difficult for leaving care services to get the right support needed for their disabled young people.
- A lack of resources could lead to rationing – some care experienced 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**



Take away 'tick-boxes' and be needs led – confidence in moving away from tick boxes.
(Professional working with care leavers)



To uphold the rights of disabled children and care leavers we must know who they are.

The absence of accurate information impacts on the development of services to effectively meet the needs of children and young people.

No national data is published on proportion of children in care and care leavers with a disability.

To address this gap we sent a Freedom of Information request (in October 2023) to all 153 English local authorities

Freedom of information findings

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



We asked local authorities to tell us more about what was recorded on their Children Social Care management information systems, specifically the:

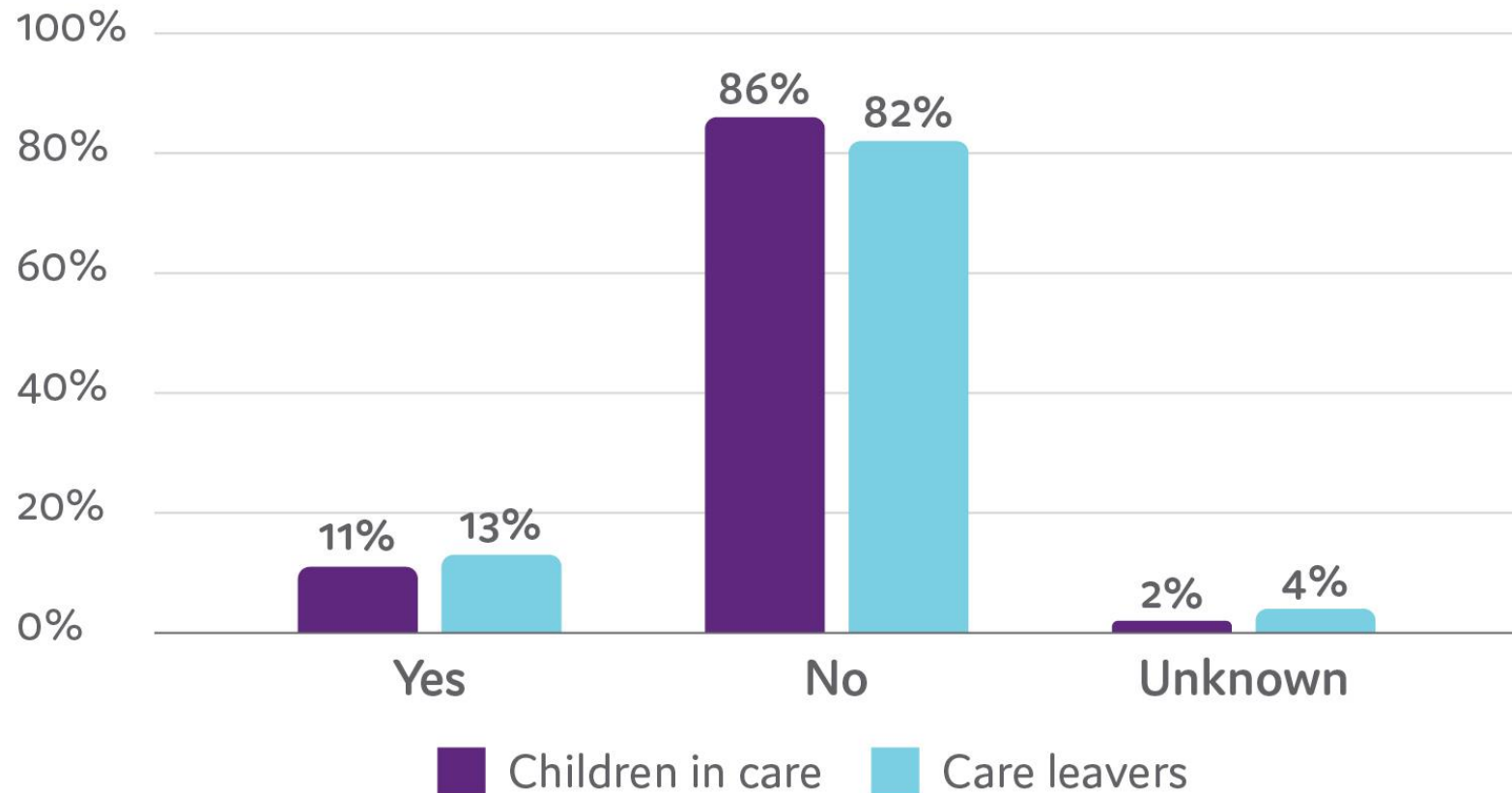
- number of children in care with a disability
- number of care leavers with a disability
- the number of children in care with different 'types of disability'
- the number of care leavers with different 'types of disability'

NB: Children in Need census instructs local authorities to collect information on disability for all children in need and looked after children – it lists 'types of disabilities' to be recorded.

Freedom of information findings

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

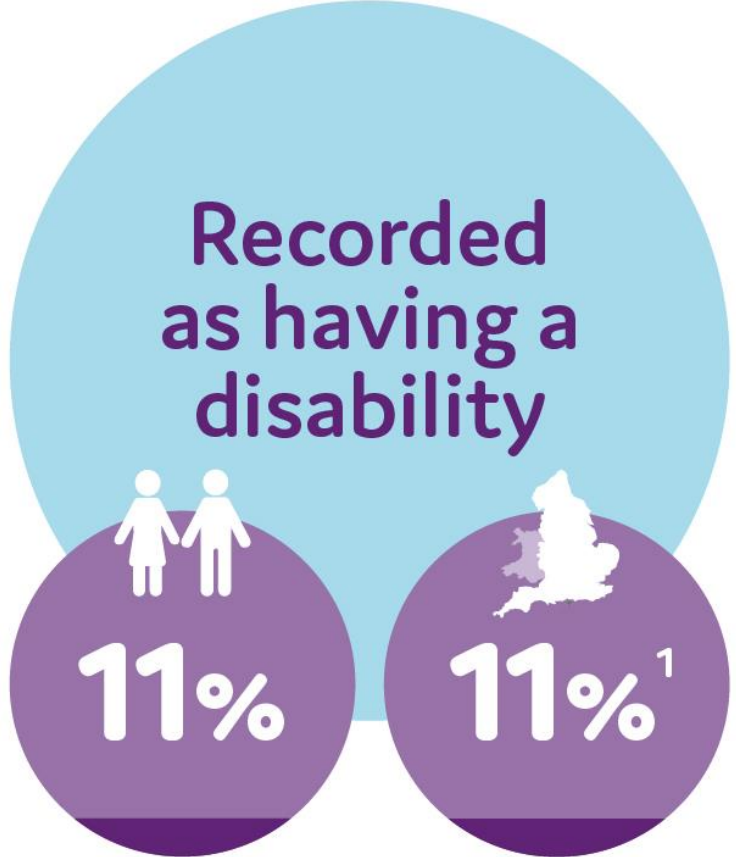
Percentage of children in care and care leavers recorded by local authority to have a disability



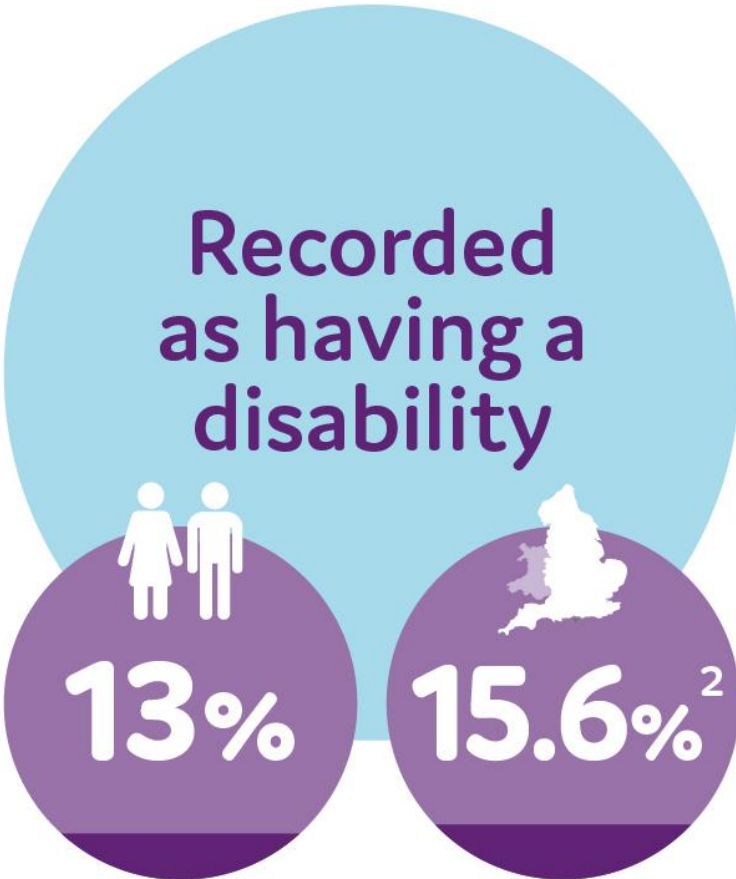
Most local authorities could provide the information, but for a small proportion the information was recorded as 'unknown' (e.g. this data was not available for around 1 in 20 care leavers).

Freedom of information findings

Rates of disability



¹ UK disability statistics: Prevalence and life experiences (2023)



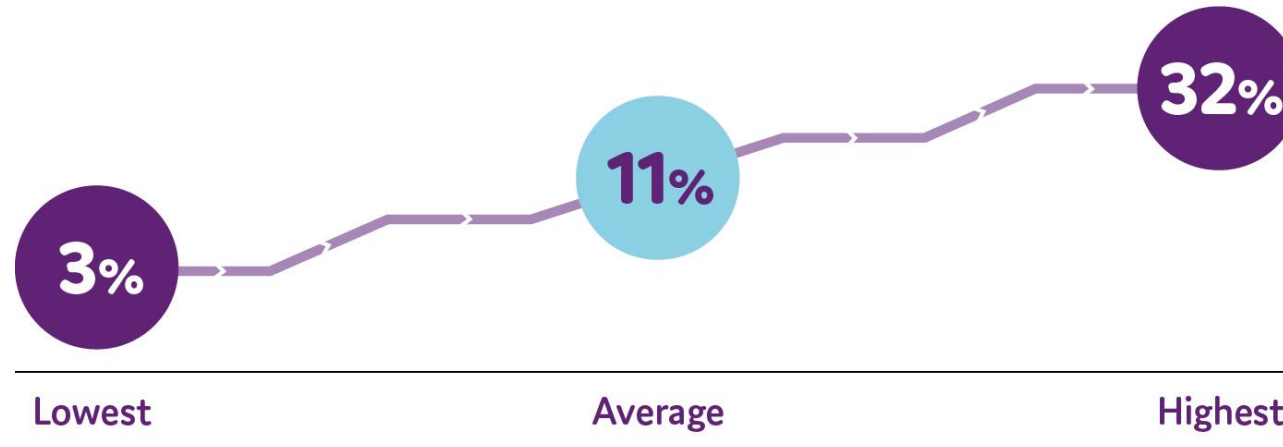
² ONS - Young Peoples Wellbeing Measures (2020)

Freedom of information findings

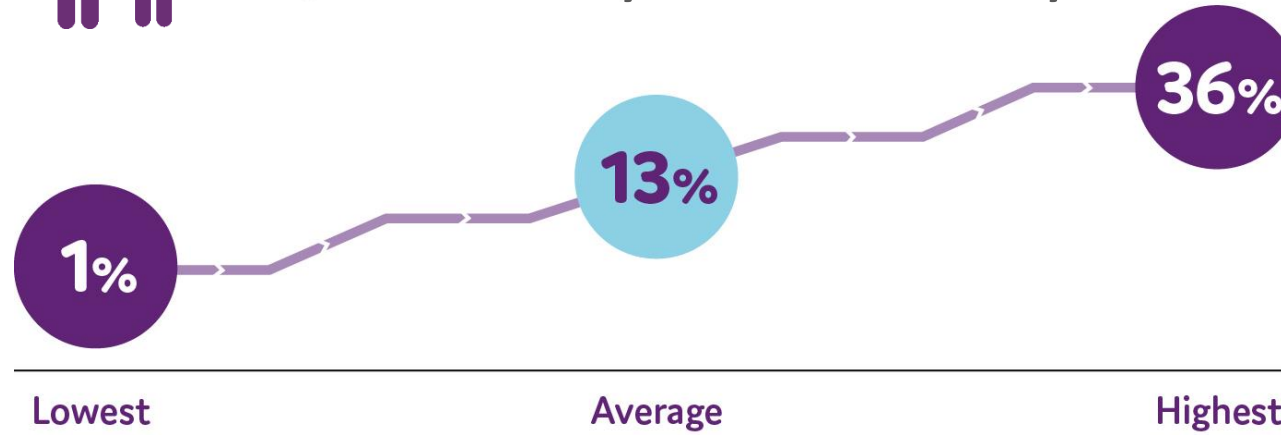
Variation



Percentage of children in care who were reported to have a disability in a local authority



Percentage of care leavers who were reported to have a disability in a local authority



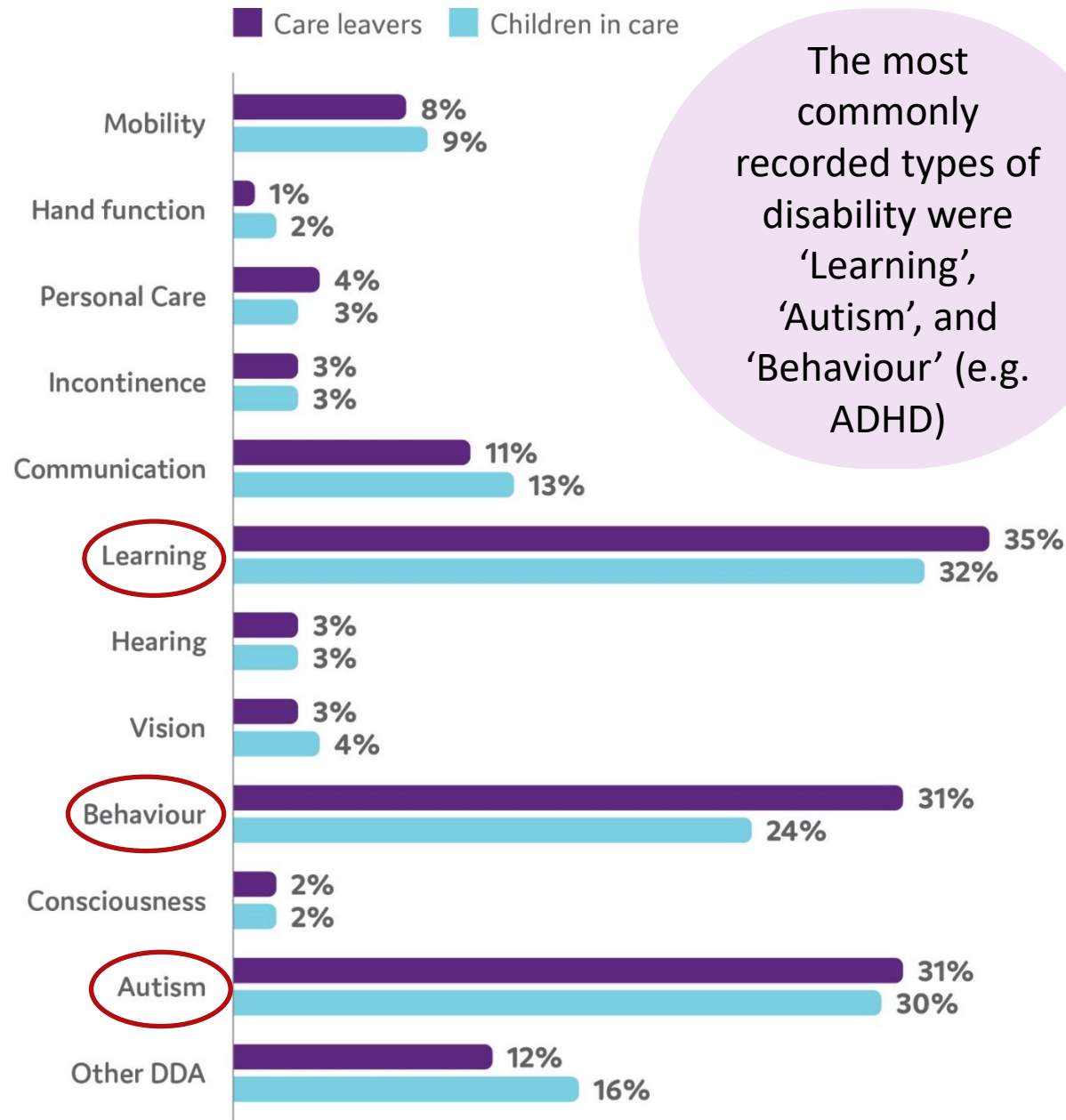
There was variation across local authorities:

- The lowest proportion of **children in care** recorded with a disability was 3% and the highest was 32%
- The lowest proportion of **care leavers** recorded with a disability was 1% and the highest was 36%

Freedom of information findings

Types of disabilities

(Children in care & care leavers recorded by LA with a disability by types of disability)



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

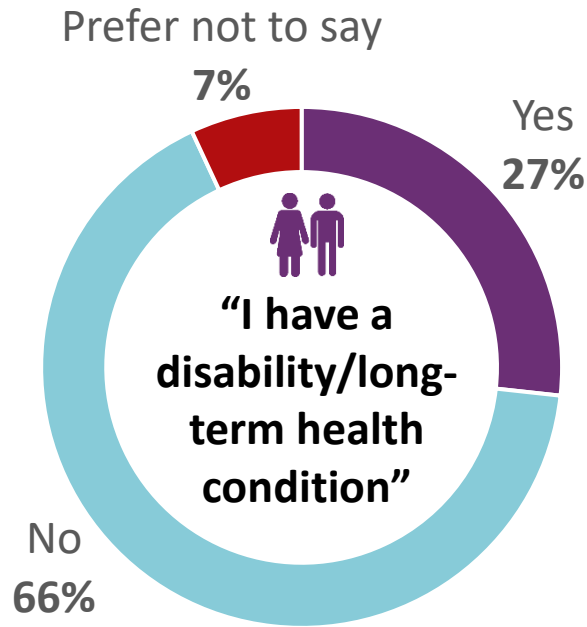
'Type of disability' categories come from the Children in Need census.ⁱⁱ Guidance details different 'disability codes' and instructs LAs to record all relevant disabilities that have affected the child i.e. children can have multiple disabilities, so more than one category can be selected.



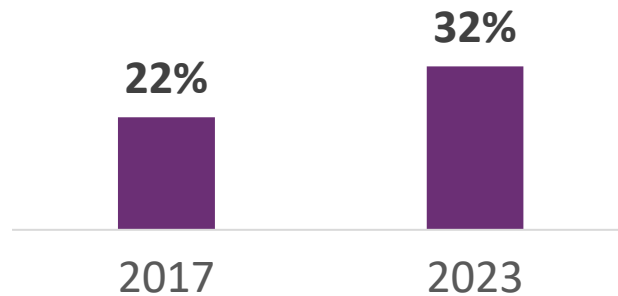
The data from local authorities is based on professionals' recording, not the views of young people themselves

Bright Spots findings

Asking care leavers directly about disability



 Percentage of care leavers who reported having a disability



- Just over a quarter (27%) of care leavers reported that 'yes' they did have a disability/long-term health condition; about two-thirds said 'no' and a small proportion (7%) answered 'prefer not to say'*

The proportion of care leavers self-reporting disability in the Bright Spots Programme has increased over time: 22% in 2017 up to 32% in 2023

*data based on 8,245 responses from 83 *Your Life Beyond Care* surveys conducted in 48 Local authorities in England, Scotland & Wales (2017 to 2024)

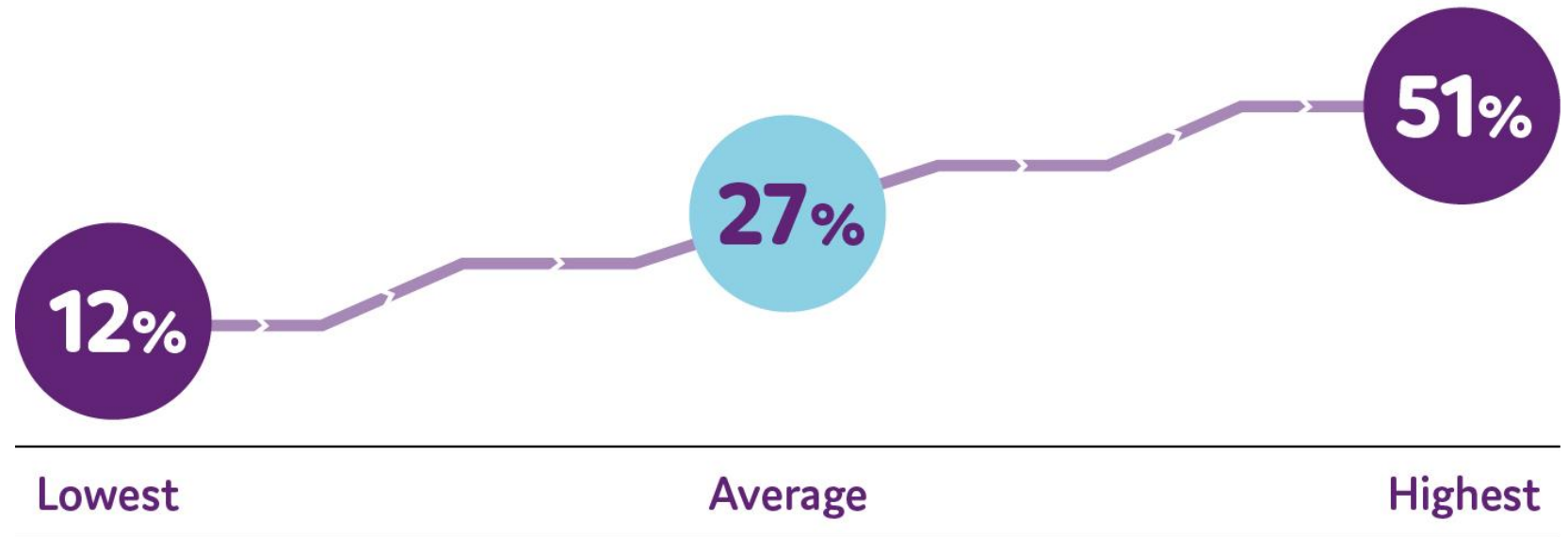
Bright Spots findings

Variation

Looking across the different LAs there was variation in the proportion of care leavers reporting disability – the average was 26%; the lowest 12% and the highest was 51%.



Percentage of care leavers who self-reported disability or long-term health problem in a local authority (Bright Spots survey data)



Bright Spots findings

‘If you want to, please tell us more about your disability or health problem’

- In 2023 we introduced a new question to the Bright Spot care leaver survey
- Responses from 10 local authorities were analysed.
- Nearly 300 (n=270) young people shared their thoughts and feeling

- It was rare for a young person to write just one disability.
- Autism was among the most frequently reported disability by both care leavers and local authorities.
- Mental health problems, which were among the most common types of health problems and disability reported by care leavers, were not recorded in local authority statistics.



Behind the numbers



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

“I have epilepsy and Autism and this can prevent me from some daily tasks.”

“I have severe mental health issues and some physical disabilities.”

“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.”

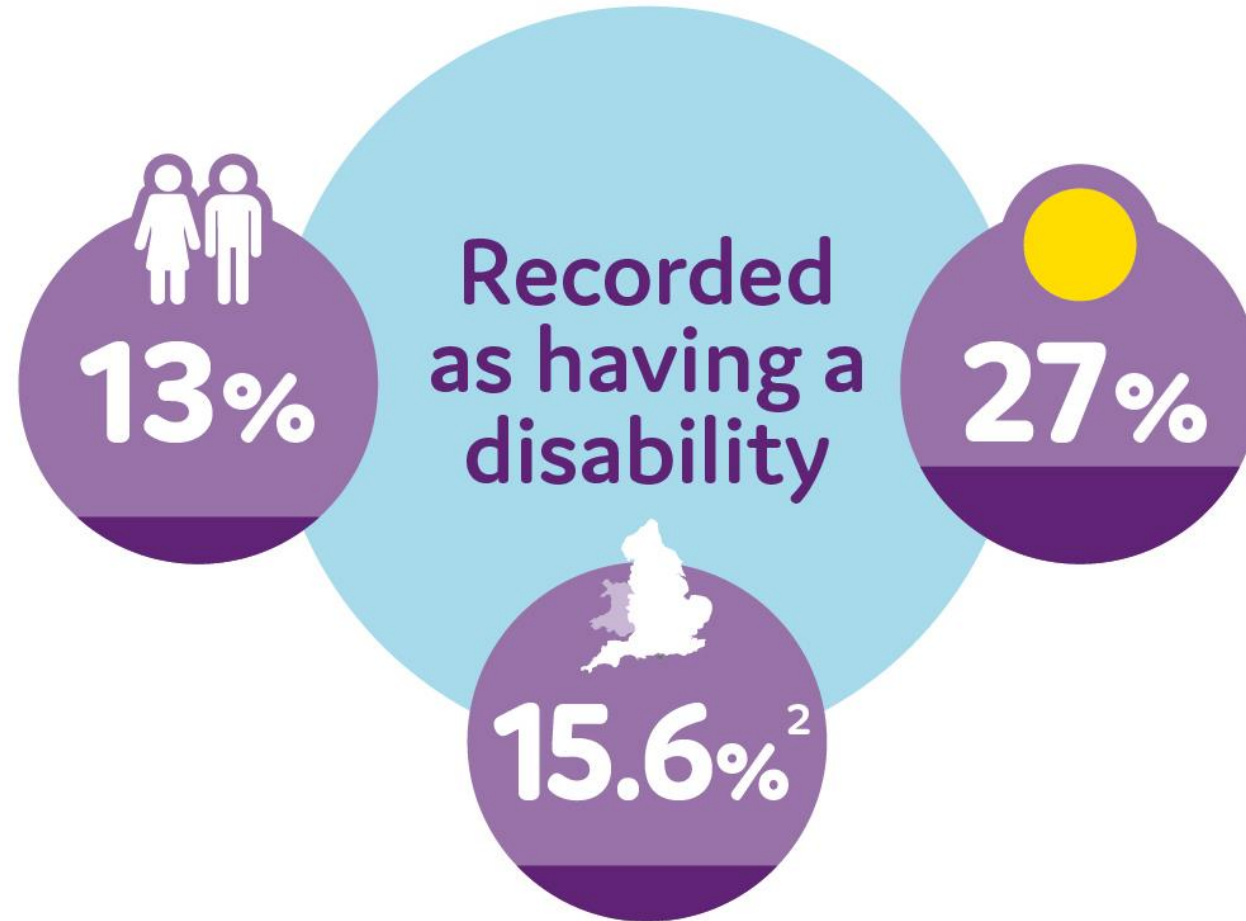
“I have PTSD which makes my day to day life a real struggle dealing with voices and flashbacks.”

“I have fibromyalgia and chronic fatigue syndrome.”

“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 leavers

Comparing rates of disability



² ONS - Young Peoples Wellbeing Measures (2020)

Whatever way 'disability' is measured and recorded a large proportion of children and care leavers appear affected. Yet we know very little about how they are doing – existing research provides some insights

Research

How disability impacts on children in care

- Children and young people with a disability are at an increased risk of experiencing abuse compared to children without disability. ⁱⁱⁱ
- Children with disabilities are more likely to be looked after than non-disabled children. ^{iv}
- Children with a disability can have different 'pathways' through care 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 and more likely to experience multiple moves or live in inappropriate placements. ^v
- As a result, they may be more likely to stay in care for longer and become 'care leavers'. ^{vi}
- Whilst in care they may not be supported to stay connected to the people who are important to them (there is evidence they have lower levels of 'contact'). ^{vii}
- Children and young people's views and perspectives may not be routinely sought in matters that affect them. ^{viii}

Research

How disability impacts on care leavers' lives

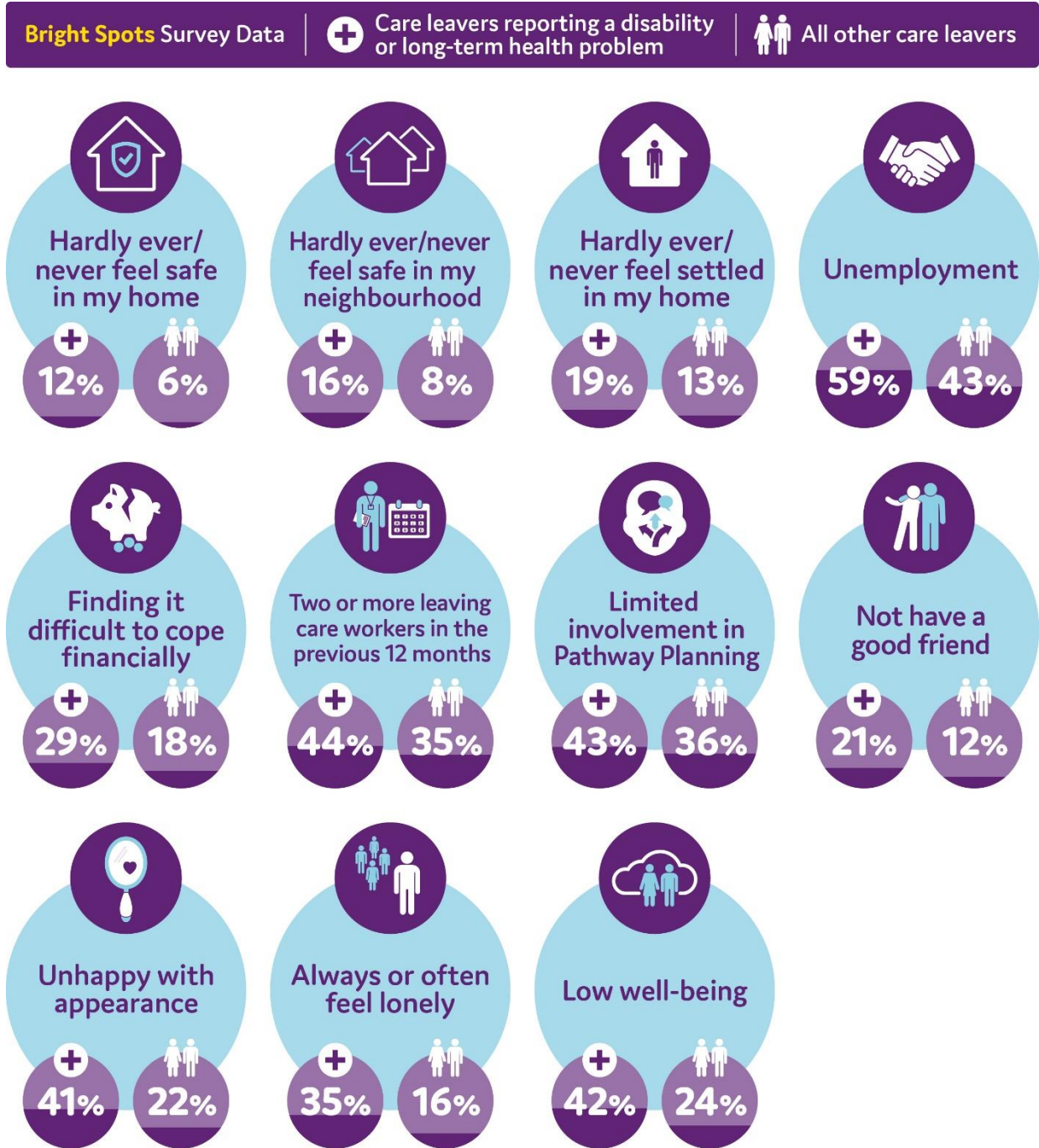
Findings from research focused on disabled care leavers include:

- 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.^{ix}
- Limited options and choice in employment, housing.^x
- In the Bright Spots surveys, care leavers who self-reported a disability or long-term health problem reported lower well-being on a range of measures compared with other care leavers.

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.
(Care leaver, Bright Spots survey)

Bright Spots findings

How do care leavers report that they are doing?



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)

Practice evidence

Challenges in transitions from care

- Law and guidance are designed to ensure children in care with disabilities experience a well-planned, smooth transition from care. But evidence from Coram Voice advocacy services and learning from serious incidents shows not all young people do.
- When we do not get things right for children and young people in and leaving care with disabilities the consequences are serious. It is important to learn lessons from serious incidents to prevent deaths and abuse or neglect happening in the future
- Advocacy case studies and learning from serious incident 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.**

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 Future death* report listed a number of failings from the Children's Services care leavers team. 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 inadequate planning, processes, practice standards, recording and training.^{xi}

Process issues

- Lack of planning or failure to plan
- Drift: decisions made about future planning, but not acted upon

Rights based issues

- Lack of recognition that disabled adults can also be 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 taken into account

Non-person centred approach

- Failure to listen to young people about their wishes
- Lack of appropriate communication with the young people
- Frequent changes of staff or no allocated worker
- Failure to recognise the emotional impact of transition

Challenges in transition from care

Failure to work together

- Poor communication between agencies
- Disagreements about what is in a young person's best interests

Funding

- Difficulties with identifying suitable options for home / college
- Disputes about which service funds what



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

(Care experienced young person)

“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 experienced young person)

“Not all disabilities need a diagnosis and are visible.”

(Care experienced young person)

“Professionals pass us to other workers who can't provide us with the necessary services.”

(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. Professionals did not always feel confident in understanding or responding to these needs
- 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.
- 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 sufficiently met by current services. Leaving care services can struggle to meet the needs of both groups.

Recommendations

- I. **Use existing data better**
- II. **Improve data and knowledge**
- III. **Listen and respond to disabled children in care and care leavers**
- IV. **Build staff confidence, skills and understanding**
- V. **Improve existing services**
- VI. **Address gaps in service provision**

We make 19 specific recommendations for the DfE (DfE), local authorities (LAs), Coram Voice and professionals.

Recommendations

Department for Education

- DfE should publish the disability data already collected as part of the Child in Need Census in the annual looked after and care leavers statistics (looked after data would need to be matched to the CIN census data).
- DfE 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.
- DfE should publish ad hoc statistic or a deep dive one-off 'data pack' on disability and children in care / care leavers.
- DfE 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.
- 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.
- DfE should establish a way to collate promising practice and a programme to test models of effective support for disabled children leaving care.

Recommendations

Local authorities (LAs)

- Local authority leaders should collate and regularly review the disability data already collected to effectively plan and monitor service delivery for children in care and care leavers.
- LAs 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.
- LAs should provide access to advocacy to safeguard the rights of children and young people in care / care leavers with disabilities.
- LAs should provide accessible opportunities for care experienced children and young people with disabilities to influence service improvement.
- LAs 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 i.e. identify training gaps; facilitate access to specialist advice & opportunities to reflect on understanding/assumptions about disability.
- LAs should improve referral pathways for disabled children in care to disability services.
- LAs should ensure that services/policies for children in care and care leavers are accessible and supportive of children and young people with disabilities and address gaps in provision.

Recommendations

Professionals working with children in care and care leavers

- 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)
- 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.

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)

Recommendations

Coram Voice

- Coram Voice should continue to 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.
- 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.

Find out more and contact the team



Email Claire.baker@coramvoice.org.uk



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Visit the [Bright Spots Resource Bank](#) for local authority good practice examples, this and other national reports, publications and much more

References

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