coramVoice
getting young voices heard

Disability, disparity & Demand

Children in care and care leavers with a disability or long-term health condition: numbers and experiences

Dr Claire Baker & Susan Lake
June 2025

Introduction

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

The report

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.

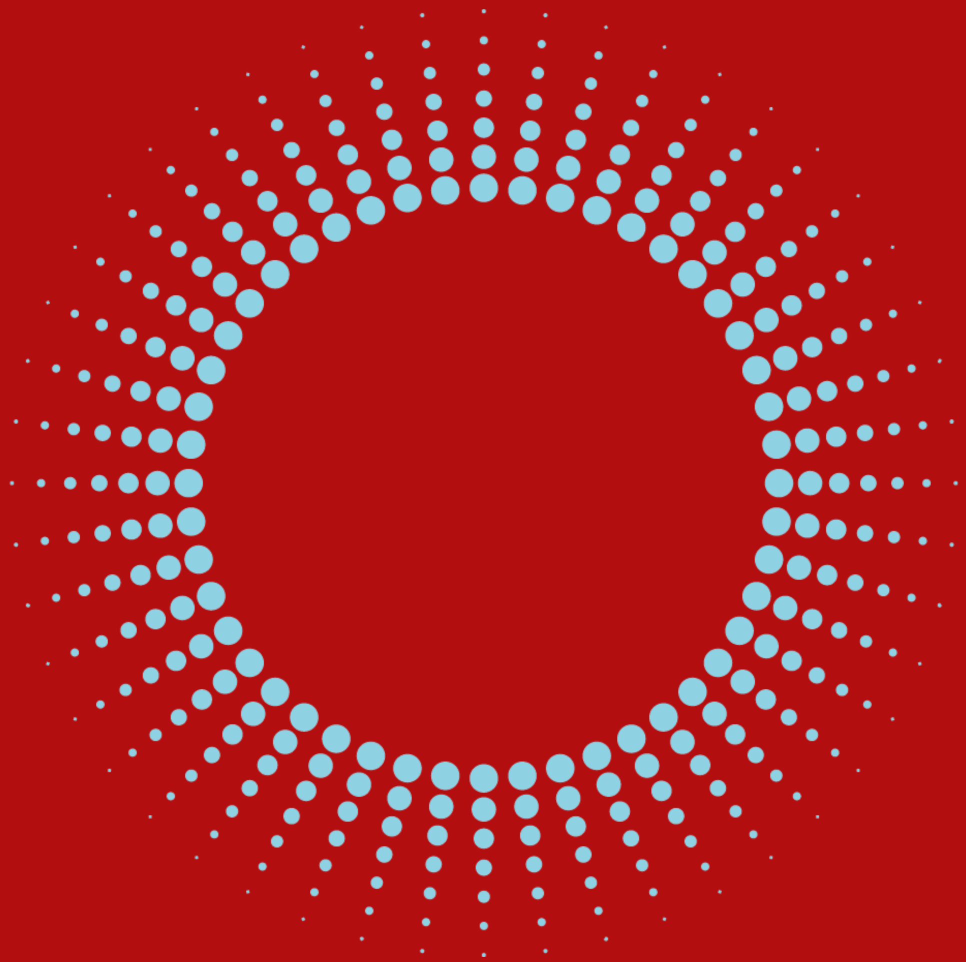
Discusses

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.

Structure of our session together

1. What do we mean by ‘disability’?
2. How many care leavers have a ‘disability or long-term health condition’?
3. Why does it matter? (what do we know about how care leavers with a disability are doing?)
4. What can we do about it? (research recommendations and what does it mean for your work…)

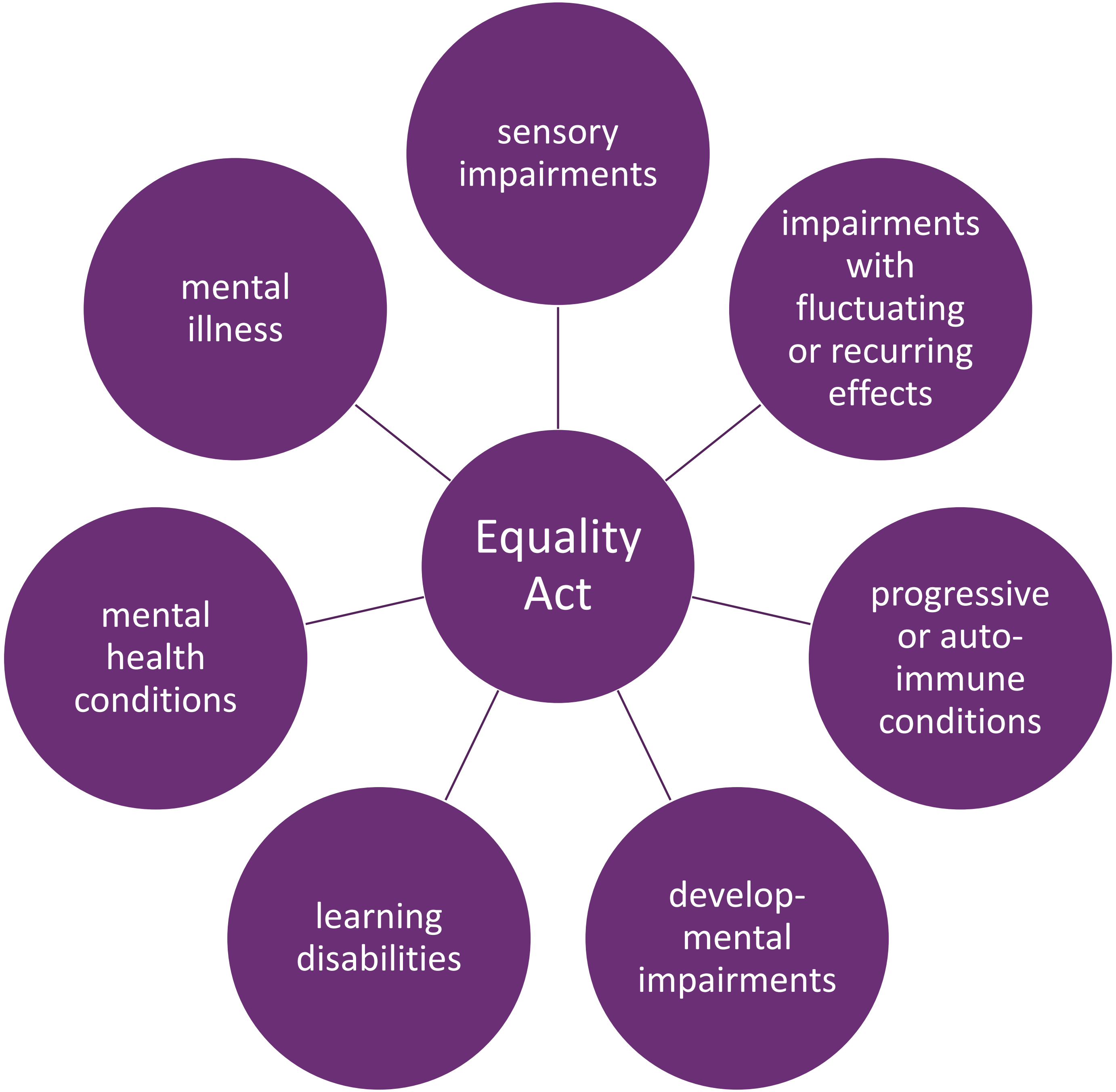


Defining ‘disability’ is not simple. It includes impairments, but also effects from social, cultural, economic and physical environments.

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 2010[i] 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

- sensory impairments
- impairments with fluctuating or recurring effects
- progressive or auto-immune conditions
- develop-mental impairments
- learning disabilities
- mental health conditions
- mental illness

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?’

Sometimes it can be good to have a diagnosis – so people know how to manage their needs (but sometimes there can be ‘mis-diagnosis’)

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.

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

Reflection (1)

‘What does ‘disability’ and ‘long-term health problem’ mean to you / your service?

Can we answer this question…

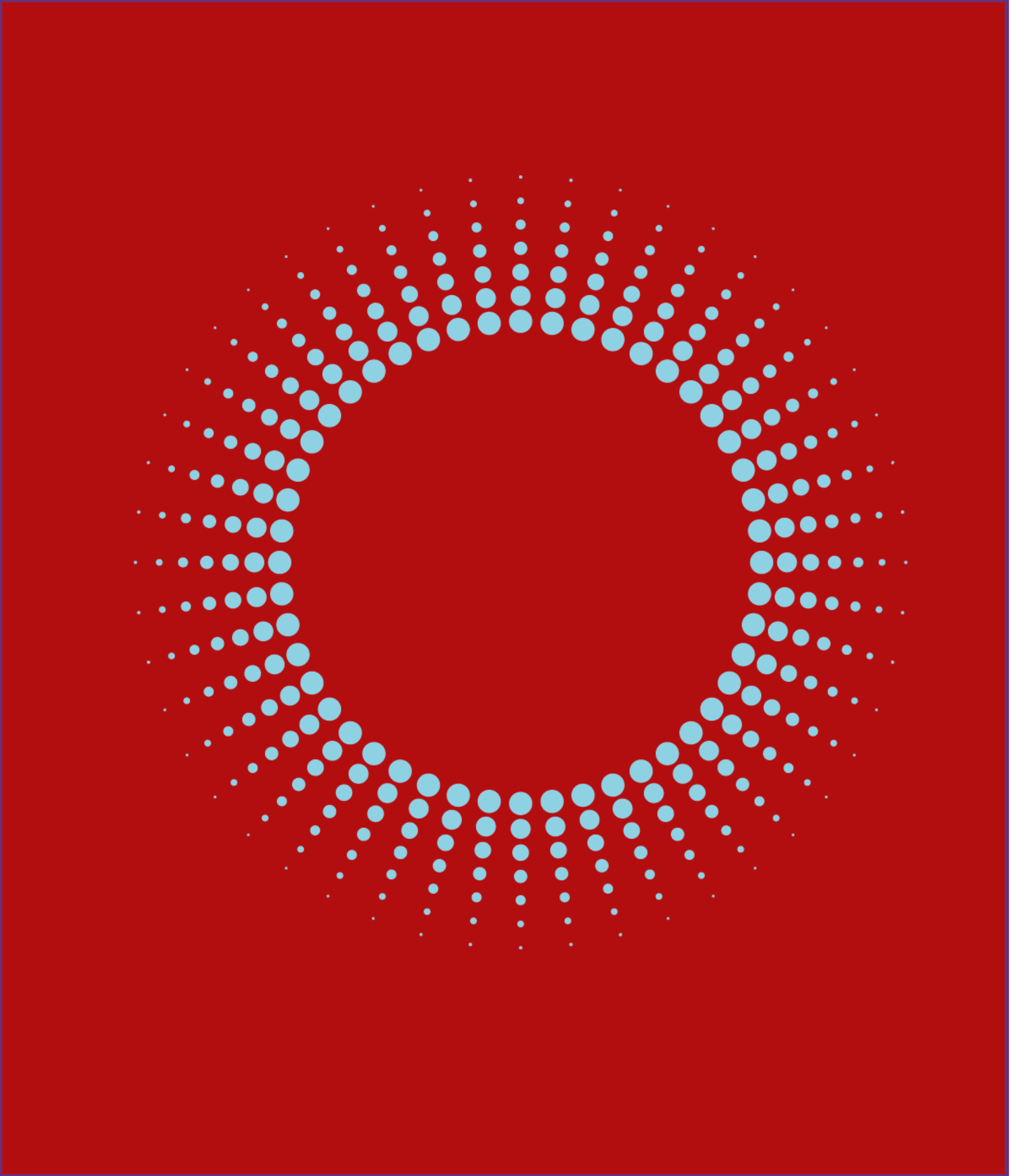
Children looked after on 31 March 2024

83,630

How many children in care and care leavers have a disability or long-term health condition?

Care leavers age 17-25

92,000



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

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 <u>a disability</u>

(SEND data is collected but ‘a child who has been identified as having special education needs is not necessarily disabled for the purposes of the Equality Act’)

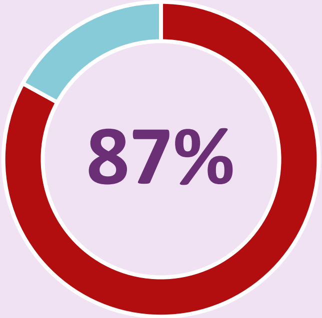
Freedom of information findings

How many children in care and care leavers are ‘disabled’?

We received responses from

133 of **153**

local authorities



about

76,528

children in care

55,222

care leavers

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

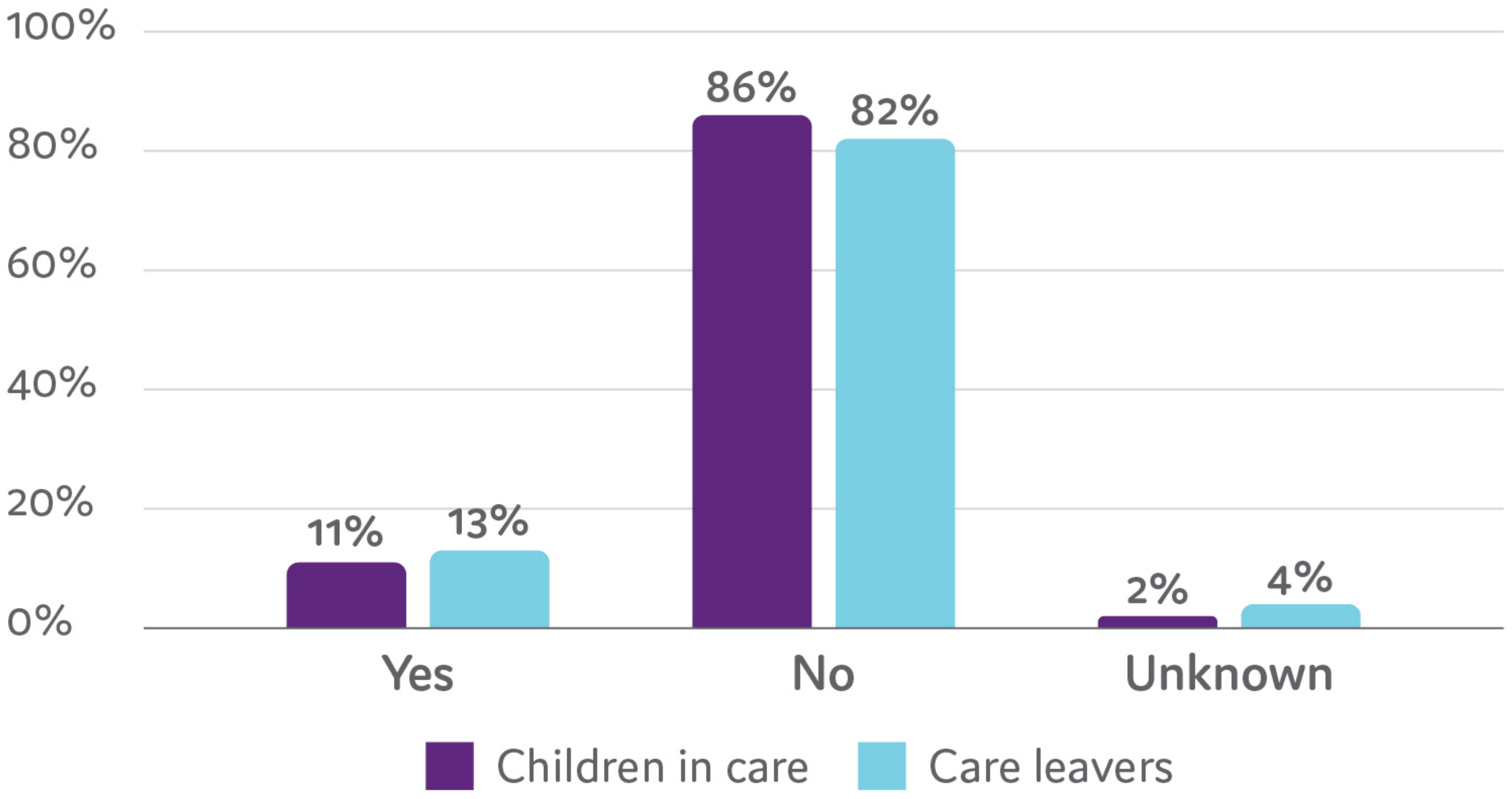
- number of children in care with a disability
- number of care leavers with a disability
- the number of children in care with different ‘types of disability’
- the number of care leavers with different ‘types of disability’

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'?

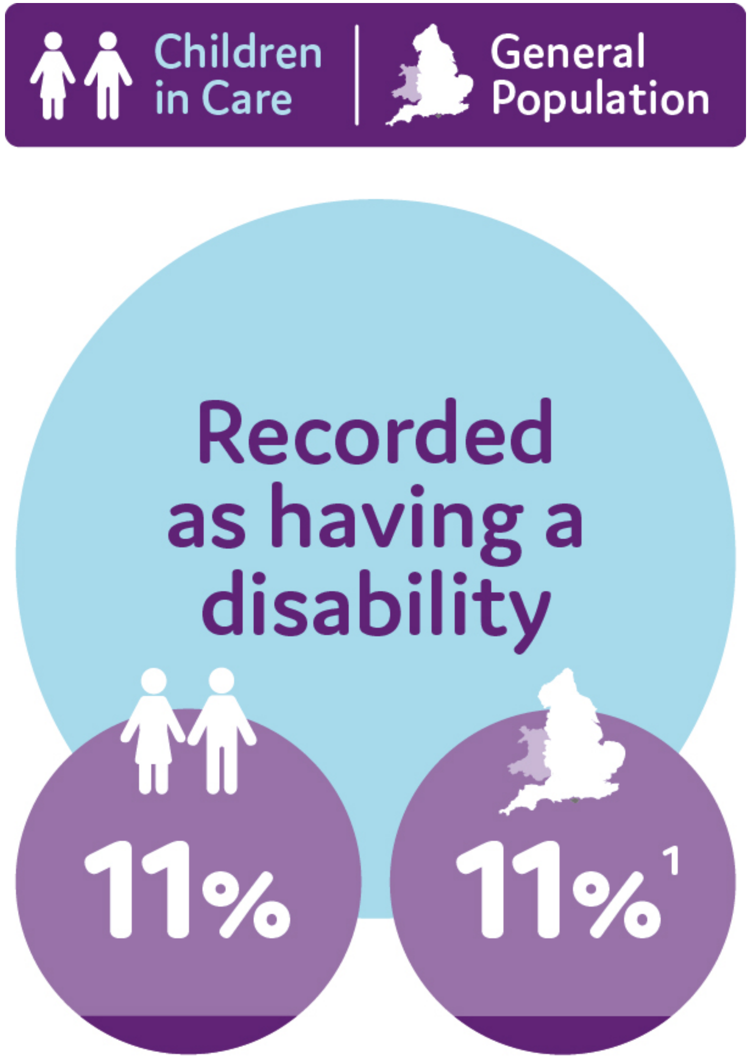
Percentage of children in care and care leavers recorded by local authority to have a disability



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



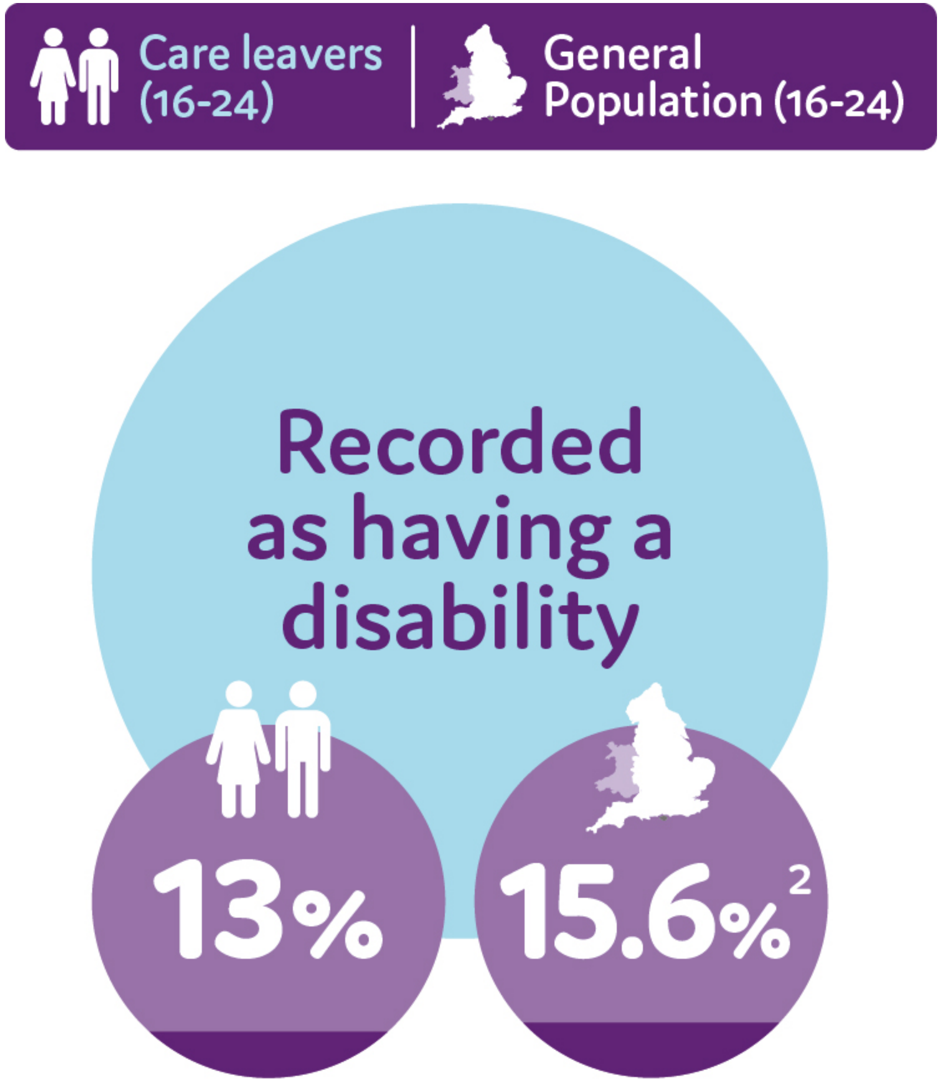
Children in Care | General Population

Recorded as having a disability

Children in Care: 11%

General Population: 11%[1]

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



Care leavers (16-24) | General Population (16-24)

Recorded as having a disability

Care leavers (16-24): 13%

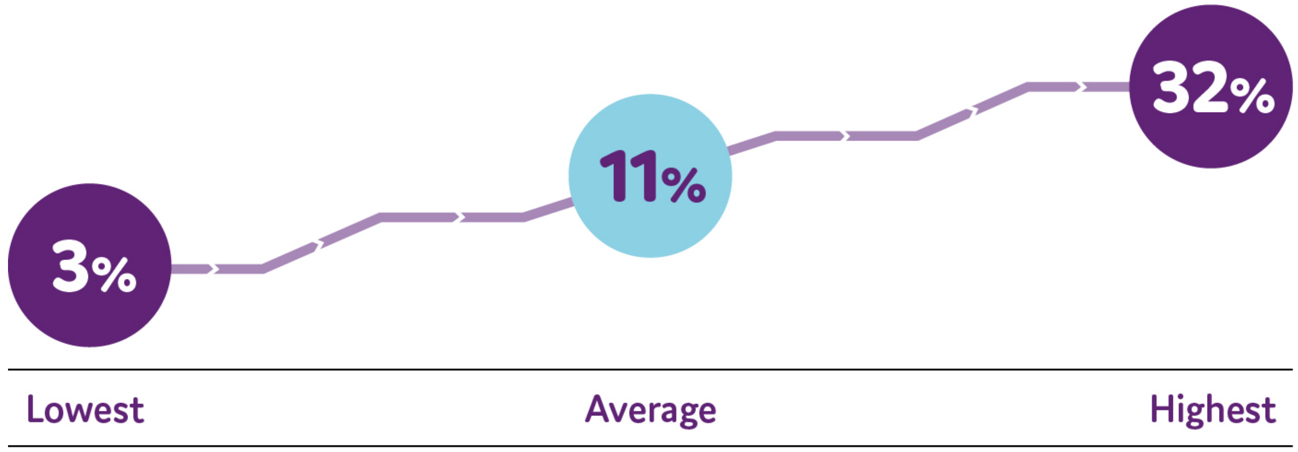
General Population (16-24): 15.6%[2]

[2] ONS - Young Peoples Wellbeing Measures (2020)

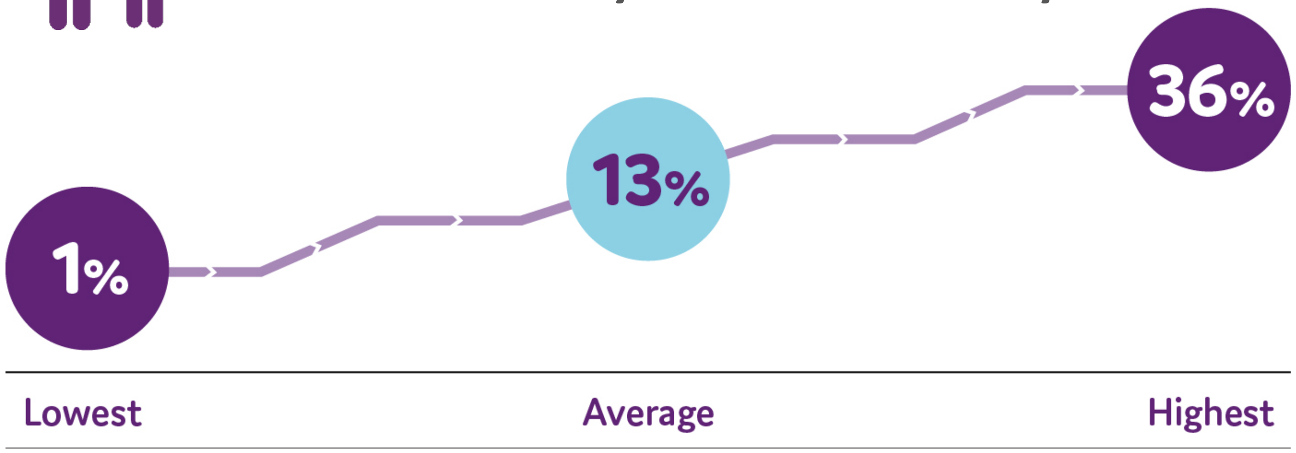
Freedom of information findings

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

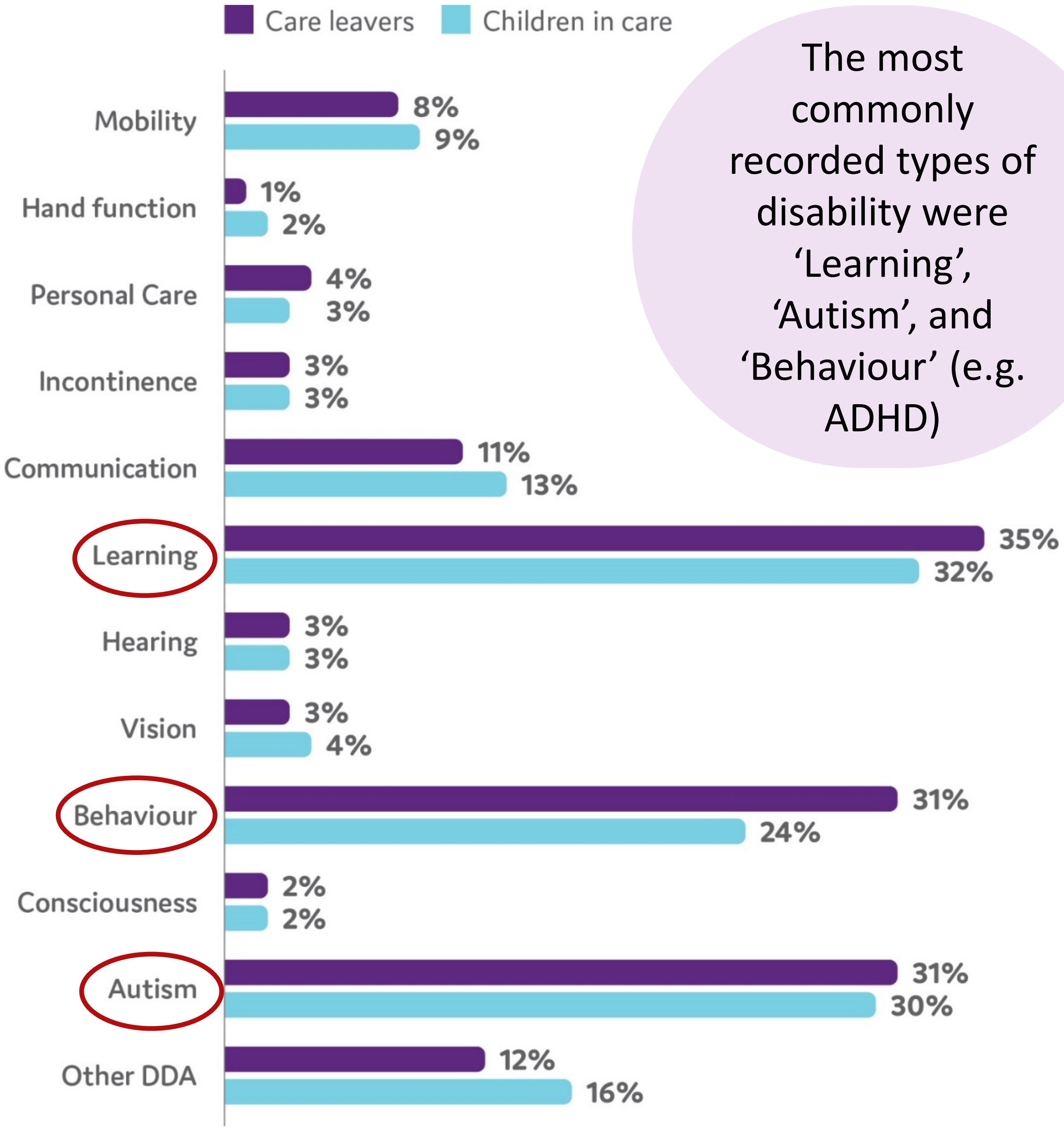


There was variation across local authorities:

- 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



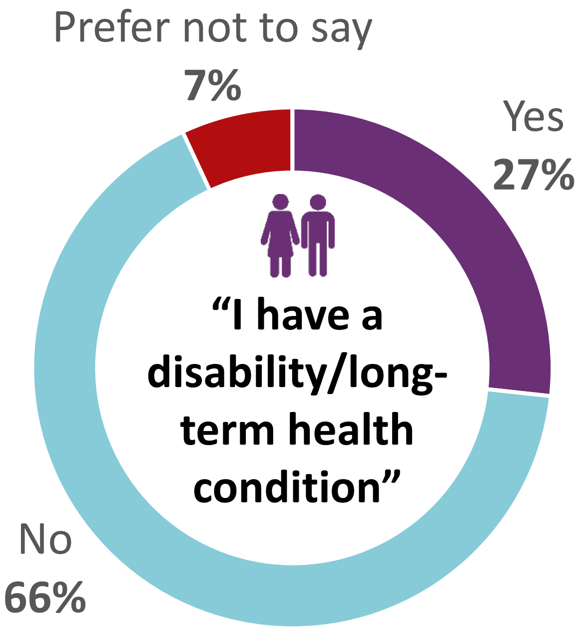
The most commonly recorded types of disability were 'Learning', 'Autism', and 'Behaviour' (e.g. ADHD)

'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.

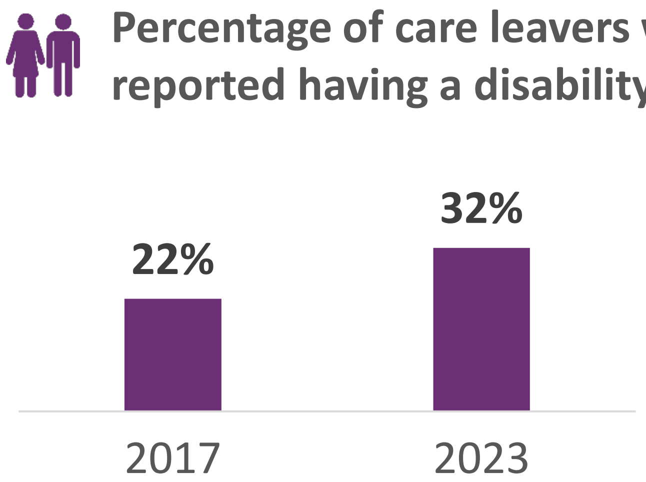
The data from local authorities is based on professionals' recording, not the views of young people themselves

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

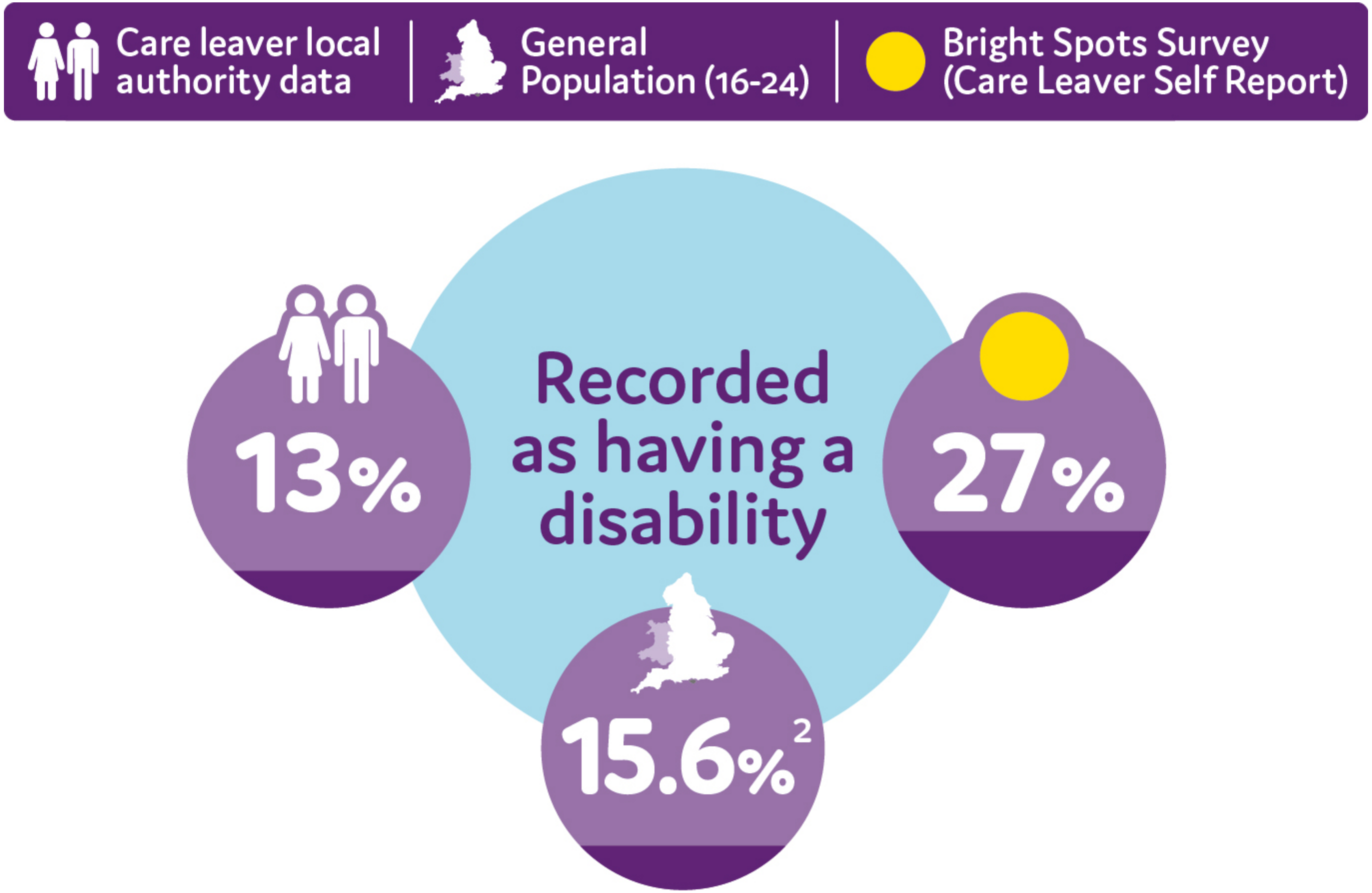
‘If you want to, please tell us more about your disability or health problem’

- 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.

Care leavers

Comparing rates of disability



Care leaver local authority data | General Population (16-24) | ● Bright Spots Survey (Care Leaver Self Report)

Recorded as having a disability

13%

15.6%[2]

27%

[2] ONS - Young Peoples Wellbeing Measures (2020)

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 (and 'disability codes' are inline with Equality Act).

Reflection (2)

How does your service record data about ‘disability’?

Are young people’s voices included in the data your service records about disability?

How do you use what is recorded?

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.
- Children with disabilities are **more likely to be looked after** than non-disabled children.
- 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.
- As a result, they may be more likely to stay in care for longer and become ‘care leavers’.
- 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’).
- Children and **young people’s view**s and perspectives may not be routinely sought in matters that affect them.

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.
- Limited options and choice in employment, housing.
- 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)*

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)

Behind the numbers

We will now listen together to Susan’s blog

Disability in the care system: the struggle for young people to access diagnosis and support

Growing up in care with multiple disabilities was extremely challenging. I did not speak or smile at aged two and was described as “depressed” by my family social worker. At four, another social worker queried whether I might have autism, but it was claimed ‘girls don’t have that’. When I was 11, my older brother was diagnosed with autism, and when I read the paperwork, it summed me up; I knew then that I was autistic. I also have a condition called **Ehlers-Danlos Syndrome** which causes mobility issues and something as simple as picking up my school bag could lead to a dislocated shoulder and land me in A&E.

https://corambaaf.org.uk/updates/disability-care-system-struggle-young-people-access-diagnosis-and-support

At 12, I suffered a traumatic brain injury. I fell off a friend’s shoulders, breaking my skull, and cerebellar ataxia followed. Whilst I re-learnt to walk with crutches for a short period, I am now a full-time wheelchair user with a visual impairment. I went into care at 14. I was always going to be vulnerable due to my brain injury, but this was not always taken seriously by the professionals at my residential care home. To ‘help’ me recover from my fear of sitting on other people’s shoulders, one of the staff sat me on his shoulders in a local park. I fell backwards and hit my head in a different area from my previous break.

While in the residential care home I was diagnosed with mixed anxiety and depressive disorder, anorexia, and complex post-traumatic stress disorder but I was never supported to understand what my needs were and how they might impact my life. I finally asked to be assessed for autism. It had been picked up by multiple professionals, including the manager of the children’s home and some teachers at the new school. However, CAMHS refused to assess me. They said that because I was in care, I could be moved at any point whilst on the waiting list and couldn’t guarantee I would still be living in the same area. CAMHS said I would have to wait until I was 18 to be put on the adult waiting list. My social worker should have fought for me at that point, but nothing happened.

At 16, I broke down. I had an anorexia relapse, and I was having daily ’episodes’, which I now know to be autistic meltdowns. The residential home placed me on a behaviour plan, which stated that if I had more than two ‘episodes’ a week, I failed. If I had more than four failures in three months and I would lose my place at the residential home. Well, I lost my place. I felt that the care system couldn’t handle my disabilities.

I was then moved to a homeless YMCA hostel that also failed to manage my disabilities. I needed to use the lift, but it was only in operation after 8am when I needed to leave the hostel at 7:30am to get to school on time. As a consequence, I was late for school every day and I was kicked out of the hostel within 26 days. Without support, I went on to fail all but two of my GCSEs and all my A Levels.

I finally received a late diagnosis of autism at the age of 21 and went on to do an access to higher education course to get into university to study International Relations. Thanks to the diagnosis, I now receive specialist support from an autism-trained mentor twice a week which helps me stay on track with my studies.

Sadly, my story as a young person with disabilities, struggling to access diagnosis and support in the care system, is far from unique.

Practice evidence

Challenges in transitions from care

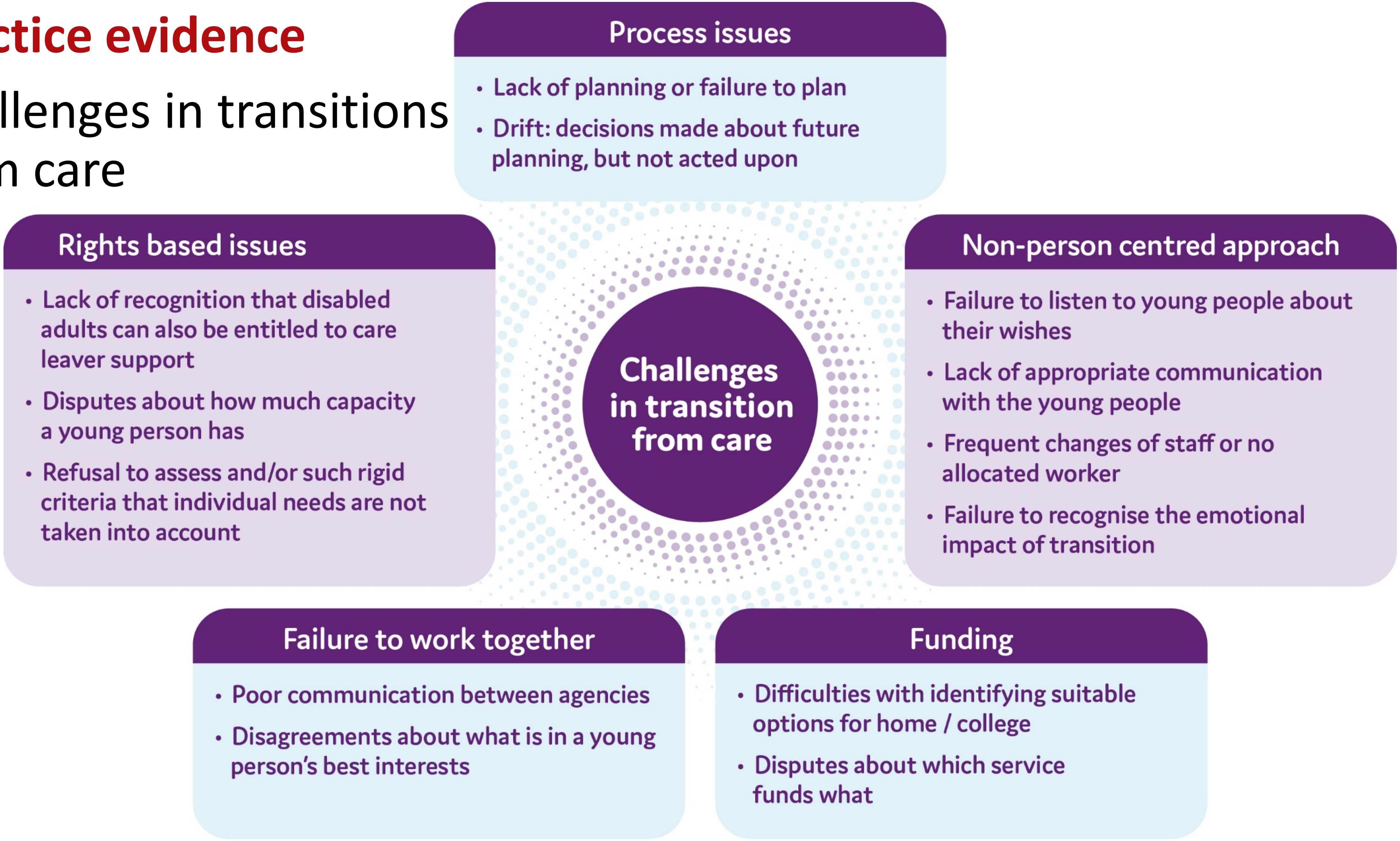
- Law and guidance are designed to ensure children in care with disabilities experience a well-planned, smooth transition from care. But evidence from Coram Voice advocacy services and learning from serious incidents shows not all young people do.
- When we do not get things rights for children and young 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 a 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.

Practice evidence

Challenges in transitions from care



Challenges in transition from care

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

Failure to work together

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

Funding

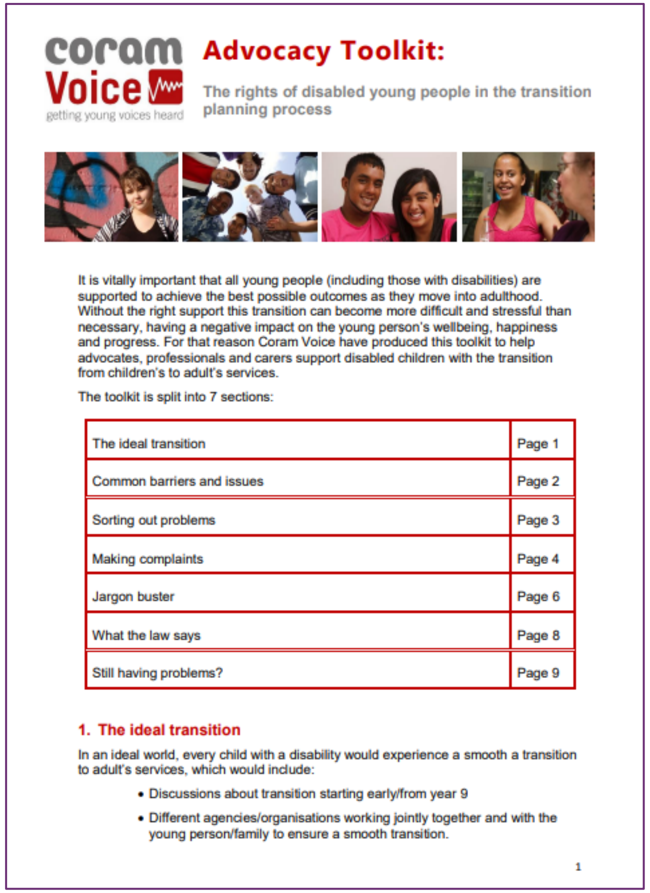
- Difficulties with identifying suitable options for home / college
- Disputes about which service funds what

Coram Voice specialist disability advocate support

- Training
  - Transition planning & rights disabled young people
  - Meaningful communication: advocacy with disabled young peple
- Transition toolkit
- FAQ / advice

https://coramvoice.org.uk/for-professionals/specialist-advocacy-service/disability/

https://coramvoice.org.uk/latest/events/



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Advocacy Toolkit:

The rights of disabled young people in the transition planning process

It is vitally important that all young people (including those with disabilities) are supported to achieve the best possible outcomes as they move into adulthood. Without the right support this transition can become more difficult and stressful than necessary, having a negative impact on the young person's wellbeing, happiness and progress. For that reason Coram Voice have produced this toolkit to help advocates, professionals and carers support disabled children with the transition from children's to adult's services.

The toolkit is split into 7 sections:

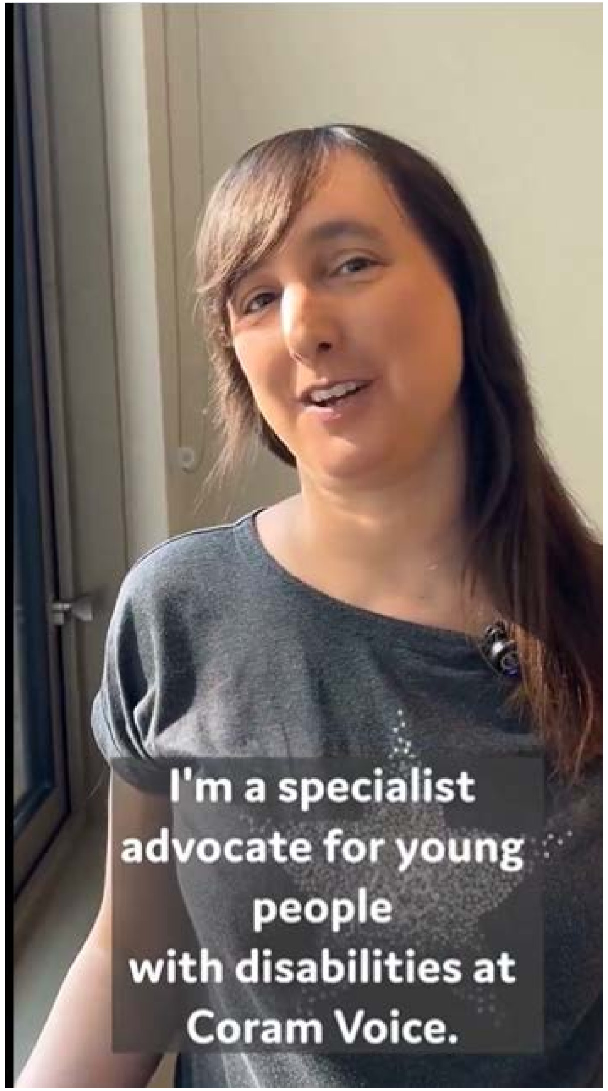
The ideal transition	Page 1
Common barriers and issues	Page 2
Sorting out problems	Page 3
Making complaints	Page 4
Jargon buster	Page 6
What the law says	Page 8
Still having problems?	Page 9

1. The ideal transition

In an ideal world, every child with a disability would experience a smooth a transition to adult's services, which would include:

- Discussions about transition starting early/from year 9
- Different agencies/organisations working jointly together and with the young person/family to ensure a smooth transition.

1



https://www.youtube.com/shorts/SOBVvQ8DRrk

Supporting all care leavers

Care leavers who meet criteria for ongoing (post 18) care and support needs under Care Act 2014 (adult social care)

Chapter 16 of Care Act Guidance: "LA should consider using the statutory pathway planning process as the opportunity to carry out a transition assessment where appropriate"

Care leavers with 'borderline impairments' / not meet threshold for services (additional needs)
(8 weekly visits, 6 monthly review of Pathway plan etc – will this support young person sufficiently;
What are the opportunities for co-ordination with other services/ support (e.g. OT; speech & language etc)

Reflection (3)

Reflections on the evidence re: how children in care & care leavers with a disability are doing

- *Anything surprising?*
- *What don't we know?*

Research 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 government, local authorities and Coram Voice.

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)*

Last word

"I struggled as a child in care with disabilities but after receiving the diagnosis I needed and the necessary support, I excelled in higher education and am now applying to study for a PhD. Now is the time to ensure the next generation of looked-after children and care leavers are given the right support to reach their potential".

***Susan Lake**, Postgraduate Student*
(November, 2024)

Access All:
Disability News
and Mental Health

https://www.bbc.co.uk/programmes/p0k7908c

Reflection (4)

So what…

Any actions you can take back?

What needs to improve to support children in care & care leavers with disabilities?

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.

Find out more and contact the team

Email Claire.baker@coramvoice.org.uk

Visit the Bright Spots Programme homepage on the Coram Voice website

Sign up for the Voices Improving Care monthly newsletter to receive updates on the Bright Spots Programme straight to your inbox.

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

Acknowledgements

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- **Authors:** Dr Claire Baker and Linda Briheim-Crookall, Voices Improving Care team, Coram Voice

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