# HOW DATA CAPTURED BY NCEPOD SUPPORTS THE IDENTIFICATION OF HEALTHCARE INEQUALITIES
# A REVIEW – UPDATED 2024

*Improving the quality of healthcare*

# CONTENTS

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD) is an independent body to which a corporate commitment has been made by the medical and surgical royal colleges, associations and faculties related to its area of activity. NCEPOD is a company, limited by guarantee (3019382) and a registered charity (1075588).

This work was commissioned by Healthcare Quality Improvement Partnership (HQIP) on behalf of the Healthcare Inequalities team at NHS England and NHS Improvement, as part of the National Clinical Audit and Patient Outcomes Programme (NCAPOP). HQIP is led by a consortium of the Academy of Medical Royal Colleges, the Royal College of Nursing, and National Voices. Its aim is to promote quality improvement in patient outcomes. The Clinical Outcome Review Programmes, which encompass confidential enquiries, are designed to help assess the quality of healthcare, and stimulate improvement in safety and effectiveness by systematically enabling clinicians, managers, and policy makers to learn from adverse events and other relevant data. HQIP holds the contract to commission, manage and develop the National Clinical Audit and Patient Outcomes Programme (NCAPOP), comprising around 40 projects covering care provided to people with a wide range of medical, surgical and mental health conditions. www.hqip.org.uk/national-programmes.

# FOREWORD

## I C MARTIN - CHAIR, NCEPOD

There has never been a more pertinent time to review the data NCEPOD has on healthcare inequalities. The COVID-19 pandemic, the recently published 'levelling up white paper' and 'health disparities white paper' have shown that we all need to play a part in helping close the inequality gaps in healthcare.

The nature of the NCEPOD method means that studies were never explicitly designed to expose healthcare inequalities. Individual datasets are rarely specific enough to identify whether healthcare inequalities are directly linked to quality of healthcare, so we have been wary of overstating our findings. However, this report simply and retrospectively highlights where inequalities have been revealed. The robust use of peer review, surveys and interviews provide rich examples at both a clinical and organisational level. Some recognised protected characteristics, such as ethnicity are not covered yet, as there was no data to report, but as this report is strengthened by future studies, this will be addressed.

I was struck by how obvious some inequalities were, 'a clinician expressing their bias in the patient's notes when they thought the patient was 'still drinking'', and some more subtle, 'the absence of a hoist' or 'the width of a doorway'. What this review demonstrates is the variety of inequalities seen in healthcare, that appear go beyond even the recognised definitions. We hope this short report will inform parallel workstreams in this area and that the examples included will encourage those providing healthcare to improve the care they provide.

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## DR BOLA OWOLABI - DIRECTOR, HEALTHCARE INEQUALITIES IMPROVEMENT NHS ENGLAND AND NHS IMPROVEMENT

It is hugely important that we learn from patient outcomes and deaths in organisations – and take action to make improvements for the future.

This deep dive into historical data pulls out the key theme of inequalities. It shows us that healthcare inequalities are pervasive and affect all aspects of patient safety and patient outcomes - from mental health, to children transitioning to adult care.

This report particularly provides a vivid account of the experiences of people with learning disability and the challenges they face which is extremely insightful information. The case study approach throughout provides powerful and moving testimony of healthcare inequalities and the impact on outcomes.

It is good to see some data relating to deprivation, but going forward, and learning from the Covid pandemic data-driven response, we need our data on learning from patient outcomes and deaths to also be disaggregated by ethnicity. There is real opportunity to further narrow the health inequalities gap.

As we strive to improve access, experience and outcomes for all, we need to use all available mechanisms to highlight where health inequalities exist. I support NCEPOD's commitment to collect, report and present data in a way that surfaces healthcare inequalities going forward. It has the potential to be an additional powerful mechanism and I look forward to working closely with NCEPOD to ensure we make it as useful and actionable as possible.

# EXECUTIVE SUMMARY

This ‘living’ report summarises a review of current NCEPOD data to identify themes relating to healthcare inequalities. The enquiry method, although not specifically designed to look at healthcare inequalities, does highlight areas through the richness of the deep dive qualitative data obtained from case note review and patient and parent carer involvement. To date, little data have been collected on ethnicity, so there were no examples to highlight but this will be reviewed in future drafts as more data become available.

## Four areas of healthcare inequalities were identified from the available data

### PROTECTED CHARACTERISTICS – AGE, DISABILITY & RACE

Inequality due to age was visible in NCEPOD studies that have reviewed the care provided to the **elderly** and to **children and young people.**

Preconceived low expectations in outcomes of the **elderly** surgical patient affected the level of care provided.

There appears to be variation in the commissioning of services geographically and between **child** and **adult** services.

**Young people** reported that healthcare professionals had little understanding of cultural differences and they faced language barriers.

### SOCIOECONOMIC DEPRIVATION

Socioeconomic deprivation was visible in the care provided to **children and young people** and to **adults.**

The impact of socioeconomic deprivation on mental healthcare in **children and young people** was very clear in terms of what services were available and whether they were accessed.

The study of **adults** who died from alcohol-related liver disease highlighted prejudice in treating this group of patients.

### INCLUSION HEALTH GROUPS

Hospital admissions have been highlighted as an opportunity to intervene in the general healthcare of vulnerable **young people** and **adults** who may not be accessing primary care or looking after their general health.

Robust follow-up of vulnerable **young people** and **adults** is essential to ensure they receive the healthcare they need as there may not be straightforward pathways in place.

### ORGANISATION OF HEALTHCARE SERVICES

Many **children and young people** have to travel long distances to receive specialist care which can separate them from their family.

Poor hospital design or lack of adjustments can hinder basic access for disabled **children and young people** and **adults.**

There are issues with the availability of suitable equipment to undertake measurements, such as height and weight in patients who are disabled or in a wheelchair. This is relevant to **children and young people** and **adults.**

## KEY MESSAGES RELEVANT TO THE CARE OF CHILDREN AND YOUNG PEOPLE

- Inequality due to socioeconomic deprivation was visible in NCEPOD studies that have reviewed the care provided to **children and young people.**
- The divide between paediatric and adult healthcare services is well known and can lead to **children and young people** experiencing a gap in care at the point of transition.
- **Children and young people** with complex conditions and disabilities have a greater number of day-to-day challenges to face. This also has an impact on the young person's parent carers.
- Many **children and young people** have to travel long distances to receive specialist care which can separate them from their family.
- The impact of socioeconomic deprivation on mental healthcare in **children and young people** was very clear in terms of what services were available and whether they were accessed.
- **Young men** were less likely to engage with healthcare about their mental health and were therefore more likely to be admitted to secondary care due to the severity of the condition once recognised.
- Access to specialist equipment for **children and young people** with long-term ventilation can be varied, leading to concern among parents.
- **Young people** seem to be experiencing, first hand, communication issues with healthcare providers and the impact of others not understand their cultural backgrounds.

## KEY MESSAGES RELEVANT TO THE CARE OF ADULTS

- Preconceived low expectations in outcomes of the **elderly** surgical patient affected the level of care provided.
- The study of **adults** who died from alcohol-related liver disease highlighted prejudice in treating this group of patients, by those providing healthcare services, which was still raised as an issue in a review of the topic nearly 10 years later.

# INTRODUCTION

The National Confidential Enquiry into Patient Outcome and Death (NCEPOD), undertakes confidential case note and questionnaire review to assess the quality of care provided to past patients to help improve the healthcare provided to future patients.[1]

In general, the core NCEPOD method involves peer review of a topic specific, sample of patient care with a resultant report and consensus agreed recommendations. The importance of healthcare inequalities in healthcare is recognised, but the sampling process used for inclusion in an individual topic means that the method has not been developed to directly assess the impact of healthcare inequalities in the quality of care. However, a retrospective thematic analysis across past reports has highlighted areas where healthcare inequalities have been recognised.

In addition to the core method used for all studies, two specific studies have included analyses of routine national datasets: one on chronic neurodisability and another on mental health in children and young people. For other studies, focus groups and interviews with patients and parent/carers have also been undertaken which have drawn attention to healthcare inequality issues in the care provided. This report aims to summarise these themes.

# HEALTH INEQUALITIES

Health inequalities are unjust differences in health and wellbeing between different groups of people (communities) which are systematic and avoidable. Health inequalities in England exist across a range of characteristics, including the nine protected characteristics of the Equality Act 2010[2] (age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation), socioeconomic status, geographic deprivation, or being part of a vulnerable or inclusion health group.

The term 'health inequalities' is also commonly used to refer to differences in the care that people receive and the opportunities that they have to lead healthy lives, both of which can contribute to their health status. Health inequalities can therefore involve differences in:

- health status, for example, life expectancy and prevalence of health conditions;
- access to care, for example, availability of treatments, accessibility, and engagement;
- quality and experience of care, for example, levels of patient satisfaction;
- behavioural risks to health, for example, smoking rates;
- wider determinants of health, for example, quality of housing.[3]

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[1] National Confidential Enquiry into Patient Outcome and Death (NCEPOD)

[2] Equality Act 2010

[3] The King's Fund: What are health inequalities

# METHOD

## THIS REVIEW

All NCEPOD reports over the last 15 years, and data collections currently in progress, were reviewed for evidence of healthcare inequalities. Evidence was extracted from:

- Clinical narratives formed from the peer review of case notes, clinical and organisational questionnaires
- Exemplar case studies
- Patient/parent/carer opinions
- Analyses of routine national datasets

These studies have been included in this report:

| TOPIC | LINK |
|---|---|
| Surgery in the elderly - **adults** | An Age Old Problem |
| Alcohol-related liver disease - **adults** | Measuring the Units<br>Remeasuring the Units - 2022 |
| Chronic neurodisability - **CYP** | Each and Every Need |
| Mental healthcare in young people - **CYP** | Mental Healthcare in Young People and Young Adults |
| Long-term ventilation - **CYP** | Balancing the Pressures |
| Physical healthcare in mental health hospitals - **adults** | A Picture of Health? |
| Transition from child to adult healthcare - **CYP** | The Inbetweeners |
| Testicular torsion - **CYP** | Twist and Shout |
| Juvenile idiopathic arthritis - **CYP** | Study in progress |

The data have been themed where possible and discussion points have been added that are applicable to the care of children and young people and to adults.

## PLAN FOR FUTURE WORK

For all future studies, the topic under review will be assessed using the Health Equity Assessment Tool (HEAT),[4] or similar, to determine how the data collections can allow NCEPOD to systematically examine healthcare inequalities in terms of deprivation, ethnicity, LGBTQ+ and other protected characteristics. These data will be added to this 'live' report as they become available to keep it up to date and relevant.

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[4] Public Health England. Health Equity Assessment Tool

# 1 – PROTECTED CHARACTERISTICS

## AGE

Healthcare inequalities have been demonstrated in NCEPOD reports both in elderly patients and in children and young people. Each are described here.

### *'An Age Old Problem; 2010'*[5]

*A review of the care provided to **elderly patients** undergoing surgery.*

It is well understood that elderly patients tend to be more vulnerable and to suffer from more comorbidities than younger patients. It is equally well known that they require a style of medicine that is correspondingly sensitive to their many needs. These may not be obvious when they enter hospital for surgical procedures. The case reviewers in this study found that far too many of the patients included were not getting a standard of care that should be expected.

Despite the high burden of comorbidity in this population, it was noted that a greater number of patients did not have enhanced care planned to support their surgery. Reviewers indicated that there may have often been low expectations of outcomes, and that this affected judgements about what level of care was both planned and received. An example of this is highlighted in the following case study.

*An 84-year-old presented with vomiting and a strangulated femoral hernia. There was concern that there was a disseminated malignancy which involved the lumbar and thoracic spine. Surgery was initially declined by the patient but went ahead 24 hours later under local anaesthesia, by which time the patient's conscious level had deteriorated, and their ability to consent was reduced. An ischaemic bowel was discovered, and treatment (latterly) discontinued.*

*Case reviewers highlighted that due to the fact that the patient "only had it under local" it may have persuaded staff that it was an ethical decision to operate, but the reviewers believed that there was insufficient documentation to assess whether the patient's original wishes had been re-considered prior to surgery proceeding.*

This theme was also reflected in the patients needing access to postoperative critical care. Case reviewers again commented that there was a low expectation in outcomes for these patients and that it may well have been extreme old age and urgency of surgery that affected judgement as to the location of care. This is important as several studies have highlighted that it is not age alone which determines outcome in the elderly surgical patient,[6,7] and many elderly patients make a very good recovery.[8]

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[5] NCEPOD. 2010. An Age Old Problem

[6] Ford PNR, Thomas I et al. Determinants of outcome in critically ill octogenarians after surgery: An observational study. British Journal of Anaesthesia. 2007; 99(6), 824-29

[7] Farfel JM, Franca SA et al. Age, invasive ventilatory support and outcomes in elderly patients admitted to intensive care units. Age and Ageing. 2009; 38(5), 515-20

[8] Hennessy D, Juzwishin K et al. Outcomes of elderly survivors of intensive care. Chest. 2005; 127(5), 1764-74

At the other end of the age range, variation in care according to age (and sex) was seen in the analysis of the routine national datasets for this study.

Clear trends were seen across the care provided for different age groups which also overlapped with sex and socioeconomic deprivation (covered in chapter 2). The analyses highlighted that:

- There was a steep increase in hospital admissions associated with depression in females and in those aged 16-24 years;
- Diagnosis of depression in primary care was more common in females than males, and increased with deprivation index;
- 21-24 year-old males consistently had the highest 'did not attend' rates for outpatient appointments;
- Proportionally more males than females were referred from primary to secondary care for all mental health conditions. This may reflect severity on presentation to primary care given known sex differences in help seeking behaviour;
- More males than females aged 11-24 years were admitted to inpatient mental health facilities. The excess of male admissions was in contrast to community prevalence where females out-numbered males;
- A larger proportion of females than males were referred to Improving Access to Psychological Therapies (IAPT) (adult service in England) but once referred similar proportions of males and females received treatment;
- Males with self-harm recorded in primary care before they were 18 years old were more likely to be excluded from school than those with no record;
- The presence of a mental health condition diagnosed in primary care between the ages of 11 and 18 years was associated with lower attainment at Key Stage 4, GCSE (except for females with anxiety and/or eating disorders where there was no significant difference) and lower attendance.

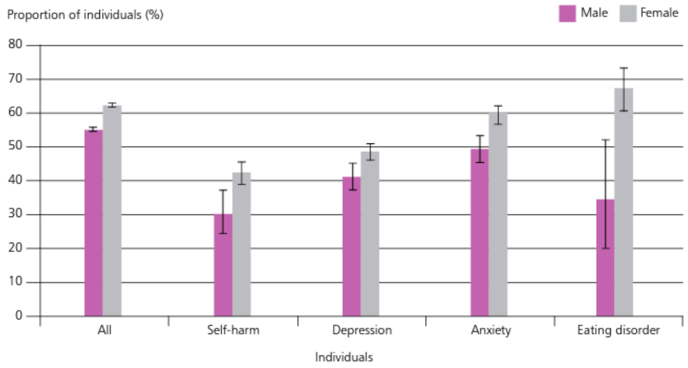

**Figure 3.8 The proportion of individuals achieving 5 GCSEs grade A* to C at Key stage 4 when diagnosed in primary care with a condition of interest between 2013 and 2016 by sex**

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[9] NCEPOD. 2019. Mental Healthcare in Young People and Young Adults

The report recommended that all healthcare providers:

- Raise awareness, improve emotional literacy, tackle stigma and particularly engage with males in improving their help-seeking behaviour;
- Design mental health services to:
  a. Promote access for children and young people from the most deprived communities;
  b. Provide access to developmentally appropriate healthcare;
  c. Provide training initiatives to promote staff awareness of the impact of inequalities, such as deprivation;
  d. Monitor the impact of any change in service provision on such inequalities.

## *'TRANSITION FROM CHILD TO ADULT HEALTHCARE SERVICES'*[10]

*A review of the quality of the transition process from* ***child to adult health services***

The gap between child and adult services was described very well in the experience of one young person who shared their story as part of the current transition study we are running. Because of her age her condition deteriorated due to poor organisation across services.

> *"I was very unwell. I presented at about midday, and I was in paediatrics A&E until about 6pm at night they just argued over whether I should be in adult A&E or in paediatrics or should I go to an adult ward.*
>
> *It was awful communication; they were going back and forth between each other. While in the meantime I was sitting in this cubicle in A&E getting no care.*
>
> *By about 4pm a doctor came and saw me and took loads of my blood and my potassium was dangerously low, and my electrolytes were off, so I had to be attached to a heart monitor and got moved then.*
>
> *And again, I didn't see a doctor for about two hours because they were apparently just arguing over who I should be under. They were going to send me up to a paediatric ward but then this adult doctor showed up and she took my bloods and took one look at me and was like: 'because you've all left her for so long, she's going to resus.' So, I end up in resus and then ended up in paediatric intensive care because they had spent two hours not communicating properly and not caring for me, so I ended up having a crash call because I was so unwell."*

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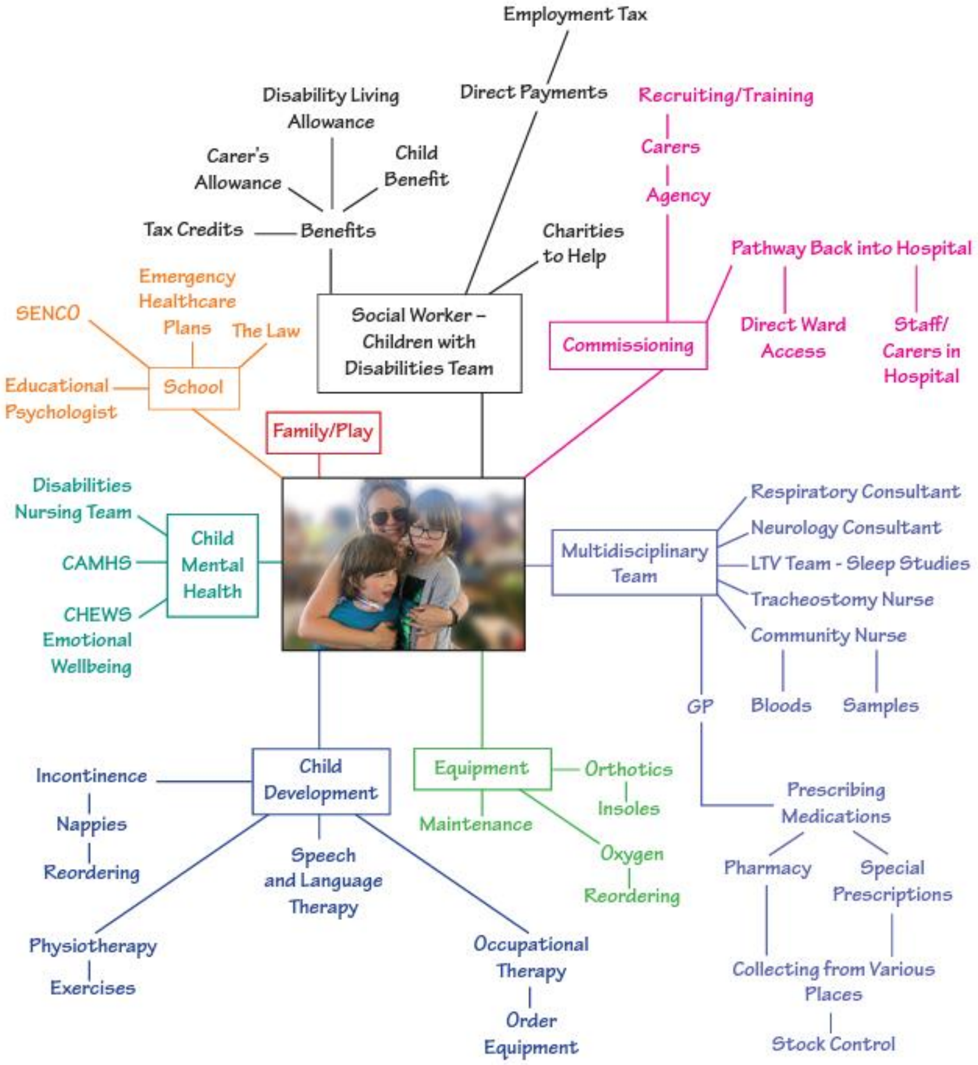
[10] NCEPOD. 2023. The Inbetweeners

## DISABILITY

### *'BALANCING THE PRESSURES; 2020'*[11]

*A review of the quality of care provide to* ***children and young people*** *receiving long-term ventilation*

The diagram below highlights one example of the number of challenges experienced by people with disabilities and long-term conditions on a day-to-day basis. Noah and Jill were involved in the study because Noah was receiving long-term ventilation. However, his many underlying conditions meant that LTV was just one of services he needed to be under. Jill, Noah's mother, drew this to try and help healthcare providers understand all the different aspects needed in caring for Noah.



For the same study, and to gain a different perspective, an interview was conducted with Fleur Perry, a young woman with spinal muscular atrophy who was dependent on long-term ventilation. She highlighted the inequality in the provision of LTV across the country, particularly around commissioning arrangements. Fleur's interview can be watched here but there is a short extract below reflecting on her concerns around the variability on LTV commissioning arrangements.

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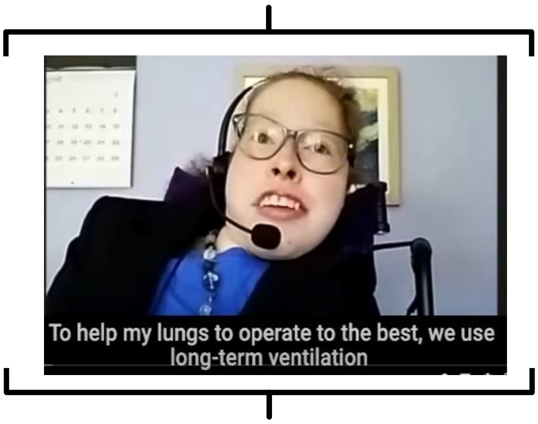
[11] NCEPOD. 2020. Balancing the pressures



To help my lungs to operate to the best, we use long-term ventilation

*"There are areas around the country where people do struggle to access long-term ventilation, particularly with the Duchenne muscular dystrophy community. There is research that shows that a person's lifespan is largely dependent on the commissioning area in which they live, as to whether or not they can access the right equipment for their breathing. I think the figures were 18 years in an area where equipment wasn't commissioned and over 30 years in an area where equipment is commissioned.[12] That's a huge difference and it's unnecessary. There are also other groups that face barriers to accessing ventilation and cough assist but may not have been researched."*

This was not the first time differences in commissioning had been raised. In 2018 NCEPOD published a report on chronic neurodisability, focusing on the care provided to children and young people with a cerebral palsy.

### *'EACH AND EVERY NEED; 2018'*[13]

*A review of the quality of care provide to **children and young people** with a cerebral palsy*

As part of the data collection for this study a survey was undertaken of children and young people and their parent carers. The infographic below summarises what they said, both positive and negative. There were frustrations about accessing services, particularly wheelchair services, which is captured by the comment that they are "disabling and disempowering".

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[12] https://musculardystrophyuk.org/get-involved/campaign/our-campaigns/healthcare-campaigns/right-to-breathe-respiratory-care

[13] NCEPOD. 2018. Each and Every Need

The themes highlighted in the survey were shared by Christopher Myers, a young man with cerebral palsy who shared his experiences of being disabled. Christopher's interview can be watched here.

It was of note that Christopher also commented on the issue of not being included in discussions or spoken to about his care. He said *" What is really really annoying is when people think because I can't talk, I must be stupid, and they don't talk to me. For an example, a new GP asking "What, can Christopher read then?" or the assessor from continuing healthcare saying, "Does Christopher have an end of life care plan?" - Err I didn't know I was dying!!!"* He also added *"A good example was at [a hospital] recently, the doctor took time to talk to me about my treatment options, he took time to learn my yes and no [eye] signals and if he wasn't sure he asked for help, he also knelt down so he could be on the same level as me. A bad thing was the continuing healthcare assessor who treats me like I am stupid, or doctors asking my dad to consent because I can't sign a piece of paper!"*

## *'TRANSITION FROM CHILD TO ADULT HEALTHCARE SERVICES'*[14]

*A review of the quality of the transition process from* ***child to adult health services***

It is well documented that the transition between paediatric and adult services can lead to a gap in service for children and young people.[15] In the current study on transition there were a number of issues raised in the early scoping work with regard to healthcare inequalities experienced by young people and their parent carers. Not just inequalities due to having a long-term condition or being disabled, but inequality even between conditions competing for services.

One parent carer felt that that their child had to be visibly disabled to access care.

> *"On the surface he seems very able this is why speech and language therapy (SLT) is so important, it shows the hidden problems that he's got. He's got a lot of problems, but you wouldn't know that meeting him, that's why he's been discriminated against so much. And this is why it's so important to get the SLT report right."*

Another stated:

> *"A lot of the services, if you haven't got a learning disability you cannot access it. If you've just got autism, then you can't access them. Fortunately, my daughter does have a learning disability. I shouldn't have to say fortunately."*

Participants indicated there is a condition lottery. Young people with particular conditions have an easier route to adult services than others:

> *"The doctors told me that it would be so much easier if I had cystic fibrosis or Crohn's because there's a mirror image team in adults."*

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[14] NCEPOD. In progress. Transition from Child to Adult Health Services

[15] Care Quality Commission: From the Pond to the Sea. 2014

Participants reported that they had to pay privately for a diagnosis or that their children's conditions were left undiagnosed. This meant that their children's complex needs were not properly understood which led to them not being able to access services and care packages:

> *"We had to do a fund raiser for my son. We spent 5 years trying to get a diagnosis. He's on the spectrum but because he doesn't tick boxes, he's in a grey area so he's never got fully diagnosed."*

The inequalities also extended to those impacted by the disability of the person they are caring for. Despite all of the parent carers saying that they had suffered from significant emotional stress associated with their experiences with the process of transition, none had been signposted to any form support or respite services:

> *"I'm an unpaid carer…I have no life, no social life, nothing. I just seem to be on robot mode."*

One parent carer explained that they needed to pay for therapy to allow her to "survive" the ordeal of transition:

> *"For me to survive this, I have to pay for therapy every week to get through this nightmare because otherwise I just wouldn't survive."*

In this study of young people moving from child to adult health services, 54/290 (18.6%) were identified, by healthcare professionals peer reviewing the case notes, as having at least one recognised health inequality that impacted on the care that they received, including **learning disabilities** (33), **physical disabilities** (16), **socioeconomic status** (11), **English not being a first language** (8), **being part of an inclusion health group** (5) and **severe mental illness** (3).

## RACE, CULTURAL UNDERSTANDING AND LANGUAGE BARRIERS

Focus groups with patients/parents/carers are undertaken for all NCEPOD studies. Race has never been raised as an issue until recent ones for a study being run on juvenile idiopathic arthritis (JIA), when it was raised as a very strong theme.

Both the young people involved, and parent carers said that healthcare professionals had little understanding of cultural differences and they faced language barriers. One parent commented:

> *"Healthcare services are…unable to understand people's culture" and many are "not patient enough and do not listen to people appropriately in terms of language barriers, for people that are not very fluent in English language."*

And one of the young people said they were seen as a burden to the workforce:

> *"…[if] you're from a minority background it can also be a barrier for the teenager to walk into the hospital or walk into the counselling, just because of that fear that phobia of racism from some healthcare professionals."*

Another said:

> *"Having a carer who is not racist or culturally insensitive is extremely important."*

## LEARNING DISABILITY

### *'Testicular torsion'*[16]

*A review of the pathway and quality of care provided to **children and young people** aged 2-24 years who presented to hospital with testicular torsion*

Of the patients with a communication difficulty, 32/45 (71.1%) had their testicle removed compared with 167/491 (34.0%) patients with no communication difficulties. Similarly, 13/24 (54.2%) patients with a learning disability had their testicle removed compared to 186/510 (36.5%) patients with no learning disability. Patients with a learning disability may be more at risk of a delay to diagnosis because of difficulties in communicating symptoms effectively. In this study the time from arrival to decision to operate took longer than six hours for those with a communication difficulty (18/45; 40.0%) compared with no communication difficulty (138/491; 28.1%).

**Only 3/17 young people were taught about testicular torsion at school or college.**

**DISCUSSION POINTS RELEVANT TO CHILDREN AND YOUNG PEOPLE AND TO ADULTS**

- Inequality due to age was visible in NCEPOD studies that have reviewed the care provided to the **elderly** and to **children and young people.**
- Preconceived low expectations in outcomes of the **elderly** surgical patient affected the level of care provided.
- The divide between paediatric and adult healthcare services is well known and can lead to **children and young people** experiencing a gap in clinical care at the point of transition.
- **Young men** were less likely to engage with healthcare about their mental health and were therefore more likely to be admitted to secondary care due to the severity of the condition once recognised.
- **Children and young people** with complex conditions and disabilities have a greater number of day-to-day challenges to face. This also has an impact on the young person's parent carers, many of whom were visibly emotional while sharing their experiences with us.
- There appears to be variation in commissioning of services geographically and between **child** and **adult** services.
- **Young people** seem to be experiencing, firsthand, communication issues with healthcare providers and the impact of others not understanding their cultural backgrounds.
- **Delay to seek help, and treatment should be considered in children and young people** with learning difficulties or communication issues.

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[16] NCEPOD. 2024. Twist and Shout

# 2 – SOCIOECONOMIC DEPRIVATION

## *‘MENTAL HEALTHCARE IN YOUNG PEOPLE AND YOUNG ADULTS’*[17]

*A review of the mental healthcare provided to* ***children and young people*** *aged up to 25 years*

As part of the analysis of the routine national datasets used in this study, the effect of social deprivation was looked at in the mental health conditions and behaviour under review.

- **Eating disorders** were more common in **females** and demonstrated the **reverse pattern for deprivation** when compared to self-harm, anxiety and depression, being most evident in the least deprived areas for both primary care and hospital admissions;

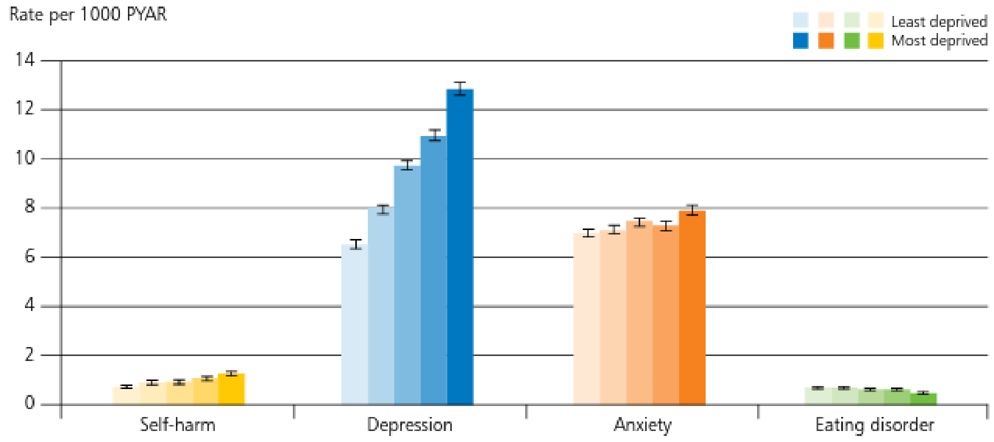

**Figure 2.7 The prevalence rate of individuals per diagnosis per 1000 PYAR with depression, anxiety, eating disorders or self harm for 11-24 year olds by deprivation quintile in primary care between 2009-2014**

*Source: England*

- The proportion of **referrals** from primary care to secondary care **for children and young people** were **highest from the least deprived areas** despite levels of most conditions being higher in the most deprived areas;
- **Children and young people** from the **most deprived** areas **attended fewer follow-up appointments** than people from the least deprived areas;
- There was a **steep deprivation gradient** for individuals **attending emergency departments** for self-harm or psychiatric conditions, with 50% of attendances from the two most deprived quintiles;
- **Re-attendance rates to emergency departments** were much **higher for self-harm and mental health conditions** than all attendances, particularly **for people from the most deprived areas;**
- People from the **most deprived areas** were the **most likely to be admitted** with any of the conditions of interest recorded, except for eating disorders;

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[17] NCEPOD. 2019. Mental Healthcare in Young People and Young Adults

- A larger proportion of children and **young people aged 11-24** years from **deprived areas** were **referred to Improving Access to Psychological Therapies** (IAPT adult service), but they were **less likely to attend** at least one appointment **and receive treatment.**

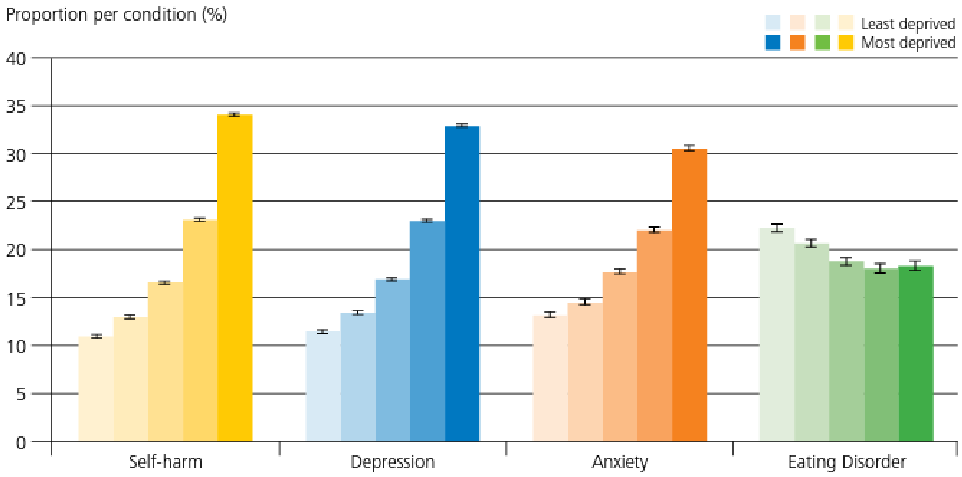

**Figure 2.12 Proportion of admissions (spells) to inpatient care with a diagnosis of depression, anxiety, eating disorder and self-harm by deprivation quintile.**
*Source: HES- NHS Digital England*

Another condition where there is a strong link with social deprivation is alcohol-related liver disease (ARLD).

*'ALCOHOL-RELATED LIVER DISEASE; 2013'*[18] *and 2022*[19]

*A review of the quality of care provide to* ***adults*** *who had died due to alcohol-related liver disease*

ARLD accounts for 60% of all liver disease and is a disease of the young. Most people with liver disease die aged between 18 to 65 years, which is in contrast to other major causes of mortality such as heart and lung disease or stroke where the average age of death is over 80 years and rising due to improved public health and medical interventions.[20]

In England there is a marked geographic variation in both the incidence and the care of patients admitted with ARLD and the influence of deprivation has been well documented. People who live in more deprived areas are up to six times more likely to die from ARLD than those who live in wealthier areas.[15] While the NCEPOD review did not assess care by deprivation index it did highlight ARLD as an example of prejudice seen in patient care.

It was reported by those caring for this group of patients that there is a reluctance by some healthcare professionals to admit patients to intensive care for organ support, through what appears to be a pessimistic or negative attitude to patients with ARLD.

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[18] NCEPOD. 2013. Measuring the Units
[19] NCEPOD. 2022. Remeasuring the Units
[20] The British Liver Trust

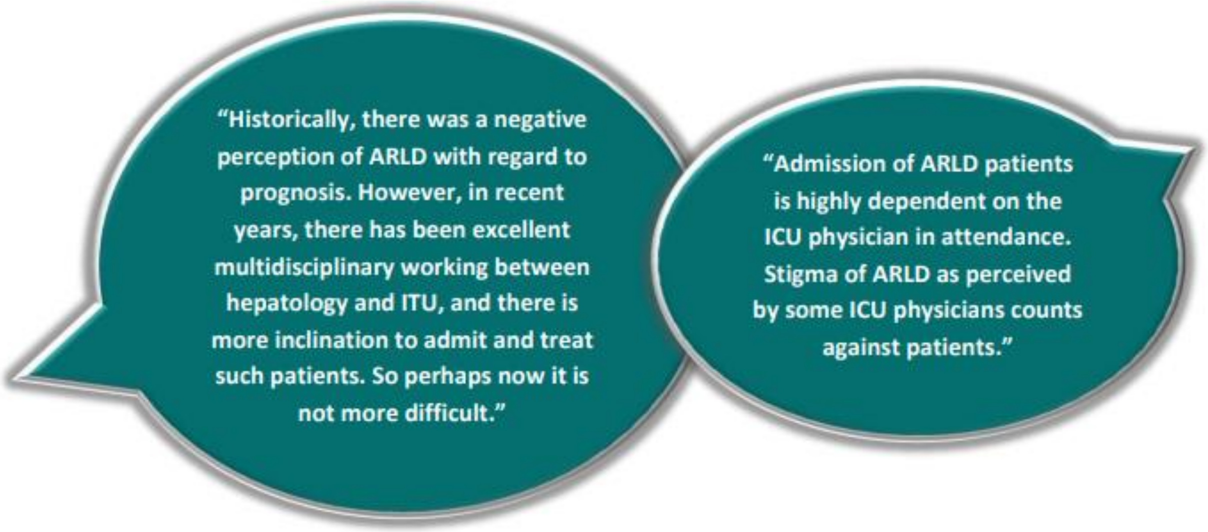
This was commented upon by the Chair of NCEPOD in their foreword when he stated, *“No decent healthcare system should write people off or deem them less worthy of the best care available to them.”*

The case study below shows an example of what was seen during the review of case notes.

*A 27-year-old patient was admitted with jaundice and abdominal distension. The patient had developed diarrhoea two weeks previously. The patient had a history of excessive alcohol intake and had stopped four weeks prior to admission and had no previous hospital admissions related to alcohol. The patient had a tender enlarged liver, normal observations and GCS 15. The patient was treated for decompensation with fluids and investigated with blood cultures, liver screen and an ultrasound scan. The patient was reviewed on the day of admission by a consultant gastroenterologist. The following night, 13 hours after admission the patient had a seizure presumed due to hyponatraemia (Na 110 mmol/L). Following this the patient was agitated with a GCS of 13. Respiratory parameters deteriorated over the next 24 hours and the patient was thought to have aspirated. The on call ITU registrar discussed the patient with their consultant and wrote: “currently not for ITU as the patient has end stage liver disease and is still drinking”. Care was provided on a general ward. An oropharyngeal airway was required due to airway compromise and the patient died the following day, three days after hospital admission.*

*On review of the case notes, the clinician responsible noted that there was a missed opportunity as the patient should have received an escalation of care. The case reviewers reported that the patient may have been post-ictal, and escalation of care would have been completely appropriate.*

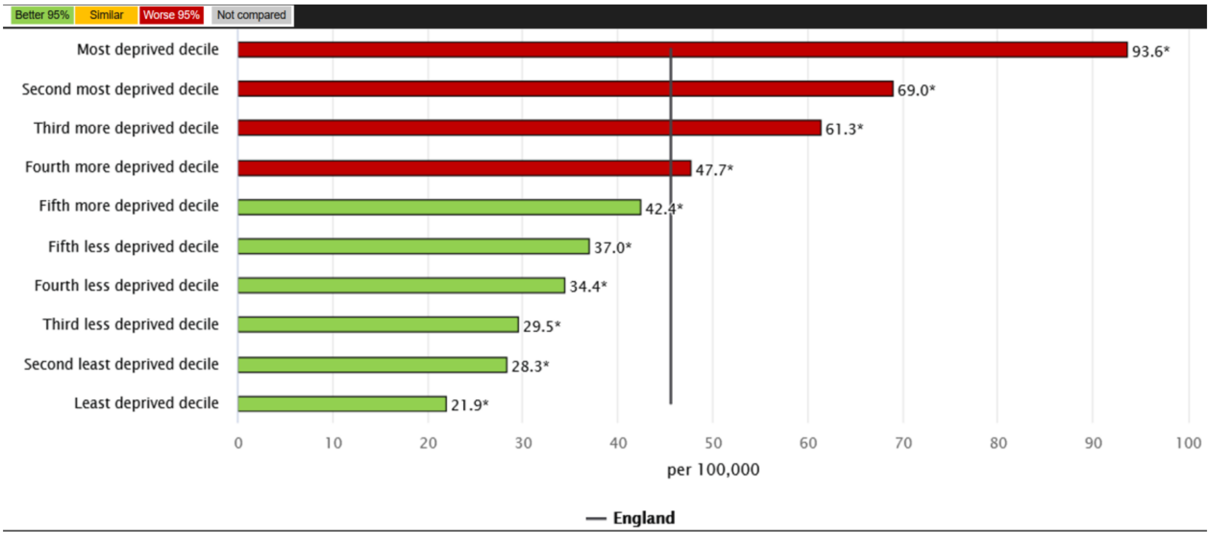
The speech bubbles were taken from the update on this work in 2022. Some positive improvement, but the not in all places.



**“Historically, there was a negative perception of ARLD with regard to prognosis. However, in recent years, there has been excellent multidisciplinary working between hepatology and ITU, and there is more inclination to admit and treat such patients. So perhaps now it is not more difficult.”**

**“Admission of ARLD patients is highly dependent on the ICU physician in attendance. Stigma of ARLD as perceived by some ICU physicians counts against patients.”**

This is of particular note as the age standardised hospital admission rate for England has increased over the past decade. In 2020/21 there were 24,544 hospital admissions for ARLD (based on date of admission). The number of hospital admissions for ARLD increased by 57.4% between 2010/11 and 2020/21, with a 4.3 fold difference in rate of admissions between the most deprived decile and the least deprived in 2020/21. In general, men had higher rates of hospital admissions than women accounting for around two thirds of admissions, but this ratio varied geographically and the gap between hospital admissions per 100,000 population between men and women was much wider in the North East (48.9) than in the South East (20.8). The gap in Yorkshire and Humber had also widened over time, where the difference in rate was 27.7 per 100,000 population in 2010/11 and 50.9 in 2020/21.[21]



Hospital admission rate for ARLD in England in 2020/21 by deprivation decile

## DISCUSSION POINTS RELEVANT TO CHILDREN AND YOUNG PEOPLE AND TO ADULTS

- Inequality due to socioeconomic deprivation was visible in NCEPOD studies that have reviewed the care provided to **children and young people** and to **adults.**
- The impact of socioeconomic deprivation on mental healthcare in **children and young people** was very clear in terms of prevalence of the condition and what services were available and whether they were accessed.
- The study of **adults** who died from alcohol-related liver disease highlighted prejudice in treating this group of patients, by those providing healthcare services, which was still raised as an issue in a review of the topic nearly 10 years later.

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[21] Office for Health Improvement and Disparities. Liver disease profile. 2022

# 3 – INCLUSION HEALTH GROUPS

None of the NCEPOD reports have specifically focused on inclusion health groups but there have been examples of case studies highlighting where care during a hospital admission was less than good. While it might be stated that other case studies of those not in an inclusion health group have also highlighted room for improvement, the ones below show how the patient's care was limited by the lack of access to healthcare records, safeguarding and robust follow-up in people who were vulnerable in addition to being unwell, where it might have been expected that extra precautions to protect the patient would have been taken.

## *'MENTAL HEALTHCARE IN YOUNG PEOPLE AND YOUNG ADULTS'*[22]

*A review of the mental healthcare provided to* ***children and young people*** *aged up to 25 years*

*A young homeless woman of 19 years was brought to the emergency department complaining of abdominal pain and vomiting. She gave a history of having been treated in Child and Adolescent Mental Health Services for Anorexia Nervosa. No notes about this were available. No cause for her symptoms was identified. She was admitted to an adult medical ward for observation and referred for a mental health assessment. While this was awaited, she refused to take any food and fluids. When confronted about this, she took her own discharge and was given details of a local organisation for the support of the homeless, and the telephone number of the local social care department.*

*Peer reviewers questioned whether this young person's situation was fully understood by general hospital staff before her discharge. No mental health notes were available, and no mental health assessment had been undertaken. There was no record of any information being sought about her past mental health conditions or current social circumstances. The cause of her current physical symptoms was not clarified. There was no record of staff consulting social care services adult safeguarding teams, nor reference to local safeguarding procedures being followed or planned mental health review.*

*A 17-year-old girl with learning difficulties was admitted via the emergency department of her local district general hospital after taking an overdose of an 'over the counter' laxative. She had a history of severe depression, bulimia and self-harm and was already under child and adolescent mental health services (CAMHS). Mental healthcare was arranged to commence after discharge with an urgent appointment secured with CAMHS the next day.*

*Whilst this young person seemed to have good follow-up arrangements in place, peer reviewers commented that her mental health plan was unavailable to admitting clinicians. There was no assessment made about her current suicide risk, with reliance on CAMHS follow-up the next day. There also appeared to be no identifiable key worker to assist with transition to adult services given that she was likely to need longer term follow-up and care.*

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[22] NCEPOD. 2019. Mental Healthcare in Young People and Young Adults

*A teenager in the care of her local authority as a result of child sexual abuse within her family had a history of emotional instability and self-harming behaviour. She moved from a children's home in her local area to a foster placement in another area and was referred to the local child and adolescent mental health services. She settled initially, but during outpatient appointments began to explore past abuse. Her mental state deteriorated, with acute self-harm risk. When this escalated to crisis, she was detained under Section 2 of the Mental Health Act to an adult mental health ward in the area of her community placement. On admission she was verbally aggressive and assaulted staff. She was nursed in a side room in seclusion with 2:1 nursing observation for 5 days until a bed was identified in a specialist mental health intensive care unit for adolescents nearer to her local authority area when she was transferred.*

*Case reviewers were concerned about the admission of a young person to an adult mental health ward whilst in crisis, and also about the limitations of the multi-agency support available to her and her to her foster carers at the time of her transfer from her local area.*

## 'PHYSICAL HEALTHCARE IN MENTAL HEALTH INPATIENT FACILITIES'[23]

*A review of the physical healthcare provided to **adult** patients admitted to a mental health inpatient facility*

*A 39-year-old patient was admitted with worsening self-harm and suicidal thoughts. They had no fixed abode and had been staying with different friends. The patient was not registered with a GP, and they had had multiple crisis admissions in the previous year. The admitting doctor who took a history was told that the patient had noticed a lump on her breast but declined physical examination as they did not want to be examined by a man. The doctor made a brief entry in the case notes for the day team to arrange for a female clinician to examine the patient. The next day during the ward round the patient terminated the review early because they were distressed that discharge was being discussed. There was no subsequent record in the patient's notes of activity to arrange physical examination and the patient self-discharged four days later.*

*Case reviewers were of the opinion that this patient would have benefited from proactive efforts to engage them in physical examination and with primary care. For example, a member of the breast clinic could have been contacted in an effort to persuade the patient to attend for assessment. They observed that the brief entry about concern of a breast lump was easily missed amongst extensive documentation of their interactions on the ward. They stated that systems to improve handover between out of hours and day teams, and to flag if basic aspects of care such as physical examination had been missed, would be helpful.*

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[23] NCEPOD. 2022. A Picture of Health?

*A 26-year-old patient with a diagnosis of emotionally unstable personality disorder was admitted with an increase in suicidal thoughts, self-harm and substance use. The patient had a past history of suffering sexual abuse and reported a recent history of injecting heroin. Access to the GP records showed a past diagnosis of chlamydia. The patient had been prescribed antipsychotic medication by the community mental health team to treat auditory and visual hallucinations. On discharge from the ward, the patient was advised to self-present to substance use services.*

*Case reviewers noted that despite a complex history suggestive of many areas of concern for psychosexual and reproductive health, including blood-borne viruses, there was no documentation that any clinician had taken a sexual or reproductive history or discussed this aspect of health with the patient. In addition, case reviewers highlighted that despite a clear history of trauma and drug use, there was no evidence that proactive and supportive efforts were made to try and engage the patient in treatment for substance use. They noted that there was no evidence that a trauma-informed approach had been used to formulate a needs or care plan for how the patient's mental health impacted their ability to look after their physical health.*

## DISCUSSION POINTS RELEVANT TO CHILDREN AND YOUNG PEOPLE AND TO ADULTS

- Hospital admissions have been highlighted as an opportunity to intervene in the general healthcare of vulnerable **young people** and **adults** who may not be accessing primary care or looking after their general health.
- Safeguarding should be considered for **young people** admitted to hospital.
- Robust follow-up of vulnerable **young people** and **adults** is essential to ensure they receive the healthcare they need, as there may not be straightforward pathways in place.

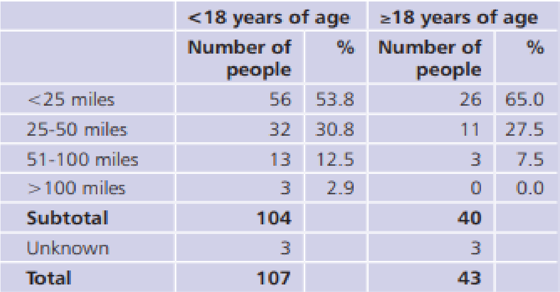
# 4 – ORGANISATION OF HEALTHCARE SERVICES

## ‘BALANCING THE PRESSURES; 2020’[24]

*A review of the quality of care provide to **children and young people** receiving long-term ventilation*

### Distance to specialist care

Whilst most children and young people receiving long-term ventilation (LTV) were cared for, at least initially, in a hospital within 25 miles from their home, many travelled further for their admission to an LTV centre.



| | <18 years of age | | ≥18 years of age | |
|---|---|---|---|---|
| | Number of people | % | Number of people | % |
| <25 miles | 56 | 53.8 | 26 | 65.0 |
| 25-50 miles | 32 | 30.8 | 11 | 27.5 |
| 51-100 miles | 13 | 12.5 | 3 | 7.5 |
| >100 miles | 3 | 2.9 | 0 | 0.0 |
| **Subtotal** | **104** | | **40** | |
| Unknown | 3 | | 3 | |
| **Total** | **107** | | **43** | |

These data may reflect the greater complexity of younger people, more of whom were receiving invasive ventilation and/or simply that there were fewer, more wide-spread, critical care facilities for children and young people.

The issue of travelling further for specialist care was also seen in the young people’s mental health report[25] and is demonstrated in this case study.

*A 17-year-old was in treatment with a local outpatient specialist eating disorders service. She appeared to be well engaged in all psychological therapies, but despite dietary plans and support, continued to lose weight. She became physically unwell with a slow heart rate, marked muscle weakness and showed signs of confusion. She was referred to her local general hospital, stabilised in the emergency department and admitted for monitoring on an adult medical ward. The following day she was transferred to a specialist private sector Eating Disorder Unit which was 150 miles from her home.*

*Case reviewers were concerned about the distance away from home that this young person experienced to access inpatient care. There was concern that an earlier, and planned referral had not been pursued given the physical deterioration with outpatient treatment.*

As part of the data collection for the LTV study  parents were invited to attend focus groups to share their experiences of the care their child had received. It was not a biased group and there were many positive experiences in some aspects of care, but there were shared experiences of the struggle to get access to services and equipment for their child, not least trying to get them home, where there was a sense of a lack of support in this situation, as described by one mother:

> *“I fought from the moment they told me it was going to take another 18 months to get out of hospital to even get her into a home environment. In terms of support, there isn't any.”*

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[24] NCEPOD. 2020. Balancing the Pressures

[25] NCEPOD. 2019. Mental Healthcare in Young People and Young Adults

Many participants had experienced severe delays getting care packages in place. Dealing with care agencies was generally not a good experience for the participants, and there was a sense they would often try to cut services and withhold information. As one mother said, describing her experience with getting the right information and care:

> *"You have to fight so hard to just get basics that sometimes you'll just give in just to have a good time, just to get through your day. You just don't know what's available, and you ask, and ask, and ask, there must be a support package out there, can I be referred for this, that, and the other".*

Once a care package was in place, the struggles would continue. Many LTV parents described how care agencies would refuse to dispense medicine or demand parents to be home at certain times. Furthermore, there was often significant staff turnover in agencies. Some participants mentioned carers doing multiple shifts in a row in order to make a living, which affected their ability to care properly for the children. The concern over turnover was also shared by an interviewed young person who described the challenges of constantly having to relate to new people.

As part of the current study on transition from child to adult health services[26] the differences experienced by patients with complex, multi-morbid conditions and parents with regard to accessing services has been very clear. A few of themes from the early scoping work are presented here:

### Transition pathways

Most of the participants reported that there were no clear pathways for transition presented to them, and that they either had to discover or create pathways to adult services for themselves. Many of the parent carers had to move out of area to find pathways of care for their children when they became too old to access paediatric services.

One parent was particularly concerned that the transition policies in their area did not provide a vocational framework for their child as they left secondary school:

> *"Although the college is very good it's limited on what will happen afterwards and we do worry. In year 9, 10 or 11 he should have a conversation about preparing for adulthood as stated in his emergency healthcare plan, as part of an annual review – not done because you can't prepare as there are no services available."*

Most of the participants expressed a feeling of 'abandonment' when it was clear that there were no corresponding pathways in adult health and social care services. Finding corresponding specialties, pathways of care and appropriate care was often down to chance, through speaking to other parents:

> *"I found out through another parent about the feeding and eating disorder service at xxx. [A specialist in eating disorders in that service] was one of the only people who ever cared for us. Her care was the best we've ever had but I was lucky to find her. That was a total lottery."*

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[26] NCEPOD. In progress. Transition from Child to Adult Health Services

The participants all felt that health and social care services were not adequately commissioned in their local areas and that the funding of care packages was a barrier to transition. As a result, they had issues accessing a wide range of services, particularly allied health professional services, and often had to pay privately and were left with significant debt:

> *"To me it's the CCG. They commission these services (AHP services etc.) but they're not enough for what your child needs. So, you never get a true picture, never get true pathway. We had to go privately and pay over £1000 for a SLT report."*

> *"I've put myself into debt, I've put myself into debt for physio because my son was in so much pain."*

The continuity of care was highlighted by many of the participants as inadequate or non-existent, particularly when it came to the handover of care from paediatric to adult specialties. Parent carers described transition as a process of "starting all over again" with adult care:

> *"In [transition] meetings she would be so anxious that almost she can't speak…continuity of care is important because it's about building relationships with these people, you can't just come in as a stranger. It's got to be relational and then you'll know if she's got capacity, you know if she understands because you know her."*

Person-centred, holistic care and the lack of planning for the whole process of a young person's transition to adulthood was one of the main areas of care highlighted to not go well. Where transition planning did occur, the participants indicated that the wider implications of transitioning to adulthood were not considered. The main concern was that that plans for transition did not make adequate provision for their young people to live independent lives.

There was also a feeling that young people and their carers were not always invited to multidisciplinary team (MDT) meetings. Having direct involvement in these meetings was felt to be an important part of making sure that any decisions about care were person-centred and accounted for the young person's holistic needs:

> *"They were having these MDT meetings but where were we!? How can they have a meeting about someone they don't know. They were more talking about process rather than a person."*

> *"In meetings, as a parent, you're never an equal. It's never a level playing ground."*

**Environmental factors**

As could be seen in Christopher's video, there were a number of limiting factors to his day-to-day activities that were aside from his physical health condition. In the 'Each and Every Need[27] report the organisation of hospital services to enable people with disabilities to attend appointments was reviewed, as well as the availability of equipment that was adapted to ensure they received an equivalent assessment to someone not physically disabled.

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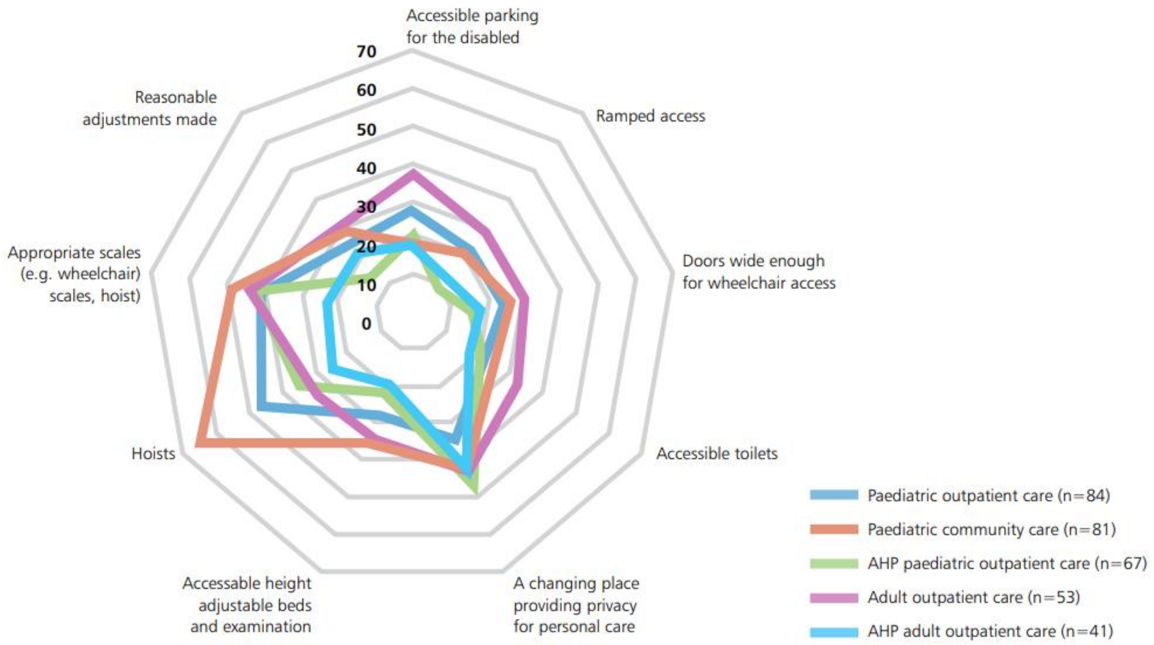
[27] NCEPOD. 2018. Each and Every Need

The Equality Act 2010[28] protects disabled people from discrimination and states that a disabled person should be able to use the services of a healthcare provider as far as is reasonable to the same standard as a non-disabled person and that the service provider must make reasonable adjustments. Equality law recognises that bringing about equality for disabled people may mean changing the way in which services are delivered, providing extra equipment and/or the removal of physical barriers. There should be accessible parking for the disabled, reasonable adjustments made for wheelchairs, appropriate scales and hoists, accessible height adjustable beds and a changing place providing privacy for personal care.

Variations in reported problems in aspects of the **outpatient** environment as reported from different perspectives are shown here.



Comments provided on environmental factors by those working in the hospitals from which the data were received included:

- “Quality of disability facilities not optimal”
- “Hoists and scales not available in every outpatient setting or child development unit”
- “Changing area not accessible for a hoist and in one setting was reported to be open so lacked privacy”
- Some child development centres were reported to be located in old buildings with no access for the disabled and no specialist equipment
- A number of disability and community paediatric services reported having changing places for infants, but not for older young people or adults.

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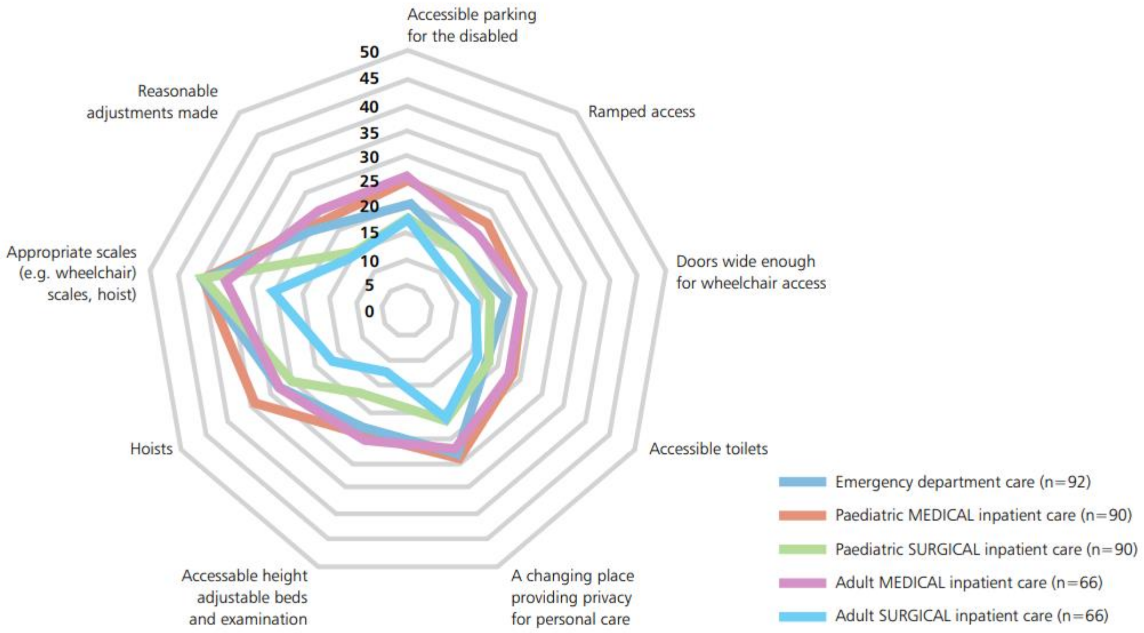
[28] Equality Act 2010

The findings in the report were summarised as:

- **Easy accessibility, hoists, scales**, **changing places** were **not available** in 38/83 **(45.8%)** organisations providing **paediatric** outpatient care and 16/49 **(32.7%)** organisations providing **adult** outpatient care;
- There was variation in terms of access to wheelchairs for both inpatients and at discharge;
- **Wheelchair services** were reported to meet the needs of the population in 31/58 **(53.4%)** organisations providing allied health professional **paediatric** outpatient care, and 22/32 **(68.8%)** organisations providing allied health professional **adult** outpatient care;
- Assessment of equipment needs on discharge was reported by reviewers to be inadequate in 81/234 (34.6%) cases reviewed;
- 40/61 **(65.6%)** organisational lead **paediatric** allied health professionals reported difficulties with equipment services and waiting times.

There were variations reported in the **inpatient** environment too, as shown here.



Where equipment was reported to be available, variation was reported between organisations in the availability in different settings, with lack of availability of equipment especially reported in inpatient paediatric settings, but the reverse for adults, where equipment was more likely to be available for inpatients but not in the community.

**DISCUSSION POINTS RELEVANT TO CHILDREN AND YOUNG PEOPLE AND TO ADULTS**

- Many **children and young people** have to travel long distances to receive specialist care which can separate them from their family.
- Access to specialist equipment for **children and young people** with long-term ventilation can be varied, leading to concern among parents.
- The divide between paediatric and adult healthcare services can lead to **children and young people** experiencing a gap in the organisation of care at the point of transition.
- Poor hospital design or lack of adjustments can hinder basic access for disabled **children and young people** and **adults.**
- There are issues with the availability of suitable equipment to undertake measurements, such as height and weight in patients who are disabled or in a wheelchair. This is relevant to **children and young people** and **adults.**

## SUMMARY AND NEXT STEPS

It can be seen clearly from the data presented that healthcare inequalities, although not always specifically looked for, shine out as examples in the ‘everyday care’ data captured by NCEPOD.

Inequalities in age, disability, sex and socioeconomic deprivation have all been highlighted as well as examples of inequality in inclusion health groups and, perhaps more subtly, inequalities in the organisation and infrastructure of healthcare services, particularly with regard to accessing specialist care and equipment.

It was also noticeable that healthcare inequalities do not work in isolation and many of the examples have highlighted more than one. For example, young men living in deprived areas unable to access mental health services or again, more subtly, the healthcare bias introduced in providing care to a young person who is perceived to be ‘*still drinking*’.

There are, however, gaps in the data presented here, most noticeably ethnicity. As this review was undertaken on data that had not been collected with the aim of looking at healthcare inequalities ethnicity was not routinely collected nor highlighted as a data point as its use could not be justified and what was available was not strong enough to pull out as a theme.

Moving forward, new data collections will be viewed through a healthcare inequality lens. For each study data points needed to help identify health inequalities will be justified and each set of case notes reviewed will be marked if a healthcare inequality is apparent.

Annually, this report will be updated to strengthen the existing themes and/or add new ones.

# RESOURCES FOR FURTHER READING

- https://www.england.nhs.uk/about/equality/equality-hub/resources/
- https://www.kingsfund.org.uk/publications/what-are-health-inequalities
- https://www.england.nhs.uk/rightcare/products/ccg-data-packs/equality-and-health-inequality-nhs-rightcare-packs/
- https://www.instituteofhealthequity.org/resources-reports/marmot-review-10-years-on
- https://www.ucl.ac.uk/news/2021/jun/framework-reduce-inequities-future-generations-launched-professor-sir-michael-marmot
- https://www.gov.uk/government/publications/health-equity-assessment-tool-heat
- https://www.england.nhs.uk/about/equality/equality-hub/core20plus5/
- https://www.gov.uk/government/publications/the-nhs-constitution-for-england/the-nhs-constitution-for-england