HEALTHCARE TRANSITION REPORT 2024-2025

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INTRODUCTION

MEET THE TEAM

My name is **Beth (she/her)**, I am 21 years old and live in Birmingham. This is my second time being part of NHS Youth Forum. I am passionate about ensuring all decisions that affect young people, have them meaningfully engaged in the whole decision-making process. I have lived experience of physical and mental health services which drives my passion. I want to see a bridge made between the “key decision makers” in the NHS and the government, and young people as we deserve to be represented at all levels to achieve true co-production.

My Name is **Katie (sher/her)**, I am 23 years old and live in Hertfordshire. As a young person with chronic health conditions, growing up within the NHS has led me to being passionate about youth voice within healthcare and helping to make changes to other young people going through similar experiences as mine. After a negative transition experience myself, I have become dedicated to trying to make a change within the transition experience for other young people so they do not have to experience the failure of care I went through myself.

My name is **Anushree (she/her)**. I am 19 years old and currently live in London. I was diagnosed with a chronic health condition when I was 14 and since then, I have experienced the hospital process both as an inpatient and outpatient. Transitional care is especially important to me, having gone through the process firsthand. I am passionate about advocating for young patients' needs and committed to raising awareness to help improve this service on a national level.

ABOUT THE FORUM

The NHS Young Researchers are a group of young people (aged 16-25) who work with NHS England to make sure young voices are heard in healthcare. We are part of the wider NHS Youth Forum who provide feedback, help shape policies, and raise awareness about issues that matter to young people within the NHS.

NHS Young Researchers complete an annual research project, working closely with NHS policy leads on different topics.

This year members are split into subgroups focusing on four key areas: mental health, transitional care, new hospitals, and NHS workforce.

106

SURVEY RESPONSES FROM YOUNG PEOPLE

EXECUTIVE SUMMARY

METHOD

Our subgroup developed a survey aiming to understand young people's experience of healthcare transition within the NHS. The survey was open for 30 days collecting first hand data from young people and parent/carer(s). The two surveys identified demographics, personal experience and potential improvements.

Our data included 106 responses from young people of which 71 had lived experience of transitional care as well as 16 responses from the parent/carer(s) survey.

FINDINGS

The national guidelines recommend children and young people should start their transition period between the ages of 11-13. The average age to start transition within physical health services was 16.6 years old. The youngest age to start transition was 14 years old and oldest was 21 years old. The average age within mental health services to start transitioning was 16.9 years old.
The average age to finish transition within physical and mental health services was 17.4 years old and 12 respondents were still transitioning which included a range of ages from 16-22. Three individuals were left with no support and lost within the system.
Young people described transitional care as non-existent and slow as well as highlighting other key issues. Within the parent/carer survey only 2 agreed that their experience was holistic.

CONCLUSION

Our survey highlights significant problems within the NHS transition process, with many young people experiencing delays, poor communication, and a lack of support. Despite NHS guidelines recommending transition from ages 11-13, all began transitioning much later, often leading to rushed and unstructured care. Poor communication between paediatric and adult services results in young people feeling lost, while gaps in mental health support left many without care during a critical period.
Our parent/carer(s) survey reinforced these concerns, with many feeling excluded from decisions despite their key role in supporting young people. To improve outcomes, healthcare services must ensure holistic care, better communication, and a more structured approach. Training led by experienced young people and greater family involvement would help create a smoother, more supportive transition that prioritizes long-term well-being.

0%

OF YOUNG PEOPLE

MET

NICE TRANSITION GUIDELINES

TARGET

OUR TOP RECOMMENDATIONS

1

Establish a national policy on transitional care.

Develop a national policy that outlines clear and structured pathways for young people transitioning between child and adult services. This policy should provide detailed guidance on the available pathways, ensuring that young people can make an informed decision about how they wish their transition to take place.

2

Healthcare workers and young people sharing equal partnership during the transition process.

Young people should be actively heard, advocated for, and empowered to make decisions about their care. The primary focus must be on meeting their individual needs, ensuring a person-centered and supportive transition.

3

Strengthen communication and relationships between children and adult services.

Establish clear communication channels and foster strong relationships between child and adult services. Implement a dedicated handover period for professionals to exchange essential information and align care plans. Additionally, facilitate joint meetings involving the young person and, if the young person would like, involve their parent/carer(s) too.

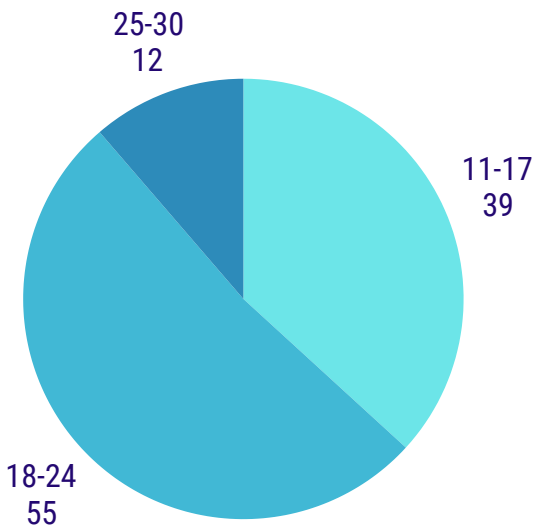
4

Ensure age-appropriate adolescent healthcare and transition support

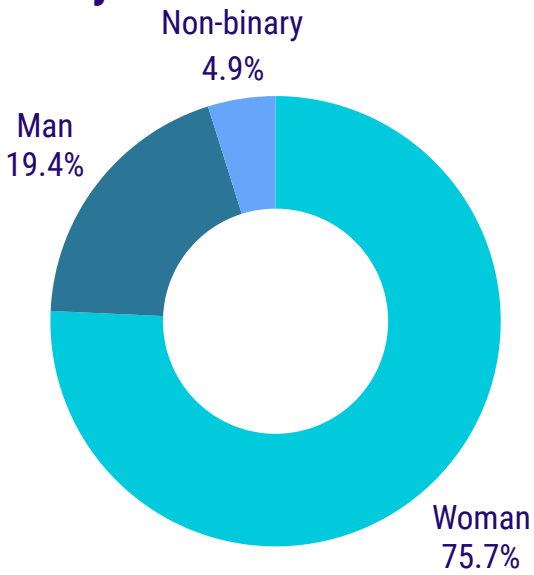
Adolescent-focused healthcare should begin at ages 11-12, with the transition process starting at 13 for gradual and structured preparation. NHS services should review the current transition endpoint of 16 to assess whether extending it would provide better continuity of care. If extending the transition age is not possible, hospitals should ensure that young people in adult wards and outpatients should receive appropriate accommodations including access to education, youth friendly spaces, the options for parents to stay overnight and age-appropriate support to ease the transition process.

DEMOGRAPHICS

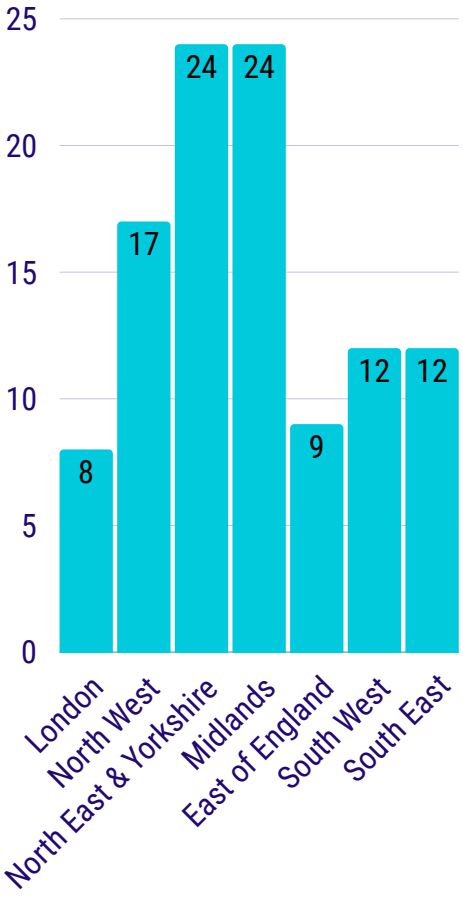
Age:



Gender Identity:



Region:



Method:

Our survey was open for 30 days and the questions were created by young people with lived experience of transitional care. The aim was to collect first-hand data from children and young people about their experience of transitional care and propose interventions to gain feedback. The survey was open to anyone within England who was younger than 30 years old. We also had a survey for parent/carer(s) who had a child/young person with lived experience of transitional care. The surveys were shared on social media, with NHS care providers, charities, youth clubs and within schools.

We received 106 survey responses that could be used as data. 20 responses had to be rejected due to the individual not gaining parent/carer(s) consent.

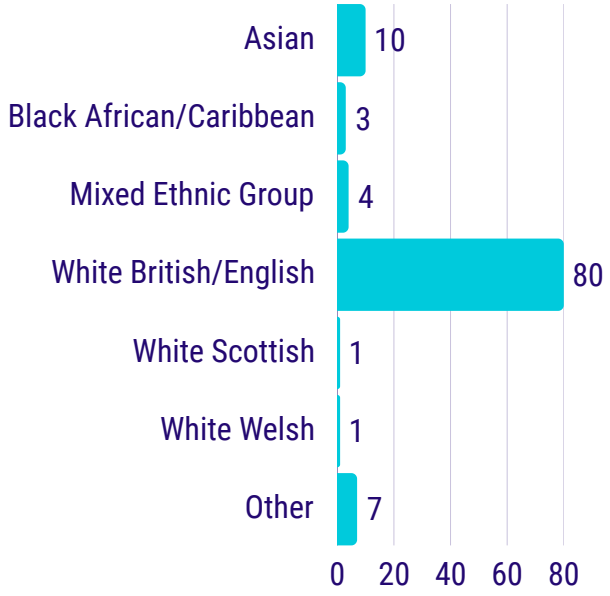
71 respondents had lived experience of transitional care.

Key demographics:

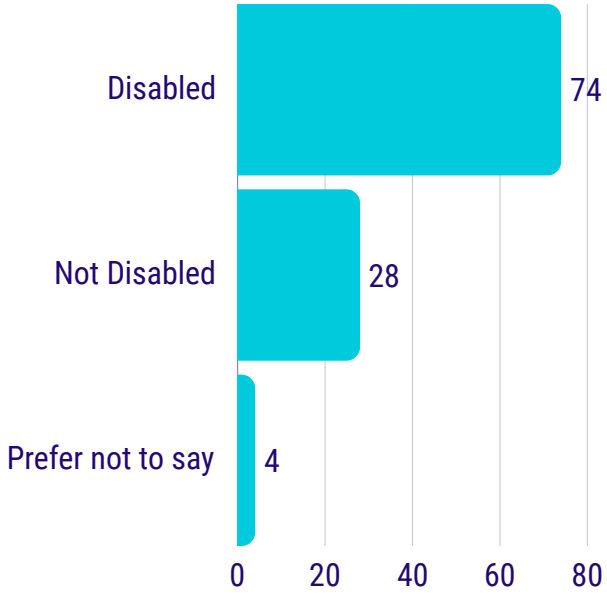
- Over 75% of respondents were female and the mode age range was 18-24.
- London and East of England were the regions with the least amount of responses.
- 80 respondents were white British/English.
- 74 stated they are disabled and over 50% identified as having a protected characteristic.

DEMOGRAPHICS

Ethnicity:



Disability:



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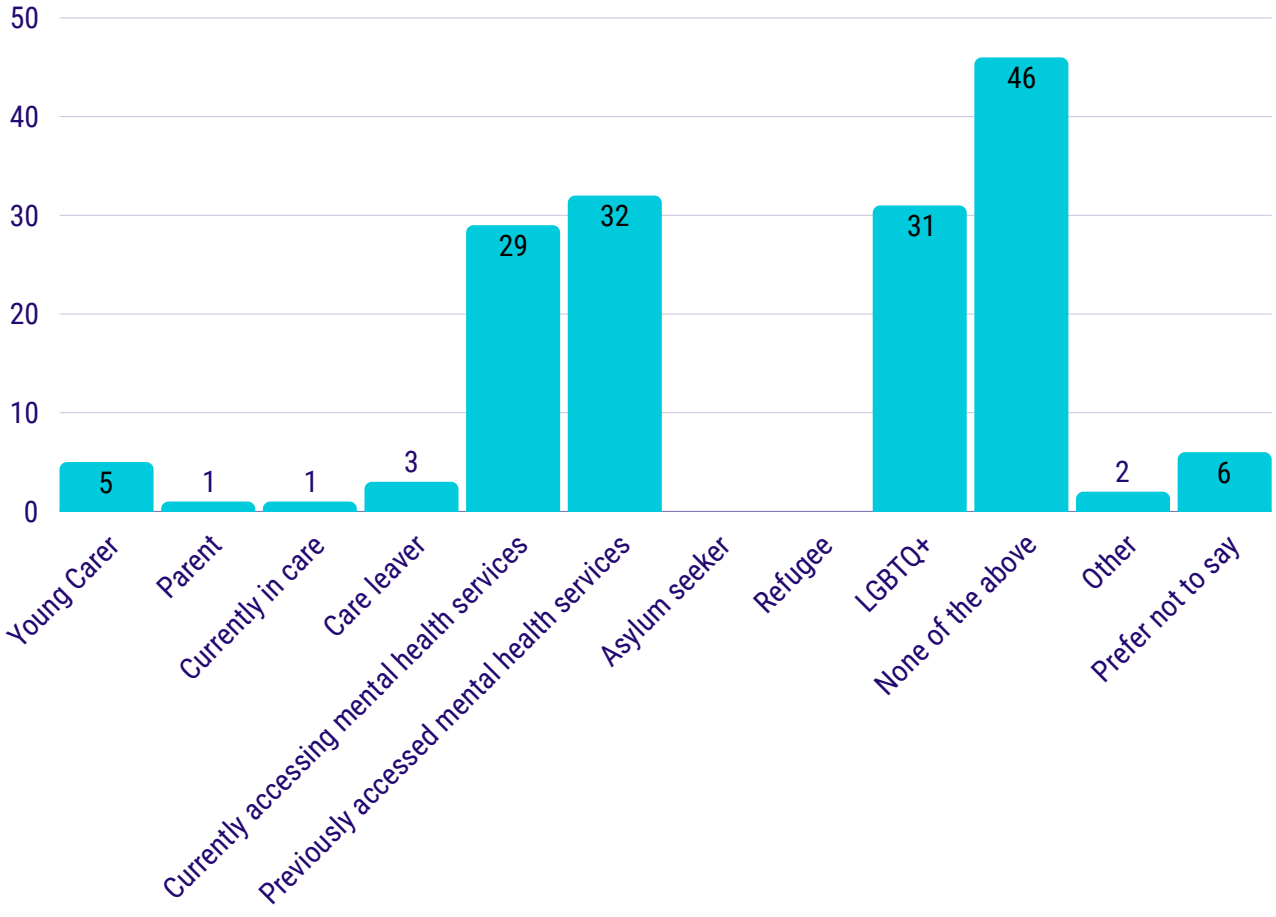


TRANSITIONAL CARE

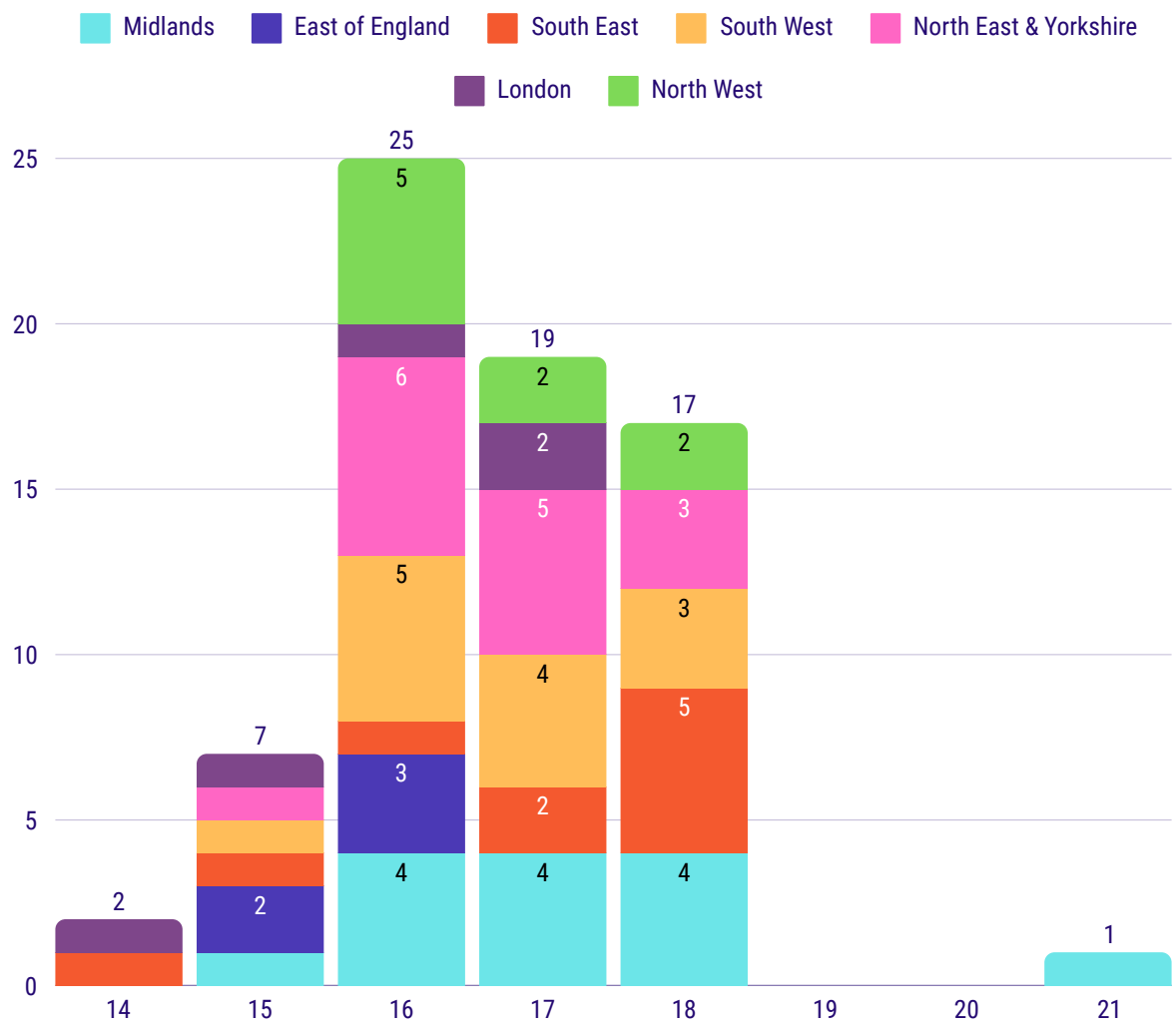
71 respondents had lived experience of transitional care. The current age guidelines set by NHS England for children and young people to start the transition process is between 11-13 years old.

No survey respondents met the target. The average age to begin transition was **16.6 years old.** The youngest age to start transition was 14 years old and the oldest age was **21 years old**. The average age to finish the transition was **17.4 years old** and the average transition period was **less than 10 months long.**

12 respondents were still transitioning and these individuals ranged in ages from 16 to 22. 3 individuals were discharged from services within their transition period and now have **no support**.

Within mental health services, the average age to start transition was 16.9 years old and the average age to finish transition was 17.4 years old, **meaning the average transition period was only 6 months long.**

The age respondents started transition:



HOW DID YOUNG PEOPLE DEFINE TRANSITION IN THEIR OWN WORDS?

THE MOVEMENT FROM **CHILD** TO **ADULT** SERVICES

x33

ENSURING A SMOOTH, EASY AND **STRESS FREE** TRANSITION FROM ONE CARE TEAM TO ANOTHER, WITH THE PATIENT AT THE **HEART OF ALL CONVERSATIONS**

x4

AWFUL, SLOW AND NOT **CONNECTED** MOVEMENT OF SERVICES

x20

TRANSITIONAL CARE IS **NON-EXISTENT**

x3

TOP ISSUES

1. Lack of Continuity of Care
2. Abrupt Movement to Adult Services
3. Negative Impacts on Mental Health
4. Limited Services for 16-18 year olds
5. Increased Travel Burdens
6. Lack of Clarity on Service Pathways

LACK OF CONTINUITY OF CARE

SERVICE GAPS AND DELAYS:

Quotes:
"I was very much forgotten about and for a period. I was not under any named consultant so had no one to turn to.**"**

"Dietician never moved me across and forgot so discharged me at 21 years old.**"**

"Disgusting. Signed off as a child and a 4 year wait to see adult services!**"**

"Still no proper doctor or team so haven't even had a proper review in a year and had to go to the bottom of all the waiting lists again.**"**

The quotes highlight that a number of young people are left with no support or without a new team. They are being missed, getting lost within the system and teams are forgetting to transition them. There are long waiting lists to see adult services, and gaps between transitioning from children to adult services where young people are going periods without receiving care or being under a healthcare team.

Recommendation: Ensure overlapping care between children and adult services for all individuals to facilitate a smooth transition without gaps.

LACK OF HOLISTIC AND INTEGRATED CARE:

71 respondents answered a question asking if they thought their transition was holistic, for example, having discussions around their mental heath, education, future plans.
67% of respondents said no.

Quotes:
"I was never given any discussion about transition beyond being told 'you are getting too old to be under this doctor, we will be moving you."

"No, it was handled really poorly and left me feeling unsupported and insignificant."

"There was no care about any of that really."

There is a lack of holistic and person-centered care during the transition process, which is essential for a young person transitioning to different services as a young adult. Young people can have many other life events/stresses occurring alongside their health conditions such as education, relationships, future plans which can significantly impact the young person further. Young people commonly do not know how to best look after themselves and cope with these changes in relation to their health.

Recommendation: Ensure transition is a holistic and person-centered process. Healthcare professionals must ask the young person about their life outside of the hospital and their treatment, as well as how the hospital team can best support the young person to have the best quality of life and independence.

LACK OF CONTINUITY OF CARE

POOR COMMUNICATION:

Quotes:
"[The new team] didn't have all the information about what had occurred in my paediatric years."

"I was very scared as I had lots of questions unanswered."

"I found myself having to constantly repeat all my health information and why I needed support."

"The services supporting me didn't communicate in any form or way - they didn't even try! We had to be the liaison between them."

Poor communication and communication issues were a key theme within our survey. Young people are having important information about their health and personal journey missed by professionals. There is a lack of communication between children and adult services, as well as professionals communicating to the young people and families themselves. They are having to repeat potentially traumatic medical histories to multiple professionals and do not have the tools or confidence to get the most out of their care and appointments. Adult services often do not have training on how to communicate with young people, creating a further barrier.

Recommendation: Developing an 'expert by experience' panel to create mandatory communication training that has been led by young people. Ensuring there is a proper handover between services, and communication between staff and patients.

"A PERIOD OF A LACK OF **COMMUNICATION** AND GETTING **LOST** IN THE SYSTEM"

"THE TRANSITION NEVER FINISHED, I WAS **CUT OFF** WITH NO SUPPORT, IT WAS **TERRIBLE**"

ABRUPT MOVEMENT TO ADULT SERVICES

LITTLE/NO TRANSITION PERIOD:

Quotes:
"There wasn't much of a transition. When I was 18 I was put straight into adult services."

"Despite being under my gastroenterology team since age 11, they forgot to start transitioning me and only did when I brought it up. I started transitioning when I was 16 and finished at 16."

"[Transition] started at 16, finished at 16."

" I don't really feel like there was a transitional process at all."

A high percentage of young people are being put into adult services with little to no transition period. Services are forgetting that a service user needs to transition to adult services and national guidelines are not being met or followed.

Recommendation: A sufficient and appropriate duration for transition should be provided, giving the young person enough time to adjust to the change. If a young person has been overlooked or unable to follow national guidelines, it is crucial to ensure that a transition period is still implemented to meet their needs.

BIG DIFFERENCE BETWEEN CHILD AND ADULT SERVICES:

Quotes:
"I was a 14 year old girl sat in waiting rooms full of largely elderly and overweight people, and I was made to feel like a baby for bringing my mum."

"It was like children's services washed my hands of me and now everything would be on me in adult services"

"Despite being only 16 I would be put on a ward with adults and wouldn't be allowed to have my mum with me?! It's not ok."

There is a stark difference between children and adult services. Often individuals as young as 14-16 are expected to attend adult outpatients or be admitted to adult wards which are often not suitable for their social, emotional or developmental needs. Navigating adult services as a young person can be challenging with a lot of barriers. For example, young people being expected to be able to cater independently to their healthcare needs after years of parents and child services completing these tasks for them. Adult services often do not have schools, space for parent/carer(s) to stay or suitable adolescent spaces.

Recommendation: Children and adult services should be adapted so adolescents have an opportunity to learn how to take responsibility for their own care. An overlap period between services should be considered so the young person can receive support and advice on how to navigate adult services before having to take the responsibility on suddenly and independently.

NEGATIVE IMPACT ON MENTAL HEALTH

Quotes:

"I met with both teams once via Zoom and then I was left with my new team. It did not give me any confidence and I was very scared as I had lots of questions unanswered."

"I was really anxious about it and felt like there was no support - I had one appointment where I saw the adult and paediatric nurse and then I was straight into adults which was incredibly different."

"It makes me feel completely abandoned by the NHS and makes me feel very unsafe."

"It was traumatising and an awful experience leading me to have a negative stance on adult healthcare."

Young people's transition period is impacting their mental health, especially when experiencing more negative transitions. This will have an increase on their stress levels, quality of life and overall mental wellbeing which can further impact other aspects of their life including their health conditions and future engagement with health services. The current recommended age of transition has been inappropriate, which can lead to the young person being forced to grow up prematurely and potentially witness traumatic situations on adult wards, emergency departments and outpatient units.

Recommendation: Young people should be made to feel safe and be provided the opportunity to express worries and questions with the aim for the team to resolve the problems. Transition should be a holistic approach, including any appropriate mental health and wellbeing aspects. Adult services should be adapted to ensure adolescent needs are met especially when young people transition before the age of 18. This may include an adolescent passport to ensure reasonable adjustments are prepared like parents/carers staying with the young person or adolescent and young people friendly spaces being available.

LIMITED SERVICES FOR 16-18 YEARS OLD

Quotes:
"There is no care from 16 to 18. Too old for paediatric and too young for adults. So just have to wait until I am 18. No one will make decisions."

"There was not a service for me. Child services were for up to 16 years old and adults for over 18 so they didn't know what to do with me."

"I have encountered issues such as being 'between' services for certain specialities where it seems there is no dedicated team for 16-18s."

"2 years later and I still have no support from adult services as I am not yet 18."

In some services and areas, a gap for patients between 16-18 years old was identified, especially within mental health services. Young people often feel lost, being discharged at 16 with no other suitable services until they turn 18. Neither children or adult services are taking responsibility for their care, or have the knowledge to care for the age range of 16-18 year olds.

Recommendation: Every patient should have access to a service that is age appropriate. A clear care pathway should be established between children's and adult services, with both sectors sharing responsibility for the young person's care during this time of transition. Staff should receive training led by 'experts by experience' on how to support young people throughout this developmental period.

INCREASED TRAVEL BURDEN

Quotes:
"I now have 2 consultants in charge and have to travel to London which is further than Oxford. I live in Reading."

"The transition does involve me travelling to a hospital further away from me which can make appointments harder to access."

"More people involved and further to travel."

Some young people experience an increased travel burden when transitioned to adult services. This can mean it is more costly and time detrimental on the young person and their family. More time is missed within school, social life, and recreational activities which can decrease quality of life in comparison to those who do not have a health condition.

Recommendation: Services should recognise if a young person is going to have to travel further for appointments with their adult team. Young people and their families should be supported to attend appointments including making relevant people aware, e.g. their school so reasonable adjustments can be made. Other appointment options should be considered where possible, for example, phone or virtual appointments to cut down on travel time.

LACK OF CLARITY ON SERVICE PATHWAYS

Quotes:

“During April 2023, I had to be admitted for pain management. I was 17, two months away from turning 18, and I was wrongfully put on a paediatric ward. I was blamed for this, and I was neglected by the nurses on the ward, verbally abused by doctors and I was left with PTSD. This could’ve been avoided with a smoother transition and a clearer transition pathway."

“I feel they started my transition very late and because I have complex needs and under a few different teams I’ve now sort of been lost in the system.”

“A few days before my appointment with adult services where I would officially transition. I was told to go to paediatric a&e. Instead of caring for me, they argued about whose care I should be under, adults or children's. No one took responsibility.”

“I am now under more specialties and the care is not as ‘joined up’ which, when you have rare conditions, makes it very hard”

There is a clear lack of clarity on the correct service pathways when transitioning young people to adult services.

There is a lack of planning of transition despite national guidance stating the ideal transition age and pathway, and there is a lack of clarity on how the pathway to adult services should be structured. Services are not receiving clear guidelines of where best to direct young people for support, and therefore young people and their families themselves are not receiving clear guidelines on where to, for example, attend for emergency help. Young people with complex needs under multiple teams are especially experiencing disjointed care and transitions.

Recommendation: A clear pathway set out for healthcare providers and service users so that everyone is informed of how the transition period should take place. This should also meet young peoples needs if they have complex or rare conditions to help navigate movement of multiple specialties.
This could also include the creation and implementation of a transition training course for healthcare professionals.

TRANSITION WITHIN MENTAL HEALTH SERVICES

Out of 106 responders, 19 young people declared they had transitioned within mental health services. **0 respondents** rated their transition as 'positive' or 'really positive'. 1 respondent had not yet finished transitioning, 3 rated 'neither positive or negative'. 5 respondents rated' negative' and 8 'really negative'. 2 did not give a rating.

> When I was first sectioned in an adult hospital **it was really hard** because there were people there **up to the age of 65**. It was **very scary** and **daunting** as an **18 year old**.

> **It took ages to get moved over** from CAMHS to CMHT and was only done after being in hospital with serious self harm and a suicide attempt. **I got left with no care for about 6 months**.

As well as negative transition experiences within physical health services, young people are experiencing negative experiences of transition within NHS mental health services, with many young people highlighting experiences of being **left without support** and **without suitable mental health care** for up to *years*. The average age of beginning the transition process was **16.9** and the average age to finish the transition process was **17.4,** meaning on average the transition process was only happening over **5 months.**

> (My) dietician never moved me across and forgot so **discharged** me at **21 years old**.

> The nurse that I was working with then became ill and **no one picked up my case.** I was **without support** for a few months and then I turned 18 and was **discharged without any support** or follow up

> My experience of transitional care was more of a **cut-off**. I was seen for my anxiety by CAMHS at 17 at which point they told me **there was nothing** they could really **do to support me** as I was nearly 18. I have **never been seen by a specific mental health professional since**.

TRANSITION WITHIN MENTAL HEALTH SERVICES

0%

OF YOUNG PEOPLE

RATED

THEIR MENTAL HEALTH TRANSITION AS

POSITIVE

KEY THEMES:

- Lack of mental health support for young people between the ages 16-18 years old, with many CAMHS units discharging at 16 but there being no relevant service for the user until they turn 18.
- Young people being discharged from CAMHS Teams instead of transitioned or referred to adult mental health services.
- Large age gaps between patients is creating fear and uncomfortable relationships for young people in mental health services
- Young people are being rejected from services due to being deemed 'not ill enough' to receive support, and often support only happening after a mental health crisis.
- Long waiting lists between children and adult mental health services.

RECOMMENDATIONS:

We recommend implementing a dedicated 16-18 transition service where possible, to prevent young people of these ages being left without care. Developing structured transition pathways and age appropriate spaces to make young people feel more comfortable and safe during their treatment. It is important to ensure this process is as smooth as possible, and that young people have continuous support during this period.

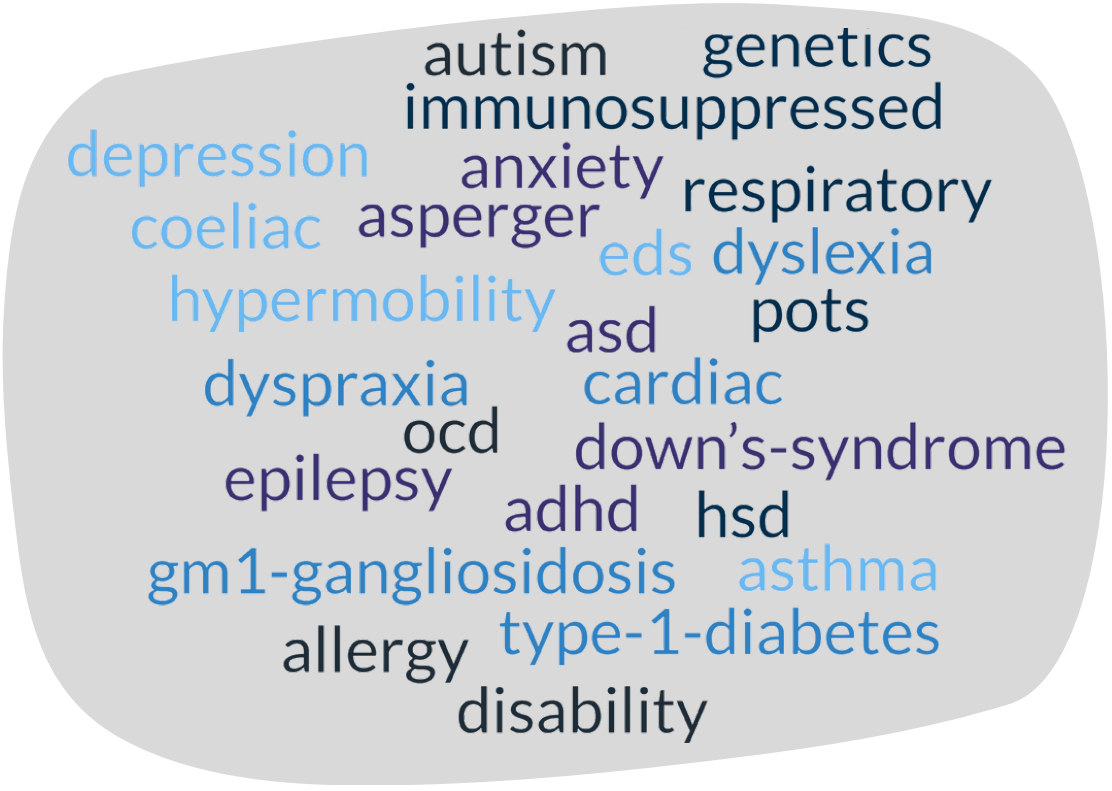
PARENT/CARER SURVEY

The average age of the young person starting the transition was 17, with a starting range of 15-20 years old. The average age to finish transitioning was 19 years old, with a finish range of 16-25 years old.

Quotes:
"We started the transition too young. Inappropriate questions/forms to complete by nurse. Worded in such a way as to suggest to him not to have a parent present at appointments moving forward. This was really unhelpful as he was unaware of his epilepsy and could not discuss or describe it, nor understand drug regime. He tries to please and do what professionals want."

16
RESPONSES FROM
PARENTS OR CARERS
WITH LIVED EXPERIENCE OF TRANSITIONAL CARE

CONDITIONS/SPECIALTY OF TRANSITION:



PARENT/CARER SURVEY

KEY THEMES:

- Not being transferred to a new service
- Being told to access a community service but unsure how to gain this support
- Having two addresses, e.g. parents are divorced, added challenges to the transition
- The transition took place at the same time as A Levels and/or GCSEs which added more stress to a significant period of the young person's life
- Lack of preparation for the transition
- Lack of reasonable adjustment for those with learning disabilities and additional needs when entering adult services

AN "IDEAL" TRANSITION:

- Wait until the young person is 18 to begin transition and finish the transition period at 25.
- Allow parents/carers to stay overnight on adult wards and attend hospital appointments, when wanted by the young person.
- Explanations in appointment letters about the transition period and how the young person can take more control of their care
- Provide relevant transition resources
- Support parents/carers and young people with a learning disability and additional needs more throughout the transition period; this may include creating a one page profile/passport
- Ensure services have a period of overlap within the transition period
- A good handover between professionals

> Transition happened at the most stressful time in my son's life (apart from his 5 cardiac surgeries!) It was during his GCSEs. He was already incredibly anxious because of the exams and really didn't need this too!

> "When you have a child with behavioral challenges and mental health problems it's not easy to access adult services."

> "When you have a child with behavioral challenges and mental health problems it's not easy to access adult services."

PARENT/CARER SURVEY

> We were hoping that our son would stay in paediatrics for longer due to his learning disabilities. However, we attended a check up appointment and unexpectedly at the end of it, the cardiologist just said that the next appointment would be in the adult department! We had no opportunity to prepare our son for this news so it caused a lot of additional anxiety and subsequently we had questions that we hadn't been able to ask.

2/3

DESCRIBED THEIR

EXPERIENCE

AS

NEGATIVE

ONLY

2

AGREED THAT THEIR CHILD'S CARE WAS

HOLISTIC

> The first appointment in adults was an extremely distressing one because it was the first time the new cardiologist had met our son and we all felt like he was telling him off without understanding his other co-morbidities or his learning differences. 10 years on we still haven't met the learning disability nurse at the hospital to discuss reasonable adjustments.

POSITIVE PRACTICES

Whilst most responders rated their transition as really negative, negative or neither negative or positive, 14 young people rated their experience as 'positive'.

What did their healthcare team do differently?

Whilst speaking about the negative experiences of young people, it is also important to highlight the positive experiences young people have had and what happened for them to view this as a positive transition experience.

WHAT DOES A POSITIVE TRANSITION LOOK LIKE?

Based on survey results, young people said that the below support helped them with their transition:

- Overlapping care between children and adult services
- Transitioning at a time that suited the young person best
- Extra support e.g.from a dedicated transition nurse
- A multidisciplinary team approach
- Everything clearly explained, with young people feeling comfortable to be open and honest to their healthcare team.
- Of those who described their experience as positive, 16 was the average age to start transition

> I was welcomed very warmly and everything was explained to me in a lot of detail. I was asked if I had any questions and my questions were answered in a lot of detail. Everyone that talked to me was very welcoming, warm and caring.

> I had plenty of time (3 years) to process the transition and make sure I am ready.

> I had plenty of time (3 years) to process the transition and make sure I am ready.

> My experience has been positive because moving to adult services has led my care to better support my condition as well as see specialists that I would not have otherwise been able to see if I hadn't transitioned to adult services

POSITIVE PRACTICES

EXAMPLES OF POSITIVE PRACTICE:

During our research, we spoke to multiple different NHS Trusts who had been trying to implement different things to help the transition process within their hospitals.

University Hospitals Bristol NHS Trust have created a dedicated website page, in partnership with young patients, with information all about the transition process. There is an A-Z list of information including things on specific medical conditions, medical care, information on how to build independence and more. It is a holistic approach, helping young people think about their condition, health, emotions and education/work all in one.

You can find the page here: ***https://www.uhbristol.nhs.uk/transition/s-u/***

Alderhey Children's Hospital is another positive example of transition. Many young people who have transitioned under Alderhey have rated positive experiences of the transition process. They have a hospital transition policy with a 10-step transition pathway, making the process clear to all professionals within the young persons care. They have a transition exception register, for young people who may need to be transitioning at a later age, and many resources to help support young people and their family through the process such as transition passports, urgent care plans and more.
You can find more information here: ***https://www.alderhey.nhs.uk/services/transition-adult-services/***

"BUILDING PARTNERSHIPS WITH EXPERTS BY EXPERIENCE GIVES HOPE FOR TRANSFORMING THE NHS"

"I WAS **WELCOMED** VERY **WARMLY** AND EVERYTHING WAS EXPLAINED **IN DETAIL**."

CASE STUDY 1

Age of Transition: Started transition at 18 years old
Service: Endocrinology
Support received: No resources given

How would you define transitional care?
Moving to adult services

How would you describe your experience of transition?
Neither positive nor negative

Why did you give that answer?
Had 1 joint clinic with consultants only, no nursing support and no referral when I moved away to uni. Have since been lost in the system. When a problem was identified, my adult consultant was very supportive and has referred me to my local hospital.

What would an ideal transition look like?
Plan for future, nursing support, awareness of when to seek help and contact details.

CASE STUDY 2

Age of Transition: Started transition at 16 years old
Service: Epilepsy Service
Support received: Leaflet given

How would you define transitional care?

I would define transitional care as the process of transferring from a department specialised in children to a department that is specialised in adult care, which takes place when you are around 16 years old.

How would you describe your experience of transition?

Positive

Why did you give that answer?

I was 16 when I attended my transition from the child services to the adult services appointment. I am still 16 now. I was welcomed very warmly and everything was explained to me in a lot of detail. I was asked if I had any questions and my questions were answered in a lot of detail. Everyone that talked to me was very welcoming, warm and caring. I have been given leaflets about different parts of transitional care and information sheets about different things I may need to know about my condition, with the process of growing up. The team asked me about school and about my own personal interests and made sure that I was very comfortable in the experience. They asked me about my future career path, my experiences and about my personal life, which made me feel very comfortable and made the whole experience less intimidating.

CASE STUDY 3

Age of Transition: Started transition at 18 years old
Service: Mental Health services
Support received: No resources given

How would you define transitional care?

The change of going from Children and young people's services and beginning accessing Adult services.

How would you describe your experience of transition?

Really negative

Why did you give that answer?

The transition never finished, I was cut off with basically no support, it was terrible. After 10+ years of experience in mental health services, I was suffering and very poorly. The week I turned 18 my CAMHS worked discharged me with no support. She put in a referral to the wrong service (adult social care) and when adult social care assessed me they said she had referred me to the wrong place and I needed adult mental health care. I was getting no support at all through this. I was then bounced around from service to service, waiting list to waiting list getting no support. It was all confusing and scary and I was left suffering alone. I am now 20, 2 years later and still have no support from adult services because they are impossible to get into and confusing even when I have been in CRISIS. The transition was terrible and it took any support I ever did have.

What would an ideal transition look like?

Easy, straight from one service to the next, continuation of support, no gaps, good communication, making sure the patient always has the service they need, it should be thoroughly discussed and their treatment should continue through the whole transition. It should be supportive and easy. I think when leaving children's mental health services if the patient is still poorly (like I very much was) they should automatically get straight into adult mental health services and move over immediately and continue to recieve support. It should feel easy. Better professional to patient communication of their needs too.

CASE STUDY 4

Age of Transition: Started transition at 15 and finished at 19
Service: Rheumatology and Gastroenterology
Support received: No resources given

How would you define transitional care?
Challenging. A period of a lack of communication and getting lost in the system.

How would you describe your experience of transition?
Really negative

Why did you give that answer?
I was very much forgotten about and for a period not under any named consultant so had no one to turn to. This was also during COVID. I was never given any discussion about transition beyond being told you are getting too old to be under this doctor, we will be moving you. I then waited over a year to see the adult services

What would an ideal transition look like?
A partnership of the childhood services and adult services, working together with the patient. Open lines of communication between the young person and professionals. An appointment were a member of the youth team and adult team are both present so there can be a true 'handover' which is patient led.

CASE STUDY 5

Age of Transition: Started transition at 16 and finished at 18
Service: Cardiology and Respiratory
Support received: No resources given

How would you define transitional care?
I don't have an understanding because it just happened at my appointment one day with no preparation.

How would you describe your experience of transition?
Really negative

Why did you give that answer?
It just happened at my appointment one day with no preparation. Timing was right in the middle of my GCSEs so I was already extremely stressed out. My first cardiology appointment in adult services, I felt like I was being told off for being me and that left me unable to sleep for a couple of weeks because it left me extremely anxious. I have a learning disability and this was and has not been considered at all.

What would an ideal transition look like?
A slow build up with proper preparation work and an actual pre-introduction to everyone and everything that I would need to know about.

CONCLUSION

Our survey highlights critical flaws in the NHS transition process, with many young people facing delays, poor communication, and inadequate support. We identified six key challenges, including rushed and unstructured care due to late transition starts. Many young people experience sudden disconnection from healthcare services, leading to significant deterioration in their health.
Another main concern is the breakdown in communication between paediatric and adult services, leaving young people feeling lost during this crucial period. Additionally, gaps in mental health support are particularly concerning, with transition periods often being more abrupt and less structured than those in physical health services. Many pathways remain unclear, making access to necessary care even more difficult.

Our parent/carer survey reinforced these concerns, with many caregivers feeling excluded from key decisions despite their essential role in supporting young people.

To address these issues, we propose four key recommendations aimed at changing national guidelines and improving training, awareness, and service delivery within the NHS.
These recommendations focus on enhancing communication, ensuring holistic care, and implementing a more structured transition process.

Future research could further explore how different factors impact young people's transition experiences, including:

- Urban vs. rural living
- Age at which transition begins
- Gender differences
- Differences between mental and physical health services
- Hospital-specific or regional variations in transition quality

By addressing these challenges and implementing targeted improvements, the NHS can begin to create a holistic and person-centred transition and adolescent healthcare process that truly supports young people in their journey to adult care.

For more information about the NHS Youth Forum and Young Researchers, visit **https://www.barnardos.org.uk/nhs-youth-forum** or email us at **NHSYouthForum@Barnardos.org.uk**

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