

FOCUS GROUPS

Four small focus groups were undertaken with a total of 14 parent/carers (two groups of three and two of four) and, three young people were interviewed, representing a mix of physical and mental health conditions, and stages of transition. Each focus group was held online on Microsoft Teams and facilitated by two NCEPOD researchers working on the study. One led the discussion and the other kept time, monitored the chat and made sure all areas for discussion had been covered.

Participants were recruited through an online survey with representation from across England and Wales.

WHAT WENT WELL DURING TRANSITION?

CONTINUITY OF CARE

Some parents/carers commented that having the same clinician provide care in both paediatric and adult services was beneficial to their young person when transitioning to adult services.

One parent explained that even though the clinician in child services was no longer providing care for their child, they could still phone them up at any time if they were concerned:

Parent: "We didn't feel as though we were being thrown in the deep end."

Joint clinics that involved both paediatric and adult teams for a period before being fully transferred were also said to be the reason they experienced a smooth transition.

The respiratory team at a major center were said to be the only team to arrange joint transfer to adult services for one young person who was under a range of specialties. The team made sure that the young person was under both paediatric and adult services for 18 months before fully transferring them to adult services. The parents did add that while the acute care was addressed well by the joint transfer, the wider needs of the young person and their family were not addressed.

COMMUNICATION

Simply having clinicians who worked in the same organisation at least knowing who each other were and having clear lines of communication, was said to aid the transition process. As was being told what the pathway for certain conditions would look like when transitioning:

Parent/carer: "...at the very least, being told which way you are going was an important starting step when transitioning to adult services."

Some parents/carers also commented that digital and shared health records were helpful in allowing healthcare professionals to organise the transfer of care and record their young person's wider needs. As some of the young people had to sometimes to move across borders, having a central point of access to their records for multiple teams was crucial when communicating about transition. Locally developed apps were given as examples of good practice.

SPECIALIST/TERTIARY CENTRES

Specific mention was given to children's tertiary centres and their models for transitioning young people with complex conditions who are under multiple specialties. These centres were said to plan from the age of 13/14 years old, in line with current guidance, which was effective in preparing both families and young people for adult services.

One parent said that having been transitioned from one specialist centre to another within the same area meant the process of transition was almost seamless:

Parent: "Handled very well and given lots of warning [about the need to eventually transition to adult services]"

CARE FOR THE CONDITION

While this was not true for all, many participants said that their or their young person's specific condition, or conditions, received a high level of clinical care and appropriate intervention. This was especially the case for life-disabling conditions in paediatric services.

POSTCODE/CLINICIAN LOTTERY

One parent described their overall experience of transition as excellent. However, they made a point of saying that they thought this was due to the lottery of where they lived and the clinician who oversaw their young person's care:

Parent: "We got the golden ticket."

PERSONAL ALLOWANCES/HEALTHCARE BUDGETS

Most of the participants said that having a degree of control over their healthcare budgets worked well during transition:

Parent: "The biggest thing we've got for [my child] is a personal health budget...it pays for everything."

This parent also stated that having control over their healthcare budget meant that they could transfer ownership of their young person's care needs to their young person and their carers gradually:

Parent: "It's all in there and we can manage that and handover the ownership of that to [my young person] and the carers over time. So, once we've got it in place we can relax."

EARLY AND EFFECTIVE PLANNING

Early planning was high on the list of things that enabled transition to work well. The importance of for the impetus for planning to come from health or social care professionals was stated. Some parents/carers suggested that when planning started at around 12 to 13 years old it provided enough time for both the young person and their family and all healthcare professionals involved to adequately prepare for the eventual move to adult services. A young person interviewed said that early planning made the process of transferring care "less of a shock to the system".

One parent who had a good experience of the process of transition said that a binding working plan, with deliverables that local authorities, CCGs and health and social care were legally obliged to action, could be more easily drawn up when discussed at an early stage. The same parent also explained that this enabled priorities to be agreed upon sooner and less time sensitive issues to be put 'on the backburner'.

Another parent described that planning for transition was especially productive when they were able to get paediatric and adult healthcare professionals in a meeting together. Parents/carers in the same session supported this, explaining that they, along with other parents in a similar situation, were able to design a more effective service in their area by sitting down with all of the stakeholders involved in their young people's care:

Parents/carers: "We don't want to be here, we want to work with people. I've worked with one clinical commissioning group which was disbanded as it was so awful. But it was so refreshing to sit in a room and work with all these people: Local Authorities, healthcare professionals, and other parents. We could all say things freely and we built a better service in the end by working together and having meetings and keeping informed. That's all we want....by working together it can help our children and us for the future."

OPEN ACCESS TO INPATIENT CARE

One parent/carer stated that open access to inpatient care in adult services had been excellent and comparable to how it worked in paediatrics:

Parent/carer: "My [young person] had open access to the paediatric ward. The paediatricians had terrified us into believing that admissions in adults would be awful, but it turned out to be quite the opposite. Every infection [my young person] has they have sepsis so they are a red flag admission to hospital via resus. It's excellent, the care is fantastic, it's worked really well. We've built up a really good relationship with the hospital, the resus, the physiotherapy team and the respiratory ward."

ADOLESCENT SERVICES AND THE BENEFITS OF NO LONGER BEING CONSIDERED A CHILD

An adolescent care service was highlighted as an example of inpatient care that works well for young people, by a young person who was interviewed:

Young person: "I love how they do it because they have the children's ward and then the adolescent ward and then they have a young adult ward and then you go onto adults. That's so good because you're not getting thrown into adult services so suddenly."

The young person also made it clear that entering adult services offered them a greater degree of responsibility and independence which had some practical benefits. These benefits were centred on being trusted to administer medications at home, thereby reducing their interactions with acute services:

Young person: "My adult team is very good because I am an adult now, they let me do more at home which keeps me out of hospital."

SCHOOL

Most of the young people represented by parents/carers were in special needs education, and they found that these organisations were helpful in planning for the transition to adult services. These organisations also allowed them to connect with other parents and professionals who could offer support and advice:

Parents/carers: "Where the schools are connected, they are very good at involving the parents and professionals. Once it gets out of school it becomes a very different ball game. Mostly because parents don't know who it is they should be speaking to, what direction they should be going in. People throw different names and you go: 'well what's that and what does that do?'"

WHAT DID NOT GO WELL DURING TRANSITION?

PERSON-CENTRED/DEVELOPMENTALLY APPROPRIATE HEALTHCARE

One of the strongest themes to come out of the meetings was the lack of developmentally appropriate healthcare and communication when engaging with young people about their care and transitioning them to adult services. This issue was reflected by both the young people and parents/carers who participated in the sessions.

For the young people, there was either little consideration for their developmental age when engaged by adult services, or their voice was not heard in children's services. The young person who transitioned through mental health services believed that mental health professionals, in particular, should approach young people in a more developmentally sensitive way, as not every young person is ready to be treated as a fully grown adult at the age of 18 years old:

Young person: "As soon as you turn 18 years old, you're treated quite differently compared to how you are as child."

Another young person agreed that in children's services they were often not listened to and in adult services they were expected to take on more responsibility than they were ready for. While under paediatrics, they developed a rare and poorly understood condition. Their main symptom manifested as fatigue which, due to them being a teenager, was dismissed by healthcare professionals:

Young person: "I got labelled as you're a teen, you're always going to be tired."

Both young people agreed that neither of them were treated in a person-centred way by either paediatric or adult services, but rather as a general age bracket.

This feeling was mirrored by some of the parents/carers. They were especially concerned that adolescents were being treated as adults by some services at predetermined ages with no consideration for the individual and their circumstance:

Parents/carers: "They've put a very hard cut off at the age of 16 years old."

Some thought this played a role in them (the parents/carers) being excluded from conversations about their young person's care when they reached a certain age. They said healthcare professionals should not automatically exclude them from conversations about their young person's care when they need to transition, as there are sometimes issues around

mental capacity that need to be addressed by the parents/carers. One example given was the Mental Capacity Act and how it is misapplied to adolescents:

Parents/carers: “[Mental Capacity Act]...not fit for children with cognitive issues...it is meant for older people. It needs to be relooked at.”

Parents/carers: “Speak to the kids and not the parents, that’s not going to work with a lot of these children.”

They also felt that there was no appreciation that their young person may not want to take responsibility for all aspects of their care in adolescence. Most parents/carers said that their young people were still heavily reliant on them to organise their care. Adult allied health professional services’ failure to acknowledge this during the transition of one young person, led to avoidable communication errors between the service and the young person:

Parent: “My [young person] was getting extremely distressed being called in college [and asked about their healthcare].”

There was a consensus among all the participants that rigidly structuring services and, importantly, communication around ‘hard cut-off ages’ and, not centring care around the individual, made the process of transition challenging. In their view, health services were not striking the right balance between giving young people more autonomy over their care and recognising that they were a unique group, distinct from fully developed adults and were still developing teenagers:

Parents/carers: “...what [their young person] really want[s] to do is go out and be a teenager.”

Parents/carers: “There are different levels of transition, it means different things...the wider transition in terms of someone’s life...it’s about housing, it’s about care staff...intelligent spending...you can have different conversations through the process but no one’s willing to have those conversations.”

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:

Parents/carers: “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.”

When they were invited, many of the participants said that they often felt as though they were on unequal footing with the healthcare professionals in MDT meetings and that there was a need for an independent advocate to be there as well:

Parents/carers: "In meetings, as a parent, you're never an equal. It's never a level playing ground."

Another strong theme that emerged was that meetings relating to transition often felt like a tick box exercise:

Parents/carers: "Transition felt like a case of filling out some paper work."

DEDICATED ADOLESCENT HEALTHCARE SERVICES/TRAINING

Many participants noted the lack of dedicated and appropriate spaces, wards and services that are tailored for young people and adolescents. The absence of adolescent services across the country was compounded by the absence of adolescent training provided to healthcare professionals in paediatric and adult services. These two factors were significant barriers during the transition process for the participants:

Young person: "[Healthcare professionals] need some type of adolescent/young adult services training."

Both young people saw adolescent training and adolescent centred wards and services as critical to ensuring a smooth transition to adult services. One young person explained that without a transitional service between paediatric and adult services, in many instances young people with complex needs are at loss as to where to go:

Young person: "I'm at the age where I can't use paediatric services and I can't use adult services, so who do I go to?"

When admitted to adult wards, the young people said they often felt intimidated and queried whether it was appropriate for an adolescent to be admitted to areas meant for adults:

Young person: "When I'm admitted I get put in a side room on an adult ward – because it can be chaotic on an adult ward...you don't feel safe."

They were both very clear that there should be specific adolescent wards for all young people, but especially when young people have ongoing complex conditions:

Young person: "If there was a young adult ward that would be amazing."

The parents/carers were concerned that when their children were admitted to adult wards they were inappropriately treated as fully grown adults. They were sometimes not consulted about the young person's care or allowed to be with them at times when they needed the support:

Parents: "[I had to fight to be with my young person] when they were going in for surgery and frightened and needed me there with them. They experienced 10 out of 10 pain when they came round. They were terrified enough but they would have been even more terrified when they came round if I wasn't there."

The young person interviewed stated that there is a need for an in between service between paediatrics and adult services, especially in a hospital setting, for adolescents when they are transitioning:

Young person: "I was very unwell. I presented at about midday. And I was in paediatrics A&E. Until about 6pm at night they spent time just arguing over should I be in adult A&E, should I be in paediatrics... should I go to an adult ward. And 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 bloods 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 them for so long they are going to resus. So, I end up in resus and then ended up in PICU 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."

The young person also wondered how an older adolescent who is still in education would access school services in an adult inpatient setting:

Young person: "If you go to A&E and you're 16 you'll go to adults and I always think how that works out because you're 16 and you're on an adult ward. What happens [because] you're legally in education until you're 18 but because you're on an adult ward you can't go to the hospital school in paediatrics?"

They also felt the young people did not have their wider needs, such as mental health, addressed as they might have had on an adolescent ward tailored to young people with complex conditions:

Parents/carers: "It depends on the child... but at 18 years old they're an adult in the eyes of the law but they still have a lot of vulnerabilities...especially, in this case, when [my young

person] finds out that they have a disease that could kill them when they're 30. They had gone from being fit and active to being in a wheelchair at 18... it's a huge mental load to take on....unless you're on suicide watch you have no mental healthcare."

CONTINUITY OF CARE

As healthcare for children with disabling conditions improves, there appears to be an ever-widening gap between the services offered to children, compared to what is offered in the adult services, when young people with complex conditions reach a certain age. The lack of parallel specialties in adult services was described by most participants across all groups as a fundamental reason for why young people with complex health needs can disengage with health services and effectively "fall off a cliff":

Young person: "At 18 you leave your paediatrician and there are empty voids of care."

In the parents/carers' experience, parallel specialties were either not available, or set up to accommodate fully developed adults with common health needs, rather than teenagers who require complex care. This was especially the case when their young people required social and palliative care from the age of 18 to 25 years old:

Parents/carers: "Especially with end-of-life care...from 18 to 25 years old there just doesn't seem to be any support."

Many parents/carers said that specialists would discharge their children at 18 years old and would not know who to refer onto in adult services:

Parents/carers: "This is how children fall down the gaps, they become unwell, and they don't know who to return to."

One parent felt the continuity of care for young people with complex conditions should have been addressed by the NHS due to the data that the service holds on all children:

Parent: "None of our children's 18th birthdays should have been a shock to anyone because the NHS knew their birth dates. At least six years before they should have made sure there was something to them to transition to, if they should survive."

One parent voiced their frustration that services put the onus on the young person and family to fit into specific services instead of making the service more accessible by considering the family and their circumstance:

Parent: "So the agencies expect the young person to be able to mould into the services, or they do not access any support."

Some parents/carers commented that services are set up to accommodate the general population and not the minority who are more medically complex and a lot more likely to require flexibility on the part of health and social services. The lack of flexibility in adult services was said to further minoritise them and their young people in society:

Parents/carers: "The minority experiences are further minoritising us families."

Parents/carers: "Often, we can't access services. There needs to be more flexibility."

Parents/carers: "We are being excluded by the inclusion products because our children are too medically complex."

They felt health services were merely transferring their young people and not fully transitioning them during a challenging developmental stage for the young person. They explained that when their young people were picked up in adult services, they no longer received the holistic care that was on offer in children's services. They specifically mentioned integration into higher education, social care, and employment as an issue:

Parents/carers: "Everything is improving medically and enabling our children to survive longer but the whole planning behind keeping them alive is that you actually need to give them a reason to live."

Parents/carers: "My [young person] loves life, they love going to school and meeting other people and doing activities, but if there's nothing there for them as an adult...if the respiratory problems and the epilepsy and the covid doesn't get them, boredom's going to."

This was also a problem for the young people with one saying:

Young person: "My transition was pretty cut-throat. I need help reintegrating into school and I didn't get that support."

Both young people said that varying standards from child to adult services also posed a significant barrier. One young person felt that in adult services they no longer had the level of input from the range of specialties that they had in paediatric services:

Young person: "In paediatrics I had my own little team around me. All the team knew me, all the registrars knew me, all the physios, OTs, psychologists. I had a little MDT."

Recently transitioned, they said that they were left with just a consultant and specialist nurse and closed off from the MDT in paediatrics who facilitated their holistic care needs:

Young person: "In paediatrics the people around you are a lot closer to you. It's like a one-on-one type of care that you get."

Young person “Yeah, they do handover but they’re not going to know like you as your old consultant did.”

Not having the same level of engagement and tailored care was especially an issue when they encountered acute issues with their condition:

Young person: “When admitted as a child I would always be in my hospital where my team were, so I still had that care from them, but in adults it’s just a general medical team looking after you and they really don’t have any idea about my disease, so it’s quite hard for them.”

COMMUNICATION

Challenges with communication were brought up regularly during the focus group sessions. Communication between specialties and between child and adult services when young people transition, was said to be especially poor. However, not forging a proper relationship with the young person in adult services and communicating the changes in adult care were two of the main specific barriers that they faced. Even when care was handed over, there was little to no communication to ensure the young person’s wider needs were addressed:

Parents/carers: “Communication and relationships are the key to making sure our young people have the lives they deserve.”

Most parents/carers were disappointed that services did not attempt to get to know them or their child during transition:

Parents/carers: “My [young person] is an expert, as a family we are experts. The people who come into our home are learners. When they learn our experience, they can marry the clinical knowledge they have with our relationship.”

Other parents/carers said that services, as well as local authorities, needed to communicate with each other in a more effective way in the form of networks of care, especially when multiple services were involved in the transition of a young person to adult services:

Parents/carers: “A central point needs to take responsibility for tying in all of these various settings [learning disabilities, social care, schooling etc.]”

Parents/carers: “The NHS and local authorities are brilliant at data capturing; the problem is they don’t speak to each another...get your computer systems to speak to each other.”

In one parent’s experience, there was no communication between paediatric and adult services because neither team within the same specialty knew who one another were, even though they worked in the same hospital:

Parents: “The paediatric and adult teams didn’t even know the names of each other in the same hospital.”

Another parent in the same group commented that when correspondence was communicated from a secondary or tertiary centre to their GP, it often fell on them as the parents/carers to action the contents:

One of the young people commented on the variation in mental healthcare when clinicians within an organisation leave, and that having to constantly explain their condition was a barrier that could easily be overcome with something as simple as a health passport:

Young person: “This area’s CAMHS team for 18–20-year-olds was really good. But when people change you have to explain your situation over and over again.”

Another young person who felt that there was a lack of appreciation for their stage of development from healthcare professionals:

Young person: “Everyone was getting annoyed because when services spoke to my mum they were like, “well we need to speak to [the young person] more because [the young person] is an adult now.” My mum was like “well she’s at school... she is still only 16.””

The parents/carers also explained that the terms of care were often dictated to their young person and that alternative methods of communication were not explored based on their needs.

Communication between paediatric and adult services when transitioning care was also said to be non-existent by most of the participants who had a negative experience. It was noted that adult healthcare professionals were particularly absent from transition planning meetings.

TRANSITION LEAD/SERVICE

Most participants said that having someone to oversee or co-ordinate their transition would have significantly improved their experience of transition:

Young person: “Specialised adolescent care co-ordinator...that would be amazing.”

For most, there was no one to help them navigate through this challenging time which left them feeling as though they were thrown in the deep end:

Parents/carers: “There is no transition service to steer you through.”

The pathway of care in adult services was rarely communicated to the participants before the transfer of care and when in adult services, none of the participants were given a contact to refer to when they needed support:

Parents/carers: "I just need someone, when we hit a problem, to phone up and ask for some advice. It's so simple but it doesn't exist."

The young people commented that as there was no overarching transition service, no one followed up how the transition to adult services went which left them feeling frustrated:

Young person: "They leave it to you...it leaves you frustrated."

Young person: "There's no one to keep in contact with."

Even when a transition pathway did exist, one parent stated that they and their child were not prepared for the eventuality of transition until the young person was in adolescence:

Parent: "I didn't even know there was a transition service...they hadn't written to tell me that this was happening."

When asked about 'Ready Steady Go' and if this template had been used during the process, most participants hadn't even been informed of its existence:

Parents/carers: "How are you meant to plug into a service if no one knows it exists."

They all said that having a plan in place from an early age and involving both child and adult services in clinics and MDTs when the young person reached adolescence, would have helped facilitate transition.

PARENT CARER ASSESSMENT/SUPPORT

For the parents/carers it was clear that their well-being was not considered during the transition process. Even if their young person received a good level of support, as carers, they were never properly assessed or supported:

Parents/carers: "You get medical care but actually there's no interest in how you as a family are coping and no understanding that your child is part of a wider family. If they're going to thrive the family needs to thrive, too."

Another parent/carer in the same group commented that they personally ***"felt completely abandoned"*** by the lack of support for them and their role as a carer. While another

commented that: ***“Families have to fight for services or know every tip or trick to access help and support. This has a massive impact on the family’s wellbeing, which is long lasting.”***

It was also apparent that the parents/carers were offered no support to pursue their own ambitions and lead a normal life with one saying that:

Parent: “It’s an isolating experience. I don’t do friends anymore.”

COMPASSION

Most participants said there was a lack of empathy from healthcare professionals for their circumstances during this particularly challenging transitional period. This led to many of the participants feeling as though they were being dismissed by health services:

Parents/carers: “We’re struggling to work with a system that tries to pretend that we don’t exist.”

For one parent/carer, the lack of empathy they encountered stemmed from healthcare professionals not taking the time to understand the family’s perspective:

Parents/carers: “My feeling is that professionals are quick to judge without understanding.”

Parents/carers: “Let’s never forget that many of us families have dealt with attempted suicides, too many times, based on lack of services or lack of understanding from professionals and agencies.”

While medical or acute crises were usually adequately addressed, many parents/carers felt that, when their young people reached adolescence, they were not given the opportunity to live beyond their conditions:

Parents/carers: “Our children are invisible.”

Parents/carers: “No one wants to know about our children. Once they become teenagers, society doesn’t want to know about whole life disability.”

Many believed that their young people would not be supported by adult services to thrive in the community when they were gone, which led to many expressing a sense of hopelessness in the future:

Parents/carers: “We hope that our children die 10 minutes before we do.”

TRANSITION POLICIES & PATHWAYS IN THE COMMUNITY

Many of the issues that the participants encountered linked to the lack of guidance on transition in their local areas. 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, as frankly put by one of the parent/carers:

Parents/carers: “I despair for families. I had to create pathways for my [young person].”

Many of the parents/carers had to move out of area to find pathways of care for their young people when they became too old to access paediatric services. They described variation in local policies that made up these pathways where they did exist:

Parents/carers: “There should be a blanket policy all over the UK – it should all be the same. Leaving councils and local authorities to write their own, that’s where it goes wrong.”

A number of parents/carers commented on the lack of a national strategy that provides for the holistic needs of young people with chronic conditions as they move away from paediatric services:

Parents/carers: “It’s going to cost them more in the long term not having the policies in place.”

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

Parent/carer: “Although the college is very good it’s limited on what will happen afterwards and we do worry. In year 9, 10 or 11 there should be a conversation about preparing for adulthood as stated in the EHCP as part of an annual review – not done because you can’t prepare as there are no services available.”

There was a sense of frustration with the lack of information relating to transition:

Parents/carers: “You just need a leaflet or a booklet to say this is what happens, and we haven’t got one – you’re just stabbing round in the dark. And without fighting for this college, I don’t know where my child would be today. They would have no future, at least now they have a fighting chance. “

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:

Parents/carers: “If you have health services as a child and then they become an adult the pathways disappear.”

Finding corresponding specialties, pathways of care and appropriate care was often down to chance, through speaking to other parents, as there were no clearly identified pathways to follow:

Parents/carers: "I found out through another parent about the feeding and eating disorder service at a particular hospital... [a specialist in eating disorders in that service] was one of the only people who ever cared for us. She cared whether we lived or died. Her care was the best we've ever had....but there was no pathway to her care...I was lucky to find her. That was a total lottery, so I was lucky to find and get the best care for my child."

NATIONAL DISABILITY DATABASE

The parents/carers were keen to see a national disability database set up where the needs of all children who have disabilities can be recorded in a uniform language (coding) that can differentiate between conditions to help different care settings and healthcare professionals know what a young person has and what their needs are:

Parents/carers: "There should be a database of children with details of their assessments instead of relying on local authorities to contact healthcare professionals."

COMMISSIONING, LACK OF/ACCESS TO HEALTHCARE SERVICES & FUNDING

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 (AHP), and often had to pay privately and were left with significant debt:

Parents/carers: "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 speech and language therapy report."

Parents/carers: "I've put myself into debt, I've put myself into debt for physio because my son was in so much pain."

Most of the parents/carers viewed accessing funding as a constant battle:

Parents/carers: "It's always funding. So many hurdles, so many criteria. Hundreds of parents are constantly fighting. They use the word battle all the time. We have to choose our battles because it's just day in day out."

Some of the participants who lived in rural areas described an inadequate distribution of services with many services being urban focused:

Parents/carers: “We had to move because there was nothing locally available and it was a big upheaval.”

The commissioning of orthotics and adult AHP services were felt to be particularly poor for young people transitioning away from paediatric services:

Parents/carers: “There’s no boots or orthotics, no physios commissioned here.”

Overly prescriptive financial support processes were seen as a major barrier to their young people being able to access the care packages they needed. One parent/carer highlighted how little trust local authorities had in parent/carers. They felt there was an over emphasis on spending their care budget on institutional care, instead of enabling their young person to live an independent life, through having their own place to live with the carers necessary to meet their needs:

Parents/carers: “They [local authorities] don’t trust parents, so they’d rather give loads of dosh to institutions.”

CONTINUITY OF CARE

The continuity of care was highlighted by all of the participants as inadequate or non-existent, particularly when it came to the handover of care from paediatric to adult specialties.

Parents/carers described transition as a process of “starting all over again” with adult care:

Parents/carers: “In transition meetings my child would be so anxious that they almost 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 my child has got capacity, you know if they understand because you know them.”

Parents/carers: “It’s about proper handover. It’s got to be handed over properly. Because you go to adults, and they haven’t got a clue because nothing’s been passed to them. It’s like you’re starting all over again. It feels like all the work you’ve done...you might as well have not bothered because you’re starting on day one again.”

One parent/carer stated that continuity of services that are contracted out such as dietetics, occupational therapy and physiotherapy in adult health was extremely lacking:

Parents/carers: “If they’re contracted out you need to make sure there’s a proper handover there, too...one service might stop for adult services and they might say: “Oh we don’t do you anymore.””

In the case of one young person, a locum had been assigned to them during their transitional period for six months, which they expressed reservations about due to the prospect of having to start over with someone else in the near future:

Young person: "I don't want to be transitioned by a doctor who doesn't really know me."

IDENTIFIED LEAD FOR TRANSITION

Most of the participants said that it was unclear whether they had an identified lead for transitional care. The parents/carers explained that not having a clearly identified lead meant that, due to the complexity of their young people's conditions, there was a culture of "passing the buck" in terms of their care:

Parents/carers: "They were playing pass the bomb. No one wanted to be left holding this bomb when it went off."

As a more general point, they expressed frustration that this led to a wider lack of accountability when it came their young person's transitional care:

Parents/carers: "There is no accountability from commissioners. There's no one we can go to."

LACK OF CLEAR GUIDANCE ON GP ROLE IN TRANSITION

None of the participants were clear on what role their GP should play in bridging the gap during the transitional period and that there is a need for set guidance on what this role should be.

Parents/carers: "You need an adult paediatrician. If it's the GP they need to step up to the plate to do it. At the end of the day they're running a corner shop, they're businessmen...if they're not contracted and they're not paid to do it, they won't."

NO JOINED-UP CARE IN ADULT SERVICES

Due to their complex healthcare needs, both the young person and the young people, cared for by the parents/carers, involved in the sessions relied on a number of AHP services and medical and surgical specialties. Coming from paediatrics where care was generally joined up and integrated, the participants viewed the adult pathway as overly complicated and inefficient. There was a shared feeling that, in contrast to paediatrics, adult specialties and services operate in silos. An even more fundamental issue came from not knowing who should be overseeing their care in any particular specialty or service:

Parents/carers: "Don't know where to go to, who to go to."

This was a commonly held view and for the young person interviewed not having a clearly defined, joined up pathway with someone in each specialty who they could contact, meant that they worried about what they would do in an emergency:

Young person: "It was difficult because I... have so many issues. With my team before it was gastroenterology but they could also take care of other stuff as well. But when I went to adults I would contact the gastroenterology team about something and they would be like: well that's not our specialty we can't help you with that. So, I would go back and be like: so who am I meant to contact? Even now I'm sometimes like what teams do I actually contact about what? No one gives you a clear path of who to talk to. Even to this day if anything happens to my ileostomy I have absolutely no clue who to contact!"

It was suggested there should be a designated person who could tell the parents/carers who should be responsible for their young person's care in each specialty and service. However, it was clear very few of the participants knew who their central point of contact for this information should be. One parents/carers remarked whether this should be their GP, yet it was stated that their GP had not relayed this information to them. When entering adult services all of the participants described having to piece together the various contacts and aspects of their care pathway themselves:

Parents/carers: "We have a paediatrician until their 16, we need an adultician."

SOCIAL CARE

There was a consensus among the parents/carers that there is poor provision of adult social care services:

Parents/carers: "There was only one adult social carer for the whole of their county."

Another parent/carer also commented:

Parents/carers: "I am just thankful that we haven't had to use social care."

Adult social care was said to be a massive barrier to transition when needed, with parents/carers' often having to pay for this service themselves or not being signposted to available services:

Parents/carers: "Adult social care particularly, you would far rather your child was dead because alive they're too expensive."

Minimum income guarantee can also mean that the young person's benefits can be significantly decreased:

Parents/carers: "Because of this minimum income guarantee the young person survives, but they do not live at all."

Several parents/carers said that social care also regularly accused them of lying about the extent of their young person's condition to secure extra funding:

Parents/carers: "We know you all lie about your children and exaggerate their disabilities."

INVISIBLE CONDITIONS AND DIAGNOSIS

Proper diagnosis of the young people's conditions was a particular area of concern. The participants reported that needed 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:

Parent: "We had to do a fund raiser for our child. We spent five years trying to get a diagnosis. They are on the spectrum but because doesn't tick boxes, therefore in a grey area so has never been fully diagnosed."

Parents/carers: "Within the NHS there is no understanding of the sensory issues to do with autism."

Parents/carers "On the surface my child seems very able this is why speech and language therapy is so important because it shows the hidden problems that they have got."

Participants indicated there is a condition lottery:

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

Young people with comorbidities or less visible psychological conditions can find transition especially challenging:

Parents/carers: "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 child] does have a learning disability. I shouldn't have to say fortunately."

Young person: "There needs to be a solid process no matter what your condition is."

EMERGENCY HEALTHCARE PLANS (EHCPs)

The provision of EHCPs and needs assessments were reported to be inadequate. The participants said that their children's needs were often "watered down" in their EHCPs which stemmed from a lack of understanding and adequate needs assessments. Where EHCPs were in

place, these were sometimes not read by healthcare professionals in acute settings or understood in primary care:

Parents/carers: "Our GPs don't even know about EHCPs, I had to educate them."

Parents/carers: "GPs said it's not lawful to have these assessments – but as he is transitioning from secondary education to further education he needs these assessments – "it was almost like I was speaking a foreign language. They just didn't understand."

Parents/carers: "It cost us thousands of pounds to get the EHCP to reflect our daughter's needs. My worry is once that EHCP's not maintained there's nothing, we've got no security."

SUPPORT FOR CARERS/ADVOCACY FOR CARERS

Despite all of the parents/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:

Parents/carers: "I'm an unpaid carer...you have no life, no social life, nothing. I just seem to be on robot mode."

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

Parent: "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."

There was also agreement that, when planning for transition, they could have benefitted from an independent advocate who could guide them through the system and advocate for them with local authorities and healthcare providers.

Parents/carers: "There are so many complications, to try and fathom what the pathway is... an advocate...who knows the system... would be a great help."