

Experiences of transition from children's to adult's healthcare services for young people with a neurodevelopmental condition

Paul Shanahan  | Lucie Ollis | Kate Balla | Rupal Patel | Karen Long

Your Healthcare CIC, Surbiton, Surrey, UK

Correspondence

Paul Shanahan, Your Healthcare CIC, 22 Hollyfield Road, Hollyfield House, Surbiton, Surrey KT5 9AL, UK.
Email: p.j.shanahan@surrey.ac.uk

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Abstract

Previous research has highlighted a lack of continuity of care when young people with a neurodevelopmental condition make the transition from children's to adult specialist healthcare services. A lack of planning, consistency, and availability of adult services has been found to lead to; increased anxiety, poor health outcomes, reduced support and some young people not receiving healthcare. The majority of transition research has focused on what health professionals consider important in the transition process, rather than focusing on the experiences of the young people and those closest to them. Our objective was to gather evidence from young people (and their families) who had experienced transition from children's to adult specialist healthcare services through semi-structured interviews. Volunteers were recruited from two London boroughs. All young people were aged between 18 and 25 years with a neurodevelopmental condition (Attention Deficit Hyperactivity Disorder, Autism Spectrum Disorder and/or an Intellectual Disability). Overall, we interviewed six young people with support from a family member. Five further family members were interviewed on behalf of the young person. In total, ten semi-structured interviews were transcribed verbatim and analysed using Interpretative Phenomenological Analysis. Four themes emerged from the analysis: (a) Parents as advocates, (b) Availability of adult's specialist health and social care services, (c) Lack of information sharing and (d) Transition as a binary, abrupt change. Our findings suggest the transition experience could be improved by changing service specifications to incorporate assessment and handover across the age range of 16–20 years. Additionally, statutory services should understand and provide the coordination role now offered by parents in transition. We suggest future research could evaluate the feasibility of a patient-owned online information sharing tool with information about relevant services for young people and their families.

KEYWORDS

adult learning disability services, adult mental healthcare, child mental healthcare, neurodevelopmental disorders, transition

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1 | INTRODUCTION

Moving away from trusted healthcare professionals during healthcare transitions can be stressful for anyone and can result in feelings of loss (Brown et al., 2019). People with Intellectual Disabilities (ID) have a higher incidence of physical and mental health problems which can lead to input from several different teams in order to meet their needs (Schrandt-Stumpel et al., 2007; Singh et al., 2010). Cross sectional analysis has identified a 9.6–125 times increased likelihood of poor health, mental health and limited daily activities in adults aged 19–24 years with ID than the general population (Young-Southward et al., 2017). A large number of health conditions including constipation, sleep difficulties, epilepsy and gastro-oesophageal reflux disease can increase behaviours that challenge when poorly managed (May & Kennedy, 2010). Additionally, studies have shown poorly planned transition is associated with non-adherence to treatment, lack of follow-up and reduced social and educational outcomes (Viner, 2008). Evidence from mental health literature highlights a similar trend indicating lack of engagement with services and poorer clinical outcomes (Singh, 2009). Young et al. (2016) suggested disruption during transition could have a number of long-term effects for young people with Attention Deficit Hyperactivity Disorder (ADHD) with regards to their psychological wellbeing and development. In addition, poor transition planning has been found to result in: anxiety and confusion for the young person, delays in accessing services and multiple unnecessary assessments (Clarke et al., 2011; Shogren & Plotner, 2012).

National guidance in the UK suggests that transition planning should begin between 13 and 14 years, however, healthcare services in the UK are not adhering to these guidelines (National Institute for Health & Care Excellence, 2015; Price et al., 2019). Crowley et al. (2011) suggest it is not always feasible due to the current economic climate and cost-saving measures. Singh (2009) indicates there may not be specific commissioned services for transition and that key workers across services do not exist (Singh, 2009). Reviews of ADHD and Autism Spectrum Disorder (ASD) transition highlight information sharing between services needs to occur and that policies that govern adult services are less comprehensive (Anderson et al., 2018; Price et al., 2019). Despite calls for policy change to support efficient, timely and gradual approaches based on needs led services, these have not occurred (Brown et al., 2019).

Inadequate consistency in the transition process is highlighted by there being up to 13 different transition protocols operating in the Greater London area alone (Hall et al., 2013). Ogundele and Omenaka (2012) report that only 15% of those with ADHD make the transition to adult services from children's services. For those with ADHD, one of the key reported problems with transition is lack of access to the appropriate adult healthcare services and ongoing care (Coghill, 2017; Marcer et al., 2008). Lack of written protocols, care pathways and inadequate information sharing between children's and adult mental health services have been cited as other reasons (Hall et al., 2013).

What is known about this topic

- Transition from children's to adult specialist healthcare services can be a stressful and anxiety provoking time for young people and their families.
- A poor transitional experience can lead to poor health, social outcomes and educational outcomes.
- Previous research has found many reasons for a negative transition experience including a lack of: information about relevant services, holistic approach, specialist adult services and consistency in written transition protocols.

What this paper adds

- It provides qualitative evidence from young people and their families who have recently experienced transition from children's to adult specialist healthcare services.
- It gives more clarity about the problems faced by those going through transition, specific to the UK.
- A springboard for future research into the cost-benefit of changes to contract specifications for transition and the feasibility of a patient-owned information tool.

Caregivers of young people with ID and ASD have expressed their frustration, anxiety and fear with the current transition process due to the lack of appropriate adult services and limited available information (Cheak-Zamora et al., 2015; Kuhlthau et al., 2016; Raghavan et al., 2013). Midjo and Aune (2018) suggest that mothers of those with ID are key in coordinating tasks and taking responsibility for their children through transition. Lack of GP knowledge about complexities of ID can lead to fragmented care as young people may be referred to a number of different specialists as a result of limited co-ordination between children's and adult services (Foley et al., 2012).

A systematic review examining experiences of transition from children's to adult's services for young people with ID found four main themes: becoming an adult, fragmented transition process and care, parents as advocates in emotional turmoil and making transitions happen (Brown et al., 2019). Although this review identified four qualitative studies, three (Okumura et al., 2015; Rehm et al., 2012; Schultz, 2013) of these were based in the USA, who operate using an insurance-based healthcare system which is not comparable to the NHS system in the UK. In addition, the qualitative study conducted by Davies et al. (2011) focused only on parents' perspectives of transition. Therefore, we aim to gain further understanding of the process of transition specific to young people with neurodevelopmental conditions living in the UK, to enable us to identify areas to improve current practice.

The use of qualitative interviews and Interpretive Phenomenological Analysis (IPA) was chosen as the participants were deemed experts in their own experience, there was limited

homogeneity within the population, and the ability to analyse small sample sizes (Smith et al., 2009). Additionally, due to the analyst's roles from practitioners to senior managers in community adult healthcare, IPA facilitated making sense of participants' experience in its current context (Smith et al., 2009).

The aim of this qualitative interview study was to explore the experiences of transition from children's to adult services for young people with a neurodevelopmental condition (ADHD, ASD and/or ID). We aim to add to existing literature focusing on transition and address the identified gap by including evidence from young people who have experienced transition from children's to adult services. We endeavour to include parents and family members in this research as previous literature has highlighted their fundamental role.

Throughout this paper if we refer to 'young people', we mean young people with a neurodevelopmental condition (ADHD, ASD and/or ID) and for 'adult services' we mean specialist adult health-care services, if not otherwise stated.

2 | METHOD

2.1 | Study design and participants

We conducted a qualitative research study using a semi-structured interview schedule. Participants were young people aged between 18 and 24 years with a self-reported diagnosis of ADHD, ASD and/or ID. The age range was selected to account for young people who had already transitioned to adult services and been discharged from children's services. Family members were interviewed on behalf of the young person if they were unable to verbally communicate with the researchers. All young people were offered the opportunity to be interviewed by themselves or with someone to support them.

A mental capacity assessment was completed by a healthcare professional (PS) if they were unsure if the young person had capacity to consent to participate and Best Interest decision to inform involvement. No participants were excluded due to the Best Interest process. Six young people with ADHD, ASD and/or ID

and 11 family members were interviewed between September and December 2019, comprising ten interviews. Two participants reported to not have a diagnosed ID, one reported a mild ID, five with moderate ID, and two with severe ID. In addition to ADHD, ASD and ID, participants also reported having health conditions including: Cerebral Palsy, Down Syndrome and epilepsy. Participant characteristics can be found in Table 1.

Ethical approval was gained from an Ethical Advisory Committee (EAC) consisting of professionals with expertise in ethics, methodology, content around neurodevelopmental conditions and transition. Ethical approval was obtained in accordance with the Declaration of Helsinki and the appropriate professional bodies.

2.2 | Recruitment process and data collection

Recruitment posters were displayed and leaflets distributed to identified locations in the two UK boroughs (e.g. health and social care providers, support groups, advocacy groups, schools, charities and local events). We followed advice from Nicholson et al. (2013) by adjusting our recruitment process to reduce potential participants' anxiety about partaking in research (e.g. meeting potential participants face-to-face, easy-read documents and sending pictures of the interviewers before the interview). We also made sure the interviewers had a health background and ensured the dissemination plan for the research was clear so that participants were encouraged to participate in future research (Nicholson et al., 2013).

Participants volunteered to take part by emailing or calling the researchers. They were screened for eligibility by LO and PS and given an information sheet before the interview was arranged. The interview schedule was developed by all the authors according to themes that emerged from the literature. We followed guidance for designing IPA research studies and collecting data through semi-structured interviews to ensure our method was reliable and valid (Smith et al., 2009). As well as adapting our interview schedule for young people with ID, we ran a pilot interview with a young person with ADHD, ASD and LD (Beail & Williams, 2014; Lewis & Porter, 2004). As a result of this

TABLE 1 Participant characteristics

Participant number	Age	Gender	Participant with ADHD?	Participant with ASD	Participant with ID	Severity of ID (self-reported)
1	23	Female	No	No	Yes	Moderate
2	19	Male	Yes	Yes	No	N/A
3	21	Male	No	Yes	Yes	Severe
4	20	Female	No	No	Yes	Moderate
5	18	Male	No	Yes	Yes	Moderate
6	18	Male	No	No	Yes	Moderate
7	18	Female	Yes	No	No	N/A
8	20	Female	No	No	Yes	Moderate
9	24	Male	No	Yes	Yes	Severe
10	18	Male	Yes	Yes	Yes	Mild

conversation, we changed some of the wording (e.g. 'transition' to 'moved from') and simplified interview questions so they were easier to understand for the young people with ID.

Questions about participant interests were included at the beginning of the interview to help participants feel at ease. The interviewer then asked the participant what they remembered about children's healthcare services and about their awareness of their transition to adult services. Questions regarding current healthcare service use and the experience of transitioning from children's to adult services were then asked. The semi-structured approach allowed the interviewers and the interviewee(s) to engage in a dialogue where questions were modified based on participants' responses and understanding of language used. Interviews were conducted by two members of the research team. The first interviewer was the researcher (LO). The second interviewer was either a clinical psychologist (KB), consultant psychiatrist (RP) or a behaviour analyst (PS) who worked in a neurodevelopmental team. We ensured that those members of the research team who interviewed participants had not worked with the participant throughout their care in adult services. In addition, although we did note which services the young people were accessing at time of interview, we have not published this information to ensure anonymity is maintained. At the organisation where the authors are employed, young people can access psychological services, psychiatry, physiotherapy, speech and language therapy, behavioural services, sexual health services and more.

2.3 | Data analysis

Interviews were audio-recorded and transcribed verbatim. Each interview was checked for accuracy and any identifiable information was removed from the transcripts. The analysis followed the six stages suggested by Smith et al. (2009) for successful IPA; reading and re-reading, initial noting, developing emergent themes, searching for connections across emergent themes, moving to the next case and looking for patterns across cases. One of the researchers (LO) conducted the two initial stages of analysis (reading and re-reading and initial noting) and all authors were involved in the development of the themes and sub-themes. Following data analysis, the themes and sub-themes were discussed with a young person with ASD, ADHD and LD and a parent to check the results accurately represented how they felt about the transition process. IPA was chosen for this particular study because our aim was to analyse the experiences and perceptions of this group, rather than to make general claims about transition for everyone with a neurodevelopmental condition (Smith, 2015).

3 | RESULTS

The analysis led to the development of four themes and eight sub-themes (Figure 1). We used quotation marks to show where text had been taken directly from the transcript and square brackets to indicate information added to add clarity or removed to maintain

anonymity. The following information is provided in brackets at the end of quotations: the source of the quote (young person: YP or family member: FM) and interview number.

3.1 | Parents as advocates

The dominant voice throughout the interviews was most frequently that of a parent or family member. Navigating the system and transitioning to adult services was described as 'unfathomable' (FM08) for young people.

3.1.1 | Parents taking responsibility for their children's care

All the participants mentioned parents and family members taking responsibility for young people's health and social care. Two parents clarified they took sole responsibility for organising health and social care services for their children:

I'm the orchestrator of all of these things which is the way it ends up being always.

(FM08)

One participant explained the important role parents undertake as advocates for their children and their lack of confidence in statutory services facilitating a successful transition between services. She mentioned the importance of planning for the future to avoid parents to 'crash and burn' (FM03) with their children:

If you as a parent aren't pro-actor, in planning for the next step, the next step just ends up being a train crash because the statutory agencies don't wake up to it.

(FM03)

Even those young people without ID who communicated well in the interviews still needed the help of family members to make sure they were receiving appropriate healthcare. Despite this, some young people wanted a level of independence for personal topics now they were an adult:

...I mean, no offence to dad but it's a bit easier, it's a bit easier to talk if I feel like it's just me and them so I wouldn't mind just having to do it myself.

(YP07)

3.1.2 | Young person's awareness of transition

Generally, parents were aware that transition would happen when their child turned 18 but many were unhappy with the process and amount of support they received:

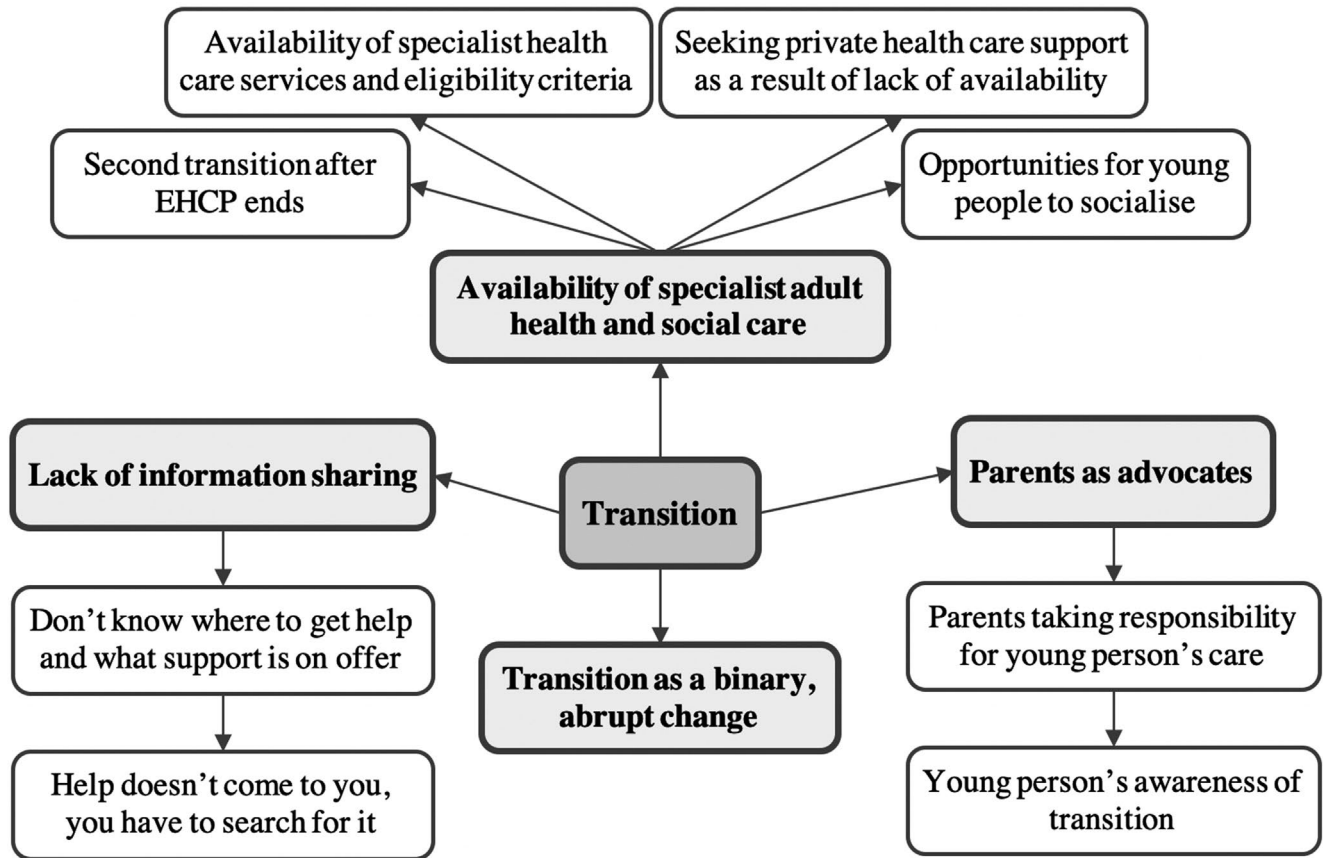


FIGURE 1 Themes and sub-themes identified

...child social services were very clear, that social services and health would switch to adults at 18, that's fine.

(FM02)

I vaguely remember the children's Physio ringing saying [young person] is going to be turning 18 in October, so we will be handing him over to the adults team. And I think that was a phone call.

(FM03)

The majority of the young people interviewed showed little or no awareness of transition:

I think they did tell us [about transition] but I wasn't really aware. They probably told mum and dad through the meeting.

(YP06)

What seemed to work well was a 'transitional meeting' where team members from both children's and adult services attended to discuss handing over responsibility for support to adult services. Although this was often difficult to organise, the young people and their parents valued this meeting.

3.2 | Availability of specialist adult healthcare and social care services

3.2.1 | Opportunities for young people to socialise

An issue raised repeatedly in four of the interviews was the lack of available social opportunities and activities:

I cannot understand why the adult's services we have so little groups compared to what we have in children's services.

(FM01)

The main problem is they're too isolated... if only they could take them to more places where there are more facilities, more things to do. I think it would make a big, big difference.

(FM09)

Parents were concerned their children were socially isolated and partaking in the same activities on a regular basis which lacked stimulation and variety. Some were worried about the amount of time their son/daughter spent in their rooms on their phones and computer games. It was clear parents were concerned that if they were

not around to care for their children, that they would be vulnerable and at risk.

3.2.2 | Availability of specialist healthcare services and eligibility criteria

The lack of availability of adult healthcare services was mentioned in every interview. Participants were frustrated with the long waiting times, difficulties with the referral process and eligibility criteria for adult services:

Children come through children's services having significantly more resources being offered and available through decision making processes and adult's services is just like a dam that doesn't want it flowing their way.

(FM03)

Another concern came from a young person without ID who had recently transitioned to adult services. She was anxious that she would not qualify for adult mental health services as she did not think she would 'make the cut' (YP07) for mental health support:

I spoke to my therapist about this because I was quite worried... There are adult's services but she didn't think that I would qualify for them because the requirements are quite sort of stringent to get into adult mental health services.

(YP07)

3.2.3 | Seeking private healthcare support as a result of lack of availability

Many of the young people interviewed were not receiving the healthcare support they needed. As a result, many parents had decided to seek private healthcare. Due to funding complications for speech and language services between the college and local council, at least one family were privately funding specialist support:

We do privately; speech and language. I took him to lessons. 12 lessons in total. 45 minutes, £74.

(FM05)

Another story came from an 18-year who had a diagnosis of ADHD, ASD and ID. Although his mother had tried repeatedly to contact the adult ADHD services, they did not receive any information until approximately 5 months after the young person turned 18. They saw no other option than to pay privately for ADHD services. At £400 for an initial appointment and £200 per session for subsequent follow-ups

every 3 months, the family was making a substantial financial investment for ADHD services that should be provided by the NHS:

I've had concerns about [young person] over the summer and I've had to go privately ... Only because I have concerns and I don't think going into the adult's services those concerns are necessarily going to be met.

(FM10)

Those who did choose to pay for additional health and social care support were conscious that not everyone would be in the financial position to fund private healthcare support and reflected on how this may affect other families.

3.3 | Second transition after Education Health Care Plan ends

In addition to the worry around transition from children's to adult services, a few parents were worried about what would happen to their child's healthcare once their Education Health Care Plan (EHCP) ended:

My fear would be what happens to him when he comes out of college and where does he go and who looks after him.

(FM02)

Although an EHCP can last until the young person is 25 years, parents were concerned about the lack of local social care resources:

I mean, I just think, what's going to happen? ... even when she finishes college, she is gonna be what 22, 21, 22, what is she going to do after that?

(FM04)

Parents were worried that when their child left the structured educational environment that organised activities would not be available to keep their children busy and that they would be left isolated from their friends.

3.4 | Lack of information sharing

3.4.1 | Don't know where to get help and what support is on offer

Nine of the interviewees talked about the lack of information available to young people and their families about adult services. They were often confused about where to go to ask for help and who to contact:

if you've got a kid with ADHD you know about CAHMS urmm and you know, although the waitlists are long, you do get to see somebody. Whereas with

the adult's services.. I don't really know, you know, where it comes from or anything.

(YP07)

For most young people, they were not known to local ID services. Parents were unsure where to go to ask for the appropriate services:

... he transitioned into adult's services, I don't even know where they are. I haven't got a clue, I don't know where they are based, I dunno what, you know, I don't know what disciplines there are in that team, I have no idea.

(FM03)

Some parents described their reliance on speaking to other parents in a similar situation, and their concern that their children would not have accessed certain services without this information through word-of-mouth. One parent mentioned there are some useful websites including information on local services for young people with ID. This participant also suggested that a specialist in adult's health and social care services would be useful to give advice and guidance to parents and young people going through transition.

3.4.2 | Help doesn't come to you, you have to search for it

Another recurrent theme was the need to ask for help rather than help being offered:

...we have to find where to go and who to come and talk to and how to organise all this stuff.

(FM01)

Parents were frustrated that they had to 'push and push and push, always' (FM10) to get their children the help and support they needed. Some parents even used language such as 'we have had to fight' (9, 369) when talking about accessing health and social care services.

Similar to a previous participant, no communication with adult ADHD services had taken place, even though the young person had turned 18 four months prior and had been discharged from children's services:

They haven't really reached out to contact me or anything.

(FM07)

3.5 | Transition as a binary, abrupt change

The abrupt change from children's to adult healthcare was difficult for the young people to understand, leading to stress and confusion

for them and their families. This was a recurrent theme with one interviewee who suggested transition needed to be more individualistic, holistic and less abrupt. Parents expressed concern their children were 18 years biologically, but in terms of their understanding about their care, were much younger.

...can I say he is an adult? Numerically he is and we treat him as an adult, but I still think he needs that extra support and guidance throughout. But again, I just feel it's very, it's too abrupt.

(FM10)

A mother of an 18-year-old with ID explained that having ID could mean that being and feeling like an adult happens much later for some young people and that the system should be more flexible and accommodating:

...it [feeling like an adult] is not going to happen at 18 under any circumstances with a child with learning disabilities... in the future it would be nice to think it was more holistic and reflecting the individual as opposed to being a cut-off at 18.

(FM10)

Parents were understanding of the system and why children were transferred to adult's services at 18 years. Nonetheless they were frustrated with how sudden the change was for their children with there being '... absolutely no continuity' (FM08).

A recurrent problem is the lack of continuity between services. This links with a previous theme, availability of adult healthcare and social care services, as the eligibility criteria for child and adult services may differ. This means young people who qualified for support as children may not be eligible for the same type of support as adults. This could leave young people without the support they need.

4 | DISCUSSION

4.1 | Summary of main findings

Many of our themes and sub-themes have been discussed in previous literature exploring transition experiences. For example, the theme 'parents as advocates' supports previous literature suggesting the importance of parents in both the transition process and everyday life of young people with neurodevelopmental condition, irrelevant of ID diagnosis (Lotstein et al., 2009; Midjo & Aune, 2018; Price et al., 2019; Schultz et al., 2012). The importance of the parental role may also explain the reduced educational outcomes, increased criminal activity, adverse life events and substance misuse identified by Barron et al. (2013). The key coordination role parents play needs to be better understood by statutory services and should not by default be provided by parents who are able to recognise it, but by statutory services.

'Availability of adult specialist health and social care services' is another theme which has been referred to in the literature (Clarke et al., 2011; Coghill, 2017; Raghavan et al., 2013). Participants cited problems with accessing services due to long waiting times, differences in eligibility criteria and a general lack of resources in the community to support young people with neurodevelopmental conditions. This theme was linked closely with 'lack of information sharing' as some participants were not accessing services which could be available to them as they simply did not know where to go. This may explain the low percentage (38%) of young adults with ID in paid employment and further education (Young-Southward et al., 2017). It was concerning that we had to facilitate referrals to adult health care services after eight (of ten) interviews, at least three of whom were in their twenties. Had they not volunteered to take part in this research study then they may not have received this information. There are clear gaps in knowledge due to the differences in services and commissioning arrangements from education, health and social care throughout the transition. Coordinators within each service are clearly needed to navigate the complex system.

Participants expressed frustration as they were left searching for services, rather than being offered them. This is not dissimilar to other research focusing on transition, yet there has not been any change to address this problem (Barron et al., 2013; Kuhlthau et al., 2016; Raghavan et al., 2013). It was clear that policy changes, patient education, needs led services, changes to service provision around transition and joint working between services involved in transition were not in place (Anderson et al., 2018; Brown et al., 2019).

Finally, being cut-off from children's services so abruptly at 18 years old means that there is a lack of continuity between children's and adult's healthcare services. Parents were concerned their children were being treated as adults because of their biological age. Previous research has suggested that some young people with ID are simply not ready to transition to adult services, as their psychosocial and cognitive maturation may be slower than their typically developing counterparts (Salt et al., 2019). This transition period for people with complex needs is not coordinated and the NICE guidance suggesting a flexible age threshold for transition is often ignored (National Institute for Health & Care Excellence, 2015). It is clear that NICE guidance around transition is repeatedly ignored from commissioning to practice across services.

5 | STRENGTHS AND LIMITATIONS

A strength of this study is that we have included evidence from young people who have experienced transition. Despite some differences between family members and the young people, they were generally concerned about similar issues including being left without health and social care support. A potential bias in sampling was that participants were not recruited directly from adult healthcare services. This recruitment bias may have increased the likelihood that

interviews were conducted with those who had inadequate experiences. In addition, the results and recommendations should be generalised with caution as the study sample may only be representative of the transition experience of the ID/ASD/ADHD population in the two London boroughs in which this study was conducted. However, the findings can still be used to highlight the importance of a good transition experience and influence policy change.

Six young people were interviewed as part of this research study, however we found the parent voice to be dominant. Our interview schedule was designed so that questions were predominantly aimed at the young person with parents inputting where the young person needed support. We found mixed results in the young people's ability to provide useful insight into their experience of transition. Some of the young people were not aware they had transitioned to adult services or what services they had access to as their parents were organising their health and social care on their behalf.

6 | RECOMMENDATIONS

In response to this research, as an adult healthcare service, we will be accepting referrals for people from 16 years. Professionals of any discipline in our team will subsequently start as a key worker on receipt of a referral. Those people will be tracked by key workers within our service until all their needs are met under adult services. Activity of key workers will be tracked and discussed with commissioners as this is currently outside our contractual obligations. Referral information will also be shared with local schools and community services twice a year. These changes were discussed with a patient's family member who agreed this would have alleviated the stress and lack of coordination caused during transition. The following are our recommendations for consideration;

- The coordination role that parents and caregivers currently hold should be understood by statutory services. This role of identifying information and resources to access healthcare should then be provided by those statutory services.
- Services providing health and social care need to ensure there is a 2-year crossover period from 16 to 20, which is specifically incorporated into commissioned contracts. Each service contract should outline who holds clinical responsibility and the role of those who do not.
 - a. We suggest specific transition clinics should be adopted by children's services as described by Crowley et al. (2011) for those aged 16–18 years, in order to provide a cost effective and pragmatic transition to adult healthcare services. Additional time should then be available within children's services for information sharing after turning 18 for those who move between boroughs.
 - b. Adult services should be able to assess the young people before they turn 18 so that they know what services they will be able to offer.

- Policies and NICE guidance need to be reviewed in light of the health inequalities highlighted and experiences of young people shared.

7 | FUTURE RESEARCH

- The authors believe that a service evaluation of the changes to service provision outlined should be conducted, including a breakdown of the additional cost of professional's time.
- Once changes are made within services, the perspectives of professionals working in transition should be sought to explore barriers and facilitators to those changes.
- Finally, understanding service provision gaps with those who are unable to rely so heavily on their parents to facilitate access to services should be explored.

8 | CONCLUSIONS

The themes identified could be used to help health and social care services to think about how they could make changes to improve the transition process for young people with a neurodevelopmental condition. For example, involving care providers earlier and equipping them with local information to ensure service provision is in place. For a young person with ADHD, ASD or ID, the concept of change and transition to adult services was evidently quite a confusing and anxiety provoking time. Meeting people in adult services through handover meetings will allow patients to become familiar with new services, ensuring their needs will be met. Commissioners should consider a transition period in service specifications to facilitate this, with clearly defined roles in both children's and adult services.

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CONFLICTS OF INTEREST

There are no conflicts of interest to report.

ORCID

Paul Shanahan  <https://orcid.org/0000-0002-7570-4649>

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