



The experience of transitions for children and young people with Special Educational Needs and Disabilities

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EXECUTIVE SUMMARY

In 2022 the Learning Disability and Autism Programme NHS England, funded the South West region of Parent Carer Forums to undertake a project to understand the transition experiences of children and young people with Special Educational Needs and Disabilities (SEND). (See Appendix b)

The project collected experiences of 225 individual parent carers across the South West and the collective feedback from the parent carer forums across the region.

The research found variability within the experiences and identified 5 key themes which impacted on the transition process.

1. Not all the relevant people are involved during transition
2. Lack of good quality accessible information
3. Communication issues
4. Transitions were too late or delayed
5. Lack of person-centred planning and following through

The experiences shared, highlighted that changes in practice could make a big difference in the transition process for families.

Starting planning for transitions earlier, better quality information and improved communication were reoccurring themes throughout the research.

The importance of a person-centred approach was a key factor in the case studies we reviewed.

Most of the feedback from families focused on how they felt during the process, rather than the process issues themselves. It was of significant note that a lot of the things that parents talked about making a difference, were reasonable adjustments, which could have been made at little to no cost. Time and patience from staff were also a reoccurring theme in successful transitions.

If we are going to improve the experience of transitions for everyone, we need a shift in focus to earlier planning across all services, with all relevant people being involved while placing the child or young person central to the process.

The following report contains the methodology used, details of the findings and the conclusion we have drawn from the research project.





BACKGROUND

The Children and Families Act 2014 shone a light of the duty of local authorities to support the development of children and young people with disabilities and support them to achieve the best possible educational and life outcomes. Since 2014 there has been a greater focus on the preparing for adulthood agenda, and extensive research into transitions has been conducted.

A review of the Joint Strategic needs Assessments (JSNA) across our region identified a consistent gap in data related to transitions and, in particular, preparation for adulthood. The data available tended to focus on educational attainment, such as the number of young people not in education, employment, or training (NEET). However, every local authority area's SEND Strategy has a priority area connected to improving transitions.

In 2022 NHS England funded the South West region of Parent Carer Forums to undertake a project to understand the transition experiences of children and young people with Special Educational Needs and Disabilities (SEND).

METHODOLOGY

The project was underpinned by our ethos that everyone should have a voice and be supported to engage in a way that works for them. To enable this to take place the consultation had to include a variety of ways to collect the experiences of families. To enable delivery of the project, we split it into the following phases:

Pre- delivery and design

As part of the predelivery and design phase, all forums reflected on the conversations they have had with members and any surveys or events they have held. The South-West region of parent carer forums decided upon a survey and case study approach to collecting the experiences of families in the region. The survey was designed collectively to ensure it would meet the needs across all forums (see appendix c). Case study templates were created to collect individual experiences and allow for a consistency of information collection (see appendix d).

A comms plan was created to ensure consistent messaging across the region. Information leaflets and animations were created to raise awareness. Additional information was created to ensure informed consent was obtained from those taking part in the case studies.

Delivery phase

The survey ran for the period running from 9 November to 21 December 2023 with forums across the region promoting within their membership. The survey was also shared on the region's website during the live period. 19 case studies were collected by the, Bournemouth Poole and Christchurch, Dorset, Cornwall, Somerset, and South Glos forums.

During the project forums fed in local experiences, through project and regional meetings. This enabled us to collect a rich picture of experiences across the South West. We also reviewed all the JSNA's and SEND strategies for the area to determine the local work and priorities. The project also reviewed various research papers from the UK, focused on transitions in Education, Health, and Social Care, alongside policy and legislation documents.

Evaluation

We received 205 responses to the survey and collected 19 cases studies. These were added to the feedback from forums to identify key themes and potential changes that could be made to improve the experience of transition. The full survey results can be viewed online at <https://shorturl.at/aqEG5>

Dissemination

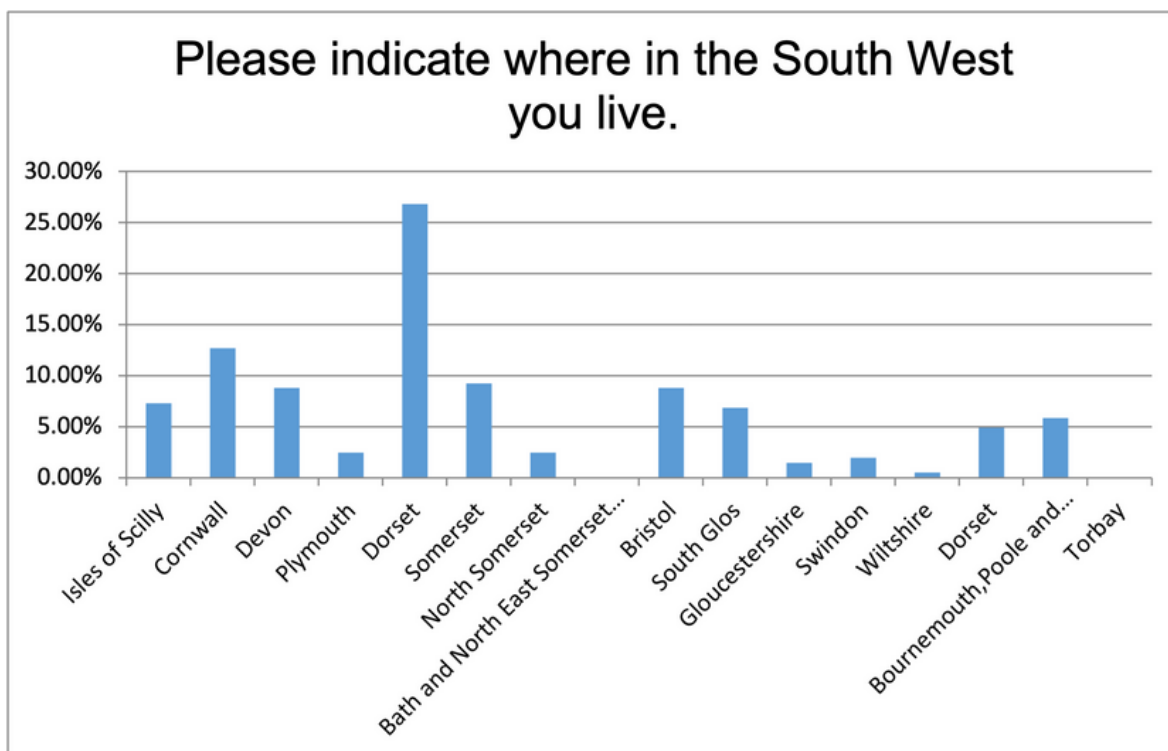
A formal report and slide pack presentation has been created to disseminate the findings of the research project. On the 28 June 2023 a Transitions conference was held where practitioners and parent carers came together to review the findings and form plans for their areas. The report will be held on the South West region of Parent Carer Forums website where it will be accessible to parent carers and practitioners.

SCOPE



All 15 forums across the South West were invited to be involved in the project with forums sharing the opportunity to get involve to their wider community.

Experiences of families has come from across the region, with children who have a wide range of needs included in the findings.



FINDINGS

“Overall found the process pretty smooth once we had the EHCP. It was stressful finding a place that was available, but that wasn't down to anyone specifically.”

Transitions and changes are part of all our lives and for a lot of people these can have minimal impact. However, for children and young people the impact of what might seem like a small transition can have a large impact. “Studies show that effective transition between paediatric and adult care improves long-term outcomes” (Naga et al 2015).

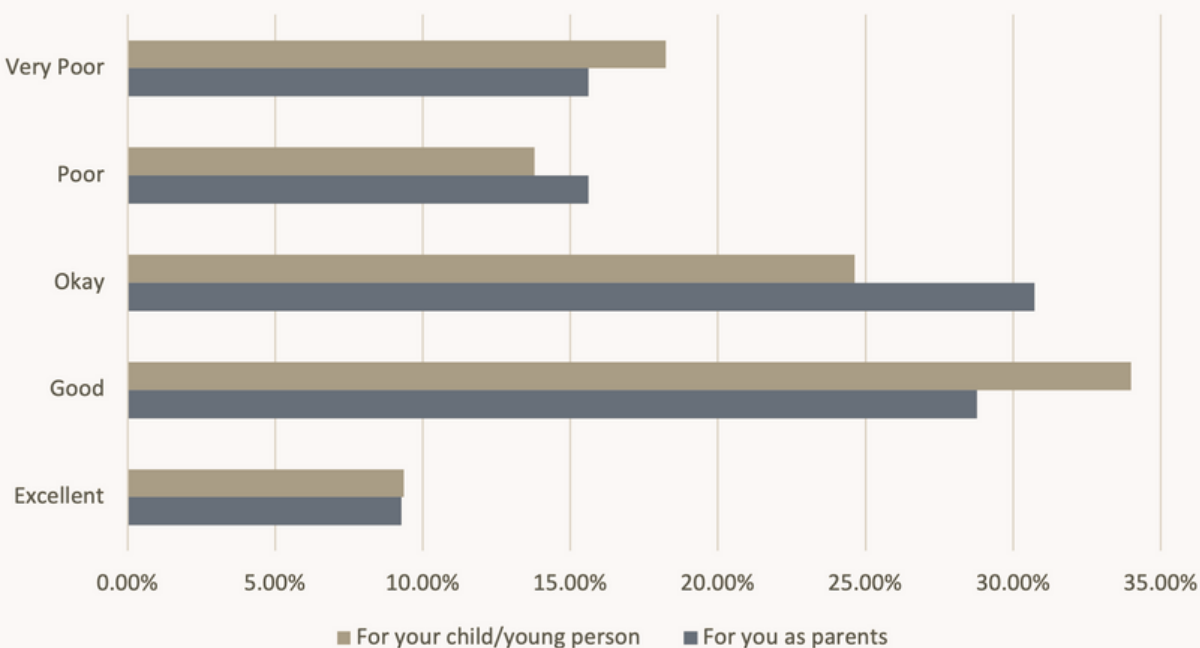
The following findings have drawn from the feedback received from parent carers, who have children with a range of additional needs and disabilities, across the South West.

Throughout our project we found a large variation in the experiences of transitions, with only 38% of parents reporting a good or excellent experience. Parents reported that process was slightly more positive for their children with 43% reporting a good or excellent experience.

The project has highlighted 5 key themes which shape the experience of transitions for children and young people with SEND and their families. Within this section we will look at these areas in detail.

“In the process of transfer, the service staff patiently listened to our needs. They gave us the transfer service according to our needs.”

Overall rating of the transition experience



THEME 1 -NOT ALL THE RELEVANT PEOPLE ARE INVOLVED DURING TRANSITION.

In a research project undertaken by the Institute for Health “Multidisciplinary staff from general practice, hospital and community care teams were interviewed about what they felt was important for a successful transition. The study identified three factors: knowing the patient; knowing staff within and across teams; and bridging gaps in the healthcare system” (SCIE, 2018).

Our research indicates that despite the importance of everyone involved in an individual’s care being a key factor in a successful transition, only 35% of families reported this happening. Within the project we heard multiple cases where key members of staff had changed during the transition process. “We have only had temporary caseworkers for the past 13 months. I was told by the caseworker manager that records were not kept properly, I had to keep repeating things all the time.”

These staff changes often led to families having to retell their story and information not being shared between teams. One parent explained the inconsistent approach in her child’s transition to adult services. “For the Social Worker it seemed like we had to repeat back from the beginning again the whole story - nothing was handed over from children's social care. For OT, they did a joint visit to home which was excellent. When a new social worker came, she was late because she went for the appointment to an address, we lived at over 10 years ago, so information sharing was very odd.”

Staffing pressures and capacity issues were also cited by families as a reason why some practitioners were not involved in the transition. For example “Health did not contribute as they had delays and we could not get appointments”.

Our research found multiple occasions where parents acted as a coordinator between practitioners. “Practitioners did not share their own thoughts and or opinions with each other therefore I was having to go to each individual separately to make sure everyone was updated”. Parents also reported feeling that if they had not planned the transition, it would not have been successful. Parents had to bring all the necessary services in and get them talking to one another.

In some transitions, information sharing issues led to a lack of understanding of the child or young person’s needs. One parent explained “Despite listing my child's diagnoses on the entry forms, it was only after they found his behaviour difficult, and I asked about his provision, that they realised he had any diagnosed needs. No paperwork other than the forms I'd completed had been sent to them, and I ended up having to provide them with copies of the paperwork I had at home instead”.

The most extreme examples of the right people not being involved is when the parent or carer has not been involved as demonstrated in the following case study (see also appendix a)

Only 35% of families reported that everyone involved with their child’s care got involved in the transition process.

CASE STUDY

X is an 18-year-old who enjoys music and sports. X hopes to find a college course and career that she can do.

During X's school life she managed well during her early years and into primary. This changed when moving into secondary school with X's parents reporting that she was taunted by other students. This impacted on x's mental health and eventually she was under the care of CAMHS. Mum reports that the care was not consistent with too many changes in staff leading to X having to retell her story.

X condition got worse, and she was moved to a mental health unit 250 miles away from her home. This resulted in limited time with her family and X struggled with missing her family. Mum reports that X was moved to another unit and although mum knew it was going to happen, she did not know the day it would happen. The unit X moved to refused to tell mum how she was doing, no one informed mum on the day she moved.



Practitioners working together in a person-centred way can have positive outcomes for young people. Parents told us of how having a lead practitioner had helped the process and several positive examples from the continuing health care team were shared. We heard how when N's placement needed changing following covid the social worker and continuing health care team worked together to find a suitable provision. Using pooled funding they secured a weekly boarding placement. N's parents report that he is gaining independence, and the health and social support he is getting is allowing him to thrive.

THEME 2- LACK OF GOOD QUALITY ACCESSIBLE INFORMATION

Several research projects in the UK have reported on the apprehension around the transition process for parents of children with Special Educational Needs and Disabilities. Baldwin's (2021) research into school transitions found that "nearly all parents expressed worry and referred to the process as overwhelming and stressful".

Within our research parents across the South West region, similarly reflected that the transition process can feel overwhelming and feel like a fight to find out what you need to know.

This can lead to worry and apprehension from both the parents and children or young person going through the transition process. One of the causes of anxiety focused on the lack of good quality information and clarity about options available.

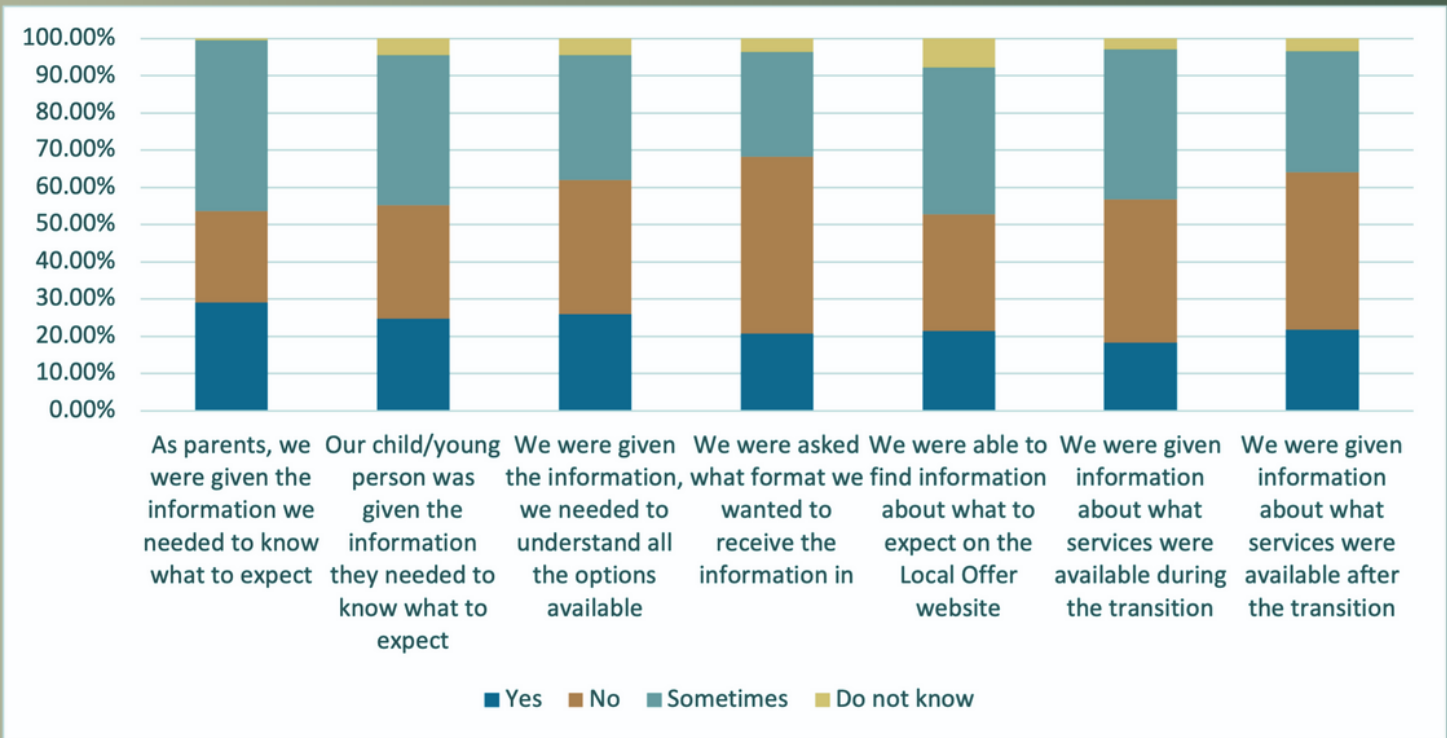
"Our experiences are only ok because I know how to navigate the send world and support my child. Without my own knowledge I am not sure we would be in such a good place"

"We have had to go and research all the schools ourselves, no list of the different schools in our area have been provided which is a very time consuming process"

78% of parents reported not consistently being given information about the options available to them, for example the choice of schools which could meet their child's needs. Parents reported that their feeling of being 'lost' was compounded when they found provision, but it was deemed as not being right. One parent told us "I had to find further education myself. The careers person never called us back or offered any support." Similar experiences were reported through the case studies and the survey responses.

Positive experiences of the availability of information given was low, with only 30% of parents reporting they felt informed about processes and options during and post transition. Some families reported feeling that professionals were either unable or unwilling to provide information.

Families reported being "passed around too many people I had to desperately try to gain information from any sources I could, as the authorities are very reluctant to tell you what choices you actually have."



From 1 August 2016 onwards, all organisations that provide NHS care and/or publicly funded adult social care are legally required to follow the Accessible Information Standard” (NHS England).

Despite the standards requiring information to be in appropriate form that meets people’s specific needs, nearly half (48%) of the parents reported not been asked how they would like to receive information and a further 28% reporting this was not consistently asked.

“Our son got very frustrated with having to repeat things many times, and he was upset that he would have to get to know the new social worker each time. He was cross that the letters just named the new social worker with no information, and that the letters were not sent in an accessible format (Braille).”



26%

We were given the information we needed to understand all the options available.

21%

We were asked what format we wanted to receive the information in

22%

We were able to find information about what to expect on the Local Offer website

25%

Our child or young person was given the information they needed to know what to expect

THE ROLE OF THE LOCAL OFFER

Since 2014 all local authorities must “(a)publish its local offer by placing it on their website” The Local Offer has two key purposes:

- To provide clear, comprehensive, accessible, and up-to-date information about the available provision and how to access it, and
- To make provision more responsive to local needs and aspirations by directly involving disabled children and those with SEN and their parents, and disabled young people and those with SEN, and service providers in its development and review (Department for Education,2015)

21% of parents responded positively that they could find the information they required on the local offer for their area, with a further 41% reporting they could sometimes find the information.

Work across the region by parent carer forums has highlighted that the content of the local offers is inconsistent, and we frequently hear concerns about the search functions within the platforms.

When information is available, this can impact positively on the transition process. “The transfer procedure of our child went smoothly. The service staff were very friendly to us and told us what we needed to know”.

Examples of things parents reported that supported transitions often centred around being informed included the following:

- college were very helpful, explained in detail the process including step by step what could happen.
- being able to visit the school on our own and meet the teaching team and classrooms etc.
- good contact SENDCO. Extra transition sessions, visual timetable, easy to read welcome pack and guidance. Extra support and being included in his 'Child in need' reviews before he started at the setting.
- The meeting of staff, the school grounds and other children in their future class was most helpful, and letting it go at our child's pace not the schools. It also helped that the school paid huge attention to our child's special interests to help promote a sense of belonging.
- Visiting was helpful, knowing about things in advance.
- When we were at a loss about the relevant procedures to go through, we got help from the service centre, who patiently explained all the relevant materials to us.



CASE STUDY

E is 17 years old who likes motorbikes and would like to work with bikes or in construction.

E's transition to secondary school was not planned and E has not attended school full time for most of his secondary school life.

Mum became concerned about E's welfare when he reported being locked in a cupboard at school and had absconded from the school on multiple occasions.

E received multiple fixed term exclusions with the reintegration's not being planned. At a reintegration meeting the head asked why E was there. The family then discovered the school had exclude the wrong child. Following this, E became more and more disengaged with school.

E was referred by the GP for an ADHD assessment, but CAMHS deemed he did not meet the criteria. On returning to the GP mum was advised to buy melatonin online. E was then referred into paediatrics, with the first appointment being cancelled due the staff member leaving. E was switched to another practitioner who read the notes and decided E had attachment disorder and didn't need to be seen. Mum was distraught at this point and struggling to manage E's aggressive outbursts so the GP prescribed medication which needs to be monitored by a psychiatrist.

E has not transitioned from school into another setting, becoming NEET. E has got involved with a local group known to the police and there have been several incidents where the police have been called. Currently mum does not know what the future for E looks like.





THEME 3 - COMMUNICATION ISSUES

Research undertaken by SQW evidenced “the importance of effective clinician-patient communications, including the substantial benefits that patients, the taxpayer and the healthcare system stand to realise from improved communications” (NHS, 2021).

It was evident from the research that communication issues impacted at various stages of the transition process. A lack of effective communication between services often led to a failure to implement a tell it once approach.

Parents reported that “having to repeat information is a constant. There seems to be a real lack of communication or ability to share information. This becomes exhausting and often, distressing.” One parent explained that she had shared her child’s diagnosis letter so many times that she’s pretty sure every service in her area has a copy.

While communication issues are often frustrating for families and practitioners alike, the more concerning side is the impact on outcomes for children and young people. Not receiving the information needed, can change a positive transition into a negative experience. “My child took part in an enhanced transition which was helpful. However, information about her dyslexia diagnosis was not shared with the new school which has meant she hasn't had any support in place for the first term.”

Ineffective communication can also result in families bouncing around the system without support. “I contacted Children's Disability Services who referred me to adults; they referred me back to Children with Disabilities. I was sent a link to a referral form, but I could not complete it since I can't answer Q is person eligible for s.117 aftercare”.

CASE STUDY

Young person A enjoys writing, online gaming and wants to become a games designer. A has ADHD and is autistic.

Just before turning 18, A was invited to an appointment to review his transition to adult services by paediatrics. The appointment was with someone new who A had never met before. This was a shock as this had not been communicated in advance and A expected to see the consultant he had seen since he was 10. A did not feel comfortable asking questions and left not understanding what would happen, except that the GP would now do his ADHD medication.

For the next 2 years A continued to get his medication from the GP without any appointments or reviews.

One day A was contacted to say he had an appointment with adult mental health services. The person who called was not able to explain why, and this caused anxiety. A's carer contacted the GP to discover that a referral had been made to review A's medication. The referral was done without A's knowledge or consent.

The communication breakdown had led to the medication reviews, which should have been happening every 6 months for the last 2 years, not been picked up during the transition.



THEME 4 - TRANSITIONS WERE TOO LATE OR DELAYED

A systematic literature review on the primary to secondary transition, undertaken by the University of Dundee recommended that "Schools should provide opportunities which enable pupils to form secure attachments with a number of practitioners in primary and secondary schools" (Scotland.gov, 2019).

Families of children and young people with additional needs and disabilities, told us that the success of transitions can often hinge on building relationships and feeling comfortable within the new service or setting. This takes time and patience.

Several parents within the survey reported that they felt the transition started too late. Some of the reason for this connected to timescales for assessments not being met leading to anxiety, and parents left questioning if the transition would happen.

"We really struggled to get any urgency from services for preparing for this transition.

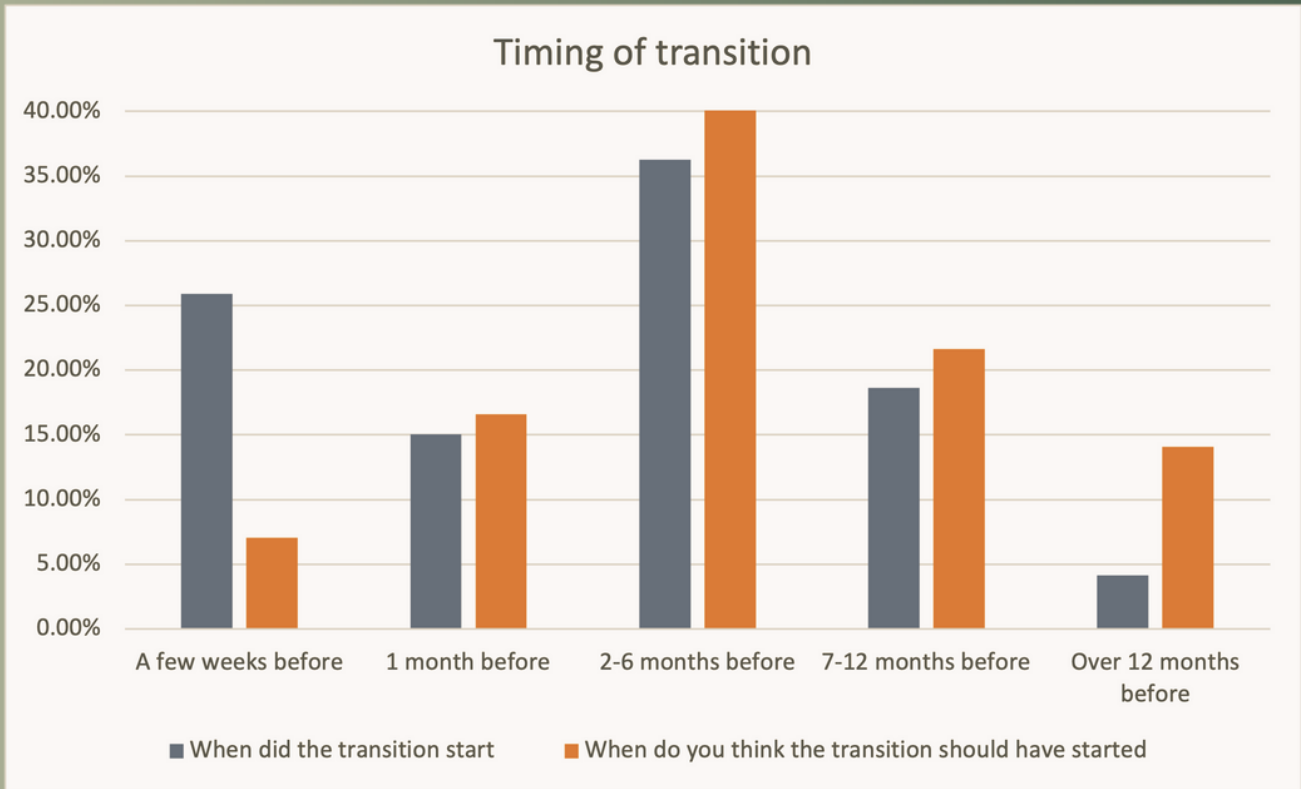
I have another child with SEND currently in Year 5 and finding the same thing again.

Services just aren't interested until the last minute and our children need time for the right settings and support to be put in place to ensure a successful transition."

26% of parents reported that the transition started a few weeks before the move to a new service or provision. The results from the survey showed a disparity between when families felt the transition should have happened, compared to when it actually did.

Delayed transitions can impact on the aspirations of young people. "Our son asked for one thing as part of his provision and his wishes were ignored. The process was drawn out and full of delays, so once a decision was made to try for what he wanted it was too late, as the provider had closed to new students for the academic year on the required course. He's now left with a gap in his timetable meaning unmet need and provision in his EHCP that cannot be offered/received this year."

Delays in transition arrangements carry the risk of children and young people slipping through gaps. For example, a parent reported they "barely had contact with Social Care team other than one meeting at college before our son finished. Then no contact at all until we pushed for support, which took 6 months from initial call." It would have been easy for this person to have dropped off the services radar.



A common theme through the research and feedback from the parent carer forums in the South West, is that the transition into adult services from children’s is a key area where planning is started too late.

A significant number of parents have reported the transition from CAMHS to adult services only started to be planned weeks beforehand.

Similarly, parents have reported that moving from children’s to adult’s social care can be left until the young person is weeks or days away from turning 18.

“For young people with special educational needs (SEN) who have an Education, Health and Care (EHC) plan under the Children and Families Act, preparation for adulthood must begin from year 9” (Department of health and social care, 2022).

CASE STUDY

L is 15 years old and enjoys going out with friends and loves adrenaline activities. L's long term aspiration is to earn lots of money and be happy.

L struggled with transitioning to primary school and eventually moved to a small private school. The transition into secondary school failed due to high levels of anxiety with the first school lasting a week. An alternative school was tried, and they could not meet needs which resulted in 1 year of home schooling.

In Year 8 L had an EHCP and was assigned a Learn 2 Live mentor, to visit home before school. The mentor would take L on walks, to swim, to have breakfast - no pressure about going to school. Staff would visit home on days of school refusal, built trusting relationships. The result was that L was able to access education.

In year 9 L was able to move back into mainstream education due to an early and extended transition allowing for L to form secure attachments with a number of practitioners



THEME 5 - LACK OF PERSON-CENTRED PLANNING AND FOLLOWING THROUGH

Nice guidance outlines that practitioners should "Hold an annual meeting to review transition planning, or more frequently if needed. ... This meeting should:...inform a transition plan that is linked to other plans the young person has in respect of their care and support" (NICE 2016). This aligns with the requirements mentioned previously for the preparing for adulthood planning under an EHCP to start in year 9.

59 % of parents reported that there was a plan for the transition, with 51% feeling the plan had clear goals or outcomes.

However, less than half of the plans were implemented. "We had someone come to talk to us about the transition - they asked my daughter and I lots of questions and sent us a pretty comprehensive report of her situation but then we didn't hear from anyone".

"The secondary school left my child out for the trial day for college. Staff didn't have anyone to take him over to college and support even though the ehcp was in place. I have completed this all myself with my child to get where needed in college"

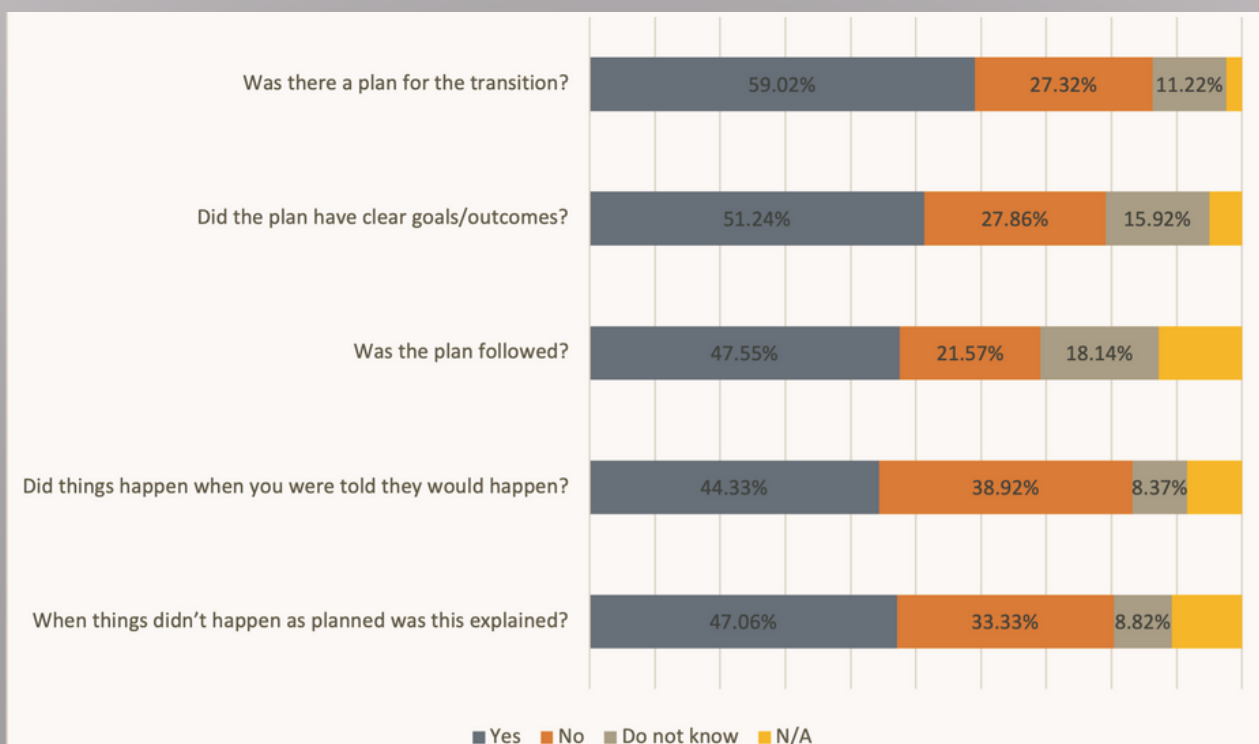
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Less than half of the respondents who took part in the research reported that the plans were followed. Findings highlighted that plans within an EHCP were not always implemented by the setting and this impacted negatively on the transition process.

One parent explained that "Despite having an EHCP, secondary school did not follow it. Said they needed to do their own assessment; child left struggling with transitions and support needed in this area was clearly identified, and recommendations made on EHCP, but not followed".





The case studies and survey findings highlighted the frustration felt by families when planning was not person centred. Situations that contributed to families feeling the child or young person was not central to the process included:

- parents being seen as over protective or fussy when asking for plans to be followed
- health and social care arguing about funding in front of the family
- lack of an explanation if things didn't go according to the plan
- having a 'voice' but not being listened to
- discussing the child's difficulties repeatedly in front of them, focusing on the negative
- sharing information that was then ignored.

Connection

The energy that exists between people when they feel seen, heard, and valued; when they can give and receive without judgment; and when they derive sustenance and strength from the relationship.

Brené Brown

CASE STUDY

J is a 12-year-old who likes sport, is obsessed with the weather, and enjoys going to banger racing. J would like to be a police officer or paramedic.

J started to show differences back in nursery and this continued to become more prominent during his primary education. J eventually was diagnosed with Autism. In year 5 it was decided that J needed an EHCP, due to the timing of the application the plan was not in place for when J started secondary school.

J had had 4 enhanced transitions at end of year 6, one of which was cancelled. This confused J, as he was in the secondary school for 2 hours then had to go back to primary school. Mum asked for the secondary school to inform who his tutor was, but they didn't, there were no move up days, so no transition other than the couple of hours 3 times in learning support. He only met the head of learning support and one of his key adults (written in his plan). He had never met his tutor. Mum asked for a photo of tutor, was told no, she asked if he could go in the day before starting but was told no. Mum asked could he meet his tutor at back gate before going in on start date, but this didn't happen.

J went to school on the second day and afterwards went to his grandmother's house. When he got there, he asked her for food as he hadn't eaten all day. He said he couldn't go in school hall as there was 3-year groups in there, and older boys spraying aftershave in year 7's eyes. In his plan it says he needs to be checked that he has eaten, he had his own lunch with him. Mum emailed school and the comments from teachers made it clear teachers had not read his plan.

J had several incidents during the next few weeks which were a direct result of his plan not being followed. Eventually in the November J stopped attending the school. The change of placement request had to go to tribunal so mum has had to give up work and J is at home until the matter can be heard.



CONCLUSION


“Young people go through all kinds of changes as they grow up – including when they move into a new class, go to secondary school, move to a new house or area, or experience changes within their family. These times of transition can be exciting. However, they can also be stressful, worrying or upsetting” (Young Minds 2023). Transitions for children and young people with additional needs and disabilities can bring additional challenges and worries.

The experiences of transitions in the South West is variable, with both positive and negative experiences being shared throughout our research. Experiences shared highlighted that changes in practice could make a big difference in the experiences of families. Starting planning for transitions earlier, better quality information and improved communication were reoccurring themes throughout the research.

The importance of a person-centred approach was a key factor in the case studies we reviewed and even if a person had a bad experience this could be rectified by placing them at the centre of the decision-making process. Most of the feedback from families focused on how they felt during the process, rather than the process issues themselves.

We know there is pressure on services and budgets are not keeping up with the needs that are presenting. It was of significant note that a lot of the things that parents talked about making a difference, were reasonable adjustments, which could be made at little to no cost. Time and patience from staff were also a reoccurring theme in successful transitions.

If we are going to improve the experience of transitions for everyone, we need a shift in focus to earlier planning across services, with all relevant people being involved while placing the child or young person central to the process.



People will forget what you said, people will forget what you did, but people will never forget how you made them feel.

Maya Angelou

REFERENCES

Baldwin, K. (2021) Exploring parents' experiences in their choices of primary school placement for their child with special educational needs and planning the transition to school for their child. [online] Available at: <https://ethos.bl.uk/OrderDetails.do?uin=uk.bl.ethos.848485> (Accessed: 03 January 2023).

Department for Education (2014). The Special Educational Needs and Disability Regulations 2014. [online] Available at: <https://www.legislation.gov.uk/uksi/2014/1530/part/4/made>. (Accessed 1 June 2023)

Department for Education (2015). SEND code of practice: 0 to 25 years. [online] Available at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25>. (accessed 10 June 2023)

Department of health and social care (2022). Care and Support Statutory Guidance. [online] GOV.UK. Available at: <https://www.gov.uk/government/publications/care-act-statutory-guidance/care-and-support-statutory-guidance>. (accessed 10 June 2023)

Nagra A, McGinnity PM, Davis N, et al (2015) Implementing transition: Ready Steady Go Archives of Disease in Childhood - Education and Practice [online] Available at: <https://pubmed.ncbi.nlm.nih.gov/26063244> (accessed 1 June 2023)

NHS England (2023) Accessible Information Standard [online] Available at: <https://www.england.nhs.uk/about/equality/equality-hub/patient-equalities-programme/equality-frameworks-and-information-standards/accessibleinfo/> (Accessed: 03 June 2023).

NHS (2021). NHS England» Improving Communication between Health Care Practitioners and Patients in the NHS in England. [online] www.england.nhs.uk. Available at: <https://www.england.nhs.uk/publication/improving-communication-between-health-care-practitioners-and-patients-in-the-nhs-in-england/> (accessed 10 June 2023)

NICE (2016). Transition from children's to adults' services for young people using health or social care services | Guidance | [online] Available at: <https://www.nice.org.uk/guidance/ng43/chapter/Recommendations#transition-planning>. (accessed 10 June 2023)

SCIE (2018). Transitions of care - activities to achieve integrated care. [online] Social Care Institute for Excellence (SCIE). [online] available at: <https://www.scie.org.uk/integrated-care/research-practice/activities/transitions-care>. (accessed 13 June 2023)

Scotland Gov (2019). Primary-Secondary Transitions: A Systematic Literature Review. [online] Available at: <https://www.gov.scot/publications/primary-secondary-transitions-systematic-literature-review-research-findings/pages/1/>. (accessed 13 June 2023)

Young Minds. (2023) Transitions, Change & Mental Health | Parents Guide. [online] available at: <https://www.youngminds.org.uk/parent/parents-a-z-mental-health-guide/transitions-and-times-of-change>(accessed 19 June 2023)

APPENDIX A

D is 18 years old who is described as empathic, caring and kind with an interest in gymnastics. D would like to have some trusted friends, live independently, and have her own family.

D enjoyed preschool and nursery and was eager to start to school. After the first 2 terms of school D did not want to go to school. She started to struggle with relationships with other children. When it came to transitioning to junior schools it was evident that she was struggling, and mum requested extra support for D to manage the transition. Mum was told that was not enough space and D was fine despite the fact D had been crying every night in bed.

In year 4 D became very fatigued and was diagnosed with ME and ended up on a part time timetable. D continued to struggle over the next few years and the move into secondary school did not go well. The transition plan was not implemented. During her first year at secondary the GP referred D to CAMHS due to suicidal thoughts.

At the CHAMS appointment Mum felt belittled by the clinician, who said to her "you seem overly concerned about your daughter's self-harm...I've been in this job xx years, and I can tell you if she really wanted to kill herself she would be cutting from here to here [demonstrating on her own arm], and not here to here." Mum was shocked to hear this, and replied "well luckily, I don't think she knows that". D remained under CAMHS and was diagnosed with ADHD and anorexia.

CAMHS said that she wasn't fit for school or full-time education. D was distressed by this as she liked the social aspect of attending school, and at one point left the house to go to school, with mum being advised by CAMHS to call the police, who returned her home on arrival.

Year 9: At the beginning of this academic year, D was admitted to an adolescent mental health unit (MHU) where she resided for 6 months. D found the experience of being separated from Mum traumatic - and has since said she felt abandoned. At the time Mum didn't feel she had a choice. D felt the environment and regimented treatment plan in the MHU was crushing, and Mum observed and fed back that their style of behavioural rewards did not suit D, and that she required a much more encouraging approach. At one point mum was asked to produce a document that would help D to understand what was happening better - which mum did but was surprised she needed to do it, rather than the setting.

Whilst in the MHU D worked 1-2-1 with the hospital educator who observed her cognition difficulties and informed school D required an EHCP. He told mum that the school were resistant to accept D had underlying learning difficulties (despite him sharing the hospital WISC assessment findings of generally low and very low) and advised mum that she would need to push this. He advised that D was instead considered to have behavioural issues. During her stay in MHU, D's boyfriend began an intimate relationship with her best friend, and the two of them began a hate campaign within the school against D, resulting in others telling her to kill herself etc.

APPENDIX A CONT....

Year 10: D's weight remained low and no educational support was offered despite CAMHs saying she couldn't attend school full-time. Covid lockdown began as D was scheduled for a second MHU admission and the unit was temporarily closed. Instead, D spent 3-4 months undergoing an admission conducted from home - up to 11 video calls per day, including supervised snacks and mealtimes - all prepared for and supported by mum. This was much easier for D as she remained in her 'safe' environment, with her 'safe' person (mum), and was offered familiar food she liked - unlike hospital where she was "forced" to eat foods she didn't like and didn't want to eat. This was more successful, and D quickly began to restore weight.

During this admission, D's diagnosis was reclassified as ARFID with some anorexic thinking alongside. It was acknowledged that talking therapy wasn't compatible with her cognition difficulties, and that she would benefit from EMDR via CAMHs.

Within a couple of weeks back in the community, the previous hate campaign resulted in her ex-friend physically assaulting D, in the street. This immediately added to D's earlier traumas, impacted D's eating, and led to continued weight loss. Still no EMDR was made available to her. Meanwhile mum had applied for an EHCP.

Year 11 - an EHCP was issued which mum immediately highlighted that it did not accurately capture D's needs (suggested outcomes - 4 GCSEs), and therefore not fit for purpose. Mum's concerns were not taken account of.

School provided a home-based tutor / mentor - as D entered her fifth year of not being considered fit to attend full-time. The tutor quickly ascertained that the EHCP did not accurately reflect D's ability or needs and requested an emergency review. The review began approx. 6 months after the initial plan was issued but the LA and school seemed obstructive. The review was never fully completed, and no changes were made. SGS college was consulted and named for post-16 provision based on the abilities and needs highlighted in the initial plan, but when D's tutor and mum spoke with them about the extent of D's needs, they confirmed they were not expecting a CYP that required 1-2-1 support. They were expecting a CYP who was expected to gain 4 GCSE's and could work independently with some support. D was placed on a CETR and began Equine Therapy, funded by health.

D finished year 11 with one low-level GCSE in Art, and the review of her EHCP began again in the Summer between year 11 and year 12, where her psychologist, and psychiatrist gave several reasons why college would be unsuitable provisions for D, and detrimental to her physical health and mental wellbeing. Still no amendments were issued.

During this year, D finally confided in mum that her ex-boyfriend had physically and sexually assaulted her, and that she had lost two babies. She had lived with this secret for 18 months, trying to process it all by herself. One of the early miscarriages had occurred following her boyfriend punching her in the stomach, and the second was whilst alone, in the MHU. During her first admission D had repeatedly been sick (bile) and the staff had asked mum if D was sexually active - mum replied no, as that is what she believed. D was never tested for pregnancy, and it was a year or more before CAMHs acknowledged D's grief about the pregnancy losses as real - rather than aligning 'her belief of miscarriage' as an emotional representation of another event.

APPENDIX A CONT....

Mum contacted the police and D made a statement. Despite some video evidence a prosecution was not possible. D received a backlash from her peer group, and further distress.

Year 12 – D’s EHCP named x college and no transition plans were made, or additional education offered. The PFA team visited D and mum, at home to discuss alternatives, and asked mum to visit x and Mum provide a list of reasons why it would not be suitable. Mum highlighted this was impractical for her as she has three children with additional needs and works. Mum also pointed out that regardless of her opinions the health professionals had clearly stated it was an unsuitable placement.

D moved out of home and Mum asked social care for support to help D find somewhere suitable to live but this was not forthcoming. After five months, the Adult Transitions Mental Health Nurse met with D and found a placement in supported living accommodation. This was a 20-minute drive from home and D felt isolated and alone.

Mum received a phone call from an EHCP team member, towards the end of year 12, to ask why D had not taken up her place at SGS. Mum explained the EHCP was never suitable, the review never completed, and that the placement was inappropriate. The EHCP team returned with the offer of a place with Make it Mentoring (MIM).

Year 13 – D returned to education with Make it Mentoring, and is progressing with maths at a functional skills level. She is feeling more confident about education, and MIM are helping her with life skills, and life choices. She is happy working with them but unhappy that Equine Therapy will stop / change venue. D dislikes change.

Initially, Mum was concerned about D’s vulnerability as concerning situations arose, for example, a new ‘friend’ photographing D’s passport, D attracting the attention of a young man released from prison on licence, no help with basic living needs, washing, cooking, etc. However, the Transitions Mental Health Nurse didn’t consider any of these situations to be of concern and was adamant that the right support was in place and that D didn’t need a social worker. Changes have taken place in D’s accommodation, and she is beginning to feel a little safer and better about living there.

As D has turned 18, mum has been asked to step back and allow D full independence, with no consideration of the delay in executive functioning, or vulnerability. The mental health nurse told mum that concerns had been raised that D wasn’t managing her own PIP (mum is her named advocate and would meter out the money across the month), and that there were considerations for mum to be reported for financial abuse. Mum was told D will learn by making mistakes and not to give her money etc if she runs out. No other support for D was forthcoming and no financial planning assistance from the supported living accommodation was provided.

D is not allowed visitors to her flat and misses her family. Mum misses not being able to support her daughter – as she normally would have – by popping round, helping her cook, having a cup of tea, etc. No social worker has been allocated since D came off the voluntary family plan as it has not been deemed necessary which Mum finds incredible given D’s vulnerability, mental health needs, physical health, and learning difficulties. Mum was told D will not meet the threshold for the disability team. D received a criminal injuries payment (applied for by mum) for the crimes against her by the ex-boyfriend. D continues to grieve for her “lost babies”, particularly on Mother’s Day, and other significant dates.

APPENDIX B

South West Region of Parent Carer Forums is made up of the following 15 forums.

1. Bath and North East Somerset (BANES)
2. Bournemouth, Poole and Christchurch
3. Bristol
4. Cornwall
5. Devon
6. Dorset
7. Gloucester
8. Isles of Scilly
9. North Somerset
10. Plymouth
11. Somerset
12. South Gloucester
13. Swindon
14. Torbay
15. Wiltshire

APPENDIX C - SURVEY QUESTIONS

1. Please indicate where in the South West you live
2. Please tell us about your child's needs.
3. Please tell us the type of transition your child had (i.e Changing education setting/classes education, changing social/health worker or moving from children to adult service)
4. Overall, how would you rate your experience of the transition?
5. Please let us know how you rate the following statements.
 - a. As parents, we were given the information we needed to know what to expect
 - b. Our child/young person was given the information they needed to know what to expect
 - c. We were given the information, we needed to understand all the options available
 - d. We were able to find information about what to expect on the Local Offer website
 - e. We were given information about what services were available during the transition
 - f. We were given information about what services were available after the transition
6. Is there anything you would like to tell us about the information you were provided with during the transition? (please do not include anything which will allow us to identify you or your child)
7. Did services share information to support the transition?
8. Did you have to repeat your story to different people during the transition?
9. Is there anything you would like to tell us about this? (please do not include anything which will allow us to identify you or your child)
10. Please let us know how you feel about the following statements.
 - a. As parents we were involved in the planning of the transition
 - b. Our child/young person was involved in the planning of the transition
 - c. As parents we felt we were listened to
 - d. Our child/young person felt they were listened to
11. Is there anything you would like to tell us about this? (please do not include anything which will allow us to identify your child)
12. Please tell us your experience of the transition process
 - a. Were all the people involved in your child/young person's care involved in the transition?
 - b. Was there a plan for the transition?
 - c. Did the plan have clear goals/outcomes?
 - d. Was the plan followed?
 - e. Did things happen when you were told they would happen?
 - f. When things didn't happen as planned, was this explained?
13. Please tell us about the timeliness of the transition.
 - a. When did the transition start?
 - b. When do you think the transition should have started?
14. Please select any of the following things which have been used during the transition process.
 - a. Meet the new team/staff member
 - b. Website links with information
 - c. Online meeting/tour
15. Please use this space to tell us if you feel covid impacted on your child/young person's transition and how.
16. Please use this space to tell us if have you experienced something that really helped your child/young person's transition?
17. Is there anything else you would like to tell us?
18. Please tell us the first part of your postcode e.g. TA20
19. How old is your child or your person?
20. What is your child/young person's ethnic group?
21. What is your child's gender?

APPENDIX D - CASE STUDY TEMPLATE

Name of child/young person		Date of birth	
Place of Education, employment or training		Parent Name	
Description of child/young person's needs			
Consent obtained	INSERT DATE	NAME OF PERSON RECORDING	
People who are involved now			
People who have been involved in the past year			
People who have been involved in the past (more than a year)			
About child/young person	Age, likes dislikes and aspirations		
Background - Preschool			
Background - Primary			
Background - Secondary			
Current Position			
Future hopes			

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