



Transition from Children to Adult Health Services

**For those with a special educational
need or disability**

April 2024



What we did

[Families and Carers Together Bucks \(FACT Bucks\)](#) told us their members had reported gaps in health care provision and that there was poor, or no, transition arrangements when children move to adult health services. We developed a survey with them, and the Designated Clinical Officer (DCO) for Special Educational Needs and Disability (SEND) at Buckinghamshire Council. A DCO works collaboratively across local health, education, social care and voluntary sectors including parent carers and young people to ensure that the integrated care system is fully engaged in the delivery of the SEND agenda.

We collected feedback about 33 young people's experiences of transition from parents/carers, via survey and/or interview. This took place in February and March 2024.

Key Findings

- Noone we spoke to had been asked to complete the nationally recognised "[Ready, Steady, Go](#)" forms which are part of the "Transition: moving into adult care" programme.
- One parent mentioned the Oxford Health Foundation Trust (OHFT) [Your guide to transitioning from Buckinghamshire CAMHS to the Adult Mental Health Team](#).
- Regardless of whether they were at the start, in the middle or at the end of the transition process, most parents/carers told us they needed more support.

- 80% (20/25) of respondents told us they were dissatisfied with the transition/planning around the young person's move to adult health services. Many did not feel included in the process.
- One person told us they had a written plan, letter or report regarding the transition to adult health services.
- 70% of those yet to start the transition process did not know what to expect.
- Where the young person had transitioned to adult services:
 - around half felt the timing of the transition planning was about right.
 - only a third had attended any meetings to discuss transition.
- 70% of respondents whose young person was discharged from children's health services (and not in receipt of adult health services) told us they did not know who to contact if the young person needed help as an adult.
- Most (4/5) of those who said they were satisfied, overall, with the move to adult health services, attended regular meetings, had a named person to support them and said the timing of the transition was about right for the young person involved.
- 60% (9/15) of respondents said poor communication causes/caused the most concern.
- One person was concerned that Buckinghamshire Council had no access to their carer contingency plan stored on the OHFT system.
- Two parents told us their young people, with autism, struggled to be ready exactly when they were called by a clinician from a waiting room.
- Several parents of young people with capacity told us that they were frequently discharged rather than transitioned. Parents then needed to step in to involve adult services a few months later when support was required. This often concerned young people who are neurodivergent and/or need mental health support.

Our recommendations

We recommend that Buckinghamshire, Oxfordshire and Berkshire West Integrated Care Board (BOB ICB) works with providers to:

- Make wider use of [Ready Steady Go](#) specifically designed for those over 11 years of age with a long term health condition.

- ✓ To better prepare people for the move from Child and Adolescent Mental Health Services (CAHMS,) make wider use of [Your guide to transitioning from Buckinghamshire CAMHS to the Adult Mental Health Team.](#)
- ✓ Improve communication between clinicians and parents/carers and young people ensure they are invited to attend regular meetings about transition and have a named person to support the young person during this.
- ✓ Support certain individuals (e.g. those who struggle to sit still, or a person needing a few minutes warning before going to see a clinician) in waiting rooms, provide a pager/text message to alert them prior to being called.
- ✓ Provide people with autism appropriate mental health support, tailored to meet their needs. ([NHS England » Meeting the needs of autistic adults in mental health services](#))
- ✓ Ensure that, when a person is discharged from a service, a clinician explains why this is and where to go for any help in future.

We recommend that Buckinghamshire Council:

- ✓ Promotes the value of a health or hospital passport, and where they may be accessed, [ensuring information about transition is accessible](#), visible, and in a format that is appropriate to the individual.
- ✓ Ensures all parties are aware of the information sharing process to access carer contingency plans stored on hospital systems.

Healthwatch Bucks will also refer the points about young people, with capacity, frequently being discharged rather than transitioned, to Healthwatch England to see whether this is a wider issue across England.

What the project was about

Background

We were approached by FACT Bucks with a question at our September 2023 Board meeting: “Can Healthwatch actively engage with adult health providers in Bucks to ensure that they collaborate with their children’s health colleagues in the planning and delivery of smooth and supportive transfers of individuals into adult services?” Parents were telling them about gaps in health care provision and poor, or no, transition arrangements in place when children moved to adult health services.

In June 2014, the Care Quality Commission (CQC) published [“From the Pond into the Sea”](#). This is a thematic review looking at children with complex health needs as they move to adult health services.

“The transition process can be a vulnerable time for young people and their families. During this period, they stop receiving health services that they may have had since a very young age... and move on to equivalent adult services which can be structured and funded differently.”

The report’s key messages were reflected in the February 2016, National Institute for Health Care Excellence (NICE) published guidelines on [transition from children to adult’s services for young people using health or social care services](#). Their recommendations included:

- A requirement for health and social care service managers in children’s and adults’ services to work together... to ensure a smooth... transition for young people especially when the young person has an education health and care (EHC) plan...
- For young people with EHC plans practitioners should start planning for adulthood from school year 9, as set out in the [Children and Families Act 2014](#).
- Meetings to review transition planning, involving all practitioners providing support to the young person and their family or carers, including their GP, at least annually.
- Help to be provided to the young person to identify a single practitioner who should act as a [‘named worker’](#) – to coordinate their transition care and support.
- Transition should be discussed with the young person’s parents/carers to understand their expectations.

- Children's and adults' service managers should ensure that a practitioner from the relevant adult services meets the young person prior to their [transfer](#) to adult services.
- All children's and adults' services should give young people, their families or carers information about what to expect from services and the support available to them.

These were extended by the NICE guidance published in March 2022: [Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education](#). This reiterated:

“Interagency teams should work together to plan the transition between children's and adults' services for each young person... When a young person is transferring from children's to adults' services, the [named worker](#) should oversee and coordinate transition, hand over their responsibilities as named worker to someone in adults' services, and give this person's contact details to the young person and their family...”

Our Aims

We want to find out about parents'/carers' experiences of transition from children to adult health services.

- Did transition start at the age which made sense for the young person involved or the service involved?
- Are some adult health services more engaged with transition than others?
- Are there challenges with the provision and communication of information?
- What is the impact of excellent and poor transition experiences on young people and their families/carers?

Who talked to us

We developed a survey with FACT Bucks and the Designated Clinical Officer for SEND at Buckinghamshire Council. FACT Bucks emailed a link to this survey to their members. They also asked Bucks Family Information Service, Bucks Special Educational Needs and Disability Information, Advice and Support Service (SENDIAS) and the SEND Inclusion Advisers to promote this. They were also offered the opportunity to volunteer to be interviewed. The survey was publicised on social media.

Full details about who completed the survey and/or talked to us can be found in Appendix 3.

We found the following:

- 81% of respondents identified as White: British.
- 89% of respondents identified as a woman and 7% as a man.
- The median age of respondents was 52.
- 79% of respondents told us their young person, transitioning from children's services, has a neurodevelopmental condition (ADHD, ASD, learning difficulties).

What we heard

We collected feedback about 33 young people's experiences in February and March 2024. 26 people completed an online survey. We interviewed four of these in more depth, as well as seven other parents/carers, who had not completed the survey. Two thirds concerned young people currently aged between 14 and 19.

The young person's special educational need or disability

Everyone we spoke to told us that the young person they cared for has a special educational need or disability. We asked specifically about the disabilities of the young person. 33 people gave at least one answer. (People could choose more than one option so the total may be more than the number of people who answered the question.)

Which disabilities?	Total
Neurodevelopmental condition (ADHD, ASD, learning difficulties)	26
Sensory impairment	18
Learning disability	19
Long term condition	11
Mental health condition	9
Physical or mobility impairment	8
Other	6

Table 1 - Which disabilities does the young person have?

We asked whether these young people had specific diagnosis and long term conditions. The full list of responses can be seen in Appendix 2.

- Of those 26 with a neurodevelopmental condition, 20 had a diagnosis of autism and 12 had ADHD/ADD.
- The top three long term conditions amongst these young people were having a learning disability (10), a musculoskeletal condition (4) and/or epilepsy (4).
- 26 people also told us more about the special educational needs and/or disabilities of these young people. The most frequent responses were that the young people

had anxiety, were non-verbal, were a full-time wheelchair user or had Down's syndrome.

Plans to support the young person

We asked whether the young person had certain support or plans in place.

- Only two respondents said the young person has a health passport.

"No, not heard of it. Where do I get one? Sounds like a great idea. Do Bucks have one?"

- 27% had a SEND support plan.
- 65% had an education, health and care (EHC) plan.

Some of the young people, now over 19 years of age, used to have a SEND or EHC plan.

Current health care provision

73% of the young people were no longer receiving any health care from children's health services.

Service Provider	Total
Only children's health services	5
A mixture of children's and adult's health services	4
Only adult's health services	13
The young person is not receiving any secondary health care services	11
Total	33

Table 2 – Who currently provides secondary health care for the young person?

Support during transition

- No-one was aware of being asked to complete any "Ready, Steady, Go" forms which are part of the "Transition: moving into adult care" programme.
- Only one parent mentioned the OHFT [Your guide to transitioning from Buckinghamshire CAMHS to the Adult Mental Health Team](#).
- Table 3 shows that most people said they needed more help than had been provided, or was being provided, during transition.

Support required?	Help not needed	Getting /got enough help	Need/ed help/ more help	Total
Someone to talk to about transition / where to find information	1	1	20	22
Someone to provide emotional and practical support for the family	1	1	20	22

Table 3 - How much help have you had with the coordination of the young person's transition?

- Most people (20/25) told us they were dissatisfied with the transition/planning around the young person's move to adult health services.

"We are satisfied with individual professional's assistance we've had. The individual services work well. But we are dissatisfied with the way transition for our son is being managed. The system is disjointed."

Those only receiving care from children's health services or from a mixture of children's and adult services

We found that those receiving a both children and adult services had not yet any actual experience seeing a clinician under adult services. We have combined their feedback with those who only have experience of children's health services.

Six young people were seeing, or had recently been signed off by, paediatricians in secondary care for a range of conditions including neurology and cardiology. Three others were under, or had recently been under, CAHMS.

Recently started the transition process

The parents/carers of two young people told us the timing of the transition process, at age 17-18, was about right for them. One spoke weekly to a named person and attended regular meetings. They felt they had enough support about where to find information about the transition process. However, they felt they needed more emotional and practical support for the family. They did not have a written transition plan.

The other person had mixed messaging which had reduced their confidence regarding transition in the other departments (where the young person is still under a paediatrician).

“We transitioned, last month, from paediatric orthopaedics at John Radcliffe, Oxford. And was told, verbally, if there were any further issues with his hips or femur (has metal plates in both) to see the GP. It feels like you’re just being dropped to fend for yourself. Subsequently, we got a letter saying he would be transitioned to adult services but there are no details in the letter saying what happens next.”

However, they were also a patient at the Royal National Orthopaedic hospital. The paediatric neurologist there had explained that he would be transitioning their young person to adult services in May 2024. He had explained that they would get a consultant’s name and department in a letter in the form of a referral. This consultant has also told them to phone any time if they have any issues.

“I found this really helpful and reassuring.”

Not yet started transition

Seven others had not yet started the process. None of them had a transition plan or a named person to go to for support. Five of these young people were aged 14–15, and two were 17–18. Five people felt they should have been better informed as to what to expect and two felt the process had started too late.

“Will lose CAMHS support soon, except medication monitoring. [She] now has high anxiety levels and is restricting food with transition away from CAMHS support.”

None had had any meetings to discuss moving to adult health services.

“I would like to have a clearer understanding of what needs to happen and when.”

One parent of a 15 year old, who had recently been discharged by a paediatrician felt that the orthotics department may cover both children and adults but was unsure. They had nothing in writing and were not sure what happened next. As far as they were concerned there had been no transition although they agreed there was no immediate secondary care needs for their young person. They also had been told to contact the paediatrician if they had any concerns in the future.

“It would have been nice to have had a conversation generally, even if it was with the GP, to tell us what happened next if that’s it.”

Those only receiving care from adult’s health services

Transition timing

One person told us there was no discussion about any transition. The young person was just discharged from CAHMS to the learning disability services at Buckinghamshire Council. This individual regularly sees a consultant psychiatrist on an annual basis. Another young person, discharged by CAHMS and not transitioned, is now receiving adult mental health services.

However, discussions about health services transition planning started for nine other young people between ages 17 and 18. For the other two, these started when one young person was 12–14 years old, and for the other when they were 20.

Six people felt this was about the right time for the young person. Five people said discussion about transition planning started too late.

“No real discussions but he was aware that he would have to transition from Great Ormond Street to an adult clinic at a different hospital.”

One parent was concerned that their young person, living with a learning disability and ADHD, had been permitted to stop taking their medication when they were 17. Their parents and school then had to step in four months later to get the medication reinstated, but this time via adult services.

“It took 9 months to get her back to where she’d been when they discharged her as a child.”

Transition meetings and support

Only a third of young people and their parents/carers told us they attended a transition meeting to discuss the move to adult health services.

“Diabetes had a special session.”

Eight people did not attend any meetings.

“No, the paediatrician just said that he’d signed her off. He’d done the referrals and would chase them. No hand over or meeting adult doctors.”

“No support or planning were offered and only a pro-active approach by parents ensured that the young adult did not fall off a cliff into a void.”

“Our experience is dire. They have a fancy **guide to transition to the adult mental health team**. They say the experiences will be person-centred, there’s a holistic approach and the young person will be introduced to the new staff who will be working with them. Absolutely none of this happened...There were meetings between CAHMS and the adult MH team but neither the young person nor parents were invited.”

Two people said the transition planning was reviewed about every 6 months. One said less frequently than annually. Eight people said the planning was never reviewed.

One person told us continuity of staff was an issue:

“He has had 5 psychiatrists and 5 care coordinators in the last 2 years.”

One person said they had a written plan but ten people said they had nothing in writing outlining any transition arrangements. Not knowing what would happen next made some parents and young people anxious.

“Nothing in place, even now. It needed to have happened a lot earlier. I need to tell her over and over again when things change (like leaving school). I need time to prepare her, and nothing is in place that I can tell her about.”

Two people said there was a named person (e.g. a nurse, social worker etc) to support them and the young person through the transition. They spoke to them several times a year. These were the only people who also said that the young person was receiving the health services discussed in the transition planning. However, one said the support from the community nurse had stopped once the ECH plan ended.

“The consultant psychiatrist’s primary role is assessing his medication, but the community nurse has the practical knowledge. We like to nip issues in the bud. There is always an issue. We don’t know who to go to now... It would have been easier just to keep the same community nurse for consistency for us and for him.”

Nine people said they had no named person they could go to for support.

“The one social worker we had for 2 months before we were signed off was excellent. But since then... we’re just winging it.”

Those not receiving any secondary health care

Three quarters of the respondents (8/11) told us that the young person was discharged from children’s services before the transition process started. Only one of these was subsequently referred back to secondary care services for the same condition. The parent felt support had not been provided when the young person moved away to university, and it was now very difficult to access.

“Had to fight to get the support and then it wasn’t provided...They need to be on the [neurodiverse] ND pathway but this [waiting list] is too long and they’ve already closed it. The support won’t come. They only assess half a day a week.”

Those with experience of transition

Two young people had received some support from CAHMS before transition. However, neither had a named person to support them through transition.

One person felt they had not had enough input from children’s health services. They said no transition discussions took place, and they had no written transition plan nor reviews. They also said their young person was discharged after transition because some support was being provided by their young person’s private school. They were dissatisfied with this decision because they felt that they were entitled to NHS support as well. They said they did not know who to contact if the young person needed help as an adult.

The other person told us the transition planning started about the right time for the young person and was reviewed over a two year period. However, the continuity of care, and building of relationships didn’t happen in adult care.

“The pre planning side of things was good - her CAMHS team were brilliant. However when she got into adult mental health services, they didn't seem to understand the complexity of her ASD as she masks extremely well, and instead questioned her diagnosis ... and made her think that she wasn't 'bad enough' (even though she is frequently suicidal ...) and that she didn't warrant any support. Now she refuses to engage as she feels so misunderstood by them.”

Those discharged prior to transition

Four people were discharged as no further treatment and/or consultation was needed at that time. All these respondents agreed with the decision to discharge the young person from secondary care services. However, only two said they knew who to contact if the young person needed help as an adult.

Three people were told their young people were discharged from secondary care because any further treatment/consultation could be provided in primary care. All three disagreed with this decision. Only one of these said they knew who to consult if the young person needed help as an adult.

Biggest concern

We asked what, regarding the transition to adult health services, caused/causes the greatest concern as a parent/carer. We have summarised the comments by theme.

- The biggest issue for 60% (9/15) of respondents was the lack of communication. Several felt ill-informed about what should happen when and whether transition should have already started or not.

“The unknown”

“I don't know what is happening. They knew she was coming up to adulthood, so why is it not a smooth process?”

One person said their biggest concern was that they felt their young person was not being empowered to access support independently.

Others were concerned about decisions being made too late leaving insufficient time to explain changes to their young person.

“My young person has a learning disability, and their mental age is much lower than their actual age so moving to adult services is quite daunting. I haven't really had much info on moving to adult services so [have to] presume it will just happen.”

For one person, the issue was around being discharged rather than moved to adult services.

“The plan seemed always to move to discharge her rather than plan for transition. She can self-advocate and is very eloquent. However, I'm always surprised by the lack of understanding health professionals have about the extent additional needs impacts on the developmental capabilities of SEND kids. Not all 18 year olds can rationalise in the same way.”

- Three people were concerned about service organisation.

“I was just left to coordinate [it] myself not really knowing who she should see/be under.”

“The health professionals and social worker are very lovely and helpful, but the amount of provision available on the frequency of appointments and contact reduces significantly when your child turns 18, and that can be very daunting when your child has long-term issues...”

- Two were concerned about how staff, who didn't know their young person had treated, or would treat them, in adult health services.

“I'm concerned about my child's lack of patience (in a waiting room) and lack of compliance in an examination room. Getting him to cooperate takes a lot of time and patience. [In adult services] is there any flexibility in services regarding how he can have his appointments or be seen by medical professionals? ”

- One person reiterated the lack of rapport with adult services staff resulting in the young person refusing to access mental health support.

- One had concerns about the quality of treatment and continuity of care for their young person.

“We used to have direct access to a paediatrician but now there’s no open access any more. Now we have to go to a GP who doesn’t know enough about her condition to be able to make decision about whether her meds should be adjusted or not. I don’t know where to go...I always got an answer from the paediatrician but now I’m literally floundering. If we get desperate we go to A&E but sitting for hours there is not great for her.”

More support and information

We asked how the health services could provide the young person with more support, information or signposting during transition to adult health services.

- Most people told us they wanted better communication.

“Any communication would have been wonderful.”

Many said they needed to know more about the process and what to expect when.

“A little more information about what would happen next would have been useful and put me more at ease and given me more of an understanding.”

Several people told us that written details (a plan or report) would be useful.

“A booklet giving me an idea of the process and how it should work. It should be given to parent/carers when the child is about 14/15. To give the parents a chance to get their heads around what will happen and prepare the young person. Adult services doctors need to get on board. They know these kids are coming their way.”

“time lines, pathway diagrams, fact sheets”

“Why don’t they have these Ready, Steady, Go documents, you mentioned, at schools in the Transition to Adulthood Fairs?”

“A roadmap or at least a letter with a route back into the community nursing team where we can seek support and stop any escalation of any issues.”

- Several people reiterated the request to involve parents/carers at every step in the process.

“Actually make a plan and involve me. They should have explained, much earlier, what they were trying to sort out and what would happen. Wish we’d had a smoother handover; it would have made it much easier.”

“Consult the people who know the child best, liaise more with the social services and education teams involved with the child and triangulate all the information before an inappropriate discharge. Don’t have such hard boundaries when treating kids with SEND.”

- People wanted named contacts they could access to ask questions and get support during this process.

“A point or contact, or a group of contacts, we could ring to get help or explain what is happening/will happen; give us more reassurance and support. We don’t know what the process is as every department in every hospital is different.”

“A direct person to help coordinate which services she should be under.”

- In the absence of a plan, written report or named contact, a few parents were not clear where to go for help once the young person became an adult.

“What happens next? Do we go to a GP now for everything or back to the paediatrician?”

- Two parents/carers also commented on there being a gap in support around healthcare when their young person was aged between 18 and 19.

“There is a gap once healthcare discharge you at 18 and the ECHP ends at 19. Education, social services and healthcare need to all work together.”

- One person suggested transition should be better funded to enable the process to be undertaken in a timely and informed way.

“These kids and parents need a little more time and planning when it comes to transition. Information and planning from 14”

“More notice, more planning, more involvement of parents. If you get cancer you have a roadmap. This is your journey; this is where you get help. There is nothing like that if you have ADHD and a LD.”

- One person wanted more reassurance that adult health services would be flexible because of their young person’s need to wander rather than sit still. They suggested a pager/buzzer could be provided to the parent in waiting rooms in these circumstances. This would allow the young person to be prewarned that they would need to return to the waiting room when this vibrated.
- Again, people wanted reassurance that the young person would receive timely, appropriate care in adult health services whether they had been discharged or transitioned.

“Mental health support via CAMHS ceased the day he turned 18. My son has access to a psychologist via the diabetic team at the hospital and this has continued into adulthood, but if he didn’t I would be extremely worried about how to find support.”

“Treat young people with disabilities in a group between 18–30. Ending support at 25 might be fine for the mainstream community but is too early for those with learning disabilities.”

“We found her CAMHS team to be great, and really understood her, it’s just sad there’s no one in adult services (that we came across) that actually seems to specialise in neurodivergence or at least tried to understand where she was coming from... There should be a service for those with additional disabilities to access MH support with people who understand the complexities of it [a neurodevelopmental condition].”

- One person was very specific in a request for a strategy to address mental health support for those living with autism.

“Oxfordshire Healthcare Trust have no autism strategy... Those at the top acknowledge the issues but don’t do anything... Those higher up are embracing change but clinicians and patient-facing staff have no buy-in.”

Any other comments

Several people left more general comments, as well as about other services.

About Transition

“We were cut loose from children’s services, and I just had to start over again with where I thought she needed to be. The only one that carried over with some support was neurology.”

“I’ve lost faith in all professionals, and I can’t work my job as often because I am the person supporting her. But she doesn’t always want this, and I become a nagging parent... I never have high expectations of any care now.”

“The transition process underlines that there is no national health service just unconnected providers funded by a central pot”

“With young people with disabilities and SEND, a conversation should be had regarding the possibility of remaining under Paediatric care. In our case, my young people rely solely on me, and are not ready for the move. As their carer, it is difficult to navigate a broken System”

“Maybe there already is and we just didn’t get into it but there should be a service for those with additional disabilities to access MH support with people who understand the complexities of it”

“In my opinion healthcare and social services are underfunded and there is not enough support, however the people who work in these services are amazing and dedicated.”

Three comments related to parents/carers believing the only support they could rely on was from school or other parents/carers.

“The NHS has a very blame culture and sadly often doesn’t listen or assist parents or children.”

About CAHMS

Three people gave us feedback about this service.

“Problem with CAHMS is you only get 6 sessions then you’re discharged.”

“CAHMS need to acknowledge young neurodiverse people can have separate mental health issues which have nothing to do with their autism... CAHMS say they aren’t commissioned to deal with those with autism.”

“The thresholds to access support are crazily high at CAHMS.”

About Aylesbury Community Mental Health Team

After a poor experience with social workers in the local authority, this parent praised the social workers in this team.

“The social workers in MH team in Aylesbury further educated themselves and took their time meaning it was easier to engage with my daughter. They had the time to build relationships.”

About dentistry

Two people told us how impressed they were with Buckinghamshire Priority Dental Service.

“[It] is excellent at adapting to his needs; extremely flexible. So, if he won't sit in a chair, they will examine his teeth while he lies on the floor. [We] don't always get this understanding elsewhere.”

About general practice

Three people praised their local GP.

“[The] GP is very good. They are very aware of his LD. They try to organise appointments first thing in the morning or after lunch when they know the waiting room will be quiet.”

About social care

One person was frustrated about the year it was taking to organise appropriate supported living.

“...there is not enough time to prepare a young person who is often anxious and wants to know what is happening now...The timescales are too tight. This impacts on his mental health as he doesn't deal well with the unknown.”

Another had concerns that Buckinghamshire Council had no access to hospital computer records.

“Social care teams at the local authority work on different computer systems to Oxford Health. My carer contingency plans are stored on Oxford Health system but there’s no record on the local authority records.”

Acknowledgements

We thank all the people who talked with us about their experiences. We also thank all FACT Bucks, and the other organisations contacted by them, who helped raise awareness about the survey and our project.

Disclaimer

Please note this report summarises what we heard. It does not necessarily reflect the experiences of all parents or carers of young people with a SEND diagnosis transitioning from children to adult health services.

Appendix 1

More about our approach

Who we included

We collected feedback from parents and/carers of young people aged between 14 and 25 years, with a special educational need or disability. These young people were all registered with a Buckinghamshire GP surgery or lived in Buckinghamshire. Who we will share our findings with

We will share our findings with the Care Quality Commission and Healthwatch England, the independent national champion for people who use health and social care services. We also share all our reports with the Buckinghamshire Council Health and Wellbeing Board and the Health and Adult Social Care Select Committee.

We will also share our findings with BOB ICB and Buckinghamshire Healthcare Trust.

How we follow up on our recommendations

We will request a formal response to our recommendations from:

- The BOB ICB
- Buckinghamshire Council

We will follow-up each formal response to confirm what changes have been made.

Appendix 2

What is the young person's current age?

Age	Count
14 years	4
15 years	2
16 years	3
17 years	3
18 years	6
19 years	4
20 years	3
21 years	2
22 years	2
24 years	1
Over 24 years	3
Total	33

Has the young person been diagnosed with any of the following?

Condition	Count
Autism (ASD)	20
Dyspraxia	1
Dyslexia	2
Dysgraphia	1
ADHD / ADD	12
Other	7

Please tell us more about the young person’s special educational needs and / or disabilities (we have listed conditions not already highlighted by previous questions)

Specific educational needs and / or disabilities	Count
Full time wheelchair user	4
Sensory processing disability	3
Downs Syndrome	4
Severe global developmental disability / CVI	3
Anxiety / OCD	5
Non-verbal	5
Stage 4 Endometriosis	1
Attachment disorder	1
Anorexia	1
Club foot	1
Swallowing issues	1
Non seizure Disorder	1

Please tell us whether the young person has either of the support plans below?

Support plans	Yes	No	Total
A SEND support plan	7	19	26
An education, health and care (EHC) plan	20	11	31

Does the young person have a health passport?

Health passport	Total
Yes	2
No	26
Don’t know	5
Total	33

Which of the following long-term conditions does the young person have?

Long-term health conditions	Count
Blindness, severe visual impairment	1
Cardiovascular condition (including stroke)	1
Diabetes	2
Epilepsy	4
Learning disability	10
Mental health condition	2
Musculoskeletal condition	4
Other	2

What best describes the young person's situation (Young person is not receiving any ongoing secondary health care services)

Service Provider	Total
They were discharged from children's services before the transition process started	8
They were discharged from children's services after the transition process started	2
They have completed the transition process but were later discharged from adult's services	1
Total	11

Which children's health services are involved in the care of the young person?

Long-term health conditions	Count
Paediatrics (Neurology, Orthopaedics, Cardiology, Unspecified)	8
Community OT/Physio	5
Speech and Language Therapy	2
CAHMS	3
Private Counselling	1
Audiology	2
GP /community nurse	2
Other	5

Do you attend meetings (online or in person) with a team of people to discuss moving to adult health services (Young person is receiving children's health care or a mixture of children and adult health care services)

Service Provider	Total
Yes	1
No	6
Don't know	3
Total	10

Overall, how satisfied are you with the transition / planning around moving to adult health services?

Satisfaction level	Total
Very satisfied	0
Satisfied	5
Dissatisfied	11
Very dissatisfied	9
Total	25

Appendix 3

What age group are you in?

Age Group	Total
18 - 25 Years	1
36 - 45 years	3
46 - 55 years	14
56 - 65 years	7
66 - 75 years	1
Prefer not to say	1
Total	27

Are you a:

Gender	Total
A man	2
A woman	24
Prefer not to say	1
Total	27

Is your gender identity the same as your sex recorded at birth?

Gender Identity	Total
Yes	26
Prefer not to say	1
Total	27

Do you consider yourself to be a carer?

Are you a carer?	Total
No	2
Yes	26
Total	28

Please tell us which sexual orientation you identify with

Gender Identity	Total
Bisexual	1
Heterosexual	23
Prefer not to say	1
Total	25

How would you describe your ethnic group?

Ethnic Group	Total
Asian / Asian British: Chinese	1
Black / Black British: African	1
Black / Black British: Caribbean	1
White: British / English / Northern Irish / Scottish / Welsh	22
White: British / White Other	2
Total	27

What is your religion or belief?

Religion / Belief	Total
Christian	14
No religion	11
Other	1
Prefer not to say	1
Total	27

How would you describe your marital or partnership status?

Marital or Partnership Status	Total
Cohabiting	
Divorced / Dissolved civil partnership	3
Married	16
Single	4
Separated	1
Widowed	1
Prefer not to say	1
Total	26

Do you have a disability?

Do you have a disability?	Total
No	19
Yes	7
Prefer not to say	1
Total	27

Which of the following disabilities apply to you?

Which disabilities?	Total
Physical or mobility impairment	4
Sensory impairment	4
Long Term condition	3
Mental health condition	4
Neurodevelopmental condition	5
Other	2

Do you have a long-term health condition?

Do you have a long-term health condition?	Total
No	13
Yes	15
Total	28

Which of the following long-term conditions?

Which long-term health conditions?	Total
Asthma, COPD or respiratory condition	3
Deafness or sever hearing impairment	1
Cancer	2
Hypertension	1
Mental health condition	6
Musculoskeletal condition	4
Other	5
Total	

If you require this report in an alternative format, please contact us.

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