healthwatch
Norfolk

Transition of Care Review

Experiences of those moving from children's to adults' health and care services – Feb 2023

Contents

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Who we are and what we do

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge.

The people who fund and provide services have to listen to you, through us. So, whether you share a good or bad experience with us, your views can help make changes to how services are designed and delivered in Norfolk.

Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more.

We also give out information about the health and care services available in Norfolk and direct people to someone who can help.

At Healthwatch Norfolk we have five main objectives:

1. Gather your views and experiences (good and bad)
2. Pay particular attention to underrepresented groups
3. Show how we contribute to making services better
4. Contribute to better signposting of services
5. Work with national organisations to help create better services

We make sure we have lots of ways to collect feedback from people who use Norfolk's health and social care services. This means that everyone has the same chance to be heard.

Summary

Why and how we looked at this

Healthwatch Norfolk was commissioned by Norfolk Community Health and Care (NCH&C) to investigate the experiences of young people, their families/carers, and professionals of the move from children's to adults' health and care services, known as transitioning, across Norfolk. The transition from children's to adults' health and social care services can be a particularly vulnerable time for children/young people and their families (CQC, 2022). For a typical NHS Trust approximately 100 young people reach the age of transition each year (Colver *et al.*, 2019).

This Norfolk-wide study looked at various services, with a focus on long-term conditions, life-limiting illness, and complex health needs to identify areas in which the transition process can be improved. We collected the views and feedback of the public (young people and their families/carers) and professionals working in children's and adults' services by conducting surveys and hosting interviews to gather more in-depth feedback on their experiences.

It was determined that due to the broad coverage and sensitive nature of the subject that interviews with individuals/families and professionals would be more appropriate than hosting a focus group.

From the surveys and interviews, Healthwatch Norfolk were able to identify themes in the experiences of young people, their families/carers, and professionals around what is working well and where improvements could be made.

What we found out and what this means

We received a total of 51 responses to our surveys, 34 responses for the public survey and 17 responses for the professional survey, covering a wide range of services/specialties. We also interviewed 8 individuals, 4 members of public and 4 professionals. The responses in this report are a small sample in relation to all those transitioning in Norfolk. However, we identified that improvements could be made in consistency, communication, and support during the overlap of services (18 – 25 age bracket).

We found that there is a variation in levels of support experienced depending on the service/specialty that was being accessed. This was more apparent for those with complex health needs accessing multiple services. We received the most feedback from people who had transitioned from child to adult mental health services. Ensuring consistency of support during transition would lead to the improvement of health outcomes for young people.

There was a mismatch between professionals and public feedback regarding communication and information. Young people and their families/carers felt that the communication from and between the services was lacking,, finding that in some cases communication just stopped and young people were left on waiting lists with no support. Whilst professionals felt that they were providing plenty of information, young people and their families/carers told us they weren't receiving this. The information and communication is not clear for all involved in the transition process and this means that young people and their families/carers are left confused and feeling like the support is not there.

Parents told us that they wanted to be more involved in the transition process, with guidance and involvement in transition care plans. This is so they have a better understanding of how they can support their young person. Consideration for including parents more where possible, and maintaining the privacy and independence of young people, would aid in easing the concerns of parents/carers.

Finally, the planning process could be improved by ensuring that these are made with young people and their families/carers in a way that is easy for them to understand. Having heard that complicated paperwork can cause confusion for families, providing support through a point of contact would help answer concerns as plans change with time. Additionally, lining-up children's and adults services' systems (e.g., by using the shared-care record) would ensure that all who needed to, had access to records and plans so patients wouldn't feel like they are retelling their story.

Recommendations

As a result of the feedback and views we collected, we have made several recommendations of how experiences of the transition process can be improved.

1. Gather feedback – Establish processes for gathering feedback from young people and families/carers. This will enable a better understanding of what

is needed by patients and families, and which services are managing the process well and which need improvements. This will also identify barriers to successful transition.

2. Improve communication – Communication with young people and their families could be improved to show what to expect from the transition process and how the adult services differ from children's. Improve communication between professionals to ensure better join-up of services and smooth transition.
3. Point of contact/Keyworker – Consideration should be given to appointing a keyworker who is responsible for supporting the young person and their family through the process, acting as a consistent point of contact during transition for both children's and adults' services. This could include specialist transition support for those aged 18-25 ensuring a smooth transition and reduce the risk of drop-off in support provision.
4. Planning process – Review the planning process for all services so that all are able to access records and minimise the need for patients and families to 're-tell their story'. Include aspects for parents/carers to ensure they have knowledge on how they can best support their young person.
5. Involvement of parents/carers – Actively encourage parents and carers to be involved in the planning for transition, as they can help the young person move toward independence in managing their care.

Why we looked at this

Healthwatch Norfolk was commissioned by Norfolk Community Health and Care NHS Trust (NCH&C) to find out how the transition process is experienced across Norfolk by engaging with young people, their families/carers, as well as health professionals supporting young people and their families through this process.

The aim of this project has been to:

- explore the experiences of young people and their families/carers accessing children's services and transitioning to adults' services.
- understand professionals' experiences of working with and helping young people and their families/carers through this process.
- provide NCH&C with insight into these experiences and identify what is working well in services, and where improvements can be made.

Transition from children's to adult services is defined as the "purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents/young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented health care systems" – Kerr et al. (2020)

For children and young people with long-term health conditions the transition from child health and social care services to adult services can be a vulnerable time for young people and their families (CQC, 2022). Up to the age of 18 these services are provided by child health and social care services, with the 'transition' process occurring between the ages of 16 and 18 (NHS, 2021). Ideally the transition process, or the planning for the process, should begin at the age of 14 (Year 9 at school) and be an ongoing process tailored for each child's needs (NHS, 2021., and Together for Shorter Lives, 2021).

The transition process typically involves the young person, parents/carers, and health professionals. In particular the young person's GP should be involved in the planning as they will become more closely involved (NCC, 2022). Those with complex health needs should have a 'transition healthcare plan' to help with the move into adult life and services. Typically this should include information on support needs, how the young person will receive support, key professionals involved in planning the transition, those responsible for delivering support, how the young person is supported to manage their condition, and the plans made for the young person to meet all new staff so that they feel safe and confident (NCC, 2022).

Over the last decade the transition process has emerged as a global health and social care issue, where a lack of engagement with adult services has the potential to result in adverse outcomes in treatments and follow ups as well as social and educational outcomes (Kerr *et al.*, 2020). NICE (2016) guidance reported that there is “much evidence about the nature and magnitude” in relation to the problems of the transition process but little on what works. They note that some of the issues can include, but is not limited to, family members/carers feeling left out causing distress and uncertainty, some young people not being able to access the same levels of support, and young people with ongoing needs falling through ‘the transition gap’ or disengaging with services.

In May 2022 the CQC reported that there are more than 40,000 people who are aged under 18 and have complex health needs in England, covering over 300 conditions. A 2019 study by Colver *et al.* stated that, for a typical NHS Trust that serves a population of 270,000, there are approximately 100 young people with complex health needs or long-term conditions who reach the age of 16 each year. The transition process is ongoing for around 7 years meaning that, at any time, approx. 700 young people will be going through this process.

How we did this

Methodology

The project aimed to collect views and feedback to explore how the transition process, from children's to adults' health and care services, is experienced by young people, their families/carers in Norfolk, and professionals.

The target audience for this project are Norfolk residents who have recently experienced the transition from children's to adults' health and social care services, whether this be the young person themselves, a family member, or a carer. Additionally, the project looked to gather the views of health professionals working in this area.

In order to give a fuller view of people's experiences of transitioning in the county, this project was not limited to just NCH&C services, and instead covered all local health and social care services for young people living with long-term conditions, life-limiting illnesses, and complex health needs.

Experiences were gathered through surveys as well as interviews with individuals who were willing to speak with us in more detail. Two variations of the survey were developed and hosted online using SmartSurvey. One of the surveys was for young people, families, and carers who have recent experience of the transition process, whilst the other was designed for health professionals who have experience of helping young people who have gone through this process.

Survey responses were collected and interviews conducted over a three month period from October 2022 to the start of January 2023.

The feedback we received is reported and evaluated in the 'What we found out' and 'What this means' sections of this report. This helped us to identify key themes around what is working well and where improvements are needed in health and social care services for young people and their families/carers. These are discussed later in this report.

Survey

To gather the experiences of participants and their feedback on the transition process, Healthwatch Norfolk developed the two surveys in collaboration with NCH&C.

The survey designed for young people, families, and carers sought to find out:

- the services being accessed, who was involved (e.g., services, nurses, parents/carers), and the overall experience of the process.
- the communication with and from these services, such as if any worries and concerns were listened to.
- if people felt that sufficient information and support was given in preparing them and their families for the transition.
- the consistency of care in the move from children's to adults' services.

The survey designed for health professionals looked to gather similar information from their perspective, looking at:

- what information and support they provide.
- communication regarding if and when patients express their concerns and worries, and how they and their families are involved.
- how information is shared between children's and adults' services, clinicians and organisations, and whether they have encountered any issues/problems.
- if there are any areas they feel work well or can be improved upon.

Surveys were available online and paper copies could be provided upon request.

Interviews

Due to the sensitive nature of individual's experiences of the transition process, Healthwatch Norfolk opted to host interviews, rather than a focus group, with survey participants who expressed an interest in sharing their experience in more detail.

These interviews were focussed around allowing participants to expand further on their experiences. Professionals provided more of an overview of their general experiences and if there was anything they felt could improve patient experience. Whereas young people/family members/carers gave details of more specific experiences, such as where they sought advice and support throughout the process and what they have found the differences to be between children's and adults' services.

Interview guides can be found in Appendix 1 & 2.

Sample Size

The sample size for this project was discussed with NCH&C, initially to be a minimum of 2 focus groups of 5 – 12 people for the data collection period. However, after discussions regarding the broad coverage and the sensitive nature of the subject, it was determined that interviews with individuals, families, and professionals, who would be identified through surveys, would be more appropriate.

As surveys were entirely voluntary, sample sizes for these were not set. Healthwatch Norfolk developed a communications plan to try to reach as many people as possible.

Copies of the surveys can be found as Appendix 3 & 4.

Participant Involvement and Consent

To encourage participation in surveys Healthwatch Norfolk developed promotional materials, which were distributed through Healthwatch Norfolk's well-established network, with a goal of reaching as many individuals, and groups as possible, including those seldom heard. Healthwatch Norfolk promoted the project by means of posters shared with specialist organisations, surgeries and relevant hospital departments, as well as social media posts, videos, a dedicated webpage on the Healthwatch Norfolk website, and in the Healthwatch Norfolk newsletter.

Additionally Healthwatch Norfolk engaged with NCH&C staff and other service staff to canvass and gather the views and experiences of professionals working with and helping young people through the transition process.

Public and professional interview participants were identified through surveys. As participants were given the option to share more detailed information regarding their experiences.

All survey and interview participants had to give their consent for their answers and feedback to be shared in this report anonymously.

Limitations

As the topic of transition covers many services for young people with long-term conditions, life-limiting illness, and complex health needs, the communications approach needed to be broad in who we approached. We developed communications materials in the form of posters, social media posts, and a video. These were shared with an extensive list of stakeholders including those within the health and social care and the voluntary sectors.

In some cases, it was not possible to interview the public and professional stakeholders. Despite expressing a willingness to be interviewed, they struggled to find time to due to workload / childcare needs.

An important limitation to note was that whilst we received several responses from young people or their families/carers concerning their experiences transitioning with mental health services we were unable to gather the views of any professionals working in these services.

What we found out

Survey Results

Please note that questions were not compulsory so the number of responses may vary by question.

Who we received responses from

The surveys for both the public and professionals received 51 responses which make up the following analysis. We received responses from 34 members of public from across Norfolk, and from 17 professionals working for various organisations and covering a range of health and social care needs.

Most of the responses we received from the public survey came from the family member (19, 58%) or carer (7, 21%) of someone who has moved/is moving from children's to adults' health and care services. We also received 5 (15%) responses from young people experiencing transitioning between services. Additionally, two responses (6%) came from professionals on behalf of a young person.

For the professional survey we heard from members of staff working for:
- Norfolk Community Health and Care NHS Trust (NCH&C)
- Norfolk and Norwich University Hospitals NHS Foundation Trust (NNUH)
- Norfolk County Council (NCC)
- Adult Social Services
- East Anglia's Children's Hospices (EACH)

For both surveys most respondents told us that they:
- Were female (38, 75%).
- Were White British / English / Northern Irish / Scottish / Welsh (45, 88%).
- Did not consider themselves to have a disability (31, 61%).

For more detailed information regarding the demographics of respondents see Appendix 5.

We obtained feedback about 24 services and the majority of these (10) were about mental health services.
A list of services that experiences relate to and where professionals specialise can be found in Appendix 6.

Interviews

We spoke to eight individuals about their experiences of the transition process, four were members of the public (young people and parents/carers) and four were professionals representing both children's and adult services.

The members of public we spoke to were given the opportunity to provide a more detailed account of their experience moving from children's to adults' services. Professionals provided their general experiences of seeing and helping young people through the transition process.

From speaking to young people and their families/carers, as well as professionals, we identified the following themes; involvement & communication, differences between the services, the process and planning, and overall support.

Overall Experience

Most of the public responses we received rated their overall experience of the transition process as being 'Poor' (5, 15%) or 'Very Poor' (20, 59%) with only two (6%) telling us that they had a 'Very Good' experience, displayed here in Figure 1.

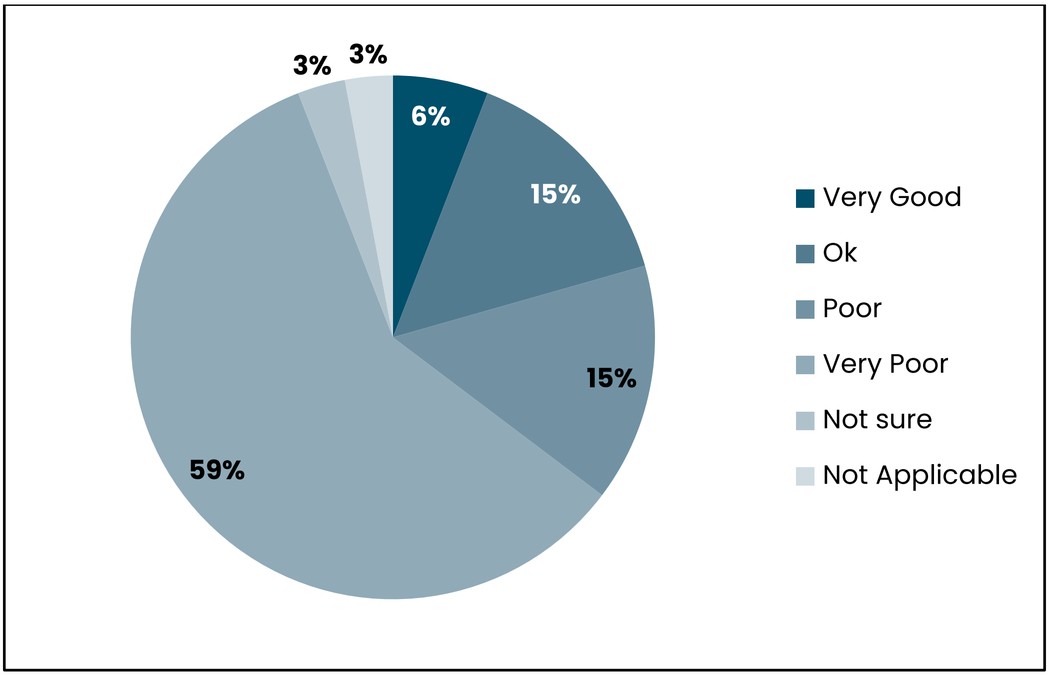


Figure 1. Public responses to the question 'How would you rate the overall experience of transitioning from children's to adults' services?' (100% = 34)

Those who rated their overall experience as being 'Very Good' referenced accessing Nephrology (diagnosing and treating diseases of the kidney) services and GP services, with one respondent telling us that they felt the process has "*gone very well*" and that "*Doctors listen and I feel they care*". Those who rated their overall experiences to be 'Poor' and 'Very Poor' reported their experience with Children's services had been good however the adults' services were lacking.

> "I was under childrens for a year and turned 16, after an admission to children's they moved me to adults where I'm now increasingly unwell but have to wait up to 50 weeks for an apt [appointment]. This is disappointing as I'm very unwell and poorly."

Of the 25 members of public, who rated their experiences as 'Poor' and 'Very Poor', 10 referenced accessing mental health services. One told us they felt "*Childrens services generally worked well*" whereas "*Adult mental health services are stretched at best and broken at worst.*" Another told us they felt "*The quality of over-18's mental health care is terrible compared to the under-18s.*"
We heard similar stories from those we spoke with in interviews. They told us that typically support during their time in children's services was very good but accessing "*support now from adult services is very hard.*" Concerning mental health services, one parent told us that they thought they were "*immediately going to get the same support*" because they were "*given that impression*" but then there wasn't "*really anything*".

> "And the young people hit 18 and children's services stop and adult services is supposed to kick in, and it just doesn't."

Others we spoke with also expressed their concern with the 'loss' of support they experience when they/their young person moved from children's to adults' services. One told us how they had previously received "*brilliant*" support from "*Starfish*" until they were referred to "*the adult learning disability services*" resulting in no support for "*well over a year-and-a-half*".

This 'drop-off' in services results in young people and their families/carers having feelings of being "*abandoned*", having previously had a solid point of contact in the services.

Personal stories: Loss of primary contact

> "I think they must feel abandoned at that age to, then, not have that support. Because the clinical psychologist's assistant was working with [my daughter] regularly up until March last year, and that's just gone, then. And these young people must feel sort of abandoned, really, as well. You know? It's so difficult."
>
> Parent of young person transitioning from children's to adults' mental health services.

We also asked professionals how they would rate the overall transitioning process, and received a mixed response of those who felt this 'Very Poor' to 'Very Good', although most responses were between 'Poor' (5, 29%), 'OK' (4, 24%), and 'Good' (4, 24%) shown in Figure 2.

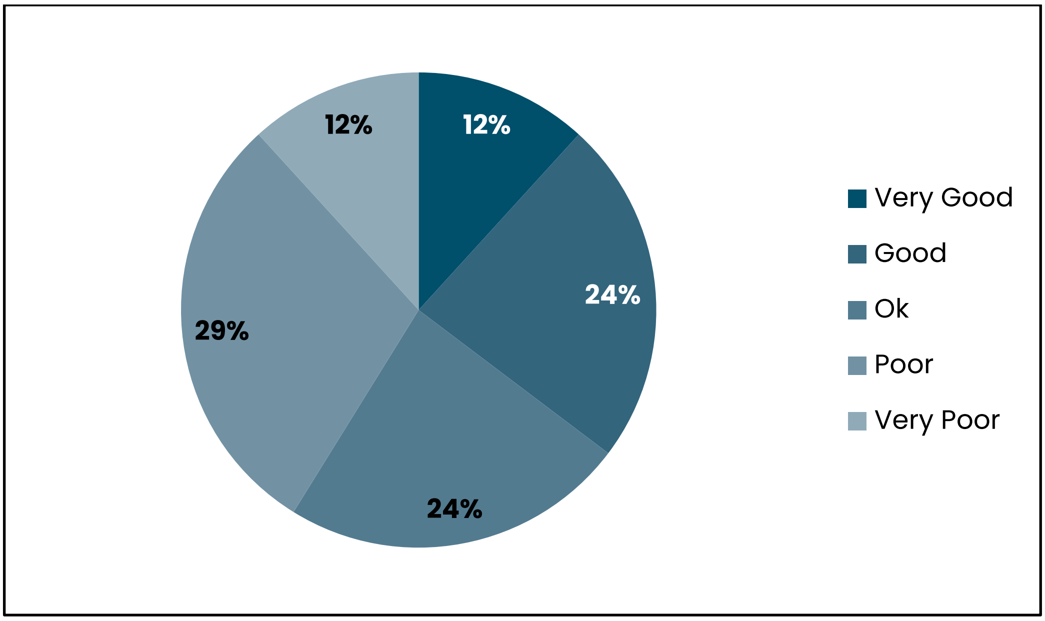


Figure 2. Professional responses to the question 'How would you rate the overall process of transitioning from children's to adults' services in Norfolk?' (100% = 17)

Professionals who rated the overall transition process as 'Good' or 'Very Good' told us that this was due to good links between the children's and adults' service, one told us that for epilepsy services they "*have a dedicated transition clinic once a month which attended by childrens and adult*", others praised the "*excellent service*" of STARFISH (the NCH&C Learning Disability Child and Adolescent Mental Health Service) in making adult services aware of individuals and their needs in handovers and meetings.

Those who rated the process as ‘OK’ told us that the transition “*varies between services and also how supported parents feel*”, with one telling us that “*The process can be hit and miss depending on the child's level of need*”.

> “The adult services do not mirror Childrens Services, so finding the correct team to transition a YP [young person]to can be tricky”.

Interestingly, professionals who rated the process as ‘Poor’ and ‘Very Poor’ told us that there were “*Gaps in service*”, “*No plan, handover, resetting of expectations*”, and that there was “*no clear process to enable seamless transition between the services.*” These responses came from a mix of professionals working in both children’s and adults’ services.

Communication, Information, and Preparing for Transition

We asked respondents how they would rate the communication between young person and service during the transition process. For the public survey we received 33 responses to this question with most rating this as ‘Poor’ (8, 24%) or ‘Very Poor’ (19, 58%), with three (9%) rating this as ‘OK’, and two (6%) as ‘Very Good’, displayed in Figure 3.

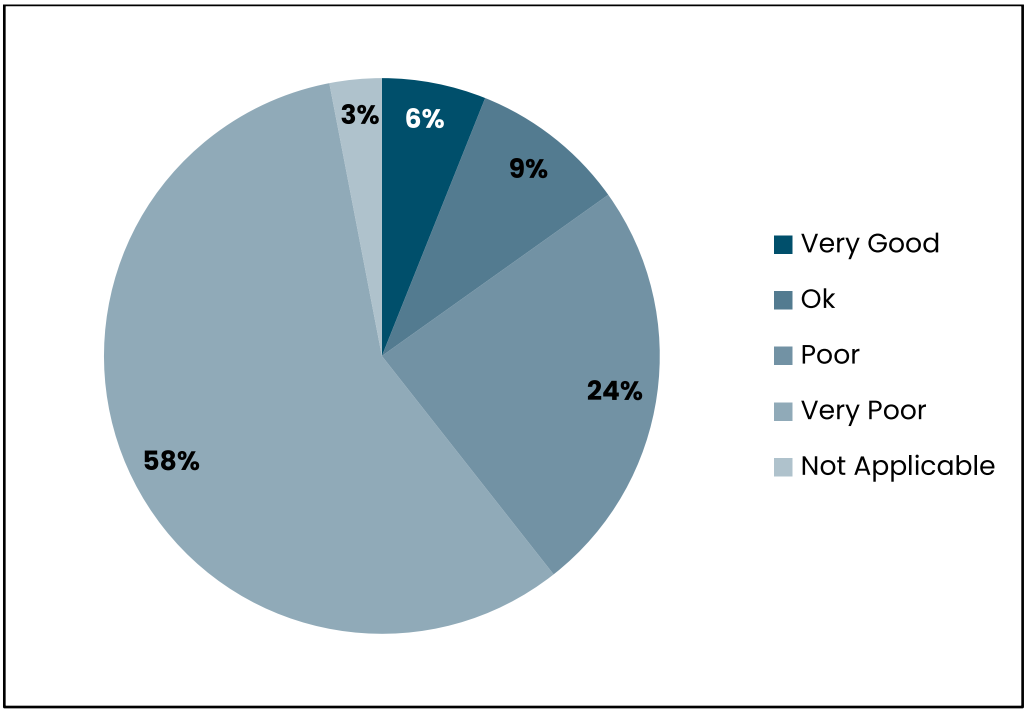


Figure 3. Public responses to the question 'Overall, how would you rate the communication from the services during the transition process?' (100% = 33)

Those who felt that the communication was 'Poor' or 'Very Poor' told us that there was a "*Complete lack of contact*", "*a sudden cut off*", and that they were "*left suddenly with no support*" regarding their experience of transitioning from Children's health services.

> "Nobody listened to us or other professionals and my daughters case was closed without the adult services team who my daughter should have transitioned to even meeting us"

Those who rated the communication as 'OK' and 'Very Good' felt the overall process went "*very well*", but also felt that the "[communication] *could have been better*". One told us that "*As a parent* [they] *would like* [their] *opinions to be listened to more*". Another respondent also told us that they felt "*there was exclusion of parental input and discussions*" which they felt "*would have been useful*".

A parent, who we interviewed, felt that the communication with them around the continuation of care could be improved. They thought that continuation "*might have been a good thing*" but "*there didn't appear to be any*" and did not know if this had been offered and declined by the young person. However, they also told us that they understood there needs to be a level of independence and confidentiality so the young person "*can feel comfortable*", but felt that if "*family or friends, or whoever is close*" to the young person could provide more information they could help clinicians identify the most "*appropriate treatment*".

> "getting support now from adult services is very hard. It seemed much easier to access children's services. Adult services it's like, "Well, you're 18 now. You should be able to deal with it," sort of thing."

Similarly, we asked professionals how they would rate the communication between clinician and young person/family during this process. Most respondents (12, 70%) rate this as 'OK' (6, 35%), 'Good' (5, 29%), or 'Very Good' (1, 6%). Three professionals (18%) rated the communication as being 'Poor', and only one (6%) as 'Very Poor'. One respondent told us that they were 'Not Sure', shown in Figure 4.

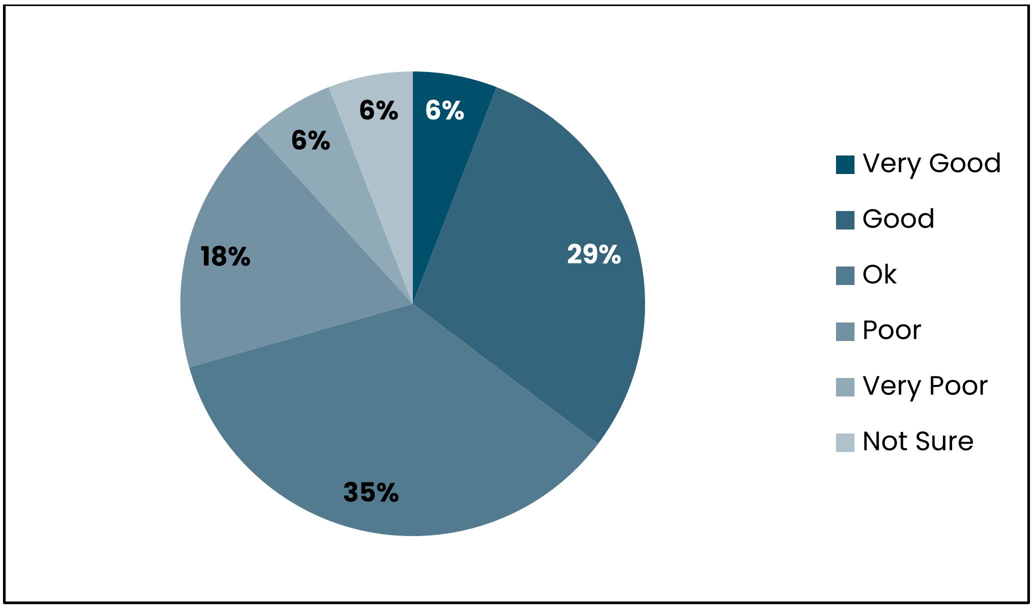


Figure 4. Professional responses to the question 'Overall, how would you rate the communication between clinician to patient/ family during the transition process?' (100% = 17)

In terms of the professional opinion of communication with young people during the transition process, those that told us they would rate this as ‘Good’ or ‘Very Good’ told us this was down to starting “*the process early enough*” and providing “*family with contact numbers*”. One told us how young people/families are provided explanations of the process in the lead up to their appointments and communicate with them to ensure “*its at a suitable and accessible time*”. However one who rated communication as ‘Good’ also noted that “*from other professionals in the adult teams* [communication] *can be difficult*” particularly with more complex cases.

> “The level of communication is hit and miss depending on the childs condition and the service that is being transitioned”

Professionals who rated communication as ‘Poor’ or ‘Very Poor’ also told us that “*It can vary hugely*” as the process is “*hard to communicate*” being unclear even for the professionals. One respondent told us that they “*have spoken to parents who have waited a long time for appointments, contact to get mental health support. Recently a parent told me they have waited three years for their child to get CBT!*”. Another respondent who told us they were ‘Not Sure’ how to rate the communication said “*I do not know what patients/families are told*”.

We also heard varying views from the professionals we interviewed. The communication between teams, for two of the professionals we spoke with, was very good. With both teams involved in regular meetings and contacting one another regarding care plans, as well as using the same system for patient records which they told us was "*really useful*" as it allowed the adult team to "*look back through previous care plans or letters*".

In terms of communication with patients, another professional told us that they made sure to liaise with parents and families to help them understand the process and address any concerns or worries. Something that professionals told us they were working on to help improve communication with young people and their families was that they were updating how they communicate to include more texts, emails, and looking to use other messaging platforms (such as WhatsApp), finding that more young people were engaging "*because of the technology*" allowing them to attend meetings virtually.

A professional working in the voluntary sector told us that they were concerned about the paperwork involved in the transition process and how this was communicated with patients and families, feeling that it is quite complicated and could be made easier to understand.

Personal stories: Paperwork can be daunting

> "It's a lot of tick boxes and a lot of it is inapplicable if that makes sense, and I think families, when you show them, it is quite daunting, especially with our children because they don't know if they're going to meet that, that age. But obviously, they might do, so that's what we started, so from a family's perspective, I think it's quite overwhelming whether it could be broken down easier, maybe."
>
> **Voluntary sector professional working with young people with life-limiting illness.**

We also asked professionals if they provided information and support to prepare young people and families/carers for the transition process as well as asking the public if they were given any information and support. Interestingly, whilst the majority of professionals (14 of 17, 82%) told us they did provide information and support, more than half of the public (24 of 34, 71%) told us they were not given anything (Figure 5).

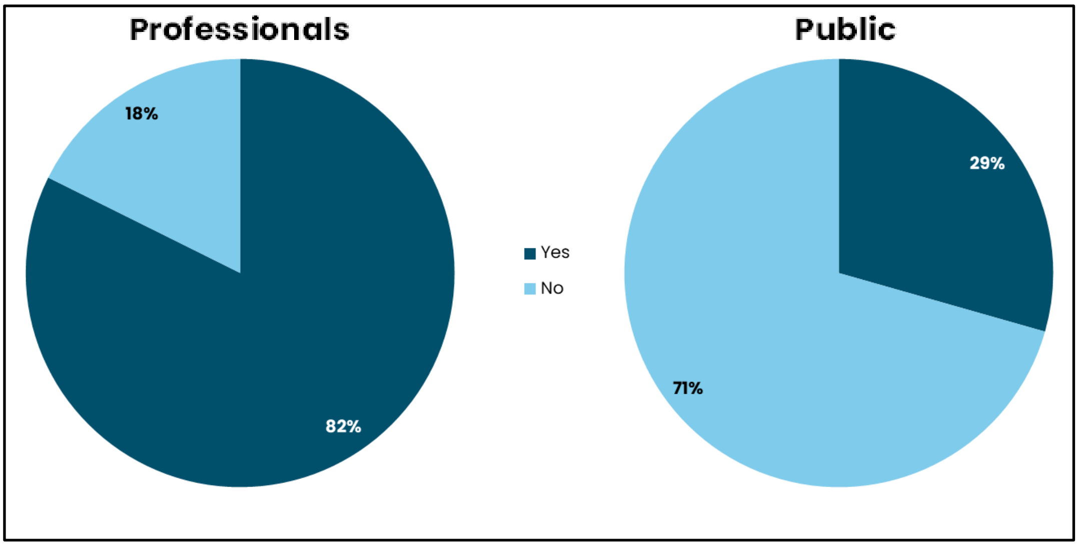


Figure 5. Professional responses to the question 'Do you provide information and support to patients and their families in preparation for the move from children's to adults' services?' (LEFT, 100% = 17) and Public responses to the question 'Were you given any information and support in preparation for the move from children's to adults' services?' (RIGHT, 100% = 34)

The public who told us that they were given information and support highlighted both positives and negatives with this.

Positives	Negatives
"*Explanation of overlap clinics; introduction to adult consultant in transition clinic; choice of when to fully transition*"	There was "*Very little support no one to ring*"
A "*Copy of letters sent to adult services about my child*" was provided	"*we knew most of it and even then it was late coming, poorly executed and has been so stressful it has made me ill*"
They received "*A care plan*"	It was an "*Absolute shambles in every aspect*"

Few of the public who answered that they did not receive information and support provided further comment. One told us that "*from speaking to service users there is very little information given when transferring*".

Personal stories: No support for transitioning

> "I got a letter a month before I turned 18 saying that I would be moved from children to adult service. I was then told for me to get support would take a lot longer and that I would be moved back. This threw me off and made me feel quite hopeless with the service as I was struggling but I understand the high demand in patients."
>
> Young person transitioning from children's to adults' services

The professionals who said they did provide information to young people and families/carers told us that they:

- Have "*Open discussions on transition, signpost to NNUH [transitions lead], attend meetings, add to transition template on system one.*"
- Provide "*Transition information, also available in easy read, parent transition information, transition tools (ready steady go)*"
- Liaise with "*the transition nurse for health in the context of ongoing health conditions*" and with "*the leaving care nursing team for post 18.*"
- Give "*Information on where to go for adult OT Services. Refer on to adult services if outstanding work/need at the time of transition.*" As well as information on "*Teams they are moving to and contact details.*"
- And provide information on "*Which adult service is likely to best meet their ongoing needs.*"

However, some of this group also told us that "*information has only recently become aligned with the information being sent out by adult teams.*"

Those who said that information and support is not provided were mostly from the adult services side of the transition process, one said that they "*think some staff from Childrens Services explain PfAL* [Preparing for Adult Life service run by County Council] *but unsure.*" Another told us that their team "*only know about them* [the patients] *at some point in mid 20's or so when there is a new need/change in need, equipment has broken and they are referred to adult services for the 1st time.*"

Regarding communication we also asked professionals how they would rate this between other professionals such as clinicians and organisations, their responses are displayed in Figure 6.

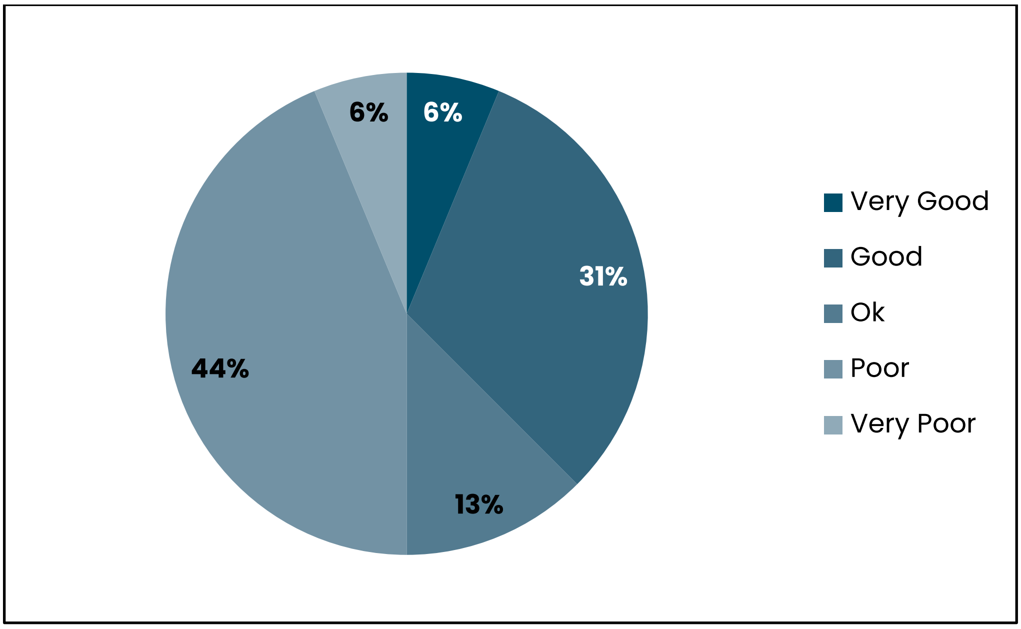


Figure 6. Professional responses to the question 'Overall, how would you rate the communication between clinicians and organisations during the transition process?' (100% = 17)

There was a varied response between those who rated this as 'Poor' (7, 44%), 'Very Poor' (1, 6%), 'OK' (2, 13%), 'Good' (5, 31%), and 'Very Good' (1, 6%). Only one respondent skipped this question.

Those who told us that they thought the communication between professionals was poor said that they had "*very little direct links with the adult services.*" and felt that "*Patients should be highlighted sooner with more overlap allowing greater understanding of care needs.*"

Interestingly, professionals who rated this as 'OK' or 'Good' told us that for their service there is "*regular contact during this process*" and that there are transition meetings between professionals but the challenge is that "*services within children's health are not reciprocated in adult healthcare systems.*" One respondent echoed comments about communication with young people and families/carers, saying that it can be "*hit and miss*" based on the condition and service.
Additionally, we asked the professionals how information is shared between children's and adults' services, and if they had encountered any problems in this process. Respondents told us that information is shared in various ways, depending on the service, including (but not limited to):

- "*a monthly Transition meeting*"
- "*information shared within a transition clinic setting.*"

- *“Report”*
- *“Referral letter”*
- via IT systems.

The problems/issue that professionals encountered were reported on both the children’s and adults’ service sides. Respondents told us that there are difficulties “*working across different systems (IT)*” and that this can make referrals harder due to different processes. One respondent told us that, whilst they are “*usually copied into clinic letters*” there is “*no feedback as to whether referrals have been picked up*”. A respondent from adults’ services also told us that there are “*Problems accessing the children’s record*” on an IT system due to restrictions which “*leave a blank canvas for adult health services.*”

> “unable to provide information for future reference to the adult LD team if there are no current needs to refer on even though you know they will need support in the future”

Planning and Involvement

We wanted to know more about the planning for transition and who was typically involved in this process. We asked young people and families/carers who had been involved in their transition planning (e.g. GPs, parents, nurses), and if they themselves felt involved. Those who we interviewed were parents/carers rather than young people themselves. Therefore, the views on involvement reflect parent perspective, whereas a young person may feel that they want less parental involvement.

Of the people who answered the survey questions, only 8 (25%) told us that they felt involved in the transition plan. However, despite feeling that they were involved, respondents told us that there were still difficulties with the services. One respondent, a parent/carer, said that they are “*the only one who sorts anything out.*” another said “*Yes, but only because we are so proactive. It was however badly executed*”.

Similarly, in the interviews we conducted, one parent told us that their planning involved PfAL creating a “*healthcare plan*” which they found very helpful and that they felt they “*were listened to*” in the creation of the plan. However, they also told us that despite “*five hours of PA support each week*” they felt there was no one “*overseeing anything or seeing if you need any help or support.*”

> “Had a long meeting to apply for my son’s continuing health care. Once this was approved, Pfal /social services weren’t involved/interested at all.”

Some of those who told us that they did not feel involved in the transition plan said that there had been “*No plan put in place*” and that they had to “*chase everything*” themselves. The parents/carers we heard from also told us that they felt that they “*had to ‘get’ involved*” creating their own transition plan, one felt that their views and their child’s views were “*not taken into account at all*”. Another told us that “*would have preferred*” if their child had their paediatric team work “*in conjunction*” with the adult team for a period of time.

Some parents we spoke with in interview also told us that their experiences of the process and planning for transition were not positive. One told us how, for their young person, they didn’t “*think there was any*” plan in place and that they didn’t “*think there was really a handover*” to adult services. They described the experience as “*rather chaotic*” and found “*it quite difficult to access services.*”

> “there is a reluctance to involve the parents in any discussions about their young persons mental health which doesn't help us as parents support them.”

Regarding who is involved in the transition process and planning, some told us they had multiple people/services involved whereas others said that only the ‘young person’ was involved, and in some cases that no one had been. Where others were involved in the process, respondents told us that this was, typically, consultants and/or parents. Others who were involved included:

- PfAL (Preparing for Adult Life)
- GPs
- Psychologists
- Nurses
- School
- Navigator
- CYPMHS/CAMHS (Children and Young Peoples Mental Health Services/ Children and Adolescents Mental Health Services)
- Paediatric leads
- Social workers
- CWD Teams (Children With Disabilities)
- CHC Teams (Continuing Healthcare)

One respondent, who told us that only the young person was involved in the process, told us that there was "*no information given to family.*"

From the interviews we heard that, for most they found that during their time accessing children's services there was more parental involvement, but as their young person moved towards adult services this reduced quite quickly. One parent told us that a children's mental health clinic "*was more inclusive of parents*" whereas the adult counselling had "*very little parental input, other than getting* [their young person] *there and back again.*"

We also heard that a parent felt that they were "*excluded*" and wasn't able to input as much to be able to give a "*more rounded picture*" of their young person, which made them concerned that the support their child was receiving was "*maybe not the best*". They told us that they felt they "*had no idea no idea what* [they] *were supposed to be doing to support*" their child.

We also asked the professionals how young people and families/carers are involved in the transition process. Responses varied depending on the service, the condition of the young person, and the complexity of their care needs. Professionals told us that some are involved in discussions for "*their ongoing needs and what referral they wish to be made*" as well as being involved "*throughout the process to ensure a smooth and co-ordinated transition*". One respondent told us that as most patients they interact with "*have a high level of disability*" the "*parents are very involved in all aspects of their transition*". The level of involvement is dependent on the service, one respondent said that they have an "*Initial phone call*" and then "*involvement with as many people as the child would like*". However, one respondent told us that they were "*not sure*" how young people and families/carers were involved in the process as a "*referral is made on their behalf*" or "*they may have to refer themselves again*".

> “Family are a key part in supporting transition especially for patients without capacity and the knowledge they have of the patients condition/s is often better than healthcare professionals so needs to be valued as such.”

Professionals we interviewed told us that they supported young people and families/carers through the transition process by having transition meetings with young people, their families/carers, and the services. One told us that because “*a lot of the children that* [they] *work with are complex needs*” these meetings can be “*multi-professional*”.

Another told us that they give the “*opportunity to go through everything transition brings*” by offering “*45-minute slots*” and this gives the young person the option to attend independently and “*bring up anything*” they have questions about. Additionally, this also give the young person the opportunity to meet with members of the adult team(s) that they will be transitioning to.

Part of this process and planning involves making sure that parents/carers are also prepared for the transition, one professional told us they also liaise with parents as early as possible to make sure parents are aware of the process. They also told us that, for complex cases, they “*check with families first*” before inviting other clinicians to the transition meetings, so that the young people are not overwhelmed.

In terms of parental involvement, professionals told us that for young people who have complex health needs, they will often have more involvement from parents or carers as they may not “*necessarily get engagement from that patient*”. However, where this is not the case they will still try to involve parents as much as possible but ultimately ensure it is the choice for the young person to decide who is at meetings.

> “And it's up to them, really, because it's on Attend Anywhere [appointment software], whether they want a carer or parents there. So it's their choice.”

Independence and concerns

As a part of the transition planning process, we wanted to know if young people felt that they had been given the skills to attend their appointments independently. Whilst in some cases, due to the specific complex health needs of individuals respondents told us that the young person would not be able to attend or “*deal with appointments alone*”.

In total, of the 33 respondents who answered this question, only 8 (24%) felt that they had been given the skills to attend appointments independently. However, some of these were parents/carers answering as they attend appoints with and on behalf of their young person due to their needs. One respondent told us that the young person did gain the skills to attend independently, but this was due to them as the parent giving knowledge rather than professionals. Another respondent told us that they felt they were “*always fairly independent with attending appointments*” but through the transition process felt that they were “*taken more seriously*”.

Those who told us that they felt they were not given the skills to attend appointments independently said that, in some cases, this type of support was “*not offered*”. Again, due to some of the complex needs of young people, we heard that they were unable to attend appointments independently but fortunate enough that parents/carers were able to continue to attend with them. Others we heard from told us that they felt they already had the skills to attend independently, “*I don’t think I was given any skills I didn’t already have*”.

Personal stories: Transition is difficult for young people and parents

> "Transitioning is an absolutely bewildering process to parents with little or no experience. We have had to learn so much so quickly and have not been particularly well informed by involved professionals. Very little information is given away and many parents are desperately under informed and inadequately supported. If parents do not have the resources to inform themselves via research or hire solicitors / advisors they are effectively walking blindfolded into a minefield."
>
> Parent of young person transitioning from children's to adults' services.

We also wanted to know if young people or their families/carers had any worries or concerns about the move from children's to adults' services and if these were expressed to the professionals. We found that, from the 34 public survey responses 28 (82%) had worries/concerns about transitioning and from the 17 professional survey responses, 15 (88%) told us that patients had expressed their worries/concerns with them (Figure 7).

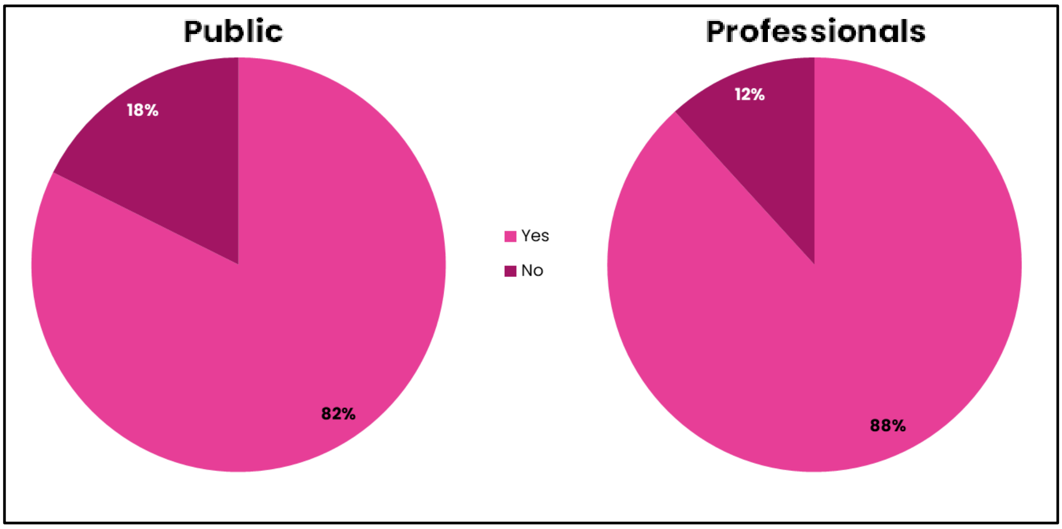


Figure 7. Public responses to the question 'Did you have any worries or concerns about moving from children's to adults' services?' (LEFT, 100% = 34) and Professional responses to the question 'Have patients expressed any worries or concerns about moving from children's to adults' services?' (RIGHT, 100% = 17)

The worries/concerns of young people and their families/carers could typically be categorised into four themes;

Theme	**Worry/Concern**
Less support in adult services.	• *"less approachable staff"* • *"I was concerned that I wouldn't be able to access the support I need and would be left helpless"* • *"That I would just be a number and that I would not be shown any compassion because I would be an adult."*
Communication with adult services would be poor.	• *"battle for decent communication"* • *"missed information going through"* • *"No communication for weeks on end."*
Parents/carers involvement would discontinue.	• *"As the patients has special needs I need to be involved in her care and this is not always recognised."* • *"they still need a parent with them to answer question just reaching 16 even doesn't mean that they know the answer to questions about their childhood history!!!!"*
Young person not prepared for change.	• *"Getting to the doctors, dealing with the receptionist and knowing how to arrive and getting my prescription."*

"Both myself and my daughters camhs worker raised concerns about the transition to adult services as we didn't want there to be a gap in provision. And in the end my daughter has ended up with no provision at all which I am extremely unhappy about"

The worries and concerns that were conveyed to professionals could also be categorised into similar themes:

Theme	Worry/Concern
Decline in support and access to supplies.	- *"won't get an equivalent service"* - *"Limited services, different services"*
Difference in communication would mean the young person wouldn't know where to go for support or who to go to.	- *"Not knowing what is available and whether it suits need"* - *"very anxious about who to go to, how to get help, no case manager"*
'Drop off' in care and they would have to 'start again'.	- *"anxiety around dropping off of services and lack of comparative support in adult services"* - *"Will I have to start my wait again in the new service."*
Parents were concerned what would happen for their children.	- *"What is going to happen next to their child."* - *"Parents worried about loss of keyworker role and the additional burden/stress this places on them"*
General fear of change and unfamiliar professionals.	- *"Fear of change and having different staff support within adults services"* - *"uncertainty about the unfamiliar."*

> "Patients identify the lack of support in adult services as a concern along with the lack of a co-ordinator for their care or a single point / person they can access for support and guidance. Adult services can be fragmented for young people."

Consistency

We also wanted to know how both public and professionals rated the consistency of care from services. Of the public responses (34) over half (20, 59%) rated this as 'Very Poor', with a further five people (15%) rating it as 'Poor'. A total of eight respondents (24%) rated consistency as 'OK' (4, 12%), 'Good' (2, 6%), and 'Very Good' (2, 6%), show in Figure 8.

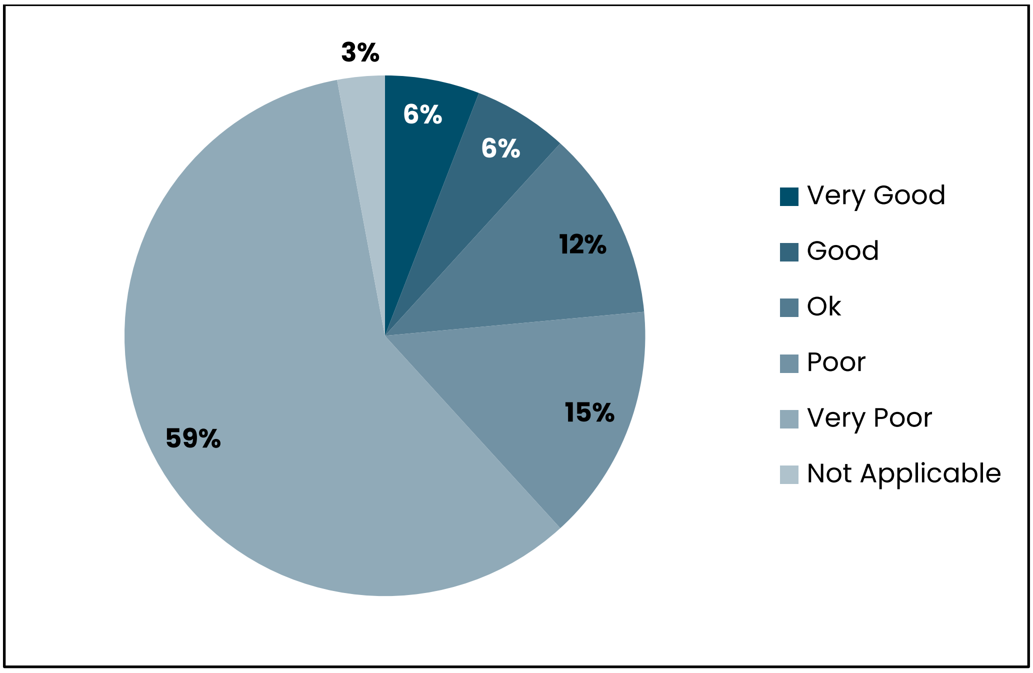


Figure 8. Public responses to the question 'How would you rate the consistency of the care from the services?' (100% = 34)

The young people and families/carers that we heard from provided details of their experiences and how there were gaps in the consistency of their care. One respondent described their child's transition as "*diabolical*", telling us how the "*assessment took months*" and that "*no one seemed to be able to communicate properly.*"

Other respondents told us how they were dissatisfied with some of the services they were accessing. One told us how some services were working well, "*Starfish Plus are brilliant and extremely caring and helpful*", whereas others were barely involved *"Pfal weren't interested once their assessment was done."* Another respondent highlight that, throughout the process the staff were "*constantly changing and not reading up on previous involvement*" which meant they were "*constantly retelling history*". They also told us that services were "*Not pro active in communicating*" so they were "*constantly chasing people for information*".

From interviews we heard that the change in the consistency of support/care can vary based on service and patient need, but is a common concern for parents and carers. One parent/carer told us that they kept "*hearing that story over and over again, that children's services stop at 18 and adult services doesn't kick in.*" Similarly one professional told us that from their perspective families are "*moving to unknown staff who don't know their children so well. And I think they hear stories about how difficult it can be.*"

> “Assessment done in June. PA agreed in August but still not informed of budget/hours offered and recruitment has not started. No care in place while waiting”

This concern is something that the professionals we interviewed are aware of and find that “*parents and carers find it really challenging*”. One told us they think that the transition process “*can be quite a scary prospect for most families*” as they are used to the paediatric staff and have known them for a long time.

In the professional survey an equal number of respondents (4, 24%) rated the consistency of care as ‘Poor’, ‘OK’, or ‘Good’, with two (12%) respondents rating this as ‘Very Good’ and a further two rating as ‘Very Poor’. One respondent (6%) told us they were not sure, displayed here in Figure 9.

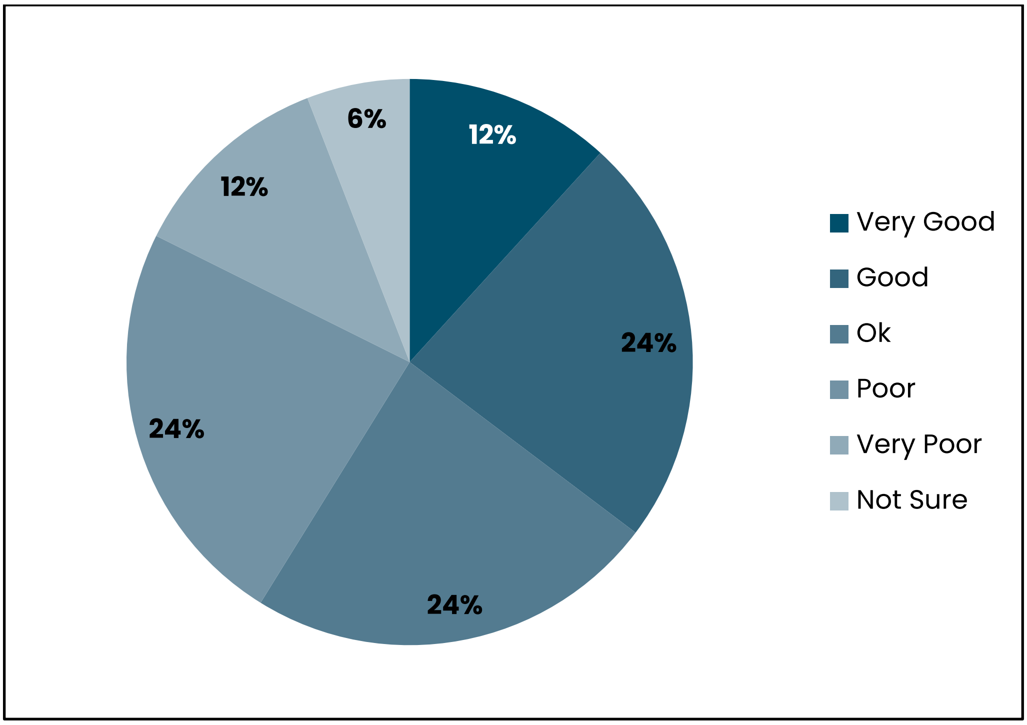
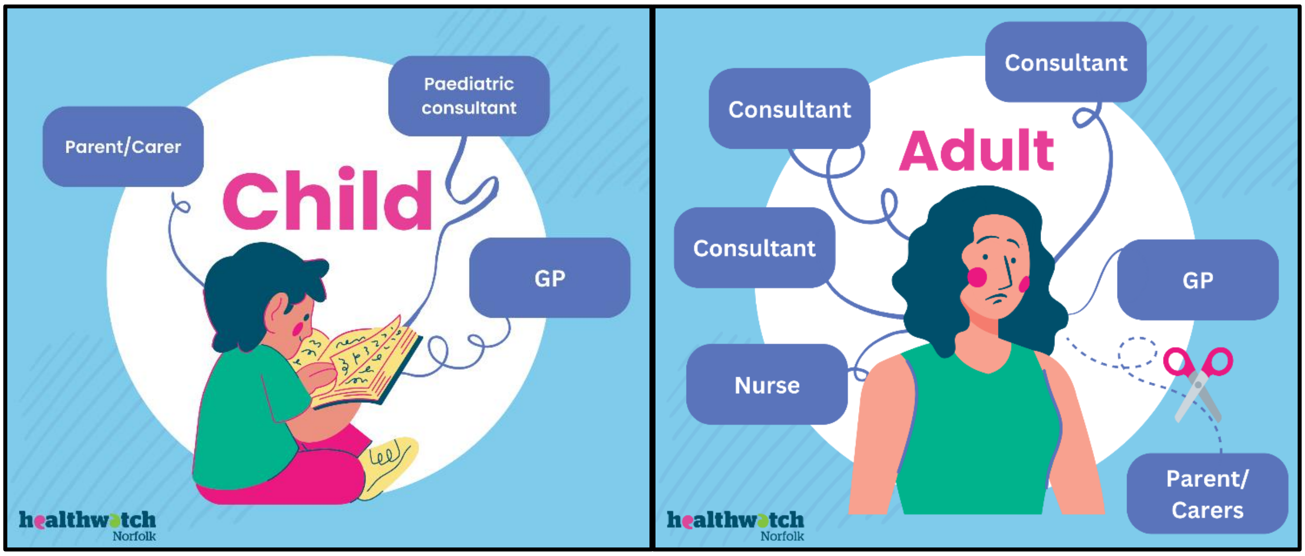


Figure 9. Professional responses to the question 'How would you rate the consistency of the care being provided?' (100% = 17)

Professionals highlighted that where there are issues with consistency in care. This is often related to poor communication, and the differences between children’s and adults’ services. One respondent echoed what we heard regarding communication and how the consistency of care can be “*hit and miss*” based on the individual’s needs. Another respondent, who gave an ‘OK’ rating, told us that in comparison to paediatric occupational therapy (OT) services, where patients can phone when a new need occurs, adult OT services may require parents to “*re-refer*” when new needs arise.

One professional we interviewed told us, they felt, this challenge comes from moving from a system where “everything is looked at in one clinic” into one where “you become different organs” and can be seen by multiple specialists rather than one clinician. This is something they found to be particularly true for complex cases, and is something that they try to ensure that young people and their families/carers are prepared for.



One professional who rated consistency as ‘Very Poor’ told us that this was because the “*Childrens & Adults services are commissioned very differently*”. Another respondent told us that consistency can vary as access is “*inequitable*” based on specialty. A respondent who gave a ‘Poor’ rating said that there is “*No set standard for care*”.

> “There are different approaches to assessment in each team but this is understandable as an adult assessment will look different to one for a younger person.”

Differences between services

We wanted to know from both the public and professionals what they had found to be the differences between children's and adults' services.

The family members we interviewed mostly told us how the levels and consistency of the care and support they received was the biggest difference between children's and adults' services with the main issues being the 'drop-off' in support. One parent highlighted how their child "*would have someone working with her about how she's feeling-- how her brain's working*" in children's services but since moving to adults' services this has become "*more like group sessions*" and they "*don't think they were particularly successful*" by comparison.

One parent also described to us the variance between two different services, having had two children transition. They found that for one child they "*always had letters after a visit to anywhere to say, "This is what happened.""* whereas for their other child they did not receive anything like this after appointments "*I haven't got a lot of documentary evidence to go back and check whereas with my son, I've got folders for.*"

For professionals, their views on the differences between services were varied depending on the service they worked in. For the professionals working in children's services, they told us that they "*generally know the children a long time*" and "*build a relationship*" with the family whereas in adults' there "*could be a different*" professional picking up "*each different piece of work*".

In terms of consistency an OT professional also told us they found children's services tend to "*keep children open on* [their] *caseloads*" whereas for adults' services they "*will just keep them open and do that piece of work and then close them*".

However, other professionals we spoke to, told us that their services work closely together between the children's and adults' side during the transition process, with both teams being involved in transitions meetings. The differences these professionals found between their sides of the services were that the "*adult service is nurse led*" and the children's is "*paediatric-led care*", which influences medication prescription. The other difference is in the care plans, with the children's side being "*the minimal bare bones*" in comparison to the adults', but this is so that young people are able to "*cope*" with them.

What works well and improving experiences

Finally, we asked professionals what they felt worked well in the transition process and was there anything they would like to see change to make the experience better for young people. As well as asking both public and professionals, during interviews, what they felt could be done to improve the process.

Two professional respondents told us that they felt, for their specialty, the communication was an aspect that worked well. Others told us they thought "*Having a Lead Transition* [Nurse]" for support and resources worked well as they felt "*having transition as part of another job*" wasn't as successful. Another respondent told us they felt the "*use of the keyworker service*" in supporting the process was one of the "*best examples*", as well as having monthly discussions for complex needs. One of the reason's professionals felt that the keyworker service worked well in the transition process was because it provided a "*central point of contact*" for young people and their families. Keyworkers were there to "*guide them* [the young person] *through the transition process*". One professional told us that "*Parents* [are] *worried about loss of keyworker role*" when their young person transitions as this adds further pressure and stress on them.

Professionals highlighted the following as working well:

- "*shared adult team post diagnostic resource pack*"
- "*NNUH transition meetings*"
- "*where needs are complex or current we do ensure they end up with the correct service before discharging them from children's OT*"

> "Everyone being at the same appointment via video virtual. The service leaflet for adult services is provided if patients/families do not wish to attend but want to have information if they need it in the future. Patient with more complex needs tend to have a transition appointment at their school to allow for people to be involved."

In terms of what professionals would like to see change, and how patient experience can be made better, respondents told us they felt a role "*similar to the key worker service*" in children's services would be beneficial for adult services and "*support smoother transition*". This would give patients "*access to named persons in specialities for advice/support*"

Some respondents told us they felt that things could be improved by "*Identifying patients earlier*" and "*Starting the process earlier*". Others told us that they would like to see "*Stronger links*" between children's and adults' teams, and that an increased "*overlap between services*" and use of "*assessment tools"* would help provide a *"greater understanding of patients needs*".

Other comments from professionals included:

- "*better relations between children's and adults teams and knowledge of what they all do so we can support families*"
- "*Realistic expectations being set. Signposting to self-management, personal health budgets*"
- "*Perhaps meetings for parents to prepare for transition - often they feel worried*"

> "In my opinion adult services need to appreciate that these young people are living longer and so transition from children's services whereas historically this has not been the case. Adult services needs rapid development in order to meet the needs of this patient group and ensure consistency of care is provided."

For those we interviewed we heard that, having the single point of contact that you get in children's services was highlighted by young people and families/carers as one of the most positive parts of the service and process. We heard from one children's service professional that young people and families "get really nervous" approaching transition age because they "don't want to lose that support", however in many cases they are simply "the number in the phone or on the fridge". The professional on the adult side of this service also told us that they provide leaflets with the team's pictures and contact so that young people and their families/carers don't lose the comfort of knowing there is someone "at the end of a line or the end of an email."

Another improvement that a parent felt there could be, was involving parents more in some of the transitions and planning meetings. Concerning their experiences with health services, they told us that they thought "*they relied very much*" on the input of their young person and not "*enough opportunity for parents to have a say*" or "*raise their concerns*". They also felt that by not being involved that the professionals may not be "*getting the whole picture*" which they felt could impact treatment decisions.

We also asked public and professionals where they felt the biggest gaps in support were and if there were any improvements they could think of that would make experiences of transitioning better.

A common theme that emerged from both public and professional interviews was that there is a gap in support for the 18 to 30 age range, with one parent telling us that they thought "*young people are too young, then, to be ditched at 18 as well.*" and that is "*is quite a vulnerable time*" in life for young people. What they would like to see is a point of contact for young people or parents/carers to be able to speak to and get support from, "*You just want someone to ring and get advice*", particularly for the young people as they feel they need someone who is not a parent to talk to.

> "it's just having someone to go to for some advice when you are having a difficult day."

Professionals felt there could be improvements made in the handover process. They told us that they felt a "*more multidisciplinary transition appointment*" would be appropriate as in many cases the young people transitioning have more conditions/complex needs. This would also allow any fears and concerns to be relayed mean that "*parents know who each of the professionals are that their young person is going to transition on to.*"

We also spoke with one professional, working with supporting children with life-limiting illness, who told us they found that the paperwork involved in the process was "*quite complicated*" and can be "*quite daunting*" for families and felt that "*it could be broken down easier*" so as not to overwhelm the families.

Advice

Finally we asked both public and professional interviewees if they had any advice they would give to someone going though, or about to go through, the transition process.

The biggest piece of advice that both public and professionals gave was to 'ask questions' and 'get all the information you can'. One parents' advice was: "*ask* *lots of questions. Stick to your guns. If you think you're not getting the support that's needed, you have to say it. But don't be aggressive, just be polite*".

> "There's no such thing as a silly question. And the luxury of the transition appointments is time."

Other advice was to start looking into the process as early as is possible and stay on top of things during the process. One professional said "*start as early as possible*" because they think time is needed to gather information and work towards adult services.

A final piece of advice from a professional was "*Not to panic*", because the process can be daunting and confusing so be sure to ask questions and raise any concerns.

What this means

There are around 123,000 students in primary and secondary education in Norfolk (Flourish, 2021) and the population of 18 year olds in Norfolk is approximately 9,000 (Norfolk Insight, 2023). The number of young people with complex health needs who receive Special Education Needs (SEN) support or Education, Health and Care Plans (EHCPs) is around 20,800 (Flourish, 2021). Therefore the responses in this report are a small sample in relation to all those in Norfolk who are transitioning. However, there are some consistent themes in the experiences of those who have given their feedback and that has enabled us to identify areas for potential improvement.

Whilst the focus of this work was on the transition from children's to adults' services, through our engagement we received positive feedback about children's services. From the responses we received the transition process for many services in Norfolk could be greatly improved in terms of consistency, communication, and support in the overlap (young people aged 18-25).

There is a variation in the levels of support experienced, during and after the transition process, depending on the services being accessed. The services that received more positive feedback included GPs, community nurses, nephrology, physio, and OTs. We received more neutral or negative feedback for mental health services as well as some learning disability services. In some cases it was reported that there was "drop-off" in support provision, which was acknowledged by some of the professionals we spoke with. Ensuring the consistency of support during transition for all services could improve health outcomes for young people, particularly those with complex health needs transitioning multiple services.

We know that access to appropriate mental health support is important for increasing the prospects for healthy and happy lives for children and young people (NHS, 2023). From our previous report on community based mental health services for adults (which can be found here: https://healthwatchnorfolk.co.uk/report/community-based-mental-health-services-in-norfolk-and-waveney-year-one-report/), we found that patients experienced issues and gaps when accessing services. Investigating which services experience this 'gap' through patient feedback, and addressing the issue by making sure young people can still access appropriate levels of support until they are fully adopted by adult services will be key to improving wellbeing. We would like to see the introduction of additional support for 18 – 25 year olds in the form of service helplines and key points of contact to help ease the transition process, manage the gap/drop-off in support, and lead to improvements in health outcomes.

In terms of the professionals' experiences of supporting young people and their families/carers through the transition process, there was a very mixed response. Some told us that the experience overall had been positive and that they worked closely with their service counterparts and the families to ensure that relevant people had the information they needed and that the process went as smoothly as possible. Professionals also told us that the process varied depending on specialism and what support was available on the adult side of the process, not only this but patient experience could vary further in more complex cases where those with complex health needs are likely to be transitioning to multiple services/specialisms.

Poor communication was a theme across many services and there is a mismatch between the views of professionals and parents/carers concerning communication. It is apparent that services could do more to improve lines of communication during the transition process. The keyworker services, on the children's side, were praised for giving young people and their families/carers a point of contact and someone to communicate with them through the process. We would like to see the introduction of a similar function/role in the adult services. This would be beneficial to help keep the lines of communication strong, and would be particularly useful for those with complex needs who are likely to be accessing multiple services.

There was also a mismatch between professionals' feedback that they provide information and young people and families stating that they didn't receive information. It is difficult to know why there is a difference; it could mean that, for some, the information being given is not clear and so the perception of the young people and their families/carers is that they haven't received any information to support the process. There would appear to be a lack of understanding in what patients and families need in terms of information, which in turn results in more confusion and lack of understanding from the young people and their families/carers.

Reviewing the information provided by both children's and adults' services to ensure that this is lined-up and that adequate information is being provided by all services involved would help to improve consistency and support a smoother process. Consulting patients and families through feedback surveys/forms would help to review the clarity of the information and ensure that it is communicated well and could also help in alleviating some of the worries and concerns young people and their families have about the transition process.

The involvement of parents/carers is variable; with some parents feeling that they were excluded from the process and others who felt that the key to the success of the transition was the work they had undertaken to make things happen. Finding suitable ways in which parents/carers can be involved in the process without impacting on the independence of the young person is important and we would like to see more consideration for the involvement and support of parents and carers through this difficult period.

There are issues with the planning for young people to move from children's to adult services. Regardless of involvement in the creation of plans, issues that were raised included poor execution and support for plans, and poor communication of complicated paperwork. It would be beneficial to look into further ways care plans can be communicated, broken down, and made more understandable for young people and their families. Not only this, but supporting them with understanding how their plan will change over time and during the transition to make this less daunting. This can also link in with potential on-going keyworker support, giving young people the opportunity to contact someone when they have concerns or are unsure on the details of an updated plan. Additionally, looking to line-up systems (e.g., using the shared care record) could aid with managing care plans and making it so young people and their families/carers don't feel as if they have to retell their story for each new adult service.

Recommendations

From the findings of this piece of work several recommendations can be made for Norfolk Community Health and Care NHS Trust (NCH&C), and for the other services (Such as GPs, hospital departments, and adult mental health services) helping young people through the transition process, to consider regarding improving young people's, and their families/carers, experience of transitioning from children's to adults' health and care services.

1. Gather feedback – Establish processes for gathering feedback from young people and families/carers. This will enable a better understanding of what is needed by patients and families, and which services are managing the process well and which need improvements. This will also identify barriers to successful transition.
2. Improve communication – Communication with young people and their families could be improved to show what to expect from the transition process and how the adult services differ from children's. Improve communication between professionals to ensure better join-up of services and smooth transition.
3. Point of contact/Keyworker – Consideration should be given to appointing a keyworker who is responsible for supporting the young person and their family through the process, acting as a consistent point of contact during transition for both children's and adults' services. This could include specialist transition support for those aged 18-25 ensuring a smooth transition and reduce the risk of drop-off in support provision.
4. Planning process – Review the planning process for all services so that all are able to access records and minimise the need for patients and families to 're-tell their story'. Include aspects for parents/carers to ensure they have knowledge on how they can best support their young person.
5. Involvement of parents/carers – Actively encourage parents and carers to be involved in the planning for transition, as they can help the young person move toward independence in managing their care.

We acknowledge that the sample size for this work was small, however, within this there was considerable feedback concerning transitioning between child and adult mental health services. From our ongoing work evaluating the Community Mental Health Transformation we are aware of the plans to transform these services in Norfolk and Waveney. As the NHS Long Term Plan includes a new approach to young adult mental health to support transition (NHS, 2019), we hope that the Community Mental Health Transformation includes plans to improve the support for young people transitioning from Children's mental health services.

Formal Response

We received an official response to this report and the recommendations from Helen Bradley, Quality Matron for Mill Lodge and Children's Services, on behalf of Norfolk Community Health & Care.

NHS
Norfolk Community
Health and Care
NHS Trust

How NCHC will respond to recommendations:
There is a national and local drive to develop and improve on the Transition experience for young people and their families. We acknowledge NCH&C are part of a system-wide approach to work alongside our partners in healthcare provision to improve these experiences and develop our services, so they meet the needs of local young people. As a result of these findings, we will commit to:

- Developing a Children and Young People's forum. This will provide a platform for capturing the experiences and opinions of local children and young people who use our services. "Young Voices Together" was launched at NCH&C in June 2023.

- Target those young people and their families who have recently gone through the transition process with the Friends & Family test to capture their feedback of their experiences.

- Share the report with NCH&C's Child to Adult Transition group and across NCHC services to support internal awareness and learning.

- Share the report with the Integrated Care Board and partner agencies to support systemwide ownership of the findings and commitment to improvement. (Note: the ICB helped in the development of the survey questions).

- Develop a NCH&C transition leaflet (with Easy read version) aimed at young people and their families to support them with the transition process

- Develop a NCH&C policy on Transition to support Trust wide standards of care around transition for both Children's and Adult services. (Completed June 2023).

- Develop individual NCH&C services' responses to transition, working with partner agencies to promote approved processes and plans of care.

- Adopting the role of "named clinician" for transition across NCH&C's Children's services.
- Raising awareness and engaging with adult services to be more involved and accountable in the transition process.

- Consider the introduction of a post-discharge contact in NCH&C's Children's services following transition, to follow up and ensure the process is working as it should.

- Extend the roll out of the Carer's passport for parent/carers as their child enters the transition process, which will then support their continued involvement. Ensure families have information around Mental Capacity Act and the role of Power of Attorney.

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Appendix

Appendix 1: Public Interview Guide

Transitions Interviews – Public

Introductions

Confirm participant is happy for interview to be recorded for transcription purposes.

Inform that recordings will be deleted once the write up is complete and any direct quotes will be anonymised.

Who we are:

‘Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people’s views of health and social care services in the county and make sure they are heard by the people in charge. Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more. We also give out information about the health and care services available in Norfolk and direct people to someone who can help.’

The Project and purpose of interview:

We are working with the Norfolk Community Health & Care NHS Trust (NCH&C) to explore the views and experiences of how young people (and their families) have experienced the move between children’s and adult’s health and care services.

We want to spend some time speaking to a small group of young people and/or their families in Norfolk.

For the purposes of the interview, you should have recent experience (in the last 12 months) of transitioning from children's health and care services to adult's health and care services.

We want to hear what it has been like accessing services yourself and/or for the person you care for.
We'd like to hear what has been positive and where you would like to see improvements or changes.

There are no right or wrong answers we are just really interested in hearing peoples' personal experiences and opinions.

The information we take away from the interview will be anonymised and will be used in a report to be given to NCH&C so they can find out what is working well and what needs improvement.

Questions/Prompts:

Could you tell us your role (parent, carer, etc).

Which service and departments where you/they accessing and which are they moving to?

If you feel comfortable doing so could you give some background for context?

Please tell us about your/the person you care for's experience of moving from Children's services to Adults' services.

Prompt: Was there anywhere that you looked for and where did you find support? (e.g. the services, charities, or friends/family)

Prompt: Do you feel that you feel that you were involved and listened to during the process/planning? Did you have a point of contact? And how was information communicated to you?

Prompt: What have you found to be different between the children's and adults' services? Is there anything you feel that is missing?

Prompt: Was there anything that was done particularly well/any positives you want to highlight?

Prompt: What would have made the experience better? (or even better if experience was good) Is there anything in particular that you felt could be improved upon?

Finally is there any advice that you would like to give for others who will be going through this move in the future?

Thank you

Thank you for your time and taking part by telling us about your experience.

Appendix 2: Professional Interview Guide

Transitions Interviews – Professionals

Introductions

Confirm participant is happy for interview to be recorded for transcription purposes.

Inform that recordings will be deleted once the write up is complete and any direct quotes will be anonymised.

Who we are:

'Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather people's views of health and social care services in the county and make sure they are heard by the people in charge. Our work covers all areas of health and social care. This includes GP surgeries, hospitals, dentists, care homes, pharmacies, opticians and more. We also give out information about the health and care services available in Norfolk and direct people to someone who can help.'

The Project and purpose of interview:

We are working with the Norfolk Community Health & Care NHS Trust (NCH&C) to explore the views and experiences of how young people (and their families) have experienced the move between children's and adult's health and care services.

We want to spend some time speaking to a small group of young people and/or their families in Norfolk.

For the purposes of the interview, you should have recent experience (in the last 12 months) of transitioning from children's health and care services to adult's health and care services.

We want to hear what it has been like accessing services yourself and/or for the person you care for.
We'd like to hear what has been positive and where you would like to see improvements or changes.

There are no right or wrong answers we are just really interested in hearing peoples' personal experiences and opinions.

The information we take away from the interview will be anonymised and will be used in a report to be given to NCH&C so they can find out what is working well and what needs improvement.

Questions/Prompts:

Could you tell us your organisation & role

Which services and departments do you typically see/help young people access and which do they moving to?

Please tell us about your experience of young people moving from Children's services to Adults' services. Are there any specific examples you would like to highlight/share?

Prompt: What kind of support do you offer for young people and their families during the move from children's to adults' services?

Prompt: What have you found to be different between the children's and adults' services? Is there anything you feel that is missing?

Prompt: Is there anything that is done particularly well/any positives you want to highlight?

Prompt: Is there anything that you think would make patient experiences better? Is there anything in particular that feel could be improved upon?

Finally is there any advice that you would like to give to patients who will be experiencing this move?

Thank you

Thank you for your time and taking part by telling us about your experience.

Appendix 3: Public Survey

Transitioning Services - Public Survey

Transition from children's to adults' health and care services

Who is Healthwatch Norfolk?

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather your views of health and social care services to ensure they are heard by the people in charge.

What is this survey about?

Healthwatch Norfolk are working with the Norfolk Community Health & Care NHS Trust (NCH&C) to explore the views and experiences of how young people (and their families) have experienced the move between children’s and adults' health and care services.

If you have recent experience (in the last 12 months) of moving between children’s and adults' health and care services we would like to hear your views.

How the survey results will be used

Anonymised survey data will be shared with NCH&C to enable them to share good practice and assess areas for improvement in the transition from children’s to adults' health and care services. Healthwatch Norfolk will not disclose any confidential information unless there is a genuine and urgent concern for an individual’s safety or wellbeing.

The survey results will also be used by Healthwatch Norfolk to make recommendations to service providers as part of our evaluation report. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications

Survey responses are being collected and analysed by Healthwatch Norfolk. You can read our full privacy policy at:

www.healthwatchnorfolk.co.uk/about-us/privacy-statement

If you would prefer to do this survey with us over the phone, please call Healthwatch Norfolk on 01953 856029 and we will arrange a time to ring you back to complete the survey. Alternatively, please email: enquiries@healthwatchnorfolk.co.uk for further support.

Survey Closing date: 6th January 2023

Please tick to confirm *

☐ I have read and understood the above statement

Healthwatch Norfolk produce newsletters about health and social care in Norfolk. If you'd like to receive this newsletter please leave your email here:

If you have recent experience (in the last 12 months) of moving between children’s and adults' health and care services please answer the questions below to the best of your ability.

1. Please check which applies to you:

☐ I am the person who has experienced moving from Children’s to Adults' services
☐ I am the family member of someone who has moved/is moving from Children’s to Adults' services
☐ I am the carer of someone who has moved/is moving from Children’s to Adults' services
☐ Other (please specify):

2. How old are you/ is the person experiencing the transition to adult services?

3. Please tell us which service(s) your experience relates to:

4. How would you rate the overall experience of transitioning from children's to adults' services?

☐ Very Good
☐ Good
☐ Ok
☐ Poor
☐ Very Poor
☐ Not sure
☐ Not Applicable

5. Were you given any information and support in preparation for the move from children's to adults' services?

☐ Yes
☐ No

If yes, please provide details:

6. Did you have any worries or concerns about moving from children's to adults' services?

☐ Yes
☐ No

If Yes: What were they? Did you raise them at the time? And were they addressed?

7. Who has been involved in the move/ transition from Children's to Adults' services? (e.g., consultants, GPs, parent and/or carers)

8. Did you feel involved in your transition plan?

☐ Yes
☐ No

Please tell us why:

9. Do you feel you were given the skills to attend appointments independently?

☐ Yes
☐ No

Please tell us why:

10. Overall, how would you rate the communication from the services during the transition process?

☐ Very Good
☐ Good
☐ Ok
☐ Poor
☐ Very Poor
☐ Not Sure
☐ Not Applicable

11. How would you rate the consistency of the care from the services?

☐ Very Good
☐ Good
☐ Ok
☐ Poor
☐ Very Poor
☐ Not Sure
☐ Not Applicable

12. Please tell us about your experience of transitioning from Children's to Adults' services. Tell us about your journey:

(E.g. What worked well and what do you feel could be improved?)

13. Is there anything else you would like to share with us regarding the transition from Children's to Adults' services?

14. If you would be happy for us to contact you to speak about your experiences in more detail please provide your name and preferred contact information below:

If not please check here

☐

4. Demographics

In this next section we will be asking you some questions about yourself and your life. Your answers help us make sure that we engage with people from different backgrounds and that we understand the needs of different groups in our community. Remember: all your answers are strictly confidential and the survey is anonymous.

15. How old are you?

16. What is your gender?

☐ Male
☐ Female
☐ Non-binary
☐ Genderfluid
☐ Genderqueer
☐ Intersex
☐ Prefer not to say
☐ Prefer to self-describe: ☐

17. What is the first half of your postcode?

☐

18. What is your ethnic group?

☐ Arab

Asian / Asian British:
☐ Bangladeshi
☐ Chinese
☐ Indian
☐ Pakistani
☐ Any other Asian / Asian British background

Black / Black British:
☐ African
☐ Caribbean
☐ Any other Black / Black British background

Mixed / Multiple ethnic groups:
☐ Asian and White
☐ Black African and White
☐ Black Caribbean and White
☐ Any other Mixed / Multiple ethnic groups background

White:
☐ British / English / Northern Irish / Scottish / Welsh
☐ Irish
☐ Gypsy, Traveller or Irish Traveller
☐ Roma

☐ Any other White background

Other:

☐ Any other Ethnic Group

☐ Prefer not to say

If other, please specify:

19. Do you consider yourself to have a disability?

☐ Yes

☐ No

☐ I'd rather not say

20. Where did you hear about this survey?

☐ GP website

☐ Healthwatch Norfolk Event

☐ Healthwatch Norfolk Newsletter

☐ Healthwatch Norfolk Website

☐ News (website / radio / local newspaper)

☐ Search Engine (e.g. Google)

☐ Social Media (e.g. Facebook / Instagram / Twitter)

☐ Through a friend or co-worker

☐ YouTube

☐ Other (please specify):

Appendix 4: Professional Survey

Transitioning Services - Survey for Staff/Professionals

Transition from children's to adults' health and care services

Who is Healthwatch Norfolk?

Healthwatch Norfolk is the independent voice for patients and service users in the county. We gather your views of health and social care services to ensure they are heard by the people in charge.

What is this survey about?

Healthwatch Norfolk are working with the Norfolk Community Health & Care NHS Trust (NCH&C) to explore the views and experiences of how young people (and their families) have experienced the move between children’s and adults' health and care services.

If you work in health and social care and have experiences of supporting young people transitioning from Children’s to Adults' services, we would like to hear from you.

How the survey results will be used

Anonymised survey data will be shared with NCH&C to enable them to share good practice and assess areas for improvement in the transition from children’s to adults' health and care services.

The survey results will also be used by Healthwatch Norfolk to make recommendations to service providers as part of our evaluation report. The report will also be publicly available on our website and may be used in other Healthwatch Norfolk communications.

Survey responses are being collected and analysed by Healthwatch Norfolk. You can read our full privacy policy at:

www.healthwatchnorfolk.co.uk/about-us/privacy-statement

If you would prefer to do this survey with us over the phone, please call Healthwatch Norfolk on 01953 856029 and we will arrange a time to ring you back to complete the survey. Alternatively, please email: enquiries@healthwatchnorfolk.co.uk for further support.

Survey Closing date: 6th January 2023

Please tick to confirm *

☐ I have read and understood the above statement

Healthwatch Norfolk produce newsletters about health and social care in Norfolk. If you'd like to receive this newsletter please leave your email here:

1. Please tell us which organisation/ specialty you work in:

2. How would you rate the overall process of transitioning from children's to adults' services in Norfolk?

☐ Very Good
☐ Good
☐ Ok
☐ Poor
☐ Very Poor
☐ Not sure
☐ Not Applicable

Please use this space to tell us why you have chosen this answer:

3. Do you provide information and support to patients and their families in preparation for the move from children's to adults' services?

☐ Yes
☐ No

If Yes: What information and support do you provide to patients and their families in preparation for the move from children's to adult's services?

4. Have patients expressed any worries or concerns about moving from children's to adults' services? If yes, what are they?

☐ Yes
☐ No

If yes, please provide details:

5. When transitioning a patient from children's to adults' services, how are they/ their family involved?

6. How is information shared from children's to adults' services and have you encountered any problems?

7. Overall, how would you rate the communication between clinician to patient/ family during the transition process?

☐ Very Good
☐ Good
☐ Ok
☐ Poor
☐ Very Poor
☐ Not Sure
☐ Not Applicable

Please use this space to tell us why you have chosen this answer:

8. Overall, how would you rate the communication between clinicians and organisations during the transition process?

☐ Very Good
☐ Good
☐ Ok
☐ Poor
☐ Very Poor
☐ Not sure
☐ Not Applicable

Please use this space to tell us why you have chosen this answer:

9. How would you rate the consistency of the care being provided?

☐ Very Good
☐ Good
☐ Ok
☐ Poor
☐ Very Poor
☐ Not Sure
☐ Not Applicable

Please use this space to tell us why you have chosen this answer:

10. What do you think works well with the current transitioning support?

11. What would you like to see change and how can the experience be made better for patients? (e.g., starting the process earlier)

12. Is there anything else you would like to share with us regarding the transition from Children's to Adults' Services?

13. If you would be happy for us to contact you to speak about your experiences in more detail please provide your name and preferred contact information below:

If no please check here

☐

4. Demographics

In this next section we will be asking you some questions about yourself and your life. Your answers help us make sure that we engage with people from different backgrounds and that we understand the

needs of different groups in our community. Remember: all your answers are strictly confidential and the survey is anonymous.

14. How old are you?

☐

15. What is your gender?

☐ Male
☐ Female
☐ Non-binary
☐ Genderfluid
☐ Genderqueer
☐ Intersex
☐ Prefer not to say
☐ Prefer to self-describe:

16. What is the first half of your postcode?

☐

17. What is your ethnic group?

☐ Arab

Asian / Asian British:
☐ Bangladeshi
☐ Chinese
☐ Indian
☐ Pakistani
☐ Any other Asian / Asian British background

Black / Black British:
☐ African
☐ Caribbean
☐ Any other Black / Black British background

Mixed / Multiple ethnic groups:
☐ Asian and White
☐ Black African and White
☐ Black Caribbean and White

☐ Any other Mixed / Multiple ethnic groups background

White:
☐ British / English / Northern Irish / Scottish / Welsh
☐ Irish
☐ Gypsy, Traveller or Irish Traveller
☐ Roma
☐ Any other White background

Other:
☐ Any other Ethnic Group
☐ Prefer not to say

If other, please specify:

18. Do you consider yourself to have a disability?

☐ Yes
☐ No
☐ I'd rather not say

19. Where did you hear about this survey?

☐ GP website
☐ Healthwatch Norfolk Event
☐ Healthwatch Norfolk Newsletter
☐ Healthwatch Norfolk Website
☐ News (website / radio / local newspaper)
☐ Search Engine (e.g. Google)
☐ Social Media (e.g. Facebook / Instagram / Twitter)
☐ Through a friend or co-worker
☐ YouTube
☐ Other (please specify):

Appendix 5: Demographics

N.B.: For some of the responses we received, individuals identified themselves as parents/carers of young people but provided their young persons age in their answers to the demographic questions.

		Percentage of Public respondents (n=34)	Number of Public respondents (n=34)	Percentage of Professional respondents (n=17)	Number of Professional respondents (n=17)
Age	16 to 25	44%	15	6%	1
	26 to 35	3%	1	18%	3
	36 to 45	9%	3	29%	5
	46 to 55	29%	10	24%	4
	56 to 65	9%	3	18%	3
Gender	Male	24%	8	24%	4
	Female	76%	25	76%	13
Ethnic Group	Any other Black / Black British background	3%	1	0%	0
	British / English / Northern Irish / Scottish / Welsh	91%	29	100%	16
	Any other White background	3%	1	0%	0
	Prefer not to say	3%	1	0%	0

Do you consider yourself to have a disability?	Yes	48%	16	12%	2
	No	48%	16	88%	15
	I'd rather not say	3%	1	0%	0

Appendix 6: List of Services

The services that respondents told us their experiences related to, included:

- General Practice (GP) Services
- General Adult Services
- General Children's Services (Paediatrics)
- Child Social Services
- A&E and Hospital Inpatients
- Nephrology
- Child and Adolescent/Children and Young People's Mental Health Services (CAHMS/CYPMHS)
- Adult Mental Health Services
- Haematology and Oncology
- Preparing for Adult Life (PfAL)
- Starfish Plus to Adult Learning Disabilities
- Epilepsy Clinics
- Children with Disabilities to Continuing Health Care (CWD to CHC)
- Day Support
- Autism Services
- ADHD Services
- Gastroenterology
- Asthma
- Physio
- Occupational Therapy
- Dieticians
- Consultants
- Community Nurses
- Diabetes Services

Areas covered by the professionals we heard from included:

- Neurodevelopmental services
- Children's/ Paediatric Occupational Therapy
- Epilepsy
- Learning Disabilities
- Palliative Care

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