

The Transition From Child To Adult Services

May 2022



The Transition From Child To Adult Services



**Information & Guidance Team Project
For Suffolk & Northeast Essex Integrated Care System
March - May 2022**

Contents

1.0 Introduction	3
1.1 Healthwatch Essex	3
1.2 Topic blurb.....	3
1.3 Acknowledgements	3
1.4 Terminology	3
1.5 Disclaimer	3
2.0 Purpose	4
2.1 Engagement methods	4
3.0 Key Findings and Recommendations	4
4.0 Conclusion.....	11

1.0 Introduction

1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience. We also provide an information service to help people access, understand, and navigate the health and social care system.

1.2 Background

Healthwatch Essex were approached by Suffolk & North East Essex to undertake a series of projects focussing on the lived experiences of people in the area in relation to their health, care and wellbeing.

1.3 Acknowledgements

Healthwatch Essex would like to thank the public who engaged with us and our network of stakeholders and partners who supported in sharing the project.

1.4 Terminology

CAMHS - Children and Adolescent Mental Health Service

ASD - Autistic Spectrum Disorder

CQC - Care Quality Commission

EWMHS - Emotional Wellbeing and Mental Health Service

ADHD - Attention Deficit Hyperactive Disorder

LD - Learning Disabilities

1.5 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during the engagement visits. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

2.0 Purpose

The aim of this project is to explore people's experiences of the transition from child to adult health, care and wellbeing services in northeast Essex.

2.1 Engagement methods



Surveys

A survey was created and distributed via our network of stakeholders and partners, as well as on our social media platforms and a dedicated page on our own website.



Interviews

In order to gain a more in-depth understanding of the transition from child to adult services we conducted a number of one-to-one interviews with participants.

3.0 Key Findings and Recommendations

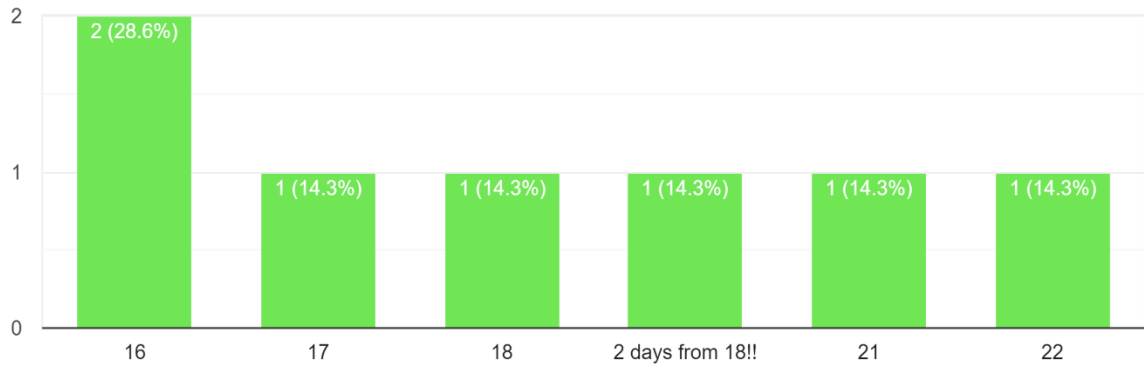
3.1 The Survey

In order to better understand the issue of GP services in northeast Essex, we circulated a survey which garnered the following data. Despite running for over two months and being shared widely within our networks and on social media, the response rate was low. We can possibly attribute this to the age of the cohort, as younger people are often more reticent to engage and discuss health, care and wellbeing matters.

We began by asking the age of the person who has, or will, experience the transition.

1. What is your current age/age of the person who will transition between services?

7 responses

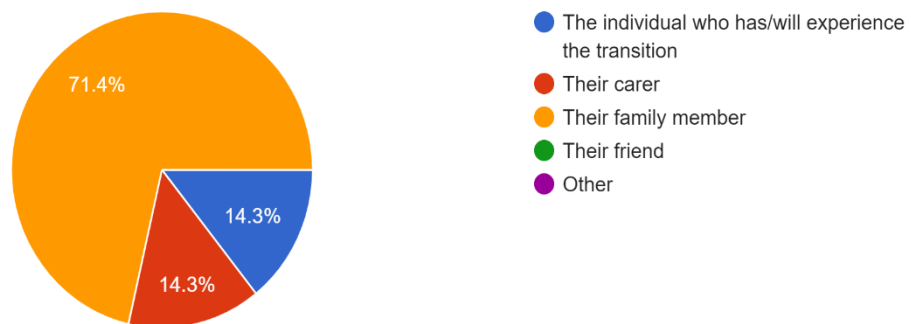


Of the seven respondents, two were aged 16, two were seventeen, one was 18, one was 20 and the eldest was 21.

We then asked the role of the person responding to the survey. Of the seven respondents, only one was the individual subject to the transition themselves, whilst five stated that they were family members and one a carer.

2. Are you;

7 responses



In our third question, we asked which specific services the individual is, or had been, engaged with through the transition. Responses were:

“Rheumatology.”

“CAMHS.”

“Health and education.”

“Paediatrician and children's mental health services.”

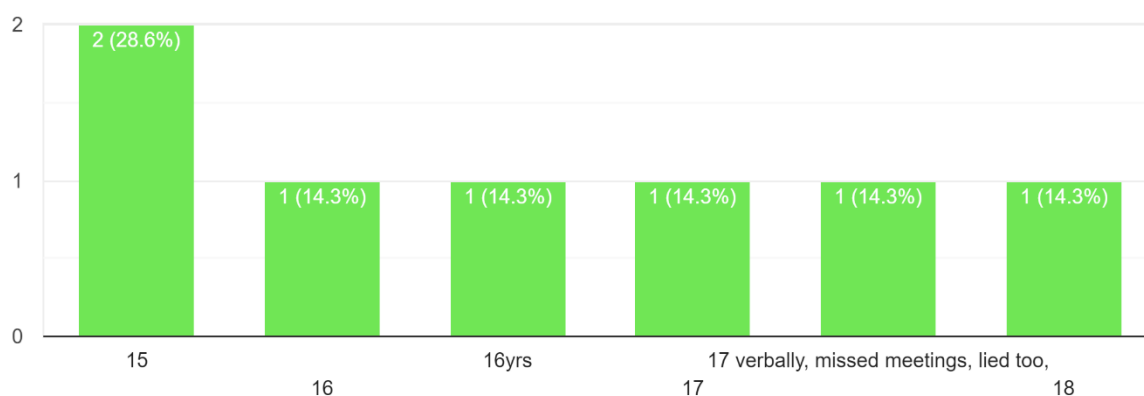
“Eating disorder/ASD/mental health inpatient provision - multidisciplinary team inpatient and outpatient.”

“Where do I begin, social care, mental health, hospital, and I can still could not tell you who the adult services are with!”

In our next question, we asked at what age the individual had been made aware that a transition between services would take place. Of the seven respondents, two had been made aware at age 15, two at 16, two at 17 and one at 18.

4. At what age were you made aware that you would transition from child to adult services?

7 responses



We then followed on by asking how the respondent was made aware that the transition would take place, and received the following responses:

“Face to face for health ... I was never informed by education or social care.”

“By a letter to my dad.”

“The nurse told us then a letter came from the transition team offering a meeting.”

“Got a letter.”

“We were told at a meeting that the next meeting would be the last one (this gave us two weeks’ notice).”

“There have been sporadic meetings, but I have no odea what the outcome of the transition is.”

“Verbally.”

Continuing with this theme, our next question posed asked who it was that imparted the information that a transition would take place, which resulted in the following responses:

“A health care professional.”

“My dad.”

“A psychiatrist.”

“A hospital psychiatrist.”

“EWMHS told me a bit but none of it is really clear.”

We then moved on to ask respondents what concerns they had/have about the transition. Five respondents answered with the following:

“None.”

“Lack of guidance / support / follow up / being left to my own devices.”

“My child having to meet and build a relationship with new staff. He has a good relationship with his current nurse in the children's team.”

“GPs are not specialists in managing ADHD medications. There are no specific services for adults with severe ADHD as well as Autism and LD.”

“Almost all of it; it seems disorganised, no structure, too many different professionals coming and going, not everyone working together, fragmented communication. overall, it has been a dreadful experience! Social care have even not turned up to meetings at times, which is a disgrace.”

“There is no adequate provision.”

We then asked how the transition process had affected the respondent when it happened, which gave the following responses:

“It was traumatic, and we felt we were on our own.”

“It's still in the process due to me having GCSE exams this summer, the full transition will happen after my exams.”

“No effect.”

“I felt lost and left to 'get on with it'.”

“It's still happening, I am waiting on them scratching around for a bed, no idea of who my social worker is, ineffective mental health team.”

“It took two years to find a suitable service. The constant concern of whether my daughter would be put in an inadequate hospital (which had happened previously) had consequences on the entire family's health.”

Next, we asked if the transition had produced any positive outcomes for the individual. Of the seven responses received, three simply stated “no” whilst another expanded by saying “I cannot say it did or has, been traumatising experience.” In addition, the remaining three respondents stated:

“I will have the same consultant as before which will be helpful as they will already know me.”

“He will stay with the same consultant which is excellent as he knows my son and his history. My son will be very happy to not attend the children's outpatient department anymore for blood tests! He feels he is too old now for that.”

“Eventually yes, as she was transferred from a hospital considered inadequate by the CQC who also felt uncomfortable having a 19-year-old. The hospital she is now in (which was located by myself and one other person high up in NHS England (my own contact) is the good hospital.”

Conversely, we then asked if the transition had produced any negative outcomes for the individual. One respondent simply stated “no” whilst the others said:

“Constantly having to battle through to get support ...feeling that we are on our own.”

“Issues with medications reviews/updates.”

“Plenty! Please ask for more information should you wish me to discuss further.”

“The stress of how long it took to find an appropriate hospital was massive. Hospitals came to assess, were agreed and then they pulled out at the last minute. It was a prolonged and protracted stressful process with seemingly no one coordinating it.”

Expanding upon the previous two questions, we then asked if the respondent had any suggestions for how to improve the transition between child and adult services. Responses received were:

“There should be a buffer for a five-year period so that education health and social care teams can liaise and provide smooth transfer of services which does not hinder or traumatise the young person.”

“Preparing several months in advance is what is needed. And services being available in the community to support complex conditions.”

“Communication, structured meetings, in these meetings some parties do not seem to do much, just one pass off information to the next and so on. We need a clear process, support for families and children. There are plenty of meetings I am yet to see the minutes of! Isn't this the law?? The need to change this failed system is a must, to be mindful that in your tick boxes these are real people with real people in need. All you are doing is failing them.”

“Having an overall care co-ordinator who knows exactly what type of provision or care is required and having that person liaising with patient, parents, current care and future care placement/care provision.”

“None at the moment.”

To close the survey, we asked the respondent for any additional comments, of which there were two:

“Currently there is a complete lack of empathy, understanding or care. I felt like a pawn and an inconvenience. Money and budgets take priority over the young person’s wellbeing and development.”

“It is a scary process and when no one appears to know what is happening or what is actually required it becomes very upsetting and stressful for everyone. My daughter was lucky because I was tenacious and kept asking questions and making influential contacts... others have had an even worse experience of this lengthy process.”

3.2 The Interviews

We followed on from the survey by carrying out a number of one-to-one interviews with members of the public. Some examples are detailed below.

Interview 1 - Aron

Aron is 16 and lives at home with his dad and sees his mum regularly.

He’s been with the children’s team for five years, and it was a year or 18 months ago that his transition to adult services was first talked about, when he was 15.

He felt very supported at the time (and still is), with everything being explained clearly. They were very open and asked him how he felt, and he felt able to be completely honest. He is still with the children’s service but will move across fully soon. His father has also helped and is aware of everything that’s happening.

He was particularly happy that they “spoke to him as an adult.” He liked that they approached and talked to him in that way, it made him feel very comfortable from the outset and made him feel more adult.

He felt assured that his opinions mattered and would be taken into account. He wasn’t just presented with something that was already done and decided, but rather as something to be discussed.

As a result, he is confident that it’s “right to move on now” and wants “adult treatment as an adult.”

Overall, Aron feels that the process has been handled very well and has been consistent and clear, allowing him to get to know them and feeling comfortable about the change.

Interview 2 - Dwayne

Dwayne was diagnosed with ADHD, autism and global delay when at mainstream primary school. He experienced a great deal of difficulty in mainstream school, struggling with understanding, peer relationships and behaviour. He was finally statemented at the end of primary school which enabled him to be enrolled at a specialist school for young people with learning disabilities for his secondary education.

At the new school the facilities were excellent, and Dwayne was thriving under the supportive, suitable environment. When Dwayne was in his last year of secondary school, the school informed his mother that he was not suitable to continue into their two-year sixth form provision because they operated an 'open door' policy which his needs were too high for.

Dwayne's mother worked with the school to try and find him another specialist school which could accommodate him for the two years of sixth form education. Unfortunately, none offered him a place, and then the Covid19 pandemic hit. Dwayne's school closed its doors and Dwayne had to isolate at home; he was classed as particularly vulnerable due to also having Coeliac Disease.

The school did not provide any at home learning activities for Dwayne and his family observed a noticeable decline in the social and learning skills that he had, during the period of lockdown.

Dwayne's mother received no contact from the school or local authorities for this period, so began ringing the local authority herself to try and find out what opportunities were open to Dwayne moving forward. Each time she contacted the local authority, she spoke to somebody different, and none seemed to have any knowledge of Dwayne's situation or needs; "I spent most of the phone calls telling the person all the background on Dwayne, they all agreed that something needed to be done but none of them could give me any answers."

Eventually the local authority arranged an interview for Dwayne at a local college. However as soon as he and his mother arrived there, the interviewer told them that it was blatantly obvious that Dwayne's needs were too high for their setting and that they could not consider him. A second college was then identified by the local authority but was quite some distance outside of the family's local area. Dwayne's mother had lost her job during the pandemic and the family was on a very limited income. Dwayne's mother was told that she would need to fund his transport to and from the college each day; Dwayne's high level of vulnerability and the location of the college meant that a taxi would be the only option, which Dwayne's mother simply could not afford, and so he could not take a place there.

Since then, Dwayne's mother has received no further support from the local authority. Dwayne turned 18 two months ago, and his mother received a letter stating that he would be transferred from child to adult services. In practice this means that his care has been transferred back to his GP rather than CAMHS and he has no support in seeking educational or development opportunities. No further contact has been received from the local authority and Dwayne's mother feels that he has just been left with no input or consideration. She is "deeply disappointed" in the lack of guidance and support that the family have received and is certain that it has been to Dwayne's detriment.

Interview 3 - Kelsey

Kelsey has found the process to get her daughter's needs met extremely challenging. Her daughter has high level physical and mental health issues, as well as a learning disability. "I would like to share my awful and painful experience of a flawed and failed system. I'm still fighting to get my daughters needs met and my voice heard. No parent should ever have to go through this, and neither should our children. We want help not a battle of trying to be heard so we can get the right consistent support. Anybody that is going to go through transitioning to adult services I would be saying get a solicitor, you will be lied too, ignored, have cover ups and laws broken. The current system is a failure and is continuing to fail our families. Anyone having gone through the service system will find themselves needing mental health support after because it's exhausting having to be heard, and make sure your child's needs are met and most of all they are safe. Appalling, shocking and so unfair that those with power are being allowed to break the laws. I for one will be heard and will keep fighting to keep my daughter safe. I will be holding all responsible if my daughter dies, due to a failed system."

4.0 Conclusion

Whilst the quantitative response to this project was not so high, the qualitative response certainly gleaned strong opinions from those with lived experience of the transition from child to adult services. There were instances of apparent good practice, such in the case of Aron, where the young person felt informed and included throughout the process. However, there were also instances where young people and their families clearly felt let down and excluded from the process, indeed to the point, such as in the cases of Dwayne and Kelsey, where it was felt that there had been a significantly detrimental effect on the young person and their wellbeing.

From the participants who engaged with us, it is evident that communication is an essential requirement in the transition between services. It is imperative for the young person particularly, and their carers, to feel fully informed about timescales, practicalities and implications in changes to their support. Not facilitating this frequently results in a sense of power imbalance, where the person most greatly affected by the transition feels that they have no control or voice in matters which intrinsically relate to them. Not involving the young person in the process also by nature precludes a person-centred approach, as without their voice being heard, the process will be purely prescriptive and impersonal.

Timeliness is also crucial, with a period of preparation for the transition working well, as it allows the young person time to get used to the concept, ask questions and have an appropriate termination of their relationship with child service providers. Leaving notification of the transition until just before it is due to take place creates feelings of shock, concern and loss of control to both the young person and their carers. Timeframes need to allow for discussion, questions and adjustment.

Respondents also highlighted a lack in a joined-up approach to the process between different agencies, such as health and social care. Whilst one agency may have executed the transition for a young person well, if there is not a tandem multi agency approach, the young person cannot have the best experience of the move between services. This can

also result in lack of confidence in services by the young person and their carers, as they observe certain agencies being less inclusive and mindful of their needs.

At a time in a young person's life when many changes are occurring, the transition between child and adult health and care services has the potential to add more frustration, instability and worry to both the individual and their families and carers. The resounding consensus from our respondents is that the key to ensuring this transition is as smooth and efficient as possible lies in consistent communication and inclusion between all parties concerned.