

Integration Index Health and Care
Experience Project Report

**Young People and Mental
Health as They Become an
Adult**

March 2021



Content

Integration Index Project Information

Introduction	1
How do we get to a world that looks like this?	1
Health and care experience profiles	2

Health and Care Experience Profile 1 - National Context

What are the characteristics of this profile?	3
Rationale	3
What kind of care should people in this profile be able to expect?	3-6
What does the national evidence tell us about experiences of integrated care for this profile?	6-8

Health and Care Experience Profile 1 - West Sussex Context

What kind of care should this profile be able to expect if they live in West Sussex?	9-10
What does the evidence for West Sussex tell us about experiences of integrated care for this profile?	11-13

Lived experience of integrated care?

How we set about understanding people's lived experience?	14
Young people (and a family) told us	14-19
Chichester College survey findings	20
Focus Group's suggestions for improving support	21

Our engagement learning

Moving forward and finding solutions

Appendix A - Transfer of Care Pathway	26
Appendix B - Website information research	27-29
Appendix C - Mental Health in Schools e-Poster	30



Integration Index project

Introduction

The NHS in England wants to provide people with the best care possible. To do this it is important that hospitals, GP surgeries and community services, like physiotherapists, pharmacies and mental health services, work well together at all times.

These NHS services also have to work well with local social care services, such as care homes and care provided in people's own homes, to ensure the help people receive supports all their needs.

This approach often requires the NHS to think about the role of other public services including things like housing, benefits, transport and education. All of these things play a vital role in supporting people's general wellbeing as well as their health.

For the people receiving care it should feel like they are being supported by one big organisation which is thinking about all their needs and responding together as one.

How do we get to a world that looks like this?



The NHS has been thinking about this issue for some time, and important changes have been made already. But to know if this is working, they need to hear from people about their experiences. This is what the 'Integration Index' is all about.

The Integration Index is split into two parts which are being tested out over the next few months:

1. **The National bit:** A regular survey of people using the NHS which will ask the same questions in every area of the country. This will ask people whether they think services are working well together or not. It will help areas see how well they are doing compared to other parts of the country.
2. **The Local bit:** A number of methods for local areas to gather more detailed views from people that are relevant to that town, city or county. This will help the NHS and its local partners to understand why things might not be working well and then work with local people to fix things.



Health and care experience profiles

The profiles project being led by Healthwatch is one of the local methods being developed to help the NHS understand why something isn't working.

We are currently testing this method in five parts of the country, with five groups of people who have lots of interactions with NHS services, care support and other public or charity services.

The groups are:

- **Young people with mental health support needs who are becoming adults**
- People with diabetes who are of South Asian origin
- People with learning disabilities who have recently been in hospital
- Black men with several health needs including a recent experience of cancer
- Women with several health needs including a recent experience of a heart condition.

Healthwatch England and Local Healthwatch have used national and local user experience data and the policies which set out what sort of care people should be receiving for each of the group. This will help NHS leaders understand how well they are doing in relation to the national picture.



Local Healthwatch has spoken to a small number of people from these groups and asked them about their experiences of care. People will be asked later in the process if their experiences have improved.

Once these tests are complete, we will have a methodology which the NHS and its partners can use to find out how any group of people might be experiencing care across different services. And because we have a network of 151 local Healthwatch across the country there is a local partner in every area who can be commissioned to help.



Health and Care Experience Profile 1 - National Context

What are the characteristics of this profile?

A young person with a mental health condition(s) who is transitioning or has recently transitioned from child and adolescent to adult mental health care services.



Rationale

This profile:

- Demonstrates a timepoint in young peoples' /adults' lives where integration between services is both inevitable and crucial.
- Provides the opportunity to explore both integration between the different health services involved and integration with other relevant services and organisations including education, community support, housing and/or social care.
- Reflects a key commitment of the NHS Long Term Plan - *a new approach to young adult mental health services for people aged 18-25 [to] support the transition to adulthood.*¹

What kind of care should those within this profile be able to expect?

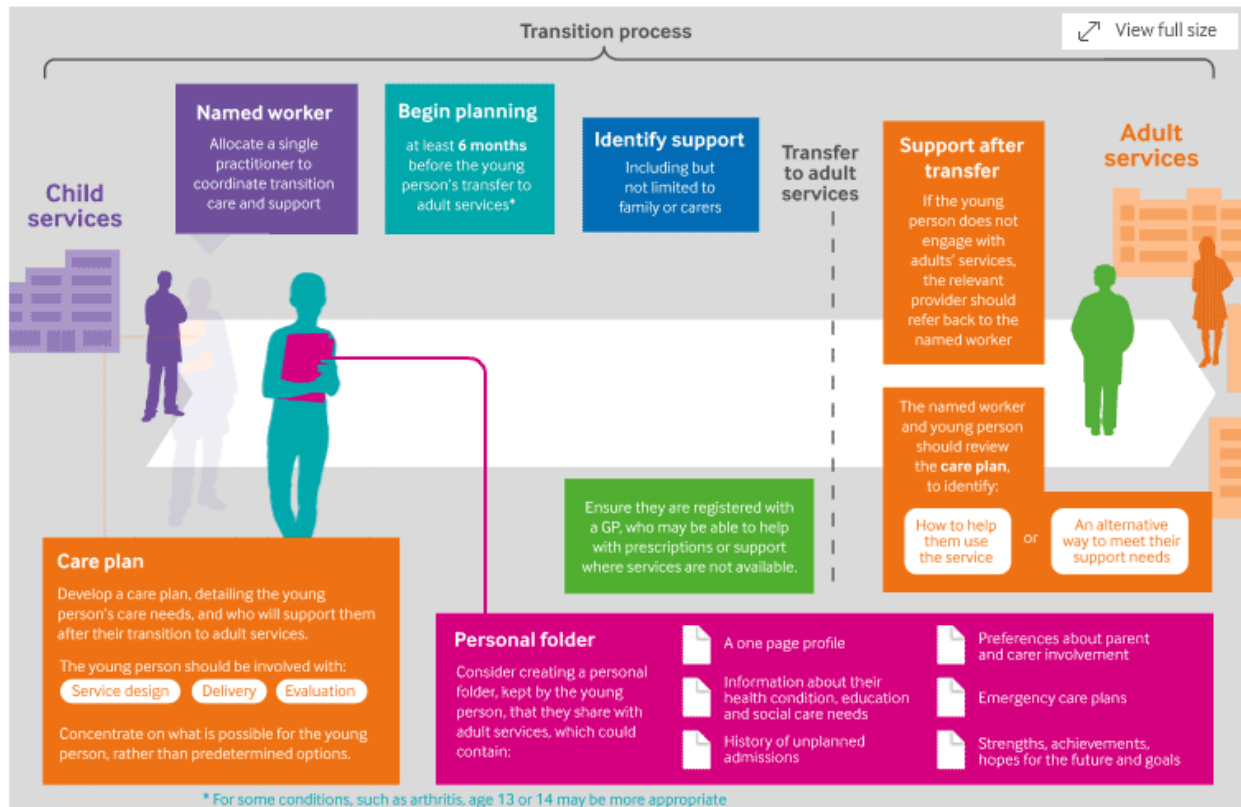
Integration of services that support young people's health and wellbeing has long been acknowledged as a critical issue during transitional care at this stage of life. There are some well-established local models for supporting and improving transition between children's and adults' services for young people with long term conditions, including mental health conditions. However, these models are usually context and service-specific, and the commissioning and delivery of mental health care for young people varies greatly across England.

¹ NHS England (2019) [NHS Long Term Plan](#)



National-level guidance from the National Institute for Health and Care Excellence (NICE),² published in 2016, is not focused specifically on mental health conditions but highlights that transition support in any health or social care service should:

- Involve the young person and their family or carers, primary care practitioners and colleagues in education, as appropriate.
- Address all relevant outcomes, including those related to: education and employment; community inclusion; health and wellbeing, including emotional health; independent living and housing options.



It also states that:

- Health and social care service managers in children’s and adults’ services should work together in an integrated way to ensure a smooth and gradual transition for young people.

More specifically, in planning the transition from children’s to adults’ services, there should be an annual meeting to review transition planning, or more frequently if needed. The outcome should be shared with all those involved in delivering care to the young person. This meeting should:

² NICE (2016) [Transition from children’s to adults’ services for young people using health or social care services \[NG43\]](#)



- Involve all practitioners providing support to the young person and their family or carers, including the GP.
- Involve the young person and their family or carers.
- Inform a transition plan that is linked to other plans the young person has in respect of their care and support.

The young person should have a single practitioner as their 'named worker' to coordinate their transition care and support. Amongst the named worker's responsibilities, they should:

- Oversee, coordinate or deliver transition support, depending on the nature of their role.
- Be the link between the young person and the various practitioners involved in their support, including their GP.
- Help the young person navigate services, bearing in mind that many may be using a complex mix of care and support.
- Proactively engage primary care in transition planning.
- Direct the young person to other sources of support and advice, for example peer advocacy support groups provided by voluntary and community sector services.

To help the young person become familiar with adults' services, service managers should ensure that a practitioner from the relevant adult service(s) meets the young person before they transfer from children's services. This could be achieved through arranging joint appointments, running joint clinics, or pairing a practitioner from children's services with one from adults' services.

Older guidance from the Social Care Institute for Excellence (SCIE)³ focused specifically on mental health service transitions for young people, reiterates the key points above that:

- Staff need to work collaboratively with other professionals and agencies; staff should know how each other's services operate in order to provide coordinated and joined-up support during transition.
- Managers should ensure that services are working together strategically; multidisciplinary services are needed to incorporate both children's and adults' mental health services, as well as voluntary sector providers, non-health agencies and GPs.

³ SCIE (2011) [Mental health service transitions for young people \[SCIE Guide 44\]](#)



- When assessing needs and planning transitions, the focus should be on the young person’s wellbeing across their whole life, including their family, friends, housing, school, college and work.

Looking forward, the NHS Long Term Plan⁴ committed to:



“A new approach to young adult mental health services for people aged 18-25 [that] will support the transition to adulthood ... We will extend current service models to create a comprehensive offer for 0-25 year olds that reaches across mental health services for children, young people and adults. The new model will deliver an integrated approach across health, social care, education and the voluntary sector.”

What does the national evidence tell us about experiences of integrated care for this profile?

The challenges experienced by young people during their transition from children’s to adults’ services are well recognised across many sources - including Healthwatch insight, other public and professional bodies, academia, and the charity sector. At this timepoint, many young people with ongoing needs disengage with services or fall through the cracks.⁵

In 2019, the Royal College of Paediatrics and Child Health (RCPCH) asked young people to share their experiences of transition from children’s to adults’ services.⁶ They highlighted six key factors needed to create a good transition process:

1. Recognise and discuss **individual needs** in young people-friendly terms.
2. Look at transition **holistically**, to include advice on: social, emotional, educational, geographical, employment, relationships and physical health.

⁴ NHS England (2019) [NHS Long Term Plan](#)

⁵ NICE (2016) [Transition from children’s to adults’ services for young people using health or social care services \[NG43\]](#)

⁶ RCPCH (2019) [Young people’s experiences of health transition](#)



3. Adult services to make social connections and have a long-term relationship with young people, to provide **continuity of care**.
4. **Multidisciplinary teams** are important and should meet regularly to prepare the young person for transition.
5. Signpost to **local services, resources and knowledge**.
6. Support young people with their **mental health**.

“My daughter was with CAMHS for her mental health for 7 years... CAMHS kept her on until she was almost 20, due to the complex nature of her mental health needs, saying they would keep her on until she transitioned to adult services.

She had a bad mental health meltdown, resulting in her wanting to kill herself. I phoned CAMHS for an urgent appointment, only to be told on the phone that she had been discharged back to the GP as she doesn't meet the criteria for adult mental health services. We went to the GP, who did an urgent referral to adult mental health, which was again rejected...

Why are young people dumped when they become adults? [...] My daughter's needs haven't changed, just because she is now classed as an adult.”

- Shared with Healthwatch England through our engagement with people across the country about the NHS Long Term Plan

Research by the Care Quality Commission (CQC) with 180 young people found that the provision of services to support their health and wellbeing were often fragmented, poorly coordinated and relied on their parents and carers to take the lead.⁷ Although this research was not specifically focused on young people with mental health conditions, CQC built on these findings in a later review of children and young people's mental health services (CAMHS).⁸ This review gathered evidence from 10 health and wellbeing board areas across England, engaging through focus groups and one-to-one interviews with over 1,300 children, young people, parents, families, carers and staff across the Health and Care Systems.

The review found examples of good practice, but also “a complex and disjointed system that produces disjointed support”, with different services and teams not always collaborating to provide a joined-up approach to the planning and delivery of care and support. Common themes identified within the examples of good practice

⁷ CQC (2014) [From the pond into the sea: Children's transition to adult health services](#)

⁸ CQC (2018) [Are we listening? Review of children and young people's mental health services](#)



included collaboration and strong communication between different teams and services, putting the young person at the centre.

The young people that were engaged with, highlighted that the transition from children's to adults' services is a key turning point in both their care and their life more generally - and as such, this time can be especially stressful. Poor transition planning was a common barrier to young people getting the support they needed; where there was no effective process to ensure the transition of their care, young people fell through the gaps. For some of these young people, this contributed to their mental health problems escalating and they had no adequate care in place.

Young people also commonly complained about having to repeat their personal narrative to multiple professionals because services had not adequately shared information with each other. For some of those who were newly engaging with adult mental health services, this meant having to undergo an assessment from scratch. Good communication and information sharing between services, along with a gradual, flexible and person-centred approach to transition were found to be key enablers of a positive move into adults' services for young people.

These findings are supported by the wider academic literature. For example, Broad *et al* conducted a qualitative thematic analysis of youth experiences of the transitions from CAMHS to adult mental health services.⁹ This work reviewed the findings of 18 studies with 253 unique service users - spanning the UK, USA and Sweden. The studies explored the perceptions and experiences of young people who received mental health care in both CAMHS and adults' services. The positive factors that were valued by these young people included having a person-centred plan for transition that adapted to their individual, holistic needs. They felt having to repeat themselves to multiple professionals was hard work - as such, they considered joint working and good information sharing between the services involved in their care to be important.



⁹ Broad *et al* (2017) [Youth experiences of transition from child mental health services to adult mental health services](#). *BMC Psychiatry*



Health and Care Experience Profile 1 - West Sussex Context

What kind of care should those within this profile be able to expect if they live in West Sussex?

Both Children and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services are provided in West Sussex by Sussex Partnership NHS Foundation Trust.

The Trust's aim is *'for all of us who work within Sussex Partnership... to deliver flexible, needs led and organised approaches, enabling young people who use our services to be fully supported during their journey into adulthood within, across and out of our services.'*

The Trust's policy¹⁰ states that, *'People who are already in receipt of services from the Trust are entitled to an ongoing duty of care and the Trust will explore all avenues for ongoing treatment, wherever this is appropriate and avoid artificial age-related divisions of care'*.

The Trust's process for *'transfer of care'* (see Appendix A) should be triggered as the young person turns 17. The lead practitioner should discuss the transfer of care to adult services (primary care, secondary care, voluntary services, transfer of care to the GP) with the young person, whilst considering their holistic needs, mental and physical health, social conditions, education and employment. This is also an opportunity to revise the person's understanding of their mental health condition(s) with them and their family.

By the age of 17.5 any agreed referral to adult mental health services should be in place and a Joint Transfer of Care Plan Review should happen no later than 3 months before turning 18. If referral is accepted by the adult mental health team, then an agreed period of joint working will start on the person's 18th birthday. We have no evidence to show if these timeframes consistently hold-up in practice, but the case study on pages 17-19 provides a better understanding of how transition periods and change impact on a young adult.

¹⁰ Sussex Partnership NHS Foundation Trust's Safe and Effective Transfers of Care (Internal & External) for Young People Using Our Services (CAMHS to AMHS) TP/CL/031



Where a referral is not accepted by the adult mental health service, then the lead practitioner would be expected to follow the Transfer of Care Pathway Out of Service or follow an escalation resolution process. Surveys exist for younger adults to complete and share feedback on their experience. However, looking at the <https://sussexcamhs.nhs.uk/get-involved/> webpage there is no reference to feedback on services and certainly no indication on how a survey can be completed.

Reviewing the public information (December 2020) available on local websites (see Appendix A) there is little information on transition from CAMHS to Adult Services specifically. That said, there were some encouraging signs that NHS Trusts might be responding to the Long-Term Plan aspirations. In particular:

- Examples of partnering with voluntary organisations better able to provide non-medical services to young adults (but this was more specific to East Sussex and Brighton)
- A strategic document 2020-2025 on the importance of improving mental health support from Surrey and Sussex Hospitals NHS Foundation Trust and Surrey and Borders Partnership NHS Foundation Trust (<https://www.sabp.nhs.uk>) for children and adults (https://surreyandsussex.nhs.uk/wp-content/uploads/2020/09/5.1b_Mental-Health-Strategy-Final-24.09.2020.pdf) but this is likely to be unavailable to West Sussex young adults

Where there was useful information, the language used was user friendly. Looking for information for coastal residents, the Western Sussex Hospitals NHS Foundation Trust's website had nothing to help, and the only link (to the Draft Sussex Health and Care Long Term Plan) was out of date. As far as we could find, there was not even signposting to Sussex Partnership NHS Foundation Trust.

Sussex Partnership NHS Foundation Trust (SPFT) delivers the CAMHS and Adult Services (such as community mental health services and acute mental health in-patient services) in West Sussex. This Trust also has an initiative for Single Point of Access (SPoAs) in East Sussex (Hastings) and Brighton and Hove, but this does not appear to be replicated in West Sussex, where there are three different numbers to call depending on geographic location. From this information it was not clear that this initiative has been evaluated or lessons learnt and therefore it would be good to understand the Sussex Integrated Care System's plans to evaluate this.

West Sussex County Council [Social care and health information for professionals, children, early-help, support for 16-25-year-olds](#) provides some information for young people transitioning to adulthood in relation to emotional support, housing and some specific 1-2-1 support but there is no reference here to mental health support. We currently have no insight into whether this is used, useful or whether local people know it is available.



What does the evidence for West Sussex tell us about experiences of integrated care for this profile?

Healthwatch West Sussex insight (from 2019) suggests that access to emotional and mental health support is difficult and once young people transition into adult services, the situation intensifies with some young people losing support overnight and on waiting lists for adult service assessments.

- There is a noticeable lack of knowledge around services, which automatically blocks peoples' access to services.
- Referrals into services are often bounced back (rejected and often not communicated back to the person/family) or lead to nothing.
- Many services have prohibitive waiting times and are often not available at the right times or their priorities effectively exclude some.

Transition stories starkly highlighted a lack of partnership working and continuous pathways, with thresholds for support changing overnight and the needs of the young person taking a back seat to the service. A young person leaving CAMHS can be told that the waiting list for assessment for adult services is 2 years with no other support or information given.

Transitions can be age related and support changes rapidly, often no one (families, young people and staff) seems aware of what can now be accessed. Other transitions come at the end of a set programme of support, and rarely offer further support or signposting.

The transition to adult services is a risk factor, with young people telling us how this increases their thoughts of suicide as their changes become even greater (moving from college to work etc., expectations of being an 'adult'), combined with the loss of the familiar support network and lack of support from adult services.

These are often the times when young people said they rely on extra support from parents. However, it can also be a time when the System makes it more difficult for parents to give this support (for example not able to make appointments, access online medical records, etc.), and many parents are struggling themselves. We heard how families have experienced financial hardship when young people turn 18, by not being told what needs to happen and when, and as a result have missed out on disability allowances.

Competition, unknown quality of service provision and organisations being happier working with what they know, potentially play a part in the segregated nature of support. It also appears that few organisations have the capacity to find out what's out there.



There has been a recognition that transition has failed families and West Sussex County Council has since developed Lifelong Services. However, more recent insight suggests that referrals into this service do not happen and for people who are not under this team there is a lack of flexibility around the use of direct payments during the pandemic.

School transition from primary to secondary has a huge impact on the mental health of young people, and there may be confusion as to what is *normal* anxiety and what is potentially more serious. Some parents rely solely on schools, with no knowledge of anywhere else. Similarly, young people told us transition from sixth form to college can be equally as challenging.

It must also be noted that the emotional wellbeing of young people is not in isolation to other areas of their life or other support services e.g. adult mental health services.

Jack, a young carer is unable to focus on his aspiration, as there is no mental health support available for his mother Emma, unless she is in crisis and ambulances are involved. The energy of teams supporting them is often directed to the parent, which is frustrating for the team and severely impacts the work they are able to do. Staff say that other services ignore their concerns and insight and aren't interested in how this impacts the family.

So, we can highlight that Emma has agoraphobia, a history of being sectioned and is struggling to do anything for herself. We know she is becoming more and more reliant on Jack, her young son. But Team B respond with 'she only needs a light touch and signposting'. We have a real fear that these situations will result in a negative spiral, impacting lives, mental health and future capabilities of young carers.

Stories shared with Healthwatch West Sussex through our engagement with people across the county in 2019

Through a comprehensive independent Sussex-wide review of children and young peoples' emotional and mental wellbeing services in 2019 resulted in the publication of the [Foundations for Our Future](#) commitment.

The independent review reported (page 98):

Services that meet the needs of young adults and provide safe and smooth transitions between children's and adult services still appear to be in the minority. The challenges faced by young people moving from adolescence into adulthood have been well documented for almost two decades.

....It is essential that we have responses and support in place to make those transitions easier for children and young people.



...The use of CQUIN (Commissioning for Quality and Innovation) has provided a helpful lever in incentivising local organization to achieve better outcomes in relation to transition. The CQUIN approach is one where NHS funded organisations can earn 1.25% extra income over and above the contracted amount as an incentive to improve the quality of care. The current CQUIN plan ends in March 2020.¹¹

The issue of poor transition can be seen in the following challenges:

- Many transitions are still unplanned and result in acute, unanticipated and crisis presentations.¹² Barriers to transition are not restricted to age boundaries. There can be differences between children's and adult services in relation to thresholds regarding acceptance criteria, professional differences and service structures or configurations that affect the transition process.
- Joint working across the two sectors is not facilitated and it does not enable a sharing of ideas and solutions. As a result, separate service development has taken place that has not properly addressed the issues relating to transition.

An improvement programme to implement, review and evaluate progress against the accepted recommendations from the review is being established, with the Programme Director in role from January 2021.

In Late 2020 Healthwatch in Sussex through community partners engaged autistic people, and those with a learning disability to understand the health inequalities and health needs, to inform the Sussex Health Strategy for Autism and Learning Disability. This work reiterates the struggles families have in accessing CAMHS. One example being that a GP has suggested to a parent to complete the referral application to CAMHS themselves, as this may be more effective. This will be their eight referral to CAMHS.

One of the West Sussex Independent Health Complaints Advocates has started to support a family with an autistic young person (under 18), who has actioned suicidal thoughts and self-harmed. Despite many attempts to access support from CAMHS the family has not been successful until the latter part of 2020. Since the assessment, and having been in crisis (with attendance at A&E) many months have passed by without any offer of appropriate support. There is no coordination and the parents are now dealing with multi agencies/assessments etc. *'It's hard to know which organisations will work and therefore we have to deal with them all'*. Currently, there is evidence of integration for this family.

¹¹ West Sussex LTP refresh October 2019

¹² Planning mental health services for young adults - improving transition, Appleton, S. Pugh, K. NMH DU/NCSS 2010



Lived experience of integrated care

How we set about understanding people's lived experience?

A focus Group event was advertised widely through social media (Instagram, Facebook and Twitter) and via a network of voluntary and community organisations, as well as through the local authority.

Despite this, we had a low uptake with only 7 people registering for the event, despite there being a participatory £25 gift voucher on offer.

The event took place as planned on 6 February 2021.

We have since worked with different youth centred organisationsto understand what may have put young adults off from participating in this event. We have included this in our learning.

We followed up the focus group event by working with Chichester College Group. Together we are running a staff survey to look at the most current situation (against the finding of the Foundations for our Future work).

Here is what young people told us

- **Understanding self-esteem**

It was clear from discussions with the participants and young people who had expressed an interest , that **low self-esteem** is an issue and this makes it hard to talk in group settings.

This is an important area for both engaging young adults with mental health concerns and also when working with those who are transitioning to adult services or out of adolescent support.

I would disagree with being involved in the planning of my care when I was younger, but since turning 20 I feel more confident to be involved and converse better with the therapist and that I can agree/disagree with things. Previously, I had confidence issues and didn't know how to say no.

The situation was that I went into (mental health support) when I was 17. At first, I only had my GP and it was a 'cloudy' situation. They didn't know where to put me. I ended up self-referring to talking therapy. A few years later I had to self-refer again and it felt like I had to keep repeating myself.

Help improve mental health care for young people aged 17 to 25

Have you used young person's mental health services in Sussex?

Tell us your experiences of these services to help the NHS make moving to adult mental health care work better.

Your experiences will help the people who plan and provide mental health services locally make sure that they understand what matters to you.

And it will support a national project to improve young people's mental health care.

Join a small online workshop

on Saturday 6th February 2021, 10.30am - 12.30pm

This will be run by one of our experiences project workers. Or you can have your say one-to-one over the phone.

You'll get a £25 Amazon thank-you voucher.

How to join

Call or text Kat on:
07967 327 257

Email:
katrina.broadhill@healthwatchwestsussex.co.uk



www.healthwatchwestsussex.co.uk

healthwatch
West Sussex



- **Recognising health literacy and offering time/information to help with understanding support**

It was suggested that GPs need to have ‘deeper conversations’ with young people who present with mental health concerns so that they gain a sense of supported understanding of their needs. There needs to be more conversations about different interventions and how they could help.

I didn't know what was good for me or understand what was on offer. It's also a difficult time to process things and it felt like there was so much pushed on me.

It felt like I was in the dark a lot of the time and there wasn't a clear plan. I was too shy and reserved to say I needed more assistance to be able to get into more help.

Similarly, there appears to be an assumption that care leavers will understand the boundaries in which personal assistants/support workers operate. This leads to frustration, mistrust and a sense of worthlessness, all of which could have been avoided if the professional had taken the time to explain.

For example: what is meant by being a ‘guarantor’. (We described this in a conversation with a young adult who then recognised it would not be appropriate for a worker to risk having to pay out of their ‘pocket’.)

With a variety of consultation methods available to GPs, those making appointments must recognise they need to ask young people what is the best way for them to talk to a healthcare professional, e.g. face-to-face, on the phone or via a digital platform. For some, virtual platforms offer the distance they need but for others, this would not work.

I remember how anxious I was contacting the doctors. I had the idea that I wasn't ‘feeling sick’, not physically sick. I'm fine - but I don't feel fine? I don't need to go to the doctors for feeling sad, as it would be wasting their time for something that wasn't physical.

- **Importance of support in educational settings**

One participant said they had been left feeling ‘angry’ at the lack of support and intervention from their school having experienced group bullying which led to a decline in their mental wellbeing. This was despite parents raising concern with the headteacher.

A lack of professional curiosity as to why the student was regularly in tears is unacceptable and has left them feeling that teachers **need more education on recognising when a student is in trouble**. In this person's experience, the bullying was happening in front of heads of year and was still ignored.

It has been recognised in West Sussex, by the Youth Parliament that there is a lack of mental health literacy, understanding of support and a need to address the route of stigma. To this end, the Youth Parliament are facilitating a webinar for



young people to explore these issues. The aim being to find out what young people want going forward. One of the areas that could be explored is how teaching in schools can support students to recognize deteriorating in mental wellbeing.

I recognise that teaching is a hard job and that they have a lot on their plates but when its something quite obvious then it should be realised.

The legacy of this experience continues into adulthood. Megan* told us that they attempted a university course but their mental health was too bad to continue.

There was also a big gap in the communication and the conversations she had with school and with the GP. She recognises that in her situation there would have been a positive impact if there had been a clearer communication path between them.

The system needs to recognise that it can feel intimidating to speak to adults/teachers/professionals. Young people have told us that there is a need to be supported informally by someone with empathy who is relatable and closer to them in age. In one example it was the person's older brother who recognised the mental difficulties and support needs they had and he was there to support them in accessing support.

- **Impact of starting over again and again**

'Filling in the gaps' was described as much better than having to start from scratch with each new service or professional. Under 18s experienced having to restart from the beginning of their history when accessing a service and *it was very hard and difficult to cover it all.*

Small steps, for example, professionals need to reassure a young person that it is OK to talk about their experiences at their own pace and not to worry if they miss out information at this stage, would have worked better for one participant (due to confidence) as they struggled to get all the information across and there were times they felt they didn't get the support needed because they could not articulate the situation.

It's very difficult during transition periods to experience and pass on the information so professionals understand what is going on when you are still going through it!

- **Availability of support**

A participant described being without support for about 4 months in 2020 because of staff sickness. Their support worker has 25 young people under their care and during their time off there was a lack of communication from the service.

Previously, the service had provided them with a worker who was supportive and motivating. However, staff turnover and absence have since negatively impacted their health. This has left them with the sense of only just existing. They have found support from [Esteem](#) beneficial.



The system needs to work together with young people to find out how they feel and what fulfilment they need to be supported.

One of the participants has experienced COVID and found this very hard as they were alone and suffering. They have recently tried contacting the GP service but gave up after being on hold (using their phone allowance) for 15 minutes without getting through. They were not aware of e-Consult but were keen to look at this as a way of getting access to primary care.

Connie's Story

“Connie superficially fits in. She looks like all the other girls. She is top of the class, but won't speak and masks effectively when outside the home, hiding her true difficulties. Because she can conform she's not getting the help she needs. Her intelligence gets in the way. She may be getting top marks but no one sees the anxiety driving this and the vicious circle it creates.”

Connie is due to go to Uni in September. She turns 18 in July.

Connie is highly anxious and can become suicidal. She has severe OCD, emetophobia and perfectionist and autistic traits. She was referred by her GP to local CAHMs for diagnosis and in May 2018 was referred to the level 2 autism assessment pathway.

“The referral initially was fairly quick, about three months for the initial appointment. We were told that the wait for the assessment would be about a year.”

However, it is now March 2021 and nearly three years on they are still waiting.

For Connie, puberty tipped the balance and made her mental health worse. The family has been struggling to get her help since she was 12. The Education Psychologist Connie saw initially said she was “*too bright*” [to be autistic] and refused to refer her to CAMHs.

Since her eventual referral to CAHMs, Connie sees a psychiatrist every four months for a medication review as she is prescribed Setraline which is not licensed for her age. However, she has seen four different psychiatrists in three years. Connie found it easier to talk to the female psychiatrist who has been providing cover during the pandemic and built up a good relationship with her. However, she is now on [long-term] leave. Connie clams up with the male doctors. However, they were not offered a choice in this. During COVID, support has been patchy, with appointments occurring on zoom. As Connie engages better in person, this has not been ideal.

Connie is highly intelligent and masks beautifully. She is excelling in school since moving to [secondary school named] where they have a good pastoral support system.



Connie's mum felt that she had to take Connie out of school and home tutor pre GCSE due to her high anxiety and lack of support from the school - ***“they were all about numbers and achievements.”*** [New school], where she is doing her A'levels is more supportive and has put counselling in place.

“It's been horrendous! I've had to fight for every bit of support for her. I've had to swap schools for her which has been good as [name] school has been great in supporting her needs unlike [original] school that were awful!”

Connie hasn't got an Educational Health Care Plan as is academically brilliant, but socially she is very anxious with few friends. [Current school] has made provision for this social anxiety e.g. her speaking and listening exam was allowed to occur with a small group of peers that she is comfortable with rather than with the whole class.

The pandemic has suited Connie in many ways as she can avoid people. She is currently excelling with school work but socially has ground to a halt and her OCD has become significantly worse (e.g. pacing and moving furniture to allow a clear path, closing shutters, food date checking and not eating non-uniform food). She previously had intensive CBT for her OCD (handwashing) to which was effective and has meant that this aspect of her OCD has not reoccurred, despite the current focus on hand hygiene. However, she has also become very germ-phobic and is very worried about returning to school.

The uncertainty around exams and schools reopening has increased Connie's anxiety levels. Her OCD has increased and she isn't eating. She is frightened of returning to school.

Her mum has spoken to CAMHs about the situation.

Connie's mum is proactive in enquiring about the autism assessment waiting time - she regularly asks about the waiting time, e.g. at appointments with the psychiatrist and rings the Autism social communication team.

Different people e.g. one of Connie's psychiatrists, have tried to push the appointment forward but the system doesn't let it happen.

“About a year ago, the psychiatrist said that a private company was being employed to address the backlog of people waiting for assessment but this didn't happen.”

Impact

The delay in getting a diagnosis is having a significant impact on Connie and her family. They are fearful of her not having the right support in place for University. Without a diagnosis, this is unlikely to happen.



Without support, Connie is likely to burn herself out with her perfectionism. The greatest fear is that she will become suicidal again. It feels she is being set up to fail without the diagnosis. After nearly three years since the initial referral, nothing has been put in place for Connie, and they feel no closer to getting a diagnosis and support.

Connie needs reassurance and constantly asks her mum, “*will it be ok by September?*” But her mum can’t answer. This increases her anxiety and is extremely distressing for her mum.

Stress and anxiety levels are rising for both of them and having the autism assessment and subsequent support would help alleviate at least some of this.

Connie doesn’t want anyone to know that she’s autistic and will not ask for help. She will never willingly share information.

Transition to adult services

I asked Connie’s mum whether any planning had happened for transitioning to adult services - she said there has been nothing and wasn’t aware that there should be.

One psychiatrist took the time to ring them before taking extended leave to reassure them that when Connie was transferred to the adult autism assessment waiting list they wouldn’t have to go back to the beginning. But this is the only conversation about the transition that has occurred. They also don’t know if Connie will still have to see a psychiatrist as her medication can be managed by a GP once she is 18. There has been no other conversation re transition into adult services or to a new area.

They are also worried as care will transfer to an unknown team in a new area when Connie leaves for Uni. To help mitigate this, she has chosen the Uni closest to home that offers the course she wants to do so that if she can’t cope she has the option of commuting.

Connie’s mum is concerned that in a new area, Connie may shut down and ignore appointment letters without her being there to support her.

What they would like to see.

“Assessments need to be timely. This process started three years ago and we’re still waiting.

We need the right support in place. She needs to be assessed in person. She wouldn’t engage online well.

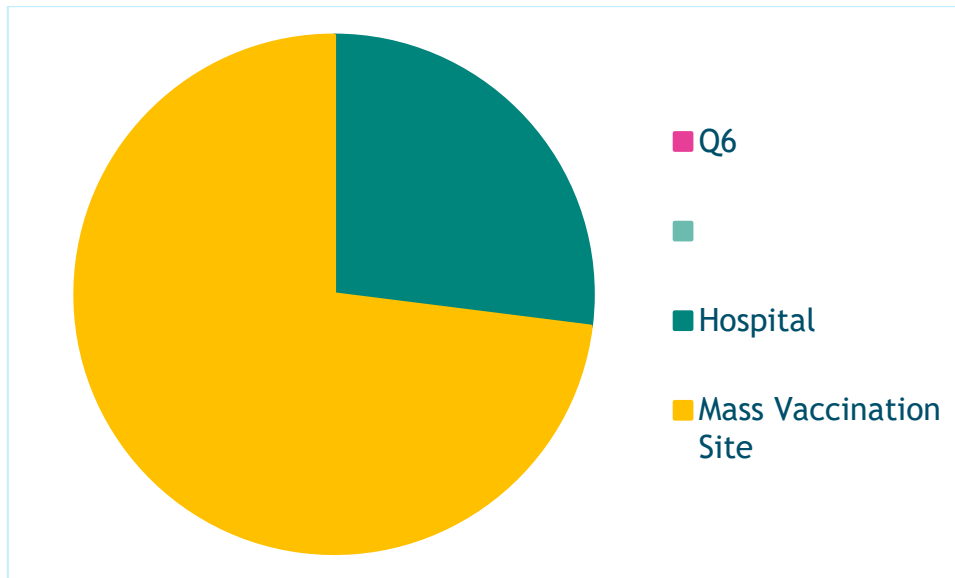
I want Connie to be ready [for Uni] and happy. For that, we need the diagnosis and support. It’s got to the point where it feels like it’s never going to happen”.Speed up!!!!!!!!!! Stop fobbing people off!!!!”



Responding to question about transfer of care

As at beginning of March 2021, 29 Chichester College staff have responded to the following question:

How have the young people or families you know experienced the change from children's services to adult services when they reached 18?



79% of the respondents who have worked with young people or families when they are transferring care to Adult Services reported with negative comments.

The comments provide some useful insight:

- *Often they went from having a designated person working with them to not having anywhere to go too when they needed help. They've felt helpless.*
- *Difficult. Again services over subscribed. Parents do not know how to access and are scared by Adult Services.*
- *No consistency with social worker. Care packages cut.*
- *They feel abandoned and desperate. They feel like they have started the process all over again because the young person is now considered an adult.*
- *This can be a bit tricky, as not all services that they have attended are available in the same format when entering adult services. This can have an impact on their social, emotional and mental health/wellbeing.*
- *Services seriously change when students turn 18. There is far less to access and no one ever available to give you advice and support.*
- *Overall, I feel that young people feel they have been dropped by children's services and are now waiting for adult services. The transition is often not smooth and ends with the young person having time without support. It is also hard to support this in college because student tutors do not support students 18 and above, and without an EHCP they are not a priority or given additional support. Our counsellors are often not able to take them on before they reaccess services. It then falls on the safeguarding team.*



Suggestions for improving support

Conversation Cafe

Your ideas for improvements? – use text boxes / chat function

- clarity
- difficult not knowing what will happen
- active conversation
- reassurance
- uncertainty is horrible
- need to know exactly what will happen and plan B

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- Through care leaver stories, it appears the foundations to support adulthood are missing. No one is explaining how systems work and this is leading to misinterpretation and decreased mental resilience.
- There needs to be clarity on what is happening and going to happen for the young adult through active and ongoing conversations, particularly for those with low self-esteem. *Anxiety needs certainty!* Conversations need to include - *if that doesn't happen, we've got this plan to back it up.*
- It was suggested that young people with low esteem need to be asked more questions (active conversations). Professionals need to ask questions about how the person feels about something, e.g. a treatment decision, and find ways of opening up the dialogue so that the young person doesn't default to passive decision making.
- It is important to know that a person is there to listen/support and have contact details.
- There needs to be more education in school about mental health - especially 15-16 year-olds. Students need to be made aware of their feelings and what to do with them to help people recognise the signs in themselves.
- Peer support is needed, so that young people accept its OK not to feel OK and that they are not alone. (Megan suggested a programme of peer support in schools, referring to this as a Big Brother Programme would be beneficial, particularly for those who are struggling with their mental health, but are not aware of the decline).



- Websites need clear and transparent information about pathways and support so that young people, parents, schools etc. know what to expect and can refer to information when they need to.

Important engagement learning

Challenges of attracting young people to participate

Information inviting young people to engage in the focus group was shared widely on social media and via support agencies. Despite offering an incentive of a £25 Amazon voucher, we had limited up-take from young people wishing to engage.

We have discussed this with various youth organisations since the focus group and are aware that consultation fatigue is a significant issue at the current time, particularly for certain groups of people. People are exhausted by spending time on screens and there is a sense of “*what’s the point*” when frequent consultations happen but change is not always seen.

The subject matter may have prevented young people from engaging with that particular format, and a choice of engagement, e.g. one to one conversations with additional support or email/text conversations may have been more appropriate.

I’d be happy to discuss my mental health with one person but not in a group. (Young Person without support, March 2021)

It has been suggested that recruiting to future focus groups may be more successful if agencies that support young people were involved in recruiting and offering support to the young person afterwards. A choice in incentive may make engagement more appealing.

Challenges in achieving participation

- Focus Groups may not be the most appropriate way of engaging young people who have valuable insight and experience, and it’s important to offer alternative ways for young adults to contribute. For this reason, time and resources need to be dedicated to such engagement.
- An ex-care leaver who now lives in a residential setting wished to participate in the online focus group but found it was using too much of their data allowance. This raises the question of why the person did not have access to WiFi from a private space?



What worked well

- Working collaboratively with [Concordia](#) has meant we have a workshop/focus group format that is age-appropriate, supportive and dynamic in enabling participation.

We would like to thank Victor, who designed and facilitated our events.

- The event concluded with an opportunity for the participants to reflect on the design and content of the workshop/focus group.



A screenshot of a presentation slide. At the top left, a purple bar contains the title 'Mad Hatter' in white. To the right of the title is a heart icon with a speech bubble inside. The main content consists of two bulleted lists. The first list has three items: 'I've been feeling useful – 1 to 5', 'I've been feeling closer to other people – 1 to 5', and 'I've been able to make up my own mind about things – 1 to 5'. The second list has three items: 'Something I heard during the session that will stick with me is...', 'I am still wondering ...', and 'Having done this session, I now feel ...'. At the bottom of the slide, there are two logos: 'healthwatch West Sussex' on the left and 'concordia Live. Learn. Experience.' on the right. A small '30:16' timer is visible above the logos. Below the slide content is a video player interface with a play button, volume icon, and share icon. At the very bottom, a Windows taskbar is visible with various application icons and a search bar.

Knowing that this will help someone will stick with (participant). I feel I'm not very useful and not doing something most of the time. I'm definitely going to have a good day because of this.

This has charged my batteries and I feel energized. I feel much better than I thought I would - especially because its in the morning!



Moving forward and finding solutions....

We've been working with National Citizen Scheme graduates throughout the pandemic to a) understand experiences and issues for young people and b) to get them exploring solutions.

We are delighted to be presenting to you their ideas so far.

Your challenge is what will you do with them? #childrenfirst
#foundationsforourfuture



Date:

To whom it may concern,

Our NCS Local Action Group in Crawley have recently been discussing issues within our healthcare system, that have arisen due to the current Covid-19 crisis. Upon discussion, we found that many of us felt that the systems in place to cope with mental health problems in young people were not efficient and more could be done to improve this.

As a school, all of your students rely on staff to look after their wellbeing at such a vital time in their lives, when mental health problems often occur. However, when we asked students, many felt that the support in place at schools was not effective or helpful. They felt that there was a stigma within schools that made them feel they could only seek help when stressed about exams and that any other reason for issues with mental health was often overlooked.

While the NHS is an option for those seeking help regarding mental health, many feel that unless the problem is acute, it is disregarded and so, we want to produce a better system in order to reach all students struggling with their mental health and ensure they get the help that they need. To do this, we would like your help in order to create a better system within schools.

Firstly, we feel that there should be better education within schools covering all aspects of mental health and proper training for teachers on how to proceed when a mental health issue with one of their students does arise.

We also think it would be best to bring in an external professional to be the main counsellor within a school because students often find it easier to talk to a professional when they are not linked to them in some other way and so feel that they can talk in confidence. This also allows the school to be aware of any ongoing mental health issues with their students, without having to ask them and can still give them the support they need which feels less invasive than the interrogation-like interviews. Not only that, but by having one main counsellor, students will have the same person for each session, giving them continuity when they are struggling, which can make all the difference in being able to open up and trust the professional.

This professional should feel more like a peer than a staff member and as a result, we feel that they should communicate firstly with the students before their parents, only talk to parents of children over 16 with their consent (or with reasonable evidence that they're putting themselves or someone else in danger), a less formal consultation where it is easy to simply chat to the worker and rather than having the end goal as just a diagnosis, have it as becoming a healthy individual again.

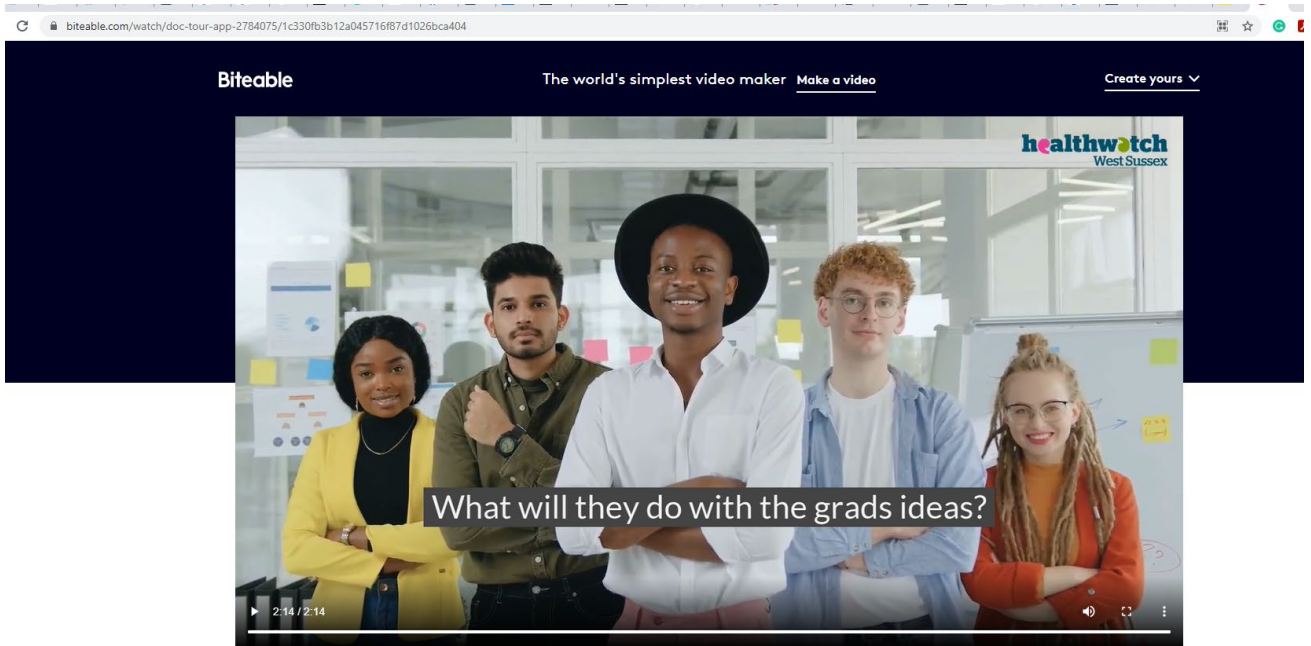
Finally, we think that these services should be made widely available to the whole school community regardless of age, gender, sexuality, and class. In order to make sure this happens, the services should be advertised on posters around the school as well as on the school's social media.

Yours Faithfully,

NCS Crawley



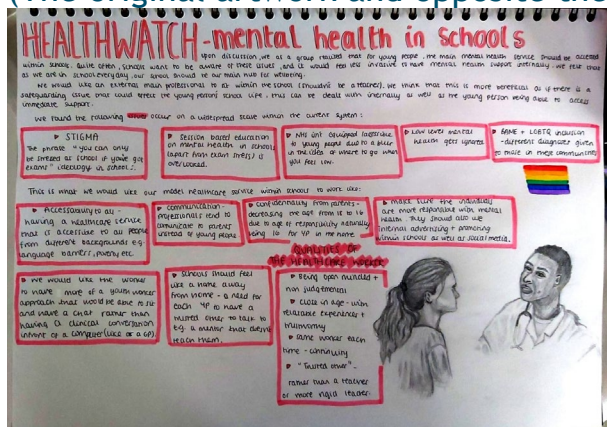
Please take the time to watch their short [pitching a concept presentation](#).



Doc Tour App

Please see Appendix C for the poster these graduates designed to challenge the system to rethink how it delivers mental and emotional support to young people.

(The original artwork and opposite the final product).



Mental Health in Schools

We had a discussion with some National Citizen Service graduates about accessing healthcare; whether there were any barriers and what they thought could be solutions. The graduates independently developed their ideas and created solutions to the barriers they'd highlighted.

These are their thoughts and valuable suggestions:

- Upon discussion, we as a group realised that for young people, the main mental health service should be accessed within schools.
- We would like an external main professional to sit within the school (shouldn't be a teacher).
- Quite often, schools want to be aware of these issues, and it would feel less invasive to have mental health support internally. We felt that as we are in school every day, our school should be our main hub for wellbeing.
- We think that this is more beneficial as if there is a safeguarding issue that could affect the young person's school life, this can be dealt with internally as well as the young person being able to access immediate support.

We found the following **issues** occur on a widespread scale within the current system:

- Stigma**
The phrase "you can only be stressed at school if you've got exams" lingers in school.
- Session based education on mental health in schools (apart from exam stress) is overlooked.
- Low level mental health gets ignored.
- IHS isn't equipped or accessible to young people due to a blur in the idea of where to go when you feel low.
- BAME & LGBTQ inclusion - different diagnoses given to those in these communities.

This is what **we would like** our model healthcare service within schools to look like:

- Accessibility to all - having a healthcare service that is accessible to all people from different backgrounds e.g. language barrier, poverty etc.
- Confidentiality from parents - decreasing the age from 18 to 16 due to age of responsibility naturally being 16 for young people in the home.
- Communication - professionals tend to communicate to parents instead of young people.
- Make sure the individuals are more responsible for their mental health. They should also use internal advertising and promoting within schools as well as social media.
- Schools should feel like a home away from home - a need for each young person to have a trusted other to talk to e.g. a mentor that doesn't teach them.
- We would like the worker to have more of a young worker approach that would be able to sit and have a chat rather than having a clinical conversation in front of a computer (like at a GP).

Qualities of the healthcare worker:

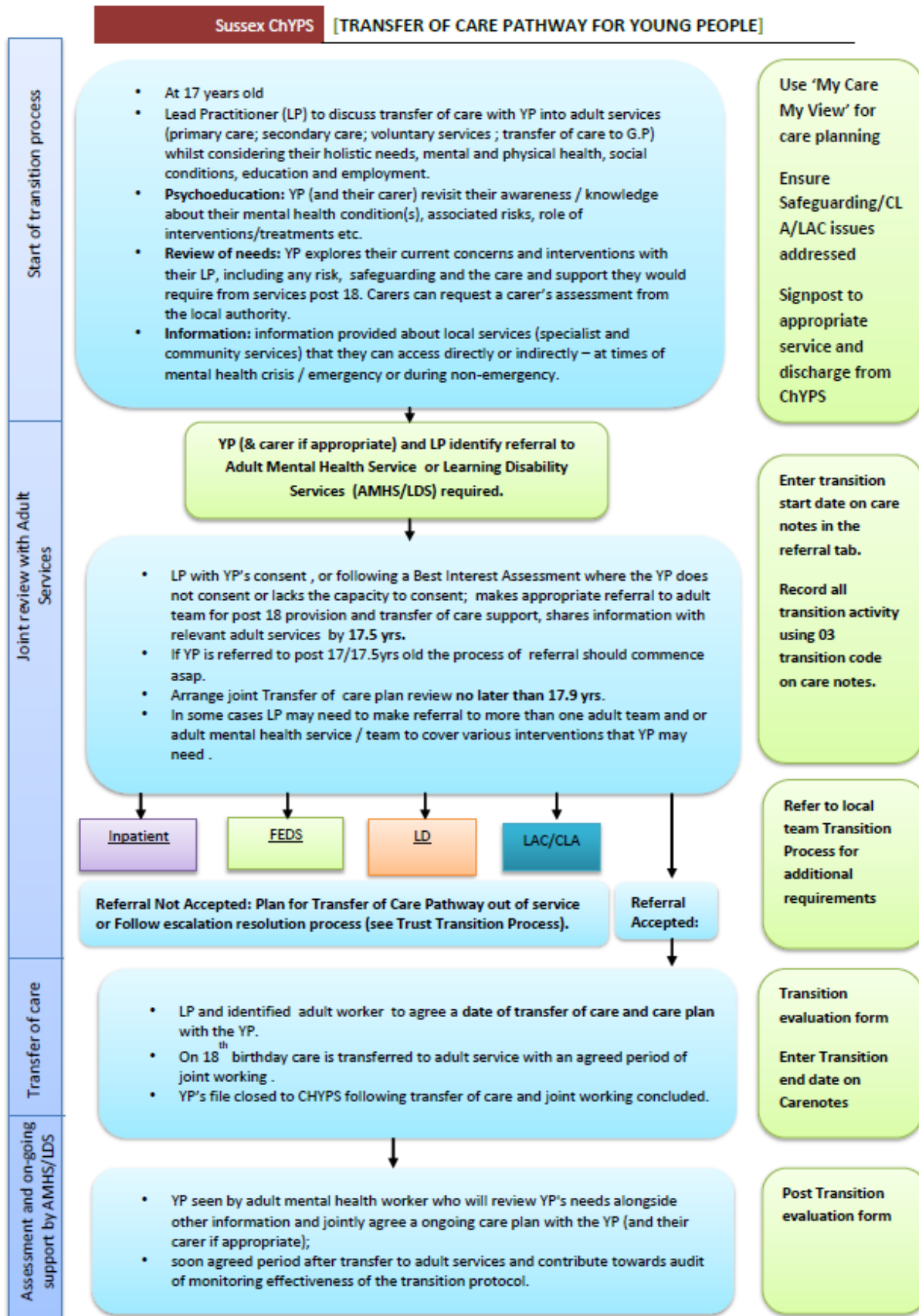
- Being open minded and non judgemental
- Close in age - with relatable experiences and trustworthy
- Same worker each time - continuity
- "Trusted other" - rather than a teacher or more rigid leader.



Image shared by NHS Local Action Group. Design of this document inspired by NHS Local Action Group.



Appendix A



Appendix B

A Volunteer Researcher was asked to adopt this *health and care experience profile* as a *mystery shopper* and to do a web-based search for information on integrated care for a young adult with mental health needs transition to adulthood in Sussex.

Methodology/Action: Search term, followed by Search Results (*direct quotes in italics*)

1. “Joined up care”:

SPFT <https://www.sussexpartnership.nhs.uk/stp>

SHCP (STP) <https://www.sussexhealthandcare.uk/priority/mental-health>

Strategic Framework for MH services <https://www.sussexhealthandcare.uk/wp-content/uploads/2018/03/170929-MH-strategic-framework-vF.pdf> written in 2017

The aim was to help determine how the voluntary sector, local authorities and NHS can work better together to meet the needs of the patients, carers, families and local communities we serve.

2. “Sussex CAMHS”:

<https://sussexcamhs.nhs.uk>

<https://sussexcamhs.nhs.uk/help-support> A free phone Mental Health Line for initial signposting. The telephone number may have changed from 0300 to a freephone 0800. Not all websites have been updated, although the 0300 number still works.

<https://www.sussexpartnership.nhs.uk/sussex-mental-healthline>

Various leaflets with Personal Support Plan being the most relevant for this project

<https://www.sussexpartnership.nhs.uk/patient-information-leaflets>

https://www.sussexpartnership.nhs.uk/sites/default/files/documents/care_programme_approach_-_easyread.pdf

3. “SPFT / transitioning”:

nothing relevant to West Sussex other than the e-wellbeing

The only link was to a press release dated June 19

<https://sussexcamhs.nhs.uk/news/hastings-drop-in-centre-for-young-people-receives-funding-to-increase-opening-hours-copy>

Viki Ashby, Local Transformation Plan Project Manager for Sussex Partnership’s East Sussex Child and Adolescent Mental Health Services

<https://www.sussexpartnership.nhs.uk/irock#locations-list-3806>

i- Rock Locations = Hastings, Eastbourne, Newhaven



i-Rock is a place where young people aged 14-25 can seek support for things including mental health, wellbeing, housing, employment and education. A partnership service led by *Sussex Partnership NHS Foundation Trust, East Sussex County Council and the three East Sussex Clinical Commissioning Groups (CCG's)*, the project works closely with a wide range of third sector providers including *Sussex Community Development Association (SCDA), Southdown Housing, Youth Employability Service and Counselling Plus.*

BUT: this leads to other news items/links

Press Release Oct 2019 The East Sussex Single Point of Advice (SPoA) launched last month. The new service arrangement, when mental health staff joined the existing County Council team, allows referrers to make one referral to the SPoA, who triage the referral and identify which service would be most suitable for the needs of the individual. The simplified referral route eliminates the need for multiple referrals to a number of organisations and services, and most importantly helps children, young people and families to access the right support for them in a timely way. <https://www.sussexpartnership.nhs.uk/east-sussex-spoa>

Sept 2020 Brighton and Hove CAMHS - Community Wellbeing Service launched as a central triage hub <https://www.brightonandhovewellbeing.org>

West Sussex CAMHS - 3 different points of contact, one each for Chichester, Worthing and Horsham

<https://e-wellbeing.co.uk/> run by YMCA Downslink with Sussex CAMHS. List of all the organisations (including voluntary organisations) to contact on front page (see Load More). Then by region.

West Sussex <https://e-wellbeing.co.uk/services?loc=west-sussex>

4. “SASH Mental Health”: information is not clear if this includes West Sussex residents

<https://surreyandsussex.nhs.uk/about-us/mental-health-strategy>

Strategy for 2020-2025 Summary at

<https://surreyandsussex.nhs.uk/wp-content/uploads/2020/10/Mental-health-V10.pdf>

“For people of all ages” Various pledges including, for example, “I do not have to keep repeating my story to get the help and care I need”

Includes an example of Integrated Health Care Page 10 in Summary

October 2020 workshops over one week with Surrey and Borders Partnership NHS Foundation Trust (SABP)



<https://surreyandsussex.nhs.uk/ideas-energy-and-optimism-improving-our-services-together>

Re CYP: 6 Goals on pages 5-6 in full report. https://surreyandsussex.nhs.uk/wp-content/uploads/2020/09/5.1b_Mental-Health-Strategy-Final-24.09.2020.pdf

E.g. Goal 6 = *“By 2028 we aim to move towards service models for young people that offer person-centred and age-appropriate care for mental and physical health needs, rather than an arbitrary transition to adult services based on age not need”*.

Researcher’s comments: Well defined strategy, so easy to monitor progress. **But:** no mention of when, or importantly, how, progress will be monitored or evaluated.

5. **“WSHFT”:** nothing of any help that researcher could find, not even a link to SPFT.

6. **Other:** Every Mind Matters Campaign <https://www.nhs.uk/oneyou/every-mind-matters>



Appendix C



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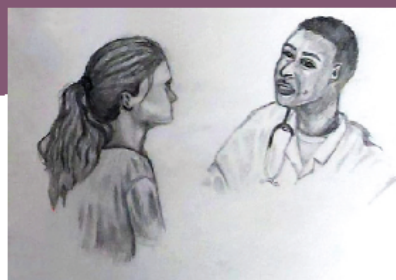


Image above by NCS Local Action Group. Design of this document inspired by NCS Local Action Group.

Cara - can you please divide as Caroline suggested. An show the poster on two pages.

Talk to us

If you have questions about the content of this report, please either call 0300 012 0122 or email katrina.broadhill@healthwatchwestsussex.co.uk

How this insight will be used?

We recognise that all health and care services are under pressure at this time and have had to adapt their ways of working. We will share this report with the local NHS, local Government, and other providers to help them understand where things are working well and services are adapting to meet peoples' needs, and to help them identify any gaps. We see this as a continuation of discussions taking place and will continue to use this fresh insight and the solution ideas presented to challenge for a better future.

For help, advice, and information or to share your experience

We are the independent champion for people who use health and social care services. We're here to find out what matters to people and help make sure their views shape the support they need.

We also help people find the information they need about health, care and community and voluntary health and care support services in West Sussex.



Here to help you on the next step of your health and social care journey

We have the power to make sure that the government and those in charge of services hear people's voices. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them.



0300 012 0122



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@NHSadvocacy



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