

Putting the Pieces Together:

An overview of people's experiences of CAMHS services
in Brighton and Hove



The Aim of the Research

Brighton and Hove CAMHS (Child and Adolescent Mental Health Service) provides young people with a wide range of support around their mental health and wellbeing. The service is arranged into tiers, which are commissioned across a range of organisations. CAMHS workers can be based in schools as counsellors or health visitors, out in the community working with families, or in hospitals and centres based around the needs of the young person. The Brighton and Hove CAMHS team is based at the Aldrington Centre in Hove, and it received 1532 referrals in 2013 alone.

Over the past year Healthwatch Brighton and Hove has been hearing talk of dissatisfaction and frustration from parents, young people, and voluntary and community sector organisations about the local CAMHS service, which has led us to look into it in more detail. Whilst a range of statutory organisations were aware that there were some concerns about CAMHS, there seemed to be a lack of an in-depth knowledge about specific issues and how they could be improved. For this reason, Healthwatch Brighton and Hove has gathered a range of recent research from public and third sector organisations, and reviewed their themes to create a clear overview of issues and suggestions for improvements. Throughout we have also included the voices of young people and those who support them on a range of key subjects.

Special thanks to Mind Live¹ for sharing the findings of their recent focus group, and to Amaze² for sharing their work on the topic. Thanks also to all those who shared their experiences directly with Healthwatch, and to mASCot³ for their input.

¹ Mind Live <http://www.mindlive.co.uk/>

² Amaze <http://amazebrighton.org.uk/>

³ mASCot <http://www.asc-mascot.com/>

Getting Started

One of the key ways for young people to access to the CAMHS service in Brighton and Hove is to get a referral from their GP. Young people between 16-18 years old have previously been told that they are too old to enter CAMHS services, but too young to be included in adult mental health services. It seems that some GPs are confused about the referral pathways and where to send young people once they near the age of transition between services. This could result in some young people never reaching the services they need to contact, leaving them in a vulnerable position. People also felt that some GPs had little understanding of autism and mental health, which made referrals and diagnosis more challenging processes.

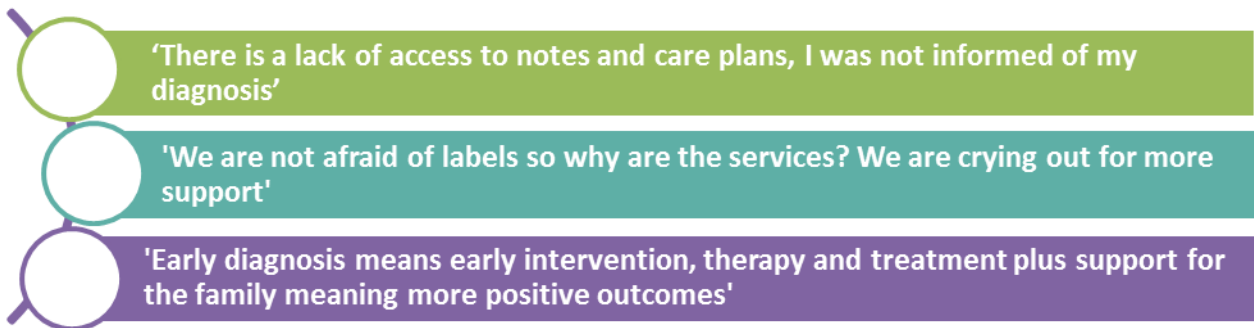
Once the service is accessed, young people and those who support them can feel daunted by the complexity of the service and their place within it. Aside from the emotional impact of being referred to mental health services, the information that is provided to them about the service itself seems to be minimal. People have said that they did not know what they could expect from CAMHS, what their rights were within the service, or where they could go to for extra support in a crisis situation.

- ‘No information about my rights as a client; I didn’t know I could change workers’
- ‘My GP wasn’t helpful when I’ve been at the end of tether, just told ‘keep going’, doing really well’ and ‘get on with it’
- ‘I would like to know more about the availability of different therapies. I was only offered CBT, but would have preferred art therapy’

Those who use CAMHS would also like to see more information about relevant community and voluntary sector organisations that can provide additional activities, support networks and events to improve wellbeing. These activities can complement the support offered by CAMHS, and can potentially provide more respite for parent carers.

Diagnosis

For the majority of young people, a diagnosis can offer a way of understanding behaviours and symptoms, and can open the door to better management of their issues in conditions in the future. However, due to the complex relationships between our local CAMHS organisations, some people have experienced multiple diagnoses, or not being informed about their diagnoses at all.



Many people have experienced professionals who seemed reluctant to give a diagnosis, feeling that this would label the young person. Some young people had diagnoses ruled out as possibilities for them, but the assessment was not carried forwards to find a positive diagnosis. Sometimes young people and their parents found out that they did have a working diagnosis on their case, but that this was not shared with them when it was first confirmed. Some parents that we spoke to sought private diagnosis and treatment for their children after experiencing diagnosis within CAMHS.

Mixed Messages



I felt as though the CAMHS service did not listen to my son and me at various points during our time with them. We have received mixed messages about his diagnosis, with his GP, specialists, a dual diagnosis specialist and CAMHS naming different conditions that they thought he had. CAMHS felt that he had Emotional Intensity Disorder (previously known as borderline personality disorder) but we were then told that this was not a diagnosis, but a term they use. CAMHS wanted to do away with diagnosis at this time saying it was merely 'labelling' and thus stigmatising young people; yet without a diagnosis, no treatment plan is put into place, hence no benefit or positive change.

Diagnosing Autism



I am aware that the Government is conducting a Parliamentary Select Committee Inquiry into the UK-wide CAMHS failings, but I think the national interest doesn't excuse our local problems. When CAMHS failed to diagnose my daughter's autistic condition, I had to push for a second opinion before she was finally diagnosed. I felt like they did not know how to engage well with children, and had no understanding of autism as a condition.

My other child has severe anxiety, and despite an urgent referral form from the paediatrician we were not supported, and as a result I am now having to source private assessment and support. If the Consultant Lead Psychologist and Autism Spectrum Disorder Care Pathway lead for the region cannot diagnose autism accurately, there is little hope for any but the more severe cases in getting recognition and support for their condition. The amount of higher functioning autistic children out there without a diagnosis because of the issues with CAMHS must be significant.

A Good Therapist


The importance of a longstanding and trusting relationship between a therapist and the young person they are supporting has been highlighted as a particularly important element of care for young people. In light of this, it is important that from the outset a regular therapist is allocated, and that if the current therapeutic relationship is not working, the process for selecting a different therapist is clear and unstigmatized.



Seeing the same therapist for 3 years, sometimes weekly, enabled me to really develop trust and open up



Continuity was very important. I saw a counsellor for 6 years who got to know and understand me and the situation



It was positive that CAMHS never gave up on me at the beginning and continued to help me for two years. Staff always arrived at appointments and if they needed to be changed, they contacted me in advance.

Impact on Parents

Parents often reported feeling blamed for their children's behaviours and conditions through general staff attitudes towards them, or because they were asked to complete a parenting skills course. When parents asked questions about processes behind things like diagnosis or raised concerns, some felt that they were labelled by CAMHS staff as being over protective or attention seeking. The four formal complaints made about the service in 2013 related to staff attitudes.

Many parents said that non-judgemental counselling sessions were more beneficial than the parenting skills lessons offered. This appeared to be particularly effective when the focus was around the parent's feelings, the impact of being a carer on their wellbeing and building resilience for themselves and their child. As one parent said; 'they dealt with my issues, rather than my parenting skills'.

In times of crisis, some parents felt unsupported if the emergency with their child happened out of office hours. With local A&E waiting times under pressure, and other resources such as the Sussex Mental Healthline orientated around adult mental health and signposting, some parents felt that they did not know where to turn when there was an emergency.



Treated with Suspicion

We are not the only family that they have failed. I am in contact with lots of local families in similar situations. CAMHS are unfit for purpose, and are often leaving vulnerable children unsupported whilst spending their time in correspondence with other professionals that blame parents for their children's behaviours. I feel like there is no respect for parents, and that we are usually treated with suspicion by the service.



Counselling Success

I was not sure if I wanted counselling but it really helped pull me out of a prolonged period of feeling depressed. I had some really negative feelings about looking after my disabled son, and I needed to stop thinking so negatively. Abbie from Seaside View Development Centre was amazing, and it really helped us as a family.



We went private

We usually came into contact with CAMHS services at times of crisis, and I did not find it helpful. Despite saying something was wrong from when he was in year three, it was assumed that the issues were a result of my parenting or something I was doing to him. He was not properly assessed until I managed to find a solicitor and went private, after which time he was diagnosed with a range of complex mental health issues.



Reaching out during a crisis


I have called CAMHS over a period of three days in a distressed state without hearing back from them or giving out any other numbers to call. It is not just the child suffering but family and friends as they see the distress and acting out but feel they can do little to stop it. During times of crisis, it has felt like the emergency assessment team were laughing at me as I told her I was distraught with worry not just about my son and his state of mind, but because I felt a failure and powerless to deal with this alone. Parents themselves often feel like failures, and sometimes when things aren't properly explained by CAMHS they feel like more power is being taken from them.

Moving on from the service


Young people who followed the service until completion felt that when their contact with CAMHS ended, the transition to adult services could have been much more planned and organised. Some experiences included a young person who missed a therapy session when they were approaching the end of their support, the service having assumed that they had left for good, and no other support being offered. Other experiences include therapy sessions finishing in mid flow with no sense of closure or moving on for the young person.

With little or no information about adult mental health services, many young people lose touch with support that is available to them during the transition. Some young people also move away to university or to different homes, making it harder still to keep informed about adult mental health options.


It has been established that a consistent and positive relationship with a therapist is considered important to young people using the service. A transition to adult services represents a movement away from the security and familiarity that this sort of relationship represents, and leads them into the unknown. Without comprehensive support to help young people through this transition, the attrition rate will continue to be high. Teen to Adult Personal Advisers (TAPA) are now available to young people to help with this transition.



I missed my last appointment as unwell and was sent a letter saying they assumed I didn't need services anymore. No signposting or information was given (after 3 years in services). It has now has been big struggle to get support.



I felt CAMHS should have referred me long before I was 18, so it would all be sorted when I turned 18. I feel I have just been left with nothing. I went from 5 years of support to nothing at all...



Transition was a letter to adult service. I was offered an assessment but dropped out of this when I went to university. There was no handover to my new area and trying to get back into services was very hard.

Conclusions and National Direction

Many of the key themes that have been established locally were also found to be notable issues nationally. The most recent national discussion of CAMHS was in the House of Commons Health Committee Meeting in July 2014⁴. It was acknowledged that the way services are commissioned is confusing and challenging to monitor effectively. With various tiers of the services provided by Brighton and Hove Council, Sussex Partnership Foundation Trust, local schools and community and voluntary sector organisations, this trend fits with our local picture. The meeting also picked up on the issue of transition from child to adult services, GP training in helping young people with mental health issues and our of hours service provision.

With similar issues locally and nationally, the approach moving forwards and addressing these issues is similar. A general attitude of empowerment for young people and those who support them would be valuable in getting them involved in care choices, and owning the treatment/support which is provided to them. This includes better links with community and voluntary sector organisations, which can provide additional support, wellbeing activities and respite. There is also a call to extend and unify the ages in which the services are available to young people. National discussions are currently looking at 12-25.

There are a number of practical recommendations below which can improve information sharing and empowerment for young people and those who support them.

⁴ Last discussion held 15.07.14 <http://tinyurl.com/oxtlfcl>

How to improve the service

1. Send a clear memo to GP practices in Brighton and Hove, informing them about the services that are available and how to refer to them appropriately
2. That when a young person enters CAMHS services, they receive an information pack which includes an explanation of the service, their rights around changing therapist or making a complaint, what is expected from them, and a list of community and voluntary sector organisation which offer support to young people with mental health issues.
3. Review diagnosis procedures to ensure a more multi-disciplinary team approach, which includes the young person and their carer(s) as often as possible.
4. CAMHS should review their assessment criteria to meet the needs of children with wide ranging symptoms mild impairments on the Autism Spectrum.
5. Prioritise having a consistent therapist for young people, and allow them access to information about how to request a change of therapist if the relationship is not developing.
6. Review the effectiveness of parenting skills courses verses therapeutic interventions for parent carers, and adjust the service accordingly.
7. Make sure young people and those who support them are aware of all the current crisis options, and review the out of hours support available to see if there are gaps.
8. Create a comprehensive policy around transition to adult mental health services, which includes A formal hand over of notes, a plan for transition to be acted on, and a reminder of extra resources available during this difficult time.

Further Reading

For young people

- [Young People's Guide to Transition](#)- Young Minds
- [Unhappy with treatment?](#) - Young Minds
- [CAMHS in Brief](#) - Royal College of Psychiatrists

For their parents and carers

- [Guide to Transition for Parents and Carers](#) - Young Minds
- [What you need to know about CAMHS](#) - The National Autistic Society
- [CAMHS Information for Parents and Carers](#) - NHS Choices

For professionals (Best practice and professional development)

- [Quality Networks for community CAMHS](#) - Royal College of Psychiatrists
- [Transitions in Mental Health Care](#)- Young Minds
- [CAMHS Handbook 2013](#) - Norfolk Council
- [Services for Children with Autism Scrutiny Panel report](#)- Brighton and Hove City Council
- [Headspace Australia](#) - National Youth Mental Health Foundation

The Commissioner's Responses

General Response

Brighton and Hove Clinical Commissioning Group (CCG) and Brighton and Hove City Council (BHCC) welcome this report as a foundation/ platform for improving the emotional health and wellbeing to the children and young people in the City. Whilst we know there are pockets of good practice across the City and across all services, we also know that the whole system does not necessarily work well together. Improving mental health and wellbeing is a key priority for the CCG and BHCC.

The emotional health and wellbeing of children and young people and support of their families/ care givers for the population of Brighton and Hove has a broad scope from universal services such as GPs and Schools and Colleges, right up to specialist inpatient services (as depicted in the bullet points below):

- Tier One - universal services (GPs, schools for example);
- Tier Two - offers targeted help for children at risk with emotional, social, behavioural and mild/moderate mental health problems, within their local community or own home. This is provided by the Community CAMHS team and also a range of Voluntary Sector organisations;
- Tier Three - local specialist community and outreach services provided locally by Sussex Partnership Foundation Trust; and
- Tier Four - regional specialist day care and inpatient care, Chalkhill in Haywards Heath, commissioned by NHS England.

This scope is reflected in our recent Mental Health Strategy (*Happiness: Brighton and Hove Mental Health and Wellbeing Strategy*)⁵. The responses in this report reflect that wider scope.

There are many forums across the City, currently focussing on improving the services for children and young people. All of these forums will help the CCG to understand the current service provision for children's and young people's mental health, where the gaps are and how to improve provision where required.

⁵ Brighton and Hove Mental Health and Wellbeing Strategy <http://tinyurl.com/kjec8po>

At present the CCG is taking stock of all the local feedback received, information gathered and reports published as well as the national strategic direction to ensure we fully understand people's needs and how services are currently configured and provided prior to any change. From the feedback we have received so far, from children, young people, families and carers we recognise there is an issue in terms of CAMHS and we intend to undertake a strategic review to inform a new model of care for the City.

Over the next 3 years we intend to work with key stakeholders to improve the model of care for children and young people.

Year One 2014/15

- Receive and review feedback from users and families/ caregivers; and
- Develop action plan as a response to feedback.

Year Two 2015/16

- Undertake a JSNA/ Needs assessment for children and young people's emotional health and mental wellbeing;
- Some immediate service improvements, for example ensuring sufficient support for children, young people and their families/ carers in crisis and in particular out of hours;
- Review of all services providing support to children and young people with mental health and emotional health and wellbeing needs, especially transition to adult services;
- Work with key stakeholders to develop new model/ pathways (consultation and engagement and co-design); and
- Start to roll out improved model.

Year Three 2016/17

- Roll out improved model.

It is the intention of the CCG to continue to involve children, young people, families and caregivers in any service improvements and developments so that we get it right for our users. It will take time to ensure we have full involvement. The review and any changes are likely to take place in 2015/16. In the meantime there will be some smaller changes

that we can implement to improve the services, and some of these are outlined in the response boxes below.

Specific Responses

1. Send a clear memo to GP practices in Brighton and Hove, informing them about the services that are available and how to refer to them appropriately

It is important to note that tier 2 and 3 CAMHS take referrals from a variety of referral sources, not just GPs. Last year (2013/14), for example tier 3 CAMHS received 1771 referrals for Brighton and Hove of which 846 were from GPs (48% from GPs). Other referrals come from self-referral, Schools and Colleges, other health providers as well as the voluntary sector and Children's Services.

For those children and young people who have already been in the tier 2 and 3 CAMHS system this includes self-referral back in and a response within 7 days.

The CCG strives to ensure that Primary Care/ GPs are informed of services that are available for children and young people with emotional health and mental wellbeing issues. This includes:

- Information for them on our CCG website about how to refer to CAMHS;
- Training for them from the Right Here project and MIND;
- Information for GPs to understand the young person's perspective on accessing their GP surgery, again through the Right Here project <http://tinyurl.com/lq38hmp>; and
- Training that AMAZE parent group has done with GP surgeries in understanding the parents' and child's journey.

We recognise that we don't ensure that GPs have access to the full range of rich information about how to support children and young people with their mental health needs and it is our intention to change that immediately. We plan to clarify the referral processes and pathways for our GPs and other referrers into the CAMHS service, provide better and more detailed information about other services available using tools already developed, such as, the interactive map `where to go for` developed by Brighton and Hove Youth Collective. <http://www.wheretogofor.co.uk/>.

We are also trying to establish a Primary Care professional to be present at Youth Advice Centre, to bridge the gap between `drop in opportunities that young people favour and the formal Primary Care services. This should also help us understand reasons for young people not wanting to go to their GP and work with young people to change that.

2. That when a young person enters CAMHS services, they receive an information pack which includes an explanation of the service, their rights around changing therapist or making a complaint, what is expected from them, and a list of community and voluntary sector organisation which offer support to young people with mental health issues.

The CCG recognises that it is important that children, young people and their families/ care givers have clear, accurate and consistent information at each stage of their pathway through services. They also need to understand who they have been referred to and why and what to expect from the service. Although there are some good examples of how to do this, we know this can be improved and wish to continue to work with our providers to ensure users of their services have clear information about services, how to access them and what to expect when receiving those services.

- There is a web based information service that has been developed (see link below) aiming to give people information about what they need to know about CAMHS. <http://mycamhschoices.org/>
- The MIND Brighton and Hove website provides details for children, young people and their families/ carers on services available and how to access them. <http://tinyurl.com/m7yfe9m>
- Young people, family/ care givers can also access an interactive map `where to go for` developed by Brighton and Hove Youth Collective <http://www.wheretogofor.co.uk/>
- We also have information on prevention and promotion of mental health wellbeing on the 5 ways website www.brighton-hove.gov.uk/thefiveways
- There is also a Sussex wide Mental Health support line that offers advice and information to children and young people in difficulty. <http://tinyurl.com/m37xvgb>

We recognise that this information may not be known about or easily accessible and intend to develop a communications plan to address that.

3. Review diagnosis to ensure a more multi-disciplinary team approach, which includes the young person and their carer(s) as often as possible.

All services strive to work with children, young people, and their families/ carers and include them in the planning of their care. The best practice is to do this in a multi-disciplinary way with multiple professionals as required⁶. We intend to involve children and young people and their parents/ carers in the development of any future models of care, drawing on their experiences to improve the system.

It is important to recognise that people shouldn't need a diagnosis to have a treatment plan. Due to the developmental nature of children and young people, not everyone fits into a diagnostic category as children and young people change over time. Best practice suggests access to a service and support should not be just based on diagnosis but also on need.

It is important that we develop services around need and not around a label. This may mean the criteria for services has to change to respond to need, for example, impact on daily living, significant difficulties with peer relationships, hyperactivity, marked preference for routine and difficulties in adapting to change.

One potential way of framing this is by considering formulation. Formulation is the process of making sense of a person's difficulties in the context of their relationships, social circumstances, and life events. It is 'a process of ongoing collaborative sense-making' Unlike diagnosis, it is not about making an expert judgment but about working closely with the child and family/ caregiver to develop a shared understanding which is likely to evolve over the course of the therapeutic work. And, again unlike diagnosis, it is not based on deficits, but draws attention to talents and strengths in surviving what are nearly always very challenging life situations⁷

4. CAMHS should review their assessment criteria to meet the needs of children with wide ranging symptoms mild impairments on the Autism Spectrum.

⁶ Putting Participation in to Practice - Young Minds <http://tinyurl.com/oujqhpd>

⁷ Formation: The Psychological Alternative to Diagnosis - Clinical Psychology and People <http://tinyurl.com/qc4q6qm>

Following the Scrutiny Panel review of services for children and young people on the Autistic Condition Spectrum (ASC), a set of recommendations have been made to the Panel. A working group has been established and an action plan is currently being developed. Tier 2 and 3 CAMHS will review their services according to that action plan.

The ASC training programme for schools, including parents, as well as the development of ASC-friendly schools continues to be rolled out across the City.

5. Prioritise having a consistent therapist for young people, and allow them access to information about how to request a change of therapist if the relationship is not developing.

All services that provide support for children and young people with emotional health and mental wellbeing across the City aim to ensure a consistent therapy through the course of the treatment. If the presentation changes, other professionals may need to be involved.

The Choice and Partnership approach is applied in tier 2 and 3 of CAMHS, whereby children and young people are given a choice of appointment for their initial assessment where they agree the treatment and next steps and which professional is or professionals are best to support the treatment and need. Treatment is carried out using evidence based partnership working⁸.

Information about these processes will be addressed as part of the information pack that will be made available to users and also the communications plan being developed.

6. Review the effectiveness of parenting skills courses verses therapeutic interventions for parent carers, and adjust the service accordingly.

The treatment plan that is agreed with the parent/carer should be based on agreed decision making and partnership and also on best evidence-based practice. A range of support can be offered, such as mindfulness groups, anxiety support, emotional regulation groups as well as parenting courses.

⁸The Choice and Partnership Approach Website <http://www.capa.co.uk/>

A parenting course is one method of support for a parent who has a challenging situation. All children are different and therefore sometimes need differing approaches.

The Positive Parenting Programme is backed up by 30 years of research. The programme provides parents with simple and practical strategies to help them confidently manage their children's behaviour, preventing problems developing and building strong, healthy relationships⁹.

We will continue to review, with providers, the interventions used and ensure they follow best evidence-based practice.

7. Make sure young people and those who support them are aware of all the current crisis options, and review the out of hours support available to see if there are gaps

The standard response time from tier 3 CAMHS (Sussex Partnership Foundation Trust) is to provide a first contact response to urgent referrals within 4 hours. This applies to referrals within or outside of normal hours. There is a Sussex wide Mental Health Support service that provides help and advice at all times out of hours <http://tinyurl.com/m37xvgb>

Other crisis services include GP (and out of hours GP services), 999 or 111, A&E and the Urgent Help Team (until 8pm 7 days per week).

The CAMHS Crisis Resolution and Home Treatment service (CRHT)/ Urgent Help service adds to existing packages of care for children and young people with acute mental health needs in an intensive way by providing 3-5 contacts per week over a time limited period of 4-8 weeks in order to maximise the coping resources of the child or young person and their support networks. The service provides intensive intervention to young people and their families and carers who require intensive support to continue to maintain their caring relationship with their child in a community setting. The service operates 0900-

⁹ Positive Parenting Programme Website <http://www.triplep.net/glo-en/home/>, Brighton based Talks <http://tinyurl.com/l8afnjq>

2000 weekdays with a weekend service in order to meet crisis and home treatment needs during this period.

The CCG recognises that perhaps this information is not easily available and that people are unaware of how to access services in a crisis. We will work with the providers to develop a communication plan to rectify this.

The CCG recognises that there is a potential gap in support for children and young people in mental health crisis and hopes to work with providers and users to understand the need and subsequently develop a service that is 24/7 with a clear pathway and access points. We aim to implement this new service in 2015/16.

8. Create a comprehensive policy around transition to adult mental health services, which includes A formal hand over of notes, a plan for transition to be acted on, and a reminder of extra resources available during this difficult time

In common with young people with long term physical health conditions, the transition from adolescence to young adulthood for young people with mental health problems requires individualised health care planning. This should recognise the wider health, social, psychological, educational and vocational impact of a young person's medical condition(s) within a developmentally appropriate culture of care. There are some policy drivers supporting this change including the Children and Families Bill 2013 (for example the Birth - 25 Education, Health and Care Plan), Children (Leaving Care) Act 2000 and the Children and Young Person's Act 2008.

Locally, the CCG and the Local Authority recognise this is a key area where change is required, and intend to work together and with our providers to ensure this is addressed, which will include a formal transition policy and look at evidence based models of best practice from other areas to inform the development of models of care for young people up to the aged of 25.

Transition is a process undertaken over time and should be based on the individual's readiness to transfer to adult services.

Young people who do not meet the threshold for adult mental health services may be best supported by primary care or the voluntary sector, or may be discharged with a clear plan which tells them and their families what to do if they become unwell.

Transfers require coordinated, documented and integrated support plans for young people and their families/ carers from all health services involved in their care and in partnership with other multi agency providers (e.g. education and social care).

We already have examples of good practice in the City where the transition from children's service to adult services can be achieved more gently, such as the voluntary sector organisations that offer their drop-in, information and advice and counselling services up to 25 year olds, and also in the CCG commissioned Early Intervention Psychosis service where support is offered up to 35 years old.

In Brighton and Hove we also have the Teen to Adult Personal Advisors (TAPA) is a young person's mental health service (14-25 years) provided by SPFT in partnership with Sussex YMCA, Impact initiatives and Allsorts to meet the mental health needs of young people across the city who are `hard to reach`. They use an assertive outreach approach that is holistic and person-centred which means they will meet with, engage, advise and support young people wherever they feel most comfortable.