



## **Mental Health and Wellbeing Services for Children and Young People with Special Educational Needs and Disability (SEND)**

***'Focus needs to be on prevention to stop people getting to crisis'***

**March 2019**

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### **1. Executive Summary:**

#### **Overview**

This report focuses on the experiences of families with children and young people with SEND accessing Mental Health and Wellbeing Services in Brighton and Hove. This consultation was organised at the request of the CCG to link with the Sussex & East Surrey Sustainability & Transformation Partnership (STP)'s 'Population Health Check'. Leading doctors, specialists and clinicians from the local area have looked at data, clinical evidence, patient experience and local knowledge and given a diagnosis of what most needs to change across the health and care system from their expert point of view to ensure people continue to get the care they need in the future. The STP identified five priority areas including Mental Health and Wellbeing in order to develop a 10-year plan, which will look at how to resolve those challenges and how to make services more sustainable.

Mental health and wellbeing, and access to support services for children and young people with SEND, is a priority for parent carers so we have carried out various consultations in recent years around this topic, and this report builds on those.

We are mindful that a significant amount of time and focus has been put into developing an improved service offer for children and young people's mental health and wellbeing in Brighton and Hove over the last three years (since the Transformation Plan 2015) and Amaze and PaCC reps have been active participants in the Partnership Group to oversee this progress. Work has included the procurement of a new Community Wellbeing Service (CWS) and a Schools Wellbeing Service (SWS) as well as a service redesign of the Specialist CAMHS service. As such, we asked parent carers to focus on their experiences of accessing current Mental Health and Wellbeing services in the last 3 years and how they would like to see these services developed further.

Despite these changes we have become increasingly concerned at the level of negative feedback that we have been hearing from the community of families with children and young people with SEND about their access to, and provision of, services to support their children's' (and their own) mental health.

**This suggests that the changes and availability of services that have been rolled out over the last three years are still insufficient to meet rising levels of poor mental health amongst children and young people with SEND.** Amaze staff and PaCC reps have talked to a number of parents where either they or their child have expressed significant levels of dissatisfaction, lack of support and crisis, and in some cases even suicidal thoughts.

Whilst the severity of the problems reported, both about mental wellbeing and access to services, seem to be increasing for our community of families, some of the issues, and suggested recommendations are the same as they were when we reported on this topic in March 2014 and June 2016. This is particularly frustrating to see. We appreciate that people who commission or work within mental health and wellbeing services for CYP will no doubt share this frustration, but it leads us to our first recommendation (see below).

Amaze and PaCC Reps attend the Children's Mental Health & Wellbeing Partnership Group. They have been key partners in feeding in parental views and suggestions to the Children and Young People's Mental Health and Wellbeing Local Transformation Plan for Brighton and Hove (2015-2020).

The findings from this report align with the development priorities identified in the updated Transformation Plan and therefore provide useful insights and suggestions.

The CCG receives an annual uplift of funding to be spent on children's mental health associated with the Children and Young People's Local Transformation Plan. In 2019/20 for example the uplift is £103,000. The CCG will prioritise this additional resource going to:

- Improving the neuro-developmental pathway;
- Improving access to services when in a mental health crisis requiring an urgent response
- Improving mental health support for vulnerable children including Looked After Children

Some findings from this consultation also align with issues relating to the assessment and diagnosis of, and support for, neurodevelopmental disorders that were highlighted in the business case within the CCG around a neurodevelopmental conditions pathway and have been explored by BHCC and partners following the Right Pro open letter <https://www.brighton-hove.gov.uk/content/children-and-education/local-offer>

We hope these will be used to inform ongoing service development plans, local CCG commissioning priorities, implementation of the NHS 10 year plan, the STP-wide review of CYP Mental Health and Wellbeing Services and the national Commission for Equality in Mental Health call for evidence.

Prior to publishing this report, we gave the CCG and providers the opportunity to review the content and their initial response to each of our recommendations can be seen in the text boxes below (from page 4). We have asked for an opportunity to explore these in more depth at a meeting with senior colleagues soon.

### Main findings of SEND families:

- 14% of parents thought Mental Health and Wellbeing services had slightly improved in the past 3 years and only 2% reported a marked improvement. 44% felt services had not improved at all and 40% responded neutrally to this question.
- 100% of parents are dissatisfied with the service the Child and Adolescent Mental Health Service (CAMHS at the Aldrington Centre) are able to provide.
- The majority of parents reflected on negative experiences, especially around how families are kept informed about referrals and the waiting times for services. 78% families would like to be able to access services when they need them
- Waiting lists and scarce provision of services are seen as key challenges to accessing support. Parent carers feel that the system fails children and young people by not providing support quickly enough when needs have been agreed. Families commented that the system continues to focus not on prevention but on crisis
- 67% families identified a need for more joined-up and better co-ordinated services, communication and follow up between providers, so that the onus is less on parents to chase updates and next steps. Linked to this 63% parents would prefer not to have to repeat themselves to different service providers during assessment processes and 54% believe their needs would be more fully understood by seeing the same healthcare provider consistently.
- 38% families had resorted to paying to access private counselling services, (but of course many cannot afford this option)
- 73% of parents reported that they had accessed local Mental Health and Wellbeing services for their child or young person, whilst 23% accessed services which are not local. Transport provision and the time it takes to travel are the main barriers to accessing services that are not local.
- 61% families want to be able to receive support at home or in the community as suits their needs.

### Update on Current Waiting Times for Services:

To supplement our findings, we thought it would be helpful to add the latest data on the actual times and associated targets for how long children and young people are waiting for assessments and treatment from each service area, please see below:

<b>Schools Wellbeing Service</b>	Assessment should be within 5 school days (currently 100% in secondary schools)	Treatment should start within 10 school days (currently 100% in secondary schools)
<b>Community Wellbeing Service</b>	Assessment should be within 20 days of referral (currently 38% meeting this)	Treatment should be within 20 days of assessment (currently 61% meeting this)
<b>Specialist CAMHS</b>	Urgent assessment should be within 4 hours (100% met).  Priority assessment should be within 5 days for priority referrals (82%)  Routine assessment should be within 4 weeks of referral for routine (47%)	Priority treatment should be within 2 weeks from assessment for (83%)  Routine treatment should be within 8 weeks from assessment (93%)

This data shows that many children are waiting longer than the set target for the CWS and for routine support from specialist CAMHS. We would like to suggest these are used as a benchmark to assess whether access to these services improves over time.

The providers are also collecting and monitoring outcomes of treatment and experiences using the same tools and scores. Each service will provide an annual outcomes and experience report at the end of 2019/20 as part of the national expectation.

### Our Recommendations:

- I. **For senior colleagues at the B&H Clinical Commissioning Group and B&H City Council to read this report and consider the severity of feedback, particularly in light of high levels of self-harm and other mental health disorders in the city, and a sustained lack of confidence over recent years in the capacity of CAMHS and Wellbeing services to meet the needs of local children and young people with SEND. To consider that for children and young people with SEND there are often associated, and complex, mental health and wellbeing issues so to agree this group should be prioritised for support.**

#### CCG and providers' response

The CCG and providers (Specialist CAMHS, Community Wellbeing Service for Children and Young People, and Schools Wellbeing Service) have reviewed the report. We would like to thank all contributors for their time and honesty. The CCG recognises that this is a subjective report however; this important content and feedback will form part of commissioning and service improvements.

Many of the improvements to children and young people's mental health over the last 3 years have focussed on general needs. This includes a re-design of Specialist CAMHS to improve access and waiting time targets, robust links with Primary Care, Schools and Social Care as well as Community Wellbeing Service, and increasing the capacity for outreach. The Community Wellbeing Service provides a central hub for mental health referrals and more capacity to support mild to moderate mental health needs including an appropriate response to children with neuro-developmental conditions. The Schools Wellbeing Service investment has enabled target support to children with the school environment working with the autism team within Brighton and Hove Inclusion Support Services.

The CCG recognises that the next phase of improvements and transformation need to take into account the specific needs of children and young people with SEND presenting with mental health/ emotional wellbeing difficulties. This will include:

- A re-commission of the Children and Young People's Community Wellbeing Service (new contract by June 2020) to address known gaps including access and SEND;
- A bid to be a Wave 2 Trailblazer (Sept 2019) for mental health in schools which will ensure a more equitable provision across our City with specific focus on special schools and needs of vulnerable groups such as SEND; and
- Continue to develop further improvements to the neuro-developmental pathway.

Specialist CAMHS will continue to develop and support neurodevelopmental services based on more joined up partnership working across the City with particular focus on joint working with the Child Development Centre on the autism assessment and diagnosis pathway.

The Community Wellbeing Service is committed to taking the views of parent seriously particularly in reference to SEND provision. Previously, service managers have attended the PaCC coffee mornings in order to understand the concerns of parents and carers in the City who access our service. From these meetings Wellbeing has further developed and improved the service based on the feedback given.

The service also recognises that there are valid concerns around waiting times and capacity. The Community Wellbeing service continues to liaise with commissioners to address these difficulties. Both service and commissioners are aware there are potential gaps in service provision for SEND children and young people and recently held a stakeholder meeting with the aim of discussing and identifying service gaps and improvements. PaCC representatives joined this meeting and the findings will influence future commissioning arrangements.

- II. **For senior colleagues to consider these recommendations alongside the 'Future Developments' section in the 2018/19 Transformational Plan Refresh and agree to (re)establish/(re)clarify the priorities that need to be addressed and set clearer/SMARTER outcomes for what improvements are expected, how these will be achieved and by when. This needs to include how waiting times for assessment and treatment can be shortened.**

CCG and providers' response

The CCG is obliged to refresh and publish the Children's Mental Health Local Transformation Plan each year. The next refresh will be due in October 2019 and will take into account the themes and issues in this report.

- III. **For the system to prioritise improving communication and co-ordination, including better listening to parents as experts in their families' needs and changing the culture at levels regarding attitude towards families. Parents need clearer information on service pathways, sharing of information across providers and regular updates on referrals and waiting times for services. This needs to include us receiving feedback about what is going to be done in response to this report, specifically in the style of a 'You Said, We Did' response from the CCG to SEND parent carers.**

CCG and providers' response

The CCG and Community Wellbeing Service recently invited the NHS England Improvement Support Team (NHSE IST) to review the service. They made a series of recommendations that has resulted in the establishment of a small but system-wide task and finish group to address their suggestions. One of the main improvements will be to provide clarity on thresholds and criteria for each part of the system as well as more clear information for parents/ carers on what to expect and how services will stay in touch.

The plan is to complete this by the summer and implementation can begin in 2019/20. The system-wide development should include representation from Amaze and PaCC.

The Community Wellbeing Service aims to balance the inclusion of family and parents with both resources and the wishes and needs of young people who are Gillick competent in line with a legal obligation to offer confidential support and treatment.

With regards parents having clearer information on pathways, how to access services and waiting times, Community Wellbeing Service is constantly reviewing possible systems to provide regular updates to people waiting to receive the service.

Specialist CAMHS will continue to provide information for families through the network and via the CCG and all partners including parent/carers representation as part for the Partnership Group including "You Said, We Did". The service will continue to communicate with GP's and Wellbeing colleagues to improve access to information across all forums.

**IV. For providers to work with families to co-produce and adjust the current assessment processes in response to SEND families' needs and experiences.**

CCG and providers' response

The review by NHSE IST also concluded that improvements are required to the triage and assessment that takes place in the Mental Health referral hub. Some work has started on developing a single assessment form that each provider will use across the system and will share across the different aspects of the system as required and with consent. The next phase would be to test this and apply to specific needs such as SEND.

**V. Following the submission of the business case to improve the neurodevelopmental pathway, and acceptance that this is desperately needed, for the CCG to commit the financial investment required to ensure that this is developed and delivered.**

CCG and providers' response

The CCG has committed additional funds to address neuro-developmental assessment and diagnosis waiting times for autism (£105,000) and has plans to invest £60,000 in ADHD and £20,000 for family support groups. This is part of a phase approach to fully implementing the improvements outlined in the business case.



**VI. For providers to work with families to improve access to services including looking at suggestions like introducing a key worker role and offering more local/mobile services nearer to homes/schools.**

CCG and providers' response

The CCG is currently working with the Schools Wellbeing Service to be a Wave 2 Trailblazer. A strong part of that bid focusses on additional resource for the team to enable them to provide assessment and treatment in people's homes, especially for children on roll but not attending school full time.

Specialist CAMHS continue to develop the assertive outreach model targeting harder to reach young people aged 14-25 years within their homes and communities across the City, including those with SEND and moderate to severe mental health needs. Sussex Partnership NHS Trust is developing urgent and crisis pathways that are fit for purpose for all young people.

Mind the Gap is part of the Community Wellbeing Service that also works with Schools Wellbeing, Specialist CAMHS and schools to support young people and families who may have difficulties navigating the system (including those with SEND and mental health issues) and who may otherwise slip between the gaps of services. It is a non-clinical community services that offers both short term (up to 4 sessions) and long term cases work (up to 6 months). This service has received a high volume of positive feedback.

Community Wellbeing Service also offers online counselling (E Wellbeing) that is sometimes a helpful stepping-stone to engaging with services as it is not face-to-face.

**VII. For Amaze and PaCC to work with the LA, CCG and SPFT to ensure up to date information about Mental Health and Wellbeing services for CYP is included on key websites including the Local Offer.**

CCG and providers' response

The CCG and providers would welcome that partnership working as we recognise the need to ensure parents/ carers remain informed about relevant information. We are also in the process of working with providers to improve the current local Mental Health website (Find Get Give).

Sussex Partnership NHS Foundation Trust continues to develop its new website specifically for Sussex CAMHS (aligned to The Local Offer). The Trust would welcome feedback and information so that children and families can collaborate to improve the site.

- VIII. **For NHS providers to ensure there is ongoing training to front line staff in neurodevelopmental conditions like ASC and PDA and other things like the ‘parent carer journey’.**

CCG and providers’ response

The CCG has worked with local providers and Health Education England to provide additional, specific training in line with the Children and Young People’s Improving Access to Psychological Treatment (CYP IAPT). This includes training in treating mental health concerns in children and young people with autism.

Community Wellbeing Service currently has a staff member on the CYP IAPT autism course and sees a small cohort as part of their training.

Appropriately trained clinical staff delivers all specialist assessments on the neurodevelopmental pathway. All specialist CAMHS front line staff can access to in-service autism awareness training and following a recent serious case review, in addition all clinical staff has been required to complete mandatory training in autism training.

The CCG and providers would welcome any information gathered on patient journeys as part of this consultation, as this will inform future pathway improvements.

- IX. **For all partners to feed into both the STP-wide review on MH and WB services for CYP and the national ‘Commission for Equalities and MH’– sharing this report if agreed.**

CCG and providers’ response

The commissioner for children and young people’s mental health in Brighton and Hove is a member of the review panel for the Sussex wide children’s mental health and wellbeing review. Other members include a parent/ carer rep, an engagement rep as well as partners from across the system. Once the review starts, the CCG commissioner will ensure SEND parent/ carer reps are fully involved in the process.

- X. **To work collectively to influence Central Government to provide more funding for local CYP Mental Health and Wellbeing Services. This could include all local partners signing a joint open letter to the Treasury and the Minister for MH.**

CCG and providers’ response

The CCG will continue to receive additional funds (until the end of 20/21) to be allocated to children’s mental health. How this is spent is will be outlined in the annual Local Transformation Plan refresh.

The recent publication of the NHS 10 Year Long Term Plan described the continued requirement to improve children’s mental health and children with neuro-developmental diagnoses. Any additional funding and allocations to achieve these improvements are yet to be agreed.

Specialist CAMHS will use its own feedback from parents/carers to inform discussions with the CCG regarding gaps in provision as well as successful outcomes for young people that may support future service users and families.



- XI. **For PaCC and Amaze to continue to represent parent carers' experiences to service providers and commissioners. Having a representative on the Brighton and Hove Health & Wellbeing Board would help ensure that the parent carer voice is heard and responded to.**

CCG and providers' response

The CCG and providers continue to welcome feedback and involvement from PaCC and Amaze with regards children and young people's mental health service improvements. There is representation on the CYP Mental Health Partnership Group and mental health is a regular theme discussed at the SEND Partnership Board.

## 2. Report

### 2.1 What Amaze does

Amaze is Brighton and Hove's 'one stop shop' for families with children with disabilities and additional needs, providing a variety of information, advice and support covering education, health, social care, leisure, finances/benefits, and training/workshops. Amaze also manages the Compass Database and the Compass Card, a free leisure incentive card for 0 to 25 year olds with significant disabilities or special needs who live or go to school in Brighton and Hove.

Since 1997 Amaze has been engaging parent carers at all levels of services provision for their child or young person, for themselves and for the whole family. Their aim is to increase parent carers' resilience and confidence which in turn has a direct effect on the lives of their children. Since September 2014, in line with the new Children and Families Act, Amaze has been supporting families, and young people with Special Education Needs and Disabilities (SEND) themselves, up to the age of 25.

### 2.2 What PaCC does

The PaCC (Brighton and Hove Parent Carers' Council), hosted by Amaze, is a city-wide engagement group with over 380 members who are parent carers who have children and young people with disabilities, complex health problems or other additional needs.

PaCC also has ten partner organisations, some of them service providers, others community groups formed by parent carers. PaCC gives a voice to parent carers using different engagement methods, for example focus groups and forums to gather views/opinions and presents these to service managers to influence service delivery. PaCC Parent Reps sit on many Local Authority Boards and strategic groups with the aim to improve services for families.

Brighton & Hove City Council (BHCC) and the local Clinical Commissioning Group (B&H CCG), through their Brighton & Hove Communities and Third Sector Investment Programme (TSIP), fund Amaze and the Carers Centre for Brighton & Hove to gather views and ideas from carers around provision and delivery of health care services. Amaze and PaCC specifically consult parent carers of families with children and young people with additional needs and/or disability – see Amaze and PaCC engagement diagram. Some of these consultations are designed and planned in collaboration with the Carers Centre for Brighton & Hove.



Amaze and PaCC engagement diagram

### 2.3 This consultation

This report focuses on the experiences of families with children and young people with SEND accessing Mental Health and Wellbeing Services in Brighton and Hove. This consultation was organised at the request of the CCG to link with the Sussex & East Surrey Sustainability & Transformation Partnership (STP)'s 'Population Health Check'. Leading doctors, specialists and clinicians from the local area have looked at data, clinical evidence,

patient experience and local knowledge and given a diagnosis of what most needs to change across the health and care system from their expert point of view to ensure people continue to get the care they need in the future. The STP identified five priority areas including Mental Health and Wellbeing in order to develop a 10-year plan, which will look at how to resolve those challenges and how to make services more sustainable.

Amaze and PaCC are aware that mental health and wellbeing and access to support services for children and young people with SEND are a priority for parent carers. We have carried out various consultations in recent years around mental health needs and service provision. In addition, Amaze and PaCC Reps attend the Children's Mental Health & Wellbeing Partnership Group and have been key partners in feeding in parental views and suggestions to the Children and Young People's Mental Health and Wellbeing Local Transformation Plan for Brighton and Hove (2015-2020). The findings from this consultation align with the development priorities identified in this plan and provide useful insights and suggestions which should be used to inform ongoing improvements to services and outcomes for children and young people.

Some findings also align with issues relating to the assessment and diagnosis of, and support for, neurodevelopmental disorders that were highlighted in the business case within the CCG around a neurodevelopmental conditions pathway and have been explored by BHCC and partners following the Right Pro open letter <https://www.brighton-hove.gov.uk/content/children-and-education/local-offer>

In order to gather detailed feedback and insights, we asked parent carers about their experiences of accessing current Mental Health and Wellbeing services and how they would like to see these services to be delivered in the future for their children. Suggestions and recommendations from this report will be widely shared to inform ongoing service development plans, local CCG commissioning priorities, implementation of the NHS 10 year plan, the STP- wide review of CYP Mental Health and Wellbeing Services and the national Commission for Equality in Mental Health call for evidence.

### 3 Methodology

To gather data and information for this consultation we used an online questionnaire that was planned in collaboration with Carers Centre Brighton and Hove and designed with support from Amaze's Data and Performance Manager. The questionnaire included a range of questions with 'please select' and 'tick box' options and boxes to provide extra information and comments. The questionnaire was sent to all parent carers in Brighton and Hove on the Compass Register held by Amaze and it was also uploaded onto PaCC and PaCC Partners' social media. We received 89 completed questionnaires, which were summarised into a report.



Mental Health and Wellbeing Question

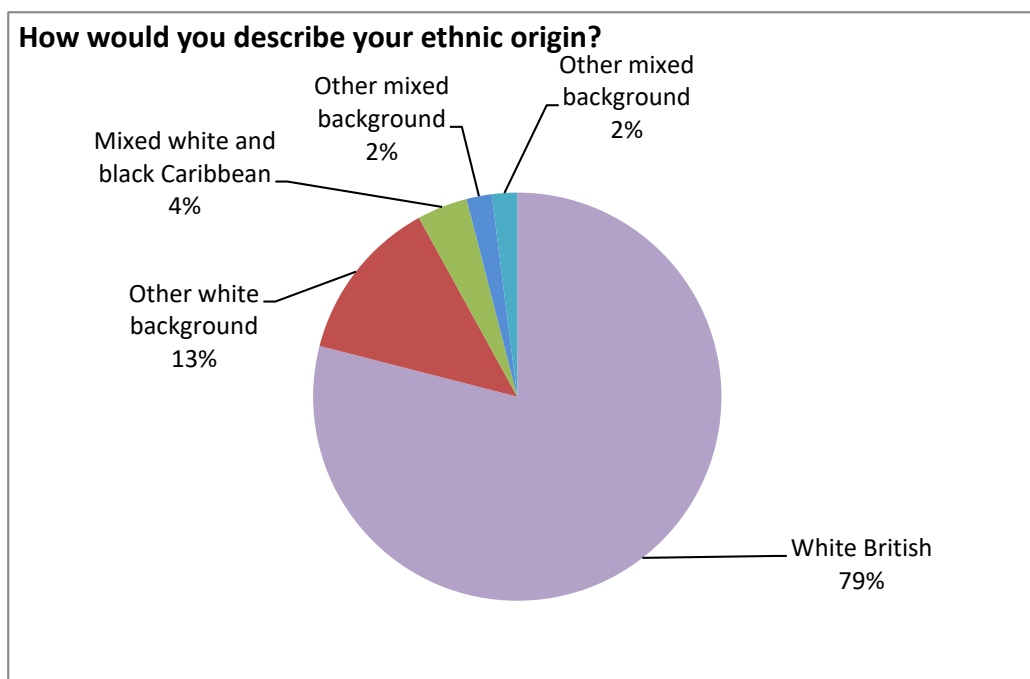
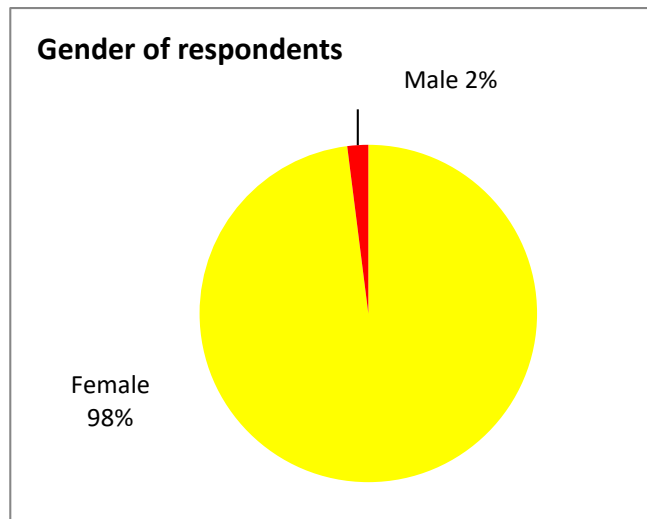
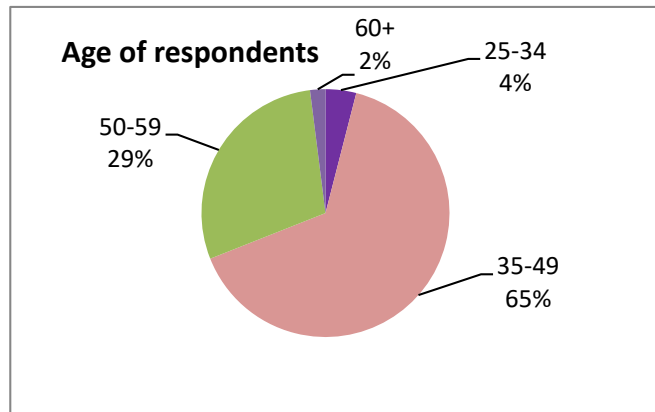


Mental Health and Wellbeing - summar

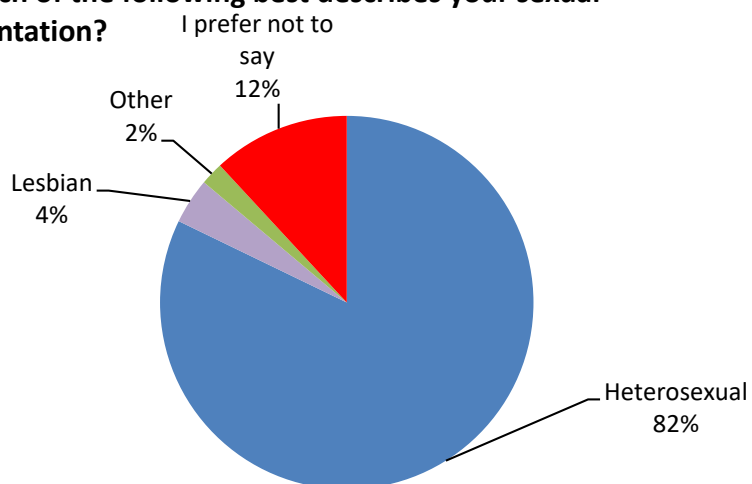
To add detail to this we also we also interviewed 4 parent carers who have accessed Child and Adolescent Mental Health Services (CAMHS).

Parent carers' contributions to this consultation are reported in *verbatim* to ensure the detail of their experiences is captured and considered.

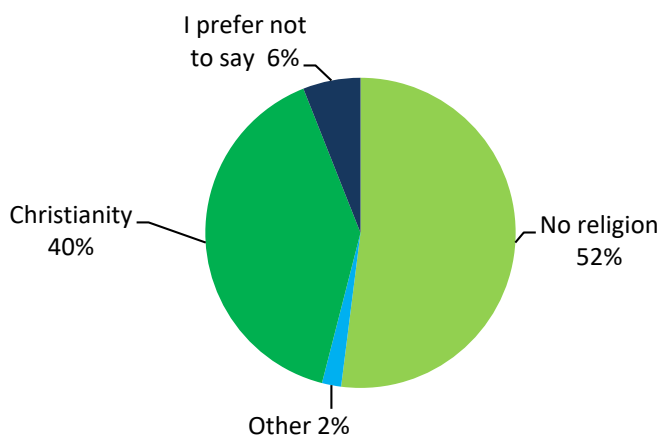
#### 4 Demographics from the online questionnaire



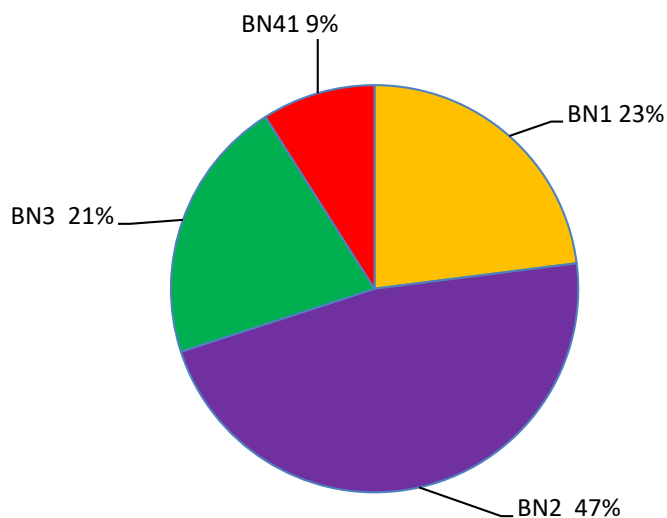
**Which of the following best describes your sexual orientation?**



**What are your religious beliefs?**



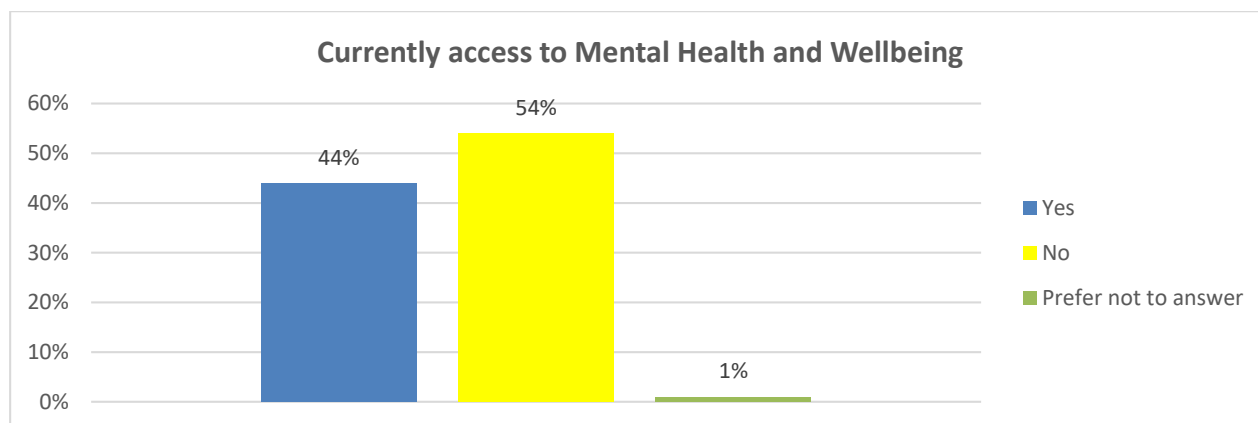
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## 5 Findings from online questionnaire

### 5.1 Children and current access to services

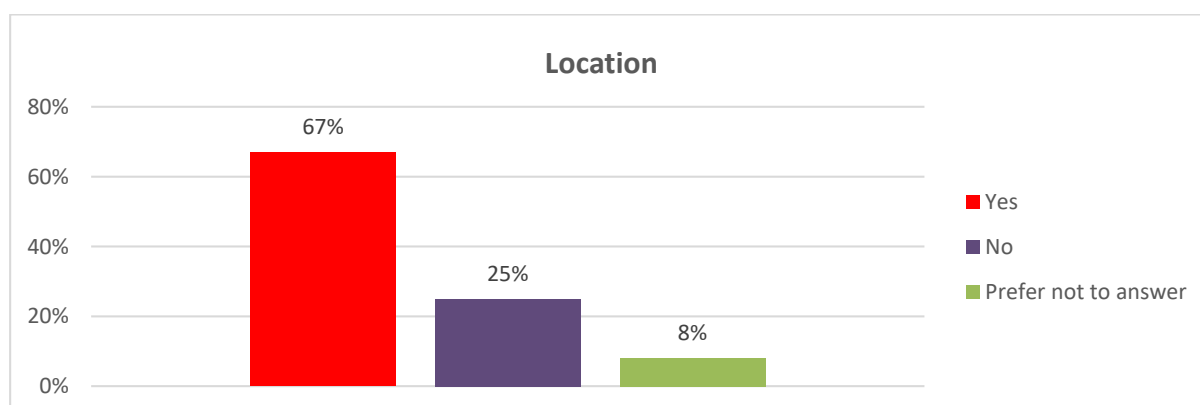
Firstly, we wanted to know how many children currently access Mental Health and Wellbeing services. To the question, *'Does your child and/or young person currently access any services relating to Mental Health and Wellbeing?'* - respondents told us:



**54% of families who responded to our questionnaire are not at present accessing services.** Their subsequent written answers suggest this isn't because they don't want to be accessing services, rather it is likely they are on waiting lists or have been unable to access support, although it could also be that they have accessed services in the past and now no longer need them. 44% are accessing services.

### 5.2 Children and local services

From families whose children are currently accessing Mental Health and Wellbeing services, we wanted to know if these services are locally provided. To the question *'If you responded Yes to the above, are these services local to you?'* – respondents told us:

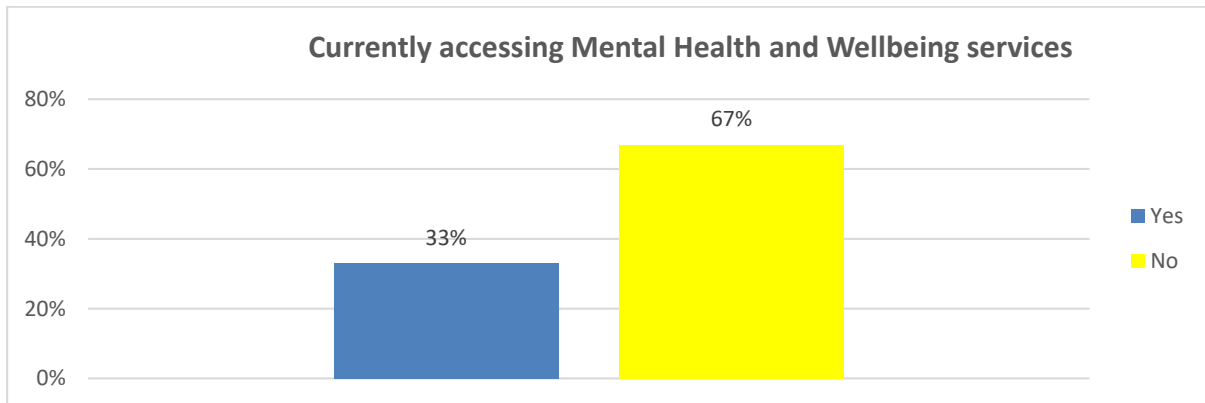


**67% of respondents reported that they access Mental Health and Wellbeing services that are local. 25% access services that are not local.**



### 5.3 Parent carers and current access to services

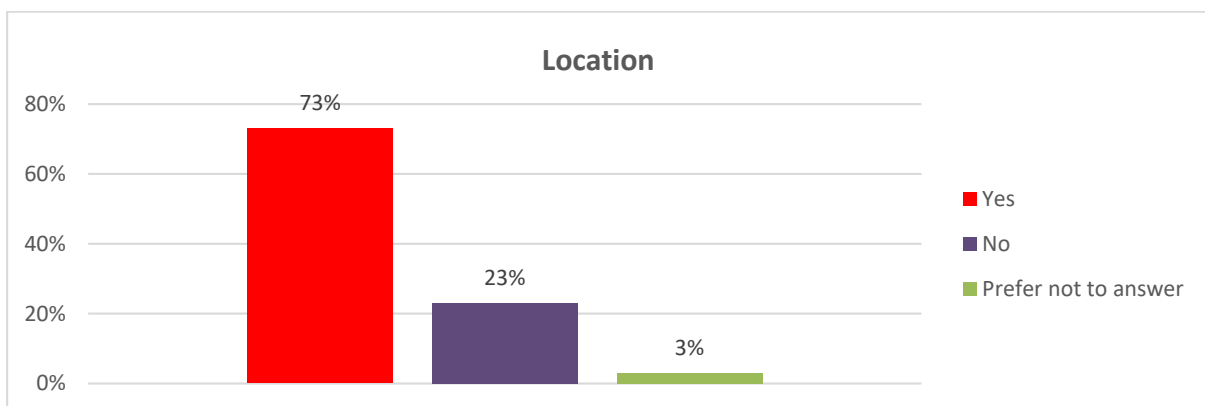
Although not the main focus of this consultation, we wanted to know how many parent carers themselves currently access Mental Health and Wellbeing services. To the question, *'Do you currently access services relating to Mental Health and Wellbeing?'* - respondents told us:



**67% of parent carers who responded to our survey are not currently accessing Mental Health and Wellbeing services. 33% of parent carers are.**

### 5.4 Parent carers and local services

For parent carers who are accessing Mental Health and Wellbeing services, we wanted to know if these services are locally provided. To the question *'If you responded Yes to the above, are these services local to you?'* – respondents told us:



**73% of respondents reported that they access local Mental Health and Wellbeing services. 23% access services which are not local.**

## 5.5 Accessing services that are not local

We asked families what difference it makes if services for them and their children are not local. To the question *'If these services are not local to you, what difference does this make to you accessing them? (Any benefits or challenges)'*, one respondent fed back that the services they access are privately provided, whilst another reported *'Travelling by bus or car and finding suitable parking takes extra time and planning'*.

In relation to services for their child, one parent commented *'I would not be able to access them'* whilst another stated *'The services are local but we had to wait 21 months to be seen because there are not resources'*.

In relation to adult Mental Health and Wellbeing services a respondent commented *'As the main carer, my mental health and wellbeing is key. It's hard at times to remember you need to look after you to look after your child to the best of your ability. You can also feel guilty when you do as well!! Sometimes low level support can make all the difference to stopping you falling over'*.

**Transport provision and the time it takes to travel to are the main barriers to accessing services that are not local. Waiting lists and scarce provision of services are seen as key challenges to accessing support.**

## 5.6 Experiences of families accessing services

We asked parent carers to rate and comment on their experiences of accessing different Mental Health and Wellbeing services. Parents were asked:

- *'Please rate your experiences of using the following services that you or any child/young person from your family have accessed within the past 3 years'*. Respondents were able to rate on a sliding scale from 'Very Dissatisfied' to 'Very Satisfied' *'Could you describe your experience of using these services? For example; did anything go very well or was there anything that didn't work or did you try to access a service but were unable to?'*

Provided below are comments from respondents in relation to each service and the average response of how parents rated their experience of that service (from Very Dissatisfied' to 'Very Satisfied').



Comments on services.pdf

### General comments:

Many respondents mentioned the fact that a **long wait** is one of the main problems facing families – *'Time taken between referral and receiving treatment/access to therapy was lengthy. Also experienced difficulties finding a time that worked with existing childcare arrangements'*.

For families who have to wait for a diagnosis or to enter the system there is not much to do but wait – *'Misdiagnosed at age 12, prescription Prozac. Had anxiety, depression, and bulimia all my life. Suspect autism. Son 8 and after 4 years still no diagnosis. System staff procedures change yearly, we just drift alongside waiting.'*

One parent commented on **a system that it is not joined up and does not focus on prevention** – *'I think the system is fragmented. Whilst they [different roles in health, education, social care] all greatly individually contribute, I think the funding structure goes for a fragmented approach, which as a parent you have to bridge. In addition, as a clinician I do not get why there is not an integrated model for a child, integrated care approach and the funding less fragmented. People who work well together is in spite of the system, rather than because of it!! My other concern is more should be aimed at prevention or early intervention. Long term it has better outcomes and costs the system less, but things have to get bad enough to get evidence for support.'*

Many parents feel frustrated by **a system that penalises young people** – *'Waiting list was so long, saw a psychologist then told we need to see a psychiatrist for meds to help with my daughter's paranoia but, they said, the waiting list is long!! Why should my daughter wait so long for the services and medication that has been agreed she so badly needs?'*

A parent commented – *'The Wellbeing service, CAMHS and the clinical psychologists at Seaside View have all turned down the referrals that have been made about my daughter. Her anxieties are getting worse and we have nowhere to go to for support or interventions.'*

**Some families access services provided by the private sector in desperation** – *'Back and forth from GP/out of hours 111 to A&E ... then to CAMHS, answerphone... get through to be told just closing, call A&E if needed, that's your safe place, then get to A&E to be told CAMHS support stops at 8; call GP or CAMHS phone number..., repeat for months until you go privately and join private waiting list...'*

**However many families can't afford to pay for privately provided services** – *'I have suffered depression but have not felt supported by the NHS or been offered face to face therapy. If you are poor working class you can't afford these [private] services. Our family need therapy between our own mental health and dealing as a carer but we would have to pay for these services as they are not [otherwise] accessible'*

**Many families felt left alone** – *'I did not know these services existed, have never had access or support – because I got my son into mainstream school when he was younger, no one was willing to give any help or support we were left to cope alone.'*

### **Different service experiences:**

The quotes in blue are examples of some of the comments provided about each of the named services. Many more are available in the full survey report. It should be noted that parents were not always clear about the names/functions of services (an issue in itself) and some comments may relate to another service. Numbers of responses relating to each service vary, nevertheless we give an average rating for each for indicative purposes. A rating scale of 0-100 was used to measure parent/carers overall satisfaction of services used. With 0-33 equating to Dissatisfied; 34-67 as Neutral; 68+ as very Satisfied. The scores for each service were collated and the average overall score used to determine the general satisfaction ratings of all respondents for the purpose of this report.

Mental Health and Wellbeing Service for CYP	Average rating
Primary mental health workers in the Schools Wellbeing Service	Neutral
<p>E-wellbeing (online counselling)</p> <p><i>'I have spent over 2 years trying to access CAMHS and finally self-referred for e wellbeing at which point my daughter was suicidal so was unsuitable and needed face to face. Couldn't help feeling that had we access earlier we could have prevented getting to this stage'</i></p>	Dissatisfied
Mind the Gap (community support)	Dissatisfied
<p>Community-based short term therapeutic interventions e.g. canine-therapy, drama therapy, play therapy</p> <p><i>'Canine counselling had to wait ages to get it. Not flexible on timings available. Wouldn't write report for us'</i></p>	Dissatisfied
<p>Child and Adolescent Mental Health Service (CAMHS)</p> <p>The majority of people who have accessed CAMHS report a service which doesn't meet their needs - <i>Doesn't have a designated ADHD nurse. Each time we seem to be assigned a different person who doesn't seem to have read up on his notes, i.e. that he's adopted and has attachment disorder. Doesn't seem to understand that he has complex needs, i.e. learning difficulties, inability to reflect and make complex decisions, lack of acknowledgement that parents know our child, even disputing that he has ADHD, although diagnosed at age 2. A general lack of understanding of our son, and unwillingness to listen to us. Also very hard to get calls returned, have been waiting on an autism assessment for a year etc.'</i></p> <p>One parent commented on the <b>lack of prevention within the current system</b> - <i>All CAMHS do is check annually due to medication. In the past they responded to crises eventually and were reluctant to retain involvement. The service is so stretched there is no prevention. For example I have had to find specialist drug counselling when it is perfectly foreseeable that someone who struggles to fit in due to atypical brain processing is more likely to turn to props like drugs/booze.</i></p> <p>Some families report a <b>mixed experience from CAMHS</b> – <i>'With regard to CAMHS, despite being in crisis we were told he just needed an EHCP. It took another appointment and the threat of complaint to have him seen. Since then he has been seen regularly and has art therapy, CAMHS have also come to the school for a multi-agency meeting etc., so this is going well. What isn't going well is access to a psychiatrist- he is on the list and is still waiting. This is against a backdrop of severe anxiety, low mood and dark thoughts. What I find difficult is the length of time you have to wait to be seen by a psychiatrist etc., while your child is clearly struggling to manage at school and home'</i></p> <p>There was one positive comment from a parent carer – <i>'We have used CAMHS before and on both occasions the service was very helpful'</i>.</p>	Dissatisfied

<p>Child and Adolescent Mental Health Service (CAMHS) Learning Disability service</p> <p><i>“Getting through the barrier and getting in touch with anyone in CAMHS is very difficult - you just get passed around from person to person and department to department - no consistency - need a fixed key worker with family who actually contacts the family”.</i></p> <p>Some families experience good support from parts of CAHMS services - <b>‘CAMHS LD service were extremely supportive. CAMHS were not as organised and we’ve had little follow up contact’.</b></p>	Dissatisfied
<p>Child and Adolescent Mental Health Service (CAMHS at the Aldrington Centre)</p> <p>One parent questioned the current system and <b>lack of communication</b> - <i>‘CAMHS is useless. Point of child's health should be GP. No waiting times for children's mental health beyond 1 week. <b>CAMHS kept son in queue for service that CAMHS did not even offer and it was almost a year of waiting and complaining before they did anything.</b> CAMHS useless at cooperating in a team for EHCP purposes. Insufficient variety of therapies. <b>Tier 3 should also be accessible to children with high anxiety and issues which make it difficult for them to leave their homes without this being community level (this doesn't trigger Eotas support).</b></i></p> <p><i>Aldrington centre is a terrible therapeutic setting in terms of decor and vibe for children. Services are not services as in they do not treat parents and children as those they are serving. They serve themselves and their own internal rules and standards. They are just therapists and there are loads of therapists so I don't understand why CAMHS is so understaffed. Inflexible treatment’.</i></p> <p>One parent commented on the <b>lack of support whilst children are on waiting lists</b> - <i>‘CAMHS have been assessing my child for ADHD for nearly two years now. During this time I have had one appointment with worker at Aldrington House and he has been observed at school once. We are waiting for his second stage assessment but have been told that it's a long wait as there are no psychiatrist within the service. There has been no support offered in the interim’.</i></p> <p>One parent commented on the <b>lack of communication, not feeling listened to and respected</b> and what a difference good communication makes – <i>‘I found it very difficult to communicate with the psychiatrist treating my son at CAMHS Aldrington House, and didn't feel she understood the issues around ASC very well. I didn't feel listened to or respected. E.g. for very valid reasons, I wanted to be able to meet without my child in the first instance, which was met with a lot of resistance. What I had said in the meeting was misreported, and she didn't really understand what I was trying to communicate. <b>The questionnaires around anxiety are not designed for someone with speech and language issues or autism, so were rendered somewhat meaningless.</b> This meant it was hard for my child to access the therapy they needed because of the obstacles created by the use of unsuitable questionnaires. We had real problems getting seen because of internal disagreements between LD</i></p>	Dissatisfied

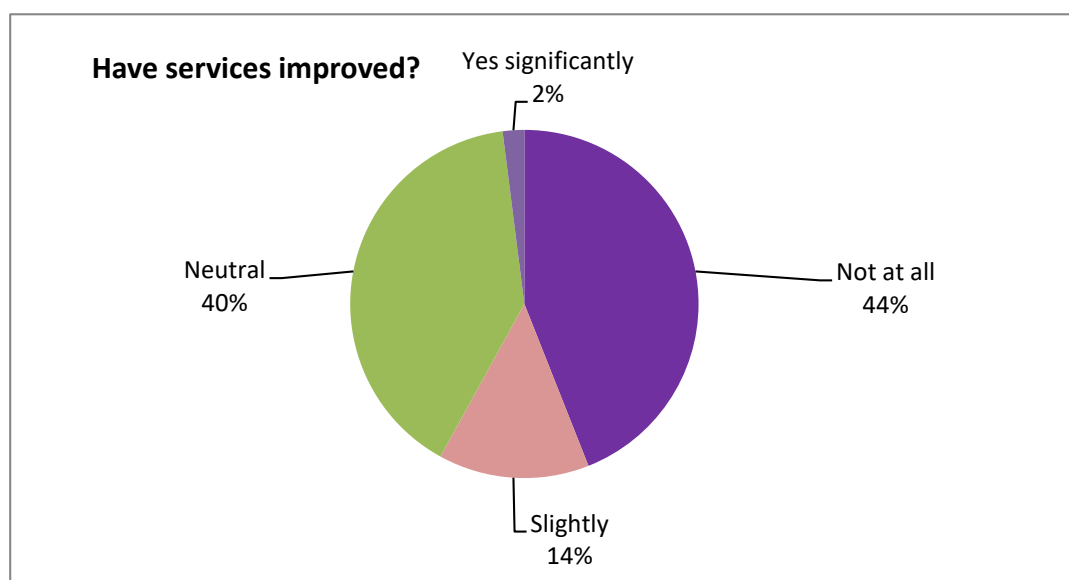
<p><i>CAMHS and CAMHS about whose care he should be under. <b>Eventually a trial of medication was followed which was very helpful for him, but it took a long time, and a lot of chasing from me to get to this point. What went well - communication with Tansy Walker was excellent. I was able to email or speak to her on the phone, and she listened to me and understood the issues faced by my son</b>.</i></p>	
<p>Child and Adolescent Mental Health Service (CAMHS at Chalkhill)</p> <p><i>“Because my child has autism we are told that he can't access these services as it's part of his autism. CAMHS said he doesn't meet their criteria. The wellbeing team have seemed better but we are waiting to see if they will helped my son”</i></p> <p>However a respondent to our online survey commented – <i>‘The NHS is far better than private! Our daughter is in a private hospital, funded by the NHS, and it is awful. Our experience of Chalkhill was 100 times better’</i></p>	Dissatisfied
<p>Sussex-wide Eating Disorder Service</p>	Neutral
<p>Mental health advice and information service at Mind</p>	Neutral
<p>Employment advice at Mind</p>	Neutral
<p>Teen to Adult Personal Advisers - TAPAS (SPFT)</p>	Dissatisfied
<p>Schools Wellbeing Service - Primary Mental Health Workers</p>	Neutral
<p>School Counselling</p> <p>One parent reported a positive experience from school counselling however waiting for support is still a problem - <i>‘<b>My child accessed school counselling which she found extremely useful. It has had a positive impact on her confidence, perspective and reducing her anxiety. But she only had a limited number of sessions</b> and she was sad when they finished as she felt she needed more sessions to get all her worries out. <b>My other child has finally begun CBT sessions with the Emotional Wellbeing Service. I self-referred her, she was assessed within 3.5 months and has been on the waiting list for 8 months before they were able to allocate her.</b> Her self-harming has become more intense and more frequent and more embedded during the waiting time since last March. It's perceived wisdom that early intervention is critical, so an 8 month wait for a vulnerable young person who is cutting herself is really awful. It has had a huge knock/on effect for me and her sibling. After 3 sessions, it's clear that she actually needs a CAMHS Psych Assessment so now we are waiting to see how long it will be before she is seen for that’.</i></p> <p>One parent stated - <i>‘The school counselling service at my child’s school was inconsistent, <b>offering online tools for teenagers who are suicidal is rubbish, children need to talk to adults or other people.</b> Online tools aren’t going to stop them committing suicide. In fact it would probably make them feel that there is no one there who will listen to them’.</i></p>	Neutral



<p>Being able to talk to someone at CAHMS and need for a key worker is underlined by another parent - <i>'CAMHS would not take on my daughter as her self-harming was not serious enough - although she had pulled out most of her hair and bitten herself badly. The initial school counsellor was regularly absent so my daughter missed 4/7 sessions provided. The more recent counsellor she has (due to a second request being made) appears more reliable. My daughter has an art therapist that we pay, who has built a positive bond with her. <b>Getting through the barrier and getting in touch with anyone in CAMHS is very difficult - you just get passed around from person to person and department to department - no consistency - need a fixed key worker with family who actually contacts the family</b></i>'.</p>	
<p>Brighton and Hove Community Wellbeing</p> <p>One parent comments on difficulties with accessing a service and services' threshold - <i>'Because my child has autism we are told that he can't access these services as it's part of his autism. CAMHS said he doesn't meet their criteria. The Wellbeing team have seemed better but we are waiting to see if they will help my son</i>'.</p>	Neutral
<p>Private Counselling or Therapy</p> <p><i>'Private help is very expensive but helpful. I do wonder if specialist help from someone who really understands life with a disabled child would be even better'</i></p>	Neutral
<p>Other service comments</p> <p><i>'There is a shocking lack of support or help for anything mental ill health. At total crisis breakdown times (there have been 2 in the past few years); I've been passed from pillar to post on the phone, trying to find information on line. <b>Being told that no service is available on that particular day. It's a shame I wasn't having the crisis on another day</b>, crisis being left to answer phone or just not answered, forced to go up to A&amp;E on the last phone person's advice and then just being sent home from A&amp;E. There is no help. None. <b>We've now been on counselling waiting lists for over 2 years being told that the only counselling available is CBT which is proven by psychiatrists not to work except for certain conditions such as OCD or ADHD and even then just short term.</b> Proper therapy (psychodynamic) was given after 1.5 years of waiting then the therapist disappeared. After investigation I was given another, so after that time only had 3 sessions and <b>was told the service is shutting down</b>. That was a few years ago now and have been on a waiting list ever since for a service that doesn't exist which makes no sense. <b>We don't have the money to go private</b>, and even then, how do you know you're going to get a good one who isn't just going to disappear? The lack of support and provision of anything is absolutely shocking. There is no help. <b>It might look like it on paper or as advertised but when you try to access these services there is NOTHING'</b></i></p> <p>A satisfied parent <i>'YMCA are helpful in letting us know about all services and help'</i>.</p> <p>Outside Brighton and Hove:  <i>'We were recommended to go to London, we did family therapy which was really good I had more understanding of the complex needs they didn't have the support in Brighton that's why we were sent to London'</i>.</p>	

## 5.7 Services – have they improved?

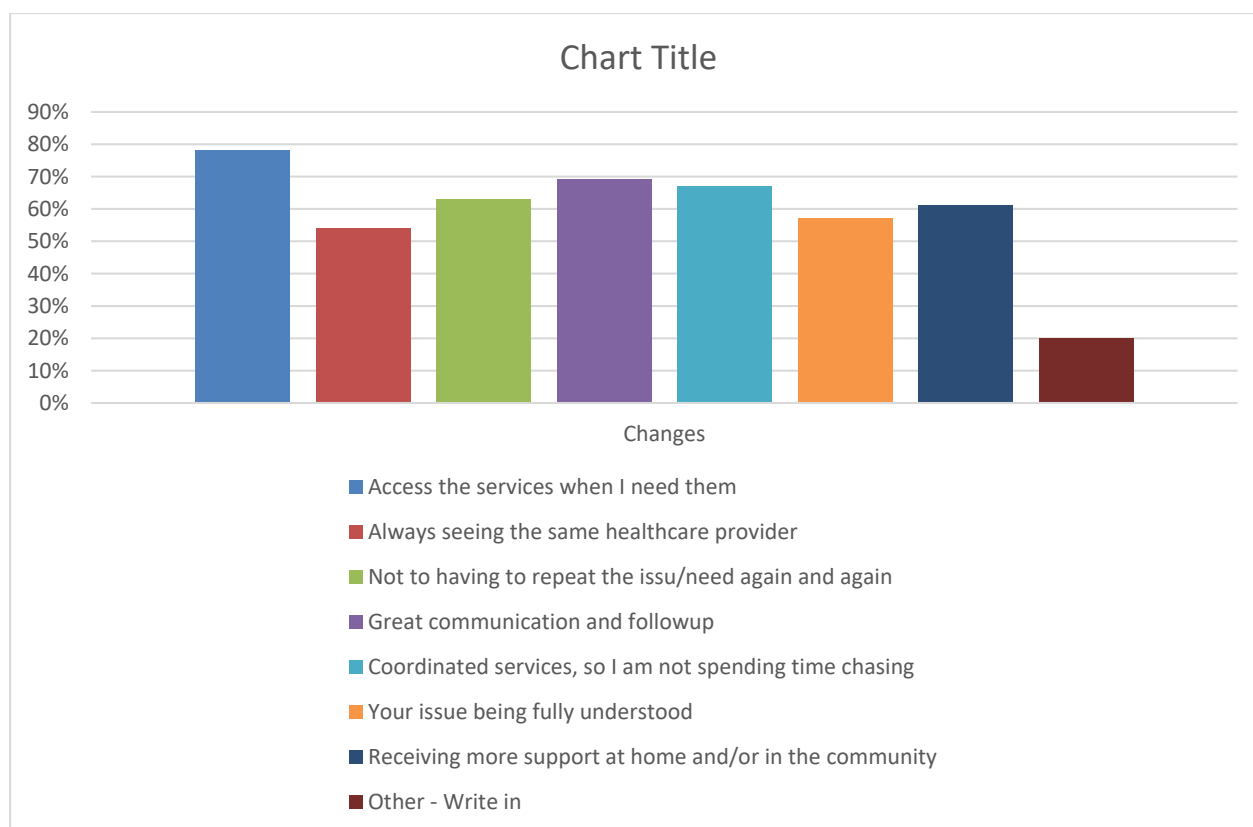
We asked parent carers if they felt services for their children and young people have improved during the past three years to reflect the period since the Transformation Plan. To the question *'In your experience, if you have used the service more than once over the past three years, has the service improved?'* – respondents told us:



**44% of respondents thought that services haven't improved at all** during the past three years. 40% were neutral about whether services had improved. 14% thought services had slightly improved and **only 2% reported a marked improvement.**

## 5.8 What parents would like to see

This consultation also asked parent carers how provision and delivery of Mental Health and Wellbeing services could be improved. To the question *'If you could change the way services are currently provided, what would you like to see? Please tick all that apply'* – respondents told us:



- 78% families would like to be able to access services when they need them
- 68% would like better communication and follow up
- 67% would like better coordinated services reducing time spent chasing updates
- 63% would like not to have to repeat themselves to different providers
- 61% would like to be able to receive support at home or in the community
- 57% said they would like to be fully understood
- 54% said they would like to see the same healthcare provider consistently so their needs are better understood.

## 5.9 Suggestions on how to improve services

Finally we wanted to explore what changes families would like to see in services. We asked our families *'Do you have any suggestions for how those services could be improved / changed?'* – respondents said:

- **Clear pathway and assessment process**

Families would like a clear pathway on where to go and what to expect - *'Clear pathways leading to MH support for autistic children and young people. Also, actual MH support for autistic people'* and also more coordination between the different organisations and/or services and information about waiting lists – *'More co-ordination with schools, this needs to be on the curriculum and schools can promote basic self-care, CBT apps etc. to Year 6&7 students as part of their preparation for secondary/teen turmoil. Transparency over waiting lists. Should be able to see how many are on the waiting list and what position you are in the queue'*.

Another respondent commented *'Being on a waiting list is NOT the same as accessing the service, so that distinction needs to be made and scrutinised'*.

A well-defined pathway would inform the family what to expect – *‘An initial appointment with CAMHS should be with a team of professionals, this would stop the constant waiting to see each person. We have already waited 9 months for an initial appointment to then go on another waiting list just to be able to see someone to get medication is ridiculous as she has already been diagnosed at the initial meeting’* another parent feedback – *‘Clarity about which service is appropriate for CYP with neurodevelopmental conditions, where medication might be necessary. Communicating this with parents’.*

- **More information and Local Offer**

More information will inform the pathway, at the same time empower the parents and young people to know what’s on offer, and so choose what service is more suitable. Many families are confused about services – *‘Make all the various services better known, I hadn't heard of some of the services. Not everyone knows where the help can be accessed, I have two children with special needs, a child who has also had mental health problems, and I had to find out most of the information myself’.*

Another parent commented - *‘There needs to be a clear Local Offer for MH that is on the council website, on NHS Brighton, on GP pages, schools’ websites etc. so that parents and young people can find the information easily and not waste time pursuing the wrong service or sitting on a waiting list, only to be redirected to a side service when they have the first appointment’.*

A respondent suggested – *‘It would be good to have a description of each service online and a method of self-referral. I did this recently with adult wellbeing service and though it was of limited use in practice it felt good to be able to try to move forward’* and another commented - *‘I have no idea what is available despite struggling and asking for help from the social care team at Seaside View. The SSV counselling service has been offered but I have private therapy. Amaze ran a PPP course - it was helpful but not enough’.*

- **More support / a key worker model**

Sometimes families struggle to find out what’s going on or where they are in the process – *‘One person to contact who checks in with us, not waiting for problems to arise. Whole family approach to care not just relating to the child in question’.*

A parent suggested that a solution could be – *‘GP is first point of call and can immediately sign for local payment of 12 therapy sessions for child EHCP form Eotas application transparent and child out of school for 2 weeks automatically has access to lessons and not encountering unstated restrictions and prohibitions. The applications should be ongoing not once a month it is too much education to miss. More external courses similar to The Recovery College for teenagers to be involved in’.*

Some parents would like support that is easier to access – *‘Closer to home instead of having to travel across the city. Perhaps remote support such as telephone/online communication would be easier to manage’* Another parent feedback – *‘More servicing that come to house - Team around family was great the lady who came to our house was great’.*

Without support some families resort to other organisations – *‘I resorted to calling The Samaritans recently because things were overwhelming and I needed to just talk for a few minutes. They were the only service manned 24/7 that I could find’.*

- **Better communication on services, between providers and with regular updates. This should include information on waiting times and improved listening to parents as the experts in relation to their child's needs**

Many respondents feel left to themselves - *'Once your allocated time has ended, you need to wait a minimum of 6 months before re-referral. This is not helpful if you are still requiring support, due to complex issues experienced. This seems unfair as it can often leave you feeling abandoned or that your time of support is up.'*

A more family centred approach, including listening to what parents say can bring lots of positive outcomes - *'Sometimes it feels like, parents should be listened to more. There seems to be a feeling that parents are being unnecessarily anxious. Early intervention would be more helpful, than waiting for a crisis. The whole stressful situation of not always being listened to leads to parents being more stressed which intimately impacts the kids'* - and more - *'Parent is the first person to be believed if identifying a child's unmet need and action to follow from this not the wait until such and such service decide'*.

Improve the way professionals communicate with families - *'Fast response and direct link with the professional, e.g. we can't email CAHMS, we can't talk to anyone, basically just answers, sometimes we do feel a robot'*.

*'Better communication - ability to contact health practitioner by phone/email, and not always via the switchboard which feels impersonal and off putting. Analysing the use of questionnaires for MH disorders for those who do not have good language skills. What could replace these?'*

- **Training for staff**

Some families would like to see more training delivered to frontline staff - *'Intensive training in neurodevelopmental conditions for all mental health personnel. Staff should for example have had specific training for Autism and ADHD etc. which are not mental health concerns but often result in co-morbid mental health issues due to poor understanding from health professionals, schools etc.'*

*'Retrain all CAMHS staff in ASDs including PDA and in how to work in partnership with parents, instead of a parent-blame culture. Stop sending parents on parenting courses and looking for environmental causes instead of assessing children for ASD and ADHD'*.

Training should focus on the 'parent carer journey' – *'Improved awareness of what the actual challenges are of parenting a child with special needs. Understanding the emotional impact on parents and offering support with it'*.

- **More money invested on more services including therapies**

Many respondents were aware that services are over-stretched – *'More professionals & staff'* - and that the situation can be only improved by more money being put into it the system– *'Tell the government to stop taking money from the services meant for disabled children and other people who need help'*

Shortage of services are impacting on families - *'For adults with learning difficulties there could be accessible counselling with good skills of communication. The tiny bit we did access struggled with clarifying how the young person's confidentiality worked with family support'*.

*'It has been an uphill struggle to have CAMHS involvement, but I do feel the art therapists and his lead practitioner support him. However, the length of time for psychiatry is unacceptable'.*

*'We need Sure Start back to limit the damage at the start and a well-funded service throughout. The professionals are mainly excellent, dedicated, caring people but they can't do their job in these conditions'*

## 6. Recommendations

We are mindful that a significant amount of time and focus has been put into developing an improved service offer for children and young people's mental health and wellbeing in Brighton and Hove over the last three years (since the Transformation Plan 2015) and we have been active participants in the Partnership Group to oversee this progress.

However, at the same time we have become increasingly concerned at the level of negative feedback that we have been hearing from the community of families with children and young people with SEND about their access to, and provision of, services to support their children's' (and their own) mental health.

This suggests that the changes and availability of services that have been rolled out over the last three years are still insufficient to meet rising levels of poor mental health amongst children and young people with SEND. Amaze staff and PaCC reps have talked to a number of parents where either they or their child have expressed significant levels of dissatisfaction, lack of support and crisis, and in some cases even suicidal thoughts.

It is telling that we have taken the decision to fundraise to provide our front line staff with clinical supervision due to the increasingly difficult conversations they are having with families who cite these issues. Whilst the severity of the problems and messages seem to be increasing for our community of families, some of the issues, and suggested recommendations are the same as they were when we last reported on this topic in March 2014 and June 2016. This is particularly frustrating to see and leads us to our first recommendation:

- I. For senior colleagues at the B&H Clinical Commissioning Group and B&H City Council to read this report and consider the severity of feedback, particularly in light of high levels of self-harm and other mental health disorders in the city, and a sustained lack of confidence over recent years in the capacity of CAMHS and wellbeing services to meet the needs of local children and young people with SEND. To consider that for children and young people with SEND there are often associated, and complex, mental health and wellbeing issues so to agree this group should be prioritised for support.
- II. For senior colleagues to consider these recommendations alongside the 'Future Developments' section in the 2018/19 Transformational Plan Refresh and agree to (re)establish/(re)clarify the priorities that need to be addressed and set clearer/SMARTER outcomes for what improvements are expected, how these will be achieved and by when. This needs to include how waiting times for assessment and treatment can be shortened.
- III. For the system to prioritise improving communication and co-ordination, including better listening to parents as experts in their families' needs and changing the culture



at levels regarding attitude towards families. Parents need clearer information on service pathways, sharing of information across providers and regular updates on referrals and waiting times for services. This needs to include us receiving feedback about what is going to be done in response to this report, specifically in the style of a 'You Said, We Did' response from the CCG to parent carers.

- IV. For providers to work with families to co-produce and adjust the current assessment processes in response to families' needs and experiences.
- V. Following the submission of the business case to improve the neurodevelopmental pathway, and acceptance that this is desperately needed, for the CCG to commit the financial investment required to ensure that this is developed and delivered.
- VI. For providers to work with families to improve access to services including looking at suggestions like introducing a key worker role and offering more local/mobile services nearer to homes/schools.
- VII. For Amaze and PaCC to work with the LA, CCG and SPFT to ensure up to date information about Mental Health and Wellbeing services for CYP is included on key websites including the Local Offer.
- VIII. For NHS providers to ensure there is ongoing training to front line staff in neurodevelopmental conditions like ASC and PDA and other things like the 'parent carer journey'.
- IX. For all partners to feed into both the STP-wide review on MH and WB services for CYP and the national 'Commission for Equalities and MH' – sharing this report if agreed.
- X. To work collectively to influence Central Government to provide more funding for local CYP Mental Health and Wellbeing Services. This could include all local partners signing a joint open letter to the Treasury and the Minister for MH.
- XI. For PaCC and Amaze to continue to represent parent carers' experiences to service providers and commissioners. Having a representative on the Brighton and Hove Health & Wellbeing Board would help ensure that the parent carer voice is heard and responded to.