PaCC Connect On Mental Health

27th April 2016

In Attendance:

- Gill Brooks - Commissioning Manager, Children's Mental Health & Wellbeing Brighton and Hove Clinical Commissioning Group, Peter Joyce - General Manager CAMHS E. Sussex and Brighton and Hove, Brenda Davis - clinical psychologist in tier 3 CAMHS, Abby Maitland - Team Leader/ family therapist with Specialist Camhs Learning Disability Service for Sussex partnership trust and Mary Finlay – Family Support Worker, Andrew Wealls, Conservative Councillor
- PaCC Steering Group and Office Members
- Parent Carers

Introduction

Overview of transformation plan - Gill Brooks

(Document outlining this information in more detail is available on request)

Section 1

- There was a requirement for CCG to work with partners locally to develop a local transformation plan (for more information visit; http://www.brightonandhoveccg.nhs.uk/plans)
- This is a 5 year plan. The plan is refreshed every year with help from different people including parent carers. Money was invested to help with transition. Mental Health has not traditionally had much investment – huge catch up in terms of funding needed.

Section 2

- Inclusion of help at the Royal Alex Children's Hospital. Professionals on site to support professionals and families at the hospital. Started November. Very well received.

Section 3 (strategic aims and principles)

- 2015/16 The Planning has taken longer but we want to get it right. Things are still being debated.
- Creation of one place for all info was via a web page and social media. Named 'Where to go For…?' it includes guidance and recommendations. We are formulating a communications and PR campaign on anti-stigma alongside this.
- E-motion – online counselling service – another choice to help young people with live counselling capability.
- We worked closely with schools. We introduced a primary mental health worker in 3 secondary and 8 primary schools – which has gone extremely

well. Education and health have a very different approach so there has been a lot of important work in terms of understanding each other. The eventual aim is to have a Mental Health worker in every school and special schools.

- Outreach counselling pilot – 18 -25 year olds.
- Bringing together services - GPs and primary care involved also – together with the other services such as, schools, CAMHS. This is to enable services to share information safely.
- Also wanted to think about parents and carers – lots of resource for 13plus but not younger. Parent carers need the support in between gaps or with helping children come to sessions. We spent some time this year beginning to set up a parent carer forum. Time was also spent asking parent carer's what they want. There is limited resource but if we can change things we will. We wanted to reduce waiting lists.

Open to Questions and Comments (Professional's responses are marked in red)

- **Parent** - What about people who are on the edges and aren't already referred to Social workers who then hit rock bottom? They are hovering below any criteria. **Gill Brooks** - Early Help will pick people up and deal with the whole family.
- **Parent** – you have to fight hard for it. If I've struggled with it other parents have too.

  Steering Group Member - Do you have to have a social worker to have a mental health problem? It's more difficult to get help without a social worker.

  Gill Brooks – You can self-refer to CAMHS – early Help refer too.
- **Steering Group Member** – the integrated pathway is really important. There is a lot of confusion about what is a mental health issue, what's behaviour, what's a learning disability and what's ASC. There is a lack of understanding about what the pathways are. What does Mental Health actually mean? There is a huge amount of confusion over the crossover between these things.

  Parent – what is the procedure? Child refers to CAMHs – child doesn't want to engage, they have an ASC diagnosis – what happens when there is a blur?

  Brenda Davis – Tier 3 CAMHS is involved with both of those things. A young person may be referred because of escalating behavioural problems. They would probably come to CAMHS for that and then as part of that emerged another type of disorder – it wouldn't be one or the other – at the same time within CAMHS they would be referred for a diagnostic assessment.
- **Parent** – what is the paper trail? After Stage 1 you sit there and there's no contact.

  Brenda Davis – this has been a real problem you're absolutely right. Stage 1 is the initial gathering of information then the decision comes to stage 2. We only want to put forward people for that stage if we are definitely sure that's what they need.

- **Parent** – You have to ‘pester’ to go on to the next stage. We shouldn’t have to be asking again and again. Where’s the paper work in the link? We don’t receive any paper work about what’s happening.
  Abby Maitland – the role of the care co-ordinator should be allocated and there should be somebody who is the ‘go to’ person. That person should be clear about keeping tabs on what’s happening. Maybe they should be doing this more proactively.
- **Parent** – For my child the ASD assessment was set up with the school. ASD and mental health merged into one when a crisis happened and so it became very muddled.
  Steering Group Member - are mental health workers in schools involved? Quite a lot of Mental Health workers don’t have experience of ASC or training.
  Abby Maitland – The LA have taken the lead on delivering ASC specific training which is part of the work force development strategy.
- **Parent** – can children refer themselves –
  Gill Brooks – yes children can self-refer
- **Parent** – do you consider children who have fallen out of mainstream school? For example home school children and children who go to private independent schools.
  Gill Brooks – there is a team that are involved in this.

Attendees were then split into 2 groups and the following questions and comments arose:

- **Parent** – How far have the reports and recommendations informed changes?
  Brenda Davis – We worked through the recommendations and have come a long way.
- **Parent** – Once we got into the process of Stage 2 we were well supported but it would take forever to see anyone. What has changed? Is there information available?
  Brenda Davis – There has been an increase to 3 extra sessions a week which has made a huge difference
- **Parent** – what’s the general wait time?
  Brenda Davis – It’s a longer process if ASC is involved – Stage 1 is a gathering of information which doesn’t take that long. Stage 2 is a longer process.
- **Parent** – what are parents told?
  Brenda Davis – Community CAHMS may decide to refer them up. There is a weekly triage meeting where new referrals are moved up.
- **Parent** – Has there been an increase in resource?
  Brenda Davis – For the first time in as long as we can remember new money has come in. The hope is that Tier 2 will be given help to manage themselves.
  Parent – Do young people just get left alone? If a child is opting out – no one gets involved

Peter Joyce – there is an assumption if we don't hear anything that things are ok. What do we do about these people? You can't force a young person to talk. The absolute final point is to section them.

- **Parent** – People are not hearing about resources or understanding exactly what different professionals can offer. What crisis has to occur before someone has to go to Tier 3? What are the Tiers?
  Brenda Davis
  Tier 1 – GP or school first refer
  Tier 2 – Emotional well being or mental health, depression and anxiety
  Tier 3 – Risk to themselves and others, not functioning and need for more intervention
  Tier 4 – In patients, in and out of community support
  It's the first time for many years that there's been any resource. We are still able to influence the 5 year plan.
  (Group then opens to wider discussion with all attendees)

- **Parent -** Will new people who come to the service be given a pack of information which includes how to complain or change therapists?
- **Parent** – Does a child have to be at crisis level before anything happens?
- **Parent** – Teachers and schools are the next port of call. Schools need to intervene.
  Andrew Wealls – What do we mean by 'CAMHS' and 'Tiers? We would like to get rid of these terms and talk about 'Needs'. Also who advocates for these people. Is there a co-ordinator who does this?
  Peter Joyce- Help is provided by various different people
- **Parent -** Kids themselves are picking up the fact that unless they hurt themselves they won't get the help.
  Gill Brooks – Tiers are a national framework. They are used nationally. We would like to get rid of these terms and talk about needs. There is stigma attached. On a low level there is support for kids in the community with drop ins and youth clubs.
- **Parent** – Where do these kids go that are the most vulnerable? Not Youth Clubs, they're out on the streets or in MacDonalds. How can we help those kids?
  Gill Brooks – The Tapa team go out and work in the community. Also schools with Mental Health workers can refer and facilitate more quickly.. How do we make it an integrated pathway? Issues are complex – it's about all professionals coming together.

Discussion brought to a close

Further Questions and Comments Submitted by Parent Carers during group discussions

- There should be better written communication between professionals and parents
- The culture of stigma around mental health in schools needs to be addressed
- There needs to be more support for families – especially siblings
- There needs to be more support for families whose children have ADHD, they are only offered medication there should be other support – talking therapies.
- Needs to be a clear plan of what services exist, who they are for, what they can do.
- ADHD is not under mental health or a learning disability – how should it be classified?
- Support and training for schools – is it happening? If so get Young People involved in delivering the training.
- I don't feel able to comment or criticize the service as I'm still using it, but have concerns about how the diagnostic process was for the child – mainly because of poor communication.
- On the grapevine conversations with parents feel that CAMHS struggles to meet the needs of those with risky behaviours, but also doesn't provide sufficient support at a lower/preventable level. General view that 'CAMHS can't cope' and as a result parents don't have much faith in it.
- How can we help children with high functioning autism with anxiety to prevent behavioural issues, low self-esteem and suicidal tendencies?
- My son talks about killing himself and he started turning words into actions – reaching for the knife drawer. He has ASC. How do I get him help so he doesn't hurt himself?
- What about children who don't present at school but school causes the anxiety that leads to challenging behaviour at home?
- A positive – Sophie Kaye – specialist nurse at Seaside View really helped addressing my son's sleep issues – he slept through for the first time at the age of 11. Also helped with some family time.
- Clear pathways that are adhered to need to be in place pre, during and post assessment/diagnosis, for service user and family.
- There needs to be more clarity around the DECISION for intervention and what level.
- Tier system confusing and seems service provider rather than service user friendly; CLINICAL need should be put first but this often isn't the case, CYP end up "parked" on tier 2 for example and some CYP have even stated that in order to get the real help they need they would need to do something drastic to move up a tier where at that higher level they will receive adequate support.
- Spot checking should take place when "off radar" esp as this can often be the time where things can go very wrong i.e. when "quiet" may be suffering in silence and end up doing something drastic.

- More clarity on what happens between ASC 1 and 2 stages, long gap in between, keep parents in the loop this is a crucial time when they need support for the CYP, themselves and family.
- Info pack of choices as to what the service will provide? Check this will be available.
- How do CAMHS intend to reach children in independent schools sector, or home educated?
- Stigma; what happens if schools become academies and can select or not select children with MH needs.
- In the case of ASC, MH may appear to be a small part of the problem, when actually it is core to the behavioural difficulties. Also people want help with MH because there is a belief that if this is addressed, other difficulties will lessen.
- How can parents be sure that with ASC CYP there will be adequately 'autism trained' MH staff who will also be sympathetic to the fact that therapies etc that help neuorotypical CYP may not work or help those with ASC and in fact could make matters worse?
- Parents need reassurance there will be a flexible Approach, tailored to CYPs needs not that of the service i.e. get out of your clinic based mentality and meet these CYP on their level! At their home or a neutral place for eg.
- Outreach for CYP with lifelong conditions like diabetes is great (at the RACH) but what about lifelong conditions like Autism where is the MH support there? It seems crisis based rather than proactive like the RACH scheme.
- Why are some CAMHS professionals insisting on using ASD when ASC is used across the board in SSV, ACSCC, other LA services. A simple thing, but it sends mixed messages to CYP and parent carers.
- The FAMILY Therapist mentioned that SSV have a team of MH workers for special schools. What about mainstream CYP? Where's their help here? It's a two tier system and seems grossly unfair.
- The Family Therapist also mentioned that 11 schools in the city have MH support, what about all the other schools? Postcode lottery?

Appendix 1. Questions and Comments submitted by a parent following the PaCConnect (Paula Donovan of mASCot)

I'd come as a parent (13 year old daughter diagnosed with complex needs - Sensory Processing Disorder with Generalised Anxiety Disorder with Asperger 'Traits' with Selective Mutism, is seen once a year by a private psychiatrist via The Learning and Assessment Centre, Horsham and London, takes a minimum level of medication and is about to move back into a mainstream girls school from a very small independent school. Symptoms are well managed, occasionally noticeable).

I came today wanting to hear current developments as am passionate that children with complex needs get the support they deserve to live well with their conditions. I also wanted to know what improvements have been implemented following the ASC Scrutiny and Health Watch's 'Putting the Pieces Together' reports. These reports made it clear how important it was that urgent improvements in mental health provision be made to prevent suffering.

1. Wasting lives - the pace of change is still too slow

Firstly thank goodness there's a new CAMHs Commissioner who seems committed to making innovative improvements.

I really liked Gill Brooke's outline for a service transforming from a splintered and compartmentalised agency approach to holistic provision based around the need of the user, rather than the need of the provider, as part of a national picture of how mental health is being re-assessed - all this is very welcome. However I'm really unsure how families struggling now are going to be helped when being caught in moving from one old system to a new world order that could take years. I did not get a sense of urgency this morning. The timeframe seems still too slow for the many suffering today. None of these problems are new, we've all been talking about them for years, many reports have been commissioned. We arrived here in 2006 with a seriously unwell child with significant mental health issues, he's now nearly 17 and we're still talking about the same provision problems for children!? This is not a criticism of Gill Brookes who has inherited somewhat of a poisoned chalice but where is the urgency when these conditions can be life threatening and life limiting.

In other words - where are the consequences for providers who mention the ASC Intervention Group - that meets about twice a year - still debating if they can implement the ASC Scrutiny recommendations? Always 'implementing' never 'in place'.

there's such a variety between agencies; finding out what best practice is; piloting introduction of mental health provision within a few schools; it might get offered to private schools (who won't use their fees to pay for it of course); needing to consider how mental health impacts on primary school age children which seemed a 'new' issue; how to support parents in the gaps between interventions; setting up a parent/carer forum for

The development ideas are very positive but I am just astonished because it feels as if mental health services have just arrived in the city - not been here for years. I'm really pleased sound developments are on the way but it begs why are they still at such a primitive stage? It's almost naïve. The idea of starting to formulate a PR campaign in the autumn to challenge mental health stigma is worthy but idealistic. My child was declined a place at a school this month because the Head said he was not confident he had the skill or expertise to deal with a mild mannered little girl who lives well with her Anxiety, for no reason other than the school does not understand mental health issues ..... too late for her then. Stigma is everywhere, all the time, we live with it today, tomorrow is too late, her childhood will have passed and I will be lucky to find a school where she can fit in, who will take her, because of the stigma of mental health in the meantime I pay privately for psychiatric support because I can't trust CAMHs to do it in a supportive manner.

In the Scrutiny SV and CAMHS kept referring to waiting times for diagnosis as the thing that seemed to bother parents. Lack of timely, effective, person centred and response provision is what bothers parents. The fact that parents were still reporting this morning 'you just sit there between ASC I and the next assessment" and the response was "that's been a problem" and there's been a "lack of clarity" is incredulous. How many reports does it take to improve a communication system?

2. Communications with CAMHs

* I made my complaint about the poor communications and staff attitudes in CAMHs in 2010. I was one of three formal complaints that year

* The Health Watch reports four formal complaints about CAMHs in 2013 related to staff attitudes

Has nothing changed? Who is challenging cultural attitudes within CAMHs about some staff and some attitudes?

Brenda Davis referred to Gill Brooke's outlining the new money for provision as though an under resourced service was the sole reason for user dissatisfaction levels.

I think it was fairly clear from the ASC Scrutiny it was the culture of how parents were communicated with that was as much a problem as the long waits for diagnosis and the little to nothing help on offer at the end of it. Certainly Brenda this morning referring to users as 'the ones' did remind me of that old 'them and us' culture I have done so well to take myself out.

A slip of the tongue perhaps but indicative of the old expert/recipient culture the new system under Gill Brooke's is clearly trying to move away from.

A problem is Gill Brookes striving to systemically re-shape a system away from the 'going round the houses' approach parents have been forced into. But if this isn't addressing the cultural top down medical model inherent in CAMHs - of hierarchal health providers with diagnostic heads on rather than supportive person centred flexible providers able to work with young people and their families - in McDonalds as that parent said, on the street - being grounded and responsive to a family 'where ever they are at' in their lives - this TAPA approach - then there's no hope of going forward while the old guard remain in post as I can't see how a can do attitude is going to prevail when Peter Joyce reflected, with no seeming awareness of the implication, that they were "unable to spot check" on cases in between the crisis moments.

Gill Brooke's challenge is how to change a system from a reactive medical model to a proactive person centred one while being saddled with CAMHs Tier 3's old ways of doing things. I'd be happy to meet with her for a chat about why it works in the private sector and seeing if we could copy over some simple interpersonal communication skills and customer feedback questionnaires so that users design the services they need, not what someone thinks they need.

- Example of lack of urgency/lack of implementation - the introduction of an information pack for new users - how to raise a concern/complaint - not done

  The ASC Scrutiny recommendations 2014 called for improved feedback opportunities for parents. This morning Brenda Davis explained they have introduced a feedback system of 'what works, what didn't, what could they do better'. I was unclear at what point this is offered to parents but when I asked if the Health Watch recommendation below (2) had been introduced an information pack for new arrivals in the service explaining how to raise a (timely) concern and or how to make a complaint and how to change therapist - ie their right to address - Brenda Davis and Peter Joyce were vague, unclear or unfamiliar with what I was referring to and said it was being developed but that a leaflet was given about the service. Two people in the group were reporting communication problems with CAMHs (that are current, not as Brenda referred to in the Scrutiny as communication being an old historic problem).

Health Watch Specific Responses (report November 2014)

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.

Commissioner response - does not include how to raise a concern.....

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<http://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.

Appendix 2: Questions and Comments submitted by a parent who was unable to attend.

1. Where can people find CAMHS' policies on disability discrimination?
2. Many parents have found CAMHS operates in a culture of parent blame *(as reported to the 2013 ASC scrutiny panel)* what is CAMHS doing to address this?
3. How long would CAMHS normally expect to provide therapy for a child, before recognising that it was not working and offering alternatives?
4. Does CAMHS not think it appropriate that a named key person is available for parents to contact, bearing in mind the difficulties parents have in reaching their child's clinician and many staff seemingly working part-time or being held up in meetings or in clinic?
5. Bearing in mind that the National Autistic Society says that approximately 1 in 10 of children CAMHS sees are autistic, what is the minimum autism training CAMHS clinicians involved in assessing and supporting autistic children have and is their training and current knowledge kept updated?
6. Why do CAMHS not actively inform parents of children who have not been diagnosed with autism following an assessment, of their right to a second NHS opinion elsewhere?
7. There was, as reported at the 2013 ASC scrutiny, an inadequate postcard feedback system reported as being in place at CAMHS, that was 3 whole years ago, why has CAMHS done nothing obvious to change this system to an effective one, with more in-depth questions and highlighting it to parents?
8. Is CAMHS understaffed and what does it plan to do to address this if so?
9. How does CAMHS record waiting lists, e.g. is a "first appointment" classed as the person having been seen, even if the therapy doesn't start until weeks or months later? If so, this potentially leads to false statistics recording unless it is broken down into when first seen and when therapy or assessment started - does CAMHS do this?
10. CAMHS does not seem to take into account sensory processing disorder in autistic patients and their parents, the waiting area needs to be monitored by ensuring the radio is not on *(particularly in view of inappropriate songs being played with children present)*, why has CAMHS not taken this into consideration, especially considering the rate of autistic patients it sees?
11. Why is CAMHS not training staff in female presentation of both autism and ADHD and keeping clinician's expertise relevant and accurate?
12. Are CAMHS staff aware of how to avoid misdiagnosing autistic and ADHD children as having attachment disorder? How relevant and up-to-date is their training on this?
13. Why are CAMHS staff not aware that autistic children with mental health problems such as anxiety and especially depression present (and may

self-report) atypically and use tick-box assessments based on neurotypical presentation that are unreliable for these children?

Appendix 3: SEMH Project Group for the Integrated Specialist Provision co-design.

As part of the proposed redesign of the Special Schools and Specialist Provision (PRUs and Connected Hub), the Council has set up 3 Project Groups to discuss the proposals in more detail. These are:

- Early years
- Learning disabilities
- SEMH

The aim is for all stakeholders to be actively involved in this. Two PaCC steering group members, Helen and Diana, sit on the SEMH group. (There are also 2 steering group members on the other two groups)

We have been to 2 meetings so far. The first was a general discussion, while in the second the group split into focus groups to come up with rough designs for the new SEMH provision, based around a few key principles. These included: governance arrangements, the curriculum, key partners, the site, transport, communication. We also looked at responses to the online consultation.

There will be two more meetings, in May and June, during which proposals will be cemented.

Appendix 4: A brief explanation of what tiers are as found on Wikipedia https://en.wikipedia.org/wiki/Child_and_Adolescent_Mental_Health_Services

---

The Parent Carers' Council (PaCC) is a parent-led forum which represents parent carers with children and young people with any kind of physical disability, learning disability, complex or long-term medical/health condition, or special educational need. The group was formed to enable parent carers to work closely together to help improve services and support. It aims to help parents get more directly involved in the strategic delivery of services for disabled children in Brighton & Hove and now has about 270 signed up members. Our partner groups are; mASCot, Kaleidoscope, Barnado's Link Plus, Extratime, Pebbles, Sweet Peas and T21.