



Parent/Carer meetings on CAMHS experiences

Meet the Commissioners (aka CAMHS Chat)

Final summary report: 8th August 2017

Top level Summary

Pages 1 & 2 are the top level summary. It is recommended that recipients of this report read the full summary (pages 3 to 10). Readers' understanding of the Summary Report will benefit from this (and it's not too onerous really!).

- There were 60 respondents over a total of 4 meetings.
- Percentage wise, 40% of respondents came from 1 meeting with ADHD Richmond. Medication is important where the primary diagnosis is ADHD.

1. Is a diagnosis important?

Yes – a resounding Yes. 100% affirmative across all the meetings.

1. provides respect for the individual and their human rights
2. enables the family, and those around the child/young person to seek appropriate help, support and therapies

2.a) What worked well about the process?

1. Support outside of CAMHS can be good (eg the educational psychologist or the school SENCo).
2. Excellent support where the school or other agency and parents are on the same page
3. There have been some local improvements to the system and waiting lists

2.b) What didn't work well?

1. Painfully long waiting times for assessments (which in turn affected the entire family as the child, young person and family are in 'no-mans-land')
2. Shoddy process; no transparency or indication of timeframes families should or could expect.
3. Springfield is another country... (it's not local)

3. What are the benefits of diagnosis (if any)?

1. A huge sense of relief for the entire family (parents, carers, children, young people and the extended family).
2. Clarity. The beginning of understanding the condition.
3. Where the primary diagnosis is ADHD – the option of medication is a significant benefit (for the child/young person and their family)
4. Sometimes, security for the child in the education system.

4.a) After diagnosis, what changed for your child?

The answers within this section are (perhaps) a little compromised – because we are asking parents and carers for their views of the affect upon their child/young person.

1. Improvement in self-esteem and self-awareness
2. Improvement in mental health. A way to explain to themselves [and others] who they are (if they choose to do so).

4.b) And what changed for you?

1. Understanding and knowledge.
2. Access to counselling services (via GP)
3. Security and protection of the child/young person's human rights (eg disability discrimination, the Care Act, Children's & Family Act)
4. A common theme – for those with autism - is that there isn't much available in terms of support for more able girls who receive a diagnosis later. For some, ASD is picked up when issues like anorexia present.

5. What services did you feel able to access whilst waiting for a diagnosis?

1. None.
2. “We received support from...” Express CIC / MeToo&Co / NAS Richmond / ADHD Richmond (always the voluntary sector)
3. Training (as mentioned): The Hanen programme / Early Bird / Early Bird Plus
4. Sometimes, schools; two received particular mention:
Kingston - Grand Avenue primary school
Richmond - Holy Trinity School SEND parents group

6.a) Who helped you?

1. Educational Psychologist (where families had access to EPS)
2. Local support groups (as per the authors of this report)
3. The educational setting (nursery or school)
4. GP
5. Other parents
6. No-one
7. Social Worker
8. Private therapists
9. Police and emergency services
10. Early Birds & Cygnets programme from National Autistic Society

6.b) ...and what else could have helped and when? (What would you like to see for the future?)

1. Understanding and helps begins at home. If someone comes to your home – and offers help – direct help - this makes all the difference (instead of attending an appointment at a clinic – and having to get your child there...).
2. Streamlined services. Local services are definitely a good idea.
3. Transition service between children's and adult's mental health services.
4. Make sure process is clear, faster and transparent is important (ie a definite timeline)
5. A point of contact. A 'named' someone.
6. Better, localised information – and include benefits advice.
7. Is there scope for Educational Psychology Service to get involved?
8. A timely diagnosis
9. More understanding and less judgment from schools; less sanctions and exclusions.

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Attendees:

Express CIC:	Date: 19th June	Total No.of respondents:	16
SFV @ MeToo&Co:	Date: 23rd June	Total “ “ “	10
ADHD Richmond:	Date: 21st June	Total “ “ “	24
Richmond NAS:	Date: 13th July	Total “ “ “	11
		<u>Total:</u>	<u>60</u>

Whilst all interested parents in Kingston and Richmond were welcome to attend any meeting, often, by nature of the host organisation:

- 1 of these meetings was mixed (adhd and asd)
- 2 of these meetings focussed on autism
- 1 focussed on ADHD.

Three notes:

1. Percentage wise, 40% of respondents came from 1 meeting with ADHD Richmond.

Whilst this does not have a bearing on the overall themes, it must be noted that ADHD, unlike autism, can be treated (to some extent) with medication.

Therefore, when reading this feedback, notice must be given that the interest in medication is particular to those families where ADHD is the primary presenting diagnosis.

2. Question 4 asks 'what changed for your child/young person after diagnosis'

We make no apology for stating that the answers within this section are (perhaps) a little compromised – because we are asking parents and carers for their views of the affect upon their child/young person.

For future formal consultations, it would be wise to talk to children and young people themselves about the effect on them of their diagnosis. Care should be taken that a wide range of children and young people are consulted.

3. Through ADHD Richmond, a consultant asked if we asked for a date of diagnosis, as he felt the referral pathways had changed recently and this may have a bearing on responses.

Whilst we did not ask for the date of diagnosis we can say that approximately 65% had been through the diagnostic process quite recently.

Whatever the date for diagnosis, the seemingly endless, uncertain wait and lack of support either side of the diagnosis is consistent.

These are the questions we explored:

1. Is a diagnosis important?

Yes – a resounding Yes. 100% affirmative across all the meetings. Because:

1. provides respect for the individual and their human rights
2. enables the family, and those around the child/young person to seek appropriate help, support and therapies

Why (key themes):

- respect for the individual; enables parents, carers and people involved with the young person to understand them.
- the child/young person often regains some self-esteem (where previously it had been eroded)
- enables the young person to understand themselves (where cognitively able)
- the right diagnosis is important (several cases where children and young people were initially misdiagnosed – leading to mental health problems down the line)
- influences and enables the correct package of therapy.

“Without a diagnosis, I couldn't tell if my child needed help with their mental health, or their neurological condition. The support, the packages, would be different depending on their need.” Parent didn't want to risk getting it wrong.

In these meetings, what was really striking was that for a young people's peer group, a diagnosis of Autism, was less of a stigma than saying they had mental health problems!

Around Y8/9 as puberty kicks in, this is a time when outwardly able young people really experience significant difficulties at school.

“Our child was not assessed for autism - but had been through 1-2-3 Magic programme. Autism was not mentioned, but it eventually became clear this was the path. Why are those with HFA [high functioning autism] constantly missed? Perhaps we can use more than one tool for assessment and diagnosis? Some children are good at mimicking behaviour and so get missed.”

[The 1-2-3 Magic programme is for parents and carers of children aged 2-12, diagnosed with ADHD or who display challenging behaviour]

A diagnosis is not a 'label' but leads to understanding, appropriate educational approaches and support groups. *“My [son's] world would have been very different without an early diagnosis”.*

An end to *“...being continually punished for not 'behaving' which has a negative effect on the child's self-esteem.”*

What happens without a diagnosis?

"You do not feel you have a proper understanding of your child; of why they are doing what they are doing. You have no starting point for research, nothing to type into google to find out what to do and where to go for support. Essentially, you have no support, and no explanation to give others. There is a lot of guilt, and loneliness – you stand out at the school-gates as the parent of 'the difficult/weird/unpopular pupil'"

Without a diagnosis, school don't have to do anything; there is no accountability.

"Teachers tend to just say everything is fine: but what is fine? If your child has no learning disability and appears to be making academic progress & has no challenging behaviours, the risk of breakdown as they get older piles up and up – no-one listens if you point out the emotional, mental health and other difficulties you're seeing at home. Sometimes the teachers are more bullying than other children in the class"

2.a) What worked well about the process?

1. Support outside of CAMHS can be good (eg the educational psychologist or the school SENCo).
2. Excellent support where the school or other agency and parents are on the same page
3. There have been some local improvements to the system and waiting lists.

"Once we got through the system, I cannot fault the service we received. The therapist allocated under CAMHS was happy to go along with the notion a working diagnosis until she had received the assessment. The doctor who gave the feedback was so positive in the way he delivered the diagnosis to our child it made a huge difference."

2.b) What didn't work well?

1. Painfully long waiting times for assessments (which in turn affected the entire family as the child, young person and family are in 'no-mans-land')
2. Shoddy process; no transparency or indication of timeframes families should or could expect.
3. Springfield is another country... (it's not local)

"CAMHS doesn't work – no information or signposting, time scales are awful."

It's not uncommon for parents to make an appointment to see the diagnosing professional and discuss the child's diagnostic report, then have to wait between 2-4 months to receive a written copy.

"Nothing felt as though it worked: It has felt like 18 months of hell. We saw a decline in our child's self-esteem and mental health."

“Waiting list isn’t just months, it is years. Everyone is in limbo, and it’s not just ASD issues that escalate but co-morbidities too, especially anxiety”

“...no one except those closest to our child could see the full extent of the turmoil inside or how low our child was. Our child’s ability to articulately and factually answer questions was misinterpreted.”

Parents repeated cite being given information that was badly photocopied, and on different ways up on each side of paper. This was a notable common experience.

Diagnosis used to be local; this is now done Springfield in Tooting.

“This isn’t a local provision and it feels quite scary – the professionals at Springfield dealing with the diagnosis have few/no links with local agencies or schools”

We were *“...sent lengthy forms to complete by CAMHS and the professional decided that this child was depressed without even assessing him (complaint lodged to CAMHS)! Eventually, the child was appropriately assessed and received an ASD diagnosis.”*

3. What are the benefits of diagnosis (if any)?

1. A huge sense of relief for the entire family (parents, carers, children, young people and the extended family).
2. Clarity. The beginning of understanding the condition.
3. Where the primary diagnosis is ADHD – the option of medication is a significant benefit (for the child/young person and their family)
4. Sometimes, security for the child in the education system.

“My son said; “Mum, please kill me and bring me back with a brain that works.” I talked to my son about his diagnosis and options. My son was clear that he didn’t want to take meds as he wanted to be Himself. He’d moved from suicide to acceptance of self.”

“We can now leave the house because we now get what we need as a family. This builds the resilience of the entire family. The diagnosis widens people’s understanding – that’s everyone around the child.”

“The world changed after diagnosis. [before] Autism didn’t exist in my world – to have this diagnosis opened doors of understanding for me and my family.”

Diagnosis has an immediate impact on Life.

“I could look things up, read books, research and get advice.”

“Access to Early Bird and other services. It gave me a peer group.”

“A diagnosis from a medical professional means you have a condition in most people’s eyes - there’s something definite & unchallengeable about it.”

Other parents are also more forgiving (the playground experience)

“As a family, we can be more understanding and put things in place. Our child can understand herself and learn to self-regulate and develop coping strategies.”

“Group support is important for the mental health of the parent and child, and this is possible to seek once a diagnosis is given.”

4.a) After diagnosis, what changed for your child?

As per page 1: The answers within this section are (perhaps) a little compromised – because we are asking parents and carers for their views of the affect upon their child/young person.

For future consultations, it would be wise to talk to children and young people themselves about the effect on them of their diagnosis. Care should be taken that a wide range of children and young people are consulted.

1. Improvement in self-esteem and self-awareness
2. Improvement in mental health. A way to explain to themselves [and others] who they are (if they choose to do so).

“We saw an improvement in our child's mental health. We could see things made sense to our child and us. I could ask specific questions to drill down and see what support our child needs and what the gaps are in social understanding. I have learned a lot about how our child feels and thinks by asking more specific questions which I wouldn't have thought about asking. ...our child feels that there is now some help.”

An EHC Plan can give security to child; often children are excluded from the school, but a diagnosis [of a disability] protects their human rights.

A diagnosis allows access to clubs, and in some cases, to schools. Without a diagnosis, the child/young person are not eligible.

“We have a family history of suicide: diagnosis gave us a different path and was reassuring.”

“We felt that professionals and our family finally took us (as parents, the pressures we are under, the allowances we have to make) seriously.”

4.b) And what changed for you?

1. Understanding and knowledge.
2. Access to counselling services (via GP)
3. Security and protection of the child/young person's human rights (eg disability discrimination, the Care Act, Children's & Family Act)

4. A common theme – for those with autism - is that there isn't much available in terms of support for more able girls who receive a diagnosis later. For some, ASD is picked up when issues like anorexia present.

"I'm not making it up!"

"We didn't know where to look, or how to understand what was going on."

"What's changed for us is that we are learning as we go and realising we don't always know what's up ahead. This can be both positive and really scary"

"School life changed dramatically. It was the difference between being in school, rather than at home."

"At a stage where we were looking to the future we are now aware there is a layer of vulnerability there which we hadn't expected. ...if our child is to go to university, there will need to be support put in place."

5. What services did you feel able to access whilst waiting for a diagnosis?

1. None.
2. *"We received support from..."* Express CIC / MeToo&Co / NAS Richmond / ADHD Richmond (always the voluntary sector)
3. Training (as mentioned): The Hanen programme / Early Bird / Early Bird Plus
4. Sometimes, schools; two received particular mention:
Kingston - Grand Avenue primary school
Richmond - Holy Trinity School SEND parents group

"Nothing in statutory sector! No-one believed ASD [ADHD] was an issue – we had to get a diagnosis privately in the end"

6.a) Who helped you?

Approximately in order (the gaps between bullet points are an indicator of response):

1. Educational Psychologist (where families had access to EPS)
2. Local support groups (as per the authors of this report)
3. The educational setting (nursery or school)
4. GP
5. Other parents
6. No-one
7. Social Worker
8. Private therapists
9. Police and emergency services
10. Early Birds & Cygnets programme from National Autistic Society

My 'golden person'

"I went to an Autism West midlands conference and spoke to a consultant who was a specialist in ASD and CAMHS in the West midlands. That doctor confirmed my instincts and gave advice of what to do."

"Better trained staff & access to support whilst we were waiting – reality is, if you've been referred for a diagnosis, there's a high chance you'll get one. Professionals should therefore start offering support and reasonable adjustments on this assumption."

"Someone to talk to"

Early intervention and support saves money down the line.

"The nursery were really good. They helped me get through the system and also sorted out my child's EHC Plan ready for school. My child went in with 1:1 support. I don't know what my child's future would look like now without this early intervention. However, my experience was not the same as my peers. Others had a much, much tougher time."

6.b) ...and what else could have helped and when? (What would you like to see for the future?)

1. Understanding and helps begins at home. If someone comes to your home – and offers help – direct help - this makes all the difference (instead of attending an appointment at a clinic – and having to get your child there...).
2. Streamlined services. Local services are definitely a good idea.
3. Transition service between children's and adult's mental health services.
4. Make sure process is clear, faster and transparent is important (ie a definite timeline)
5. A point of contact. A 'named' someone.
6. Better, localised information – and include benefits advice.
7. Is there scope for Educational Psychology Service to get involved?
8. A timely diagnosis
9. More understanding and less judgment from schools; less sanctions and exclusions.

Repeatedly, parents stated that understanding and helps begins at home. If someone comes to your home – and offers help – direct help this makes all the difference (instead of a clinic). They can see your child in the home – in the environment they live in – and can make practical, applicable suggestion in situ. This cannot happen the same way in a clinic.

Please do not reduce funding – instead offer streamlined services. Local services are definitely a good idea.

Transition service between children's and adult's services. Not dependent on an Education, Health & Care plan but an entitlement if there is a diagnosis – this could include specialised paediatric services that continue smoothly into adult services

"Why wait until it's too late and people start to self-medicate with alcohol etc"

Make sure process is clear. Ideally faster. But clear and transparent is important (ie a definite timeline, like the EHCP process in the golden binder)

A point of contact. A 'named' someone. Where parents had this, it was invaluable.

The information given was poor (see above). So... better information. Localised information – and include benefits advice.

"I gave up work to look after R, but didn't find out about DLA for a long time."

Is there scope for Educational Psychology Service to get involved?

Not having a timely diagnosis and not receiving relevant support/interventions can lead to an escalation of that child or young person's difficulties and possibly very serious consequences, eg: self-harming, suicide attempts.

More understanding and less judgment from schools; less sanctions and exclusions. More adjustments that took into account what the child/young person's underlying difficulties might be (look to the cause, not the symptom).

"Initially, the teachers were negative about my child's behaviour. However, after a domestic incident [DV] in which the police were involved, a referral to CAMHS led to the teachers changing their approach plus giving my child access to therapies within school." This child is still on the waiting list for a diagnostic assessment (some months on).

...ends//

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