

25th June 2015

June 2015

CAMHs Focus Group



Introduction

This report is a record of a focus group held on 25th June 2015 around the topic of Child and Adolescent Mental health services (CAMHs) and Emotional Mental Health and Wellbeing. There were two elements; an update on CAMHs and group work to gather views/ solutions around CAMHs. The focus group was put in place to gather views from parent carers in Peterborough alongside a series of Pinpoint Network meetings taking place across Cambridgeshire. Some work in the focus group mirrored the network meetings but there were also some differences based on previous experience of running focus groups in Peterborough and having prior knowledge of what works well.

The focus group was attended by 13 parent carers, two CCG staff and a Peterborough City Council Officer. A general update was delivered via a PowerPoint presentation, followed by group work and finally a feedback/ open discussion session. Data on the needs of the children/ young people (CYP) of the parent carers was gathered on feedback forms completed at the end of the session.

Method

Participants

13 parent carers all female attended the focus group; there were White British, Albanian and American. They had CYP aged between 7 and 15 whose needs ranged from Autistic Spectrum Disorders (ASD) to Learning Disabilities (LD). 9 parent carers reported their CYP as having ASD (be this Autism, Asperger's, Dyspraxia). 3 parent carers reported their CYP as having Tourette's as a secondary condition.

Details

The focus group was broken in to three parts; an update on CAMHs from the CCG, group work and an open discussion. For the group work the parent carers were split into three groups during which they had the opportunity to explore personal issues/ concerns, identify possible solutions and answer questions taken from the Pinpoint Network meetings:

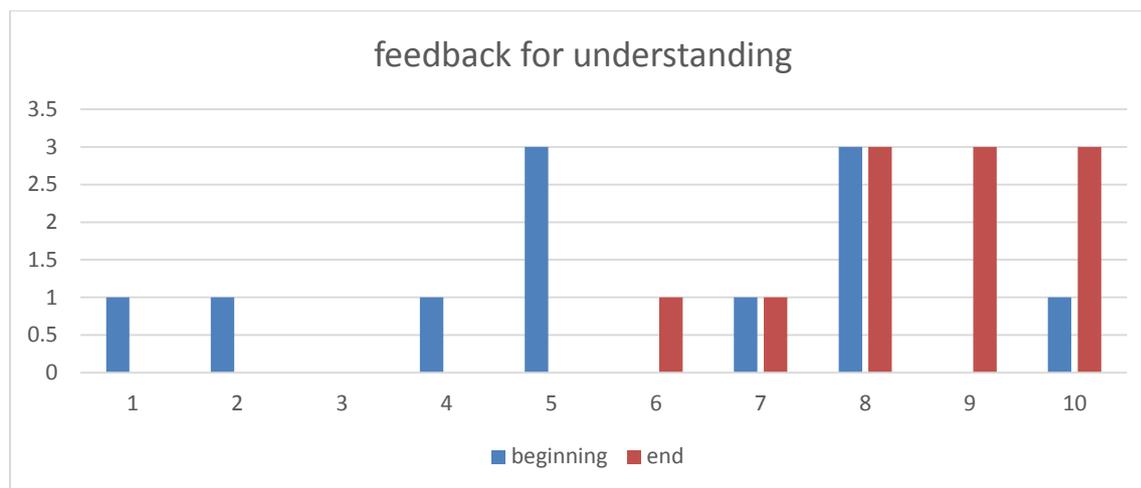
1. What services do you value and think work well? Why?
2. Where are the most suitable places to receive services?
3. How can we improve access to services?
4. How can we do things differently?

The professionals from the CCG, LA acted as facilitators and scribes during the group work and then fed back the information captured on flip charts.

Results

The following table and graph detail parent carer self-rating for understanding of CAMHs and the current situation at the start and end of the focus group.

| | low | | | | | | | | | high |
|-----------|-----|---|---|---|---|---|---|---|---|------|
| | 1 | 2 | 3 | 4 | 5 | 6 | 7 | 8 | 9 | 10 |
| beginning | 1 | 1 | 0 | 1 | 3 | 0 | 1 | 3 | 0 | 1 |
| end | 0 | 0 | 0 | 0 | 0 | 1 | 1 | 3 | 3 | 3 |



- a) 11 forms were returned out of 13 parents who attended = 85%
- b) 6 at the beginning scored themselves as 5 and below in their understanding
- c) In the end all those who had scored their understanding as below 5 had switched to 5 and above - their level of understanding had improved
- d) 1 respondent scored their understanding the same at the beginning and at the end

The table below relates to rating of the venue, timing and presentations and this is followed by some comments under each section, all respondents completed this section of the form

| | venue | | Timings | | Presentations | |
|------|-------|---|---------|---|---------------|---|
| low | 1 | | 1 | | 1 | |
| | 2 | | 2 | | 2 | |
| | 3 | | 3 | | 3 | |
| | 4 | | 4 | | 4 | |
| | 5 | | 5 | | 5 | |
| | 6 | | 6 | | 6 | |
| | 7 | | 7 | 1 | 7 | |
| | 8 | 2 | 8 | 2 | 8 | 4 |
| | 9 | 2 | 9 | 3 | 9 | 1 |
| high | 10 | 7 | 10 | 5 | 10 | 6 |

- a) Venue - the venue rated highly with one comment being recorded relevant to this category "too noisy at times"

- b) Timing - rated well with one respondent commenting "*maybe needs to be a longer session. Parents with children with additional/ complex needs want to be heard and tend to require a longer session to be heard*"
- c) presentations - issues with noise linked to venue, wanted tables, the feedback from the workshops was enjoyed

Other comments

- a) "*Was great to give suggestions that could help improve services for not just my child but others*"
- b) "*more information sent out from professionals, support groups for kids and special play groups. More passport books handed out*"
- c) "*Workshops around anxiety etc for CAMh at first point of referral (my idea for CCG to take forward for early intervention)*"

Questions asked and answers

1. What services do you value and think work well? Why?

- a) Early intervention services. Basic information sharing between schools and services
- b) Early intervention services. Constituency health visitor services
- c) Behavioural, family support workers in schools. Parent carer advice and support
- d) Autism outreach

2. Where are the most suitable places to receive services?

- a) Anywhere, just accessing services would be good.
- b) professional clinics
- c) schools, pre-schools, clinics

3. How can we improve access to services?

- a) Quick triage, keep parents informed of waiting times and give basic advice "coping advice" for in the meantime. Why not hold regular workshops and allow many parents to get strategies/ advice to help while waiting for assessment.
- b) Access to courses without formal diagnosis
- c) more workshops for parent carers, open clinics, parent carer chat groups, parent to parent support

4. How can we do things differently?

- a) Don't keep telling us " we cope well so don't need input" - we have to cope well there is nobody else to do it
- b) Broaden the courses, like for anxiety, compulsive behaviours, sensory issues
- c) more sensory advice, better training for TA's

Some of the comments from the work groups are as follows:

- *Once in the system it's good, need more support when first diagnosed. Not to keep going on about the same information, have it all merged together*

- *When diagnosis is given, parents should be given good information pack, This is important as parents go straight home and google which can be very negative;*
 - a. *Information on condition*
 - b. *Local support groups*
 - c. *Website/ phone numbers*
- *Health passport and information book to write in (sometimes it has taken SALT to write up)*
- *When attending appointments, if specialist/ practioner can fill out carbonated forms so when you leave appointment you have a written plan and next steps and what was discussed to take away (like an IEP) and take to future appointments to share with school etc*

Some of the notes captured during the group discussion

- *There was agreement that services need to be ‘needs’ led rather than diagnosis led, but again concerns were raised that without a diagnosis people find it difficult to access the help they need*
- *We all agree that this type of parent to parent support is useful, although not all advice is good advise or right for your child. That needs to come from professionals with good training and experience.*

Analysis

Some themes that are evident through the discussion notes/ work group comments

1. Lack of communication and confusion around waiting list closure
2. Diagnosis and access to services, view of parenting
3. Use of workshops, support, information sharing to make things easier with and without the need a diagnosis

Some suggestions from parent carers

1. When attending appointments, if specialist/ practioner can fill out carbonated forms so when you leave appointment you have a written plan and next steps and what was discussed to take away (like an IEP) and take to future appointments to share with school etc
2. Broaden the courses, like for anxiety, compulsive behaviours, sensory issues
3. Workshops around anxiety etc for CAMh at first point of referral (my idea for CCG to take forward for early intervention)

The focus was attended primarily by parents who reported their child's needs as ASD and all those who attended were women. The group was diverse in terms of their ethnicity and age of their children.

Understanding was rated as higher at the end of the focus group compared to the beginning of the focus group and all who attended reported wanting to take part in future focus groups.

APPENDIX 1

CAMHs Group Work Notes

Group 1

Positive

Behavioural family support worker in Heltwate
Parent to parent support
Additional Support

Negative

Needs led not diagnosis – there should be equal services
Thresholds are too high

Solutions

Better communication with parents
School training to recognise needs and provide support
More sensory input and support
More integrated health = GP, Paed, LD
More group sessions

Other comments

Behaviour/ Emotional Wellbeing
Do we rely too much on untrained TA's
Stop telling us we are coping

Group 2

1. Once in the system it's good, need more support when first diagnosed. Not to keep going on about the same information, have it all merged together
2. Tell your story once, read your notes before they see another patient
3. Doing a multidisciplinary every two years so they don't get missed. Contact with local doctor or paediatrician, GP should have more information about children with difficulties
4. Having the right information, knowing and telling the parent some support groups and information
5. Health visitor and more information, 2.5 to 5 should have services. More knowledge about sleep when 2, go through medical conditions before sleep solutions
6. Smearing – portage 2.5 didn't pick it up or health visitor, they need more training or have a child with difficulties
7. Ask parents about giving other agencies information eg OT/ SALT, receive different invites to support groups

Post It Notes

- A. Confidence building and sessions for the children

- B. Support groups for the children
- C. When diagnosis is given, parents should be given good information pack, This is important as parents go straight home and google which can be very negative;
 - a. Information on condition
 - b. Local support groups
 - c. Website/ phone numbers
- D. Health passport and information book to write in (sometimes it has taken SALT to write up)
- E. Support and counselling for children
- F. Health visitors to have more input in the early years not just up to 2.5. Their specialist knowledge is needed to support pre-school and nurseries. So then responsibility is not on childcare
- G. When attending appointments, if specialist/ practioner can fill out carbonated forms so when you leave appointment you have a written plan and next steps and what was discussed to take away (like an IEP) and take to future appointments to share with school etc
- H. Better transition support between schools (front line staff support). Support considering – pupil views form, parents input, school support, specialist support
- I. More families to benefit from multi-disciplinary meeting + support, so everyone receives up to date information about the child – CAF

Group 3

- Problem with CAMHs understanding around the closure of the waiting list. People's perception of why list is closed, who it is run with.
 - Speech and language run workshops to deal with their waiting list. 20 people workshop on how to deal with stammer for example
 - Can CAMHs run workshops to offer some support, for example workshops on anxiety.
 - If child has a diagnosis professionals need to be more proactive
 - If GP doesn't write correct things on a report may not meet criteria
1. What services do you value and think work well? Why?
 - a. Autism outreach work – really good service, not enough teachers available. If no diagnosis can you access this? YES – Why not widely known.
 - b. Need more specialist services like play workers at Amazon, A+E, books in picture forms, LD team at hospital, support for children and parents, patient passport (not widely known about)
 2. Where are the most suitable places to receive support
 3. How can we improve access to services
 - a. Schools
 - i. If schools don't recognise the problem you have a problem
 - b. School nurses
 - i. Too long waiting lists
 - c. GP practices
 - i. Specialist or low level support
 - ii. Make better use of GP practices
 - iii. GP's don't understand the problem
 - iv. Depends on which GP you see

- d. Child Development Unit
 - i. Recognised facilities
 - 1. Child friendly
 - 2. Adaptive
 - 3. Recognised
 - ii. Important that it is not a hospital location
 - e. Hospital
 - i. Support needed when need to go for other appointments in other departments
 - 1. Ophthalmology
 - 2. Dentistry
 - 3. Orthodontics
 - 4. A+E - some people do not feel pin, have sensory problems.
Special Patient Notes
4. How can we do things differently?
- a. Improved signposting

APPENDIX 3

Notes taken by Jane Coulson

Family Voice Peterborough meeting on Mental Health Issues.

The Fleet, Peterborough.

25 June 2015.

Notes on feedback from parents.

CAMHS waiting list

- There was a lot of confusion on who could or couldn't now be seen. Explanations were provided that this waiting list was not closed to those already in it, but was not taking any new referrals until a better system could be put into place.
- Support for the idea that a diagnosis should not be the only route into services, however some concerns were raised that without a diagnosis how will parents be believed, or taken seriously?
- Parents expressed concern, that without early diagnosis for under 5s it would be hard to access key services like speech and language therapy that supports their key developments at this stage. Help is needed as early as possible, preferably before they start school.
- There was agreement that services need to be 'needs' led rather than diagnosis led, but again concerns were raised that without a diagnosis people find it difficult to access the help they need.

General discussion and comments

- There are more and more children getting diagnosed with autism. How can you say you are moving away from giving people a diagnosis?
- The Autism team were brilliant for my family, I had been struggling with the school for ages, the reports I received from the team were exactly what I needed, my child is now getting the support and understanding they need.
- When you talk about reforming the whole system, will you be looking at school/home/community support as well? Will you be joining it all up?
- When we talk about support we don't just mean clinical people, support can come from other parents going through similar experiences.
- We all agree that this type of parent to parent support is useful, although not all advice is good advice or right for your child. That needs to come from professionals with good training and experience.
- We used to have a befriending service that was funded through grants and charities, but that has gone. That was a good service.
- There was/is a befriending service for young people with Autism. (There was some uncertainty as to whether this service still exists.)

- Why can't we be given the equivalent amount of money? Then if we can afford it we can top it up and get treatment privately. Similar to personal budgets. It was explained that without the services receiving a set amount of money managed through NHS contracts, they couldn't be provided. There needed to be certain amount of money in the system to pay professionally trained staff, pay for premises and equipment etc. and guarantee that services were there when people needed them.
- On the subject of parent to parent support, parents need some training to deliver this. People can be in crisis and an untrained person can say the wrong thing.
- Many of us parents would love to be trained to offer the right sort of support, we have all needed it at some point and probably will again, this is a long journey.
- In adult services they have 'recovery colleges.' This is often used in drugs, drink or self harm support. People who have been through the system and are in recovery are trained to support those going through it. This offers training and skills to the person in recovery, gives them confidence in their recovery, and also offers hope and real person to person support for the person going through the system.
Could something like this work for parents, or young people?
How does open access to services work? What does it mean? Will I have access to a wider range of services?
- Often the clinical thresholds to access services are too high. We might only need low level support, but that can make a huge difference, yet we can't get access to it as things are not 'that bad.'
- Please, please, stop telling us we are coping! Stop telling us we are doing a great job. Think about the parents, we are often at crisis point, and if this is a good job it doesn't feel like it, or that we are coping!
- There are cultural issues around the recognition and treatment of Learning Disabilities and Mental Health issues in some communities. Especially how children are managed within the community and family.
-