PCAN

Registered Charity no: 1147436

Parents of Children with Additional Needs Making a Difference in Kirklees

CAMHS Event Thursday 12th December 2013

Report containing feedback from all three groups

13 parents attended the meeting and a further 8 contributed information, experiences and suggestions to be discussed at the event.

Yellow highlighted areas indicate parents' priority action areas for SWYFT to consider

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EXPERIENCES	SUGGESTIONS
Access	**Access**
Parking difficulties. Inappropriate venue for many young people. Cost of getting there, eg some people having to catch two buses. One parent has to travel from the other side of the authority and her daughter describes Glenacre House as the Old People's Home. Difficulties when having to bring other siblings – what can they do while appointment is taking place? Inappropriate to talk in front of them about their sibling with difficulties, and to talk in front of the child themselves.	Community or home based appointments, eg school, doctors' surgeries, SureStart centres, other centres where another professionals/therapists are present so could group appointments (eg Princess Royal Hospital, Huddersfield); ideal would be one point of access, one-stop shop, including sensory, speech and language etc. Consideration of family friendly accommodation, eg. Have a behavioural support worker or nursery nurse as part of staff to look after siblings or child when parents talking in private if needed. Would also encourage more effective inter-professional work. In a town centre, close to transport networks, eg old Huddersfield college campus. Facilities for other children who have to come along.
Appointment times often inflexible. Parents are likely to have other children (see above) and other appointments. Child may have to attend lots of other appointments as well. Shouldn't have to take too much time off school for appointments. Lunchtimes can be an issue if children are hungry, and times are an issue for lots of children who need to adhere to a routine. One parent works three days so requested to see someone on the other days. This was	Need to be more flexible about this – ring to offer choice of appointments not rigidly stick to times offered in a letter. Consider that parents are work. Parents can then choose most appropriate time. After school may be good for parents who don't have to bring other siblings along.

ignored and the parent was offered a support worker who works the same days! This meant that parent had to pay for extra childcare and re-arrange work hours. The appointments did not involve the child.	
If child attends appointment and "performs" (ie appears that there are no issues), then CAMHS will want to sign off immediately rather than seeing the child in another environment, for example in home or school where a child is able to express themselves.	As above – offer alternative venues, and possibly a series of appointments. It is well known that children can internalise issues, and other difficulties can mask underlying problems so a professional taking one look at that child is not a holistic approach, and is not going to pick up hidden issues. Listening to parents is also critical to pick that up.
No clarity about what CAMHS does and what it doesn't; also no explanation about the different tiers. No obvious place to get information from.	Make sure information is available on relevant websites (eg. Parent partnership, special and mainstream schools, early years provision) in a range of formats.***(Quick fix)*** Information to GP's, health visitors, social workers, schools, speech and language, OT etc. Information in range of formats and languages available in waiting rooms. Include in PCAN pages.
Difficulties getting GPs and schools to refer to CAMHS. One parent having consistently failed to get her GP or school to refer ended up being reported to Social Services for neglect and got her referral that way. This had serious implications for the family as husband who was a teacher was suspended from job while being investigated. One parent stated that her GP said services from CAMHS were poor, another one said waiting list is too long. Also there appears	Clarity to all about eligibility criteria – ensure that this is easy to understand and not too rigid and prescriptive to enable professionals to look at possible hidden disability and make an appropriate referral. Learning need of GP's and other professionals – training from SWYFT? Is it possible to create a self-referral system and publicise it as discussed in earlier examples?

to be a lack of training and/or awareness from GP's, health visitors, nursery nurses and school staff about some of these EBD conditions. Therefore early recognition doesn't occur and child/family are left unsupported. Parents cannot self-refer to CAMHS (and if they could would that carry any weight as opposed to a referral from another professional?) Where do they go if GP and school won't refer? It is also difficult to get back into the system if child's fiel has beenclosed.	Would be useful to have flexible pathways into the service (enhanced communication with multi-disciplinary teams around the child).
No clarity about diagnosis of autism – children have been removed from waiting list without any notice to parents and not referred to anywhere else. This has happened more with girls.	Clarity needed over this point. If CAMHS is not doing the diagnosis, who is? Appropriate onward referral required from CAMHS – they are not taking ownership of this issue.
People have been taken off the CAMHS waiting list after CAMHS clinicians have contacted schools or other involved professionals and not informed the parent. One parent had been on a waiting list from December 2012, parent rang in July 2013 to be told her child had been taken off the list.	Does this relate to targets? Caseload? Is it about poor administration? A letter should be sent to parents informing them of progress on list, or phone call to let people and see if there any changes – has it gone into crisis mode, do CAMHS need to intervene more urgently? Children should not be removed without consultation with parents and seeing the child for themselves. School staff are not in a position to state that the child has no issues – they are not qualified to do so. There needs to be a clear pathway of how to be re-referred.
Some parents have funded private diagnosis but sometimes	If there is a diagnosis of a condition and that child is in need

this prior diagnosis is not taken seriously, or not seen to fit CAMHS' criteria fully – but no exploration made.	of support, then that diagnosis should be taken seriously. The child should be supported. Mental health condition still exists regardless of whether diagnosis is on CAMHS' eligibility list or not.
Ethos of CAMHS flawed – blame culture and pre-conceived ideas even before you walk in the door, ie all issues are parenting issues. CAMHS appear to see parents as a problem rather than a partner and part of the solution. A large number of parents have had this experience with a wide range of phrases used eg. environmental issues, copied behaviour from parents, learnt behaviour from parents with issues, adoption and fostering used as excuse for behaviour - additional needs not considered. Therefore parenting courses are encouraged, even though these techniques do not work with children with certain, specific needs eg PDA, ADHD, OCD. Parents get the impression that they don't want your child on the case load. There is evidence from parents of marriage breakdown, other siblings becoming severely stressed and no support being put in place in school etc as there is no evidence or diagnosis of issue. All as a result of dealing with challenging and sometimes violent behaviour at home. Without CAMHS support many doors are closed including support to get a statement of special educational needs, evidence for DLA, evidence for social care support, ie respite. etc.	Learning need of staff? Clinicians' first thought should not be parenting issues, even where these are present. Should not make assumptions. Perhaps training from SWYFT? Clinicians should be objective: schools can sometimes be quick to blame parents too. Clinicians should take a more rounded approach. Learned or copied behaviour could be masking a child's underlying condition or be a coping mechanism for additional needs. Wider range of "parenting classes", eg managing challenging behaviour Priority for SWYFT – nothing will improve if this ethos does not change.

Very difficult to get back into CAMHS once signed off eg. One parent had this issue due to lack of support from GP. Another parent experienced referral, then re-referral then closed case. Assessments don't involve the child and sometimes not even the parents!	Set up a process to enable this to happen which is easy and accessible, eg. parent self-referral, referral via other involved services (many children accessing CAMHS are also accessing other services)
Too easy to sign children off from or prevent access to service if don't appear to meet critieria, eg children with PDA, or don't have a diagnosis. Doesn't diminish the fact that they need specialised support regardless of diagnosis, and PDA can mask autistic spectrum conditions, as child can appear much more sociable and able. Example: one child has had complex needs since age of 2, problems exacerbated when attended mainstream school. After along struggle, school referred him to CAMHS. First referral was missed, went through again in 2009 but was not seen until 2011. Diagnosis of ADHD in 2013, outcome of wisc report showed PDA. CAMHS psychiatrist advised the parent that they should not have been told PDA as it is not recognised and practitioners are not qualified to tell them! The family have visited their GP for them to refer to the Elizabeth Newsome Centre for an assessment of PDA/ASD but GP has advised that parent must provide evidence. Parent knows that going back to CAMHS will take too long and in the	CAMHS practitioners needs to think holistically and not in tick boxes, ie don't sign people off because diagnosis doesn't fit the box – treat the condition not the diagnosis. Is this a staff training issue? If more than one practitioner was involved during the assessment, one interacting, one observing and one taking notes, "hidden" issues would not be overlooked, minimised or missed altogether. System to highlight children who are repeatedly referred (especially those who were refused a service). Appropriate signposting if CAMHS is not the required service.

meantime her son has deteriorated drastically in school (he now attends a special school, but even they are not meeting his needs and need support with strategies that work). Parent accessed CAMHS for more medication as a desperate measure but is at her wits end. Her child is unsupported and in addition to his stress, this has impacted on the whole family. Another parent has been refused CAMHS assessment 5 times. Problems haven't gone away.	
Children who are assessed and it is felt that they don't fit full criteria and only have traits of say, ADHD or Autism are written off and left without a service, even though their issues are still there and require specialist support (anecdotal evidence suggests that quite often these children are diagnosed with such a condition later in life).	This is about the child's stress and anxiety and how this affects them and their family, not about diagnosis. If a child has a mental health condition, they should receive specialised support from CAMHS. (If practitioners feel unable to support these children, the child needs to be seen by someone who can support them. Perhaps this is a learning need in the organisation? Or a supervision issue?). Staff need to feel that they can be transparent with their managers, and say I need help, or I can't do it, with no negative consequences, perceived or otherwise.
Parents have experienced that when the interventions suggested by practitioners didn't work, the response was that the child didn't meet the criteria for CAMHS services. One practitioner observed child self-harming and provided information on a DLA form for a parent regarding suicidal and self-harming behaviour. The practitioner hand-wrote this onto the form with contact details. However, this	See above. In addition, it is essential that CAMHS practitioners record accurately and in detail as this can have implications for the child's support. In this case, as this was not recorded, other practitioners stated that there was nothing wrong with the child and it has been very stressful for the parents to try to support their child and get the appropriate service from

information has never appeared in any reports that CAMHS have produced about the child, even when requested by the parent. It was not recognised by any other CAMHS practitioners that the child had any difficulties, but this vital evidence was missing from her file. She therefore did not receive an appropriate service.	CAMHS. Record keeping is basic stuff and at the heart of the work. It should be transparent and **parents receive a copy of them.** Information should be shared with other services working with the child.
No crisis appointments or drop in available to access immediate advice – not dealt with well by staff on the phone, suggestions made to ring the police in the case of violent behaviours! Neither appropriate or helpful. It is usually impossible to get hold of anyone to talk to and to help avoid a situation getting worse. If you do speak to someone, they just offer an appointment which can take months of waiting (eg. One child was referred as urgent in July and the parent is still waiting for a response).	Set up a system for crisis appointments with clear referral criteria of crisis, eg. Suicidal, not eating (anorexic), violent behaviours or severe self-harming, school refusal. Suggest telephone access as appointment may not be necessary and it is quick and accessible. **(Please note that this point is repeated under response and waiting as the two are linked).**
Correct skills to match the case/child. Inappropriate professional attitudes, eg. "It's not my area".	Skills matrix to ensure appropriate cross-section of staff skills and system to ensure that child is referred to most appropriate professional. Explore professional standards.
Improve response time and reduce waiting times:	**Improve response time and reduce waiting times:**
Lack of support while waiting for appointment, eg how to manage in the meantime – this includes siblings and parents and general stress on the family. If this was in place could minimise difficulties for all concerned - including parents	Support could be given at schools, nurseries, doctors' surgeries, support groups; Children with a Disability Team could be involved. Supporting the behaviour rather than waiting for diagnosis. This involvement could help to

having to give up work or reduce working hours, break-up of the family unit.	prevent crisis or identify situations needing immediate access to a CAMHS professional.
No correspondence to let people know they are still on waiting list. One parent was told they had to wait 3 months for an Asbergers' appointment. They rang after 4 months to ask why no appointment and were told that they would receive a letter to say the decision went to panel and they were turned down.	Simple letter or phone call to let people and see if there any changes – has it gone into crisis mode, do CAMHS need to intervene more urgently? This letter also needs to include emergency or crisis contact details, and information about managing in the meantime. Again lack of clarity over eligibility criteria for the service.
If your child doesn't meet criteria of a condition, they get signed off, eg if child has behavioural issues or anxieties, or sensory difficulties and doesn't meet ADHD/Autism criteria fully, child is left unsupported and told CAMHS can't do anything for you (quite often these parents have had to pursue other avenues for diagnosis, eg funding privately or being eventually referred elsewhere).	Appropriate signposting of alternatives needs to take place. Why can't they just support the behaviour or issue – child might never get a diagnosis.
No crisis appointments or drop in available to access immediate advice – not dealt with well by staff on the phone, suggestions made to ring the police in the case of violent behaviours! Neither appropriate or helpful. It is usually impossible to get hold of anyone to talk to and to help avoid a situation getting worse. If you do speak to someone, they just offer an appointment which can take months of waiting (eg. One child was referred as urgent in	Set up a system for crisis appointments with clear referral criteria of crisis, eg. Suicidal, not eating (anorexic), violent behaviours or severe self-harming, school refusal. Suggest telephone access as appointment may not be necessary and it is quick and accessible.

July and the parent is still waiting for a response).	
One parent shared experience of dual assessment. This involved one practitioner observing two children in a class. This was not carried out effectively and did not save time – the parent thought that this was why they carried out a dual assessment.	If this was a time saving exercise, it did not help. One of these children is still on a waiting list after more than one year. Surely more than one practitioner is required to carry out observations on two children? One could be interacting, one taking notes. At the end of the session both professionals can compare notes and reflect.
Improved involvement with parents, carers and children	**Improved involvement with parents, carers and children**
Poor communication, and administrative errors. eg.Parent was waiting for appointment (over a year), situation came to a head at school and she made an appointment for a CAMHS clinician to come in at the end of the week to school. They didn't turn up and didn't g;et in touch. Parent made a formal complaint. Got a letter back giving her a range of actions for her to do, with no contact details or anything for the agencies suggested. Other examples of poor communication are, not sending reports out to parents, not including relevant information in reports, cut and paste errors (eg. Letters with other children's names in), not turning up at CAF meetings, phone calls alleged to have been returned but were not, lost letters and files, incorrect information being given and the generally unhelpful and unprofessional attitude of some	Correspondence where CAMHS encourage a parent to contact other providers should include contact names (where possible) and up to date contact numbers. Initial appointment letter should include other helpful agencies/providers, with phone numbers, short breaks information, and contact/procedures for feedback and complaints. It would be helpful to use email for updates, or for parents to provide up to date information prior to the appointment, eg. New triggers or other stresses that are happening for the child at the moment to make the appointment more child-centred. Email is currently not considered, but when it is difficult to get hold of people, an email is an effective way of sending information. It also provides a paper trail.

staff.	Effective communication and accurate, timely information is essential in any organisation: is this a learning need or reaction to stress in the organisation?
Parents' reports and views are not listened to or respected, even if the parents are professionals themselves (eg. Parents who are nurses, teachers), or if they have experience of learning difficulties or mental health, or even where there is clear family history of a condition. Eg. Child on waiting list in early 2011, CAMHS contacted school and wrote to parent saying not enough evidence and that they would be removing child from waiting list, even though parent clearly had evidence from home but was not consulted.	Learning need of staff. Parents' views are an essential part of any assessment, not just reports from school. Family history is relevant and should not be ignored, but not taken out of context either.
There is a lack of support for child and family while on the waiting list for CAMHS. Often siblings end up being referred to other support services as a result of this lack of support and the effects this may have, so there is more than one child needing support.	CAMHS need to consider how to support the child, family and siblings during the stressful waiting period. Could be a specific individual who can signpost to support, activities and networks or provide specific support that can keep the family going until the appointment. That individual should have the authority to move someone up the waiting list if they perceive a crisis situation. The person could be available to contact by phone, email or via Skype even. Broader support network through a web forum for example, where parents can support each other.
No follow up. Sometimes given diagnosis, then just left. No	Ownership – someone to look at the whole person and

assistance, for example helpful behaviour techniques, what works well etc.	respond accordingly. Sound, accurate, timely advice with strategies and a plan (how to help the whole family, not just the individual).
Appointment letter comes to the parent, not the child. Child often has severe anxieties about attending the appointment. Two parents had an excellent experience from another service provider (see opposite) which made a very big difference to their children and made the whole situation manageable.	Someone from CAMHS should ring parent up to find out information about the child 2 weeks prior to the appointment, eg. What does the child like, what do they like to do,etc and then create an appropriate letter, with pictures of staff and venue, reflecting the child's interests, eg pictures of toys etc in playroom, or art materials,colour of paper, telling them in simple language, step by step what to expect and what will be happening. This will help parents as well to prepare the child for the meeting. Also CAMHS should enable parents to provide an outline of triggers for the child before the appointment to minimise stress.
Evaluation opportunities limited. New evaluation system at Glenacre house – practitioner failed to mention at a recent visit by one family.	Prior to recently, no evaluation opportunities. Current system of electronic feedback box, good but needs improvement, ie. Location. At Glenacre House it is in the waiting room which you don't exit through, so you would have to remember to go back. Also if your child is stressed and anxious it is not possible to do it. There needs to be an additional system to gather feedback eg, phone call after the appointment, email or letter. However phone call is more likely to succeed as parents rarely have time to follow up in writing afterwards (Could be random 1 in 3 or 1 in 5

	phone call). Could commission another organisation (eg PCAN) or a researcher from the University, who can take an unbiased, objective approach.
Lots of parents have requested training on behaviour management, toileting issues, feeding issues, sleep issues – anxiety related issues.	Training on these issues as part of specific parenting classes (not general parenting classes – parents are offended by this). Parents would be happy to learn about management, hints and tips on specific issues.
Following on from this, parents would appreciate advice on self-management for young person, ideas on self-regulation, coping mechanisms which are appropriate that child's needs. Too much advice is given that isn't appropriate.	CAMHS to consider how to give this information and train parents on how to help their child (and possibly training for the young people). This could reduce the amount of time parents and children need to spend in front of practitioners or in crisis situations.
Child was referred within CAMHS to Family Therapy – parent was informed that this was because there was nothing wrong with the child, all the issues were environmental. On arrival at first appointment (stressful to get child to attend) practitioners had not read the child's notes so weren't prepared to interact with her at an appropriate level – activities embarked upon sparked a meltdown and an attack on sibling. Family's experience was that there was no recognition of child's issues, and that it was a waste of resources. A complaint was made.	Practitioners need to listen to parents. Practitioners should not be misled by the fact that a child can appear sociable and chatty and make eye contact, and hurry to get them off the caseload.
Medication: A large number of parents have experienced lack of monitoring by CAMHS of their child's medication. For example, not checking child's weight and growth, not being	A system is of appointments, telephone or in person is required for medication to be monitored. Perhaps CAMHS could work alongside nurse practitioners at local GP

available to discuss side effects, or to discuss dosage where parents might be asked to experiment to achieve the optimum dose. Implications are massive – one child had collapsed at school.	practices to monitor weight gain, side effects, and monitoring of dosing to achieve optimum effect. They do still need to offer regular medication reviews as well. This is also an access issue.
Appropriate communication with parents and children: a parent related that a clinician took their child to the clinic room on his own, without parent's informed consent. The parent had no idea that the clinician wanted to meet the child on his own so she was unable to prepare him and he blamed her for a confusing and stressful situation. The parent has no idea what was discussed during the meeting – her child was 8.	Clear pathways so that parent and child know what to expect and there is opportunity to prepare the child (see earlier point re information letter. Informed consent to be gained from parents. Session to be recorded and parents informed of discussion details.
Practice issues: Some clinicians think it's ok to talk negatively about a child while the child is in the room. One clinician conducted a pre-screening parental interview while the child was present despite the parent repeatedly saying that this was not appropriate. Clinicians sometimes not seeing the child or the parents.	Professional standards: Ensure appropriate guidelines in place for assessments and interviews. Examine practice around contacting other agencies, eg school for information but not the parents. Some services are not well-informed about many EBD conditions so may not be able to provide reliable evidence on which to base a decision about whether to meet with a child or not.
Working with other organisations	**Working with other organisations**
Child accessing CAMHS service – parent was not informed of other services that could help, eg. Learning disabilities team, short breaks.	CAMHS need to think about working as a team with other support services – be part of a team around the child. CAMHS should have the ability either to forward refer, or to signpost effectively and ensure in a tactful way that parents follow up. This may require some fact finding to find out

	about local services.
Families often have to repeat information to several services. This is very difficult and it is easy to forget information. Some parents find it very hard to discuss their child's condition or even understand it.	CAMHS need to consider working closely with other providers, perhaps using shared handheld notes – data protection issues need to be agreed between various parties. Parents would be happy to give permission for this, if asked. Would be a basis for true multi-disciplinary working.
Improved methods of working with other agencies involved in the child's care. CAMHS will have to work with other agencies regarding the new Education Health and Care plans. A child's mental health does have a big impact of their school life so CAMHS are likely to be an essential part of the process.	SWYFT need to consider how they will work going forward for the benefit of the child and family and also because EHC plans commence in September 2014 and task and finish groups are already working on the content of these plans and the implementation.