

Issue for consideration of Priorities Panel

For official use only:

Issue ID Number: 035

Date received by Operational Director

02/03/10

Date to Priorities Panel

10/03/10

Office use:

Name:

(JJ, RA, KT, All)

Date completed and initials:

Date of referral to LINK	14/ 01/2010
Date issue arose	____/____/____
Title (Headline/short title of issue)	Inadequate provision for young people with Autistic Spectrum Disorder (ASD) from the Children and Adolescent Mental Health Services (CAMHS) in Kent.
Nature of interest/standing of person in relation to issue:	
Recipient of service	<input checked="" type="checkbox"/> Family <input type="checkbox"/> Friend <input type="checkbox"/> Advocate/Campaigner <input type="checkbox"/> Other
If other, please state what their standing is in relation to the issue:	
Is the person raising the issue a:	
	<input checked="" type="checkbox"/> LINK participant?
	<input type="checkbox"/> Member of the public?
	<input type="checkbox"/> Priorities Panel Member?
	<input type="checkbox"/> Governor Group Member
	<input type="checkbox"/> LINK Development Worker
	<input type="checkbox"/> Part of an organisation
If raising issue on behalf of an organisation, state name and brief details of what they do	The National Autistic Society South Kent Branch supports parents of children with Autistic Spectrum Disorder (ASD). They provide crucial ongoing advice, guidance and signpost parents to the necessary services. The organisation plays an essential role to parents whose

	<p>children have been recently diagnosed with ASD as information provided by statutory services is limited.</p>
<p>Summarise issue (no more than 100 words). If necessary, a more detailed account may be submitted on page three with additional pages attached if necessary</p>	<p>The NAS South Kent branch has approached the LINK with concerns that an insufficient service is being provided by the Children and Adolescent Mental Health Services (CAHMS) particularly to children with Autistic Spectrum Disorder (ASD).</p> <p>In Shepway, 324 children are currently on the paediatric database having been diagnosed with ASD by the paediatric team. This figure does not include those diagnosed separately by CAMHS staff. Effective help needs to be available for these children. Shepway CAMHS only has three staff not the sixteen they need. The group has reported constant problems with cancellation of appointments due to lack of staff.</p>
<p>Please use this space to give a detailed account of the issue to be raised with the Priorities Panel. (N.B: Form will expand to accommodate additional text – other documentation can be appended, as necessary)</p> <p>1 in 100 children in England have an autistic spectrum disorder, approximately 1 in 10 children who accesses CAMHS has an ASD - not to mention the many who cannot get access. The branch reports that CAHMS is failing to provide an effective service to many children with Autistic Spectrum Disorder at present.</p> <p>Parents have reported :</p> <ul style="list-style-type: none"> • Long waiting lists, for example a year or more for initial assessment. • No crisis intervention for children with suicidal tendencies or self harming behaviour • Lack of alternative therapies for example: Cognitive Behaviour Therapy, family therapy, small group, sibling therapy or parenting programmes. • The service provision for Shepway is different to that which is provided for relatively local areas such as Dover, Canterbury and Ashford. These do not seem to have long waiting lists which are experienced in Shepway. • Lack of multidisciplinary collaboration between service providers such as speech and language therapists, occupational therapy and paediatricians. • There is a need for CAMHS staff to be able to offer outreach into schools so they can be involved in observing the children in the classroom setting. • CAMHS have refused to be involved with pupils who have mental health issues, leaving no other service available to parents. • CAMHS does not offer any help on an emergency / crisis basis where there is violence by an ASD child to siblings or parents. <p>This appears to be a national problem, supported by research carried out by the National Autistic Society. 65% of CAMHS reported having supported someone with an ASD, only 10% provided targeted support for this group.</p> <p>Findings from focus groups children with autism who had received services through CAMHS and their parents by the National Autism Society in summer 2009 echoed the issues raised by the local branch. They also highlighted further issues in their work, as outlined below, showing a wider context of failings with CAMHS services for children with ASD:</p>	

- *Lack of autism knowledge and expertise among professionals* – the lack of any specialised knowledge of autism with CAMHS was felt keenly with some CAMHS professionals having little experience of it and many services having no autism specialist staff employed at all. Many interventions, such as cognitive behavioural therapy, need to be adjusted in order to work for children and young people with autism. Without adequate training or access to autism specialists, many professionals remain unable to make such adjustments.
- *Diagnostic overshadowing and the assumption that mental health problems are a 'part' of autism* – professionals often wrongly told parents that anxiety or depression were inevitable consequences of autism, and that they should simply accept this.
- *Misdiagnosis of autism as a mental health problem* – a lack of knowledge of autism within the professional community can present particular problems for young people with autism. Some of the behaviours associated with autism, like sleeping difficulties, personal obsessions, rituals and routines, can easily be interpreted as a mental health disorder to the untrained eye. Misdiagnosis will inevitably lead to inappropriate intervention and existing problems will continue or worsen.
- *Inappropriate or inadequate interventions* – some services offered by CAMHS were not only unhelpful, but had a significant negative effect on their mental health problems. This was often because the professionals involved did not have a good understanding of autism and did not make the necessary adjustments to the interventions offered.
- *A lack of resources* – much needed professionals, for example, occupational therapists (OT) and speech and language therapists (SALT) were felt to be badly needed, yet there was little access to these kinds of professionals. Communication and sensory issues can be a significant factor in increased anxiety, for instance, and OTs and SALTs can be key to addressing these.
- *Family support* – having a child with ASD affected the whole family, yet there is little support available for parents and siblings within CAMHS with most either unsupported or relying on charities and other local organisations.
- *Parents blamed for child's problems* – parents themselves were often blamed by professionals for their child's mental health problems or autism because of a lack of parental love, bad parenting skills, or being over-anxious or over-protective.
- *Non-existent transition planning* – further problems with teenagers were apparent as the transition from CAMHS to adult mental services brought extra difficulties, as nothing was in place that supported them at this crucial time.

The need for support and early intervention for children and parents is addressed in the Department of Health's New Horizons: Towards a Vision of Mental Health strategy which was launched recently following consultation.

Is the issue currently under investigation, via a complaint or inquiry or being dealt with by somebody else (this includes being part of a wider campaign on the issue)?

Yes

No

If yes, give details of actions already taken including contact details of others dealing

with the issue:

The National Autistic Society are planning to embark on a national campaign about improving support for children with autism who also have a mental health condition and their research so far has looked at the support which is provided by CAMHS services for this group and identified areas for improvement as stated above. They support this request for the LINK to carry out a review by the local branch and are looking for LINKs across the country to review services in each area in order to give a local focus to the campaign.

Contact: Sarah Best (Campaigns Officer – Local) at the National Autistic Society.

Research has also been undertaken at Canterbury Christchurch as part of the CAMHS Pathway Project. This will give examples of interviews with parents of disabled children throughout Kent who have accessed the CAMHS service and found that it has not met their needs. It is hoped that the LINK could have an opportunity to engage with this project in an appropriate capacity.

Is there a timescale/deadline/circumstance affecting this issue which may mean the LINK will have to act quickly, e.g. closure of a unit, change of service, a particular urgency?

Yes

No

If yes, what is that circumstance and what is the timescale by which action has to be taken?

What expectation does the person raising the issue have of the LINK, i.e. what does that person want the LINK to do/what action does it want it to take?

1. Investigate consistency of CAMHS services throughout Kent, highlighting any inequalities of service.
2. Survey parents of children with ASD to assess their experiences.
3. Investigate consistency of CAMHS services throughout Kent, highlighting any inequalities of service.
4. Survey parents of children ASD to assess their experiences.
5. Approach CAMHS to find out:
 - a) the reasons for the staffing shortages in Shepway and other districts and what measures they are taking to improve the situation.
 - b) what other services are CAMHS going to implement to help parents and siblings of ASD children, i.e. siblings support groups, parent information groups, additional support workers to help children, who are unable to leave the house with their parents, to gain independence and personal development to overcome social anxiety etc.
 - c) how they could offer more support at school to work with a child, educate school staff about the disability and how best they can collectively help the child. Offer effective outreach programmes from CAMHS to other professionals about ASD.
- 6.

What would be a good outcome from the perspective of the person raising the issue?

- For a significant improvement to services and attitude of CAMHS teams throughout Kent to support children with ASD.
- An effective early intervention service to increase well being of children with mental health issues and their families, enrich the child's opportunities as well as

their future life skills and experiences and allow them to develop independence. Depending on where the child was on the spectrum, this would limit the need for extensive adult services when appropriate early therapy has taken place.

- Effective outreach programmes from CAMHS to other professionals about ASD to encourage a joined up approach to benefit the child.
- Availability of alternative therapies as an alternative to drug therapy, which appears to be usually the first port of call.

What evidence does the person raising the issue have to support the case they are putting for the LINK to take action? List or attach evidence and sources, if available.

Personal statements from parents affected by this issue – evidence attached
Evidence from Canterbury Christchurch University project.
Research from National Autistic Society

How widely does this issue affect other people?

In 2004, the Office of National Statistics (ONS) reported that 30% of children with autism had another clinically recognisable mental disorder, as compared to 10% of all children and young people.

In a more recent study of children with autism between the ages of 12-14, researchers found that 70% of participants had at least one co-morbid mental disorder, while 41% had two or more, such as social anxiety disorder, attention deficit and hyperactivity disorder, oppositional defiant disorder and depression.

Failure to get adequate support affects everyone who is involved with the child; this includes schools, relatives, families and the child's peers. The lack of professional support can cause severe depression for the child and family alike which has resulted in the break up of families, and ill health of carers. Siblings suffer from depression and ultimately do not want the disabled child to be part of the family. This tension creates further anxiety and stress for parents and leads to the inability for families to have outings or socialise thus causing a sense of isolation for the child and family.

In what ways are other people affected by this issue.

- Lack of support and understanding for the disorder causes family members to experience low self esteem and results in the inability to cope. Issues at school and refusal to attend school.
- Teachers not knowing how to cope and handle the child can lead to the child being excluded.
- Lack of respite intervention reduces the chance for parents to partake in activities outside the home

Signed: Cate Boland

Date: 28 January 2010

Responses from parents about their experience of CAMHS

"My son has been referred to CAHMS via speech therapy to assess for ADHD. That was over a year and half ago and I had a letter back saying there is a long wait and nothing since. I don't know what's going on, whether they have decided not to assess him after all or he is still waiting. Who knows!"

"My daughter is no longer in school due to her extreme anxiety; it just got too difficult to get her there. The school have applied for a statement (again!) & we are waiting for a referral to hospital schools. Anyway the reason I am telling you all this is because we were referred to CAMHS twelve weeks ago for her anxiety. We had the first assessment appointment last Thursday, we were warned there was a waiting list. They diagnosed her as having extreme anxiety causing her to be school phobic, this all goes with her diagnosis of ASD & selective mutism. We were not told of any support groups. We are now on a waiting list for her to have some art & play therapy. We did not know about the out of hours service."

"My experience was very negative....I was having the worst time imaginable with my son and they said that the Dover CAHMS do not accept children with ASD...even though other areas do! My son's paediatrician even wrote to them and said they should be involved and they still would not help!"

"At the time of referral to CAMHS by the paediatrician, my son's behaviour was spiralling out of control. Despite really risky situations we had to wait for months for an initial appointment. I believe that there are long and long waiting lists and that referral is determined by crises (rather than preventing them!). You get seen when things get dicey! However, I have to say once you are in the system you tend to be O.K. Of course this depends on the quality of who you see"

"We have been visiting CAMHS in Shepway since last August-ish when we moved from London. We used them in London for about two years and used the service as kind-of a brainstorming for strategies for management of our son's behaviour and problem areas. With the Shepway CAHMS, we didn't have to wait very long, however, when we have seen them, the person hasn't really been very helpful. He has asked how our son is doing, and we tell him the positives and the areas we have problems with. He asks what medication he is on and if we need any prescriptions, he makes notes on what we say then he says he'll see us again in six months. We haven't been given any information regarding our child's conditions at this stage of his life. We've been given no details of further support - especially having moved to the area from London 18 months ago, it would have been handy. We haven't been offered any therapy services, and actually, our son has an ASD and epilepsy and speech and language disorder and ADHD. We have had no therapy or support offered for his siblings or the family. We were never aware of out of hours services. I actually don't understand what the point of going to CAHMS is and what the benefit is. The person there is not very understanding towards my son's issues and the effect it has on us. Despite my feelings towards CAHMS, I continue to go with my son because I feel that if we refuse any service offered, then if you need it again it's back to the waiting list, and in London we found it so helpful."

"We originally started on CAMHS Tier 2, until our son became very depressed etc and after an assessment with a psychologist we were escalated quickly to the services at Tier 3. We attended whilst in Tier 2 meetings as a couple to talk over our feelings and perhaps strategies of dealing with our son's behaviour etc. They were supportive but short staffed."

We have been seeing monthly until recently the Consultant and a Family Psychotherapist as a whole family. The Consultant is usually able to come back to us quite quickly if we have encountered any major problems. Our visits are now termly especially as our son is now at specialist school all week.”

“Our daughter is now almost 16 and has had absolutely no support in any way whatsoever. She eventually had a CAHMS assessment a year ago after a 13 month wait. She currently has just begun 4 hrs a week home tuition following some school bullying last September since when she has not been back to school.

**Kent LINK Priorities Panel Recommendation Proforma
ID 035**

No	Recommended action	Please tick	If additional information required, please specify	Additional comments, if any
1.	No further action			
2.	Watching brief			
3.	Letter to Trust/Social Care calling for comment before taking any further			
4.	Urgent action as issue concerns patient/client safety			
5.	Further information required, please specify			
6.	Consult/ survey participants to check level of interest/concern before proceeding to any other action			
7.	Start discussion on LINK web site/through LINK Bulletin			
8.	Question to Citizen Jury			
9.	Topic for local meeting			
10.	Urgent unscheduled visit –specify purpose of visit in comments column			
11	Refer to regulator, e.g. Care Quality Commission, Ofsted, Health and Safety Executive, Royal Colleges, etc –please specify			
12	Potential to develop as possible LINK project			
13	Any other recommended actions			