

## Issue for consideration of Priorities Panel

**For official use only:**  
 Issue ID Number: ID 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 <input type="checkbox"/>	
If other, please state what their standing is in relation to the issue:	
Is the person raising the issue a:	
LINK participant?	<input checked="" 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 <input type="checkbox"/>	
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 children have been recently diagnosed with ASD as information provided by statutory services is limited.
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	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). The group has reported constant problems with cancellation of appointments and an overall lack of specialist support for ASD.
<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>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.</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 NAS South Kent branch reports that CAHMS is failing to provide an effective service to many children with Autistic Spectrum Disorder at present. This has been echoed by the Swale ASD forum.</p> <p>Parents have reported the following problems with the CAMHS services in Kent:</p> <ul style="list-style-type: none"> <li>• Shepway in particular has long waiting times compared to relatively local areas such as Dover, Canterbury and Ashford. In some cases children have had to wait for a year or more for an initial assessment.</li> <li>• No crisis intervention for children with suicidal tendencies or self harming behaviour</li> <li>• Alternative therapies such as Cognitive Behavioural Therapy, family therapy, small group, sibling therapy or parenting programmes have not been offered to all children.</li> <li>• More multidisciplinary collaboration between service providers such as speech and language therapists, occupational therapy and paediatricians is needed.</li> <li>• There is a need for outreach into schools so CAMHS staff can observe the child in the classroom setting.</li> </ul>	

- A lack of additional support for parents and carers and children when CAMHS is not involved
- CAMHS does not offer any help on an emergency / crisis basis where there is violence by an ASD child to siblings or parents.

There also appears to be a national issue with regard to CAMHS not providing the necessary support to children with ASD, supported by research carried out by the National Autistic Society (see attached evidence). 65% of CAMHS reported having supported someone with an ASD, only 10% provided targeted support for this group. This is also something that needs to be addressed with commissioners.

The LINK has been advised that commissioners in Kent are addressing waiting times for CAMHS in particular across East Kent and working on streamlining targeted Tier 2 services for children and young people including those with ASD. There has been some work in East Kent on care pathways for children with ASD and further work will be done in the rest of Kent. The commissioners are looking to develop a single point of access for CAMHS which they hope will reduce waiting times for assessment and treatment, and commission services fit for purpose for children with ASD. They have identified the opportunity for service user input in this work, which is currently in the planning and reviewing stages.

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 **X**

No

If yes, give details of actions already taken including contact details of others dealing with the issue:

Research into CAMHS being undertaken at Canterbury Christ Church as part of the Pathways Project. Attached is a document referring to the progress of the project. It is proposed that the LINK could have an opportunity to engage with this project through identifying participants with an interest in this area (such as the referrer) and supporting them to get involved.

The National Office of the NAS are planning to embark on a national campaign aimed at improving support for children with autism who also have a mental health condition. They support this request by the local branch for the LINK to get involved with this issue and are going to be looking to LINKs across the country to support the campaign in each area in order to give a local focus to the campaign.

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

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?

The original expectation was for the LINK to undertake an investigation into the consistency of CAMHS services throughout Kent, highlighting any inequalities of service and surveying parents of children with ASD to assess their experiences.

However further investigation has identified Canterbury Christ Church's Pathways Project is undertaking work in this respect, and researchers have expressed an interest in working with the LINK to identify participants willing to get involved with this. The LINK would also monitor recommendations which will be made to the PCTs to ensure that these are implemented in due course.

It is also anticipated that the LINK could initiate opportunities for parents and carers to work directly with commissioners of CAMHS to feed into the work around setting up a single point of access to CAMHS which is being done to address the waiting list issues as well as identifying:

- a) what other services CAMHS could 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.
- b) how CAMHS 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 and offer effective outreach programmes from CAMHS to other professionals about ASD.

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 in many parents' experience.

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 – see Appendix 1  
 Evidence from Canterbury Christchurch University project – see Appendix 2  
 Research from National Autistic Society – see Appendix 3

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.

In what ways are other people affected by this issue.

- The lack of professional support and understanding of the disorder 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.
- Issues at school and refusal to attend school, and many teachers do not know how to handle the child which can lead to them 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

## Appendix 1

### A selection of 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. 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 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. Tier 3 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."

## Appendix 2

### Findings from focus groups children with autism who had received services through CAMHS and their parents by the National Autism Society in summer 2009

The research echoed the issues raised by the local branch. It also highlighted further issues, showing a wider context of failings with CAMHS services for children with ASD:

- *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.

# Pathways Project Newsletter

## Overview:

The Pathways Project was commissioned by the Kent based NHS PCTs to explore the CAMHS pathways, examine interfaces and bottlenecks, highlight areas of good practice, and provide recommendations for commissioners of services. The project is due for completion in January 2011.

## NEWS

Joseph Pelletier was the Project Worker on the Pathways Project from October 2009 but unfortunately he had to leave the UK suddenly due to visa issues at the end of February 2010. Joseph worked on the first phase of the project, meeting many people to talk about CAMHS services and building a picture of some of the bottleneck issues, gaps, and also good practice that was occurring in CAMH services across Kent. A new project worker, Georgie Boorman, has been appointed to continue work into the next phase (as outlined below).

## First phase of project

The first phase of the project (October 2009- February 2010) was a scoping exercise with the aim of getting an idea of how CAMH services work across Kent and putting together a project plan for the remainder of the year. There was also a specific focus on the Common Assessment Framework (CAF), Single Point of Access (SPA) and waiting times for services as these were areas highlighted by the commissioners for initial investigation. A brief outline of findings from this first phase is shown below.

### Waiting times

Data from the National CAMHS mapping (Durham University Mapping Team 2008-2009) were reviewed to look at waiting time in specialist CAMHS teams. The data suggested waiting times in specialist services were not substantially different in Kent than the national average and that the majority of children and young people were seen within the recommended 18 weeks. However, there were differences between the two provider Trusts in when young people were seen more regularly, the number of cases seen in a year and the workforce distribution. These differences may benefit from further investigation.

### CAF and SPA

The CAF and the SPA have begun to be implemented across Kent. Our review indicated that there were variations across Local Children's Service Partnerships and that there was some variation in how people understood the CAF process to work. These inconsistencies suggested a need to look more closely at how people's beliefs and expectations about a service or a system might get in the way of open communication. Some dissatisfaction with Tier 3 services was expressed and this appeared to be around access. These issues will be picked up on in later phases of the project.

## Next phases of the project:

The next phase of the project will be on bottlenecks in services and how vulnerable groups in the county fare when there is a need for assistance from services in the county (this follows on from some of the conversations Joseph had with carers, parents, clinicians and managers of services as well as being a key area for further investigation raised by the commissioners of services). Examples of 'vulnerable groups' in this instance include hard to reach children and young people, Looked After Children, children and young people with learning disabilities and difficulties, ADHD, ASD, and young offenders. We would like to do a '360 degree' assessment by talking to as many different stakeholders as we can. We hope that this will include young people, parents, carers, clinicians, GPs, teachers, voluntary workers, admin staff and many other groups of people.

### PROJECT STAFF:

**ALEX HASSETT**  
Senior Consultant  
(CAMHS)

**CHARLOTTE HARTLEY**  
CAMHS Consultant

**GEORGIE BOORMAN**  
CAMHS Project Worker



*If you would be able to help us with this project or would like to contact us please email Charlotte or Georgie*

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**Recommendations 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			