

Redesigning the Child and Adolescent Mental Health service (CAMHS) around the needs of children and their families

Forum: PCAN – Kirklees,
web: www.pcankirklees.org ,
Icarus: Contact: Richard Sorton _
email: richard@icarus.uk.net
NHS Commissioner Debi Hemingway,
Debi.Hemingway@Kirklees.nhs.uk

Background

Debi Hemingway, NHS commissioner for Kirklees Child and Adolescent Mental Health service (CAMHS) heard that parents of children with learning disabilities were unhappy with how the existing CAMHS service was meeting the needs of their children. Debi Hemingway wanted to find out more about parents' concerns and also understand what pressures points in the child's life might contribute to them developing mental health issues.

In Kirklees, children with learning disabilities and mental health issues were offered either:

- a tier 2 service, for children with less severe mental health issues, which was mainly provided by counsellors working at separate geographical location to schools; or
- a tier 3 service, for children with more severe mental health problems, which was provided through CAMHS but which did not focus on their learning disability .

There was no targeted service for children with a learning disability (LD) and a mental health problem.

What they did

The Commissioner asked the Forum to help get parents input to the design of a new tier 3 CAMHS /LD service. A Saturday morning event was planned and promoted to members of the parent carer forum. The session involved a dozen parents of children with learning disabilities and mental health issues in a structured dialogue with the commissioner and a colleague. The session was facilitated by Icarus, a consultancy that had supported the development of the forum.

What parents said

The dialogue was structured to:

- ask about pressure points in the child's life and the impact these had on both the child and their family

- explore parents' experiences of the existing service and what support they thought would help
- invite the parents to describe the type of service they wanted.

Common pressure points included changes in routine, school holidays, children aged 9 to 10 becoming more self aware, not having or losing friends, difficulties in communicating with other people, and transitions –whether starting school, changing school or moving on to adult services.

A major factor that emerged was the relationship the child had with school and schools' ability to identify, cope with and understand children's emotional needs. Children were being labelled as disruptive or naughty as a result of poor understanding of children's emotional needs. Schools were quick to exclude children and had no understanding the impact this has on parents. Secondary schools were felt to be significantly worse at managing emotional wellbeing and behaviour and communicating with parents than primary schools.

The impact all of these pressures could have on children included embarrassment, stress, anxiety, not being able to access social activities, and not having someone to talk to about their feelings. Their parents' lives were also negatively affected. They often had to cope with aggressive behaviour from their child towards them. They found it difficult to carry out routine chores, have a social life, go on holiday, or hold down a job. Their relationships with others were also affected, with friendships lost and strain on their marital and couple relationships. All of this had an impact on the disabled child's brothers and sisters.

The parents found assessments and appointments difficult and frustrating. Appointment times were only offered during work hours making it difficult for both parents to attend. Parents found it difficult to get professionals to listen to them and take into account their interpretation of their children's behaviour. The parents did not like being asked to talk about their children in front of the children. They felt that professionals were putting children in a goldfish bowl without looking at the stress points which caused their behaviours.

The existing service was very limited in terms of the support it offered. Tier 2 counselling support was often a long journey from the children's homes and schools. Children in tier 3 were often only offered medication and parents were not being given information about how the medication worked.

What parents said would help

The parents were asked what would help. For their children this included:

- a more appropriate ethos and approach from schools
- for other children to be more understanding
- support from staff who are skilled in working with children with additional needs and have a range of communication abilities, including skills in non-verbal communication
- for support to be developed and delivered through relationships which are built up over time and are consistent
- simple, honest, open communications with children.

For themselves, parents made suggestions that included:

- support with coping with parents' emotional and mental health needs
- support in understanding children's emotional and mental health needs
- support in communicating well with children (including non-verbal communication strategies)
- support in managing children's behaviour and developing management strategies.

The parents also wanted help understanding and coping with the feelings for their brothers / sisters, group activities for siblings and family-wide support.

Outcomes

Kirklees decommissioned the tier 2 and 3 CAMHS service, and drew up new service specifications using some of the important information provided by the parents. A procurement process began and two new contracts have been awarded.

The new service will focus on looking at the children and young people's whole circumstances, such as education, social activities and levels of support, in conjunction with their mental health needs. Joint care planning and partnership working with the child/young person and their families and carers will be a priority in meeting needs. This will include focusing on all their holistic needs and linking with other services involved with the child/young person, bringing these elements together in a more coordinated way for the benefit of the child/young person.

The tier 2 service will include staff going into schools and working with SENCO and other school staff to help them gain a better understanding of a child's needs, and develop strategies that will help the child. The tier 2 service staff will also be supporting parents of children with learning

disabilities so they can receive the support and training to help them understand their child's emotional needs and learn management strategies to help them cope with their child's behaviour.

Three priority areas were incorporated into the Tier 3 service specification:

- mental health services for young offenders (often with ADHD)
- CAMHS for Looked After Children
- services for children with mental health issues and learning disabilities.

The Tier 3 service specification for children with learning disabilities and mental health issues has been designed around what the parents asked for regarding access, information and being listened to. The core team for the new service will include a learning disabilities nurse, a mental health nurse and a number of hands on, flexible support workers. The core team will be supplemented with access to psychologist and psychiatrists.

The commissioners are also hoping the parent carer forum will continue working with them to help monitor the new service.

Why this worked

- The focus group was held on a Saturday, making it easier for parents to attend.
- Use of independent facilitation enabled a constructive dialogue to take place.
- The commissioners listened to parents taking into account the stresses which could contribute to a child developing mental health issues.
- Instead of commissioning more of the same. they designed a service around the child and families needs.

Debbi Hemingway, the commissioner involved said

'I can get information from CAMHS about numbers of children being seen but I could only get this rich qualitative data by listening to parents. Working with the parent carer forum has been invaluable.

'Some commissioners can be anxious about working this way, worried they might have to face a room full of angry people. I would say just get on and do it – bite the bullet – it is well worth doing and very rewarding. In the past, commissioners were offered training to help them do this. This might need to be considered again with the development of Clinical Commissioning Groups'

Contact a Family

209-211 City Road, London, EC1V 1JN

Tel 020 7608 8700

Fax 020 7608 8701

Email info@cafamily.org.uk

www.cafamily.org.uk

Incorporating The Lady Hoare Trust
Registered Office: 209-211 City Road, London, EC1V 1JN
Registered Charity Number: 284912 Company Limited by guarantee
Registered in England and Wales Number: 1633333
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