

CAMHS Response from North East Lincolnshire Parent Participation Forum

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This is the response to Children and Adolescent Mental Health Services (CAMHS) Consultation and Engagement from Accord. We have taken guidance from the *Children and Young People's Mental Health Coalition* to ask parents their thoughts and concerns as it discusses the policy, the progress made and the challenges.

North East Lincolnshire Parent Participation Forum agree with these challenges:

- promoting mental health in the early years of a child's life
- stigma
- the lack of mental health promotion actually occurring at an individual, community and societal level despite the policy, and the ongoing need to develop emotional resilience in children and young people
- a lack of recognition at an individual, community and societal level of the link between physical health and mental health, for example, the links between nutrition and mental health, and obesity and mental health
- the training of the whole of the children's workforce
- early intervention
- the interface between Child and Adolescent Mental Health Services (CAMHS) and Early Intervention in Psychosis Teams
- the transition between CAMHS and other adult services
- reaching adulthood; supporting children's mental health as they become young adults
- specialist services operating in a silo and the quality of some specialist provision
- the mental health of children and young people whose voices are seldom heard
- poverty and health inequalities

- the necessity of more accurate needs assessments and joint commissioning by experienced commissioners, which includes commissioning community and voluntary sector providers
- a severe lack of funding for mental health promotion, insufficient funding for service provision and the short-term nature of funding for policy initiatives.

(Children and Young People's Mental Health Coalition)

http://www.cypmhc.org.uk/media/common/uploads/CYP_coliation_policy_paper1.pdf

We have asked parent/carers what they think:

- Parents believe that their child should be seen as soon as possible to stop further deterioration of their mental health.
- Waiting times are terrible for their child to be seen.
- Building resilience is not welcomed by parent/carers compared to developing resilience. The capacity for the individual to recover quickly from different forms of mental health conditions, is specifically down to the individual's recovery rate. Ongoing intervention for developing resilience is welcome.
- Waiting times are poor unless it is an urgent referral or high tier situation. This service is underfunded.

A parent/carer's point of view:

“I feel the professionals are only following the rigid guidelines laid out to them by their bosses and/or what their funding will allow them to do. However I do also believe that the criteria used when assessing for High Functioning Autism especially in girls needs updating. This category of individuals is too specific and required a different assessment to those who fall into general autism. My child was discharged

because she only answered 'Don't Know' in their assessment. This should not have happened.”

- Risk factors are never taken into consideration.
- Better support and communication when your child turns 16-18 and if they move into adult services.

Viewpoint from a parent/carer:

“There appears to be a huge gap as to who treats and looks after a child who turns 16 but is not yet 18 and fitting into Adult services.”

- The threshold for support is too high even with the severest examples of mental health.
- The pathway into CAMHS should be clearer.
- Parents/carers are signposted to other organisations, who then refer the child back to CAMHS. They are moving in circles as they are getting moved forwards and backwards, then back to the beginning of the process.

Quote from a parent/carer:

“School say it's down to the GP for referrals, the GP says it's down to the school. We are going round in circles.”

- Parent/carers feel that the professionals are not adequately trained with up to date diagnoses. A response from a parent/carer:

“My child has been declined from CAMHS several times even though their neurology consultants have said they need seeing. Still nothing 3 years on!”

Another parent/carers viewpoint:

“There is not enough qualified staff. There are a lot on maternity leave. The therapists either lack the experience or expertise. My child has been passed from one therapist to another with still no answers. I have had to find a specialist myself and pay privately.”

Comments from another parent/carer:

“Therapists who are usually used do not have the experience to deal with some of the issues a young person may have. How do we know the therapists are fully accredited? Do the therapists follow guidance from world leading experts about current and changing diagnoses?”

- The boxes to be ticked to access the CAMHS service are too rigid. There seems to be no support for children that are clearly struggling with anxiety but do not fit the criteria to warrant support from CAMHS.

Statement from a parent/carer:

“We have been told there is no Anxiety Disorder but my child needs support for anxiety. As there is no disorder present (i.e. need for medication, CAMHS have discharged). Where do we go now?”

- Parent/carers feel that they are being required to do additional parent courses that they have already fulfilled. They understand their child better than anyone and feel that this is a tick box exercise.

Viewpoint from a parent/carer:

“We have been turned down twice for a single assessment (pathway into CAMHS). This is even when my child has been under consultant care for 10 years and has attempted to end his life.”

Another parent says

“I feel like we're being passed from pillar to post. There is no clear defined pathway. It is a complete nightmare on who to go to be referred into CAMHS.”

- Parent/carers believe CAMHS are not diagnosing autism. They are deeply concerned how endemic this is becoming. Children are reaching their teenage years, they are undiagnosed, and they have developed more acute anxiety disorders.
- Parent/carers are still having to involve the Police to help their child. The lack of arrangements for children who are in crisis is clear from the literature currently available from CAMHS: *If we think the situation is urgent (which relates to a possibility of risk to life and/or presentations such as serious eating disorders), we will offer an appointment within 5 days. For emergencies (which relates to definite risk to life and presentations such as psychosis), an appointment is arranged within 24 hours.* What do the parent and the child do in this situation if they are told no? A crisis is immediate. Parents have attended Accident and Emergency to get help and support in the immediate crisis situation.
- The lack of crisis numbers and helplines is another theme. Parents are being told to ring the Single Point of Access 256256 and being told that this service is for adults. There is a lack of clarity and information for parents to gain this intelligence.
- There needs to be structured approach to referrals from education, health and care providers to CAMHS. To say there is a structured approach in place already does not equate to the amount of children that are slipping through the net in North East Lincolnshire.
- Are trends with the impact of bullying and of digital culture?
- The paperwork used for parents and families' needs to be in an easy read language.
- Information and self-help sheets need to be in an easy read format.