



## Submission by Contact a Family

### Health Select Committee – Children's and adolescent mental health and CAMHS Inquiry

1. Contact a Family is the only UK-wide charity providing support and information to families with disabled children and young people across the UK – regardless of disability, health condition or special educational needs (SEN).
2. This submission is based on our experience of providing advice to parents through our helpline, online and face to face services. In addition, over 100 parents shared their experiences of CAMHS via our facebook page on the 11<sup>th</sup> March 2014. One of the highest ever feedback responses we have received on a topic. Overall parents report shocking levels of failures to access support from CAMHS. All response can be views at [https://www.facebook.com/contactafamily/posts/10153847992360214?stream\\_ref=10](https://www.facebook.com/contactafamily/posts/10153847992360214?stream_ref=10)
3. Responses from parents are used throughout this submission (in red text). Such as those of Nicola from Cheshire: *“The staff at CAMHS were very sympathetic, but they failed to provide any helpful diagnosis for my son. My son has an autistic spectrum disorder (ASD) and because he didn't fit with their criteria – for example because he laughed at their jokes and engaged in conversation he was told he didn't have ASD ...which was completely wrong. It took me a further 2 years of primary school to recognise his disorder. So much time was lost. It also delayed getting disability living allowance because the DWP said I needed a diagnosis.”*

### Summary

1. It is widely recognised that although disabled children and young people including those with long term health conditions are at an increased risk of mental health or behavioural problems, there is a serious lack of appropriate mental health provision to meet these needs<sup>1</sup>.
2. These children are less likely to access appropriate mental health services. Even when they do, they are less likely to have their psychiatric and developmental needs recognised, understood and addressed in an evidence-based, holistic or therapeutic way.

<sup>1</sup> <https://www.rcpsych.ac.uk/PDF/DevMHservCALDbk.pdf>

3. Child and adolescent mental health services (CAMHS) are, in general, lacking in the expertise and resources required to provide comprehensive assessments and ongoing management for those with developmental disabilities. This affects the child's mental health, and educational and social needs.
4. Additionally, there is a negative impact on family life, with an increased likelihood of sibling and parental emotional distress and mental ill health<sup>2</sup>, family breakdown and expensive residential placements.
5. CAMHS remains underfunded causing massive waiting lists, no crisis beds, and no appropriate inpatient provision for young people with autism and learning disabilities who then develop mental health issues.
6. A range of preventative and targeted measures is urgently needed including increased investment, workforce development, a culture change where a multidisciplinary approach is the norm and improve parent carers led joint commissioning of mental health services for disabled children and young people.
7. Specific measure would include:
  - Better parent carer led commissioning. For example [Kirklees: Redesigning the child and adolescent mental health \(CAMHS\) service](#) - commissioners developed a new service for children with learning disability and mental health issues based on what families said would help.
  - Better parent friendly information is needed that increasing transparency and confident in the system.
  - A strong CAMHS presence in the multidisciplinary approach between the child development team, schools, local authorities and local private and voluntary organisations.
  - As set out by NICE guidelines<sup>3</sup> local autism teams should be must be available in every area 0-19 years to ensure assessment by clinical psychologist input. A move away from the clinical assessment model where assessments take place in both child's home and school.

---

<sup>2</sup> Contact a Family's research based on the experience of over 1000 parents of disabled children found almost three quarters (72%) experience poor mental health such as anxiety, depression or breakdown.

<sup>3</sup> <http://publications.nice.org.uk/managing-autism-in-children-and-young-people-ifp170/your-local-autism-team>

- In light of the SEND reforms as set out in the Children & Families Act 2014 increased capacity within the CAMHS service is urgently needed to engage in joined up support for children and their families.

## **Evidence**

8. The following areas of concern are based on our experience of providing advice through helpline, online and face to face services and commonly reported by parents.
9. **Poor information on referral routes and criteria across the country** – parents report that information is difficult to find, not parent friendly, or clear about what standards to expect from the service. Our helpline also have difficulty answering parent questions regarding CAMHS as we don't know the procedures or where to find the information either.

*“There doesn't seem to be any customer care policy, code of practice or transparency for parents like me. I would like to know if the waiting times are normal, if it is the same elsewhere in the country.”*

*“GOSH referred my daughter to local paediatrician who referred to CAMHS for managing pain from intracranial hypertension and stress headache techniques. CAMHS said this was 'not an appropriate referral' and refused support. No appointments out of school hours and this during GCSE exams.”*

There are **inconsistencies between different local authorities**.

*“CAMHS in Teesside were great in helping us with the first steps on an asd diagnosis for my 15 year old daughter, but we had to move house before it was completed and here in Lincolnshire CAMHS doesn't deal with any ASD so have to go through community paediatrician.”*

10. **Ping pong between services to get into the system** - families who finally have an initial meeting with CAMHS to be asked whether a CAF/child in need assessment is in place or whether the school are involved. Schools report exasperation at CAMHS, having supported families to refer and desperately needing a joined up approach to support children in school and home.

*“We have been a yoyo between paediatricians and CAMHS, neither much help. Round here getting a CAMHS referral is like gold dust, a professional said to me there’s no point even trying as unless your child is hurting themselves or seriously hurting others they don't want to know.”*

*“My son is almost 16 with ADHD/ODD/ASD and comorbidity disorder. We have been pushed from one place to another with no support in any way shape or form.”*

Families can also struggle to attend appointments and non-attendance results in being discharged from the service.

- 11. Lack of capacity and expertise in CAMHS to diagnose ASD.** - too many children requiring input from CAMHS for ASD diagnosis results in delayed identification and families left without support.

*“Our service is so stretched that we have to turn families away, either through not diagnosing or requiring families to jump through hoops before accessing the service.”*

*“My son has ASD and is being 'assessed' by CAMHS for schizophrenic symptoms. They sent a worker who has no experience of ASD to assess him and find out if his symptoms are not ASD. I was forced onto a parenting class before they would even help me, I’m still waiting for help now, over a year later I’m still waiting on an assessment.”*

*“At first when the Disabled Children's Team (DCT) referred him CAMHS they just referred us back to DCT. 3 referrals later he finally got an assessment who said she had no experience of children with learning disabilities but decided you couldn't have learning disabilities and mental health problems. After appealing they are finally carrying out a proper full assessment. They have visited him at school 3 times, will visit him at home and then make the decision on whether they can help him. If his old therapist lived in the area still we would take him to her or would go privately if we could find someone suitable. I wish they could be more honest and say they haven't got sufficient resources to help and try to refer on to therapist who could help.”*

*“CAMHS staff tend to be dismissive, you have to fit into a box - they know best. “*

A **reduction in the number of child development teams** with a clinical psychologist input available to them<sup>4</sup> will have a significant impact on diagnosis for pre-school children with autism.

School aged children need to see CAMHS who operate a 'clinical' model with appointments only offered in clinic settings. CAMHS should offered appointments in school/family home. Where a local autism team or learning disability CAMHS services is available, this is usually much better and more flexible.

12. **Long waiting times** - young person experiencing serious mental health issues have to wait for a considerable time (months in some cases) for an appointment.

*“My GP referred him back to CAMHS a year ago yet we still haven't heard anything.”*

CAMHS don't appear to prioritise or fast track emergency cases. Or if they do fast track they still take an age to see these families. Our helpline have spoken to parents who have called following their child's suicide attempt.

*“There are simply not enough CAMHS workers. Families wait months or years to be seen and then aren't provided with the support required, i.e. a package of support, intensive support, family therapy etc.”*

13. **Help only available at crisis point** - Parents are often told that unless their son/daughter attempts suicide they will not be seen urgently. This is different from adult services. An adult with severe depression or alarming behaviour would be seen fairly quickly by a Psychiatrist.

*“My son went into crisis in September. It resulted in a hospital admission and 6 weeks in a CAMHS unit! Worst experience of my life & probably his! Totally inappropriate provision for the nature of his disability. Accused us (parents) of horrendous things & broke us as a family!”*

*“CAMHS were awful for us. I took my son there when he was 5 as he was suspected of having Autism and learning difficulties. My sons ASD assessment took months because they kept changing*

---

<sup>4</sup> Parr, J. R., Jolleff, N., Gray, L., Gibbs, J., Williams, J. and McConachie, H. (2013)

*appointment around. Twice I went there for an appointment only to find out it had been cancelled when I got there. I also asked them for help with my son as he was self harming, and was told "you'll figure something out" and sent on my way with no help. This is a service that definitely needs a lot more work."*

#### **14. A lack of support and/or inappropriate provision following assessment**

When CAMHS input is focused on diagnosis, there often isn't a lot of support available after this when people are struggling to understand or comes to terms with the diagnosis. Many won't write anything in reports which may influence support in school.

*"Once you 'get in' so to speak, which took 3 referrals and a suicide threat, you have to push and push for any attention. I appreciate they are completely under staffed and underfunded but in times of extreme crisis it's hard to be satisfied by that."*

*"We managed to get some CBT and art therapy for our daughter and counselling for our son, but it seems to take a long time to get anything to be honest; when the help comes it's good but they need more staff and a more efficient appointments system."*

Where a young person has a possible diagnosis of Autism or ADHD for example, then CAMHS may be unable to continue to work with the young person and there is a gap (often a very lengthy gap) in other service provision.

*"It took YEARS to see a qualified professional at CAMHS. They kept fobbing us off with unqualified workers who accused me of rubbish parenting for years. He is now diagnosed with a brain injury and a variety of psychological disorders. Our local adult mental health services are very good in comparison! It's hardly a surprise loads of these kids will grow up with eating disorders, depression, psychosis etc etc. Because they were never addressed as children!"*

**15. Families report getting 'blamed' for causing the mental health problems** especially those who aren't articulate or have English as a second language. They face increased disadvantage in access support or a diagnosis.

*"We were told (by the Paed) we couldn't get a diagnosis without their input. They then refused the referral twice, wasted almost a year, then when they finally accepted us, they spent 8 months analysing my parenting skills, failed to recognise the Autism in my AUTISTIC child, and then after diagnosis (which eventually came after 3 years of battle without their report as they hadn't bothered*

*to get round to typing it up) they discharged us as they couldn't offer anything of any use to my son. They nearly drove me off a cliff mentally, we were already on our knees begging at the very beginning of all this. Lack of training in Autism and PDA, refusal to accept the existence of PDA, despite other areas accepting and diagnosing it, and assumptions that behaviour issues are all caused by 'attachment disorder' as that is their latest 'trend'."*

16. For more information about this submission please contact:

Una Summerson on 020 7608 8742 or [una.summerson@cafamily.org.uk](mailto:una.summerson@cafamily.org.uk)

Contact a Family

209-211 City Road

London EC1V 1JN

Date: 18 March 2014