



National Network of Parent Carer Forums

'Our Strength Is Our Shared Experience'

**Date: January 2017**

**Commons Select Committee Inquiry: Children and Young People with Mental Health issues – role of education**

The National Network of Parent Carer Forums (NNPCF) is made up made up of local Parent Carer Forums from across the 152 Local Authority Areas of England, and has a steering group which consists of 10 Parent Carer Representatives from each of the nine regions in England, and the Co-chairs of the Network. Our current membership is in excess of 77,000 parent carers. These parent carers representatives link into the regional Parent Carer Forum Networks,

The NNPCF Steering Group has where possible worked within their region to gather evidence to support our response to this call for evidence. We believe that our response helps to identify the most common experiences and views of Parent Carers of children and young people SEND (birth-25).

At the NNPCF Annual Conference in October 2015, delegates were asked to provide the Steering Group with their 'Burning Issues'. 'Burning Issues' were defined as being the most common and current issues that forums were focussing on at that time. These issues were collated in a national report: [www.nnpcf.org.uk/wp-content/uploads/2016/03/NNPCF-National-Priorities-2015-16.pdf](http://www.nnpcf.org.uk/wp-content/uploads/2016/03/NNPCF-National-Priorities-2015-16.pdf).

This report highlighted that CAMHs is a real problem for parents of children with SEND.

**Context**

Recent research undertaken by Contact a Family identified that a third of disabled children and young people are waiting more than a year to get help with mental health problems once a referral is made and that referrals are a real battle too.

Families tell us that local CAMHs services are underfunded, unable to meet demand and parents face long waiting lists for their child. Many families report that children and young people with a special educational need or disability (SEND) are not a priority group. This is further compounded where SEMH is not seen as the child or young person's primary need but rather as a consequence of their diagnosed disability.

Forums have also reported an increase in the number of children and young people with SEND being excluded from school. These exclusions maybe 'soft' exclusions where the family are advised that Child A cannot cope in school full time or that the school does not have sufficient funding to support Child B on a full time basis so parents need to come and collect. Other exclusions are fixed term or permanent which families being advised not to bring their child into school or they will be permanently excluded and then no school will take them.

This is in direct conflict with the vision of the Children and Families Act 2014 and the statutory duties set out in the SEN & Disability Code of Practice.

Some forums are involved in their local Transforming Care programme which is an all age programme for children and young people (and adults) with learning disabilities, autism or both,



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which aims to transform the way that care and services are provided to help children and young people have a meaningful and positive life. The programme also aims to prevent children and young people with learning disabilities and/or autism who also have behaviours that challenge or a mental health condition being admitted to specialist hospitals such as assessment and treatment units (ATUs).

In local areas, Transforming Care Partnership Boards are leading on this work to improve services and the lives of children, young people and adults with learning disabilities and/or autism. This work needs to link with the SEND agenda and implementation of both the Children and Families Act and Care Act.

### **NNPCF response**

The NNPCF welcome the decision by Government to include SEMH as a category of SEND in the SEN & Disability Code of Practice. However, we are extremely concerned that CAMHs services are not currently commissioned to undertake assessments for EHC Needs assessment or do not have adequate resources to do so. Many families have reported long delays and 'exceptions' to the 20 week EHC needs assessment process due to delays resulting from CAMHs services.

CAMH services can often be the first step in getting the diagnosis of autism or ADHD which then opens the door to families being able to access support from other services to manage their child's conditions/behaviour. Failure to identify and access needs early and effectively has a negative impact on the child's educational and social needs and outcomes. It also leads to a negative impact on the siblings and family life where stress and emotional strain may result in mental health issues with other family members and even family breakdown.

**The NNPCF strongly requests that as part of the drive to improve mental health support that there is a focus on disabled children and young people and those with special educational needs. This cohort is a vulnerable group and should be included in the debate.**

In addition, we request that you listen to the experiences of service users, the day in the life of a child or young person with SEND and their families, to identify the underlying stresses that lead to mental health issues. This will enable the Government to develop support and services around the needs of the child, young person and their families through coproduction.

### **Examples of Good Practice**

Many forums have been working with their local Clinical Commissioning Group (CCG) and Local Authority to improve CAMHs services. We would like to share two examples with you.

Kirklees Parent Carer Forum (PCAN) worked with their NHS Commissioner for CAMHs and ICARU (an external consultancy) to transform how CAMHs was delivered locally. This was in a direct response to parents of children and young people with a learning difficulty sharing their concerns with the current service. The forum held focus groups and carried out structured conversations. These views were then collated and used to inform the service specification for the CAMHs tender. The outcome was that services were developed and commissioned that were based on holistic needs working



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with the child, young person and family in a co-ordinated way with other services involved. At Tier 2 level, staff worked with schools (SENCo) to better understand the child's needs and develop strategies to deliver better outcomes. Parents were also offered training to support needs and develop strategies. At Tier 3 level, parents were able to influence better access, information and a listening culture.

In the LB Bromley, Bromley Parent Voice was invited to get involved with the CAMHs Transformation Programme by their CCG's Engagement lead. This involved parent representatives attending a multi-agency workshop (including schools) and running a focus group with parents which was facilitated by an external consultancy. Since Bromley CCG published their Bromley Five Year Transformation Plan earlier this year (with the ambition) to improve the emotional wellbeing and mental health of children and young people in Bromley, there has already been a number of local improvements. This includes the single point of access to services through Bromley Y, increased capacity and reduced waiting lists.

In order to successfully deliver the transformation plan in Bromley, commissioners committed to working closely with young people and their families, providers and other partners to ensure we have a system of care designed to meet their needs. Therefore, over the summer NHS Bromley CCG commissioned New Economics Foundation (NEF) to lead a co-design and co-production programme with communities and partners from across Bromley. This approach was adopted so that young people, families, schools, providers and other stakeholders were all actively involved in designing how services should be delivered to meet needs, improve outcomes and help build resilience in the younger population. This approach also supports delivery of the national CAMHS transformation priorities as set out in *Future in Mind (2015)*.

The report sets out the honest and open feedback that young people and parents shared about their needs and experiences. It also recommends a course of action to deliver the outcomes that are needed to support local services. There is clearly much more that needs to be done to build resilience and have in place a system of care that identifies and responds quickly to the needs of our children and young people, and also, reduces the risk of needing intensive intervention to meet needs now and into adulthood.

The CCG Clinical Executive team and the Bromley Mental Health Strategic Partnership Board discussed the report and unanimously agreed that this was a hugely important piece of work and that the co-production approach should continue. The Clinical Executive and the Mental Health Partnership Board are keen to move ahead on the next steps in the journey towards authentically co-designed and co-produced services which means that it is crucial that communities, providers and partners support that process and commit to participating in the co-production programme.

### **NNPCF Recommendations**

1. NNPCF acknowledges the importance of the role schools and colleges play in supporting the needs of children and young people with SEMH, including those who have SEND. There needs to be a better understanding of SEMH and the behaviours that may challenge within all schools.



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2. There needs to be a training programme to upskill all professionals and school teams around SEMH and challenging behaviour. [www.rcpch.ac.uk/disability-matters](http://www.rcpch.ac.uk/disability-matters)
3. There needs to be a shared vision, strategy and joined up policy/practice at a national, regional and local level to ensure everyone is working together to improve outcomes for children and young people with SEMH including those children and young people with SEND where SEMH is not their primary need.
4. Local Authorities and Clinical Commissioning groups need to jointly commission services that will support:
  - the effectiveness of the local area in identifying children and young people who have special educational needs and/or disabilities
  - the effectiveness of the local area in assessing and meeting the needs of children and young people who have special educational needs and/or disabilities
  - the effectiveness of the local area in improving outcomes for children and young people who have special educational needs and/or disabilities.



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## **Annex A – The NNPCF**

The National Network of Parent Carer Forums (NNPCF) was launched in 2011, and is funded by central government.

We became a formally constituted Group in November 2013. The NNPCF membership is made up of Parent Carer Forums of which there is one in almost every local authority area in England. Each parent carer forum in receipt of the Department of Education participation grant is a member of the NNPCF.

The function of the NNPCF is to develop cohesive good practice and effective participation and a solution focused approach at all levels, locally, regionally and nationally.

The aims of the NNPCF are to:

- Ensure that good practice, knowledge and shared expertise about parent participation continues to grow and strengthen.
- Develop a cohesive and coherent structure to sustain and develop the effectiveness of parent carer forums across England.
- Strengthen the pan disability, parent/carers led model of local forums and boost our collective voice.

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### **Contact Details**

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