



National Network of Parent Carer Forums

'Our Strength Is Our Shared Experience'

Date: February 2017

NNPCF Response on

Transforming Children and Young People's mental health provision Green paper

The National Network of Parent Carer Forums (NNPCF) is 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. We represent children and young people (birth-25 years) and are pan disability. Our current membership is in excess of 85,000 parent carers. These parent carers representatives link into the regional Parent Carer Forum Networks,

The NNPCF Steering Group has where possible worked within their regions to gather evidence to support our response to this green paper. 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).

Question 1

- **creating a new mental health workforce of community-based mental health support teams:** The NNPCF agree with this proposal and think that this could be useful provided it is properly funded, and staff have the right level of expertise.
- **every school and college will be encouraged to appoint a designated lead for mental health:** The NNPCF believe that this is a good idea in principle, however we believe that unless specific funding is given and ring-fenced, lack of funding will mean that few schools will actually implement this in practice.
- **a new 4-week waiting time for NHS children and young people's mental health services to be piloted in some areas:** The NNPCF fully support this proposal, as well as the proposal to make waiting times even shorter than this for young people who need very urgent help. At the moment waiting times are far too long, resulting in the child being in crisis by the time that they receive any treatment. Early intervention before this point is critical to preventing problems from escalating and gives a much better chance of a successful outcome in a reasonable timeframe.

Question 2

We also feel that the government should look at:

- Providing better clarity on thresholds for individuals to receive help, and more consistency.

- Providing adequate funding to make the proposals work in practice.

Question 3

As all children and young people with social and emotional mental health (SEMH) needs are now children and young people with Special Educational Needs, funding for training could be distributed to schools and colleges through delegated SEN funding to schools or high needs funding for specific children/young people. Any funding should be used for the purpose for which it is given and there needs to be robust accountability in place to demonstrate impact.

Question 4

Area: Rotherham, Yorkshire

Forum: Rotherham Parent carers Forum

Research carried out in Rotherham by the forum, the Educational Psychology and Learning Support Services illustrated how a child's wellbeing affected the wellbeing of parent carers. Many parent carers expressed sadness and frustration and questioned their own capacity when they found themselves incapable of effecting change for their child in school. The forum worked with the Educational Psychology, Learning Support Services and Parent Partnership service to develop a Parent and Child Charter for schools. This included a self-monitoring document, toolkit and training package to help schools develop good practice. A bid to develop this work as a Lamb Innovative project was successful in raising funds from the Department for Education. Forum parent carers are now trained to deliver training to services and schools alongside key service partners through an Implementation Team. Parent carers have supported other parent carers in delivering training on parental confidence to CAMHS and Early Years Services and local college.

Area: Kirklees – Redesigning Child and Adolescent Mental Health Service (CAMHS) around the needs of children and their families

Forum: PCAN (Parents of Children with Additional Needs)

The NHS commissioner for Kirklees Child and Adolescent Mental Health service (CAMHS) heard that parents of children with learning disabilities were unhappy with the existing CAMHS service. She approached PCAN, the local parent carer forum for help in running a focused workshop to gather parent's experience.

The forum invited 12 families whose children had learning disabilities and mental health issues to attend a focus group held on a Saturday. The parents were asked to talk about the pressure points in their child's life, the impact these had on their child and their family, their experiences of the existing service and what support they thought would help.

Kirklees drew up new service specifications designed around what the parents asked for and commissioned new Tier 2 and 3 CAMHS services for children with learning disabilities and mental health issues. The Tier 2 service included staff going into schools and working with the SENCO and other school staff to help them gain a better understanding of a child has needs, and develop strategies that will help the child. The Tier 2 service staff also supported parents of children with learning disabilities so they receive 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. The Tier 3 service specification for children with more complex needs included a learning disabilities nurse, a mental health nurse and a number of hands on, flexible support workers who could also help coordinate support for the child in the community; for example access to short breaks. The core team was supplemented with access to psychologist and psychiatrists.

The forum was invited to help monitor the new service.

Area: London Borough of Bromley

Forum: Bromley Parent Voice

SEMH Champion Programme within mainstream schools. Each school nominate SEMH Lead who has access to a Special Advisory Teacher based at the Local Authority, training, information and Peer network.

Question 8

Other – children and young people with SEND

Question 9

Through the implementation of the SEND Reforms (CFA 2014) many Local authority areas have established CYP forums for SEND. These forums could be used to seek the views of children and young people with SEND in the development of Mental Health Support Teams.

Other forums include:

Youth and Looked After Children Councils

School Student Councils.

At an individual level, children and young people are supported to make decisions regarding their hopes for the future, outcomes and support. Children and young people are supported to explore what is important to them and what is important for them, both are very important when we are considering mental health and wellbeing.

Question 10

The NNPCF are aware of considerable delays across our 9 regions for children and young people with SEND accessing CAMHS support. This has been identified as a key priority for the NNPCF. Locally many parent carer forums are working with CCGs on the CAMHS Transformation and Transforming Care programmes. These programmes are looking at developing robust early intervention support locally to prevent escalation to breakdowns in education placements and families leading to children/young people being placed in residential settings/ATUs away from home.

Question 11

The Children and Families Act 2014 and its' associated Code of Practice requires all schools to publish and update annually a Special Educational Needs (SEN) Information Report. The purpose of

the report is to explain how the school's SEN Policy is implemented; how children and young people with special educational needs and disability are identified and supported; how they and their parents and carers can contribute to assessment, educational opportunities and out-of-school activities and how all involved can access the information and support they need.

Feedback from parent carer forums suggests that the information contained in school reports varies considerably both within each Local Authority area and across our regions.

Question 12

SEMH is now considered to be a special educational need in the SEND Code of Practice.

Schools and colleges should use the Plan, Do, Review cycle within schools at SEN Support or EHC Plan level to set holistic education and other outcomes, to track progress and to measure the impact of support on a child/young person's mental wellbeing.

Involve parent carers and child/young person in discussions in line with Section 19 CFA 2014.

Question 13

There is evidence to show that early intervention and prevention works for all groups of children and young people. Support teams should learn from examples of good practice in other agencies and/or geographical areas.

For example, the Early Support model incorporated into CFA 2014 and local authority early help support offer:

e.g. Local hubs

Multi-agency approach

Named worker/ key working

Team around child or young person

Holistic and person-centred approaches

Questions 14 & 15

The NNPCF are concerned that too many Children and Young People with complex ASD and/or challenging behaviour become looked after due to a lack of integrated local services which can meet needs.

In her review entitled 'These are Our Children', Dame Christine Lenehan writes:

'So is it too hard? Are they really too complex? Is this the best we can do? It can't be and it isn't. There is enough evidence of good practice in the system to show a different picture. There are too many individuals who want to make a difference for it not to change. This report is about making that change happen everywhere as it is already happening in the best areas, and ensuring that it delivers the best possible benefits for this group of children.'

https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/Lenehan_Review_Report.pdf

This links with Transforming Care agenda which has introduced CETR reviews and at risk registers to better identify and support those children/young people with SEND who are at risk of becoming looked after.

The NNPCF would like to see services available locally so that children and young people with the greatest needs can remain close to those they love and who love them.

Question 16

The Local Area SEND Inspection Framework (Ofsted/CQC) set outs a model for assessing whether children and young people with SEND are able to access the support they require.

Focus is on early identification and effectiveness of intervention, leading to positive education and other outcomes.

This inspection framework could be used or adapted to test whether children and young people with SEND are receiving the support they require to support their emotional and mental well-being.

Local Authorities and CCGs are required to have systems in place to track and monitor progress towards outcomes, and to ensure that commissioning is outcome focused.

Other measures could include KPIs around the advice submitted for EHC Needs assessments from schools, Mental Health Support teams and CAMHS.

The NNPCF would like to see Local Offers (Local Authority) and SEN Information Reports (Schools) audited to ensure parents have access to the information they require regarding the support that is available and the impact that this has on their child's mental wellbeing.

The NNPCF would encourage the Department for Health and Social Care to work with the NNPCF and local parent carer forums to seek the views of families regarding service user experience. We would also welcome a review of exclusions (legal and 'soft') and the impact this is having on SEND children and young people's self-esteem and mental wellbeing.

Question 17/18

National data regarding children and young people with SEND is poor. *'The national data set on disabled children is inadequate: it has gaps, anomalies and inconsistencies. It is unfit for purpose.'*

http://www.truecolourstrust.org.uk/wp-content/uploads/2017/02/CDC.datareview.final_revised.pdf

Given the above, the NNPCF are concerned that there are an increasing number of children and young people with SEND who may have mental health disorder (diagnosed or undiagnosed) who would benefit from support from the Mental Health Support Teams.

However, parents report that often children and young people with SEND do not receive the support that they need, when they need it from local Mental Health Support teams (CAMHS tiers 1-4) because their emotional and mental wellbeing needs are not given priority if it is not their primary area of need (e.g. autism).

Often children and young people may have mild or low-level needs which do not constitute a diagnosable mental health condition but due to their needs not being appropriately met (in

education or through access to leisure activities in the local community) are at risk of developing depression, anxiety etc. from social isolation.

The NNPCF national priorities document highlighted CAMHS and Short Breaks as key areas of concerns for our members.

<http://www.nnpf.org.uk/national-priorities-report-burning-issues/>

Question 19-21

None available

The SEND Code of Practice describes supporting children and young people to prepare for adulthood from the earliest years in order for them to access education and training, have good health and wellbeing, develop independence and have friends and access to their communities. The NNPCF would encourage the Department for Health and Social Care to share the vision of colleagues from the Department for Education and give children and young people with hidden disabilities the opportunity to lead happy and fulfilled lives. Many children and young people with SEND would benefit from access to Mental Health Support teams to enable them to be part of their local community, to be safe and to achieve better life outcomes.

The NNPCF would welcome the opportunity to work with the Department for Health and Social Care to support the development of better life outcomes for children and young people affected by disability. As parent carers we are experienced individuals who have been working with the Department for Education or many years and have a wealth of knowledge and experience to share in a spirit of coproduction.

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