



National Network of Parent Carer Forums

'Our Strength Is Our Shared Experience'

NNPCF Steering Group response to the consultation on the Government's mandate to NHS England to 2020

1. The National Network of Parent Carer Forums (NNPCF) Steering Group welcomes the opportunity to proposals set out in the consultation document published on 29 October. The NNPCF are parent carers of children and young people with special educational needs and disabilities (SEND), including long term health conditions. Our interest is in the needs of families aged from 0-25. We are also parent carers and have health care needs ourselves. The NNPCF represents Parent Carer Forums across England.

The definitions of Special Educational Needs (SEN) and Disabilities

2. These are related but different. The SEND Code of Practice states that a child or young person has SEN if they have a learning difficulty or disability which calls for special educational provision to be made for him or her. A child of compulsory school age or a young person has a learning difficulty or disability if he or she:

- has a significantly greater difficulty in learning than the majority of others of the same age, or
- has a disability which prevents or hinders him or her from making use of facilities of a kind generally provided for others of the same age in mainstream schools or mainstream post-16 institutions

3. For children aged two or more, special educational provision is educational or training provision that is additional to or different from that made generally for other children or young people of the same age by mainstream schools, maintained nursery schools, mainstream post-16 institutions or by relevant early years providers. For a child under two years of age, special educational provision means educational provision of any kind. A child under compulsory school age has special educational needs if he or she is likely to fall within the definition above when they reach compulsory school age or would do so if special educational provision was not made for them (Section 20 Children and Families Act 2014).

4. Many children and young people who have SEN may have a disability under the Equality Act 2010 – that is '...a physical or mental impairment which has a long-term and substantial adverse effect on their ability to carry out normal day-to-day activities'. This definition provides a relatively low threshold and includes more children than many realise: 'long-term' is defined as 'a year or more' and 'substantial' is defined as 'more than minor or



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trivial'. This definition includes sensory impairments such as those affecting sight or hearing, and long-term health conditions such as asthma, diabetes, epilepsy, and cancer.

5. Children and young people with such conditions do not necessarily have SEN, but there is a significant overlap between disabled children and young people and those with SEN. Where a disabled child or young person requires special educational provision they will also be covered by the SEN definition. The Equality Act 2010 sets out the legal obligations that schools, early year's providers, health providers and others have towards disabled children and young people:

- They must not directly or indirectly discriminate against, harass or victimise disabled children and young people
- They must not discriminate for a reason arising in consequence of a child or young person's disability
- They must make reasonable adjustments, including the provision of auxiliary aids and services, to ensure that disabled children and young people are not at a substantial disadvantage compared with their peers. This duty is anticipatory – it requires thought to be given in advance to what disabled children and young people might require and what adjustments might need to be made to prevent that disadvantage
- Public bodies, including health bodies, local authorities, maintained schools, maintained nursery schools, academies and free schools are covered by the public sector equality duty and, when carrying out their functions, must have regard to the need to eliminate discrimination, promote equality of opportunity and foster good relations between disabled and nondisabled children and young people.

6. Public bodies also have specific duties under the public sector equality duty and must publish information to demonstrate their compliance with this general duty and must prepare and publish objectives to achieve the core aims of the general duty. Objectives must be specific and measurable. The general duty also applies to bodies that are not public bodies but that carry out public functions. Such bodies include providers of relevant early years education, non-maintained special schools, independent specialist providers and others making provision that is funded from the public purse.

7. The duties cover discrimination in the provision of services and the provision of education, including admissions and exclusions. All providers must make reasonable adjustments to procedures, criteria and practices and by the provision of auxiliary aids and services. Most providers must also make reasonable adjustments by making physical alterations.



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Children and Families Act 2014

8. New additional legal duties regarding disability and special educational needs are contained in the Children and Families Act 2014. These are explained in The Code of Practice, which is statutory guidance published by the Department for Education (DfE) and Department of Health (DH) on the duties, policies and procedures relating to part 3 of the Children and Families Act 2014. These duties came into force in September 2014 and place responsibility on the local area, which includes the local authority and health commissioners and providers, together with all of the area's early years settings, schools and post-16 further education sector, to identify and meet in a timely and efficient way the needs of disabled children and young people and those who have special educational needs aged 0 to 25 and to improve their health and other outcomes.

A mandate from the Government to NHS England: April 2015 to March 2016

9. The background to and need for the Children and Families Act reflects the fact that, for this group of children and young people 0-25, outcomes across health, education, employment, friendships and community access are nationally recognised to be much poorer than their peers. Therefore the NNPCF SG was pleased to see a specific mention in the current Mandate to SEND and to participation, in particular in paragraph 4.13, as follows:

"4.11 The second objective for NHS England, which will require joined-up care between the NHS and local authorities across health, education and social services, is to improve the standards of care and experience for women and families during pregnancy and in the (13) early years for their children. As part of this, we want NHS England to work with partner organisations to ensure that the NHS:

- **takes forward the pledges they signed up to in "Better health outcomes for children and young people: Our pledge" to improve the physical and mental health outcomes for all children and young people;**
- offers women the greatest possible choice of providers;
- ensures every woman has a named midwife who is responsible for ensuring she has personalised, one-to-one care throughout pregnancy, childbirth and during the postnatal period, including additional support for those who have a maternal health concern;
- reduces the incidence and impact of postnatal depression through earlier diagnosis, and better intervention and support.



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4.12 Our ambition is to help give children the best start in life, and promote their health and resilience as they grow up; and the Government's commitment to an additional 4,200 health visitors by 2015 will help to ensure this vital support for new families. **We expect to see the NHS, working together with schools and children's social services, supporting and safeguarding vulnerable, looked-after and adopted children, through a more joined-up approach to addressing their needs.** We welcome NHS England's commitment to its full participation in local safeguarding arrangements for vulnerable children and adults. **We will work with NHS England, and Healthwatch England, to consider how best to ensure that the views of children, especially those with specific healthcare needs, are listened to.**

4.13 **One area where there is a particular need for improvement, working in partnership across different services, is in supporting children and young people with special educational needs or disabilities. NHS England's objective is to ensure that they have access to the services identified in their Education, Health and Care plan, and that parents of children who could benefit have the option of a personal budget based on a coordinated assessment across health, social care and education.**

4.14 Timely access to services is a critical part of our experience of care."

The Consultation questions

10. Against this background, the response of the NNPCF SG to the consultation questions is set out below.

1. Do you agree with our aims for the mandate to NHS England?

The aims are broad and refer to preventing ill health and improving outcomes. While these are welcome in general terms, the draft mandate also makes clear that resources are stretched. This is especially the case across children's health services. The references to long term conditions are not broad enough to include children with SEND.

However we would like the mandate to refer specifically to children including those with disabilities, SEN and long term conditions and to the need to work jointly with public health and other services to ensure they have the best possible start in life and an effective and joined up early intervention response. The consequence of not doing this is what we currently see across children's health with poorer health outcomes and poorer health. The consequence will be more costly in the longer term, for their children and their families.

2. Is there anything else we should be considering in producing the mandate to NHS England?



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While there is a commitment to the draft to reducing health inequalities and to improving access and so on by 2020, the current legislation in the Children and Families Act has placed a legal duty since September 2014 on all local areas including health commissioners, in public health, CCGs and NHS England, to deliver better health and other outcomes for children and young people with SEND, including long term conditions. Additionally the Equalities Act duties have been in place for longer.

There is therefore a requirement to deliver on this now for children and young people with SEND. With so many varied and competing pressures within the NHS, we do not believe, based on many years of experience including of working, with others, on national mandates for Health and Wellbeing Boards, that the essential and necessary work to improve health and wider outcomes, to which health contribute, for children and young people with SEND will be afforded the necessary national, regional and local prioritisation within health without having stronger language about SEND as a priority.

While it is good to have specific and more detailed references to some groups within SEND, such as learning disability, the language in the new Mandate on SEND in paragraph 3.21:

“There is much more to be done to ensure mental and physical health are considered equal, while care for people with special educational needs and learning disabilities needs further improvement.”

is weaker and will not have the necessary imperative and priority within health commissioning and prioritisation than the current wording (above). We would therefore at the very least like the wording from the current mandate to be reinstated in this document.

3. What views do you have on our overarching objective of improving outcomes and reducing health inequalities, including by using new measures of comparative quality for local CCG populations to complement the national outcomes measures in the NHS Outcomes Framework?

This is welcome and necessary as it is required by the Equalities legislation and existing NHS legal duties under the NHS Act. However we cannot wait until 2020 for action by the NHS to deliver on better outcomes for children and young people with SEND. It is welcome that a new DH/NHS England led Complex Health Needs Implementation Board for SEND has been set up and the NNPCF parent carers are very pleased to be part of it. That top level commitment needs to be matched in this mandate so that the implementation gaps that we all see are prioritised with local, regional and national health commissioning frameworks. That is unlikely to happen without a more explicit commitment to children and young people with SEND in this Mandate. While we welcome the commitment to CAHMS Transformation,



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the same practical commitment is needed to the wider and statutory imperative of SEND transformation within and by health.

4. What views do you have on our priorities for the health and care system?

Many children and young people have needs across the health and care system. It is welcome that children are being included within the IPC pilots. However the requirement to look at joint working and integration, including joint commissioning, exists now within the Children and Families Act. That is why it needs a specific and more detailed commitment.

We would also like to see children and young people with SEND referenced specifically within 3.9:

"3.9. We also want to see the quality of life improve for people living with long-term conditions and those with dementia. We expect NHS England to contribute to the delivery of the Prime Minister's Challenge on Dementia 2020 to transform dementia care support, awareness and research".

We also do not see how choice and control and personal (health) budgets are to be delivered for young people with SEND. Personal budgets are now a mandated requirement within health and within the Children and Families Act, yet not all areas are offering Personal Budgets and the arrangements for Continuing Healthcare for children and young people is unclear.

5. What views do you have on how we set objectives for NHS England to reflect their contribution to achieving our priorities?

We do not believe that children including children with SEND will receive sufficient priority without being specifically referenced in the Mandate. To deliver improved outcomes requires coproduction with families and children and young people, looking at clinical care pathways and service and resourcing across NHS England, community and public health services. This is what Section 19 of the Children and Families Act and other aspects requires: it has raised expectations among families of children and young people with SEND that it will therefore happen across education, health and social care. This is at the heart of the SEND reforms and the statutory underpinning for its commitments to improving outcomes including through better collection and understanding of data and joint commissioning.

Children's data is weak within health and should be another priority. The NNPCF parent carers were proud to be part of developing a new dataset to allow for the first time collection of accurate information nationally and locally about the health needs of disabled



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children and their families. Currently data systems tend to focus on one area of need without looking at others. It is the understanding of comorbidities that will allow for real population based commissioning within health. This new dataset should be a priority within health.

There are references at various places in the document to saving money, delivering more for less and moving to seven day working. It is unclear how this and improving children and young people's health and related life outcomes can be improved without additional investment. It may be that a solution for SEND transformation like that for CAHMS transformation will be required by the NHS.

We see participation and coproduction as key to the success of the NHS at all levels. That is a central strand of the SEND reforms – person centred planning at an individual, family and strategic level in local, regional, and National Health Service development and commissioning. We would therefore like to see references to participation by children and young people with SEND and their parent carers added to paragraphs 3.12 and 3.13:

"3.12. The NHS should provide the best quality care for all. As part of this, we want NHS England to improve early diagnosis, services and outcomes for cancer patients, in particular survival rates, by taking forward the new strategy recommended by the Cancer Taskforce and by continuing the Cancer Drugs Fund. **We will also expect NHS England to make further progress in creating a more person-centred NHS, in which people are empowered to shape and manage their own health and care, and can make meaningful choices to achieve better outcomes, particularly in maternity, long-term conditions and end of life care**".

"3.13. The mandate will set out that we expect NHS England to ensure the NHS is equipped and incentivised to seek, listen to and act on feedback in all its forms from patients and staff, including through the Friends and Family Test. Feedback is vital to improve services to deliver safe, high-quality care for all patients, particularly the most vulnerable".

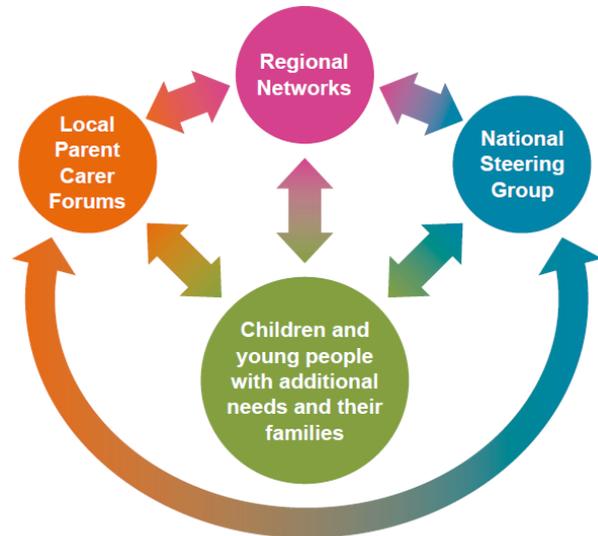
There is not a need to create new organisations to represent the views of families and parent carers of children and young people with SEND. These representative organisations exist already at a local, regional and national level through Parent Carer Forums, regional clusters and the National Network of Parent Carer Forums. The structure of the NNPCF is shown below:



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Each Parent Carer Forum includes parent carers with a full range of experiences in Health, Education and Social Care as their children have a wide range of conditions. Parents in the network total over 65,000.



Working with parent carers through Parent Carer Forums and with the NNPCF at a regional and national level does require resourcing of parent carers' time.

If correctly implemented with the right expertise, then 3.17 is good for children and young people with SEND. However it is not clear that children or children with SEND are reflected in this and would like to see this stated more explicitly:

"3.17. We want to transform the health and care system to ensure high quality care is accessible to everyone when and where they need it, with more services provided outside of hospital in the community and closer to patients' homes. The Five Year Forward View reinforces the need to join up primary care, community health services, mental health services and adult social care, to work alongside specialists in hospitals. These services need to tackle causes, not just symptoms; to treat the whole person, not just an individual ailment; and to be more proactive in supporting people with long-term health conditions to manage their health and avoid unnecessary hospital stays".

NNPCF Steering Group November 2015



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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/carer led model of local forums and boost our collective voice.

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