

Talking points

The NNPCF is a membership organisation and our mission states that “we aim to empower our members to ensure that their voice is heard at a local, regional and national level.”

Working with our membership we have identified a number of key “talking points” - these are topics and themes that are the most important to our membership and the ones that have been prioritised by the NNPCF.

Based on feedback from our membership and from other partners and stakeholders, the “talking point” summarise:

- The lived experience of our members about each topic,
- What is working and what is not working, and
- What we would like to see changed.

The talking points have been created using a range of feedback which includes:

- Surveys (including the SEND surveys)
- Feedback from our annual conferences
- The topics raised at regional meetings
- Themes and topics raised by our membership on social media
- Face to face conversations with our membership

Engagement and co-production with Health

We continue to work with our colleagues in the NHS to build strong relationships that will allow us to co-produce with them in a truly productive way.

Whilst increased focus on parent carer forums from NHS England and the SEND local area inspections continue to provide a boost to this engagement, many forums and regions still report that engagement with CCGs, NHSE transformation projects and providers remains sporadic and sometimes ineffective.

Some areas have seen improvement in health engagement since our first Talking Point (2017).

Individual co-production

Parent carer forums up and down the country are reporting widely varying levels of individual co-production with families from Clinical Commissioning Groups and providers. Often families report that staff remain very provision focussed, rather than outcome focussed.

The NNPCF would like to see person centred planning and an outcome focus fully embedded in all interactions by health staff with families.

Parent carer forums across the country continue to report that the ability of health professionals to support the SEND reforms is limited by their capacity and the quality of health advice to Education Health and Care Plans is still cause for concern.

These key messages are reflected in Ofsted/CQC Local Area SEND Inspection findings. For example:

“Children with SEND are not easily identifiable in health records at an individual, service or trust level. This makes it harder for health professionals to be aware of children’s needs in a holistic manner and negatively impacts on the tell-it-once approach for parents and carers. This also reduces the effectiveness of leaders’ oversight because they cannot easily identify the outcomes achieved by the health care received.” Kent (March 2019)

“Health practitioners routinely measure and track the progress of individual children and young people towards better health outcomes. However, these health improvements are not identified sharply in EHC plans.” Kent (March 2019)

“Health teams are not able to collate outcomes to check whether a service is effective.” Calderdale (May 2019)¹

¹

https://reports.ofsted.gov.uk/search?q=&location=&lat=&lon=&radius=&level_1_types=4&level_2_types%5B%5D=18

The NNPCF believe that there needs to be a focus on earlier intervention and prevention, especially in and linked to schools and colleges. We welcome the government's work to provide earlier mental health support for all children and young people including those with SEND through new Mental Health Support teams in trailblazer areas and plans to support all schools and colleges to put in place a Designated Senior Lead for Mental Health by 2019-20².

Strategic co-production

The NHS constitution and the Five Year Forward View enshrine public involvement.³

We have seen an improvement in strategic co-production from Health agencies since the introduction of the LA SEND inspection framework and following the work done by the Children's and Young People team at NHS England. Despite this progress, some parent carer forums still report that engagement is patchy with some areas still not working with forums and health services remaining detached from the SEND agenda.

We would like to see strategic co-production more consistently embedded in Health Partners at every level.

This is reflected in the fact that relatively few parent carer forums at a local or regional level are funded by health bodies.

We would like to see systemic funding of parent carer forums by health bodies (either nationally from NHS England or the Department of Health) or locally through CCGs (there should be clear guidance about this).

The NNPCF continues to raise this issue with NHSE and DHSC.

² <https://schoolsweek.co.uk/government-names-first-25-areas-to-get-school-mental-health-support-teams/>

³ <https://www.england.nhs.uk/publication/patient-and-public-participation-in-commissioning-health-and-care-statutory-guidance-for-ccgs-and-nhs-england/>

In addition, we have noted that there does not appear to be a co-ordinated approach to strategic co-production from the various parts of the NHS. Our members have noted a number of different approaches. These include:

- Directly including the NNPCF in strategic discussions
- Asking members of the NNPCF to apply to join boards directly as individuals
- Commissioning other organisations to set up parallel (and perhaps even duplicative) co-production models without engaging with the NNPCF.

The NNPCF is a member of Complex needs board and has been actively involved in the development of the NHSE Long Term plan.

We will continue to work with NHS England to help inform and develop more consistent models of co-production across the NHS. This would enable the NHS to work with a range of partners including the NNPCF in a way that recognises and leverages their different strengths and specialisms.

Changing landscape across health

In summer 2018, to mark the 70th anniversary of the NHS in July, the Prime Minister (Theresa May) announced an extra £20 billion of funding between now and 2023. In return, she asked the NHS to develop a new 10 year plan for health provision.

The landscape for health is rapidly changing and there are four main things that forums need to be aware of:

- Long Term Plan (LTP)⁴
- Sustainability & Transformation partnerships
- Integrated Care Systems
- Primary Care Networks

Sustainability and Transformation Partnerships (STPs) were asked to feedback to NHS England with their response on how they would implement the LTP for their area. These are still in development and engagement with NNPCF/individual forums has been a mixed picture.

⁴ <https://www.longtermplan.nhs.uk/publication/nhs-long-term-plan/>
<https://www.longtermplan.nhs.uk/publication/implementation-framework/>

With some specific parts of the LTP work is already underway and there has been engagement with NNPCF (e.g. Key working role identified for inpatients of Assessment Treatment Units - formally part of Transforming Care).

It is important forums link into their local STP to develop ways to engage especially as this move to Integrated Care Systems.

Sustainability & Transformation partnerships (STP)

In 2016, NHS organisations and local councils joined forces in every part of England to develop proposals for improved health and care. They formed new partnerships – known as sustainability and transformation partnerships (STPs) – to run services in a more coordinated way, to agree system-wide priorities, and to plan collectively how to improve residents' day-to-day health.

Partnerships published their initial proposals in 2016 which have since continued to develop to reflect local priorities, views from people who use and provide services, elected representatives and local voluntary organisations.

Forums should contact their STP lead to establish how they propose to implement the NHS 10 year plan (see details below for SEND in the LTP). Forums should try to forge engagement links to help inform LTP delivery going forward.

Integrated Care Systems

In some areas, STPs have evolved to become integrated care systems, a new form of even closer collaboration between the NHS and local councils. The NHS Long Term Plan (LTP) set out the aim that every part of England will be covered by an integrated care system by 2021, replacing STPs but building on their good work to date.⁵

As at November 2019 there are 14 ICS areas covering more than a third of the country. **It is key that forums are proactive in establishing engagement opportunities with these.** In the London Region, PCFs are working with a partnership of six CCGs in south London (OHSEL) to develop a model of coproduction. This work is still in its infancy.

⁵ <https://www.england.nhs.uk/integratedcare/integrated-care-systems/>

Primary Care Networks

From 1 July 2019, all patients in England are now covered by a primary care network (PCN) – the most significant reform to general practice in England in a generation. PCNs should help to integrate primary care with secondary and community services, and bridge a gap between general practice and emerging Integrated Care Systems.

Since January 2019, practices have been organising themselves into local networks to provide care at greater scale by sharing staff and some of their funding. GP practices have begun working together and with community, mental health, social care, pharmacy, hospital and voluntary services in their local areas in primary care networks. There is concern that while PCNs offer huge potential to integrate care and improve services, there is a risk that the speed of implementation will undermine the best intentions of the policy.⁶

NHS England Long Term Plan

What does the LTP say about Children and Young People with SEND?

The LTP sets out a number of overarching principles including:

1. Put children and young people and their families at the centre of care
2. Involve children, young people and families in the design and delivery of our work
3. Target action at reducing health inequalities, including addressing the needs of vulnerable children and those with complex needs.

There are a number of named SEND related areas in the LTP. These include:

Designated Key Worker

The role of the key worker is to work with children and young people with a learning disability and/or autism by 2023/24. Initially, keyworker support will be provided to children and young people who are inpatients or at risk of being admitted to hospital, and will be extended to other vulnerable groups, including adopted and looked after children.

⁶ <https://www.health.org.uk/publications/reports/understanding-primary-care-networks>

Mental Health

The LTP describes greater funding for children and young people's mental health services. Investment in expanding access across community based mental health service (NHS-funded mental health services and school or college-based Mental Health Support Teams).⁷

Learning disabilities, autism or both

The LTP promotes greater understanding of the needs of children, young people and adults with learning disabilities and autism.

Forums could help to promote the 14 plus health checks for Learning Disabled young people.⁸

Support during the autism diagnostic process

Reduce waiting times for specialist services

Children and Young People's Transformation

The LTP sets out the creation of a Children and Young People's Transformation Programme to oversee the delivery of the Plan's commitments to care for children and young people.

Improving children's transition to adult care services

Extending services to cover 18-25 to support transition to adult services in line with the Children and Families Act 2014.

Sight, hearing and dental checks

The NHS Long Term Plan also contains a pledge to deliver hearing, sight, and dental checks for children and young people with a learning disability and/or autism in special residential schools.

Forums should ask what is being done locally across all these areas and insist that they coproduce it. For further information visit Long Term Plan webinar: <http://www.nnpfc.org.uk/join-us-for-nhs-long-term-plan-webinars/>

⁷ <https://www.annafreud.org/what-we-do/schools-in-mind/our-work-with-schools/the-link-programme/>

⁸ <https://www.england.nhs.uk/learning-disabilities/improving-health/annual-health-checks/>

The NHS traditionally looks to their Public & Patient Advisory Groups for engagement. These may not have parents of SEND children involved. It may help forge links if some forum members joined their local Patient Advisory Group (PAG) or develop links with their local Healthwatch for engagement.

The NNPCF would like to see NHS England outline expected engagement of parents to inform the LTP, STPs and where they exist, ICN. We feel this is imperative as traditional Public and Patient engagement does not always ensure SEND communities are represented.

The Children and Young People's Transformation Programme Board will, in conjunction with the Maternity Transformation Programme, oversee the delivery of the children and young people's commitments in the LTP.

The NNPCF are represented on the SEND and Learning Disability and Autism work streams which report to the Children and Young People's Transformation Programme Board and are well placed to support the implementation of the LTP at a national, regional and local level.

The NNPCF will continue to work with NHS England, local NHS organisations and their partners to turn the ambitions in the plan into improvements in services for children and young people with SEND in England.

Appendix A: Children and Families Act requirements for Health Service Providers

Principles

1. All services should be based upon the principles of co-production:
 - a. Individual co-production with young people, parents-carers and families to ensure a person centred and outcome focus for individual service delivery
 - b. Strategic co-production with representative groups for children and young people and their families to ensure that service design reflects the changing needs of patients and their families.

Joint working

2. Providers to contribute data and information for the Joint Strategic Needs Assessment.
3. Providers should share information as necessary between different agencies and services to ensure a joined up approach and reduce the need for the duplication of information requests on children, young people and families.
4. Providers should work in an integrated way with other agencies and services to ensure a seamless transition between children's and adult services
5. Where a child or young person's primary need is a health condition, providers should be prepared to identify and act as a key worker.

Education Health and Care Plans

6. Provider must supply EHCP advice in the agreed format (suggest we use the June 2017 formats published by the Council for Disabled Children) with the 6 week required timescale. This advice should be produced in a person centred and outcome focussed way.
7. Providers should attend multi-agency meetings for EHCPs where required.

Local offer / Information Advice and Support (IAS)

8. Providers are required to update the local offer of significant service changes and to respond to feedback on services from the local offer. At a minimum the local offer should be formally reviewed and signed off once a year.

9. Providers should supply information as required by IAS services to support their work

Workforce development

10. All staff are required to attend the following training as a part of their induction:

- Introduction to the Children and Families Act 2014
- Person centred planning and outcome focus which includes (co-production with families and young people, creative use of personal budgets)

Personal budgets

11. There must be some provision in the new contracts to enable personal budgets to be expanded beyond continuing care. There is a requirement in the Children and Families Act that “demand from parents and young people for funds that cannot, at present, be disaggregated should inform joint commissioning arrangements for greater choice and control” (code of practice section 9.106)