

## 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 SEND local area inspections have provided 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.

### 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.

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

Ofsted / CQC inspection feedback<sup>1</sup> notes that:

“many parents feel they are “let in” to the process rather at the heart of it.”

“Health outcomes remain based on a model of service deliverables rather than being part of a fully person centred... approach”

### Strategic co-production

We have seen a great improvement in strategic co-production from Health agencies since the introduction of the LA SEND inspection framework and following the work done by the Senior Children’s and Young Person’s Lead at NHS England. However, 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).*

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.

The NHS constitution and the Five Year Forward View enshrines public involvement. See “Patient and Public Participation in Commissioning Health and Care”<sup>3</sup>

In the 8<sup>th</sup> SEND survey<sup>2</sup> Only 54% of forums state they are working in partnership with CCGs / children’s joint commissioner.

It also reports that only 7 % of parent carer forums believe that health is fully engaged in joint commissioning.

Ofsted / CQC inspections support this view<sup>1</sup>:

“Joint commissioning of services is under-developed

This has been raised by the NNPCF in its conversations with NHSE and DoH. It was also raised at the Q&A panel at the 2018 conference.

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

*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.*

The NNPCF is a member of Complex needs board and the review of specialised commissioning for critical care and surgery.

We have been asked to apply as individuals to join to join the clinical reference group for the review of neo-natal care

The Young Minds project is working on setting up co-production models that potentially overlap with the NNPCF.

### The transformation agenda

There are several significant NHS England change programmes under way. All of the following have a major impact upon the SEND agenda:

- Children and Young People’s Mental Health Transformation Programme
- Transforming care
- Integrated Personal Commissioning (IPC)
- Review of specialised commissioning
- Sustainability and Transformation Plans (STPs)

Each of these programmes has separate governance at a local, regional and national level.

*We would expect to see that parent carer forums are actively engaged and co-producing in each of*

The NNPCF attends the Children with Complex Needs Implementation (SEND) Board which has oversight over the whole SEND agenda. In addition, we attend the CAMHS and Transforming Care Boards.

With reference to STPs, the Royal College of Paediatrics and Child Health reports that there is “limited engagement with clinicians and the public.”<sup>4</sup>

*these programmes at a local, regional and national level.*

In particular, STPs are going to have a major say in how services are delivered in each locality and we would like to see parent carer forums more actively engaged.

*We would like to see a more co-ordinated approach across these programmes that identifies the common principles and themes to create a more holistic, outcome focussed approach.*

STPs will be reviewing things such as which services are provided in community settings, developing collaborative ways of working between hospitals, closing beds, local departments and even hospitals.

Commentary on the NNPCF Facebook page in June 2017 reflects forums concern about some aspects of STP work, notably expenditure caps for CCGs within STPs.

### **Resources to support the implementation of the SEND reforms**

Parent carer forums across the country report that the ability of health professionals to support the SEND reforms is limited by their capacity.

The 8<sup>th</sup> SEND Implementation Survey<sup>2</sup>, identifies the timeliness of advice from health professionals and the capacity of health professionals to provide advice as two of the top 5 barriers to completion of EHCPs within the 20 week timeline.

The quality of health advice to Education Health and Care Plans is consistently raised as a concern by forums. They report that practitioners do not have an outcome and person centred focus and have not been trained in the requirements of the Children and Families Act 2014.

This view is supported by Ofsted / CQC inspections<sup>1</sup>:  
 “Access to therapy services was a weakness in half of the local areas inspected”<sup>7</sup>

“weaknesses in the process for securing the statutory contributions from health professionals”

*We would like to see the requirements of the Children and Families Act reflected in clear protocols and contractual arrangements for provider organisations. This would include things such as training and job descriptions that reflect responsibilities for all relevant Health staff. For a guide of desirable items see appendix A.*

This view is supported by the Council for Disabled Children:

Page 6 Children and Families Act – Implementation Update – Issues relating to Health<sup>5</sup>

## 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)

**Notes:**

1. Ofsted / CQC Local Area SEND Inspections: Key messages about inspection practice and findings to date. 3 March 2017

<https://www.slideshare.net/Ofstednews/localareasendinspections210217>

2. Eighth Special Educational Needs and Disability Reforms Implementation Survey for Parent Carer Forums November 2016

[https://www.cafamily.org.uk/media/1038801/survey\\_8\\_summary\\_final.pdf](https://www.cafamily.org.uk/media/1038801/survey_8_summary_final.pdf)

3. Patient and Public Participation in Commissioning Health and Care May 2017

<https://www.england.nhs.uk/wp-content/uploads/2017/05/patient-and-public-participation-guidance.pdf>

4. State of Child Health – Royal College of Paediatrics and Child Health 2017

<http://www.rcpch.ac.uk/system/files/protected/page/STP%20short%20report%20FINAL%2015.05.2017.pdf>

5. Council for Disabled Children. Children and Families Act – Implementation Update – Issues relating to Health

[https://councilfordisabledchildren.org.uk/sites/default/files/field/attachment/CFAUpdate\\_Issues%20relating%20to%20Health%20%28004%29.pdf](https://councilfordisabledchildren.org.uk/sites/default/files/field/attachment/CFAUpdate_Issues%20relating%20to%20Health%20%28004%29.pdf)

6. Local Area SEND inspections: one year on Care Quality Commission and Ofsted October 2017

<https://www.gov.uk/government/publications/local-area-send-inspections-one-year-on>