



National Network of Parent Carer Forums  
'Our Strength Is Our Shared Experience'

## The Hewitt Review

This document outlines the NNPCF response to the Hewitt review on Integrated Care Systems.

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.”

Based on feedback from our membership and from other partners and stakeholders, we summarise using the following methodology:

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

We collate this feedback by

- 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

Please share examples from health and care systems, where local leaders and organisations have created transformational changes to improve people’s lives.

The NNPCF membership has received very few examples from the health and care system where leaders have created transformational change to improve people’s lives. One exception is where parent carer forums (PCFs) have been invited to be integral to autism and learning difficulty work streams in South Yorkshire. Although this work started before the creation of the ICB it has continued. The ICB partnering with PCFs and other voluntary sector organisations has resulted in effective all age peer support, providing rich data to ensure meaningful planning and provision or pre and post diagnostic services for the neurodivergent community across education, health and employment. Ongoing evaluation and progression through the 3 workstreams support meaningful partnership alongside the provision as well as identifying any gaps.

The national autism in schools project is an example of how education, health and community services can work together to effectively transform outcomes.

The NNPCF is aware of one ICB aiming to increase the uptake of annual health checks for children and young people (CYP) with special educational needs and disabilities (SEND) through measurable targets, and another who has an effective data sharing system to track and target services for CYP with SEND. However, these aren't necessarily linked to the effect they have on people's lives.

Overall, the membership of the NNPCF has only heard of limited examples whereby ICSs create transformational change to improve the lives of children and young people with special educational needs and disabilities.

Do you have any examples where policy frameworks, policies and support mechanisms have enabled local leaders, and in particular ICSs, to achieve their goals?

No. ICSs and ICBs are relatively new organisations, and whilst there would be low expectations of them achieving their goals in the short time frame, NNPCF members report observing little evidence of ICSs being set up in a way to enable them to achieve their goals. Parent Carer Forums (PCFs) report written statement of actions (WSOA) from a joint inspection from Ofsted/CQC dominate improvement plans. They report complications where an ICB covers different geographical areas to those inspected. One PCF has to work with 3 different ICBs across one local authority. Each organisation looks to align services across their footprint, which doesn't aid effective co-production of services. The NNPCF has no data to suggest that children and young people are a priority for ICBs, nor are those children with special educational needs and disabilities.

Nationally, Lorraine Mulroneys (National Specialist advisor NHS England) team has pushed to have localised engagement representation and the NNPCF has seen areas with specific leads for certain conditions, to make sure children and young people's voices are heard.

What do you think would be needed for ICSs and the organisations and partnerships within them to increase innovation and go further and faster in pursuing their goals?

The NNPCF believes co-production and understanding of lived experience of parent carers of children and young people with special educational needs and disabilities would enable ICSs to improve services, increase innovation and reach their goals sooner, as well as improve the lives

of children and young people with SEND. To date very few parent carer forums (PCFs) report true co-production occurring within ICBs. Several PCFs report co-production and working with parents has decreased since the introduction of ICSs.

Improving clarity over roles and responsibilities, particularly where ICBs have yet to form effective working partnerships with local councils over shared responsibilities (e.g. for elements of social care or support for education services) would help goals be pursued quicker. An explicit objective for ICBs is “care” in the holistic sense. This links in directly with the SEN green paper. There should be clear requirements to work with and jointly commission services not only with councils but with multi-academy trusts. To improve outcomes for children and young people with disabilities the NNPCF believe there needs to be representation from parent carers at board level of both ICSs and ICBs. The majority of PCFs report not knowing who the CYP lead is for their ICB. Having parent carer representation at board level would ensure the voices of CYP with SEND and their parents are represented at board level.

Improving accountability and assessing whether they are set up in accordance with legislation and in a manner to achieve their goals would be beneficial.

### What policy frameworks, regulations or support mechanisms do you think could best support the active involvement of partners in integrated care systems?

Currently the NNPCF is hearing its membership have less active engagement with ICBs than they had previously with health before ICBs were established. The NNPCF is probably one of the most developed community networks across the country, and this decrease in engagement is probably indicative of broader community engagement. Although engagement is already legislated for, work could be done to show examples of good practice as well as the benefits. NNPCF members report decisions being made and then partners being consulted on them, which has more of a feel of being informed, than active engagement and co-production. Funding issues can also limit active involvement of partners, with some ICBs choosing to help fund the engagement work of PCFs and others choosing not to.

Evaluation of the effectiveness of active involvement with partners and how that helps improve services through any inspection or regulation regime may help improve not only engagement but also its impact. Data capture could scrutinise the level of active engagement, not only where it is legislated for, but also in its impact in improving services. Embedding the already in place legislation from the Children’s and Families Act around joint strategic needs assessments and joint commissioning would also enable the participation of partners

## What recommendations would you give national bodies setting national targets or priorities in identifying which issues to include and which to leave to a local or system level decision-making?

The starting point should be the law, and national bodies should ensure the legislation is followed and have powers to ensure its implementation

To date the NNPCF have no data that suggests children are a priority for ICBs despite specific provisions being required. To increase the visibility of CYP within ICBs this could be a national priority, and scrutiny needs to explicitly form part of any inspection and/or regulation regime

NNPCF members report ICBs request lower level of engagement than before they were established. Performance indicators which measure active engagement with partners and participation might help drive co-production, and so improve outcomes.

Local issues feed into the national picture and so national priorities should be shaped by trends that affect all areas. National targets and priorities should help to eliminate postcode lotteries for services across the country. National broad frameworks should set national priorities. Local feedback should then identify where further work could be done to meet these priorities and additionally should reflect the needs of the local population. However, the NNPCF has heard reports that national messages can sometimes be lost within regions.

The NNPCF is concerned that national priorities could reduce the focus on CYP and particularly those with SEND. The NNPCF would like to see national priorities seeking to improve outcomes for CYP with SEND. The NNPCF believe that improving outcomes in childhood has the potential to reduce need for services for CYP as they transition to adult services.

## What mechanisms outside of national targets could be used to support performance improvement?

The NNPCF believes co-production can be used to support performance improvement by bring lived experience of CYP with SEND to decision makers. Joint commissioning arrangements in conjunction with families can be more cost effective and impactful for our families. The NNPCF would be delighted to discuss how co-production and families sharing lived experience can support performance improvement further.

The NNPCF believe joint-commissioning arrangements are potentially more cost-effective and impactful for our families and can effectively support performance improvement of ICBs. The NNPCF is concerned that ICBs can have multiple LAs as well as health organisations making

decisions and the tension which can occur between organisations, especially when considering funding, has been observed to hinder improvement.

Reflection and learning from data already in existence locally can also drive improvement. Consideration of topics which parents of CYP with SEND have taken to appeal or tribunal, have discussed with the local SENDIASS service, or have discussed with PALS would also give helpful insights into areas which are not working for families and could be improved.

Local Parent Carer Forums could be used to capture data on families' experiences of ICB provision in a more formal way, to help ICBs identify areas of weakness families are experiencing and also to consider whether improvement plans are delivering for those using the services.

Examination of EHCP outcomes and whether these have been achieved could give helpful insight into the effectiveness of provisions and how to improve them further.

**Do you have any examples, at a neighbourhood, place or system level, of innovative uses of data or digital services?**

The Parent Carer Forum from Bedford report an effective data sharing agreement between the Local Authority and the health providers and commissioners to track and target services for children and young people with special educational needs and disabilities.

The NNPCF are aware of few examples here, though this may be because ICBs are still in their infancy.

**How could the collection of data from ICSs, including ICBs and partner organisations, such as trusts, be streamlined and what collections and standards should be set nationally?**

A decent national data set could help identify trends and areas of concerns. The NNPCF would be interested in helping design a national data set that captures the needs of our families.

Data from health outcomes on EHCPs should be monitored to ensure provisions and interventions are impacting outcomes.

Data from EHCPs could also be used to intelligently plan for transitions in a child's life, as well moving to adult services. Significant data is captured through the EHCP process by LAs which could be useful for health to know, and it is important to consider whether the right data is being captured, and whether it is intelligently used. It is also important to consider whether this data is informing the joint strategic needs assessment correctly.

Data on the impact of health on school attendance should be collected. For instance, where a school exclusion has its root in SEND, is data collected on whether appropriate provisions interventions have been put in place from health? Are there any trends from exclusions or school absence that could be improved by ICBs through their provisions in health? Are there any trends in challenging behaviours in schools and ICB provisions across the country?

Data should also look at children who are schooled or housed out of area (e.g. looked after children, or those in residential settings). How is this affecting outcomes? Are they still getting the right health provision despite being in a different ICB or LA to the one who has responsibility for them.

### What standards and support should be provided by national bodies to support effective data use and digital services?

The NNPCF believe having families of CYP with SEND and their lived experience involved in data analysis and performance improvement can help ensure data use is not only a numerical exercise but one that drives improvement through quality assurance. The NNPCF would be willing to help develop effective data use to include lived experience to ensure performance improvements leads to transformation of lives in a real sense.

National bodies should support data use by analysing what there already is out there for CYP with SEND, and how it can be used, as well as identifying what data is needed to help improve outcomes for CYP with SEND. Those with lived experience need to be part of this process as if you aren't a service user you may not be able to identify areas of concern from the data.

The NNPCF has heard reports of some health services still being dependent on paper notes and report that this is hindering service delivery. Where ICBs are struggling to transfer to digital services support should be given.

### What do you think are the most important things for NHS England, the CQC and DHSC to monitor, to allow them to identify performance or capability issues and variation within an ICS that require support?

The NNPCF would like to see monitoring to ensure the law is being followed on a local level. Particularly that improvement plans include CYP and that active engagement with parent carers is meaningful and helping to improve lived experiences. We would also like to see monitoring of decision making and whether those making decisions regarding CYP with SEND have due regard to their needs, either by experience or by seeking lived experience from families.

The NNPCF would like to see accountability across the board. The NNPCF has reports of local areas improving services where there is a written statement of action (WSOA) following a joint inspection from OFSTED/CQC, leading to a lack of improvement or decline in areas not included in the WSOA, even when concerns have been raised by the inspectorate. Areas which have not received WSOAs have been reported to be complacent and lacking desire to improve services.

The NNPCF believe monitoring of feedback through complaints and complements, as well as the subjects of tribunals and appeals from EHCPs could lead to helpful indicators of where there may be capability issues or variations within an ICS.

The NNPCF would like to see planning intent in the workforce monitored, and how ICBs use data they have from EHCPs to train and develop their workforce to be able to cater for the needs of CYP.

The NNPCF would like to see school exclusions linked to CAMHS and SEND monitored, including how performance and capability issues in early intervention affects outcomes.

What type of support, regulation and intervention do you think would be most appropriate for ICSs or other organisations that are experiencing performance or capability issues?

The NNPCF believe learning from lived experience can be invaluable for improving services. Support to develop good working links with their local parent carer forum and understanding user experience can help improve performance and capability. The NNPCF would be willing to support his work.

Developing the workforce through assessing training and professional development would also be of benefit. As well as ensuring professionals have a safe space to ask questions, highlight things that aren't working well or suggest new ideas. Professionals should also be able to give their opinion on the ICB and how things can be improved from their perspective.

Support with communications, especially with an ICB who is struggling, could help improve confidence of parent carers in the ICB, as well as understanding better the needs of families. Families need to see their lived experience and their feedback is valued by ICBs and is used to improve services and outcomes for CYP.

Support should also look for ways to improve services. The NNPCF has reports of services that are still paper based which is hindering service delivery.

Support could look at trends in children attending at A&E. For CYP with SEND there can often be an underlying cause that needs assessing in an outpatients setting. Could A&E refer to the right services, or ask the GP to do so, rather than instructing the parent to do so? And are there any trends which could identify missing provisions, which if in place could reduce demand on A&E?

### Is there any additional evidence you would like the review to consider?

The NNPCF is a network of parent carer forums which has approaching 110, 000 members spread over nearly every Integrated Care Board in England. We would like to invite the Hewitt review to meet with our steering group to hear more about the experiences of parent carer forums with active engagement with ICBs, as well as hear lived experience of using their services.

At present very few ICBs are reporting to the NNPCF that ICBs are being set up in a way to reduce inequalities for CYP with SEND. PCFs report concern around the lack of active engagement between ICBs and PCFS and with parent carers as a whole, with most not feeling able to work strategically with their local ICB. Few are reporting that ICBs are aware of the needs of CYP with SEND and their families and are seeking to improve their experiences of health care. Very few PCFs reported to us in a recent survey that ICBs are being set up in a way to achieve their stated objectives. Most PCFs are reporting not having a clear picture on how ICBs are set up, and do not feel valued as stakeholders.

The NNPCF is concerned outcomes for CYP with SEND are not visible enough in this new system and that targets and scrutiny focus more on mortality and morbidity in (older) adults).

The NNPCF believe there would be great benefit of having representation on ICB boards from those with lived experience, including representation from parent carer forums.