

NNPCF State of the Nation

May 2019

Introduction

The NNPCF is the independent national voice of parent-carer forums. It comprises of up to 151 local parent carer forums with over 93,000 members across the country.

Parent Carer Forums are representative local groups of parents and carers of children and young people with disabilities who work alongside local authorities, education, health and other service providers to ensure the services they plan, commission, deliver and monitor meet the needs of children and families.

This paper is a “State of the Nation” overview of the experiences of families of children and young people with special educational needs and disabilities (SEND) a year after the end of the implementation period for the Children and Families Act. In it, we summarise the key issues that have been identified by the membership of National Network of Parent Carer Forums (NNPCF).

These are the right reforms in the wrong environment

Why are these the right reforms?

Our membership wholeheartedly endorses the key principles of the 2014 reforms, namely a system based on:

- Coproduction not confrontation
- Joint working across agencies, not silo based working
- Person centred services rather than provision led services

Where we see these three elements together, parent carer forums have been involved in transformative changes to services. Parent carer forums have provided many examples of best practice, some are:

- In a city local authority area, **a new Autism and ADHD pathway** has been developed in coproduction with the parent carer forum. Previously families waited up to two years for a diagnosis and only 10% of cases received help.



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Under the new pathway, more than 70% of families receive support and now within weeks or months.

- In County local authority, the **short breaks** service was used by less than 100 families. It has now been redesigned and is used by 1500 families and has is positively viewed by 98% of families in a recent survey of 1200 users.
- In a county local authority, the area has developed a **special schools strategy** that will see a £50m investment over the next few years.
- In a small unitary local authority, a new **short breaks** contract was torn up and is the process of being recommissioned when the parent carer forum highlighted fatal flaws in its design to the Director of Children's Services.

However, these are relatively isolated examples.

Across the country, we cannot say that we have met the aspirations of families or consistently delivered the legal requirements of the SEND reforms.

Why is this the wrong environment?

The environment into which the reforms have been launched means that they have not led to the wholesale transformation that is required. Our membership have highlighted four key reasons why:

Financial constraints on local areas

We have seen an increase in concerns from forums that their local areas cannot deliver the legal requirements of the Children and Families Act with constrained resources. The demand and scope of services for SEND is increasing at a time when local authority finances are under ever increasing pressure (for example the number of EHCPs and statements have grown by 82,000 to 320,000 between 2014 and 2018)¹.

In a recent NNPCF survey, 94% of parent carer forums that responded stated that they did not think there was enough funding in the high needs funding block to meet local needs².

¹ Department for Education: Statements of SEN and EHC Plans 2018

<https://www.gov.uk/government/statistics/statements-of-sen-and-ehc-plans-england-2018>

² NNPCF SEND Funding talking point

<http://www.nnpcf.org.uk/wp-content/uploads/2017/12/Talking-points-SEND-resourcing-201901.pdf>



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In addition, the failure of many areas to make meaningful progress with joint commissioning has amplified this situation. What resources there are have not always been deployed in the most effective ways. In our survey only a third of forums said they thought that their local area had an excellent or good understanding of the needs of their local SEND population whilst two thirds thought the understanding was fair or poor³. Leading on from this, only 12% of parent carer forums said that they thought the distribution of funding to meet local need was excellent or good. Sadly, too many local areas continue to provide services that are “commissioner led” rather than needs led. Budgetary constraints and available provision drive services rather than the needs of families.

Incentives for school leaders

Our membership reports that mainstream schools are becoming less inclusive. Currently, school leaders are not sufficiently incentivised to adopt inclusive practices. For example:

- The existing Ofsted inspection framework is very academically focused. The new draft inspection framework goes some way to addressing this.
- School success measures (e.g. Progress 8) remain academically focused
- The national curriculum and, in particular, further education courses have narrowed in the last 10 years

All of this means that many schools do not take a holistic, graduated approach to SEND. Those that do, rapidly become “SEND magnets” as parents of children with SEND recognise their inclusive approach and flock to them.

Accountability

There are few hard-hitting measures that local authorities can take if schools are not adopting an inclusive approach. The fragmentation of the school system over the last decade means that local authorities have only limited levers to change the behaviour of schools and local services.

³ NNPCF survey of parent carer forums December 2018..

Low prioritisation of SEND across health and social care

SEND is not a high priority for most local social care teams or many clinical commissioning groups. This means that many local social care and health commissioners have not focused on the requirements of the SEND reforms:

- Many practitioners are not aware of their responsibilities under the Children and Families Act
- Families report shortages of key services (e.g. long waits for ASD diagnosis and services, speech and language therapy)
- Carers assessments are often not carried out resulting in more families in crisis.
- Services are not delivered in the joined-up way required.

All of this means that the experience of children and young people with SEND falls short in many areas:

Children and young people with SEN in mainstream schools

The experience of children and young people with SEND in mainstream schools is being raised as a major concern by families at present. There is an uneven pattern of support, delivery and provision meaning that too many children with SEN in mainstream schools are being let down:

- There is a move away from children with SEND being educated in mainstream schools with increasing numbers being placed in specialist provision. Official Department for Education statistics show an increase in exclusions for children with SEND and an increase in the proportion of children with SEND attend specialist provisions⁴.
- A disproportionate number of children with SEND are being excluded either officially or unofficially. In an NNPCF survey, 95% of forums were aware of children and young people with SEND in their Local Authority that have been excluded from school. Forums also report a worrying increase in off-rolling and unofficial exclusions (e.g. part time timetables, missing certain school activities, encouragement to be home schooled, isolation)⁵.

⁴ Department for Education: Statements of SEN and EHC Plans 2018

<https://www.gov.uk/government/statistics/statements-of-sen-and-ehc-plans-england-2018>

⁵ NNPCF SEN Support talking point



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- Early help is often not easily available and many parents report that schools and local authorities will only act when there is evidence that their child is failing and has reached crisis point. There is a clear perception that financial constraints mean that services are rationed. This is amplified by the lack of transparency on funding for children with SEND in mainstream schools.

It is now five years since the Children and Families Act became law, in that time tens of thousands of children have left the school system without the reforms having changed their experience and outcomes.

Education health and care plans and annual reviews

The quality of plans remains a key focus. Many forums have concerns that the quality of plans has been sacrificed to meet the conversion deadline of March 2018. The quality of advice and input from Health and Social care providers remains a concern and many forums report that all too often the provision that has been written into a plan (for example, therapy services) is simply not being delivered. Data from the national trial of a single route of redress (SEND tribunals) shows often different parts of local authorities (education and social care) are often in disagreement whilst children and families suffer.

However, where families have good quality EHCPs they report that these do make a difference to their child achieving their outcomes.

Preparing for adulthood

Families describe their young people approaching school leaving age as “the cliff edge”. Upon leaving school, the offer from many local areas is not clear. Families are unable to see how the services and provision available will deliver the best possible outcomes for their young people. Part time education provision for their young person (often only 3 days a week) is a major concern. Families report that frequently that there is no or inadequate provision on offer for the other days. For some families this can result in parents having to stop or reduce paid employment.

Parent carer forums report that opportunities for employment, community inclusion and independent living are very limited.

Families are often thought to be behaving “irrationally” when insisting on young people remaining in education post 19. In the absence of a meaningful alternative, families will fight to hang onto what they know works.

What needs to change?

Appropriate funding for SEND services

The SEND provision in local areas must be appropriately funded. The upcoming comprehensive spending review is an opportunity to secure the necessary funds. The LGA estimates a funding shortfall of £470 million in the high needs funding block⁶. Parent carer forums typically report a £2-5 million shortfall in high needs funding in each local authority area.

Better joint working and joint understanding of local needs

Local leaders must develop a better joint understanding of needs and work together across the system more effectively.

The SEND system leadership board presents an opportunity to model best practice at the highest levels of government and to drive changes through to the local system. Similarly, the NHS long term plan includes much that is good and necessary for children and young people with SEND. It is vital that the joined-up decision making, commissioning and coproduction are placed at the heart of the emerging implementation plans. The role of Integrated Care Systems in this will be key.

Align incentives for schools

The incentives for schools must be aligned to embed the principles of a whole school approach to SEND. We believe changes to the Ofsted inspection framework, placing a greater emphasis on inclusion and holistic schooling, will help. In addition, we would like to see earlier intervention (not waiting before a child reaches crisis point) for children with SEN, greater support for the role of the SENCO. With the right setting, the right structure and the right support, children with SEND can make remarkable progress. All children with SEND must have this opportunity.

⁶ Local Government Association: Have we reached “tipping point”? Trends for spending for children and young people with SEND in England
<http://www.isospartnership.com/uploads/files/LGA%20HN%20report%20published%2012.12.18.pdf>

Improved accountability

We are pleased that the regime of local area inspections will be extended beyond 2021 and that revisits for areas with a written statement of action have started. We urge the Department for Education and NHS England to take the strongest action for those local areas that have been revisited and have been found to have made insufficient progress. The credibility of the inspection regime is at stake.

We would like to see the powers of the SEND tribunals permanently extended to enable them to make binding judgements on health and social care.

We would like to see an improvement in the powers of local authorities and regional schools' commissioners to hold schools to account and incentivise and reward more inclusive practice.

Leadership and workforce

A workforce development strategy for leaders across the SEND sector is required. This would inform leaders across education health and social care of their obligations to children and young people with SEND and to promote joint working to create a system wide approach.

More "real" coproduction

Effective coproduction does improve services – the "WOW moments" compiled by Parent Carer Forums demonstrate the difference that real coproduction can make. The most effective coproduction has happened in those areas where local leaders have embedded a culture of coproduction and have supported their local parent carer forum as an independent and equal partner.

Appendix: Parent Carer Forums

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To compile this report, we have gathered feedback from our members and stakeholders in a number of ways including:

- Local and regional meetings. Our steering group and national representatives attended over 100 meetings last year and spoke to many thousands of parent carers from across the whole country and across the range of SEN and disability.
- Our annual conference and AGM. November 2018 over 90 forums and 200 parent carers attended.
- Surveys of our membership to identify and understand their experience of key themes.
- Data that comes from recent SEND surveys to analyse the key messages that these were giving us.
- Activity on our social media platforms.