

NNPCF State of the Nation

May 2018

Introduction

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) at 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).

The NNPCF is the independent national voice of parent-carer forums. It comprises of up to 152 local parent carer forums with over 85,000 members across the country.

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

- Local and regional meetings. Our steering group attended over 50 regional meetings last year.
- Our annual conference and AGM. November 2017 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.

KEY THEMES BEING RAISED BY FORUMS

The impact of tightened local resources

In the last few months, 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. In addition, the failure of many areas to make meaningful progress with joint commissioning has amplified this situation. What resources there are have not necessarily been deployed in the most effective ways.

Forums have also shared the impact on the local workforces. Re-organisations, temporary staff, and frequent changes in personnel have meant that continuity and morale of practitioners is often poor. Embedding the cultural and behavioral changes required by the Children and Families Act against this backdrop is difficult.

Education health and care plans

The quality of plans is a key focus. Many forums have concerns that quality has been sacrificed to meet the conversion deadline of March 2018. They report that Local Authorities are also struggling with ongoing requirements to review plans. Families report a number of common themes:

- The engagement from Health and Social Care agencies continues to be an issue with reports that attendance at meetings is often sparse and advice is not written in a person centred or outcome focused way. In some cases, the required advice is not produced within the specified timeframes, or sometimes at all.
- When the process is being led by schools there is a concern that not enough focus or energy is put into the child and family input. Ownership of plans still

feels like it is with the education setting rather than with the children and family.

- Some forums report that mainstream schools are less willing to take children with EHCPs, being concerned about their ability to meet their needs. This in turn is fueling the move towards more children in special school.

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.

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.

Forums report many concerns with the transition to adult services, common themes include:

- FE settings do not always understand the EHCP process or the need for that provision to be in place in a timely fashion
- Joint working between children and adults social care remains an issue, few forums report an effective transition team being in place in the Local Authority.
- Transport policies for post 16 education are not in line with the requirements of the Children and Families Act.

- Employment opportunities can be sparse, are often of poor quality and with limited choice particularly in rural areas. Families report that the information and support for pathways into employment is confusing.
- Independent living and other housing places and options are often limited.

SEN support (including exclusions)

There are concerns around the level and quality of support for those young people on SEN support and the settings they are in. Exclusions are increasing and a recent NNPCF survey found that over 90% of forums that responded had witnessed potentially illegal “unofficial” exclusion practices (such a part time timetables, missing school trips and after school clubs). Exclusions impact not only the child but the whole family with parent and carers often having to forgo work. Our survey found that children and young people with autism and ADHD are particularly at risk of exclusion. We welcome the current national review into exclusions.

Forums are reporting that inclusion in mainstream schools is becoming more challenging for families with a marked drift towards specialist education for children and young people with SEND. They report that reasonable adjustments to enable a young person with SEND are not always made in schools meaning a child is removed not just from an education setting but also from the heart of a local community.

We believe that adopting a whole school philosophy, a graduated approach, transparency of how notional SEND budgets are used and high quality information advice and support for families are the keys to addressing this. There are examples of good practice in almost all areas - parents know which local schools and head teachers “get it.” This suggests that there is a leadership issue in some settings.

Some forums have reported that development of parental groups within education settings is one way to approach inclusion, that isolated parents can come together to work with the setting to improve the experience

Local area inspections

These have been an overwhelming success from the point of view of forums and we would like to see them extended beyond the current 5-year period.

Forums have raised some concerns about some aspects of the inspections, specifically, making suggestions on how they could be conducted differently to engage parent-carers more effectively and to minimise the impact on forums.

Forums across the country report a renewed focus on the reforms as a result of the inspection regime and improved engagement from partners, notably CCGs as a result. We hope that similar benefits will result from the single route of redress national trial.

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 meaningful way. 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 report widely varying levels of individual coproduction with families from Clinical Commissioning Groups and providers. Often families report that staff remain very provision focused, rather than outcome focused.
- **Strategic co-production**-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, whilst we have seen great improvement with some Health agencies since introduction of LA SEND inspection framework. There is still a lack of recognition from CCG's to work forums contribute to strategic coproduction.

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 which can be a challenge for not only local parent carer forum but also the local area to engage with.

There is an opportunity to provide clear, combined leadership from a government department and ministerial level across health and education endorsing and modelling the need for joint working and co-production.

Conclusions

The Children and Families Act sweeps away the most pernicious aspects of the “old” system and seeks to replace them with fairer, more effective practices – co-production not confrontation, outcome focused not provision led services, joint arrangements not silo working.

These wide reaching, complex and profound changes need to be applied across the country by multiple agencies and organisations working together in each locality. This is not a trivial undertaking and we are not surprised that there have been challenges in the implementation of these reforms.

However, the Act contains the right principles and ambitions and quite rightly raises the bar to deliver better outcomes through working in more effective ways. The NNPCF is calling for renewed focus, strong leadership and the right level of financial support to deliver on the requirements of the legislation and on the aspirations of families.