

## NNPCF - National Disability Strategy February 2021

### Introduction

The NNPCF is the independent national voice of parent-carer forums. It comprises of up to 151 local parent carer forums. Our membership is approaching 100,000 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 response to the National Disability Strategy consultation provides an overview of the experiences of families of children and young people with special educational needs and disabilities (SEND) 6 years after the implementation of Children and Families Act 2014.

In it, we summarise the key issues that have been identified by the membership of National Network of Parent Carer Forums (NNPCF):

1. The role of parent carers
2. The impact of Covid 19
3. The importance of access to Short Breaks (respite)
4. The SEND Reforms – the right vision in the wrong environment
5. Financial constraints on local areas
6. Low prioritisation of SEND across health and social care
7. The experience of children and young people with SEND in mainstream schools
8. Education health and care plans and annual reviews
9. Preparing for Adulthood
10. The importance of Coproduction

## Parent Carers Matter – The Wider Context

The NNPCF would ask that when developing the National Disability Strategy, the Government seeks to understand and address not only the challenges faced by children and young people with special educational needs and disabilities (SEND) in society but also the significant additional caring responsibilities that families face on a daily basis. Many families describe their worries for their child or young person's futures, acceptance in society, health and wellbeing as well as access to the right support at the right time.

It is really important to recognise the change in the parent carer's standing in wider society, e.g. friends and acquaintances not knowing how to react when a person has a disabled child, the financial impact of a parent having to have time off work to care for a child and attend appointments or in many cases leave their paid role to provide full time care.

Parent Carers are often not recognised as carers, because they are seen as parents first, or they have to fight hard to be part of Carers Groups who, often commissioned by CCGs, tend to recognise only carers of adults as carers. The overall sense amongst our members is that a local focus on the Care Act leaves Parent Carers out as they are seen as parents; the legal rights in the CFA 2014 and other legislation are either not being shared or are not understood by commissioners and others in local areas.

Sometimes Parent Carers are told their assessment is part of their children and young person's social care assessment. Most Parent Carers do not know about the legal frameworks and what they mean.

We would like the Strategy to address and value the role of parent carers in society. We ask the Government to consider the wider holistic impact on family life. All families are faced with a challenging landscape due to the impact of Covid 19 including home schooling, financial pressures, illness and bereavement, however, when a SEND need is added the impact is exacerbated.

## The Impact of Covid 19

Parent Carers have told the NNPCF that they *"would like to highlight that the effects of caring on Parent Carers seem to be underestimated or not recognised by all professionals. I would like to raise awareness that the demands of caring*



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*for a disabled child can cause emotional, social and physical problems for the carer."*

The Covid 19 Pandemic has highlighted a number of significant education, health and social care inequalities for children and young people with SEND; these include missed education, missed medical and therapy appointments and the social care impact (no respite). Parent carers of young adults (18-25) describe the lack of opportunities for their sons or daughters, lack of parental rights and the complexity of navigating the legal framework around mental capacity.

For example, in recent surveys of our members:

- 82% of forums on Elective Home said that the numbers of EHE requests for children and young people with SEN (EHC Plan and SEN Support) had increased in their local area during the Pandemic.
- 41% of forums reported an increase in young people with SEND who are not in Education, Employment or Training (NEET).

Forums are reporting that the support offered by schools during Lockdowns for pupils with SEND varies. Forums are telling the NNPCF that school work is not always differentiated for children and young people with SEND and that some families were not able to access the resources that they needed e.g. laptops, access to broadband.

Some children and young people with more complex needs are not able to access their learning or therapy online. This means that many children and young people have lost key skills, experienced poorer health outcomes and seen a reduction in their overall health and wellbeing.

**All of this means that children and young people with SEND are disproportionately impacted both academically and non-academically by the pandemic when compared to their peers.**

The impact of Covid-19 has been *"disastrous"* for employment; Supported Internships and Apprenticeship opportunities are severely limited or supported employment courses are restricted or closed.

Forums report that it is *“even worse than normal”* and there is a *“total lack of employment”*.

*“My daughter completed a supported internship in June 2019, it was meant to lead to a job. It didn't. She wasn't given enough training to make her employable. She doesn't meet criteria for any support & is now claiming benefits when she would prefer to work.”*

Parent Carer Forum member

Hope for the future is low *“there's even less chance of find work”* and some parents see the pandemic as *“an excuse not to employ or to sack.”*

## Short Breaks

Forums have described the additional support some families have needed as a result of the lockdown. Often, this can be over and above the things that a “normal” vulnerable person needs (e.g. shopping, medical supplies). Many families have struggled on with no support including children who are difficult to contain – e.g. those who may do physical harm to themselves, others around them or their environment.

Most respite offers have not been available to families. Whilst families may still be in receipt of Direct Payments or Personal Budget, they have been unable to use those funds in the traditional ways to pay for activities or personal assistant support.

We have heard from families who are struggling with the restrictions in place during this period. This is especially, but not exclusive to, the autistic community. Changes to routine, lack of structure, limited access to outdoor space and the need to exercise outside in a familiar and safe space and maintaining social distancing have been particular problems for families.

In addition, the mental health and social care needs of SEND families are increasing during this time as both formal and informal support networks are reduced.

## The SEND Reforms

Our membership wholeheartedly endorses the vision of the 2014 reforms.

*“Our vision for children with special educational needs and disabilities is the same as for all children and young people – that they achieve well in their early years, at school and in college, and lead happy and fulfilled lives.”*

Parent and carers of children and young people with special educational needs and disabilities share the same hopes for their futures as other families but the challenges are far greater.

*“Those who have learning difficulties find it much harder to have the aspiration or see relevant opportunities for work but this starts at college level as very limited courses are on offer 6 years after the SEND Reforms.”*

Parent Carer Forum member

The NNPCF welcomes the key principles of the reforms, namely a system based on:

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

Where we see these three elements together, parent carer forums have been involved in transformative changes to services. **However, across the country, we cannot say that we have met the aspirations of families or consistently delivered the legal requirements of the SEND reforms.**

The environment into which the reforms have been launched means that they have not led to the wholesale transformation that is required. Our membership has some 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.



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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. Sadly, too many local areas continue to provide services that are “commissioner led” rather than needs led and outcomes based.

Budgetary constraints and available provision drive services rather than the needs of families.

### 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 provisions<sup>1</sup>.

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<sup>1</sup> Department for Education: Statements of SEN and EHC Plans 2019  
<https://www.gov.uk/government/statistics/statements-of-sen-and-ehc-plans-england-2019>



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- 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)<sup>2</sup>.
- 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 six 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 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

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<sup>2</sup> NNPCF SEN Support talking point

<http://www.nnpcf.org.uk/wp-content/uploads/2017/12/Talking-points-SEN-Support-201807-Final-1.pdf>



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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?

The National Disability Strategy must reflect the vision of the CFA 2014 and embrace our children and young people’s hopes for a better future. A future that offers them the same opportunities as their peers in employment, health and wellbeing, independence, relationships and as valued members of society.

## Our final messages

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.

The NNPCF would like to see a unified strategy across Government departments which join up the Disability strategy, Autism Strategy, NHS LTP for Learning Disability and/or Autism and the SEND Review.

### Contact Details:

Kay Moore – Policy and Consultation Lead, NNPCF  
consultation@nnpcf.org.uk

Mrunal Sisodia – Co-chair NNPCF  
cochairs@nnpcf.org.uk

Web: [www.nnpkf.org.uk](http://www.nnpkf.org.uk)

Address: Contact, 209-211 City Road, London EC1V 1JN