



National Network of Parent Carer Forums

'Our Strength Is Our Shared Experience'

Evidence to inform the Unequal impact: Coronavirus (Covid-19) and the impact on people with protected characteristics Inquiry

The National Network of Parent Carer Forums (NNPCF) welcomes the opportunity to submit evidence to inform this inquiry. During the passage of the Children and Families Act through Parliament, the NNPCF was, with others, instrumental in having the legislation for the Parent Carers Voice strengthened and outcomes for children and young people with SEND improved.

1 Who we are

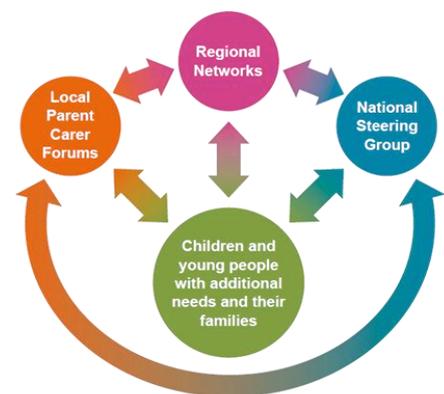
1.1 The National Network of Parent Carer Forums (NNPCF) is the independent national voice of parent carer forums.

Our mission is to deliver better outcomes for families living with special educational needs and disabilities (SEND). We aim to:

- create a culture of participation and co-production across the education, health, social care and the voluntary sectors. This means that we are involved in all aspects of designing, commissioning, delivering and reviewing services as an equal partner.
- empower our members to ensure that their voices are heard at a local, regional and national level
- inspire our partners by sharing good practice and knowledge.

Our vision is a for the best possible opportunities and futures for all children and young people with SEND and their families

1.2 The National Network of Parent Carer Forums (NNPCF) was launched in 2011, and is funded by central government. We became a formally constituted Group in November 2013 and Community Interest Company in 2019. The NNPCF membership is made up of Parent Carer Forums of which there is one in almost every local authority area in England. Each Parent Carer Forum in receipt of the Department of Education participation grant is a member of the NNPCF. The structure of NNPCF is shown here:





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Parent Carer Forums are pan disability. This means each Parent Carer Forum includes Parent Carers from a range of backgrounds with a wide range of experiences in Health, Education and Social Care as their children have a wide range of conditions. We currently have over 90,000 members.

1.3 The NNPCF is a representative organisation, it consists of up to 152 local parent carer forums at any time across England. Each of the 9 geographical local authority regions is collectively represented within the NNPCF Steering Group. This means that each region has a parent carer forum representative whom has been appointed to represent their regional and local interests at the national level to empower and enable strategic parent carer participation.

2 Our Approach to this Inquiry

2.1 As a membership organisation, the NNPCF Steering Group have based this report on a range of sources including:

- Feedback from Forums through their regional networks to their Steering Group member.
- Feedback on our social media platforms
- Key issues identified through direct conversations with parent carers at a local, regional and national level.

3 Parent Carers Matter – The Wider Context

3.1 The NNPCF would ask that when considering the responses to this inquiry, the All Party Parliamentary Group seeks to understand and address not only the challenges faced by children and young people with special educational needs and disabilities due to Covid-19 but also the significant additional caring responsibilities that families face on a daily basis including worries about their child or young person's health and wellbeing, SEN provision and schools during this pandemic.

3.2 Parent Carers have told the NNPCF that:

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

The mental health and social care needs of SEND families may increase during this time. The NNPCF would like this inquiry to help Government, NHSE, local authorities, Clinical



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Commissioning groups/Integrated Care Networks and professionals who work with our children, young people and families to understand the needs of Parent Carers better and ensure they get the support and help they need at this time.

We would like the APPG to consider the wider holistic impacts for family life. All families are faced with a challenging landscape including home schooling, financial pressures etc. however, when a SEND need is added the impact is exacerbated. Please consider the wider family needs such as lack of respite for carers and siblings as well as loss of therapies for the child or young person with SEND.

4. Our Key Issues

4.1 The definition of vulnerable

There are a number of different definitions of 'vulnerable' being used which is causing confusion and anxiety for parents of children and young people with Special Educational Needs and/or disabilities.

For example:

Medically vulnerable – includes children and young people who have respiratory or immune system concerns or mental health conditions for whom isolation, increased anxiety or change in circumstances may have a greater detrimental impact.

Socially vulnerable – children and young people who may have some sort of safeguarding issue and are at increased risk outside of the usual school or social care structures.

Educationally vulnerable – children and young people for whom a change of routine or extended period outside of school may cause issues.

This might be for several reasons – including:

1. Increased anxiety
2. Distress if they are autistic or have a learning disability
3. Are very difficult to educate / occupy outside of a specialised setting (e.g. families may not have the right resources / equipment at home)
4. Where the vulnerability of some families may increase with children at home. For example: the "pressure cooker" scenario or the risk to family members from a small cohort of children or young people who may display behaviours that challenge arising from their SEND.

At present the term "vulnerable" is being used interchangeably which is causing concern and confusion e.g. families with EHCPs are contacting parent carer forums asking why they haven't had a letter telling them to self-isolate, other families are concerned about being classed as vulnerable because they think this means they will have to have a social worker going forwards with all the stigma and misinformation that brings.



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Parent Carers often have to deal with the reluctance of some groups and organisations including schools/academies to include children with special educational needs and disabilities as well as negative attitudes from other parents or staff. Unfortunately, this continues to be the case for some families at the present time.

4.2 Assessments and Annual Reviews

We would like clarification on the powers within the Coronavirus Act pertaining to disabled children and young adults. We are concerned that rights are being stripped away for up to two years. Many parent carers and forums have queried this and it has heightened anxiety in an already stressful environment.

There will be many parents anxious about what all this means for their child's future placement, especially where they are reaching a Key Stage move. Here is a sample of the questions being raised:

- a. My child is waiting for an early help assessment what do I do?
- b. How can I gather information to not delay a diagnosis and support?
- c. Will we now have longer waiting lists for services?
- d. I am waiting for an Education Health and Care needs assessment, what should I do?
- e. I have no diagnosis for my child and now I am at home and no support where do I go?
- f. Will CAMHS still see children and young people known to them and/or new children?
How will families be able to refer into this service?
- g. What will happen to the annual review of my child's Education, Health and Care Plan?
- h. How can I make an informed choice on new setting without being able to visit?
- i. Will my child's EHCP be ceased through lack of wider evidence e.g. Educational Psychology report?
- j. We have been offered an online meeting but what happens if we do not have the technology to take part?

The NNPCF would like to see further clarification around the assessment process and timescales, including changes to regulations.

We are particularly concerned about those families who's child is currently in the EHC Needs assessment process; those who currently receive support via high needs funding without an EHCP, those who are hitting key transition points or those whose needs will be exacerbated by the COVID-19 restrictions.



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4.3 Support and Services

SEN Support

Forums are reporting that the support offered by schools for pupils with SEND varies. Some schools have given out work packages and are available to answer questions, but others are not able to offer such a robust support offer. Parents need further guidance around the Assess, Plan, Do, Review cycle to ensure that they are able to support their child's learning.

Home Educated

Some SEND families who were already home educating prior to Covid 19 were told that their LA home education officer is still expecting full reporting on what child has been doing along with evidence. The parents' ability to do this at the present time is limited and they report feeling pressured into reporting within unrealistic timescales.

The NNPCF would request that some of the reporting requirements are relaxed at this time.

EHCPs

For those families who opt to have their child at home, clarification is sought as to how they can keep in touch with their child's school and Local Authority. Some families reported that their school were only taking children of keyworkers. These families felt pressured to keep their child at home.

The NNPCF would like to see school work being set for those electing to keep child at home.

However, this needs to be set with reasonable expectations. Some families with more than one school child are seeing very different expectations from schools regarding home schooling. Some settings have been very supportive whereas some are placing a lot of pressure on families, with one example where the school wrote to parents advising on discipline measure for late return of work. Whilst we all wish to minimise the impact of being out of school, and can see the benefits of building routine, there does need to be recognition of:

- a) Parental capacity to teach
- b) Parental need to work from home
- c) Different ages & stages of children's education
- d) Potential ltd access to online technology (time sharing)
- e) Accommodation space to allow room to work. Some families were already struggling for space for child(ren) to perform homework
- f) Impact of arrangements on SEND child i.e. some will struggle with the concept of doing school work in the home environment.



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- g) Ability of parent to give the high level of support to the SEND child that may be needed (some require 1to1 in school) whilst still supporting other siblings
- h) Potential limited access to specialist equipment or resources needed to support child with learning e.g. eye gaze technology or Picture Exchange Communication Cards
- i) Potential trauma relating to Covid restrictions and/or bereavement.

Where there are siblings attending different settings there can be a marked difference in the expectations from the schools. This can lead to resentment between siblings in an already fraught environment.

We are concerned on the educational impact on other siblings who may not get the support due to attention being focused upon SEND child. They may feel they are losing ground from their peers and this could build into resentment on the SEND child.

We would like the DfE to help families by managing the expectations of all schools in terms of home-schooling. It would be good to model the good practice of schools that have shown support to their families.

NNPCF would like to seek clarification regarding access to SEND travel assistance at this time.

Short Breaks

Forums have described the additional support some families need as a result of the lockdown. This can be over and above the things that a "normal" vulnerable person needs (e.g. shopping, medical supplies). What additional support can be put into place for those families whose children will be difficult to contain – e.g. those who may do physical harm to themselves, others around them or their environment.

Most respite offers are no longer available to families. Whilst families may still be in receipt of Direct Payments or Personal Budget, they may be unable to use those funds in the traditional ways. Can Government provide direction for more flexible use of these monies? It would help to relax some of the rules e.g. allow payment for Personal Assistant to relieve pressure by shopping for family. Or use of Direct Payments to buy tech equipment or subscription to online media.

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. The following points are areas where we would like to see greater flexibility or exceptions to the rules:



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- The NNPCF welcomes the decision by Government to relax the rule for those children and young people who need to exercise outside more than once a day, recognising that this helps to reduced anxiety and help prevent violent behaviours. The NNPCF would like to request that the use of play parks be considered for children and young people with SEND as the equipment available in parks can often been used to self-regulate e.g. swings.
- Inability to queue for long periods of time and maintaining social distancing. This is particularly a problem for families who need to take their child/young person with them to food shops. The queuing, distancing, rules on numbers in shops combined with a lack of preferred foods and general anxieties around change of routine are a recipe for challenging behaviours. Such families are stuck as many are not able to obtain an online slot. Some SEND children and young people will only accept certain branded foodstuffs even when everything is running normally. In this period the inability to obtain certain foodstuffs is a significant issue for such families.

We have feedback from some families where they were turned away from shops due to having too many in the group. However, some SEND youngsters require two to one support when in the community.

Will school workers/personal assistants be able to come into the home?

We have heard from some forums that local authorities are pulling back on direct payments and personal budgets. We have also heard from some families that there is reluctance for Personal Assistants to support the child or young person without PPE. Others have raised concerns about being asked to furlough the Personal Assistants.

The NNPCF would like to see more flexibility around the use of direct payments (for example to purchase equipment) and an increase in the use of direct payments to families where their usual support workers (perhaps provided by a service or agency) can no longer support them because of COVID-19.

Whilst the NNPCF recognises that schools have remained open during the lockdown and over the Easter holidays to provide care many forums are reporting specialist Short Break centres and activities are closed. Parents have raised concerns about the availability of PPE and appropriate training in its use.

Preparing for Adulthood

Sadly, forums report many concerns with the **transition to adult services**. Parent carers are very concerned about the suspension of the duties in the Care Act 2014 that were brought into force from the 31st of March 2020 through the Coronavirus Act, especially:



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- The local authority will not have a legal duty to assess needs in accordance with the Care Act, however it will have to carry out a proportionate assessment and keep a record of person's needs.
- The duty to carry out transitional assessments for young Disabled people who are moving from children to adult social services is suspended. The local authority also no longer has duties to continue support in transition periods, unless it is necessary to prevent the breach of a person's human rights.
- The local authority will not have a duty to determine which needs are eligible in accordance with the Care Act eligibility framework.
- The local authority will not have to develop a Care Act compliant care and support plan, but it still has to develop a support plan and involve individuals concerned.
- Local authorities are no longer required to carry out reviews, but they can still do so and if so, they have to involve individuals in the process.
- Local authorities are no longer required to carry out financial assessments, but they will be able to carry them out and charge retrospectively.
- Most importantly, local authorities will no longer have a duty to meet eligible needs, but they still can choose to do so under the Care Act Easements guidance which says Local Authorities will still be expected to take all reasonable steps to continue to meet needs.

This is very complex and difficult for families to navigate through. Many forums are reporting that their Local Authorities have not provided any information, advice or guidance to families regarding these changes.

The NNPCF would like to see further clarification around the Care Act Easements and what that means for young people with care needs. At such a worrying time for families is it right to expect families to fight for their child's rights?

Benefits

Many parent carers have asked what happens to benefit (DLA and PIP) claims and renewals during the lockdown if people cannot gather the information or attend face to face assessments; they need to renew the claim.

The NNPCF strongly request that the DWP ensure that no-one's benefits will lapse in this period because of administrative difficulties.

4.4 Communication and Information, Advice and Support

Forums are reporting that communication is confusing and there is a mixed picture in terms of the Information, Advice and Support being provided by Local Authorities. Many families are unaware of or are being let down by weak Local Offers.



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For example, the arrangements around schooling became very confused which was largely due to schools being left to decide how to respond. The published guidance went a long way to help resolve this with regards to who should be attending however, there are still ambiguities around home school expectations and some of the organisational arrangements for those attending school. We have heard from families who were informed their child's school would be closed yet they have not been advised on alternative school/care arrangements. There does not appear to be clarity on how families can raise this issue.

We understand that most LAs delegated the school arrangements to the individual settings however, we would like to see LAs checking with their EHC cohorts to see if they are coping with whatever arrangements/choices were made.

The NNPCF ask for greater clarity with all communications. This is to minimise unnecessary anxiety through mixed messages or misunderstanding. We need clarified joined up guidance from the DfE and NHSE about the level of services that local areas are expected to provide. Local areas must ensure that they are making joined up decisions across education, health and social care about which services they continue to provide and what additional services are required. These decisions must be made with an understanding on the impact this will have on the lives of families.

What additional support can Government add to statutory Information, Advice and Support Services during this time?

4.5 Coproduction

Research shows that coproduction can bring out positive solutions to the many difficulties faced by families caring for a child with SEND.

Parent Carers Forums have told us that their experience of coproduction at this time can differ both within their Local Authority and across local authorities and areas. There appears to be a postcode lottery where some forums have had little or no contact from their LAs and/or CCGs.

We understand that coproduction can be difficult at the best of times however; it appears that some forums are not receiving information from their local authority or CCG to share with families whereas other forums experiences have been more positive.

We would like the Government to reinforce the message to Local Authorities and other partners on the need to co-produced solutions.



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4.6 Health

Many parent carers have asked about wider support such as therapies, outreach services and behaviour support. Some settings have shown good practice by their therapists making regular contact with families, giving advice and support on trying to deliver therapy at home where possible. This has also been the case with Mental Health with setting staff checking on both physical and mental wellbeing. We would like to see this good practice model shared across other settings.

Parents have been extremely concerned about what might happen should either they or their SEND child become ill requiring hospital treatment. They are fearful of taking their child to hospital in case they contract Covid. Also there are fears around the child contracting Covid and parents not being allowed to stay with child. We would like to see guidance around this with a standard template adopted by way of a communication/health passport. Some families report that their child find hospital settings elevate their anxiety to a point where their behaviour may become challenging. Families are fearful that this may result in the CYP being sectioned and placed within an Assessment Treatment Unit.

The NNPCF would request that Local Areas work in partnership with their local Parent Carer forum to discuss and agree how key supported can be maintained at this time e.g. virtual meetings, telephone contact.

The NNPCF would like to see Local Areas highlighting both good practice and the challenges that Local Authorities and their partners face in these difficult and uncertain times. We would also like to help co-produced re-integration planning guidance for such times as schools may come out of the lockdown measures. We see this planning as crucial given that many of our SEND children and young people struggle with transitions.

The planning would need to be holistic to look at re-integration to society not just school. This may include looking at what bereavement support might be needed, with this tailored around the child or young persons communication needs. Some youngsters moving through transition points may need to have a form of closure from previous setting. Some may need support to overcome the anxiety of relaxing lockdown measures as some families are finding their child or young person sticking rigidly to rules of staying inside.

There will be a need to work on re-integration for all school aged children but this should be nuanced to meet particular SEND needs.