



National Network of Parent Carer Forums

'Our Strength Is Our Shared Experience'

Evidence to inform the Education Commons Select Committee impact of COVID-19 on education and children's services Inquiry

1 Who we are

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

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.

2 Our Approach to this Inquiry

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.



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3 Parent Carers Matter – The Wider Context

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.

The mental health and social care needs of SEND families are increasing during this time as both formal and informal support networks are reduced. 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. What is working

National, regional and local teams are working really hard and we appreciate that.

At a national level coproduction is working well; we feel involved and listened to.

We are walking a tightrope – trying to balance the risk of C19 spreading to children and adults vs the risk of long term damage being done to the welfare of children (educational, social, emotional) by them being out of school. The already disadvantaged are further disadvantaged the longer they are out of school.

5. Our Key Issues

5.1 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.

At present the term "vulnerable" is being used interchangeably which is causing concern and confusion.

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



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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.

5.2 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.

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.

5.3 Support and Services

SEN Support

We must not forget pupils with SEND in mainstream schools. So far the focus has been overwhelmingly on those with EHCPs and in specialist settings. The majority of SEN pupils are in mainstream and on SEN support – we need to make sure their needs are supported in this period too.

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



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There is huge variability in the way in which local areas are applying the Coronavirus Act easements. Some Local areas are withdrawing services in a blanket fashion and not involving families. There seems to be little tracking, follow up or enforcement to protect families.

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 number of factors including parental capacity to teach; parental need to work from home and limited access to online technology (time sharing).

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.

SEN Transport

Many local authorities will be looking to commission SEN Transport provision from September 2020. Children and young people with SEND who require travel assistance to return to school will need to be prepared for any changes including protective measures that will need to be put into place.

Support for Families (including Short Breaks)

There is a need for a greater focus on supporting families whilst they are at home. Many families report that they are getting little help and support, particularly those without a social worker and on SEN support.

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



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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:

- 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.
- 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.

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.



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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:

- 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.
- 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.

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.

5.4 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.

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.



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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.

5.5 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.

5.6 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.

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. Some families report that their child



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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.

5.7 Education settings re-opening

The NNPCF have the following key messages regarding the phased reopening of early years settings, schools and colleges.

- Communicate with parents and engage them in making decisions about what is right for their child. They must feel like they “own” the decision for their child to return to school and must understand why it is safe – it’s NOT just a letter. Doing this up front will save hours of time later and also give schools a much better idea of who is returning and what support they might need.
- Schools must be able to communicate really clearly how they have implemented the national guidance (e.g. class sizes, PPE, cleaning, staffing, social distancing) – any deviation from national guidance will cause concern and confusion; this will undermine parental confidence leading to pupils not returning.
- Schools must make reasonable adjustments to accommodate those with SEN (EHCPs and SEN support) to ensure they can re-integrate effectively and successfully. For example, each child or young person could have an individualised support plan to support this transition.
- If there is provision or support that a young person needs to do this (either as a part of their ongoing schooling or through this period) schools should work with local authorities, health and other providers to understand how this will be put in place. If it cannot because of C19, then what alternative arrangements can be reached.
- Work with local areas to make sure schools know how to access early help offers for things like anxiety, abuse, behaviour.

5.8 Other Issues

Timeliness of guidance – sometimes the guidance has been behind events (e.g. risk assessments and the easements guidance both came out 3-4 weeks too late and guidance on secondary schools and special schools / SEND pupils is already way too late for 1 June.

Co-ordination across Government departments - For example, NHSE guidance on community services pulling back from therapies clashed with DfE guidance that easements had not been applied yet.

New community health guidance has STILL not been issued.



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We need to ensure that those reasonable adjustments are made for disabled children and young people in the guidance issued (e.g. have to keep pressing for changes to behaviour policies in schools).

5.9 Our final messages

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.

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