

Caring Together's evidence to House of Lords Select Committee on the Children and Families Act 2014

Summary

1 This evidence is submitted by Caring Together in response to the question as to whether the Children and Families Act 2014 has improved the lives of parent carers and their families.

2 Whilst the creation of distinct statutory rights for parent carers should be the springboard for improved awareness and support for parent carers, our experience is that this is not the case. Parent carers appear to slip through the net when compared with other groups of carers.

3 The feedback from parent carers is that either they cannot access assessments, or if they can, then they have made no difference. In many local authorities, assessments are not leading to any meaningful change, or merely result in signposting to information and service that parent carers could have accessed without an assessment.

4 There are still seemingly many areas where pathways for assessments are not clear, particularly for those parents whose children do not qualify for a social worker, and local authorities have no sense as to how many parent carers there are in their area.

5 Some local authorities have still not yet implemented systems to record assessments having been completed, or what the outcome of the assessments were, and as a carers' organisation, we are often asked how many parent carers we think there are.

6 All of this evidence is based on our own experience, and from speaking directly to parent carers, both in our local area, and through Contact. But there appears to have been very little (if any) work done nationally to examine how well the rights for parent carers are being implemented.¹

7 The Government need to make it clear whose role it is to ensure that local authorities are meeting their statutory duties towards parent carers. Currently it is being left to local carers' charities to ensure that the rights are being upheld. The Government also needs to ensure that local authorities have sufficient resource (both financial and staffing) to meet their duties.

8 Without this accountability, and the required resource to ensure assessments lead to support, we are concerned that parent carers will continue to go unsupported.

¹ There has been research commissioned by the Department of Health and Social care in relation to Young Adult Carers - https://www.childrenssociety.org.uk/sites/default/files/2020-10/young-carer_transition_report.pdf and the Care Inspectorate in Wales have examined the implementation of mirroring rights for parent carers in Wales - <https://careinspectorate.wales/sites/default/files/2021-11/211129-national-overview-report-disabled-children-en.pdf>

Who we are and why we are submitting evidence

9 This evidence is submitted by Caring Together in response to the question as to whether the introduction of statutory rights for parent carers in the Children and Families Act 2014 has improved their lives.

10 A parent carer is a person aged 18 or over who provides or intends to provide care for a disabled child for whom the person has parental responsibility²

11 Caring Together is a charity supporting carers of all ages across Cambridgeshire, Peterborough and Norfolk. As well as providing services in our own area, we also work to raise awareness and bring about change for carers on a local and national level. In March 2022 we founded the Young Carers Alliance network, and so fully support the evidence submitted by them in relation to young carers and this legislation.

12 We are submitting evidence because whilst the Children and Families Act 2014 should have led to earlier, improved support for parent carers, our experience from speaking to parent carers locally and also nationally through Contact (a national charity that supports the families of disabled children) is that in many areas, the legislation is not making the required difference. This is often because parent carers are 'falling through the gap' in relation to commissioning between children's and adult's services (because the person being impacted and potentially with their own support needs is an adult, but the person they are caring for is a child).

The Children and Families Act and parent carers

13 The Children and Families Act 2014 introduced specific legal rights for parent carers. Section 97 placed a duty on local authorities to assess whether a parent carer has needs for support – this being done through a Parent Carer's Needs Assessment (PCNA). This assessment could be standalone or combined with another assessment being carried out in relation to the parent carer or disabled child.

14 Section 97 also places a duty on local authorities to take 'reasonable steps' to identify the extent to which there are parent carers in the area in need of support.

To what extent has the Act improved the situation for parent carers?

Has the Act improved identification of parent carers?

15 Our experience from speaking to parent carers is that in many areas, little is being done to proactively improve the identification of parent carers, and that local authorities do not have any sense as to the potential number of parent carers in the area.

² S17ZD Children Act 1989

16 We believe this is partly as a result of local commissioning. In many local authorities, such as Norfolk, organisations are commissioned by adult's services to provide support to adults who are caring for adults, and are commissioned by children's services to provide support to children under 18 who are carers (young carers), yet there is no similar provision commissioned for adults caring for children.

17 As a result, whereas local authorities could get a useful indicator as to the potential number of adult carers (caring for an adult) or young carers from the numbers known to the commissioned support provider, there is no equivalent for parent carers. Similarly, in Cambridgeshire and Norfolk, the specifications for the contracts for both adult carers and young carers included a requirement to undertake awareness-raising activity with organisations such as education, health, social care and other voluntary sector organisations. This is the same in many other areas, and so there is a great deal of awareness-raising activity in relation to adult carers and young carers – helping to improve understanding of who they are, what issues they face and how they can be supported, there appears to be no-one tasked with doing the same for parent carers.

18 In Norfolk, on the back of a survey which we co-produced with parent carers and the local authority last year which highlighted the significant impact that caring was having on parent carers (81% said their own mental health is negatively affected, 79% felt lonely/isolated and 44% said they don't feel able to cope), we set up and chaired a multi-agency steering group in relation to parent carers. This group has representation from the local authority across both children's and adult's services, health, the local parent carer forum and other voluntary sector organisations and is now looking to address various issues relating to parent carers, particularly the improving the local implementation of the statutory duties under this Act.

19 Despite this, we are still finding that parent carers across the country are going years without any support because they haven't been identified as carers:

"I've been a parent carer for almost 20yrs now and never once have i had a carers assessment carried out with any of my children.... I haven't even heard of them tbh!" **Parent Carer**

20 We believe the multi-agency model is one which should be recommended as a model of best practice, and we would like to see clear guidance around the implementation of this duty to help local authorities. This guidance also needs to make clear the need for children's and adult's services to work together, particularly in relation to parent carers of young people approaching the transition into adult services.

21 Whilst Ofsted and the Care Quality Commission often ask how parents and carers are being included by local authorities, and often ask for their direct

input into local inspections, from our experience this tends to focus solely on the experience in relation to the disabled child, rather than the parent carer. It is therefore also vital that in inspections, Ofsted is asking local authorities how they are complying with their statutory duties in relation to parent carers.

Has the introduction of a legal right to Parent Carer Needs Assessments improved the situation for parent carers?

22 Despite parent carers having a clear legal right to an assessment in the legislation, there does seem to be issues with parent carers being able to access them.

23 In a survey by Caring Together last year of parent carers in Norfolk, out of 110 respondents, only 12% reported having had a Parent Carer Needs Assessment, with a further 9% who didn't know if they had received one.

24 When we asked a local authority recently how many Parent Carer Needs Assessments they complete a year, they were only able to find information on 50 for the whole county. By way of context, whilst there is not a definitive number of parent carers in the local authority, there are estimated to be over 13,000 children and young people with a disability.

25 Whilst not directly relevant for this particular call for evidence, the Committee might be interested to know that this experience was also reflected in Wales (where the rights under this legislation are mirrored in the Social Services and Wellbeing (Wales) Act). In a report by the Care Inspectorate Wales in 2021 it was identified that very few parent carers had received a carer's assessment. In that report, 66% of parent carers said they had not been offered an assessment.³

26 From speaking to parent carers, it is clear there is a combination of them not knowing they were entitled to an assessment, but also situations where parent carers tried to access assessments but couldn't or were passed from department to department:

"Been trying to access one for years!" **Parent Carer**

"One department said to try another department." **Parent Carer**

Eligibility for an assessment

27 There is also the need for more clarity in relation to eligibility for Parent Carer Needs Assessments. We have heard from numerous parent carers who have not been able to have an assessment because their child is not 'disabled enough'. Multiple parent carers have also reported being turned down for assessments, despite requesting one (which is all that is required in the legislation to trigger an assessment):

³ <https://careinspectorate.wales/sites/default/files/2021-11/211129-national-overview-report-disabled-children-en.pdf>

"A few years ago, I had someone come out to my home and the first thing I was asked was "does your child have a formal diagnosis?" the answer at the time was no, so I was told they couldn't help me. I've heard others say that they've also faced the same issues." **Parent Carer**

"My twins are 10, both have different needs. I've 2 older boys. Yet I don't 'qualify' for any assessment" **Parent Carer**

"I've requested one 3 times over the past 1.5 years and was told the LA just don't do them, and what I'm doing is 'parenting and not caring'. And unless there's a safeguarding issue, there is no 'need' as there's no services for under 5's." **Parent Carer**

"My LA told me they don't do it for parents of disabled children because where does the parenting end and the caring begin" **Parent Carer**

"Every LA I have ever asked has said no. It's always safeguarding team do assessments so just let them do safeguarding assessment." **Parent Carer**

"Still waiting for ours. It's been 2.5 years." **Parent Carer**

"I got refused one I asked many times over the years." **Parent Carer**

"I've been turned down 4 times now for help from social services" **Parent Carer**

28 What makes the situation more difficult for parent carers is whereas with adult carers and young carers, there is nearly always a requirement on the commissioned carers support provider to offer information and advice to carers about their rights, entitlements and support available, there is often nowhere dedicated for parent carers to go to in their local area, often leaving them to rely on national organisations such as Contact. For example, in Norfolk, adult carers of adults can contact the Carers Matter Norfolk service for information, and young carers (or their parents) can contact the Young Carers Matter Norfolk service. But parent carers in the area have no-one to tell them what their rights are or how to access them.

Parent Carers (and professionals) information

29 We therefore believe that there needs to be much clearer information available for parent carers in every local authority that sets out how to access an assessment, and what an assessment could lead to. We have come across numerous examples where information is either non-existent, or contradictory and confusing.

30 On one local authority website it says parent carers are entitled to request an assessment but doesn't say how to request one. In another, it says:

"Parent carers who look after a disabled child... can have an assessment under the Children and Families Act. We are in the process of updating our information for parent carers but in the meantime please contact the All-Age

Disability Service" – we found that when you visit that service information, there is no reference to Parent Carer Needs Assessments on that webpage.

31 In contrast, Suffolk is an example of where there is clear information – the local authority produced an animated video about parent carers' statutory rights and gives examples of the types of support that might follow an assessment.

32 It is also key that professionals working with both children's and adult's social care, as well as other backgrounds such as health and education have a good understanding of parent carers, their needs and statutory rights.

33 Section 23 of the 2014 Act places a duty on health bodies to bring children who have (or probably have) special educational needs or a disability to the attention of the local authority. It would be a big improvement if there was a similar duty to ensure that at the same time, any potential parent carers are similarly brought to the local authority's attention.

Systems

34 Our experience is that 7 years on from the legislation coming into force, many local authorities do not have the systems in place to record how many assessments have happened, or what the outcome of them were. For example, whilst one local authority was able to tell us that they do around 50 stand-alone PCNAs a year, they do not record anywhere if a PCNA is completed as part of/alongside an assessment of a child.

35 We have also found that a number of local authorities have no processes or systems in place to ensure if a parent carer does have an assessment, that the information then transfers to any adult carers support service, so that parent carers do not have to tell their story all over again when their child turns 18.

What difference have Parent Carer Needs Assessments made?

36 One of the key issues is that not enough appears to be known about what difference parent carer needs assessments have made.

37 The Children and Families Act 2014 made it clear what an assessment must cover and what local authorities are required to do if a parent carer is in need of support:

"A local authority that carry out a parent carer's needs assessment must consider the assessment and decide—

(a) whether the parent carer has needs for support in relation to the care which he or she provides or intends to provide;

(b) whether the disabled child cared for has needs for support;

(c)if paragraph (a) or (b) applies, whether those needs could be satisfied (wholly or partly) by services which the authority may provide under section 17; and

(d)if they could be so satisfied, whether or not to provide any such services in relation to the parent carer or the disabled child cared for."

38 Assessments must also take into account '*the wellbeing of the parent carer*' and '*the need to safeguard and promote the welfare of the disabled child cared for and any other child for whom the parent carer has parental responsibility*'

39 Despite this, it is clear from speaking to parent carers across the country that there are many local authorities where this is clearly not happening in practice. In many local authorities, Parent Carer Needs Assessments tends to lead to signposting to services which are available to all parents, or all adults. There is also often no difference in what is offered to parent carers even if there is a significant difference in the level of caring provided or the level of impact the caring responsibilities are having.

"We get told no services are available in our area been like that for years"

Parent Carer

"3 years of being told no one does them anymore and a formal complaint they finally gave me a carers assessment. Listed all the things that would help me then sent me a letter to say even though there are things that would help me they can't provide any as carers assessments have no funding available, but they could send me some leaflets!!!" **Parent Carer**

"I did this in October 2020. The lady dealing with us was helpful in explaining things and did try to put the assessment forward for a referral, but this wasn't able to happen. I feel that the process didn't actually help put any extra support or help in place and seemed to go to nowhere." **Parent Carer**

"Even those that so have a diagnosis and a parent carer assessment it leads to no help or sign posting anyway. So it's almost a pointless task when your already overwhelmed & exhausted to have to find time to fill in multiple bits of paperwork and constantly chase a disjointed system." **Parent Carer**

"We had an envelope full of information and that was it? We've had no support at all, a lot of other families have had the same!!"

"The only thing we were offered was respite which was totally unsuitable for a child who has attachment trauma and needs to know we aren't going anywhere!" **Parent Carer**

"They're a waste of time anyway, they do the assessment, tell you what you need then tell you that you can't have it" **Parent Carer**

40 In one local authority, they even have a statement on their website in relation to assessments which says, *'The assessment will consider your needs as a parent carer, but it will not lead to a direct service or budget for a service. It will help identify support available for you and your family, from our other departments or other local agencies'*. Whilst this particular webpage and approach is now being changed through a multi-agency steering group which we chair, our concern is that there will be many other local authorities where this approach is not being challenged.

41 In another area, the following is listed as examples of the types of 'support' that could follow an assessment:

"Examples of support

1. *You may feel that the needs of your child with a disability impacts on your other children, and that you are unable to offer them the time and attention you would like. The plan may identify a referral to young carers, where they can meet with other young people who have a sibling with a disability*

2. *If you have health or mental health needs, a referral could be made to our adult services for support in your own right*

3. *You may feel that you would benefit from your child with a disability attending activities outside the home. This would allow them to have new experiences and allow you to have a break from your caring role. An application for short breaks might be appropriate"*

42 Whilst it is positive that it provides some examples of support available, these are all services that are available to any parent carer, irrespective of the impact of their caring role.

43 Some parent carers in various parts of the country have reported that they don't even know what the outcome of the assessment was:

"When I asked, I was offered an assessment that was years ago never got to see the report" **Parent Carer**

"My sons social worker did an assessment as she said we were entitled to one, but I've not heard anything back." **Parent Carer**

44 As part of our work around the implementation of these rights for parent carers, we have heard from over 120 parent carers from different parts of the country. We did not have anyone come back with examples of how having a Parent Carer Needs Assessment had resulted in positive changes for them or their family. This is something we are extremely concerned about and feel needs to be reviewed in further detail.

45 Speaking to parent carers, there appears to be a reverse cliff-edge in place, by which in many local authorities, if a parent carer has an assessment

when their child is 17 years and 364 days old, then the parent carer will be eligible for little more than signposting to universally available services. Yet when their child is 18, it opens the door to commissioned carer support services, and carers assessments with the possibility of personal budgets.

"I've had a carers assessment within the last month, and was told they wouldn't offer any help because my son is under 18, he's actually 18 next month" **Parent Carer**