



Parent Carer Survey







April 2021



Responses





- 🌸 110 responses
- 🌸 34 parents caring for at least 2 children with support needs
- 🌸 8 parents caring for at least 3 children
- 🌸 3 parents caring for 4 children
- 🌸 Majority caring for someone because of Autism Spectrum Disorder

Impact on parent carers

-  85% not able to take a break from caring role
-  81% feel there is not enough support for them
-  81% say their own mental health is negatively affected
-  79% feel lonely/isolated
-  54% say it's affecting their ability to get/stay in work
-  53% not in work of any kind




Impact on parent carers

-  44% don't feel able to cope
-  39% know where to go for information to help them
-  36% feel they have good support from friends/family/community
-  35% have a plan as to what they would do in an emergency (e.g. carer becomes unwell)





Impact on parent carers

 “I feel I am the only one who consistently provides support for my child. I bring him home for lunch each day because school says they have no money to provide the 1:1 he requires and also home-school 2 half days a week so he can survive school. I never get enough sleep, am constantly battling for the support he needs and filling in forms or going on courses to give him best chance in life. I am a qualified teacher but have to work as much lower paid TA because I can't send him to any other childcare.”




Impact on parent carers

 “I do feel exhausted, family aren’t the greatest support and I feel like everyone stands back and says how hard it must be but nobody wants to actually help. Portage have been a great help to me and our portage worker helps and listens with any worries or concerns I have. Covid has made it difficult to get out, however I prefer to stay at home due to my daughter having to be in a buggy and everyone staring at me when she has a meltdown or gets upset.”




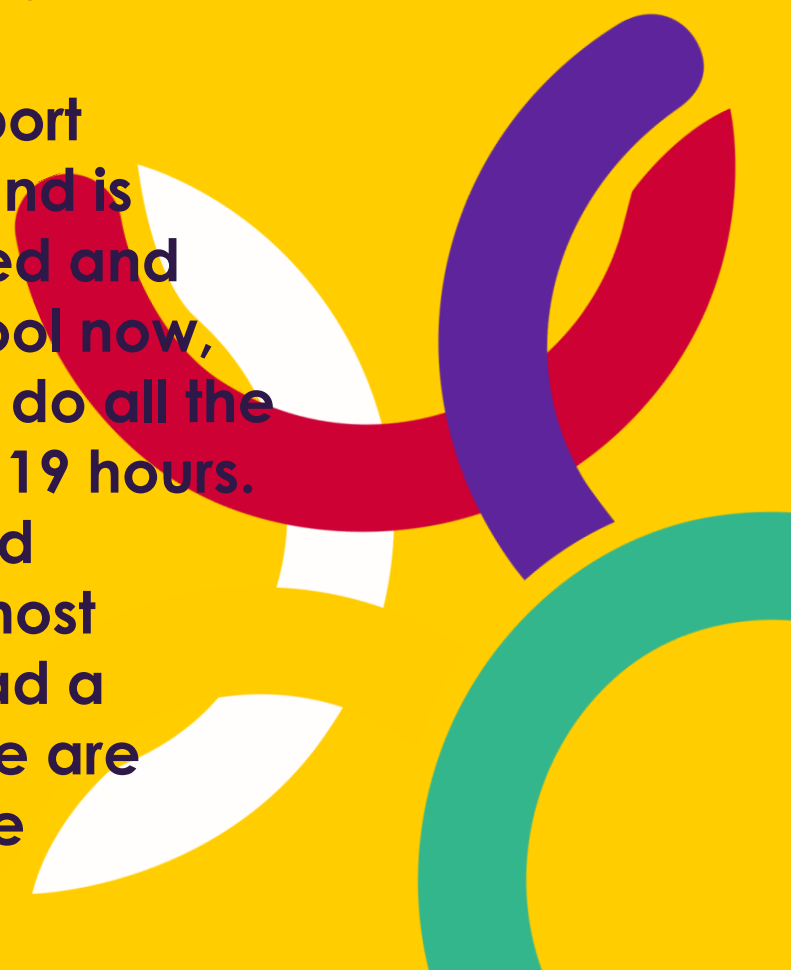
Impact on parent carers

-  “I have only had one day to myself since March 2020. I've had to spend 5-6 hours a day supporting my youngest child with his home-schooling because of his inability to sit still and focus. My teen son has had severe mental health issues, particularly during the first lockdown but no help was forthcoming from CAMHS "*because he's autistic*’ I came very close to having a breakdown during the first lockdown and even now I'm teetering on the edge. My medication was tripled but I'm still struggling to sleep. I gave up my part time job in August because I couldn't cope.



Impact on parent carers

 “I’m a single parent (sole carer, no shared care) caring for my son alone, previously working as a RN. I live in a small flat with my son with complex disabilities. During the pandemic our respite package collapsed and for the first lockdown his SEN school closed completely, to all pupils, even vulnerable pupils. My son and I lost all support overnight and it was a very dark time. He has a social worker, though at one time she was also off sick and wasn’t replaced. I felt completely abandoned. I don’t have a support bubble. My son has very high care needs (day and night) and is usually cared for in other settings on a 2:1 basis. I’m very tired and haven’t had a full night’s sleep in months. He’s back at school now, which is the only thing that’s kept us going—it allows me to do all the things in those 5 hours so I can safely care for him the other 19 hours. However he still isn’t receiving the full range of therapies and interventions that his EHCP states he needs. He hasn’t had most therapies for over one year and I’m worried this will have had a permanent affect for his development. Now, a year later, we are finally in the early stages of setting up a replacement respite package. It’s been one of the hardest years of my life.



Parent Carers and NCC

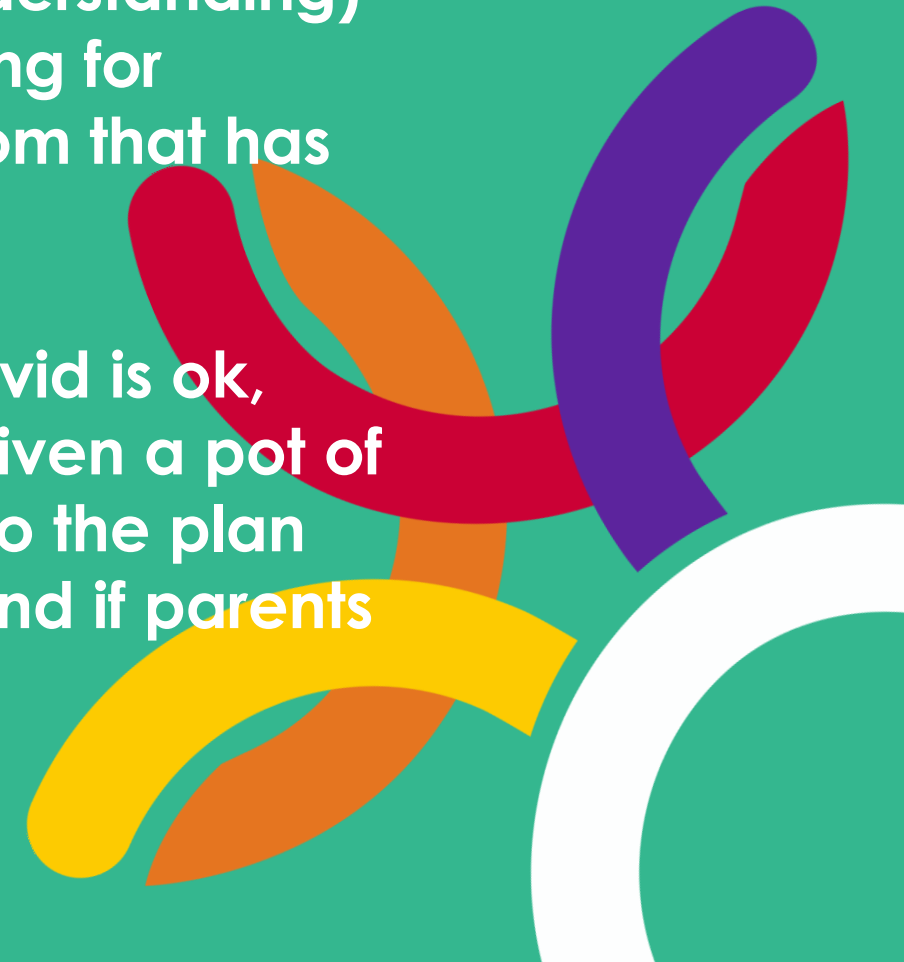
- 41% have had support from Short Breaks
- 12% have had a Parent Carer Needs Assessment (9% didn't know if they'd had one)
- 3% have had support from PFAL



Parent Carers and NCC – Short Breaks

“We really needed short breaks and our daughter enjoyed going to different places and activities, but we had to fight to get this provision in the first place. We had a good(knowledgeable and understanding) practitioner who did our daughters assessment for Preparing for Adulthood. The experience and knowledge we gained from that has continued to help us.”

“Waiting for PFAL team to contact Short breaks before Covid is ok, very difficult to recruit a PA so it’s all very well if you are given a pot of money but cannot find a suitable Pa, and the outcomes to the plan aren’t being met, more needs to be done to recruit PAs and if parents can’t the LA should”

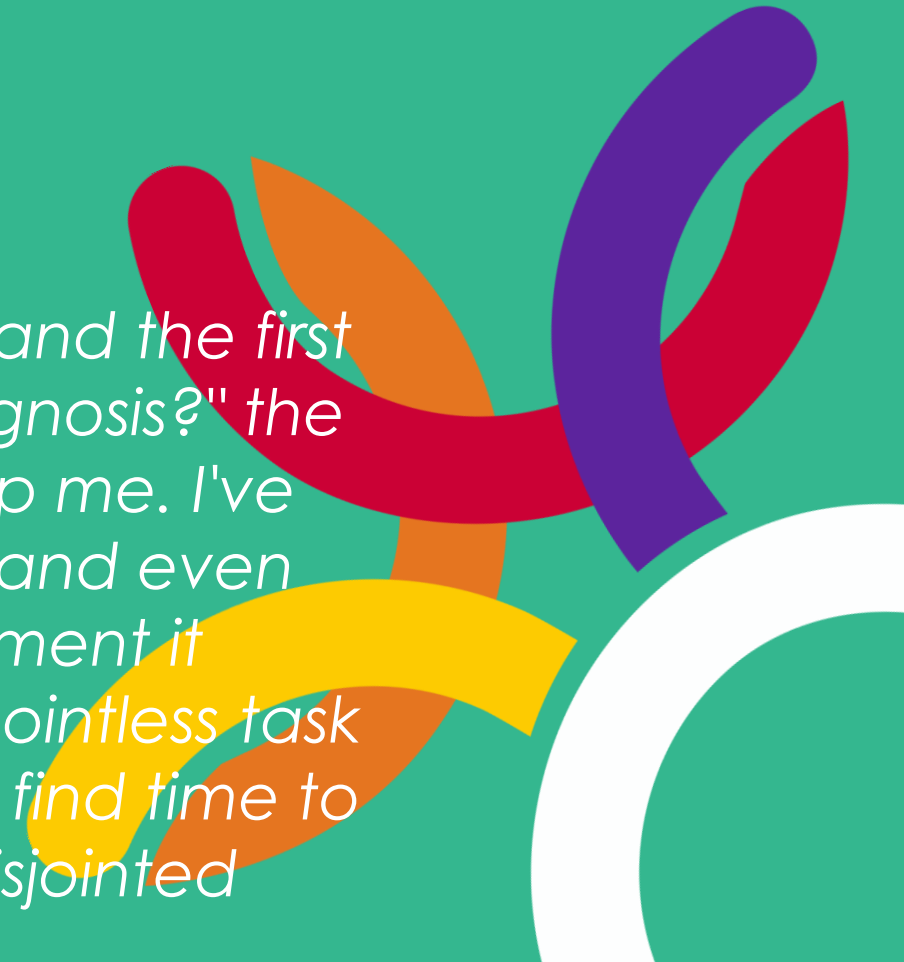


Parent Carers and NCC – Assessments









“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.”

“Been trying to access one for years!”

“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 and 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 ”



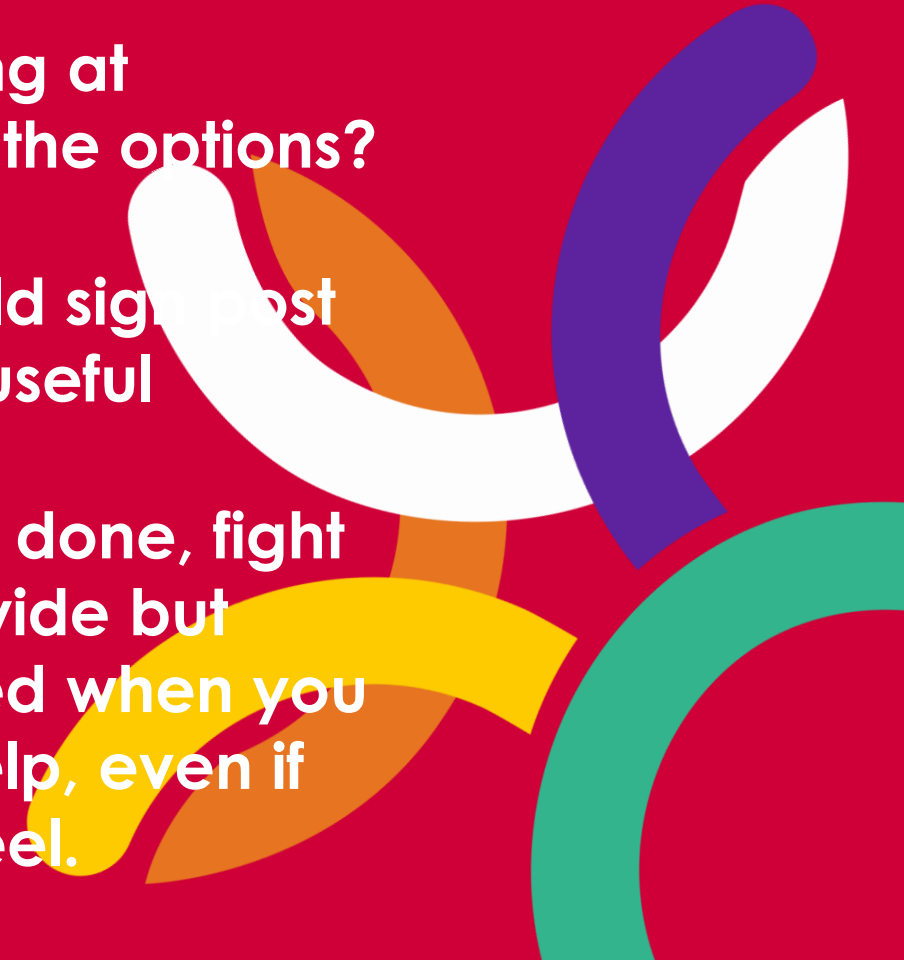
Top priorities for support

-  49% - Support to have a break from caring role
-  45% - A single number / place to contact for information and support
-  44% - Key worker for 1-2-1 support
-  44% - Training/practical support
-  42% - Support for siblings
-  36% - Someone to talk to
-  32% - Emergency Planning
-  31% - Support around finances



What support would be helpful?

- “All of the above, and equitable service as carers of adults have, an all age and stage carers service, parent carers of children need supporting too, we could be sandwich carers caring for elderly parents, and caring for our children for perhaps all of our lives.”
- Help with next steps....eg When could we be looking at independent living? How do we do that? What are the options?
- Someone to call as an umbrella of needs who could signpost where to go for help/explanations would be most useful
- Someone I can rely on to chase people, get things done, fight for me and my son. It's probably impossible to provide but some sort of emergency care that can be accessed when you are at rock bottom or ill. Someone to come and help, even if just for a short time, to get you back on an even keel.



What support would be helpful?

- ✿ “A joined up carers assessment when one person is caring for both a child and an adult. Practical support eg a cleaner, someone who did the laundry or prepared a meal.”
- ✿ Advice around MCA, Court of Protection, assistive technology, how to find suitable accommodation, social clubs/activities for young people with SEND
- ✿ Online first aid training support. Online resource website to signpost support available
- ✿ Childcare for children with SEND, particularly in my local area so that I can feel confident going to work and having good provision for my son (someone who understands and can deal with his behaviours) outside of school.



What next???



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