



Parent Carers in Norfolk

Carers Week 2021

The session will start at 1:05pm

#CarersWeek



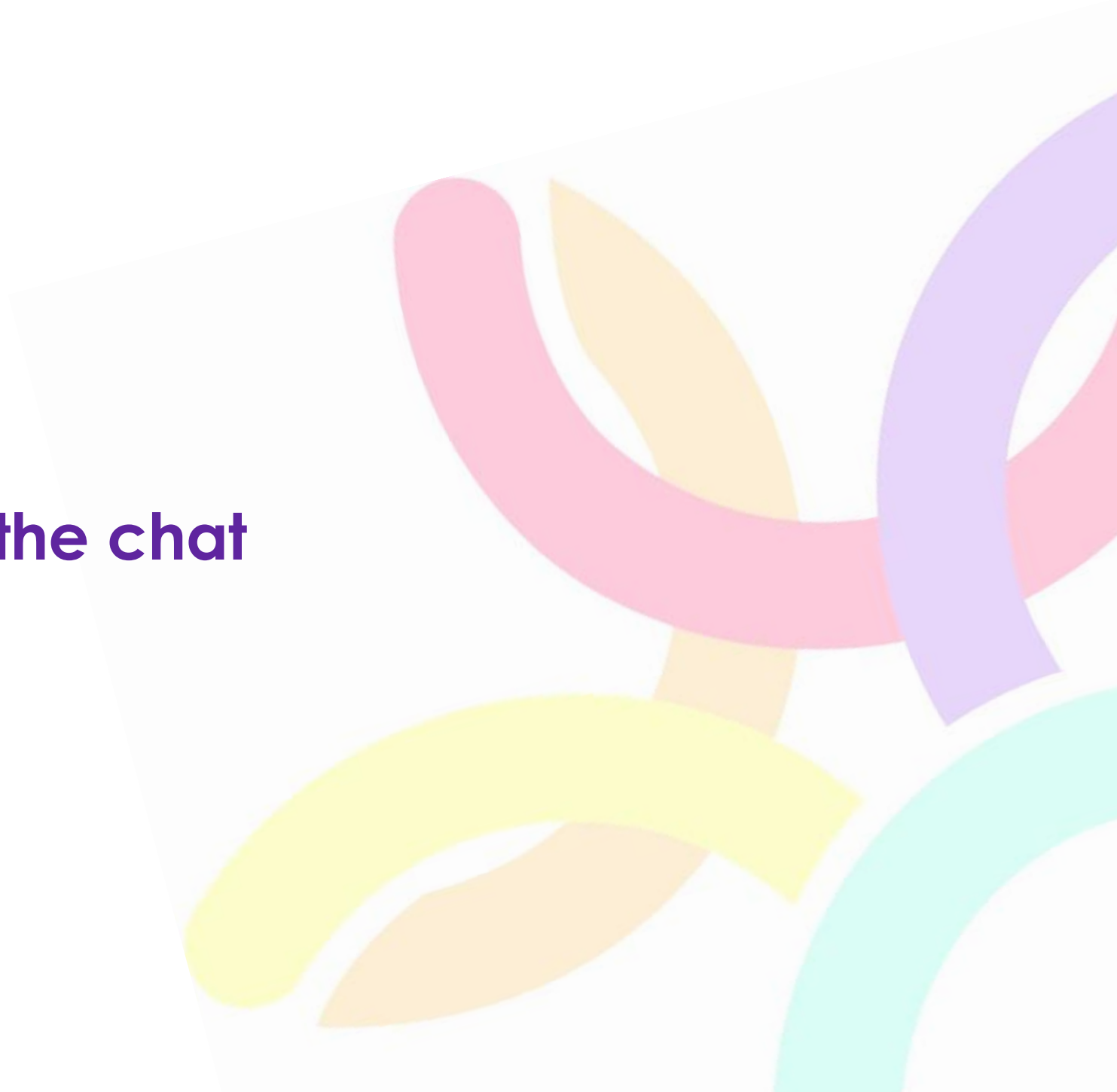
Agenda

- 🌸 Welcome/housekeeping
- 🌸 Norfolk Parent Carers Survey
- 🌸 Initial response
 - Norfolk County Council
 - Family Voice Norfolk
 - SENsational Families
- 🌸 What next???
- 🌸 Closing remarks
- 🌸 Networking









Housekeeping

- 🌸 **Microphones on mute**
- 🌸 **Recording the session**
- 🌸 **Comments/questions in the chat**
- 🌸 **Purpose of the event**
- 🌸 **#CarersWeek**







Norfolk Parent Carer Survey

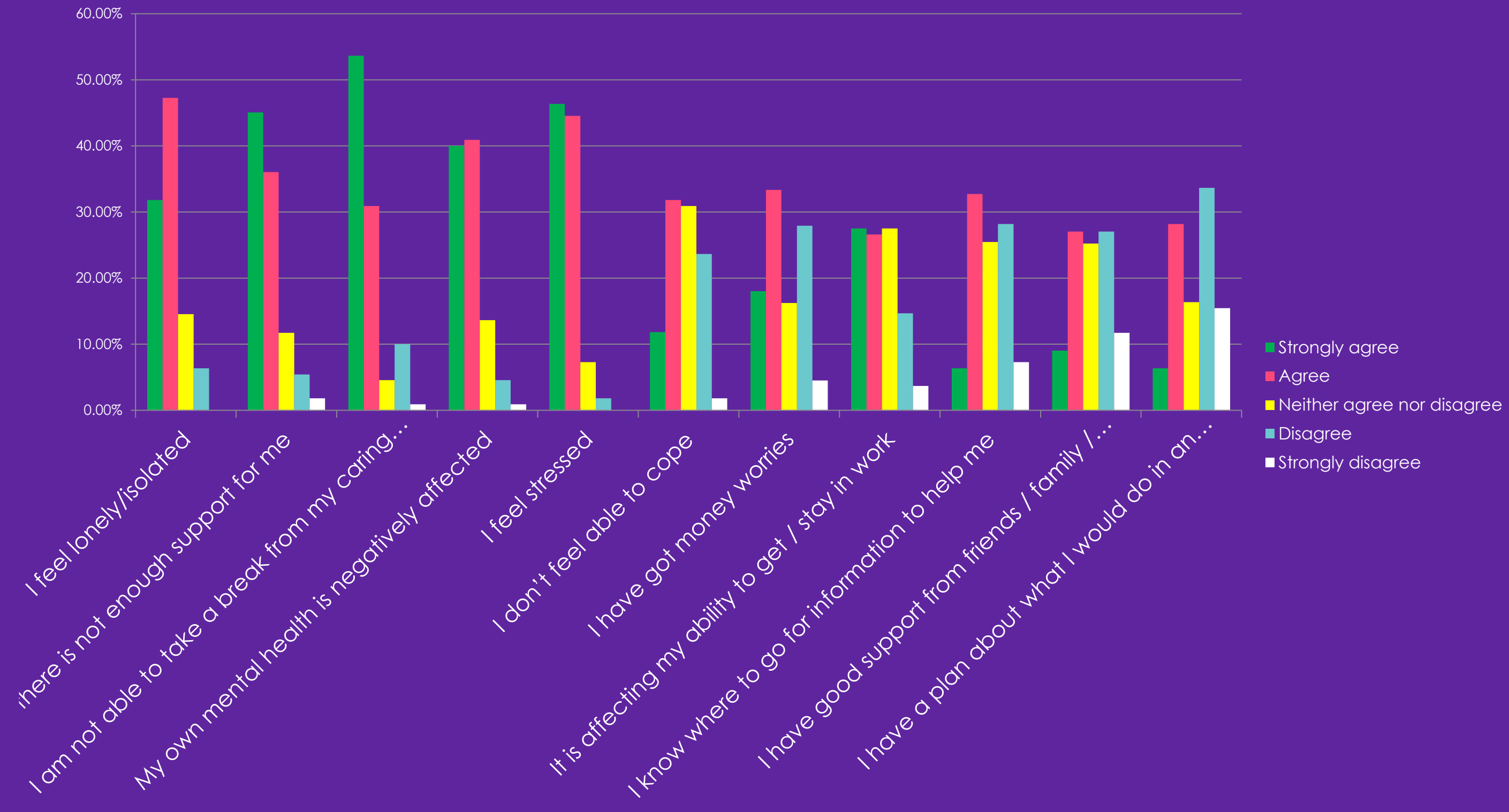
-  Live during March 2021
-  110 responses
-  Highest response from South Norfolk and Breckland, lowest from North Norfolk
-  34 parents caring for at least 2 children with support needs
-  90% caring for child(ren) aged 18 and under
-  Majority caring for someone because of Autism Spectrum Disorder



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





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.”



Impact on parent carers

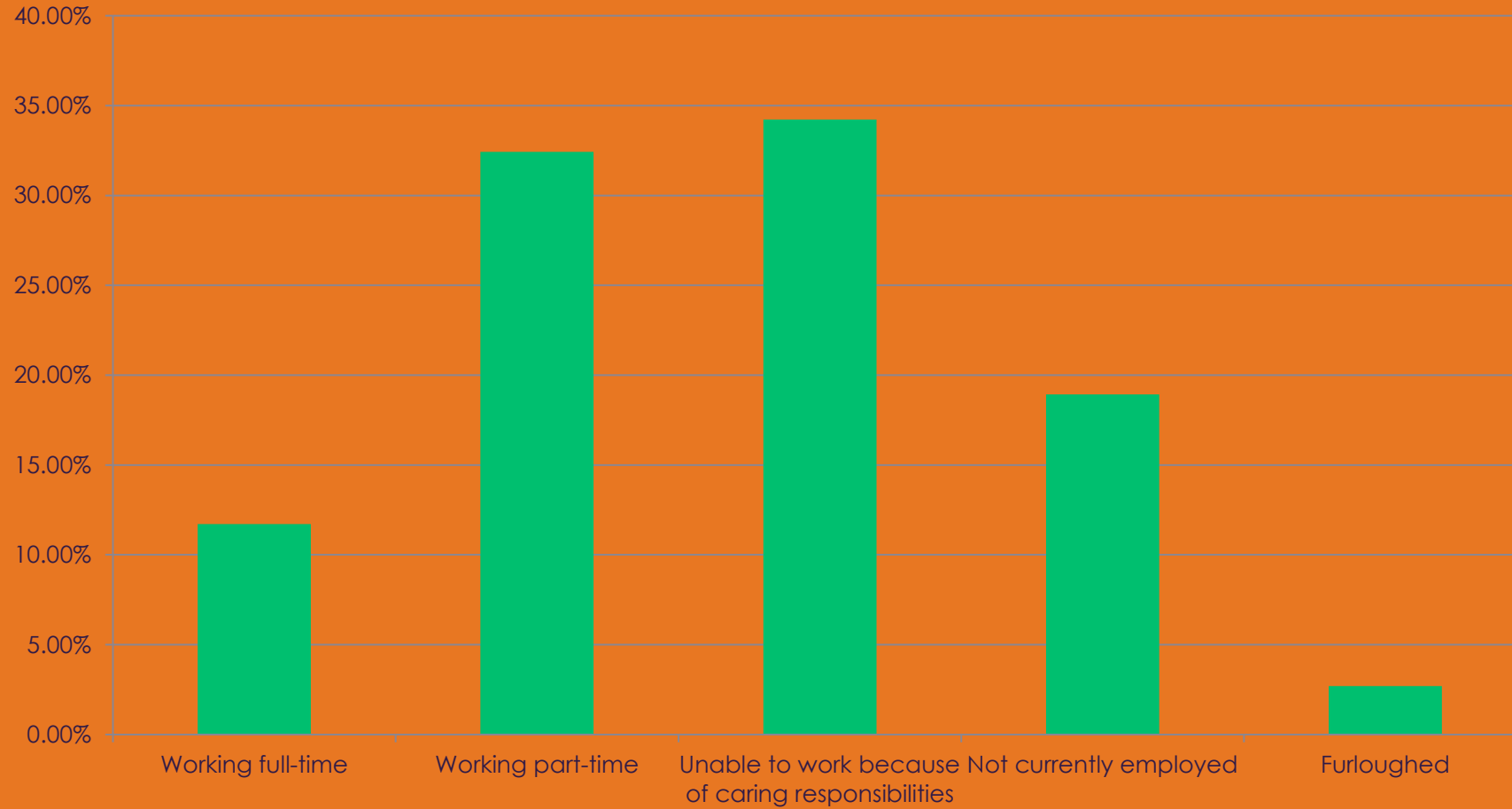


“I do feel exhausted, family aren’t the greatest support and I feel like everyone stands back and says how hard it must be but nobody wants to actually help. Covid has made it difficult to get out, however I prefer to stay at home due to my daughter having to be in a buggy and everyone staring at me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



Parent carers and employment

Are you currently trying to balance your caring responsibilities with paid work?



Parent carers and employment



“I am a qualified teacher but have to work as much lower paid TA because I can't send him to any other childcare.”



“I gave up my part time job in August because I couldn't cope.”



“Work offers flexible time, but hours still need to be made up or lose holiday or pay - in reality I am trying to hold down 2 full time jobs - work and carer.”



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.”



Services/organisations who have been helpful



ADHD Norfolk



Electric Umbrella
Online



Portage



Beyond the Wall



Family Fund



SEND Network



Break



Family Voice



School



CAMHS



GP



SENsational Families



Caring Together



Hamlet Centre



Short Breaks



Carers Matter Norfolk



Independence Matters



Social Services



Contact



National Autistic
Society West Norfolk
Branch



Specialist health visitor



Early Childhood and
Family Service



NHS Physio/OT



Sunbeams



Early Help



Thera



Whizzkids

Services/organisations who have been helpful



The Cove Clinic at the James Paget Hospital



“Fiona at the N and N is amazing”



“The autism nurse at the NNUH has been amazing. I’ve also had a lot of support from key medical professionals such as a paediatric dietician.”



“Our CWDT social worker has tirelessly fought to get us the support we need over this past year, but the goalposts for access to and preservation of support keep moving.”













“Respite/short breaks nurse - she has been an absolute life line!”



“Laura from Early Childhood Services”





Things that have not been helpful

-  Can't access support without diagnosis
-  GP surgery not registering parents as carers on their carers registers
-  Having to fight for support all the time
-  Lack of support available compared to other carers or if you don't have a social worker
-  Long waiting lists
-  No responses to e-mails/no communication
-  Not knowing where to turn to for information/support
-  Not listening to our concerns
-  Support from schools has been mixed
-  Thresholds

Things that have not been helpful

“School referred her to Point 1 for her anxieties a few years ago but they refused as she was 'only tier 3' and they were only accepting tier 4 at that time. CAHMS wouldn't see her as 'probably due to autism'. Dietician wouldn't see her and saw me for 30min appointment to say that it was 'probably psychological' and she couldn't help. GP referred us to CAHMS Eating Disorder Team who rejected her as her eating disorder wasn't due to her having body issues. Eventually got an appointment with the paediatricians only for COVID lockdown to happen and it was a telephone call and said 'Oh, that's due to the Autism'. I begged for a blood test which happened eventually and they cancelled the next appointment we had!”

Parent Carers and Norfolk County Council

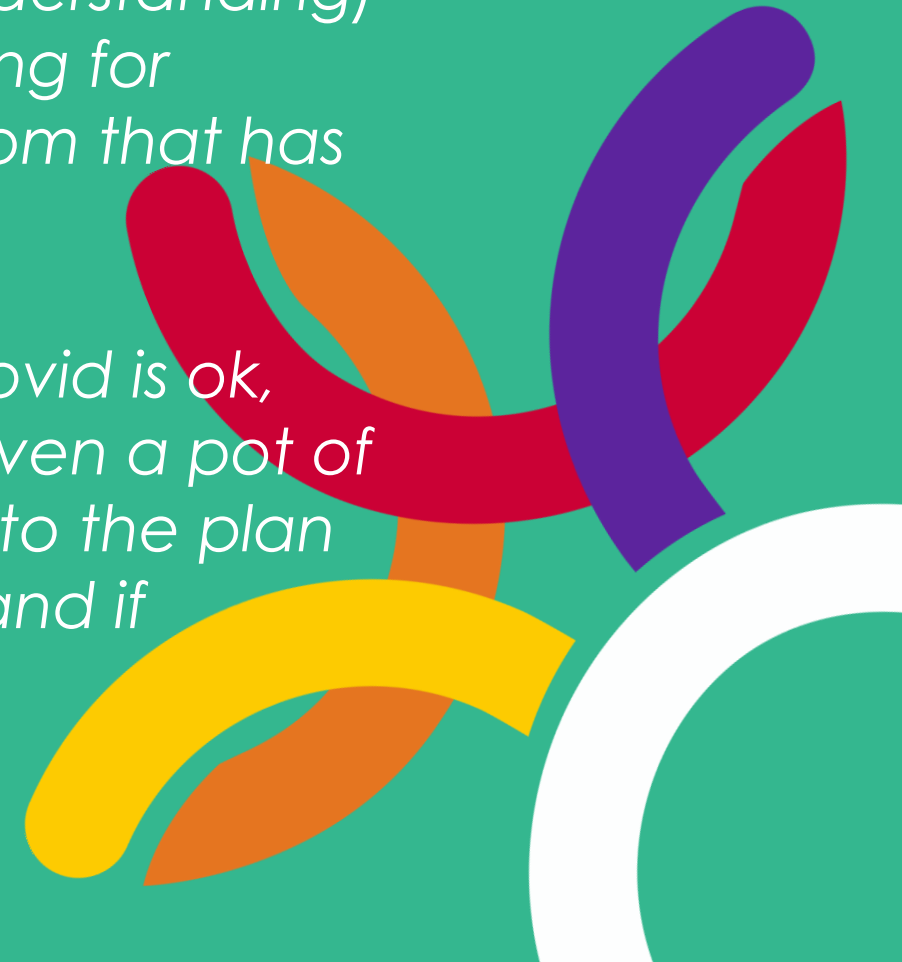
-  41% have had support from Short Breaks
-  12% have had a Parent Carer Needs Assessment
-  Nearly 1 in 10 didn't know if they'd had a parent carer needs assessment
-  3% have had support from the Preparing for Adult Life service (PfAL)



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 daughter's 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”

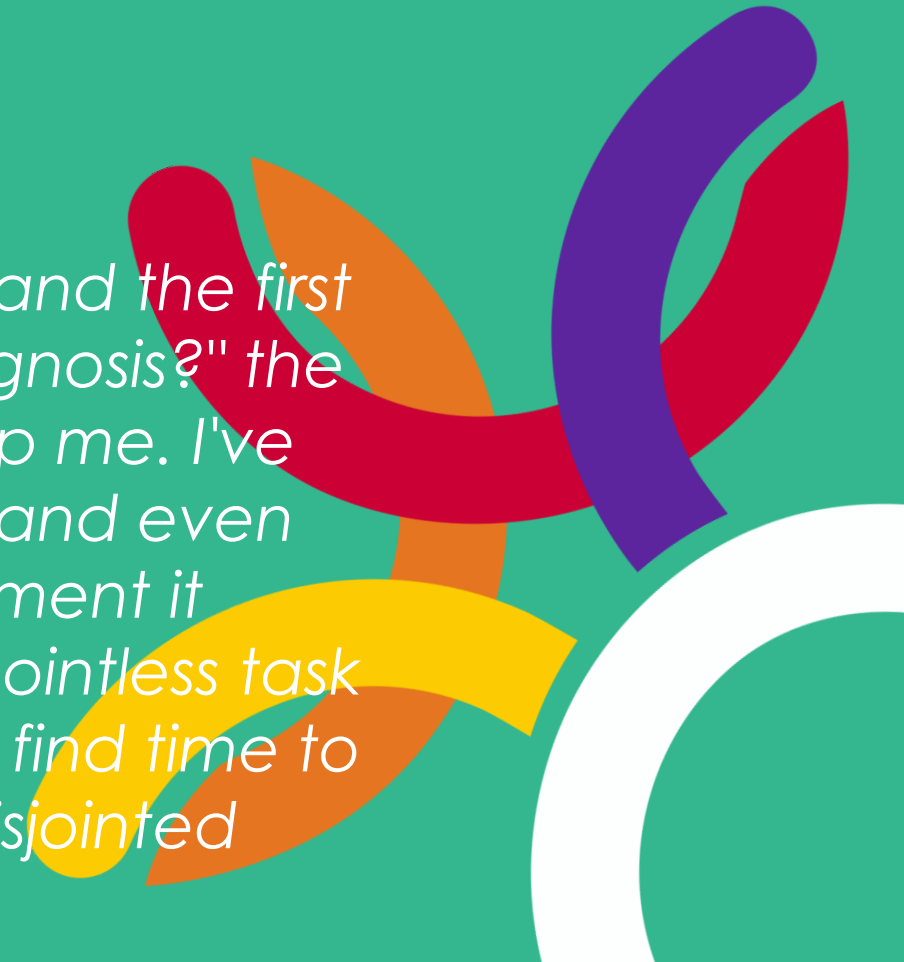


Parent Carers and NCC – Assessments

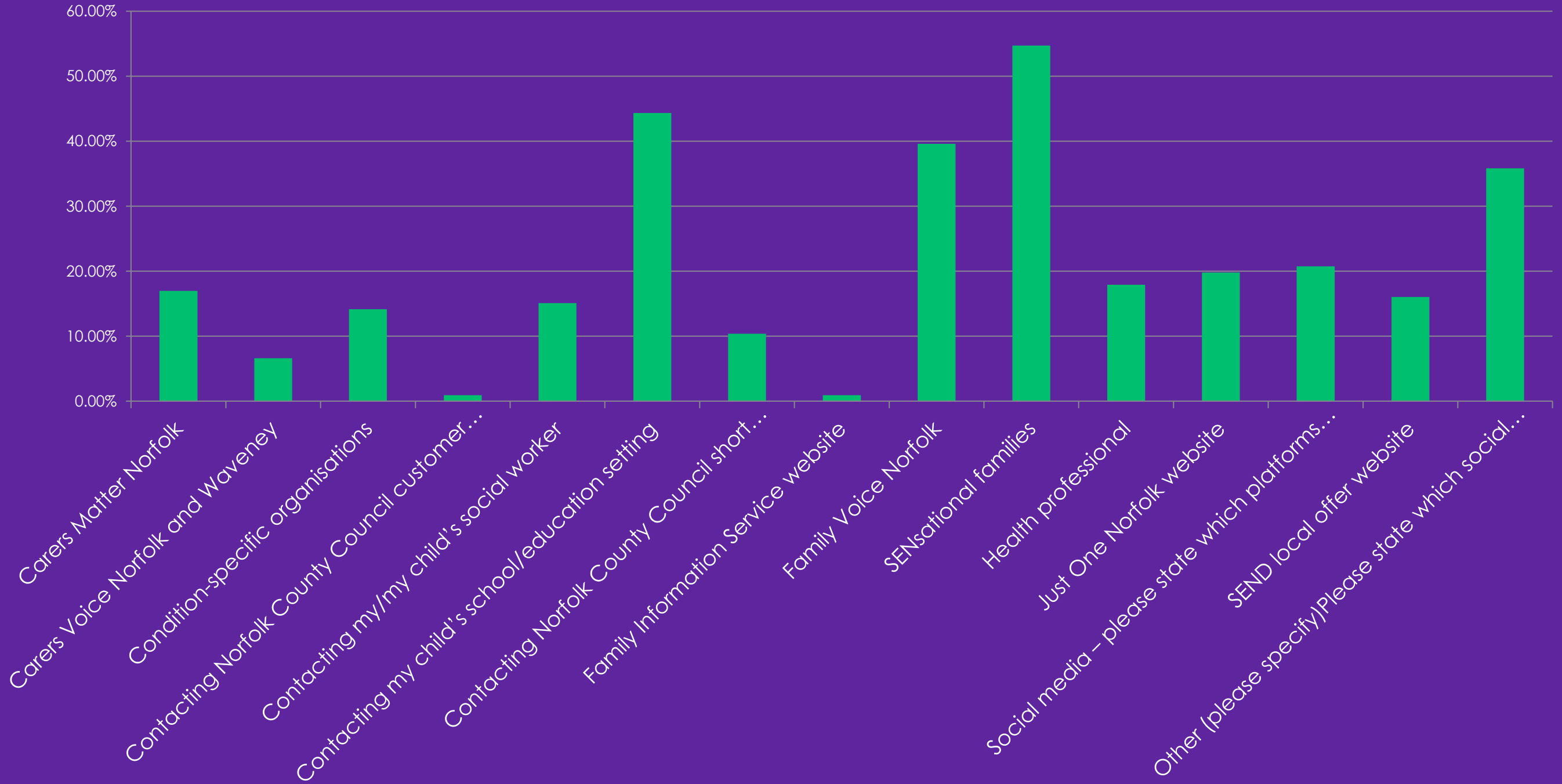
“I did this in October 2020. The lady dealing with us was helpful in explaining things, and did try to put the assessment forward for a referral but this wasn't able to happen. I feel that the process didn't actually help put any extra support or help in place and seemed to go to nowhere.”

“Been trying to access one for years!”

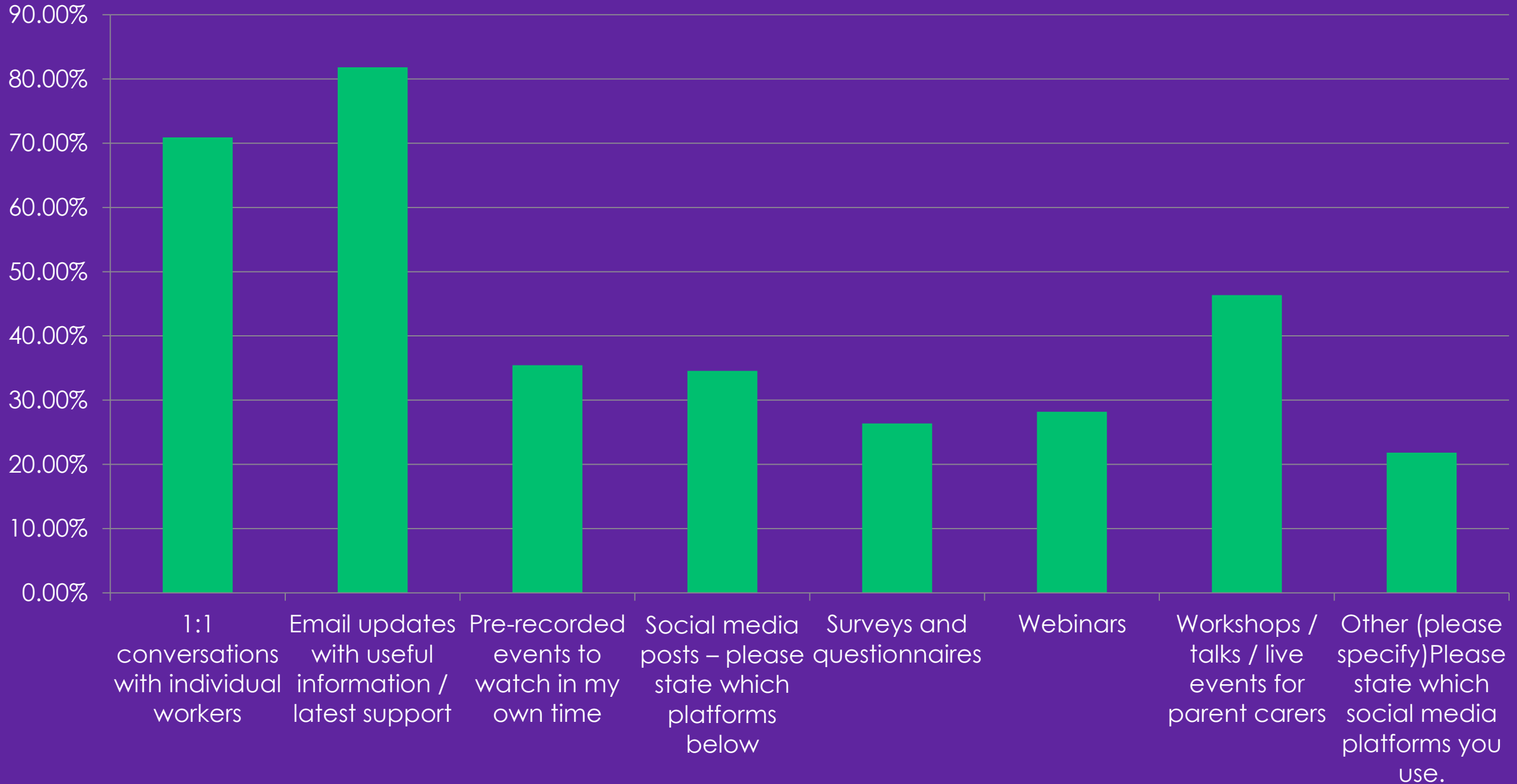
“A few years ago I had someone come out to my home and the first thing I was asked was “does your child have a formal diagnosis?” the answer at the time was no, so I was told they couldn't help me. I've heard others say that they've also faced the same issues and even those that so have a diagnosis and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










Where do you currently go for information, advice and support?.



What is the best way to communicate with you as a parent carer?



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







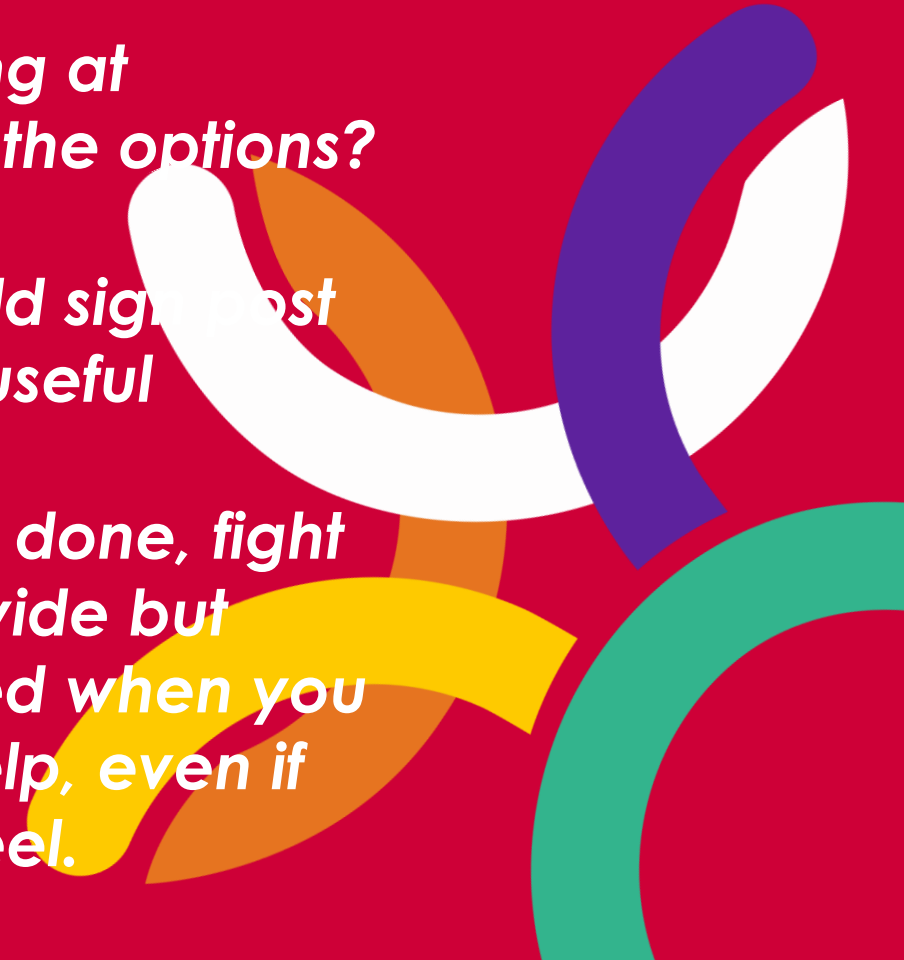
Top priorities for support

- 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.”*





Norfolk
County Council

Initial Response

Norfolk County Council

Tim Eyres

Assistant Director Commissioning and Partnerships

Children's Services





Initial Response

Family Voice Norfolk

Tracey Sismey
Chair




SENsational Families

Nicki Price
CEO



What next???

Break-out rooms

-  What are your thoughts to what you have heard from the survey results?
-  What else can be done to provide the best possible support to parent carers in Norfolk?
-  Who else needs to be involved in this work?





Closing remarks and networking

#CarersWeek

