

Topic of Importance – Parent care resilience

Parent Carer Resilience

As a parent carer the parenting journey can present itself with a range of emotional, financial, and social challenges. Resilience is the opportunity for and capacity of individuals to bounce back from adversities.

Daniel and Wassell mode of resilience (2002) defined resilience behaviours as

- Good health
- Friendship
- Investing in talents and interests
- Understanding and controlling emotional and behaviours
- Access to good education
- Security

Being a resilient parent helps to build a resilient child, parental wellbeing can have direct impact of child wellbeing.

Family voice have collected data as a scoping exercise with the view to developing an understanding of what factors impede of parent carers developing resilience. Any work in this area is also informing medium term plans.

What are parents telling us?

Themes are being raised by a range of parent carers covering topics such as those listed below.

1. There are concerns over changes to household finances due to benefit changes, primarily the DLA ending and the related concerns over:
 - a. Whether a young person will qualify for PIP
 - b. How to apply for PIP
 - c. Lack of understanding over appointeeship
2. Lack of knowledge/ awareness/ understanding around what is available in terms of home care support (respite/ domiciliary care/ independent living) making future planning anxiety provoking.
3. Concerns that families are not aware of the support available and where to find information.
4. Concern over lack of specific information regarding mental health and neurodivergent differences and challenging behaviour.
5. Parent carers reporting feeling tired, anxious, stressed over growing worries around wider household finances, being unable to access general health care and carers support.
6. Lack of wider short break/ respite opportunities.

Where we get our evidence from

1. Contact with parent carers via Facebook
2. Email/ phone requests from parent carers for signposting, information and advice
3. Attendance at external and internal Forums and Workshops
4. Feedback from training and other activities
5. Responses to surveys

How have FVP responded

FVP have conducted a series of surveys in this area after hearing the concerns raised anecdotally by parent carers and seeing an increase in wider requests for household support. Two surveys particularly covering this area were Cost of Living where are we now and Carers and Support needs.

Carer Support

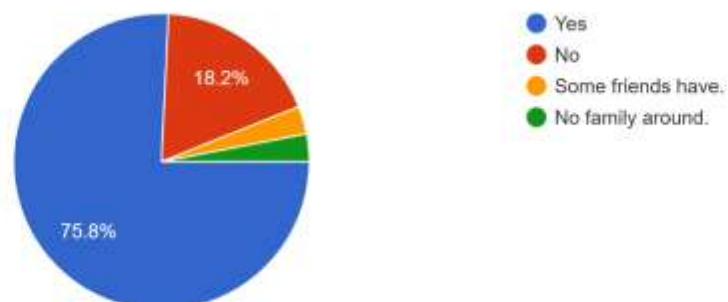
Our survey 'Carer Support' had 33 responses; majority of respondents stated that their child had a neurodivergent diagnosis with autism spectrum disorder being the most common condition. Themes identified from parent contact with the charity highlights accommodation, food poverty and social issues, such as poor housing conditions, relationships difficulties and risk of homelessness.

The issues raised were:

Future planning and worry.

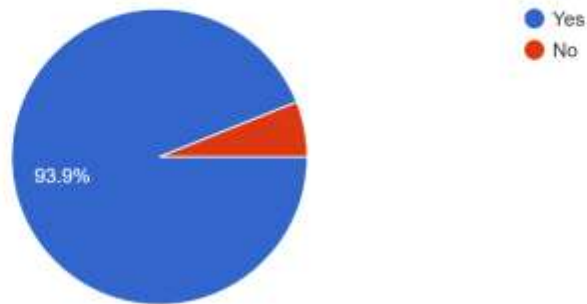
Since realizing your child/ young person has needs have you noticed changes in how family and friends treat you and your family?

33 responses



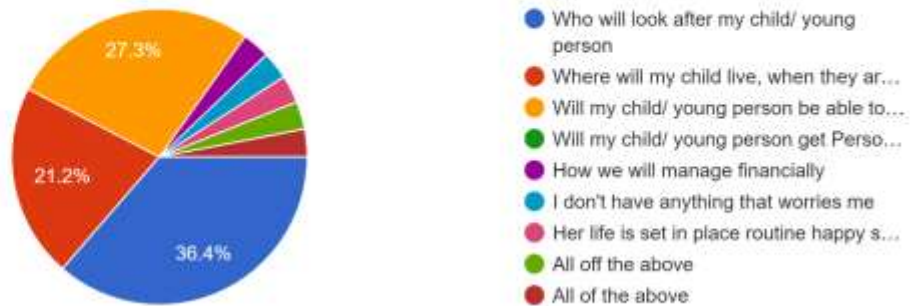
Do you worry about the future?

33 responses



What is it that worries you the most about the future?

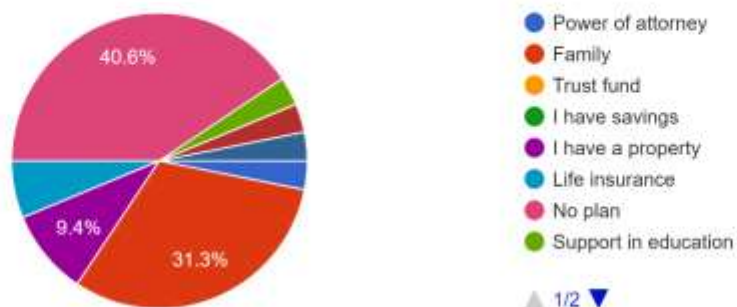
33 responses



Majority of the respondents stated that they had no real plans for the future.

What measures have you put in place to reduce this worry

32 responses



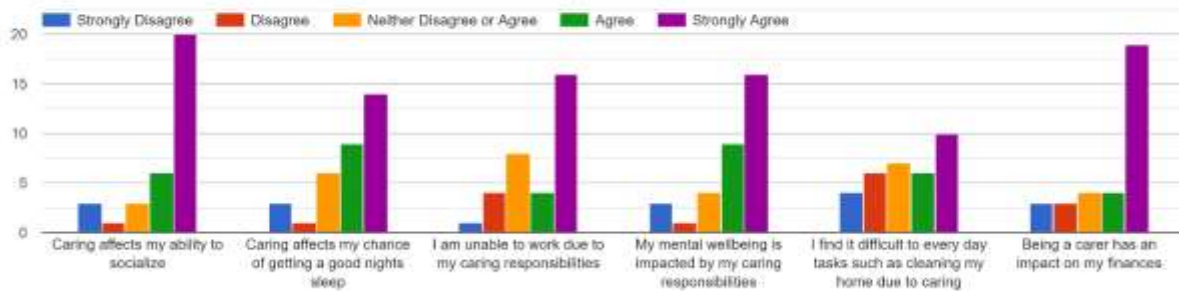
The psychological impact of parent caring on parental mental health is significant, respondents stated that their day to day parenting has caused isolation, stress, worry and anxiety.

- *"I worry a lot more, I am exhausted from needing to work to pay for his needs and activities and of course household bills, I don't sleep very well, I am less patient than I used to be, I no longer have any energy to do anything, everything from housework or taking my child out is like a chore. I also don't have time for my next older child, he has exam pressure and stress and spoke about not wanting to live recently due to school bullying, feeling a failure - so have been more tearful recently whilst I try to make more time for my older son."*
- *isolating*
- *all focus on SEND child and supporting their development*
- *Everyday life, holidays, where we can go and meltdowns, not wanting to go to school*
- *Well being not been able to work for 18 years and isolation, challenging but empowering at same time*
- *Stressing,*
- *Sometimes I feel lonely*
- *Makes me think about things differently*
- *I worry a lot more, I am exhausted from needing to work to pay for his needs and activities and of course household bills, I don't sleep very well, I am less patient than I used to be, I no longer have any energy to do anything, everything from housework or taking my child out is like a chore. I also don't have time for my next older child, he has exam pressure and stress and spoke about not wanting to live recently due to school bullying, feeling a failure - so have been more tearful recently whilst I try to make more time for my older son.*
- *Socially isolated exhausted mentally drained*
- *Depression, anxiety, feelings of isolation, left out, no life other than my sons needs*
- *Worried sad who will look after them*
- *Stress, ill health, worrying all the time and tired all the time*
- *Main thing is the worries for their future who will look after them if I die.*
- *I too have physical and mental health issues*
- *Mentally Physically exhausted*
- *It is exhausting and leaves little time for me to have to myself and withy other children.*
- *Extra stress, work issues, lack of support from family/friends*
- *Effects a lot*
- *I dont have alot of free time i have to do all her banking and checking of everything but its manageable*
- *Hits hard, you feel alone and feel that you are always judged*
- *Does not get time to myself*
- *It's a struggle and not much support*
- *Profoundly disadvantages me. Socially, economically, health wise...*
- *I don't have any childcare support around me. The childcare on offer is non existent for send children. What is on offer is unsuitable. Sorting childcare stresses me out when I am working. Carers allowance is a pittance. It means I can't have the career I want. Employer expectations do not consider caring for send children. The lack of support in general we get impacts us all. My 10 year old without needs suffers*

mentally. My 19 year old can't look after herself, there is nothing out there that helps her to achieve independence for young people who are reasonably intelligent. It is assumed intelligence and independence are linked when they are not. My 5 year old had to wait a year before getting an OT appointment which meant I had to give up my job to be able to support him.

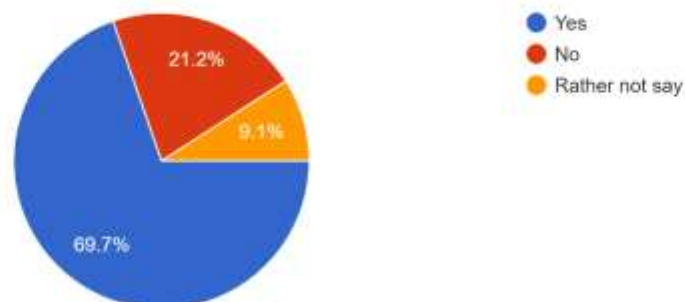
- It affects every element of life. I cannot work. Emotionally and physically, it is very difficult. We have spent a lot building an annex to move my parents in for extra support

Please read the following statements and rate how being carers affect you.



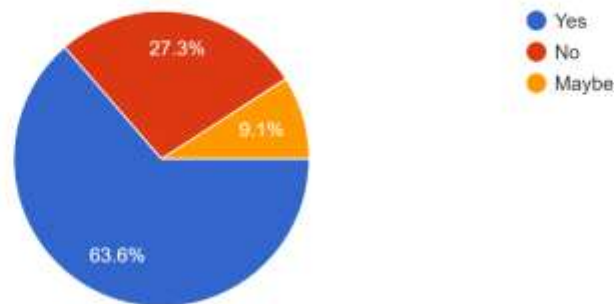
Have you experienced financial difficulties in the past 3 months?

33 responses



Are you aware of any other parent carers in your community?

33 responses

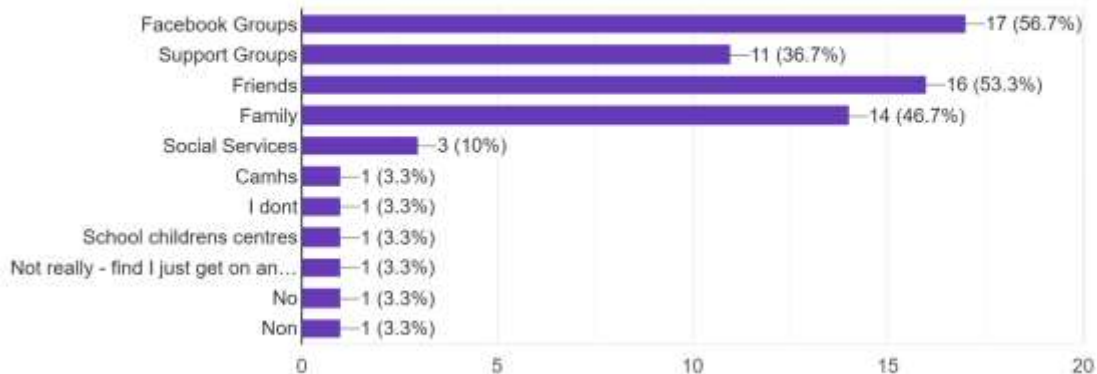


What additional support do you as a parent carer believe you may require?

- None
- *help with understanding my sons needs*
- *More clubs for special needs*
- *Adulthood prepare*
- *Friend circle ,community circle*
- *For my additional needs son to have somewhere to go, so I can have some rest and space to be with my older son.*
- *social events*
- *A break or some respite to allow my other children quality time*
- *Gave up asking.*
- *Help with legal aid information my rights*
- *Activity*
- *Clear Guidance as to what help is available*
- *A listening ear someone who can just listen to my worries.*
- *Hone calls papers benefits help I'm only one person*
- *Social*
- *A break so i can rest and regroup mentally*
- *Help outside of family, play groups etc where he can stay on his own.*
- *More money, better childcare, better support for my child.*
- *Just the usual friends with children who understand*
- *Get help go on holiday with the children and trips*
- *Unsure*
- *Support groups in Louth Lincolnshire*
- *Social support and financial*
- *Financial support; carer's allowance is means tested and at an appallingly low rate.*
- *Education*
- *Specialised childcare. Better benefits. Job flexibility.*
- *Better financial support. Holiday care for my disabled child and social groups for both myself as a carer and my son as a young carer*

Do use any of the following to access support currently?

30 responses



Overall, the survey results confirm that parent carer resilience is affected by the demands of caring for SEND children. The impact of caring and the demands have an impact on mental health, financial security, and social support. This includes employment and social interactions.

Although majority of the respondents reported that they have contact with other parents and that they use online social media to engage with other people they also reported that the impact on their mental health is significant, particularly worry and anxiety regarding future planning.

The number of parents contacting the charity highlighting issues with accommodation, food poverty and isolation suggests that Parent carer resilience is compromised. Parent carer suggestions are in line with factors required for individuals to develop emotional resilience.

Limitations

The number of participants is small however the findings provide an overview or a snapshot of factors which effect parent carer resilience.

The information gathered can be used to develop targeted sessions for parents to develop a better understanding of how parent carer role is interlinked with parent carer burnout and therefore sessions can be used to help prevent carer burnout.

Where FVP have shared this talking point

1. FVP Website
2. FVP Social Media Channels
3. FVP E-News
4. Peterborough City Council Decision Makers

Next Steps and Areas for Consideration

1. FVP to feedback these concerns at the relevant SEND, Mental Health and Communities Boards
2. Regular updates on the progress of any FVP work and responses to any Tol to be shared with parent carers via FVP media channels.

3. Provision of further surveys and workshops/forums across all areas identified in this Tol and exploration of activities that may help build resilience.
4. LA to consider concerns/ issues/ views of parent carers and work with commissioned services to facilitate parent carer resilience building.

Timescales

1. PCC to provide a response within three months of this being presented to the SEND project board
2. This Tol to be posted on the Local Offer and FVP website within one month of production