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2016

# Parent Carer Survey



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## **Introduction**

Family Voice Peterborough (FVP) enables parent carers to act as Parent Representatives on various work streams. The Parent Representatives are parent carers who have taken part in a training course and received mentoring support to help them in learning to take part in strategic meetings in a representative capacity. When attending meetings Parent Representatives share the views of parent carers from the wider community via varying reporting methods and provide the perspective of parent carers in decision making processes.

This report provides details and results from a survey created by the lead Parent Representative for carers work. The report demonstrates parent carer views across a number of areas in relation to “carers support”. The results presented are both qualitative and quantitative in nature.

The survey was based on general concerns the lead Parent Representative had gathered when speaking to other parent carers. The survey was then shared with parent carers via social media. It provides a snapshot of the views of parent carers in Peterborough.

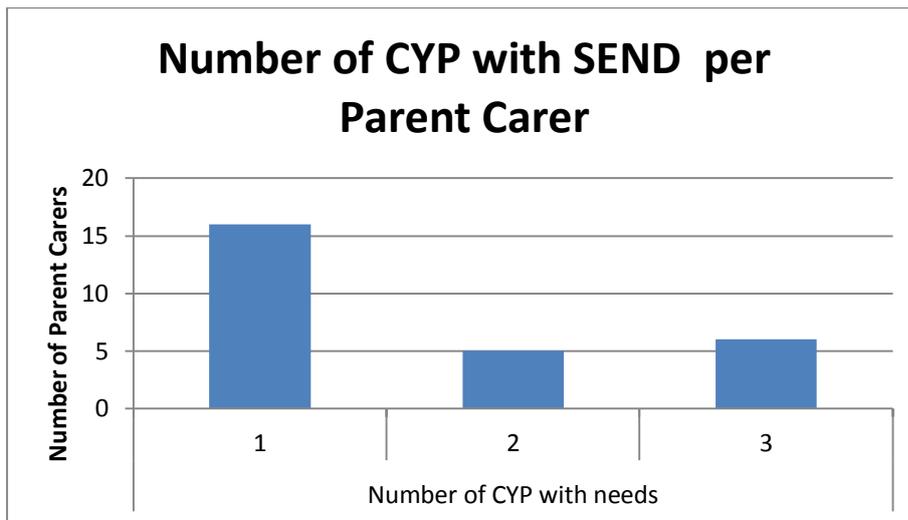
Currently Parent Carers have a right to assessment of need “*A local authority in England must, if the conditions in subsections (3) and (4) are met, assess whether a parent carer within their area has needs for support and, if so, what those needs are.*” (Children and Families Act 2014, Part 5, Sub Clause 97, p. 83) and parent carers anecdotal feel this right is not being met. This belief helped to shape the survey and some of the questions asked.

## Parent Carers and Children/ Young People Data (CYP)

27 parent carers took the survey anonymously.

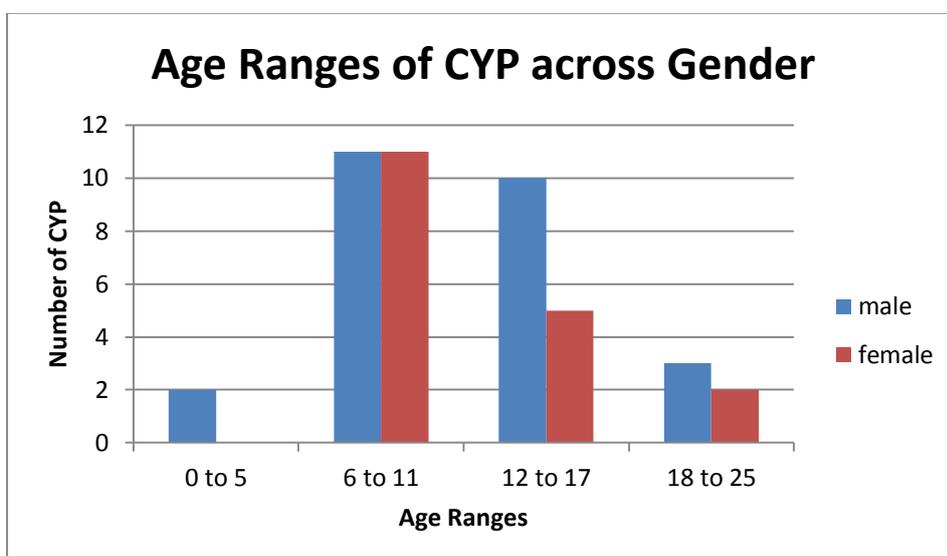
Basic details relating to the children/ young people (CYP) of the parents were captured. This data helps to demonstrate why parent carers may self-identify as carers and provide a general idea of what caring may be provided that is over and above general parenting.

Chart 1



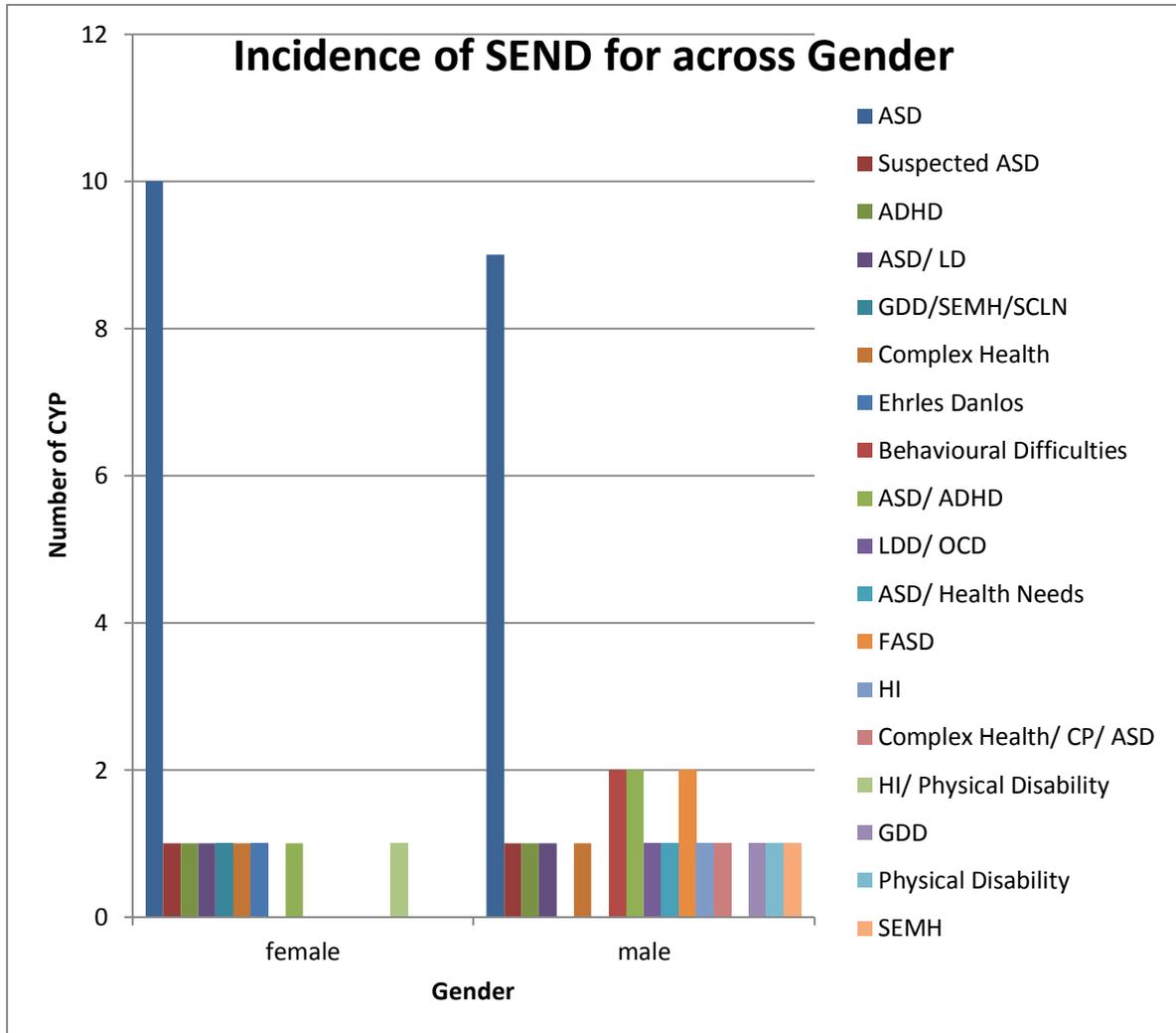
The parent carers had the opportunity to provide details of how many CYP they had with Special Educational Needs and Disabilities (SEND). 16 parent carers reported have only one CYP with SEND and six parent carers reported having three CYP with SEND. In total details of 44 CYP with SEND were provided.

Chart 2



The most frequent age range (modal class) is 6 to 11. This is also the same for male CYP and Female CYP when looked at separately. There were more male CYP than Female CYP in all other age groups.

Chart 3



The most frequent SEND (modal class) reported was ASD across all CYP and for male and female CYP separately. Many parent carers recorded multiple needs so to be able to ascertain the frequency of different SEND a basic coding was applied to cluster SEND according to the primary or first reported.

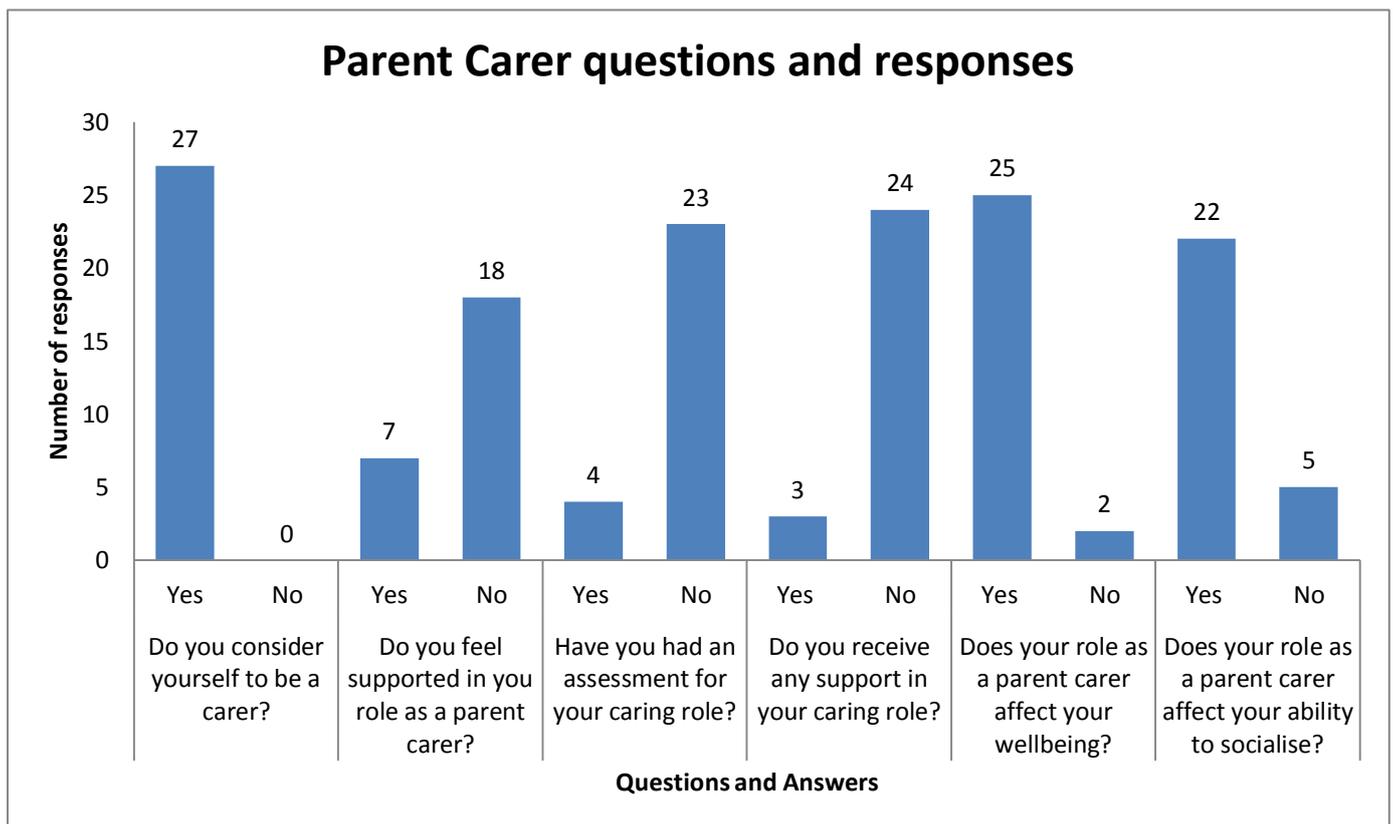
## Questions

There were a range of closed and open questions asked and an open comments box at the end of the survey. Some of the closed questions were followed by open comments options

1. Do you consider yourself to be a carer?
2. Do you feel supported in you role as a parent carer?
3. Have you had an assessment for your caring role?
4. Do you receive any support in your caring role?
5. Do you know what support if any is available?
6. What support if any do you feel you need as a parent carer?
7. Does your role as a parent carer affect your wellbeing?
8. Does your role as a parent carer affect your ability to socialise?

## Results

Chart 4



100% of the parent carers who took the survey defined themselves as a carer and two expanded on this further with comments that qualified their view point

1. *I translate the world for my daughter and keep her safe and on track, as details don't stay in her mind.*
2. *I am the mother of a child with autism and other co morbid.*

3. *Supporting and encouraging socially, personal care, emotional well-being, medical support and safety in and out of home*
4. *Yes as I have to do more than what a "normal" parent would do. Sit up and watch over my son though the night to make sure he is safe.*

When asked if parent carers felt supported in their role only 7 said yes. Some of the parent carers went on to provide comments in answer to this question

Answers where parent carers said they received support

1. *I feel supported as best as I can with school and some of the groups that we are involved with*
2. *I feel supported because I have Family Voice and my sons school if I have any issues with my sons needs*
3. *Only from close family and friends network and FVP, PCVS and Carers Trust*
4. *I access Little Miracles and have participated in parenting courses and autism workshops. LM is a very important place for me and many other parents with children with additional needs. The knowledge of other parent carers is invaluable and the support we give each other necessary.*
5. *Because if I have an issue I can speak to other parents who might have been in the same predicament*
6. *Don't get much support partt from local charity*
7. *We have respite and LINK care in place but we do find we have to chase the social worker*

Where parents answered that they did not receive support they provided comments such as follows:

1. *Fed up doing the LA job and policing my sons Provision, adding more stress to an already difficult family life.*
2. *I am a single parent of three children with additional needs. I receive no help what so ever from anyone*
3. *I now have mental health problems which in turn have an effect on my role as a carer*
4. *No health or mental health input apart from hearing and visual loss .*
5. *I have had very little support from the lea, social services even after requests for help. I find i have to do chasing up for them to do anything and what they do manage to do os inconsistent and usually ends with broken promises or refusal or just dont bother to do amything.*
6. *I have not gone to any carers activities with the exception of the cinema once about 4 yrs ago, which was brilliant.*
7. *Completely alone and isolated*
8. *I have had a carers assessment done nearly a year ago and still I haven't had a single reply. So I wonder why I bothered to do it in the first place*

*No I feel that with both kids I've been left to deal with it all by myself and sometimes feel alone.*

9. *There is not a lot of help from the authority's in regards to either of my child's needs conditions, we have to learn and deal with it as we go along.*
10. *You have to fight to get any help from the NHS and LA*
11. *I have no help what so ever.*
12. *I have to do all of it my own never rid of of the pressure and never switch off*

Only 4 parent carers said they had ever had a carers assessment and when asked what the outcome was one said they had “*direct payments*” and another said “*None. Since I filled in the assessment form I haven't got any reply back.*”

When asked “Do you know what support is available if any?” 14 parent carers said no, and five said yes however none of them expanded on this. One parent carer provided the following “*I've regularly been told to look on the local offer but the site is complicated and difficult to use with little information about the offers... rough costs, how to access these things.. and even after emailing some of local offer items... they never responded*”

Parent Carers were also asked “What support if any do you feel you need as a parent carer?” and some provided the following answers:

### **Support/ Emotional Support/ Respite**

1. *A shoulder to cry on would be nice. The cinema was memorable. An exotic holiday? Ok I am dreaming...*
2. *Support when at my wits end. Maybe an hour break once in a while.*
3. *Time off for me and seperate time off for my children... time to recuperate and reconnect oportunities for older children to get outings with a supporter. Preparing my teens for the future and getting things sorted. Child care for a teen unable to be left alone but is a flight risk to enable me to work again.*
4. *I need a break.*
5. *A bit of time out*
6. *Someone to talk to when it all becomes too much*
7. *Help with anxiety and respite*
8. *Time to have time for myself. To be able to just have a break*

### **Activities**

1. *More support in the holidays in terms of more places for my son to go. Many play schemes won't take him because he isn't 'disabled enough'*
2. *Support and activities during the school holidays and weekends suitable for my child specific needs. Help with children with disabilities to take them out*

3. *Maybe what is out their during school holidays*

### **Knowledge**

1. *help for siblings to understand the disabilities of the other sibling*
2. *Just what happens to my child if he doesn't go to school on a regular basis*
3. *Understanding. Knowing where to go to access services and what to do when things go wrong.*
4. *Someone/ somewhere to go to be able to gain knowledge*

### **Not categorised**

1. *Quicker assessments and early intervention instead of waiting until situation hit crisis point then more in depth work needs to happen*
2. *Feel more intervention required with asd once transfer to adult*
3. *For the local health authority to offer more help would be good instead of just chucking meds at the condition and leaving you to it*
4. *For LA to provide holistic education and health care plans for children with school placements that can actually meet a child's needs and work with families. This will cause less stress for the entire family unit.*

The areas that parent carers feel they need support in based on the answers provided could be categorised as general and emotional support, activities for their children during the school holidays and knowledge.

Overwhelmingly parent carers also felt that their caring responsibilities affected their ability to socialise and wellbeing.

Finally parent carers were provided the opportunity to provide further comments and six did:

1. *Socialising is a complete no no for me really. I even don't think about it. Who would I leave her with. Carers have no life of their own*
2. *If myself and my husband want an evening off to go out at all there are only a few people that understand our children to actually be able to handle and understand them, sad but true.*
3. *As a carer by the time the kids are at school im emotionally worn out.. there is nothing left. Ibe lost my identity except that of a carer and often feel thaty life is mot my own and its over.!*
4. *Issues arising to not being able to work due to no care facilities for teenagers*
5. *I hardly ever go out as my daughter gets worried. She is with me 24/7. She has a little 18 month daughter who also lives with me.*
6. *How do we find out what is out there in ways of support. Look on the local offer. That's a big fat joke in itself!*

## **Analysis**

Although the sample represented in this survey is small the results still support the view that parent carers feel unsupported. The qualitative responses from the survey demonstrate that parent carers feel their wellbeing is affected and that their caring responsibilities impact on their lives. Support is required in areas best categorised as emotional support/ respite, knowledge and school holiday activities.

The majority of the parent carers who took the survey have one or more children with ASD although a small number of parent carers who took the survey did report having children with complex health needs. Interestingly the majority of parent carers who took the survey stated that they have children aged between 6 and 11 and these parent carers reported feeling unsupported.

This report is not intended to draw conclusions or make correlations of any kind between feelings of a lack of support and the needs of children self-reported. The report simply provides details on the results of the survey.

## **Recommendations**

1. The LA takes on the board the results and provide a response and incorporate the results in planning of services for carers.
2. This report be followed up where possible by some more in-depth discussions/ focus groups with parent carers