

# Topic of Importance – Early Help, Support and Carers Wellbeing

Early Help, Early Support and Carers wellbeing and support are linked for parent carers far more than the SEND system locally accounts for; services relating to Early Help and Early Support are delivered by different teams and for different age groups birth to 5 and over 5 although they do have a similar aim in relation to CYP with SEND; Providing help and support as early as possible to help achieve good outcomes. On the Local Offer<sup>1</sup> The following is provided in terms of explaining Early Help and Early Support

## Early Help

The term Early Help is used to describe the process of taking action early and as soon as possible to tackle problems and issues emerging for children, young people and their families. Effective help may be needed for at any point in a child or young person's life.

## Early Support

Early Support in Peterborough is a pathway for children in their pre-school years with complex health, education, or care needs. These children will require considerable ongoing support from across education, health and care. This includes:

- children who have great difficulty with communication
- children who have sensory or physical difficulties
- children who have complex health needs

From a parent carers perspective support can be required at any age of their child(ren) with SEND and for any number of reasons. Also parent carers generally do not know about the difference in services, they just experience lived differences. In the Local Area SEND Inspection report<sup>2</sup> presented to the Local Authority it was reported that “*Early support is well embedded for children in early years, but does not follow through in all areas of the lives of children and young people as they get older. It takes too long for children, young people and families to get the support they need.*” And although not detailed in the report the forum have detailed on a number of occasions concerns over the use of Early Support term locally which is at an incongruence with how the term is used nationally, even in the SEND CoP 2015<sup>3</sup> - **Early Support Programme:** The Early Support Programme co-ordinates health, education and social care support for the parents and carers of disabled children and young people from birth to adulthood.

Further to this Chapter 2, p. 35 of the SEND CoP 2015 is more explicit about the type of support Local Authorities should provide:

**2.21** Local authorities should adopt a key working approach, which provides children, young people and parents with a single point of

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<sup>1</sup> [https://fis.peterborough.gov.uk/kb5/peterborough/directory/localoffer.page?familychannel=8-](https://fis.peterborough.gov.uk/kb5/peterborough/directory/localoffer.page?familychannel=8-1&loboolean=1)

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<sup>2</sup>

[https://search3.openobjects.com/mediamanager/peterborough/fsd/files/final\\_send\\_inspection\\_letter\\_pcc.pdf](https://search3.openobjects.com/mediamanager/peterborough/fsd/files/final_send_inspection_letter_pcc.pdf)

<sup>3</sup>

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/398815/SEND\\_Code\\_of\\_Practice\\_January\\_2015.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/398815/SEND_Code_of_Practice_January_2015.pdf)

contact to help ensure the holistic provision and co-ordination of services and support. Key working may be provided by statutory services in health, social care and education, or by the voluntary, community, private or independent sectors. Key working can be offered to any family where children and young people have SEN or disabilities, for example if they receive SEN support in schools or nurseries or in preparing for adulthood.

Approaches will vary locally, but the main functions of key working support should include some or all of the following:

- emotional and practical support as part of a trusting relationship
- enabling and empowering for decision-making and the use of Personal Budgets
- co-ordinating practitioners and services around the child or young person and their family
- being a single point of regular and consistent contact
- facilitating multi-agency meetings
- supporting and facilitating a single planning and joint assessment process
- identifying strengths and needs of family members
- providing information and signposting
- advocating on behalf of the child, young person and/or their family
- facilitating the seamless integration of clinical and social care services with
- specialist and universal services

## **What are parents telling us?**

Through three surveys, Facebook chatroom discussion/ Polls and contact for signposting parent carers are telling us overwhelmingly that they feel isolated, tired and unable to cope. This also follows on from our annual report in which we presented a range of evidence pointing towards a decrease in parent carer resilience and a desire to seek more traditional hands on forms of support. Common themes are:

1. Where support is received it makes a difference to how the parent carers cope with caring.
2. Support is good in early years but doesn't translate to other areas past early years.
3. Not enough information about where to go for help/ lack of knowledge of the Local Offer.
4. Feelings of isolation, exhaustion and in some cases sleep deprivation.
5. Seeking information to navigate the SEND system, especially in relation to EHC needs assessment applications.
6. Needing support with finances, managing CYP behaviour, accessing family based activities, emotional wellbeing,
7. Loss of community, family and friendship networks

## **Where we get our evidence from**

So far evidence has come from data gathered in survey format that was used to inform the FVP annual report; especially two surveys around Early Support and Help and Support and

also a series of questions that formed the annual survey relating to carer support and early help.<sup>4</sup>

### Early Support

17 Parent carers completed the survey and they reported their CYP details as:

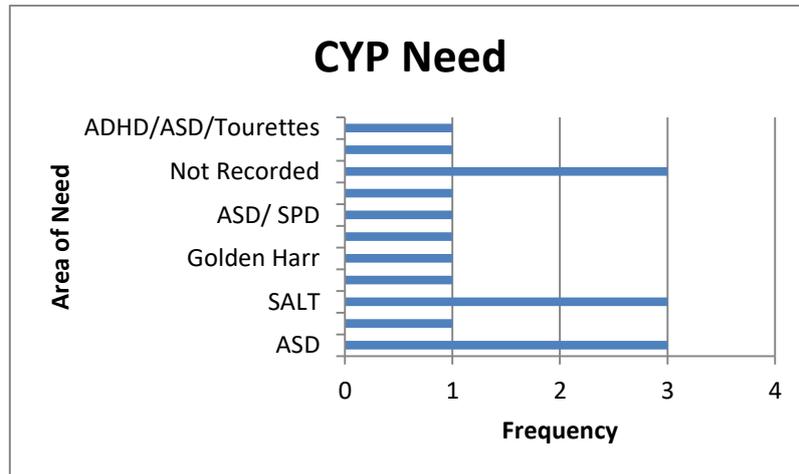


Fig. 1 CYP Needs

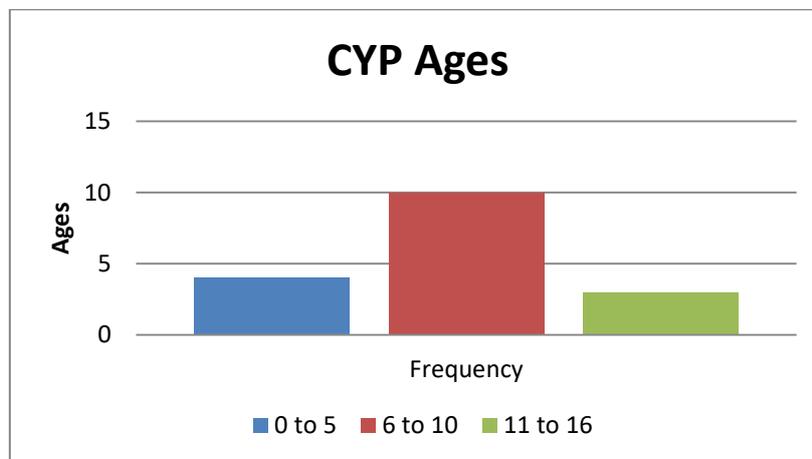
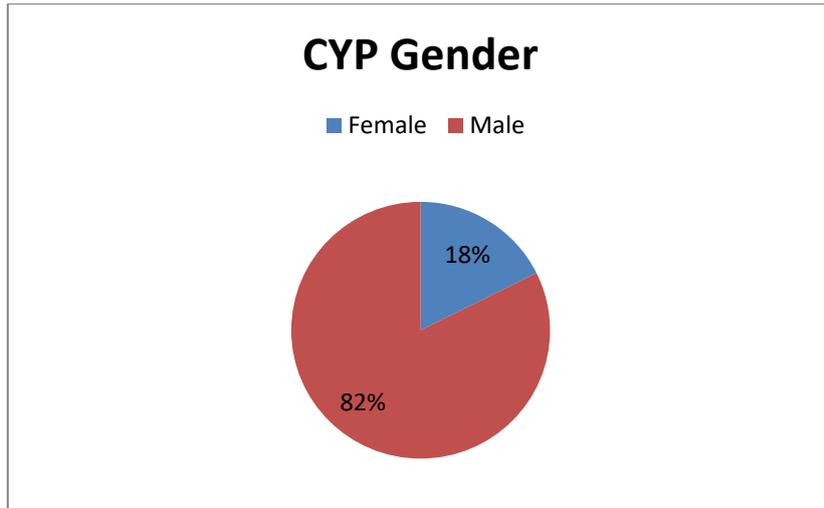
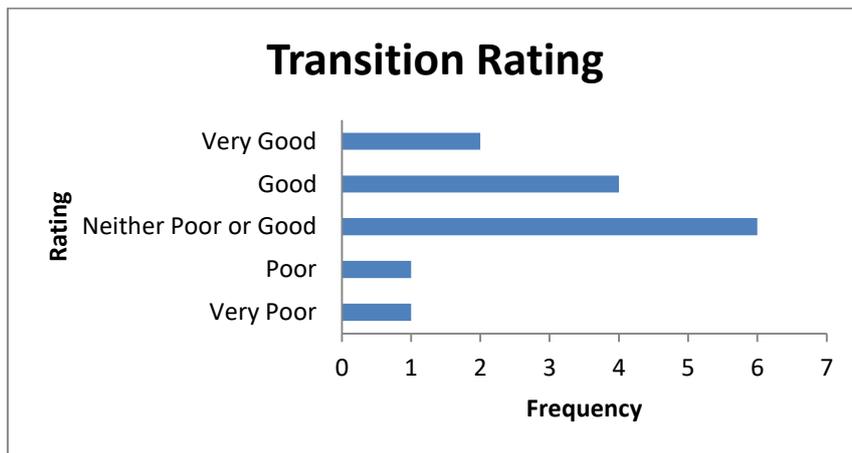


Fig. 2 CYP Ages



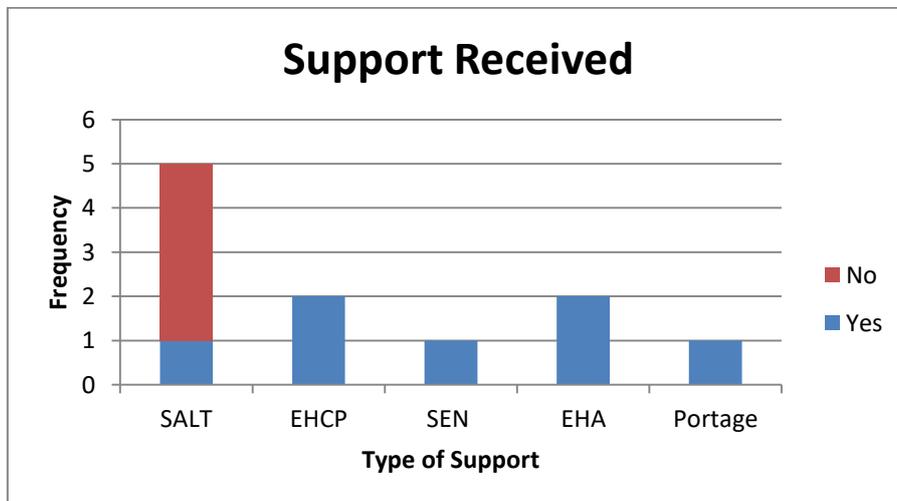
**Fig. 3 CYP Gender**

Of those who completed the survey 82% had CYP who had already transitioned from Early Years to Primary or over. When asked to rate their transition from early years more parent carers rated their transition as good or very good compared to poor or very poor.



**Fig. 4 Rating of Transition from Early Years**

11 of the parent carers stated that their CYP had received support either during or past early years.



**Fig. 5 Frequency of support received after early years**

## General Comments from parent carers

Help with getting an ehcp if needed before transition if possible and any transition to include all diagnosis and areas needed to support individual to their best ability like a personal journal of the individual would be fab in order to ensure smooth transition or this is me folder with everything in

All was really good and I like all help what he received.

My child hasn't had any support I've been fighting for some for a while his teacher is great and understands but the sendco is useless

I feel .....should of had a health plan put into place before he went to primary school

Earlier intervention with her needs being picked up in nursery and the relevant support being put in place for her at primary school. Rather than the long battle we have had to get her diagnosis which has taken since 2017 till 2021.

All was really good and helpful.

He had an icp in primary...but with no diagnosis at the time there was little help

All what teachers done made easy for him.

Earlier and quicker ehcp

Early intervention works. Salt and OT support too hard to come by.

Help for parent Carers to be kept in loop on how preschool school are supporting our young

My son has deiculty in alot ways his still in nappies, and finds genral stuff hard

Signposted to charities I had to find them for myself

Help and Support

16 parent carers completed the survey and they reported their CYP needs as:

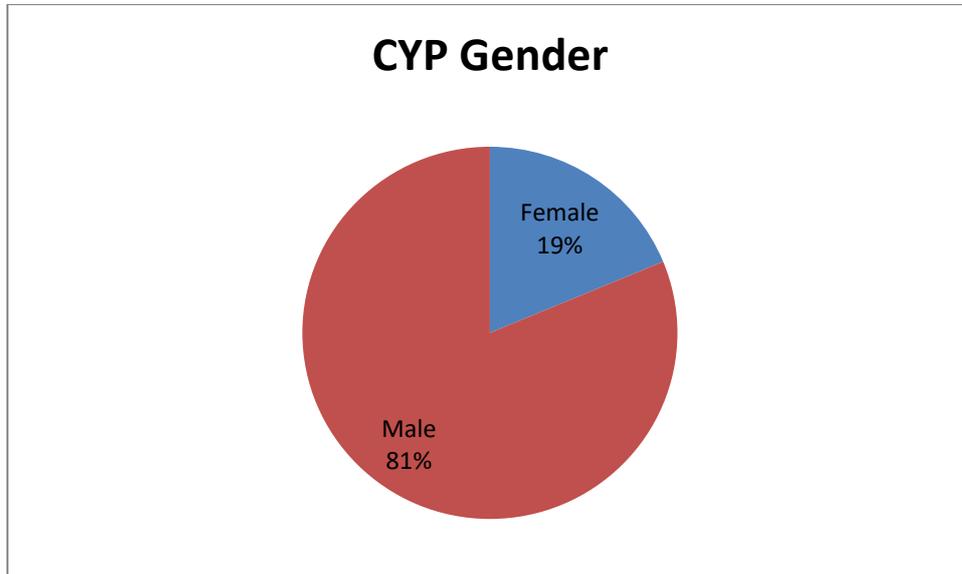


Fig. 6 CYP Gender – Help and Support

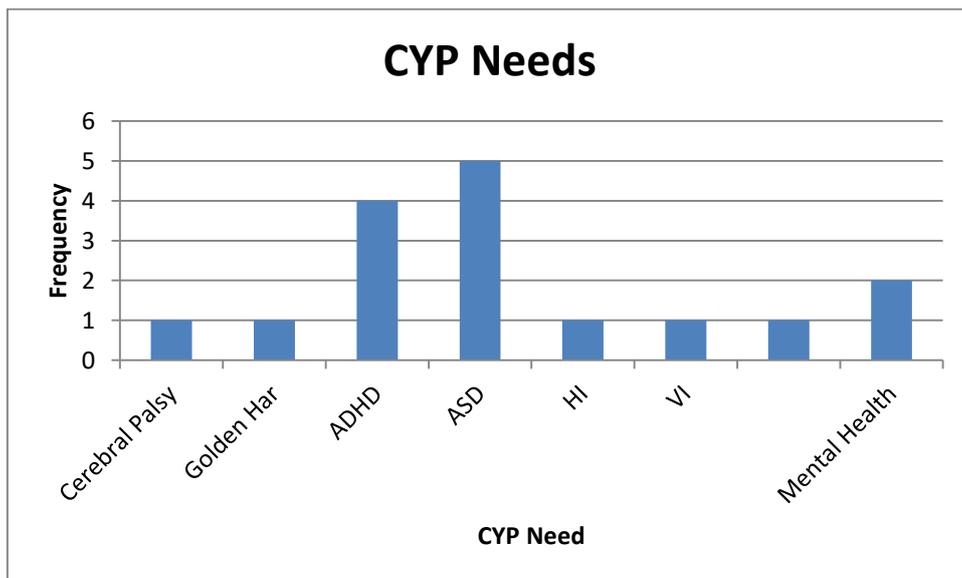
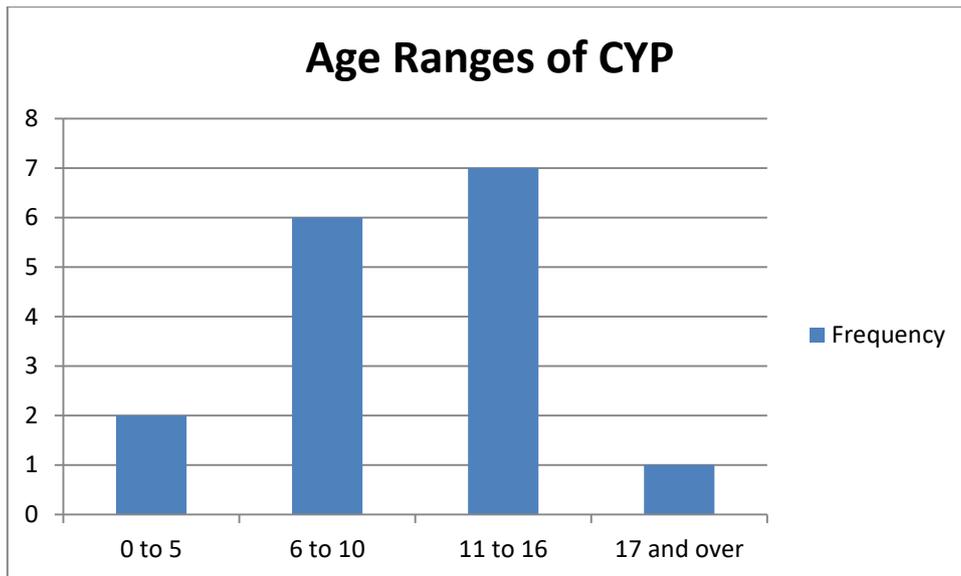
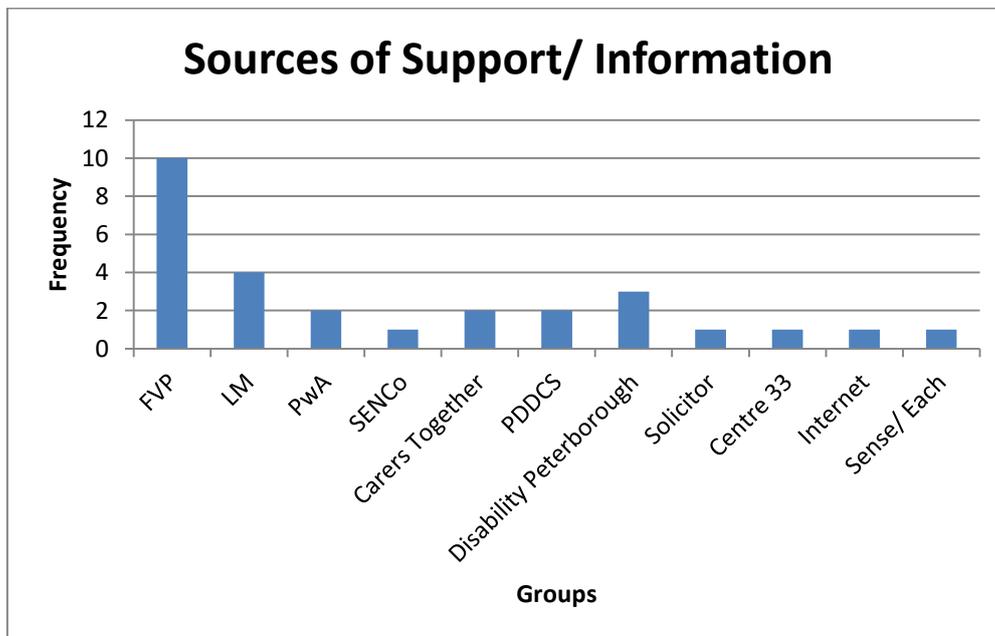


Fig. 7 CYP Needs – Help and Support



**Fig. 8 Age Ranges – Help and Support**



**Fig. 9 Sources of Support and Information for Parent Carers**

Support Required	Frequency
Emotional Support	12
Legal Advice	2
Advice relating to your child/ young persons education	5
Assistance with filling in forms	6
Help with EHCp needs assessment applications	4
Advocacy	2
Peer to Peer Support	3
Benefit Applications	1

**Fig. 10 Frequency of Types of Support Sought by Parent Carers**

Comments expanding on sources of support

<b>Support being looked for</b>
I needed advice about early help and my child's education. I received very good advice from someone at family voice.
Emotional support
Help with my child at school, help with filling in forms for EHCP and phone calls support for mediation and medical appointments
Help with food and essentials during Covid pandemic
General support throughout pandemic through to help with food and emotional support people just checking in to see how we are doing
Advice about transition to secondary school
Advice on what i can ask for in an ehcp. someone to talk to during pandemic and activities for home
Benefit forms are very convoluted and unnecessarily complicated, especially as you have to be careful how you word your answers so they can't be twisted and used against you!
Information about Tommy transition to secondary school and help and support services through covid
Just general advice and support
At current moment I am looking for support in making my garden accessible for my daughter, so she is able to enjoy the outside space. I also feel, I need to meet other parents who care for children with physical disabilities. I have previously asked for support for taking my daughter on holiday

## What Parents about how providing care impacts on their lives

It is a daily struggle. It's harder to do the easier day to day things when you have a child with SEND. It impacts the whole family and affects everyone's mental health.

Occupies all free time for family.

Feel isolated, alone and sometimes very anxious

We feel totally isolated at times and alone with it all as their behaviours are not accepted by many in society and we feel safer to just keep ourselves to ourselves so we don't get hurt or let down like we have in the past by so called family or friends

You often feel isolated and alone affecting our own mental health but when we realize we have others around us who are in the same situation we try and support one another acting like family to each other

it means we have to research everywhere we go beforehand to check we can change my son and wheelchair friendly. Rarely get time with my husband away from children as no one else can look after our son at present. disturbed sleep, lots of forms and appointments. difficult emotionally.

Being so busy and not having enough hrs in the day for yourself

Emotionally you feel like you need a break especially when you have a few children with additional needs. It's also hard physically you feel exhausted & mentally drained & you feel like you can't connect with the 'perfect neurotypical'

Leaves you lonely, always feeling like you have to fight to defend their needs. A most of all an emotional mess.

Find it very isolating and can't always plan to do anything with friends due to .....having lots of hospital appointments

It makes life a bit more difficult, each day brings its own challenges and a lot more time is needed on my daughter to support her with

I have spent the last 16 years of my life not working so I can be a stay at home parent and carer and to be available at all times for my son and his school needs and other needs over the years

Raising my daughter, has at times left me feeling guilty for my other children as well as isolated from other families. I have avoided going on days out due to worrying about the struggles it may bring for myself and my daughter.

## How have FVP responded

FVP developed and ran a third survey relating to Carer Support and four Facebook Polls of a similar topic.

### Facebook Polls

Early Help/ Early Support General Awareness

Poll Option	Response Rate
I Know What Early Support Is	5
I Know What Early Help Is	3
I Do Not Know What Early Support Is	1
I Do Not Know What Early Help Is	1

Has Your Caring Responsibility Affected Your Mental Health

Poll Option	Response Rate
It has affected my personal relationships	13
Most days I feel stressed	12
I don't eat well	11
I sleep less	11
I am anxious	9
I am sleep deprived	9
Most days I feel in a low mood	9
It has affected my financial situation	7
I feel socially isolated	6

As a parent I

Poll Option	Response Rate
I make sure my child has clean clothes	14
I take my child to the GP when they are unwell	13
I make sure my child attends school	12
I drive my child to activities like football	7

As a Care I

Poll Option	Response Rate
I have developed an understanding of behaviour (challenging and otherwise)	9
I monitor my child's diet	8
I organise my day around my child's needs	8
I attend my child's hospital appointments	7
Manage family finances	7
I have to be assisting/ supervising my child at all times	6
I attend EHCp/ Child in Need Meetings	5
I spend my time supporting my young person to prepare for adulthood	4

I spend a lot of time appealing decisions	3
Organising hospital appointments/ time management	3
I provide personal care for my young person	2
I have developed a better understanding of benefits	2
I have to find staff for my child	1

Following from the Polls about what a parent and carer mean/ do a conversation ensued between 4 parents

**Parent 1** - The attitude of "if you can do those things then you as a parent/family unit are not struggling" needs to change. The amount of times I've heard this makes me not even bother to ask for help any more as it then becomes a 'thing' that is brought up time and again!

**Parent 2** - I totally agree, I have found that the wider system including health and social care have a limited understanding of how different the Parent Carer role is and how this impacts the individuals mental state. Often leading to safeguarding processes (unintentional neglect etc etc) when actually it's the parents mental health which is deteriorating. If identified early enough and with the right support in place I am pretty certain that a lot of distress, anxiety and harm to the family can be prevented.

**Parent 1** - I used to work in NHS learning disability services and during my youngest child's diagnosis process I met with former colleagues and other therapists I'd worked with and their attitude was you used to do this why are you here - it's different as a parent!

**Parent 3** - Totally agree with this, the amount of times I've reached out for help and been fobbed off (especially during home schooling times) just meant I stopped asking!

**Parent 2** - I can only echo your experience, but I trained as a nurse in my later years. Professionals (social workers, nurses , GP, teachers) appear to assume that parenting a disabled child is the same as parenting a typically developing child, it isn't! the impact on parental mental health is totally different to any other mental illness. Anxiety, guilt, sadness, depression, lack of sleep, poor diet, no time recharge the battery, poor quality of social interactions, worries about money all contribute towards mental illness, in addition to dealing with a broad range of professional approaches which generally speaking are rather paternalistic and at times quite judgmental.

**Parent 3** - As a mum of 5 children, 2 with additional needs I can 100% say that parenting a neurotypical child is totally different to parenting a child with additional needs/autism/disabilities the roles are totally different as a parent! 😊

**Parent 2** - Did the change of role affect your mental wellbeing more so that than the worry and stress of typical parenting?

**Parent 3** - yes I think so, it affects anyone with this role in my opinion, the stress and worry of caring for 2 additional needs children is far greater then the stress and worry of parenting my neurotypical children, my 2 with additional needs need someone constantly there to help them with day to day tasks, my oldest additional needs child is almost 16 and can't cross a road safely 😊👧👦👧👦 not through lack of trying! They wake through the night, my daughter with additional needs has to be helped to wash, brush teeth, get dressed and doesn't sleep

etc etc .... I'm lucky if I get 4-5hrs sleep a night, my 6 year old however who is neurotypical can do all these things independently, and don't even get me started on homeschooling on and off for a year .... I'll have to find a loop hole for them to be in school if we end up in another lockdown 😊 or I might have a breakdown ☐🗉☐

**Parent 2** - Goodness sounds a like busy household! 😊 do you feel that the professionals working with you have considered the impact of parent carer role on your wellbeing?

**Parent 3** in all honesty I don't have any professionals working with me/us (apart from those at their schools).....sometimes being a parent/parents of additional needs children can feel quite isolating tbh as I feel that once we were given their diagnosis we were set free to get on with it as such

**Parent 4** - I would like to add that social isolation has impact on parental well being. During early socialisation -going to playgroups , having play dates etc - some children with additional needs struggle with the sensory environment of some groups . The child can become overwhelmed and distressed , this can become distressing for the parent and eventually some parents will avoid groups therefore reducing social support.

Due to the high level of supervision and care needs of their children often coupled with childrens sleep difficulties can mean that some parents are unable to safely have a shower /bath ,self care when they would like too.

### Carers Survey

46 parent carers took the survey from a range of back grounds and with CYP with a range of needs. As with previous surveys the generally parent carers who completed the survey are "White British" and have CYP with "ASD", although more parents who have CYP with other needs have also taken the survey compared to in previous years; needs such as Cerebral Palsy, HI, VI, Physical Disability and Complex Health needs. It is also worth noting here that there a growing number of parents who lists their CYP needs as multiple, including HI and ASD for example.

The survey although used to capture some quantitative data primarily focussed on open questions to statements/ questions allowing for more scope for parent carers to share their views. The statements were:

How do you believe that caring for a child/young person with SEND affects you?

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

Where do you go for support currently?

What is your first point of call for support?

What do you find most useful?

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

What type of support of you found the most useful?

Some broad comments were:

Makes you lonely, angry afraid no one listens always judged
Tired all the time, juggling hospital appointments, surgeries, sensory needs with another 2 children to cater for. It's emotional, physically and financially exhausting
Lonely isolated exhausting

Always busy, cannot put my needs first, have to advocate for my child. Have to fight on behalf of my child. Everything feels like a fight.
Isolated, drained
Having to constantly fight to be heard and for accessible education increases anxiety and feels like you're under so much more pressure as I'm my son's voice and want to get it right for him.
suffocated sometimes by the pressure. No downtime or activities for me in the hours I don't have him because I have no money for myself it all goes on my son. So a lot of tears and feeling sad.
Challenging, tired, physically challenging
Limited help available - feel no one understands
It makes simple daily tasks a challenge.
Physically, mentally and emotionally drains myself and my family. Our daily lives aren't the same as a normal family so much more thought and stress go into simple tasks, constantly feeling like I'm at risk accessing every single thing. And my other children miss out due to my daughter's challenges
Constant supervision means no rest
Had to leave work to be full-time carer, also not able to leave my child for longer periods of time.
Not as much as it used to now I'm used to I get on with it however accessing services for him is difficult
I am not able to plan anything
Stress and worried for the future
That my time is devoted a lot to my son's needs. My off days are devoted to meetings and appointments regarding my son, some days feel emotionally drained.
I have left my long career to provide for my son. He hasn't attended school in 18 months and his mental health declined. Which has a huge impact on him and family dynamics, physically, mentally and financially.
Isolates us as we don't have a usual 9-5 working career unfortunately due to caring for our young person
Struggle to understand how to help from and where to get best support for him from
Mentally draining, never get a break
It is very difficult to hold down a job - holding within a fine thread, hardly any help from social services. Disability social workers contact you when they want to tick a box exercise. But no help when you need it!!!
Stressing, hard
The pressure can be really hard having two children with special needs it is hard work trying to balance both their needs, my son is diagnosed but I can't get my daughter taken seriously it is so frustrating she displays very similar to my son has meltdowns etc etc but can't get anywhere
It affects every aspect of our daily lives
It affected you in all possible ways, lack of sleep has given me a heart problem
It affects you a lot due to lack of sleep I have a heart condition and mental health problems
Permanent elevated level of stress, significant time expenditure chasing appointments and responses to letters. Significant expenditure on things to benefit our child

Massively, I work full-time and struggle for childcare due to her behaviours she presents. It upsets the home regularly. I'm exhausted as she doesn't sleep more than 2-3 hours a night and for safety reasons I need to be awake with her.
It can become quite stuff but I have a strong support network
Not sure
Isolation, anxiety, has a big strain on your well being
It puts pressure on whatever you have to do in life. My problem is wjo to trust to leave with her so basically i do not go anywhere with her as i feel peopke would not understand her needs as i do. I worry a lot about her vulnerability
I have to be available for everything like college work cooking bathing etc and explaining things so its 24 hour needs at times it makes things hard to do things personally as i have to be available there is no one else who understands her needs etc apart from her step dad so for me it can be very stressful as i am the one to deal with everything and meltdowns
Isolated
Stressful
Burn out, fatigue, my mental health, being able to take care of myself so I can care for them
Mentally it's hard watching a child in pain and the dressings take up a lot of time and are distressing
Find it difficult to cope with mood changes on my own

The full survey report will be shared on our website [www.familyvoice.org](http://www.familyvoice.org)

## 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. Early Help to look at what works in Early Support and see where this can be mirrored
2. PCC to consider options for implementing time bound initiatives such as the independent support programme which was used at the start of the reforms
3. PCC to explore befriending initiatives/ Peer to Peer support initiatives
4. PCC to explore use of webinars/ guides/ vlogs/ group training sessions to provide hints/ tips/ signposting for areas relating to benefit applications for example.

## Timescales

1. This ToI will be presented to the SEND Partnership on 6<sup>th</sup> July
2. PCC to respond within one month
3. This ToI to be posted on the Local Offer and FVP website within one month of production

