

for children and young people with disabilities and additional needs

Introduction

The idea behind this work is to support the Co-production of the 0- 25 service as this is coming up To be re – commissioned, so in accordance with the children and families act 2014 FVP will be looking at the impact and asking the opinions from Service users in order to support positive change. This will be delivered by breaking this down into three main areas that we could look at.

- 1 being communities
- 2 being Respite and overnight care
- 3 being the personalizing and including direct payments

The aim is to Facilitate this over a three week time frame in which FVP will look at the service form the Service users Prospective, which will be collated by and facilitating workshops and focus group and FVP using our social media page. All the information collected will be feed in to the commissioning Team which will shape and design this service going for would.

Update week 1

The scope of families and the services they used

They had use were part of the short breaks offer and there for were not able to answer **question one.**FVP started by ring families and asking some individuals face to face about the services they use and what they think? In addition to this as part two we also used social media were we had discussions in the chat room **Results part two – social media**

FVP posted on social media this week's questions which were seen by 124 individuals. 7 individual's active participants in this conversation.

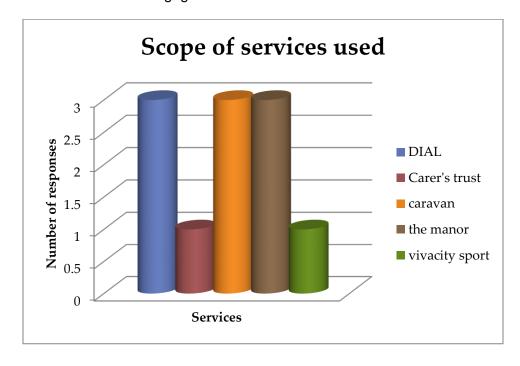
We used the same questions as a discussion point that we had facilitate in part one

However at the beginning of the conversation there seemed to be some confusion as to what short breaks are and its name and meaning.

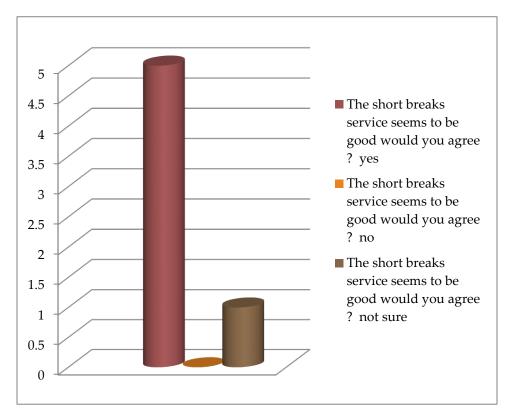
Interestingly there were three individuals that had used at least one form of short break services however two of them had not realized that the service

The scope of services accessed Part one and part two

For this week's questions the individuals that we spoke to use a number of services on a regular basis including – the Manor, Vivacity sports, Carer's trust, DIAL, FVP – caravan's Results Part one – engagement



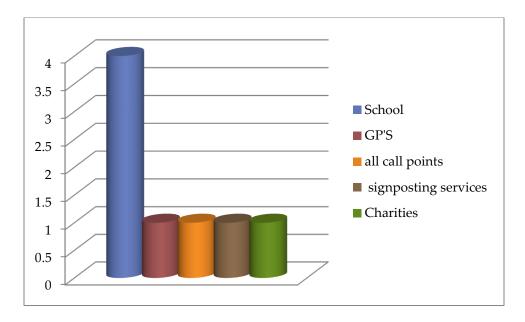
The questions for week one that the local authority and Family voice Peterborough were asked to feedback on week one)



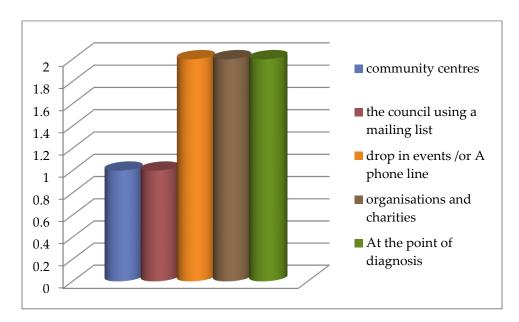
1) The quality of the Short Breaks offer is generally seen as good; is that right?

2) Knowledge of the services available could be improved; in addition to Peterborough City Council's Local Offer, where should Peterborough's Short Breaks offer be seen or advertised?

Part one – group engagement



Part two - social media



Social media conversation – green FVP staff, yellow – parent / career views, turquoise – trustee The quality of the Short Breaks offer is generally seen as good; is that right? Knowledge of the services available could be improved; in addition to Peterborough City Council's Local Offer, where should Peterborough's Short Breaks offer be seen or advertised?

The short break service is terrible for a 22 year old. The is no choice if there is only one place (Lyons gardens)

Please confirm what short breaks service is available and age range.

Just out of curiosity what is available to adults? I say this because this Friday my we have paid for my father to go to Park House, in Sandringham. It's a bloody fortune!!

For adults only lyons gardens. We have to do what your doing 🕒 x

More needs to be done for adults to!!!

I was told there were no future plans to put this right even tho they are aware of the problem x

What the hell who told you that

My sons social worker

Not good enough who strives to improve services for adults do we know?

I agree it's not good enough. Are family voice addressing this at all?

I don't know but the mood I'm in I feel like chaining myself to Bayard Place!!

Would be with you chained by your side

Hi yeah we are addressing this but the short break service we are discussing here is 0 to 19 only x

I was told it was being addressed 5years ago. Lyons gardens starts at 18

Hi I going to try and upload the current services that are available if I cannot do this I will get it put up tomorrow in the chat room hope this will help:)

So what about the adults who deals with this

Looks like we will have to chain ourselves to the bike racks outside Bayard

Looks that way. I'm sure if enough of us did (not forgetting to invite the ET) they would have to talk to us. It doesn't help that our MP Stewart Jackson has an appalling record for voting against us, not with us

Hi I'm not sure but I will ask for you smile emoticon

Although I'm fighting other battles in different counties I agree 100% my mum and dad live in Peterborough and I lived here as a child so I too want what is right

Hi anything for adult social care needs to go to either adult social care at Peterborough city council or carers trust

We welcome everyone's views so please join in the conversation

I don't know anything about this Hun...I haven't seen or heard anything x

I'm the same haven't seen or heard anything about it before

if you haven't heard about Short Breaks...previously called Respite...or how to or where to get time away with the family then we need to know so information can be more widespread and available.

If you wanted help with a holiday or a day out and wouldn't know how to access then others might not.

So would you mind answering the questions so we can update PCC please

Yeah that's fine...heard of respite but never used it...have no idea how to access it either Hun

Leisure events and caravans available for short breaks. It should have its own heading/click which then parents can see what's available

Respite/short breaks I'm also not aware of.we have 9 children (2 have disabilities).We don't have babysitters or any practical help....any info would be great.

Can i follow this as wasnt aware how u apply ect

Of course huni, need as many voices as possible..What are your views or knowledge of the questions?

There is a lot of parents I know who don't use the internet and wouldn't even be aware anything is available. They also won't have heard of the local offer or would go and check out the thing at bayard if it's still there

That's interestingThis is also my opinion...And these parents should join in this conversation and if you are able to get some views from them and they are happy for you to share that would be fab

Not always about access to internet it's about wanting to use it. Although this is the age of technology not everyone likes doing everything online and still prefers in person or phone.

As it's a 0-19 service working with local community centres or organisations within the centres who would know local families and who can share the info with them at drop ins events etc would be worth considering. The council already have access to contacts for them all.

You would think the council have access to contact information for everyone that are/could/should be entitled, but that's not necessarily true. There are many, me included, that fall under that radar because of not having an EHC plan or (the old Statement) just SEN support. Then those who feel they don't want a diagnosis for what ever reason but they still have a form of disability or special need. Or the hard to reach community..such as grandparents/guardians etc who care for young people with needs

FVP are working to try and extend the age that the service will accommodate from 0-19 to 0-25, to bridge that gap for families and will keep you informed of any developments

The community centres they have the contact details for. I know quite a lot of the parents in my local area who have children with additional needs most community centres who have interactions with the families will get to know which families could do with the info if they know what it is

There must be a lot of people (myself included)who's child has disabilities/medical needs with statements/care plans,but since diagnosed don't get offered any support are just expected to cope & get on with it.

Agreed, so do you think, that while going through the diagnosis procedure/getting final diagnosis, as well as providing support information or where to go for advice and support (eg, Family Voice, Carers Trust, Family Action, Little Miracles, NAS, PDDCS etc.) you would welcome information about "Short Breaks" as well as info about the diagnosis

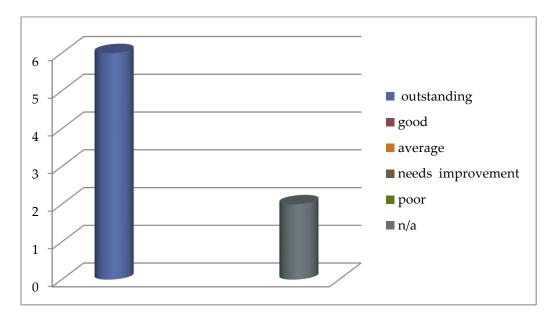
Yes,I think everything that is available should be mentioned & given contact details.we were only told about little miracles as my sons dr said they run a Tourette's group,but other than that there was no more info on any support. Yes you can look online for groups but it's better with someone telling u in person what groups/support is available especially someone that has experience. The we struggle through tiredness with my other little girl who has lung problems....it seems to me like u only gain respite or support if ur child is not looked after properly. If u seem to be coping ur left to get on with it.

Thanks everyone for taking part

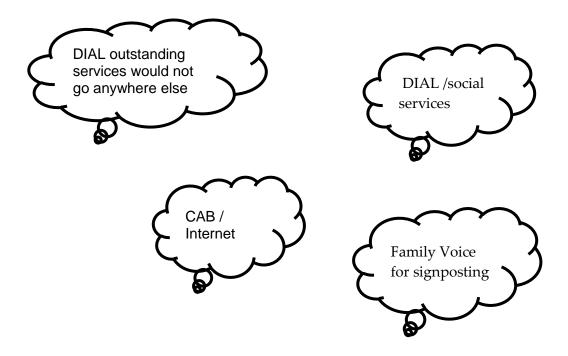
Update week 2

FVP started this week by posting the questions on social media. Then we asked people to share their experience about this service. By day four of posting these questions it had been seen by 112 people. Five individuals joined in the discussion around their experiences on FVP social media page. FVP also asked parents to participate both face to face and over the telephone asking them about their thoughts and feelings based upon the following three questions. There were five parent / carers that participated in this and then the results have been combined.

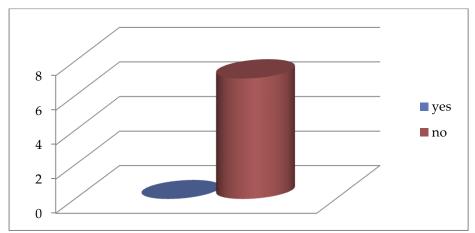
A very small number knew about the Information, Advice and Guidance (IAG) service. The current service supports benefits and entitlements information and guidance: how would you rate the knowledge and quality of the current IAG service with Disability Peterborough (DIAL)?



Where might you get entitlements and benefits advice, now and in the future?



Does this IAG service fit or belong within the Short Breaks agenda?



Overwhelmingly parents were not sure where it should fit but felt that short breaks was the wrong place.

Social media conversation **green** FVP staff, yellow – parent / career views, turquoise – trustee

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Never used dial so I can't personally rate it. Others have said it's quite good with helping with the forms like dla and pip. They can be rather overly complicated. Not sure it fits with the short breaks agenda though. Think it may be confusing some people

That's useful thank you xx

Dial is very good for form filling help. Family have used them

Disability Peterborough were very good in supporting my review with dla just lately

Thank you both x

Never used the service.

I am not sure that it belongs in the short breaks service as there is no relevance.

This is really important service and therefore, should have its own heading/click within the Local Offer. Perhaps, a link that allows the parent/ career to go straight to there website.

Who is in charge of this local offer by the way

Hi I know it's the local authority but I'm not sure who and thank you it's useful to here this

I know it's the LAlol but whose in charge

Hi not sure but il ask tomorrow for you x

I am just curious nothing more.

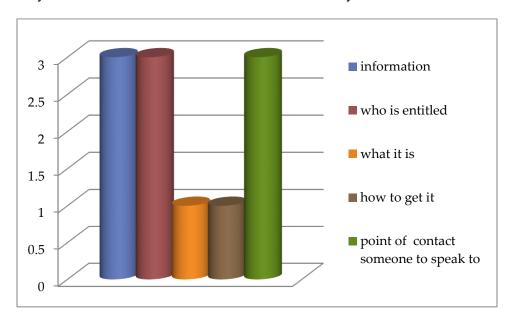
Hi it Jackie cousins

Update week 3

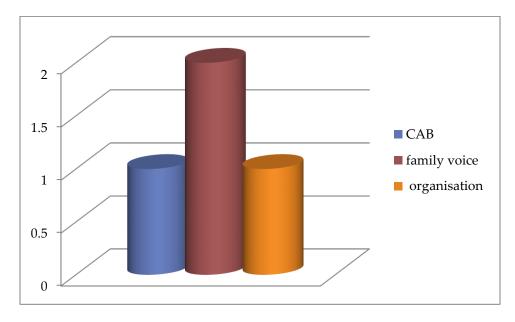
As before FVP started the week by posting the questions on our social media page. Seen by 113 the people with 4 individuals

FVP then asked a group of parents their opinions and in total FVP had seven parent / cares form both group and social media page.

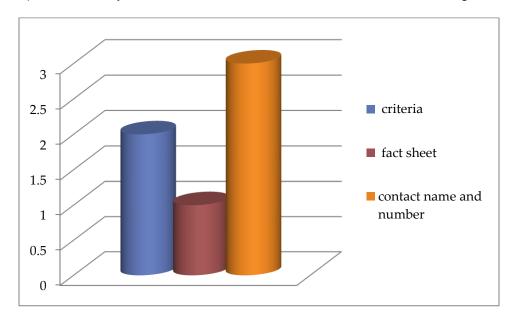
6) Very few people said they access, or knew about, Direct Payments. From your current understanding, what do you think families need to know about Direct Payments?



7) Where might you want/expect to get that information?



8) What would you need to consider, or think about, before accessing Direct Payments?



Social media conversation - green FVP staff, yellow - parent / career views, turquoise - trustee

Perhaps, the reason very few families know about the service is because the SEN team at PCC don't know themselves I speak from experience. Therefore, they can't make parents aware of the service they know very little about themselves and whether or parent/carer is entitled.

It should be raised and discussed at every annual review, or interim review of the child's EHCP, regardless. If the SEN officer doesn't attend the review, a phone call should be placed to parent/carer by SEN officer to discuss service and entitlement.

The authority has a record of children with statements/EHCP start with a leaflet drop, and a covering letter with a number parents can ring to discuss. Although, with funds limited probably not achievable. The SEN team are the point of contact for parents representing the authority they need to be trained and knowledgeable on the service in order to pass the knowledge to the service to deliver to parents. When considering direct payments you need to consider who you will employ, and how this person can help with getting the child as functional, happy and independent as possible. Because that's what the service is about and can be very beneficial to our children.

Personally, and if the authority is keen to really make parents aware of service. It wouldn't be to hard to ask a parent to confirm the rewards for the service together with the authority in the Peterborough Telegraph. They have connections they should use them.

Families need to know & be made aware if they meet the criteria & what that criteria is.we was using the copass holiday club as means of respite for a few hrs a day, just so my other children could get a little 'normality'....not ideal as could only access this for 2 weeks of the 6 week sch holidays, obviously quite costly at around £20 a day.....without being made aware of anything available to us & no other child care it was a last resort.

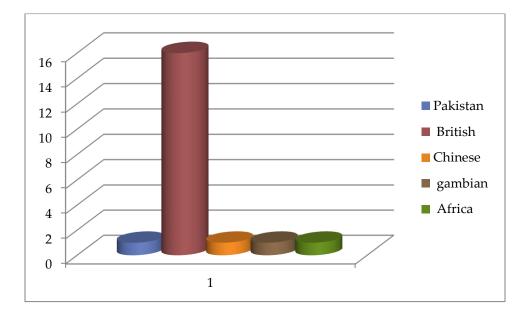
Information should be given out at every diagnosis meeting, schools, gp's etc we've never been given any info.

I only found out through other parents, and took them months to do a assessment. I simply got told by my social worker that not old enough to leave the family unit even tho he goes school the board made the decision!

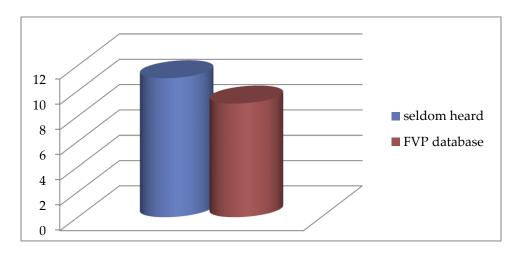
I was told the same as even now I do not get any respite care for She goes to her dad's everyother weekend but this has never been consistent. I get 4 hours a week outreach and this is never fully fulfilled either. Inless your at breaking point they will not pull their finger out to help... or you need to know how to work the system in order to get anywhere. School is my childcare! I work also so school holidays are not something I look forward to.... if I cannot sort then I lose wages as I can't work. No one tells you the additional support and when you do get told or apply for it your rejected. Someone already cried Wolf and got the help they needed

Thats absolutely shocking! Maybe u need someone to fight your corner &x

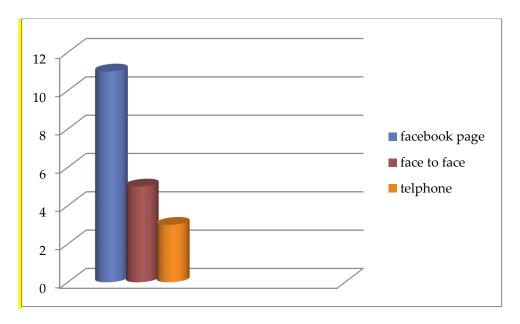
Facts Ethnicity



Category



Ways of participation



Scope of their CYPS need

