

19th February

Hard To Reach Groups

Hard To Reach Groups – January/ February



Introduction

Family Voice Peterborough (FVP) have started work around “hard to reach” groups based on requests for support/ information/ SEND updates from parent carers individually and collectively. As FVP have started asking for parent carers to take part in specific themed work streams relating to the Local Offer specifically parent carers from various BME, New Arrival and ESOL backgrounds have come forward to take part but have also requested ways be explored for others not being heard to take part too.

At a Local Offer/ Short Break focus group run in November 2014 three parents attended who raised issues relating to language being used for categories around the Local Offer and specifically what is meant by short breaks. One parent was Dutch and the other two parents were Pakistani. All three parents questioned the language being used and also pointed out that some of the language would not translate easily and could lead to confusion. The parents also went on to ask if they could be kept informed/ included in the further development of the Local Offer and help to make sure it was suited to the needs of those families from the backgrounds mentioned above.

During discussions on the day of the focus group and shortly after when feedback to those who attended another topic that came up was the engagement with community leaders by the LA to keep the families informed. It would seem from these discussions that families may not have contact with community leaders in relation to SEND in particular. Families are isolated from their communities in relation to SEND for a variety of reasons. One parent had the following to say on this issue:

“Isolation can be felt double as hard for parents from different cultures and due to language problems and differences in culture and religion. They are not able to share the journey they have with their kids and the difficulties they encounter with those from the same background out of fear of exclusion off the community. On the other hand they are also not able to discuss it with others in the country they live in due to limitations in the languages and this completely isolates those parents at a time they are in need of understanding and support. For them it is vital to find confidential support that understands the issues they are facing and who can help them navigate the system to get the best support for their kids and themselves. With this knowledge and support they empower themselves to accept the diagnosis/condition of the child and break out of their isolation.”

Given these discussions mentioned above and the requests from these parents and also others known to FVP to be involved more it was felt it would be useful to explore further with the parents how they could be involved and what they wanted to be involved in.

Evidence

Parents Meetings

DS expressed an interest in more involvement with FVP and had asked if there was any way parents who are ESOL could be enabled to know about more about the SEND work locally. Due to this and a request to be more involved from the chair of the “aiming high group” (AHG) at the focus group mentioned in the introduction FVP went back to the chair person and DS and asked if they would like to be enabled to have a “voice” via sub-group to FVP. After agreeing to this a meeting was set up with these parents and also three other parents from AHG which FVP facilitated. There were two other parents who had also heard about the meeting and had asked to be included; they could not attend on the day due to childcare issues but asked to be kept informed and shared how they would like to be kept informed.

A trained parent rep took minutes and the participation lead for FVP facilitated the meeting. At the meeting it was decided by the group that DS would chair the group and a date was set for another meeting. The parents discussed what they wanted from such a group and they felt should be involved. (The minutes are in the appendix)

Some of the topics discussed were:

1. Signposting
2. School based concerns
3. Training

A second meeting was then held with two parents who couldn't make the first meeting and the minutes from their meeting are also in the appendix. The parents at the second meeting were from European countries. The issues they discussed were different from the issues discussed in the first meeting.

Some of the topics discussed were:

1. Social Services Myths/ Cultural Concerns
2. Support for those with ASD
3. Use of the child development centre and CAMHs

Parents

Four mothers of Pakistani heritage who access AHG, their children's disabilities/ additional needs are hearing impairment, GDD and complex health

One mother who is Dutch and has twins with SpLD and possible GDD;

One mother who is Albanian and has a young person with ASD

One mother who is from the former Yugoslavia and has a young person with ASD – did not attend meetings but will be involved

One mother is from Portugal and has two children both with ASD

Linked Work

At the same time the parents have asked FVP to start a group for them to engage through the local Children's Community Health and CAMHs provider (CPFT) has expressed an interest in FVP facilitating parent participation for those parents who access their services. This work will include the parents in the new group being facilitated by FVP.

A FVP parent rep, FVP participation lead, a representative from Peterborough Area Down Syndrome Group (PADSG) and the parent mentioned above DS met with the clinical lead for the local health service provider to discuss parent participation and joint working. The minutes from this meeting are in the appendix. The information and actions from this meeting will be fed back to the parents group and also the wider forum on FVP.

One particular action from this meeting is already being carried out and DS has taken the lead; the production of a signposting pack for parent carers who are new to the service. Currently some of the staff at the clinics give new parents a poly pocket file with a selection of leaflets they feel may be useful.

At the meeting it was decided it would be good for parents from FVP and the new sub group to take the lead on this and help shape the pack going forward with information selected by parents and also information that can be easier to understand by parents who have ESOL. DS has started work on this and shared the pack with other parents to gauge their views. The following comments have been shared from this work:

- 1. I personally like networking, informing people and organising things. It was also mentioned that they would like parent trainers next to the professional trainers which is something I am qualified in and would be interested in as well.*
- 2. Most groups are not a one stop shop so if there is a team which works directly with parents of newly diagnosed kids then parents can be directed into the right direction of what they need and don't run the risk of being in a bubble at one particular group.*
- 3. First meeting went very well and a lot was discussed which now needs to be actioned to make this happen.*
- 4. I have started on the folders which parents now receive and have added information and have come up with some ideas. I will work on this further next week when kids are back at school. Will take this to our next meeting on the 11th to discuss further with the others and get more ideas and feedback to improve even further. As this is a help for the EHC request I have added quite a few questions, but would like the input as well from MM and her team what she would think would be good to add to this.
(DS)*

- 1. I would like to be involved by manning a stand for fvp at the city care centre on clinic day and use my expertise of knowledge around send to help other parent/carers and be able to signpost them to the correct place to solve their query.*
- 2. Many groups will benefit from this as more parent carers will be aware of the services they provide and therefore more likely to access them on a regular basis for help and support.*
- 3. The first meeting went really well, great to see the true potential of CDC once the proposed work is all finished and it is lovely to know the health team do really understand our children and their needs,*

4. *I would like to see the actions put in place at the last meeting made a reality and some of our volunteers who have qualifications in childcare put forward for DBS checks by the CDC to be able to volunteer as and when needed, also look forward to our next meeting x (TS)*

Actions from all meetings

CPFT Meeting

1. Draft survey/ tick box for feedback from parents to make service much better, and be more child and parent friendly. 15 step challenge
2. Take some pictures and create social story to relieve anxieties, help with understanding what to expect. Make available in reception.
3. Create a parent friendly, designed information pack for families new to the service.
4. They would like to have group of volunteers to help out in waiting room, all to be DBS checked and information should be in clinic days. Need to have a play team to support single parents who have siblings at appointments due to no childcare, could have training through CPFT
5. Once a month in team meeting, one child and parent to share experience for 15 minutes
6. List of groups and activities across Peterborough where CPFT can send one of

Parent Meeting One

1. Contact PCVS to liaise with Kasia re polish school

Parent Meeting Two

1. LR to liaise with Jon Lewis/Head of Education about translation software for use by group.
2. Signpost ESOL parents to English language courses which are delivered for free.
3. LR to get details from Christine Atkinson for carers advocacy.
4. Get list of the various Clinic days that are held at the CDU.
5. Plan focus group to discuss the 'All about me folder' in more detail.
6. Carers/Direct payment to be contacted, because they are not responding to parents queries.
7. Claire Nunn and her Manager need to be contacted about what information they give to parents going on early bird course. This information should be accessible to parents with children who do not go on the course as well so need to go in the new pack.
8. Local Offer needs to be at the front off the 'All about me folder'.
9. Find out what training parents need, how they can access this and how it will help them.

Appendix

CPFT Meeting

1.0 Attendee's	Louise Ravenscroft (LR), Dr V Reddy (Dr), Dafne Stoelhorst (DS), Tanya Smith (TS), Laura Tilley (LT)
2.0 apologies	
3.0 Working together	<ul style="list-style-type: none"> • Had a tour of the city care centre and discussed certain improvements. • There is a quiet waiting area for children with anxiety/ mental health issues – rarely used due to staffing capacity • Dial could come in with FVP as well on clinic days to provide information to parents on benefits • Early support program being introduced hopefully will lead to better outcomes, one person collects story and discuss what support is put into place all captured in a folder. Means not having to repeat your story. • LT to commit to once a month clinic for Downs Syndrome clinic • Gina Yates potentially to be involved around CP
4.0 Training	<ul style="list-style-type: none"> • ESOL families need extra support, could bi-lingual parents be trained in interpreting? • Discovery college has space to deliver training– how to discover having a “normal” life as one possible training idea. • CPFT offering training in sign language if necessary.
4.0 Services	<ul style="list-style-type: none"> • BME, new arrival – almost 50% coming through don't have English as first language • Concerns over sleep and face2face as services being lost due to lack of funding. Services compliment the work being discussed • CCG need to fund this as so many children come off melatonin as see sleep solutions but now not funded, and now going to be back to Dr
4.0 Actions	<ul style="list-style-type: none"> • Draft survey/ tick box for feedback from parents to make service much better, and be more child and parent friendly. 15 step challenge • Take some pictures and create social story to relieve anxieties, help with understanding what to expect. Make available in reception. • Create a parent friendly, designed information pack for families new to the service. • They would like to have group of volunteers to help out in waiting room, all to be DBS checked and information should be in clinic days. Need to have a play team to support single parents who have siblings at appointments due to no childcare, could have training through CPFT • Once a month in team meeting, one child and parent to share experience for 15 minutes • List of groups and activities across Peterborough where CPFT can send one of team to observe children and families. Part of paed training in disability awareness. • Join Annual fundraiser with CPFT • Train the trainer in some courses they deliver

First Parents Meeting

1.0 Attendee's	Louise Ravenscroft (LR), Dafne Stoelhorst (DS), Tanya Smith (TS), Robila Jan (RJ)
2.0 apologies	
3.0	Leonie and Kasia from PCVS to be contacted and engage with them Action:contact Leonie at PCVS
4.0 Parents	RJ : Aiming High Group Chair (AHG)– GDD, Jarka Van Syndrome, hearing loss Gazala (AHG) 2 children, 8yr old son with GDD. Nabila (AHG) 2 children, 10 & 5, moderate hearing loss, developmental delay Farah (AHG) 1 child born with genetic abnormalities
5.0 Personal Issues	5.1 Child at Gladstone and needs help getting into Heltwate, as has been rejected, has tried to contact Marion Deeley but no response. He has a statement 5.2 Nursery never picked up problems, labelling child as naughty, 18 months delay. .3 5.3 Area SENCo not spending long enough doing assessments, school, pre-school not listening. 5.4 struggles with signposting as not out in the community as much.
6.0 Information	6.1 Parents have used Google to educate themselves about what they need 6.2 Groups exist such as Carers Trust, Scope, RNIB, Inspire, PCVS, Little Miracles. These groups can help with Carers Prescription, PDDCS, Carers Assessment. 6.3 Ask about SEN support, ask about schools SEN report, ask about how they are recording progress about your child 6.4 Contact SEN team and ask for re-assessment of childs needs if they have a statement 6.5 Dr Reddy does training programmes, Early Bird – keen to deliver training 6.6 Educational Psychologist Service – every Thursday term time 12-3pm 01733 863689
7.0 Next Meeting	Next Meeting 11 th March 2015 9.30

Second Parents Meeting

1.0 Attendee's	Louise Ravenscroft,(LR). Dafne Stoelhorst, (DS). Claudia Dies, (CD). Davida Behrami, (DB).
2.0 Parent Details	<p>Four mums</p> <ol style="list-style-type: none"> 1. British Parent of 2 children with additional needs. One with profound needs and one with anorexia, vision impaired, personality disorder 2. Dutch Parent of 3 children of which 2 with additional needs SplD 3. Portugese Parent of two children who are both ASD 4. Albanian parent of three children of which one diagnosed ASD other under investigation
3.0 Topics discussed and issues raised.	<ul style="list-style-type: none"> • Explain aim off the BME group and what has happened so far. • Issues with languages but also that ESOL need to work on language skills. Courses they can find often expensive or at impossible times. • Issues of understanding Social Services. Child protection and safeguarding under one umbrella with disabled children. Fear and stigma to even consider applying for support when you have a child with SEN or disability. Also what SS is allowed to do, clear questions around use of CAF. • What did you need or miss when first diagnosed and why do parents keep on trying to access services like paediatrician when they no longer need them. Parents feel lost, get depressed, lose contact with their own community and are trying to access services they do not need, but are not aware off services that exist and could help. Parents need more orientation to know what they need from whom and if it is possible. They have a diagnosis but they need support with the symptoms/problems/behaviour of the child and where to find this/access this. When diagnosis is given parents are never asked what services/help they think they need. Also what is said/promised that they will do often does not happen due to various reasons. If no budget for certain help than professionals need to be clear on this so we can stop fighting trying to get a service which is not accessible. • Different professionals from different backgrounds are giving different results and advise and this confuses parents. Also they need to be clear about the services, because these are misunderstood and then used for wrong reasons. i.e. Person with selective mutism does not need SALT but needs psychiatrist. • Knowledge and experience is lost due to staff leaving and this results in conflicting information for parents. • Serious issues where autism fits and what services are needed and what CAMHS can do. Struggles with professional support and misunderstanding and the need for peer to peer support. i.e. self-harming in a child with ASD needs different strategies than self-harming in a child with mental health issues. • Which groups are struggling as it is not only newly diagnosed, but also parents with children in transition ages.
3.0 Important dates	<ul style="list-style-type: none"> • 11th March, 2015 / 9.30 -12.00 next meeting for the target parents BME at Northminster • 19th March, 2015 / 10.00 - 12.00 CDU for further discussion to get group off the ground • 20th April, 2015 / 9.30 - 12.30 Part one of Expert Parenting • 27th April, 2015 / 9.30 - 12.30 Part two of Expert Parenting
4.0 Actions	<ul style="list-style-type: none"> • How to support ESOL parents with language issues as letters are no longer translated by CDU and other services. LR to contact Jon Lewis/Head of

	<p>Education about translation software.</p> <ul style="list-style-type: none"> • Signpost ESOL parents to English language courses which are delivered for free. • LR to get details from Christine for advocacy. • How we can support parents after diagnosis. Not goodbye and let parents with the feeling they just had a diagnosis, but no support. Through peer to peer they can access both support from parents who have been there, but also receive information where they can get specific support for their child's needs. • Making sure parents understand what the services are for and how they will benefit their kids. Better that this information get delivered by confidence support groups who understand your position and kids conditions instead off given by professionals with no practical experience living with a child with SEN/disability. • Befrienders needed from different cultural and religious backgrounds. • Get list of the various Clinic days that are held at the CDU. • Plan focus group to discuss the 'All about me folder' in more detail. • Carers/Direct payment to be contacted, because they are not responding to parents queries. • Claire Nunn and her Manager need to be contacted about what information they give to parents going on early bird course. This information should be accessible to parents with children who do not go on the course as well so need to go in the new pack. • Local Offer needs to be at the front off the 'All about me folder'. • Find out what training parents need, how they can access this and how it will help them.
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