FVP Interim Report

October - December 2021

FVP Parent Representatives

Introduction

As with the past two quarterly reports, this report is structured along four main areas all of which are designed to mirror annual reporting:

- CAMHs Work
- SEND Data and Schools Work
- Seldom Heard Communities
- Co-production and Change

The above themes also fit overall funding streams of ‘Early Intervention’, ‘CAMHS Transformation’ and SEND. Some of the work included also fits with other funding streams, as they align fairly closely to the work under discussion. It is very difficult to separate fully all aspects of FVP work, as much of the work relates to parent participation overall, and also staff and volunteers cross over all areas in their work.

Generally work has settled into a blended approach, with a mix of face to face, online and delivery of activities/ items occurring. There is ongoing uncertainty in much of what is happening in the local parent carer community due to a number of external variables; from Government Agenda’s and the ongoing global pandemic COVID-19 (C-19) through to continued change at a local level across the Council and in SEND services. All of this is reflected in the work of the forum/ wider charity.

Sessions have taken place in relation to Seldom Heard Communities; SEND Services; Mental Health and Wellbeing and Behaviours that Challenge. From data collated the main method of participation has been via Surveys with 5 being conducted between October and December. Facebook have changed their settings so Polls are no longer possible, although discussions do continue in the closed group.

There have been 9 online sessions covering Seldom Heard Communities, Open Forum Discussions, Wellbeing and more Signposting and Support with a total of 117 attendees. Work does need to take place to keep the YouTube channel updated and ensure most of these are available in the public domain. Work has also continued to ensure where possible that the sessions are sign supported with BSL interpretation. As well as the online sessions there have also been 704 individuals supported in some way by; delivery of wellbeing packs and/ or activity passes, vouchers from completing surveys or attendance at sessions such as a seldom heard community festive get together.

Participation/Engagement/Involvement October to December 2021

Headlines

1) 295 named parents in total have been involved at some level which is a 55.26% increase since the last quarterly report
2) Parent carers where known report having a total of 369 which is an increase of 57.14% children and young people with SEND within their house-holds, and 143 siblings an increase of 48.79%.
3) 17 fathers have been involved, an increase of 88.88%.
4) 55 parent carers have participated across 5 online surveys.
5) Children's/ Young people disabilities/ needs have been reported by parents as including (This list is not exhaustive);
    a) Autism Spectrum Disorder
    b) Attention Deficit and Hyperactivity Disorder
    c) On the Neurodevelopmental Diagnostic Pathway
    d) Varying degrees of Learning Disabilities and Difficulties
    e) Global Developmental Delay
    f) Genetic Disorders
    g) Downs Syndrome
    h) Cerebral Palsy
    i) Spina Bifida
    j) Achondroplasia
    k) Social, Emotional and Mental Health Needs, including Eating Disorders and Anxiety Disorders.
    l) Non Binary/ Trans
6) Parent carers reported the ages of their children/ young people as between 2 to 25.
7) Participation methods used included; online surveys, Facebook polls, case studies, virtual seldom heard group sessions, one-to-one telephone or email engagement and parent representation.
8) Evidence is both qualitative and quantitative in nature.
9) Ethnicity has been self-reported as; White British, Asian, Gambian, Nigeria, Kenyan, Sierra Leonean, Lithuanian, Polish, Russian, Afghan, Portuguese, Latvia, Indian, Pakistani and White European.

CAMHs Transformation/ Parent Carer Mental Wellbeing/ Online Support

Introduction

In this quarter It has in this period been possible to deliver one Challenging Behaviour workshop and two mental health and wellbeing workshops. Other areas of work have been incorporated here too, as such areas have an impact on the parent carer and the wider family, these include; Food Support, Wellbeing Packs and Activity Voucher use.

Some of this work is funded via more than one source especially where the grants have similar outcomes. The funding split can include one grant covering the cost of items for example and another grant covering the cost of staffing and volunteers to administer the work.

Food Support

One of the key themes arising from the work started during lock down as a result of Covid-19 which continues to be impacting families is that parent carers are still finding it incredibly difficult to feed their families well. This is for a number of different reasons including:

1) Long waits for Universal Credit
2) Still being on furlough,
3) Increased food costs.

Support has been provided to 7 households this quarter:

Adults	Children (Total)	Children with SEND
20	31	12

Table.1 Numbers of adults and children receiving food

Of the households in receipt of support in this quarter over 71.43% report having an adult with a disability the majority of which relate to physical health.

> Dwp benefits messed up after renewals in appeals lost tax credits cms not being paid

> I have recentley lost my mum to heart attack and im helping with paying her funeral off

> With covid and birthdays and Xmas money has become very short cost of school trips and for all 7 kids

> Just moved here a few months ago had to furnish whole house, have six children , due baby in 3 weeks had to get everything for her. Have nothing for Christmas and my universal credit barely gets us through on essentials.

> I am on low income i am struggling with bills and with my children who are under 5

Virtual Workshops

Virtual workshops have taken place in relation to the CAMHS funded mental health and behaviours that challenge and DfE funded coffee mornings.

From Fig. 2 it can be seen that it was still possible to deliver 2 sessions relating to CAMHS funded work resulting in 7 individuals receiving support. Drop-out rates are high, but those who attend report positively on their experience. There was an overall 21.88% attendance rate. Work does need to improve in gaining feedback, as people often don't complete forms after the sessions which is the same as the last quarter..

CCG/ Training	Date	Number of Adults
Parent Carer Wellbeing - Anxiety	12/10/21	4
Parent Carer Wellbeing - Care vs Over Care	23/11/21	3

Table 2. Workshop Attendance Information

Support and Signposting	Date	Number of Adults
Beeches Coffee Morning	19/10/21	2
Challenging Behaviour Beeches	24/11/21	2

Table 3. Attendance Information for Coffee Meetings

Signposting/ Support Requests

4 families have completed our new support request e-form with the support relating to provision of food, and access to short breaks.

We have had a further 12 requests for support parent carers via phone/ email. 2 of the requests have come via school SENCo's/ Parent Liaison Officers and the rest from the parents themselves. This time we have also seen requests from fathers as well. 41.66% request relate to White British Families and 58.33% relate to British Asian Families. Requests generally relate to the following areas; accessing services such as wheelchairs, school placements, lack of social care support, EHCp concerns and short short breaks access.

Wellbeing and Activities

Family Based Event/Activity/ Wellbeing	Date	Number of Adults	Number of Children
October Half Term Packs	25/10/21		205
Halloween Goody Bags	25/10/21		105
Non Halloween Goody Bags	25/10/21		100
Carers Rights Day Wellbeing Packs	26/11/21	50	
Seldom heard community forum survey	15/10/21	17	28
Seldom heard community Leaders survey	15/10/21	4	
Preparing for adulthood survey	22/11/21	6	15
Local Offer Survey	22/11/21	12	21

Table 4. Voucher and Wellbeing Pack Information

The use of hand delivered wellbeing packs and vouchers for local activities sent out in time for school break periods has proved popular again, also as has the provision of vouchers in response to survey completion (the survey vouchers are funded via the DfE grant). It is also a more cost effective way to enable access to short breaks for families and some time for parents carers to support their own emotional health. The work has been joint funded across Pears/ DfE and CCG funds. In total 89 adults and 474 children have benefitted

> *Being a disabled carer is very difficult during half term it limits what you can do with the children so these boxes are vital to keep them busy and gives us plenty to do at home" me 39 and disabled and a carer*

Schools Data/ SEND

Surveys

During this quarter there have been 5 surveys conducted which have yet to be completed analysed and reported on separately. The seldom heard and leaders surveys will be reported on in the Seldom Heard Section of this report.

Survey Title	Responses
Seldom Heard	20
Community Leaders	10
Preparing for adulthood	8
Local Offer	14
Cease to Maintain	5

Table 5. Survey Response Numbers

What are parents telling FVP?

Surveys

From the surveys conducted and more generally information is still an area of concern.

Local Offer

When looking at the survey relating to the Local Offer (LO) it is still generally unknown despite it being a good source of information. Fig. 6 to 8 show there is still little awareness and usage of the LO when the questions are asked in any survey about it.

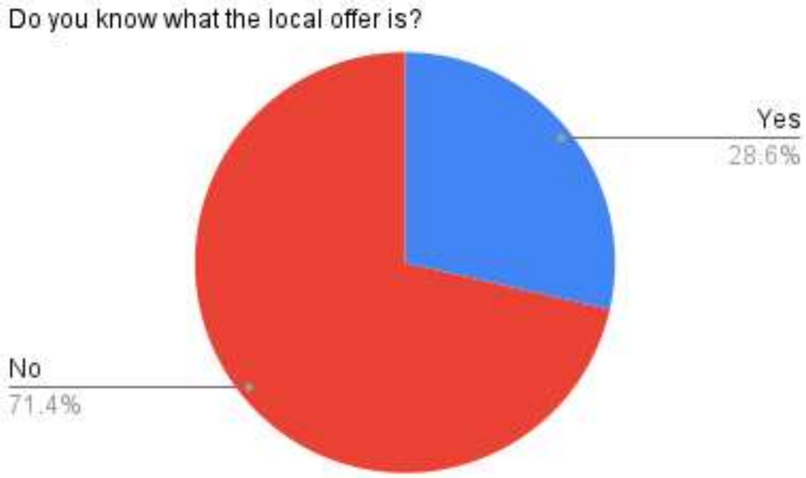


Fig. 1 LO Awareness

Fig. 2 LO Usage

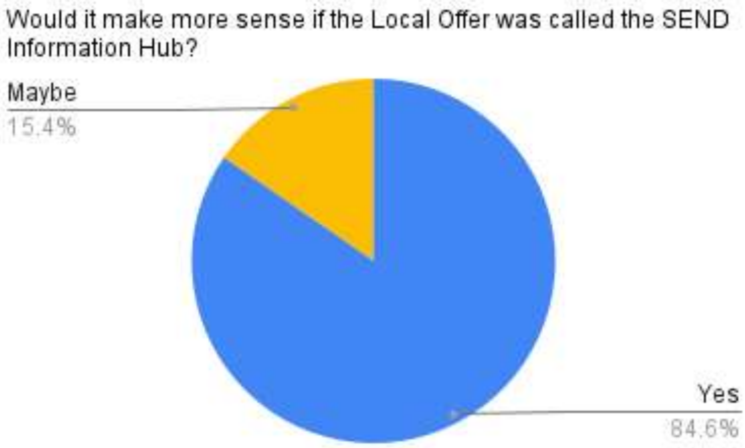


Fig. 3 LO Name Change

Some general comments when asked what is being searched for, what information is required and whether the LO is searchable are as follows:

- *Don’t know what’s available here. Everything is a no because i live with someone. Its be single and you’ll get help but be lonely or get no help and go without a life so your child has... so i have no life!*
- *Don't know anything about their services*
- *Respite searching but you just get sent round in circles.*
- *More for children with SEN at post 16 and young adults, day groups or hubs with support and sessions for young adults with Autism who are not in full time education*
- *Opportunity for carers to attend gyms and health activities while their children are at school for their mental health..... they get no respite help so their only tim is when th child is at school but then no money for themselves..... itll never happen but just a thought. And the dr referral so you pay £25 doesn’t help when you have to pay your half of the bills on 67 pounds a week carers.*

Preparing for Adulthood (PfA)

The theme of lack of information continues in the survey where parents were asked questions relating to PfA; from knowing what PfA means (fig. 9) to receiving enough information during the process of transition (fig. 12)

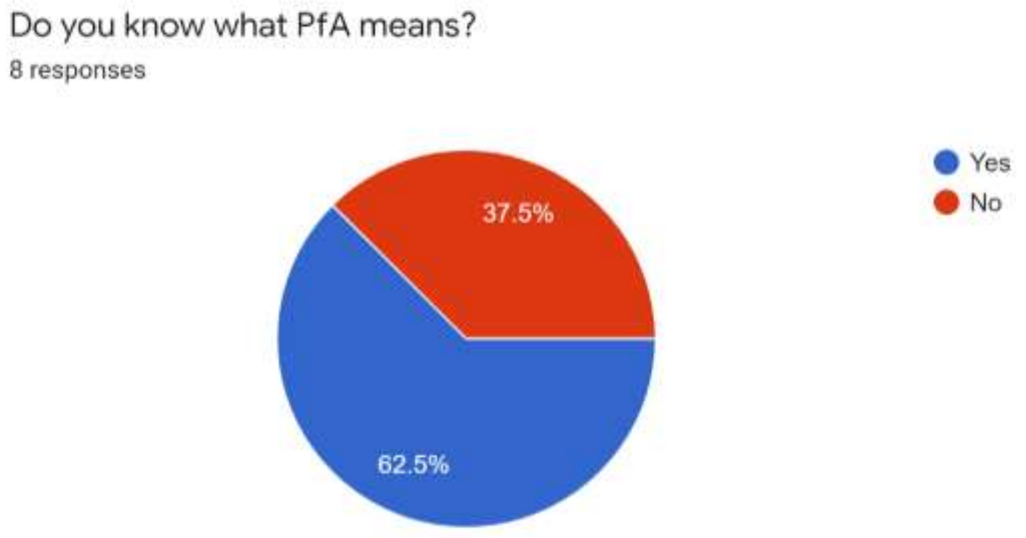
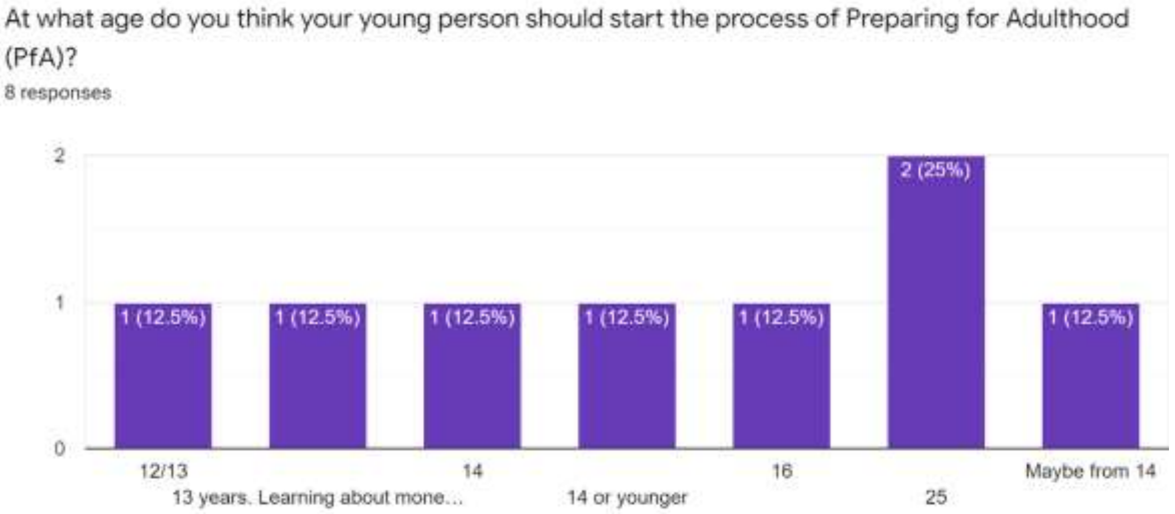


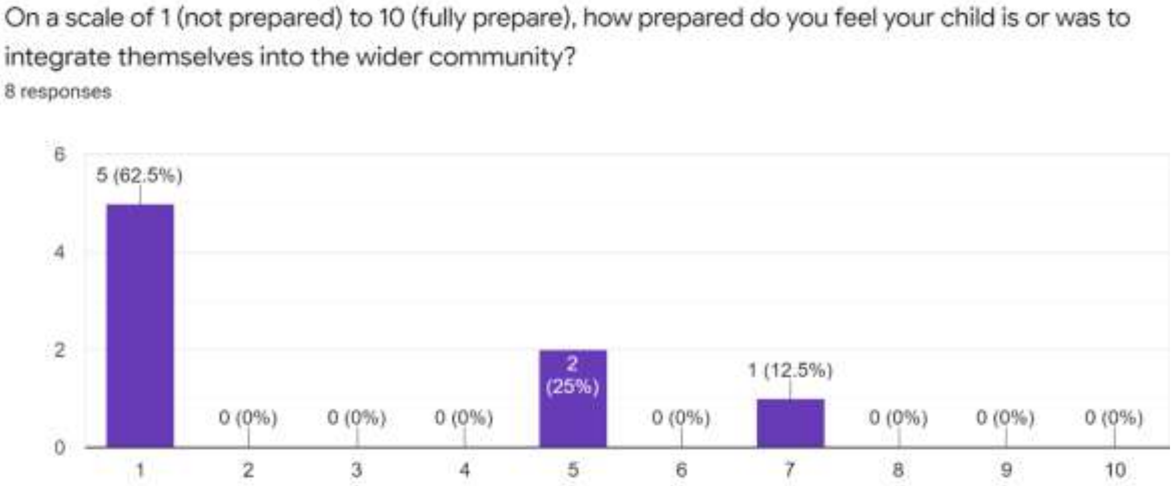
Fig. 4 PfA Awareness



At what age do you think your young person should start the process of Preparing for Adulthood (PfA)?

8 responses

Fig. 5 Age of transition



On a scale of 1 (not prepared) to 10 (fully prepare), how prepared do you feel your child is or was to integrate themselves into the wider community?

8 responses

Fig. 6 CYP preparedness

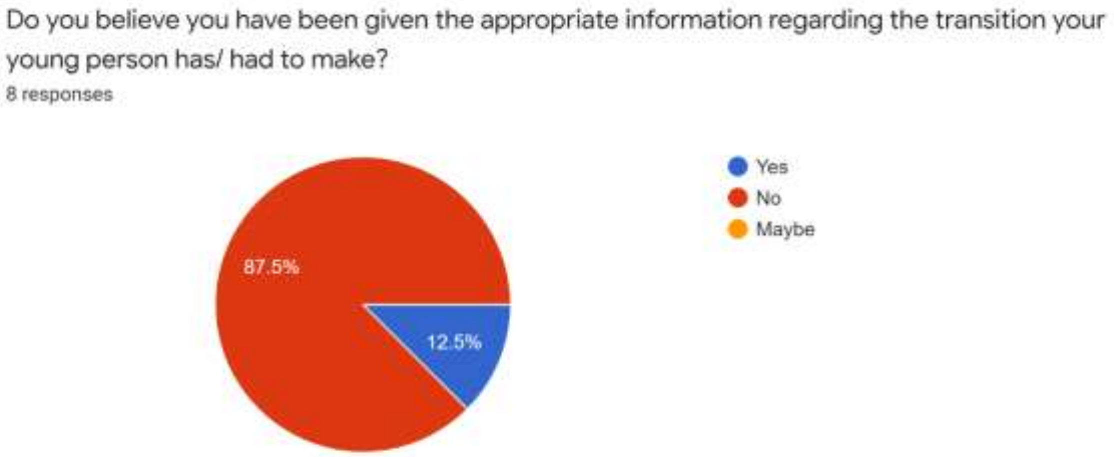


Fig. 7 Information in preparation for transition

When asked 'Is there any further information about Preparing for Adulthood that you would like to know or feel you should have known?' Parents had the following to say:

- *I'm just worried he's not ready for independence college/work*
- *We haven't had any information & been left to deal with it as if my eldest boy is a mainstream young person*
- *Help/ support in work placements.*
- *I don't know how she will live on her own with budgeting and no concentration at times wht support there will be*
- *"It would have been helpful to be part of the 0-25 disabilities team at an earlier stage. We asked about this several times but never received a clear explanation. Some people have said the LA don't offer support for 'invisible disabilities'.*
- *Would also like to know why there is an insistence that no criteria assessment for adult support can be carried out until 17 1/2, leaving a ridiculously short window for securing services given how much drift is involved with these processes. "*
- *Further education options, it's been left to me to find out what's available from other parents. The local offer is poor*

Overall Analysis

Across these surveys and the other ones conducted, it is clear the needs of the CYP (ASC, Transgender, Complex Health, Genetic Disorders, Hearing Impairment for example), of the parent carers who respond are varied and so is the ethnicity (Indian, White British, African, European for example) of the families. Although responses are anonymous enough data is gathered to give a snapshot view of family dynamics. It is also clear as with other areas of work being conducted by FVP that many parent carers also have their own needs or find themselves in 'sandwich caring' situations.

Facebook Discussions

23 different parents too part in 8 separate discussions in the closed Facebook chatroom managed by FVP. Topics initiated were:

Hi is there someone who can help me to complete my online application for PIP this has to be completed by today as deadline is tomorrow? Any help would be appreciated thank you.
Are there any social needs parents here from Spalding Linconshire. Just moved here and feel lost .

Thanks
I am looking to start an online support group in January for parents of children and teenagers with ADHD in the Peterborough region. This will be a space for you to share your concerns, challenges and pick up any tips and offer/receive support.The group would run in the evening. Who would be interested?
Has anyone experienced issues with their child struggling to eat/swallow? Holding food/liquid in their mouth or just nibbling tiny amounts and taking a long time to eat. Unsure if this is just a tick or something more serious. Would this be a paediatrician referral or should I be consulting with a different specialist? Thank you
So a group of us parents were trying to arrange a get together at FlipOut for their Snowball Fight on Christmas Eve.We attend regularly for the SEND sessions, and our children's conditions allow them to interact in regular sessions as long as we are there to support/supervise/co-regulate. Didn't seem to be any 'Spectator' (i.e. parent/carer) option so messaged them to query.
We applied for the disability element of UC for our 18 year old in January.Still waiting. When we call, they say it's down to the business (presumably outsourced) who do the eligibility interview, nothing they can do to speed it up, basically 'tough.'Surely there must be legal timeframes, SLAs etc which they are required to mee
Hi, can anyone help? Hubby and I both work. Our youngest is autistic. He has extreme sensory and behavioural reactions and can projectile vomit. This is in his EHCP, however it is difficult to assess whether he is ill or it is behavioural/sensory because I'm not in school to oversee.The trouble is at times he can vomit frequently, other times he can go quite a while. It is making it very difficult for me to hold down a job. Is there any support I should be applying for or asking for? Is the only option I've got to give up work and be a carer?
It breaks my heart not knowing what to get my pre reading, pre writing 11 yr old son with ASD for Xmas. He is minimally verbal. He likes sensory stuff but has had every sensory toy under the sun over the years. Any gift ideas most welcome

Table 6. PfA Comments

Again this shows that parents are seeking information and on a broad range of topics.

Strategic attendance

Through the ongoing use of the online forum used for parent representatives to report on strategic meetings attended, it has been easier to demonstrate time invested and work/ actions as a result of the meetings attended.

FVP have a total of 7 parent carers who have been attending meetings either through volunteering their time or as casual workers. Fig. 7 shows the number of meetings attended where reports have been completed; there is a slight margin of error in the numbers due to at times, having outstanding reports.

Number of Sessions	Hours Spent at Meetings	Administration Time (Hours)	Travel Time (Hours)	Total Hours
71	113.5	45.5	1.5	**160.5**

Table 7. Breakdown of Time spent at Strategic Meetings Oct-Dec

Open Forum (OF) Sessions

The use of online ‘open forum’ sessions has also continued in this quarter with some mixed attendance, but general good feedback in the sessions.

Information and Awareness	Date	Number of Adults
Open Forum Communications	7/10/02	11
Open Forum Carers Rights	25/11/21	10
Open Forum EHCNA	7/12/21	9
Open Forum ICA	9/12/21	33

Table 9. OF Attendance

Seldom Heard Communities

Seldom heard community engagement has continued primarily online with the opportunity for one face to face event held outside where community leaders came together with local ward councillors and The Mayor. In a move towards letting the communities take the lead more, the community development worker now chairs the online session and the seldom heard parent rep works to ensure topics under discussion are based on the requests of those attending the sessions. Feedback form the sessions is generally for more time/ longer sessions.

Seldom Heard Themed Sessions	Date	Number of Adults	Number of Children
Seldom Heard Exclusions	25/10/21	13	
Seldom Heard Foster Care	17/11/21	18	
Seldom Heard PfA	24/11/2021	16	
Seldom Heard Festive Get Together	2/12/21	17	

Table 10. Seldom Heard Engagement

Feedback was gathered for the Foster Carers sessions which worked better as it was face to face.

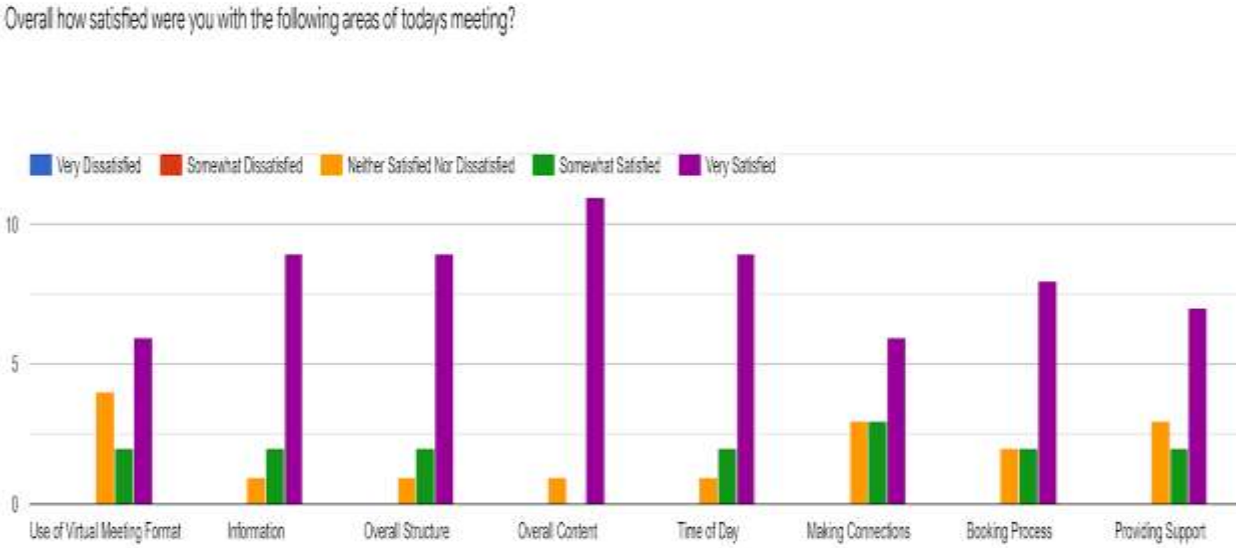


Fig. 8 Satisfaction Ratings

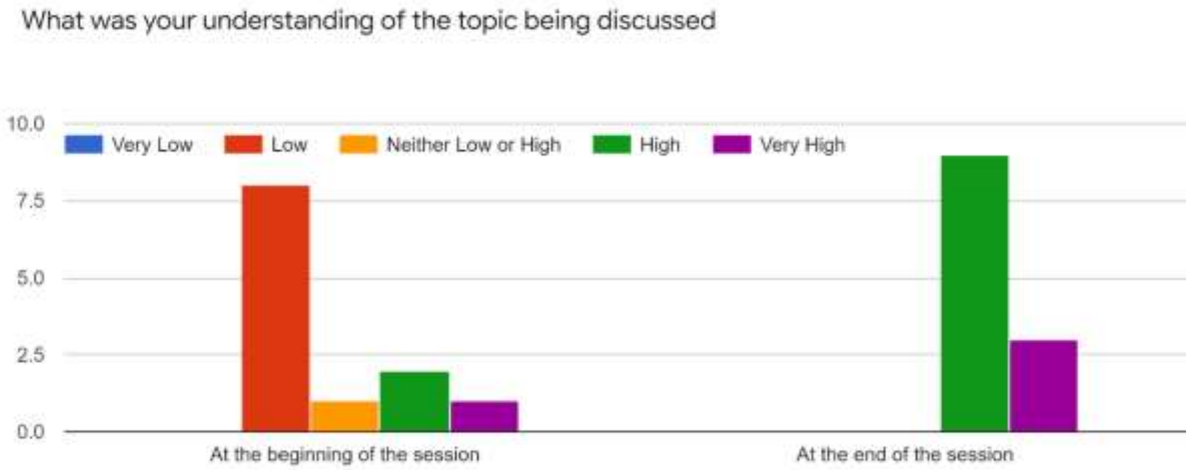


Fig. 9 Topic Understanding

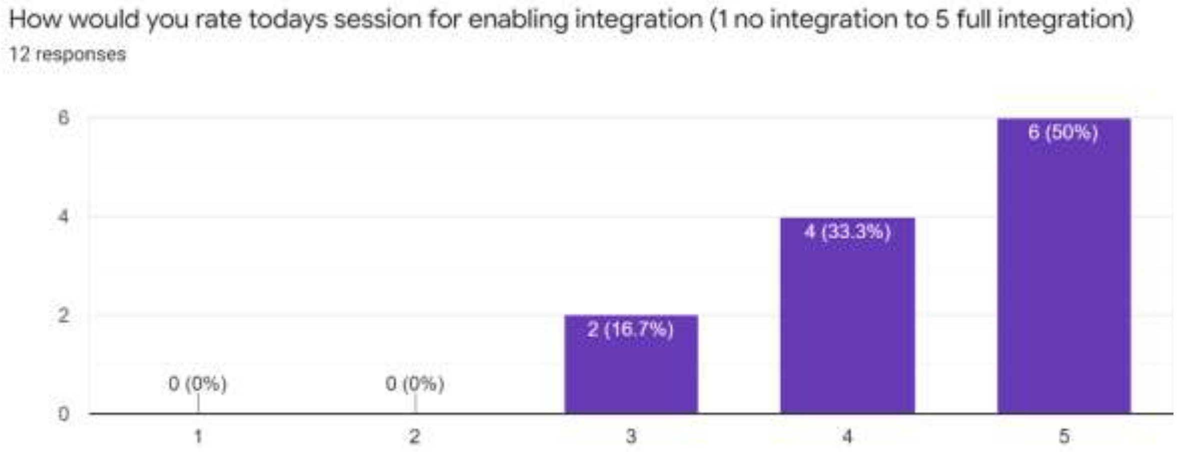


Fig. 10 Integration

The only real critique was that the session was not long enough.

Parent Carer Support

FVP have also seen an increase in individual seldom heard parent carers seeking support of some kind. 58.33% or those seeking support this quarter self-declared as British Asian, one of whom was a father.

Surveys

This quarter saw two surveys conducted targeting seldom heard parent carers and community leaders.

Seldom Heard Communities

Fig. 11 and 12 related to the parent carers who completed the survey and were designed to elicit information relating to familial ethnicity and CYP needs. Also though 40% who completed the survey effectively chose the “White British” category the rest of the categories together made up 60% of the overall ethnicity data set.

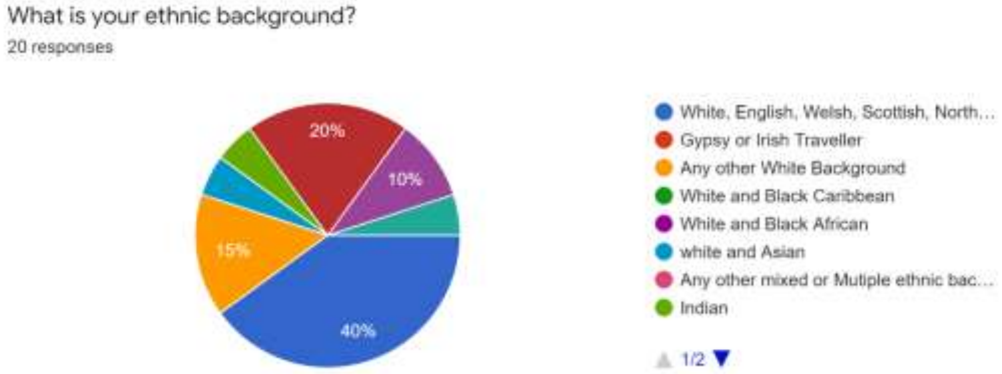


Fig. 11 Self-Declared Ethnicity

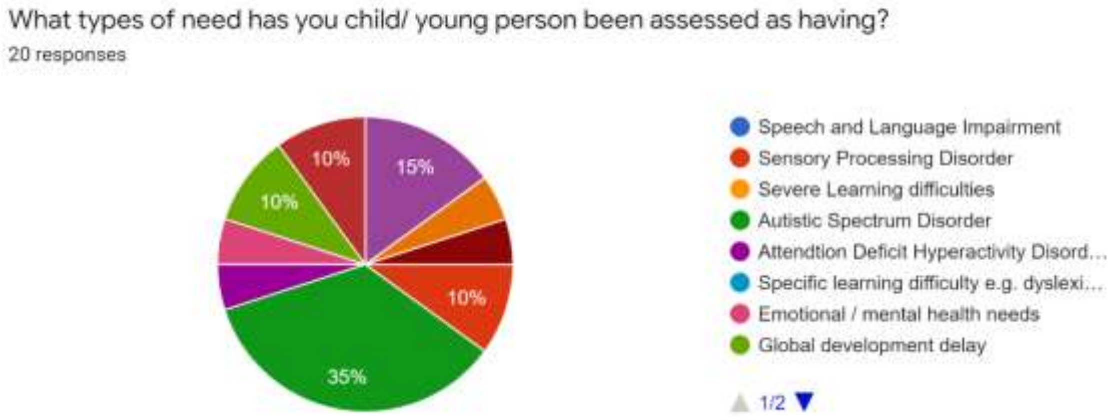


Fig. 12 CYP Needs

Those taking the survey were also asked a series of questions related to slightly broader issues about SEND and Ethnicity; whether cultural needs are being met, how different areas of need are viewed in different cultures, has information provided been adapted to meet need and are there specific barriers to accessing services (fig. 13 to 16).

Overall there do seem to be cultural barriers and differences which may be due to differing ethnic background. Lived experience does matter when it relates to understanding SEND. In fig. 13 only 30% felt that their CYP cultural needs had been met.

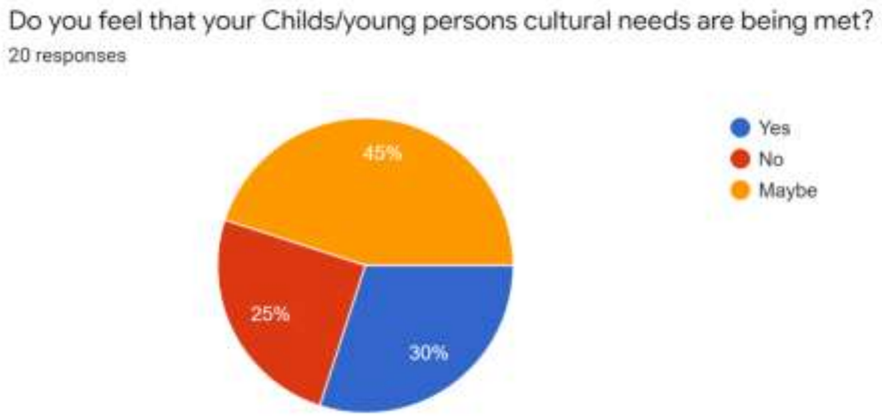


Fig. 13 Cultural Needs

It has been considered from previous anecdotal evidence gathered during the work of the forum, that different needs may be viewed differently based on cultural understanding. When asked whether ‘physical disabilities are viewed differently from neurodevelopmental disorders such as ASC and Mental Illness 70% of those who took the survey felt they are as shown in fig. 14.

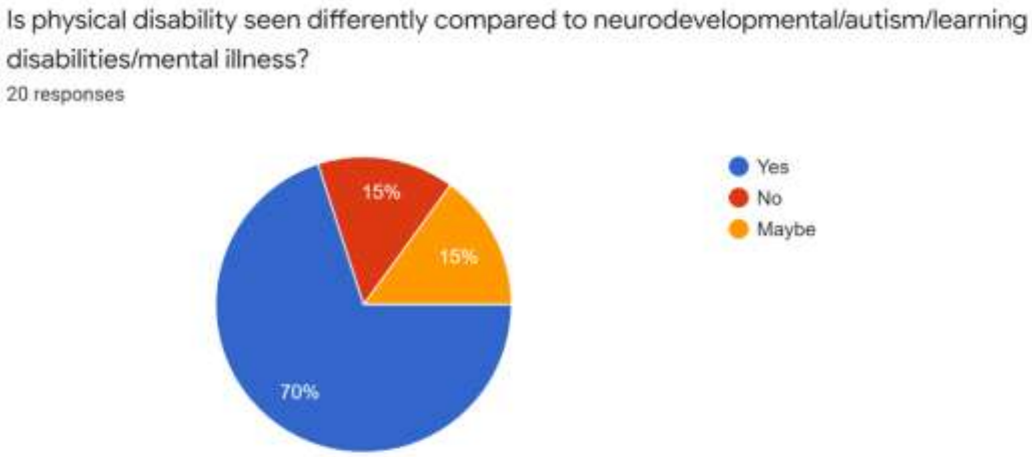


Fig. 14 Physical Disability vs Other Needs

A supplementary question to this was ‘Disability is often perceived differently in different communities, what does being disabled mean to you in your community?’ This led to the following responses:

It mean less worthy so we don’t have contact with other Polish families.
It is looked upon as they can’t be successful in life unfortunately and very shameful having a child with special needs
Understanding
Needing extra support
It means I should be ashamed but I am learning not to be as they believe it is a punishment sent from god
Means we are unique and special in our own way and talented and we have difficulties some times because of the way our brain works.
They don't understand the needs
Can be seen as an outcast
Not developing according to your age group
different kind of difficulties being different than ordinary people, you are a burden to others.
It often means unable to complete anything
Person who is at a disadvantage and may need extra support compared to their peers
Not good
Not good, spoiled child
Being 15ifferently abled and having specific needs
It means being isolated and unsupported.
Someone hope could benefit from some support
An adjustment to their needs

Table 11. Disability Understanding

In the survey parents carers were also asked 'Has information been adapted to meet your needs?' To which over 70% said not applicable and the responses below were provided by four parent carers

information was translated into a different lanugage
Verbal explanation from the doctor.
Information was translated into a different lanugage
The professional used other methods including videos to explain the diagnosis

Table 12. Information

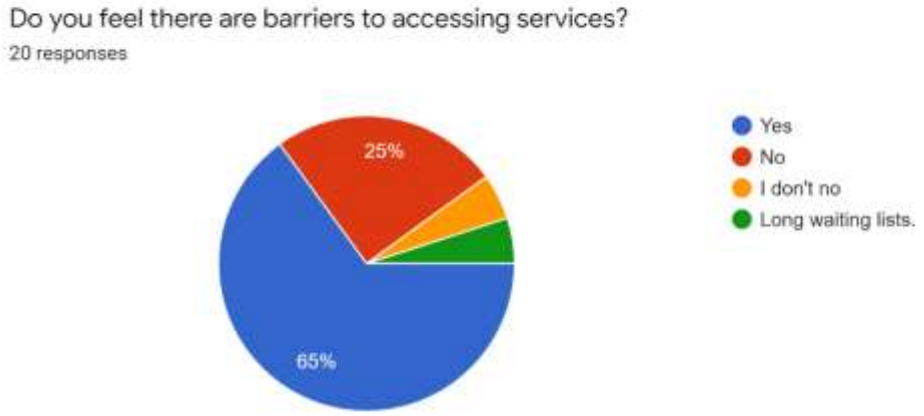


Fig. 15 Barriers to Accessing Services

Further to the last question, parent carers were also asked 'If you feel there have been barriers, what are these?' The following answers were provided.

No way to access any support or help
Language barrier and understanding my culture is difficult for many professionals
Language
Not enough appointments
Not knowing where to go when you need help
To get the support from services in time and to get the professional support.
Language barriers, communication barriers and feeling she's unwell
Long waiting list
Getting the right sport
Social care declining help stating not qualify under child or adult needs
Can only access when at crisis. Otherwise there is none. Carers allowance is a pittance.
Funding, lack of support workers and not knowing what help is really out there.
Covid and waiting times

Table 13. Types of Barriers

The work in this area has proved to be well received and the survey answers demonstrate that the specific focus on Seldom Heard Communities is an ongoing requirement. Although there is commonality in the needs of the general parent carer community, there are very specific needs for Seldom Heard parent carers that need ongoing focus; especially understanding of disability and use of language when accessing services/ key SEND communications.

Community Leaders

Community leaders were also asked a set of questions, relating to parent carers in their communities; there were responses from Nigerian, Pakistani, Lithuanian, Traveller, Gambian, Fathers, People with Disabilities and Single Parent / Domestic Violence Reps.

The respondents were asked "What sorts of support do you think Parent Carers may need?" and stated:

Frequent meet ups, coffee mornings, trips and activities
How to apply for schools and Benefits
Social support
signposting, respite, financial advice & support
Any support that can them better their lives
Translating, advice, information, signposting, childcare, help with food, transport.
Mental health support
Rest breaks from caring so they can charge their own batteries
Guidance, respite care, training, friendship
Physical, emotional caring, professional support. This, ideally should also be financial.

Table 14. Support Required

After this a few questions were asked specifically about the impact of COVID.

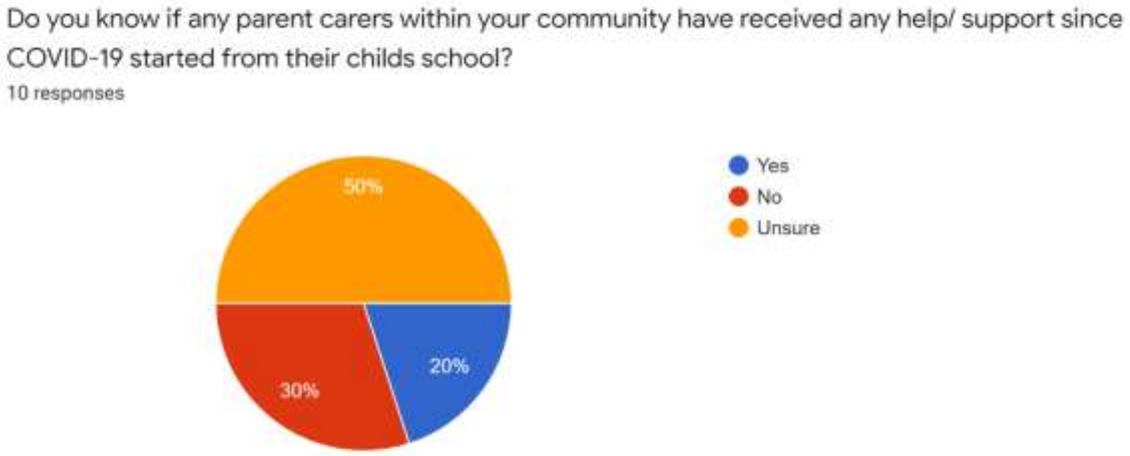


Fig. 16 Support Received During C-19

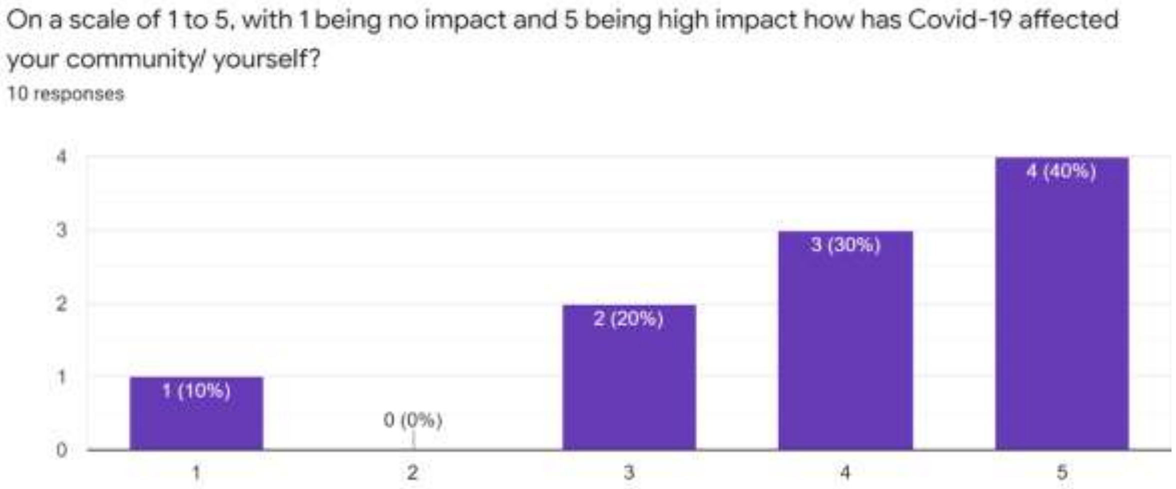


Fig. 17 C-19 Impact

Please use the space below to provide further details on how, if at all COVID-19 has affected your community/ yourself.

Felt isolated
Isolated us all
There has been huge impact on our community coming together and socialising
Loss of jobs and incomes, some people lost their homes, families breaks, raise of domestic abuse and addiction of alcohol and drugs. Also a huge negative impact to Mental Health and Wellbeing to all kind of age of people – kids, young people, adults, elderly people.
Misinformation regarding vaccines has deterred people from vaccination
I am unsure about this
Loneliness
Dogsthorpe is a residential ward with a large number of elderly people who have felt isolated. There are also a large number of parent/ carers and they too have felt isolated. I do not have any data to suggest they have been any more or less disadvantaged than the national or regional average.

Table 15. C-19 Impact on Seldom Heard Parent Carers

From looking at the responses of the community leaders two main factors can be identified; information and support.

Co-production and Change

Topics of Importance (ToI)

In the last quarter the ‘Educational Experience’ ToI was published and a response[1] has now been produced. The areas for consideration by PCC were:

1. For PCC to consider developing easy to digest guidance for EHC Needs Assessment Requests – this to mirror guidance for PfA coproduced after a previous ToI

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[1] https://www.familyvoice.org/sites/default/files/Topic%20of%20Importance%20Response%20-edcuational%20expereicne%20Nov%2021%20.pdf#overlay-context=Participation

2. For continuation of key messages to all SEND parents via letters from the PCC, as started during periods of lockdown
3. For PCC to share more widely their statistics relating to EHCp's from requests to assess to plans issued

Recommendations/ Forward Plans

1. Develop the next round of ToI's starting with Seldom Heard Communities.
2. Raise the needs and concerns of Seldom Heard parent Carers and Community Leaders at the appropriate strategic boards.
3. Work continues to engage with a wider more diverse section of the parent carer community locally.