
FVP Interim Report

January - March
2022

FVP Parent Representatives

Introduction

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.

Work continues using a hybrid model with a mix of face to face and online based on individual need and the types of activities being delivered. This has proved to be cost effective, and beneficial to a range of different individuals included the FVP work force who are primarily parent carers.

12 Workshops, focus groups, and training sessions have taken place in relation to; SEND services, Seldom Heard communities, The Expert Parent Programme and Mental Wellbeing. Some of these have been online and others have occurred face to face. 2 surveys have taken place looking at Digital Access and SEND Services. & community cafes and 2 meet and eats also took place.

Participation/Engagement/Involvement January to March 2022

Headlines

- 1) 309 named parents in total have been involved at some level which is a 4.74% increase since the last quarterly report
- 2) Parent carers where known report having a total of 383 which is an increase of 3.72% children and young people with SEND within their house-holds, and at 143 siblings no change.
- 3) 18 fathers have been involved overall up from 17 in the last quarter.
- 4) 91 parent carers have participated across 2 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, Nigerian, 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 Expert Parent Programme workshop and two mental health and wellbeing workshops. FVP have also started to introduce community cafes, although not directly relating to this area alone, they do have an impact on emotional health and wellbeing. General signposting and support has also continued.

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.

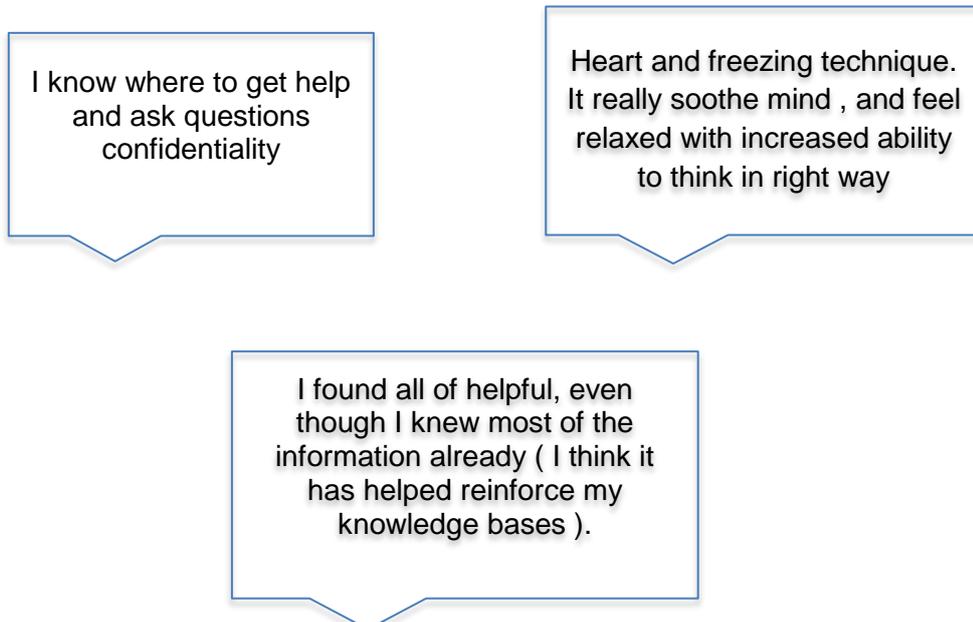
Virtual Workshops

Three virtual workshops have occurred in this quarter. From Fig. 2 it can be seen that it was possible to deliver 3 sessions relating to CAMHS funded work resulting in 14 individuals receiving support. There was an overall drop-out rate of approx. 43%

CCG/ Training	Date	Number of Adults
Wellbeing (sleep)	1/2/22	6
Beeches - Expert Parent programme	7/3/22	10
Wellbeing (resilience)	22/3/22	4

Table 1. Workshop Attendance Information

What did you learn, what helped?



Community Café

Community	Date	Number of Adults
Community Cafe	15-Dec-21	11
Community Cafe	12-Jan-22	4
Community Cafe	19-Jan-22	4
Litter Pick (Goldhay Centre)	5-Feb-22	6
Community Cafe	9-Feb-22	7
Community meet and eat	16-Feb-22	7
Community Cafe	9-Mar-20	7
Community meet and eat	16-Mar-22	11
Community Cafe	23-Mar-22	4
Community Cafe	30-Mar-22	3

Table 2. Café and Other Community Activities

Signposting/ Support Requests

3 families have completed our new support request e-form with the support relating to education, and access to short breaks.

We have had a further 15 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. 42.86% of the parents who have requested support do not classify themselves as White British. The parents have a range of CYP who are aged between 5 and 10 or 15 and 20 primarily. Their needs range from AS through to complex health and visual impairment.

Work in this area has been slightly lower, in part due to this quarter being the last of the financial year, and some focus being diverted to end of year work, data monitoring and closing grant programmes. There has also been less board/ meeting attendance in this area due to strategic level changes within the health sector.

Care Education & Treatment Reviews (CETR) Attendance

FVP have provided an Expert by Experience (EbE) for 16 CETR's this quarter, with the EbEs reporting concerns about lack of provision within the community to meet the growing complexities of needs of the CYP requiring a CETR. A blocker to good outcomes does appear to relate to community provision and also lack of joined up working at an operational level between services across health, education and social care. It has been reported though that the key work programme is starting to make a difference and enable good support for CYP with LD and/ or ASD.

Schools Data/ SEND

Surveys

During this quarter there have been 2 surveys conducted with the main survey (Annual Survey) having been reported on separately in the annual survey cross comparison report, which is available via our website www.familyvoice.org. The digital access survey will be reported on in the body of this report.

Survey Title	Responses
Annual Survey	62
Digital Access	29

Table 3. Survey Response Numbers

What are parents telling FVP?

From the surveys conducted and more generally there are still three main areas of concern; Support, Involvement and Information whether this is in relation to Education, Health or Social Care and more specifically EHCp work, PfA, Settings or Carers Services. These are just some of the examples of areas where parent carers have expressed their views.

Digital Access

The digital access survey was completed online and via postal surveys with 29 responses. The survey was conducted with the support of CPFT and looked broadly at barriers to accessing information in a digital world.

CYP Demographics

Parent carers who responded reported having 51 CYP with needs and 37 without needs. The needs included; Down Syndrome, Dyslexia, ASD, ADHD, GDD, Visual Impairment, Hearing Impairment, Spina Bifida, SEMH, Physical Disabilities, Cerebral Palsy, Epilepsy and other health needs. Their ages ranged from 1 to 20 and the majority were recorded as male. Of the 18 recorded as female, they were more likely to be recorded as having needs other than ASD/ ADHD. Those CYP in school attend a range of settings including Maintained, Academies across Primary, Secondary and Special.

Parent Carer Household Demographics

Parent carers opted to provide further information relating to their household; of these 9 self-declared as White British, and 1 declared as Polish, 2 as Black African, 1 as Indian and 1 as British Pakistani. 8 of those who completed the question also stated they had one or more adults in the household (including themselves) with a health need or disability. 6 stated they were in receipt of some form of household benefits.

In answer to the more specific question 'Is English Your First Language'

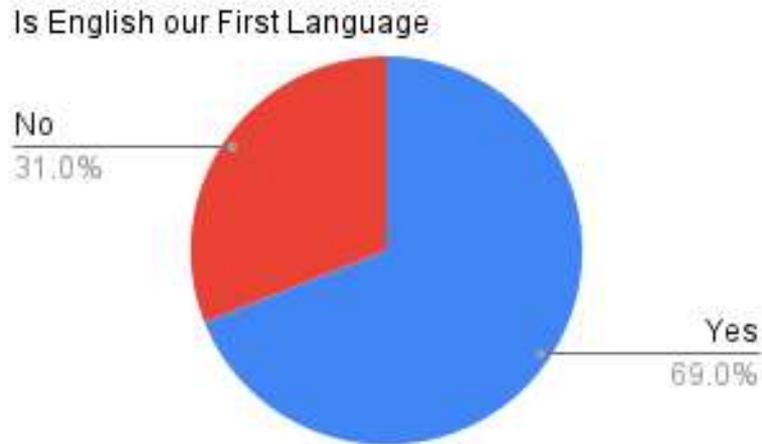


Fig.1 Parent Carer Language

It should be said this is not in itself a barrier to access in terms of digital access

Current Digital Access

Questions relating to current access were

1. Do you have access to the internet?
2. Do you have access to any of the following digital equipment?
3. Do you use social media?
4. Do you have an email address?

In regards to the above questions the responses were as follows:

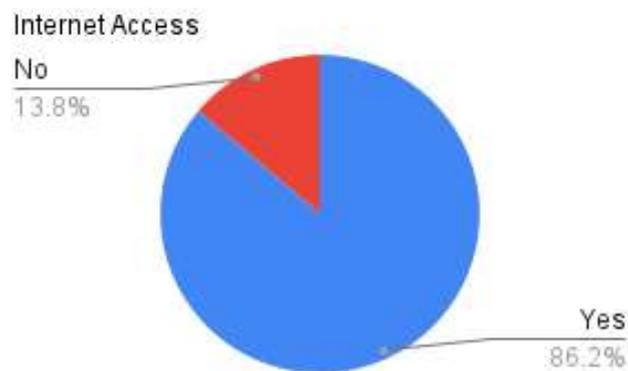


Fig. 2 Internet Access

The internet is accessed in a variety of ways, as shown in fig.3 below

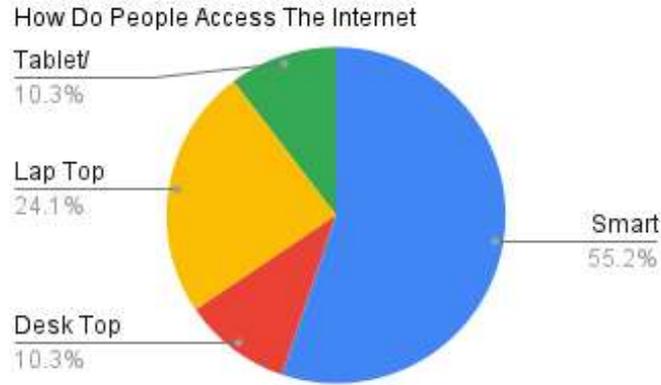


Fig.3 Accessing the Internet on different devices

Social Media Use is varied, and only one person stated they do not use social media. This can be seen in fig.4.

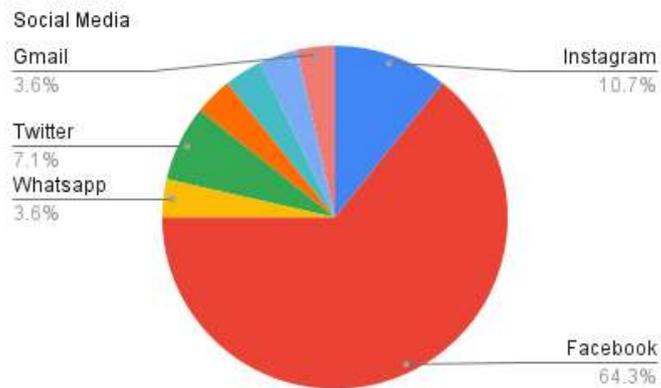


Fig.4 Social Media Access

Interestingly when asked the questions “Do you have an email address?” two people stated No, yet one of these selected having access to a smart phone and IPad and sated they used social media, where an email address is required.

Potential Barriers to Digital Access

- Can you afford access to the internet?
- Do you know how to use information technology?
- What are the key barriers/ challenges/ difficulties in you accessing the internet or digital equipment if any?

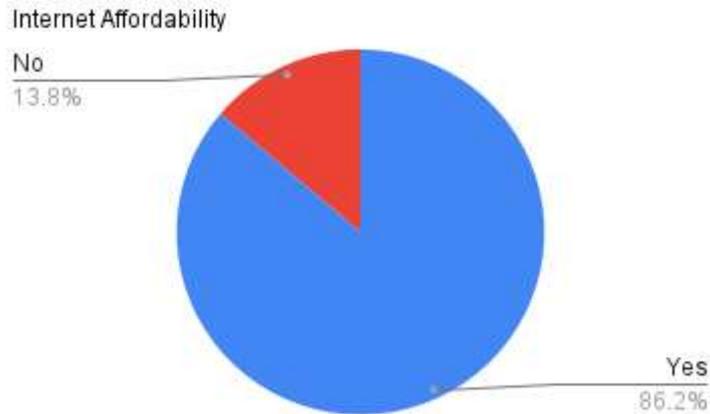


Fig. 5 Internet affordability as a barrier

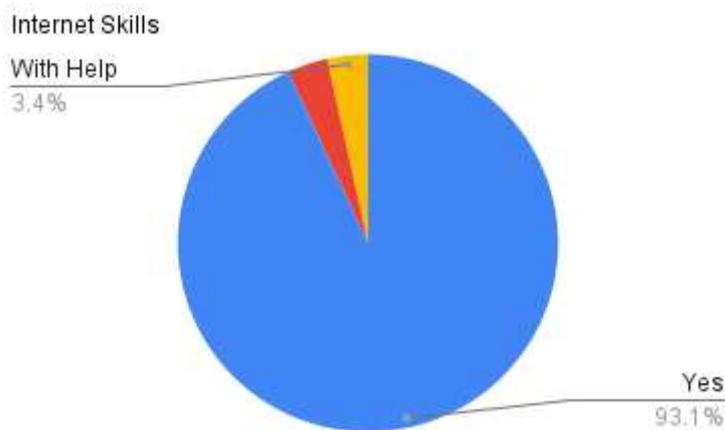


Fig. 6 Internet Skills as a barrier

Is there a digital access barrier?	Responses
I do not have any problems accessing the internet or using digital devices	14
I am a survivor of Domestic abuse and avoid using the internet/social media	1
I can't afford internet or laptop	5
I struggle due to barriers relating to language	2
As long as it is explained clearly it is fine	1

Table 4: Digital Access Barriers

Overall Analysis

Digital access is a more complex issue, than people may realise and relates to factors such as digital poverty digital literacy and device access to name a few, as highlighted here. Some families experience range of factors, which may explain why accessing services digitally is problematic and leads to people facing barriers. An example her, may be where a person has a smart phone, which is ok for general use and social media access may may not be sufficient for online meetings.

Facebook Discussions

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

Anyone have experience of Wild Lodge School? There is a possibility that my son may end up needing a specialist placement and this was once of the places brought up in the meeting
Hi all. My 11yr old son with ASD has stopped eating. It appears he can eat/swallow and used to be ravenous but over the past 3 months it's declined hugely and he's lost weight. He rolls the food about in his mouth or just holds food/liquid. Have resorted to feeding at times out of desperation. Bloods came back ok. SALT dysphagia team say his swallowing is fine although he chomps rather than chews. Dentist says teeth are fine. Went private to see a paediatrician who says mouth tonsils etc are fine. Suspect this is sensory as it coincided with him having wobbly molars/losing teeth. Any help support much appreciated 😊
What do you think an autism specialist is and what do you expect from them?
"I'm looking to set up regular meetings for parents of autistic children/young people. The purpose will be: - To lobby government via our local MP to get funding for services for our children. - To influence local spending and have a say where money is spent - To identify gaps in provision, establish a communication channel into health, education, social care If you are interested, please comment below and pm me with your email address. Many thanks."
"Hi Just wondering if you've had to remove your child from a school due to safe guarding issues and have followed the complaints procedures, can you ask/pull the EHCP funding to facilitate home learning and educational support. The LA have said the school are to provide suitable home schooling and support but we have waited 14 days with nothing and want to support our child. TIA"

Table 5. Facebook Discussions

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
38	56.5	41	0	160.5

Table 6. Breakdown of Time spent at Strategic Meetings Jan to March

Information & Awareness 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. Most sessions are made available to the public on YouTube https://www.youtube.com/channel/UCN-Zqf_9Sbz0a_kTQ1SsY2w

Information and Awareness	Date	Number of Adults
Open Forum-EHCp Annual reviews with focus on transition points	18/1/22	9
Open Forum-Health services and digital access	8/2/22	6
SENDIASS focus group	09/03/2022	9

Table 7. Information and Awareness Sessions

Schools Engagement

Information and Awareness	Date	Number of Adults
Beeches Coffee Afternoon	03/02/2022	2
Beeches Coffee Morning	31/3/22	5

This work area has had a slow start, but more recently has seen two new settings make contact to secure support of the forum for document review and SEN Information report development. Work with Beeches Primary, has informed the ongoing pilot work to establish what does and does not work.

What has gone well?

Sharing other agencies, charities, specialist services and just for parents to know they are not on their own and widen our community.

What has not gone so well?

Ensuring parents know of the services that are available to them, for me to learn about new services I can refer to and/or invite in for other coffee mornings

What could be improved?

SEND information report workshop/collaboration but this was affected by COVID/being on zoom etc

General Feedback

Working with Family Voice has been very important for our school over the last academic year. It has provided opportunities for parents to know there is a network of people they can talk to and ask questions to, we have learnt lots as a school community about the resources and services that are just at our doorstep.

Online courses have also increased confidence of parents.

I look forward to working with them more in the future!

FVP have also now started work with William Law and Ken Stimpson, with work planned for next financial year.

Seldom Heard Communities

Work with Seldom Heard communities continues and it has also been possible to factor in one session with the Parent Carers from the Aiming High Group (AHG), who are particularly interested in moving towards PfA as this is where their young people are. It was also beneficial to the parents to get together for their own emotional health and wellbeing, especially as they had not been together since before Lock Down

Seldom Heard Themed Sessions	Date	Number of Adults
SHCF-Appointeeship	19/1/22	9
Community Leaders Event-Inclusion (Caring together event)	11/03/2022	10
AHG Get Together	31/03/2022	7
SHCF- GP	31/03/2022	8

Table 8. Seldom Heard Engagement

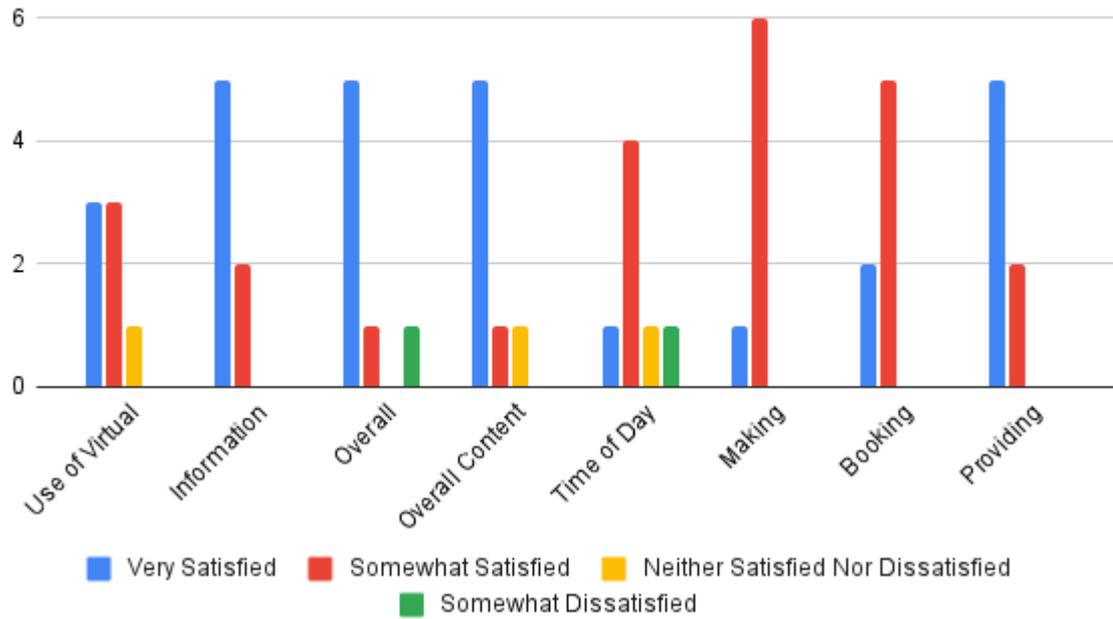
Parent Carer Support

FVP have also seen an increase in individual seldom heard parent carers seeking support of some kind. 47.05% of those seeking support this quarter self-declared as British Asian, Polish, Black British or Indian. Three of those who had made contact are also Fathers.

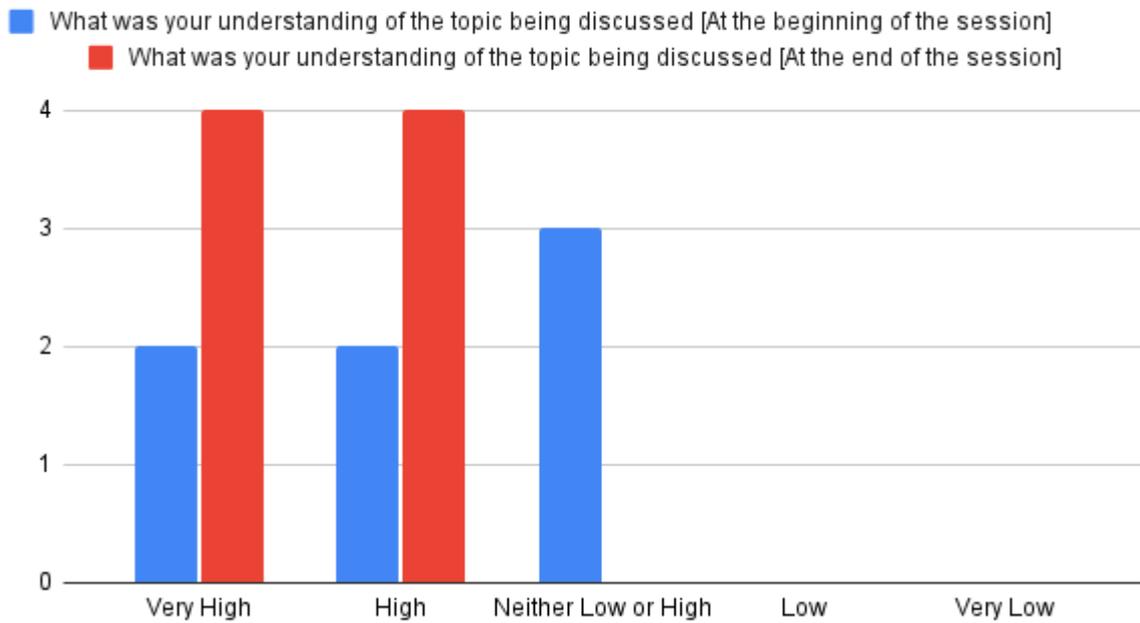
Requests for support have related to PfA, Education, Social Care in particular Respite and Benefits.

We also ran once session specifically for Seldom Heard Community leaders in conjunction with Caring Together to raise awareness and facilitate support. 10 people attended and 7 provided feedback. Communities represented were Nigerian, Kenyan, Chinese, and Kurdish.

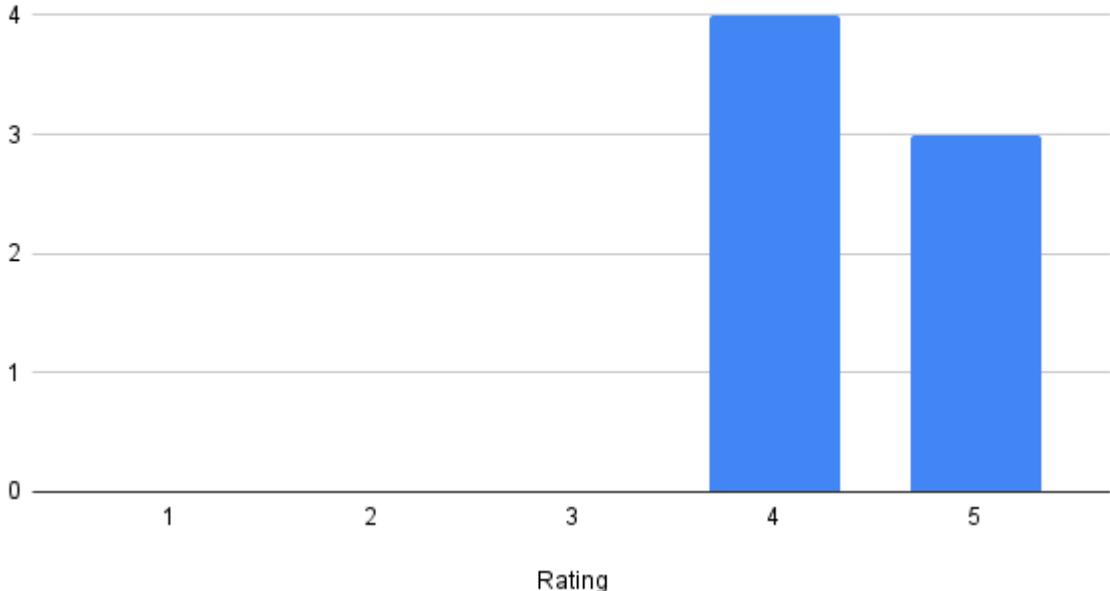
Satisfaction Rate Across Event Areas



Understanding of Topic



Enabling Integration (1 no integration to 5 full integration)



Co-production and Change

There have been no Tol's produced in this quarter, as there has been more focus on gathering information, parent carer views and focusing on ensuring charity variability. This does not mean that co-production and change has not been occurring though.

Having Parent Reps on so many work streams, and being actively involved in the OFSTED/ CQC Area Wide SEND Re-visit demonstrates that at a strategic level co-production is readily occurring. There is far more strategic involvement of parent carers on an ongoing basis than in previous years, this area has grown and continues to do so.

Work is still required to see proper co-production at an individual/ operational level, as evidence by the views shared in the Annual SEND Survey. There needs to be a great focus by SEND professionals strategically and operationally to work towards enabling individual voice and involvement.

Recommendations/ Forward Plans

1. Develop the next round of Tol's starting with Preparing for Adulthood.
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.
4. Work to enable SEND professionals to seek ways to ensure the involvement of individual families, in their own SEND journey.