



# Voice Collective Evaluation Report

June 2014



Part of  
**Anna Freud  
Centre**



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## GLOSSARY

AFC - Anna Freud Centre

BAU - Bethlem Adolescent Unit

CAMHS - Child and Adolescent Mental Health Services

CYP - Children or Young Person

EBPU - Evidenced Based Practice Unit

EIP - Early Intervention in Psychosis

GFT - Group Facilitation Training

IoP - Institute of Psychiatry

PLE - Psychotic like Experience

SLaM - South London and Maudsley

UCL - University College London

## RESEARCH GROUP

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# EXECUTIVE SUMMARY

This report presents the findings from Voice Collective evaluation. Voice Collective is Mind in Camden's London-wide project to support young people (aged 12-18 years) who hear voices. Voice Collective seeks to enable young people, and their families in the Greater London region who hear voices, to improve their life prospects, self-esteem and coping strategies, and reduce their isolation by building capacity in existing services to provide improved information, advice and support.

## AIMS

The evaluation ran from 2011-2014 and set out to examine the following aims: whether and to what degree Voice Collective was achieving its aims. To achieve this, the aims were examined in light of the following research questions:

- A. Does accessing Voice Collective services increase young people and their families' self-esteem and coping strategies. If so, through what mechanisms are this achieved?
- B. Does professionals' access to Voice Collective services lead to improvements in access and quality of services provided? If so, through what mechanisms are these achieved?
- C. Has Voice Collective improved the quality and quantity of online information and advice for children and young people who hear voices, their families and carers?

## DATA COLLECTION

To examine the aims, a mixed methods approach was used:

- To assess aim A: Whether Voice Collective has increased young people and their families self-esteem and coping strategies, and if so, through what mechanisms; anonymous questionnaire feedback was collected from young people who attended peer support groups (n=16) and parent who attended peer support groups (n=15). Follow up interviews were also conducted with young people (n=3) and parents (n=4).
- To assess aim B: Whether professionals' access to Voice Collective services, lead to improvements in access and quality of services provided, and if so, through what mechanisms; anonymous questionnaire feedback was collected from professionals that attended workshops (n=314) and those that attended facilitator training (n=39). Follow up interviews were also conducted with professionals (n=12) and those that attended facilitator training (n=3).
- To assess aim C: Whether Voice Collective improved the quality and quantity of online information and for children and young people who hear voices, their families and carers; a number of websites were selected (n=30) to identify whether any changes appeared over the course of the evaluation. Questionnaire feedback on Voice Collective's own website was also examined (n=9).

## DATA ANALYSIS

The collected data were then analysed in the following ways:

- Questionnaire feedback was collated and descriptive analysis undertaken.
- Interview data was examined using thematic analysis to identify individual's perspective and experiences, and to the impact on the individual of support from Voice Collective.
- A change in online resources was examined using a pragmatic content analysis.

## MAIN FINDINGS

Findings are presented below in relation to the research questions:

### Aim A: Key perspectives and impact of support for young people and families

- Overall, data collected from young people indicated that they found individual and peer support useful. Thematic analysis from interviews and feedback from questionnaires suggested that young people perceived the Voice Collective as an organisation that: taught them new coping strategies, listened to them, reduced their feelings of isolation, and approached voice hearing in a normalising, non-stigmatising way.
- For young people, this resulted in them feeling empowered by not seeing themselves as mentally ill, as well as being able to cope with voices better in their daily lives.
- Data collected from parents also indicated they found Voice Collective support useful. Thematic analysis from interviews and feedback from the questionnaire suggested that parents perceived the Voice Collective as an organisation that: reduced their feelings of isolation, listened to them, approached voice hearing in a normalising and non-stigmatising way where they could share and gain knowledge about voice hearing, and that could be a safety net in times of need.
- For parents, this resulted in them feeling empowered to support their young person that heard voices.
- Both parents and young people felt peer support was appropriate for their needs.
- Barriers and improvements suggested by young people were to have peer support groups with narrower age ranges.
- Barriers and improvements suggested by parents were to have peer support groups in more locations outside London.

### Aim B: Key perspectives and impact of support for professionals and facilitators

- Both professionals and facilitators perceptions and feedback from workshops were that they contributed to their understanding of the experience of voice hearing, as well as how to work with young people who hear voices.
- For professionals, this enabled them to feel more confident in working with young people who hear voices, feel more compassion and empathy for young people that hear voices, and being able to better normalise the experience of voice hearing.
- For facilitators, this enabled them to feel more confident in setting up a peer group and working with young people who hear voices.
- Only one facilitator interviewed had set up a peer support group, but thought that young people enjoyed having a space to talk, feel listened to, and feel less isolated.
- Facilitators who had yet to set up peer support groups thought that training still helped them to improve working with young people who hear voices, as they reported using less stigmatising language and normalising the experience of voice hearing.

### Aim C: Changes in quality and quantity of online resources

- Voice Collective has influenced the quality and quantity of some web-based literature. Websites such as Childline had referenced them in their interactive 'Ask Sam' discussion page. However, with some other websites such change cannot be directly attributable to Voice Collective, but may be due a wider shift in the hearing voices movement.
- Most young people, parents and professionals found Voice Collective's website useful for gaining further information and support on voice hearing. Some individuals said they found the website difficult to navigate and spoke about difficulties with the forum section. However, the latter has since been improved.

## LIMITATIONS

Whilst these findings are encouraging, one should bear in mind:

- The sample sizes were small for questionnaire and interviews collected from parents and young people that may affect results.
- All parental interviews conducted were with young person's mother.
- This evaluation captured young people and parents who had prolonged access with Voice Collective services in a voluntary capacity, and as a result may be happier with the support received than those who dropped out after initial contact.

## AREAS FOR FURTHER DEVELOPMENT

Future areas Voice Collective may want to focus on include:

- Setting up age related peer support groups to better fit the needs of young people who hear voices.
- Setting up peer support groups (parent and child) throughout the UK so that more people have access to such resources.
- Developing web-based support further for individuals who cannot physically access such events.
- To investigate reasons why young people and parents may not attend Voice Collective services, or choose not to return to individual and group support.
- To investigate the role and impact of Voice Collective on other family members such as siblings and fathers.
- To investigate further what different professional groups (generic vs. mental health professionals) take away from Voice Collective services



# INTRODUCTION

## BACKGROUND

'Hearing voices' is a term commonly used to describe unusual sensory perceptions or hallucinations, such as seeing visions or hearing voices, in the absence of identifiable stimuli. Whilst voice hearing was once thought to be an indicator of severe mental illness, most notably psychotic disorders (Bettes & Walker, 1987; Green et al, 1992; Galdos & Murray 1993; Galdos & van Os, 1995) epidemiological evidence suggests that these experiences are relatively common in childhood and adolescence, with prevalence rates between 5.7 and 21% (Bartels-Velthuis et al, 2010; Dhossche et al, 2002; McGee et al; 2000; van Os et al, 2009; Yoshizumi et al, 2004).

Attitudes towards, and explanations for, voice hearing have changed over time (Leudar, 2000). Traditionally, action taken by professionals in response to voice hearing would be to pathologise such experiences, prescribe antipsychotic medication, and see such individuals as 'patients' or 'sufferers' (BPS, 2000; Leudar, 2000). However, in light of voice hearing being more common than previously thought (Bartels-Velthuis et al, 2010; Dhossche et al, 2002; McGee et al; 2000; van Os et al, 2009; Yoshizumi et al, 2004) and that such individuals are not always adversely affected by their experiences (Romme and Escher, 1989), it has been proposed that alternative explanations to voice hearing should be examined (BPS, 2000). One such approach, pioneered by Romme and Escher, is to treat the experience as unusual rather than abnormal; meaningful, rather than just symptoms to be eliminated or dulled by medication; and a part of human experience that is a response to trauma, rather than as a specific 'illness'.

In adult populations, group work for people who experience auditory hallucinations has been reported to be beneficial in providing a supportive and empathetic environment, to discuss the difficulties associated with this condition (McLeod et al. 2007a, McLeod et al. 2007b; Newton et al. 2007). Similar supportive groups have been trialled for young people who experience voice and other hallucinatory experiences, with reported success. Research published by Escher et al. (2002) suggests that there is considerable scope for improving the experience of young voice-hearers. By building on the work already undertaken on voice hearing with adults in Holland by Professor Marius Romme, Escher et al. (2002) carried out research with 80 children and young people who heard voices, aged between 8 -18 years. When these young people were encouraged to discuss their experiences of voice hearing in an open and supportive environment, to make sense of their voices and their voices relationship to their life experiences, research showed that they were less likely to experience long term problems.

## VOICE COLLECTIVE PROJECT AIMS

Voice Collective is Mind in Camden's London-wide project that supports young people who hear, see or sense things that other people do not. It aims to enable children and young people (CYP) who hear voices, to improve their self-esteem and coping strategies, and to reduce their isolation by providing opportunities for CYP and families with similar experiences to meet together, by providing one-to-one support, and by building capacity in existing services to provide improved information, advice and support. Specifically, it aims are to:

1. To increase young people's self-esteem and coping strategies by creating and supporting opportunities for children and young people who hear voices and their families, to come together for support;
2. To increase access for children and young people who hear voices to generic services by increasing the skills, confidence, and capacity of staff in generic agencies to offer their services to them;

3. To improve the quality of services received by children and young people who hear voices, by increasing the skills and confidence of mental health workers in providing recovery-oriented support;
4. To improve the quality and quantity of information and advice resources available for children and young people who hear voices, their families and carers.

## ACTIVITIES

The Voice Collective project had various activities for young people and their families:

- Peer support groups: for young people who hear voices, and their families/carers to meet with other families with similar experiences, facilitated by a member of Voice Collective team.
- Creative arts workshops for young people using a range of creative activities.
- Workshops for families/carers and professionals that work with CYP.
- One-to-one support: via telephone, email and face-to-face meetings, accessed 'as' and 'when' needed by young people, their families and professionals that work with CYP.
- Information and advice: about hearing voices, including details of groups and other supporting services via Voice Collective website.
- Training courses and presentations for professionals that work with CYP.

Peer support groups were run in partnership with external youth agencies, and were facilitated by trained and supported staff and volunteers from that agency (alongside Voice Collective staff and volunteers where necessary). All other activities were provided by members of Voice Collective project team (including some staff and trained volunteers with personal experience of voices and visions).

## VOICE COLLECTIVE GROUPS

Voice Collective has 4 groups; within the boroughs of Bromley (Bethlem Adolescent Unit, South London and Maudsley NHS Foundation Trust), Greenwich (Interesting Minds; Greenwich CAMHS, Oxleas NHS Foundation Trust), Lambeth (Lambeth CAMHS, South London and Maudsley NHS Foundation Trust) and Camden (The Anna Freud Centre). For all sites except BAU, young people and families' could self-refer to Voice Collective via Voice Collective website ([www.voicecollective.co.uk](http://www.voicecollective.co.uk)) or could be signposted to Voice Collective via NHS staff or other agencies.

## BREAKDOWN OF USE OF VOICE COLLECTIVE SERVICES

Table 1: Breakdown of use of Voice Collective services

	2011-2012	2012-2013	2013-2014
<b>Number of young people supported</b>	46	99	104
<b>Number of young people engaged in peer support groups &amp; creative workshops</b>	14	36	66
<b>Number of parents supported</b>	36	38	40
<b>Number of parents engaged in peer support workshops</b>	10	9	24
<b>Number of 1-2-1 sessions for young people and their families (in person or by phone)</b>	110	113	148
<b>Number of email support sessions</b>	175	281	720

	<b>2011-2012</b>	<b>2012-2013</b>	<b>2013-2014</b>
<b>Number of workers trained/ mentored</b>	178	234	281
<b>Number of unique visitors to website</b>	17,376	27,429	39,704
<b>Number of parent booklet downloads</b>	705	1,452	3,917

## KEY QUESTIONS FOR THE VOICE COLLECTIVE EVALUATION

The purpose of the evaluation was to evaluate progress made by Voice Collective in relation to achieving its four key aims during its capacity building phase. These objectives were operationalized in Table 2 into three key research questions:

The aim of this report is to present findings in relation to these evaluation questions, and highlight key learning as well as areas for further consideration.

Table 2: Research questions relating to the aims of Voice Collective

AIM	ASSOCIATED RESEARCH QUESTIONS	SUB QUESTIONS
<p><b>Aim 1: To increase young people's self-esteem and coping strategies by creating and supporting opportunities for children and young people who hear voices and their families, to come together for support</b></p>	<p>1. Does accessing Voice Collective services increase young people and their families' self-esteem and coping strategies,</p> <ul style="list-style-type: none"> <li>If so, through what mechanisms are this achieved?</li> </ul>	<p>A. What were perceptions and experiences of Voice Collective's peer support groups and one-to-one provisions?            B. What is the impact of Voice Collective peer support groups and one-to-one provisions on the coping, self-esteem and quality of life for young people that hear voices?            C. How appropriate were they for young people that hear voices and their families' needs?            D. Were there any barriers to accessing the peer support groups and one-to-one services?</p>
<p><b>Aim 2: To increase access for children and young people who hear voices to generic services by increasing the skills, confidence, and capacity of staff in generic agencies to offer their services to them and</b></p>	<p>1. Does professionals' access to Voice Collective services, lead to improvements in access and quality of services provided?  <ul style="list-style-type: none"> <li>If so, through what mechanisms are these achieved?</li> </ul> </p>	<p>A. What were their perceptions and experiences of these training opportunities?            B. What was the impact of these training opportunities for attendees' on-going practice, in relation confidence and skills in engaging and working with young people who hear voices?            C. What was the wider impact of these training opportunities on generic and specialist agencies' attitudes to voice hearing?</p>
<p><b>Aim 3: To improve the quality of services received by children and young people who hear voices, by increasing the skills and confidence of mental health workers in providing recovery-oriented support</b></p>		
<p><b>Aim 4: To improve the quality and quantity of information and advice resources available for children and young people who hear voices, their families and carers</b></p>	<p>1. Has Voice Collective improved the quality and quantity of information and advice of web based resources available for children and young people who hear voices, their families and carers?</p>	<p>A. To what extent has Voice Collective influenced the quality and quantity of existing materials to support young people who hear voices and their families?            B. What was the feedback from Voice Collective from young people and families accessing website?</p>

## EVALUATION METHODOLOGY

In order to evaluate the services provided by Voice Collective, a Realistic Evaluation framework was used to assess the outcomes of the project against the underlying programme theory, particularly in relation to achieving its objectives.

Realistic Evaluation was chosen for three main reasons:

1. Because type of support provided by Voice Collective draws specifically on premises developed by Romme, Escher and colleagues and we wanted to incorporate this underlying programme theory in our approach
2. Because lends itself well to a mixed qualitative and quantitative approach
3. Because the emphasis of this approach is not just on outcomes but also how positive outcomes are achieved and under what conditions

Under this framework, views and responses were collected from CYP, families/carers and professionals based on a) questionnaire feedback collected at peer support and at workshops and b) interviews. In addition information will also be collected by scoping and reviewing existing information and advice resources available to young people who hear voices and their families.

## QUESTIONNAIRE FEEDBACK

Questionnaire feedback was used by Voice Collective to collect information on the workshops and peer support groups. Questionnaires contained a mixture of open ended questions and 6 point Likert scales. For professionals, the content of the questionnaires focused on what they found helpful in the training, and how it improved their understanding knowledge and skills in relation to voice hearing (see appendix). For young people and their families, the content focused around how the workshop helped them or their young person that hears voices (see appendix).

With professionals, 314 questionnaires were collected across 36 workshops. Questionnaires were administered in paper form at the end of the workshop, and completion was optional. Questionnaires were then collected by a member of Voice Collective staff, and given to the researcher during monthly meetings with Voice Collective.

For children that hear voices, 16 questionnaires were collected from across 4 peer support workshops. These were located at: the Anna Freud Centre, Bethlem Adolescent Unit, Lambeth, and Greenwich. Young people were given the option of completing paper questionnaires at the end of the peer support workshops, approximately every 5 weeks. These were then collected by a member of Voice Collective staff, and given to the researcher during monthly meetings with Voice Collective.

For parents, 15 questionnaires were collected. Parent peer support workshops took place once every 3 months at varying locations. After the peer support workshops had taken place, parents were given the option of completing the questionnaires. Completed forms were then collected by a member of Voice Collective staff and given to the researcher during monthly meetings with Voice Collective.

## INTERVIEWS

11 professional interviews, three facilitator interviews, three CYP interviews, four parent interviews were carried out as part of this evaluation. Interviews were semi-structured, using interview schedules (see appendix). To conduct interviews, evaluation slips were also provided at the end of the professional and peer support workshops, when questionnaires were handed out. The evaluation slips briefly informed that an evaluation was taking place, and for individuals to fill out their details if they wanted to find out more (see appendix). Voice Collective staff passed completed evaluation slips to the researcher who contacted the participants to give them more information over the phone, as well as sending information sheets by email or post (see appendix). Participants that wanted to take part were sent consent forms; and parental ones for those aged under 16 (see appendix) with a stamp addressed envelope back to the Anna Freud

Centre. Interviews took place over the phone, if the interviewee was over the age of 16, or in a location that was chosen by the interviewee if they were younger. Interviews with participants that were under 16 took place with another adult (in the one case included in this evaluation, this was the parent) to abide by safeguarding procedures.

## REVIEW OF WEB-BASED INFORMATION AND ADVICE RESOURCES AVAILABLE TO YOUNG PEOPLE WHO HEAR VOICES AND THEIR FAMILIES

Voice Collective also aimed to target organisations that they could make strategic links with, as well as aiming to target webpages from organisations with content that had information about voice hearing, but may benefit from including other (non bio-medical) approaches. Identified sites were monitored throughout the duration of the project for any signs of change, such as links, direct references to Voice Collective or changes in content/language to a more normalising approach consistent to that of Voice Collective.

## FINDINGS

Findings are discussed in terms of the three primary evaluation questions:

1. Does accessing Voice Collective services increase young people and their families' self-esteem and coping strategies, and if so, through what mechanisms?
2. Does professionals' access to Voice Collective services lead to improvements in access and quality of services provided?
3. Has Voice Collective improved the quality and quantity of information and advice of web based resources available for children and young people who hear voices, their families and carers?

FOLLOW THE YELLOW BRICK ROAD TO 'COMMON GROUND', BEWARE SHORTCUTS  
 WE'VE MOVED FROM YOUNG PEOPLE WHO HEAR VOICES AT OUR HEADS  
 LET YOUR VOICE BEARD WORKING - AUGUST 2013  
 WWW.VOICECOLLECTIVE.CO.UK



280 MILLION PEOPLE USE VOICE COLLECTIVE'S HEADS  
 A STORY LETS US TRY TO...  
 VOICES & VISIONS  
 A guide to coping with...  
 VOICES & VISIONS  
 A straight talking introduction...  
 VOICES & VISIONS  
 DOES IT FEEL LIKE YOU...  
 VOICES & VISIONS  
 IF YOU'VE EVER...  
 VOICES & VISIONS  
 Q. CAN YOU TELL WHO HEARS VOICES?  
 VOICES & VISIONS  
 THE VOICES IN MY HEAD INSPIRED ME TO CHANGE THE WORLD  
 Q. CAN YOU TELL WHO HEARS VOICES?  
 VOICES & VISIONS  
 VOICES GAVE ME THE SECURITY OF BEING...  
 VOICES & VISIONS  
 VOICES HOLD EXPERIENCES I CAN'T...  
 VOICES & VISIONS  
 VOICES TOOK THE PLACE OF MY PAIN AND GAVE WORDS TO IT  
 VOICES & VISIONS  
 VOICES ARE SANTS, PROPHETS, SHAMANS, CLERICS AND ORacles OF THE FUTURE  
 VOICES & VISIONS  
 VOICES ARE THE SILENT PART OF ME, THE MADNESS IS NOT LISTENING TO THEIR PAIN  
 VOICES & VISIONS  
 Q. WHAT DO THESE FAMOUS PEOPLE HAVE IN COMMON?  
 JOHN FRUSCIANTE  
 MAHATMA GANDHI  
 ST JOAN OF ARC

**ROACH WIDDINGHAM MANAGER**  
 HEARING VOICES IS NOT A SIGN OF ILLNESS - IT'S A SIGN OF OUR ABILITY TO SURVIVE  
 FIND OUT MORE: WWW.INTERVOICEONLINE.ORG

**ROBIN TIMMERS, PSYCHOLOGIST**  
 EXPERIENCING VOICES & LEARNING TO LIVE WITH THEM MADE ME A MORE SPIRITUAL & IDEALISTIC PERSON  
 FIND OUT MORE: WWW.INTERVOICEONLINE.ORG

**DOLLY SEN, WRITER & MANAGER**  
 MY VOICES ARE THE SILENT PART OF ME, THE MADNESS IS NOT LISTENING TO THEIR PAIN  
 FIND OUT MORE: WWW.INTERVOICEONLINE.ORG

**our services**  
 For young people  
 For workers  
 For young people  
 For workers

**Q. HOW OFTEN HAVE YOU SEEN A HEADLINE LIKE THIS?**  
 THE VOICES IN MY HEAD INSPIRED ME TO CHANGE THE WORLD

**our services**  
 For young people  
 For workers  
 For young people  
 For workers

# 1. DOES ACCESSING VOICE COLLECTIVE SERVICES INCREASE YOUNG PEOPLE AND THEIR FAMILIES' SELF-ESTEEM AND COPING STRATEGIES, AND IF SO, THROUGH WHAT MECHANISMS?

## RELEVANT SUB-QUESTIONS

1. What were perceptions and experiences of Voice Collective's peer support groups and one-to-one provisions?
2. What is the impact of Voice Collective peer support groups and one-to-one provisions on the coping, self-esteem and quality of life for young people that hear voices?
3. How appropriate were they for young people that hear voices and their families' needs?
4. Were there any barriers to accessing the peer support groups and one-to-one services?

## SUMMARY OF FINDINGS:

From the data collected, it appears that accessing Voice Collective has positively impacted young peoples wellbeing and coping strategies. The young people surveyed were keen to participate in peer support provided by Voice Collective as they: wanted to meet other young people that heard voices, be able to talk about the experience of voice hearing, and to learn new ways to cope with voice hearing. Perceptions and experiences of support provided from Voice Collective was overall positive. Young people suggesting they got a lot out of both peer and individual support; stating that it helped them 'feel more listened to'. Themes drawn from interview data indicated that young people saw Voice Collective as a place: where they could learn new techniques to cope with the experience of hearing voices, which reduced their feelings of isolation, where voice hearing was approached in a normalising and non-stigmatising way, and which provided them with an outlet for expression. The impact of support from Voice Collective on young people was that they were able to cope with the experience of hearing voices better in their day to day lives, and that they felt empowered as they no longer saw themselves as 'mad' or 'ill'. All young people interviewed indicated that they felt Voice Collective was appropriate for their needs, and that support was there when needed. Barriers in accessing support were focused around the diverse range of age for inclusion (11-18) in peer support groups; which meant that the content and topics of discussion were sometimes unlikely to appeal to those at the lower and upper age limits.

Similarly, support from Voice Collective has positively influenced parents' self-esteem and skills for supporting their young person who hears voices. Parents' perceptions and experiences of support provided from Voice Collective were overall positive, with all rating peer support workshops as 'excellent'. In particular, parents rated helping 'to become better informed' and 'being around other parents' as areas that were particularly useful from peer support. Like young people, parents saw Voice Collective as a place: which reduced their feelings of isolation, where voice hearing was approached in a normalising and non-stigmatising way. Other experiences and perceptions from parents was that Voice Collective was a place: where they felt listened to, where they could share and gain knowledge about voice hearing, and that could be a safety net in times of need. The impact of peer group and one-to-support was that parents felt empowered to support their child. All parents indicated the support they received was appropriate for their needs and that when needed, Voice Collective was able to answer their questions and support them. Barriers in accessing support were related to peer support groups only being located in London. As a result, parents who lived outside had to travel a considerable distance if they wanted to attend.



## BACKGROUND

The aim of this chapter is to characterise young people's perceptions and experiences of accessing Voice Collective's services. Specifically, based on the programme theory, the aim was to assess whether access had improved young people's self-esteem, sense of coping and quality of life; and also to consider the fit between young people and parents' need and the services that were offered, including any potential barriers to access.

Information relating to these aims was primarily derived from two sources: 1) feedback from parents (n=15) and young people (n=16; 7 Greenwich, 2 Anna Freud Centre, 2 Lambeth Child and Adolescent Mental Health Services (CAMHS), 5 Bethlem Adolescent Unit (BAU) about peer support groups, 2) interviews with parents and young people (n=4 and n=3 respectively).

The chapter will first begin with looking at young people in light of the main and sub research questions, before moving onto examining these questions in relation to the parents. The final section of this chapter will draw on the study's findings, looking at wider implications and also reflect on some of the reports limitations.

## YOUNG PEOPLE

### WHY YOUNG PEOPLE WERE INTERESTED IN JOINING A PEER SUPPORT GROUP

Questionnaire feedback from young people on the three things that interested them in joining a peer support group are outlined in the wordcloud below (Figure 1); with a bigger word indicating a more frequent response. Analysis of responses indicated that individuals interests in joining peer support groups were:

- Meeting other people that heard voices
- Being able to talk about their experiences and listen to others
- Learn new coping strategies.

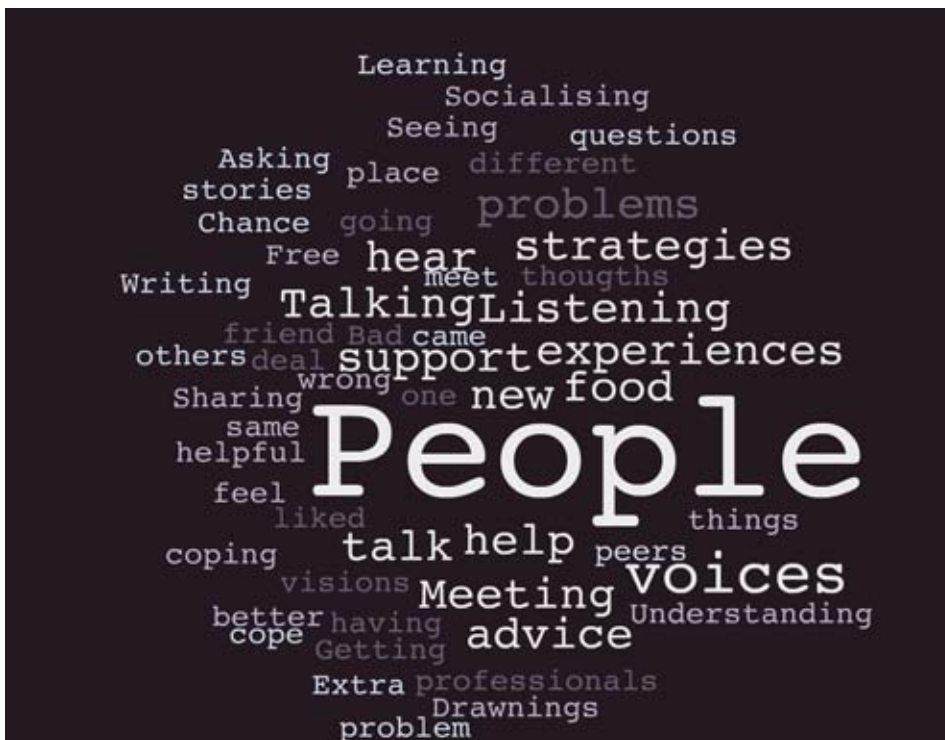


Figure 1: A wordcloud showing responses from young people into reasons they were interested in joining a peer support group

## Q1: YOUNG PEOPLE'S PERCEPTIONS AND EXPERIENCES OF VOICE COLLECTIVE SUPPORT

### Questionnaire feedback

Information from young people's feedback relating to peer support sessions was generally positive with over 50% of total responses being either 5 (helped a lot) or 4 (see Figure 2). The two items that the children and young people felt helped them the most was 'giving them more hope for the future' and 'feel more listened to'. The area that helped them the least was 'helped me find some coping strategies' with four responders giving a responses or [1] or [2] for this. However, the majority of answers this question was still overall positive with 75% of responses being either 5 (helped a lot), 4, or 3.

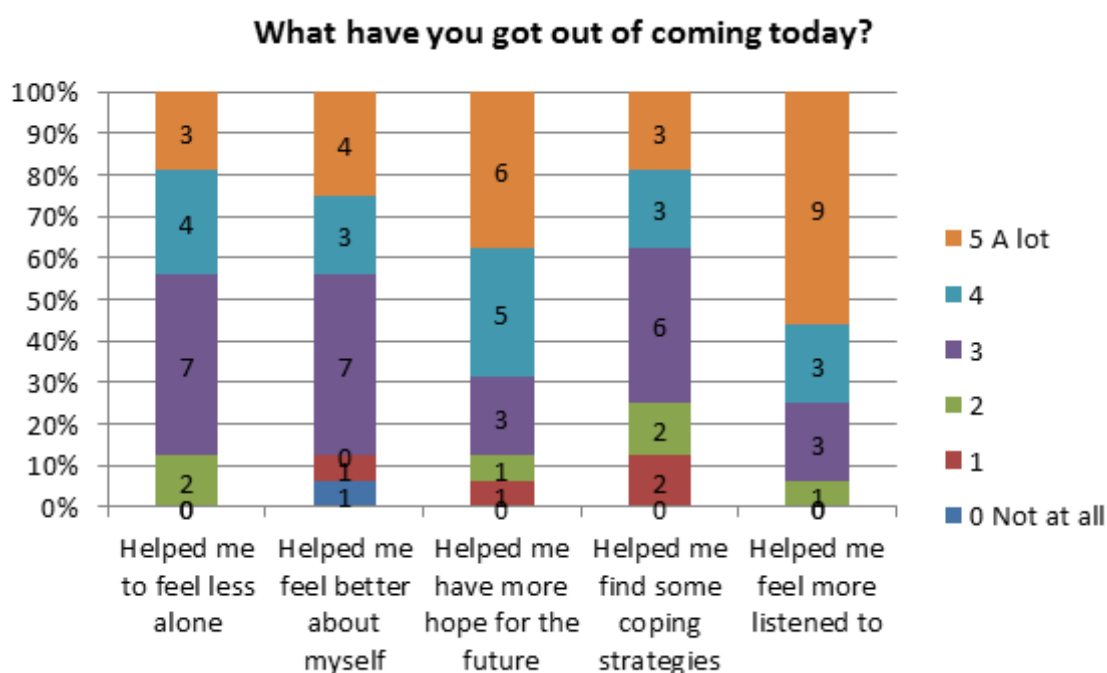


Figure 2: What young people got out of peer group support sessions

### Interviews

Young people were interviewed about their perceptions and experiences of Voice Collective, and their responses analysed using thematic analysis. Four superordinate themes emerged (outlined in Table 3). Their perceptions and experiences of Voice Collective is that it was an organisation that helped them: Learn new techniques and coping strategies to manage voice hearing, reduce feelings of isolation, approached voice hearing in normalising and non-stigmatising way, and provided them with an outlet for expression where they could express their feelings about voice hearing, be that verbally or through creative channels.

Table 3: Themes of perceptions and experiences of what CYP gained from accessing Voice Collective services

SUPERORDINATE THEME						
Name	Age	Ethnicity	Learned new techniques and coping strategies to manage voice hearing	Reduced feelings of isolation	Approached voice hearing in normalising and non-stigmatising way	An outlet for expression
Evie	14	Caucasian	x	x	x	x
Axel	18	Caucasian	x	x	x	x
Zane	18	Caucasian	x	x	x	

Each theme will be discussed individually and narrative support provided. <sup>1</sup>

### Perceptions and experiences, theme 1: Learned new techniques and coping strategies to manage voice hearing

All three young people who hear voices spoke about discussing strategies/techniques with staff or other young people to manage voice hearing. Evie describes this in a peer support context below:

*“well we talked about lots of ways to manage what was going on and like techniques so she would tell me about like grounding techniques and how to manage it well at the time with what was going on I was just in a mess... yeah so it was a lot about managing ways to cope with it”*

Zane also describes a technique he learnt whilst at a creative workshop that helped him to cope with negative thoughts:

*“There’s the one where we had, like, all the bad thoughts about what... when you hear a voice, picking up your special bag to, like, up. I don’t know exactly what it is, you see, it’s something like that...the one with the bag, that was like... that really helped”*

Likewise, Axel also describes a technique that helped him cope with his voices, this time from one-to-one contact with a Voice Collective worker:

*“they [Voice Collective ] helped with regarding coping strategies and stuff like that, just... well, [Voice Collective Project Manager] is like an adult hand at, like, finding various different ways of, and... dividing it into... four categories of coping strategies like distraction and expression and there’s other ones I can’t remember the name of right now but there’s four areas and having something that’s that kind of structured and easy to remember is very helpful because it lets you kind of tick them off as you go around if you’re having a hard time. So I think, yes, it’s definitely boosted that a lot, and my well-being a lot as well”*

For these young people, equipping themselves with tools to manage their voices helped them to feel more in control and had a positive impact on their general well-being.

### Perceptions and experiences, theme 2: Reduced feelings of isolation

All three young people spoke of feeling lonely prior to finding Voice Collective. Evie describes this below:

*“At the time I felt like alone... with what was going on I felt like there was no-one else... around that had the same experience as me...”*

<sup>1</sup> All the names are pseudonymised

Then she expanded on this to describe the benefits of the peer group:

*"I think just being around other people who had the same experiences as you was really good and you felt able to talk about things amongst them that you wouldn't normally say to like people in your everyday life... and I think just being able to escape like 'cause normally I'd hold it all in I wouldn't tell anyone about it but I guess like having the other people around that's really nice...."*

Similarly, Axel described what he liked about the peer groups:

*"It's like a network of other people who have that experience and I find that very helpful because... I don't know why I find it helpful but I find it less isolating as an experience and it makes me feel kind of like a little bit like there's other people who understand, like there's almost like a fraternal feeling in it. I know that sounds a bit weird but like a fraternal idea that there's other people who experience the same thing as you, whereas if it wasn't for that I feel like I'd feel a lot more isolated in society and a lot more weird and freakish, if you know what I mean"*

Zane echoes Evie and Axel's remarks, summing up the way he sees Voice Collective in the following way:

*"If you feel like you're alone, then that's like the common place to go to, definitely"*

For all three young people, being around other young people who were able to understand the experience of voice hearing helped them to understand that there were not alone, reducing the feelings of isolation they were experiencing, and led to a sense of solidarity and understanding among others with similar experiences.

### *Perceptions and experiences, theme 3: Approached voice hearing in normalising and non-stigmatising way*

All young people commented on the how Voice Collective approach made them feel more normal and less stigmatised. When asked to sum up Voice Collective, Axel gave this answer:

*"it's a place where you can talk to other people who have the same experience as you or whatever, you know, something like that or where you can just feel you express how you feel about your voices without fear of being judged or people thinking you're unwell or ill or whatever"*

Similarly, Zane explains that before coming to Voice Collective, he thought the experience of hearing voices was rare, but on coming to Voice Collective workshops, he discovered other individuals like him that heard voices:

*"It sounds like, like, before I came I thought, hearing voices, I thought that was a rare thing. But, apparently it's more common, so it was quite interesting to, like; see other people who heard voices as well"*

For Evie, Voice Collective's normalising approach removed some of the negative connotations associated with voice hearing:

*"they definitely helped me understand that I'm not mad crazy and that's given me definitely given me a confidence boost and I feel a lot better in myself... and... definitely like knowing that there's lots of other people around and that it's okay to hear them and just to generally..."*

### *Perceptions and experiences, theme 4: An outlet for expression*

For Evie and Axel, Voice Collective was also a way of being able to speak and express their feelings and voices. Axel sums this up when describing a peer support group:

*"There was, like, in some... sometimes it would be a lot of talking and discussing things, anything specific to do with voices and feelings and stuff like that, and sometimes it would be more creative pursuits like artistic things, you know, but I suppose as an means of expression towards your feelings and voices and stuff and that kind of stuff so yes"*

For Axel, it was being able to speak to someone individually about his voices, as well as any other topic, that he found beneficial:

*"When I'm talking to her about stuff, it can be a lot of stuff to do with my voices and stuff and, like, feelings and deep things and stuff, but equally I like to talk to her a lot about stuff to do with my course, and just how my life's going in general, and sometimes I just talk to her about fun kind of, like, things that I really like, and I think it's quite nice to have someone to talk to like that who you can talk to about almost anything... Yes, yes, kind of, it's all round but there's always an element of both in every conversation but sometimes it goes towards either side so it's either heavy stuff or light stuff or kind of both. Sometimes it's more there or it's more there, but it's always a mixture of both if you know what I mean..."*

Evie also describes the importance of being able to speak to someone in a one-to-one context:

*"I was able to speak to her [Voice Collective worker]...because I've had a lot of issues with hospitals in the past and them not believing me... accusing me of lying about it and I think... I really felt she believed me and she was interested in what I was saying which was like a big breakthrough at the time for me to have like a professional"*

For Evie, being able to articulate her experiences to someone who was a professional who accepted her description of her experiences meant a great deal to her:

*"that [Voice Collective worker] actually listened rather than just brushed it off and didn't care... she definitely cares and... she's just really, really supportive. I don't feel CAMHS are they don't really listen to me at all I think it's about the listening... and understanding.."*

Moreover, Axel and Evie both indicated that peer support workshops and creative workshops were ways of expressing voice hearing. Axel describes the creative workshops below:

*"a lot of it was themed around voices and stuff, it varied because sometimes you'd have ones that were very explicitly about voices, but sometimes the themes would be a lot more subtle and so there wouldn't actually be much discussion with the subtle ones, but in the very explicit ones they would sometimes coaxed the discussion to the voices or anything else or feelings or, you know, stuff like that so there wasn't actually... other than that, there's not that much of that kind of discussion, if you know what I mean. I would say a lot more of the creative expression stuff. Yes, they're all related to the voices and feelings and stuff, but, yes"*

Evie described how the peer support groups helped her express herself:

*"we would talk, we'll do activities sometimes as well which was really helpful but they would be related into the voices... but I found the creative stuff really helpful 'cause it was just a way of expressing how I felt but through art and stuff..."*

Thus, in some instances young people found the creative outlets for expressing their experiences towards voice hearing helpful, whereas others valued being able to explicitly discuss their voice hearing experiences either one-on-one or in peer groups.

## Q2: IMPACT OF SUPPORT FROM VOICE COLLECTIVE ON YOUNG PEOPLE

The impact of support from Voice Collective on young people that were interviewed produced two super-ordinate themes (outlined in Table 4). The first theme was that they were able to use techniques to cope with voices when outside a Voice Collective setting, and the second theme was that some young people reported feeling self-empowered as they no longer saw themselves as mad or ill. Each theme will be discussed below with narrative support.

Table 4: Themes of impact of Voice Collective services on young people <sup>2</sup>

SUPERORDINATE THEME				
Name	Age	Ethnicity	Being able to cope with voices better in day to day life	Self-empowerment
Evie <sup>2</sup>	14	Caucasian	x	x
Axel	18	Caucasian	x	x
Zane	18	Caucasian	x	

### Impact, theme 1: Being able to cope with voices better in day to day life

Young people reported that learning new coping strategies helped them manage voice hearing when outside Voice Collective setting. Zane describes a coping strategy that he learnt during peer support which he still uses even though he no longer attends Voice Collective sessions:

*“Oh, I mean the first thing which really helped, and I’ve, kind of, used that actually, now... the one where we had, like, all the bad thoughts about what... when you hear a voice, picking up your special bag to, like, up. ”*

Axel also described using coping strategies to help manage his voice hearing and relates this to increase wellbeing:

*“...there’s four areas and having something that’s that kind of structured and easy to remember is very helpful because it lets you kind of tick them off as you go around if you’re having a hard time so I think, yes, it’s definitely boosted that a lot, and my well-being a lot as well”*

Whilst Evie describes using coping strategies at night from the website:

*“I think [being] able to go on the website find the strategies in like a crisis I would be up at night I’d been having a really difficult time just to be able to go on and know that feel that they’re there”*

### Impact, theme 2: Self-empowerment – not seeing themselves as ill

The impact on young people as a result of contact with Voice Collective, was that it allowed them to see things from a different perspective, and in doing so, allowed them not to see themselves as ‘normal’ and not ‘mad’. Axel outlines this:

*“It’s really changed the way I look at the whole situation, and I think it’s... I can’t state that strongly enough really that had I not have met them I think I would have a really, really different approach to the entire mental health thing, scene in general. Like I’m very sceptical of psychiatry now and I’m very sceptical of lots of other status quo kind of mental health doctrines, and I think that’s a very helpful thing, and this approach of, like, just compassion and kindness and, like, treating people as people and not as patients I think is very helpful and very useful. I think that’s... I can’t state strongly enough how good that is.”*

For Axel, his empowerment came from not seeing himself as a patient anymore and challenging psychiatry. Evie also describes a similar response:

*“I think it’s just generally like the confidence they definitely helped me understand that I’m not mad crazy and that’s... definitely given me a confidence boost and I feel a lot better in myself...”*

<sup>2</sup> All the names are pseudonymised

### Q3. APPROPRIATENESS OF SUPPORT PROVIDED BY VOICE COLLECTIVE FOR YOUNG PEOPLE

All three young people found the support provided by Voice Collective appropriate for their needs, stating that Voice Collective helped them with questions they wanted answering, and were a form of support that they were able to access when needed. Evie describes this below:

*"they've just they've always been I've known them for a long time I feel Rachel, Claire, and all of the team there they really... they're really supportive and they're just all really nice people... and... when I was able to email and speak to them on the phone they always gave me really good ways of managing... and so they've always been there for me..."*

Similarly, Axel describes liking all support and activities provided by Voice Collective:

*"I liked pretty much everything about it because it was helpful; so there's nothing specifically that I really liked apart from just having the opportunity to talk to someone..."*

### Q4. BARRIERS IN YOUNG PEOPLE ACCESSING SUPPORT FROM VOICE COLLECTIVE AND SUGGESTED IMPROVEMENTS

Few barriers were reported by any of the young people but one young person did state that the broad age range of young people attending group sessions was sometimes a challenge:

*"I suppose a couple of things which was just through no fault of anyone else I think was that obviously because it's open to such a wide age group because there's no... like, because obviously there's such a large difference between someone who's, like, 13 and someone who's 18 or 17 or whatever, the balance between what they want to do and what they want to achieve in the group's been very different. For example, older people quite regularly just want to talk and just, like, have a chat, whereas the younger people want to be stimulated by something or have something to do, and it can be, that can create a slight discrepancy in what various different group members want, including myself sometimes, so, yes."*

Therefore, it may have been helpful to have different aged groups. A further potential barrier was that whilst Voice Collective support was usually available fairly quickly, one young person preferred meeting in person to discuss difficulties and stated that this was sometimes difficult to do due:

*"It can be quite difficult to organise it [meeting to talk] sometimes and quite difficult for me to get to a mutual location and meet and talk and stuff"*

However, it was acknowledged by the young person that email and phone support was more accessible.

## PARENTS

### Q1: PARENTS' PERCEPTIONS AND EXPERIENCES OF VOICE COLLECTIVE SUPPORT

#### **Questionnaire feedback**

All parents rated peer support as 'excellent'. Feedback across different domains that peer support may have helped (below) was overall positive, with 70% of total responses being either 5 (helped a lot) or 4 (see Figure 3). The things that parents felt helped them most was 'being with other parents' and 'getting more informed', with 100% of these responses being either 5 (helped a lot) or 4. The area that helped them least was 'helped me to have more hope for the future' with four responders giving a response of [3] for this. However, the majority of answers this question was still overall positive with 73% of responses being either 5 (helped a lot) or 4.

- Questionnaire feedback into what parents found most useful from peer support is highlighted below in the wordcloud (Figure 4). In line with the quantitative data, the qualitative responses indicate that the most useful things of peer support workshops were:
- Being around others that had the same experiences

Being able to talk, listen, share and find out about voice hearing within the peer group environment.

### What have you got out of coming today?

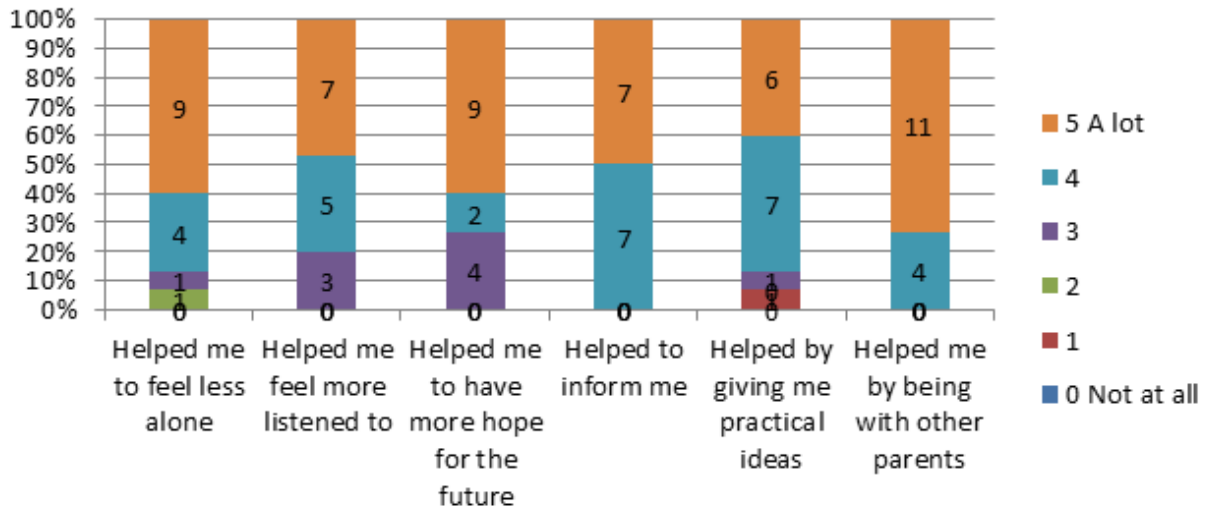


Figure 3: What parents got out of peer group support sessions



Figure 4: A wordcloud of things parents found most useful from peer support sessions



## Interviews

Parents were interviewed about their perceptions and experiences of Voice Collective, and their responses analysed using thematic analysis. Six superordinate themes emerged (outlined below in Table 5). Their perceptions and experiences of Voice Collective is that it was an organisation that helped them: feel listened to, reduced feelings of isolation, shared and gained knowledge of voice hearing, learned how to support young people that hear voices, provided them with a 'safety net' to turn to in times of need, and approached voice hearing in normalising and non-stigmatising way.

Table 5: Themes of perceptions and experiences of what parents gained from accessing Voice Collective services

SUPERORDINATE THEMES								
Name	Age	Ethnicity	Feeling listened to	Reduced feelings of isolation	Shared/gained knowledge of voice hearing	Learned how to support young voice hearers	A 'safety net' to turn to	Approached voice hearing in a normalising/non-stigmatising way
Alice	40's	Caucasian	x	x			x	x
Mary	40's	Caucasian	x	x	x	x		x
Jane	40's	Asian	x	x	x	x	x	x
Catherine	40's	Caucasian		x	x		x	x

Each theme will be individually explored below with supporting narrative.

### *Perceptions and experiences, theme 1: Feeling listened to*

Prior to attending the peer support groups, some parents indicated that they had not felt listened to by mental health services. Jane describes telling a CAMHS worker about her daughter hearing voices, but feeling she was ignored:

*"I briefly explained it to the CAMHS worker... but he hasn't really touched on it again... so I actually got far more help from Voice Collective than CAMHS..."*

Mary also describes the experience of not being listened to when she was talking to a psychiatrist about her daughter's experience of hearing voices:

*"She had a community psychiatrist... who... it was very unhelpful there was no therapeutic input it was just listening to the symptoms and then prescribing medication... and then I would say I wanted CBT for her, I wanted some kind of therapeutic input... we were told "well we're not really sure what it is so we don't know if it will be beneficial let's just keep giving medication"*

Parents noted the contrast between their previous experience of not being listened to and their experience within Voice Collective peer support groups. Alice describes this when comparing Voice Collective to CAMHS services:

*"whereas obviously Voice Collective... is far more open to hear what you've got to say... and you know sort of a nurturing model I suppose as opposed to a medical model... and that's just far more receptive then and you feel like you're being listened to..."*

As a result, parents interviewed were happy that they had found an organisation that listens to their points of view.

### *Perceptions and experiences, theme 2: Reduced feelings of isolation*

All parents described experiences of feeling alone prior to attending Voice Collective. For many, this was the first time that they had spoken to someone outside statutory services about their child's experience of voice hearing. Alice describes this below:

*"for me it was the first time... except for one other adult I've not spoken to anybody else... about it so it was a good opportunity just to be able to speak about it... and also hear other people's experiences"*

Similarly, Jane describes the reasons she felt unable to talk to anyone:

*"as a parent I was embarrassed and I couldn't speak to family members about it... so it actually provided me with a crutch and someone to... talk to that... understood where I was coming from... yeah so support basically because... I come from an [Asian] background and to hear something like that sometimes people might say you know the child's possessed or something you know it's not you know it's not something that is easily digested at all..."*

For Jane, the feeling of being understood and feeling less alone went hand in hand. Mary also echoes this experience:

*"it's not something you would really necessarily discuss with friends or that they would understand... I think it was just knowing that you weren't isolated and that you had shared experiences with other people..."*

As does Catherine:

*"I think that was it really, and just really as a sense of not being alone in it, that, you know, they were people who really understood, with all sorts of things I said, you know, that had happened"*

Thus for all parents interviewed, peer support groups provided by Voice Collective allowed for a space to share their experiences with other parents of young people who hear voices. Doing so allowed them to express their feelings, worries and concerns around people that would understand their experiences.

### *Perceptions and experiences, theme 3: Shared/gained knowledge of voice hearing*

Prior to attending Voice Collective services, parents reported a lack of knowledge of the experience of voice hearing. Jane, who was unsure if her daughter even heard voices, describes how accessing support led her to understand what her daughter was experiencing:

*"I was able to actually learn about their- you know the children's world and you know anyone that hears voices that's their world... and that is, it is what it is... you know..."*

As a result of this increased understanding, Jane was able to provide better support for her daughter. For Mary, learning about the voice hearing through hearing other parents' experiences meant that for her, she was able to begin to normalise her daughter's experiences:

*"yeah I think also just learning that many of the experiences my daughter was having and reporting was shared by many... some of them very unusual things I'd never heard of you know unusual thoughts unusual beliefs... very unusual things that were being said I learnt that... she wasn't the only person in fact many of the things mainly thinking she was being poisoned many of things were shared by many of the other young people"*

Whilst Catherine describes how her increased knowledge of voice hearing came from recommended information from Voice Collective staff:

*“she [Voice Collective worker] sent me information by email, with lots of links to different things, ranging from their particular information leaflets to things like TED talks, and listening to that, which was very helpful, and some other links to other people in the field, basically. And all of them I found very, very interesting...”*

Also adding:

*“they mentioned a number of books that were helpful, and we bought two of them, which Abi and I have talked about quite a bit; I’ve read both of them completely, Abi’s [Catherine’s daughter] read some of them”*

For parents, obtaining further knowledge about voice hearing in children and young people allowed them to begin to better understand what their child was going through.

#### *Perceptions and experiences, theme 4: Learned how to support young people who hear voices*

One-to-One support and peer support also equipped parents with knowledge of how to support their children with their experience of voice hearing. Mary describes learning techniques to help her daughter express and ground herself:

*“[Voice Collective worker] provided both of us with... techniques on how to... manage those experiences which we did. You know, lots of valuable things and also she did some art therapy and things as well one-to-one with Evie and gave me ideas of things to do some you know just some art things a way for Evie to... express what she was feeling and how to help her distract and ground her when she was having those experiences...”*

Mary went on to comment on how being taught some techniques, could help her to prevent her daughter experiencing a bad episode in future:

*“I learnt lots of new things... I think... it was one of the things they would focus on as well was looking at the triggers for voices... and also the other thing they would do is that... like if things were leading up to a-a bad episode... [Voice Collective worker] would help me do a map of events and triggers and things that led up to it and then go back and look at how could this situation have been managed differently to avoid reaching a certain point...”*

Jane also picked up helpful techniques such as talking to her daughter and her daughter’s voices:

*“I would definitely would talk to them... have an argument with them if we need to... yeah definitely have a communication with them ask her what they’re saying... just confirming that they’re not asking her to do anything dangerous or you know... but yeah I’d definitely... the talking to them was one of the best things that I found helped as well... like actually answering them back you know leave me alone come back... I don’t know... when I finish doing this or something like that... yeah that was one of the things that we learnt...”*

#### *Perceptions and experiences, theme 5: Provided them with a ‘safety net’ to turn to*

Parents spoke about having Voice Collective as a place to turn when they needed help. Jane and Alice (both of who were not currently using Voice Collective services) felt that Voice Collective was useful to have there if they felt they or their child need help in the future. Alice describes this below:

*“for me I’d say it was more of a sort of safety net thing, so Luke hasn’t had any sort of problems with voices -he hears them... but I was aware that they-that situation might change... so I wanted to just have had a contact with a group which I might at some point need to use the facilities in a different way and I wanted to already have made that contact and touch base and sort of sussed the organisation out and all that sort of thing”*

Similarly, Jane explains attending Voice Collective a number of times in the beginning but doesn't feel that she needs to as she felt so equipped from the sessions she went to:

*"I don't even have to at the moment I felt... so equipped once I'd gone there... that it was enough..."*

Catherine (who still uses Voice Collective services) also speaks of Voice Collective as an important resource to turn to when needed:

*"It's been incredibly helpful, and I think it's helped us as a family a huge lot, just to feel that, you know, we're not alone, and we have resources if we need it, you know, with them, to talk to them"*

In the above instances, it appears that many parents see Voice Collective as an important lifeline that can be drawn upon when they or their child needs them.

### *Perceptions and experiences, theme 6: Approached voice hearing in normalising and non-stigmatising way*

All parents described the value of an approach to voice hearing that was non-stigmatising and normalising. Catherine describes picking up a postcard advertising Voice Collective in CAMHS and wanting to find out more due to their normalising approach:

*"they were postcards that obviously Voice Collective had put out, there were two different ones I remember, and one of them was saying about the number of famous people who've heard voices, and, you know, kind of normalising that experience in that way... the other one was about percentages of a number of people, so, you know, it was very interesting to me and my husband, because we hadn't come across it before, and so it made me think, well, these people know a lot about this"*

Elaborating on what she found helpful about Voice Collective once initial contact was made, Catherine again speaks of the normalising approach:

*"I found them to be so much clearer and more helpful than all the other people I've spoken to, and reassuring too, and normalising, and able to say, you know, there are a lot of people who have these experiences, and people managed it, and learned to deal with it"*

Alice also describes this below:

*"I'd say was good and... I think yeah just hearing about what they do... and... the... the fact that they normalised it so much... was good because obviously there is a lot of stigma attached and it's good to hear it... just spoken about..."*

Mary elaborates on this further, explaining that the statutory service she accessed told her to ignore her daughter's voices, whereas Voice Collective allowed space to explore the voices:

*"we're looking for something different... we found their [Voice Collective's] approach was very unique and very different from the... the CAMHS experiences that we'd had... they're just... they're more understanding of the experience... and just the way they're approach their whole approach to hearing voices... like looking at the hidden meaning behind them and... not ignoring them. CAMHS were very much for wanting the... I was not allowed to refer to them as voices for example even though that's what Evie was saying we were clearly told it was very much you... almost like you ignore them... if you don't ignore them... then you're focusing on them whereas [Voice Collective worker] it was more of a... exploring why it was happening and how to manage it was a much more helpful approach than just ignoring... which was overall their [CAMHS] approach..."*

## **Q2: IMPACT OF SUPPORT FROM VOICE COLLECTIVE ON PARENTS**

The impact of support from Voice Collective on all parents that were interviewed was that they felt empowered to support their child that heard voices. This is discussed below with narrative support.

### *Impact, theme: Empowerment to support their child*

In the cases of Jane and Mary, feeling supported as parents, meant in turn they were able to support their child. Mary describes this:

*"yeah I felt much more empowered as a mother and I felt much stronger as well... because I felt supported I felt Evie was being more supported so I think there was definitely a strengthening within our family..."*

As does Jane:

*"I think with Voice Collective they really... listen and put the family first... and empower me as a parent you know so I'm not disengaged-disempowered... I've actually been empowered to support her rather than made to feel blamed that she's actually experiencing so much stress that they can now hear noises you know... something like that yeah..."*

Importantly, both Mary and Jane touch on the importance of family, with Mary explicitly saying how having peer support through Voice Collective has strengthened her family unit.

On a similar vein, Catherine also describes gaining confidence from attending Voice Collective and translating this to how to manage and work with her daughters' voices:

*"I think it gave me more confidence in managing what was happening ... it was important for her [Abi - her daughter] as well as me to see that other people have experiences like this, and learn to manage them, and work through them"*

As such, it appears that empowerment came through developing an understanding of voice hearing, skills to help their children cope, and feeling supported as parents.

### Q3. APPROPRIATENESS OF SUPPORT PROVIDED BY VOICE COLLECTIVE FOR PARENTS

Questionnaire feedback from parents rated peer support groups as 'excellent', supporting the idea that parents thought peer support groups were appropriate for their needs. However, some parents indicated that they would have liked the sessions to be longer.

*"It would be good to have more time in peer group support"*

Interview data also support that overall idea that services delivered by Voice Collective were appropriate for parent's needs. Alice, speaking about Voice Collective, summed this up well saying that if she hadn't found what she needed she would have continued looking elsewhere.

*"It seems a very well-run and established organisation and you know the things that they're doing are very positive... so... yeah everything felt very good about it. I suppose if I'd had the contact and -I hadn't felt good I would have been still searching then for something else... that I might then need to use but I feel like they've fulfilled what I needed them to do at this point in time and obviously you know read the leaflets and all different stuff so... that was good to know and it's good to know that's there an organisation out there the fact that they... you know they might work with schools and all these sort of things I just... I had that sort of ammunition if I needed to use it so... yeah I'd say they definitely fulfilled... what I needed..."*

Catherine also feels that the support she got was beneficial saying Voice Collective where there when needed:

*"It's been incredibly helpful, and I think it's helped us as a family a huge lot, just to feel that, you know, we're not alone, and we have resources if we need it, you know, with them, to talk to them. I mean, over the last six months I guess I've had three or four major email contacts with Claire [Voice Collective Worker], and a couple of phone calls, you know, it's not all the time, but, you know, when I've got questions, she's really, really helpful"*

#### Q4. BARRIERS IN PARENTS ACCESSING SUPPORT FROM VOICE COLLECTIVE AND SUGGESTED IMPROVEMENTS

Barriers in accessing Voice Collective services were mainly focused around peer support groups. One parent indicated that a potential barrier was that the groups were only London based, and sometimes they (or other parents they knew) had to travel considerable distances to attend:

*"Well, I mean, I think it'd just be better to be across the country as opposed to just in London, as we have to come in from [outside London]...another parent that I met ...had come into London, you know, to come to the day as well, and clearly they would really benefit from local support"*

A suggestion for improvement from a parent was to change the name 'Voice Collective' as it was felt that this could be a barrier for young people that see things attending this service. A further improvement suggested by a parent was to hold classes in schools and voluntary youth organisations; whilst this already happens, this could be expanded.

#### DISCUSSION

The aim of this chapter was to assess whether accessing Voice Collective services led to an increase in young people and their parents' self-esteem and coping strategies. In reference to young people who heard voices, the findings from the quantitative and qualitative data lend support to Voice Collectives original aims. The quantitative data points toward this with young people highlighting peer support as a place where they felt listened to, and a place to learn coping strategies. For Axel, learning techniques other than distraction (the only one he had been taught when in hospital) was useful in helping him manage his voices. Whilst for Evie, going to the website to implement coping strategies during times of crisis was beneficial. Young people also said they accessing both individual and peer support was beneficial in helping them reduce their feelings of isolation; with individuals pointing out that prior to participating in Voice Collective, they felt like they were the only person that hear voices. Participating in activities such as peer support allowed them to interact with other young people who hear voices, and in doing so reduced their feelings of isolation. Young people also perceived Voice Collective as non-stigmatising and normalising organisation/approach; this helped young people see themselves as not 'mad' or 'ill'. Lastly, Voice Collective provided young people with an outlet for expression; this could be through talking or alternatively, through creative pursuits.

The impact of peer and individual support was that young people gained coping strategies to manage voice hearing in their day-to-day lives. A further impact Voice Collective had on young people was that it empowered them to develop more positive connotations about themselves and voice hearing, rather than seeing themselves negatively. No single underlying mechanism was identified, however it is likely that the themes identified from young people's perceptions and experiences of Voice Collective helped positively impact their self-esteem and coping strategies. All three young people indicated that they felt the support was appropriate for their needs and that they were happy with what they had received from Voice Collective. However, it should be noted that those who were interviewed had prolonged and regular contact with Voice Collective and thus are more likely to have found the support appropriate for their needs. In contrast, those who may not have felt the support was appropriate would be less likely to return and consequently, may have been missed by the evaluation. Barriers in support were focused around the diversity in age and the impact that could have on discussions in peer support settings. As a result, it could be recommended that 'older' and 'younger' peer support groups for young people that hear voices be set up to accommodate differing needs.

In reference to the parents of young people that hear voices, it appears that they have also gained much from Voice Collective support. Prior to attending Voice Collective services, parents stated feeling alone and not feeling able to share what their child was experiencing with others. Additionally, parents also felt that CAMHS services that they had accessed, did not listen to their concerns surrounding voice hearing, and in some cases, did not believe them. Perceptions and experiences of Voice Collective support was that it was a place where parents could go to feel listened to by staff and other parents. For many parents, this was the first time they had spoken to someone outside of a CAMHS environment that their child experienced

hearing voices. They reported this helped reduce feelings of isolation, as well as help them to feel listened to. Parents also stated they found the normalising approach beneficial; particularly the information given around the number of people that heard voices. As a result, parents reported feeling Voice Collective was a place where they could enrich their knowledge of voice hearing through staff and other parents. Interestingly, it appears that some parents saw the Voice Collective as a 'safety net', with them indicating that they would only periodically draw on Voice Collective services when they felt they or their child needed further support. This may be said to show the importance of Voice Collective in helping parents and young people to develop the tools they need to cope with voice hearing in their day to day lives, whilst also being a lifeline if further support is ever needed.

The impact of accessing Voice Collective services was parents felt more empowered and confident in being able to help their child that hears voices. No single underlying mechanism was identified, however it is likely that the themes identified from parents perceptions and experiences of Voice Collective helped positively impact their ability to cope and feel empowered. Parents spoke about support from Voice Collective being appropriate for their needs, as access and support were there when required. Like the young people interviewed, it could be that those who didn't feel Voice Collective met their needs, did not return and thus were missed in this evaluation. Similarly, whilst bad experiences with CAMHS were reported by some parents in this evaluation, this may not be representative of CAMHS services as a whole. Instead, it could be that those who received such experiences were more likely to go in search of other organisations such as Voice Collective. Lastly, barriers to support from parents focused on all peer support groups being focused in London, meaning that parents who lived outside either had to miss out, or travel long distances in order to attend. As such, it could be suggested that setting up peer support groups for parents in locations outside London could benefit parents who otherwise may not be able to attend, or an alternative could be setting up a web support group that parents could dial into and discuss on a regular occurrence.





## 2. DOES PROFESSIONALS' ACCESS TO VOICE COLLECTIVE SERVICES LEAD TO IMPROVEMENTS IN ACCESS AND QUALITY OF SERVICES PROVIDED?

### RELEVANT SUB-QUESTIONS

1. What were their perceptions and experiences of these training opportunities?
2. What was the impact of these training opportunities for attendees' on-going practice, in relation to confidence and skills in engaging and working with young people who hear voices?
3. What was the wider impact of these training opportunities on generic and specialist agencies' attitudes to voice hearing?

### SUMMARY OF FINDINGS:

Overall, it appears that professionals' access to Voice Collective services has led to improvements in access and quality of services provided. Perceptions and experiences from questionnaires and interview data across all three workshops indicated that the training had contributed to their understanding of the experience of voice hearing, as well as how to work with young people who hear voices. The direct impact of these was that professionals felt more confident in working with young people who hear voices, and using techniques they learnt in workshops. Professionals also highlighted that as a result of the training they had more compassion and empathy with young people who hear voices, and were able to normalise their experiences. The wider impact of the training on professionals work was focused around integrating the approach into where they work, teaching others about Voice Collectives approach, and recommending colleagues to go on training to develop resources in their services.

Overall, it appears that facilitators' access to Voice Collective services has led to some improvements in access and quality of services. Perceptions and experiences from survey and interview data responses were overall positive, with most individuals rating the course as 'excellent'. Like professionals', facilitators' indicated that attending workshop(s) helped them by contributing to their understanding of the experience of voice hearing, and their understanding of how to work with young people who hear voices. The impact of the group facilitation training was that individuals felt more skilled and confident working with young people who hear voices and in most cases, felt ready to set up a peer support group. However, it appears that only one facilitator interviewed has successfully set up a peer support group so far. Despite this, facilitators said that they still were able to take things they had learnt during training and apply it to their practice; stating they now normalised the experience of voice hearing and used less stigmatising language. The facilitator, who had set up a peer support group, outlined that the group was peer led, with wide range of topics being discussed. Moreover, it was felt by the facilitator that young people enjoying speaking to others with similar experience and felt less isolated as a result.

### BACKGROUND

The aim of this chapter is to characterise professionals' perceptions and experiences of accessing Voice Collectives' services. Specifically, based on the programme theory, the aim was to assess whether training had led to improvements in the access and quality of services provided by increasing confidence, and skills; and also consider the wider impact of this training on attitudes.

Information relating to these aims was primarily derived from two sources: 1) feedback from professionals that attended workshops (n = 314) and group facilitation training (n = 39) delivered by Voice Collective, and 2) interviews with professionals that attended workshops and group facilitation training (n= 11 and n = 3 respectively).

The chapter will first begin with looking at professionals in light of the main and sub research questions, before moving onto examining these questions in relation to the group facilitators. The final section of this chapter will draw on the study's findings, looking at wider implications and also reflect on some of the reports limitations.

## PROFESSIONAL WORKSHOPS

- Throughout the evaluation, 314 questionnaires were collected. Broken down, this consists of the following:
- Core/Level 1 courses: consisting of increasing awareness and understanding of voice hearers and can be attended by anyone that works with young people (n=148). This included in-house training specific organisations requested training for its staff (n=46).
- Level 2 courses: aimed at individuals who work with young people that hear voices and have completed the level 2 course (n=106). This also included in-house training specific organisations requested training for its staff (n=13).
- Level 3 courses: Builds on the content learned in level 2 courses so professionals can further support individuals that hear voices (n=33).

Specialist workshops: workshops with specific focus, including dissociation and psychosis (n=10) and working with violent voices (n=17). Individuals will need to have completed core/level 1 in order to participate (n=27).

## Q1: PROFESSIONALS' PERCEPTIONS AND EXPERIENCES OF VOICE COLLECTIVE WORKSHOPS

### Questionnaire feedback

Questionnaire feedback is split into four sections: overall perceptions of workshops, whether workshops increased understanding on the experience of voice hearing, whether workshops increased understanding of how to work with voice hearers, and what professionals found useful about training.

#### *Perceptions and experiences, feedback 1: Overall perceptions of the workshops*

Overall, most individuals who attended workshops rated them positively, with 98% (n=301) rating them as either 'excellent' or 'good' (see Figure 5). Nobody that provided feedback thought that the training was unsatisfactory, and it was only on the level 1 course that 6 individuals rated the course as satisfactory.

When asked how Voice Collective could improve the content of their training courses, most professionals indicated that they didn't think anything needed improving. However, some commented that they would like the sessions spread out longer, more time to practice techniques, and follow up sessions.

#### *Perceptions and experiences feedback 2: Professionals perceptions on whether the workshops contributed to their understanding of the experience of voice hearing*

Most professionals agreed that the courses gave them a better understanding of the experience of voice hearing (see Figure 6), with 93% (n=269) of individuals across all workshops rating that their understanding of voice hearing had improved a lot or [4]. 97% of individuals (n=85) who attended level 2 courses found that the course had given them a lot better [5] or [4] understanding of the experience of voice hearing.

In most cases, participants chose not to elaborate further in the free text box, but those that did elaborated on feeling more confident in working with young people who hear voices, and gaining understanding through real life stories. Below are two examples:

### How did you find the workshop overall

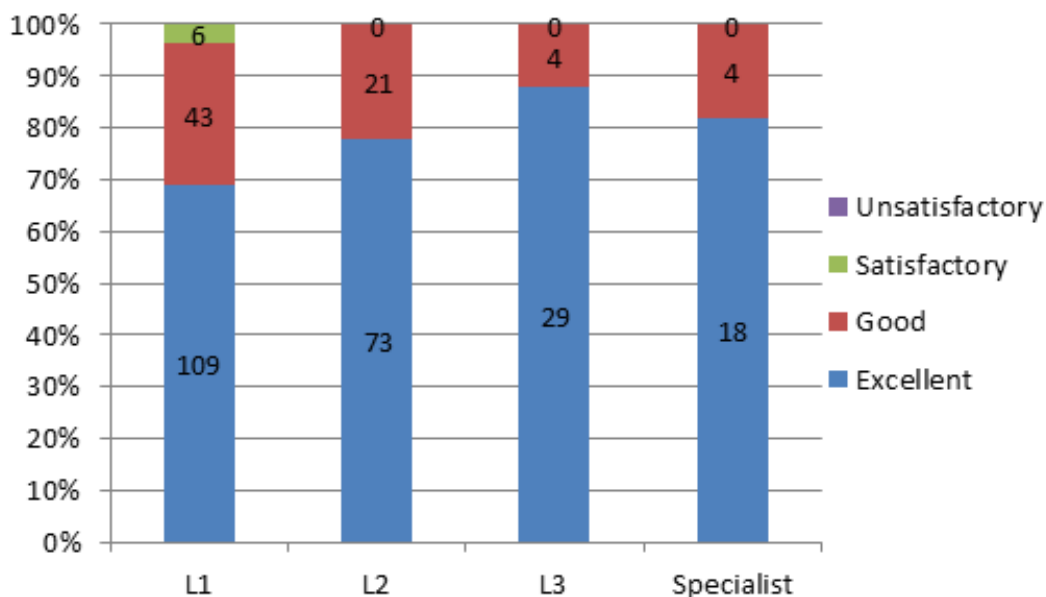


Figure 5: Professionals' ratings of Voice Collective workshops

"I feel less fearful and more confident. It normalised the situation and that hearing voices was quite common (although varying from individual to individual). It became a risk if the person was distressed by what they were experiencing."

"Really helped me understand voices especially from a hearer point of view"

### This training event improved my understanding of the experience of voice hearing

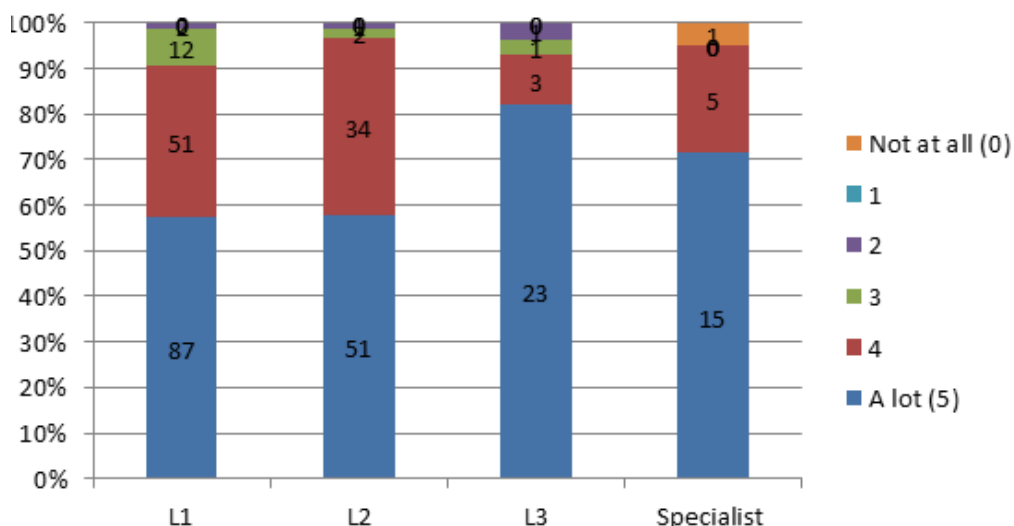


Figure 6: Professionals' perceptions on whether the workshop improved their understanding of the experience of voice hearing

*Perceptions and experiences, feedback 3: Professionals' perceptions on whether the workshops contributed to their understanding of how to work with young people who hear voices*

Most professionals agreed that the courses gave them a better understanding how to work with young people who hear voices (see Figure 7), with 87% (n=251) of individuals across all workshops rating that their understanding of how to work with young people who hear voices had improved a lot or [4]. 94% (n=30) of those who attended the level 3 course felt that it improved their understanding on how to work with young people who hear voices 'a lot' or [4]. In most cases, participants chose not to elaborate further in the free text box, but those that did elaborated on feeling knowing how to approach young people who hear voices in new ways:

*"The practical grounding ideas are good and ways of being creative with young people"*

*"Being creative, using creative ways to support and particularly the voice profile"*

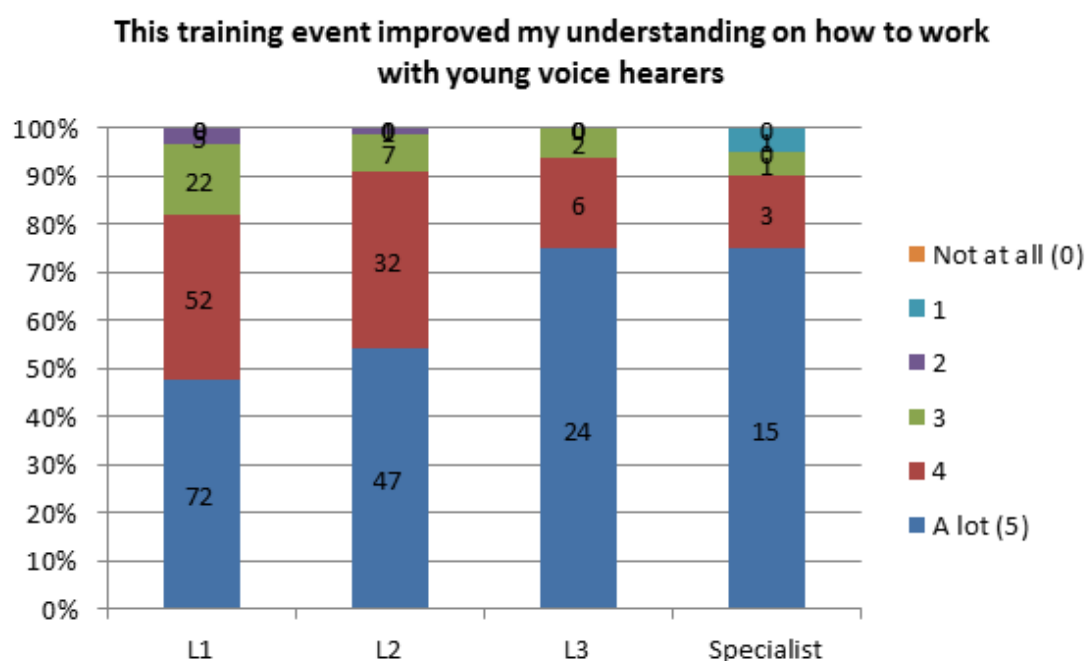


Figure 7: Professionals' perceptions on whether the workshop improved their understanding of how to work with voice hearers

*Perceptions and experiences, feedback 4: What professionals felt was useful about training*

Questionnaire feedback into what professional's found most useful from the workshops is highlighted below in the wordcloud (Figure 8). For professionals the most useful things were:

- Person stories from people that hear voices
- New strategies and techniques for young people that hear voices
- A greater understanding of the experience of voice hearing.

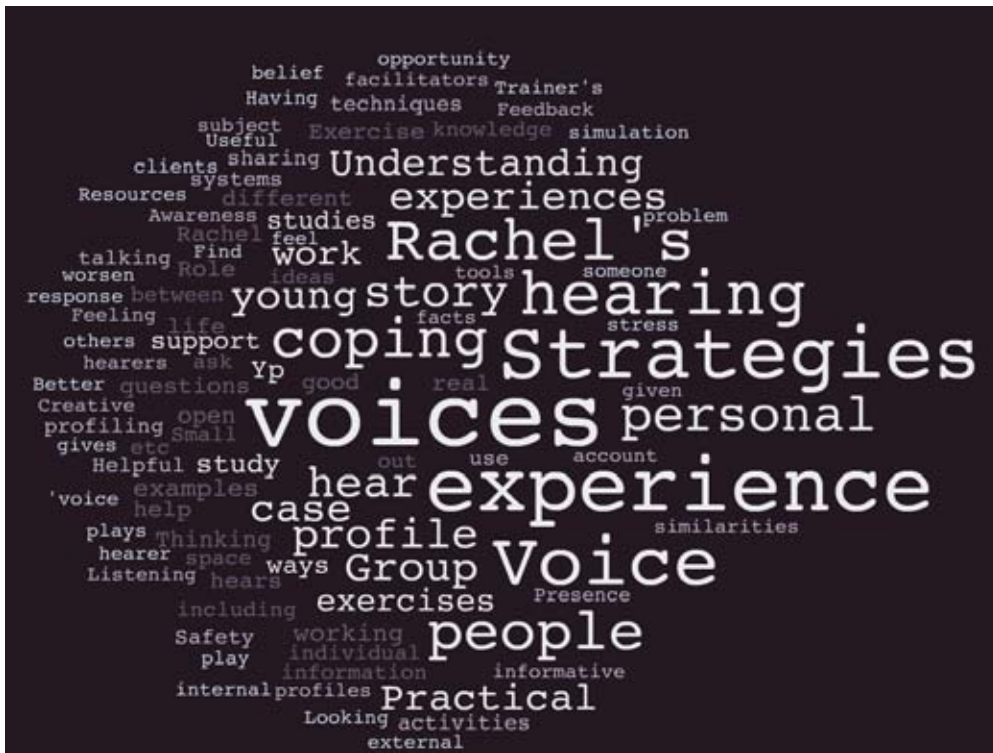


Figure 8: A wordcloud of things professionals found most useful from workshops

## Interviews

Professionals were interviewed about their perceptions and experiences of Voice Collective, and their responses analysed using thematic analysis. Three superordinate themes emerged (outlined below in Table 6). Their perceptions and experiences of Voice Collective is that it was an organisation that helped them: gain new perspectives of voice hearing, understand what it is like to hear voices, and gain new tools and techniques to work with young people who hear voices.

Table 6: Themes of perceptions and experiences of what professionals gained from Voice Collective workshops

<b>SUPERORDINATE THEME</b>			
<b>Name and professional grouping</b>	<b>New perspectives of voice hearing</b>	<b>Understand what it is like to hear voices</b>	<b>New tools and techniques to work with young people who hear voices</b>
<b>Jess (mental health professional)</b>	x	x	x
<b>Sophie (mental health professional)</b>	x	x	x
<b>Jen (non-mental health professional)</b>	x	x	x
<b>Kat (mental health professional)</b>	x	x	x

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**SUPERORDINATE THEME**

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<b>James (non-mental health professional)</b>	x	x	x
<b>Amy (mental health professional)</b>	x	x	x
<b>Izzy (mental health professional)</b>	x	x	x
<b>Claire (mental health researcher)</b>	x	x	
<b>Mel (mental health researcher)</b>	x	x	
<b>Lilly (mental health professional)</b>	x	x	x
<b>Steve (non-mental health professional)</b>	x	x	

Each theme will be discussed below with supporting narrative.

### *Perceptions and experiences, theme 1: New knowledge on perspectives of voice hearing*

All professionals said that they obtained a new knowledge and perspective in voice hearing from attending Voice Collective workshops. For, Jess and Sophie (both Mental Health Professionals) the training challenged their pre-existing views on what it means to be a young voice hearer. Sophie (Mental Health Professional) describes this below:

*“what you read in books is not necessarily helpful but that idea about hearing a voice... someone who hears the voice... it’s like-it’s in an ordinary situation with an ordinary person let’s say... that would be thinking thoughts and perhaps having a dialogue in one’s head about... you know debating with one’s self about... what’s the best thing to do or which decision to make... so but that can get exaggerated... you know the different-because of different vulnerabilities...”*

Jess (mental health professional), also describes a similar experience:

*“I mean I did my training back in the ‘80s... and-and the rule of thumb at that point was oh well if you’re a voice hearer you know you’re sort of doomed to a life-you-a life you can’t really live you know you’re always going to have to have medication, you’re always going to you know find life difficult... and you may not amount to-you know and this sort of thing that was really the consensus during the training oh you know you can just sort of just medicate these people but they can’t sort of get jobs or anything like this. This is true, this was-I think the feeling much thought of back then... whereas the biggest thing I picked up on was well you know something yes you can be a voice hearer but you can... hold down a job you can have a family you can lead a, “normal”, in inverted commas life so to speak... and that really struck home... with me... that part of it... you know...”*

As such, for some professionals that attended the workshops, Voice Collective challenged their previous models (bio-medical model) and assumptions of voice hearing. For others such as Kat (mental health professional), James (non-mental health professional) and Mel (mental health researcher) the training was an opportunity to get further knowledge on a topic that was unfamiliar to them. In the case of Kat (mental health professional) she had just finishing her professional training, but felt that voice hearing in children had not been covered as part of it:

*“this is my first job after finishing my training and I was interested in doing a bit more... training on hearing voices...I’d already obviously had some training about hearing voices on my professional training... so yeah just to try and really... gain a bit more knowledge about hearing voices specifically in young people because most of the teaching that I had about hearing voices on my training course was more related to*

adults... so to hear a bit more of the sort of... work specifically relating to young people..."

For James (non-mental health professional) working with people who hear voices (both young and old), most of the time without discussing the experience of voice hearing, meant that the workshop allowed him to get a more general knowledge on what voice hearing is about:

*"It was just-just general knowledge so that I... just general I just wanted to learn more about the people I work with"*

Whilst for Mel (mental health researcher) the new knowledge focused around the commonality of voice hearing, as well as where to signpost if she came across a young person that heard voices:

*"[Voice hearing] it's a lot more common than you might think... and the sort of support that people can get which I think would help when speaking to young people... so if they wanted some sort of help based on what they've said I'd have a better idea of where to recommend them..."*

As a result, whilst professionals agreed that they gained additional knowledge about voice hearing, it appears that how they gained new knowledge differed. For some, the workshops challenged previously held convictions of voice hearing (from a psychiatric approach) whilst for others, with the workshops addressed a lack of knowledge in the area.

### *Perceptions and experiences, theme 2: Understanding what it is like to hear voices*

For some professionals, understanding what it was like to be voice hearer was something that they took away from the training. Many professionals describe hearing the 'lived' experience of a voice hearer as insightful and helpful. Sophie (mental health professional) describes this below:

*"there was a lady who basically did a talk about her... her journey with voices from a young age and she spoke about that experience and she spoke about the experience and... that was really, really... good to listen to somebody who'd actually gone through it..."*

For Sophie, as with many other professionals, being able to hear a first person account from a voice hearer allowed them to see a different perspective of voice hearing that they might not have considered or perhaps listened to before. Jen (non-mental health professional) highlights this point further, saying that listening to the first person account of a voice hearer gave her insight into the experience of people who heard voices:

*"one of your ambassadors ... hears voices herself so she gave a very... authentic and... helpful insight into her own story... she gave us that insight....."*

A further way professionals' gained a better understanding of what it was like to be a voice hearer was through a practical activities. Claire (mental health researcher) gives an account of this:

*"I think the-the best kind of training that was offered was the role playing because you get to see you get to role play either the voice or the person... and... who's using the service or the person who's providing the service and... you get I got to understand... very experientially how this would how this would feel which was exactly what I wanted to see how does it feel for someone who lives who hears voices"*

Steve (non-mental health professional) also feels the practical activity provided him with a better understanding of what young people go through:

*"We had a little demonstration of what it might be like to hear voices, having a three... a two-way conversation with someone else talking in your ear and you've got a kind of blocker person talking in your head which, again, I found very... quite haunting, actually, to know that's what some of the young people go through"*

For professionals, the voice hearing exercise, as well listening to a first person account of a person that hears voices, equipped them with a greater degree of understanding, and insight into what it was like to be a voice hearer.

### *Perceptions and experiences, theme 3: New tools and techniques to work with young people who hear voices*

Most professionals stated that they had come away from training equipped with new ways in which to work with young people who hear voices. Izzy (mental health professional) described gaining tools to work with young people who hear voices, as the main reason that she came to the workshop:

*“it was probably more around... getting the better understanding of some practical ways... in which you support a voice hearer...”*

Below, Jess (mental health professional) recalls one of the tools she took away for the training:

*“they showed how to... keep ... like a voice chart you know naming, the name of the voice – you know, is it positive or negative and describing it and this sort of thing and actually charting and helping... young people chart it and see-and this sort of thing that was really useful...”*

Similarly, Kat (mental health professional) states how she has taken away practical tools to help inform her when working with young people who hear voices:

*“I’d say actually probably most useful in terms of what I’ve taken forward to use in my clinical work was the more sort of the teaching bit about how to assess voice hearing in young people so there was I think 3 different sort of ways that it was introduced that you could sort of work with, quite practical, just about who the voices were, how old they were things like that but then sort of more creative ways of understanding each young person’s experience of hearing voices so I think that was probably the most useful”*

## Q2: IMPACT OF TRAINING FROM VOICE COLLECTIVE IN RELATION TO ON-GOING PRACTICE

### **Questionnaire feedback**

Usefulness of the workshop in providing professionals with skills and confidence in working with young people that hear voices.

Most professionals agreed that the courses provided them with tools, skills and confidence to successfully work with young people who hear voices (see Figure 9), with 85% (n= 228) across all workshops agreeing a lot [5] or [4] that workshops had provided them with skills and confidence. In most cases, participants chose not to elaborate further in the free text box, but those that did elaborated on feeling more confident and expanding their skill set:

*“It has given me more confidence on how to approach the conversation about voices/ visions”*

*“I believe that my skill base has been broadened by attending this course”*



**How useful has this course been in providing you with the appropriate skills & confidence to successfully work with young voice hearers**

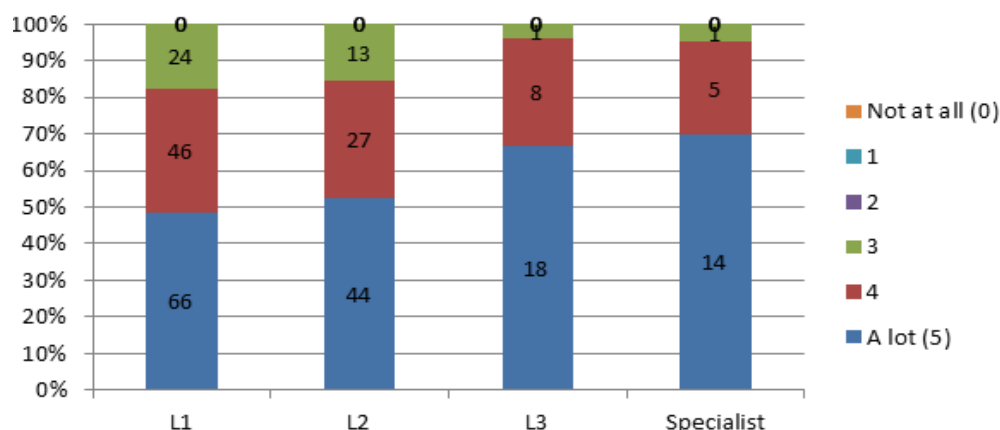


Figure 9: Professionals perceptions on the usefulness of the course in providing skills and confidence

## Interviews

Thematic analysis on interviews with professionals revealed three superordinate themes relating to the impact Voice Collective workshops had on them/their practice (outlined below in Table 7). The themes consisted of: feeling more confident in working with young people who hear voices, more compassion and empathy, and being able to normalising the experience of voice hearing for young people who hear voices.

Table 7: Impact of training on on-going practice

<b>SUPERORDINATE THEME</b>	<b>Confidence in working with young people who hear voices</b>	<b>Compassion and empathy</b>	<b>Being able to normalise the experience of voice hearing</b>
<b>Jess (mental health professional)</b>	x	x	x
<b>Sophie (mental health professional)</b>	x	x	x
<b>Jen (non-mental health professional)</b>	x	x	x
<b>Kat (mental health professional)</b>	x	x	x
<b>James (non-mental health professional)</b>	x		
<b>Amy (mental health professional)</b>	x	x	x
<b>Izzy (mental health professional)</b>	x	x	x

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## SUPERORDINATE THEME

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<b>Claire (mental health researcher)</b>	x		
<b>Mel (mental health researcher)</b>	x		
<b>Lilly (mental health professional)</b>	x	x	x
<b>Steve (non-mental health professional)</b>	x		

Each theme will be discussed below with supporting narrative.

### *Impact, theme 1: Feeling more confident in working with young people who hear voices*

For some professionals the acquisition of knowledge, greater understanding, and tools for working with young people who hear voices, gave them greater confidence when working with this group. Jess (Mental Health Professional) sums this up below:

*"it has given, you know, great understanding... and therefore more confidence... in what I know because of the knowledge that I have and also the information I was given with regards to... the various ways in which to work with people that are voice hearers..."*

Prior to the workshops, some professionals had worried how to interact with young people who hear voices, particularly when it came to talking about their voices. Individuals indicated that they were worried about damaging young people who hears voices by acknowledging the voices. Izzy (Mental Health Professional) gives an example of this below:

*"yeah... it has it certainly has given me a lot more confidence for example... when... I work at [London Hospital] ... with young people who hear voices there. I would before not be confident to encourage them to verbalise their experiences but now you know I don't sort of press it too much but I would encourage them with more confidence to verbalise their experiences so for example... someone who I'm working with who's 15... and has a bullying voice... you know I now would... I encourage them to expose that bully... and... to put into words as far as I can... their experience of... being bullied... so it's actually reduced the threatening... content... of that young person's... voice you know the bullying voice... It's actually worked so I would say that it's really helped in terms of me doing... a more informed, in a clearer way about what is considered to be helpful and what's not considered to be helpful form people"*

Thus, in this instance, after attending the workshops, individuals made direct links between gaining skills to work with young people who hear voices, and a greater sense of confidence in their abilities to work with young people that hear voices when addressing the voices.

### *Impact, theme 2: Compassion and empathy towards young people who hear voices*

For Sophie (mental health professional) hearing and being able to understand the experience of voice hearing through hearing the first-hand account from a person that hears voices, meant that she had greater insight into the challenges faced by those who hear voices and, therefore a greater compassion for them:

*"I think I've got a lot of time and a lot of energy and a lot of patience for everybody but I think... it gave me more compassion for... what people were trying to deal with... daily you know while trying to do something else I guess the complexity of yeah again like how difficult or how... yeah how difficult it must be and how... and how that challenge really would have a massive effect on your life so I guess it's more compassion and more kind of empathy for the situation that people are in..."*

Similarly, after hearing the first-hand account, as well as participating in the voice hearing exercise, Kat (mental health professional) describes how she is more able to identify with a young person hearing voices and understand how difficult a clinical session may be for them:

*"I think it helped me sort of understand a bit more of that experience and how difficult it must be to sort of concentrate in a therapy session... or to focus on any sort of conversation when you've got the voices when you're hearing voices as well..."*

For Jen (non-mental health professional), the training allowed her to become more sensitive to her clients' needs, and as a result, she feels that the young person is able to talk to her about her voice hearing experience:

*"and I used to get a bit frustrated with it thinking really but because I'm more aware and I'm more sensitive she feels able to say I can hear him again... you know and they'll-there's a new voice now"*

Thus, after attending Voice Collective workshops, individuals showed an increase understanding on what it was like to be a voice hearer, and this translated into compassion and empathy when working with them in professional contexts.

### *Impact, theme 3: Normalising the experience of voice hearing for young people who hear voices*

For some mental health professionals, learning information about voice hearing meant that they were then able to treat their patients in a less stigmatizing way. Kat (Mental Health Professional) highlights how she uses this new knowledge during clinical sessions:

*"I think there was one bit that really stuck with me from the training about how more young people experience voices than have red hair or who are left handed and I think I've used that sort of statistic in pretty much every... assessment I've done with young people who hear voices so also in terms of the... I guess normality isn't quite the right word but actually in terms of... that it is quite a common experience and so it's not something that... is very sort of unusual and actually it's about the distressing nature of the voice that is sort of more of the-the clinical problem rather than the fact that they experience the voice... you can experience voices and actually... function very well but it's when those voices become distressing that it then becomes sort of more a clinical problem that we might be sort of working on in our team..."*

For Izzy (mental health professional) having attended Voice Collective workshops meant she was better informed, and able to direct young people to an organisation that would normalise voice hearing:

*"so for example when we have we have a number of young people who... feel that they are the only people in the world that hear voices and so being able to direct them to Voice Collective ... in terms of either the website or the groups... have been very helpful for them and has helped... normalise their experience quite a bit..."*

For some mental health professionals, having further information around voice hearing meant that they were able to normalise voice hearing in young people that came to them, by conveying the commonality of it and directing them to peer support groups.

### **Q3: WIDER IMPACT OF THESE TRAINING OPPORTUNITIES ON GENERIC AND SPECIALIST AGENCIES' ATTITUDES TO VOICE HEARING**

Many professionals articulated that they found the training beneficial, and as a result encouraged others to attend, Jess (Mental Health Professional) describes this below:

*"when I saw the importance of the training I actually emailed the [CAMHS] team and they sent 3 workers... and since that you know... I've actually sort of tried to encourage them to work with [Voice Collective] to actually set up a voice hearing group for young people in this area..."*

Elaborating on this further, Kat (mental health professional) speaks about how, due to their perceived benefits of the training, most of her team has attended, and consequently Voice Collective is frequently discussed, both within her team and in clinical supervision:

*"the majority of people in our team have been on Voice Collective training... and... it's something that we all discuss quite a lot within the team... I sort of took back and shared with the team... just because everyone's done the training and so I as a new member of the team was sort of a step behind really... but I talk about it a lot in... in supervision... but yeah I think probably everyone in the team has been on at least one... of Voice Collective workshops so yeah it's something that's sort of very highly thought of within the team..."*

Going one step further Amy (mental health professional) felt going on Voice Collective training had helped her support and give advice to others in her team:

*"I've really kind of taken on board what I've learnt and passed it on and I think it's helped colleagues to feel more confident and more sure, especially those who don't have the experience of hearing voices..."*

## FACILITATOR TRAINING COURSES

Throughout the evaluation, 39 questionnaires were collected. Broken down, this consists of the following:

- Facilitators Training course: a course for individuals that have attended Voice Collective workshops, and are thinking about setting up their own peer support groups for young people that hear voices (n=33)
- BAU Facilitators course: A specialised one day course for professionals at Bethlem Adolescent Unit who wanted to set up a peer support group (n=6)

## Q1: FACILITATORS PERCEPTIONS AND EXPERIENCES OF VOICE COLLECTIVE WORKSHOPS

### Questionnaire feedback

Questionnaire feedback is split into three sections: overall perceptions of workshops, whether workshops increased understanding of how to work with voice hearers, and what professionals found useful about training.

#### *Perceptions and experiences, feedback 1: Overall perceptions of the group facilitation workshops*

All individuals that attended workshops rated them positively, with 100% (n=39) rating them as either 'excellent' or 'good' (see Figure 10). In total 90% (n=35) of forms received across the courses all courses rated the course as 'excellent'.

When asked how Voice Collective could improve the content of their training courses, most facilitators indicated that they didn't think anything needed improving. However, some commented that they would like having more resources to take away:

*"Perhaps if there was a facilitation pack containing resources for getting a group started..."*

Facilitators perceptions on whether the workshops contributed to their understanding of the experience of voice hearing.

Most professionals agreed that the courses gave them a better understanding of the experience of voice hearing (see Figure 11), with 88% (n=24) of individuals across all workshops rating that their understanding of voice hearing had improved a lot or [4]. Some individuals stated that the course did not increase their understanding of voice hearing; however further analysis indicated these individuals were themselves

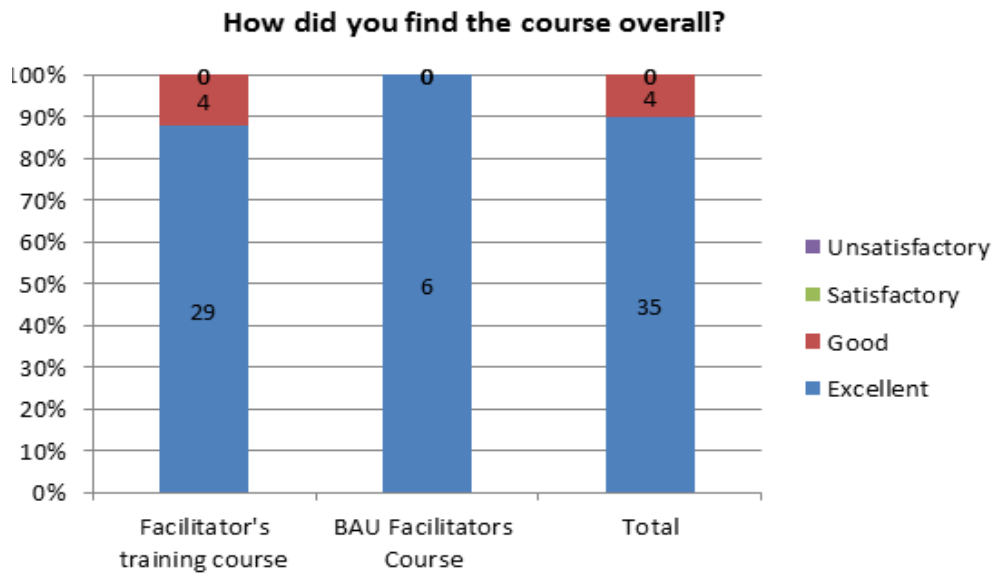


Figure 10: Facilitators rating of Voice Collective workshops

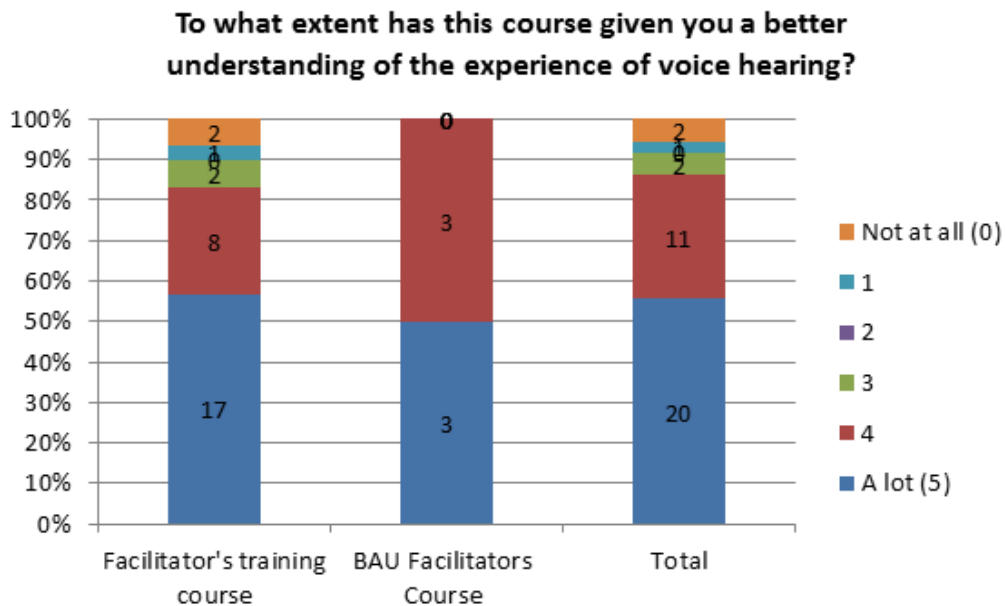


Figure 11: Facilitators perceptions on whether the workshop improved their understanding of the experience of voice hearing

individuals people who hear voices, and so this may be expected. In most cases, participants chose not to elaborate further in the free text box, but those that did elaborated on building upon previous knowledge:"

*Perceptions and experiences, feedback 2: Facilitators perceptions on whether the workshops contributed to their understanding of how to work with young people who hear voices*

Most professionals agreed that the courses gave them a better understanding how to work with young people who hear voices (see Figure 12), with 87% (n=34) of individuals across all workshops rating that

**How useful has this course been in providing you with the appropriate skills & confidence to successfully work with young voice hearers?**

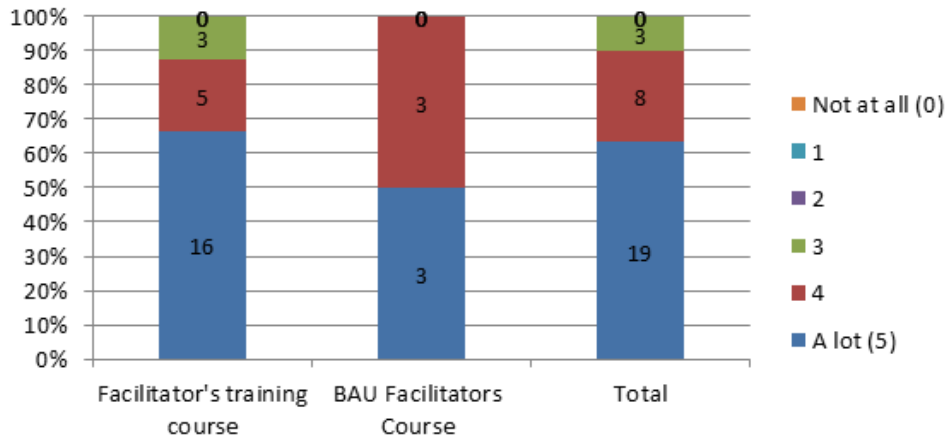


Figure 12: Facilitators perceptions on whether the workshop improved their understanding of how to work with young people who hear voices



Figure 13: A wordcloud of things facilitators found most useful from workshops

their understanding of how to work with young people who hear voices had improved a lot or [4]. In most cases, participants chose not to elaborate further in the free text box below, but those that did elaborated on learning on new ways to work with young people who hear voices:

*"I feel able to use creative activities to help a young person express their emotions/feelings"*

### Perceptions and experiences, feedback 3: What facilitators felt was useful about training

Questionnaire feedback into what facilitators found most useful from the workshops is highlighted below in the wordcloud (Figure 13). This included:

- how to set up a group
- role playing
- games/activities to include in peer group sessions
- A better understanding of voice hearing

## Interviews

Facilitators were interviewed about their perceptions and experiences of training, and their responses analysed using thematic analysis. Two superordinate themes emerged (outlined below in Table 8) focusing around: gaining new perspectives of voice hearing, and practicalities of setting up a peer support group.

Table 8: Themes of perceptions and experiences of what facilitators gained from training

SUPERORDINATE THEME	How to set up a group (practicalities)	New perspectives of voice hearing
<b>Stef (mental health professional)</b>	x	x
<b>Charlie (mental health professional)</b>	x	x
<b>Stasi (mental health professional)</b>	x	

Each theme will be discussed below with supporting narrative.

### Perceptions and experiences, theme 1: How to set up a group (practicalities)

One theme that emerged from interviews with facilitators was that they had a clearer picture of the practicalities of setting up a group. Charlie outlines this below:

*"there was just such a lot of useful information about sort of engagement and... just how to go about setting up the group that I wouldn't have thought of before..."*

Before elaborating on the content further:

*"the content of that was really about you know... how to engage young people to come along promoting the-promoting the group, dealing with difficult situations within the group, group sort of group dynamic stuff how you'd evaluate the group how you'd get them involved in actually the design and delivery of the group..."*

Stasi echo's this response when asked to describe facilitator training:

*"there were lots of practical issues that we had to think about in terms of running a group... how to organise risk...there were lots of practical issues about getting it set up"*

As such, professionals who received group facilitation training took away practical skills that were needed in order to set up a group.

### *Perceptions and experiences, theme 2: Alternative perspectives on voice hearing*

Professionals that attended facilitator training also found the training allowed them to look at voice hearing from non-medical perspectives. Stef outlines this below:

*"I'd describe it as a really useful way to think about voices in a different way that isn't medicalised... and to think about and to help you really think about people's personal experiences and how you might intervene in helping them... because of those experiences"*

Charlie also describes getting something similar from the facilitator training:

*"we talked about... what it must be like to hear voices and see things; we talked about... the academic reasons as to why people think that might happen and challenging psychiatry..."*

As a result from this, Charlie now tries to avoid psychiatric language when working with young people who hear voices:

*"... the language that I use is... certainly make an effort to use non-psychiatric non-negative terminology now... and... you know recognising that actually that is quite damaging to some young people... and so that's pretty significant..."*

## Q2: IMPACT OF TRAINING ON FACILITATORS'

### **Questionnaire feedback**

Questionnaire feedback focused around facilitators rating on how much the workshops provided them with appropriate skills and confidence in working with young people that hear voices

#### *Impact, feedback: providing skills and confidence*

Most professionals agreed that the courses provided them with tools, skills and confidence to successfully work with young people who hear voices (see Figure 14), with 90% (n=27) across all workshops agreeing a lot [5] or [4] with the statement. In most cases, participants chose not to elaborate further in the free text box, but those that did elaborated on feeling more confident in working with young people who hear voices, though some still felt nervous:

*"I feel a bit more confident but also a bit scared to actually put in to practice"*

Facilitators rating on how ready they feel in setting up a peer support group for young people that hear voices following training.<sup>3</sup>

Overall, most participants indicated that they felt at least partially ready in setting up a peer support group (see Figure 15), with 69% of individuals overall scoring that they were very ready or [4]. Like responses to the above question, facilitators responded feeling nervous:

*"I think confidence needs to grow but this is a personal thing and this something separate to training"*

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3 N.B. There are fewer responses for this question due to a different questionnaire being used the training.



**How useful has this course been in providing you with the appropriate skills & confidence to successfully work with young voice hearers?**

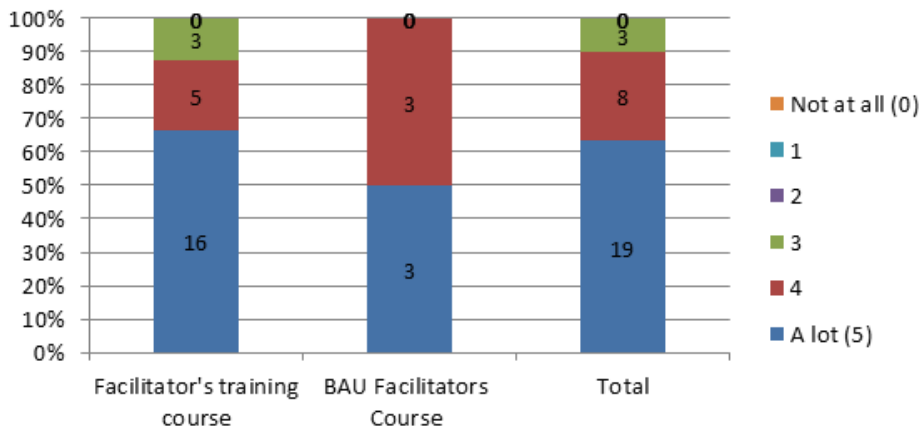


Figure 14: Facilitators ratings on the course in providing skills and confidence

**How ready do you now feel to set up a peer support group?**

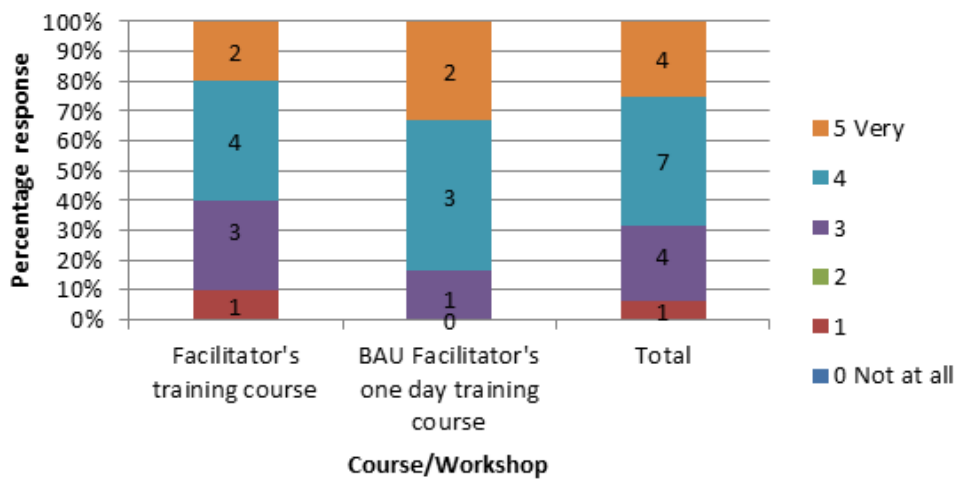


Figure 15: Facilitators readiness to start up a peer support group

**Interviews**

*Impact, theme 1: normalising the experience of voice hearing*

At the time of being interviewed, only Stasi had set up a peer support group. As such, most individuals were unable to speak on how group facilitation training had impacted their direct work on working with young people in a group setting. Instead, they spoke about how the training allowed them to normalise the experience of voice hearing when working with young people.

Stasi describes how as a result of the training she tries not to label experiences:

*“And I think, always that broad view that I think in CAMHS we always like to put a sort of a mental health label on something, and just thinking about it as an experience, and what’s that experience mean to them, rather than trying to get in a, sort of, a mental health box”*

Similarly, Charlie indicates that she approaches people she works with from a non-psychiatric perspective:

*“it has certainly changed it and it’s changed it in a way that I feel happier working... from a Voice Collective trauma based sort of angle rather than... from the psychiatric sort of you know approach...”*

### *Impact, theme 2:*

For Stasi who had set up a group, the impact that the facilitator training has on her was that she got to know the young people in a more personal way:

*“I struggled really hard to not be a [mental health professional] in that group to start with, but I think there’s some value to actually, initially, not be ... and actually get to know a young person, get to know their interests, and, sort of, talk about their voices, at their pace. I think sometimes that hasn’t always been the case. ... I get them to talk about those things...and I think I pay more attention than I did before. I think there’s always an in attention in my mind about their experiences and their lives and how they fit with their experiences, but I think I pay more attention to that now, and spend more time looking to keep up, what are the connections? How does this fit with their life experiences?”*

Consequently, attending group facilitation training may be said to have changed Stasi’s approach in working with young people who hear voices, as now as a result she tries to make links between their experiences and voice hearing.

## **Professionals opinion on the impact of support on young people**

Stasi also elaborates on what the peer group sessions consist of and how she thinks that has impacted young people:

*“We’ve talked a lot about voices in different senses, so we’ve talked about voices in terms of their own experiences, and some have been able to do that to a greater degree than others. We’ve talked about voices in terms of what does it mean, what are the explanations. We had a big conversation about schizophrenia, psychosis, voices, and what are the differences, what are the similarities. We talked a bit about being in hospital, because some people have been in hospital in the time they’ve been in the group, some people haven’t, and some people are worried about being in hospital, so we’ve had a bit of talk about that...we’ve talked about a lot of things that I don’t even, kind of, understand, they’re very teenage, so we’ve talked about video games, things on YouTube, Internet, chat rooms, and social media ... Oh, and lots about, yes, growing up, who you are, identity kind of stuff, what you want to do when you’re older, what people like about you and what don’t they like about you”*

**Before concluding:**

*“I think on the whole it’s been lovely to see them, despite there have been a few tensions, a few fallings out, they have really come together as a group, and really felt it’s possible to talk about these experiences, which for most of them, they don’t really talk about, apart from in a CAMHS setting, or occasionally with the parents, because sometimes some of them aren’t ready to talk to their parents about it. So it’s nice to... because they’re so isolated. I think that’s why I really like seeing...”*

Interestingly, this echos what young people said about their perceptions and experiences of support from Voice Collective, however it is difficult to generalise this due to a small sample.

## **DISCUSSION**

The aim of this chapter was to assess whether professionals’ access to the Voice Collective services led to improvements in access and quality of information for young people that hear voices and their families. It appears that in terms of access and quality of information provided, Voice Collective has made a positive impact on professionals. Professionals perceptions and experiences of Voice Collective workshops, was that it provided them with a greater knowledge into voice hearing and how to work with young people that

hear voices. In relation to greater knowledge, this happened by providing professionals with knowledge in an area they were unfamiliar with, or in the case of many mental health professionals; challenging pre-existing psychiatric models on why people heard voices. In relation to how to work with how to work with young people who hear voices, professionals indicated their practice had changed through hearing the 'lived experience' of a voice hearer, as well as through role plays, this allowed them to better understand what young people were experiencing.

The direct impact of these on the work of the professionals was that many felt that they were more confident in working with young people who hear voices; using techniques such as, naming, categorising and acknowledging the voices. Interestingly, prior to Voice Collective training some professionals outlined they were worried about acknowledging the voices in case it was detrimental to the young person. Professionals also highlighted that as a result of the training, particularly the demonstrations on what it was like to hear voices and first-hand account from people that heard voices, they were more compassionate and empathetic towards young people who hear voices. Additionally, professionals spoke of the usefulness of being able to normalise the experience of voice hearing, with some using statistics about voice hearing when giving information to young people, and others signposting individuals to the Voice Collective website. The wider impact on professionals practice was that the training become integrated into their practice, and in some cases became embedded into their teams and organisations; this was particularly true when many colleagues had been on training and subsequently recommended others.

Those that went on group facilitator training many be also said to fulfil the aims of the Voice Collective in increasing access to services and quality of information. Perceptions and experiences were that like professionals, the facilitators' workshop(s) helped by contributing to their understanding of the experience of voice hearing, and their understanding of how to work with young people who hear voices. Regarding contributing to their understanding of the experience of voice hearing; facilitators indicated that the course built on previous knowledge and provided them alternative perspectives on voice hearing; moving away from psychiatric models of voice hearing and stigmatising medicalised language. Whilst in relation to understanding of how to work with young people who hear voices, professionals indicated that they learned games, and creative ways to engage young people. Professionals also indicated that facilitator workshops also provided them with the practicalities of setting up a group; such as how to set up and dealing with risk.

In terms of impact, facilitators indicated they felt that they had been provided with the appropriate skills and confidence to successfully set a peer support group; with most professionals indicating they felt ready to set up a group. However, from the interview data collected, it appears that only one of the facilitators had at the time of interviewing successfully set up a peer support group.

It should be noted that the evaluation is aware of other groups being set up, and some others being put on hold or frozen, but as these facilitators were not interviewed, it is difficult to draw conclusions relating to quality and access. As a result, the impact of the training focused mainly on gaining further knowledge and alternative perspectives around voice hearing, and using this within professional contexts. From the facilitator interviewed who had set up a peer support group, it was felt that young people benefited from peer group support as it provided them with a place to discuss many different topics such as topics around voice hearing, social media and growing up. This the facilitator felt, helped young people feel listened to and less alone.

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### 3. HAS VOICE COLLECTIVE IMPROVED THE QUALITY AND QUANTITY OF INFORMATION AND ADVICE OF WEB BASED RESOURCES AVAILABLE FOR CHILDREN AND YOUNG PEOPLE WHO HEAR VOICES, THEIR FAMILIES AND CARERS?

#### RELEVANT SUB-QUESTIONS

1. To what extent has Voice Collective influenced the quality and quantity of existing web based materials to support young people who hear voices and their families?
2. What was the feedback for Voice Collective from young people and families accessing website?

#### SUMMARY OF FINDINGS:

Overall, it appears that Voice Collective has begun to influence both the quality and quantity of web based materials that support young people who hear voices and their families. In terms of increasing the quantity of information, it was found from the scoping exercise that two websites now include information on voice hearing when they previously hadn't had anything. The scoping exercise also identified websites with existing information that Voice Collective had directly impacted; either through links now being on their website, or through changes in literature towards a non-medicalising, normalising perspective. Other websites demonstrated changes in stance towards Voice Collective's ethos, but with no direct links to Voice Collective or information on voice hearing in young people, it was difficult to say whether these changes were due to the 'Hearing Voices Movement' more generally.

Feedback from professionals, young people and their families, of Voice Collective's website was overall positive; with most individuals using the website as a source of information and knowledge. Responses from young people suggested they found the website helpful, as they could use the website for coping strategies and techniques to deal with the voices, as well as finding the website useful due to its 'normalising' response to voice hearing. Parents also found the website useful citing it an important information resource to turn to when needed; this was particularly true for those that were located outside the London area and may have found it difficult to attend Voice Collective groups. Professionals also found the website helpful and often used it as a signposting resource to direct young people to more information. In some cases this was because they were too far afield to access training or support groups, but it also appears that professionals within London are using Voice Collective website as resource. One suggested topic for improvement of the website focused around having a better layout as some found the website difficult to use. Another topic for improvement focused around getting better functionality of the forum as a resource.

#### BACKGROUND

The aim of this chapter is to examine the extent to which Voice Collective has influenced the quality and quantity of web based materials, and to get feedback from users accessing Voice Collective website.

Information relating to the influencing of websites was drawn from a scoping exercise of possible websites that Voice Collective may target due to their nature and content. Feedback about Voice Collective website was derived from three sources: 1) feedback questionnaires on what users thoughts of the website (n=6) and what they wanted from Voice Collective in future (n=8), and 2) qualitative data from interviews conducted with professionals, parents and young people that hear voices.

The chapter will first begin with examining Voice Collective's influence of websites, before moving onto examine feedback about Voice Collective website from young people that hear voices, their families and professionals. The final section of this chapter will draw on the findings, looking at wider implications and also reflect on some of the reports limitations

## Q1: INFLUENCE OF VOICE COLLECTIVE ON EXISTING WEB BASED MATERIALS TO SUPPORT YOUNG PEOPLE WHO HEAR VOICES AND THEIR FAMILIES

In order to capture the extent to which Voice Collective have had an impact on the quality and quantity of existing materials and information provided by other organisations, a scoping exercise was carried out to assess the extent to which other web-based information drew on materials directly attributable to the VC or reflected the ethos of Voice Collective. This scoping focused on organisations which Voice Collective had prioritised to make strategic links with (see Table 9 below for the full list).

Table 9: Website examined as part of a scoping exercise into changes in literature

	<b>Content changes attributable to the Voice Collective or link now included to website</b>	<b>Content in line with VC ethos but not directly attributable</b>	<b>No relevant content evident</b>
<b>Childline</b>	✓		
<b>Kidscape</b>			✓
<b>MOSAC</b>			✓
<b>The Hideout</b>			✓
<b>Women's Aid</b>			✓
<b>Mumsnet</b>			✓
<b>B-eat</b>			✓
<b>Self Harm</b>			✓
<b>Papyrus</b>			✓
<b>CALM</b>		✓	
<b>Victim Support</b>			✓
<b>Counselling Directory</b>		✓	
<b>Winston's Wish</b>			✓
<b>The Site</b>	✓		
<b>Rethink</b>	✓		

	Content changes attributable to the Voice Collective or link now included to website	Content in line with VC ethos but not directly attributable	No relevant content evident
Mental Health Care	✓	✓	
Young Minds	✓	✓	
Mind <sup>4</sup>		✓	
Mental Health Foundation		✓	
Intervoice	✓	✓	
Hearing Voices Network <sup>5</sup>	✓	✓	
Early Intervention Network (IRIS)	✓		
Chimat	✓		
Albert Kennedy Trust <sup>6</sup>			✓
Safe Network			✓
LGBT Youth			✓
Pace Youth			✓
Bgiok			✓
YPAS (GYRO)			✓
Queer Youth Network <sup>7</sup>			✓

## Sites with little or nothing about the experience of voice hearing at start of Voice Collective Evaluation that have now changed

Childline: At the start of the project, the Childline website had no information on voice hearing. There are now references and links to the Voice Collective within the Childline 'Ask Sam' section. The 'Ask Sam' section is where children and young people can write in with their problems (in the cases mentioned, voice hearing) for Sam to answer. These links are available for other young people to see and thus provide a route for young people to access Voice Collective.

4 Mind in Camden is responsible for the Voice Collective project

5 RW the project manager for the Voice Collective in involved with this organisation and their website

6 In 2013 the Voice Collective strategic plan was to spread out from just mental health organisations to include other organisations that they could link with. This included LGBTQ charities

7 Queer Youth Network: Site currently being redesigned so no information currently at present

CALM (Campaign Against Living Miserably): At the start of the project, the CALM website had no information on voice hearing. Their website now has a page around hearing voices (which it credits as lifting from the Mental Health Foundation along with a link), explaining that whilst it can be a sign of mental illness, it can also be part of the variation in human experience.

## **Sites with information on voice hearing that the hearing at baseline that Voice Collective indicated they would like to target at the start of the evaluation**

ChiMat (Child and Maternal Health Intelligence Network): Voice Collective has successfully managed to foster good connections with ChiMat. Not only does ChiMat have a page on Voice Collective (outlining the organisation) with links directly to the VC website, but it also has information and links to the VC workshops for professionals with links to the website and how to sign up.

Counselling Directory: At the start of the project, the Counselling Directory had schizophrenia pages that were very medicalised when referring to symptoms. It now has a dedicated section of the website now on hearing voices with paragraphs about voice hearing as part of normal human experience and as a mental illness; including a comprehensive account of what could cause, and exacerbate voice hearing in both these cases. There is no specific information for young people, but there is a link to the hearing voices network.

The Hearing Voices Network (HVN): Being a sister network to the VC, the HVN approach to voice hearing is similar. Both the project manager (RW) at Voice Collective and the organisation have been mentioned in posts for young people.

Intervoice: Like the HVN, Intervoice share a similar approach to voice hearing and thus has fostered good links with the VC, with links to a number of materials and information (an animation for children, booklets) and their website.

Early Intervention in Psychosis (IRIS) network: Voice Collective now features on their useful links page, but does not appear to have affected the content of the website at present, with most of the literature being related to Psychosis

MentalHealthCare: The Mental Health Care website run by the IoP/Slam has also fostered good links with Voice Collective. Whilst they already had good information on voice hearing, they now have a wide range of resources to cover the experience of voice hearing in children, including within 'Ask a Psychologist' where carers can have their questions answered, and through videos of Voice Collective's project lead, speaking about psychotic like experiences (PLE's). There is also a direct link to Voice Collective in the useful links section.

The Mental Health Foundation: The Mental Health Foundation has information related to hearing voices in a less categorical and less stigmatising way. However, there is no information relating to hearing voices in children specifically, nor any mention or links to Voice Collective.

Mind: At the beginning of the project, Mind had information in Psychosis and young people including a comic book style magazine. Mind now has a dedicated section of their website dedicated to voice hearing, including parts about commonality, types of experiences and when voices may be a problem. However, they do not have information specifically for young people and there is no link to the VC.

Rethink: When Voice Collective began, Rethink had a childhood schizophrenia page that Voice Collective wanted to target. This appears to have been removed. Rethink now includes many pages and links to hearing voices in a non-stigmatising way; and have a link to the Voice Collective at the bottom of their psychosis page.

The Site: Voice Collective has been successful in fostering links with the site, so that people can access their site. However, the site is still predominantly focused upon associating hearing voices with diagnostic categories of Psychosis and Schizophrenia; and the links to the VC are found within these terms. Within the discussion board, there is evidence of moderators directing young people to the Voice Collective website.



Young Minds: Voice Collective has successfully also fostered links with Young Minds with links direct to Voice Collective for concerned parents. At the start of the project, Young Minds had little content focused on voice hearing that wasn't related to psychosis or schizophrenia. There is now information on hearing voices in a non-stigmatising way, now stating that 'hearing voices is not necessarily a sign of mental illness'.

## Q2: FEEDBACK FROM YOUNG PEOPLE THAT HEAR VOICES, THEIR FAMILIES, AND PROFESSIONALS ON VOICE COLLECTIVE'S WEBSITE

Feedback on the Voice Collective website was provided through two online questionnaires and interview data. The first online questionnaire focused specifically on what individuals thought of the website with four young people, one family member, and one professional providing feedback. The second online questionnaire was a more general focusing on individuals having 'their say' on the Voice Collective with relevant responses being left by one professional, two parents and four young people. Data from interviews (where appropriate) will also be examined here.

### Reasons for accessing the website

Data from the two online surveys highlighted that all young people accessed the Voice Collective website to get more information and support. This is outlined by one respondent below:

*"[I] found this site very helpful and informative, been searching a long time and best one I've found"*

In regard to how young people came to find the Voice Collective website, questionnaire responses indicated that they heard from it professionals, or from other young people. One young person that completed the survey highlighted that they shared the Voice Collective website with other young people:

*"I share the link to many people that experience voices etc. and they find it so helpful"*

Interview data also indicated that young people heard about the Voice Collective website through their parents searching for resources/information. Evie outlines this below:

*"well it was through my mum I know she was researching for some trying to find some support for me online... and I know she found Voice Collective ..."*

As does Zane:

*"To be honest, I didn't really hear about them; it was more my mum because I was quite unwell at the time and she was searching around for stuff that could help...So thinking about how she heard about them, I think just finding them through the internet"*

Like young people, survey responses indicated that parents also came to the website looking for information. Whilst there were few responses given to this question, most parents suggested coming across the website when searching for information/literature online:

Alice outlines this below in her interview:

*"I think I must have just Googled something about hearing voices... and I think I very briefly went on the site..."*

Conversely, Catherine went on the website after picking up a postcard/flyer designed by Voice Collective about voice hearing, and impressed with its stance, went on the website to find out more:

*"[the postcard] was saying about the number of famous people who've heard voices, and, you know, kind of normalising that experience in that way... it was very interesting to me and my husband, because we hadn't come across it before, and so it made me think, well, these people know a lot about this...so I went on the website and found out a bit more, and then ended up ringing and talking to Claire"*

Thus from the above, it appears that both parents and young people that hear voices are accessing Voice Collective looking for further support on hearing voices. Additionally, the number of parental booklet downloads (Table 1, page 11) may also suggest that parents are looking for further information and support. This has significantly increased from 705 in the first year of the evaluation to 3,917 in the final year, which also highlights that Voice Collective is contributing to and increasing information on voice hearing.

For professionals, information was limited to the survey data. The survey responses indicated that they were looking at ways to support a young person that heard voices, and to learn about 'good' practice. It is not known how these individuals came across the website, though from information in chapter 2, it is likely they heard about it through other professionals.

## Helpfulness of website

Both survey data and interviews suggested that young people found the website useful. In particular, survey responses indicated that young people found being able to learn about ways to cope with voice hearing helpful. One respondent outlines this below:

*"I've found it really useful with the thread on how to cope/recover and if this site wasn't here I wouldn't know where to go".*

Similarly, Evie highlights that when she felt 'in crisis' at night, she was able to make use of the facilities on the website to help her cope:

*"I think able to go on the website find the strategies in like a crisis I would be up at night I'd been having a really difficult time just to be able to go on..."*

Other young people indicated from survey responses that they found the website useful as it normalised their experience of voice hearing:

*"After starting to hear voices, I was directed to this website where I found personal stories from other people who hear them too, from reading those, I have realised that this isn't such a bad thing, I'm unique and shouldn't 'beat myself up' about it"*

Similarly, another respondent reiterates the normalising nature of the website:

*"It made me feel like I was normal, before I came on the site I felt like a freak but it helped me realise other people are like me. I hear voices and last week I told my friend. It's made thing a lot easier and I am going to now tell my parents. This site has helped me so much. It's saved my life"*

As a result, it appears that young people find the website helpful in terms of information and knowledge relating to coping strategies, and by normalising the experience for them.

Parents also found the website helpful as they described findings a 'resource' that they could use to help their young person that hears voices. This is outlined by one parent below:

*"I've been distraught for the past few days since my daughter came to me with the fact that she hears voices. I'd been feeling hopeless because she's wants to keep this a secret but wants to be cured. Crying and losing my own mind this morning, I stumbled on to this site and feel a glimmer of hope and found a real resource for my daughter!"*

This point is also echoed by another parent that completed the survey, however within this context, the Voice Collective website and email contact was a helpful resource as they lived in Scotland and were unable to attend training events based in London:

*"Even though I have not yet managed to attend any of the training or events as I stay in Scotland, the emailed information from VC responding to my emails and the info on the website has been incredibly helpful. It would be fantastic to develop this service further"*

Professionals, like parents found the website helpful as a resource to support young people. In a similar stance to the parent that lived in Scotland, a professional that lived further afield where voice collective services were easily or readily accessible, used the website to sign post for young people to more information:

*"There is little or no support for young people experiencing the distressing effects of hearing voices and seeing things. We live in rural Devon and this website alone has become an important part of our signposting young people to see that they are not alone"*

However, it was not just professionals further afield that used the website as a resource for young people. Interview data from Izzy (mental health professional) who works in London highlighted that she too pointed people towards the Voice Collective website:

*"so for example when we have we have a number of young people who... feel that they are the only people in the world that hear voices and so being able to direct them to the Voice Collective.. in terms of either the website or the groups... have been very helpful for them and has helped... normalise their experience quite a bit..."*

## **Suggested improvements**

Survey responses indicated that overall, most young people, parents and professionals found the website helpful. Two areas for improvement came from feedback; one to do with layout, and one to do with the forum. In relation to the website layout, one young person indicated that they found it puzzling and had difficulties navigating it:

*"It [the website] is really hard to use as it's got a really complicated layout"*

A similar response was also stated by a professional accessing the website:

*"Not sure what the symbols meant to enter the various pages. Ok once I had clicked on though"*

Thus, one thing that the Voice Collective may wish to consider going forward is altering the layout of the website a little to make it more user friendly.

During interviews, Catherine expressed her and her daughter, encountered difficulties with the forum:

*"[Their] website thing...where you can send in questions... we've tried to use that [but] it wasn't working very well"*

It appears that the forum section of the Voice Collective has run into some technical difficulties during part of the evaluation, and resulted in some questions not coming through to the Voice Collective, or being delivered. This has however, since been resolved.

## **DISCUSSION**

The aim of this chapter was to examine whether Voice Collective has influenced the quality and quantity of existing web materials to support young people who hear voices, and their families. In terms of web-based literature, it appears that Voice Collective have begun to make an impression on other websites in both terms of quality and quantity. In relation to the quantity of information, the scoping exercise indicated that two sites that had no information about voice hearing at the start of the evaluation now included information specifically on voice hearing related to Voice Collective's ethos. One of these websites, Childlines 'Ask Sam'; where young people could ask questions to a site moderator, directed children that had questions around voice hearing to Voice Collective's website and provided links to get there. Other websites that the Voice Collective wanted to target appear to have little or no change. In particular, it appears that websites aimed at particular groups such as LGBTQ remain unchanged; this could suggest that some organisations feel the topic being too broad in scope for this group to include on their website.

Voice Collective also identified websites that they wanted to target due to the content and/or medicalising stance they took on voice hearing. This appears to have been somewhat successful, with a number of websites having undergone content changes since this evaluation has taken place. For example Mental-HealthCare has links to the Voice Collective along with a video of the Voice Collective's Project Manager, Rachel Waddingham speaking about PLE's (Psychotic Like Experiences). However, for other websites, it is difficult to tell if the change is directly attributable to Voice Collective, or that of the Hearing Voices movement in general. Whilst outside the remit and scoping exercise of this evaluation, a copy of the site log (provided by Voice Collective, see appendix) confirms that a number of different organisations have linked to the Voice Collective website including other mental health and bereavement charities, academic/research institutions, NHS trusts and youth organisations. More interestingly, these are not limited to England with sites from Wales, Ireland and America making links to the website. This can be said to highlight the impact of the Voice Collective literature in affecting existing literature in terms of quality and quantity.

In reference to the feedback from individuals that used the Voice Collective website, many found it helpful. Most individuals used the website as a source of information. In the case of young people, the website was useful in helping them develop coping strategies to help them deal with voice hearing. Evie highlights this saying that she went on the website for coping strategies at night to help her with her voice hearing. Young people also indicated that the website was useful in providing normalising information on voice hearing, such as statistics and famous people that heard voices. As a result of this normalising approach, young people indicated that they were able to feel better about themselves; with one young person saying he no longer 'beat himself up' that he heard voices, instead seeing himself as unique. Parents also found the website a useful resource, providing them and for the young person they looked after with knowledge on voice hearing. In particular, one parent found the website useful as they were based in Scotland and would have been unable to easily access workshops or peer group support. Professionals also found the website helpful and often used it as a signposting resource to direct young people to more information. In some cases this was because they were too far afield to access training or support groups, but it appears that professionals within London may also direct young people to the Voice Collective website.

One suggested topic for improvement of the website focused around having a better layout as some found the website complicated and difficult to navigate. Another topic for improvement focused around getting better functionality of the forum, particularly in relation to getting questions and answers function up running. This appears to have been caused by a technical failure, and has since been resolved.

# CONCLUSIONS AND COMMENTARY

This research set out to answer 3 key questions:

1. Does accessing Voice Collective services increase young people and their families' self-esteem and coping strategies. If so, though what mechanisms are this achieved?
2. Does professionals' access to Voice Collective services lead to improvements in access and quality of services provided? If so, through what mechanisms are these achieved?
3. Has Voice Collective improved the quality and quantity of online information and advice for children and young people who hear voices, their families and carers?

Each research question will be considered in turn below:

1. Does accessing Voice Collective services increase young people and their families' self-esteem and coping strategies. If so, though what mechanisms are this achieved?

## **Conclusions:**

From the data collected, it appears that Voice Collective does increase young people's self-esteem and coping strategies. This may be said to be demonstrated though the impact Voice Collective support had on them; making them feel empowered and not seeing themselves as ill, as well as using coping strategies that they learnt in their daily lives. Whilst no single mechanism was identified, young people's perceptions and experiences of Voice Collective as an organisation that: taught them new coping strategies, listened to them, reduced their feelings of isolation, and approached voice hearing in a normalising, non-stigmatising way may be said to play an important role.

From the data collected, it appears that support from Voice Collective does have a positive impact on parents of young people who hear voices; analysis showed that parents felt self empowered to support their young person after receiving support from the Voice Collective. No single underlying mechanism was identified, however it is likely that the themes identified from parents' perceptions and experiences of Voice Collective: reduced their feelings of isolation, listened to them, approached voice hearing in a normalising and non-stigmatising way, where they could share and gain knowledge about voice hearing, that could be a safety net in times of need and could play an important role in this helped positively impact ability to cope and feel empowered.

## **Commentary:**

Young people and parents interviewed as part of the evaluation clearly found Voice Collective support beneficial. Whilst is important to highlight this positive impact, it is important to note that this is a small sample size which means a saturation of themes was not reached. It may be that those interviewed may have had more positive things to say about Voice Collective as they had had prolonged and regular contact indicating a good relationship. In contrast, those who did not return after initial contact were more likely to have been missed in the evaluation, and may have had differing viewpoints. Furthermore, interviews conducted with families were limited to mothers. From an evaluation perspective, it would have been interesting to take into views of siblings, fathers and other carers to see if support from Voice Collective affected them differently.

1. Does professionals' access to Voice Collective services, lead to improvements in access and quality of services provided? If so, through what mechanisms are these achieved?

## **Conclusions:**

From the data collected, it appears that workshops for professionals and trainee facilitators have led to some improvements in access and quality of service provided. Professionals indicated that after attending workshops they felt more confident working with young people who heard voices, had more compassion and empathy toward them, and were better able to normalise the experiences of voice hearing with this group. This was indicated to be the result of the workshops increasing their knowledge and understanding on voice hearing.

Facilitators also indicated that training was useful, stating that after attending training they felt more confident working with young people who hear voices, and setting up their own peer support group. This was through the workshops teaching them the practicalities of setting up a group and giving them other (non-medical) approaches to voice hearing. Only one facilitator interviewed had set up a peer support group, and thought that young people enjoyed having a space to speak about things, feel listened to, and feel less isolated. Facilitators who had not set up a group, still said the training helped them work with young people who hear voices, as they now used less stigmatising language and normalised the experience of voice hearing.

## **Commentary:**

Professionals and trainee facilitators feel that attendance to Voice Collective workshops has impacted on their professional work and improved the quality of service provided; with many mental health professionals speaking about using techniques and skills gained through workshops when working with young people. Interviews from non-mental health professionals was limited to three interviews; with more data it would be interesting to look further at differences between what non mental health professionals take away from Voice Collective and how this related to mental health professionals.

Voice Collective's aim to improve access is supported by the evidence from one facilitator interviewed who set a peer support group, and reported that young people enjoyed having a place to come and talk, listen and feel less isolated. Researchers are aware that other peer groups have started, stopped and been put on hold, but as interviews have not been conducted with these facilitators, further conclusions cannot be drawn. Voice Collective may wish to investigate this area further.

2. Has Voice Collective improved the quality and quantity of information and advice resources available (explored through web based materials) for young people who hear voices, their families and carers?

## **Conclusions:**

From the data collected, it appears that Voice Collective has begun to impact on the quantity and quality of information out there. In terms of quantity, at the start of the evaluation Childline had no information on Voice Collective on their website. Now Childline have referenced Voice Collective in their 'Ask Sam' section, with links being provided directly to Voice Collective's site. Other websites such as Mind have changed in content towards a less medicalised and stigmatised approach, but with no links present to Voice Collective, the researchers cannot say whether is directly attributable to Voice Collective, or due a wider shift in the hearing voices movement.

Young people, parents and professional's opinions of Voice Collective's website were that it was helpful for getting more information and support around voice hearing. Users of the sites were located both in and out of London, with those out of London stating the website was useful as they were not easily able to access other services from Voice Collective. Some individuals said they found the website difficult to navigate and spoke about difficulties with the forum section. However, the latter has since been improved as it was due to a technical issue.

**Commentary:**

Voice Collective has started to impact on the quality and quantity of information out there, with some successful changes in the quantity and quality of information available. In terms of targeting specialist websites such as LGBTQ, this appears to have been less successful with no changes being observed on these websites. It may be that the topic of 'hearing voices' may be too broad for them to include on their website and Voice Collective should consider whether to direct their resources in targeting these websites. In terms of the Voice Collective's own website, young people, professionals and parents all found this useful. Voice Collective may wish to consider developing this resource further this is a particular source of support for individuals who are far away and do not have access to other Voice Collective support.

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# APPENDIX 1: PARENT PEER SUPPORT WORKSHOP QUESTIONNAIRE



## What Did You Think About This Peer Support Workshop?

We want to make Voice Collective services as helpful to you as possible. You could really help us with this by telling us about your experience of today's workshop, and how (if at all) you think it has helped! You can do this by answering the questions on this page.

1. How did you find this workshop overall?

Excellent     Good     Satisfactory     Unsatisfactory

2. What did you find most helpful about the workshop?

3. What do you think could be improved?

4. What have you got out of coming today? Please look at the list of statements below and tell us which (if any) apply to you, and by how much:

This peer-support workshop...	Not at all					A lot						
Please rate by ticking	0	1	2	3	4	5	0	1	2	3	4	5
Helped me to feel less alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helped me to feel more listened to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helped me to have more hope for the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helped to inform me	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helped by giving me practical ideas	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helped me by being with other parents	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5. Is there anything Voice Collective can do to help you in the future?

6. Do you have any other comments or suggestions that you would like to let us know about? If so, write them here:

E: [info@voicecollective.co.uk](mailto:info@voicecollective.co.uk) | T: 020 7625 9042 | W: [www.voicecollective.co.uk](http://www.voicecollective.co.uk)  
 Voice Collective, Mind in Camden, Crossfields Centre, 8 Fairhazel Gardens, London, NW6 3SG

# APPENDIX 2: PROFESSIONAL WORKSHOP QUESTIONNAIRE



## What Did You Think About This Training Event?

We want to make Voice Collective services as helpful to you as possible. You could really help us with this by telling us about your experience of today's training, and how (if at all) you think it has helped! You can do this by answering the questions on this page.

1. Date of the training attended:

2. What were your reasons for coming today? (E.g. this could be because of a specific experience you have encountered at work, you wanted to gain additional training, or any other reason that is relevant to you)

3. How did you find this training event overall? (Please tick)

Excellent  Good  Satisfactory  Unsatisfactory

4. What 3 things you find most helpful about today's training?

1.

2.

3.

5. What, if anything, should we improve?

6. What sort of follow up would you like following attendance at this training event?

Please turn over



# What Did You Think About This Training Event?

7. What have you got out of coming today? Please look at the list of statements below and tell us which (if any) apply to you, and by how much:

This training event...	Not at all					A lot
Please rate by ticking	0	1	2	3	4	5
Improved my understanding of the experience of voice hearing	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please tell us more if you like						
Improved my understanding of how to work with young voice hearers	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please tell us more if you like						
Has helped me feel more equipped to support young people who hear voices (tools, skills, confidence)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Please tell us more if you like						
Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
_____						
Please tell us more if you like						

8. Do you have any other comments or suggestions that you would like to let us know about? If so, write them here:

# APPENDIX 3: YOUNG PERSON'S PEER SUPPORT QUESTIONNAIRE



## What do you think about being part of this peer-support group?

We want to make Voice Collective services as helpful to you as possible. You could really help us with this by telling us about your experience of today's Peer Support group, and how (if at all) you think it has helped! You can do this by answering the questions on this page. Thank you so much for helping us with this!

1. How long have you been in touch with Voice Collective for?
2. Which group are you in?
3. What were the three things interested you in joining this peer support group? (don't worry if you only have one or two)
  - 1.
  - 2.
  - 3.
4. What do you think about being part of Voice Collective peer-support group? Please look at the list of statements below and tell us which (if any) are true for you, and by how much:
 

Being part of this peer-support group has...	Not at all						A lot
(Please rate by ticking)	0	1	2	3	4	5	
Helped me to feel less alone	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helped me to feel better about myself	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helped me to have more hope for the future	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helped me to find some coping strategies	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Helped me to feel more listened to	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Is there anything else you would like to get from coming to future groups?
6. Do you have any other comments or suggestions that you would like to let us know about? If so, write them here:

E: [info@voicecollective.co.uk](mailto:info@voicecollective.co.uk) | T: 020 7625 9042 | W: [www.voicecollective.co.uk](http://www.voicecollective.co.uk)  
 Voice Collective, Mind In Camden, Crossfields Centre, 8 Fairhazel Gardens, London, NW8 3SG

## APPENDIX 4: EXPRESSION OF INTEREST EVALUATION SLIP



### The Voice Collective Evaluation Project

We are looking for people to be interviewed or to join focus groups as part of an on-going evaluation of the Voice Collective services. If you would like to be part of this evaluation, or want to find out a bit more about it, please fill in your email and/or telephone details below.

Email: \_\_\_\_\_

Telephone: \_\_\_\_\_

## APPENDIX 5: INTERVIEW SCHEDULES (FACILITATOR)

Can you tell me your background?

- What were you doing before joining the VC?

How did you come to work/hear about the VC?

- How did you hear about the VC ?
- What made you want to work with VC? [prompt: versus other organisations]

Can you tell me what work you contributed to/undertook whilst at the VC

- Prof workshops (training), CYP CW and parent (peer support) workshops, CYP peer support groups
- Group facilitator workshops, emails, one to one contact, telephone contact
- Can you tell me what you did in the groups/spoke about?
- What did you enjoy the most, why?
- What did you enjoy the least, why?
- Based on comments/feedback you received, what do you think others (CYP, parents, professionals) enjoyed the most why?
- What do you think others (CYP, parents, professionals) enjoyed the least why?

How has working for the VC impacted you?

- Skills, knowledge, confidence, etc.
- Are there any particular points of your voice collective experience that stand out for you – can you tell me about this

Do you feel the VC has changed your perspective of young people that hear voices? If so, how?

- What was your understanding of voice hearing before joining the VC
- What were your perspectives after

How do you feel the VC impacted (a) professionals, (b) CYP that hear voices, and (c) parents/carers from working with the VC, can you provide examples?

- Did you give them greater knowledge
- A safe space to meet others
- A safe space to express themselves
- Answers to questions
- Support

How accessible do you think the Voice Collective is to young people and their families?

- Do you feel there are any barriers for CYP accessing services
- If so, can you think of any ways that these can be overcome

Compared with other services that support voice hearers and children, what makes the VC stand out from the rest i.e. What do they do better?

- Do they offer things that other services don't? Tell me more
- What things would you want to see more of
- Are there aspects in other businesses/services that you feel could be incorporated into the VC

If you were summarising your job to other people that were interested in joining the VC in the same context, what would you say?

# APPENDIX 6: INTERVIEW SCHEDULES (CYP)

## Interview CYP 12-18

1. How did you hear about Voice Collective?

- a. If someone told you about the Voice Collective, who was it that told you about it and what did they tell you?

2. Which of Voice Collective's services have you used?

- |                    |                          |
|--------------------|--------------------------|
| Peer support group | <input type="checkbox"/> |
| Creative workshop  | <input type="checkbox"/> |
| One-to-one chat    | <input type="checkbox"/> |
| Telephone contact  | <input type="checkbox"/> |
| Email contact      | <input type="checkbox"/> |

3. Can you tell me a bit about the activities you have been a part of?

Prompts:

- What did you do?
- What did you talk about?
- How many people were there ( for groups/workshops)?
- Did anyone go with you?
- What did you like?
- What did you not like so much?
- Have you also been to any other activities put on by Voice Collective?
- Have you contacted the Voice Collective by email, phone or for a face to face talk?
- If more than one... which ones did you find helped you most/least

4. What did you want Voice Collective to help you with when you contacted them?

5. How do you feel now after having got in touch with the Voice Collective?

Prompts:

- Did getting in touch with Voice Collective help? If so, can you tell us how it helped?
- If not, could you tell us why it didn't help?

6. What things did you find most useful about getting in touch with Voice Collective?

Prompts:

- Did it make a difference to the way you feel?
- Did it make a difference to how you manage particular issues?
- Did you learn anything new?

7. Have you tried getting help about the same issue from anywhere else?

a. Which other places/people did you try?

b. Were they helpful?

c. What would you say is different about Voice Collective from the other kinds of help?

Prompts:

- What would you say is better at Voice Collective?
- What would you say is worse about Voice Collective?

8. Have you been in touch with VC lots of times or just once or twice?

a. If lots, why? (e.g., found support useful, liked meeting with others)

b. If just once or twice why? (e.g., not as useful as hoped or solved problem you were looking for help with, or no longer need any help)

9. Can you tell me some things that the Voice Collective aren't so good at or could do better?

Prompt:

- What would you like to see more of?
- What did you not like?
- What would you like to see less of?
- What would you do/change if you were in charge?

10. How would you describe/explain Voice Collective to other young people?



# APPENDIX 7: INTERVIEW SCHEDULES (PARENT)

## Interview Schedule Parent/Guardians

1. How did you hear about Voice Collective?

- a. If someone told you about the Voice Collective, who was it that told you about it and what did they tell you?

2. Which of Voice Collective's services have you used?

- |                       |                          |
|-----------------------|--------------------------|
| Peer support workshop | <input type="checkbox"/> |
| One-to-one chat       | <input type="checkbox"/> |
| Telephone contact     | <input type="checkbox"/> |
| Email contact         | <input type="checkbox"/> |
| Training              | <input type="checkbox"/> |

3. Can you tell me a bit about the Voice Collective services you have accessed?

Prompts:

- What did you do?
- What did you talk about?
- How many people were there (for groups/workshops)?
- Did anyone go with you?
- What did you like?
- What did you not like so much?
- Have you also been to any other activities put on by Voice Collective?
- Have you contacted the Voice Collective by email, phone or for a face to face talk?
- If more than one... which ones did you find helped you most/least?

4. Why did you get in touch with the Voice Collective – what did you want them to help you with?  
(If relevant)

5. How do you feel now after having got in touch with the Voice Collective?

Prompts

- Did getting in touch with Voice Collective help?
  - a. If so, can say a bit about how it helped?
  - b. If not, could you say why you didn't feel this helped?

6. What things did you find most useful about getting in touch with Voice Collective?

Prompts:

- Did it make a difference to the way you feel?

- Did it make a difference to how you manage particular issues?
  - Did you learn anything new?
7. Is there anything that you found unhelpful about the Voice Collective?
- Prompts:
- Was there anything they were unable to help with?
  - Is there anything you did not like?
8. Have you tried getting help about the same issue from anywhere else?
- a. Which other places/people did you try?
  - b. Were they helpful?
  - c. What would you say is different about Voice Collective from the other kinds of help/ services?
- Prompts:
- What would you say is better at Voice Collective?
- What would you say is worse about Voice Collective?
9. Roughly how many times have you been in contact with the Voice Collective?
- a. If a number of times (>2) why? (e.g., found support useful, liked meeting with others)
  - b. If just once or twice why? (e.g., not as useful as hoped or solved problem you were looking for help with, or no longer need any help)
10. Can you tell me some things that the VC aren't so good at or could do better
- Prompt:
- What would you like to see more of/less of?
  - What would you do/change if you were in charge?
11. How would you describe/explain Voice Collective to other parents?

# APPENDIX 8: INTERVIEW SCHEDULES (PROFESSIONAL)

1. What is your profession?

2. How often do you come into contact with young people who hear voices or see visions in your job?

Prompts:

- What age range do they primarily tend to be?
- What proportion of the young people you work with are voice hearers?

3. How did you first come to hear about the Voice Collective?

- a. If someone told you about the Voice Collective, who was it that told you about it and what did they tell you?

4. What were your reasons for accessing Voice Collective services?

Prompts:

- Did you have a specific questions that you wanted answered?
- Had you had a voice hearer that you were unsure what to do with?
- Was this as a part of continued professional development?
- Was this because of a change in role entailing working more closely with voice hearers?

5. Which of Voice Collective's services have you used?

a. Workshops/Training:

- Introductory
- Advanced
- In-house

b. One-to-one contact:

- Telephone
- One-to-one meeting
- Email

i. Can you tell me a bit about the workshops/training you attended?

Prompts:

- What did you do/talk about?

ii. Can you tell me a bit more about one-to-one contact you had?

Prompts:

- What did you do/talk about?
- Were the Voice Collective accessible?

6. What things did you find most useful about getting in touch with Voice Collective?

Prompt:

- Did you get specific questions answered?
- Further support or advice?
- Increased awareness?
- Training?

7. Is there anything you would change about the support from the Voice Collective?

Prompts:

- Are there any aspects that were not helpful?
- Is there anything additional you think they should be doing in terms of the information, help and advice they are able to offer you?
- Something you were hoping contact with them would cover which it didn't?

8. Has the Voice Collective changed the way you would work with young people who hear voices and see visions?

If yes....

- a. could you give some examples of how your approach has changed

Prompts

- b. Has it affected your confidence in working with voice hearers?
- c. Has it made a difference to your skills in working with voice hearers?
- d. How, if at all, has their help/training made you more aware of available coping strategies for young voice hearers?
- e. Have things you learnt from the workshop, had an effect on other colleagues in their service or any other changes to the way the service works with these young people

9. To what extent has your understanding of voice-hearing changed since contacting Voice Collective?

Prompts:

- Have you learnt anything that you did not know before?
- Has it provided you with increased access to other services, education, training, talking to professionals/service users?

10. Have you received any support or advice from other services about the experience of voice hearing?

Prompts:

- What services were you in contact with?
- How did you find help from these services?
- What would you say is different about Voice Collective?
- What would you say is better at Voice Collective?
- What would you say is worse about Voice Collective?

11. How would you describe Voice Collective to other professionals?

# APPENDIX 9: INFORMATION SHEET (AGES 8-10)

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## **PATIENT INFORMATION SHEET (8-10)** **The Voice Collective Evaluation Project**

### **What is the Voice Collective Evaluation Project?**

The Voice Collective is a group for children and young people, who hear, see and sense things that other do not. The Voice Collective also runs courses for adults who work with children that hear see and sense things.

### **What is research? Why is this project being done?**

Research is a way of finding out the answers to questions. We want know how well the Voice Collective has been in helping young people who hear, see and sense things that others do not. We also want to find out how parents/carers and professionals have found Voice Collective services and training.

### **Why have I been asked to take part?**

You have been asked to take part as you have joined in Voice Collective activities and filled out a form saying you would like to speak about your experiences

### **Did anyone else check the study is ok to do?**

Before any research is allowed to happen, it has to be checked by a group of people called a Research Ethics Committee. They make sure the study is fair. This project has been checked by the Hampstead Research Ethics Committee.

### **Do I have to take part?**

You do not have to take part if you do not want to. If you want to take part, we will ask for your parent or guardian to agree too. You can stop taking part at any time. If you stop, you can still take part in all Voice Collective activities.

### **What will happen to me if I take part in the research?**

You can take part in the research by talking to one of the researchers about how you found the Voice Collective. This will be in person at a time that works for you. We will ask your parent/guardian if it is ok for you to take part in this research, and for them (or another adult) to be there.

You could also take part in a focus group. This is where a group of people get together and talk about how they found the Voice Collective together. To do this we will need a few people to take part, so we will try and find a time that suits everybody.

All interviews and focus groups will be voice recorded so we can type up what you have told us – after we have typed them up, we will delete them.

**Might anything about the research upset me?**

We do not think anything in this research will upset you. If you do not like a question, you do not have to answer it, and you can stop taking part at any time.

**Will joining in help me?**

Joining in will not help you, but it will help us see what is helping and what else the Voice Collective can do.

**What happened when the research stops?**

When the research finishes, we will write a report and give it to the Voice Collective. This will include things you have told us about the Voice Collective. We will not write your name or other things that show it was you who said it, so no one will know it was you.

**What if something goes wrong during the project?**

Nothing should go wrong going the project, if it does there are things in place to protect you and look after you. If something happens that you don't like, and you want us to know, talk to the researcher or your parent/guardian. We will make sure what you have told us is acted upon.

**Will my details be kept private if I take part? Will anyone else know I'm doing this?**

We will keep all your details private and no-one can see these outside the research team. Any reports that we write will not contain your name or other things that show it was you who said it, so no one will know it was you. If you take part in a group talk, other people will be there who have also been taken part in Voice Collective activities, they will know that you are taking part, but we ask everyone who takes part in the focus group to keep everything private.

The only time that we may have to tell someone is if you tell us something that makes us think that you or someone else would be in danger or if something bad was happening to you or someone else

**What happens if I don't want to do the research anymore?**

If at any time you don't want to take part in the research anymore, just tell your parents/guardian or the researcher. They will not be cross with you, and you can still take part in all Voice Collective activities.

# APPENDIX 10: INFORMATION SHEET (AGES 11-15)

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## **PATIENT INFORMATION SHEET (11-15) Voice Collective Evaluation Project**

We are asking if you would like to join in a research project to find out how well the Voice Collective has been in helping young people with experiences of hearing, seeing and sensing things that others do not. We also want to find out how parents/carers and professionals have found Voice Collective services and training.

### **Why are we doing this research?**

We want to find out how well the Voice Collective has been in helping young people, and find out what they are doing well, and what can be improved.

### **Why have I been invited to take part?**

You have been asked to take part as you have joined in Voice Collective activities and filled out a form saying you would like to speak about your experiences. We will also talk to between 10-20 children and young people that attended Voice Collective activities to hear their experiences too.

### **Do I have to take part?**

No. It is up to you if you want to take part. We will ask for yours and your parent/guardians consent. We will also give you a copy of this information sheet and signed form for you to keep. You are free to stop taking part at any time during the research without giving reason. If you decide to stop, this will not affect you being able to take part in any Voice Collective activities.

If, after you have taken part in the evaluation, you decide that you want us to remove your data, you can contact us and ask us to delete it. This can be done up to 3 months after you have taken part in the evaluation. After this stage, we make all the recording unidentifiable and will not be able to delete it as we will not know which one is yours.

### **What will happen if I take part?**

If you decide to take part, we would like to hear your views and experiences about the Voice Collective. You could do this in one of two ways:

- 1) You could take part in an interview. This will involve talking to the researcher face-to-face about how you find the Voice Collective. This will take place at a time to suit you and will last 20-30 minutes. We will ask your parent/guardian if it is ok for you to take part, and for them (or another appropriate) adult to be there.
- 2) You could take part in a focus group. Here you will discuss your experiences and views with other people who have used the Voice Collective, and it will last about an hour. Focus groups will be dependent on other people wanting to take part as well. If you want to take part in a focus group, we will find out yours and

others availability to find the most convenient time for everybody. Everybody that attends the focus group will be asked to keep everything strictly confidential to protect everyone's views and opinions.

Both the Interviews and focus groups will be audio recorded so that we may type up the conversations so we can study them later on

**What will I be asked to do?**

If you want to share your views with us, the first thing we will ask you to do is sign a form saying that you agree to take part. We will also ask your parent/guardian to sign a consent form saying they agree for you to take part

If you want to take part in an interview, we will then find out when would be a good time for us to conduct the interview with you and ask your parent if they would like to attend with you (if not another appropriate adult from the AFC or an adult suggested by your parents will join us).

If you want to take part in a focus group, we will ask when you are free and see how this fits in with other people's availability to try and find a convenient time for everyone. If we are running a focus group which you are unable to attend, we will ask yours and your parent/guardians permission to keep your details on file to let you and you and your parents/guardians know about upcoming focus groups.

**What are the possible disadvantages of taking part?**

There are no known risks to taking part in these interviews or focus groups. If any risks become known during the research, we will tell you straight away.

**What are the possible benefits of taking part?**

There is no guaranteed benefit in taking part. One advantage is that you get to help shape the future of the Voice Collective. Most people find taking part in research rewarding, as they contribute to the development of knowledge that may benefit other people in the future.

**What happened when the research stops?**

When the research finishes, we will write a report and give it to the Voice Collective. This will include things you have told us about the Voice Collective. We will not write your name or other things that show it was you who said it, so no one will know it was you.

**What if something goes wrong during the project?**

Nothing should go wrong going the project, if it does there are things in place to protect you and look after you. If something happens that you don't like, and you want us to know, talk to the researcher or your parent/guardian. We will make sure what you have told us is acted upon.





**Will my details be kept private if I take part? Will anyone else know I'm doing this?**

We will keep all your details private and no-one can see these outside the research team. Any reports that we write will not contain your name or other things that show it was you who said it, so no one will know it was you. If you take part in a group talk, other people will be there who have also been taken part in Voice Collective activities, they will know that you are taking part, but we ask everyone who takes part in the focus group to keep everything private.

The only time that we may have to tell someone is if you tell us something that makes us think that you or someone else would be in danger or if you tell us that something bad was happening to you or someone else.

**Who is organising and funding the research?**

This research is being carried out by researchers at the Anna Freud Centre (in association with University College London) in collaboration with Mind in Camden. The research is funded by the City Bridge Trust.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This research has been reviewed and given a favourable outcome by London Hampstead ethics committee

**Contact details:**

If you have any questions about research in general, this research in particular, your rights as a participant, or would like to report any problem or complaint arising from this research, please contact either of the following staff members of the Anna Freud Centre:

Dr Nick Midgley, Independent Advisor.

Tel.: 020 7794 2313. Email: [Nick.MidgleyDPsych@annafreud.org](mailto:Nick.MidgleyDPsych@annafreud.org)

Mr. Daniel Hayes, The Voice Collective Evaluation Project.

Tel.: 020 7443 2220. Email: [daniel.hayes@annafreud.org](mailto:daniel.hayes@annafreud.org).

Dr. Jessica Deighton, and Dr Miranda Wolpert, The Voice Collective Evaluation Project.

Tel.: 020 7443 2223. Email: [hearingvoices@annafreud.org](mailto:hearingvoices@annafreud.org)

This research is insured by University College London.

# APPENDIX 11: INFORMATION SHEET (AGES 16+)

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## **PATIENT INFORMATION SHEET (16+)** **Voice Collective Evaluation Project**

We would like to invite you to take part in this research. Before you decide, we would like you to understand why the research is being done and what it involves. A researcher from the Voice Collective evaluation will go through this information sheet with you and answer any questions you may have. This should take about 10 minutes. Talk to others, if you wish, and ask us if there is anything that is not clear.

### **What is the purpose of the study?**

We want to find out how well the Voice Collective has been in helping young people with experiences of hearing, seeing and sensing things that others do not. We also want to find out how parents/carers and professionals have found Voice Collective services and training.

### **Why have I been invited to take part?**

You have been invited to take part as you have filled out an evaluation form provided by the Voice Collective, and have indicated that you are willing to be contacted to take part in an interview/focus group.

### **Do I have to take part?**

It is up to you to decide whether you are willing to join the study. We will describe the study and go through this information sheet. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. This would not affect your ability to take part in any Voice Collective activities.

If, after you have taken part in the evaluation, you decide that you want us to remove your data, you can contact us and ask us to delete it. This can be done up to 3 months after you have taken part in the evaluation. After this stage, we make all the recording unidentifiable and will not be able to delete it as we will not know which one is yours.

### **What will happen if I take part?**

If you decide to take part, we would like to hear your views and experiences about the Voice Collective. You could do this in one of two ways:

- 1) You could take part in an interview. This can take place over the phone or face to face (whatever you prefer) and will last about 20-30 minutes. We will conduct the interview at a time convenient for you.
- 2) You could take part in a focus group. Here you will discuss your experiences and views with other people who have used the Voice Collective, and it will last about an hour. Focus groups will be dependent on other people wanting to take part as well. If you want to take part in a focus group, we will find out yours and others availability to find the most convenient time for everybody. Everybody that attends

the focus group will be asked to keep everything strictly confidential to protect everyone's views and opinions.

Both the Interviews and focus groups will be audio recorded so that we may type up the conversations for future analysis.

**What will I have to do?**

If you want to share your views with us, the first thing we will ask you to do is sign a consent form saying that you wish to take part.

If you want to be interviewed, we will then find out when would be a convenient time for us to conduct the interview with you, and how you would like to be interviewed (over the phone or in person).

If you want to take part in a focus group, we will ask you availability and see how this fits in with other participants' availability to try and find a convenient time for everyone. If we are running a focus group which you are unable to attend, we will ask your permission to keep your details on file to let you know about upcoming focus groups.

**What are the possible disadvantages of taking part?**

There are no known risks to taking part in these interviews or focus groups. If any risks become known during the research, you will be informed straight away.

**What are the possible benefits of taking part?**

There is no guaranteed benefit in taking part. One advantage is that you get to help shape the future of the Voice Collective. Most people find taking part in research rewarding, as they contribute to the development of knowledge that may benefit other people in the future.

**Will my taking part in the study be kept confidential?**

All information we collect from participants is strictly confidential, though we may have to break confidentiality if you tell us something that puts you or others at risk. We will assign you a unique code, and this will appear on any data we collect from you. Consent forms will be kept in their own locked filing cabinet, and transcribed interviews will be identified only by the unique code we assign to you. Audio recordings will be kept for a maximum of 3 months for transcription purposes on a password protected computer before being deleted. Only members of the Voice Collective Evaluation Project will have access to full transcribed data. Quotations from interviews and focus groups will be provided to the Voice Collective for reports, however any information that may identify a participant will be redacted (e.g. if job title is mentioned).

**What will happen of the results of the study?**

The anonymised results will be published in project reports, scientific journals, presented at conferences and disseminated on Mind of Camden and the Voice Collective websites. The results will be shared once the last person completes the research and the results have been analysed. You will not be identified in any report or publication.

**Who is organising and funding the research?**

This research is being carried out by researchers at the Anna Freud Centre (in association with University College London) in collaboration with Mind in Camden. The research is funded by the City Bridge Trust.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This research has been reviewed and given a favourable outcome by London Hampstead ethics committee

**What if there is a problem?**

If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask a member of the research team if you would like more information on this. In the unlikely event that you are harmed by taking part in this study, compensation may be available to you. If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with a researcher, please make the claim in writing to Dr Miranda Wolpert who is the Chief Investigator for the research and is based at The Anna Freud Centre. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

**Contact details:**

If you have any questions about research in general, this research in particular, your rights as a participant, or would like to report any problem or complaint arising from this research, please contact either of the following staff members of the Anna Freud Centre:

Dr Nick Midgley, Independent Advisor.

Tel.: 020 7794 2313. Email: [Nick.MidgleyDPsych@annafreud.org](mailto:Nick.MidgleyDPsych@annafreud.org)

Mr. Daniel Hayes, The Voice Collective Evaluation Project.

Tel.: 020 7443 2220. Email: [daniel.hayes@annafreud.org](mailto:daniel.hayes@annafreud.org).

Dr. Jessica Deighton, and Dr Miranda Wolpert, The Voice Collective Evaluation Project.

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# APPENDIX 12: INFORMATION SHEET (PARENT/GUARDIAN)

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## **PATIENT INFORMATION SHEET (Parents/Guardians)** **Voice Collective Evaluation Project**

We would like to invite the child you are a parent/guardian to, to take part in this research. Before you decide, we would like you to understand why the research is being done and what it involves. A researcher from the Voice Collective evaluation will go through this information sheet with you and answer any questions you may have. This should take about 10 minutes. Talk to others, if you wish, and ask us if there is anything that is not clear.

### **What is the purpose of the study?**

We want to find out how well the Voice Collective has been in helping young people with experiences of hearing, seeing and sensing things that others do not. We also want to find out how parents/carers and professionals have found Voice Collective services and training.

### **Why has my child been invited to take part?**

Your child has been invited to take part as they filled out an evaluation form provided by the Voice Collective, and have indicated that they are willing to be contacted to take part in an interview/focus group.

### **Does my child have to take part?**

It is up to you to decide whether you are willing for them to join the study. We will also ask for their permission too. We will describe the study and go through this information sheet with you (and an age appropriate information sheet with them). If you agree for them to take part, we will then ask both of you to sign a consent form. Either of you can withdraw at any time, without giving a reason. This would not affect your ability to take part in any Voice Collective activities.

If, after your child has taken part in the evaluation, you or they decide that interview/focus group data should be removed and no longer used for the evaluation, you can contact us and ask us to delete it. This can be done up to 3 months after they have taken part in the evaluation. After this stage, we make all the recording unidentifiable and will not be able to delete it as we will not know which one is theirs.

### **What will happen if I agree for my child to take part?**

If you decide that your child can take part, we would like to hear their views and experiences about the Voice Collective. This can be done in one of two ways:

- 1) They could take part in an interview. This will take place face to face at a time to suit them. You can be there if you would like or we will provide an age appropriate adult (whatever you prefer). The interview will last about 20-30 minutes.
- 2) They could take part in a focus group. Here they will discuss their experiences and

views with other children and young people who also use the Voice Collective. The focus group will last about an hour. Focus groups will be dependent on other people wanting to take part as well. If you agree for your child to take part in a focus group, we will find out yours, theirs and others availability to find the most convenient time for everybody. Everybody that attends the focus group will be asked to keep everything strictly confidential to protect everyone's views and opinions.

Both the Interviews and focus groups will be audio recorded so that we may type up the conversations for future analysis.

**What will my child and I have to do?**

If you agree for your child to share their views with us, the first thing we will ask you to do is to both sign a consent form saying that you wish to take part.

If your child agrees to be interviewed, we will then find out when would be a convenient time for us to conduct the interview with them, arrange a suitable place, and find out if you want to be there (or another appropriate adult from the AFC, or one suggested by you).

If your child wants to take part in a focus group, we will ask their availability and see how this fits in with other participants' availability to try and find a convenient time for everyone. If we are running a focus group which your child is unable to attend, we will ask your permission to keep their details on file to let you and them know about upcoming focus groups.

**What are the possible disadvantages of taking part?**

There are no known risks to taking part in these interviews or focus groups. If any risks become known during the research, you and your child will be informed straight away.

**What are the possible benefits of taking part?**

There is no guaranteed benefit in taking part. One advantage is that your child will get to help shape the future of the Voice Collective. Most people find taking part in research rewarding, as they contribute to the development of knowledge that may benefit other people in the future.

**Will my child's participation in the study be kept confidential?**

All information we collect from participants is strictly confidential, though we may have to break confidentiality if your child tell us something that puts them or others at risk from harm. We will assign your child a unique code, and this will appear on any data we collect from them. Consent forms will be kept in their own locked filing cabinet, and transcribed interviews will be identified only by the unique code we assign to you. Audio recordings will be kept for a maximum of 3 months for transcription purposes on a password protected computer before being deleted. Only members of the Voice Collective Evaluation Project will have access to full transcribed data. Quotations from interviews and focus groups will be provided to the Voice Collective for reports, however any information that may identify your child will be redacted (e.g. names, school they attend).

**What will happen of the results of the study?**

The anonymised results will be published in project reports, scientific journals, presented at conferences and disseminated on Mind of Camden and the Voice Collective websites. The results will be shared once the last person completes the research and the results have been analysed. Your child will not be identified in any report or publication.

**Who is organising and funding the research?**

This research is being carried out by researchers at the Anna Freud Centre (in association with University College London) in collaboration with Mind in Camden. The research is funded by the City Bridge Trust.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This research has been reviewed and given a favourable outcome by London Hampstead ethics committee

**What if there is a problem?**

If you wish to complain, or have any concerns about any aspect of the way you or the child you look after has been approached or treated by members of staff you may have experienced due to your participation in the research, National Health Service or UCL complaints mechanisms are available to you. Please ask a member of the research team if you would like more information on this. In the unlikely event that you are harmed by taking part in this study, compensation may be available to you. If you suspect that the harm is the result of the Sponsor's (University College London) or the hospital's negligence then you may be able to claim compensation. After discussing with a researcher, please make the claim in writing to Dr Miranda Wolpert who is the Chief Investigator for the research and is based at The Anna Freud Centre. The Chief Investigator will then pass the claim to the Sponsor's Insurers, via the Sponsor's office. You may have to bear the costs of the legal action initially, and you should consult a lawyer about this.

**Contact details:**

If you have any questions about research in general, this research in particular, your rights as a participant, or would like to report any problem or complaint arising from this research, please contact either of the following staff members of the Anna Freud Centre:

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Mr. Daniel Hayes, The Voice Collective Evaluation Project.

Tel.: 020 7443 2220. Email: [daniel.hayes@annafreud.org](mailto:daniel.hayes@annafreud.org).

Dr. Jessica Deighton, and Dr Miranda Wolpert, The Voice Collective Evaluation Project.

Tel.: 020 7443 2223. Email: [hearingvoices@annafreud.org](mailto:hearingvoices@annafreud.org)

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# APPENDIX 13: INFORMATION SHEET (PROFESSIONALS)



## The Voice Collective Evaluation Project

### What is Voice Collective?

- Voice Collective is peer support for people who hear, see and sense things that others do not.
- Voice Collective helps children and young people who hear voices to improve their self-esteem, coping strategies, and feel less isolated.
- The Voice Collective project also runs a range of activities to help and support young people, parents and professionals who are affected by voice hearing.

### What is the Voice Collective Evaluation Project?

*What is the purpose of the study?*

- We want to know how well Voice Collective has been helping young people with their experiences of voice-hearing.
- We also want to see how useful parents and professionals have found Voice Collective services and training.

*How will we do this?*

- We will do this by asking people who have had experience of voice collective, what they thought about it.
- These will be young people who have received help from Voice Collective, parents who had had help or attended workshops, and staff who received training or coaching.
- We will mainly use short interviews and focus groups but we will also look at questionnaire feedback collected by the Voice Collective

*Who has reviewed the study?*

All research is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This research has been reviewed and given a favourable opinion by UCL Ethics Committee

### What does taking part involve?

Being involved in the evaluation would mean telling one of our evaluation team about your experiences of Voice Collective by taking part in an interview. Interviews can take place face-to-face or by phone at a time that suits you.

If you decide to take part in an interview, we will ask you to sign a form saying that you agree to participate in the research. If you do take part, you do not have to answer any questions you do not want to, and you can stop at any time and change your mind about being involved.

Hearing Voices Evaluation Project: e-mail: [hearingvoices@annafreud.org](mailto:hearingvoices@annafreud.org) Tel: 020 7443 2220  
UCL ethics reference: 3511/001 Version 3 Date: 29/04/13





## The Voice Collective Evaluation Project

### What happens to the information you give us?

- All information will be treated privately and not be shared beyond the research team.
- We will audio record the sessions so that they can be transcribed. After transcription we will delete the recordings and won't keep any information that links the transcription to your name or other personal details.
- All data will be collected and stored in accordance with the Data Protection Act 1998.
- The overall results will be presented at conferences and may be used as part of academic publications

### What if you decide to withdraw after today?

- Data collected will be kept for 3 months within which if you should decide to withdraw you can contact the research team and let them know. After 3 months all names and identifiers are destroyed and the research team will not be able to identify your data and hence it will not be possible to withdraw it.

### What if there is a problem?

- If you wish to complain or have any concerns about anything to do with the way you were approached or treated during participation, there are ways of raising these problems with UCL. Please ask if you would like more information on this.
- In the extremely unlikely event that you are harmed by taking part in this study, compensation may be available. If you suspect that the harm was due to this research you can make a claim by contacting Dr. Miranda Wolpert who is the Chief Investigator of this project and is based at the address provided below.

If you have any questions, concerns or would like to withdraw from the study please contact:

CAMHS Evidence Based Practice Unit  
12 Maresfield Gardens  
NW3 5SU  
Email: [hearingvoices@annafreud.org](mailto:hearingvoices@annafreud.org)

# APPENDIX 14: ASSENT FORMS (CYP)

**ASSENT FORM CYP (Under 16)**  
**The Voice Collective Evaluation Project**  
(to be completed by the child and their parent/guardian)

Child/Young Person to circle all they agree with:

1. Has somebody explained this project to you? Yes/No
2. Do you understand what the project is about? Yes/No
3. Have you asked all the questions you want? Yes/No
4. Have you had your questions answered in a way you understand? Yes/No
5. Do you understand that it's OK to stop taking part at any time? Yes/No
6. Are you happy to take part? Yes/No

If any answers are 'no' or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below:

Your name \_\_\_\_\_

Date \_\_\_\_\_

The researcher who explained this project to you needs to sign too:

Print name \_\_\_\_\_

Sign \_\_\_\_\_

Date \_\_\_\_\_

Thank you for your help

# APPENDIX 15: CONSENT FORMS (16+)

Tel +44 (0)20 7794 2313  
12 Maresfield Gardens, London, NW3 5SU  
www.annafreud.org

South London and Maudsley   
NHS Foundation Trust



## CONSENT FORM (16+) The Voice Collective Evaluation Project

Please initial box

1. I confirm that I have read and understood the information sheet dated \_\_\_\_\_ version \_\_\_\_ for the above study. I have had the opportunity to consider the information, ask questions and have had them answered satisfactorily.

2. I understand that the participation is voluntary and that I am free to withdraw at any time. This will not affect my participation in any future Voice Collective Activities

3. I consent to the storage and processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.

4. I agree to take part in this study.

Participant name \_\_\_\_\_

Participant signature \_\_\_\_\_ Date \_\_\_\_\_

Name of researcher taking consent \_\_\_\_\_

Researcher signature \_\_\_\_\_ Date \_\_\_\_\_

# APPENDIX 16: CONSENT FORMS (PARENT/GUARDIAN)

Tel +44 (0)20 7794 2313  
12 Maresfield Gardens, London, NW3 5SU  
www.annafreud.org

South London and Maudsley **NHS**  
NHS Foundation Trust



## CONSENT FORM (Parent/Guardian) The Voice Collective Evaluation Project

Please initial box

1. I confirm that I have read and understood the information sheet dated \_\_\_\_\_ version \_\_\_\_ for the above study. I have had the opportunity to consider the information, ask questions and have had them answered satisfactorily.

2. I understand that participation is voluntary and that I am free to withdraw my child at any time. This will not affect mine or my child's participation in any future Voice Collective Activities

3. I consent to the storage and processing of my child's personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.

4. I agree for my child to take part in this study.

Participant name \_\_\_\_\_

Participant signature \_\_\_\_\_ Date \_\_\_\_\_

Name of researcher taking consent \_\_\_\_\_

Researcher signature \_\_\_\_\_ Date \_\_\_\_\_

# APPENDIX 17: CONSENT FORMS (PROFESSIONALS)



## The Voice Collective Evaluation Project

### CONSENT FORM

#### The Voice Collective Evaluation Project

Please initial box

1. I confirm that I have read and understood the information sheet dated \_\_\_\_\_ version \_\_\_\_ for the above study. I have had the opportunity to consider the information, ask questions and have had them answered satisfactorily.

2. I understand that the participation is voluntary and that I am free to withdraw at any time. This will not affect my participation in any future Voice Collective Activities

3. I consent to the storage and processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.

4. I agree to participate in this study.

Participant name \_\_\_\_\_

Participant signature \_\_\_\_\_

Date \_\_\_\_\_

Name of researcher \_\_\_\_\_

Researcher signature \_\_\_\_\_

Date \_\_\_\_\_



## The Voice Collective Evaluation Project

### CONSENT FORM

#### The Voice Collective Evaluation Project

Please initial box

1. I confirm that I have read and understood the information sheet dated \_\_\_\_\_ version \_\_\_\_ for the above study. I have had the opportunity to consider the information, ask questions and have had them answered satisfactorily.

2. I understand that the participation is voluntary and that I am free to withdraw at any time. This will not affect my participation in any future Voice Collective Activities

3. I consent to the storage and processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.

4. I agree to participate in this study.

Participant name \_\_\_\_\_

Participant signature \_\_\_\_\_

Date \_\_\_\_\_

Name of researcher \_\_\_\_\_

Researcher signature \_\_\_\_\_

Date \_\_\_\_\_

