



12th November 2014

An Inventory of hearing voices groups: A request for your support and participation

To: Hearing Voices Group Facilitators and Members

Dear Facilitators,

InterVoice asks for your support and co-operation in undertaking an inventory of hearing voices groups

INTERVOICE would like to ask for your co-operation in undertaking an inventory of existing peer support groups for voice hearers (usually known as “hearing voices groups”).

INTERVOICE www.intervoiceonline.org is the international organisation for supporting the exchange of information and the holding of annual meetings for the 29 national networks of voice hearers and their supporters.

This inventory will be conducted by Marius Romme and Manuel de Chavez.

Marius Romme carried out the research which led to the formation of the hearing voices movement and Manuel de Chavez has for many years facilitated groups with patients diagnosed with schizophrenia.

Why do we need an inventory?

Hearing voices groups could be called the backbone of the hearing voices movement. The hearing voices groups have proven to be very useful to voice hearers and they have also been critical to the successful dissemination of the hearing voices approach.

To date though, we have not systematically gathered and shared information about the way groups are organised and operate. We have not assessed their impact on supporting the recovery of voice hearers.

Our objective is to collate a book like “Living with voices” in which we published 50 stories of how people experiencing distressing voices recovered their lives. We want to do the same by telling the stories of hearing voices groups.

Therefore to increase our knowledge we would like to undertake an inventory as described below.

How you can participate

We are asking you as a facilitator of a hearing voices group to inform us about the group you facilitate. Firstly, we would like you to write an essay about your group broadly following the attached schedule of the information we are gathering.

We would like to publish your story about your group so that others will be better informed and possibly inspired by the way hearing voices groups are working.

This book will not be a “scientific” inventory but an informative inventory. Therefore we not only want you to describe your group according to the schedule attached, but also tell us about specialties you have developed for the group you facilitate. We ask you to try to tell the story of your group in about 4 pages, that is about 2000 words. We will publish the full story or edit your story back into 2000 words and will of course discuss that with you before publishing.

We also will extrapolate the most important issues that arise from the different stories, concerning organisation, the ways of working and the results. In this way we will consider the differences between group therapy approaches and facilitated groups in supporting voice hearers to learn to cope with their voices, to discover their meaning and the impact the groups have had on their recovery from the distress caused their voices.

We hope you will not only participate in this venture but that you will also enjoy writing about your group.

We would like to thank Paul Baker and Hywel Davies for their help in issuing this invitation.

Please return the completed inventory by scanning it and sending it as an attachment to Marius Romme at m.romme@skynet.be

Or send it by post to Marius Romme, Gielessestreet No 6, Fouron le Comte, Postal Code 3798 Belgium

With warm regards.

Marius Romme

Manuel de Chavez

Hywel Davies

Sandra Escher (Board member of Intervoice)

Guide for describing the hearing voices group you facilitate Part 1: Organisation

Please briefly describe:

1.1 Who you are:

Include your full name, your main education/training and tell us if you have experienced hearing voices (or not); your experience and role as a professional in mental health care services (or not). Do you have any other role? If so please tell us?

1.2 What you do:

Do you facilitate the group on your own or with someone else?

If you work with a co-facilitator please provide information about your colleague and describe any possible role differentiations between the two of you.

1.3 Who you work for: (If you do please describe briefly the organisation you work for).

1. What is your relationship to the organisation you work for as far as facilitating a hearing voices group, is concerned? Are you supporting the group within the service of the organisation?
2. Are you paid for facilitating the group?
3. Are you a voluntary worker, are your expenses paid or not?
4. Are you working freelance and either paid or not to facilitate the group?
5. Are you satisfied with the way facilitating your group is organised? Either within the service you work for or the way you organised it yourself? Please give some comments.
6. How long have you facilitated the group you describe in your essay?
7. Is this the first and only group or have you facilitated more groups? *If more than one, please then select one hearing voices group that you will write about in this essay, and briefly explain why you selected this one.*
8. Who encouraged you to set up this hearing voices group?
9. Did you receive or undertake training to set up and guide such a group? If so, by whom?
10. If you did not receive training what were the circumstances for your facilitating the group? For instance, did you read about groups first or did you just start the group?

1.4 Information about your group

1. Is this group you describe an open or a closed group? (An open group welcomes new members throughout the life time of the group, closed groups have a fixed membership). Can new voice hearers participate when they wish to or are they referred? Do you have a steady membership of voice hearers coming to your group.
Is this an ongoing group or a group that runs or has run for an agreed number of weeks, months, or number of meetings? If so please describe how many or how long?
2. How do or did you promote/advertise your group? *For instance do you or did send out or disseminate brochures/leaflets about your group? Do you use social media? Do you make contact with people by telephoning people/organisations, who may be interested?*
3. In what other ways do voice hearers get referred or motivated in participating in your group
4. If you have an explanatory leaflet what are the main points you emphasise in attracting members to your group?
5. Do you telephone, correspond or email the group members before each meeting?
6. Do you have a selection procedure for voice hearers before they can participate in the group. If yes, how do you do this and why?
7. How many voice hearers generally participate in your group?

8. Do you interview voice hearers to get to know them better before they participate in the group? *If so, is this for selection purpose; to have a better idea about his/her coping possibilities and/or being able to speak about his/her voices; or to have a measure from the start so you can get a better idea about the improvement, progress and/or development of the voice hearer involved? Or all three? If you do not interview voice hearers, why is this the case?*

9. Do you use an evaluation form to get an impression of the development of voice hearers in your group? If so, could you send us a copy? Do you use this form regularly when your group is an open, ongoing group? Do you use it only at the end or when a voice hearer leaves the group?

10 There might be a risk when groups commence that there are too many voice hearers who are afraid of talking about their voices, which can result in an underdeveloped group. Have you experienced this? How did you solve this problem?

1.5 Programme

1. Can you describe your programme? If so, do you have it written up and can you send us a copy?

2. Do you follow a certain structure in programming your meetings? If so please describe this structure.

3. Do you invite guests to provide talks on specific information or for giving general information? Can you describe the kind of guests and the kind of information your group has been interested in?

4. Do you use instruments like the *Maastricht Hearing Voices Interview Schedule* or any other Interview Schedule for discussion in the group or for other learning purposes?

5. Do you hold discussions about certain books or articles within the group? If so, which ones have you used?

6. Do you encourage the group members to focus on and discuss the development of coping strategies with individual voices?

7. Do you focus and discuss the relationship of the voices with the voice hearer's life story?

8. How do you encourage the group to discuss recovery issues? For instance discussing the power structure and/or altering the relationship between the voice hearer and his/her voices? Do you do something else?

9. If you facilitate a closed group, that ran over an agreed time and/or number of meetings, did you select the issues that would be discussed beforehand? Also how did you organise a programme for your closed group?

10. Do you facilitate your group in a democratic way? Is everything decided by the group as far as the programme is concerned?

11. Are there some basic rules that are discussed at the beginning or is the group just informed about them? Are the basic rules also formulated on paper? If so, please send us a copy.

12. Do you have discussions about the language that is used in the group or by individual participants, can you give some examples?

13. How do you avoid that sometimes participants want you as the facilitator to solve their problems? Can you describe an example of this and how you handled it?

Part 2: Impact on and Outcomes of Group Membership on Recovery

We are asking for responses to the twenty three outcomes listed below. The first eleven are derived from a study into hearing voices groups by the English Hearing Voices Network published in 2005 by Julie Downs. Furthermore we have incorporated a further twelve outcomes from other studies into hearing voices groups: Pennings and Romme (1997); Wykes, Parr & Landau (1999); Morland (2003); Medding et al. (2006); Conway (2006); McLeod et al. (2007). (Romme et al 2009)

We would like to ask you to give each of the members of your group the following list of possible outcomes as a result of their participation in your group, and ask them to circle the answer differentiated as:

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

First name of the participant:

Length of participation (months/years):

Number of meetings you have participated in:

List of outcomes to filled in by an active group member:

1. Being a member of the group helps me to talk about the experience of hearing voices in an open and respectful atmosphere.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

2. I am supported in the group to accept my voice experiences as real.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

3. The group is helpful for me as I meet other voice hearers and realise I am not alone.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

4. It is helpful to be a member of the group as I no longer have to hide my experience or be defensive about it.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

5. I feel supported because I am accepted and I am able to talk about my voices without being laughed at or belittled.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

6. I feel good because the voices are not being rejected or denied.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

7. I feel less isolated because I am able to talk about the experience.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

8. I can exchange experiences about coping with my voices.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

9. I have improved my ability to cope with my voices

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

10. I realise that I can relate to the voices without suppressing them.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

9. I have learned that there are different phases in learning to cope with voices and I have benefitted from this.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

10. I have learned that certain situations or emotions can trigger my voices.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

11. I get positive feedback about the improvements I make.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

12. I increasingly realise that the voices have to do with me as a person.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

13. I have gradually realised that I don't have to do what the voices say, but I have my own opinion and my own power.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

14. I gradually realised that the only power the voices have is the power I give them.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

15. I learned to listen to my voices better in order to try to understand what they really wanted to tell me.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

16. I realised because of talking about my voices I could start discussing topics with other people that I previously kept to myself.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

17. I became more active in my everyday daily life: e.g. shopping, sport, going to the cinema, socialising.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

18. I became a member of a club and/or began to follow courses in order to start work again.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

19. I felt better in my daily life and this has helped me to cope better with my voices.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

20. I changed my relationship with (some of) my voices and became friendly with them. As a consequence they became more friendly with me or/and I learned to appreciate their messages.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

21. I now recognize the feelings the voices express or provoke in me as partly being my own feelings, which initially I found difficult to cope with.

(--) Disagree (+-) Not sure (+) Agree (++) Strongly agree

22. Are there any other outcomes that are not described above?. If so what are they? *(Please describe below, whatever you found important for your recovery, either from the group or from elsewhere).*

23. Are there things that you did not get from the group that would have been helpful? *(please describe below)*

Other outcomes you have experienced, please describe below:

Part 3

As the last part of your description of your experience as a facilitator of a hearing voices group, we would like you to reflect on the following statements about the group context and tell us if you think the following are useful statements about hearing voices groups. You could also discuss these in the group and tell us their conclusions. These statements are derived from group therapy literature.

We would like to know how many differences and how many similarities there might be between group therapy and a hearing voices group as it functions within the Hearing Voices Movement.

1. The meeting provides the people who have a psychosis sensitivity, a place and time to create more equal relationships.
2. Meetings provide a safe place to overcome attitudes and behaviour such as lack of confidence, defensiveness and isolation.
3. Meetings provide an empathic and receptive environment that facilitates self revelation and more meaningful communication.
4. The meeting facilitates the participants independence and autonomy.
5. The meeting creates opportunities for socialising and motivation.
6. The hearing voices group becomes a reference group, that allows participants to acquire a more dynamic view of themselves, their own lives and the achievement of their objectives.
7. The group enables members to act as mirrors for one another, this can occur in many different ways.
8. Group mirroring unblocks the difficulties to achieve insight. It promotes self knowledge.
9. Members can see their own reactions and behaviours in others and begin to know themselves through other people.
10. The group can promote change by encouraging factors such as acceptance, cohesiveness, universality, hope and altruism.
11. The group opens possibilities to learn from the other members by imitation, identification, advice, information, education and vicarious learning.
12. The group provides insight, self-knowledge and interpersonal learning.

We like to thank you very much for providing a description of your group either alone or together. We might contact you to ask you some more questions after reading your story. We hope you will thank all the participants in our name for their cooperation. We will give you feedback after editing your story if it has become too long for the planned publication.

With warm respect,

Marius Romme and Manuel de Chavez