

INTERVOICE

The International Network for Training, Education and Research into Hearing Voices
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Open letter to Oprah Winfrey in response to the programme about "The 7-Year-Old Schizophrenic"

Introduction:

This letter has been written in response to the Oprah Winfrey programme about Jani, "The 7-Year-Old Schizophrenic" broadcast on the 6th November 2009. We want to tell you about an alternative and more empowering approach to the experience of hearing voices that we believe will be of interest to your viewers. 85 members of the mental health community around the world, including voice hearers, relatives, citizens, academics and educators, therapists, nurses and researchers have been moved to sign this letter. Such is the level of concern we feel about the circumstances that Jani finds herself in.

Dear Oprah

We are writing this letter in response to your programme about "The 7-Year-Old Schizophrenic". This concerned Jani, a child who hears voices, and was broadcast on the 6th October 2009.

We do so in the hope we can provide a more hopeful and positive alternative to the generally pessimistic picture offered by the members of the mental health community featured in the programme, and in the accompanying article on your website.

What upset us most and moved us to write the letter, is that, as a result of the programme, parents of children who have similar experiences to Jani will be left with the impression that they are powerless and will not be able to do anything constructive to help their children to come to terms with their experience of hearing voices.

For it is simply not true that nothing can be done.

We say this because we have been researching and working with adults and children like Jani and their parents for the last twenty years, and in doing so have reached very different conclusions from the ones reported on your programme.

We write this letter primarily for parents and carer givers, in the hope that it will enable them to develop a new and more empowering way of thinking about their children's experiences, and that it will help them to find ways to help those children with their emotional development and with recovering from being overwhelmed by hearing voices.

Unfortunately, there is very little practical advice available about children who hear voices which addresses the needs of parents or other members of the family. This is a shame because they are the most important form of support to such children. So, we want you to know that there are some simple commonsense things that parents can do to help children who hear voices - even children in seemingly hopeless situations, like Jani.

We would like to make the following observations:

One of our founding members, Dr. Sandra Escher from the Netherlands, is an expert on the issue of children who hear voices. She has spent the last fifteen years talking to children who hear voices, and to their parents and carer givers. To date, on this issue, Sandra has carried out the most detailed and thorough research in the world. As a result of her work she offers a new perspective on what troubling voices may represent, and how parents can help a child cope if he or she hears voices.

First of all, from the research carried out into the experience of adults and children who hear voices it has become apparent that:

- To hear voices in itself is a normal experience. Of course it is unusual, but at some time or another, many people hear a voice when nobody else is actually present.
- However, it is possible for people to become ill as a result of hearing voices when they cannot cope with them.
- For most children (60%) the voices disappear over time as the child develops and as they learn to cope with life's problems, and with the emotions and feelings involved with those problems, which led to the voices starting in the first place.

Several large-scale population (epidemiological) studies have shown that about 4 % of the population hear voices. Of this 4%, about 30% seek assistance from mental health services. Amongst children, however, even more hear voices (8%), and as with adults, about 30% are referred to the mental health services.

This means that there are apparently many more people who hear voices who do not require the support of mental health services than those who do. This is because the majority can cope with their voices and function well in everyday life.

Unfortunately, most of the information that we have about the experience of hearing voices comes exclusively from research with patients: people who obviously cannot cope with the voices and needed help. These are people who feel that the voices made them feel powerless and who were overwhelmed by them. This is the case for research about adults and children who are hearing voices.

However, in our research we found that a common theme in both groups (adults and children) is the high percentage of traumatic experiences that have been the trigger for hearing voices. In adults, around 75% began to hear voices in relationship to a trauma or situation that made them feel powerless. Examples of the kinds of traumas that trigger voices include the death of a loved one, divorce, losing a job, failing an exam, but also longer lasting situations like being physically, emotionally or sexually abused.

The percentage of traumatic experience found as the trigger to hearing voices was even higher amongst children. It stood at 85%, with some traumas specifically related to childhood. These traumas might include being bullied by peers or teachers, or being unable to perform at a certain level at school. Another commonly reported traumatic incident related to hearing voices was being admitted to a hospital for a long time due to a physical illness.

Generally, our research indicates that hearing voices is a reaction to a situation or a problem the child or young person cannot cope with. Voices act as messengers and it may well be a mistake to try to kill the messenger - for instance through administering medication.

Another striking finding is that what the voices say often indicates the problem which troubles the child, but in an elliptical manner. Take just one example: *The voices told an 8-year-old boy to blind himself. This frightened his mother. But when we discussed whether there was something in the life of the boy he could not face, she understood the voices' message. The boy could not cope with his parents' problematic marriage. He did not want to see it.*

In Jani's case, has anyone tried to establish why the rat is called "*Wednesday*", why the girl is called "*24 Hours*", and why is the cat called "*400*"? What do these mean for her? Are there reasons behind this? Furthermore, why did she want people to call her "*Blue-Eyed Tree Frog*" and "*Jani Firefly*".

Is this something she associated with safety, and if so why?

Our research also revealed that when full attention was given to the problems facing the child, he or she was able to establish a more constructive relationship with the voices. As a result children became less afraid of their voices. When a child is able to consider the problems that are at the root of his or her distress, and with the emotions and feelings involved, the child is no longer preoccupied with the voices.

Recently, Sandra conducted a three-year follow up study on eighty children who heard voices, aged between 8 and 19. Half of this group received mental health care because of their voices. However, the other half were not given any special care at all. She interviewed the children four times, at yearly intervals. By the end of the research period 60% of the children reported that the voices had disappeared.

Of course figures and statistics like this do not directly relate to Jani. But the overall message is that the chance that the voices might disappear are quite high.

We saw that when children have problems which bring on the experience of hearing voices, their ability to learn to cope with their voices is inhibited. However, if the problems were dealt with or the child's situation changed - for example, because of changing schools - the voices disappeared.

It is important that we appreciate that the desire to make the voices disappear is a goal of the mental health care services and not necessarily that of the children themselves. There are some children who did not want to lose their voices. This is OK, for the most important thing is that the voices no longer remain at the centre of their attention. This is because, as the relationship with the voices change and became more positive, instead of hindering the child the voices start to take on an advisory role. If children find within themselves the resources to cope with their voices, and the emotions involved with hearing them, then they can begin to lead happier and more balanced lives.

The most important element in the process of positively changing a child's relationship with his or her voice is support from the family. Unfortunately, our research has shown that being in the mental health care system had no positive effect on the voices. However, we did find that what had a positive influence on how the child coped with hearing voices was being referred to a psychotherapist who accepted the reality of the voices and was prepared to discuss their meaning with the child.

We also saw that 'normalising' the experience can help parents to deal with the voices. Try not to think of it as a terrible disaster but rather as a signal for something that troubles your child and which can be resolved.

On the other hand, if parents cannot accept that hearing voices is fairly normal, but believe only that it is a symptom of an illness, and are afraid of them, then the child naturally picks up this feeling. Imagine for a moment if you were the child and were afraid of the voices, and when you looked for support from your parents you found that they were even more afraid of the voices than you. Obviously, this would put you under great pressure and probably mean that you would become reluctant to talk about your experiences at all.

There is a second problem. If a person is afraid of the voices then he or she can become obsessed simply by the fear of them. If one is distressed and anxious one cannot listen very well to the story a child tells about his or her experiences. This means that a sympathetic other may fail to pick up on the related emotions and problems that the voices represent.

In our experience, what helps children the most is a systematic approach to understanding the voices. So, in order to help we have developed an interview to help map the experience. This can be used as a way to understand the stress the child is under, and then to work together to find solutions for the problems raised by the experience of hearing voices.

We would like to offer this 10-point guide for parents, indicating what they can do if their child tells them that he or she hears voices:

1. Try not to over react. Although it is understandable that you will be worried, work hard not to communicate your anxiety to your child.
2. Accept the reality of the voice experience for your child: ask about the voices, how long the child has been hearing them, who or what they are, do they have names, what they say, etc.
3. Let your child know that lots of children hear voices and that usually they go away after a while.
4. Even if the voices do not disappear your child might learn to live in harmony with his or her voices
5. It is important to break down your child's sense of isolation and difference from other children. Your child is special - unusual perhaps, but really not abnormal.
6. Find out if your child has any difficulties or problems that he or she finds very hard to cope with, and work on trying to fix those problems. Think back to when the voices first started. When did the voices arise for the first time? What was happening to your child when the voices first appeared? Was there anything unusual or stressful that might have occurred?
7. If you think you need outside help, find a therapist who is prepared to accept your child's experience and work systematically with him or her to understand and cope better with the voices.
8. Be ready to listen to your child if he or she wants to talk about the voices. Use drawing, painting, acting and other creative ways to help the child to describe what is happening in his or her life.
9. Get on with your lives and try not to let the experience of hearing voices become the centre of your child's life or your own.
10. Most children who live well with their voices have supportive families around them who accept the experience as part of who their child is. *You can do this too!*

In conclusion we would like to stress that, in our view, labelling a seven-year-old child as schizophrenic and subjecting her to powerful psychotropic medication and periodic hospitalisation is unlikely to help resolve her problems with voices. Indeed, the opposite is most probable: Jani will simply become more powerless when it comes to finding ways to cope with her voices.

Because your well respected, award winning show reaches out to so many people, we are concerned that there will be many viewers who will be left with the impression that the kind of treatment Jani receives is the only one available. If this is the case then there will be children who will be subjected to an unnecessary lifetime in psychiatric care because their families believe there are no alternatives. It is very important to recognise that hearing voices, in itself, is not a sign of psychopathology - and - voice hearers who are patients can be helped to recover from their problems by being supported in developing their own ways of coping with their emotions.

We hope you will give consideration to the possibility of making a future programme showing the other side of the story, one of hope, optimism and with a focus on recovery. Perhaps you could make a programme about a child with similar voice experiences to Jani, who has been helped to come to terms with her or his voices and to discuss with the child, parents and therapists how this was achieved? If there is anyway we could help make this happen, please contact us.

We look forward to hearing from you on the issues raised in our letter.

Yours sincerely,

Paul Baker
INTERVOICE coordinator

Signed by:

85 people from 14 countries (listed in order of time received)

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Further information:

INTERVOICE - The international community for hearing voices

Working across the world to spread positive and hopeful messages about the experience of hearing voices.

We have found there are many people who hear voices, yet are not troubled by them or have found their own ways of coping with them outside of psychiatric care. This is very significant as it shows you can hear voices and remain healthy.

However, there are also significant numbers of voice hearers who are overwhelmed by the negative and disempowering aspects of the experience. Many are diagnosed as having a serious mental health problem such as schizophrenia.

The experience of hearing voices prevents some people from living a fulfilled life in society (especially those in psychiatric and social care) and can lead to having a very poor quality of life. We seek to enable voice hearers troubled by their experience to change their relationship and attitude to their voices and to take up their lives again. We also want to ensure that our innovative approach is better known by professionals, family members and friends.

We have spent the last 20 years trying to better understand why some people can cope with the experience and others can't. We have discovered that those people who are not able to cope with their voices, on the whole have not been able to cope with the traumatic events that lay at the roots of their voice hearing experience.

Many voices can be unthreatening and even positive. *"It's wrong to turn this into a shameful problem that people either feel they have to deny or to take medication to suppress."* - Professor Marius Romme

Visit our website at www.intervoiceonline.org for more information about the aims, objectives and worldwide reach of INTERVOICE.

See articles about our work with children here:

Silencing unwelcome voices in children, The Guardian, 22/11/2001

A psychosocial therapist in Holland has adapted an innovative approach to voice hearing to help very young children dispel the imaginary friends that become realistic foes <http://www.guardian.co.uk/society/2001/nov/22/mentalhealth/print>

'She was like a personal coach': An account of hearing voices as a child, The Guardian, 16/11/2001

'They would set her impossible tasks' The Guardian, 16/11/2001

<http://www.guardian.co.uk/society/2001/nov/16/mentalhealth1/print>

Most children hearing voices stop within three years, Royal College of Psychiatry, 03/09/2002

<http://bjp.rcpsych.org/cgi/content/full/181/43/s10>