

Hearing voices peer support groups: a powerful alternative for people in distress

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Hearing voices peer support groups offer a powerful alternative to mainstream psychiatric approaches for understanding and coping with states typically diagnosed as “hallucination.” In this jointly authored first-person account, we distill what we have learned from 10 years of facilitating and training others to facilitate these groups and what enables them to work most effectively in the long term. Having witnessed the transformative power of these groups for people long considered unreachable as well as for those who receive some benefit from standard psychiatric treatment, we describe effects that cannot easily be quantified or studied within traditional research paradigms. We explain the structure and function of hearing voices peer support groups and the importance of training facilitators to acquire the skills necessary to ensure that groups operate safely, democratically, and in keeping with the theories and principles of the Hearing Voices Network. The greater use of first-person experience as evidence in deciding what works or does not work for people in extreme distress is advocated; randomized designs or statistically significant findings cannot constitute the only bases for clinical evaluations (Elisabeth Svanholmer, in Romme et al. 2009, p. 151).

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Hearing voices peer support groups are transforming the lives of people all over the world, allowing them to understand and cope with experiences that have long confused and frightened them. Many have spent years in the psychiatric system – treated with “cocktails” of powerful medication or repeated hospitalization – yet continue to struggle with extreme states or anomalous thoughts, perceptions, or feelings. Often labeled as “chronic” or “treatment-resistant” patients, they become increasingly isolated from others and estranged from themselves. Hearing voices groups offer a crucial alternative, allowing the transformational power of relationship to foster a deeper understanding of mental life, both in themselves and in other people.

For more than 10 years, the two of us have facilitated and trained others to facilitate hearing voices peer support groups in the UK, US, Australia, Holland and Ireland. We have witnessed the profound effects of these groups for people who have long been considered unreachable as well as for those who have received some benefit from standard psychiatric treatment. These effects cannot easily be quantified

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or studied within traditional research paradigms. Yet they are powerfully real to the people who experience them, just as voices themselves are.

In our work together over the past decade, we have tried to forge a new style of egalitarian collaboration in which Jacqui's background as an activist and voice-hearer, and Gail's as an academic researcher who has been radically changed as a consequence of involvement with the Hearing Voices Network (HVN), can come together to offer an alternative, experientially grounded perspective. Our goal is to write in a way that reflects the work we are doing. We have chosen to construct this piece in the form of our own testimony, as a jointly authored first-person account distilling what we have learned from facilitating and training others to facilitate hearing voices peer support groups, and what enables such groups to work most effectively in the long term.

We have made the choice to write in this way for two key reasons: first, because we want to foreground the "expertise of experience" which is a core assumption of the hearing voices approach; and second, because we think that the genre of the "first-person account" ought to be opened up to encompass a wider range of experiences and modes of presentation. There is still too much bifurcation between "personal accounts" and "research findings" and too differential a valuation of these types of writing, even in a journal like *Psychosis* that explicitly values both sources of understanding. By demonstrating that contributions to knowledge and scholarly debate can depart from the narrow conventions of a standard research paper, we hope to encourage a deeper exploration of the evidence of experience.

We begin with brief introductions of how we each became involved in this work.

Jacqui: I began hearing voices as both a consequence of and a solution to, the horrendous abuse, neglect and deprivation that I was subjected to as a small child. That my mind was able to create such a complex, alternative reality in the face of such brutality and isolation now seems like a miraculous achievement to me and something that I have grown to appreciate with awe.

Like many psychiatric survivors, active participation and social action was and remains an important aspect of my healing and recovery. I first became involved with the Hearing Voices Network in 2001 when I began working for a community mental health project in East London, my first paid job since "going mad". I was working with adults deemed to have serious and enduring mental health problems. Many of them had spent years in and out of psychiatric hospitals and all of them were on large doses of psychotropic medication. I saw how my life might have turned out very differently if I hadn't found alternative help for myself, if I hadn't had people in my life who had loved and believed in me. I believed in these people.

Along with Rufus May, a clinical psychologist and someone who had previously been diagnosed with schizophrenia, I set up a hearing voices group, one of four that were operating in London at that time. We formed a steering group with other facilitators to try and think about how to get more groups started and were successful in securing funding for a national conference and later for a pilot project, which I led, to develop hearing voices groups across London. As part of that project I designed a hearing voices group facilitator training course in order to create a systematic approach to developing a network of sustainable, user-led, hearing voices groups. The training course, which, unusually, trains people with personal experience of voice-hearing alongside mental health staff, has proven to be an extremely effective method of increasing the number of hearing voices groups. The course, initially piloted by the London Hearing Voices Network, has since been run in many other

parts of the world and has led to the formation of hundreds of hearing voices peer support groups. The course covers all of the practical and theoretical aspects of running groups, from critiquing traditional and innovative approaches to voice-hearing, creating safety and ground rules, the group development process, group dynamics, the role of group facilitators and a model for starting and establishing groups. Gail attended the first course held in London in 2005 which led to the formation of one of the first hearing voices groups in the US. One of the most striking things about Gail when I first met her in 2003 was that she needed no persuasion that attending to people's own, first-hand experiences of madness and distress was crucial, if we are to better understand the mind. Like the best collaborations, the combined efforts of our differing perspectives and expertise have expanded our own thinking, and led to the creation of a number of innovative projects.

Gail: I am a professor of psychology in the United States, and have taught research methods and the history, theory, and practice of psychology, psychiatry, and psychoanalysis for more than 35 years. Since my undergraduate days, I have been critical of the narrowly quantitative and medicalized models that dominate psychology, and my research and teaching have focused on creating alternative approaches that can do justice to the complexity, contradiction, and creativity of human psychology.

What first convinced me of the necessity of such alternatives were the personal accounts that people wrote about their experiences of breakdown. I discovered these books as a teenager, and what most struck me in them were the testimonies about the crucial role of support from fellow patients (in those days, usually in the context of long-stay psychiatric institutions). I planned to write my PhD thesis on "peer interaction among hospitalized psychiatric patients" and to focus my research on the power of such relationships. However, that proved impossible when hospital authorities refused to allow access for such a project. But recent years have brought dramatic change to the power dynamics of the mental health world, and my original goals are now being fulfilled. One of the most significant unintended consequences of deinstitutionalization has been its creation of the structural conditions that facilitate peer collaboration. Once people diagnosed as psychotic were no longer being locked up for long periods, they could work together to form an international movement, in which the Hearing Voices Network has been a key participant. Voice-hearers could develop their own organizations and design forms of peer support based directly on their experiences, and they have made it possible for me to participate in these efforts, to analyze these alternatives, and to help disseminate and distill the key principles that they reveal.

As a consequence, I have spent the past 10 years writing and lecturing internationally about HVN and the nature and function of hearing voices groups. My book *Agnes's Jacket: A Psychologist's Search for the Meanings of Madness*, helped to bring HVN's ideas to a broad US audience. Since the mid-1990s, I have also compiled a *Bibliography of First-Person Narratives of Madness in English*, now in its 5th edition with more than 1000 titles, whose goal is to highlight the extent and diversity of experiential accounts. I speak widely about mental health issues in the US, UK, and Europe; design and run training workshops to foster alternatives to standard treatments for psychosis; and organized (and for the past five years have co-facilitated) one of the first hearing voices peer support groups in the US (in Holyoke, Massachusetts). Ever since Jacqui and I met at the Beyond Belief conference HVN organized at the University of London in 2003, she has been a

close colleague whose insights significantly inform my own work and with whom I have collaborated on a variety of projects in both the US and the UK.

Ethos of the Hearing Voices Network approach

HVN sees voice-hearing as significant, decipherable and intimately connected to a person's life story. Despite the well-established link between hearing voices and traumatic life experiences, HVN explicitly accepts all explanations for hearing voices, and encourages people to explore their own beliefs, be they spiritual, religious, paranormal, technological, cultural, counter-cultural, philosophical, medical, and so on. HVN welcomes people with a range of experiences, including people who see visions or have other unusual perceptions or sensations. Hearing voices groups create sanctuary, safe spaces to share taboo experiences, where there are real possibilities for healing and growth. People are free to share and explore their experiences in detail, including the content of what their voices say, without the threat of censorship, loss of liberty or forced medication, an unfortunately all-too-common feature of disclosure in traditional psychiatric settings. HVN encourages and supports people to pay attention to the detail and content of their voices, visions, sensory experiences and altered states of consciousness and to attest to their reality in order to better understand their meaning. There is a genuine interest in the range of people's inner, subjective experiences; when phenomena that are deemed "psychotic" are described, the focus is on the meaning in that madness. Sometimes people use metaphorical or symbolic language to convey their realities and sometimes they are talking literally about things that have happened to them. However distressed someone appears, HVN assumes that they are making a meaningful attempt to survive maddening experiences. Unlike the traditional psychiatric relationship of "them vs. us" – dominant, expert clinician and passive, recipient patient – HVN is based on mutually respectful relationships, authentic partnerships between experts by experience and experts by profession, working together to bring about the emancipation of voice-hearers. This shift from traditional hierarchies and power structures creates a number of new possibilities and the potential for shared bonds among all concerned.

Structure and function of HVN support groups

Hearing voices groups share certain characteristics with other types of support groups, but they also have distinctive features that follow directly from the ethos just outlined. To understand why hearing voices groups have had such powerful effects on so many thousands of people around the world, we need to appreciate these distinguishing characteristics.

At first glance, it can seem as if hearing voices groups vary so widely as to have few common features. For example, their structure takes many forms: some have fixed membership, while others operate as drop-ins; some are co-facilitated by nurses, social workers, or occupational therapists; others are run entirely by voice-hearers themselves. HVN groups are never as tightly structured as those of 12-step organizations like Alcoholics Anonymous, whose meetings have a fixed order and everyone knows in advance exactly what will happen. And they're certainly nothing like group therapy, where one person (i.e. the therapist) is charged with structuring key aspects of what takes place. What HVN groups share is a general goal of

helping voice-hearers to articulate and better understand their individual experiences. Members ask one another questions like these: What do the voices say? What tone do they use? How many different voices are there? Are they male or female? Have they changed over time? Are there certain situations when they're most likely to appear? How do you feel when they are there? What purpose do you think they serve? Encouraging this kind of detailed contextual analysis helps people to make sense of experiences that have often baffled or terrified them. And because there is no judgment, no covert message that voices are pathological, people feel – often for the first time in their lives – that they can reveal what is happening inside of them.

A particular benefit of HVN groups is that they help people to identify the circumstances most likely to trigger the voices, thereby offering more control over the experience. Many people don't realize until they are in these groups that there *are* specific triggers, or that the voices vary in frequency or intensity in different contexts or over time. One participant described it this way: "Being in the group encouraged me to develop a vocabulary to describe my own experiences, and also gave me a sense of understanding and coherence about the way I'd been and the way I had needed to be to survive. By challenging the critical content of the voices, the group helped me feel more able to take control of my own fate."

Another member of this group wrote: "Talking with the other members has increased my self-awareness of what's happening to me, my state of mind, and why I need to do certain things to help myself. I've become more responsible for myself and feel less helpless. I realize now that I do have some power over my situation." Since the most difficult part of the experience for many people is feeling completely at the mercy of the voices, unable to affect or control them in any way, trying out new strategies can be a tremendous help. And as people start to cope more effectively, they feel less distracted or preoccupied by the voices and more in control of their own minds.

Most people who come to these groups have spent years struggling on their own. Any experience that continues for so long and is as confusing, isolating and heavily stigmatized as voice-hearing can eventually become overwhelming. Being in a supportive group, with other people who are struggling as you are, who seem genuinely interested in helping you understand your experience, can be an enormous relief.

But hearing voices groups are not just a place for sufferers to commiserate. By reframing the problem itself – not voice-hearing per se, but the anxiety, guilt, or fear that often accompanies it – HVN groups help people to analyze the symbolic significance of the voices. For example, someone who is too overwhelmed to make decisions might have a voice that tells her what to do. A person who has been abused may have a voice prohibiting him from talking about it, thereby keeping the threats of the abuser alive in his mind. Someone who comes from a family that forbids talking about emotions might have a voice instructing her not to trust others. By taking a curious, interested, and accepting attitude toward the whole experience, hearing voices groups help people to realize what functions the voices might be serving so that they can consider other ways of handling these problems.

Of course, psychotherapy or counseling can also accomplish some of these same things. And while interpreting voices in psychotherapy can be crucially helpful for many people, for others it can reinforce dependency on the therapist and make the person feel more vulnerable to falling apart when on their own. In addition, the power dynamics inherent in psychotherapeutic work may be too reminiscent of previous abuses of power, hampering safe exploration of frightening experiences. The

egalitarian, low-pressure, collaborative nature of peer support groups can thus offer a useful alternative to the hierarchy inherent in treatment by professionals. For example, the group in East London that I (Jacqui) co-facilitated in 2001–2006 sometimes had group members attend who were still in-patients in the local psychiatric hospital. One day a nurse turned up who was escorting a man currently detained in hospital. He had accrued two hours leave from the hospital and wanted to use his leave to attend the group. The nurse was slightly taken aback when I explained that the group was open only to people with lived experience of voices and related experiences, so it wasn't possible for her to sit in and just listen, as she had expected. She seemed mollified when I found her a comfortable place to wait outside the room, made her a cup of tea and offered her my newspaper to read. The man she had escorted shuffled into the group, apparently experiencing strong side effects of the medication he had been prescribed. He sat and stared into space, never made eye contact with anyone and didn't speak a word. At the end of the meeting, he got up and shuffled out of the room. He came back the following week, escorted by the same nurse, again said nothing, and then came back week after week for about three months until one day, in the midst of a heated debate between two group members, he lifted his head and said, "I disagree". I asked him what he thought and he offered a coherent explanation of why he saw things differently. He went on to become a highly valued member of the group, making extremely insightful and supportive comments to other group members. He later told us that it had taken him some time to work out whether we could be trusted – he had been let down so many times before – so he had just come along to check us all out. It is quite likely that in a clinical setting his behavior would have been interpreted in such a way that he would not have been able to make such a choice in his own way, in his own time, and that the tremendous changes he made in his own life and in the lives of others would never have occurred.

Like support groups of any kind, each hearing voices group has its own "culture," a function both of the group agreements/ground rules that members formulate when the group starts, and of the distinctive features of its specific situation – national context, environment where it meets, the personal style of its members and facilitators, etc. For example, the group in Holyoke, Massachusetts that I (Gail) have been co-facilitating since 2008 decided at the community meeting preceding its founding that family members of voice-hearers would be welcome under certain circumstances (in fact, after completing facilitator training, a member of our group whose daughter hears voices has now become one of our co-facilitators). Our style is very informal, which fits the atmosphere of the relaxed, library-style room where we meet at the Western Massachusetts Recovery Learning Community (a peer-run center, offering a range of alternative approaches to supporting people in distress, www.westernmassrlc.org). We sit on couches or comfortable chairs surrounded by shelves of books and artwork, munch snacks, and adhere to a few simple rules (mutual respect, confidentiality, clearing up the room at the end of meetings, etc.). Our group is a drop-in, so new people frequently appear and old members leave or take a break and then return; in any given six-month period, however, there is always a core who come every week. The group has been successful since its start five years ago in significantly improving the lives of its members and has inspired the development of a number of other groups in our region.

But like every hearing voices group, we have faced challenging situations, which is one key reason why facilitator training is so essential to creating safety. For

example, a member of our group got very angry in the middle of a meeting and accused the rest of us of putting vodka into the jug of water sitting on the table. Essentially, she felt as if she were about to be poisoned, as alcohol had long had a very destructive effect on her. We were all too stunned by what she was saying to react fast enough to keep her from stomping out and refusing further contact with any of us. The facilitator team (a voice-hearer, the mother of a voice-hearer who is not in our group, and me) talked at length afterward about what we could have done differently. We realized that one of us could have jumped up, poured the contents of the jug down the drain in full view of the distressed person, and encouraged her to refill it herself from the water cooler. This might have been reassuring enough to allow her to stay or to return on another day. In the past, interventions like this have worked effectively to reduce tension in the room while allowing group members to express themselves fully. In this situation, even though we did not succeed in diffusing the person's anger, the facilitator team was able to create a safe enough context in subsequent meetings for other members to feel comfortable discussing what had happened and to reaffirm the group's commitment to treating all feelings – even anger – as valid expressions.

When I asked the members what they saw as differences between our hearing voices group and other kinds of support groups they have been part of, their responses were immediate. "No one tells you what to do. They don't assume they know you better than you know yourself. No prescriptive solution is presented, the way it is in AA (e.g. if you are having a hard time, no one says "Have you read the Big Book today?") Most importantly, you learn from other people that it's possible to get better. Your life can really change, no matter how many psychiatrists have said that you have an incurable brain disease. Being in the group is not just about accepting your illness and getting on the right medication; it's about transforming your experience of what's happening in a way that makes sense to you."

People who come to hearing voices peer support groups always arrive with some kind of framework for their experiences, based either on what doctors have told them or on their own ideas. But because HVN explicitly welcomes people with many different types of explanation (including the medical model), it's likely that whatever view a person comes in with will develop or change as they are exposed to other ways of thinking. Psychiatrists often try to discourage people who hear voices from delving into the experience or telling others about it, but this often just makes the person feel even more isolated, confused, and strange. HVN groups do precisely the opposite; they enable people to feel safe enough to talk openly about their distressing experiences (often for the first time) and to construct narratives of their lives that make them feel more like other people and less anomalous.

An essential feature of hearing voices groups is that they help to create the scaffolding upon which a coherent account of experience can be built in the first place. Narratives need structure if they are to hold together and perform a useful ordering function. But erecting this scaffolding requires a series of actions: deciding what types of events to try to recall, what specific information about these events is most relevant, how to contextualize each one, and so on. Through empathic listening and uncritical noting of inconsistencies, gaps, or areas in need of further exploration, the group can help to foster attentiveness to triggers, patterns, and explanations that a person might not notice or be able to formulate on his/her own.

Another key function of such groups (often shared by other types of support group) is the creation of new identities capable of challenging the stigmatizing labels

assigned by professionals. For example, people diagnosed with schizophrenia are often described as “narcissistic”, “egocentric”, or “unable to take the role of the other.” Such dismissals of patients’ human qualities blinds many mental health professionals to the ways that people experiencing extreme states can and do in fact help one another. In peer support groups, empathy and role-taking are constant presences, as members help one another to become aware of talents and strengths that might directly contradict doctors’ dire prognostications. Even people who are very withdrawn or suspicious in other contexts (e.g. at appointments with professionals or during hospital admission interviews) often make astute and useful comments when with their peers.

In hearing voices groups, people do everything possible to make each other feel heard, understood, and validated as fellow sufferers. They listen thoughtfully, ask one another subtle questions, take and offer advice, and laugh together in bitter recognition of the ironies of their shared circumstances. Beyond the concrete help and validation this provides, people often leave these meetings having seen evidence of parts of themselves that others have ignored. This helps to build their capacity for resistance (“Doctor, you may think that I lack insight into my illness, but I and others don’t agree with that assessment”), and their ability to think for themselves (which is hard to do when you are repeatedly told that you are “seeing things” or “hallucinating” or that your beliefs are “delusional”). Creating “possible selves” that challenge the pessimism of professionals or family members is fundamental to the work of all support groups and is often astonishing in its effectiveness. Groups also significantly widen the range of experiences to which people are exposed so that their thinking about their own minds expands (whether or not they actually articulate this out loud to the group).

Skills necessary to facilitate hearing voices groups

In our experience, the skills required to facilitate a hearing voices group effectively are not necessarily what one learns in a clinical psychology or social work program or in nursing training (although there are people in these professions who have these qualities), nor is being a voice-hearer in itself a qualification.

Rather, regardless of whether a facilitator is an expert by experience or an expert by profession, the aim is to lead by listening. This means that wherever possible, the group as a collective is encouraged to make decisions about direction, activities, changes in procedure, etc. It is the facilitator’s role to enable this process, and a key part of the work is to magnify the voices of people who are not normally listened to, by emphasizing the belief that each person in the group has a deep wisdom and expertise about ways of managing and dealing with problems. Once different views are brought out into the open, a debate about the merits and values of competing ideas can occur and the group can democratically decide its future direction. Because the group is stronger than the sum of its parts, this joint decision-making will always be a better investment than one or two people (e.g. the facilitators) making decisions, assuming that they know what is best for the group.

The aim of the facilitator is to show respect for the reality of the trauma and suffering that members have experienced, and a keen awareness of how these experiences may limit their expression of feelings, ability to think clearly, etc. A non-judgmental attitude about what people are able to do or not do, talk about or not talk about, on any particular occasion is crucial. So are validation and support

for people's resilience, creativity, stamina, and emotional strengths, even when they themselves doubt that these exist. A relaxed, informal, improvisational tone in facilitating the discussion is important, allowing what happens naturally to occur instead of imposing a predetermined or fixed agenda or plan upon the situation.

In hearing voices groups, people are never given false hope, or made to think that situations over which they have no control will in fact turn out in one way rather than another. Facilitators must be willing to share some details of their own experience when these are relevant so that people have a sense of them as individuals without on the other hand allowing such self-revelations to take up too much time when what is needed is a focus on group members. Meetings need to be carefully preserved as a safe space, with clear beginning and ending times, protection from intrusions, respect for confidentiality, needs for boundaries, etc. The facilitator needs to be able to share useful coping strategies or other elements of HVN's approach in a natural way, rather than being didactic or judgmental if people don't find these ideas useful or have other approaches of their own. Facilitators need to show a genuine interest in and curiosity about the range of people's subjective experiences, regardless of whether they themselves have ever felt or thought or perceived anything similar.

For both experts by experience and experts by profession, developing self-awareness is crucial for good facilitation, as is being able to sit with anxiety, uncertainty and silence. The above-described requirements are also characteristics of good clinical work, but there are key differences between professional training and the skills required to be an effective facilitator of hearing voices groups. In circumstances where the facilitator feels she cannot escape legal responsibilities (e.g. she is a nurse and the group takes place in her facility), she might want to consider moving the group to another location, or meeting in the evening so that she is less constrained (e.g. in maintaining confidentiality). Or the group might decide that she is not actually the person best positioned to be a facilitator, if her involvement threatens to curtail the freedom of the group to follow its own trajectory. For voice-hearers, coming to some acceptance of their own experience and making the journey from a "me" to a "we" position – being able to appreciate the diversity of experience and shared commonalities across people – is essential, and it is the facilitator's responsibility to create and protect a structure that can allow this to happen.

Importance of facilitator training

In England, hearing voices groups and the "Hearing Voices Approach" are now accepted, widespread and embedded within mainstream services. Although most groups run in community locations, they also operate in a variety of other venues including acute and secure settings – both hospitals and prisons – with a number of specialist groups developed for Black and minority ethnic communities and for children and young people. A Healthcare Commission report (2008) commends mental health trusts which provided hearing voices groups as offering "appropriate and safe interventions" in inpatient settings. While we welcome these developments, we have also learned the dangers of having HVN's approach assimilated into orthodoxy. This is a key reason why structured training is essential for facilitators, as it ensures that the theories, approaches and principles of the Hearing Voices Network, which have developed directly from the work of voice-hearers and their allies all over the world over the past 25 years, are actually put into practice in a coherent

and consistent fashion. Training safeguards the well-being of members by making sure that facilitators are adequately equipped to bear witness to the painful and difficult material which naturally arises in hearing voices groups, and have developed the skills and resources to support people trying to make sense of what can be intensely frightening and overwhelming experiences. It allows potential facilitators to have an opportunity in advance of their setting up a group to think about and prepare for issues and difficulties which may arise in the work. In our experience, groups are much more likely to remain safe and to be sustained over long periods when this preparation has been done. Systematic training also ensures that experts by experience and experts by profession get to work alongside each other as equals, which may be a new and significant experience for all concerned, and makes it more likely that groups will be run with voice-hearers as true co-facilitators.

Conclusions

Our intent in this article has been to share some of the insights about hearing voices peer support groups that our work – individually and together – has taught us over many years. We are not “speaking for” the Hearing Voices Network or “against” mainstream psychiatric approaches. Indeed, we think that too much of the discussion in the mental health world has been distorted by factional disputes, and that we would all be better off by trying to listen more to one another.

However, we have clearly taken a position here in support of the greater use of first-person experience as evidence. Both in the context of what we have presented and in the form we have chosen to write, our goal has been to broaden the frame for presenting ideas about what works and what doesn't for people in extreme distress. We reject the idea that randomized research designs or statistically significant findings constitute the only bases for making evaluations. Whether a hearing voices peer support group is effective or not for a given person can only be determined by him or her. At the core of every aspect of HVN's approach is a deep respect for the reality of subjective experience in whatever form it occurs.

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