

UNEDITED VERSION OF MANUSCRIPT of the chapter in  
Lefley, HP, Johnson DL (Eds) (2002) Family interventions in mental illness: International  
perspectives. Westport, CT, London: Praeger

## THE "FIRST VIENNA TRIALOGUE" – EXPERIENCES WITH A NEW FORM OF COMMUNICATION BETWEEN USERS, RELATIVES AND MENTAL HEALTH PROFESSIONALS

Michaela Amering, Harald Hofer, Ingrid Rath

### **Introduction**

"Triologue" stands for the encounter of the three main groups of individuals who deal with psychosis and with the mental health system – people with experiences of severe mental distress, family members/friends and mental health professionals. This encounter occurs under special conditions - outside the family, outside psychiatric institutions, outside a therapeutic setting. It is the aim of the Triologue to facilitate communication about the personal experiences in dealing with psychosis and its consequences. The participating groups strive towards giving up their isolation and lack of common language. Mutual understanding and necessary delimitation from the vast variety of the participant's different backgrounds concerning experience and knowledge should be established. Trying to understand and share the complex and very heterogeneous subjective experiences may well lead towards establishing a common language, which implies building the basis of a culture of discussion seen to be necessary for working together effectively. It is widely argued from different areas of research that acknowledging the personal experiences of users in planning, organizing and doing practical work is necessary to improve both research and practice in dealing with psychosis (Stastny P and Amering M, 1997; Zaumseil M, 1996). Engaging in the Triologue is the necessary training to further enhance this process.

Ingeborg Schürmann (1997) elaborated in her chapter of the book "Schizophrenie in der Moderne – Modernisierung der Schizophrenie" (Schizophrenia and Modernity – the Modernization of Schizophrenia) edited by Manfred Zaumseil and Klaus Leferynk (1997) on the everyday life and ways of relationships within the framework of today's psychiatry. Based on a research project set up in East and West Berlin she describes different patterns of relationships between professionals and long term users i.e. positive regard, commitment, goodwill, distancing, friendship and partiality, each of them having different strengths and weaknesses. To start with she draws a picture of different service-"cultures" which can be found to a certain degree in different psychiatric situations: The culture of care characterized by well-meaning help and patronizing attitudes as well

as a restriction of one's personal autonomy; the culture of treatment, being based on experts and expertise and demanding users to be "compliant", drawing on different mostly contradictory etiological models as the psychotherapeutic or the biomedical; the pedagogical culture which strives towards achieving normative goals using pedagogical means on a friendly and structured basis; the culture of empowerment seeking a balanced power-structure at the cost of expert based power offering a resource-oriented viewpoint and trying to work on conditions that may enable people to live their own lives and increase personal development. It is within the framework of these different cultures that users experience help but also limitations and devaluation.

People who are or have been in touch with the mental health system are doing so in the roles of "mental patients", "schizophrenics", "mentally disabled" individuals, people "with mental illness", as people "with experience of psychosis", "with experience of psychiatric services", "ex-patients", "survivors", "clients", "consumers", "users" or "long-term users". Each of these different labels expresses different treatment concepts, identities and value systems. Users are facing interdisciplinary teams of nurses, psychiatrists, psychologists, social workers, occupational therapists, physiotherapists, patient's advocates, advocates, relatives, volunteers and peer-specialists who are supposed to work together and share responsibilities. The growing amount of diverse approaches with their different concepts of providing help and support, and the new roles that are taken on by users, their friends and families, require that all participants take a close look at their own roles, limitations and opportunities inherent in the relationships being formed. Only if we all engage in a constant dialogue we might achieve some clarity in this complex situation and benefit from its opportunities. But in order to achieve this, a new culture of communication needs to be established, developed, learned and experienced in new settings.

The "First Vienna Trialogue" was established after the World Conference for Social Psychiatry in Hamburg in 1994 by a small group of people representing users, relatives and professionals. Since then, Trialogue meetings are being held twice a month – every other Thursday – with 15 to 40 people in attendance. In the beginning, the meetings were only publicized verbally, followed by newspaper ads and announcements within user- and professional organizations. Everyone interested in participating in the Trialogue was welcome. It was our experience that users formed the largest share of regular participants, followed by family members/friends and professionals (social workers, psychologists, nurses, patient's advocates, guardians, psychiatrists), whose attendance was regrettably limited. As an open group, the number of attendants and the compositions of members from the three groups vary each time, and there is a mix of regulars and of those who drop by to see what the group is like. During the time of the group's existence the venue of meetings has changed a couple of times. Besides financial considerations, we strived towards finding a place outside psychiatric institutions, unaffiliated with a particular self help organisation and apart from therapeutic or family relations thus offering a "neutral ground" that does not offer an advantage or a privilege for any of the participating groups. This was also the reason why we decided to alter the policy of most existing "psychosis seminars" (1996) by not relying on

professionals as group moderators, but rather setting up a rotating system of the different members instead.

A role model for the "First Vienna Trialogue" was the psychosis seminar in Hamburg (Bock Th, Deranders JE, Esterer I 1992, 1994). Currently, more than 70 of these seminars can be found in Germany (Bock Th, Buck D, Esterer I (1997); Buck D (1996)), some of them using different names such as "exchange of experiences with psychosis" or "From dialogue to Trialogue" (Psychose-Seminare, 1996). In April 1996 a first meeting of all German groups took place in Bonn. As a result of this meeting comprising 170 members, a team of people began to evaluate the results of the psychosis seminars and published a guideline (Bock Th, Buck D, Esterer I (1997)).

We hope that the following accounts of our experience will demonstrate how new, different, extraordinary and unusual this type of encounter is. We want to emphasize the great opportunities it engenders as well as the immense difficulties that are bound to arise once you engage in a Trialogue. In neglecting this fact there is a big danger of misusing the term Trialogue as a hollow expression in order to "cover up problems, blur existing contradictories and paralyse productive tensions" (Finzen A (1994)/ translation by authors).

## **Personal reports**

For our personal reports we chose a "trialogic" form: Three founder members of the "First Vienna Trialogue" – a user, a relative and a psychiatrist – each give a statement about their personal experiences of the group, followed by comments of the other two authors.

### 1. EXPERIENCES OF A USER IN THE TRIALOGUE

#### *Thoughts of the "court-jester"*

Sunday night - an unreal silence hovers over the town.

Yesterday Reinhard phoned. His flat-mate, a homeless man whom he had taken in recently, had given up, finally, for ever. He didn't even make an announcement. Such a thing is quite frequent. He is the third one I'm hearing about this month.

"An atmosphere of fear, ignorance and hopelessness broods over the individual wards, rather than any medical concern. How much longer?" (Kay Winter in a newspaper report about her stay at "Steinhof", psychiatric hospital in Vienna: "Better not to ask")

But of course, we do ask questions. We are able to express what we want to say. We can hold lectures and write articles. We can issue magazines and write books. And make movies. And yet - they will never understand us - never ever! Because it is impossible to understand something that one is not willing to understand.

They are simply drilled to never take note of anything we say, except when it fits into their narrow miserable concept of diagnosis. I am really tired of all this talk about "users". We are the abused!

A latest round of the "First Vienna Trialogue" took place a few days ago. 18 people were present: 10 users, 6 relatives, and 2 professionals. One of them was a psychiatrist and the other was a fairly young patients' advocate. She looked a little uneasy at the sight of such an imposing majority of self-confident users who were quite capable of defending their own interests. The psychiatrist was one of traditional kind, sticking to his medical training. No matter what we told him about our experiences, he desperately kept defending his traditional standpoint. He was badly shaken but did not break down. Ten users, supported by several relatives, were not able to explain to him what they really needed. The score of the game is 10:1 at the moment. Anyway, the psychiatrist already indicated that he would not be likely to join the Trialogue very often in the future.

From the beginning, there were rather few professional helpers in attendance at the Trialogue. Most of them felt uneasy at the prospect of holding discussions on an equal level with representatives of the other groups. Preachy, oppositional statements and confessionals were frequent enough. But the relative proportion and composition of attendants revealed something else altogether. Social workers comprised the biggest group of professionals, which didn't surprise. They are sort of underdogs at the lowest level of the helper-hierarchy of psychiatry. Like us, the users, they feel a natural need for acceptance and equality.

My viewpoint in this story is rather unromantic. Whereas some of the professionals came in order to make sure they wouldn't miss a chance of getting on a new career train, others came just to hear that they were the best of all helpers..."Mirror, mirror on the wall - who is the most benevolent helper of all ?"

Concerning the relatives one can say that they were generally not the "typical" relatives of mentally ill individuals, but rather self-assured people ready for battle. They are prepared to do everything humanly possible, as long there is anything to do. From the beginning they were deeply interested in learning about everything that could be helpful. Most of them are not very pleased by the kinds of therapeutic products offered at the psychiatric supermarket. But alternative remedies are rare, so that they too must make a virtue of necessity. All types of guilt feelings and a strong desire for unburdening contributes to their use of "the illness" as an explanation for the inexplicable behaviour of their relatives. Consequently, discussions about "insight" and acceptance of illness were dominant among the family members in attendance.

Moreover it is indeed scandalous that the "psychiatric reform", which in reality has never taken place, is being carried out at the expense of family members. Not only in and around Vienna but also in other districts of Austria the essential community-based services are still missing to a great extent. And no support whatsoever was given to overburdened relatives until very recent times. Not to mention the many unsolved problems that arise at the sudden outbreak of a crisis when the patient refuses to be treated in some of the existing hospitals or institutions, which have been known to discriminate against certain patients. Relatives often ask us for advice on how to prevent compulsory hospitalisation in such situations, being torn between the need for immediate intervention and their fear of not being able to justify their actions in the future.

What could be done is not a secret, however. A social-psychiatric crisis service ready to make home visits night and day without immediate brandishing of an injection needle would be helpful. Areas free of psychiatry where individuals with experiences of abuse would feel safe from the danger of being violated by compulsory treatment are also needed. Yet, unfortunately politicians and psychiatrists have so far been deaf to these kinds of proposals. The traditional expectation that psychiatry should contain psychic misery outside of public view still dominates the field. And if such containment is not possible with the user's consent, then it must be done by the force of state powers.

Concerning the users, we have been the majority from the very beginning. Amazingly, the number of user participants has increased rather than decreased over time. It is obvious that the Trialogue has meant a great deal for their further development. I had known most of the initial participants for many years, but I had never before experienced them in the way they presented at the Trialogue.

They kept discussing joyfully, with passion and persistence. At times, however, the discussions turned into performances. In those times, everyone knew that it was just for show. Just as we had been used to act helpless, we now assumed the role of the self-assured. And the best thing is, not only the two other groups, but we ourselves were taken in by the show! Whenever I am the moderator it is infinitely great fun to watch my friends giving each other cues at lightning speed. And it is even more fun to watch the professionals trying to keep the pace of the game, but they stand no chance. Actually, - to tell the truth - we would be able to communicate among ourselves without using words, but then the others would be excluded which would be rather useless. And it is not very funny to realize that 10 persons, more than half of whom are gifted with extraordinary eloquence, can't make a single psychiatrist understand the essence of their communications. We have engaged in the Trialogue with the expectation that the representatives of the three main groups within the psychiatric field could share their experiences, opinions, hopes and fears, trepidations and desires, in partnership and on a level of equality. We are still far away from partnership. We are doggedly fighting for equality.

## THE RELATIVE'S COMMENT

My comment regarding this literary text, that impresses with its open honesty and its level of hurt, is limited. It would be presumptuous of me to respond with criticism. Especially since as relatives we too suffer frequently from the "overprotection" of an insensitive psychiatric machinery.

## THE PSYCHIATRIST'S COMMENT

It is not without reason that we as professionals seek professional help whenever we are confronted with a patient's suicide. However, I am finding it hard to imagine, what it must feel like to regularly hear about people from one's own peer group who decided to end their lives. Distance can be felt deeply and sadly. My respect can never be a source of comfort.

From my perspective, sympathy and openness determine the relationship between family members and users within the Trialogue. Without being tangled up in the confusing burden of biography of parents and their children, the participants can offer each other precious help and concrete advice. Usually this can be done without the attribution of blame. Looking at the relationship between professionals and users you will find a different picture. I often find myself in a position of not understanding what users want to say or what implications this might have for myself and for my work. The professional care-givers in the Trialogue expressed frequently that they would like to see greater interest in their situation and their problems. I personally believe that knowing the "medical agenda" can be of great help for people experiencing mental distress. Once the people working in psychiatry can reveal the reasons and motives behind the things they do or say, it becomes much easier to discuss their concepts openly with the users. Some of these professional concepts may turn out to be based on misunderstandings and/or oversimplification and could be improved. It should be taken for granted that professionals are both willing and able to learn.

It seems important to me that the users will never leave us to our own devices again. We need their active participation in events, in the process of contemplation and planning for future developments. The inherent irritations and tensions might well offer an effective shield against burnout in all aspects of clinical practice, research and academic activities.

## 2. EXPERIENCES OF A RELATIVE IN THE TRIALOGUE

### *Beginnings*

We began in the autumn of 1994. The idea had been brought back from the 14th World Congress of Social Psychiatry in Hamburg in June 1994. There the "people with experience in psychiatry" (Psychiatrieerfahrene), as they called themselves, fascinated us with their self-confident way of acknowledging their mental illnesses in front of an audience of 3500. In Germany a user movement had already been established, while in Austria for the first time a consumer had given a terrific and widely acclaimed talk about his psychotic crises and the response of the "helpers" and the public at a family advocates' conference in the spring of 1994. We wanted to bring along the atmosphere of the Hamburg Congress filled with sparkling ideas. It radiated the hope that as long as one had the right attitude the confusion of tongues could be overcome and a change for the better in the entire psychiatric system could be achieved. Therefore we proceeded to approach each other as well, in Vienna, in the following fall – without any preparation, just with the desire to understand a little better, what seems so hard to understand and so frightening.

### *Great enthusiasm among the relatives*

The relatives came in large numbers to the fortnightly meetings. At first they naturally wanted to contribute their own personal problems: disillusionment, abandoned hopes, slight, their search for absolution from guilt, everyday problems and the desire to finally shed light on the origin of the changes in their mentally ill family member.

### *Criticism must be tolerated - a learning process*

It soon turned out that the problems of the relatives have to take second fiddle to the problems of users. For users the dam of hurt feelings was too large, the backlog of critical comments too vast. "But it was precisely this criticism, that was also massively levelled at the relatives, that taught me the most", one mother said, "I learned to endure it. I learned to hear, that I had made mistakes, that I had been too overpowering. Learned to concede that my son rejects psychiatry and psychotropic drugs. And I learned not to intervene when he had to go through painful experiences again and again. That was very difficult for me."

### *No harmony at all cost*

If our conversations were to become really fruitful, we had to abolish "harmony at all cost". Whoever wanted to have a cosy chat at the Trialogue was disappointed. What we do is hard work. Sometimes there are arguments. One reason for these fights are the rigid attitudes, the fundamentalist missionary zeal of some participants, who try to exploit the Trialogue for their own goals.

Undoubtedly changes in the mental health system must be achieved, we all agreed to that. Such deeply seated changes can only be achieved gradually by evolutionary means through a revised image of humanity - says one part of the group. Others were strictly for the abolishment of psychiatry altogether. Here and now. Instantly.

How? And what would come in its stead? That we can discuss later.....

All participating groups, especially the relatives, exercised steadfastness and self-delineation in these discussions. The aim cannot be to merge harmonically with each other, but to learn to say: "No".

Or: " I am of a different opinion".

("If my mother would only say NO once", one of the users said, "I could at last take her seriously.")

### *The mystery of psychosis*

Mortal dread and infernal journey, space-travel, creation and curse – after years of Trialogue we relatives still can only see psychosis as a shadowy figure in the fog. This will most likely stay this way. "It is terrible that I cannot reach him when he is suffering so much." "I accept it the way it is. And you as our family members have to accept it as well."

### *How shall we call "it"?*

That brings us to the next major controversy: Illness? Crisis? Psychiatric problem? Interesting and exciting battles were fought around the issue of "illness or no illness". During these arguments we felt that the users were exaggerating, painting things in black and white, unable to differentiate. Continually we argued against this, but with doubtful success.

### *Whom to address*

Of course we primarily addressed the users, and among them some more vocal spokes-people that emerged early on. Most impressive was the longstanding open display of fights for leadership among them. They were fought hard, honestly, emotionally and with lowered guards. No bourgeois pretence infected these fights. The group of professionals (doctors, psychologists, social workers, advocates and others) also directed their comments primarily at the users, rarely at us. This may be due to the dominance of users in our every day life, where they are, albeit to a different extent – the centre of our attention. Psychiatrists as the representatives of institutional psychiatry were the prime targets of aggression.



### *What unites us*

Psychosis or psychotics as side-show attractions? The merely curious and the smart-alecks stayed away very soon! But those who allowed themselves to be touched were drawn in by the dynamics of the Trialogue. More than once a participant was driven away by some dramatic turn of events. But at some point or other they all came back. Sympathy and solidarity prevailed. Mental health professionals should do something that does not come naturally for them – they should talk more about themselves, about their ups and downs, their vulnerabilities and presumably also about frequent feelings of loneliness. They stand to gain considerably in human stature.

### THE USER`S COMMENT

#### *Criticism must be tolerated - A learning process*

It is not the point to endure criticism, or to endure anything for that matter. What matters is to accept and fully respect users as human beings. Relatives need not step back with their own issues, but they should become aware of their own needs and should no longer confuse them with the needs of their ill relatives.

Yes, we want to abolish psychiatric institutions altogether. We want to abolish everything that discriminates and stigmatises human beings. And this is just what psychiatry keeps doing. On the one hand, psychiatrists complain about the discrimination of "their" patients and on the other hand they do everything possible to keep up just this kind of discrimination - by defending the special kind of "prisons" which they call hospitals or by telling disgraceful tales about mental illnesses, about "schizophrenia." And when I call them "tales" I mean it literally. Because none of the theses, hypotheses, theories and analyses that purport to be based on science would stand a test according to scientific methods. Eventually we have to face the fact that , besides science, there are things between heaven and earth that man cannot explain and that we have to live with anyway.

### THE PSYCHIATRIST'S COMMENT

It can happen quite easily that family members are put in a defensive position. From my experience in working with care-givers in different settings, removing guilt feelings about being the cause of the illness is the most important and yet the most difficult task. These feelings quite often propel relatives to act in rather outlandish ways towards individuals who suffer from mental distress. However, this task fails quite frequently and then becomes an obstacle in involving family

members to exert a positive influence on people's recovery. Within the Trialogue I often observed how users working on the same issue were much more successful in relieving guilt feelings of relatives. Furthermore users tend to be much more practical in offering the family members concrete suggestions about how they could behave in certain situations, which they in turn are taking in with great interest.

The aforementioned arguments within the user group have not threatened the strong bonds between them, which was really astounding for the professionals and the family members. In my encounters with the user movement in Germany or New York I often wondered whether a special quality of people with psychotic experiences was at work here. I have never witnessed such a vast amount of solidarity, friendship and mutual support coupled with great differences in opinions and vehement controversies -- a phenomenon well worth emulating. The fact that professional caregivers tend to be very different in that respect might be an explanation for them being viewed as less "human" in the Trialogue. The fear of losing the solidarity of the own profession, the concern of relinquishing collegial loyalty and the risk of departing medical or other therapeutic may well be hindering our openness. Surely another important reason why professionals speak only very little "about themselves, their ups and downs, their own vulnerability" is the fact that we find ourselves compelled to neglect our own difficulties and weaknesses when supporting someone in crisis. There are advantages and disadvantages in this specific professional attitude that should be discussed in that context.

### 3. EXPERIENCES OF A PSYCHIATRIST IN THE TRIALOGUE

After a limited amount of experiences with "psychosis seminars" in Germany it became perfectly clear to me that we should establish a similar forum in Austria. My contacts with service users at the psychosis seminars and at user- projects in New York were of a very different quality than the interactions that prevailed during my professional work in several psychiatric settings. Finally the time had come to find out which types of communication would be possible in a "trialogic" situation. At this point I would like to list and share some of my essential experiences as a member of the Trialogue.

*There are certain things which can be experienced and understood only in the Trialogue*

Right from the start it was clear to me that I had discovered a treasure. I heard about things in a way that never would have been possible in another situation. Consequently, I made an effort to attend the meetings regularly despite a significant amount of additional work and personal stress. Even in times of great difficulties and frustrations I never really considered to give up.

*Service users are tough and persistent partners in discussion*

From the very beginning the debates have been very focussed, hard and controversial. The users displayed unexpected resilience and endurance. It happened quite often that we engaged in a lively discussion for up to four hours. It is also true that the group of users regularly outnumbered the two other groups. They quickly assumed the leading role in defining the issues which were being discussed. Their personal accounts as well as their sharp and critical analyses of their experiences within psychiatry filled a great deal of time and left deep impressions on professionals and care-givers. Contrary to our expectations there were rather few problems resulting from the fact that users were frequently unstable and even stark mad at various times during the Trialogue. My impression was that the users themselves were very sensitive and aware of the level of madness that is still tolerable and never pushed the limits beyond a certain line.

*Giving up a therapeutic attitude is difficult, but necessary and rewarding*

It was an ongoing conflict for me in my role as a mental health professional whether I should assume responsibility for individual destinies and for the course of the Trialogue group as a whole. A therapeutic attitude is certainly not wanted nor needed in the Trialogue we desired, and yet there are times when it is very tempting and even demanded by the participants to take on that role. Being a participant, a consumer within the Trialogue has been very difficult in a situation where hierarchy and clear job descriptions have been rejected formally but are still informally present. The knowledge I derived from my clinical experiences and professional training, the lesser degree of personal involvement compared to the two other groups, and the greater familiarity with thematic discussions and verbal arguments contributed to a distance which needed to be challenged. In this regards it was helpful to experience a separation between institutional psychiatry and the role of a single professional helper, the possibility to talk about one's own problems, and, most importantly, to get advice and help, to witness fights and friendship. A definite disadvantage is the fact that the group of professionals remains under-represented. Possible reasons for this fact (lack of time or interest, fear of controversies) were frequently discussed in the Trialogue. I am certain that the combination of neediness and aggression, of devaluation and overestimation, as I experienced it from the user's side, can be rather stressful. I often felt it very unfair that some of the participants described and criticized my professional engagement as being patronizing, repressive, limiting of personal freedom or even coercive. That hurts. To make things worse, a wish for help and support was expressed simultaneously without clear ideas about the way it could be provided.

*Participants from the three groups are heterogeneous and not representative*

The users who are taking part in the Trialogue are definitely a selected and non-representative group. On the one hand they were patients or ex-patients suffering from "psychoses", which in professional language would mean psychosis from the schizophrenic spectrum, schizo-affective and manic-depressive disorders. Most of them have suffered from mental difficulties for many years and hence have been in touch with psychiatry for a very long time. Many of them had very bad experiences with the way psychiatric system offers help. Many use explanatory models for their mental problems or their situations that are in clear opposition to current professional explanations. In fact, attacks against the bio-medical illness-model took up a lot of room in the discussions. In that respect I wager the opinion that the major difference between the users in the Trialogue and those I encountered in therapeutic settings has to do with the freedom they find within the Trialogue to express criticism without fear of negative consequences, i.e. coercion or neglect. Of course there were also differences in the sources of motivation to take part in the Trialogue. While some of the users attended the Trialogue due to personal difficulties and the need for support, others turned up with ready-made political programs that included discarding psychiatry altogether. A third group of users was primarily interested in the exchange of opinions and in social contacts. Therefore the discussions ranged from effecting social revolution to improving the psychiatric system, either in the sense of expanded psychiatric services and better community care or in challenging the professionals to provide alternative ways of treatment, and to demanding support for self-help projects. It was astounding how much tolerance was shown amongst the group of the users for those different opinions.

That is not quite the same among professionals, especially those who participated in the Trialogue who can be all characterized by a particular, even an exaggerated commitment to their work (a circumstance paraphrased by some of the users as the "fig leaf" for a psychiatry that is basically inhuman underneath). Everyone in the Trialogue realized how great the diversity of opinions and scientific positions among professional helpers really is. This often led to vehement debates between different professional subgroups, i.e. patient advocates and medical doctors.

Equally heterogeneous and not representative of the entire group were the family members within the Trialogue who can be characterized by considerable experience, strong engagement or, in some cases, extremely high level of suffering.

*Relatives have a difficult position. They have other problems than users and professionals*

It happened repeatedly that statements from family members about their personal experiences and their suffering caused great and often speechless concern. Their requests for support in current difficult situations were not always heard. It seems to be very difficult for family members to accept that their problems and aims are often contradictory to the ones of the users. The frequent attempts of relatives to assuage and avoid conflicts and injustices were probably quite convenient for the other participants, but were nevertheless rejected summarily and not positively reinforced.

The one time we considered having a Trialogue with swapped roles most of us were fond of this idea, but nobody volunteered to take the part of a family member.

### *Everybody learns*

One of the most thrilling aspects of the Trialogue groups has been the realization that patients who spend a lot of time within psychiatric institutions have an extremely accurate, almost intimate understanding of the situation we professionals work in. "Professional knowledge" however is rather limited among users and relatives alike. Therefore the need for establishing an equal level of information is both a necessity and a challenge for users and professionals. To set aside the "patient role" and to take note of the personal and professional statements of professionals in order to discuss them free of clichés obviously involves quite a bit of effort.

Though unfamiliar, it might still be easier to find out about each other, to ask questions, to discuss opinions and ideas within the Trialogue, where relatives, users and professionals for the first time have a chance to meet each other without pressure and personal concern, compared to the situations where we normally see each other, like in one's own family or in a therapeutic setting.

### *Psychiatric practice needs to be improved*

Participating in the Trialogue offers professional care-givers the opportunity to obtain insight into the personal experiences of users with psychosis, psychiatric professionals and institutions, which they would not be able to get within a therapeutic setting. A whole range of suggestions and ideas arises from sharing experiences and concerns in this way, contributing to a better approach to the difficulties of professional care-givers, relatives and users, as well as for necessary additional services and alternatives. We often discussed several practical alternatives such as "Soteria", "Windhorse", "peer-specialists" but unfortunately it remained unclear, whose responsibility it would be to start organizing such projects. Without doubt, people with psychotic experiences do have very diverse needs. Whether it is possible to verbalize and acknowledge these divergent needs in crisis situations is a very important question. Within that context we discussed issues like the "psychiatric will" and advance directives for treatment.

### *Other things happen around the Trialogue*

The Trialogue can be seen as a point of origin for impulses relating to other initiatives. For example, several user-led activities in the domain of self-help were inspired by the Trialogue. Mutual counselling and impulses for various projects were sought and found there. Some ideas from the Trialogue took hold in other areas, stimulating, for example, academic research projects.

Family members, service users and professional helpers established ongoing communication with each other through the Trialogue. They started inviting each other to some of "their" events, either as participants or as presenters. Hence the "trialogic" character of mental health events was promoted on several levels.

### *The Trialogue itself changes*

If you look at the Trialogue on a time line I would argue that the initial stage was marked by curiosity, the establishment of contacts, and at times rather tedious discussions about formal procedures like meeting times, locations, and leadership. This was followed by a phase of stormy confrontations, the clashing of totally incompatible opinions, attitudes and prejudices, which contributed to the acknowledgment of boundaries among the participants. More recently the group seems to be engaging in a well differentiated discussion about the positioning among the three groups of participants. At the same time we are thinking about the future of the Trialogue. Should there be more than one group, or can everyone be accommodated by one meeting? Should we start to establish groups that work on specific topics or projects? Do we want to start a formal association or non-profit organization? Is it desirable for the Trialogue to address itself to a larger audience, and if yes, in what ways?

*There is much laughter within the Trialogue, which is seen as a powerful remedy*

### THE RELATIVE'S COMMENT

*Regarding: "There are certain things which can be experienced and understood only in the Trialogue."*

I agree. The Trialogue can make you understand – in a rather uncomplicated way – the kinds of things that can otherwise only be found in the theoretical literature, where they are presented in a deficient and lifeless fashion. In trialogic communications people who are personally affected can make others feel personally affected too by expressing their issues in emotional and rational terms. Trialogue participants have the opportunity to grasp certain connections, even in a physical sense. But can they always be understood? We are dealing with very personal, complex and deep-rooted experiences, that are being addressed in open and honest ways. Only whenever these reports touch something familiar in us, can they be truly understood. (It is not at all rare that we all resonate with madness at some level.)

*Regarding "Service users are tough and persistent partners in discussion"*

Again and again we are impressed by highly intelligent and interesting people in our discussions, some of whom have had psychotic experiences. It must be said that it was not easy for us relatives to maintain an emotional distance to some of the things we hear. For example, the tendency to relate personal experiences of users with psychiatric treatment modalities to one's own "case" can aggravate our own problems. Relatives, mostly parents and especially mothers, tend to hear accusations in almost everything they are being told. This is caused by their shattered self-confidence. In their shock and helplessness – at least at the onset of the problems –they often acted as uncritical accomplices of psychiatry, which is now being criticized by the users. To listen to reports of appalling treatment experiences leaves the relatives with feelings of confusion and uncertainty. Based on their understanding of the parental role, they are always prepared to take on the "management" of their ill family member and to readily accept the authority of the medical staff. A more critical attitude towards their role as parents and towards their management of the problems with mental illness needs information, time and distance.

One question that was frequently posed in these discussions was: "What would you expect us to do? There is no other psychiatry!" However, trying to answer that question was rarely taken on during the user-dominated first phase of the Dialogue. This has to be done, since the resulting answers would give us some guidance in the way psychiatry should be reformed. The alternative methods of treating psychosis that were mentioned are impressive, but unfortunately quite abstract, not backed up by sufficient evidence or cannot be implemented on a large scale. Their main common denominator is a different view of human beings.

*Regarding "Giving up the therapeutic stance is difficult, but necessary and rewarding"*

Mental health workers need the courage to "take off the white coat" and to pull up their blinders. The fact that this does not come easy was very obvious and means that people must resort entirely to the strength of their personality. And this is precisely the precondition for an unprejudiced communication on an equal level.

*Regarding "Participants from the three groups are heterogeneous and not representative"*

Yes, they are a colourful bunch, the people of the Dialogue. Extremely diverse in every respect, but altogether highly motivated, alert, and prickly people. Of course they are not representative. Many are missing, especially those, who are not well enough to appear in public, those who are not articulate enough or decide to remain in the dark. I find the users in the Dialogue altogether a little too adolescent in their way of dealing with conflicts. I observe a certain dissociation from reality, uncompromising attitudes coupled with the wish to stay together and be loved anyway, in spite of it all.

*Regarding "Relatives have a difficult position. They have other problems than users and professionals" and regarding "Everybody learns"*

The relatives' position truly is a difficult one. But they do realize that, and for each of us there comes the time to rise above it. Naturally, the mothers in the Trialogue have to suffer all prejudices that come their way from the users as well as the professionals. Naturally, they react in a way that reinforces these prejudices. It is important to understand that they often come from a generation, that experienced conflict as threatening and evil. That makes them want to support the unjustly accused and to make peace among the contestants. Relatives then appear touching, but a little ridiculous, behind the times, and are not always taken seriously. Nevertheless I had the impression that the users treated us with kid gloves at times, possibly as a consequence of their ambivalent relationship with their own parents. The relatives in the Trialogue are capable of learning and realize that it is very important to make good use of the opportunities offered by these encounters. They can help us to gain more distance, to mark our boundaries and – in the Trialogue and in our personal lives – to be more assertive and save our own skin. Should the Trialogue adopt the suggestion to evaluate the state of information of its members, this would certainly foment new arguments. Nevertheless it would be extremely helpful in order to increase the quality of the discussions.

*Regarding "The psychiatric practice needs to be improved"*

It is evident, that the needs of users in crisis situations are diverse. That is equally true for rehabilitative measures, should they be successful for each individual. One of the saddest and most incomprehensible mistakes of the psychiatric establishment is their rigidity and lack of vision within its hierarchic organizations.

*Finally*

The Trialogue needs to be broadened in the direction of a tetralogue including politicians. How long do we have to wait until the first user will make a presentation to parliament regarding mental health politics? Organizations like the user movement and the Trialogue are important, because they can force politicians to address them officially.

Regarding the importance of laughter: Laughter means taking it easy – in spite of everything or just because, indicating a lack of self-importance. Laughter is a simple, but very effective and economical way of solving conflicts. Relatives especially need to laugh more. We should practice this art more frequently in our self-help groups.



## THE USER'S COMMENT

The participants are heterogeneous and not representative of the three groups. No, we users in the Trialogue are not representative of the patient image that informs the professionals. According to that image we have to be helpless and in need of care. Nothing else corresponds with this view and the understanding of their professional identity. It is beyond my understanding why an intelligent, clever and well educated professional with many years of work experience can be so naive in some very important respects.

We are no longer helpless, frightened, shy, submissive, and stigmatised by psychiatric treatment for the rest of our lives. We have accepted and are coping with the challenge of living with psychosis. Actually professionals should look at us as great success stories. Moreover we have accepted the challenge of stepping up to an equal relationship with our helpers. But this seems quite impossible since it would question the foundation of the helpers' role, which affirms that their knowledge should dictate what is good for us.

And we are heterogeneous, indeed. There is no greater number of contradictions in the world like the ones embodied by a dozen psychiatric survivors in one place. We are as individualistic as self-centred. My personal remedy to counter my own self-centeredness is to concentrate on other people's lives, loves, and suffering, not superficially, like at "small-talk-parties" but by getting deeply involved. This is hard work indeed.

*Moreover, besides, after all, anyway*

Criticism directed against professionals seems to me absolutely legitimate. Beds with netting and bars make things pretty obvious. Less so the more subtle ways of restricting personal freedom. Apparently it takes an extremely long time and hard work for professionals to become aware of the fact that actions based on good intentions to safeguard patients may turn into the coercion, oppression and violence, which must be questioned every time it's use is being considered. Is this measure really necessary or is there an alternative?

For example I kept having debates with the patients' advocate about living up her professional role and joining the Trialogue just as a human being. Obviously she felt the need to engage in a heavy controversy with the psychiatrist, seeing this as her responsibility in representing the users - which is of course her job. At times, when I was the facilitator of the group, I even felt compelled to intervene, especially when her attacks of the psychiatrist took on a rather personal flavor. Of course I also understood her difficult function as a patient advocate, being quite useless in the Trialogue where the users excelled in representing themselves. However, in real life, in a moment of crisis,

the autonomy we practiced within the virtual world of the Trialogue, cannot always be maintained and we will again resort to the helpers' intervention, (which should be more efficient through their Trialogue experience) as before.

### *Finally*

Summing up I would like to state that the central importance of the Trialogue, not just for myself, lies less in the group discussions than in the various relationships to some of the participants that developed beyond our meetings.

As an example I would like to mention my encounter with a psychiatrist on a level of friendship that has enriched my life in many respects. Of all of us she has held the most difficult position. In the Trialogue she is an exception. In her professional surroundings, she is recognized as a competent psychiatrist, but just one of many. Her leading position among the group of professional helpers is a double-edged one, though. As a person she is respected by everyone. As a representative of the dominant medical profession she was confronted with the attacks of all groups that are against institutional psychiatry.

In the many very personal one-to-one conversations that we had around the Trialogue, she taught me a different way of looking at life. Her openness, her frankness, her authentic way of speaking, the revelation of her humanity has made me understand many things, not only about psychiatrists, her being not at all representative of that group. We have tested the authenticity of all professionals that participated in the Trialogue. Only few passed the test. Once I attacked the psychiatrist very heavily. Usually I am not very sensitive, but for once I got frightened - she had come too close to me. She had granted me the closeness I had always longed for. So I pushed her away.

It's a damned thorny path, god-forsaken, desolate. But I wouldn't miss it for the world.

### **References**

Bock Th, Buck D, Esterer I (1997) "Es ist normal, verschieden zu sein." Psychose-Seminare - Hilfen zum Dialog. Psychosoziale Arbeitshilfen 10. Psychiatrie Verlag, Bonn.

Bock Th, J E Deranders, Esterer I (1994) Im Strom der Ideen - Mitteilungen über den Wahnsinn. Psychiatrie Verlag, Bonn.

Bock Th, J E Deranders, Esterer I (1992) Stimmenreich - Mitteilungen über den Wahnsinn. Psychiatrie Verlag, Bonn.

Buck D (1996) Sieben Jahre, siebzig Seminare - Bedeutung und Perspektive einer Idee. Psychosoziale Umschau 11: 1-2.

Finzen A (1994) Auf dem Weg zum biopsychosozialen Quadrolog. Psychosoziale Umschau 9: 1-2.

Psychose-Seminare: Im Mittelpunkt stehen die Erfahrungen. Psychosoziale Umschau 11: 1; 1996.

Schürmann I (1997) : Beziehungsformen zwischen Langzeitnutzern und Professionellen im Kontext der Moderne. In: Zaumseil M, Leferink K (eds): Schizophrenie in der Moderne - Modernisierung der Schizophrenie. Edition Das Narrenschiff im Psychiatrie Verlag, Bonn.

Stastny P, Amering M (1997) Integrating consumer perspectives on quality of life in research and service planning. In: Katschnig H, Freeman H, Sartorius N (eds): Quality of life in mental disorders. John Wiley, Chichester, New York.

Zaumseil M (1996) Neue Praxis braucht neue Theorie. Wissenschaftliche Argumente für eine neue Form der Begegnung. Psychosoziale Umschau 11: 3-5.

Zaumseil M, Leferink K (eds) (1997) Schizophrenie in der Moderne - Modernisierung der Schizophrenie. Edition Das Narrenschiff im Psychiatrie Verlag, Bonn.