Trialogue: An Exercise in Communication Between Users, Carers, and Professional Mental Health Workers Beyond Role Stereotypes

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"Nothing About Us Without Us"

The reality of "Nothing About Us Without Us" seems to have arrived and is irreversibly here to stay: no policy development, no amendment of legislation, or elaboration of new regulations shall be undertaken without including experts in their own right, persons with a lived experience of mental health problems and services. Whether the Mental Health Action Plan for Europe, the WHO Global Mental Health Action Plan, or the recommendations of the first trialogic task force of the World Psychiatric Association (WPA) providing for a partnership with users of services and their families and friends (Wallcraft et al. 2011), the call for "user involvement," a "partnership approach," or participatory approach is evidence that henceforth no significant development can be advanced without the meaningful involvement of experts in their own right.

In many ways the first human rights treaty of the twenty-first century epitomizes the essentials of recovery orientation. Forged between diplomats and a throng of civil society representatives – many of them persons with disabilities as experts in their own right, including those with psychosocial disabilities (Sabatello and Schulze 2014) – the treaty is the product of a truly participatory process. In a corresponding logic, it makes the consultation of its constituency – persons with disabilities and their representative organizations, respectively – an obligation: "In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively

involve persons with disabilities, including children with disabilities, through their representative organizations" (Article 4 Para 3 CRPD).

Such participation is a response to the growing understanding of the impact of decades of societal and therewith structural exclusion. It is, however, also a key method to enable genuine autonomy for a societal group that has been largely ostracized from mainstream society and frequently been subject to various forms of paternalism, neglect, and oftentimes violence in different forms. Ensuring equality for persons with disabilities thus necessitates an intervention into the composition and structures of debates and decision-making processes. Interactions have to be re-tooled based on the understanding that disablement is importantly a result of social and attitudinal barriers of the mainstream. Stereotypes, prejudices, and imagery of disability are the main hurdles that need to be overcome.

"Fix Society, Not People"

"Fix society, not people," captures the core of the Convention (Schulze 2014). The focus on the perceived deficits of a person has to be replaced by an understanding that impairment is "an evolving concept" and, importantly, one that is far more defined by the attitudes of society than the impairment as such. New forms of interaction and negotiation strategies emerged from the process toward the UN Convention for the Rights of Persons with Disabilities. Maya Sabatello and Marianne Schulze's book (2014) on how the CRPD came to be gathers exciting accounts about new strategies and forms of communication and negotiation. Two aspects stand out in relation to the topic of Trialogue. Firstly, the notion that "everyone ultimately has an intimate interest in upholding disability rights" as disability is viewed as "an integral part of common human experience" (Sabatello 2014). Based on the prevalence rates for disabilities across the life span, clearly, almost everybody will have either personal lived experience or experience within the group of family and friends. Secondly, the acknowledgment of the fact that many diplomatic delegations and civil rights organizations "simply lacked the expertise, knowledge, and understanding to properly address the needs of persons with disabilities" and the willingness to learn from organizations and people with a lived experience background highlights an urgent need for change with regard to communication skills. Despite difficult circumstances from financial to organizational matters, the inclusion of persons with disabilities into the negotiation process was furthered by their great engagement as well as welcomed by different United Nations bodies. These historical developments lead to new and essential opportunities of impact and were successful in breaking down existing barriers: "the proportion of delegates with disabilities at the AHC (Ad Hoc Committee) simply made the phenomenon impossible to ignore" (Sabatello 2014). Among the resulting "new diplomacy" strategies, abstract legal terminology was importantly amended by communications that were able "to challenge their imagination, as if it all happens to them" (Grandia 2014) and "providing first-hand testimonies of persons with disabilities who experienced discrimination and who could point to what should have been done differently": "With hundreds of persons with disabilities in the UN corridors, in the negotiating room, in the various meetings, and in the cafeteria" ... "it became impossible to avoid a dialogue" (Sabatello 2014).

Never again letting the dialogue breakdown had been an essential goal of the creators of Trialogue and the Trialogue movement. The experience of the worst forms of human rights violations, including forced sterilization and the murder of people with disabilities, especially also people with mental health problems, at the time of the Nazi regime in Germany had motivated the survivor Dorothea Buck. She talks about how she experienced the psychiatric system as so inhumane, because nobody spoke with us. A person cannot be more devalued than to be considered unworthy or incapable of conversation. This very notion brought it about that in the 1980s Mrs. Buck shared her ideas about the need to prevent such inhumane conditions with Thomas Bock and Ingeborg Esterer and as a consequence the Trialogue was born (Bock et al. 2000). "Trialogue" stands for communication among and between the three main groups of individuals who deal with psychiatric problems and disorders and with the mental health system – people with experiences of severe mental distress, family members/friends, and mental health professionals. Trialogue encounters occur under special conditions – outside familial, institutional and therapeutical hierarchies, and clinches. Trialogue group participants meet on neutral ground and communicate on equal footing.

An illustration of the historical context and the difficulties of speaking to each other openly and on eye level is the fact that for the first time only decades after the atrocities, in the year 2010, during its annual congress in November, did the German Association for Psychiatry and Psychotherapy ask the victims and relatives of the victims for forgiveness (www.dgppn.de/english-version/history/psychiatry-undernational-socialism.html). In his speech the president of the association Frank Schneider said among many other things:

I stand before you today as President of an association that has taken nearly 70 years to end this silence and recall the tradition of enlightenment through science in which it stands.

..... At this point I would like to express my admiration for Dorothea Buck. The sculptor and author, who was herself one of the victims, co-founded the "Federal Organisation of (Ex-) Users of Psychiatry" in Germany. She has tirelessly dedicated herself to raising awareness of the issues and to ensuring that they are not forgotten.

.... In the name of the German Association for Psychiatry and Psychotherapy, I ask you, the victims and relatives of the victims, for forgiveness for the pain and injustice you suffered in the name of German psychiatry and at the hands of German psychiatrists under National Socialism, and for the silence, trivialisation and denial that for far too long characterised psychiatry in post-war Germany.

In Austria the similarly difficult process of ending the silence following the same atrocities was greatly enhanced by the efforts of Harald Hofer, a prominent user/survivor activist. He focused in a commemorative speech 1995 on a *conspiracy of indifference* as the obstacle to recognizing victims of discrimination and exclusion not only historically but also today (Hofer 1997). He also was a founding member of the First Vienna Trialogue in 1994 (Amering et al. 2002).

The Trialogue Experience: An Exercise in Communication Between Service Users, Families, and Friends and Mental Health Workers on Equal Footing

What is true for the hope-inspiring historical firsts of the negotiation processes and the "new diplomacy" in the context of the UN Convention on the Rights of Persons with Disabilities (Sabatello 2014) as well as for trying to overcome the silence after a history of horrific crimes and discrimination against persons with disabilities is of course strongly related to the communication between the Trialogue partners everywhere: we need to learn new forms of communications, a language that allows us to interact in a context of nondiscrimination.

Trialogue groups are training grounds for working together on an equal basis. It is a new and exciting form of communication, a chance to interact beyond role stereotypes, and an opportunity to gain new insights and knowledge. Participants learn to accept each other as "experts by experience" and "experts by training." In other words Trialogue participants acquire skills that are well suited to recovery-oriented and rights-based work as well as to participatory approaches in therapeutic and service development decisions as well as policy developments (Amering and Schmolke 2009).

"Trialogue" stands for the encounter of the three main groups of individuals who deal with psychiatric problems and disorders and with the mental health system – people with experiences of severe mental distress, family members/friends, and mental health professionals - on equal footing (Amering et al 2012). This encounter occurs under special conditions – outside the family, outside psychiatric institutions, and outside a therapeutic setting. Trialogue facilitates communication about the personal experiences in dealing with psychiatric problems and disorders and their consequences. Participants of diverse experience backgrounds - lived experience as users and carers as well as professional working experience in mental health services – strive toward giving up their isolation and lack of common language. Mutual understanding and necessary delimitation from the vast variety of the participants' different backgrounds concerning experience and knowledge are to be established. Trying to understand and share the complex and very heterogeneous subjective experiences leads toward establishing a common language, in which different forms of expertise and experience of participants of the three groups can be exchanged. For any particular topic of discussion, a wealth of knowledge and experience is brought to exchange and provides a comprehensive resource for problem solving. Every participant has the chance to observe different interpretations of similar roles in participants of his or her own groups as well as of the other two groups. Subjective views can be complemented by objective knowledge and put into perspective of different interpretations and handling of similar experiences. Thus a skill base for effective forms of collaborations can be acquired, which then extends its value into other situations, like clinical encounters or problem solving within family life as well as working together on different levels of policy development and decisions.

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 with 10-40 people in attendance. In the beginning, the meetings were only publicized verbally, followed by newspaper ads and announcements within user- and professional organizations. Trialogue is an open group – everyone interested in participating is welcome. It was our experience from the start that users formed the largest share of regular participants, followed by family members and friends and professionals (social workers, psychologists, nurses, patient's advocates, guardians, psychiatrists). 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. For many years now, the Trialogue groups in Vienna enjoy the hospitality of a highly reputed adult education facility. Besides financial considerations, we strived toward finding a place outside psychiatric institutions, unaffiliated with a particular selfhelp organization and apart from the apeutic or family relations thus offering a neutral ground that does not offer an advantage or a privilege for any of the participating groups. For the same reason, we prefer a rotating system of different members in the role of moderator to a model of professional moderation.

Psychosis Seminars

The role model for the "First Vienna Trialogue" was the psychosis seminar in Hamburg. Currently, over 150 of these seminars can be found in Germany, some of them using different names such as "exchange of experiences with psychosis" or "from dialogue to trialogue" and some in Switzerland and Austria. As a result of a meeting of many different members of such groups, a team of people began to evaluate the results of the psychosis seminars and published a guideline (Bock et al. 2000).

The published accounts of our experience of the first years of Trialogue (Amering et al. 2002), which we reported in a trialogic format, were meant to demonstrate how new, different, extraordinary, and unusual this type of encounter is. We emphasize the unique personal and professional learning opportunities it engenders as well as highlight the difficulties that can arise when you engage in a Trialogue as a whole person, start to accept the different members of the group as equally entitled experts, and try not to avoid relevant conflicts of interest. However, when we encourage taking Trialogue seriously, we also point out all the fun that it brings. *There is much laughter within the Trialogue*, *which is seen as a powerful remedy* is one important conclusion by a mother talking about her experiences as a Trialogue group member.

Trialogues and psychosis seminars usually take place weekly, biweekly, or monthly and last between 90 and 120 min (often including a short break). Attendees vary between 10 and 60 people. Ideally there should be an about equal number of participants from the groups of professionals, users, and carers. Community, education, or communication centers are well-suited locations. Trialogue groups are moderated. Moderators can be recruited from all three attending groups. They can rotate

or stay stable for some agreed time. Rules concern mainly that only one person should be speaking at a time and that personal information disclosed should not be spread outside the group. Participants may introduce themselves with their full name and identify themselves as belonging to one of the groups. However, this is not necessary if anonymity is desired.

A few years ago, a woman and a man attended a Trialogue by mistake of entering the wrong room. They had nothing to do with mental health issues, but during the group exchange about a specific psychotic experience of one of the participants, the woman, who used the chance to talk about her hurtful experiences with her sister, got very emotional and was supported by the group. At the end of this particular Trialogue group, she and her husband thanked the group and expressed that they had not yet encountered a social environment that granted them such freedom of expression and thus, was such a relief for a big problem that had been waiting to be formulated and shared for a long time.

The above example illustrates the exceptional nature of the communication possible within the Trialogue framework and its opportunities to reach out to people outside the psychiatric subculture in the wider community. More specifically, the experience gained in Trialogue groups is also extremely useful for people who want or need to engage into policy activities that need the participation of all three groups represented in Trialogue, like serving on quality control boards of psychiatric services, in advisory groups for planning and evaluating psychiatric services, in antistigma and anti-discrimination initiatives, and in all sorts of other much-needed advocacy activities.

Research

One may conclude that Trialogue groups have been widely established with a wealth of practical experiences and anecdotal evidence for positive effects in all three participating groups and on their efforts to collaborate more successfully. Yet, the effects have only rarely been systematically studied. One reason might be that they represent an unconventional setting, which is in line with neither the didactic approaches of psychoeducation nor the usual rules of group psychotherapy. However, there are strong indications that all participants do gain in knowledge and that language and communication style develops and therapeutic effects can be documented.

Bock und Priebe describe in their 2005 publication characteristics, history, and possible benefits of psychosis-seminars and trialogue groups (Bock and Priebe, 2005). From a lot of experience and from the few data on psychosis seminars, in Germany it looks like:

- Many participants are characterized by a lot of experience, often over many years.
- Main benefits for carers stem from gaining knowledge, sharing experience, and being able to discuss concrete issues they struggle with within their family with persons, who know similar situations from their own experience, but with whom they are not intimately entangled through emotional and biographical bonds.

- Consumers benefit from respect for their psychotic experiences and a chance to make sense of these and other experiences in their personal social and biographical context.
- Professionals value not only the opportunity to gain new insights into the experience of psychiatric problems but also review their role and their practices in new and comprehensive perspectives.
- Many attendants share the wish to improve current psychiatric practices and advance the concepts of mental illness and health.

The European Families Organization (EUFAMI 2003) recommend Trialogue groups also for those outside German-speaking countries. Looking at example of topics covered by Trialogue groups does lend credit to the idea that people all over the world might benefit from such exchanges:

- Stigma and discrimination
- · Work and social integration
- Power, powerlessness, and empowerment
- · The family doctor as a Trialogue partner
- From dialogue to trialogue where are the professionals?
- The "good" psychiatrist users' and relatives' perspectives
- · When help has more unwanted than wanted effects
- Diagnosis as a trap being put in a box
- Religion and psychosis
- False hopes for recovery and healing
- Day clinics why so few?
- Clinical and field trials experimenting with patients
- Silent users who is helping them?
- From aftercare to prevention easy access to early help

A recent mixed method study of a newly emerging Trialogue in Berlin (von Peter et al. 2015) clearly showed that communication in Trialogue groups is considerably different from communication in clinical encounters. All three groups cherish and aspire to interest for each other, goodwill, and openness. Daily clinical routine with role prescriptions, power balance, and constant pressure to act is experienced as an obstacle. Sadly, professionals feel that they cannot be the persons they want to be in their working environments. And that they are not empowered to change this situation, which certainly is a source of disappointment when realized by family carers and users of these services. Users and ex-users describe the healing effect of creating a narrative in a public environment and are willing to allow insights into their lived experience thus enabling family carers, friends, and mental health workers to better understand and cope with difficult situations. Family carers worry that their own family member with a psychiatric diagnosis might have more serious problems than the users or ex-users attending the Trialogue. They appreciate the chance to pose their questions to somebody with a lived experience, who is not their own relative, and they do feel empowered to keep up the hope also after long times of great difficulties through the stories of their Trialogue partners with similar experiences.

Trialogue is found to facilitate a discrete and independent form of communication and acquisition and production of knowledge. Trialogue groups seem to be experimental grounds, teaching participants how to develop equal relationships.

The group around Thomas Bock in Hamburg has developed an instrument to measure subjective experience and meaning of psychoses: the German Subjective Sense in Psychosis Questionnaire (SUSE) involving user and professional experience (Klapheck et al. 2012). They used this instrument as well as measurements of coping and recovery to assess quite large groups of Trialogue participants with user, family carer, and psychiatric professional backgrounds. Results show a positive effect on Trialogue participants with experience of psychosis either themselves or as carers with regard to a more positive attitude toward symptoms, less anxiety and better sense of coherence, as well as wider mutual understanding, and more empowerment for everybody (Ruppelt et al. 2014).

International Developments

Trialogue experiences in other parts of the world have shown impressively how the Trialogue setting has very similar effects in different cultures. Trialogue meetings at WPA Congresses in recent years in Istanbul, Buenos Aires, and Beijing (Amering 2010) invariably resulted in animated discussions that were characterized by an openness and mutual appreciation of diverse experiences and positions. Considerable interest and energy toward implementing and sustaining a setting that regularly allows such moving and richly informative exchanges were expressed.

This is in line with WPA's work in its first trialogic working group within the framework of the WPA Action Plan 2008–2011. The Task Force on Best Practice in Working with Service Users and Carers under the leadership of Helen Herrman published its recommendations to the international mental health community in 2011 (Wallcraft et al. 2011). The ten recommendations call for a partnership approach on all levels of mental health policy and care and *promote shared work worldwide to identify best practice examples and create a resource to assist others to begin successful collaboration*. In consultation with the task force, the WPA Committee on Ethics drafted a paragraph based on these recommendations that has been unanimously endorsed as an amendment to its Madrid Declaration on Ethical Standards for Psychiatric Practice by the WPA General Assembly in 2011.

Trialogue meetings in North America have in the past often been difficult due to long-standing conflicts between the user and survivor movement geared toward alternatives to the biomedical model and families looking for best practice in professional help for their relatives. A commitment to trauma-informed language and communication styles for Trialogues has been identified as an important prerequisite for talking openly to each other, especially in the face of the growing database on the association of different diagnoses from the psychosis spectrum and traumatic life histories of people affected (e.g., Schaefer and Fisher 2011).

Growing international interest has led to the recent establishment of Trialogue groups in Poland, French-speaking Switzerland, France, Greece, and Ireland. The

Mental Health Trialogue Network Ireland (MHTNI) is an exciting new community development initiative in Irish mental health and will also serve as a web base for international exchange on Trialogue in the future (www.trialogue.co). The aim of the Irish Network was to empower communities in Ireland to become proactive in communicating about mental health through a powerful open dialogue and participatory process called Trialogue. Project leaders talk about how in the past mental health was often seen as the domain of service providers, carers, and the people who used the mental health services. However, within communities there is a huge diversity of knowledge and experience that can be used to transform our services.

This aspect highlights the possible effects of Trialogues on the wider communities over time. Trialogue groups can serve large part of communities. Reaching out to everybody with a firsthand lived experience – that is a lot of people as we know from epidemiological research – friends and family – is there anybody who is not at some point during their life? – and people working in mental health and mental health-related fields, Trialogue really does not leave nobody out. Consequently, if a community can use the learning opportunities that Trialogue provides, expertise with successful interventions with regard to secondary and tertiary prevention for persons with mental health problems could grow. Such growing capacity is likely to profit also in terms of primary prevention for the wider community. Learning about mental health and illness and helping community members with mental health problems can strengthen communities' mental health capacities and improve mental health literacy for everybody. The currently often hidden knowledge of a large part of the community – namely, that of families and friends of people with mental health problems as well as the expertise of those who are dealing with or have overcome such problems in their own lives - can be validated and shared for the benefit of all.

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