

Working Together Responsibly: An evaluation research of FARE's program on mental illness

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Abstract

«Fare Assieme Responsabilmente (FARE)», Italian for «Working Together Responsibly», is an innovative program of the Department of Mental Health of Trento aimed at promoting a positive culture of mental health and working towards reducing the stigma and fear surrounding mental illness. The program's recovery approach conducts training sessions based on the premise that «problematic» people can be valorised (or validated) by redefining their challenges. In the FARE program, life knowledge of mental illness service users, family members, and general citizens is combined with life knowledge of mental health professionals. Attendees of FARE were encouraged to consider mental health service users or those suffering with mental illness as «experts by experience» based on their own life experiences. Participants were encouraged to learn from the experts by experience, and by using this approach, the gap between learners and educators could be overcome. Mental illness sufferers' involvement as «experts by experience» occurred through several stages, from planning to realization of training sessions. A two-step evaluation of FARE was conducted to identify positive and negative aspects for future editions. First, data were collected via ad hoc surveys with all participants. Participants were then divided into four focus groups—participants, speakers, expert service users, and FARE session organizers. Two important findings emerged after analysis:

- The simultaneous presence and interaction of mental health service users, family members, and practitioners as «teachers» was considered valuable as it allowed users and their family members to recognize their resources.*
- The participation of mental health service users as «experts by experience» allowed participants and practitioners to address emerging needs of the local community and presented those interested in learning more about this field with the chance to connect with others with similar experiences.*

Keywords

Mental Health, Recovery, Evaluation, Working Responsibly Together, Relational Paradigm

Background

Recovery is one of the most commonly used paradigms in health and social services and serves as a reference point for future health and social policies. «Recovery involves talking, group intervention, and the application of the word 'hope'. Most importantly, it involves acceptance and partnership while working with affected individuals» (New Horizons: a shared vision for Mental Health, Department of Health, 2009, p. 1). Davidson et al. (2009) define recovery as the development of personal resources and the discovery of one's personal social role in community.

A recovery-based approach does not only consider ways in which people can access services and receive help, but also ways to help others suffering with mental health issues by sharing mental health experiences faced in their own lives. Recovery is about building meaningful and satisfying lives, as defined by those undergoing the process of recovery themselves, in on-going and recurring problematic situations. Hope is central to the process of recovery and can be enhanced by observing how others with mental illness have gained active control over their lives and found a way through. Partnership between mental health service users and practitioners is fundamental to a recovery- focused approach. Those with mental health issues follow a recovery process comprised of phases and objectives that are defined in partnership with practitioners. Practitioners suggest that individuals with mental illness who want to manage their recovery program require the following:

1. information related to mental illness,
2. opportunities to experiment their capabilities and personal resources,
3. assistance to successfully execute the process of recovery.

Recovery can also be practised through local community knowledge. It is thus very important to be aware of the advantages and disadvantages of one's local community. The main idea of the recovery approach is that people who have been considered «problematic» can be valorised by society by redefining their life challenges (Davidson et al, 2009). As one of the cornerstones of the Relational Paradigm of Social Work (RPSW) (Folgheraiter, 2011), mental health service users, family members, and citizen experts work together with practitioners with technical expertise.

RPSW presents a challenge to social work theory and practice. It asks people to adopt a strength-based approach towards helping each other. Individuals in need of support or those experiencing difficulties are considered to possess capacities and capabilities within their social networks with which they can achieve the required change. RPSW places emphasis on an individual's capacities to achieve change and harness social networks to promote and support change (Folgheraiter & Raineri, 2017). «*Speaking of mental illness means referring to a problem that involves one's whole life, so it is essential to consider the point of view of users and family members*» (Folgheraiter, 2009, p. 57).

This claim recalls the concept of relational empowerment. The RPSW process is a rebalancing of therapeutic and manipulative powers in which the party with the most

power—generally the professional practitioner—cedes some power to the less empowered interlocutor so that the individual becomes more autonomous and active in dealing with the situation. This operation is not zero-sum, i.e., the power surrendered is not lost, but rather, 'invested' in social relations so that it yields high-interest returns for the social worker (Folgheraiter & Raineri, 2017).

For hope to succeed in changing approaches for the treatment of mental illness, consideration must be given to the fact that people with mental illness and their families need help exercising their capacities (Folgheraiter, 2009). In particular, RPSW focuses on relationships as the basis for change. It is a practice paradigm in which practitioners identify and resolve problems by facilitating coping networks—conceived as a set of relationships between people with a common aim—to enhance resilience and capacities for action at both individual and collective levels (Folgheraiter & Raineri, 2017). The central idea of RPSW is that change emerges from a reciprocal aid, between people in difficult circumstances, family members, friends, and neighbours, and between the network and the social worker. The practitioner helps the network develop reflexivity and improve itself in enhancing welfare, and, in turn, the network helps the practitioner better understand how he/she can help it, even when the goal is to counter structural inequalities (Folgheraiter & Raineri, 2012).

Several studies exist in the literature related to participation of mental health service users and their families. Researcher highlight that real participation between users and their families produces wellbeing for everyone involved—users, parents, other family members, as well as social and health workers (Barnes & Cotterrell, 2012; Forbes & Shashidharan, 1997; Tait & Lester, 2014).

As participation in the treatment of mental health issues increases, those suffering with issues are finding more answers in terms of what they need as only they can honestly describe what it means to live with mental illness (Folgheraiter, 2009). In light of this, we must consider their perspectives and allow them to explain their struggles to agencies and experts.

The context

This study is an evaluation of FARE, an innovative training program in mental health that addressed citizens, mental health service users and their family members, and mental health practitioners of Trento. FARE was developed by the Department of Mental Health of Trento and conducted between February and May of 2015. The program's approach was rooted in the concept of recovery, which is a widely used paradigm in health and social services and a reference for various health and social policies.

FARE aimed to serve as an intersection of subjective/expert knowledge with objective/technical knowledge. In general, people suffering with mental health issues do not work

or study and are treated as outcasts in their local communities. The citizenship of FARE allowed such individuals to cope with their problems by providing a sense of belonging to the community. In order to promote citizenship, it was important that citizens made the most of their skills and expert knowledge. In other words, this program required the necessary participation of every stakeholder in the field of mental illness (Barnes & Bowl, 2001).

In FARE, life knowledge of service users, family members, and citizens was combined with life knowledge of mental health professionals. Participants were encouraged to consider mental health service users as experts by experience, and thus, as avenues of learning. In this manner, FARE hoped to bridge the gap between learners and social workers. Mental health service users' involvement as «experts by experience» occurred during several stages of the project, from planning to realization of the training sessions. The program included three main actions:

- First, to establish five mixed work-groups comprising of mental health service users, social and health workers, family members, and citizens. These groups defined the training modules.
- Second, to promote FARE training sessions in every territory in the Italian region of Trentino-Alto Adige.
- Third, realization of training modules.

The training modules, 25 in all, were initiated in February, 2015 and concluded in May, 2015. Each meeting had a specific topic, namely:

- Get to know the Department of Mental Health of Trento
- Learn about mental illness
- Communicate well for our well-being
- Being conscious of lifestyle
- Meetings related to specific topics as suicide prevention and psychoactive drug abuse.

The goals of this innovative training program were:

- To spread awareness about the Department of Mental Health of Trento
- To improve sensitivity towards mental health issues within the community
- To promote a positive culture of mental health that contributes towards reducing prevalent stigma, shame, and fear associated with mental illness

The Research

This work was conducted by researchers at the Centro Studi Erickson, in partnership with the Department of Mental Health of Trento, with an aim to study the innovative training program of FARE in order to understand strengths and critical issues, and offer suggestions for future editions of training programs. A mixed methods research approach

was decided upon, using qualitative and quantitative research. The researchers were interested in hearing perspectives of everyone involved in the program, which included teachers, students, witnesses, and volunteers, and data were collected using two tools:

- Questionnaires
- Focus Groups

The questionnaire

Quantitative data were collected at FARE meetings using a questionnaire on customer satisfaction, and was administered to participants at the end of each meeting. The questionnaire comprised 15 items, with open- and close-ended answers, spread across 4 categories:

- Personal data
- Meeting attended
- Evaluation of meeting
- Proposal

A total of 1225 participants, including mental health service users, family members, practitioners, regular citizens, volunteers, doctors, social workers, nurses, and educators, returned 781 questionnaires. While constructing the questionnaire, numbers were assigned for each answer; an Excel spreadsheet was used to log data, which were then analysed quantitatively. To switch variables into numbers, in the third section of the questionnaire which investigated evaluation about each meeting, the researcher used a scale of attitudes ranging from 0 to 3, where 0 was unsatisfactory, 1 was less satisfactory, 2 was quite satisfactory, and 3 was very satisfactory.

The focus groups

A total of four focus groups were realized after analysing the data. The goal of this tool was to better understand perspectives of the participants and to better evaluate their participation during FARE training sessions. Five questions were asked to the various focus groups:

- Which session did you attend?
- What was your role in this session?
- What was your favourite part of the session?
- Which critical issues did you discuss during the session?
- What suggestions would you like to offer for future sessions?

The focus groups had 40 participants each and were conducted in four sessions, two in April, and two in June. The focus group sample was selected according to two criteria:

residence and role played during the training program. Due to challenges in finding candidates interested in participation, Table 1 shows the non-uniform composition of the four focus groups.

	1st Focus Group (April)	2nd Focus Group (May)	3rd Focus Group (June)	4th Focus Group (July)
Social workers	2	1	2	4
Clinicians	2	0	0	0
Volunteers	2	2	2	1
Experts by experience	1	1	1	1
Citizens	5	6	5	2
TOTAL	12	10	10	8

Table 1 Composition of the focus groups

Each focus group session was audio-recorded and transcribed verbatim. After transcription, the five questions discussed during focus groups were identified, and a coding frame was developed. The researchers made detailed notes on the focus groups' transcripts regarding content (point of view and evaluation of the training program from mental health service users, family members, practitioners, and citizens). The interpretation of both data (quantitative and qualitative) were conducted from within the framework of RPSW.

Results

The questionnaire analysis started with this methodological consideration: the number of respondents doesn't correspond to the number of participants in FARE meetings, because not all participants completed or returned questionnaires. Table 2 shows comparisons between the number of questionnaires and the number of people present in each session.

Meeting	Number of participants	Number of completed questionnaires	Completion percentage values
18 Feb	52	49	95%
25 Feb	56	55	99%
03 Mar	70	65	93%
04 Mar	35	35	100%
10 Mar	115	105	92%
11 Mar	26	26	100%
17 Mar	125	89	72%
18 Mar	30	22	74%
24 Mar	12	92	74%
25 Mar	27	21	78%
31 Mar	75	62	83%
01 Apr	23	23	100%
07 Apr	81	73	91%
09 Apr	29	28	97%
14 Apr	80	67	84%
15 Apr	25	0	0%
22 Apr	22	0	0%
23 Apr	60	52	87%
05 May	27	22	82%
12 May	26	26	100%
13 May	22	0	0%
19 May	25	24	96%
20 May	19	19	100%
26 May	20	6	30%
27 May	29	29%	100%

Table 2 Comparison of completed questionnaires to the number of participants present in each FARE session

Data analysis revealed descriptions of participants. In the first edition of the training program, participants were job-holding female residents of Trento City aged 47 with secondary education. The second section of the questionnaire investigated motivation to participate in each session. While 44% of participants attended training programs because of their direct knowledge of mental health (as victims or family members), 22% attended because of their professional roles as doctors or social and health workers, and 36% attended due to personal interest in learning about mental illness. This data is very important as it presents citizens' interest in mental illness for the first time. As observed, these participants wanted more information on mental illness and the training must, thus, respond to this need.

The third section of the questionnaire investigated evaluations of each meeting. In particular, the variables analysed were:

- Return of new information
- Topics discussed
- New motivation received
- Discussion and support among participants
- Meeting environment
- Ability of involvement by speakers

The evaluation of the training program is positively incorporated into the questionnaire and the score of scale attitudes is 2,8, almost maximum (from 0 unsatisfactory to 3 very satisfactory). Table 3 shows number of answer and percentage values for each variable of evaluation.

	Return new information	Topic discussion	New motivation received	Discussion support among participants	Meeting environment	Ability of involvement by speakers
0 Unsatisfactory	0%	0%	0%	3%	0%	0%
1 Less satisfactory	3%	2%	3%	12%	1%	1%
2 Quite satisfactory	36%	23%	34%	42%	22%	22%
3 Very satisfactory	58%	73%	60%	36%	74%	74%
4 No answer	3%	2%	3%	7%	3%	3%
Total	100%	100%	100%	100%	100%	100%

Table 3 Evaluation of meetings expressed as percentages.

The highest value for unsatisfactory variable emerged for discussion and support among participants (3% unsatisfactory, 12% less unsatisfactory, 42% quite satisfactory).

Some participants wanted further discussions with other participants at the end of each meeting, but it was likely that there was inadequate time for the same.

The variables of meeting environment, topics discussed, and ability of involvement by speakers were found to be very satisfactory among participants (74%, 73%, and 74% respectively). The simultaneous presence of mental illness practitioners and experts in sessions proved to be a satisfactory choice among participants. The training program was a success for over 80% of participants. The focus groups' analyses also showed positive evaluations, with groups feeling enriched by reflections and additional information, through data collected for the following items:

- Motivation to participate
- Positive aspects of FARE
- Negative aspects of FARE
- Suggestions for the next edition

Most focus group participants became aware of FARE through leaflets and brochures distributed by friends, as the questionnaires revealed. One element that facilitated participation was the option to choose which topic to follow. For many people, FARE was a unique opportunity to observe some workings at the Department of Mental Health.

In general, focus group participants described FARE training sessions in a positive manner. Several participants found it very interesting to witness the experts by experience—or people with mental illness—who have become experts on their life conditions and learnt to manage their illness. FARE allowed participants to gain a deeper understanding of mental illness and view it without prejudice. A participant from the second focus group, who was the mother of a son with mental illness, said, *«It is important to conduct such sessions. FARE meetings can help remove the prejudice and shame that has persisted for a long time. With such meetings, things could improve.»*

Another positive aspect that emerged from the questionnaires was the added value of mental illness practitioners, as well as sufferers as experts. This double presence of teachers in meetings i.e. two sources to learn from, allowed participants to get better informed of the recovery process, even as experienced directly by people with mental illness.

However, there were two negative aspects of FARE identified by focus group participants. The first was the lack of time available for comparison during meetings, and the second was the absence of people who did not accept the recovery process. A participant from the third focus group said, *«There was a lack of a level playing field; the mental health sufferers felt beautiful to witness, very grateful to God for improvement of the disease and the situation. However, it is not always like that, there are also situations where things don't go well and those voices were not heard during these sessions.»*

The last question for focus group participants asked for suggestions for the next edition of FARE. Some recommendations that emerged were:

- Make sure to reach more young people
- Promote FARE in newspapers and across other media

- Organise meetings at different venues and times
- Involve participants from the first edition, such as experts by experience, when the second edition is organized

Some of the most enjoyable aspects of the FARE training sessions, as reported by focus group participants were:

- Learning about the history of mental illness and the strategy for recovery
- Valuable information gained about experts by experience (those suffering with mental health issues) and experiences of their families
- Feeling as if everyone present was a peer; there were no distinctions between doctors, patients, family members, and volunteers. This was also reported by a researcher in the focus group, who couldn't tell the difference between patients, family members, and doctors
- Getting an in-depth understanding of mental illness

The most important information that emerged from the focus groups' analyses was that the language used by session instructors was simple and could be understood by everyone. Language plays an important role in creating a relationship of confidence between doctors and patients. If patients understand doctors, the relationship can promote empowerment and help patients cope better. During the FARE program, sufferers with mental health issues experienced the role of teachers by being experts by experience, and this was considered to be extremely innovative. This new role allowed them to express personal emotions, while letting those observing understand how difficult it is to live with the problem of mental illness. Additionally, it gave participants the chance to put themselves in each other's shoes and become aware of the recovery process.

Focus group participants reported two negative aspects of the FARE training program:

- The need for more debates with other participants, instructors, and experts by experience
- Lack of representation of the bad side of mental illness, specifically, people that were not in the recovery process

This information is important when comparing any difficult life situation. Some participants from the first focus group said, *«We need to compare our situation with other families in crisis. We're impotent because our illness doesn't understand the recovery process.»*

The last focus group's question was related to suggestions for the future edition of FARE. Some concerns about the promotion of the initiative were:

- Make sure to reach more young people
- Advertise the event more, perhaps in newspapers
- Distribute informative material outside churches, before or after mass
- Promote the event through various professional orders such as Social Worker's Associations

Another set of suggestions concerning the organisation of FARE sessions were:

- Organise meetings in «neutral» environments that are not related to mental illness

- Provide for different locations and different times

A final aspect concerns the possibility of involving people who participated in the first edition as learners in future sessions. This suggestion, according to the Relational Social Work approach, could help introduce new issues and new organisational solutions—thanks to the observations of those who had experienced the first edition.

The real innovation in this training program was the presence of «experts by experience», who played the roles of speakers during each meeting. Their voices alternated with the voices of practitioners, and allowed participants the chance to truly understand the complexity of mental illness. In particular, practitioners reported learning what it means for the mentally ill to live every day with mental illness and these sufferers, in turn, reported return of new information about medicines for mental illness.

Discussion and conclusion

The FARE training sessions promoted an intersection of knowledge through the equal participation of professional practitioners and those who were mentally ill, with both parties sharing experiences. Due to this approach, both voices were heard, building confidence in the possibility of working together for a common goal. Such a participatory approach gives practitioners and service users the same level of relevance.

Mutual respect and a positive atmosphere were reported in the questionnaire administered during training sessions, as well as in the focus groups. Maria, a participant in the first focus group of the FARE training program, reported, «*What I liked best was that doctors, practitioners, and mental health service users had the same importance and the same values is what I liked best.*»

Almost all respondents to the questionnaire reported appreciation about the positive environment of mutual respect and the fact that all participants were perceived as equals. In other words, the simultaneous presence of mental health service users, family members, and practitioners as «teachers» represented an added value and also generated double the interest. Mental health service users and their families were more interested to learn technical-theoretical information about mental illnesses, while on the other hand, practitioners were keen to understand daily lives of mental health experts by experience and those living with the illness. Such tension between the two types of knowledge—technical and experiential—is necessary to promote relational mental health services.

The less positive evaluation of the training program related to the need for more comparison discussions between participants, with many participants desiring additional time to interact with each other. This innovative training program promoted imparting of expert knowledge, and encouraged working together towards a shared goal. Therapists and social health workers appreciated insights shared by the experts by experience, while others with mental illness and/or their families appreciated this approach of professional

teaching and professional knowledge. This shows that both types of knowledge are necessary to promote recovery and relational mental health services.

As a result of the community placing value on the experience of mental illness, the FARE program initiated a democratic perspective on working towards successful mental health services, thus reducing risks for those suffering with mental illness.

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