

Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers

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WPA President M. Maj established the Task Force on Best Practice in Working with Service Users and Carers in 2008, chaired by H. Herrman. The Task Force had the remit to create recommendations for the international mental health community on how to develop successful partnership working. The work began with a review of literature on service user and carer involvement and partnership. This set out a range of considerations for good practice, including choice of appropriate terminology, clarifying the partnership process and identifying and reducing barriers to partnership working. Based on the literature review and on the shared knowledge in the Task Force, a set of ten recommendations for good practice was developed. These recommendations were the basis for a worldwide consultation of stakeholders with expertise as service users, families and carers, and the WPA Board and Council. The results showed a strong consensus across the international mental health community on the ten recommendations, with the strongest agreement coming from service users and carers. This general consensus gives a basis for Task Force plans to seek support for activities to promote shared work worldwide to identify best practice examples and create a resource to assist others to begin successful collaboration.

Key words: Service users, family carers, mental health, partnerships, best practices

(World Psychiatry 2011;10:229-236)

During the last years, several countries (including USA, UK, Ireland, Australia, New Zealand, and Canada) have embraced recovery-orientation as a guiding principle of their mental health policy (1). Key to this development is a partnership approach between mental health experts and users of mental health services and their families and friends.

Service users and their families have an important role in advocacy in order to enhance the reputation of mental health expertise and services as well as that of people with a lived experience of mental ill health. In recent years, service users and carers have been involved positively in a range of activities including advocacy for support for research, care and social inclusion, and self-help projects. The WPA has cooperated on several levels with different user and carer organizations, as with triologic symposia at congresses and affiliated memberships, with encouraging results. Efforts in several countries to change community attitudes and improve mental health care in partnership have produced resolutions and guidelines, but their wide use and the structural changes they call for are yet to be achieved (2).

The founders of WPA included among its aims an important role as a voice for the dignity and human rights of patients and families (3). Subsequently, the WPA has developed ethical guidelines for psychiatric practice, including the Madrid Declaration (4), which sets out standards for respecting patients, treating them as partners in the therapeutic process, and safeguarding human dignity and legal rights.

WPA TASK FORCE ON BEST PRACTICE IN WORKING WITH SERVICE USERS AND CARERS

In 2008, a Task Force on Best Practice in Working with Service Users and Carers was established by WPA President M. Maj under the leadership of H. Herrman to support the WPA Action Plan for the years 2008 to 2011 (5) and one of its goals: "To support international and national programmes aiming to protect the human rights of persons with mental disorders; to promote the meaningful involvement of these persons in the planning and implementation of mental health services; to encourage the development of a person-centred practice in psychiatry and medicine; and to promote equity in the access to mental health services for persons of different age, gender, race/ethnicity, religion and socioeconomic status".

The WPA invited service users and family carers to join the Task Force, recognizing their essential contribution to improving mental health in any country. The Task Force had a remit to prepare recommendations for the international mental health community on best practices in working with service users and carers.

The Task Force defined the primary need to develop a unified approach to advocacy for mental health and human rights at country and international levels. Adequate support for mental health services and improvement of mental health in any population require a united voice. Achieving this will need support for the capacity of each group to work effec-

tively in partnership. As service users and family carers typically lack the power to interact equally with professionals and government decision makers, assistance in developing this power is mutually important for them and for the WPA and the wider international mental health community (2).

LITERATURE REVIEW ON SERVICE USER AND CARER INVOLVEMENT

A literature review on service user and carer involvement in improving mental health was carried out. The brief was to identify and summarize existing research and guidelines relating to collaboration between mental health professionals and service user/family/carer stakeholders in the areas of policy, practice, research, evaluation, training, education, fighting stigma and discrimination, and joint lobbying for resources to support good practice in research, care, rehabilitation and social inclusion. The literature review methods included: searching databases, and making links with service user and carer organizations, and with national and international mental health bodies and other entities that involve and promote the rights of people with disabilities. The results of the review are set out in the following paragraphs in terms of the key themes found in the literature.

Terminology

Terminology is an important aspect of working in partnership, as it enables clarity about who should be involved, how those people and groups see themselves and their respective roles, and the forms and levels of involvement, and where and how it happens (6,7).

Terminology for each stakeholder group can be controversial even among the group concerned, for instance, whether people want to be called “consumers”, “service users”, “patients”, “clients” or “survivors” differs from one person and group to another, as well as causing controversy among the other groups. Similarly, people who are involved as family members may want to be called “carers” or “caregivers” or simply “family” or “friends” (8).

Partnership is defined as a collaborative relationship between users, carers and clinicians. Forms of partnership can range from information giving to service user- or family/carer-run services, and include various types of collaboration (9,10). The forms and levels, from informing to power-sharing and leadership by families and service users, must be a key aspect of guidelines, as clarity about what is on offer or available is an essential aspect of setting out the terms for partnership (11).

Sites for partnership include personal care at the basic level (12), all the way through local, regional, national and international sites where involvement can happen. Each site can have its own levels (13,14). For instance, at the site of the person, someone can be informed of his/her choices, sup-

ported to make choices, or given the resources to buy his/her own services. At the national site, people can be informed of decisions made, consulted at an early stage via surveys, invited as members onto national committees, or given funding to develop their own national programmes.

Other criteria for partnership include the type of service, or the diagnostic group, when partnership is focused on particular aspects of psychiatric work, for instance on developing new community services for people diagnosed with personality disorders (15).

Clarifying the partnership process

This begins with setting goals, and proceeds through all the actions to specify how the work will proceed, how to monitor and evaluate the work and use what has been learned to inform future work. The review identified a range of work in which service users and families have been involved, including training and education, advocacy, research and evaluation, planning, management, and service provision (16-18). Clarity on the aims, objectives, processes, outcome measurement and learning from doing are relevant to each of these and help assure success and longevity (7).

Barriers to partnership

The review showed that the same barriers to partnership emerge repeatedly in the literature (19,20), while actions and systems that support involvement are also becoming clear.

Partnership can be hindered by lack of clarity on the issue of representativeness or accountability (21). Lack of commitment by service providers, planners and professional staff is often shown in “tokenism” – i.e., low numbers involved, poor support in terms of funding and access to resources, or lack of support and training for the stakeholders (9). Everyone needs training in how to work together.

Another typical barrier relates to policy and strategy. Organizations need a clear policy about partnership, and staff should be aware of existing policies and how to implement them.

Differing objectives among stakeholders can create barriers to successful partnership working (22,23), and the literature review showed a range of objectives each group may bring with them to the process. Service users and patients may be concerned with basic facilities and treatments, human rights and choices, while families also seek better care for the person cared for, plus the right to be more involved in care, and more help for themselves. Staff concerns can range from concern about what is expected of them and how to add involvement to their other duties, to overall service improvement and meeting targets. Managers may be concerned with costs and government objectives. Commissioners have to balance public concerns with choice and rights, and governments want to deal with issues of concern to the electorate.

Good practice that supports partnership

The review identified several aspects of good practice in involvement of service users and families, including the following: involvement from the outset in new ventures and in changing existing services; awareness of cultural issues that relate to different groups within the population; addressing stigma and discrimination among public and staff; clarity and honesty about what is possible, what is expected, what is not possible; ensure that involvement is not tainted with coercion, control or manipulation; ensure there is a genuine willingness to instigate change; a range of involvement methods and opportunities to suit needs and abilities; accessibility issues addressed (practical and financial); giving more control of involvement budgets to service user/carer groups; support and supervision available and regular for persons involved; support and finance to enable representativeness and accountability to wider groups; capacity building for service users/families/public; staff training in involvement good practice; involvement championed and supported from the highest levels downward; support for staff to do involvement work; clear involvement policies that are “owned” and understood by all stakeholders; monitoring and evaluation of involvement and dissemination of results; involvement being valued and being seen to be valued by service providers and planners.

Examples of involvement that work

The literature review identified examples of successful partnerships. Service users and carers are involved in training mental health workers in the UK (17). Service users are involved in monitoring of services or developing outcome measures in some countries (24,25). In many countries, service users and carers sit on committees to plan and manage services (26), though family involvement on committees is less frequent (27). Consumer consultants are successfully employed in Australia (20,28). Trialogue (regular discussion meetings outside work environments between stakeholders) is another method that has been found effective in Germany and Austria (29,30). Guidelines for partnership working have been developed in some countries (11,31,32).

TASK FORCE CONSULTATION PROCESS

The first meeting of the Task Force was held in Vienna in March 2010. Before the meeting, members were asked to rate and comment on the relevance and importance of the themes drawn from the literature. The Task Force drew on the literature survey and this thematic analysis, as well as best practice examples in their own countries and personal experiences of mental health systems and practice. The meeting set an example of partnership and cooperation, bringing together a range of stakeholders. One person took part from India through a Skype connection. Over two days, the group

brought together a range of knowledge and ideas, debated the issues, and drew shared conclusions that were set out in the first version of the ten recommendations.

Consultation methods

Two methods of consultation were developed. The first was an online survey of service users and carers and the WPA Board and Council members. In the second, the Task Force sought to consult ordinary people who are service users and carers. C. Underhill and S. Raja, special advisers to the Task Force from BasicNeeds, offered this organisation’s experience of grassroots consultation to reach people with personal experience of mental illness in Kenya, Laos and Sri Lanka. The consultation was designed to enable people in remote areas and those who could not read to be consulted. B. Davar coordinated a series of micro-consultations with organizations and one individual expert in four cities in India.

The Task Force also consulted the WPA Committee on Ethics and invited the Chair and an additional member, who is also an officer of the World Association of Psychosocial Rehabilitation, to attend the Task Force as special advisers to consider amendments to the WPA’s Declaration of Madrid.

Online survey

Individual experts were contacted by e-mail and invited to complete a short electronic questionnaire. For the survey of service users and carers, a consultation list was drawn up. Some people included were leaders in non-governmental organizations (NGOs) working in the mental health field. Other organizations and individuals were identified from the literature review. Each of the Task Force members had a contribution to make in terms of individuals, groups and networks that could participate in the consultation. Expert stakeholders were sought in every country where the Task Force group members had contacts, which included most of the world’s continents. Since there were no resources for translation, participants had to be English-speaking. The decision was taken to consult individual experts, as consulting members of organizations could take too long. However, one organization, the European Federation of Associations of Families of People with Mental Illness (EUFAMI), was able to consult its membership.

Each of the ten recommendations was the subject of a question. Respondents were asked to rate agreement with the recommendation, and were also given space for an optional comment. The eleventh question was an open invitation to list additional topics.

The survey was circulated in June and July 2010 and responses returned in August. Among the 151 service users and carers who were invited to participate, 126 responded. There were 24 responses from 30 members of the WPA Board and Council.

The results were presented and discussed at the second meeting of the Task Force at the WPA International Congress in Beijing in September 2010.

Consultations in four low-income countries

A series of consultations with users and carers participating in BasicNeeds' field programmes was held in three countries. A total of 1197 users and carers participated: 32 in Lao PDR, 62 in Sri Lanka and 1103 in Kenya. Most came from rural low-income families. In Kenya, consultations were also held with existing national organizations of service users, namely the Schizophrenia Foundation of Kenya, and The Users and Survivors of Psychiatry, where participants were drawn from urban middle and upper class families. In Sri Lanka and Kenya, discussion topic guides were developed based on the recommendations selected for use in the consultations. In Lao PDR, a discussion instrument was developed which had six questions, as prompts to facilitate the discussions at the consultations.

In a similar time period, consultations with five organizations and one individual expert were carried out in four cities in India (Pune, Bangalore, Delhi and Chennai).

RESULTS OF SURVEYS AND CONSULTATIONS

In the following paragraphs, we report the outcome of the survey concerning each of the ten recommendations drafted in March 2010.

Respecting human rights is the basis of successful partnerships for mental health

Service user and carer respondents generally agreed that rights are the basis for partnerships. However, there were differing opinions about the application of human rights. Some argued that, even if physical restraint is needed, attitudes and behaviour should be respectful of the person. Others argued that coercion is almost always experienced as disrespectful, and were concerned that enactments of human rights legislation in some countries explicitly exclude people with a psychiatric diagnosis from some provisions. Some argued that human rights have to be set aside when someone is in a psychotic state.

Respondents from the WPA Board and Council similarly agreed that human rights are a basis for practice, but some argued that respect was more important than generalized rights. Some stated that health and treatment are rights, and this could necessitate treatment against someone's will when psychotic.

Legislation, policy and clinical practice relevant to the lives and care of people with mental disorders need to be developed in collaboration with users and carers

Service user and carer respondents agreed that collaboration is needed; otherwise legislation, policy and clinical practice will be based on a one-sided agenda led by government and service providers. Since mental health is a contested area, service users need to ensure the service they receive is respectful of persons as citizens. There were concerns that power differentials between patients and service providers can make genuine collaboration difficult.

Respondents from the WPA Board and Council agreed there should be more progress towards genuine collaboration, but raised concerns about who would be consulted, to ensure genuine representation of those who suffer most serious mental illness and their families, and local needs and cultures.

The international mental health community should promote and support the development of users' organizations and carers' organizations

Service user and carer respondents called for greater recognition of the contribution of peer support and service users' movements in supporting well-being and improving service provision. There were concerns that there should be strong, independent organizations to express the voices of service users and carers both separately and collaboratively where possible, without pitting them against each other.

Respondents from the WPA Board and Council agreed that support for service users and carers' organizations is important, with some reservations about which organizations would be supported and their aims and objectives, and that respect for different local cultures and values is important.

Improving the mental health of the community should be a fundamental condition for formulating policies to support economic and social development. This requires participation of all sectors of the community

Service user and carer respondents felt that mental health is a central aspect of health and called for a move beyond a focus solely on medical understandings of mental health, towards working also in ways that support the well-being of communities and healthier environments. However, reservations included the fact that some people might not want to participate, and also that community psychiatry could be misused to widen compliance with psychiatric medication without a broader focus on well-being.

Respondents from the WPA Board and Council agreed generally that there is greater need to lobby governments and try to educate the population about mental health, and that mental health cannot exist where basic needs for water, san-

itation, food and housing are absent. However, concern was expressed that money spent on wider mental health promotion would not necessarily help people living with mental illnesses.

International and local professional organizations, including WPA through its programs and member societies, should seek the involvement of consumers and carers in their own activities

Service user and carer respondents agreed inclusion is an important principle and there should be funding to ensure enough people could participate to make a real difference. Reservations included the fact that involvement might only be lip service and not make a real difference to service choices offered. There was concern raised that service users and carers should not be seen as interchangeable, and that groups invited to be involved should be independent of funding from the pharmaceutical industry.

Respondents from the WPA Board and Council agreed that professional organizations should be proactive in opening their ranks to non-governmental organizations and service users' and families' organizations.

The best clinical care of any person in acute or rehabilitation situations is done in collaboration between the user, the carers and the clinicians

Service user and carer respondents agreed that involvement needs to be meaningful, not just tokenistic. They argued that people need to contribute to discussions around their own care and health, and to be able to take responsibility for their own recovery. There was concern about who makes the decision about treatment, and about possible conflicts of interest between service users and family members. Family members were concerned they are often left out. Some service users questioned whether collaboration was possible when acute treatment can be forcibly administered.

The BasicNeeds consultation found that service users and carers see access to treatment and sensitive engagement with service providers as important to keep up their motivation for treatment. Carers felt they need support to deal with crises such as suicidal behaviour. They see collaboration between service users, carers and clinicians as important and much needed. They want to ensure clinicians understand that there is more to patients than their illness.

Service user participants in the micro-consultations in India generally commented on their wish for greater involvement in their own treatment, to be listened to by doctors, and to receive explanations for treatments. They ask for treatment that takes into account people's creativity and spirituality, and want to be offered alternatives to medication or medicines with fewer side effects. Family members in India expressed concern that people with mental illness receive

worse services than other health groups. Doctors are held in high respect, but this gives their words great power and they should take care about the effect of their words. Family members also want more multi-dimensional diagnoses and interdisciplinary teams.

Respondents from the WPA Board and Council agreed that collaboration is important but that this might not always require all three members of the dialogue, and may at times engage others such as community elders in traditional societies.

Education, research and quality improvement in mental health care require collaboration between users, carers and clinicians

All groups of respondents agreed with this principle. Service user and carer respondents noted its importance given new ideas and paradigms such as recovery and community care which are changing treatment and care in some countries. Some wanted service users to lead the way to enable new understandings of mental health topics from their perspectives. Family members also argued for a stronger role based on their contribution to care. There was a suggestion that traditional healers could also be involved.

The path to recovery of mental health should include attention to economic and social inclusion (e.g., in areas such as the provision of appropriate education, housing, employment and legal and family support)

Service user and carer respondents generally agreed that recovery should go beyond symptom control, and include improvement in the quality of people's lives. Concerns included worries that there is now too much emphasis on employment, which may not be appropriate for everyone. Also it was pointed out that people might need to recover from the side effects of drugs and electroconvulsive therapy used in treatment.

The BasicNeeds consultation found that users and carers want education and work opportunities as these are important factors, which can enable people to manage their illness and to contribute to their family and gain social acceptance. Recovery includes being able to participate in religious and community activities.

Family members in India wanted more community support, in touch with local cultures, and taking in environmental factors.

Respondents from the WPA Board and Council generally agreed that social and economic determinants of mental health are important. However, some said there is a need to get the balance right between medical psychiatric treatment and the provision of education and housing, and some expressed a concern that there is a current movement to ignore the biological causes of severe mental illnesses and understand these illnesses as "diseases of society".

WPA Member Societies and other professional groups should collaborate with users' organizations, carers' organizations and other community organizations to lobby governments for political will and action for better funding of services, community education and fighting stigma

Service user and carer respondents generally agreed that this is important, and that fighting stigma and discrimination is essential. However, there were concerns that there are economic and power differentials, as well as differences of perspective between the groups that might make this collaboration difficult. There were reservations about anti-stigma work, which has been seen as unhelpful when led by governments or funded by the pharmaceutical industry. Anti-discrimination, especially in rights and employment, is preferred as a concept for which to struggle.

The BasicNeeds consultation found that service users and carers feel it is important to educate and sensitize their communities as well as local administrators about mental health and the needs of affected families, and about shortages of psychotropic medicines and availability of skilled personnel.

Enhancing user and carer empowerment includes the development of self-help groups, participation in service planning and management boards, employment of people with mental health disabilities in mental health service provision, user-run community centres and psychosocial clubhouses, speakers bureaux and local anti stigma programs

Service user and care respondents carers basically agreed with this, but also suggested that in some cases it meant moving beyond services and diagnosis to mainstream living. Carers said that they could also be employed in mental health service provision. However, in developing countries there is a long way to go to realize these aspirations. One person drew attention to the new United Nations convention giving equal rights to disabled people, and argued that this is a new agenda beyond empowerment.

Respondents from the WPA Board and Council agreed with some reservations, including a concern that employment of people with mental health disabilities in mental health service provision could lead to further stigmatization rather than empowerment.

TASK FORCE RESULTS AND ACHIEVEMENTS

At the second meeting of the Task Force in Beijing, the draft recommendations were discussed in the light of the consultation findings. Minor revisions were made. The new version was subsequently accepted by the WPA Executive Committee and posted on the WPA website (Table 1).

In consultation with the Task Force, the WPA Committee on Ethics drafted a paragraph based on six of the recommen-

Table 1 Recommendations for the international mental health community on best practices in working with service users and carers

Based on the understanding that recovery from mental illness includes attention to social and economic inclusion as well as adequate access to a balanced system of hospital and community mental health care, the World Psychiatric Association (WPA) recommends to the international mental health community the following approach for collaborative work between mental health practitioners**, service users** and family/carers**

WPA recommends that:

1. Respecting human rights is the basis of successful partnerships for mental health.
2. Legislation, policy and clinical practice relevant to the lives and care of people with mental disorders need to be developed in collaboration between mental health practitioners, service users, and carers.
3. The international mental health community should promote and support the development of service users' organizations and carers' organizations.
4. Improving mental health is essential for economic and social development. This requires participation of all sectors of the community.
5. International and local professional organizations, including WPA through its programs and member societies, are expected to seek meaningful involvement of service users and carers in their own activities where appropriate.
6. The best mental health care of any person in acute or rehabilitation situations is done in collaboration between mental health practitioners, service users, and carers. Working in this way generally benefits from special skills and training.
7. Education, research and quality improvement in mental health care requires collaboration between mental health practitioners, service users and carers.
8. The recovery process in mental health includes economic and social inclusion, as well as medical care. Examples of economic and social inclusion are access to: education and training, housing, employment, advocacy and family support.
9. WPA member societies and other professional groups should collaborate with service users' organizations, carers' organizations and other community organizations to lobby governments for political will and action for better mental health services, community education and fighting stigma and discrimination.
10. Enhancing user and carer empowerment should be sought through a range of different approaches and ideas, for example: the development of self-help groups; participation in service planning and management boards; employment of people with mental health disabilities as service providers and inclusive local anti-stigma-anti discrimination programs.

* These recommendations are intended for the international mental health community. Each country needs specific guidelines to apply these recommendations.

** "Mental health practitioners" include psychiatrists and other mental health service providers.

The term "service users" refers here to the people receiving or who have received mental health services. Other terms in common use are clients, patients, consumers, ex-patients and survivors. No one of these terms is current in all settings and countries, and different groups of practitioners and people with mental disorders have traditionally used different terms. Their historical, cultural and personal meaning carry considerable significance (for example, patient implies to some people the passive receipt of health care), but this is beyond the scope of these recommendations.

The term "carers" refers to family members and other people who are living with, or informally looking after, people with mental health problems. This differentiates these people from professional carers meaning employed mental health personnel.

dations that is proposed as an additional paragraph for the Declaration of Madrid. It will be presented to the WPA General Assembly in 2011 for endorsement.

CONCLUSIONS

The consultations produced strong consensus across diverse groups in the international mental health community on the ten basic recommendations. This is a notable result in itself. It is not surprising that considerable differences are found in individual and group opinions on the prominence of topics such as access to treatment and the right to decide. These differences correspond among others to the fact that mental health situations vary dramatically across countries and cultures and sometimes to a difference in agendas between service users and family members even with considerable overlap. The recommendations can encourage interest groups in each country or locality to work together in areas of consensus and continue (through dialogue and other means) to discuss the contentious topics.

This process is strengthened by the accompanying work of the WPA Committee on Ethics, a process that is likely to lead to WPA embedding the essence of these recommendations in the Declaration of Madrid, the ethical guidelines for psychiatric practice.

The Task Force did not include members from a number of important countries and regions, including China and Latin America. Furthermore, in the time and with the resources available, the survey was carried out only in English. This was partly mitigated by the grassroots consultations. In future projects, it will be important to develop this aspect of the work, and to involve all world regions.

The Task Force plans to seek support for a series of activities that will promote these movements in countries worldwide. Collecting a series of best practice examples of collaboration, addressing each of the recommendations, is a useful next step. This becomes a demonstration of the value of collaboration, and also a resource to assist others to begin successful collaboration. The Task Force will also encourage the development of country projects that provide further examples and stimulate others to follow. An example may be the development of a workshop in a low-income country to create a network between users, carers, professionals and government, including leaders of organizations. Specific efforts to enhance the dialogue in various settings would also be valuable as evidenced by recent experience in Beijing. The WPA could also consider a global project to investigate pathways for psychiatrists engaging with service users and carers and implementing the guidelines. At the international level, it will be important for professional bodies to consider how to promote the involvement of service users and carers in major congresses and events.

Proposals are being developed for some of these ideas that will ideally result in projects in low- and high-income countries designed to test selected recommendations and create

new networks to encourage partnership and collaboration between stakeholder groups. Working with one or two countries in a more concerted way to create guidelines based on the recommendations and evaluating these experiences is a feasible and desirable way to continue the work initiated in this project.

Acknowledgements

The Task Force has three members with a background as service user (B. Davar, India; S. Katontoka, Zambia; and J. Wallcraft, UK), three with a background as family carer (D. Froggatt, Canada; H. Jafri, Pakistan; and S. Steffen, Austria) and six psychiatrists associated with the WPA (M. Amering, Austria – Co-chair; J. Freidin, Australia; H. Herrman, Australia – Chair; S. Rataemane, South Africa; H. Wahlberg, Sweden; and R. Warner, USA). The members were appointed as individuals, although several also hold leadership positions in relevant organizations. C. Underhill, founder and director of BasicNeeds and S. Raja, Director of Policy and Practice for BasicNeeds, are special advisers, as are two members of the WPA Committee on Ethics, its Chair S. Tyano and A. Javed.

The Department of Mental Health and Substance Abuse of the World Health Organization is helping by offering its experience and advice.

The authors thank all who participated in the online surveys. They thank those who designed, coordinated and participated in the consultations coordinated by BasicNeeds in Kenya, PDR Lao and Sri Lanka, and by B. Davar in India, including: J. Kingori in Kenya, T. Senarathna, M. Kurrupu and V. Surendranathan in Sri Lanka, V. Manibod and C. Choulamany in PDR Lao; Schizophrenia Awareness Association (Pune), Bapu Trust for Research on Mind and Discourse (Pune), CSCS (Bangalore), M. Gupta (Dwarka, Delhi), World Center for Creative Learning foundation (Pune), Banyan/BALM (Chennai).

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