Document Title: WPA Position Paper on developing partnerships with persons with lived experience of mental health conditions* and family and informal carers

Document Type: WPA Position Paper
Date Created: February 14th 2023
Author/s: WPA WG on Developing Partnerships with Service Users and Family Carers

Approved at the General Assembly in Vienna on 30 September 2023

Post-GA statement on authors of approved WPA Position Paper on developing partnerships with persons with lived experience of mental health conditions* and family and informal carers:

The WPA WG on Developing Partnerships with Service Users and Family Carers produced this paper. The names of the individual group members and their affiliations had been omitted unfortunately due to technical reasons when the last version was submitted. Here they are:

Miia Männikkö
EUFAMI
Tampere University, Finland

Guadalupe Morales
Guadalupe Morales Cano
Fundación Mundo Bipolar
Spain

Martha Savage
Victoria University of Wellington/Te Herenga Waka
New Zealand

Charlene Sunkel
Global Mental Health Peer Network,
Paarl, South Africa

Spyridon Zormpas
Greek Carers Network EPIONI
Greece

Michaela Amering
Department of Psychiatry and Psychotherapy
Medical University of Vienna,
Austria

Afzal Javed
WPA President 2020-2023

Roger MK Ng
Department of Psychiatry
Xiangya Second Psychiatric Hospital
Changsha, Hunan, China

Maria Rodrigues
Community Works
Melbourne, Australia

WPA Position Paper on developing partnerships with persons with lived experience of mental health conditions* and family and informal carers GA23.10.9

14.2.23
WPA WG on Developing Partnerships with Service Users and Family Carers

Foreword

WPA has established partnerships with persons with lived experience of mental health conditions and family and informal carers over many years. The 2011 WPA recommendations on best practices in working with service users and family carers (Wallcraft et al, 2011, World Psychiatry) are a result of a cooperation with psychiatrist WPA members and people with personal experience of mental health conditions and family carers. The ten recommendations range from respect for human rights as the basis for partnerships to a collaborative approach in clinical, training and research contexts to the obligation to promote and support the establishment of meaningful and authentic inclusion of users' and carers' representation within international and local professional organizations including WPA.

The ten recommendations were developed for the international mental health community and subsequently six of these were incorporated into WPA's Madrid Declaration of ethical principles (www.wpanet.org/current-madrid-declaration). All ten recommendations remain relevant for WPA and its Member Societies. WPA calls for constant efforts to ensure the recommendations are endorsed as obligations and furthermore that progress in meeting these obligations is reviewed and monitored.

The WPA Working Group on Developing Partnerships with Service Users and Family Carers was founded as a WPA Advisory Group in 2018 and has worked to support WPA in planning and conducting its Congresses and on core work programs such as the WPA program on implementing alternatives to coercion. Their participation was key to the WPA 2020 Position Statement on Implementing Alternatives to Coercion: A Key Component of Improving Mental Health Care.

This position statement focuses on the obligations of professional psychiatric associations including WPA and its Member Societies to meaningful, authentic and sustainable involvement of persons with a personal experience of mental health conditions, family and informal carers and their representative organizations in all training, research, decision-making processes and policy and practice developments concerning mental health.

Introduction

With human rights, respect for dignity and non-discrimination at the centre of international and national mental health policies worldwide, no significant development can advance without the meaningful and authentic involvement of experts in their own right. Persons with a lived experience of mental health conditions and family and informal carers bring their unique expertise and perspectives to the table in different ways. In a historic first, in the early years of this century, mental health related conditions became recognised as part of the broader disability sector and within this context, were referred to as psychosocial disabilities. This allowed for persons with mental health conditions to feature prominently in global disability-related advocacy initiatives to promote and protect human rights of all persons with disabilities.

In another historic first, self-advocates were an essential part of the negotiating and drafting process of the UN-Convention on the Rights of Persons with Disabilities (www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html). The first human rights treaty of the 21st Century is the product of a truly participatory process and makes the longstanding request of 'Nothing about us without us!' a legal obligation: No policy development, review and amendment of legislation or additions to regulations shall be undertaken without including experts in their own right, namely persons with psychosocial disabilities.

What the Position Statement aims to achieve

The position paper aims to update and expand upon WPA's position on the necessity and the opportunities of international, national and local professional psychiatric organizations to work in partnership with persons with a lived experience of mental health conditions as well as with family and informal carers. This position paper highlights the obligations of professional organisations and international examples on best efforts towards meaningful and authentic involvement of persons with lived experience backgrounds.

International consensus and examples

The international consensus on working in partnership is in the process of turning into reality around the globe. The 2020 World Health Organisation's Mental Health Atlas reported that 35% of the 171 countries that responded to their 2020 survey report ongoing formal collaboration with service users and/or family/caregiver advocacy groups (https://www.who.int/teams/mental-health-and-substance-use/data-research/mental-health-atlas).

To promote successful partnerships, professional psychiatric organisations have a crucial role to play to create opportunities for meaningful, authentic and sustainable involvement of persons living with a psychosocial disability in their work. International examples include the World Association of Psychosocial Rehabilitation, which includes persons with lived experience of mental health conditions and family carers as board members; the European Psychiatric Association, which includes ex-officio members of the boards of the European Federation of Associations of Families of people with mental illness (EUFAMI) and the Global Alliance of Mental Illness Advocacy Networks (GAMIAN), and the Collaboration Agreement between Mental Health Europe (MHE) and the European Network of (Ex-) Users and Survivors of Psychiatry (ENUSP).

Examples of national psychiatric organizations include the Royal Australian and New Zealand College of Psychiatry (RANZCP) with their Community Collaboration Committee, whose members contribute to the training, assessment and accreditation of psychiatrists as well as to mental health policy direction and to internal operations of the RANZCP, and the Royal College of Psychiatrists of the UK with a family carer and a user representative as council members.

Government bodies also have persons with lived experience background on board. Examples include the National Mental Health Commission of the Australian Government and the Advisory Committee of Mental Health set up by the Hong Kong SAR Government. The Advisory Committee is the top advisory body of mental health policy development. With their advice and support, the Hospital Authority of Hong Kong has ensured that every mental health service cluster recruits a specified minimum number of trained peer expert workers in their mental health teams for people with serious mental health problems.

International policy and research endeavours with partnerships include the 2021 Lancet Commission on Mental Health, Stigma and Discrimination, which includes people with lived experience background in key leadership roles, and the WHO QualityRights initiative, which has taken multipronged actions to put people with lived experience at the centre of its global and country level work to transform policy, law and services and to build capacity on person-centred and rights-based approaches to mental health.

The GMHPN (www.gmhpn.org) developed formal partnerships with several international organisations, such as with the International Initiative for Mental Health Leadership, Ember, Recovery IPSS, amongst other academic and research institutions. These partnerships are aligned with the GMHPN's 'Considerations when working and engaging with persons with lived experience with mental health conditions' (www.gmhpn.org/lived-experience-engagement.html). Rules of engagement for successful partnerships include principles of transparency and fairness, ways of finding a common language, making decisions by consensus or democratically, and moving from tokenistic participation to active and engaged partnerships.

Examples of training partnerships include the US National Association of Mental Illness (NAMI)'s in-service training for mental health professionals taught by a team consisting of an adult with a mental health condition, a family member and a mental health professional who is also a family member or has a mental health condition themselves (www.nami.org/Support-Education/Mental-Health-Education/NAMI-Provider), or the Fundación Mundo Bipolar (Morales Cano & Wooley, 2016) trainings developed within the EU Horizon2020 Research Project Recover-EU (www.youtube.com/watch?v=b4A2Sw2eU3s), or EUFAMI's training programme 'Prospect for People' (https://eufami.org/?s=prospect+programme) joining together all three groups to improve their communication. For more than three decades, the Trialogue (Amering, 2017) experience of learning and practicing communication on equal footing has been providing a discrete and independent acquisition and production of knowledge for people with lived experience of mental health conditions, family members and friends as well as persons working in the mental health field.

Conclusions and Recommendations

The ethical and legal consensus on the obligations to include persons with psychosocial disabilities, personal experience of mental health conditions, family members and informal carers in all aspects of mental health policy and practice developments create an urgent need for successful global implementation of authentic and meaningful partnership work for education, research and quality improvement.

- WPA recommends that all international and local professional organizations, including WPA programs and member societies, find appropriate ways to work in authentic and meaningful partnerships with people who have personal experience of mental health conditions as well as with family and informal carers. In many cases it might be most appropriate to partner with organisations that represent these groups. The training of psychiatrists and other mental health professionals should involve and be informed by these partnerships, as should research and policy development. Psychiatrists need to be trained in supported/shared decision-making and to become fully aware of their roles and how best to exercise them in supporting alternatives to coercion (WPA, 2020).
- WPA recommends that member organizations actively look for organizations and persons to realize such partnerships.

- WPA recommends using and developing educational materials and and methods to prepare psychiatrists and other mental health professionals to work in meaningful, authentic and sustainable partnerships
- WPA recommends including these partnerships in research on mental health practice and quality improvement, and policy development.
- WPA recommends developing activities with service users, family members and their representatives in a respectful framework and from the beginning of an activity, making sure that the conditions are clear and understood by all parties.
- WPA recommends being very careful to never instrumentalize these groups, maintaining equal and mutual respect among collaborating groups.

** In line with the Lancet Commission on Ending Stigma and Discrimination in Mental Health 'We refer here to "persons with lived experience of mental health conditions" when referring to a person who has or had received a diagnosis of a mental health condition and/or who may be receiving or have received treatment in the past, for mental health problems. Our choice of terminology is derived from the Lancet Commission on Ending Stigma and Discrimination in Mental Health who conducted a survey with people with lived experience of mental health conditions where these terms were identified as more acceptable by the lived experience community. In terms of family members or other types of caregivers who are or have been the primary carers of a person/s with a mental health condition we refer to as "formal and informal carers". Our intention is not to exclude any person/s or groups who prefer to be identified with other terms used in the mental health space. We do acknowledge that there is no consensus on one universally preferred term. We further note that terminology, as it has in the past, evolve over time and may change in the future.' (Thornicroft et al, 2022)*

Amering M (2017) Trialogue: An Exercise in Communication Between Users, Carers, and Professional Mental Health Workers Beyond Role Stereotypes. In: Gaebel W, Rössler W, Sartorius N (Eds) (2016) The Stigma of Mental Illness – End of the Story? Springer, Switzerland, pp 581-90

EUFAMI https://eufami.org/

Global Mental Health Peer Network www.gmhpn.org

Morales Cano, G, Wooley, S. (2016). Perspectives for public policies in mental health. Sick or well – a citizen first: The (Ex-)User/Survivor Voice in Democracy. L'Information psychiatrique, 92(9): 723-30 https://www.cairn.info/load_pdf.php?ID_ARTICLE=INPSY_9209_0723

Thornicroft G, Sunkel C, Alikhon Aliev A, Baker S, Brohan E, El Chammay R, Davies K, Demissie M, Duncan J, Fekadu W, Gronholm PC, Guerrero Z, Gurung D, Habtamu K, Hanlon C, Heim E, Henderson C, Hijazi Z, Hoffman C, Hosny N, Huang FX, Kline S, Kohrt BA, Lempp H, Li J, London E, Ma N, Mak WWS, Makhmud A, Maulik PK, Milenova M, Morales Cano G, Ouali U, Parry S, Rangaswamy T, Rüsch N, Sabri T, Sartorius N, Schulze M, Stuart H, Taylor Salisbury T, Vera San Juan N, Votruba N, Winkler P. The Lancet Commission on ending stigma and discrimination in mental health. Lancet. 2022 Oct 7:S0140-6736(22)01470-2. doi: 10.1016/S0140-6736(22)01470-2. Epub ahead of print. PMID: 36223799.

Wallcraft J, Amering M, Freidin J, Davar B, Froggatt D, Jafri H, Javed A, Katontoka S, Raja S, Rataemane S, Steffen S, Tyano S, Underhill C, Wahlberg H, Warner R, Herrman H (2011) Partnerships for better mental health worldwide: WPA recommendations on best practices in working with service users and family carers. World Psychiatry 10(3):229-36.

World Psychiatric Association (2020) Implementing Alternatives to Coercion: A Key Component of Improving Mental Health Care. Position Statment. 2020 [Available from: https://www.wpanet.org/_files/ugd/e172f3_635a89af889c471683c29fcd981db0aa.pdf

www.gmhpn.org/lived-experience-engagement.html

www.nami.org/Support-Education/Mental-Health-Education/NAMI-Provider

www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html

www.wpanet.org/current-madrid-declaration

www.youtube.com/watch?v=b4A2Sw2eU3s