

Open Letter to the organisers of the Global Ministerial Mental Health Summit, 9 - 10 October 2018, London UK

We are writing to express our serious concern about the organisation and make-up of the Global Ministerial Mental Health Summit being hosted by the British government. It seems systematically to be excluding the diverse voices of mental health service users, those with psychosocial disabilities and our own organisations.

There is increasing recognition internationally of the importance of involving and including people with experience as mental health service users/patients and those with psychosocial disabilities equally in the development of policy and practice. The UN Convention of the Rights of Persons with Disabilities (UN CRPD) signed and ratified by numerous countries that will be represented at this through their respective Ministries actually obliges member states to "closely consult with and actively involve" people with disabilities through their representative organisations in all the decision making processes and matters concerning our lives (Article 4, paragraph 3).¹ This international human rights treaty explicitly refers to people with psychosocial disabilities. Yet this is not reflected in the organisation of this key global event and its lead-up.

The agenda of the Summit can be criticised on several points. However in this Open Letter we want to focus solely on the process and politics of invitations to take part in this event. We believe these prevent a much-needed dialogue with those whose lives this high-level event claims to be about. Mental health service users' own organisations, our long established advocates and 'experts by experience' do not seem to have been invited to contribute on anything approaching an equal basis. Both the European and the World Network of Users and Survivors of Psychiatry (ENUSP and WNUSP) have contacted the Summit organisers in an attempt to suggest their representatives. This attempt to provide meaningful involvement has been ignored as the Summit obviously prefers to involve individuals with 'lived experience' rather than organisational representatives. While expenses to cover costs of those on low incomes have been mentioned, some invited service users who need such support have already been denied it and are therefore unable to take part. We are particularly concerned about the exclusion of mental health service users and people with psychosocial disabilities from the Global South, the marginalisation of indigenous peoples and the adversity faced by autonomous collective user-led organisations. There has been zero transparency about the whole involvement process. The 'global' is here again being narrowed to the most powerful stakeholders, notably those involved in the problematic mental health systems as psychiatrists, psychiatric researchers and powerful NGOs which do not necessarily represent the interests of all their constituents.

Our grassroots representative organisations tend to be poorly resourced, if resourced at all. The ENUSP founded in 1991 was the only international grass roots network that attracted some funding in its first 13 years. From 2004 it has worked without any operational funding. The same is the case for WNUSP established in 1991 and the Pan-African Network of People with Psychosocial Disabilities founded in 2005. These unique organisations pursuing the autonomous agendas of those subjected to psychiatric treatment across the globe completely rely on work of committed volunteers. An approach to mental health/distress and psychosocial disability coming onto the agenda of global economic development, to which this expresses commitment, should also mean

¹ For the full text of the UN CRPD see http://www.un.org/disabilities/documents/convention/convention_accessible_pdf.pdf

support for our independent organising and enabling us to become real stakeholders and to have our say in all the matters concerning our lives. But this is not the case, and not even this Summit proved capable of responding to our demands to send our own representatives. We are again reduced to individuals with 'lived experience' and our work and collective knowledge of many years will not be adequately contributing to the debate to "shape the future" as the conference organisers intend. The power asymmetry is stark.

This failure to enable involvement also reflects wide and growing concerns about the inadequacy of and crisis in UK mental health policy and provision and the failure to listen to service users, their families, communities and organisations in both mental health and welfare reform policy, both of which are having catastrophic consequences for many service users, their families and communities. In their concluding observations the UN CRPD committee has expressed serious concerns in regard of the implementation of "Adequate standard of living and social protection" (Article 28) in the UK. The UK Government's measures of the last years are qualified as having "the detrimental impact" and "sanctions on persons with disabilities" (p.13)² This raises legitimate questions about the adequacy of the UK government to positively combat global poverty and calls into question its status as host country for the Summit.

The signatories of this letter are seriously concerned that the outcome of this first such Summit will seriously misrepresent the issues and problems of mental health and mental health service users globally because of the systematic exclusions that seem to have applied. We call instead for service users and our experiential, non-medical knowledge to be supported and for our autonomous organisations to be enabled to join the debate on equal and inclusive terms that fully address diversity and challenge our continued exclusion.

Signed

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Jasna Russo, individual member, European Network of (ex) Users and Survivors of Psychiatry.

Sarah Yiannollou, Managing Director, National Survivor User Network, England.

Dr Sarah Carr, on behalf of Survivor Researcher Network Working Group, England.

Rita Bins, Recovery in the Bin, user led group for mental health survivors and supporters, UK.

Linda Burnip on behalf of Disabled People Against Cuts Steering Group, England.

Denise McKenna, co-founder of Mental Health Resistance Network, UK.

Paula Peters, Disability Rights Activist, London, England.

² Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland, 3 October 2017, available at:

https://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD/C/GBR/CO/1&Lang=En

Olga Kalina, Chair, on behalf of European Network of (ex) Users and Survivors of Psychiatry.

Jolijn Santegoeds, Co-Chair, on behalf of World Network of Users and Survivors of Psychiatry.

In alliance:

Paul Atkinson on behalf of the Free Psychotherapy Network, UK.

Richard Bagnall-Oakeley on behalf of Psychotherapy and Counselling Union, UK.

Alec McFadden, Press Officer, Salford Trades Union Congress, England.

Professor Ian Parker, President, College of Psychoanalysts, UK.

Psychotherapists and Counsellors for Social Responsibility (PCSR), UK.

Psychologists for Social Change, UK.

Social Work Action Network (SWAN), UK.

Dr Jay Watts on behalf of the Alliance for Counselling & Psychotherapy, England.