

Dear Mr. Hunt,

I am writing with some comments about your recent report on mental disability and the right to health, and would welcome dialogue about any of these issues.

If you are in a position to bring out any of these points in your presentation to the CHR or can think of any other way to assist us in gaining recognition for the rights and perspectives we advocate, it would be much appreciated.

First, it is welcome that you acknowledge the deficiency of the MI Principles with respect to the right to free and informed consent – that the exceptions swallow the rule. WNUSP and our colleagues in the International Disability Caucus at the UN argue that there is no defensible reason at all to make exceptions to this right. Disability does not mean inability and is no justification for restriction or limitation of rights – instead it calls for adjustment of the environment to make every aspect of society, including legal rights and remedies, accessible to all people. We have begun to articulate what that means in the context of legal capacity and forced interventions, in the papers I have sent you. I hope that you can help us to take this important conversation further towards establishing that the right to free and informed consent as an aspect of health is a right of all people without distinction based on disability, and that any instrument or jurisprudence to the contrary must be re-examined.

A related issue that you have not addressed in this way is psychiatric detention or involuntary commitment. In the drafting and negotiation of the Disability Convention, WNUSP and our colleagues have argued that this constitutes deprivation of liberty based on disability and as such is unlawful because it is discriminatory. WNUSP's objections to the MI principles apply equally to involuntary commitment as they do to free and informed consent. There is no defensible justification to intern people based in any part on an actual or perceived disability, and no procedural guarantees or legal standards can remedy this. I was somewhat surprised that you did not treat this issue in the same way as you did the right to informed consent, and would be interested to know if there was a reason for this.

To elaborate some more on the issue of detention: There are three possible scenarios for psychiatric detention. In the first, the person has committed a crime but instead of being arrested and detained through the criminal justice system, he or she is placed in the psychiatric system. In this scenario, the person loses the right to have guilt or innocence adjudicated, and a determinate sentence imposed if guilty. Instead of being imprisoned for an act constituting a crime, the person is imprisoned merely for being who she or he is. Whether a prison or a psychiatric institution is a worse place to be deprived of liberty is debatable and there are those with preferences on either side – but that is not the point. We need to look at the principles and underlying legal and philosophical framework, and understand that reasonable accommodation for disability is the appropriate response to the harshness of prison, which may be disproportionate for people with disabilities with various kinds of impairments.

The second scenario is that the person has not committed a crime but is alleged to be dangerous to other people. In this scenario, deprivation of liberty is imposed as preventive detention and is arbitrary for two reasons. First, there is no objective standard of conduct to guide a person, as is required for a criminal law (the principle of legality, there can be no crime and no punishment that is not clearly defined in law). Secondly, deprivation of liberty is imposed differentially based on disability. A person without a disability may be engaging in the same aggressive, annoying or hostile conduct but only the person with a disability is even at risk of losing his or her freedom, unless the behavior crosses the line of breaking a law.

The third scenario is paternalism – the person is alleged to be dangerous to him or herself, or to be in need of treatment. Here, detention is a subcategory of forced interventions and should remain subordinate to the right to free and informed consent.

When you deal with guardianship, you should also be aware that WNUSP and our colleagues in the IDC have gone further than the Montreal Declaration and argue that there is no justification to deprive any person with a disability of legal capacity by imposing substituted decision-making. Our colleagues at the Center for International Rehabilitation have accepted the premise that guardianship and incapacity laws are a legal barrier to the rights of people with disabilities, not a form of protection, see their report on the Americas at <http://www.cirnnetwork.org/idrm/reports/americas/>

I would like to briefly mention an issue of language. WNUSP uses the term “psychosocial disability” as an equivalent to “users and survivors of psychiatry,” to refer to people who have “experienced madness and/or mental health problems and/or have used or survived psychiatry/mental health services.” We do not differentiate as you do, between minor and major difficulties. For us, psychosocial refers to an area of human functioning comparable to physical, intellectual and sensory, the other major categories of disability or impairment. We would rather be known through this term than through a term that refers to a part of the medical profession (as in “psychiatric” disability).

A third issue is the distinction between people with intellectual disabilities and people with psychosocial disabilities. In discussions between WNUSP and Inclusion International, both organizations have agreed that there is no such general category as “mental disability” – there are two separate and distinct groups of people with psychosocial disabilities and people with intellectual disabilities. Your report intends to cover issues common to both groups, but the bulk of the report deals with issues in the mental health field with the exception of the part dealing specifically with people with intellectual disabilities. This is a problem because it contributes to confusion of the two groups. At the same time, some issues that you cover for people with intellectual disabilities apply to us as well, for example barriers in access to quality health care, and the fact that we do not consider our disability to be a disease or illness.

The remaining issue is difficult for me to address, probably because it is not a field I have worked with extensively. WNUSP advocates a change from a medical model of mental illness to a non-pathologizing one that recognizes mental and emotional differences and

distress as part of everyday life, even when such experiences are disruptive to the person's ability to carry on life as usual. Wellness should be defined as "being able to live well, whatever that means for an individual." We believe it is of vital importance to challenge the dominance of the medical model and have included this as a reason for our objection to the MI principles, in the paper I am enclosing (which you might have seen already). Colleagues in the user/survivor movement have done some important work in the area of non-pathologizing alternatives such as self-help, peer support, non-coercive community-based support and safe places to go when in crisis. Furthermore, in communities that still have traditional healing practices, these practices should be accepted on their own terms and not subordinated to a medical-model mental health system. This is an overall issue that has implications for many areas covered in your report. Some of my colleagues would be better equipped than I am to have the full discussion with you and I would welcome for such a dialogue to happen.

Turning to advocacy matters, I think it is helpful that you spoke about the convention process and urged that the convention should strengthen and not water down existing rights. It is also welcome that you mentioned the emphasis in the Standard Rules on participation of disabled people's organizations. The implications of this for the process of strengthening rights, on both the national and international levels, might be underlined.

There is another instrument that would be helpful to address although it has not yet been adopted by the General Assembly – the supplement to the Standard Rules that was proposed by the former Special Rapporteur Bengt Lindqvist. WNUSP and the other international disability organizations helped to develop this supplement, which recognizes a right to self-determination including the right to accept or refuse treatment, and an obligation on governments to protect people with disabilities from unwanted medical or related interventions. It also implies that there is a right to refuse forced institutionalization. See UN Doc. E/CN5/2002/4 paragraphs 27 and 33.

In closing, I thank you for the opportunity to comment on your report and begin a dialogue on these issues of great concern.

Sincerely,

Tina Minkowitz, J.D.
Co-chairperson, World Network of Users and Survivors of Psychiatry