Detention and disability

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CHECK AGAINST DELIVERY

Introduction

I would like to acknowledge the traditional owners of this land and pay my respects to their elders past and present. I would also like to thank the Castan Centre for Human Rights for inviting me, and for the role it is playing in convening this important conference. I look forward to learning from you all.

My colleagues and I at the Mental Disabilities Advocacy Center are working on preventing torture and other forms of ill-treatment in various settings in central and eastern Europe and Africa. Part of our work is conducting actual monitoring (we came out with a report on Croatia last year), training inspectorates, litigating abuses and neglect, and we are involved in a project on disability and torture in India and Nigeria. We are also active at the European and United Nations level with various torture-prevention and disability rights actors.

My paper outlines some key developments in monitoring the rights of people detained – either *de jure* or *de facto* – in what I will call "disability institutions". I use this term to include psychiatric hospitals, psychiatric wings of general hospitals, as well as any institutions/homes which constitute congregated settings for people with psycho-social disabilities, users and survivors of psychiatry, intellectual disabilities, brain injuries, people with degenerative diseases of ageing and those with degenerative diseases unrelated to ageing. By using the term "disability institutions" I do not endorse or legitimize them; on the contrary, as I will outline.

I will also use the term "monitoring bodies". By these I mean international bodies such as the UN Subcommittee for the Prevention of Torture (SPT) and the European Committee for the Prevention of Torture (CPT), as well as domestic bodies which may be National Preventive Mechanisms (these are the bodies which have to be set up by the Optional Protocol to the UN Convention against Torture – OPCAT), or may be ombudsman bodies or other types of national or sub-national national human rights mechanisms or inspectorates. Monitoring bodies include the generic (such as an ombudsman) and the thematically-specific (such as a prison inspectorate).

I want to make some observations about the operationalisation of contemporary human rights law and in doing so, to quote the American jurist Oliver Wendell Holmes "wash it with cynical acid". My paper makes five recommendations which would, in MDAC's view, enhance human rights protection for all.

> First, the UN Sub-Committee for the Prevention of Torture (SPT), should visit a more balanced range of places of detention.
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> Second, research needs to be conducted into the effectiveness of monitoring bodies.
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> Third, monitoring bodies need to be less deferential to medicine.
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> Fourth, monitoring bodies need to embrace the participation of experts by experience as monitors.
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> And fifth, monitoring bodies need to call for the right to live in the community.

Let's take these in turn.

First, the UN Sub-Committee for the Prevention of Torture (SPT), should visit a more balanced selection of places of detention.

MDAC has carried out research on the places of detention which the SPT has visited since its first visit in 2007. It has visited 225 places of detention. Less than five were to disability institutions.

Article 4(2) of OPCAT tells us that "deprivation of liberty means any form of detention or imprisonment or the placement of a person in a public or private custodial setting which that person is not permitted to leave at will by order of any judicial, administrative or other authority". In fact, the word "prison" appears once in OPCAT, in the part about the experience required by SPT members; that candidates should have experience in "administration of justice, in particular criminal law, prison or police administration, or in the various fields relevant to the treatment of persons deprived of their liberty". There is no suggestion in OPCAT that there should be an exclusive focus on prisons.

The SPT's focus is strange for two reasons. First, there is now ample evidence that disability institutions are places where a person is at an increased risk of being subjected to torture (yes, torture) and forms of cruel, inhuman or degrading treatment or punishment. See www.stoptortureinhealthcare.org. In March there will be a briefing in New York for Juan Mendez, the UN Special Rapporteur on Torture, on ill-treatment in healthcare settings.

Second, there are very considerable numbers of people affected. Data on people in disability institutions is patchy and there is no global data. A report in 2007 estimated that in the 27 Member States of the EU, there were nearly 1.2 million children and adults living in long-stay residential institutions for people with disabilities. Curiously, this data included Turkey which is not in the EU, and excluded Germany and Greece – which are EU Member States for which data was not available.

The SPT has not explained why it has chosen to visit such a paltry number of disability institutions. Perhaps it is an operational decision: what do we have capacity to do? Perhaps it is a political decision: where do we want to have initial impact? Ultimately it is a moral decision: do we value the lives of human beings equally, irrespective of what the name of the place of detention is?

My suggestion is that inspectorates carry out visits to places of detention in the same proportion as the numbers of people in different types of place of detention. Human rights work should be holistic and pluralistic, yet the torture prevention community seems stuck in an atomistic approach to human rights, an almost exclusive focus on torture (not inhuman, cruel and degrading treatment and punishment) and on prisons.

In the OPCAT framework it is crucial that the SPT leads by example, practising what it preaches to NPMs at the domestic level. We can hardly expect NPMs to be inclusive if the SPT is not.

Second, research needs to be conducted into the effectiveness monitoring bodies.

There is no independent and regular monitoring of the effectiveness of inspectorates. There is a wide variation of practice of inspectorates. Some inspectorates don't visit these places, some fail to address serious human rights issues, some do not make their reports public (some do not bother to write reports at all), some make vague and non measurable recommendations, some do not engage with policy reforms and so on.

In countries where the effectiveness of inspectorates is compromised, the task falls to NGOs, but:

a. These are often countries where freedom of association and expression are limited, and where human rights defenders are persecuted;
b. NGOs generally lack the financial and operational capacity to carry out regular and thorough evaluation;
c. There might also be a conflict of interests as many service NGOs receive financial support from the state;
d. NGOs that also do monitoring need the State's permission to access places of detention. If they are good at monitoring vigorously it will be uncomfortable

for the State, and access may be withdrawn – as happened recently in Hungary.

The SPT has the mandate to be critical towards NPMs, but it is not politically realistic for them to play this role. A positive development is that starting this year the SPT will dedicate three of six visits to focus solely on NPMs. However, it is likely that their work will focus more on the successful designation of the NPM and its compliance with OPCAT requirements instead of looking at the effectiveness of their preventive work.

It falls on civil society to play a watchdog role to monitor the monitors, and MDAC is coordinating a set of NGOs working across a range of detention sectors to develop a tool to assess inspectorate effectiveness. If you would like to be involved in this venture please see me afterwards.

Third, monitoring bodies need to be less deferential to medicine and medics.

Worldwide, we are moving away from a medical model of disability which focuses on deficits, treatment, charity, best interests, management, pity and fear. We are making headway towards the social model of disability which focuses on equality, inclusion, capabilities, autonomy, environmental adjustments and awareness-raising. The CRPD marks a historic shift in how human rights law does and societies should look at persons with disabilities. This shift needs to be reflected in the work of inspectorates.

I am not suggesting that medicine and doctors do not play an important role; my point is that medicine dominates: disability institutions are places which are often run by doctors, and human rights abuses are sometimes carried out in the name of medicine. As the then chief psychiatrist of Slovakia said to a BBC camera some years ago, "cage beds are not about human rights or a humane way of treating patients, they are about the advancement of psychiatry as a science".

There are often no national prescribing guidelines, and certainly no international ones. Human rights are supposed to be universal, and the human rights community needs to engage in a much deeper way with the uses and abuses of pharmacological drugs and electroconvulsive therapy. These are often the subject of very serious complaints by users and survivors of psychiatry, and there is evidence of alternatives to ab/using psychiatric medications. The human rights community also needs to push back very vigorously on the use of physical restraints and seclusion, which are often used because of inadequate staff numbers or training.

Fourth, monitoring bodies need to embrace the participation of experts by experience as monitors.

Inspectorates tend to reproduce a medical dominance dynamic in their team when visiting disability institutions, thereby reinforcing unhelpful medical supremacy. We recommend having a medic as part of a multi-disciplinary monitoring team (see the ITHACA toolkit), but the team and the resultant report should not defer solely to this person's point of view, otherwise the team will not engage with key concerns of detainees, namely the negative side effects of medication and the consequences of coercion and force. If these side effects were produced by injecting chemicals into detained dissidents in a prison, inspectorates would be unhesitatingly critical.

Part of a multi-disciplinary monitoring team is the inclusion of experts by experience. However, there is still very little practice of involving mental health service users – let alone people with intellectual disabilities – on monitoring teams. At one level the SPT shares this approach. One of SPT's guiding principles is having a diverse monitoring team. "expertise" they say, "[of] vulnerabilities is needed in order to lessen the likelihood of ill-treatment".[1]

The SPT has identified as a guiding principle that a holistic approach must be taken; to "engage with the broader regulatory and policy frameworks relevant to the treatment of persons deprived of their liberty and with those responsible for them." Article Art 33(3) of the CRPD says that people with disabilities and their representative organisations should take part in the monitoring of that Convention. There should be a read-across into OPCAT world.

Fifth, monitoring bodies need to call for the right to live in the community.

There is a surface contradiction between detention monitoring and Article 19 of the UN CRPD, which lays out the right to live independently and be included in the community in order to prevent isolation and segregation from the community. Thomas Hammarberg will come out with an issue paper on A19 in March. This contradiction could be somewhat eased by monitoring bodies if they embraced the UN standards in their work and valorised the CRPD as the globally-agreed standard went further than commenting on the conditions in the institutions. It is time that inspectorates recognized a systemic human rights violations, and made the explicit link between detention and the risk of ill-treatment. They need to start advocating for the closing down of institutions, and the development of community support services.

Practice varies. The SPT has said nothing on this topic. In Europe, some CPT recommendations are progressive, but others fail the CRPD. For instance, the CPT

[1] The approach of the Subcommittee on Prevention of Torture to the concept of prevention of torture and other cruel, inhuman or degrading treatment or punishment under the OPCAT, CAT/OP/12/6, 30 December 2010, para 5(j).

Standards note the positive development of closure of long-stay social care institutions. But this policy-speak needs to be ratcheted up. Closure of large scale residential institutions is no longer a policy nicety – it is a core human right enshrined in international law.

Making recommendations about the right to live in the community falls well within the mandate of torture prevention inspectorates. Further challenges await them in the next decade, including monitoring inappropriate mid-size solutions to de-institutionalisation including 12-bed group homes and smaller residences: these can often be as regime-like as large institutions, and still be places where people are *de facto* detained. Add community treatment orders (famous in Australia!) to the mix and we have the ingredients of coercion with real implications on restrictions of liberty, thereby triggering monitoring.

Cooperation is essential between the different actors to further develop and clarify standards, especially how inspectorates should engage in these key policy issues. Collaboration needs to take place horizontally between UN treaty bodies – it is fantastic we have the chairs of the CAT and the CRPD Committees in this room. At national level this needs to be replicated, as does vertical collaboration between international, regional, and national inspecting bodies. Outwards collaboration needs to take place to ensure that civil society are brought in, including people with experience of detention and high-level actors – indeed Article 4(3) of the CRPD says that people with disabilities and their organisations should be involved in the development of laws and policies which affect them.

Conclusion

We need a radical rethinking of the role of monitoring to achieve full participation in society of people labelled with disabilities. As Professor Jerome Bickenbach from the Universities of Toronto and Lucerne has observed in relation to a focus on deficits and disablement, "Eventually the folly of this will dawn on people and we shall all joyously realize that we are all abnormal, disabled, impaired, deformed and functionally limited, because, truth be told, that is what it means to be a human being.

Ladies and gentlemen, we can no longer accept impunity for rights violations against people who are placed in situations of considerable vulnerability. Inspectorates need to be vigorously challenging accepted practices, naming and shaming, holding a mirror to reality, speaking truth to power. Preventing ill-treatment means that inspectorates need to be fearless defenders of rights of *all* human beings wherever they may be detained.