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**Submission to Special Rapporteur on the Rights of Persons with Disabilities**

**Regarding the highest attainable standard of the right to health**

**Outline**

 Introduction

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**Introduction**

The Center for the Human Rights of Users and Survivors of Psychiatry conducts advocacy and capacity-building related to legal capacity, abolition of involuntary commitment and forced treatment, and support based on the person’s autonomy, will and preferences. CHRUSP is based in the United States and works at national and global levels and through cooperation with partners in other countries.

This paper expresses concerns about emerging patterns of violations in health care generally that are heightened from a survivor of psychiatry perspective, and addresses the violation of both positive and negative rights by mental health systems that start from pathologizing the human condition, concluding by proposing consultations on a way forward out of the disaster of forced and dehumanizing psychiatry.

1. **Concern about overall erosion of respect for autonomy in health care, US context**

In the United States we have seen an increasing erosion of patient autonomy in health care coupled with a decline in quality of services, which is related to the bureaucratization of both payment and actual care provided. Doctors are expected to ration their time with patients, often fail to perform routine physical examinations or ask about areas of physical well-being or functioning. Instead the purported shift to focus on preventive medicine has rationalized intrusive and irresponsible mental health screening, superficial dementia screening, questions about alcohol and drug use, body mass index, and membership in demographic identity groups that have a tenuous relationship to health care as such. In the name of prevention, the practice of medicine is being co-opted to serve purposes of social engineering, management of the behavior of individuals and reframing health care in terms of physicians’ management and direction of patients to strive for idealized behaviors instead of physicians’ responsibility to provide care and healing for conditions of which patients complain.

This ongoing erosion of quality and autonomy is exacerbated by the institution of third parties as ‘care coordinators’ beyond the individual’s expected relationship with their primary care provider. Care coordinators can be intrusive, badgering people who do not want their services, obtaining access to health records and potentially intervening in health care planning without the person’s knowledge. While care coordination is believed in the US to be a feature of managed care under the auspices of insurance companies, similar features exist in countries that have national health care, and legislation proposed in New York State to move to a single payer system would entrench the institution of care coordination as a **requirement** for all those who are covered.[[1]](#footnote-1)

This has a relationship to disability in several respects. 1) People who are currently trapped in coercive psychiatry or who are using long-term mental health services for any reason, become even more trapped when primary health care is coordinated with psychiatry. 2) People who are known to have received a psychiatric diagnosis are likely to have physical complaints ignored as the psychiatric label becomes a ‘master status’ to which everything else is ascribed and subordinated. 3) Survivors of psychiatry are among the groups that may be especially sensitized to the use of health care for social management and restriction of autonomy.[[2]](#footnote-2) Reacting to intrusive screenings and raising questions or objections related to privacy and autonomy may have detrimental impact on our ability to get care, and could even trigger the feared result of being targeted for restrictive measures, especially as we age and fall under the forms of scrutiny of mental capacity that are based in age-related discrimination. 4) Survivors of psychiatry, users of psychiatry and other people with disabilities may be high users of health care because of disability-related needs, and/or because of needs created iatrogenically by abuse such as forced/nonconsensual/insufficiently informed psychiatric drugging and electroshock and its impact on the body and mind. 5) There is a very real concern about potential for care coordination and other managerial features of current paradigm to be mobilized to implement measures such as guardianship, institutionalization or forced interventions related to any age- and/or disability-related discrimination in the exercise of legal capacity. So long as policymakers and lawmakers have failed to consider, much less internalize, the CRPD paradigm of legal capacity, a wide spectrum of the population is continually at risk knowingly or unknowingly of having health care turned against them. This impacts negatively on the willingness of individuals to disclose relevant complaints to health practitioners, and increases stress, which is among the primary causes of significant health problems such as heart disease.

Lastly there are technologies that have a primary purpose of coercive health management, such as long-acting injectable forms of neuroleptic drugs (in use for decades now)[[3]](#footnote-3) and microchipped pills that report back on compliance, now approved for the neuroleptic aripiprazole,[[4]](#footnote-4) Compliance technologies will always be targeted at people with psychosocial disabilities and others with whom the health industry (or government) has an adversarial relationship, and who are denied the right to make their own health decisions.

Recommendations:

1. Lessons from CRPD as human rights paradigm need to be internalized and transversalized in health care laws, policies and practices, highlighting especially the right to autonomy and a robust approach to free and informed consent of the person concerned.[[5]](#footnote-5)
2. It is necessary to remove the actuality and threat of restrictions of legal capacity in order to both respect all individuals’ right to recognition before the law and to deliver services that respect and fulfill the right to the highest attainable standard of health.
3. Health care needs to be organized and delivered in a way that expects and demands a high quality of care from practitioners and that responds positively to self-advocacy and movements for health care autonomy and empowerment.
4. Screening and management of personal health-related behaviors should be shifted to optional offers.
5. Prevention is not the same as management, and needs to emphasize empowerment to adapt information to one’s own self-knowledge and needs.
6. Related to prevention, health care needs to incorporate non-western modalities like Traditional Chinese Medicine and other forms of nurturant healing as primary and not merely auxiliary care.
7. Compliance technologies should be banned.
8. Laws, policies and practices should be reviewed to eliminate those that infringe on autonomy and privacy of individuals receiving health care.
9. **Global failure to respect autonomy and integrity in mental health services – violation of positive and negative rights**

The Special Rapporteur is well aware of the global emergency that continues to exist whereby states maintain laws, policies and practices that systematically institutionalize, hospitalize and forcibly treat people for actual or perceived mental conditions, violating their human rights to equal recognition before the law, liberty and security of person, freedom from torture, liberty of movement and right to live independently and be included in the community, and the right to the highest attainable standard of health.

The impact on the lives of people with actual or perceived psychosocial disabilities, or those who were treated as such in the past, is stark and massive, and includes significant impact on health. Neuroleptic drugs, as the most widely administered example of destructive medical-model treatments, which should be replaced by human support and non-toxic somatic treatments if desired, cause both short- and long-term health detriments, characterized as adverse effects.[[6]](#footnote-6) Administered against a person’s will, the impact on consciousness, physical and mental capabilities, and physical sensations amounts to severe pain and suffering that, given the discriminatory motivation (which is sufficient alone, but is nevertheless often combined with purposes relating to coerced change of behavior or punishment) satisfies the criteria for torture.[[7]](#footnote-7) It is common for several neuroleptics to be given at once, and to be combined with other mind-altering drugs, to produce extreme states of sedation and alienation from self with severe restriction in capacities for feeling and thinking. Among the physical health detriments caused by neuroleptics are movement disorders such as akathisia and tardive dyskinesia, diabetes and other metabolic disorders, and bowel impaction. Tardive dyskinesia, diabetes and many other health conditions last beyond the term of the drug regimen, and are considered permanent and irreversible. Studies have shown that people taking neuroleptic drugs have a shortened life span; the impact increased with the number of drugs taken.[[8]](#footnote-8) Even for people who voluntarily take neuroleptic drugs, the respect for free and informed consent is often questionable, as there may be no alternative forms of relief offered, the drug may be presented with inaccurate information that minimizes risks and hyperbolizes benefits, and laws and practices make it clear that coercive measures can be taken if the person does not consent. Subjugation of the person to a regime of degradation is apparent in the demand to adopt and internalize pathologizing diagnostic labels that are deemed to justify acts of torture, ill-treatment and arbitrary detention.

Social impact and psychological impact of forced drugging, institutionalization and related human rights violations also have an impact on physical health. Stress from the presence in one’s life of traumatic abuse that has little recognition from one’s family, neighbors, and wider society, and from which one has no guarantee of non-repetition, has negative health impacts that have not been adequately studied in this population due to social non-recognition. Silencing reinforces itself with the result that people suffer with little offer of relief except from the system that abused them, or if they are lucky enough, in circles of support within the survivor community or other communities of practice such as lesbian-feminism where there is a value of mutual care and listening outside the mental health framework. Hiding one’s history of psychiatric abuse produces one kind of stress while being open about it produces another. Being open with health practitioners can result in pity and other discrimination, while non-disclosure may omit facts relevant to health risks. Not everyone has a choice, with the universalization of health records a recent psychiatric diagnosis and hospitalization can follow the person forever with no escape and no possibility to obtain health care free from prejudice.

People who seek mental health services, or who need support in dealing with life challenges and an experience of actual psychosocial disability (limitation in desired activities or participation related to mental/emotional distress or altered consciousness) are ill-served by a mental health service system that contains the possibility of coercion, much less one in which coercion is a central pillar. Medical model services based on pathologizing labels (pseudo-medical diagnoses), the falsehood of chemical imbalance that pretends the problem is ‘broken brains’, and the use of destructive methods as forms of treatment all developed in tandem with coercion and in context of paternalistic, patriarchal and colonial assumptions about the inferiority of people with psychosocial disabilities and their rights and place in society. While there is a need to evaluate carefully in close collaboration with users of those services the value of maintaining any parts of the medical model system, it is abundantly clear that new forms of service and supports need to be developed in line with the paradigm shift of the CRPD that starts with the person concerned, their perspective, their anguish and complaints, and their right to full respect for personal autonomy and integrity.

Recommendations:

1. States must confront the human rights emergency that has resulted from their practice of confining and forcibly treating people with perceived psychosocial disabilities, and that has an intolerable human cost in ill-health as well as personal loss of freedom.
2. They need to shift their focus from care-providers’ perspective to the perspective of the people concerned. This does not mean consultations about whether coercion should continue, but rather first eliminating coercion to create a safe context for people to explore their needs and priorities. Support and training must be provided in line with CRPD human rights paradigm for people with psychosocial disabilities to conduct personal and collective self-advocacy to the extent desired, with an emphasis on peer support and training provided by human rights experts with psychosocial disabilities.
3. States should be continually reminded of their immediate obligation to release all individuals who wish to leave mental health services and to immediately cease forced drugging and electroshock, restraint and solitary confinement, as these practices amount to arbitrary detention and torture.
4. Medical model treatments that cause damage to brain structure and functioning such as electroshock and neuroleptic drugs should be removed from practice, and replaced by human support and non-toxic somatic alternatives.
5. States should provide free of charge all needed support in withdrawing from psychiatric drugs and meeting other health care needs caused by psychiatric treatments or the consequences of torture, other ill-treatment and arbitrary detention (institutionalization, unwanted hospitalization or drugging, etc.)
6. **Proposal for discussions and consultations on way forward**

I have long thought about and promoted the view that full and comprehensive reparations is a way forward to abolish the destructive system of forced psychiatry together with all its linked oppressions such as legal incapacitation and substitute decision-making, discrimination in child custody and marriage and voting, social exclusion and systematic prejudice against mad people, etc.[[9]](#footnote-9)

The Special Rapporteur on Health has outlined a different approach, one based on transformation of mental health services by creating alternatives to coercion with a view to the elimination of coercion.[[10]](#footnote-10) I have criticized his approach as inadequate to respond to the immediate obligation to release all persons from confinement in mental health services, and also remaining centered in a clinical perspective that assumes mental health services are the framework for answering questions and meeting people’s needs related to psychosocial disability.[[11]](#footnote-11)

The World Health Organization has taken an approach similar to that of the Health Rapporteur, creating training modules that are designed to shift mental health practices in the direction of approaches that may be compliant with CRPD.[[12]](#footnote-12)

Other survivors, and other allies and colleagues in general, may have alternate ideas for ways forward. It would be welcome at this point in our work to look at proposals for what it would mean to move forward on abolition of forced psychiatry as a specific system of oppression based in the hegemonic medical practices of the global north, and achieve full guarantees of autonomy and equality for people with actual and perceived psychosocial disabilities.

Recommendation:

The Special Rapporteur on the Rights of Persons with Disabilities, the Committee on the Rights of Persons with Disabilities, OHCHR, and other interested human rights mechanisms to convene an expert meeting along with wider consultations on ways forward to realize the rights of the CRPD for people with psychosocial disabilities with an emphasis on Articles 12, 14, 15, 19 and 25, in line with the obligations of an immediate and progressive nature as explained in CRPD General Comments No. 1 and 5 and the Guideline on Article 14.

1. See definitions section 5100, section 5105 on care coordination in Assembly Bill A4738. http://nyassembly.gov/leg/?default\_fld=&leg\_video=&bn=A04738&term=2017&Summary=Y&Text=Y. [↑](#footnote-ref-1)
2. I will add that survivors of sexual assault, especially female survivors for whom it is emblematic of systemic sex-based oppression, exploitation and discrimination are also especially impacted by coercive, authoritarian and paternalistic practices in health care. Gender on its own as well as intersectional with disability converges on the value of personal bodily autonomy and integrity. [↑](#footnote-ref-2)
3. See <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3000189/>. [↑](#footnote-ref-3)
4. <https://www.fda.gov/NewsEvents/Newsroom/PressAnnouncements/ucm584933.htm>, <https://www.madinamerica.com/2015/11/medication-mechanization-microchip-sensors-in-abilify-to-increase-medication-compliance/>. [↑](#footnote-ref-4)
5. Minkowitz, Free and Informed Consent and the Right to Refuse Treatment, presentation to ERC Voices workshop Jan 11, 2017, slides at <https://www.dropbox.com/sh/2goh5uuvel8rufq/AABP8nMxR3ZuaZbdwPuq1eXBa?dl=0&preview=MinkowitzNUIConsent.pptx> and video at <https://www.youtube.com/watch?v=HMtwP5DLqEc&t=0s&index=1&list=PLvKS9kpe3SYPAkFNESullduLXp9gknajx>. [↑](#footnote-ref-5)
6. CHRUSP et al, Joint Submission to Human Rights Committee for its review of the United States in October 2013 on nonconsensual psychiatric medication, sections I and II, <http://www.chrusp.org/file/294433/CHRUSPUSICCPRshadowreportFINAL.docx>. [↑](#footnote-ref-6)
7. See Minkowitz, The UN CRPD and the Right to Be Free from Nonconsensual Psychiatric Interventions, Syracuse Journal Intl Law & Commerce 34:2 (2007), <https://papers.ssrn.com/sol3/papers.cfm?abstract_id=1481512>, and Minkowitz, Forced Interventions and Forced Institutionalization as Torture /CIDT from the Perspective of Persons with Disabilities, Annex III to report of OHCHR Expert Meeting on Torture and PWD (2007), <http://www2.ohchr.org/english/issues/disability/docs/torture/AnnexIII.ppt>. [↑](#footnote-ref-7)
8. Joukamaa et al, Schizophrenia, Neuroleptic Medication and Mortality, British Journal of Psychiatry 188:2 (2006), <https://doi.org/10.1192/bjp.188.2.122>. See also <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4471960/>, <https://www.psychologytoday.com/us/blog/science-isnt-golden/201109/full-disclosure-needed-about-psychiatric-drugs-shorten-life>, <https://www.madinamerica.com/2011/11/%EF%BB%BFearly-death-associated-with-antipsychotics/>. See also WHO Information Sheet which acknowledges phenomenon of early death but ignores contribution of psychiatric drugs including to the causation of illnesses such as diabetes that shorten life span, <http://www.who.int/mental_health/management/info_sheet.pdf>. [↑](#footnote-ref-8)
9. Minkowitz 2007 presentation to OHCHR expert meeting (see fn 7); Minkowitz, Reparations: It is Conceivable, <https://www.madinamerica.com/2012/12/reparations-it-is-conceivable/>; Guiderails and Reparation, <https://tastethespring.wordpress.com/2016/08/23/guiderails-and-reparation/>; Minkowitz, Forced psychiatric interventions: right to remedy and reparation, in Open Minds, <http://www.chrusp.org/media/AA/AG/chrusp-biz/downloads/254413/Open_Minds_Reparations_article.docx>; also Orefellen, Torture and other ill-treatment in psychiatry – urgent need for effective remedies, redress, guarantees of non-repetition, <http://www.chrusp.org/file/294485/Side_event_CRPD_Art15_March2015_Hege.pdf>. The Special Rapporteur on Torture (A/HRC/22/53), Working Group on Arbitrary Detention (A/HRC/30/37), and Committee on the Rights of Persons with Disabilities (Guidelines on Article 14) have acknowledged a right to reparation in connection with human rights violations related to forced medical/psychiatric interventions and hospitalization. [↑](#footnote-ref-9)
10. Report of Special Rapporteur on Health, A/HRC/35/21 (2017). [↑](#footnote-ref-10)
11. Minkowitz, New UN Report: Steps Forward, But No End to Impunity, <https://www.madinamerica.com/2017/05/steps-forward-but-no-end-to-impunity/>. [↑](#footnote-ref-11)
12. WHO Quality Rights training modules, <http://www.who.int/mental_health/policy/quality_rights/guidance_training_tools/en/>. [↑](#footnote-ref-12)