Free and Informed Consent and the Right to Refuse Treatment

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Overview

- CRPD text and jurisprudence
- Purposive understanding of free and informed consent as a human right
- Pre-CRPD and CRPD approaches to consent
- Making free and informed consent meaningful for using and/or refusing mental health services

CRPD freedoms

- Legal capacity on equal basis with others, all measures to respect person's will and preferences (Article 12)
- Free and informed consent in health care on equal basis with others (Article 25)
- Liberty and security of the person on an equal basis with others, no deprivation of liberty based on disability (Article 14)
- Freedom from torture and other ill-treatment (Article 15)

CRPD jurisprudence: GC 1 and Art 14 Guidelines

- No restriction of legal capacity (decision-making) based on actual or perceived mental capacity
- Best interpretation replaces best interest determinations when after significant effort not feasible to determine will and preferences
- Right to refuse support
- Legal capacity at all times including in crisis situations
- Access to independent support and non-medical options in relation to mental health treatment decisions
- Involuntary commitment in mental health facilities violates Articles 12 and 14
- Non-consensual treatment violates Articles 12, 14 and 15

CRPD entitlements

- Access to support and accommodations in exercising legal capacity (Article 12)
- Support services for living in community and preventing isolation (Article 19)
- Adequate standard of living, social protection (Article 28)
- Health care and services including those related to disability (Article 25)

Meaning of free and informed consent

- Requirement of free and informed consent protects personal autonomy and physical and mental integrity
  - Human rights perspective, centers rights-holder
- Medical personnel prohibited from acting without consent
- Must not employ force, coercion, incentive, deception or undue influence
- Must provide rights-holder with information that is complete, accurate, accessible and with ability to have questions answered

Pre-CRPD standard

- Traditionally, pre-CRPD, ‘competence’ was thought to be part of free and informed consent
- Poor decision-making skills thought to negate autonomy
- Assumption that one person can legitimately judge another’s decision-making skills
- Folded into ‘informed consent’ standard in formulations such as ‘understanding and appreciation of the nature of a treatment and its risks and benefits’

Pre-CRPD standard 2

- Political character highlighted in mental health context, where the 'nature' and 'risks and benefits' of treatments are highly controversial and disputed
- Treatments used to control and punish
- Rights-holder de-centered, protects medical personnel from liability and assigns authorized decision-maker to satisfy legal system

CRPD legal capacity

- Article 12 establishes a human right to universal adult legal capacity (right to make decisions)
- No restriction of legal capacity based on actual or perceived mental capacity (decision-making skills)
- Accommodations and support provided in exercising legal capacity, subject to the will and preferences of the person concerned
- Right to make decisions must be respected at all times including in crisis situations
- When after significant effort, not feasible to determine will and preferences, 'best interpretation' rather than 'best interests' determination is applied

Implications for consent

- With no ‘competence’ element, free and informed consent no longer regulates the rights-holder, only the duty-bearers (medical personnel and the state)
- Paradigm shift is beneficial not only to PwD but to society as a whole

Issues re free and informed consent in mental health system

- Forced 'treatment'
  - Dialectical interweaving of legal capacity/right to refuse, and freedom from torture and ill-treatment
  - Survivors create caring spaces to disclose harm and its impact and to heal
  - Our intuitive understanding: violence authorized or sponsored by state = torture
    - See Minkowitz (2004), (2007a) and (2007b) for analysis of forced psychiatric interventions as torture
    - Special Rapporteur on Torture Manfred Nowak (2008) substantially adopted Minkowitz/WNUSP formulation holding that treatments aimed at correcting or alleviating a disability may be torture or ill-treatment when enforced or administered without free and informed consent of the person concerned

Issues, forced ‘treatment’ cont’d

- Unequivocal, absolute prohibition of all coercive mental health interventions must be incorporated into law
- ‘Mental health laws’ like ‘apartheid laws’ or ‘sodomy laws’ must be abolished and not reformed
- Forced ‘treatment’ practices taint the possibility of any free and informed consent in mental health

CRPD-compliant law reforms

- Law reforms to implement CRPD Article 12 cannot violate Article 14, and vice versa
- Shifting involuntary hospitalization and involuntary treatment from stand-alone mental health law to incapacity legislation continues to violate Articles 12 and 14
- Removing references to mental health condition to create 'disability-neutral' coercive measures based on predictive assessments such as danger to self or others continues to violate Articles 12 and 14
  - Retrogression in human rights if it imposes such measures on general population
  - Outcome-based deprivation of legal capacity and 'best interests' protectionist measures prohibited under GC1

CRPD-compliance

- Avoid non-compliant reforms and ensure cross-referencing
- Holistic and comprehensive approach to CRPD implementation with transversal perspective of users and survivors of psychiatry/ people with psychosocial disabilities
- Reparations framework can support coherent measures to mark break with violations, align policy with survivors' perspectives, promote 'truth and reconciliation' based on CRPD-compliant measures acceptable to survivors

CRPD free and informed consent

- Free and informed consent *by the person concerned* required for all health care and services including mental health
- Comprehensive Article 12 and 14 reforms resulting in prohibition of all forced, coerced or otherwise non-consensual treatment
- Duties placed on medical personnel to comply with CRPD standards:
  - Respect decisions at all times including in crisis situations
  - Best interpretation after significant effort replaces best interests
  - Discuss treatment directly with person concerned and seek their response, rather than supporter's
  - Provide accurate and accessible information about proposed treatment, including non-medical options and 'wait and watch'
  - Maintain good practices of accessibility, accommodations and access to independent support for treatment decisions

Systemic measures to support free and informed consent

- Review law and policy frameworks to detect and eliminate legacy of coercion in mental health services; enact positive measures:
  - Bundling of services (e.g. housing or income assistance together with mental health treatment) with purpose or effect of promoting compliance and punishing noncompliance
  - Compliance with mental health treatment as requirement in penal system for parole, probation, good behavior, diversion, restorative justice measures
  - Culture of compliance in mental health services, fear and shame and misinformation used as tactics, undermining self-confidence
  - Family and community use threats, deception, coercion, force, exclusion and withholding of resources, pejoratively label behavior as 'mental illness' and view treatment resistance with suspicion
  - Housing, education, health, social service providers refuse to serve individuals who resist mental health treatment
  - Dementia settings often locked and drugged

Systemic measures cont'd

- Establish standards for information provided on mental health treatments such as psychoactive drugs, electroshock, and psychosurgery, that are based on unbiased evidence (independent from industry sources) and take full account of adverse effects, dubious efficacy and nature of the treatment as somatic remedy for psychological distress
- Provide easily accessible system for service users to report adverse effects (NGOs can supplement state system, but state system should also be accessible)
- Overhaul research and oversight to disengage from industry

Systemic measures cont'd 2

- Shift policy and resource emphasis to new paradigm of social inclusion,* user-driven supports for dealing with distress and madness based on Articles 12 and 19
  - See Memorandum (2016); Intentional Peer Support website
- This is complementary to doing away with force and coercion, paradigm is based on mutual respect for autonomy, maintaining connection in times of distress and tension, unlike medical model that is managerial and hierarchical, objectifying and depersonalizing 'illness' and 'symptoms'

Conclusion

- Free and informed consent inseparable from ‘logical corollary’ right to refuse treatment
- Right to refuse (and duty to respect refusal) is a starting point for CRPD-compliant law and policy reform, additional measures needed
- CRPD by eliminating ‘competence’ as component of consent allows us to unequivocally center the rights-holder perspective
- Users and survivors of mental health services should lead reforms and monitoring

Resources

- Minkowitz (2004) − Forced Interventions Meet International Definition of Torture Standards (Advocacy Note)
- Minkowitz (2007a) − UN CRPD and the Right to Be Free from Nonconsensual Psychiatric Interventions
- Minkowitz (2007b) − Forced Interventions and Institutionalization as Torture/CIDT from perspective of persons with disabilities (ppt)
- Nowak (2008) − Report of Special Rapporteur on Torture, A/63/175
- Memorandum on Model Law for Inclusion (2016)