

SUBSTITUTED DECISION MAKING AND COERCION: THE SOCIALLY ACCEPTED PROBLEM IN PSYCHIATRIC PRACTICE AND A CRPD-BASED RESPONSE TO THEM

GILES NEWTON-HOWES, LEAH KININMONTH, SARAH GORDON*

ABSTRACT

Psychiatry has a long tradition of enforcing 'care' within mental health settings, through formal and informal coercion, often with little regard to decision-making capacity. Despite scant evidence for the effectiveness of coercive interventions and the wide variation in their application, indicating structural as opposed to health-driven reasons for use, coercive practices continue to be routinely used internationally. This is notwithstanding the recovery model of care that is endorsed on a national public policy level in many countries. Further, the Convention on the Rights of Persons with Disabilities (CRPD) and its Committee make plain that the use of practices of coercion for those who experience disability, including people who experience psychosocial disability, are unacceptable and in breach of their and other international conventions. The CRPD is interpreted as demanding an end to coercion, primarily through substitute decision-making being replaced with supported decision-making. This critical analysis examines the development of coercive practices in psychiatry, how they have become embedded as both common and socially acceptable, and approaches that may help to reduce their use in light of the CRPD. Models of care where changes have been successful in reducing substitute decision-making and promoting supported decision-making are highlighted to challenge some of the inertia to change.

I. INTRODUCTION

The World Health Organisation defines health as, "...a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." (1) Health in this context stretches beyond the correction of a physiologically abnormal marker, the anatomical correction of a physical abnormality or the support of a person to the point of temporary happiness. Health includes and is reliant on the support of resilient psychological well-being. Despite this, medicine continues to be increasingly specialised (2) with the focus being biological and narrow (3). In the area of psychiatry, change over time has not led to a similar degree of subspecialisation (4) and there have been some attempts to introduce a more holistic stance, such as through adoption of the biopsychosocial model of care (5, 6).

Despite this, many problems faced by people who experience psychosocial disabilities create challenges in relation to the delivery of effective support. Endemic poverty, substandard housing, disparities as victims of violence, exploitation and abuse (7),

* Associate Professor Giles Newton-Howes, University of Otago, Wellington, New Zealand; Leah Kininmonth, World of Difference, University of Otago, Wellington, New Zealand; Sarah Gordon, World of Difference, University of Otago, Wellington, New Zealand. Corresponding author: Giles Newton-Howes, contact e-mail giles.newton-howes@otago.ac.nz.

discrimination in employment and economic opportunities (8), coercive and discriminatory legal and medical treatment (9) and disparities in physical health care provided to those who experience mental distress continue. Arguably some of these problems occur at the interface of psychiatry, public policy and society, constraining psychiatric practice within a context where systemic injustice exists (10). The normative societal position, and that of psychiatric practice, minimises the value of the voice of those who experience mental distress (11), adding barriers to even recognising the extent of problems, including those at the socio-political level, that impact negatively on individuals and the support they receive (12).

These problems result in reduced quality and effectiveness of support. The consequence of this are inequities and disparities in terms of patient outcomes, physical illness, and premature mortality (12, 13). The deprivation of usual legal freedoms, such as presumed capacity, violate fundamental human rights, and act to deepen these inequities and disparities and make challenging them difficult (14). The long-standing power imbalances in psychiatry (15), facilitated through coercive practices (16), create a globally established psychiatric normative practise, which is critiqued in this paper.

II. THE CALL TO REDRESS THE PROBLEM OF COERCIVE PRACTICE

Both the evidence that coercion is of limited effectiveness and human rights imperatives are coalescing to challenge coercive practice. The variation in compulsory treatment within the same jurisdiction, between regions and individual psychiatrists (9, 17, 18) suggests non-clinical factors drive decision making in relation to the use of coercion (18, 19). The evidence for many coercive treatments are weak. Community treatment orders, a form of coercive treatment, are an example of this (20). Furthermore, the use of coercive treatments are increasingly becoming less accepted and more often challenged from the perspective of international human rights conventions and bodies (21). This raises the question of how mental health services could be configured without elements of legal coercion (17).

A. The CRPD

The CRPD (22) was adopted by the United Nations in 2006 and came into force in 2008. Importantly, the CRPD does not create any new rights for people with disability (including people who experience psychosocial disability) but rather it clarifies the application of rights and seeks to protect the rights of persons with disabilities that exist in other international treaties (23). These have been described as including: dignity, equality, non-discrimination, individual autonomy, fair access to resources and support, and full social participation and inclusion (24). Interestingly the CRPD, developed with considerable input from those with experience of disability, recognises that disability occurs when society does not sufficiently accommodate an impairment or, in other words, where 'various barriers may hinder the full and effective participation of persons with impairments in society...' (14). As Article 1 states:

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

This contrasts with the current biomedical model of disability (25) that sees deficits as being within the individual. One of the most contentious provisions of the CRPD is Article 12, equal recognition before the law, which entails the right to legal capacity (25, 26). Legal capacity involves two strands – legal standing (to hold rights) and legal agency (to act on those rights and have them recognised), including specifically in relation to fundamental decisions regarding health.

The premise of the CRPD is the contention is that despite a perceived or actual impairment in decision-making ability (often referred to as mental capacity), people experiencing psychosocial disability maintain the right to legal capacity. No matter how impaired a person's decision-making capability might be, this must not be used as justification for denying legal capacity. As an example, consent or rejection of medical intervention involves an exercise of legal capacity (27), and this is free of the normative value of the decision itself (28).

B. Supported decision making as opposed to substituted decision making in light of the CRPD

In 2014, the Committee (29) issued a general comment making it clear that Article 12 and the right to legal capacity should be interpreted to ban any form of substituted decision making (where people make a decision on behalf of another person). This radical stand was considered necessary as: "there are ongoing violations found in mental health laws across the globe, despite empirical evidence indicating its [forced treatment's] lack of effectiveness and the views of people using mental health systems who have experienced deep pain and trauma as a result of forced treatment" (29).

To support coercion within the most commonly based 'best interests' framework is an example of substitute decision-making and remains non-compliant with the CRPD. The act of substituting a decision in the patient's presumed interest requires an outcome that is 'the good' in the substituter's perspective, and this approach by its very nature is a tautology.

The CRPD Committee identify that support in the exercise of the right to legal capacity requires a paradigm shift in the practice of services - from the approach of substitute decision-making that involves the determination and delivery of supports considered by others to be in the best interests of individuals to the approach of supported decision-making that involves the determination and delivery of supports in accord with the will and preferences of individuals.

The interpretation of the CRPD Committee has caused significant debate in the literature, with the response by some scholars and clinicians being critical, defending the need for coercion (30, 31). Concern has been raised that potentially serious adverse consequences could arise from a 'supported decision-making' only stance (25, 32). These consequences are identified as including possible legal (33, 34), social (33),

and societal impacts. Unintended consequences, such as increased criminalisation (24, 25), is given as an example of this. It has been argued that to leave persons with mental disorder, "...free to destroy their own lives and ruin the lives of their loved ones" (35) severely endangers the interests of that person, or others, by blocking necessary preventive action, and preventing extra, positive entitlements being conferred (24). Others go so far as to say that failure to provide (involuntary) treatment in response to the impact of a person's disability is in conflict with Article 25 of the CRPD (the right to the highest attainable standard of health (23, 24, 36)) and is therefore itself discriminatory (24). Taken as a whole, this view considers that the Committee fails to offer adequate guidance on how to resolve situations where rights are in conflict (e.g. autonomy versus protection of interests of vulnerable persons (14)), where there are conflicts between will and preferences in different moments (37), when there is a radical change in a person's preferences (potentially related to psychopathology) (14) or what to do in emergency situations (25). The fundamentally 'supported only' view is considered by these critics to ignore the realities of imminent threats to the safety of a person who is experiencing mental distress, or threats to the safety of others around them (24).

As such, there is additional concern that the duty of countries to protect the vulnerable is in conflict with the Committee's interpretation of the CRPD (24, 35, 36).

These rights are, however, automatically granted to every other adult. People are allowed to make many poor choices, which may lead to harm to themselves or others. This is true of other medical decisions, such as the decision to smoke or refuse a cancer curing operation but these choices are not removed from those individuals just because of the obvious harm that will occur.

Although the CRPD reflects a rights-based ethic, the underlying basis is deontological. This perspective is radically different from a utilitarian position that is focused on providing 'the good'. Such a view necessarily examines the 'ends', to support a 'good'. The practice of psychiatry involves some of the most challenging ethical questions in medicine and the CRPD highlights key tensions inherent in much clinical practice. As a result of the potential issues considered by critics to be a consequence of implementing change in accord with the position of the CRPD Committee, there is a consistent call for exceptions to the "absolutist" position of the Committee which is in "stark contrast" with the reality of current mental health care (30) and is "dramatically at odds" with centuries of legal acceptance of involuntary detention and treatment (14) where prevailing concepts have been widely considered as reflecting a human rights perspective (33). It is thought that the CRPD provisions threaten to "disrupt" long-standing approaches to mental health law which negates traditional approaches to protection of those without capacity (23) and is contrary to the fundamental principles of virtually any sophisticated legal system (24).

Despite the fact that there is no jurisdiction in the world that has legislated the 'absolutist' recommendation of the CRPD, any suggestion that the status quo is the best or most appropriate system for the support of those who experience mental distress no longer holds up to scrutiny. The current psychiatric system in many parts of the world causes harm, at least from some patient's perspectives, and includes

powers that do not respect the means of people to make choices for themselves, even if they are not considered to be the 'right' choice by others (38).

Zinkler (30), a leading psychiatrist and academic who has led a coercion-free psychiatric support system, states that changes in mental health practice toward a system based only on support, without any resort to the use of coercion, are possible and can be operationalised. Under this approach, psychiatric diagnosis and/or any other manner of rendering a determination of psychosocial disability, would not lead to restrictions of liberty. Rather the task of healthcare professionals would be to change the nature of the support provided, to encompass both informal and formal support arrangements that enable individuals to make decisions in accord with their will and preferences (14). The type and intensity of support required will vary based on need in relation to decision-making abilities. For example, those in crisis situations may require more support. In such a system, the abolishment of coercive practice should not equate to the abandonment of support. So, if a person declines the assistance of mental health and social services, it would then be incumbent upon those services to be creative in identifying various options that may be more or less acceptable to the individual, plus identify and implement effective forms of engagement to determine wills and preferences, and develop further individualisation of support. One of the keys to supported decision-making will be the provision of options in terms of the where, how, when, what, and who of service delivery. For example, in terms of where, services could be provided in an environment of the individual's preference such as at home, in a crisis centre or at a friend's home.

Engendering change by amending the law is, however, difficult and may ultimately prove impossible to do in a way that adequately addresses the problems with the psychiatric system that exist, at least from the perspective of the CRPD and its committee. The CRPD was widely ratified over a decade ago, and every legal amendment to mental health law globally since that time falls short of the standard of supported decision making as recommended by the Committee. Critique of efforts to legislate with the CRPD in mind suggest they are superficial (8), and it is difficult to conceptualise what law reform would actually involve to meet the standards of the CRPD. Greater effort than simply those of policy makers or government is required. A concerted and multisystem international change program is needed to support systems and services to convert to more human rights-based models of practice.

C. Alternative models of care: CRPD compliant mental health practice

Successful alternative models of psychiatric practice, involving conceptual changes on the meso-level, have been developed. In their systematic review, Lloyd-Evans and Johnson (39) note that mental health wards may be "harmful, frightening, stigmatising, and socially dislocating". They suggest that community-based residential crisis services can provide a feasible and acceptable alternative to hospital admission for some people experiencing acute mental distress. For these to succeed Lloyd-Evans and Johnson identify a rapid response to distress and the management of acuity as key principles. Specific models, as detailed below provide real-world evidence that support can be delivered in a fashion that would be considered CPRD compliant. Notably, none of these models arose in response to the CRPD. However, they do act

as examples of how change, even at this level, can be implemented to work in practice and result in dramatic changes to the individual experience of mental health care. They also provide a practical counter-argument to those who suggest implementing the CRPD as understood by the committee is impossible. Obviously these examples exist within a social framework where coercion still exists, as no jurisdiction has yet provided for a fully CRPD-compliant system. However, this should not be seen as a reason to dismiss them. They are models that provide alternatives, and do not require the broader coercive system to enable them to exist. As such they provide a direction of travel for jurisdictions to consider more widely.

The Heidenheim Mental Health Service in Germany is an example of a new coercion-free environment. Since 1995, they have operated an open-door system with no seclusion. The use of antipsychotic medication has reduced by more than 40% without coercive use (19). A critical element of this service is well trained staff.

Another example is reported by Mezzina (40). Trieste is a sustainable, community-based system that provides a 24/7 network of walk-in community mental health services, where service users are considered guests. The shift of focus is from hospitalisation to hospitality. The no-coercion system of support for recovery involves the health and welfare systems working together based on a whole-of-life vision. This service has led to decreased acute presentations and crises. There are low rates of hospitalisation and compulsory treatment rates are less than 10 per 100,000 of population, which is internationally admirable (17, 18). Again, they have a strong focus on training, motivation, and professional development of staff that facilitates a high standard of positive attitudes and skills.

The Soteria project (41) is a third example of innovation in service delivery that is aimed at minimising coercion and facilitating supported decision-making, in line with the requirements of the CRPD. Designed for those early in the course of psychosis, 58% of Soteria subjects received antipsychotic medication during the follow-up period, and only 19% were continuously maintained on antipsychotic medications. This suggests significant recovery for those participants.

One notable reflection from these services is that the lack of coercion and the facilitation of supported decision-making appears to result in reductions in medication use. Contrary to assumptions in this area and clinical guidelines, the published data is inadequate to conclusively evaluate whether long-term antipsychotic medication treatment results in better outcomes (42). The fact that coercion is then used to compel people to adhere to such treatment regimens provides further support for CRPD-compliant models of service delivery.

As these projects show, a CRPD-compliant, recovery-oriented and sustainable coercion-free psychiatric environment can be conceptualised and implemented without the resultant adverse consequences predicted by some. Whilst all these are currently smaller scale projects, they do serve to provide some challenge to the inertia in response to recommended legal reforms; and some guidance around operationalisation. The CRPD and these exemplar projects provide a fulcrum around which social opinion can be levered to support such changes on a national level. It is

multi-system changes, including shifting social perspectives, psychiatric developments in practice as well as legislative reform that will support more extensive reform of services in accord with the CRPD recommendations. Further, this approach to change does not place the burden for insisting on foundational human rights on those who experience psychosocial disability.

III. CONCLUDING REMARKS

Changing any national and international systems to improve health is a challenging task. International human rights instruments and bodies act to articulate basic rights and freedoms that every person in the world should have and monitor countries in relation to the protection of those rights. In this case it is the CRPD, clarifying that the application of existing human rights requires coercive practices (substitute decision-making) in psychiatry to be abolished and replaced with supported decision making. Progressing such change is proving slow, despite over a decade of work from the direction set by the CRPD. In examining the international landscape, examples can be found of CRPD-compliant services, albeit within jurisdictions that still enable coercion. Nonetheless these examples appear to flourish from the development of thoughtful training, care systems design and founding principles in line with those of the CRPD. These not only function but are also reported to be engendering good outcomes, which appear to be sustained over prolonged periods, for people who experience psychosocial disability. As such there is both the international legal convention and practical examples of how supported decision making and non-coercive practice can occur. It is not for individual clinicians, or patients, to enact change alone. As this paper identifies, ever increasing travel towards a socio-political climate enabling non-coercive psychiatric practice is imperative and needs to be supported.

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