Global Mental Health

Changing Norms, Constant Rights

Lawrence O. Gostin and Lance Gable

Of all the vulnerable groups that face stigmatization in our society, persons with mental disabilities are perhaps the most disadvantaged. The litany of abuses perpetrated against persons with mental disabilities is long and sadly varied. Persons with mental disabilities have been involuntarily confined without due process or adequate cause, subjected to squalid living conditions, denied appropriate care and treatment both within and outside of institutions, and confronted with daunting physical and social barriers that prevent their full participation in society. Moreover, the widespread recognition of this mistreatment has not prevented it from continuing to occur in multiple locations around the world. The vast majority of communities continue to treat individuals with mental disabilities according to the hurtful and incorrect stereotypes associated with incompetency and dangerousness.

This article will explore the changing norms in mental health systems around the world. Frequently, these systems—and the societies that implement them—fail to protect the health and well being of persons with mental disabilities. In order to remedy these historical and ongoing problems, mental health policies should incorporate human rights standards and corresponding notions of fairness and justice. More specifically, mental health law and policy should provide due

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process and humane treatment for persons housed in institutional settings, facilitate individualized mental health care plans and community care wherever possible, and recognize the right to health in the form of public access to mental health care.

The Abiding Myths of Mental Illness. Persons with mental disabilities have faced three historic burdens that have been transformed into powerful and enduring myths in the social consciousness. These pervasive myths inform much of the public discourse surrounding mental illness and guide many of the related policy decisions. Unfortunately, the perpetuation of these myths has resulted in continuing misperceptions regarding the reality of persons with mental disabilities and has contributed to enduring negative stereotypes.

The myth of incompetency revolves around the concept that individuals with mental disabilities are incompetent to make rational decisions or give consent. In reality, incompetency is not synonymous with having a mental disability. Mental disabilities vary greatly. While some mentally disabled people lack so-called competence, many mental disabilities do not cause any sort of incompetency or only limited forms of incapacity. Competency is not an all or nothing proposition. It is tied to specific services, decisions, or functions. Policies that assume a constant state of incompetency or impute a finding of incompetency in one area to apply to all other areas of decisionmaking misunderstand mental disability and violate human rights standards. Rights violated by policies that presume incompetency include rights to work, vote, maintain privacy, and have a family life. In addition, these policies may contravene the rights to health, the benefits of scientific advancements, bodily integrity, and procedural rights and protections.

Another common misconception is that individuals with mental disabilities present a danger to society. The evidence suggests that persons with mental disabilities are no more dangerous than the population in general. A key variable in predicting dangerousness is co-morbidity with alcohol and drug addiction, rather than mental illness. Research demonstrates that there is no statistical correlation between mental disorders and the potential to pose danger to others.[1] In fact, most violence is committed by people who do not have a mental illness.[2] Nevertheless, the media often exaggerates the relatively few instances where a mentally ill person commits a violent act.[3] Media accounts of these incidents highlight mental illness as the cause of the violence and thereby increase stigma for all persons with mental disabilities. In the United Kingdom, such singular incidents have sparked sufficient public outrage to serve as an impetus to change existing mental health laws. The recently enacted Mental Health Act of 2007 attempts to address this "dangerousness" by placing more emphasis on preventive confinement at the expense of treatment and patients' rights.[4] The mental health law reform slogan in England and Wales was, "safe, sound, and secure," which evokes stubbornly resistant stereotypes about persons with mental disabilities.[5]

The third myth is that deinstitutionalization solved many or most of the human rights problems faced by persons with mental disabilities. The discovery of powerful psychotropic drugs in the 1960s and 1970s sparked a revolution in the

treatment of mental disabilities. Prior to the advent of these medications, many persons with severe mental disabilities required institutional care and were compulsorily admitted to mental health facilities for indefinite periods to receive that care. The new medications proved to be a remarkable new way to treat many mental disabilities and allow for the release of many institutionalized patients back into the community. This development had the potential to benefit both the patients, many of whom regained their freedom to move freely and associate with others in society, and the governments who ran the institutions and were able to save money from the decrease in institutionalization.[6]

This putative win-win situation nevertheless has turned out to be another myth. It has been widely noted that deinstitutionalization was not the panacea envisioned by mental health policymakers and mental disability advocates.[7] Treatment with pharmaceuticals in the community is only effective if there is a well-established infrastructure to ensure that medications are available. In countries where deinstitutionalization was not coupled with the creation of a community care system, such as in the United States, many persons with mental disabilities do not have sufficient access to medication or any other treatment for their mental disabilities. Moreover, anti-psychotic medications, even when available, offer sharply mixed results. Although they ameliorate many of the serious symptoms of schizophrenia and other forms of major mental illness, they have disabling adverse effects, especially when administered in large doses and over prolonged periods of time. Powerful antipsychotic medications have caused uncontrollable and usually irreversible tics and shaking—a debilitating neurological condition called *tardive dyskinesia.*

Community mental health services that have been established often remain chronically under-funded, fragmented, and punitive.[8] As a result, incarceration and homelessness have become part of life for society's most vulnerable population.[9] What eventually transpired was a massive transmigration of mentally ill people from "old" psychiatric institutions to "new" institutions—jails, remand centers, prisons, nursing homes, and homeless shelters.[10] Prisons have become the de facto mental health systems in many countries around the world, leaving this population segregated and forgotten. Tragically, a policy designed to allow persons with mental disabilities greater freedom ended up with many of them incarcerated, usually for minor offenses, in a prison system that similarly restricts their liberty but does not provide adequate, if any, treatment.

These changes to the mental health system have affected the range of relevant human rights concerns. In the past, the biggest human rights problems were connected to civil liberties issues related to involuntary confinement and other restrictions on autonomy and dignity.

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However, new human rights issues have arisen as the consequences of deinstitutionalization: prison suffering, drug side effects, reduced access to care and treatment in the community setting, and homelessness.

The Proliferation of Human Rights. The development of human rights protections for persons with mental disabilities represents the culmination of the collective efforts of two of the great international social movements of the last sixty years: the human rights movement and the disability rights movement.[11] The human rights movement has generated foundational principles for protection of the rights and freedoms of people around the world. Human rights apply to all individuals regardless of nationality, geography, or disability status. The disability rights movement has championed the rights of persons with disabilities through many national and international settings, often using the language and moral grounding of human rights.

The links between human rights and disability rights have strengthened as human rights have proliferated and evolved in international legal instruments, national legislation, and court rulings. Several notable developments have expanded the scope of human rights norms and enhanced the structures in place to enforce these norms.[12] The UN General Assembly adopted the Principles for the Protection of Persons with Mental Illness and for the Improvement of Mental Health Care (MI Principles) in 1991.[13] The MI Principles recognize human rights principles such as respect for dignity, non-discrimination, and natural justice, and apply these principles to persons with mental disabilities.[14] The UN Convention on the Rights of Persons with Disabilities (CRPD), completed in 2006, embodies the most direct and comprehensive articulation of human rights to persons with mental disabilities within the UN system.[15] Regional human rights systems in Europe and the Americas also have developed jurisprudence applying human rights to persons with mental disabilities.[16] Yet, despite the promise of expanding applications of human rights to mental health, achieving this reality remains elusive. Ongoing abuses defy human rights enforcement and continue a shameful history of stigma, discrimination, and mistreatment of persons with mental disabilities across many societies.

The Need for Human Rights Protection. Persons with mental disabilities continue to face numerous violations of their human rights. Most often, these violations of human rights comprise four interrelated categories: liberty, dignity, equality, and entitlement.[17] The *liberty* interests of persons with mental disabilities may be infringed through unwarranted detention. Without appropriate due process protections, people with mental disabilities may be confined against their will and often without justification. Even if involuntary confinement is warranted, persons with mental disabilities frequently are not provided with humane living conditions in institutional settings. Failure to assure suitable standards of sanitation, access to needed care and treatment, and other conditions necessary for a person's well being undermine *dignity*. Multiple barriers erected in law and misperceptions in public understanding exacerbate the perpetual stigma and discrimination that confront persons with mental disabili-

ties. These pervasive waves of social opprobrium engender ongoing *inequality* between persons with mental disabilities and other members of the community. Finally, access to high quality mental health services in the community is central to the health of persons with mental disabilities. This *entitlement* to services is consistent with the right to health and bolsters other human rights such as liberty and dignity. However, these services often are not provided due to cost and political opposition.

International legal instruments recognize the importance of these four principles and apply these rights to persons with mental disabilities. In so doing, these international instruments can act as a tool to enforce the welfare and human rights of persons with mental disabilities.[18] All four categories of human rights violations arise from circumstances in which systemic conditions and individual actors fail to treat persons with mental disabilities fairly. Consequently, it is imperative that these human rights receive appropriate consideration and protection to guarantee justice and fairness for persons with mental disabilities. Human rights jurisprudence, principally in Europe and now emerging in the Americas, addresses these four themes of liberty, dignity, equality, and entitlement through cases involving involuntary detention, conditions of confinement, civil rights, and access to mental health services.[19]

Liberty: Involuntary Detention. Human rights instruments and courts assert broad protection over liberty interests. The CRPD and Article 5 of the European Convention on Human Rights, for example, guarantee liberty and security of the person.[20] The European Court of Human Rights (ECHR) has been highly active in protecting the human rights of persons with mental disabilities. In a series of cases, the ECHR required proof of a recognized mental illness and a speedy independent hearing by a court for involuntary admission to a hospital pursuant to Article 5 of the European Convention on Human Rights. *Winterwerp v. The Netherlands* established that civil commitment must follow a "procedure prescribed by law" and cannot be arbitrary; the person must have a recognized mental illness, and require confinement for the purpose of treatment.[21] *X v. the United Kingdom* mandated speedy periodic review by a court with the essential elements of due process. The availability of habeas corpus was not sufficient for these purposes because it simply reviewed the technical lawfulness of the detention, but not the substantive justification.[22]

The ECHR has also addressed the problem of "non-protesting" patients, those that are physically confined but not under the force of law. A person may succumb to a show of authority or may be unable to provide consent.[23] In *HL v. United Kingdom*, however, the ECHR held that the "right to liberty in a democratic society is too important for a person to lose the benefit of Convention protection simply because they have given themselves up to detention, especially when they are not capable of consenting to, or disagreeing with, the proposed action."[24]

The shift toward community care has resulted in much lower numbers of persons involuntarily confined in psychiatric hospitals. In the aftermath of this deinstitutionalization, however, prison confinement remains a substantial human rights problem for persons with mental disabilities. Rates of mental ill-

ness in the prison population frequently exceed rates in the community.[25] In many different countries, severe mental illness occurs five to ten times more frequently among people in prison than in the general population.[26] Data from countries as diverse as Australia, Iran, New Zealand, the United Kingdom, and the United States confirm this conclusion.[27] Due to their condition, persons with mental disabilities are more susceptible to becoming imprisoned for minor behavioral disruptions. Once confined, they often have difficulty complying with prison rules and, as a result, suffer from additional punishment, isolation, and longer prison sentences. Imposing such severe consequences does not seem to be compatible with notions of fairness and justice.

Dignity: Conditions of Confinement. Non-governmental organizations continue to discover appalling conditions in institutions and residential homes for persons with mental disabilities.[28] These include long periods of isolation in filthy, closed spaces, lack of care and medical treatment, and severe maltreatment, i.e. being beaten, tied-up, and denied basic nutrition and clothing. The ECHR said that vigilance is vital due to "the position of powerlessness which is typical of patients confined in psychiatric hospitals."[29] Despite this vigilance, the ECHR's early jurisprudence was highly deferential to medical opinion in cases involving inhumane and degrading treatment.[30]

More recently, the Court has required increased medical attention and appropriate facilities for persons with mental illness.[31] More importantly, it has emphasized that the European Convention's proscription of inhuman and degrading treatment includes actions designed to humiliate persons with mental illness.[32] Further, the ECHR has found that inhumane and degrading treatment can be found when the cumulative effects of prison conditions are sufficiently abhorrent.[33]

The Inter-American Commission on Human Rights (IACHR) has begun to apply human rights standards to protect persons with mental disabilities from inhumane treatment.[34] In *Victor Rosario Congo v. Ecuador*, the IACHR found a violation of the right to humane treatment.[35] A person with mental illness had been struck in the head, denied medical treatment, and left in his cell for forty days. The Commission, relying on the MI Principles and other international obligations, asserted that "a violation of the right to physical integrity is even more serious in the case of a person held in preventive detention, suffering a mental disease, and therefore in the custody of the State in a particularly vulnerable position."[36] In December 2003, for the first time in its history, the IACHR approved "precautionary measures" to protect the lives, liberty, and personal security of 460 people detained under deplorable conditions in a psychiatric institution in Paraguay.[37]

Violations of dignity occur in prison settings as well. Mentally ill prisoners are highly vulnerable in these settings. This population is twice as likely to have been homeless before entering prison.[38] They also suffer disproportionately from problems with drug and alcohol abuse.[39] While in prison, few inmates receive access to adequate mental health services, both psychological care and essential medicines. Mentally ill prisoners are at very high risk of harm or death.[40] Many experience physical or sexual abuse and are injured before and during their time in confinement.

Equality: Civil Rights. Human rights norms extend to the exercise of a wide array of civil rights both within and outside institutions. Simply because a person has a mental illness, or is subject to confinement, does not mean he or she is incapable of exercising the rights of citizenship. Human rights bodies have helped secure equality through norms of access to the courts and privacy. The ECHR has found violations of the right to a fair and public hearing in the determination of a person's civil rights. The subject matter of these cases includes the right to control property, exercise parental rights, and be granted a hearing in the determination of incompetency, or placement into guardianship.[41]

The right to a "private and family life" under the European Convention can be a powerful tool to safeguard the civil rights of persons with mental illness. The ECHR, for example, has applied this privacy protection to free correspondence, informational privacy, marriage, and the parent-child relationship.[42] It has thus far declined to do so for sexual freedoms, but advocates are pursuing cases to defend this form of intimacy. The CRPD also explicitly protects many of these civil rights and will serve as an impetus for expanding these rights as the CRPD is implemented.[43]

Entitlement: Right to Mental Health Services. The final human rights theme, entitlement, is more fragile than the others because it involves the right of access to core mental health services. Although essential health services have a basis in ethics, they are more difficult to attain under international law. The right to health is a social and economic entitlement. Notably, the European Convention of Human Rights does not capture this set of entitlements. The IACHR also has not pursued the right to health even though the Protocol of San Salvador enunciates a full set of health rights.[44] Consequently, the scope and definition of the right to mental health has remained vague and variable.

Several contemporary initiatives on health rights in general and mental health rights in particular seek to further develop the right to mental health. The UN Committee on Economic, Social and Cultural Rights issued General Comment 14 on the Right to Health.[45] The UN Commission on Human Rights subsequently appointed a Special Rapporteur with a mandate to focus on the right to health.[46] The Rapporteur's first report in 2003 identified three primary objectives: promote the right to health as a fundamental human right, clarify its contours, and identify good practices for the implementation of the right.[47] The Rapporteur subsequently published a report on the right to health for persons with mental illness, which offers a complete account of the elements of adequate mental health services.[48] The

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CRPD also affirms a right to the highest attainable standard of health, access to habilitation and rehabilitation services, and inclusion in the community.[49]

Conclusion. The persistent human rights violations that continue to affect persons with mental disabilities will only be reduced through diligent efforts to recognize and remedy these violations at all levels. There are several possible solutions: legal, practical, and economic.

Legislation related to mental health should incorporate human rights norms and avoid pernicious misperceptions about the dangerousness and incompetency of persons with mental disabilities. Countries should ratify the CRPD and implement its human rights provisions. At the level of national legislation, the World Health Organization has published a mental health legislation manual that provides a tool for countries to adopt international human rights norms into domestic legislation.[50] International human rights norms will have maximum impact only if they are adopted by nations into domestic laws, policies, and programs.

The practical implementation of mental health policies consistent with human rights norms has the potential to greatly improve the well being of persons with mental disabilities by reducing stigma, increasing public acceptance, and reducing social barriers to living a full life. Institutions that provide services to persons with mental disabilities should be strictly monitored—whether civil psychiatric facilities or prisons—to ensure compliance with human rights norms of dignity. Institutions should conform to the rule of law and uphold principles of human rights. Institutions providing mental health care and treatment should ensure settings more similar to hospitals than to prisons or warehouses. Whenever possible, length of stays in these facilities should be limited and the model of community provision of care should be followed. Also, mental health policies should strive to provide care in the least restrictive setting possible, preferably in the community. Ideally, countries should offer a range of mental health services, including screening for mental illnesses, mental health education, and psychiatric services in hospitals and the community. Finally, communities should take affirmative steps to improve equality of opportunity for and reduce discrimination against persons with mental disabilities.

Countries and communities should ensure adequate funding for community mental health services. Human rights standards require robust community services to get people with mental disabilities off the streets into community care, and to facilitate their integration and inclusion in the community. A strong commitment of resources is a necessary underpinning for these efforts.

These approaches—legal, practical, and economic—can contribute to a mutually reinforcing support structure for persons with mental disabilities based on human rights standards. The widespread and consistent adoption of policies and practices consistent with human rights can help address the longstanding inequity and injustice faced by this population. Moreover, this model can provide the impetus to eliminate the insidious myths that surround mental disabilities and allow for persons with mental disabilities to fully participate in our societies.

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