WORLD PSYCHIATRIC ASSOCIATION POSITION STATEMENT ON THE RIGHTS OF PERSONS WITH INTELLECTUAL DEVELOPMENTAL DISABILITIES (IDD) AND CO-OCCURRING MENTAL DISORDERS

Kerim M. Munir, Ashok Roy, Working Group on IDD, World Psychiatric Association, and Afzal Javed, President, World Psychiatric Association

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Preamble

The Working Group (WG) on Intellectual Disabilities/Intellectual Developmental Disorders (IDD) under the auspices of the World Psychiatric Association (WPA) leadership was charged for developing a comprehensive statement on the Rights of Persons with IDD with co-occurring mental disorders. To date, no such prior document exists. The statement addresses the needs for inclusive services, training, and research for improved mental health outcomes for persons with IDD across the lifespan. An important justification for this effort is that mainstream psychiatry as a profession has the means and motivation to appreciably improve the mental health care of persons with IDD with special relevance for low resource settings.[1] A major change is required in emphasis that is inclusive of grassroots efforts in implementing person-centered care tailored to the abilities and aspirations of persons with IDD and their families and communities, blending the social and medical models of development and disability within a human rights framework.

Foremost, in considering the preparation of this statement we would like to address head on:

- Why we believe the United Nations (UN) Universal Declaration of Human Rights[2] serves as the foundational framework and why universalism and world citizenship on this topic is critical
- How such a statement on the rights of persons with IDD and co-occurring mental disorders interfaces with the UN Convention on the Rights of Persons with Disabilities (CRPD)[3]
- How such a statement on rights of persons with IDD and co-occurring mental disorders is relevant for optimal Public Mental Health globally as intended in the WPA Presidential Action Plan[4] – providing synergies between Public Mental Health, Disability, and Human Rights and points of reference in terms of development of "benchmarks" to be assessed and compared across persons with and without IDD and across world populations
- What can been learned in adapting these benchmarks in terms inclusive services, training, and scholarship in psychiatry and allied mental health sciences

Universal Declaration of Human Rights

A year following the introduction of UN Universal Declaration of Human Rights in 1948, the philosopher Hannah Arendt, in the aftermath of Second World War and Holocaust, was first to wonder about their universalism[5]. The Declaration had been adopted emphasizing the right to life, liberty, and security of all persons in society, but there was only secondary mention of disability. The idea of human rights belonging to all, simply by virtue of being human, is the basis of the Universal Declaration. According to Mahatma Gandhi this moral entitlement was not seen as adequate unless it was combined with duty. In a letter written to Julian Huxley, then Director-General of UNESCO, Gandhi boldly asserted that *"all rights come to be deserved and preserved from duty well done."* For Gandhi, *"the very right to live accrues to us only when we do the duty of citizenship of the world,"* encouraging us to "begin with a charter of Duties of Man." The rights he promised the will follow "as spring follows winter."[6,7]

The ratification of human rights by states has been necessary, but not sufficient, and for universalism to be achieved there would need to be an open world where human beings transcend borders and national jurisdictions. Universal Human Rights therefore applies beyond state borders, and to all persons who are citizens of the world, including those who are stateless and those who are state protected wards, among whom persons with IDD stand as a most vulnerable group.

The Universal Declaration foundational Article 1, translated in 500 world languages, asserts that all human beings are "*born free and equal in dignity and rights*" entitled to full equality under the law, including free speech, freedom of assembly, social and economic rights, education, social security, right not to be tortured, not to be subject to arbitrary arrest, and with right to seek asylum from danger and persecution. The Declaration, as well as the treaties and conventions that have flowed from it, is not merely a secular numeration of these basic rights, but the essential point is that the character of such rights are inalienable and cannot be taken away or given up. The rights imbued in the Declaration were therefore not created in 1948, but rediscovered, and part of an international *magna carta* of human rights worldwide. Indeed, when the UN human rights commission membership were convened at Eleanor Roosevelt's home in Manhattan in 1947, as the United States delegate, to draft the Universal Declaration (to which Mahatma Gandhi had been invited but could not attend due to other commitments), the voices of many traditions and peoples of the world were absent, including the voices under colonial rule from Africa, India, as well as China, and the Islamic world[8].

Ironically, the same year in 1947, in Staten Island, 20 miles southwest of Manhattan, the New York State Department of Public Health opened the Willowbrook State Residential School for children with IDD, among those housed there were many with autism spectrum disorders, cerebral palsy with and without intellectual impairments, as well as Down syndrome, and other congenital developmental conditions, referred to then as "the mentally retarded". Children were tied to chairs, slept naked on cold floors, and were denied medical care and food. Many were also used in the notorious hepatitis research studies and countless died. After a visit, the late Senator Robert Kennedy called the place "a snake pit."[9] With the efforts of families, activists, and lawyers Willowbrook finally closed in 1987. A US Congressional bill, drafted by the Disability Rights International (DRI) will help support disability activists and families in many countries worldwide to make sure that children grow up within families and help shut down Willowbrook like institutional settings that still exist around the world[10].

The question then and now remains: Is human rights universal as they apply to the most vulnerable with IDD and co-occurring mental disorders? Are human rights immersed in cultural values, or are they universal because they are considered natural and inalienable? As the rise of fundamentalist and authoritarian regimes further challenge universalism in many world contexts, our world order now is vastly different than in the aftermath of the Second World War.

On the upcoming 75th anniversary of the Universal Declaration of Human Rights, irrespective of these challenges to universalism by politicization and by authoritarian revival, a central framework is a timely undertaking for the WPA, that human rights of persons with IDD with co-occurring mental disorders ought not be based on the good faith alone, but a professional ethos in promoting care linked with rights for all vulnerable persons with IDD and co-occurring mental disorders. Such a framework needs to be attentive to poor resource settings, attentive to women and children, people with limitless sexual orientations and gender identities, minorities, people of all races, religions, and ages. Indeed, such an idea of universalism is not a Western construct, its roots lie across time and space, beginning in 539 B.C., when Cyrus the Great, first king of ancient Persia, on conquering Babylon, declared that all people had the right to choose their own religion, establishing racial equality, and freeing the slaves with decrees recorded on a baked-clay cylinder in the Akkadian language in cuneiform script[11]. The Cyrus Cylinder record is now recognized by the UN as the world's first charter of universal human rights.

United Nations Convention on the Rights of Persons with Disabilities (CRPD)

In 2001, initiated by Mexico, with subsequent crucial support of New Zealand, the UN General Assembly established the *ad hoc* committee for a Convention to be developed to uphold dignity and rights of persons with all disabilities. In December 2006, this work eventually led to the CRPD, and its accompanying Optional Protocol (OP) that eventually entered into effect in May 2008. The CRPD is currently ratified by 186 member states, with 164 signatories of OP emphasizing "*one voice*" and the notion of "*nothing about us without us.*" The OP endorsement signifies intent of state legislatures to take binding steps for (1) reasonable accommodations; (2) no-gaps; (3) habilitation and rehabilitation (Article 26); (4) international cooperation (CRPD article 32); and (5) assistance in situations of risk and emergencies. The CRPD has come to represent a "paradigm shift": persons with disabilities are no longer to be considered as objects under the law but citizens with equal rights. An 18-member Committee on CRPD continues to annually monitor the application of the treaty with representation of persons with lived disability. Although disability is not specifically defined under CRPD, it includes long-term physical, mental (euphemistically referred as "psychosocial"), intellectual, or sensory impairments which in interaction with various barriers hinder effective participation in society on an equal basis with those without disability.

In 2015, the UN Department of Economic and Social Affairs (DESA) in collaboration with the Secretariat of the CRPD and Government of Japan, organized the Sendai Framework 2015-2030 for Disaster Risk Reduction[15] that adopted the Charter on Inclusion of Persons with Disabilities in Humanitarian Action with 5 commitments: (1) non-discrimination; (2) participation; (3) inclusive policy; (4) inclusive response and services; and (5) cooperation and coordination. The goal has been to enhance recovery needs of persons with IDD with provision of psychosocial support and mental health services. Further, in 2015 the UN also adopted the *2030 Agenda for Sustainable*

Development Goals (SDGs) emphasizing disability-inclusive development as an essential condition for a sustainable future[16]. In 2018, the UN launched a first-ever, flagship report on disability and the SDGs entitled, *"Disability and Development Report on the Realization of the SDGs by, for, and with Persons with Disabilities"* pledging to leave no one behind[17]. Finally, in 2018, the Sphere Handbook was published and has become an interactive movement allowing posting of links to newly published resources, share of case studies and success stories of persons with disabilities and their families in decisions affecting their lives[18].

In summary, the CRPD has been an extraordinary instrument supporting the lives of persons with disabilities, mental and physical, with unprecedented implications for social, economic, political, and legal systems with relevance for mental health providers globally. Significant changes have arisen in the aftermath of the CRPD, notwithstanding the remaining challenges. Most important among these has been the protection from non-discrimination and freedom from coercion based on legal capacity (CRPD Article 12) representing a shift from a substitute decision model to supportive decision making[12]. First, this has necessitated a shift in emphasis from an impairment-focused Biomedical to Social Model of Disability (as a product of an individual's interaction with his or her environment), applied to both mental and psychosocial disabilities. Second, there has been the Social Model of Disability needing to be assessed with relevance to context – equalizing differentially abled persons with the same rights and opportunities. Third, since the Social Model could not offer adequate guidance in changing the circumstances that marginalize persons with disabilities as equal citizens, further shift was needed for persons with disabilities (especially those with co-occurring mental disorders) to be valued as part of human diversity. Therefore, the Human Rights Model has emerged as an the foundation stone of CRPD, with the social justice discourse in terms of disability laws and policies representing a revolution in thinking.

An important question remains with respect to the question of "legal capacity" related to circumstances of persons with impaired Decision-Making Capacity (DMC) and the exercise of their rights. The UN system has remained somewhat divided on this issue. The International Covenant of Civil and Political Rights (CCPR) has accepted the "necessary and proportionate" involuntary placement and non-consensual treatment of persons with mental health problems ("psychosocial disabilities") as a last resort[19]. On the other hand, CRPD calls for their elimination. Indeed, the UN Working Group on Arbitrary Detention (WGAD) states, *"denial of legal capacity of persons with disabilities with detention in institutions against their will, without their consent or with the consent of a substituted decision-maker constitutes deprivation of liberty in violation of international law."*[19] The contrast between substitute vs. supportive decision-making is highly salient in the care of the most vulnerable persons with IDD with adaptive and cognitive impairments and co-occurring mental disorders. The discussion is also relevant across the psychiatric care of persons with loss of DMC, e.g., dementias, schizophrenia, and bipolar illness, irrespective of a pre-existing diagnosis of IDD[13, 14].

Increased prevalence and ascendant recognition of the importance of mental disorders in the Global Burden of Disease (GBD) and the rise of neurodevelopmental disabilities with improved childhood survival in LMICs disproportionately effects the most marginalized communities (10-15% of the global population with range of disabilities, and 80% of persons with disabilities live in LMICs)[1, 14, 20]. The GBD burden therefore is increasingly highlighting a significant role for the Human Rights Model in addressing disparities in the care of vulnerable persons with IDD with co-occurring mental disorders.[14] In such poor resource settings health systems continue to lack capacity to provide basic services, including access to basic primary healthcare[21]. The COVID-19 pandemic has further exacerbated inequities producing further obstacles in mental health care with disproportionate impact on persons with disabilities[22]. It is clearly not adequate for mental health services to prioritize certain rights, as in access to care and treatment, while not emphasizing importance of autonomy, choice, and community care. This underscores the inter-sectoral commitment of psychiatry, i.e., in humanizing our understanding of mental health, access to education, habilitation, rehabilitation, and alliance with work environments that are "*open, inclusive, and accessible*" (CRPD Article 27 of CRPD – Right to Work and Employment). Consistent with this view, the CRPD Article 7 emphasizes early intervention approaches combined with taking "*all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children*." Development of child and youth orientation with (1) robust tele-health access and legal platforms, financially supported intervention packages for economically distressed families; (2) appreciation of Adverse Childhood Experiences (ACEs) and social determinants disproportionately impacting persons with IDD[23]; and (3) reduction of pathologizing with emphasis on healthy parenting and caregiving.

World Report on Disability and WHO Rehabilitation 2030

In 2017, the World Health Organization (WHO) in tandem with CRPD published the World Report on Disability in 2011[24], has followed by the launch of an important initiative to promote universal access to rehabilitation entitled "Rehabilitation 2030: A Call for Action" with more than 200 rehabilitation experts from 46 countries in attendance[25]. The goal was to develop a "unified message" to become a "political priority worldwide." In July 2019, the WHO convened a "Second Global Rehabilitation 2030" meeting with stakeholders from member states, international and professional organizations, NGOs, rehabilitation service users and experts—including journal editors. This was followed In May-July 2021, by the convening of the WHO Development Groups on Rehabilitation 2030, including sections on IDD, autism spectrum disorders, schizophrenia, and dementia with (1) linkage to Chronic Non-Communicable Disease (NCD) framework, (2) creation of a Crosswalk between WHO International Classification of Disease (ICD) and International Classification of Functioning (ICF), (3) emphasis on preventive interventions and habilitation entails, (4) emphasis on habilitation as well as rehabilitation, and (5) application of evidence-based approaches and developing further research to study contexts.

Statement on Rights of Persons with IDD and Mental Health

The Human Rights Model therefore represents a "consilient" approach (linking-together)[26] IDD and mental health long beset by a historic cleavage since 1980s with paucity of mainstream inclusive psychiatric services, training, and research[27,28]. This WG on the rights of persons with IDD and co-occurring mental disorders proposes several principles, envisioned as "benchmarks" to be implemented with implied responsibility in remedying the current situation that is especially urgent in the context of LMICs globally:

- Persons with IDD with co-occurring mental disorders shall enjoy the same human rights and fundamental freedoms as all other citizens (Benchmark: Equitable Human Rights and Freedoms)
- Persons with IDD ought not to be subjected to stigma and discrimination on the grounds of co-occurring mental disorders. They ought to be protected from exploitation, abuse, and degradation, in accordance with the Declaration of Hawaii ethical standards approved by the General Assembly of the WPA in Vienna, Austria, in July 1983[22] (Benchmark: Protections from Harm).
- Persons with IDD and co-occurring mental disorder have the right to humane, dignified, and professional treatment. The aim of psychiatry, as affirmed in the Declaration of Hawaii[29], ought to be inclusive of the treatment of persons with IDD with co-occurring mental disorders and the promotion of their mental health consistent with accepted scientific knowledge and ethical principles. Persons with IDD and co-occurring mental disorders, as a principle, ought to be treated along the same lines as other patients, favored by the fact that great majority of patients may be treated informally and voluntarily in outpatient facilities without hospitalization (Benchmark: Equitable Care and Treatment).
- Whenever possible, psychiatric services for persons with IDD and co-occurring mental disorders ought to be integrated within the general health and social care system and all such persons ought to be cared for, as far as possible, in the community where they live, and not excluded in receiving the same standard of treatment as those without IDD. (Benchmark: Integration and Inclusion in Mainstream Health and Social Care).
- The mental health services for persons with IDD and co-occurring mental disorders ought to be of adequate standard with safeguards of both their right to effective treatment within the care system (Benchmark: Standard of Care).
- The mental health service provision to persons with IDD and co-occurring disorder ought to pay attention to the training of care personnel (Benchmark: Training of Care Personnel).

Action Points

As directed by this statement, the WG on IDD will:

- Take steps to enhance and further the public mental health with regards the human rights of persons with IDD with co-occurring mental disorders (Benchmark: Enhancing IDD and Public Mental Health Interface)
- Include perspectives of persons with IDD and co-occurring mental disorders from low-resource regions and LMICs, as well as perspectives of persons with lived experience of disability to reclaim their histories (Benchmark: Including LMIC and Lived Experience Perspectives)
- Plan to understand communities — past, present, and future — drawing upon efforts to consult and convene resource persons, enable consequential conversations, and help set agendas for action (Benchmark: Consulting, Convening, Collaboration)
- Embedding the work into the life of WPA with visibility and accountability. Ensuring that the efforts continue with assessments, improvements, and new ideas over time — not

just over the short term — this is critical, as the human rights perspectives in IDD and mental health and disabilities is at an important threshold (Benchmark: Visibility, Accountability, Continuity of Efforts)
- Attract individuals who will carry on this work, and who can contribute to the thinking on: How can we move ahead in improving the status of IDD and mental health within psychiatry? It is important to establish a sustainable framework to pursue efforts, to ensure cross-fertilization, and sharing across sections (Benchmark: Recruitment, Training and Cross-Fertilization)

Postscript

The WG on IDD and the President of the WPA are committed to the success of this effort, and an important aspect of the effort is to support the implementation of the recommendations. For the achievement of these benchmarks, the commitment needs to be long term, the effort does not operate as a grant-sponsored body, but nevertheless the WPA will stay committed to a long-term process in terms of building a foundation for learning, teaching, and research promoting human rights and care of persons with IDD and co-occurring mental disorders.

This statement recognizes that there is still a lot to learn, both about how to address and redress the human rights violations of persons with IDD and co-occurring mental disorders, and their legacies, in specifically creating and support educational opportunities for those who do not have real, effective access to knowledge and resources in the field. We approach this work with humility, and it needs to be a long-term commitment, that needs to be sustained well beyond the work of the WG on IDD is completed.

We are very grateful for the time and reflectiveness of those who helped assist in this process, and in beginning to address legacies of human rights violations of persons with IDD, thankful for the wisdom and experiences of the contributors to this process. The persons with IDD with lived experience of stigma, discrimination, and suffering, have taught us important lessons, and there is still much more for us to learn. For too long, people whose lives have been affected most directly by the legacy of discrimination and abuse have not had the sustained attention, not only the WPA, but across other institutions in society, in terms of health, education, and social care, that has often contributed to the supporting hierarchy, and injustice and suppression of the rights of persons with IDD and co-occurring mental disorders. This is a time for listening and learning while dedicating ourselves to a different future. This statement emphasizes the need for repair of the legacies of locked institutionalization, eugenics, inhumane care (*'out of sight and out of mind'*)[30] and invasive treatments of persons with IDD and co-occurring mental disorders. In the light of lived experiences of persons with IDD and co-occurring mental disorders, we need to be cognizant of our shared responsibilities especially with respect to establishment of these principles and benchmarks for LMICs[31,32]. We are inspired by the examples of persons globally who have committed themselves to thoughtful and intensive efforts to address human rights violations, past and present, of persons with IDD and co-occurring mental disorders. The WG on IDD is not the first to undertake work, and we must learn from those who are already doing it.

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