

COMMENTARY

IPA and WPA-SOAP joint statement on the rights of older persons with mental health conditions and psychosocial disabilities¹

Introduction

The United Nations (UN) has proclaimed that “Mental health is a human right” (Office of High Commissioner Human Rights, OHCHR 2018) a position is supported by the World Health Organization (WHO) over 20 years ago (WHO, 1998). Globally, mental health systems have been in crisis, and in violation of basic human rights, segregated from the rest of health care, prompting calls by the UN Special Rapporteur on the Right to Health, for a sea change in mental healthcare systems to end decades of abuse, neglect, and violence (OHCHR 2017).

This imperative is driven by global population aging, with progressive rises in the proportion of the population aged over 65, from 6% in 1990 to 9% in 2019, projected to rise to 16% in 2050, by which time 1.5 billion people will be over 65 (UN Department of Economic and Social Affairs, Population Division, 2020). Of these, approximately 20% will have mental health conditions such as dementia, depression, anxiety, and substance use, often complicated by physical and psychosocial comorbidities culminating in disability.

As such, older people may experience multiple jeopardies of discrimination and stigma conferred by age itself (ageism) and having a mental disorder (“mentalism”) (WHO-WPA, 2002; Chang *et al.*, 2020; Peisah *et al.*, 2012, 2019), with marginalized groups such as Lesbian, Gay, Transexual, Bisexual, Intersex (Peisah *et al.*, 2018), and indigenous elders (Viscogliosi *et al.*, 2020) faring worst. “Segregation” in residential care, whereby people living with dementia or other mental health conditions or psychosocial disabilities are congregated together, confined within the care home, and segregated from other residents and the community at large, can exacerbate this discrimination and societal abandonment (Steele *et al.*, 2019). Older persons facing this level of stigma are often “invisible”, have no voice, nor support for autonomy, nor advocacy. Older people facing ageism and mentalism are often

left behind and disproportionately excluded from social protection and survival support, profoundly evident during the COVID-19 pandemic (Ayalon *et al.*, 2020; Carrieri *et al.*, 2020; Fraser *et al.*, 2020). On a backdrop of a perfect storm brewing globally for older persons pre-COVID-19, the human calamity of the pandemic has been disproportionately felt by older persons (World Economic Forum, 2020), particularly those with mental health disorders (Lee *et al.*, 2020).

This “grossly unmet need” for rights-based mental health and psychosocial care is the result of a combination of several factors. Among these are the failure to incorporate the voices of those most affected in health and government policy and inadequate environmental, social, home, and family supports. Such lack of supports often leads to over-reliance on the biomedical model, psychotropic drug use, and physical restraints, especially in institutional care, despite evidence based, best practices recommendations to the contrary (OHCHR, 2017). Much of this is attributable to “structural ageism” – ageist discrimination in institutional policies, practices, behaviors, and procedures – rife in health across clinical and research settings, and increasing (Chang *et al.*, 2020).

The International Psychogeriatric Association (IPA) and the World Psychiatric Association Section of Old Age Psychiatry (WPA-SOAP) join the call to change the status quo. We seek to ensure that older persons with mental health conditions and psychosocial disabilities are not discriminated against based on their age, or their mental health or psychosocial disability status, and are treated as full citizens enjoying all rights on an equal basis with other citizens. This Joint Statement aims to (i) lend IPA and WPA-SOAP support to the call for a rights-based approach to mental health; (ii) raise awareness among mental health professionals regarding the human rights of older persons; and (iii) provide practical guidelines on “how to” recognize, support, manage, mitigate, and advocate to ensure that human rights are front and center on the radar of health professionals in everyday clinical, research, and medicolegal practice.

¹This title was purposefully chosen to recognize the rights of the spectrum of older people at risk of, or living with, mild-to-severe mental health conditions and psychosocial disabilities.

Human rights challenges for all older people

The human rights of older people with mental health conditions and psychosocial disabilities are the same as those of all older people. Since the 1948 Universal Declaration of Human Rights, a raft of human rights treaties have addressed various civil, economic, social, cultural, and political rights, but older person's human rights were not specifically addressed until the UN Principles for Older Persons (1991) (OHCHR, 1991) and the Madrid International Plan of Action on Ageing (2002). The rights of persons with disabilities were given treatment under the UN Convention on the Rights of Persons with Disabilities (CRPD; United Nations, 2006). However, the rights of older people under these treaties have not been actualized due to ageism, systemic inertia, and failure to recognize their specific needs (Byrnes, 2020; Doron and Apter, 2010). This has led to a debate regarding the need for a UN Convention on the Rights of Older Persons (Byrnes, 2020; Doron and Apter, 2010; Doron, 2015; Herro and Byrnes, 2020), proponents for which include several governments, UN institutions, and leaders (including the UN Secretary-General and the High Commissioner for Human Rights), civil society organizations, older people's organizations, and human rights institutions.

IPA and WPA-SOAP support the efforts of the international community in this pursuit and reiterate that older persons with/or without mental health conditions and psychosocial disabilities hold and should exercise their rights to be treated without discrimination on an equal basis with other citizens. Key themes that underpin human rights peculiar to all older people include autonomy, dignity, care, and treatment, safety, and privacy. Specifically, human rights most relevant to older people's mental health include, but are not limited to, the rights to (not in any hierarchical order):

1. enjoyment of the highest attainable standards of affordable mental and physical health, including at the end of life, and respecting specific needs that arise on account of disability;
2. autonomy with equal recognition before the law, including the right to equal legal capacity, expression of will and preferences, with support for decision-making when required;
3. dignity and quality of life;
4. an ageism-free world;
5. safeguarding against undue influence and abuse, freedom from cruel, inhumane, degrading treatment, and punishment;
6. living independently and being included in the community, participating in the cultural and social life of the community;

7. making contributions to the community through work or other activities, and to be protected during these activities as any other citizens;
8. provision of adequate income to meet basic needs for food, housing, clothing, and other necessities;
9. accessible, integrated, affordable housing, the right to which is protected even when legal capacity is compromised;
10. accessible leisure and education as available to other citizens;
11. respect for family, relationships, sexual health, and the right to intimacy;
12. confidentiality and privacy; and
13. to practice a spiritual life of one's choosing.

Walking the talk: strategies supporting human rights in our professional roles working in mental health

IPA and WPA-SOAP are committed to bridging the implementation gap between the articulation and actualization of older person's human rights by embracing human rights frameworks as standards of accountability and advocacy in our everyday work (Peisah *et al.*, 2020). Practical behaviors and measures undertaken by mental health professionals to support the human rights of older people with mental health conditions and psychosocial disabilities include:

1. Be vigilant and speak out against ageism in health care as manifested by lack of diagnostic and treatment zeal, and therapeutic nihilism (Peake *et al.*, 2003), in which older people with chronic or severe mental health conditions are most vulnerable, despite having greater physical health burden, comorbidities, and premature mortality (Houben *et al.*, 2019). In a practical sense, this often means advocating for our patients' equal right to medical treatments in acute care environments and ensuring triage decisions for life-saving treatment are based on individualized assessment, not diagnosis nor place of residence such as a care home (Peisah *et al.*, 2020). We need to accept the responsibility that as mental health professionals, we are often the conduits to equitable access to health care;
2. Recognize that equitable access to high-quality end of life and palliative care, including pain relief is a human right owed to all, regardless of diagnosis or place of residence (Lapid *et al.*, 2020). This right is often not enjoyed by those with mental health conditions, particularly those living in care homes, necessitating proactive attention from clinicians to ensure that appropriate care and attention is available and provided at the end of life (Froggatt *et al.*, 2020);

3. Ensure that paternalistic and excessively medicalized approaches toward support for those with mental health conditions give way to participatory, psychosocial care, and support in the community to promote autonomy and resilience. This means supporting the social and care environment regardless of the physical setting, whether it be residential or home care, supporting the family (who may themselves be aging), professional caregivers, and the wider community;
4. Understand the human rights violations that drive changed behaviors in dementia with regard to unmet needs, will, and preferences, such as those arising from miscommunication, social isolation, and unmet intimacy. Respecting specific needs that arise on account of disability will often (not always) negate the need for psychotropic medication;
5. Understand and utilize the construct of relational autonomy (i.e. autonomy and identity of individuals founded upon their social connections and context) (Ells *et al.*, 2011) to support the human rights of older people with mental health conditions and psychosocial disability. Older people with mental health conditions and psychosocial disability do not exist in isolation, but rather function within various interacting social and family systems, often in dependent relationships with family members and carers (Peisah, 2006). This can confer both disadvantages – by way of undue influence (Wand *et al.*, 2018) and advantage – whereby interconnectedness, communication, and collaboration with their social network can empower, promote relationships and community involvement. Specifically, in care facilities, staff must maintain vigilance and a commitment to respecting residents' will, preferences, and autonomy by supporting the exercise of decision-making skills wherever possible, regardless of the severity of the mental condition (Sherwin and Winsby, 2010; Peisah *et al.*, 2013);
6. Prioritize autonomy and respect for will and preferences in clinical settings when delivering treatment by rigorously pursuing free and informed consent and supported decision-making when required. Presume capacity unless there is evidence to rebut that presumption, understand that capacity is not diagnosis bound (i.e. linked to a diagnosis of mental disorder), and revert to substitute decision-making only as a last resort (O'Neill and Peisah, 2019; Peisah, 2016);
7. Reference human rights when undertaking medico-legal work and adopt an eyes-wide-open approach with regards to elder abuse in both clinical and medicolegal roles;
8. When government action is taken to protect persons with impaired capacity, support the provision of stringent substantive and procedural protections of the sort found in modern mental health statutes. These include narrow criteria to determine incapacity and the need for hospitalization and the rights to (i) hearing before the appointment of a substitute decision maker, (ii) representation by legal counsel; (iii) advance notice of hearings; (iv) testify on one's

own behalf, (v) call witnesses, (v) appeal adverse findings to a higher court, (vi) periodic review, and (vii) abolishment of plenary orders.

9. To support access to the highest standard of health, address the lack of representation of older people in research, trial participation, and guideline development, from which older people are often excluded due to arbitrary upper age limits and a range of other exclusion criteria, even in diseases that predominantly affect older people (Ilgili *et al.*, 2014; Gottlieb *et al.*, 2011).

Conclusion

This Joint Statement builds on previous WPA Position Statements and Bills of Rights for people with mental conditions and disabilities (WHO-WPA, 2002; WPA, 2017a; WPA, 2017b; Katona *et al.*, 2009). As the adage goes: “What you permit, you promote”. Neither civil societies nor health systems can be permitted to be complicit in promoting the devastating violation of human rights of older persons.

Conflict of interest

The authors have no conflicts of interest to declare.

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