Women's Political and Economic Participation

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Abstract

The private and public realms of life are in large part culturally defined as female and male, respectively. Various human rights treaties and political agreements call on States to enable women to participate in the male-dominated public sphere.

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Obstacles abound for girls and women, who find themselves excluded not only because of their gender but also when they experience mental health problems and the perceived consequences, including potential “dangerousness.” Manifold factors play into the state of mental health of girls and women, among them the status quo of gender relations, the interactions with every day life, and the consequences of male-oriented health policies. The latter do not adequately cater to the accessibility needs of girls and women, especially those with mental health problems.

These challenges are magnified in the development context, where the Sustainable Development Goals (SDGs) aim to ensure that no one is left behind, including girls and women with mental health problems. Humanitarian crises serve as a powerful example of the threats to the lives of girls and women with mental health problems. Against this backdrop, the empowerment of self-advocates, particularly in the context of the negotiations of the Convention on the Rights of Persons with Disabilities, provides a salient counter-narrative.

Keywords
Participation · Human rights · Women’s rights · UN-CRPD · Trialogue

Introduction

Development is a multipronged effort as evident in the 169 targets of the 17 Sustainable Development Goals (SDGs). A key role in most of the targets is the participation of persons left behind in previous development efforts. This chapter will focus on the ways in which girls and women, particularly those with mental health problems, are enabled to participate and which forces, particularly those emanating from patriarchal structures, stand in the way of ensuring their meaningful contributions as experts in their own right.

Gender Equality Changes Everything

Gender equality changes everything. Gender equality leads to better health and mental health for women and girls. It will improve public health and mental health for all. This perspective and the expected positive effects of gender equality on societies’ economic and social development lead to gender equality being one of the 17 SDGs of the UN Sustainable Development Agenda 2030. The recent UN report “Turning Promises into Action: Gender Equality in the 2030 Agenda for Sustainable Development” provides for “robust, gender-responsive monitoring” of the 2030 SDG Agenda and opens by explaining that “gender equality is central to the achievements of all 17 SDGs” and arguing for “an integrated and rights-based approach to implementation.”

Women Must Be Involved at All Levels of Developmental Action

Gender equality programming for humanitarian action is not an exception, but a particularly pointed example of how policies, monitoring, and implementation efforts are shaped by the new policies of inclusion and the participation of women and girls on all levels.

The risk to fail women and girls in humanitarian crises is high. While empowerment of women and girls is central for the health for all at any given time, humanitarian crises pose a special risk for the mental health of all adults and children. Most often, women and girls are already the most marginalized and vulnerable members of their communities, have their resources constrained, and suffer differently and often to a significantly greater extent. Women are at elevated risk of many forms of gender-based violence and have their sexual and reproductive rights and health needs undermined in life-threatening ways. Core examples of tasks warranting gender-specific attention concern access to reproductive health care and protection against gender-based violence. The United Nations Population Fund (2018) estimates that 34 million women of reproductive age, 5 million of whom are pregnant, needed humanitarian assistance and protection in 2018. The need for better obstetric and newborn care is implied by the fact that 60% of preventable maternal mortality deaths take place in settings of conflict, displacement, and natural disasters, according to a recent Care International report (2017). There is also convincing evidence on the impact of different contraceptive measures and the need to integrate safe abortion and post-abortion care into emergency care. While the lack of bathroom equity and the so often deplorable menstrual hygiene situation are a terrible disadvantage for women under even the best of circumstances, in humanitarian crisis situations they constitute grave extra risks for women and girls.

The heightened interest in investment in gender responsive humanitarian programming, however, does not stem only from awareness of women's specific needs and the desire to stop failing them. It comes also from growing evidence that investment in women can impact the whole community and contribute to making help more effective for all. Gender responsive humanitarian programming plays a significant role in the success of emergency responses. A focus on empowering women and girls strengthens the effectiveness and improves the long-term impact of interventions in reaction to humanitarian crises and can promote additional lasting positive effects for communities and societies (UN Women 2018b).

Consulting women and girls in recognition of their specific capabilities, needs, and human rights is in turn central to the successful introduction and investment in gender-responsive humanitarian programming. Even though it has been almost two decades (October 2000), since the United Nations Security Council adopted its first ever resolution on the importance of including women in peace-building processes, women continue to be sidelined in most of these (UN WOMEN 2018). Survivors of mines and other explosive remnants of war (ERW) increasingly join such consultations, with evident success (ICBL 2015), underlining the value of participation in pursuing this agenda (see ▶ Chap. 7, “Challenges in Women’s Mental Health: Care in Conflict and Post-Conflict Situations”).

Guidelines and programming have focused in recent years on gender-sensitive and equality approaches in order to strengthen crisis responses. An example is the United Nations Office for the Coordination of Humanitarian Affairs (OCHA) Policy Instruction on Gender Equality 2016–2020 (2016). Humanitarian crises can offer special opportunities for the empowerment of women and girls with lasting positive effects as evidenced by changes in social structures and power dynamics in war and post-war societies.

Frequently, women and girls are molded to maintaining and expanding their roles and their resilience in the face of adversity. However, the risk of men losing their accustomed roles or taking over traditionally female roles can create additional risks for women. Preexisting disadvantages in rights and resources can lead to women and girls being the first to lose access to scarce resources like food and water. Girls’ education is endangered to an even greater extent than boys’, and the risk of child marriage can increase dramatically for girls. The specific needs and resources of adolescents in humanitarian crises, however, still feature as one of many data gaps.

There is also little information on the contextual factors for the risks and opportunities inherent in having to cope with humanitarian crisis and even in profiting from its transformative potential. These are insufficiently understood or taken into account. While there is some knowledge from recent reviews on how programs can address underlying dynamics of power abuse and violence in affected communities, there are data gaps in understanding effective interventions (Blanchet et al. 2017; UN Women 2017). Such measures allow for earlier prevention and protection, as well as comprehensive clinical and psychosocial care for survivors to be characterized and implemented. Evidence-based, economic as well as human rights perspectives all do agree on the fact that women and girls must be involved on all levels of humanitarian action such as prevention, response (including search and rescue), recovery and rehabilitation, community rebuilding, and peace building.

However, not all consequences of specific strategies to harness the increased effectiveness that women’s participation in emergency aid brings are well understood. There is a risk, therefore, of unintended consequences exemplified by historical and recently reported backlashes against the gender equality movement. Another factor in fostering positive gender relations in the humanitarian setting is female representation in leadership roles in institutions involved. One main factor that should be a focus of change is the need for better female representation among aid workers on all levels, including local and international leadership.

The current queries into alleged sexualized crimes in some humanitarian organizations might be an opportunity for decisive changes in this regard too.

Data clearly indicate that strengthening political and economic participation is the central element for the success of gender equality programming in humanitarian emergencies. Other core elements include creating safe spaces, ensuring gender-specific safety and health interventions, and meeting the specific needs of men, boys, and persons identifying as LGBTIQ.

A central challenge exists in the parallel development to the evolving policies and practices in humanitarian crisis situations, concerning persons with disabilities. The UN-Convention on the Rights of Persons with Disabilities (UN-CRPD) was negotiated for the first time in history with the full participation of persons with a lived experience of disability (2006). In another historic first, it explicitly includes persons with mental health problems. Article 11 of the UN-CRPD formulates the obligation to "ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disaster." The UN Charter on Inclusion of Persons with Disabilities in Humanitarian Action in accordance with the Sendai Framework on Disaster Risk Reduction (2017), based on the CRPD (Preamble (p)), specifically calls attention to multiple and intersecting forms of discrimination and the need to empower women and girls with disabilities in humanitarian crisis contexts (see ▶ Chap. 7, "Challenges in Women's Mental Health: Care in Conflict and Post-Conflict Situations").

No One Is to Be Left Behind

The Sustainable Development Goals (SDGs) aim to ensure that no one is left behind in accelerating development in all its forms, particularly in addressing structural aspects of inequality, including in ensuring the participation of all to enable their equal inclusion in societies. Acknowledging that some persons start their lives or soon find themselves in circumstances that make them vulnerable, the SDGs try to address some of the disabling factors in the pursuit of equality. Girls and women with mental health problems are often rendered vulnerable by a variety of factors that compound to manifest insurmountable exclusion: the perception of their sex as well as their gender and the misconceptions of mental health. Various expressions of patriarchy, not least "traditional expressions of masculinity" (American Psychological Association), including toxic masculinity, compound such perceptions. Frequently, other factors aggravate the exclusion further such as lack of social capital, inadequate language skills, ethnicity, or family status – to name a few.

Structural Problems in Ensuring No-One Is Left Behind

As the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) contends in its opening paragraphs: "The full and complete development of a country, the welfare of the world and the cause of peace require the maximum participation of women on equal terms with men in all fields." This assertion rings particularly true for girls and women with mental health problems: their overrepresentation in the "deep pockets of deprivation" (UN WOMEN 2018) is caused by a plethora of structural factors, including traditional expressions of masculinity and gendered expectations. There are differences in wealth, location, and ethnicity that contribute to disadvantage and which, importantly, do not operate in isolation (UN WOMEN 2018).

As discussed earlier, representation matters – women with mental health problems need to speak for themselves in peace-building processes and partake in disaster preparedness. Anecdotal evidence around visual representation of persons with mental health problems in gravely under-resourced contexts hints at the representation – and therewith likely treatment – of women and girls with mental health problems. Images of persons with mental health problems chained to trees and held in cages and other inhuman and degrading conditions bordering on torture by and large display men. Neither author can recall having seen a woman or girl depicted in such documents. As anecdotal as this impression is – and this is obviously not an encouragement to divert resources to the quest for female representation in imagery of the abuse of persons with mental health problems – it reflects the blackout that mental health problems mean for many women and girls with mental health problems, starkly so in under-resourced contexts.

Representation and empowerment of women and girls with mental health problems as advocates in their own right is thus key in tackling the structural undercurrents and ensuring that the necessary paradigm shifts are meaningful and sustainable.

Social Constructs Impede Participation

Human rights serve a multitude of functions. Depending on the perspective, they address inequalities in communities, societies, and public spaces in a variety of ways. At their core, they aim to ensure that everyone can be who they are and participate in all spheres of life as the person they are or chose to be. “Freedom from stigma” (EHRC 2009) is another way of expressing the goal that each individual should live in dignity. The biggest and most sweeping force to take away that dignity is abuse of power. Power is assigned, attributed, presumed, and assumed in manifold ways. The commonality: social constructs play a decisive role.

A socially constructed overpowering power is that of male superiority. In many societies, this results in girls and women being placed in subordinate and disadvantaged positions. It is frequently “culturally justified as part of the ‘natural’ order” (Ibahow 2014). Recently, the American Psychological Association highlighted the impact of “traditional masculinity ideology” (American Psychological Association); the mainstream media has noted that the concept of toxic masculinity “has been around forever; but suddenly, the term seems to be everywhere” (*New York Times* 2019), reflecting the recent upsurge in discussing forms of sexualized violence also as a result of gendered expectations and limitations.

Accordingly, “spheres of action” have been created, which are based on structural obstacles creating a “dichotomous allocation” of both power and therewith radius and action (Wittkopp 2012). Such spheres of action are a prerequisite for the meaningful participation of girls and women.

Structural obstacles are magnified when "exclusionary impulses" (Ibahow 2014) enter the sphere. Contemporary mainstream spheres frequently resort to "competing claims of religious and cultural rights" (Ibahow 2014) as if they were not questionable enough in their origins and toxic in their impact: Add the stigma of mental health, and obstacles in accessing public space and seizing – and maintaining – power become overwhelming.

The bridge between girls and women and poor mental health has many pillars:

- Growing up in sexualized environments and building resilience
- Discovering the importance of mental health and learning to protect it
- Having one's capacity – and therewith frequently mental health – questioned
- Being treated unequally when mentally ill
- Potentially being persecuted for being perceived as mentally ill
- Frequently being the main care-taker of family members with mental health problems

Further pillars support the bridge between girls and women and good mental health or promoting mental health:

- Finding a voice as a girl or woman with mental health problems
- Empowering those in family care
- Supporting people with mental ill-health: as a medical professional
- Planning, carrying out, and publishing evaluation and research

At the same time, the field of mental health research and academic psychiatry suffers from considerable deficits with regard to diversity. Despite considerable gains, women are still underrepresented in academic psychiatry, including in leadership positions. Continuing efforts and interventions are required to enhance the participation of women on institutional, political, and editorial levels in order to advance toward the goal of gender equity (Süßenbacher et al. 2017).

In their recent practical guidebook on addressing sexualized violence, Hassan and Lambert Sanchez (2019) highlight the importance of focusing on the environment that enables such behavior – and the power(s) that support it – rather than just the individual behavior.

Perceived Dangerousness Upends Right to Life

"Women's rights are human rights." Those pushed to the margins of society – and possibly beyond – magnify the mantra's importance: girls and women with mental health problems. "If women are perceived as dangerous and a threat [...], their labelling as witches, and consequently their destruction, is then seen as justified" (Manjoo 2012). Girls' and women's participation is thus made impossible by denying them their right to life. As the Special Rapporteur on Violence Against Women, Its Causes and Consequences notes – in describing the possible violations of women's right to life more generally – there are manifold ways to instigate those killings: direct – with a defined perpetrator – but also indirect and passive (Manjoo 2012) (Bullet (sic!) points added for clarity).

The direct category includes:

- *Killings as a result of intimate-partner violence*
- *Sorcery/witchcraft-related killings*
- *Honor-related killings*
- *Armed conflict–related killings*
- *Dowry-related killings*
- *Gender identity- and sexual orientation-related killings*
- *Ethnic- and indigenous identity-related killings.*

Some of these may be the result of a girl or woman being perceived as having a mental illness – such as sorcery and witchcraft-related killings as well as gender identity–related killings. Those violations of the right to life intentionally perpetrated by the State should be added: the death penalty for persons perceived as having a mental illness (Kari 2016).

The indirect category includes:

- *Deaths due to poorly conducted or clandestine abortions*
- *Maternal mortality*
- *Deaths from harmful practices*
- *Deaths linked to human trafficking, drug dealing, organized crime and gang-related activities*
- *The death of girls or women from simple neglect, through starvation or ill-treatment; and deliberate acts or omissions by the State* (Manjoo 2012).

Harmful practices encompass a wide range of human rights violations. The African Union Protocol on the Rights of Persons with Disabilities in Africa notes it as "behaviour, attitudes and practices based on tradition, culture, religion, superstition or other reasons, which negatively affect the human rights and fundamental freedoms of persons [with disabilities] or perpetuate discrimination" (Article 1 para e).

Cognizant of the fact that the application of human rights prior to birth is not covered by United Nations human rights obligations, the gender violence pre birth should be noted in the context of indirect categories: female infanticide is a – growing – fact and, among others, sends a clear message of male dominance, power, and destruction (Sen). There are both direct and indirect mental health implications for pregnant women as well as for girls growing up in societies that enable such proceedings. The "socially constructed right to [kill]" (Manjoo 2012) sends a chilling effect into efforts to break the mold and attain access to all spheres of life and thus enjoy the right to participation unobstructed and meaningfully (Perinatal Section 3, Violence Against Women Section 5).

Right to Health

Based on the World Health Organization's Constitution, the "right to the highest attainable standard of health" has been recognized in a number of United Nations' treaties as well as human rights documents of other fora. The Covenant on Economic, Social and Cultural Rights (CESCR) provides the most universally accepted provision on the right to health – Article 12; the CRPD enshrines it in an accessible and inclusive way – Article 25. There is a growing understanding of what the right to health means and implies; among the human rights principles discernible are:

- Right to health care: "At the heart of the right to health is a functioning health system, accessible to all, without discrimination" (Backman and Mesquita 2012).
- Availability: the services provided must be attainable in good quality across the country – including rural areas – for everyone, which includes economic accessibility.
- Affordability: the healthcare system and its services must be provided at affordable cost and for free for those who would otherwise go untreated.
- Accessibility of the built environment at the healthcare facility but also accessible in terms of reaching the venue safely (harassment, hate crimes en route), without obstacles (Monsoon flooded roads) and with affordable transportation.
- Communication accessibility: the right to seek information about one's health and receive responses that are presented accessibly and – where necessary – in accessible formats such as alternative modes and means of communication, without compromising the confidentiality of personal information.
- Acceptability: state-of-the-art medical ethics, gender sensitive, age-appropriate, as well as culturally adequate.

  Quality: scientifically sound and delivered in good quality by health professionals using good-quality medication and equipment in surroundings with adequate sanitation and access to safe drinking water (CESCR, GC Health).

Recently, the World Health Organization reinforced these human rights principles as part of the Universal Health Coverage policy (WHO 2019).

These principles are frequently violated when it comes to the needs of persons with mental health problems, particularly girls and women. One may, as a seemingly random starting point, think of images of alleged mental health patients in utterly under-resourced contexts: most images of persons chained to trees or held in cages are male. The lack of resources only heightens the likelihood of discrimination, ill-treatment, and threats to the integrity of girls and women with mental health problems. Making human rights principles the basis is thus key (Schulze 2016), but as the first Special Rapporteur on the highest attainable standard of mental and physical health, Paul Hunt, has noted: the above is a "minimal list" (Hunt 2016). Accordingly, he adds the following – human rights – obligations to ensure the fulfillment of the right to health for everyone:

- Progressive realization: the principle by which governments have to commit a minimum of resources even if the overall economic situation of their country is challenging; the CRPD (in Art 4 Para 2) makes clear that problems that pertain to nondiscrimination are not to be subject to such progressive approaches but are rather to be fulfilled immediately.
- Maximum available resources: governments have to provide all financial and other support they can; this principle is laid down in Article 2 Para 2 (CESCR).
- International assistance and cooperation: historically framed as an entirely monetary issue, the CRPD provides for a paradigm shift by suggesting this includes the facilitation and support for capacity building, exchange and sharing of information, experiences, training programs and best practices, as well as transfer of technologies and facilitating cooperation in research and access to scientific and technical knowledge.

Adding to the aspect of scientific knowledge: in his 2010 report to the United Nations General Assembly, the Special Rapporteur on the right to the highest attainable standard of physical and mental health, Anand Grover makes the important case for applying positive discrimination – that is, preferential treatment due to aggravated discrimination – to the obligation to share the advances of science (Article 15 CESCR). Distinctly discussing harm-reduction implementation in prison settings, he suggests that services need to be made available even though they may not yet be fully available in the communities (Grover 2010).

Implementing the trifecta of right to health, international cooperation, and scientific advances in a gender-sensitive approach may well alleviate some of the most common experiences of girls and women with mental health problems and, accordingly, foster their participation in line with the SDGs.

Women Have Specific Mental Health Needs

Inequity and inefficiency of mental health resources affect men and women all around the globe. Some important mental health needs as well as barriers to care are gender-specific. Women have specific needs in specific phases of life, for example, the perinatal period, as well as specific risk factors, for example, interpersonal violence and sexual abuse. Developments of women only services as well as the implementation of gender-specific approaches in routine care are underway and need to be improved further and expanded. Training as well as research requirements are numerous and urgent.

Mental health stigma and discrimination interact with gender inequality and the discrimination against women and girls to their mental health detriment. Clinical and scientific responsibilities in mental health essentially include gender-specific attention to the needs of women and girls and their families.

Family carers are an essential mental health resource. A majority is female with significant unmet needs. Family advocacy in mental health is prominently supported by female activists as is the psychiatric user movement. Because of the cumulative and interacting gender-based and other forms of discrimination, regulations such as those following the adoption of the CRPD include specific provisions for women and girls with psychosocial disabilities (Section 6).

In a recent discussion of the right to health framework the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health discusses the specific circumstances of women in the mental health context, highlighting that

> Multiple and intersectional forms of discrimination continue to impede the ability of individuals, including women and persons from racial and ethnic minorities with disabilities, to realize their right to mental health. Discrimination and inequality are both a cause and a consequence of poor mental health, with long-term implications for morbidity, mortality and societal well-being. discrimination, harmful stereotypes (including gender) and stigma in the community, family, schools and workplace disable healthy relationships, social connections and the supportive and inclusive environments that are required for the good mental health and well-being of everyone. (Puras 2017, 46)

The Special Rapporteur goes on to stress the impact these phenomena have on policy-making: "Likewise, discriminatory attitudes influencing policies, laws and practices constitute barriers for those requiring emotional and social support and/or treatment. Consequently, individuals and groups in vulnerable situations who are discriminated against by law and/or in practice are denied their right to mental health."

He specifically addresses the situation of women with regard to mental health:

> Special attention should be paid to women, who suffer disproportionately from mental health practices that are based on paternalistic and patriarchal traditions, inappropriate and harmful gender stereotypes, medicalization of women's feelings and behaviour, and coercion. Women who have suffered from violence and inequalities within their families, communities and societies, and who have mental health conditions very often face situations in mental health settings that amount to violence, coercion, humiliation and disrespect for their dignity. It is unacceptable that after suffering from violations in family and other settings, women suffer from violations again within services that are supposed to promote their mental health. In that regard, it is very important to emphasize that violations of sexual and reproductive health rights have a direct, negative impact on the mental health of women.

Yet another angle on the specificity of women's mental health needs derives from disarmament: Most mine casualties are men, and therefore many indirect victims are women, including widows. The needs of widows have largely been overlooked among efforts to provide assistance for mine/explosive remnants of war (ERW) victims, even though States Parties have obligations under the Mine Ban Treaty and Convention on Cluster Munitions to ensure that the rights and needs of mine/ERW widows are met in accordance with relevant international law. There is little information about how States Parties themselves are meeting those obligations. A lack of accurate and usable disaggregated data is among the barriers to effective victim assistance for widows (ICBL).

Capacity as the Pillar of the Right to Act

Equal participation for girls and women with mental health problems requires different forms of capacity. Most fundamentally, the legal capacity to be recognized equally before the law as persons who have the right to exercise their legal capacity needs to be established. The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) draws this important distinction between the written word and the practical application of girls and women making their own informed decisions. Attaining this capacity is no small feat given practices and "traditions" that would counsel otherwise.

With prevailing stereotypes of girls and women's diminished capability to make good on that capacity, it is still frequently disputed and – in terms of the right to *act* the capacity – easily upended. This particularly applies to girls and women with mental health problems: the stereotype that "women are incapable of making medical decisions" (Cook and Undurraga 2012, 318) is frequently overextended to a complete nullification of legal capacity.

Also described as "civil death" (Toledo 2013), the removal of legal capacity strips a person of the core of being a human being endowed with rights: being a subject – rather than an object – and therewith a rights-holder.

Questioning legal capacity takes various forms, many of them are subtle; most of them rely on paternalistic social codes that attribute more weight to the decision-making capacity of men with profound consequences for the participation of girls and women in society. The right to participate in elections, the right to stand for elections, the right to hold and manage a bank account, inheritance laws, property rights, and many more distinctly legalistic rights come to mind. In addition, there are the very many ways in which women's decision-making is ridiculed and invariably found to be inadequate and therefore gutted, largely by patriarchal customs, "norms," and practices.

International human rights norms recognize the right to legal capacity and – in some instances specifically the right to act that capacity. The pronoun "everyone" in the Covenant on Civil and Political Rights (CCPR, Article 16) has, as Amita Dhanda observes, an "all inclusive ambit" (2012). Its origins are more closely connected to the aftermath of colonialism – particularly racism – than any other of the many exclusionary tendencies of societies. Dhanda rightly exhorts the lack of feminist perspectives in these regulations: these "so called universal norms are male values in disguise" (Dhanda 2012).

CEDAW then recognizes the legal capacity of women and adds the important right to also act that capacity. The social prerequisites for the right to act legal capacity are numerous, particularly when it comes to capabilities: there are so many pinpricks that send a message of incapability, an incapacity to render a judgment, an inability to make a decision. These are reinforced and perpetuated in institutions dominated by male perceptions and outlooks, practices, and customs. In many cases the result is a learned helplessness that needs to be undone and rehabilitated.

The label of mental health problems is then the penultimate pinprick in asserting in capacity. The assumption is frequently that there is neither capacity nor capability, making the pertinent provision in the CRPD (Article 12) so central to most any discussion of implementation of the treaty. For girls and women with mental health problems, the nonconforming with social norms quickly makes for a confining of legal rights. The CRPD accordingly shifts the emphasis on the impact of societal perceptions of disability to emphasize that the exclusion and resulting denial of rights is largely due to the reaction to an impairment rather than necessary on account of the impairment. "If the reason for not recognizing legal capacity in some persons with disabilities arises from the practical necessities of social functioning, then it is only correct that such practical necessities have balancing relevance and not trumping status" (Dhanda 2012).

Supported decision-making is increasingly recognized as the state of the art of ensuring the legal capacity of persons with disabilities. With a view to deal with aggravated forms of discrimination, support for girls and women with mental health problems needs to be thought and implemented as broadly as possible: undoing layers of stigma and objectifying personhood requires a plethora of tools in an extensive understanding of "empowerment." Per Grover's suggestion, for positive discrimination, special measures – may be necessary to tip the balance.

By way of example: girls and women with mental health problems are highly likely to experience stigma that in turn is very likely to increase the exposure to violence. Particularly in settings with low coverage of specialized mental health care and corresponding rampant levels of misconceptions of mental ill-health, women and girls with mental health problems are often punished for their illness, too often murdered or gravely injured for their – perceived – illness.

Experiencing violence may in and of itself cause mental health problems and then the expectation of more stigma and the fear of victimization add another level of violence as well as negative impact on mental health that compounds and intensifies the underlying mental health issue. A possible learned helplessness based on gender stereotypes is exacerbated by avoidance behavior(s) fueled in large parts by shame and fear.

Against All Odds: Participation of Women

Many factors contribute to the unequal terms of societies and therewith public space. The participation of women is "stymied by gender norms and expectations that restrict their access to leadership opportunities" (UN WOMEN 2018). Gender norms around participation are largely defined by the dichotomy of the private and public spheres, which continue to be considered distinctly female (private) and male (public), respectively. The private realm is treated as off-limits, and any work performed therein is not considered of much – monetary – value. The fact that violence against women was not discussed as part of the 1979 Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) pointedly summarizes the state of the play on the stronghold that is the "private sphere." Leaving it to engage in the public and stepping over a threshold that is largely defined by male culture and practices is an act of courage in too many instances. The public sphere is respected, anointed with money, and provides a large area for activities, most of which yield at least some form of respect, if not monetary acknowledgment.

Cultural traditions have played a strong part in all this, and increasingly, religion is used as a basis for defining the role of the private and public space, and thus cultural norms and practices are strengthened, which confine women to the private sphere. As the CEDAW Committee has observed: “Even historically stable democracies have failed to integrate fully and equally the opinions and interests of the female half of the population. Societies in which women are excluded from public life and decision-making cannot be described as democratic” (CEDAW Committee 1997).

Female Carers Are Essential Activists

“Despite being foundational to all societies, unpaid care and domestic work is neither recognized as work nor valued,” states the UN WOMEN seminal report on the SDGs (UN WOMEN 2018) (see ▶ Chap. 1, “Women as Caregivers in the Elderly”). The impact of the unequal distribution of this kind of work is described as a “powerful constraint on gender equality,” which in turn has implications for achieving other goals and targets in the SDG framework (UN WOMEN 2018).

The family carer burden on relatives of persons with mental health problems is considerable. It is higher in women than in men. Data keep showing considerable unmet needs of families. It is higher when caring for parents, spouses, and children than siblings. It is “vital to develop effective interventions that support family caregivers” (WHO WMH survey, Viana et al. 2013). In Europe, the typical family caregiver for a person with severe mental illness is female (80%) and around 60 years old, 76% taking care of a son or daughter, 7% for a brother or sister, and 10% for a partner or spouse spending an average of 22 h each week caregiving (C4C, EUFAMI 2015). There is some information on specific women family needs. Mothers of daughters and sons living with schizophrenia report a higher burden and higher needs than fathers (Wancata et al. 2008). Daughters of mothers with schizophrenia suffer from lower quality of life, associated mainly with resource loss (Alkan et al. 2016).

Support for families works. It improves the caring experience, reduces carer burden, improves the quality of life of family carers, enhances an essential resource for patients, improves the course of illness, and through all the above ensures great financial savings for the public (Yesufu-Udechuku et al. 2015). However, “the continuous support of relatives of . . . people (with longstanding mental illnesses), has been neglected in many places and is almost exclusively the responsibility of self-help groups” (EUFAMI, C4C, Global report 2015). Thus, to this day most help for families comes from self-help and peer support, much of which is provided and organized by women. Also, the highly effective advocacy efforts with respect to mental health care and destigmatization have come about through the leadership of many formidable mothers, sisters, daughters, and other highly engaged women.

The Self-Advocacy Movement Is Shaped by the Engagement of Women

Historically as well as to date the movement of users, ex-users, and survivors of psychiatry has been shaped by the engagement of women, who gave voice to the lived experience and advocate and accomplish participation and change. Among those, who lent their personal experience as evidence and basis for the model development of empowerment and recovery-orientation, eminent women stand out. Examples include Pat Deegan, Laurie Ahern, Helen Glover, and Mary Ellen Copeland (Amering and Schmolke 2009).

The Wellness and Recovery Action Plan (WRAP), developed by Mary Ellen Copeland, not only made it on the SAMHSA's (Substance Abuse and Mental Health Services Administration) National Registry of Evidence-Based Programs and Practices in the USA, but has been translated into many different languages and used around the globe. In her text "Remembering Kate – A Story of Hope" (www.mentalhealthrecovery.com), Mary Ellen tells the story of her mother, who became ill at the age of 36, when Mary Ellen was eight. Her mother spent the next 8 years in a State mental institution diagnosed with a severe manic-depressive condition. The doctors said that she was incurable and would never recover. Against all expectations, the mother did recover and stayed well until her death at the age of 82. Mary Ellen assumes that one reason for her mother's improvement might have been the attention she received from a volunteer intern and another hospital worker, who had developed a particular interest in this patient. Some of the mothering time she had lost with her own children, she devoted on very needy kids. Her social net of mutual supports kept expanding; by the time she reached her old age, she was embedded in loving relationships in her community, with friends, and a large family with 24 grandchildren and 19 great-grandchildren.

Such experiences across generations also shape the engagement of the World Network of users and Survivors of Psychiatry exemplified by their Submission to the Committee on the Rights of the Child for General Comment on the Right to Health (www.wnusp.org) and their statement on the fact that "Some of our members experienced the mental health system as children, including severely traumatizing and invasive interventions such as electroshock. . .."

Bhargavi Davar, eminent feminist and mental health activist and researcher from India, draws from her own choices for her mental health as well as her families' experiences with violence and abuse in the mental health system and covers in her engagement the situation of children in India:

> Indian institutions do admit children. In our community work, we regularly come across children who have been given shock treatment from the age of 6, and not just once, but many times through the childhood. Yes, I do think we must talk about "inhuman, degrading,

> torturous" treatments and protections from those. Children should not be admitted into mental asylums. In the slums where we work, children with disabilities are indeed kept in physical restraint 24x7. We work with parents and siblings to slowly release them and give them some semblance of humanity. These practices are atrocities; yet, the families are so poor that the parents have to go out to eke out a small living... their survival is at stake. We provide the "circle of care" where some volunteers go in and engage the child in activities or play; and counsel the family members to address the human being in the child. We are seeing more and more of children having breakdowns in the early teens. In our work over here, which is largely peer support, counselling, psychotherapies and arts based therapies, we try to establish a "circle of care" for the child. We work with parents to reduce conflict and criticism within the household; reduce the "control /command" environment; practice peace and establish empathy with the child. Where needed, we provide skills to parents and grandparents to give non-violent care."

Another big step regarding participation of persons with mental health problems concerns their involvement in scientific research. Again, in this important new field, significant impact comes from excellent women scientists ranging in their engagement from user involvement in mental health research (Wallcraft et al. 2009) to fostering mad studies (Russno and Sweney 2016). Finally, noteworthy are the women involved in the negotiations of the UN-CRPD (Sabatello 2013) as well as one of the key representatives of the World Network of Users and Survivors of Psychiatry in these negotiations, human rights lawyer, Tina Minkowitz (2017).

The experience of the worst forms of human rights violations, including forced sterilization and the murder of people with disabilities, especially also people with mental health problems, at the time of the Nazi regime in Germany had motivated survivor Dorothea Buck, the most eminent figure in the German user/survivor movement over many decades. She talks about how she "experienced the psychiatric system as so inhumane, because nobody spoke with us. A person cannot be more devalued than to be considered unworthy or incapable of conversation" (www.bpe-online.de/english/dorotheabuck.htm). This very notion brought about that in the 1980s Buck shared her ideas about the need to prevent such inhumane conditions with Thomas Bock and Ingeborg Esterer and that is how the Trialogue was born (Bock et al. 2000).

"Trialogue" stands for communication among and between the three main groups of individuals who deal with psychiatric problems and disorders and with the mental health system – people with experiences of severe mental distress, family members/friends, and mental health professionals. Trialogue encounters occur under special conditions – outside familial, institutional, and therapeutical hierarchies and clinches. Trialogue group participants meet on neutral ground and communicate on equal footing (Amering 2016).

Trialogue Is a Training Ground for a Participatory Approach

What is true for trying to overcome the silence after a history of horrific crimes and discrimination against persons with disabilities is of course strongly related to the communication between the Trialogue partners everywhere: we need to learn new forms of communications, a language that allows us to interact in a context of nondiscrimination.

Trialogue groups are training grounds for working together on an equal basis. They allow interactions between "experts by experience" and "experts by training." Trialogue groups teach many of the skills urgently needed in order to make use of the mandated communications and collaborations between mental healthcare users and user activists, family carers and friends, and mental health professionals and policy makers outside and beyond traditional clinical and pedagogic encounters, which are needed to strengthen a participatory approach in the field of mental health and further civil society involvement. Trialogue groups are training grounds for working together on an equal basis.

Trialogues offer new possibilities for gaining knowledge and insights and developing new ways of communicating beyond role stereotypes. The knowledge of a large part of the community that is currently often hidden – namely that of families and friends of people with mental health problems as well as the expertise of those who are dealing with or have overcome such problems in their own lives – can be validated and shared for the benefit of all. Trialogues also function as basis and starting point for trialogic activities on different levels – for example, serving on quality control boards or teaching in trialogic teams – and different topics – for example, a task force on stigma busting or a work group on trauma and psychosis.

The Trialogue experience – an exercise in communication between service users, families and friends, and mental health workers on equal footing – is indicative of our capacity for surviving and gaining from serious discussions of adversities, such as coercive intervention, as well as the great possibilities of cooperative efforts and coordinated action, such as fighting stigma and discrimination.

In German-speaking countries, Trialogue groups are regularly attended by several thousand people. International interest and experiences are growing fast (www.trialogue.co). The first worldwide trialogic effort through the WPA Task Force on Best Practice in Working with Service Users and Carers under the leadership of Helen Herrman within the framework of the WPA Action Plan 2008–2011 published ten recommendations to the international mental health community (Wallcraft et al. 2011). The ten recommendations call for a partnership approach on all levels of mental health policy and care and "*promote shared work worldwide to identify best practice examples and create a resource to assist others to begin successful collaboration.*" In consultation with the Task Force, the WPA Committee on Ethics drafted a paragraph based on these recommendations that has been unanimously endorsed as an amendment to its Madrid Declaration on Ethical Standards for Psychiatric Practice by the WPA General Assembly in 2011.

Currently, Trialogues need to devote special attention to new roles and responsibilities arising from the historical challenge of the UN-Convention on the Rights of Persons with Disabilities for mental health professionals, users of services as well as relatives and friends.

Actual developments regarding new rights to patient autonomy as well as new entitlements for support for living in the community including the right to family life, reasonable accommodation, and supported decision-making warrant a partnership approach in order to have a positive real-life impact.

Participation as a Human Rights Obligation

Participation, also in human rights terms, is frequently associated with and strongly tied to the right to vote and be elected: the very basis of democratic processes and constitution. Therefore, most any reference to participation immediately links up with the pertinent provision in the Universal Declaration of Human Rights. Participation of women shows how embedded the rituals and practices of exclusion and inclusion are that define participation in a broader sense: it is all about the ways and style in which a person or a group of persons is considered, listened to, taken seriously, and genuinely involved in the fabric of society. Zooming in on the participation of girls and women with disabilities it may well be summed up with the phrase "inclusion – or being asked to dance." It is not about being allowed to be present in the room – that is integration – but to be seen and meaningfully involved in all aspects of society without obstacles of any sort. Particularly without attitudinal barriers as the CRPD calls them (Preamble (e) CRPD). Participation at its core is thus about being enabled and empowered to be oneself, speak for oneself, and in so doing live the freedom of stigma.

One of the challenges of participation in the context of the CRPD is that frequently the question of independence and independent-living is conflated: one need not be able to do everything by oneself in order to participate: one may fall back on various forms of support and assistance and live independently, including by having a say and participating in various aspects of society. Accordingly, the CRPD is peppered with references to participation in various meanings. Participation is a red-thread from the CRPD purpose (Article 1), via the General Principles (Article 3) throughout various aspects of life – education (Article 24), rehabilitation (Article 26), living in the community (Article 19) – but also in some of the fundamental aspects of inclusive societies such as accessibility (Article 9) and access to information as part of freedom of expression and opinion (Article 21). Furthermore, the treaty emphasizes the importance of participation in accountability measures such as the monitoring mechanisms at national and international levels (Articles 33 & 34).

The CRPD enshrines the importance of supporting the "development, advancement and empowerment of women and girls with disabilities" (Article 6 CRPD) in order to enable their meaningful participation. The CRPD Committee, in a yet to be adopted General Comment on Participation says clearly that "the denial of equal access to participation of women and girls with disabilities in public decision-making" is one of the areas of great concern (CRPD Committee 2018, 11). Accordingly, the Committee calls for specific support in the representation of women with disabilities: "Organizations of women with disabilities, ensuring the participation of women with disabilities, must also be considered a requisite in consultations addressing specific problems impacting exclusively or disproportionately on women with disabilities, as well as problems related to women in general, such as gender equality policies."

Describing the diverse needs of participation requirements, the CRPD calls on governments to "actively involve DPOs/OPDs who represent the vast diversity in society, including but not limited to women, children, refugees and asylum-seekers, stateless persons, the LGBTIQ community, persons with psychosocial and/or intellectual disabilities, autistic persons, persons with albinism, persons with hearing and visual impairments, persons with HIV/AIDS, persons with neurological and genetic conditions, Roma and Sinti and other ethnic minority groups, indigenous and rural communities and persons requiring high level of support" (CRPD Committee 2018, 36).

Conclusion

With regard to the performance of unpaid care work, UN WOMEN (2018) observes that taking on the "bulk of this [care] work," women and girls are left with less time for various other problems in life, including political participation. This in turn means that the odds of their being left behind in contemporary development efforts are increased, particularly for those portrayed as more vulnerable such as girls and women with mental health problems.

While current debates around toxic masculinity provide ample ground for critique, they offer a helpful glimpse at what remains to be undone on the verge between public and private spheres to ensure that women can meaningfully participate speaking for themselves in various areas of the public realm. This is particularly true for women and girls with mental health problems, who are likely to depend more than others on the public sphere providing a certain level of "safe space."

States have committed to numerous human rights obligations and other political pledges aimed at ensuring the meaningful participation of women and girls with mental health problems in the life of their communities. The Sustainable Development Goals provide a renewed impetus to reaching that position. The data generated as part of the process of meeting them adds to the urgency of implementation.

Cross-References

- ▶ Challenges in Women's Mental Health: Care in Conflict and Post-conflict Situations
- ▶ Refugees and Asylum Seekers

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