

# Barriers to WHO Mental Health Action Plan updates to expand family and caregiver involvement in mental healthcare

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In 2021, the 74th World Health Assembly endorsed updates to the WHO's Comprehensive Mental Health Action Plan extending to 2030, including revised indicators to measure progress towards reaching defined targets and expanded implementation options for various facets of the plan. Some of the latter are to foster the empowerment and involvement of persons with mental disorders, their families and caregivers in mental healthcare and address the mental well-being of children and carers when a family member with severe illnesses presents for treatment at health services. Other implementation options suggest providing information to people with mental disorders, their families and carers about the causes and potential impacts of the illness, treatment, recovery options and healthy lifestyle behaviours to improve overall health and well-being. The Action Plan also covers related options such as intervening to manage family crises and providing care and support to families and carers in primary care and other service levels.

Decades of cumulative research findings<sup>1–10</sup> have provided evidence demonstrating the effectiveness of family and caregiver support for those with mental illness; this has led to worldwide policy development on caregivers and families in mental health services. Yet, despite these developments, the implementation of family interventions and caregiver involvement for mental healthcare—at the service and clinical delivery level and on a global scale—still suffers significant obstacles and remains alarmingly inadequate. As a result, family and caregiver involvement falls far below the recommended levels even though the evidence of beneficial outcomes for both patients and caregivers has been known for decades.

Several questions require consideration: (1) Why is the task of implementing greater family involvement often overlooked, poorly understood and largely unaddressed in clinical practice? (2) Why is family involvement in mental disorder treatment plans seldom incorporated worldwide? (3) How can we reach those who need it most—persons with mental illness, their families and caregivers in areas throughout the world where psychiatric care is inaccessible or unavailable?

In 2021, the second year of the global pandemic, several studies worldwide indicated an urgent need to increase the involvement of families at all levels of psychiatric care. These studies, including some from Norway, Denmark and Singapore,<sup>11–14</sup> emphasised the need for more research focusing on identifying and implementing core aspects of caregiver involvement and family engagement in routine psychiatric care.

A 2014 systematic review by Eassom *et al*<sup>15</sup> indicated that implementing family participation in psychiatric care carries challenges beyond those generally associated with translating research into practice. Incorporating a model of care that regularly involves families may require a shift in work culture and organisation (eg, changes in work routines, approaches, ethos and practices) until it finally becomes accepted and integrated by clinical teams and management. The barriers to family and caregiver involvement in mental healthcare identified in this review also resonate closely with others found in the scientific literature.<sup>16</sup> A 2017 systematic review by Selick *et al*<sup>17</sup> investigated the barriers and facilitators to delivering family-based interventions. They identified four key themes related to implementing family support: family/client interest and readiness, family ability to access support, family support needs/preferences



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and support for staff. Whereas the first three themes related to the uptake of families, the last theme focused on programme implementation. Selick concluded that several core elements generally recognised as critical to successful implementation include staff training and supervision, leadership, feedback for programme improvement, and sufficient time, space, materials and staff.

A systematic search into primary studies addressing diverse stakeholder perspectives on barriers to family involvement by Landeweer *et al*<sup>18</sup> reported differences in the interpretation, perception and experience of various barriers. The results indicated that individuals with mental illness, their families and mental health professionals varied in their understanding, assumptions, interests, needs and expectations of family and others' roles in care because of differing contexts, experiences and backgrounds. The authors concluded that these differences could themselves be barriers to family and caregiver involvement if the stakeholders do not discuss them and acknowledge the possible differences in perception.

Overall, substantial research supports the existence of numerous varied barriers that prevent increased family and caregiver involvement in the provision of mental healthcare. These originate at all levels—patients, family members, professional staff and mental health authorities—and reflect the major obstacles blocking increased implementation of family and caregiver participation in routine psychiatric clinical practice.

Due to the complexity of these ongoing, multifaceted difficulties, much work remains to be done if WHO's plans for increased family engagement and caregiver intervention are realised by 2030. Lucksted *et al*<sup>5</sup> have emphasised the paradox of robust evidence showing the effectiveness of family intervention versus persistently low rates of its execution. Furthermore, they argued that likely no single implementation strategy will suffice. Indeed, given the decades of consistent results of similar studies, barriers at all levels persist in implementing tasks, research and strategies related to expanded family and caregiver participation in mental healthcare. An undeniable observation is that the vast majority of families and caregivers of those with mental illness still do not have access to family-related interventions or caregiver guidance due to the widespread unfamiliarity and other impediments in fulfilling the necessary implementation tasks.<sup>19</sup>

Some have argued that expanding family and caregiver involvement in mental healthcare requires tailoring each situation across different levels due to the considerable variations among countries, regions, cultures, clinical practices, management styles and organisational ethos. More specifically, Landeweer *et al*<sup>18</sup> suggest awareness and dialogue about various stakeholders' experience of the barriers are needed to comprehend better the dynamics that hamper the uptake and quality of family involvement. Only then could mutual understanding be fostered, collaboration enhanced and possible conflicts of interest be resolved.

In conclusion, little change has occurred in developing and disseminating expanded family interventions and caregiver engagement in mental healthcare globally. Further change is unlikely as long as significant implementation challenges remain at all levels. Despite solid advocacy recommendations from WHO and abundant evidence showing the effectiveness of family and caregiver involvement, more consistency is required in reporting implementation strategies and barriers. Moreover, the news of this failure to implement suggested programmes is not unfamiliar to governments worldwide. For example, the most recent *Mental Health Atlas* report by WHO in 2021<sup>20</sup> shows significant gaps globally between the existence of policies, plans and laws, the implementation and monitoring of these, and the allocation of resources. At the opposite end of the spectrum at the primary healthcare level, similar breaches are seen in implementing greater involvement of families and caregivers.

There is little doubt that a large population of families and caregivers would benefit from the proposed WHO implementation options to improve mental healthcare. Unfortunately, they will not receive this aid soon. To continue highlighting the need for improved participation of families and caregivers in providing mental healthcare, more scientific expertise, political will and grassroots prowess are needed. Without actionable steps, WHO recommendations do not automatically translate into practice. A targeted focus at all levels of the mental care system addressing the notable barriers to implementing expanded family and caregiver involvement would expedite this noteworthy and vital evidence-based practice. Everyone would benefit.

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