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Service User and Family Carer Advisory Group, December 2020

End of Triennium Report

1.0. Background

The World Psychiatric Association has given priority to establishing best practice in engaging with service users and family carers. This work builds on an earlier initiative, when the Association established a task force on best practices in working with service users and family carers. The task force developed a set of ten recommendations for good practice. This became the basis for a worldwide consultation of stakeholders, including the WPA officers and over 200 national and international civil society organizations. Several of the recommendations were included as a new paragraph in the Declaration of Madrid in 2011.

The Advisory Group for Service Users and Family Carers is therefore an expression of WPA commitment to best practice in this area. It represents a logical progression from the task force and an aspiration to bring achieve integration of this work to the ongoing activities of the Association.

2.0. Purpose

WPA established the Service User and Family Carer Advisory Group in November 2019. The specific objectives agreed by the group were:

1. To develop a productive partnership between WPA and service user and family carers
2. Identify areas of work in which WPA should develop new activity
3. Explore and initiate approaches to improving systems that affect the lives of service users and family carers

Specifically, The Advisory Group set out to provide advice and information to the WPA on a range of matters relevant to their experience. During the year, the group also started to talk about identifying projects or other initiatives that could be implemented by the Advisory Group and which could attract funding, enabling a sustainable program of work to be developed.

3.0. Membership

The membership of the Advisory Group included four people with lived experience of service use and four people with experience as family carers. Two members of the WPA Executive Committee also participated as members of the group.

The Advisory Group met every two months between November 2019 and December 2020 and included in its program a special meeting on Alternatives to Coercion in Mental Health Care (see Section 4.2. below).

4.0. Activities

The Advisory Group focussed on the following key subjects:

4.1. WPA Congress

The Advisory Group was active in providing suggestions to WPA on the organisation and content of its planned Congress in Bangkok in 2020, which was ultimately postponed due to the global health pandemic. The value of that advice remains, especially to ensure that service users and family carers contribute to panel sessions, are involved in high-impact parts of the program and are integrated into the mainstream flow of the event, rather than sessions that refer only to the needs or interests of service users.

4.2. Implementing alternatives to coercion in mental health care

During 2019, in partnership with RANZCP, WPA initiated a project to research and publish a discussion paper on the current situation relating to coercion in mental health care and strategies to reduce and minimise it. The paper considered how best to:

- Discern and support the contribution of psychiatrists and other mental health professionals to implementing the provisions of the CRPD (UN Convention on the Rights of Persons with Disabilities)
- Improve practice, conditions, care and links with community supports in institutional and other settings for people with long-standing mental illnesses and disabilities and their carers.

The discussion paper is titled 'Implementing alternatives to coercion in mental health care'. During 2020, the Advisory Group provided a range of comments and suggestions on a draft version, including participating in a special meeting at which the paper was presented by the Co-Chairs of the WPA Task Force on Minimising Coercion in Mental Health Care, Silvana Galderisi and John Allan. The process was supported by Helen Herrman, president of the WPA.

Overall, the project demonstrated how the Advisory Group can play an effective role in informing and influencing the work of WPA.

4.3. Building a network internationally

In considering how best to reach a wide range of user groups, the Advisory Group started to pool resources on user groups internationally. They agreed that there is great scope for building a network of relevant organisations internationally that are representing, involved with or relevant to the needs of service users and family carers.

In addition, easy access to testimonials from people with lived experiences and a list of people who could be invited to participate in activities relevant to presenting or sharing the experiences of service users and family carers would be initiatives that increase the positive influence of service users and family carers through WPA. This work remains in its early stages and will continue with new impetus in the next triennium.

4.4. Development of educational resources

The Advisory Group discussed the potential for bringing together existing educational materials as a single resource that could be made available for the work of WPA and other organisations with an interest in working effectively with service users and family carers. An example is the development of a list of educational materials for psychiatrists.

This aim is likely to be realised in the next triennium as the group transitions to become the Working Group on Developing Partnerships with Service Users and Family Carers.

5.0. Conclusion; a partnership for the next triennium

Aside from the specific work described above, an achievement for the Advisory Group during this very early period of its existence is that it has established an effective strategy for bring the voices and experiences of services users and family carers directly into the thinking of WPA.

Martha Savage is a member of the Advisory Group. She says:

“As a representative of family carers, I have been very pleased at the welcome extended to me by the WPA. The regular meetings of the group have been fruitful and I feel that we have particularly had an impact on the planning of the WPA Congress in October. For example, many of our proposed sessions are to be included and we were asked to appear on panels at sessions that others proposed. My particular interest has been in minimising coercion and I was pleased at how attentive the Task Force was to my input in the discussion document on that subject.”

We anticipate the next triennium will build on the ground-breaking work of the Advisory Group in its first twelve months of operation.