

Paper Three: ‘The Differing Needs of Support People and Consumers’

April 2021

Our position on the differing needs of someone experiencing mental ill health and or substance misuse (‘service user’ or ‘consumer’) and the people who support them (‘unpaid support people’ or ‘family members and friends’) is informed by the lived experience of mental health family members and friends.

Mental health family members and friends tell us that their needs do not always align with the needs of the person they support, or, that person’s mental ill health or substance misuse diagnosis.

Where a consumer might seek specific support relating to their diagnosis (for example, Dialectical Behaviour Therapy for those experiencing Borderline Personality Disorder), family members or friends most often seek generalised support which may be unrelated to the specific conditions the people they support experience. For example, support or training to navigate differing relationships, have tough conversations, set boundaries, establish emergency response plans, advocate for themselves and the person they support, work with service providers as a support person, or implement personal self-care strategies.

Families and friends also tell us of times when the person they support has been coping well and managing their mental ill health experience:

“While my sibling had a period of doing ok, going to work and sleeping regularly, my anxiety levels remained high – I was preparing for the next crisis period while continuing to coordinate their appointments, medication and service payments. For me, nothing had changed.”

This experience demonstrates that **the needs of a consumer and those of a support person can fluctuate, or remain constant, at different times, irrespective of the needs of the other.**

The State Government has also acknowledged this difference. This is reflected in the funding of separate peak bodies to support and advocate for the interests of mental health consumers (Flourish Tasmania) and the unpaid family members and friends who support them (Mental Health Families and Friends Tasmania (MHFFTas)). This distinction is also reflected at a national level (for example, our National Body, Mental Health Carers Australia, which specialises solely in advocating for the needs of unpaid mental health support people).

Within Tasmania, each peak body (Flourish Tasmania and MHFFTas) separately coordinates a Lived Experience Representative Program - the Consumer Representative Program and the Family Friend Representative Program. Our program coordinators and lived experience participants both tell us about the importance of acknowledging the separate and unique voices of each lived experience.

In this context, **a consumer can speak directly to the experience of receiving the delivery of a service.** In contrast, **a family member or friend is not directly consuming a service and might have an opinion about their involvement in the process as an unpaid support person, but not necessarily of the service itself.** For example, a young person experiencing depression might seek support from a youth mental health service. They would experience the care planning process and the therapy (or care) delivered. Their support person

might be involved in providing care before and after the appointment, accessing the service, as well as the care planning process. However, the support person would not receive the individualised therapy. It is because of this difference that both consumer and carer representatives are invited to share their voice, and differing experiences, on the committees, panels and advisory groups that seek their input.

Here, MHFFTas makes an important distinction. While we advocate for the inclusion of unpaid support people in service delivery, we understand that they are not the primary recipient of that service, but rather a partner in the provision of care and support that the service seeks to achieve.

In the time that MHFFTas has been supporting family members and friends, we have taken care to keep our training and peer support offerings exclusive to unpaid support people. This is because **family members and friends tell us that they do not always feel comfortable talking about their own experience or support needs when the person they support is also present.**

Flourish Tasmania tells us the same is true for mental health consumers. For example, a consumer might wish to speak to the stress and anxiety caused by a family member or friend, while a support person might speak to stress and anxiety caused by a mental health consumer. While both experiences are valid, it can be difficult for one to be voiced in front of another within a peer support or training context. Alternatively, at times, one voice can be louder than the other, meaning that each participant is not heard equally.

Here, MHFFTas makes a second distinction. The situation above is different to a situation in which a family member or friend and a consumer might sit on the same advisory group and provide input. In the latter, both lived experience representatives have been trained in sharing their lived experience within a professional setting and are prepared for, and mindful of, the differing views of others.

Over the past 37 years, MHFFTas has worked to build collaborative and supportive relationships with its consumer representative counterparts. A consumer who has contacted the MHFFTas referral line will be directed to the relevant consumer peak body (for example, Flourish Tasmania or the Alcohol, Tobacco and Other Drugs Council Tasmania). Similarly, an unpaid support person who reaches out to a mental health consumer organisation, for example, will be redirected to MHFFTas.

Going forward, MHFFTas welcomes the opportunity to further discuss the differences between the needs of the person accessing a service, and the needs of their support person.

Contact our CEO, Maxine Griffiths AM

Phone: 0437 010 934

Email: ceo@mhfamiliesfriendstas.org.au

Office: 2 Terry Street, Glenorchy 7010 (ground floor)

Website: www.mhfamiliesfriendstas.org.au

Facebook: @MHFamiliesFriendsTas

Our Vision

Families and friends of people affected by mental ill health are understood, respected, valued and supported to build their capacities and improve their quality of life.