

## 4. SUMMARY OF COMMENTS

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The following section gives a summary of the main issues raised in the workshops from the Consultation Forums and through the other consultation processes. For the most part, similar issues were raised in all the Consultation Forums across the country, so comments are aggregated and not specified according to State/Territory. Diverging comments between States/Territories tended to reflect jurisdictional differences in the level and types of mental health services available in the jurisdiction. For example, the Psychiatric Disability Rehabilitation Sector (PDRS) is much stronger in Victoria than elsewhere; consequently, comments from and related to this sector were generally restricted to Victoria. Mostly, however, similar themes were evident across Australia.

### 4.1 Comments on the relapse prevention framework presented in the Discussion Paper

Overall, there was a very positive response to the *Discussion Paper*. Respondents were pleased that this issue was finally receiving long-needed attention. Moreover, respondents appreciated that the *Discussion Paper* was grounded in lived experience and had prioritised consumer voices. People particularly liked the use of consumer (and other) statements throughout the *Discussion Paper*, which they felt grounded the paper within lived experience and gave it an appropriate balance between the lived experience and academic research.

Many consumers and carers commented on the positive and optimistic approach taken by the *Discussion Paper*, which they felt was empowering and affirming. They appreciated that prevention was placed within a recovery focus and viewed as an ongoing learning process whereby people needed to be supported to learn over time what works best for them. It was felt that the *Discussion Paper* contributed to a hopeful and proactive approach for people with mental illness.

Many consumers confirmed the issue raised in the *Discussion Paper* that they didn't like the terms "relapse" and "relapse prevention". However, it was difficult for people to agree on a preferred term, as people used diverse language to refer to their ongoing mental health status. The terms "episode" and being "well" versus "unwell" tended to be preferred to relapse. While consumer respondents generally preferred a stronger wellness focus, they did agree that the illness and prevention focus of the *Discussion Paper* was a useful and practical step forward in the area of continuing care. Most people agreed that prevention was an essential component of recovery, even though it was more illness focused. Interestingly, there was a significant number of consumers who also objected to the term "recovery", arguing that it was a misuse of the word to apply it in the context of mental illness and that it set up unrealistic expectations of "full recovery" for many people.

Respondents universally endorsed the 4As Framework. Consumers, carers and service providers all agreed that the Framework was practical, holistic and captured all the elements needed that impacted on relapse. The broader focus on the factors affecting mental health, such as living situation, physical health and the need for meaningful involvement, was strongly endorsed. People felt that having a wider range and choice of service options, which could be matched to people's unique needs and preferences, was essential to future wellbeing.

Most service providers stated that the 4As Frameworks provided a comprehensive and useful set of principles, which were practical and able to be translated into practice in different service contexts. Importantly, the Framework validated the way some people and sectors already operated, particularly those providing psycho-social and rehabilitation services. While the Framework did not provide any real innovations in approach, its value was that it brought together an approach that advocated an holistic approach to mental health and wellbeing. Many commented that it was timely that the broader promotion, prevention and early intervention (PPEI) focus was brought to the continuing care end of the mental health intervention spectrum. This shifted the focus from a medical model to a model that emphasised risk and protective factors, and that supported a more active role for consumers and their families and carers.

As the Framework was seen to be validating of the way that many services were already operating, it was argued that there needed to be greater acknowledgement of those services and sectors that were already implementing this approach. For example, the PDRS in Victoria has effectively used this approach for many years. This sector is not widespread elsewhere, however, and it was agreed that the mental health system, overall, did not support full implementation of the Framework and there were service gaps in all areas. While the emphasis on the role of general practice was commended, it was argued that greater consideration of the broader community sector was warranted.

Some gaps were noted in the content of the *Discussion Paper*. During the consultations it became evident that there needed to be more consideration of the unique issues for: parents with mental health problems and their children; people with complex problems, especially those with co-occurring drug and alcohol problems; forensic clients; people with suicidal ideation; and people from culturally and linguistically diverse and Aboriginal and Torres Strait Islander backgrounds. It was noted, however, that these were areas of developing understanding and that there was not a lot of easily available material to draw upon; greater emphasis, therefore, needed to be placed on developing better understanding in these areas. While some people felt the sections on Aboriginal and Torres Strait Islander peoples and people from culturally and linguistically diverse backgrounds needed further elaboration, others maintained that the paper acknowledged cultural differences in presentation of relapse and had a good focus on Indigenous mental health.

It was felt that there could be greater emphasis on carers, including children as carers. Some respondents argued that throughout the *Discussion Paper* there was an assumption that carers were well and capable of fulfilling the substantial role that was assigned them; yet, there were many reasons whereby the carers' role was made more difficult that had not been adequately covered.

With the exception of the terms "relapse" and "relapse prevention", most of the terminology used in the *Discussion Paper* was validated. In particular, respondents stated that it was very useful to have the terms "recovery", "rehabilitation" and "relapse prevention" clearly described and their differences made clear. However, the term "case management" received some criticism, and some people preferred the term "key worker".

It was clear to respondents that the *Discussion Paper* was only a first step toward progress in this area and that there needed to be much more in the way of resources to support implementation. For example, it was suggested that there needed to be concrete examples of the 4As Framework as well as examples of action plans that were being used in different services and local areas. The *Discussion Paper* was far too long to be accessible to most people, and needed to be translated for different audiences. This was seen to be a particular

challenge for some community groups, such as remote Aboriginal and Torres Strait Islander communities, although programs such as AimHi were already developing resources in this area.

## **4.2 Other experiences of relapse prevention**

Overwhelmingly, the type of support put forward as providing the best experience of relapse prevention was peer support for consumers. Being involved in consumer-related and run activities was commonly cited as an essential component of maintaining ongoing wellbeing. Peer support was generally provided through non-government organisations and often focused on social or vocational programs, education and advocacy. It was through this type of support that people gained social interaction and companionship, acceptance and relief from stigma, meaningful activity, and most importantly, hope. Opportunities to be involved, even through volunteer work, were cited as very effective in supporting wellbeing. Many consumers argued that they needed meaningful activity, connectedness, and structure to their day to stay well. However, this type of support was not widely available outside major metropolitan areas, and consumers in rural and remote areas were particularly poorly served.

Peer education was also one of the main ways that people learned to recognise early warning signs and to understand the risk and protective factors for their mental health. The Wellness Recovery Action Plan (WRAP) by Mary Ellen Copeland was a peer-based initiative that was especially useful helping consumers understand the factors that affected their ongoing wellbeing and ways to manage their mental health. Tools, such as self-rating scales to encourage self-monitoring of symptoms and wellbeing, were effectively used by many consumers, and some family and carers, to support wellbeing. Many of these tools were developed by consumers for consumers. However, tools developed by the Commonwealth Rehabilitation Service to help support people to stay well and get back to work were also valued.

Approaches such as Collaborative Therapy, and other programs that were attempting to develop partnership models and enhance self-management for consumers, were praised in the few areas where they were available. Many local areas and jurisdictions are developing partnership models, and where these are able to be developed and effectively implemented they are very effective. However, there are many obstacles to developing effective partnerships that require perseverance to overcome.

Many services had examples of self-management, discharge and care plans that were being effectively used. However, these appear to be available on an ad-hoc or informal basis and are not a routine component of the mental health system. Furthermore, even when a service implemented such planning, there was rarely the whole system support within the community to effectively support the plan. Nevertheless, many consumers and service providers had experience of useful prevention and recovery planning. Advanced Directives, as a way to plan for preferred options if the consumer becomes acutely unwell, were highly valued by consumers in areas where their implementation was supported.

It was noted that plans needed to be holistic and include a whole of life focus, as recognised by the 4As Framework. This needed to include accommodation and physical (including dental) health. A few programs and planning approaches had a specific focus on physical health, which consumers and carers found to be very important for supporting ongoing wellbeing and improved mental health.

Healthy lifestyle programs more broadly, including stop-smoking programs for people with mental illness, were reported found to be helpful. A focus on physical wellbeing, and its impact

on mental health, was essential. Physical activity, even simply walking or gardening, was used by many consumers to maintain their wellbeing. However, for consumers who were isolated or lacking in motivation, recreation link officers had been used in some areas to successfully help people to get involved in physical activity and other recreation activities that helped prevent future illness.

Many services and service providers used prevention models that they found effective. Stress-vulnerability models, stages of change approaches, and other holistic models that considered the dynamic nature of the risk and protective factors that affected people's mental health were incorporated into many approaches. These types of models were put into practice by case managers and support workers, PDRS, community service providers, and allied health professionals such as psychologists and counsellors.

Many consumers, as well as service providers, reported the effectiveness of Cognitive Behaviour Therapy, mindfulness therapies, Yoga and other forms of meditation and relaxation as fundamental to their ongoing wellbeing. There were numerous stories that while medication had been essential for a person to stabilise their mental health, ongoing wellbeing was achieved through these cognitive techniques.

Carers noted that ASSIST training and Mental Health First Aid were programs that were very useful for them, providing them with skills to help support the consumer, as well as knowledge that reduced the stress they experienced.

The Children of Parents with Mental Illness (COPMI) program was repeatedly mentioned as an essential and greatly valued support for this population group, who had significant needs.

Finally, while many and varied examples of ways to prevent relapse and support wellbeing were provided by respondents, it was evident that these were available only on an ad hoc basis. They had often been developed either informally or on a limited service basis, and very often consumers and their families and carers only came across them by luck, accident, or persistence. There was no routine approach to incorporating ongoing prevention within the mental health system in any jurisdiction. Consumers, and their families and carers, could have no expectation of receiving an holistic, ongoing and planned approach to continuing care. Importantly, service providers, particularly psychosocial service providers, had no expectation of being part of an integrated and holistic system of mental health care.

### **4.3 Implementation**

Overwhelmingly, many of the feedback comments related to implementation issues. While respondents strongly supported the 4As Framework, they did not believe that the resources and system supports necessary to effectively implement and sustain such an approach were in place. Moreover, respondents were doubtful that more resources would be forthcoming, and that this approach could not be achieved without a significant injection of money and additional support. Many people voiced the view that, like so much other Australian mental health policy, yet again we had produced excellent rhetoric that was not implemented in practice.

Key implementation issues were:

- resources;
- translating policy into practice;
- reorientation;
- attitudes, education and training; and

- applications for people with complex conditions and comorbidities, Aboriginal and Torres Strait Islander peoples, and people from culturally and linguistically diverse backgrounds.

## Resources

It was strongly felt that the resources to implement the 4As Framework were not available. In particular, there needed to be much improved resourcing of the peer support sector. While this sector was developing and had become very strong in some areas, there needed to be support for the sector to grow and to reach areas where it was currently not available, such as rural and remote areas.

Similarly, the carer support sector needed to be better resourced. This sector was much less well developed than the consumer support sector, but equally important for families and carers, and needed to have additional resources to enable it to significantly expand. Other supports for carers also needed to be resourced; such as more flexible working arrangements that enabled time off when their family member was unwell.

Jurisdictions and local areas needed to be enabled to map their resource needs as a first step toward determining the gaps in service provision. Few areas had the data and information required to determine exactly what level and type of services were required for the population needs of the local area. To support a population health approach, there needed to be information and guidelines available to determine the actual resource needs of a local area.

While the acute care sector was overstretched in many areas, resources for the non-government organisation and psychosocial disability sectors, in particular, needed to be significantly improved. With the exception of Victoria, the PDRS sector is significantly under-resourced, but essential to implementing the 4As Framework.

A wider range of accommodation and treatment options was also imperative. This needed to include respite care, step-up/step-down services, and sub-acute models of care and support. Service options needed to be available to bridge the 'all or nothing' focus of acute care.

Services specific to the needs of particular population groups required resourcing; these were rarely available outside the major metropolitan areas. This included younger people and older people with mental health problems, Aboriginal and Torres Strait Islander peoples, people from culturally and linguistically diverse backgrounds, and people with complex conditions including people who had been forensic patients and those who had co-occurring drug and alcohol problems.

Importantly, the resources that *were* available in a local area needed to be better understood and more accessible. Up-to-date lists of the options for self-help, peer support and mental health and allied health services needed to be available in all local areas.

Another area where lack of resources significantly impacted was the lack of research funds. This meant that many alternatives to the medical model did not have an evidence base. This did not mean that the alternative was not effective, but rather that no research had been carried out to determine its effectiveness. While the evidence base for CBT was expanding, partly because it was the focus of much of the research effort, there was a paucity of research devoted to other types of therapies and supports. Furthermore, some types of health promotion and community-based supports were not amenable to being researched through the 'gold standard' of a randomised controlled trial, and a wider range of research evidence needed to be valued. More treatment and support options needed to be available for clinicians, community support workers,

and consumers and their families and carers. This required greater research support and effort, and dissemination of the evidence base for effective alternatives.

### **Translating policy into practice**

A common criticism of the *Discussion Paper* was that it did not give any guidance regarding implementation: either how to go about implementing the 4As Framework or who was responsible for making it happen.

Regarding making it happen, most respondents felt that the Federal government needed to take a more active role in terms of leadership, particularly around ensuring accountability. It was felt that implementation should not be left to the States/Territories. Jurisdictions, local areas and the managers of mental health services needed to be mandated to put into place the supports to enable the 4As Framework to be implemented. For example, it was suggested that national accreditation systems, such as the National Standards for Mental Health Services, be used to support the Framework, and regular audits be carried out to ensure effective implementation.

A significant amount of system development needed to take place before the 4As Framework could be effectively adopted. This included the development of Information Technology systems that could support information sharing, integrated service approaches and longer-term planning. There were many innovations in this area, particularly supporting general practice, but the further and accelerated development of these system supports needed to be prioritised. In parallel, guidelines to ensure privacy and confidentiality, while information was effectively shared, needed to be strengthened.

It was acknowledged that significant progress was occurring in the area of preventing and managing chronic illness, particularly around the development of primary health care networks. Stronger links should be forged with this area as there were many commonalities. For example, the role of community pharmacy was not strong in the mental health field, but was increasingly being acknowledged as part of primary health care.

Essential to implementing the 4As Framework were a range of other supports that could turn the rhetoric into reality. Suggested additional resources included:

- summaries of the Framework that were in formats that were appropriate for different population groups, such as young people and Aboriginal and Torres Strait Islander peoples;
- examples of good practice for example in discharge plans, identification of early warning signs;
- templates and guides for implementation at local levels;
- development of standard tools; and
- ways to share experiences and information.

### **Reorientation**

The need for reorientation of the mental health system has been argued since the advent of the National Mental Health Strategy, and considerable progress has been achieved. However, implementation of the 4As Framework requires even greater effort in this direction.

Respondents acknowledged that the mental health sector needed to change its acute focus to become more holistic, proactive, integrated with primary health care, and long-term. It was argued that reorientation needed to occur at all levels, including: recruitment, orientation, supervision, and professional development for staff; and for all types of health and community

services. Some respondents argued that the focus of the entire mental health system needed to be reversed: currently the model was of acute clinical services supported (where available) by community support and psychiatric disability services; instead the model should be community and disability services supported by acute and clinical care.

The need for flexibility and the ability to work in an integrated and holistic way were emphasised. In current mental health services, too often exclusion criteria were used that meant that many people fell through the cracks. This applied particularly to people with drug and alcohol problems, physical or mental disabilities, and other conditions that made their situation more complex. Part of this was attributed to the specialist nature of mental health care; many professionals wanted to be specialists in their particular area and guard their expertise, rather than work with a more holistic and integrated approach. This was especially evident between specialist mental health and drug and alcohol services; where people with co-occurring problems were either rejected by both or batted back and forth between the specialist services.

Furthermore, it was argued that many mental health services spent more time assessing suitability to be in a program than they did on longer-term planning. Lack of forward planning was a common complaint; many services had no planning mechanisms, and even when they were available, they were often not implemented. It was argued that policy and procedure manuals should prioritise self-management and recovery planning. For example, on readmission to an acute service the previous discharge plan should be automatically reviewed to determine what worked and what didn't and what needed to be changed in planning for the next discharge.

Intersectoral cooperation was thought to be the foundation of reorientation, and this required formal mechanisms to be in place. At present, where reorientation was occurring, it was generally being achieved through informal arrangements, which then broke down if any of the people who had put them together left the organisation. Services with more formal arrangements, such as discharge plans, often had problems ensuring that they were taken up and implemented outside their own service. It was noted that one area that was rarely considered was the integration of private practice with publicly provided services.

Concerns were also raised about the privacy issues that arose with more integrated service arrangements. Effective partnerships were predicated on sharing information between services, and also with consumers and possibly family and carers. While there was an urgent need for more communication, there were sensitive issues to be resolved in this area and a great deal more needed to be done to develop protocols for sharing information while protecting privacy. For example, several carers noted that there needed to be triggers negotiated for when carers needed to be notified, such as when consumers were discharged from hospital.

On the other hand, the risk averse culture of mental health also needed to change. Services and service providers needed to be supported to be more flexible and proactive so they could effectively meet the changing needs of consumers and their families and carers.

### **Attitudes, education and training**

Attitude change was argued to be fundamental to reorientation and supporting implementation of the 4As Framework. The elimination of stigma and improved attitudes were required in many areas, including the media and general public, but was a particular problem in mental health services themselves. It was argued that mental health services and service providers that did not believe in recovery could not effectively implement the Framework.

While attitudes in mental health services were improving in many areas, there was still considerable room for improvement. It was suggested that the curricula of all the professions involved in the delivery of mental health services be examined to ensure that they promoted a holistic, preventive approach. Cross-sector training was argued to be an effective way of helping to change attitudes and encourage new practices, particularly training that involved both clinical and psychosocial service providers, and where consumers and carers were involved in delivering the training. In particular, the value of the role and experience of non-government organisations and the psychiatric disability sector needed to be emphasised; rotating staff through different types of services, such as hospital and community services, was put forward as a way of encouraging better collaboration.

Stigma was particularly strong in some culturally and linguistically diverse communities, particularly for older generations and people who had experienced torture and trauma. This discouraged the early use of services needed for preventive approaches. It was suggested that younger people from culturally and linguistically diverse communities should be targeted to change their attitudes and to then act as agents of change throughout their communities.

### **Applicability for diverse population groups**

There was some concern that the Framework was developed within a mainstream context and that there needed to be greater understanding before it could be applied to other population groups. The *Discussion Paper*, itself, argues that prevention within the context of Aboriginal and Torres Strait Islander communities is poorly understood.

The understanding of cultural differences in mental health is a developing area that requires more research and funding. For example, families were argued to be especially important for culturally and linguistically diverse communities, and the different roles of families and how to better integrate them within the mental health system needed to be a focus of investigation. Better understanding of recovery and the different factors that support mental health and wellbeing in diverse cultures needed to be explored.

As mentioned earlier, additional resources needed to be provided to translate the 4As Framework into format that were appropriate and applicable to the diverse range of population groups that made up Australian society.

## **4.4 How will we know that relapse prevention has become standard practice?**

Respondents were asked to consider how we would know whether the 4As Framework had been implemented and become standard practice. Respondents came up with a wide range of outcome and process indicators, which included the following:

- Decrease in readmission rates
- All consumers will have a care plan that has been negotiated with them
- Increased consumer satisfaction with mental health services
- More client control of mental health services
- Consumer roles, such as consumer consultants, will be a regular part of the mental health system
- Greater participation of consumers in community activities, work and social activities. In particular, greater participation of consumers in paid employment.
- Improvements in outcome measures like HoNOS
- Decreased suicides

- Reduced homelessness
- Improved physical health, including dental care, for consumers
- Broader scope of services will be available and consumers will be empowered to try different approaches and have a wider range of options to try
- Increased carer satisfaction with mental health services
- Decreased stress for carers
- Greater service access for people from culturally and linguistically diverse backgrounds
- Earlier service use
- Increased funding to NGO sector, including funding for training
- Substance use will be incorporated and addressed
- Evidence of collaborative partnerships
- More cost-effective services
- Less staff turnover in mental health services, and more satisfied staff
- Decreased workloads for mental health workers
- Key Performance Indicators (KPIs) for mental health services will include measures of return to hospital, such as length of time between admissions and admissions within 28 days.
- Reduced stigma
- Decreased activity of Mental Health Tribunal
- Less adverse publicity
- Decrease in coercive services and CTOs
- Less police involvement with mental health clients