




**Response to the
Department of Human Services Discussion Paper:**

**Because mental health matters:
A new focus for mental health and
wellbeing in Victoria**

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Health Issues Centre wishes to commend the vision and detail articulated in the Department of Human Services' Consultation Paper *Because mental health matters*. Health Issues Centre hopes this mental health reform strategy will lead to a high quality, comprehensive and responsive mental health system for Victoria.

Health Issues Centre

Health Issues Centre is an independent, not-for-profit organisation that has been promoting equity and consumer perspectives in the Australian health system since 1985. Its mission is to improve the health outcomes for Australians, especially those who are disadvantaged. The focus of Health Issues Centre's work is mainly in Victoria but we take a national approach where appropriate. We work with a wide range of consumers, health providers, researchers, governments and other health organisations to achieve this through:

- ▶ Policy analysis and advocacy from consumer and equity perspectives
- ▶ Consumer-focused research
- ▶ Promoting and supporting consumer participation
- ▶ Disseminating information.

Health Issues Centre has members and a Board of Governance that consists of consumers, health professionals, managers and researchers elected or co-opted from amongst its membership. Individuals and organisations can become members of Health Issues Centre to support and influence its activities.

Consumer Participation

The Centre has made a significant contribution to the acceptance of consumer participation as an effective approach within health care. We increasingly collaborate with health providers to improve the breadth and effectiveness of their consumer participation strategies through:

- ▶ Supporting Victorian Community Advisory Committees
- ▶ Assisting organisations to plan their participation activities
- ▶ Offering learning and development programs (training) to health staff and consumers in effective participation approaches
- ▶ Offering the extensive wealth of resources via our website www.healthissuescentre.org.au

Comments and feedback

Health Issues Centre understands that the Department of Human Services is seeking feedback on its Consultation Paper *Because mental health matters*; in particular, feedback that:

- ▶ Focuses on outcomes for individuals and communities
- ▶ Changes to service systems and policies required to achieve outcomes.

The observations, comments and recommendations detailed in this response are based on the historical and ongoing dialogue and work Health Issues Centre has carried out over the past 22 years with consumers and community members in Victoria. In particular, our recent work in training and supporting consumers and carers to play key roles in the statewide survey program for mental health services and a project we conducted between 2006 and 2007 to facilitate active consumer involvement in mental health service planning, delivery, monitoring and evaluation.

We have provided a response only where we feel we have sufficient experience and expertise.

Mental health promotion and prevention

Health Issues Centre is supportive of the shift to a mental health system that is based on wellness and mental health promotion.

Health Issues Centre also supports the need to recognise mental health as a population health issue and believes that, in doing so, actions can be undertaken to reduce the burden on individuals and communities.

Health Issues Centre agrees with the document when it states that 'new outcomes are needed that focus on positive and active participation in society, better education, employment achievements, reduced crime and victimization' (p. 13).

Improving outcomes for carers

Health Issues Centre recognises that carers play an important role in the journey of a person accessing the system and utilising services as well as during treatment and recovery.

Health Issues Centre believes that Part A of the *Because mental health matters* document provides inadequate attention to the role of carers in the Victorian public mental health system. However, we feel that Part B includes more of a focus and details specific actions that will be taken to enhance the support and contribution of carers.

Health Issues Centre recommends the Department of Human Services strongly support efforts to involve and support carers in future reforms. This view is consistent with findings of a number of projects that Health Issues Centre has undertaken, including work to ascertain the role of consumers and carers in the planning and implementing of cancer, palliative care, primary health and mental health services.

Workforce

Health Issues Centre acknowledges that very little attention is given to the mental health workforce in the *Because mental health matters* document. Particular issues that could have been considered include supply, retention and career development.

However, we appreciate that the document is not focused on implementation issues specifically and that workforce issues maybe the focus of future work.

Health Issues Centre hopes that due consideration will be given to workforce issues and that specific actions will be taken to ensure the workforce is equipped to address prevention and early intervention approaches and to work in an enabling and facilitating way with consumers and carers.

In recent years Health Issues Centre has designed and delivered training to a vast number of health professionals in both Victoria and Queensland. These professionals have been interested in enhancing their capacity to involve consumers in quality improvement and service planning. One project involved training 250 managers at Southern Health. Through all our training work we have heard that managers and staff want guidance, information, resource materials and practical support to enable them to plan and implement effective consumer and carer participation strategies. We hope that the Department of Human Services will consider supporting appropriate skill development initiatives for the mental health sector.

Access

Health Issues Centre agrees with the research referred to on page 19 of *Because mental health matters*, which suggests that Victorians find navigating the public mental health system problematic. Health Issues Centre is also familiar with the findings of the Senate Select Committee on Mental Health (2006), which concluded that 'seriously ill people are being turned away from public services' (p. 296).

While investment in services is crucial, Health Issues Centre believes that efforts need to be undertaken to ensure all Victorians are well-informed about the mental health system and know where to go for assistance. This is particularly important given the complex structure of the health system, with its mix of private and public services.

Within the past year Health Issues Centre has undertaken two significant projects that have identified consumers' concerns with accessing health services. One was for the North East Melbourne Integrated Cancer Service and the other for the Department of Human Services. Findings from this work suggest consumers need support to access and navigate their way through the system. Reports from both projects will be available in the coming months at www.healthissuescentre.org.au

Our strong position on the need to support consumers and carers to access and navigate the service system is supported by a number of studies, including one by Harris (2005), which has suggested accessing treatment and recovery support for people living in rural areas is particularly problematic.

Health Issues Centre believes that clarifying Commonwealth and state responsibilities for public mental health will go some way to reducing the confusion consumers and carers experience when accessing and paying for mental health services. This area of work should be a key priority of the Victorian mental health service reforms and be seen as a key enabler for change.

Consumer, carer and community participation

Health Issues Centre wants to see a high quality, comprehensive, responsive and efficient mental health system in Victoria. In order to achieve this vision we want to see more effort being directed towards involving consumers in decisions about their care and treatment, the wellbeing of themselves and their communities, and in the planning of policy and services. This position is consistent with the Department of Human Services' consumer participation policy *Doing it with us not for us* (2006). Health Issues Centre would like to see the mental health strategy integrate consumer participation in a similar way as that described in the *Doing it with us not for us* policy and include actions at the following levels:

- ▶ Individual level
- ▶ Ward/program level
- ▶ Organisational level
- ▶ Department of Human Services level.

Health Issues Centre believes that effective and sustainable consumer and carer participation should be an overarching principle for future mental health reforms, given the increasing evidence of its effectiveness, as described by the following selected studies:

- ▶ Development of patient information
(Health Issues Centre, 2006; Johnson, 2007; Nilsen, Myrhaug, Johansen, Oliver, & Oxman, 2006).
- ▶ Program planning and evaluation
(Allwell, Spink, & Robinson, 2004; Hider, Hurworth, Gill, & Wilcox, 2003; Naksook, Romios, & Spink, 2003).
- ▶ Providing feedback and input into complaints management
(National Resource Centre for Consumer Participation in Health, 2001; Varney, Connely, & Phillips, 2005).
- ▶ Service planning and delivery
(Capp, 2005; Daye J. et al., 2003; Ermacore, 2004; Holm, Oliver-Weymouth, & Wright, 2001; Moss, 2003; O'Neill & Mullins, 2002; Slater, 2002).
- ▶ Consumers involved in staff selection
(Grimshaw, 2003).

Health Issues Centre believes that a greater emphasis on the role and contribution of consumers, carers and communities is required in Part A of *Because mental health matters*. Enhancements to the document could include a review of the evidence on consumer participation in mental health (see Kroschel, 2005, and Pinches, 2005 for a useful brief overview) as well as the good work undertaken in Victoria to integrate consumer consultants and develop policies relating to privacy and rights.

Health Issues Centre understands there are complexities associated with consumer participation within the mental health system, but believes that, with good consumer input and involvement, policies and procedures that enable consumers and their carers to be at the centre of decision-making can be developed and implemented.

Health Issues Centre is excited by the potential for a Centre of Expertise 'for consumers and carers to provide mental health and mainstream services with access to technical expertise, education, training and evidence-based practice' (p. 85) and looks forward to working with the mental health sector to contribute to its development. Our experience in managing the Consumer Nominee Program—a program funded by the Quality and Safety Branch of the Department of Human Services—is that government departments and health services are increasingly seeking consumer perspectives to inform service and policy planning as well as to have input into the development of professional training and research projects. A centre that facilitated such consumer expertise for the mental health sector could ensure consumers are provided with adequate skill development and support and mental health services and government agencies are able to access expertise from diverse consumers.

As part of a consumer participation strategy, Health Issues Centre would like to see more consumer positions available in the system. Our experience of managing two recent projects that have involved supported consumers to participate in clearly identified roles within the mental health system has strengthened our belief in the benefits and possibilities of systematically implementing such an approach. If more positions for consumers are created within the mental health system, consumers could effectively be involved in the following key roles:

- ▶ Research positions
- ▶ Ethics committees
- ▶ Human resources and recruitment
- ▶ Staff training
- ▶ Staff selection
- ▶ Complaints and incident reviews
- ▶ Governance arrangements.

Health Issues Centre would also like to see future reforms in the mental health system include funding for consumer perspective research and consumer-led research. Most of the research agenda has been set either by clinicians or by academics or bureaucrats with limited participation by consumers (INVOLVE, 2004; National Health and Medical Research Council and Consumers' Health Forum of Australia, 2004). Consumer participation in research teams could ensure a good basis for research design, collection, analysis and dissemination. Appropriate information and skill development should be provided to consumers to enable their engagement in such important roles.

Health Issues Centre supports the potential for using Advance Care Plans 'as a strategy to empower consumers in their treatment and care planning' (p. 85). Advance Care Plans have been found to be an effective approach in ensuring individuals receive health care in their place of choice as well as in supporting consumers in avoiding unwanted and often burdensome treatments (Austin Health, 2006). Health Issues Centre has been actively involved in the Department of Human Services' Advanced Care Planning

Advisory Group, whose role it is to advise the Department on the development of the policy and implementation of the Advanced Care Planning policy across Victoria.

Health Issues Centre is committed to the philosophy and role of self-help groups for consumers with 'moderate mental health issues' (p. 85) and hopes that the reforms will ensure adequate funding for these groups to continue their important work. Health Issues Centre's experience is that there are mixed opinions about the role of self-help groups, with some consumers finding them very valuable and others not so. We recently undertook work for Cancer Australia to develop guidelines to support the formation and ongoing encouragement of self-help groups. Through this work we discovered that the establishment of self-help groups can be a complex process and key questions relating to the stage of a condition, the support available, the role of the group and whether it will focus on social and emotional support or education and information, need to be considered. We hope the Department of Human Services will invest in funding research in this area.

Funding for consumer participation

Health Issues Centre believes that state and federal governments need to allocate dedicated funding into the area of consumer, carer and community participation and to work in partnership with consumer and carer organisations to create appropriate models.

Health Issues Centre views consumers as pivotal to the government's success in implementing these positive reforms.

Role of the Victorian Charter of Human Rights and Responsibilities

Health Issues Centre sees the Victorian Charter of Rights and Responsibilities (Victorian Equal Opportunity and Human Rights Commission, 2008) as pivotal to underpinning the future provision of mental health services. Raising awareness of the role and implications of the Victorian Charter of Human Rights and Responsibilities has been a key area of work for Health Issues Centre in 2008. This work has involved consultations with consumers, communities and health professionals in collaboration with Ballarat Health Services and the Victorian Equal Opportunity and Human Rights Commission. A discussion paper outlining our findings and experiences will be released shortly.

One of Health Issues Centre's key observations of the Victorian Charter of Rights and Responsibilities is that health services and health consumers need support in the form of information and training to enable them to access and use the Charter. We believe that the Charter needs to be made transparent and meaningful within a health context. The rights in the Charter as they pertain to health are not consistently obvious and are subsumed under more generic rights. Yet in the process of reflection and learning about the Charter we have observed both health services and consumers offering feedback that suggests discussion on human rights helps deepen their reflection on key health issues.

General comments

Health Issues Centre agrees with the key elements of change described in the document (p. 22). We support the need for a greater focus on prevention and early intervention and for the development of a responsive system. However, we recommend that patient/person-centred care should be considered as an additional element, given its growing acceptance.

Health Issues Centre welcomes the use of the term 'social inclusion' and the recognition of the need for more consumer-oriented services. We call for more consumer-orientated services as our experience suggests they have the potential to foster principles of self-determination. We support the view of (Roper, no date) who has suggested consumer-driven services can 'assume a more social/recovery model of mental health, rather than a medical one' (p. 8) and can lead to a greater emphasis on group decision-making processes and mutual support.

Health Issues Centre commends the Consultation Paper for recognising that Victoria does not currently have a systematic model for 'planning services based on population needs, evidence of effectiveness and local capacity' (p. 15).

Health Issues Centre agrees that the framework should be focused on an outcome-driven system and acknowledges the need to have indicators and measures that are linked to the key determinants of mental health.

Future work

Health Issues Centre recognises the enormous amount of work that is required to implement the reforms described. We hope there will be some quick progress in certain areas and that actions to address prevention, early intervention and consumer and carer participation will be included in the initial stages.

Health Issues Centre hopes the future system will allow consumers and carers to experience an accessible, safe, high quality and efficient mental health system and one where they have the opportunity to participate in decisions about their care and treatment.

Health Issues Centre trusts these comments are valuable and would be happy to discuss them further with the Department of Human Services. All questions can be directed to Tony McBride, Chief Executive Officer, Health Issues Centre, on (03) 9479 5827 or at t.mcbride@healthissuescentre.org.au

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