



Towards an independent and effective national mental health consumer organisation: response to the national scoping project 'Consumers Speak: seeking a national voice'

18 December 2009

Peter Dodd, Solicitor – Health Policy and Advocacy

Introduction

The Public Interest Advocacy Centre

The Public Interest Advocacy Centre (PIAC) is an independent, non-profit law and policy organisation that works for a fair, just and democratic society, empowering citizens, consumers and communities by taking strategic action on public interest issues.

PIAC identifies public interest issues and, where possible and appropriate, works co-operatively with other organisations to advocate for individuals and groups affected. PIAC seeks to:

- expose and redress unjust or unsafe practices, deficient laws or policies;
- promote accountable, transparent and responsive government;
- encourage, influence and inform public debate on issues affecting legal and democratic rights;
- promote the development of law that reflects the public interest;
- develop and assist community organisations with a public interest focus to pursue the interests of the communities they represent;
- develop models to respond to unmet legal need; and
- maintain an effective and sustainable organisation.

Established in July 1982 as an initiative of the (then) Law Foundation of New South Wales, with support from the (then) NSW Legal Aid Commission, PIAC was the first, and remains the only broadly based public interest legal centre in Australia. Financial support for PIAC comes primarily from the NSW Public Purpose Fund and the Commonwealth and State Community Legal Services Program. PIAC also receives funding from Industry and Investment NSW for its work on energy and water, and from Allens Arthur Robinson for its Indigenous Justice Program. PIAC also generates income from project and case grants, seminars, consultancy fees, donations and recovery of costs in legal actions.

The current study

PIAC welcomes the opportunity to respond to the *Discussion Paper: Scoping Study to Inform the Establishment of a New Peak National Mental Health Consumer Organisation* (the Discussion Paper).

PIAC commends the Commonwealth Government for its proposal to initiate and fund an independent organisation

PIAC endorses the proposed focus of the organisation, referred to on page 1 of the Discussion Paper, as 'a socially inclusive human rights approach to mental health consumer issues'.

However, PIAC does have concerns about the suggested name of the organisation, its role in relation to existing mental health consumer organisations, potential conflict of interest problems and the need to have stronger mechanisms to preserve the independence of the organisation than those set out in the Discussion Paper. These concerns are expanded and explained in this submission below.

The submission begins with a set of principles that PIAC recommends be applied to the structure and policies of organisations working with consumers.

PIAC's work on consumer mental health issues

PIAC has a long history in working towards the goal of making the health care system more accessible and transparent for health consumers. One of PIAC's strategic aims is to assist to ensure the appropriate care and treatment of people with mental illness that respects the dignity and rights of the individual. Another of PIAC's

strategic aims is to assist in ensuring the delivery of appropriate quality of health care for people in various institutional settings such as psychiatric hospitals and prisons.

PIAC has undertaken a considerable amount of work on patient or health care rights over its 27 years of operation, in particular around patient safety, complaints and investigations processes and the development of an Australian Health Consumers' Charter. PIAC welcomed the endorsement of the Australian Charter of Healthcare Rights by the Australian Health Ministers in July 2008. PIAC participated in the consultation process that led to the Commission's draft charter, including providing a written submission in response to the Consultation Paper on the draft charter.

In 2006, PIAC established the statewide Mental Health in Prisons Network for consumers, health professionals, lawyers and advocates to examine the issues of mental illness in NSW prisons.

In July 2007, Legal Aid NSW provided two years' funding for PIAC to commence a project to develop effective responses to the unmet legal needs of people with mental illness in NSW. The Mental Health Legal Services (MHLS) Project was created to address demonstrable, systemic, access to justice problems for people in NSW who are mentally ill. The MHLS Project aims to develop and implement sustainable legal solutions for people with mental illness. To that end, four pilot projects and two training modules have been devised. The emphasis in these pilot projects and training modules is on prevention, early intervention, working holistically and collaboratively within a social inclusion framework. PIAC has received separate funding from the NSW Public Purpose Fund, with the support of the NSW Attorney General, for these pilots to be implemented and evaluated over a two-year period. The NSW Attorney General officially launched the pilots in November 2009.

Principles for working with consumers

In July 2009, PIAC made a submission to the Hon Chris Bowen, (then) Assistant Treasurer and Minister for Competition Policy And Consumer Affairs, in response to the Issues Paper *Consumer Voices*.

The PIAC submission set out general principles for organisations working with consumers¹. PIAC submits that any new national mental health organisation should follow these principles.

The principles are as follows.

- Information must be provided to consumers in appropriate formats and in a timeframe that allows for discussion, analysis and response.
- Processes and practical support should ensure that the workload associated with representing consumer interests is manageable. For example, one consumer is not expected to represent all interests.
- Staff members involved in consumer consultation need to meet relevant competencies in working with consumers to facilitate their input, present or incorporate their views and provide feedback on outcomes.
- Avoid conflict of interest. Consumers or consumer bodies should not be represented by members of the particular service industry. For example, a nurse should not be on a consumer health committee representing consumers.
- Consumers should receive the training, support and funding they need to participate in consultation processes at all levels of the framework.
- Organisations that have a position on an advisory committee should have freedom to choose their representatives. The individual is representing the organisation and not participating in a personal capacity. Consumer representatives are kept informed of the process and provided with information about the outcomes of their involvement.

¹ Brenda Bailey *Ensuring effective consumer voices; proposed consultation and research framework* (2009) Public Interest Advocacy Centre [6] <http://www.piac.asn.au/publications/pubs/sub2009072_20090720.html> at 18 December 2009.

- Consumer representatives have access to information needed to participate in consultation processes. A culture exists where consumers are safe to contribute, free from retribution.

In the remainder of this submission, PIAC expands on these principles and advance how they should be applied to the proposal for any new National Mental Health Organisation.

Role of the organisation and models

PIAC submits that any proposed organisation should be created to assist, collaborates with and supplements the work of existing mental health consumer organisations. To this end, PIAC supports the proposal for the organisation to undertake the roles set out on pages 3 to 6 in the Discussion Paper. PIAC considers these roles as appropriate for a national organisation providing leadership and support to organisations of mental health consumers. The name of the organisation should reflect these roles.

PIAC has considered the range of models outlined in the Discussion Paper and believes that the most realistic options are Model 3 or Model 4. It is not clear to PIAC that all of the organisations listed under Model 1 as potential members are 'peaks' in the way this term is commonly understood.

The key benefit of the hybrid model (Model 4) is that it provides for the direct involvement of mental health consumers as well as consumer organisations. The participation of those who personal experience mental illness and the health system and its treatment of mental illness could positively enhance the deliberations of the organisation proposed in the Issues Paper. The presence of some individual consumers in the organisation should, however not be used to assert that the organisation is able to articulate a policy position on behalf of all Australian mental health consumers, to the exclusion of the views of other organisations and individuals.

Put another way, what would concern PIAC would be a situation where the Commonwealth Government only consulted the new organisation when the Government or particular Ministers wanted input from consumers or consumer organisations.

To ensure this does not happen PIAC submits that:

- The Health Minister and the Commonwealth Government should provide assurances to existing Consumer organisations that they will undertake to consult widely if there are policy changes and/or legislative changes that effect the rights of consumers diagnosed with a mental illness.
- The structure, role and name of the organisation reflects that the organisation is designed to assist and resource individual consumers and consumer organisations in their interaction with government, not to capture and monopolise that role.

Potential conflicts of interest

PIAC notes that one of the principles referred to above is to 'Avoid conflict of interest. Consumers or consumer bodies should not be represented by members of the particular service industry.'

PIAC is concerned that if organisations representing service providers or representing health professionals are allowed to participate in the deliberations of the consumer organisation (as occurs at present with the Consumers Health Forum), then consumers may feel that that the resulting conflict of interest may be reflected in the decision making of the organisation.

PIAC recognises the complexity of this problem, in that many consumer organisations and non-government organisations (NGOs) are also providers of services—including mental health services—to consumers. There is

a varying degree of self recognition of this potential conflict of interest among health consumer organisations and NGOs.

PIAC submits that the new organisation could play a positive role in raising awareness of these issues in consumer organisations that also provide a health or welfare service.

But the difficulty remains if the new organisation purports to speak on behalf of all Australian consumers, yet the input to its decision-making comes from membership that includes organisations with conflicting roles.

PIAC submits that the solution is that the organisation should be the facilitator of the bringing together of the many voices that represent mental health consumers in Australia and of drawing the attention of government to those voices, rather than trying to speak with one voice on behalf of all mental health consumers.

Establishing and preserving the independence of the organisation

It is vital that the organisation maintains a high level of independence from government.

PIAC notes on page 14 of the Discussion Paper that although it is envisaged that the organisation will be an 'independent and autonomous' organisation, it is accountable to both 'mental health consumers Australia wide' and to its funding bodies 'for the performance of contractual arrangements and the acquittal of funds'. Although these dual accountabilities are not in any way without precedent, there is nothing in the Discussion Paper about how any conflict between these two accountabilities can be resolved.

PIAC also notes that the organisation will report directly to the Department of Health and Aging. PIAC submits that the independence of the organisation would be better enhanced by the organisation having a direct reporting line to the Minister for Health.

In 2006, the Australian Research Council funded a project looking at, among other issues, the relationship between funding and independent advocacy.² The study was conducted under an industry partnership involving the Council of Social Service of NSW, PIAC, the University of Technology Sydney, Charles Sturt University and the University of Queensland. The study looked at written compacts between advocacy organisations and government, in particular looking at compacts such as those in NSW and Queensland.

The study concluded that, in 2006:

... there appears to be decreasing tolerance of 'political advocacy' by organisations funded by state governments. The repeated use of words such as 'compliance' and 'accountability' and 'micromanagement' suggest concerns with government funders remain and run deep. It appears that collaboration tends to disappear when organisations seek to challenge existing policy, or press for new items on the policy agenda. Some departments are willing to allow such challenges, but others are not. Even where collaboration does occur, organisations are often limited in consulting with other organisations, and/or making public statements. In these cases, it appears that dependency on government funding places strong limits on the form and extent of allowable advocacy.³

Although the study focused on state-government funded organisations, even harsher criticisms in this regard were made regarding the (then) Commonwealth Government's demands on independent advocacy organisations at that time.

² Professor Jenny Onyx *et al*, 'Advocacy and Funding' (2007) 26 *PIAC Bulletin* 1
<http://www.piac.asn.au/publications/pubs/Bulletin26_20071130.html> at 18 December 2009.

³ *Ibid* 4.

The study concluded that varied sources of funding are the key to independence for advocacy organisations. PIAC strongly agrees with this conclusion.

The study pointed to the existence of the Public Purpose Fund (PPF) in NSW, and similar funds in other states. The NSW PPF partially funds PIAC.

The NSW fund is established under NSW State legislation, but is kept at arm's length from government. The Fund is made up of 'all interest on money in any general trust account at an ADI [Authorised Deposit-taking Institution], which is payable to the Law Society' for the Public Purpose Account. *Legal Profession Act 2004* (NSW). This amounts to millions of dollars. The Fund is managed and controlled by four Trustees: the Director General of the NSW Attorney General's Department and three appointees of the NSW Attorney General, two of whom are nominees of the President of the Law Society.⁴

The study concluded that three organisations that received PPF grants were among the most effective in terms of advocacy programs.

There are similar funds in NSW that source their income from gambling and the interest on rental bonds.

PIAC submits that, although there are not the immediately obvious sources of income for the Commonwealth Government to fund such a public purpose trust than those found in the states and territories (although returns on investment to the Future Fund may be a possible source), there is no reason why the Commonwealth could not show its good faith in this regard, and set up a fund with independent directors that could fund advocacy bodies like the organisation proposed in the Discussion Paper, the Consumers Health Forum and consumer organisations in areas other than health.

There are other factors that lead to more independent advocacy. As the principles set out above state, it is essential that within a consumer organisation a culture exists where consumers are safe to contribute, free from retribution. Whether this culture exists from the start very much depends on the attitude and policies of those initially setting up the organisation.

Government itself plays a crucial role. As the study referred to above highlights, there are often significant differences between how various government agencies deal with criticism and robust advocacy. There should be an ethos, from Cabinet level down, that encouragement of independent consumer advocacy is a positive that enhances the effective decision-making and policy development processes of government.

PIAC believes that if the organisation that is suggested in the Discussion Paper is structured and funded to achieve maximum independence, so that it can assist mental health consumer organisations to provide appropriately robust and effective advocacy on behalf of mental health consumers to the Commonwealth Government, then its establishment will be actively supported by all the existing organisations that support, work with and advocate on behalf of consumers of mental health services in Australia.

⁴ Ibid 4,13.