Mental health advocacy – lessons from HIV activism

It is encouraging that since 1994 the South African government has worked hard to create legislation and policy that place equality, human rights and justice at the centre. This is the case for health, education, social development and the legal system. However, it is a depressing reality that in many (if not most) cases, those charged with implementing the transformative changes in society have failed due to a host of reasons. Lack of skills coupled with unwillingness to consult with those working at the coalface has resulted again and again in poor planning, inappropriate interventions and a waste of valuable resources. Nowhere is this truer than for the provision of psychiatric and mental health services for our communities.

Two papers in this edition of the *SAMJ* address this issue and provide data from KwaZulu-Natal to substantiate claims that in that province good legislation has not translated into good practice as far as psychiatric service provision is concerned. Ramlall and colleagues[1] outline some of the progressive changes enshrined in the Mental Health Care Act (2002), including the introduction of the 72-hour observation period at designated general hospitals and the appointment of Mental Health Review Boards (MHRBs). The former development, as these authors explain, was intended to increase access to mental health care, avoid unnecessary and stigmatising admission to psychiatric hospitals, and improve medical care for those with acute psychiatric disorders. The MHRBs were intended as 'ombuds-bodies' that would safeguard the interests and rights of individuals treated under the Act. Burns[2] draws attention to the fact that the South African government has committed itself on the international stage to the principles of equality, non-discrimination and human rights for those with disabilities, including mental disorders (through signing and ratifying the United Nations Convention on the Rights of Persons with Disabilities and its Optional Protocol). On paper, therefore, South Africa scores high on its public commitments to improving the lives of those with mental illnesses. But from these two reports we learn that psychiatric and mental health services in the most populous province are in a sad state, and that the law and policy makers have not moved 'beyond mere rhetoric'[2] to ensure transformation. In fact, the mental health services are characterised by inequitable funding and resource allocation, shortages of mental health facilities and professionals, almost non-existent tertiary psychiatric services and a lack of proper planning, provisioning, training and support at general hospitals to enable them to perform their mandated functions in terms of the MHCA (2002).

Those working in the mental health field often bemoan their sorry lot by referring to themselves in terms such as the 'poor cousins' or the 'soft under-belly' of the health services. In using such language they are correct, as psychiatric disorders and mental health care are usually not high on the list of priorities for politicians, health planners and funders. As Burns[2] acknowledges, our country is faced with innumerable social and public health challenges that require attention and rightly consume the lion's share of budgets. However, it is not enough for those who care about mental health just to complain and bemoan their lot. History has shown that the mere wringing of hands does not bring about change. More is required. We are very fortunate in South Africa, because we have an excellent recent example of what kind of action firstly draws attention to a public health crisis and secondly brings about a tangible response that is felt on the ground. That example is the HIV/AIDS pandemic.

During the 1990s it was increasingly clear that HIV was having a massive impact on the social and economic life of South Africa. Internationally, many countries with a lesser burden of HIV/AIDS were rapidly implementing preventive and treatment strategies with apparently good outcomes. As we well know, the South African government did not respond timeously or appropriately. Then in the past decade we have witnessed a change of attitude that has resulted in unprecedented efforts to meet this crisis head-on. Why did this transformation happen? What brought about the change of heart? Like mental illness, HIV and AIDS are highly stigmatised conditions. As in the case of mental illness there is too often a veil of secrecy and shame around affected individuals and their families. And, as with people living with HIV/AIDS, those with mental disorders have too often been victims of social alienation, victimisation and abuse. So, what can advocates of mental health service transformation learn from the extraordinary success of the HIV/AIDS advocacy movement?

The first lesson is that any successful advocacy movement must, at its core, be represented and driven by 'user activists' – that is, individuals living with HIV, mental illness, etc. The Treatment Action Campaign (TAC) was founded and spearheaded by a group of HIV-positive individuals who were no longer prepared to be passive victims of an unjust system. TAC is now 'the world's most effective AIDS group',[3] has 16 000 members, and was nominated in 2004 for the Nobel Peace Prize. A number of countries in Europe and Australasia have strong user-led mental health advocacy movements that are starting to bring about change. South Africa, like many developing nations, does not have such an advocacy movement. This is a key limitation to effecting transformation in our mental health services.

Secondly, the highly successful HIV campaigns in South Africa and elsewhere have recruited champions to help raise the profile of their cause. Bono (of the Irish superstar band U2) is a regular star attraction at the Global Economic Forum, talking about poverty and HIV/AIDS, and has his own global campaign focused on HIV in Africa called 'Red'. Annie Lennox, another famous rock star, talks about HIV every time she gets on stage. Ex-US vice-president Al Gore is a major asset for the climate change advocacy movement, while glamorous actress Angelina Jolie is arguably the public face of the causes adopted by the UN High Commission for Refugees. As Thrall and colleagues[4] explain, 'The trick for any cause, then, is to get and maintain public attention long enough to influence policy outcomes.' In the UK, a nationally organised mental health anti-stigma campaign ('Time to Change') recently recruited boxing legend Frank Bruno as a spokesman – Bruno was diagnosed with bipolar disorder in a much-publicised psychiatric hospital admission in 2003. Given the very high prevalence of mental illness in the population, it should not be an insurmountable challenge to find similar celebrity 'users' in South Africa to help focus public attention on mental health needs in our country.

The third factor contributing to the success of the HIV campaign in South Africa is that of evidence. Methodologically water-tight research yielding important data on epidemiology, natural history, biological processes, treatment response and health services functioning has been (and continues to be) critical in shaping policy around HIV/AIDS prevention, detection and treatment.[5] To this end, the *Lancet* published a series on global mental health in 2007 that presented in a coherent manner the overwhelming evidence for a significant 'treatment gap' between mental health needs and services, especially within low- and middle-income countries. Subsequently,

international advocacy groups such as the Movement for Global Mental Health (www.globalmentalhealth.org/) have used these publications and the evidence they present as a powerful weapon supporting their cause. In South Africa there has until quite recently been a relative paucity of good data that both describe the extent of the burden of disease attributable to mental disorders and document the deficiencies in mental health service provision. Now, however, the evidence is beginning to accumulate. The two papers published in the *SAMJ* this month add to this evidence-base by reporting data obtained at the levels of both health systems organisation[2] and actual service provider experience.[1]

The problems that beset the provision of psychiatric and mental health care in KwaZulu-Natal are likely to be generic across all provinces. These problems are not going to go away in a hurry, especially in a context where poverty, infectious diseases and non-communicable diseases give rise to a massive burden of ill-health and disability. The mental health community – both professional and lay – needs to take a leaf out of the HIV/AIDS advocacy movement's book and mobilise itself into a high-profile, populist force to be reckoned with. Mental illness and its service-related needs must be thrust into the public eye as a major issue which, if ignored, will threaten the well-being of society in all its facets – social, economic and political. Sitting and waiting for the government to experience a spontaneous change of heart will, as we know from sorry experience, lead to nothing.

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