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Mental health care user participation in mental health policy development and implementation in South Africa

SHARON KLEINTJES[1], CRICK LUND[1], LESLIE SWARTZ[2], ALAN FLISHER[1], & THE MHAPP RESEARCH PROGRAMME CONSORTIUM

[1]*Department of Psychiatry and Mental Health, University of Cape Town, Rondebosch, South Africa, and* [2]*Department of Psychology, Stellenbosch University, Stellenbosch, South Africa*

Abstract

This paper describes current support for mental health care user participation in policy development and implementation in South Africa and suggests strategies for improving participation. The World Health Organization (WHO) Mental Health Policy Checklist and WHO Mental Health Legislation Checklist were completed. Between August 2006 and August 2009 96 semi-structured interviews with national, regional and district stakeholders were conducted. Most respondents felt that inclusion of user perspectives in policy processes would improve policy development. In practice, mental health care user consultation in policy development and implementation has been limited during the 16 years of democracy in South Africa. Strategies to create a supportive environment for user participation include social action directed at reducing stigma, advocating for acceptance of users' rights to participate in decision making, crafting a supportive regulatory framework to promote participation, and equipping providers and policy makers to support inclusion. User capacity for participation could be strengthened through early and effective access to treatment and support, development of a national user lobby, skills training and practical exposure to the policy and service development environment.

Introduction

Mental health care users' recovery process can benefit from their participation in policy-related decision making (Crane-Ross, Lutz, & Roth, 2006; Hickey & Kipping, 1998; Linhorst & Eckert, 2003). Their participation can also have a positive impact on the relevance of mental health policy development and implementation (WHO, 2001, 2005a).

User involvement in policy development and implementation is particularly pertinent, given the historical disempowerment and marginalization of people with mental disabilities (Crane-Ross et al., 2006; Horton, 2007; Saraceno et al., 2007; Thornicroft, Brohan, Kassam, & Lewis-Holmes, 2008). User involvement has received attention at service and strategic levels in developed countries (Baggott & Forster, 2008; Boardman, 2005; HASCAS, 2005; Linhorst, Eckert, Hamilton, & Young, 2001; Malins, Oaders, Viney, & Aspden, 2006; McClean, 1995; Peck, Gulliver, & Towel, 2002), but less so in developing countries (Katontoka, 2007; Ntulo, 2006; Underhill, 2005), including South Africa.

Self-determination for disabled people has long been part of the broader struggle for liberation in South Africa, with the post-apartheid legislative framework supporting equality of participation of disabled people. Disability rights are enshrined in South Africa's constitution (RSA, 1996), and the White Paper on an Integrated National Disability Strategy supports access and participation of disabled people in all aspects of public life in South Africa (RSA, 1997). More recently, in October 2007, South Africa signed and ratified the United Nations Comprehensive and Integral International Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities (UNCRPD) (UN, 2006) and its Optional Protocol.

Article 29 of the UNCRPD calls for state parties to guarantee that 'persons with disabilities can effectively and fully participate in the conduct of public affairs, without discrimination and on an equal basis with others' and that they will 'encourage their participation in public affairs, including participation in non-governmental organizations and associations concerned with the public and political life of the country'. Government and civil society machinery is in place to facilitate participation of disabled people in public affairs. The country has an active national disabled people's organization, Disabled People South Africa (Rowland, 2001). There is a

Correspondence: Ms Sharon Kleintjes, Research Officer, Mental Health and Poverty Project, Department of Psychiatry and Mental Health, University of Cape Town, 46 Sawkins Road, Rondebosch, 7700, South Africa. Tel: +27 21 6851223. Fax: +27 21 6851223. E-mail: sharon.kleintjes@uct.ac.za

Department for Disabilities within the Ministry for Women, Children and People with Disabilities located within the Presidency. This new ministry is responsible for mainstreaming disability issues in policy development, and monitoring the implementation of policy provisions for the inclusion and empowerment of disabled South Africans (Tyakume, 2009).

Despite these achievements, there remain gaps between progressive policies and the challenges of full participation by disabled people in South African society (Watermeyer, Swartz, Lorenzo, Schneider, & Priestley, 2006), including participation of people with mental disabilities (Cooper et al., 2011).

This paper addresses a gap in South African policy and service development literature with respect to the participation of mental health care users in mental health policy development in South Africa. The aim of the paper is to report on opportunities and barriers to improving mental health care user participation in mental health-related policy development and implementation in South Africa.

The paper draws on the findings of the first phase of the Mental Health and Poverty Project (MHaPP): a situation analysis of mental health policy development and implementation in Ghana, South Africa, Uganda and Zambia (Flisher et al., 2007).

Methods

Semi-structured interviews (SSIs) and policy document analysis were used to understand user involvement in mental health policy and legislation. Findings were triangulated.

Semi-structured interviews

A total of 96 SSIs were conducted. This included 56 purposefully selected respondents and 40 mental health care user respondents identified using the snowballing method. The 56 purposefully selected respondents included public sector policy makers from the Departments of Health, Education, Social Development, Housing, Justice and Constitutional Development and Correctional Services, professional regulatory council representatives for nursing, social work, psychology, occupational therapy and medicine, and representatives from non-governmental organizations (NGOs), disabled people's organizations (DPOs), mental health interest groups, religious leaders, professional associations, universities and research institutions. The remaining 40 user respondents comprised mental health care user advocates ($n = 20$), and users of public mental health services in one urban ($n = 10$) and one rural ($n = 10$) district in two provinces.

The interviews were conducted in English, except the 10 rural district interviews which were conducted in IsiZulu. Interviews were recorded with respondents' permission. English interviews were transcribed verbatim. The isiZulu interviews were translated and transcribed into English by the interviewer, and back-translated by an independent bilingual speaker.

A framework analysis approach (Ritchie & Spencer, 1994) was used to develop a coding frame for analysis of the transcripts using NVivo 7 qualitative data analysis software. Transcripts were multi-coded on the basis of coding frame themes, with additional themes added to the frame as they emerged from the data.

Document analysis

Policy. The WHO Mental Health Policy Checklist (WHO, 2005b) was used to assess South Africa's current mental health policy. The checklist includes items assessing user involvement in decision making. Using the checklist, a review was conducted of South Africa's first post-apartheid mental health policy guidelines, the *National health policy guidelines for improved mental health in South Africa* (DoH, 1997a) and chapter 12 of the White Paper for the transformation of the health system in South Africa (RSA, 1997) which focuses on mental health services in the country. Both documents were reviewed, as the policy guidelines specifically state that it should be read in conjunction with the White Paper. The MHaPP team completed the checklist in consultation with the former national director for mental health who drafted the policy. A final review was conducted by the Mental Health and Substance Abuse Directorate, WHO, Geneva.

Legislation. South Africa promulgated the Mental Health Care Act No. 17 of 2002 in 2004 (RSA, 2002). The WHO Mental Health Legislation Checklist (WHO, 2007) was used to review the Act. The Checklist includes items assessing legislative provision for user participation in policy, legislation and service development. Three national health department policy makers, the director of a national mental health NGO and two user representatives reviewed the document. Independent ratings were collated into one consensus document which was reviewed by the Mental Health and Substance Abuse Directorate, WHO, Geneva.

Ethics

Permission to conduct the research was obtained from the Research Ethics Committee of the Faculty of Health Sciences, University of Cape Town.

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Participants provided signed informed consent and confidentiality was assured by removing identifying material from all interviews.

Results

User involvement 1994–2009

Both the checklist reviews and SSIs indicate limited involvement of users in policy and legislative developments since the demise of the apartheid state in 1994. When the 1997 mental health policy guidelines were drafted, the Department of Health consulted with the only national mental health NGO at that time providing support for users to articulate their ideas as part of internal organizational policy processes. This NGO had also started to include user representatives on some affiliated members' boards of management. At that stage input was still led by service providers, with little direct user representation in policy inputs.

Three senior policy makers working in the public sector since 1994 commented on their difficulty finding user advocacy groups to consult. As a result, they had primarily consulted users through available NGOs.

> Interviewer (I): And organizations for people who are mental health care users?
> Respondent (R): We have one or two big ones. The other ones are very small kind of organizations. Sometimes an individual. We need to . . . coordinate them better, like the other disability sectors have been coordinated. (National policy maker, health).

From 1999 to 2001, the Department of Health consulted widely in the development of the Mental Health Care Act of 2002. SSI stakeholders working as providers in mental health NGOs and policy makers at the time felt that users had been more widely and directly consulted during this consultation.

> This is the one piece of legislation where there was a great call for participation, and not only from the organizations or service providers, but also from the service recipients. For example (advocacy body for people with mental disability) were given an opportunity to really engage with the Act and give feedback. (Director, provincial mental health NGO).

User advocates who participated in the consultation mentioned above, however, felt that the quality of consultation was poor.

> We were informed there was this upcoming Act and here's the draft, that is the extent of the consultation . . . It's unacceptable . . . legislation

developers had to take this thing seriously even if it means they had to pay people . . . but get them involved, so that there is real credibility. (Mental health user advocate, urban province).

For users not affiliated to a consulted mental health NGO, opportunities to provide comment on legislative, policy and service reviews were even less readily available:

> Those who make policies are the 'can't get' people. You have to be somebody to locate them. You know them: you really get cold shoulders, but with the help of [other national NGO] we manage sometimes to locate them and workshop them . . . sometimes we manage to get the directors of several departments. (Mental health user advocate, rural province).

The consultation process was also complicated by stigma towards mental health service users. A few users from smaller, independent user groups noted that users may choose to exclude themselves from the public domain due to their experience of being discriminated against once their status as users was known. Other respondents across stakeholder groups echoed user concerns about the impact of stigma on user participation in civic life. They felt that the paucity of user involvement in policy making was in part due to the lack of recognition and acceptance of users as legitimate partners in the policy process by policy makers, practitioners, user supporters and some users. Some respondents suggested that more exposure to user advocates could help change these stigmatizing views:

> The stigma is, they cannot even participate in the policy making. My point is, you can have people who are affected . . . being the advocates . . . I mean, in the mental advisory committee . . . he (referring to user advocate) stood up and said his experience with it; that was also an education for me . . . if we have those that are champions . . . that will help. (National policymaker, housing).

Current support for user involvement

Despite differences in stakeholder perceptions about the adequacy of consultation in the past, most SSI respondents across all respondent groups supported inclusion of users in legislative and policy development and implementation processes in the future. Stakeholders felt that users, as citizens of the country, have a right to influence the development of public mental health policies and services. Many respondents felt that these rights extended to all users, whether private sector, service-paying users or indigent beneficiaries of state support.

Several respondents noted that users bring a unique perspective to mental health policy, through their experience of mental illness. They felt that this could focus policy developers' attention on the most appropriate directions for local mental health programmes. Checklist reviewers agreed that invaluable insider information obtained from users can positively influence service, policy and law development.

> We need to engage patients who have gone through a process of recovery...their personal experiences must be able to assist to formulate an understanding of mental illness, and contribute towards...the broader base of stakeholders that formulate policy (Religious leader, Muslim Judicial Council).

The majority view amongst these stakeholders was that users can participate on a par with other citizens, when they are well enough to engage in public discourse.

> R: Like for example, psychiatric disability...most of them, they take their medication and they can actually participate.
> I: People with psychiatric disability, you feel that if they are stable, they should be consulted themselves?
> R: They should actually be consulted themselves, yes. (National policy maker, social development)

A few respondents did not have an opinion about user participation in legislation, policy and service development, as it was a novel concept for them. Three other respondents felt that policy development is best left to others better equipped for the task, such as policy makers, health service providers or those who support users.

> R: We as traditional healers, because we practice within the community, we hear the problems that cause this mental illness that is within the family, you know what I mean?
> I: Dr, are you saying that you don't think it's necessary to consult clients when making a policy, that it's the traditional medical practitioners that should be consulted because they know the issues well?
> R: Yes, yes exactly, 100% correct. (Healer, National Organisation for Traditional Healers).

Strategies for increasing user participation

The main strategies respondents identified for the promotion of direct consultation of users in mental health policy and legislation processes broadly fell into three categories, namely regulatory support, organizing for participation, and building user capacity.

Regulatory support for participation

Mental health legislation. The Mental Health Care Act does not include provisions to 'ensure that users of mental health services are involved in mental health policy, legislation development and service planning' as recommended in the WHO legislation checklist (WHO, 2007). Policymaker and practitioner reviewers felt that, as provisions of the South African constitution supersede provisions of the Act, and the constitution provides for participation of citizens with disabilities in parliamentary and governmental processes related to legislation and policy, this need not be specified in mental health legislation. One policy maker stated that such a specific provision would be difficult to implement as a law.

> I've got no problem whatsoever about consulting...but it's a very hard thing to legislate because somebody might come and say: 'the law says you must consult with consumers and we're a consumer group and you didn't consult with us so you've broken the law,' but then you say: 'No, no, we consulted with those people,' and they say 'Well, they weren't representative,' and then it goes to court. (National policy maker, health).

At most, these reviewers felt that it would be adequate to address this issue in revised mental health policy. A few SSI respondents from the user, disability and non-governmental sectors, however, felt that despite the support of constitutional provisions, people with mental disabilities continue to be excluded from public processes. With South Africa's ratification of the UNCRPD, many felt that mental health legislation and regulations should be revised to broaden its scope beyond its current treatment focus to address broader mental health concerns, including user participation in legislative, policy and service development and implementation.

Mental health policy

Neither the White Paper nor the mental health policy guidelines mention user involvement in legislative or policy development. The White Paper does provide for input from service users in the planning of mental health services, while the mental health policy guidelines include the principle that 'community, and specifically users of mental health services and their families should be involved in planning and evaluation of services'. Current norms and standards for psychiatric care in South Africa provide for 'greater partnership with users, their caregivers and the community in the planning and evaluation of services' (Flisher, et al., 1998, p. 199).

At the time of writing, the National Directorate for Mental Health and Substance Abuse in the

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Department of Health is in the process of drafting a new national mental health policy, with the intention of consulting users.

> There will have to be...consultation which includes all the stakeholders; experts, consumers, other departments and all that (National policy maker, health).

A few mental health NGO-based practitioners and several user respondents suggested that as policy sets the agenda for which issues are prioritized and funded for implementation, provisions of the new policy should explicitly promote user participation in all aspects of mental health policy in the country. Going further, a few user respondents who favour the development of user-led self-help projects felt that the policy should endorse strategies which emphasize self determination and support users' participation in the implementation of these policies.

Organizing for participation

Building a social movement for mental health.   A few respondents noted that during the apartheid years, civil activity was focused on anti-apartheid activism, with little attention to the social agendas usually addressed by civic action during peace time.

> One of the things is that all of us had a common enemy before: apartheid. We knew our places, we knew that we were on the one side opposing this system (Professional guild).

They felt that since the demise of apartheid, grass-roots social action had dwindled in the face of expectations of the new government delivering on policy provisions, but that civil society had more recently begun to voice its dissatisfaction about lags in policy implementation.

> You promised them bread, you promised them cake and you're now giving them brown bread, whereas brown bread is actually very good, but not good enough...if we all go out and say these things take time...we're talking about a nation, it takes time, so you can't do it overnight (Statutory Council member, Health Professions Council of South Africa).

Several respondents spoke of their support for the resurgence of civic voices, and supported the growth of such a 'voice' to address the needs of people with mental health problems.

A few respondents noted that there are examples of good advocacy work on a national and local level from some mental health NGOs and interest groups, but generally, respondents felt that professionals, lay people and service users within the mental health field have not taken up the challenge of a sustained

and coordinated role in eradicating discriminatory practices toward people with mental illness.

> We should be getting together – providers, consumers, programme managers and forming, you know, a very strong lobbying body, using the legislation...and getting lawyers involved when we really feel we are not getting anywhere...advocacy, and then, if necessary, legal action (Psychiatrist).

Building a user lobby

Many stakeholders, drawn from all stakeholder groups, felt that the impact of users' participation in social and political decision making could be improved by building a coordinated user lobby through which users can raise their voices regarding policy directions and outcomes, as an equal stakeholder.

> R: The best practice that I saw at the UN was that internationally, people with mental disabilities are taking things into their own hands and having their own organizations and raising their own issues. There were papers written by them and...they came there as organized formations.
> I: Are you in favour of this kind of organization of mental healthcare users to raise their own issues?
> R: I think they would understand them better, and they would educate us better. (Respondent from the Department of Justice and Constitutional Development).

Building user capacity for participation

Treatment and support.   Some respondents saw the right to accessible and effective treatment and support not only as a health right, but a necessary tool for supporting user participation in decision-making.

> I: Input to service reviews, service improvement, and mental health policy development; what is your view around their role there?
> R: Ja. There is room for them. These people are not mentally ill all the time...They have been saying that they deserve better treatment...treatment in terms of rehabilitation, treatment in terms of job opportunities for them. Treatment is just not only physical; it's psychosocial and it also has to look at economic issues (Respondent from the Health Professions Council of South Africa).

Several respondents supported the notion that recovery support should go beyond medication

provision to action which enables participation in everyday life. The point is illustrated by the work of a user advocate who runs a self-initiated recovery programme for 68 poor service users on his inherited land in a rural province.

> Even now I think the government has tried to grow for us a Bill and say 'no, you have got a right to talk'...I was trying to connect these people who didn't have anything, bring them together and get them something to eat and try to teach them how to do for themselves...But when you just dump them and they start to do funny things, they can't say to you 'I have the right' because you will say 'you are just nothing'. But when you get them on the same place together and do for them everything which we think is better, and show government that we try to do this, then they will help us. (Mental health user advocate, rural province).

Skills training and experience

Respondents noted a need to provide a platform for increasing the capacity of mental health users for participation in policy issues. Some respondents mentioned training programmes in advocacy, policy participation and organizational skills, and skills development programmes to support self-help initiatives, but the lack of these, others felt, should not prevent the development of skills through participation itself.

> R: I've seen the people with mental disabilities participating, you know, in various forums and I think that if they are given the opportunity...I take myself...I was part of developing the legislation on skills development. I didn't have experience, I didn't know how you do that, but because I was exposed and because I participated through the National Skills Authority, I began to grapple with the issue and I used my knowledge and my experience.
> I: So similarly, people with mental disability may need some time to orientate and develop capacity for it?
> R: Exactly. (Leader, national disability organisation).

Discussion

Stakeholders interviewed in this study were generally in favour of user participation in mental health-related policy, legislative and service developments. Existing policy and legislation in South Africa can also broadly be interpreted to support user participation in policy, legislative and service developments. This is in line with the international trend away from sole reliance on professional expertise for knowledge generation and implementation, to the inclusion of health care users in developing and implementing evidence-based policy and programmes (Albert, 2004; Albert & Hurst, 2004; Crane-Ross et al., 2006). The focus has moved to the synergistic interface between professional knowledge and user experience in generating effective research to inform policy and programme development for recovery (Diamond, Parkin, Morris, Bettinis, & Bettesworth, 2003; Marsh, 2000; Tritter & McCallum, 2006; Underhill, 2005).

Despite stakeholder, legislative and policy support, results confirm that actual participation in these processes by mental health care users has been poor in the 16 years since the first democratic elections in South Africa. Stakeholders identified several areas of action which could improve inclusion of users in mental health policy, legislation and service development and implementation processes. These are discussed below in terms of (1) creating a supportive environment and (2) increasing the capacity of users to participate.

Creating a supportive environment

Advocating for participation as a rights issue. Existing social mores which authenticate the exclusion of the mentally ill from civic life and political decision making should be recrafted from a rights-based perspective (Kelly, 2006). As others have reported, policy makers, providers, family and community members tend to relate to mental health care users as sick or impaired people, and this can be disempowering (Borg, Karlsson, & Kim, 2009; Cottrell & Langzettel, 2005; Disabled People South Africa, 2000; Watermeyer et al., 2006). Incapacities ascribed to a sick role may be used to restrict user participation in other roles in society (Kakuma, et al., 2010; Katontoka, 2007). Users' access to social, political and economic opportunities and influence may dissipate under the cloak of mental illness (Kelly, 2006; Thornicroft et al., 2008). Stigmatizing attitudes and beliefs about people with mental illness detract from the need to focus policy and practice in the service of supporting user recovery (Borg & Kristiansen, 2004; Disabled People South Africa, 2000; Farcas, Gagne, Anthony, & Chamberlin, 2005), and on re-building their ability to contribute to their own and others' recovery through self-help initiatives (WHO, 2008). In terms of civic participation, lack of belief in users' abilities and withdrawal of user rights to participate in policy development and implementation can become a self-fulfilling and disabling cycle, which reduces user confidence

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(McDaid, 2009; Tritter & McCallum, 2006; WHO, 2005a).

Building vehicles for rights-based social action

Lobbying by interest groups and NGOs has been found to have enormous potential for influencing the direction and implementation of social and health policy (WHO, 2008). Kelly (2006) notes, however, that mental health interest groups have not generated the level of influence on public processes which one might expect, given the numbers of potential members of this group in society. He suggests that people with mental illness be equipped to engage in democratic processes, and to build 'larger, more effective interest groups' for mental health.

Many respondents in this study supported this point. Firstly, some respondents suggested that a coordinated social movement for mental health be formed to address the stigmatizing beliefs, attitudes and discriminatory practices which perpetuate user exclusion at all levels of society, and to develop appropriate supports for user recovery. A few respondents supported the development of a country-level social movement similar to the international social movement launched in 2008, the Movement for Global Mental Health (MGMH). Membership of the MGMH is diverse, and includes service users, practitioners, policy makers and researchers. The movement aims to use best practice to advocate to policy makers and funders to prioritize, integrate and scale up mental health services (Horton, 2007; Lancet, 2008, 2009). In South Africa, a similar movement could provide a united platform from which to work on shifting the current low priority given to mental health in public policy and service delivery (Kakuma et al., 2010; Saraceno et al., 2007). Advocacy could also promote the inclusion of people with psychosocial difficulties as key stakeholders in all processes related to the development and implementation of laws, policies and services in the country.

Secondly, respondents suggested the development of a country-wide user lobby through which users can provide representative input to policy and service development. This echoes literature supporting the notion that meaningful involvement of users in collective action requires 'representative networks of engagement' through which they can advocate for their concerns (HASCAS, 2005; Simpson & House, 2002; Tritter & McCallum, 2006). Robust user organization and user representation is needed to enable users to exert influence and advocate for their agenda, given the power inequities which users still face in participating in decision making (Kelly, 2006). Users need to hold their own as stakeholders within a broader social movement for mental health,

engage with powerful policy makers and legislators to influence service provision, and raise their voice as a lobby within the broader disability movement.

In Africa, there are already examples of user networks for people with mental disability, for example in Zambia, Uganda, Tanzania, Kenya and South Africa (Katontoka, 2007). However, networks in South Africa are in their infancy. The South African Federation for Mental Health (SAFMH), for example, supported affiliated users to establish a working group that aims to build a national user lobby over time as recently as 2009 (SANHAM, 2010), with user groups still mainly operating at local level. Disabled People South Africa was launched in 1984, four years after the establishment of Disabled People International (Rowland, 2001). Similarly, the fledging networks of people with mental disability in South Africa will need time and opportunity to mobilize and organize their agenda as a sector within the broader mental health and disability movements in the country.

Crafting supportive regulatory frameworks

Existing legislation, regulations, policies and protocols should be revised and new regulatory guides formulated to support institutional, professional and civil commitment to the rights of users to engage in processes which impact on their recovery (WHO, 2009). A supportive regulatory environment requires concerted action to increase the likelihood of policy makers building mental health concerns into public policy and practice. These policies should promote implementation of their provisions by creating incentives for institutions and organizations to address mental health concerns in their policies and practices (HASCAS, 2005; Linhorst & Eckert, 2003). At the institutional level, policy and practice guidelines should build in strategies for user involvement in decision making. Practitioner implementation of these strategies should be encouraged by building user consultation requirements into staff practice and performance reviews, and dedicating staff time for the implementation of these requirements (Linhorst et al., 2001). The role of users as a stakeholder in policy development should be clearly spelt out and user options for participation in implementation of policies should be elaborated within these frameworks.

Reorientating and equipping providers and policy makers for inclusion

Internationally, the move from a symptom-management approach to mental health care, to an approach which focuses on the long-term recovery, quality of life and self-determination of service users

has been slow (Davidson & White, 2007; Farkas, 2007). In this study, the need for this change was articulated by individuals drawn from all stakeholder groups, most often from DPOs, NGOs and users. This reorientation requires a change in the mindsets inculcated during professional training and institutional acculturation (McDaid, 2009; Thornicroft et al., 2008). Professionals should be equipped to locate the biomedical tasks of 'sick role' management within the broader context of life role enablement. Symptom management should be embedded in a comprehensive response to supporting and encouraging users' efforts to return to and have agency in valued life roles such as that of citizen, family member, neighbour, friend, lover, co-worker and learner (Davidson & White, 2007).

Within the treatment setting, this involves a power-sharing collaboration between the user and provider (Borg & Kristiansen, 2004; Thornicroft et al., 2008). Here the focus should be on users regaining or developing confidence in their ability to have agency in and exercise choice within different areas of their lives (Barbato, 2006; Kelly, 2006; Koscuilek, 2005).

Within the arena of broader public processes, practitioners and policy makers will need to accept users as 'partners in the management of their own health and that of their community' (WHO, 2008). Service providers, policy makers or programme developers also need to improve their capacity to understand and provide reasonable accommodation for user participation and to engage respectfully and appropriately with users within this new working alliance (McDaid, 2009).

Developing user capacity for participation

Treatment and support as an aid to participation. Regaining one's health and taking up satisfying roles can boost our sense of well-being and confidence (Ashcraft & Anthony, 2006). For mental health care users, the provision of accessible and effective treatment for symptom management, along with other social and economic supports, is crucial to strengthen their health. These supports may be seen as the 'assistive devices' required to promote and sustain the return of users to their roles in society, including that of policy and service development participant. A lack of appropriate treatments and supports can delay recovery and increase the likelihood of secondary disability, as well as reduce user's interest, energy and belief in their ability to participate (Katontoka, 2007).

Practice as an aid to participation. Tritter and McCallum (2006) note that, at a practical level, time and expertise are needed to develop capacity to participate effectively in policy and service development. The need for time to develop skills for participation presents a dilemma for both policy makers and users. Policy makers are often driven by demands for urgent solutions, leaving little time for pre-consultation capacity development of participants. Less capacitated stakeholders may be left behind or given token acknowledgement within time-pressured consultation activities. This 'hit and run' approach, not surprisingly, may serve to confirm ideas of users' limited ability to participate meaningfully, both in the minds of policy and service providers, and in the minds of the users subjected to this inappropriate approach. At the same time, the idea of first developing capacity and then involving users in policy development will not be practical in a demanding policy context. Tritter and McCallum's (2006) contention that capacity can be incrementally developed through the participation process is in line with similar sentiments expressed by DPO-based participants in this study. 'On the job' capacitation, however, does not exclude the need for training, mentoring and support of users in these roles.

With regard to participation in service delivery, the WHO (2009) report on task shifting includes a recommendation that people living with HIV-AIDS should be included in recruitment drives for community health workers, a programme currently being reintroduced within the human resource development plan of South Africa (DoH, 2005). Further, the WHO report recommends that people living with HIV-AIDs should be equipped to take greater responsibility for aspects of their own and others' care at community level. Similarly, given the limitations of the public health services to service current levels of demand for mental health services, the sector will do well to invest in the inclusion of mental health care users in task-shifting plans for community-based service provision through self help and peer support initiatives (Saraceno, 2007; WHO, 2008).

Conclusion

Mental health care users have made slow progress in participation in policy development and implementation processes in the 16 years of democracy in South Africa. Stakeholder, policy and legislative support for the inclusion of users in policy development and implementation processes are necessary but not sufficient for such participation to occur. Tangible strategies are needed to move support to action. Stigmatizing attitudes amongst the general public and health care providers, and within the corridors of public policy need to be replaced with acknowledgment and acceptance of users' rights to participate in decisions which have an impact on their lives. Inclusion should be strengthened

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in regulatory and institutional operating frameworks, with participation roles of users clearly spelt out. User capacity for participation should be strengthened through early and effective access to treatment and support, the development of a national user lobby, and through skills training and practical exposure to the policy and service development environment.

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