CHAPTER 8

Conclusion

At a World Health Organization (WHO) meeting in 2012, Robinah Alambuya, Information Officer at the NGO Mental Health Uganda and Chair of the Pan African Network of People with Psychosocial Disabilities (PANUSP), declared that:

> The history of psychiatry haunts our present. Our people remain chained and shackled in institutions and by ideas which colonisers brought to our continent and many other parts of the world. Indeed, we do remain 'objects of treatment and charity' and some of the worst human rights violations do occur in the very institutions that claim to provide mental health care services.[1]

Alambuya, who has lived with bipolar disorder for over twenty years, is one of the most passionate members of the mental health service user movement in Uganda. Although she has had many negative experiences in navigating the psychiatric system, she does not believe that psychiatry is incapable of offering relief to those suffering from mental illness. Rather, she cannot see why psychiatric services and disability legislation have failed to evolve to meet the needs of those they claim to help and protect. Parliamentary discussions over the reform of the Mental Health Treatment Act exemplify this lack of change. First enacted under colonial rule and last revised in 1964, the Act does not differentiate between different types of mental disorder, largely neglects community care,

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and defines those with mental health disabilities as 'persons of unsound mind' and 'idiots'.[2] Such is the power of its outdated and derogatory language that the law is regarded as one that 'spurs more injustice than justice'.[3] Alambuya, for one, maintains that it has led to the exclusion of mental health service users from the processes of reform. Yet:

> There can be no mental health without embracing our expertise. We have always remained the untapped resource in mental health care. We must be involved and consulted in raising awareness, service delivery, monitoring and finding solutions to the barriers faced by users and survivors of psychiatry and people with psychosocial disabilities.[4]

When history is evoked in discussions like these, it is often done to stress the perceived failings, even irrelevance, of psychiatry. Commentators draw attention to divergences between 'modern' or 'international' psychiatric practices and those in Uganda; they focus on outdated mental health legislation and psychiatric facilities, all of them relics of the colonial period. In a successful petition to the Constitutional Court in 2011, human rights lawyers at the Centre for Health, Human Rights and Development (CEHURD) and Daniel Iga, a mental health service user, contested degrading practices and use of language towards people with mental disabilities in the criminal justice system. They argued that individuals who had been acquitted of a crime by reason of insanity should not be kept in custody indefinitely, because this contravened 'the right to liberty and freedom from discrimination' guaranteed by the Constitution. They also challenged the use of the words 'idiot' and 'imbecile' in the Penal Code Act—language that had not been changed since 1950—and argued that the word 'lunatic' was dehumanising and devoid of any form of dignity. In doing so, they set colonial attitudes towards mental illness against the hopes and aims of those who had written the 1995 Constitution of Uganda, as well as the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) and the African Charter on Human and Peoples' Rights.[5]

The history of psychiatry and decolonisation reveals a more dynamic picture, with psychiatrists and others actively engaged in processes of innovation and reform, but which, as evidenced by complaints about the unchanging nature of psychiatry, have not had a long-lasting

effect within Uganda. This in part reflects the long-contested nature of psychiatric practices, which have always been subject to criticism by those who have navigated them. But it also highlights how psychiatry has been tied to shifting periods of stability, upheaval and crisis. Efforts to reorganise mental health care, and to refigure the relationship between psychiatry and patients, stalled with the political and economic insecurity of the 1970s and 1980s. In the post-conflict context, it has proved difficult to revitalise psychiatry, with government policies only adding to the perception of psychiatry as static and unchanging. Like other areas of medicine and health, the government's approach to the rebuilding of services during the 1980s and 1990s prioritised the physical rehabilitation of existing infrastructure, failing to use the opportunity to rethink the organisation of services and ignoring, as Joanna Macrae, Anthony Zwi and Lucy Gilson have noted, 'issues of equity and sustainability'.[6] Despite the dominance of decentralised approaches and the policy of mental health in primary care within international mental health, psychiatric services remained highly centralised, with Butabika Hospital as the focal point of psychiatric provision and expertise. While mental health was included in the First Health Policy of the National Policy and Health Sector Strategic Plan in 1999, moves towards integrating mental health in primary care were not made until the early 2000s.[7]

During the 1990s and 2000s, psychiatry was actively promoted within Makerere Medical School, first under the leadership of Emilio Ovuga and then under Seggane Musisi. Yet change has nevertheless been slow, with psychiatry and mental health remaining one of the most neglected areas of medicine. As of October 2017, there were 33 registered psychiatrists to serve a population of approximately 38 million, over half of whom were based in or on the outskirts of Kampala.[8] Approximately 1% of the government's national health care expenditure is directed towards mental health, and this seems unlikely to change in the near future. Of this, just over half is directed towards Butabika.[9] Patients who are admitted to Butabika receive food and have free access to essential psychotropic medicines, but because of severe shortages of personnel, patients tend to be heavily medicated. Outpatient care is growing but can be expensive. A WHO survey in 2006 found that approximately 37% of the daily minimum wage was needed to pay for one day's worth of antipsychotic medication while approximately 7% of the daily wage was needed to pay for one dose of antidepressants.[10]

Many of the challenges facing psychiatrists today are reminiscent of those experienced by psychiatrists as they took over responsibility for psychiatry at the end of empire—those of underdevelopment, financial neglect, large custodial institutions and low prestige. In the contexts of development and nation building, and facing ongoing difficulties in persuading government officials of the importance of psychiatry, psychiatrists challenged their prescribed custodial and curative roles. They took on social advisory roles and experimented with new ways of delivering mental health care. While patients were not given a voice, their activities were premised not only on the assumption that demand on psychiatry would only grow in the future, but that action needed to be taken to bring psychiatry closer to the mentally ill. Nor was psychiatry limited to the national context during the years of decolonisation. While local and national political and economic forces shaped the ability of psychiatrists to participate in international mental health, during the 1960s and early 1970s, Uganda became a prominent voice in regional and international discussions on the organisation of mental health services in developing countries. While there was a broad divide within Africa between English- and French-speaking nations, psychiatrists found common ground in a sense of shared challenges in their professional lives. The practical experiences of psychiatrists in experimenting with mental health care during the 1960s and 1970s came to dominate international discussions on mental health care, feeding into the WHO's policy on mental health in primary care.

Today, most Ugandans are aware of the existence and purpose of Butabika Hospital, whether through word of mouth or informative articles published in newspapers like the *Daily Monitor* or the *New Vision*. Yet it is clear that psychiatry, perhaps more than any other medical discipline, has lingered on the edge of a much broader therapeutic landscape. In a study of severe mental illness in two districts in eastern Uganda, Catherine Abbo reported that just as communities drew on multiple explanatory models for psychosis, they also sought multiple solutions. 'Traditional healing and biomedical services', she noted, 'were used concurrently by over 80% of the subjects'.[11] Uganda is not unique here. In a study of the routes to psychiatric care centres in Nigeria, Oye Gureje and colleagues found that spiritual healers, traditional healers and general practitioners were the first to be consulted by 13, 19, and 47% of patients, respectively.[12] Explanations of why psychiatry has been and remains a last resort for so many necessarily touch on questions of cost,

distance and the perceived severity of symptoms. But they also reveal much about differing ways of understanding, communicating and treating mental illness, as well as the difficulties psychiatry has had as a discipline in claiming universal models for understanding the mind. While concerns about the social and cultural gap between psychiatrists and their patients occupied a central position in justifying the Africanisation of psychiatry, as well as in arguments for reform during the years of decolonisation, the gulf between psychiatrists and patients was not resolved.

Despite the ongoing challenges facing psychiatry, the mental health landscape in Uganda today has never been more vibrant. Since 2010, there has been a proliferation of mental health organisations, increasingly led by people with lived experience of mental illness, and which are engaged in outreach activities and home visits in urban communities. An increasing number of organisations are also working to build capacity in mental health activism and self-advocacy, drawing on the skills and knowledge of service users, as well as sympathetic allies such as journalists and occupational therapists. In the absence of a large body of Ugandan psychiatrists, and in the context of low government investment in mental health, the global mental health movement has entered the psychiatric landscape, creating new alliances and shaping perceptions of rights and how to claim them. One of these alliances is an international health partnership between Butabika and the East London NHS Foundation Trust, set up in 2005, and known as the Butabika-East London Link. They have worked with mental health service users to bid for funding, facilitated international exchanges and are currently among those working with peer support workers at Butabika Hospital to provide recovery-oriented training and support in a new Recovery College.[13] Such alliances are connecting a select group of Ugandans to global bodies of knowledge and ways of talking about mental illness in ways that evoke the wider literature on 'global citizenship' in medicine and health.[14] As such, the nascent mental health movement raises important questions about the politics of intermediaries, knowledge and legitimacy, as well as who is included and who is left out. Terminology is also difficult, as the use of the terms 'service users' and 'survivors' risk excluding the vast majority of those in Uganda who suffer from mental illness but who either do not have access to western medical services or who choose to seek different forms of therapy. Many of those involved in mental health organisations are aware of these problems of terminology, and as such, a wide variety of terms are in use, including 'people with lived

experience of mental illness', 'people with psychosocial disabilities', and 'people with mental health problems'.[15] In spite of this, there is still slippage and conflation of these terms.

Mental health organisations started to proliferate in the mid-1990s in the context of what has been referred to as 'the NGO-isation of society'.[16] In 1999, Mental Health Uganda was founded. Mainly donor-funded, it came to operate across 18 districts, setting up drug banks to ensure the consistency of medication supply and organising group saving schemes, with provision for start-up loans so members might have an opportunity to generate income and contribute to their families' well-being. Other organisations included the Uganda Schizophrenia Fellowship, with active user bases in Masaka and Jinja, and Basic Needs Uganda, which remains a leader in advocacy training and income generation projects across the country. The organisation which pioneered service user involvement, however, was Heartsounds. Founded in 2008 in collaboration with mental health service users and psychiatrists in the Butabika-East London Link, Heartsounds defined itself as being the first to truly tap what it referred to as the under-utilised resource of people with lived experience of mental illness. It was the first organisation to be run entirely by service users, aiming to create a community in which people could share their stories about treatment, the problems encountered in daily life, and build a sense of belonging among members. According to one founder member, 'When one peer visits another and talks they give hope. If this one can do it then the other one can do it'. Led by Joseph Atukunda, the organisation had a base in Kampala, with its own Internet café, library and guest house. By 2013, it had 107 registered members, including service users, 'survivors' and mental health professionals. Until 2016, when the organisation disbanded, it had a board of trustees which comprised of seven mental health service users (including Alambuya), a caretaker and three advisory members who were leaders of other mental health organisations.

Heartsounds were vocal about the importance of speaking out about mental illness and giving testimony as a way of fighting stigma and discrimination. This was particularly important because many of the more prominent members of Heartsounds were relatively well-educated and from financially stable backgrounds—not the stereotypical mad person seen wandering the streets in rags. They created a website containing film clips of members giving testimony about their lives and journeys to recovery. These testimonies fell into remarkably similar patterns, centred

around periods of 'crisis' from which they are now in recovery. It was clear that there were many stories of discrimination, prejudice and stigma, but also messages that suffering could be overcome. Much of the language used reflected the international and even global outlook of organisations such as these, particularly in their use of terms such as 'crisis' and 'recovery', and in statements about patient rights. One of the videos showed Daniel, a teacher who for a long time did not want to be open about his mental health problems for fear of what his students might think. He explained, 'When I was young I used to see *mulalu* (a mad person) and I was like, what did they do? You know perhaps people have say here don't mind him he robbed someone so they bewitched him. I know that mystery, but the end of the day he's a human being, whose mind is a bit disoriented, and he needs to be taken care of'. Another video showed Elizabeth, who had a history of alcohol and drug abuse, and had suffered from depression for a few years. In her words, 'It was at Heartsounds that I first found comments of, "wow, you're brilliant", "wow, you can do this". Those comments first came from Heartsounds'. Elizabeth continued to explain how with family you could do good things and you could do bad, but 'they are always ready to criticise the bad…And you can live life knowing you can never do anything good'.[17]

For the first few years, the peer support work pioneered by Heartsounds was relatively informal, but in 2012, the Butabika-East London Link was successful in securing funding from DfiD and the Tropical Health and Education Trust to run 'Brain Gain'. This project formalised and expanded peer support work by training approximately thirty-six peer support workers over a two-year period. Peer supporters then went out into communities in Kampala and met with people who had recently been released from Butabika.[18] While the project reportedly had success in convincing psychiatrists at Butabika, who had initially been resistant, of the benefits of the approach, overall the project faced financial mismanagement and fraud, with some of the money from the international partnership being diverted into other projects. Some of those involved also point to power struggles within Heartsounds, with some feeling that Atukunda was not mentally stable enough to run the organisation, and that women who had childcare commitments were being pushed out of peer support work. When the Butabika-East London Link was successful in securing funding for 'Brain Gain 2' in 2015, the project was moved into Butabika itself. Atukunda was no longer involved, and many of the other original members went on to

set up new mental health organisations in and around Kampala. Brain Gain 2 saw the creation of Africa's first Mental Health Recovery College, extending peer support into the wards of Butabika, and providing a centre within the grounds to which patients could come, use the internet, and take part in recovery-oriented training and education. In a project organised by the London School of Hygiene and Tropical Medicine (LSHTM) in 2015–2016, moreover, peer support workers and psychologists worked alongside each other to evaluate peer support and recovery, looking through patient files and identifying 'revolving door' patients in need of special attention.

The movement of peer support into Butabika is just one way in which traditional spaces of psychiatry are being renegotiated by mental health organisations and the global health movement that fund and support them. And this belies any overly simplistic claims of neo-colonialism or cultural imperialism within psychiatry. Peer support workers are reshaping hierarchies at Butabika that have long been rigid and well defined. Since the inception of the Recovery College in 2015, peer support workers have entered the hospital every day, walking freely around the grounds, stopping to greet nurses and requesting appointments with the Executive Director. Although they have not received salaries, they have been sworn in as official officers of Butabika and wear a uniform. This makes the 'peer' aspect of their roles problematic, raising new questions about the roles of peer support workers as intermediaries in psychiatry. It has not been unusual, for example, for a female patient to kneel in front of a male peer support worker when meeting them in the corridor. While this is a normal sign of respect in Uganda, particularly by women, it is suggestive of some of the ways in which peer support workers have become another group of workers within Butabika's hierarchy, occupying a difficult position between patient and staff. Being conversant both in the local languages and in an international language of self-care, they are also in positions to translate information about patient rights and medication. While the peer support workers are clear that medication is a vital part of recovery, and that people should encourage and remind each other to continue with their medication after being discharged from hospital, some of them have doubts and are in positions to share their experiences of adjusting their dosage and negotiating treatment regimes with medical professionals. They talk about how shocked patients are to discover that they do not have to accept all treatments that are offered, that they can question them, and work with their doctors to draw up their

own plans. While patients have long contested and challenged psychiatric practices, as seen in this book, the public manner in which patients are encouraged to speak out now sets this work apart.

It is clear that peer support workers have come to occupy an uneasy space at Butabika, something not helped by the reliance on international funding. There have also been concerns about the increasingly close links between mental health services users and psychiatrists, with disagreement as to whether peer support workers are best off working within the system or outside it. As one peer support worker noted, 'as we research more about mental health on the internet by reading books, we have come across some antipsychiatry stuff that we find difficult to ignore'. They referred to the book *Anatomy of an Epidemic* by the American journalist Robert Whitaker, which sees psychiatrists as colluding with the psychopharmaceutical industry in creating an epidemic of mental illness. 'Voicing out our thoughts', they added, 'after reading such stuff, is putting us at loggerheads with the service providers who are meant to be our partners'. Kabale Benon, moreover, was actively involved in court cases against Butabika management while working as a peer support worker in the Recovery College. In 2016, with support from CEHURD, Benon successfully lodged a civil complaint against the Attorney General for mistreatment at Butabika Hospital during two periods of admission, in 2005 and in 2010. While at Butabika, Benon was undressed and locked in seclusion—a small cold dark room measuring about two square metres, and that supposedly helps 'cool' the patient when they are agitated. The room had no windows or source of light, bedding, toilet or urinal. He was forced to urinate and defecate on the floor, sleep on a concrete platform and received no medical attention during this time. The case highlighted how seclusion practices violated the human rights of patients at Butabika Hospital, and were in contravention both of Uganda's Constitution and numerous international conventions on disability rights. Benon won the case in November 2016, received compensation, and, in addition to his peer support work, continued to work to assist with other court cases against Butabika.[19] Increasing antagonism between Benon and the authorities at Butabika, however, saw him removed from the Recovery College in 2018.[20]

The most problematic aspect of the new mental health landscape is the ongoing reliance on international funding. This has shaped aims and goals as well as meaning that many organisations and their projects have been short-lived. In this context, some have started to question

the usefulness of the dominant global language of 'scaling up' in mental health care in the Ugandan context. If they had full control, as one staff member at Butabika commented informally, they would prefer instead to 'scale down'—to focus on the most troubled people and really make a difference in their lives. Yet, in spite of such challenges and concerns, many of those involved in Uganda's nascent mental health movement are hopeful about the future and the possibilities for the greater participation of people with mental illness in public life.

Notes

1. R. Alambuya, 'Human Rights Violations Experienced by People with Psychosocial Disabilities', Keynote address delivered at the Launch of the WHO QualityRights Project and Tool Kit, New York, 28 June 2012.
2. Uganda Government, *The Mental Treatment Act*, Chapter 270, Revised Edition, 1964.
3. C. Nyombi, 'A Critical Review of the Uganda Mental Health Treatment Bill, 2011', *East African Journal of Peace and Human Rights* 18(2) (2012), pp. 499–513.
4. Alambuya, 'Human Rights Violations'.
5. The Counsel for the State did not dispute the petition and the terms 'idiots' and 'imbeciles' have now been removed from the Penal Code. *Uganda Constitutional Petition no. 64 of 2011.*
6. J. MacRae, A. B. Zwi, and L. Gilson, 'A Triple Burden for Health Sector Reform: "Post"-conflict Rehabilitation in Uganda', *Social Science and Medicine* 42(7) (1996), p. 1106.
7. F. Kigozi et al., 'An Overview of Uganda's Mental Health Care System: Results from an Assessment Using the World Health Organization's Assessment Instrument for Mental Health Systems (WHO-AIMS)', *International Journal of Mental Health Systems* 4(1) (2010), p. 2; F. Kigozi and J. Ssebunnya, 'Integration of Mental Health into Primary Health Care in Uganda: Opportunities and Challenges', *Mental Health in Family Medicine* 6 (2009), pp. 37–42; E. Ovuga, J. Boardman, and D. Wasserman, 'Integrating Mental Health into Primary Health Care: Local Initiatives from Uganda', *World Psychiatry* 6(1) (2007), pp. 60–61.
8. Uganda Medical and Dental Practitioners Council, Specialist Register. Available at: www.umdpc.com/registers/Specialist%20Register.xls, last accessed 17 December 2017.
9. Kigozi et al., 'An Overview of Uganda's Mental Health Care System', p. 3.
10. World Health Organization, *WHO proMIND: Profiles on Mental Health in Development: Uganda* (Geneva, 2012), p. 40.

11. C. Abbo, 'Profiles and Outcome of Traditional Healing Practices of Severe Mental Illnesses in Two Districts of Eastern Uganda', *Global Health Action* 4 (2011), p. 11.
12. O. Gureje et al., 'Results from the Ibadan Centre', in T. B. Üstün and N. Sartorius, eds., *Mental Illness in General Health Care: An International Study* (Chichester, 1995), p. 158.
13. D. Baillie et al., 'Diaspora and Peer Support Working: Benefits of and Challenges for the Butabika-East London Link', *BJPsych International* 12(1) (2015), pp. 10–13.
14. See, for example, V.-K. Nguyen, *The Republic of Therapy: Triage and Sovereignty in West Africa's Time of AIDS* (Durham, 2010).
15. This and the following paragraphs are based in part on a series of interviews conducted with peer support workers in Kampala in August and September 2016. The interviewees are listed in the bibliography, but I have not attributed statements here in order to protect their privacy.
16. J. Hearn, 'The "NGO-Isation" of Kenyan Society: USAID & the Restructuring of Health Care', *Review of African Political Economy* 25(75) (1998), pp. 89–100.
17. Videos are available at: http://heartsounds.ning.com, last accessed 2 February 2017.
18. *BRAIN GAIN: Training Peer Support Workers (PSWs) to Support Community Mental Health in Urban Uganda*, UKAID/DfID Medium Paired Institutional Partnership Progress Report, mPIP.14.
19. 'Butabika Plaintiffs Submissions' (Unpublished document, copy in possession of author).
20. Personal communication with Kabale Benon, 20 January 2018.