De-institutionalization and the implementation of community-based care and rehabilitation services in South Africa: Where do we stand, what can we add?

Dr. Anneliese de Wet[1],
[1]Center for Psychiatric Rehabilitation, Boston University, USA (adewet@bu.edu)

De-institutionalization, where service users are discharged from psychiatric institutions and re-integrated into communities (Farina et al., 1992), has been implemented and supported in mental health contexts in many countries all over the world (Anthony & Liberman, 1986; Fakhoury & Priebe, 2002; Turner, 2004). It is a necessary and important ideal and when fully realized and combined with good quality community-based mental health care and rehabilitation services, can contribute to the personal and social recovery processes of connection, hope, identity, meaning and empowerment (Leamy et al., 2011).

De-institutionalization in South Africa is a complex and difficult process to address because of the general historical context as well as the mental health context in South Africa. Institutionalization, which has a long history in South Africa and was still enforced under the Mental Health Act, 18 of 1973, has continued for longer than in some other countries with recovery-progressive policies and actual implementation of those policies. It was not until the South African Mental Health Care Act, 17 of 2002, that de-institutionalization was fully legislated. Despite some legislative and policy documents referring to it, its full realization is still marred by many factors, which include the country's long history of inequality and institutionalization, lack of and poor distribution of resources within society, poor allocation of financial resources to public mental health care by government, high rates of stigma related to mental illnesses and barriers to access to mental health care for the largest portion of the population. In this article I share some ideas of why limited progress has made in the process of de-institutionalization and moving towards stronger community-based care and rehabilitation. Such community-based care and rehabilitation, grounded in a recovery-oriented approach, could hopefully contribute to this process moving forward.

Mental health context in South Africa

In 2009 the South African Stress and Health (SASH) study was published (Herman et al., 2009). It was the first and still is the only population-based mental health epidemiological study conducted in South Africa. This study was part of the World Health Organization World Mental Health Survey Initiative and revealed that one in every three South Africans is challenged by a common mental disorder in their lifetime, providing evidence of the high burden of mental illness in South Africa (Herman et al., 2009). Focus on public mental health care, which should include good community care and rehabilitation supports, is required to address this great burden, yet public mental health care receives the smallest allocation in the national health care budget, approximately 5% of the annual budget (Docrat et al., 2019). This indicates the lack of political willpower to prioritize mental health care and severely limits what services can be provided within public mental health care, with emphasis naturally falling to crisis management.

South Africa has a well-known history of racial inequality, most noticeably, during Apartheid, when non-white psychiatric service users were treated and accommodated differently and separately from their white counterparts (Gillis, 2012). In 1994, with a new democratic dispensation, changes were brought about that saw the integration of mental health services for all races. The aforegoing historical inequality, however, resulted in the poor distribution of resources throughout South African society generally, and within the mental health system, which regrettably still suffers from its effects today, despite racial integration. This is also evident in the inequality and poverty that continues to increase and affect black South Africans more than other racial groups (Lund et al, 2010). The inequality and poor distribution of resources in public health care in general (Omotoso & Koch, 2018) and, consequently, in public mental health care, remain.

This translates to the poorest persons in society, who are often still black persons or persons of mixed-race origin, despite the political changes, being served by under-resourced and over-burdened public mental health services. These under-resourced and over-burdened public mental health care services, together with the large burden of disease mentioned before, keeps the focus on symptom stabilization in the interest of a speedy discharge to attend to the large amounts of persons requiring care. Despite sterling efforts over the past more than 100 years by non-profit organizations, such as Cape Mental Health (Cape Mental Health, 2019) and South African Federation for Mental Health (South African Federation for Mental Health, 2022), to mention but two such organizations, large scale progress towards a comprehensive public community mental health care and rehabilitation system that prioritizes recovery in the country is still hampered by the unwillingness of the government to put sufficient budgetary resources towards good quality community-based mental health care.

Where do we stand?

The National Mental Health Policy Framework (NMHPF) (South African Department of Health, 2013), which was the first such policy framework in the country, had progressive aims and goals, such as to put in place measure to integrate citizens experiencing mental health issues back into communities to improve mental health care and rehabilitations and even the implementation of recovery-oriented practices. Regrettably, these aims and ideals were not implemented, as the South African Human Rights Commission pointed out in its report on the status of mental health care in South Africa (SAHRC, 2017) and the policy has since lapsed with no other in its place (Booyens, 2022). As a result, despite these lofty aims and ideals, public mental health care service users in South Africa are mostly still required to depend on mental health care at an institutional level and community-based mental health care and rehabilitation has not been developed sufficiently.

Mental health care users should have a range of options in terms of care, that is culturally sensitive, to choose from – safe home and work environments and meaningful activities, which should include community mental health care and rehabilitation. A choice to not be institutionalized should therefore not amount to refusal of any care at all (Booyens, 2022). However, the largest portion of the public mental health care budget, approximately 86%, is spent on out and in-patient services, with a predominant allocation to in-patient services, and almost half on care in psychiatric hospitals (Docrat et al., 2019; Docrat & Lund, 2019; South African Human Rights Commission (SAHRC), 2017). Almost 25% of patients are re-admitted within 3 months of discharge and this amounts to close to 20% of the funds that are spent on mental health care (Docrat et al., 2019). All in all, this leaves very little of the budget available for community mental health care and rehabilitation services let alone the expansion of services to incorporate recovery-oriented strategies that might lead to improvement of such services.

Apart from the attention paid to task-shifting of some mental health care services to primary health care level in the past years, services such as community mental health workers and Assertive Community-based Treatment (ACT) teams serve mental health care service users in their communities. ACT teams have been shown to effectively reduce re-admissions, especially for persons who make use of mental health services often (Petersen & Lund, 2011). Yet, despite providing much needed care, these services are often too overburdened and can only serve a few. Community mental health workers are sometimes also not provided with comprehensive training, which limits them in the assistance they can provide. Once again, the political willpower is not there to allocate the necessary funding to improve these services much less expand them to include recovery-oriented approaches.

Many communities in South Africa still carry the weight of high levels of stigma related to mental illness. Lack of knowledge of mental illness and factoring in cultural conceptualizations of mental illness play a role. Efforts need to be made to integrate mental health services and traditional practices, since service users

often rely on both to address mental health conditions (Petersen & Lund, 2011). These issues further isolate and even ostracize mental health service users from communities and exacerbate the challenge of integration of service users in communities (Petersen & Lund, 2011). Governmental expansion of the necessary community supports, and structures is needed to assist service users to have the opportunity to better integrate in their communities.

In the non-governmental sector, many good quality organizations step in to fill gaps in community mental health care services. These organizations offer services that range from day treatment centers to residential facilities based in the community (Lund et al., 2010). Some even have progressive services albeit on a small scale, such as paid peer support workers, who use their lived experience to support mental health care service users in their recovery journey (Cape Mental Health, 2019).

However, there are also varying degrees of quality in community-based care. Failed attempts at furthering de-institutionalization, in an effort by provincial Departments of Health to cut costs without regard for the quality of community-based care, also impede the move to any other community-based care and rehabilitation – the Life Esidemeni tragedy, where over 140 service users lost their lives due to being moved in a deliberate way from institutional care to incapable community-based care settings, being a prime example (SAHRC, 2017).

Where should we go? What the implementation of peer support work could add

Peer support work, as described earlier, refers to persons with lived experience of mental health conditions, who are trained to use this experience to work to support mental health care service users on their recovery journey. The peer support work referred to in this discussion, is formal peer support work, which should be distinguished from informal peer support work which takes the form of support towards peers without training or compensation (De Wet et al., 2022). Peer support work has its roots in the personal recovery movement.

The potential benefits of the implementation of peer support work for the South African public mental health care and rehabilitation context could be manifold.

This type of peer support work, although still highly uncommon in mental health care and rehabilitation in South Africa, has as an important, perhaps the most important, benefit that it may support and improve recovery processes for service users by building a sense of hope, connection, and empowerment (Trachtenberg et al., 2013) and motivating them to progress on their recovery journey (Burke et al., 2018; De Wet, 2021). The learned helplessness that originates from stays and poor outcomes in institutional care settings continues once service users are in the community with no recovery-focused services and peer support. Implementation of peer support work has the potential to lead to more effective use of mental health care funds by the South African government. When calculating the costs of re-admissions and considering some evidence that peer support work may lower such rates (Johnson et al., 2018), it makes sense to implement peer support work. When looking at the move to de-institutionalize mental health care, funding cuts by government in tertiary care have, however, not been re-routed to community mental health care and rehabilitation (Brooke-Sumner et al., 2016; Petersen & Lund, 2011; Sunkel, 2014). Government should indeed channel these funds into quality community-based care and rehabilitations services, as has been suggested (Petersen & Lind, 2011) and especially in the light of the Esidemeni tragedy (SAHRC, 2017). It is also suggested to incorporate peer support work as part of community-based rehabilitation resources.

Incorporating peer support work not only makes sense from an effective use of budget perspective, but can provide income, purpose and meaning to persons, who have been service users before (Slade et al., 2012) and may struggle to find employment in a context of more than 30% unemployment rate in South Africa (Department: Statistics South Africa, 2022). The burden on overburdened mental health care staff and services, where the turn-over rate is high, may also be lowered through the implementation of peer support

work (De Wet & Pretorius, 2020). The inclusion of peer support work in community-based rehabilitation services may furthermore impact prejudicial attitudes by providing evidence that mental health service users improve and live meaningful and productive lives in their communities. The use of peer support work can also help to bridging the gap between western conceptualizations of care and traditional mental health care, leading to the improvement of the "cultural congruence" (p. 404) that Lund et al. (2012) refer to.

The implementation of peer support work should be preceded by educating key recovery stakeholders, such as service users, their relatives or carers and service providers, about what personal and social recovery is and that it is possible. Much confusion and even lack of understanding exist about the meaning of personal recovery and how it is distinguished from clinical recovery. In a context such as South Africa, where much of the focus is still on clinical outcomes, it is important to clarify this distinction. This should start with recovery and peer support allies collaborating with persons with lived experience to advocate for opportunities to educate stakeholders in public mental health care settings and stepping up to provide such opportunities to learn about the potential of personal and social recovery. Such education has the potential to mobilize service users to speak up for themselves and advocating for more recovery-focused care, which should include peer support work.

It is important to emphasize and learn from challenging experiences and lessons in other contexts (Walker & Bryant, 2013). As I have advocated for before (De Wet, 2021), peer support workers should be sufficiently trained and remunerated, and supported through good supervision (Vally & Abrahams, 2013) to make a smooth transition from service user to peer support worker possible. In addition, it is also critical that the clinical teams and environments, that peer support workers are placed in, are adequately trained in the role of a peer support worker to minimize discrimination against and increase understanding of the gain to be had from adding such colleagues to the team, so that there can be the proper regard for peer supporter workers in the certainly challenging environments they will enter . Overall, the necessary supports and developments within communities need to be put in place to fully realize de-institutionalization. Peer support work is one such step, albeit an important one.

Conclusion

South Africa has performed sub-par in its move from institutionalized care to community-based care and rehabilitation, despite progressive mental health legislation and policies in the late 1990s and early 2000s paving the way, and the addition of the idealistic 2013 national policy framework, which never came to bear, leaving South Africa without such a framework currently. Although de-institutionalization has been implemented, community-based care and rehabilitation has not received the funding and support it requires to provide such services to fill the gap. As a result, where community-based care and rehabilitation has been implemented, it has been under-resourced and meagre in comparison to the need for such services. In this paper, the need to improve and strengthen community-based care and rehabilitation through increased allocation of funding and resources by government has been re-iterated. To this has been added the potential benefit that could be gained from supplementing such services with peer support work. The South African government urgently needs a re-commitment to extended, expanded and good quality community-based care, but more than that, this time around putting their money where their mental health legislation is.

References

Anthony, W. A., & Liberman, R. P. (1986). The practice of psychiatric rehabilitation: Historical, conceptual, and research base. *Schizophrenia Bulletin, 12*(4), 542-559.

Booyens, M. (2022). Community-based mental health care for adults with psychosocial disabilities in South Africa through a right to health lens. [Unpublished master's thesis]. Stellenbosch University, South Af-

rica. https://scholar.sun.ac.za/handle/10019.1/124611

Brooke-Sumner, C., Lund, C., & Petersen, I. (2016). Bridging the gap: investigating challenges and way forward for intersectoral provision of psychosocial rehabilitation in South Africa. *International Journal of Mental Health Systems, 10*, Article 21. https://doi.org/10.1186/s13033-016-0042-1

Burke, E. M., Pyle, M., Machin, K., & Morrison, A. P. (2018a). Providing mental health peer support 1: A Delphi study to develop consensus on the essential components, costs, benefits, barriers and facilitators. International Journal of Social Psychiatry, 64(8), 799–812. https://doi.org/10.1177/0020764018810299

Cape Mental Health. (2019). Time to act now for mental health: Annual review 2018/2019 (Report). https://www.mhinnovation.net/sites/default/files/downloads/organisation/CMH%20Annual%20Review%202018-19%20-%20Time%20to%20Act%20Now.pdf

Department: Statistics South Africa. (2022). Quarterly Labour Force Survey (QLFS) – Q2:2022. https://www.statssa.gov.za/?p=15685

De Wet, A. (2021). The development of a contextually appropriate measure of individual recovery for mental health service users in a South African context. [Doctoral dissertation, Stellenbosch University]. SUN-Scholar Research Repository.

De Wet, A., & Pretorius, C. (2020). From darkness to light: Barriers and facilitators to mental health recovery in the South African context. *International Journal of Social Psychiatry, 68*(1), 82-89. https://doi.org/10.1177/0020764020981126

De Wet, A., Sunkel, C, & Pretorius, C. (2022). Opportunities and challenges: a case for formal peer support work in mental health in a South African context. *Advances in Mental Health, 20*(1), 15-25. https://doi.org/10.1080/18387357.2022.2032776

Docrat, S., Besada, D., Cleary, S., Daviaud, E., & Crick Lund, C. (2019). Mental health system costs, resources and constraints in South Africa: A national survey. *Health Policy and Planning, 34*(9), 706-719. https://doi.org/10.1093/heapol/czz085

Docrat, S., & Lund, C. (2019, October 9). We did the sums on South Africa's mental health spend. They're not pretty. The Conversation, https://theconversation.com

Fakhoury, W., & Priebe, S. (2002). The process of deinstitutionalization: An international overview. Current *Opinion in Psychiatry, 15*(2), 187-192. https://doi.org/10.1097/00001504-200203000-00011

Farina, A. Fischer, J. D., & Fischer, E. H. (1992). *Societal factors in the problems faced by deinstitutionalized psychiatric patients.* In P. J. Fink & A. Tasman (Eds.), Stigma and Mental Illness (pp. 167-184). American Psychiatric Press, Inc.

Gillis, L. (2012). The historical development of psychiatry in South Africa since 1652. *South African Journal of Psychiatry, 18*(3), 78-82. https://doi.org/10.7196/SAJP.355

Herman, A. A., Stein, D. J., Seedat, S., Heeringa, S. G., Moomal, H., & Williams, D. R. (2009). The South African Stress and Health (SASH) study: 12-month and lifetime prevalence of common mental disorders. *South African Medical Journal, 99*(5), 339-344.

Johnson, S., Danielle Lamb, D., Louise Marston, L., David Osborn, D., Oliver Mason, O., Claire Henderson, C., Gareth Ambler, G., Alyssa Milton, A., Michael Davidson, M., Marina Christoforou, M., Sarah Sullivan, S., Rachael Hunter, R., David Hindle, D., Beth Paterson, B., Monica Leverton, M., Jonathan

Piotrowski, J., Rebecca Forsyth, R., Liberty Mosse, L., Nicky Goater, N., . . . Lloyd-Evans, B. (2018). Peer-supported self-management for people discharged from a mental health crisis team: A randomised controlled trial. *The Lancet, 392*, 409-418. https://doi.org/10.1016/S0140-6736(18)31470-3

Leamy, M., Bird, V., Le Boutillier, C., Williams, J., & Slade, M. (2011). Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *British Journal of Psychiatry, 199*(6), 445–452. https://doi.org/10.1192/bjp.bp.110.083733

Lund, C., Petersen, I., Kleintjes, S., & Bhana, A. (2012). Mental health services in South Africa: Taking stock. *African Journal of Psychiatry, 15*, 402-405. https://doi.org/10.4314/ajpsy.v15i6.48

Lund, C., Kleintjes, S., Kakuma, R., Flisher, A. J., & The MHaPP Research Programme Consortium. (2010). Public sector mental health systems in South Africa: Inter-provincial comparisons and policy implications. *Social Psychiatry and Psychiatric Epidemiology, 45*, 393-404. https://doi.org/10.1007/s00127-009-0078-5

Omotoso, K. O., & Koch, S. F. (2018). Assessing changes in social determinants of health inequalities in South Africa: A decomposition analysis. *International Journal for Equity in Health, 17*(1), Article 181. https://doi.org/10.1186/s12939-018-0885-y

Petersen, I., & Lund, C. (2011). Mental health service delivery in South Africa from 2000 to 2010: One step forward, one step back. *South African Medical Journal, 101*(10), 751-757.

Slade, M., Williams, J., Bird, V., Leamy, M., & Le Boutillier, C. (2012). Recovery grows up. Journal of Mental Health, 21(2), 99–104. https://doi.org/10.3109/09638237.2012

South African Department of Health. (2013). National mental health policy framework and strategic plan 2013-2020. https://www.health-e.org.za/wp-content/uploads/2014/10/National-Mental-Health-Policy-Framework-and-Strategic-Plan-2013-2020.pdf

South African Federation for Mental Health. (2022). Homepage. https://www.safmh.org/

South African Human Rights Commission (SAHRC). (2017). Report of the national investigative hearing into the status of mental health care in South Africa. https://www.sahrc.org.za/home/21/files/SAHRC%20Mental%20Health%20Report%20Final%2025032019.pdf

Sunkel, C. (2014). Mental health services: where do we go from here? *The Lancet Psychiatry, 1*(1), 11–13. https://doi.org/10.1016/S2215-0366(14)70239-1

Trachtenberg, M., Parsonage, M., Shepherd, G., & Boardman, J. (2013). Peer support in mental health care: Is it good value for money? [Report]. https://www.centreformentalhealth.org.uk/publications/peer-support-mental-health-care-it-good-value-money

Turner, T. (2004). The history of deinstitutionalization and reinstitutionalization. *Psychiatry, 3*(9), 1-4. https://doi.org/10.1383/psyt.3.9.1.50257

Vally, Z., & Abrahams, L. (2016). The effectiveness of peer-delivered services in the management of mental health conditions: A meta-analysis of studies from low- and middle-income countries. International *Journal for the Advancement of Counselling, 38*(4), 330–344. https://doi.org/10.1007/s10447-016-9275-6

Walker, G., & Bryant, W. (2013). Peer support in adult mental health services: A metasynthesis of qualitative findings. *Psychiatric Rehabilitation Journal, 36*(1), 28–34. https://doi.org/10.1037/h0094744