Managing de-institutionalisation in a context of change: The case of Gauteng, South Africa

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Abstract
The paper draws on documentary sources and the author's experience as the official responsible for chronic mental health care in Gauteng between 1998 and 2003. An account and assessment of efforts to effect changes to the inherited system of primarily institutional care is presented. While rooted in the reality of Gauteng, these experiences contain lessons for others engaged in policy making and planning in this area of mental health care.

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Introduction

Decades after its initiation in the United States of America and Western European countries, the concept and implementation of de-institutionalisation remains a subject for debate. It has been pointed out that there is no standard definition of de-institutionalisation.[1] However, from the outset, informed policy statements have encompassed not just the discharge of patients and downsizing of hospitals, but also the development of alternative, community-based services. In a review of the recent history of mental health services, added to the above was the need to prevent inappropriate admissions to mental hospitals.[2] In this regard, these authors stressed the importance of easy access to and adequate numbers of acute beds in general hospitals for treating acute relapses.

In recognition of some of the negative outcomes of certain de-institutionalisation programmes, there has been greater emphasis on two further aspects. Firstly, it is essential to retain a certain minimum number of chronic beds and the resources to adequately care for a minority of patients who are very difficult to manage in the community.[3] Secondly, there is a need to ring-fence funds allocated for mental health care, so that, with downsizing of hospital care, funding is transferred to community care.[4]

Finally, what is often over-looked is that de-institutionalisation is a process, involving 'all elements of the service system; no agency [being] exempt'.[1] As in any process, there will be adjustments and changes as the process unfolds (Table I).

Although the various components have long been acknowledged as essential to ensure effective de-institutionalisation, in practice there has generally been greater emphasis on bed reductions.[5,6,7] Thus, while noting the difficulty of evaluating an extremely complex set of processes, Bachrach's overall assessment of de-institutionalisation in the United States was that provision of community alternatives to hospitalisation has generally not matched the extent of need.[1] Similar trends have been observed elsewhere. These trends may reflect the fact that the starting point for de-institutionalisation has generally been the hospital. This may be compared with a more recent shift of emphasis: rather than community care primarily seen as supportive of hospital care, the recommended approach, referred to as balanced care, is "essentially community-based, but [with] hospitals [in] an important backup role".[2]

Nevertheless, despite some caveats, reducing reliance on

Table I: Essential components of de-institutionalisation
Reduction of hospital beds – discharge of suitable patients – preventing unnecessary admissions
Retention of necessary minimum number of beds – for hard-to-manage patients – adequate quality of care
Simultaneous expansion of community-based care options (extent, range)
Ring-fencing and transfer of funds ("funds follow the patient")
Process involving all elements of the mental health care system

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institutional care and shifting the emphasis to community care – that is, de-institutionalisation as defined above - continues to be promoted as an appropriate and effective policy option, particularly in settings with limited financial and other resources for mental health care.

De-institutionalisation in South Africa: policy and concerns

In South Africa, as part of a package of reforms of mental health care post-1994, a key governmental policy initiative (expressed in various forums and in unpublished documents) has been an attempt to reduce the historical reliance on long-term institutional care for people with severe and chronic mental disorders. Instead the policy has promoted the development of community care. In response, local advocacy groups and policy commentators have echoed international concerns about de-institutionalisation.[8] These concerns have been expressed despite evidence of extreme deficiencies in the quality of institutional care locally.[9,10]

The principal concerns regarding de-institutionalisation reflect those expressed elsewhere and may be summarised as follows:

Indiscriminate discharges ("dumping")

Pressure to reduce beds may result in indiscriminate discharges, with patients discharged without careful assessment of their readiness for discharge, or of the availability or readiness of placement options to which discharge will take place.

Inadequate family and community preparation and support

Linked to the above, insufficient effort and time may be put into preparing family members to accept and manage the discharged individual in the home environment. In addition, there may be insufficient support for the family over the longer term to assist them in maintaining the individual in the community. Examples of the latter would include difficulty obtaining chronic medication, problems in obtaining and retaining disability grants, as well as limited or no access to emergency assistance in crises. Inadequate family support may be exacerbated when there is no attempt to assist the family in dealing with the concerns, fears and prejudices of neighbours and the community more widely, or to assist the family to elicit support from available resources. The same concerns may apply to other placement options like non-governmental organizations, particularly if (however good their intentions) they are relatively inexperienced in managing individuals with mental disorders.

Inadequate community resources

For families or other placement options, the availability of community resources may be critical in lessening the burden of caring for an individual with a chronic mental disorder. These resources would include day care, workshops, or drop-in centres, that are available relatively close by. Lack of such resources may make placement unsustainable because other family members cannot maintain employment, their usual daily activities, or (even in the case of other placement options) there are inadequate means to occupy or supervise the individual.

Inadequate continuity of mental health care

If links between institutional and community care are non-existent or fragmented, or there is inadequate provision for mental health care within community health services (e.g. insufficient staffing, interruptions in medication supply, limited ability to respond to crises), the chances of relapses are greatly increased. Arranging re-admissions, even for what may be little more than temporary respite care, may also be more difficult. The result of such difficulties may be greater reluctance on the part of all parties to try community placement again.

Revolving door admissions and discharges

It is generally considered that the above mentioned factors may lead to a pattern of revolving door admissions and discharges. The likely outcome is that patients are neither adequately treated in hospital nor effectively integrated into the community.

Neglect and abuse

More hidden, but nevertheless of great concern, is the potential for neglect and abuse within families and other placement options, particularly when there are limited resources for monitoring placements. In South Africa, a specific concern is that families or other placements use most, if not all, of the discharged individual's disability grant for purposes other than the support of that individual.

Homelessness

The figure of the bag-lady or garbage-picker on the city streets is a potent symbol of the perceived failure of de-institutionalisation. 'Housing for all' still remains a distant dream for many South Africans. People with chronic mental disorders are even more likely to be ejected or unable to access even the more basic shelters.

Inherited system of care

The concerns outlined above are real and important. However, they must be considered in relation to the system of mental health care inherited by the new South African administration in 1994, as well as the resources available and constraints on transformation. In this regard, reviewing the experience of Gauteng Province, which inherited a very large number of institutional, custodial care beds, may be instructive.

Hospital care in Gauteng comprised chronic and acute care beds (Table II). Chronic beds included both psychiatric beds and beds for individuals with intellectual disabilities. The latter included many from an era where even mild to moderate disability frequently led to institutionalisation. Chronic beds made up 87% of the total hospital beds for mental health care. Of these, an estimated 5100 (61% of total beds and 70% of chronic beds) were for psychiatric patients (including patients with a dual diagnosis with intellectual disability).

Chronic beds were located in specialised state mental hospitals and in institutions supplied by a private contractor, with the latter making up 67% of the total mental hospital beds and

Table II: Chronic and acute beds: 1994

Chronic	
Total (psychiatric and intellectual disability)	7270
Chronic psychiatric only	5100
Contracted (psychiatric and intellectual disability)	5570
Non-Gauteng patients (contracted care only)	1850
Acute	1100

77% of the chronic beds. Contracted beds thus comprised a significant proportion of the already high number of chronic beds.

A significant number of patients in chronic care (approximately 30%, most of them in chronic care institutions) had been transferred to these facilities from other regions of the country; many even decades ago. This reflected the limited extent of mental health facilities in those regions at the time, as well as the fact that the private contractor's facilities were concentrated in what is now Gauteng.

As regards acute beds, most were located in specialised mental hospitals, with a limited number in general hospitals. Acute beds made up only 13% of the total. Set against the number of chronic beds, the skewed nature of provision is clear.

As for community care, a fairly extensive basic psychiatric service was by then already in existence. However, there were few other resources for community care. These were generally operated by non-governmental organisations, with limited financial support from the state. In terms of the then applicable legislation, most catered for white people only.

To put the above in context: in 1994, chronic psychiatric beds alone (excluding those for people with intellectual disability) amounted to 70 beds per 100 000 of the population. This contrasts with the figures specified in national bed norms developed since then. These norms specify an initial target of 35 chronic beds per 100 000, reducing thereafter to 30 beds per 100 000. As and when more resources for community care become available, the norms suggest an eventual maximum of 10 chronic beds per 100 000.

Chronic care: issues

On the basis of figures alone, the number of chronic beds and the number of patients maintained in them appeared to be excessive and reflected an inappropriately skewed distribution of resources. What were some of the underlying issues?

Many chronic patients were in fact suitable for discharge. This was reflected in the findings of an unpublished internal investigation (Mental Health Directorate Task Team, Gauteng Health Department, 1997). Ward psychiatric nurses assessed 61% of a representative sample of patients in contracted care as dischargeable on the basis of factors such as sufficient independence, high functioning, or not needing supervision. This high figure may reflect the nature of the investigation, which was a rapid assessment, intended to provide an overview of the patient population at the time. However, in a more detailed and careful assessment of a similar patient population in institutions elsewhere in the country, 40% of patients were found to be dischargeable.[8] On this basis, there can be little doubt that significant numbers of patients – probably at least some 20-30% - were in fact dischargeable.

That these patients had not been discharged reflected an outdated, hospicentric and custodial model of care, to which the concept and possibility of rehabilitation was foreign. The name of the contracted care provider summed up the approach as being 'care for life'. However, even within the terms of that model, the quality of contracted care – the bulk of chronic care - was poor.[11] The overall picture was one lacking any perspective of patient or human rights, such as rights to effective and humane care, dignity and promotion of independent living skills.

There were also undeniably significant barriers to discharge. These included:-

– Disability due to long-term institutionalisation (mean years in hospital: 9 years)
– Families lost to contact, living far away and having little or no contact with patients, or unwilling to take back patients
– Lack of accommodation
– Difficulty and delays in obtaining disability grants
– Few community resources (especially as alternative placement options)

The above also point to another factor affecting de-institutionalisation: the inadequacy of inter-sectoral collaboration with particular reference to social welfare and housing.

Policy imperatives and strategy

Against the background of experience elsewhere and the particular concerns locally, it was accepted that the goal of de-institutionalisation should not merely be bed reductions, but the development of a comprehensive mental health care system capable of providing *continuity of care*.

However, movement towards this goal had to take account of certain policy imperatives. Firstly, there was recognition of having to work with limited resources. The budget for health services in general was tight. Thus, contrary to what might have been hoped, there were no additional funds and no bridging finance for mental health care - specifically to transform the inherited system of care. The only mechanism available was to use budget shifts, with sustainability and questions of cost and cost-effectiveness key considerations, whether at institutional or community level.

Secondly, the fact of limited resources increased the need for integrated planning. The focus in Gauteng could not be solely on hospitals and bed reductions. All elements and levels of care – hospitals and chronic care institutions, acute care hospitals, community mental health services and placement options – and other key role-players, such as related government departments, needed to be factored into and become involved in the process.

The strategy adopted was the following:-

- Reductions in chronic bed numbers should occur in parallel with discharges, with resultant savings ring-fenced and transferred to support expanded community care.
- Known risks associated with de-institutionalisation should be acknowledged and actively managed.
- Bed reduction should involve a shift of emphasis towards a necessary minimum number of beds for hard-to-manage patients.
- An appropriate admission and active discharge policy should be implemented.
- Efforts should be made to improve quality of institutional care, including not only psychiatric, but also basic physical and medical care, within a framework of promoting respect for patient and human rights.
- A rehabilitative emphasis should pervade all levels of mental health care, whether acute, specialised, or chronic.
- Limited professional mental health resources in chronic care settings (especially contracted care) should be utilised primarily to train and give direction to auxiliary staff in the rehabilitation of patients. Similarly, in community care,

available professional resources should be used to support families and NGOs in caring for individuals with chronic mental disorders.
- A shift in the approach to families and caregivers would be necessary - from taking over responsibility toward sharing responsibility.
- Community psychiatric services should be strengthened to provide the necessary support for discharged patients and their caregivers.
- The resourcefulness and flexibility of NGOs as providers of community care should be acknowledged and supported in order to expand community-based options for placement, care and support.

Related initiatives included:-
- Negotiations with other provinces, which were necessary to ensure shared responsibility for the significant number of non-Gauteng patients placed in Gauteng institutions. The preferred option was for patients to be returned to their home provinces (some to be discharged there), but, in the alternative, with the cost of care in Gauteng institutions carried by the province concerned.
- Efforts to improve liaison with home affairs, social welfare and housing departments were necessary to facilitate access to appropriate documentation, disability grant and accommodation.

Table III: Factors contributing to reduction in chronic beds
Transfers to other provinces 1994:1850 non-Gauteng patients; 2003: approx. 300
Deaths in an ageing population 1997: mean age 45 years, SD 10 years*
Increased rate of discharge *1994 discharge figures not avail*able; 2000: approx. 100; 2003: approx. 200
Reduced admissions Revised admission criteria, fewer transfers, regular monitoring to ensure adherence to admission criteria
More effective external review system Monitoring that patients are not inappropriately retained
** Unpublished internal investigation (Mental Health Directorate Task Team, Gauteng Health Department, 1997)*

Assessment of implementation

The most obvious outcome has been significant chronic bed reductions. Contracted care bed numbers reduced from 5570 in 1994 to 3150 in February 2004. This translated to a chronic bed to population ratio of 35 per 100 000, the maximum specified by the national norms, and a significant reduction from the previous figure of 70 per 100 000. This apparently dramatic reduction is accounted for by a number of factors (Table III).

As significant, if not more so, have been increases in community-based residential and day care. In 1994, there were 1400 beneficiaries of subsidies paid by the Gauteng Health Department (GHD). By 2003, this had increased to 2725 (with places for a further 300 in development).

This growth reflected a number of factors:-
- A number of existing community-based organisations (CBOs) that were already offering informal services were licensed. They then became eligible for subsidy and, as a result, were in some cases able to expand capacity.
- New non - governmental organisations (NGOs), supported by GHD staff were established, while in a number of instances, the capacity of existing NGOs was expanded.
- New NGO funding was made conditional on the organisation's accepting patients discharged as part of the deinstitutionalisation process and taking steps to correct racial inequities.
- After more than a decade of no increases, subsidy rates have been increased annually, although they still remain low. In the case of day care, subsidies were increased by more than the rate of inflation.
- A programme of regular monitoring of NGO services and training to improve quality of care, was instituted. This resulted in closer working relationships with district mental health staff and gave support for further growth.

Outcomes

Since patient outcomes are clearly the acid test, it is unfortunate that there is a lack of systematic information and review. Anecdotal case reports from service providers in hospitals, contracted care institutions, community psychiatric services and NGOs reflect the following:
- satisfactory adjustment with families or NGOs
- inadequate preparation of patients and/or families
- inappropriate discharges
- difficulty accessing community care (psychiatric services and day care)

Obstacles

There are clearly a number of obstacles to effective implementation. These relate, firstly, to the system of care and include:
- The entrenched organisational culture of custodial care has proved extremely resistant to change.
- Staff constraints and attrition have affected the extent and quality of rehabilitation offered in institutions.
- Staff constraints and attrition have also reduced the capacity of community psychiatric services to provide effective continuity of care and support for families and NGOs.
- The limited extent of community-based care (both residential and day care) placed limits on discharges.
- Continuing community stigmatisation of mental disorder contributed to difficulties in arranging community placements.
- Inter-sectoral co-ordination, though improved, remained uneven and inconsistent.

Secondly, there have been organisational and structural obstacles. These include:-
- Competing priorities within the GHD in the context of limited and declining (financial) resources;
- Difficulties on the part of other agencies in utilising transfers (of savings as a result of bed reductions) appropriately. In the case of:-
  – Community psychiatric services: lack of a mechanismto facilitate internal ring-fenced budget shifts for operational

expenditure;
- NGOs: long lead times for development of new or expanded capacity, allied with restrictions on what maybe funded (in general, operational rather than capital costs); The effects of more general restructuring and transformation within the GHD (lengthy and often inconclusive processes, changes in management, staff constraints) on implementation and on staff morale.

Challenges and lessons

In summary, the experience in Gauteng has reflected much of that reported elsewhere. There have been significant achievements, but limited resources and competing priorities have been obstacles to achieving the goal of linking de-institutionalisation to transformation of the mental health care system as a whole.

A number of challenges remain. These are, firstly, to continue to protect the chronic mental health care budget and ensure transfer of resources to enhance community care. Secondly, it is necessary to maintain and extend gains, especially in the areas of appropriate admissions, improved quality of institutional care, psychosocial rehabilitation, and increases in NGO-provided care. Thirdly, there is an urgent need to improve information and tracking systems. Fourthly, the focus on integrated planning and development across the system of care should be maintained. Finally, efforts should be made to engage users, families, NGOs and other community stakeholders more effectively.

Key lessons learned are, firstly, that to counter paternalistic and overly cautious attitudes towards the care of people with mental disorders. It is essential to maintain a focus on human and patients' rights, and to persistently challenge entrenched attitudes and practices in this regard. Secondly, there is a need for sustained advocacy with multiple stakeholders. This often involves walking a tightrope between competing interests, while encouraging collaboration across traditional boundaries. Finally, it is necessary to focus on the feasible without losing sight of the goal, and to take the long view of not expecting immediate results, whilst acknowledging incremental gains.

References

1. Bachrach LL. Lessons from the American experience in providing community-based services. In Leff J, ed, Care in the Community: Illusion or Reality? Chichester: Wiley, 1997; 21-36.
2. Thornicroft G, Tansella M. What are the arguments for community-based mental health care? Health Evidence Network (HEN). Geneva: WHO Regional Office for Europe, 2003.
3. Trieman N. Patients who are too difficult to manage in the community. In Leff J ed op cit 1997; 175-187.
4. Beecham J, Hallam A, Knapp M, Baines B, Fenyo A, Asbury A. Costing care in hospital and in the community. In Leff J, ed, op cit, 1997; 93-108.
5. Rosen A. Integration is as essential as balance. World Psychiatry 2002; 1(2): 91-93.
6. WHO. The Mental Health Context. Mental Health Policy and Service Guidance Package. Geneva: WHO, 2003.
7. WHO. Organisation of Services for Mental Health. Mental Health Policy and Service Guidance Package. Geneva: WHO, 2003.
8. Dartnall E, Modiba P, Porteus K, Lee T. Is Deinstitutionalisation Appropriate? Discharge Potential and Service Needs of Psychiatric Inpatients in KwaZulu-Natal and the Eastern Cape, South Africa. Johannesburg: Centre for Health Policy, University of the Witwatersrand, 1999.
9. Mental Health & Substance Abuse Committee. Human Rights Violations and Alleged Malpractices in Psychiatric Institutions. Pretoria: Report to the Department of Health, 1996.
10. Porteus K, Sibeko M, Lee T, Soderlund N, Gilson L, Peprah E. Cost and Quality of Care: A Comparative Study of Public and Privately Contracted Chronic Psychiatric Hospitals. Johannesburg: Centre for Health Policy, University of the Witwatersrand, 1998.