



DEINSTITUTIONALISATION:

Why community living has been accepted as the appropriate model

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1. Introduction

'International and Australian research shows consistently that community based treatment is superior to hospital centred care for the vast majority of people with acute and long term mental illness.'¹

Too often in society, those who are different are seen to be a threat. Their weaknesses or needs are not constructed in terms of what can be done to help, but rather their differences are misconstrued and vilified, further ostracizing those in need. Nowhere is this more prevalent than in the treatment of those considered as societies most vulnerable; people affected by mental illness. The myth that mentally ill people pose a threat to society is contradictory to the facts: "people with serious mental illnesses are fourteen times likely to be the victim rather than the perpetrator of crime"² with ninety-five percent of homicide offences being carried out by people without mental illness.

While Adrian Keller suggests that management of "severe and persistent mental illnesses without recourse to using mental health legislation would be foolish and naïve"³, the need for deinstitutionalisation becomes apparent through the case of Saeed Dezfouli. Dezfouli, a non-violent

¹ Alan Rosen, Liz Newton. Karen Barfoot, "Clinical Perspectives: Evidence based Community Alternatives to Institutional Psychiatric Care" *Medicine Today*, vol 4, no. 9 (September 2003), p. 90.

² Collins, B "Mental Illness Myths Exploited" *Justice Action Media Release* (15 July 2011). Web 5 September 2011 <<http://justiceaction.org.au/cms/mental-health/item/404-mental-illness-myths-exploited>>

³ Adrian Keller "Billions more for the mentally ill but the buck stops elsewhere" *The Sydney Morning Herald* (13 July 2011) p. 13

man, unintentionally killed a woman after setting fire to the foyer of the Community Relations Commission in an attempt to grab their attention for failing to acknowledge his concerns about his own safety and the death threats he had received. Coincidentally enough, he was institutionalised at Kellers hospital after pleading not guilty due to mental illness. Since his imprisonment, Dezfouli has been subjected to a number of human rights abuses such as:

- Numerous periods kept naked in a solitary confinement cell for days to “break him down”.
- Broken ribs and severe bruising and pain from forced medication.
- Periods of incarceration in cells without basic hygiene, such as four days without toilet paper.
- In January 2005, he was brutally assaulted by DCS officers resulting in a permanent back injury.
- Hospitalization due to injuries inflicted by DCS officers.

As a result, Dezfouli now suffers from a number of health conditions such as a heart condition, ulcers and diabetes⁴. Access to Dezfouli for visits has also been impossible with Keller continuously ignoring applications. This is a gross violation of both his dignity the section 68a of the New South Wales Mental Health Act 2007, where “people with a mental illness or mental disorder should receive the best possible care and treatment in the least restrictive environment enabling the care and treatment to be effectively given”⁵. Not only is has the need for deinstitutionalisation practices been recognised in Australia, but also worldwide making it a universal issue.

2. History of Deinstitutionalisation

a) International Origins

The need for deinstitutionalization is self-evident. For decades, on going research has proven that community responsibility for mental health is crucial. In the early 1970’s Italy, the influential Triste model was established by Dr Franco Basaglia. Here he advocated deinstitutionalisation and led a reform that resulted in the mental health hospital unlocking its doors in 1974, allowing patients to come and go freely. Prior to the Triste model, Italy ran a substandard psychiatric system where patients were routinely subjected to concentration camp conditions and neglect was common⁶. Such conditions raise concerns regarding foundational human rights, which will be addressed further on in this report.

The UK, Germany, Italy and the Netherlands have all made good progress “rebalancing this care.” (Knapp et al, 2011) (Ravelli, 2006). In the Netherlands, “Phases of the reform process during the last 25 years have been marked by the integration of ambulatory services...subsequent implementation of community mental health centres (RIAGGs), differentiation of target populations, dehospitalisation of patients, differentiation within the field of sheltered housing accommodation, and the merger process of the above three entities into *integrated regional mental health care organizations.*” (Ravelli, 2006).

In the UK, Leff et al carried out two TAPS projects in 1994 and 2000 assessing the social and clinical outcomes of psychiatric patients discharged in the community after five years. Both reports concluded that community care services and programs served to improve and enhance the

⁴ Justice Action “Detention in Long Bay Hospital” *About Saeed* (2011). Web 29 August

2011<<http://justiceaction.org.au/cms/mental-health/campaigns/saeed-dezfouli/item/412-about-saeed>>

⁵ New South Wales Consolidated Acts “Section 68 Principles for care and treatment” *New South Wales Mental Health Act* (2007). Web 5 September 2011 < http://www.austlii.edu.au/au/legis/nsw/consol_act/mha2007128/s68.html>

⁶ Kendall, T “Triste: The Current Situation” *Third International Conference on "Psychosis: Integrating the Inner and Outer Worlds"* University of Essex, Colchester, England (September 1996)

wellbeing of mentally ill patients. In their first report, no patient had been charged with a criminal offence nor had they been imprisoned⁷, going against myths that mental illness equates criminality. In addition to this, appreciation for autonomy increased significantly over the 5 years (18%) indicating a growing appreciation of their increased freedom. Similarly, in Leff and Trieman's second study, patients expressed a high satisfaction with their increased freedom, autonomy and less restricted living conditions⁸. While these projects experienced their own limitations and difficulties, their impact has been significant; allowing us to understand the exact improvements of patient's lives.

b) History of Deinstitutionalisation in Australia

In regards to Australia, the 1992 Burdekin National Inquiry showed an alarming number of prisoners (20%) suffering from treatable mental illnesses⁹. The 1994 Burdekin Report that followed outlined the challenges mentally ill patients faced when dealing with the criminal justice system. The report demonstrated that mental health prisoners were incarcerated due to a lack of understanding and recognition of mental health symptoms or as a direct result to actions that emanated from their treatable illnesses going untreated. Mentally ill people also became at increased risk of being charged with offences they did not commit. Getting released on bail was also difficult as many were too poor to raise bail due to no fixed address or because they do not comprehend or comply with bureaucratic requirements. An inability to obtain bail meant that people affected by mental illness were frequently remanded in custody, even on trivial trials making it virtually impossible for their illnesses to be treated. Prison conditions were seen to be unsafe and unsupportive, with forensic prisoners suffering greater levels of abuse and uncertainty regarding the duration of their imprisonment. A lack of support for mentally ill people released from jail became another problem, prompting the implementation of deinstitutionalised policies¹⁰

Valerie Gerrand has explicitly examined the effectiveness of deinstitutionalisation in Victoria between 1993-1998. Between 1993-1998, Victoria's mental health service system underwent a major transformation. Taking into account the problems arising from institutionalised services, the Victorian government implemented a range of community care services before shutting down its psychiatric institutions. As a result, Victoria was able to fund new, locally accessible services with institutional savings quarantined for its purpose¹¹ as well as improving the well being of its patients.

However, after the conservative governments 1996 re-election, mental health reform lost priority (Gerrand 2005) with its reform process remaining undeveloped and incomplete.

3. Models of Deinstitutionalisation

From: Alan Rosen, Liz Newton. Karen Barfoot, "Clinical Perspectives: Evidence based Community Alternatives to Institutional Psychiatric Care" *Medicine Today*, vol 4, no. 9 (September 2003) pp90-95

⁷ Leff, J, Thornicroft, G, Coxhead, N and Crawford, C "The TAPS Project. 22: A Five-Year Follow-Up of Long-Stay Psychiatric Patients Discharged to the Community" *British Journal of Psychiatry* (1994) vol. 165, suppl. 125, pp 13-17

⁸ Leff, J and Trieman, N "Long-stay patients discharged from psychiatric hospitals: Social and clinical outcomes after five years in the community. The TAPS Project 46" *British Journal of Psychiatry* (2000) vol. 176, pages 217-223

⁹ Burdekin, B "National Inquiry into the Human Rights of People with Mental Illness: Launch Report" *Australian Human Rights Commission*. 20 October 1993. Web. 29 August 2011.

<http://www.hreoc.gov.au/disability_rights/speeches/mii93.htm>

¹⁰ Burdekin, B "People with Particular Vulnerabilities" *Report of the National Inquiry into the Human Rights of People with Mental Illness* volume 2, no 1 pp 509-803

¹¹ Gerrand, V "Can deinstitutionalisation work? Mental health reform from 1993 to 1998 in Victoria, Australia" *Health Sociology Review* (2005) vol. 14 pp 255-271

- Recovery oriented services → want services to develop a culture to “stimulate, enhance, and support individual recovery by promoting health, healing, empowerment and connection in the lives of each individual served” p90.
- GP’s have a pivotal role → know the person and family and are in a position to organise all aspects of clinical care. Stabilised persons can be transferred to a GP for co-ordination of care focussed on counselling and support
- Crisis intervention → “evidence now clearly indicates that 24hr home visiting crisis response services should be integrated into local services for people seriously affected by mental illness and their families” p. 91
 - People affected by psych illness more likely to co-operate when interventions are tailored to their needs and when family is given choice, receive sufficient information and low dose interventions are offered p. 91
 - Reduces the trauma of hospitalisation
- Family interventions – have been shown to prevent relapses. Techniques include problem solving skills to minimise conflict and hostility
- Assertive community treatment → “is an intensive, mobile community case management system for people with severe and prolonged mental illness”. Research shows it is efficient and cost effective and works best for heavy users of mental health services p. 91
- Day and evening programs → including ‘drop in’ and ‘club house model’ where users participate and manage the centre.
- Vocational rehabilitation → focused on living skills and leisure activities. Can create work opportunities. This is a “pathway’ for other opportunities p. 92
- Open employment → can be an achievable goal. Traineeships, apprenticeships specially funded should be pursued
- Individual placement and support schemes → helps users find a job within their interests and provides support for both the employee and employer
- Supported employment → successful. Mainstream jobs with on job training for people with a mental illness. Partnerships include cafes, nurseries.
- Transitional and sheltered employment → enables members to have short-term jobs in local businesses with support. Provides work experience, confidence and skills.
- Service users as paid service providers → create paid work from within mental health service budget within the mental health industry. Studies show v positive outcomes.

The majority of Rosen’s recommendations such as day and evening (“drop in”) programs and crisis intervention have focused on individualising treatment to suit the needs of the service-user to provide comfort and enhance co-operation. However, some models such as the assertive community treatment have proven to be the most efficacious and cost effective for heavy users of mental health services or those with severe symptoms. The services provided in this model (medication administration, monitoring and assisting with functional needs just to name a few) are used to prevent repeated ‘revolving door’ hospitalisations (p. 91). It appears interventions in the form of monitoring; personal assistance and counselling are required for sufferers of severe and prolonged mental illness (SPMI) however Rosen does not mention hospitalisation as preferred model. Instead, he states that it can be easily done in the community.

“...a good care system would aim to offer the services most suitable to meeting their needs and responding to their preferences.” (Knapp et al, 2011)

4. Public Policy reasons for deinstitutionalisation

(a) Human Rights

When institutionalised, patients are stripped off their basic rights such as the right to freedom, allocation of resources, treatment, research and the protection of their human rights (Burdekin, 1993). Community based programs would allow patients to retain these rights, providing them with social support. However, it appears that treatment for SPMI patients still restricts their living conditions and freedom as well as their ability to make their own decisions.

(b) Costs of institutionalisation

Institutionalising and medicating individuals comes at a great cost (\$200 000¹² to be exact). While deinstitutionalization and community-based programs may come at a relatively high cost, when properly set up and managed, they deliver better outcomes than institutions.

“Overall community care costs less than half the cost of hospital...” (Knapp et al, 2011)

“However, there were a number of long-stay inpatients with very challenging needs who were more costly to accommodate in community settings...than in hospitals.” (Knapp et al, 2011)

5. Australian Reference Articles

(a) Hobbs 2000

From: Hobbs C, tenant, C Rosen, A, Newtown, L, Lapsley, H.M, Tribe, K and Brown, J.E

“Deinstitutionalisation for long-term mental illness: a 2-year clinical evaluation” *Australian and New Zealand Journal of Psychiatry* (2002) vol. 34, pages 476-483

- Study assessing patients’ clinical outcome over a two-year period after discharged into the community from a mental health hospital
- Psychiatric ratings contradicted presumptions that the pressure of integrating into the community would exacerbate patients’ psychiatric symptoms
- Patients were chosen on the basis of whether they were willing and suitable to transfer to the community.
- Those who were considered were aged 16-65 years, with a diagnosis of a serious mental illness and a continuous hospitalisation period exceeding 2 years
- While many residents still required some assistance with living skills after 2 years, some residents improved to the point where they were moved to less supervised homes
- This study supports the integration of long term mentally ill individuals provided they have adequate resources

(b) Owen 2004

Owen 2004 in Louise Young and Adrian Ashman, “Deinstitutionalisation in Australia: Historical Perspective” *British Journal of Developmental Disabilities*, 50, no. 98 (January 2004), p. 24

- Report on relocated adults with intellectual disability from large state run institutional in Victoria into community houses or smaller group residences
- Those who left the institution showed increased activity level and skills, empowerment in decision and choice-making, community integration and improved quality of care
- Given 10 yrs since this study took place this article questions whether the socio-political circumstances that existed then would have the same impact as today.

(c) Jones and Marks 2000

From: Jones, M and Marks, L.A.B “Approaching Law and Disability” *Law in Context* (2000) vol. 17 no. 2, pages 1-6

¹² Justice Action “Introduction” *Mental Health* (2011). Web 19 August 2011 <<http://justiceaction.org.au/cms/mental-health/item/86-introduction>>

- There is a general assumption that people with disabilities are dependent and in need of special protection
- International mechanisms have made it clear that people with disabilities are entitled to the same human rights as other members of the community
- In “Mental Illness – Freedom and Treatment”¹³, Gardner surveys the law and the judicial decisions relating to mental illness. He points out the necessity for a fine balance between the vigilant scrutiny of a person for the good of his or her or others and potentially violating human rights
- Active facilitation of participation for people with disabilities is crucial

(d) Chenoweth 2000

Chenoweth, L “Closing the Doors: Insights and Reflections on Deinstitutionalisation” *Law in Context* (2000) vol.17, no. 2 pages 1-24

- International deinstitutionalisation has significantly impacted Australian government policy and legislation responses to individuals with disabilities
- A shift from institutional to community-based services for people with disabilities in the past 30 years is one of the most significant human services events of the 20th century
- The UN Declaration on the Rights of Mentally Retarded Persons in 1971 and the Declaration on the Rights of Disabled Persons in 1975 emphasize the right to a decent life as close to the norm as possible
- The Penhurst study found that while 55% of parents opposed the closure of institutions initially, only 5% continued their opposition after the move to deinstitutionalisation.¹⁴
- Social integration is imperative
- Many studies throughout Australia (Young, Sigafos, Suitte, Ashaman and Grevell 1998) have found that moving individuals into community-based facilities substantially improve daily living skills, communication and social skills as well as providing individuals with family contact
- The principles and objectives in the Commonwealth Disability Services Act 1986 are heavily oriented around community integration

6. Rebuttals to Criticisms of Deinstitutionalisation

(a) Relationship between homelessness and mental illness

‘Studies have shown that many homeless people with mental illness, rather than having been deinstitutionalised, have actually spent very little time in mental hospitals.’¹⁵ The explanation for this lies in the fact that they are often “independent in nature, out of reach services or not inclined to ever go anywhere near a hospital (Rosen 2003, pg. 92).

‘The myth that there is a linear relation between deinstitutionalisation and the homeless mentally ill population was dispelled in a five-year follow up of schizophrenia in homeless men.’¹⁶ Rosen also argues that studies have shown that community treatment can stabilise homeless mentally ill individuals including those who would otherwise have been imprisoned or repeatedly arrested.

7. Conclusion

¹³ Gardner, J. “Mental Illness – Freedom and Treatment” *Law in Context* (2000) vol. 17 no.2 pp 1-27

¹⁴ Conroy, J and Bradley, V. *The Penhurst Longitudinal Study: A Report of Five Years Research and Analysis* (1985) Philadelphia: Temple University Developmental Disabilities Center

¹⁵ Alan Rosen, Liz Newton. Karen Barfoot, “Clinical Perspectives: Evidence based Community Alternatives to Institutional Psychiatric Care” *Medicine Today*, vol 4, no. 9 (September 2003), p. 92.

¹⁶ Teesson M and Buhrich N 1990 quoted in Alan Rosen, Liz Newton. Karen Barfoot, “Clinical Perspectives: Evidence based Community Alternatives to Institutional Psychiatric Care” *Medicine Today*, vol 4, no. 9 (September 2003), p. 92.

The above report has reiterated community living as the most appropriate model for mental health treatment. The history of deinstitutionalisation, both nationally and internationally have been significantly influential in determining the ways it is practiced. The Italian Trieste Model set up by Dr Franco Basaglia impacted the way which mental health treatment was viewed as it challenged substandard psychiatric systems and proved community based practices to be more effective for the lives of mentally ill patients. Similarly, both Leff et al's TAPS studies (1994 and 2000) further emphasized the Trieste Model by concluding that the lives of mental health patients were enhanced after being discharged into the community, and at low cost to health budget. After five years, they showed an increased satisfaction due to their freedom, autonomy and less restricted living conditions.

A number of Australian cases have also shown social support practices as the preferred option to dealing with mental health patients. Gerrands (2005) study on the effectiveness of deinstitutionalisation in Victoria between 1993 and 1998 has proven that it improves the well being of its patients while being cost effective at the same time. Hobbs (2000), Owen (1994), Jones and Marks (2000) and Chenoweth (2000) have all also concluded that the community play a detrimental role in improving the lives of these people, stating that active facilitation and participation increases the level of their skills, decision and choice making, community integration and quality of care.

Alan Rosen (2003) has proposed community alternatives such as recovery-oriented services, crisis intervention, family interventions, assertive community treatment, day and evening programs, vocational rehabilitation and individual placement and support schemes in order to improve the wellbeing of mental health patients.

The stigmatisation of people suffering mental health disorders is disappointing. Although medication and monitoring is required for SPMI patients, Adrian Kellers claim that community based initiatives would undersourced and of no help, contradict the facts. Rosen has explicitly outlined strategies for how these required services can be implemented in the community.

This report has shown that living in the community has proven to be the most appropriate, cost effective way to eliminate the alienation these vulnerable people experience everyday and allow them to live equally with the rest of the community.

Reference List

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Knapp, M. Beecham, J. McDaid, D. Matosevic, T. Smith, M. "The economic consequences of deinstitutionalisation of mental health services: lessons from a systematic review of European experience" *Health and Social Care in the Community* volume 19, no. 2 (March 2011) pp 113-125

Ravelli, D. P. "Deinstitutionalisation of mental health care in the Netherlands: towards and integrative approach" *International Journal of Integrated Care*, volume 6, no. 4 (March 2006)