

Equity and Social Justice Issues for Residents and Staff of Supported Residential Facilities.

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Abstract

This paper discusses issues that arose during a recently completed community based project that aimed to develop continence promotion strategies for people who have mental illness. We researched with people who had mental health issues residing in Supported Residential Facilities (SRF) and the managers of those facilities. The policy of de-institutionalisation for people with mental illness has assumed that people will have somewhere suitable to live in the community with an appropriate level of support. These assumptions have resulted in people with mental illness relying on low cost accommodation in SRFs or hostel type accommodation. In this paper, we reveal the social paradox that SRFs operate in because of their exclusion from major government funding programs and the expectation that, as private enterprises, they will operate for profit. At the same time, SRFs provide housing for some of our community's most vulnerable, disenfranchised and impoverished groups of people. Residents of SRFs have been largely hidden from the community and missing out on many services that other people with disabilities receive.

Keywords: Supported Residential Facility, mental health, challenging behaviours, housing, equity, social justice.

Introduction

Adequate housing is a basic human need and is, therefore, universally recognised as a fundamental human right. People living with mental illness, developmental disabilities, or both of these conditions, are among the poorest and most disadvantaged in our community (Buhrich et al, 2000; Zerwekh, 2000). Many have multiple and complex social and health needs, however they have few advocates (HSA, 1999).

This paper reveals the tensions between social justice, public health and housing opportunities which were revealed during a study that focused on researching with people with mental health issues who reside in Supported Residential Facilities (SRFs) and the managers of those facilities. SRFs provide hostel type accommodation that is similar to boarding houses but with some direct personal care provided to residents. The title of the study was: *Development of a collaborative model of care for long term management of incontinence for people living in the community with mental illness.* Primary health care principles guided this inquiry which were (1) equity, (2) social justice, (3) health promotion and (4) working *with* people in the development of their communities (Koch and Kralik, 2001).

In the effort to embrace the primary health care principle 'working *with* people' we researched *with* three key groups: residents, managers of SRFs and

community mental health workers. The findings from the project have been a motivator for some improvements in the health status of residents. As researchers and health workers, we were challenged by the complexity of the issues that surrounded residents and looked toward primary health care principles to guide a quest for reform. In this paper we share our concerns about the plight of residents and explore the role of SRF managers and staff to show that equity and social justice issues impact on all players.

The complete report and the information resource developed for this project can be accessed on www.rdns.net.au or by contacting the authors. Ethics approval was obtained and the names used in this paper are pseudonyms.

Background

This project responded to an issue identified in the practices of community mental health workers who were working with people living with mental illness in Supported Residential Facilities (SRFs). It had been identified that urinary and faecal incontinence was common for this group of people.

The research team consisted of the three authors and a Continence Nurse Advisor who was recruited to the project. This research was undertaken over a 12 month period during 2001/2002 and involved collaborating with a group of community dwelling people with mental illness, the managers and staff of SRFs and community mental health workers all from the Western suburbs of Adelaide in South Australia.

The aim of the research was to develop continence promotion strategies that would have meaning in the lives of people with mental illness and could be implemented in the environments in which they lived so this was the focus of group conversations. The group conversations were audio taped and transcribed verbatim. Analysis occurred following each meeting and was distributed to the participants for further discussion, therefore providing a feedback loop.

Supported Residential Facilities

It had previously been recognised that a significant obstacle in the lives of people living in the community with mental illness has been obtaining affordable and secure accommodation.

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Access to appropriate accommodation is regarded by many as the most important determinant in the success or failure of people with chronic mental illness living in the community.

(Burdekin, 1993: 337)

The policy of de-institutionalisation the integration of people with mental illness into the community has assumed that people will have somewhere suitable to live in the community with an appropriate level of support. In addition, the money saved from de-institutionalisation of people has not been channelled back into community care (Robinson, 2003). Many psychiatric hospitals have closed but the number of people requiring twenty-four hour care in appropriate supported accommodation has risen significantly. There are many people with long-term mental illness, aged from 40 and 50, requiring some level of support to help them retain tenancies in Public Housing or to survive in rooming houses. They are not eligible for residential Aged Care or for Community Aged-Care Packages because their disabilities such as mental illness are not age-related (Koch et al, 2002).

While this paper has focused on residents of SRFs in one geographic area, we contend it can be situated in a broader international context, adding to a growing body of work in this area. Taking an international perspective, several authors have revealed that unavailability of adequate, low cost

housing for people with mental illness to be a similar issue across America, United Kingdom and parts of Europe (Cohen, 1994). Short term initiatives have been attempted in many countries that are invariably hampered by a lack of coordination between charities and quasi-governmental agencies (Garety and Toms, 1990; Hollingsworth, 1992; Dear and Wolch, 1999; Dowding and King, 2000; Robinson, 2003).

In South Australia, the local council holds the responsibility for administering the licensing of Supported Residential Facilities located within the council boundaries and ensuring that these premises meet a set of required, but elementary, standards. According to council regulations, a Supported Residential Facility (SRF) is one where a person or organisation provides a 'personal care service' to two or more persons who are not immediate family. SRFs are not boarding houses or hostels, but are shared accommodation with all meals provided, and basic assistance with care, management of medication, and management of personal finances, health and hygiene for people who are disabled by age and/or health conditions. The residents' level of physical and/or mental health, as well as their low average income, limits their ability to live independently in the community. The reality is however, that SRF accommodation can be substandard or inappropriate for people with mental illness, with little or no opportunity for privacy, occupational therapy or co-ordinated activity (Koch et al, 2002).

SRFs in South Australia have diverse origins. Many started in the 1970s as special mental health hostels when the intention of the South Australian Health Commission was to establish mental health hostels that were to serve the psychiatric outpatient sector. At that time, there was a sub department of the Health Commission that provided psychiatric and social welfare services to residents of mental health hostels. This department no longer exists, and the SRF Act has arrogated what were formerly mental health hostels. It was expected that these privately owned mental health hostels would be operated for profit and therefore not require government support. An undated report from The Supported Residential Facilities Association of South Australia suggests that the 'for profit' label has doggedly pursued SRFs for decades without

any authority showing that it was possible to operate in the residents' best interests and also 'for profit'. The fact that SRFs are labelled 'for profit' and therefore receive no government funding for their residents, seems to have been stamped into the 'folklore' of the South Australian health and welfare system.

Burdekin's (1993) comprehensive report of the National Inquiry into the Human Rights of People with Psychiatric Illness described the living conditions in many of the supported residential care facilities as disgraceful and completely unacceptable for people with disabilities. Although small gains have been made to improve living conditions for people living in the community with mental illness, there remain many issues unaddressed and unresolved. This situation is made more complex by the lack of uniformity of SRF legislation across Australian States and Territories.

Generally, most SRFs are operated by caring people who are attempting to provide an adequate standard of housing to a vulnerable and disadvantaged group of people. However, the living conditions in some SRFs are depressing, depersonalising and dehumanising. The décor is dark and decoration sparse. For some residents, there is little or no opportunity for privacy or personal space because they share bedrooms, have little control over their lives and few responsibilities. In some SRFs, residents have little choice with whom they shared their bedroom.

Reform however appears frustratingly slow. A decade following the release of Burdekin's controversial report, the responsible government bodies continue to be challenged by the complex issues surrounding people with mental health issues living in SRFs. A document recently released by the government (Department of Human Services, 2003) reported that:

... three boarding houses in Adelaide were facing closure by the State Government following a damning report into the official neglect of 1500 mentally ill South Australians. The Department of Human Services has found government agencies have left privately owned supported residential facilities to provide care 'which fails to meet current policy and standards'.

The Residents of SRFs

In this study, the residents of SRFs in the western Adelaide suburbs came from diverse backgrounds with varying degrees of acuity and need for daily support. The age of residents in SRFs was also diverse, ranging from people in their early twenties to older residents. They included people with complex medical co-morbidities, mental illness, intellectual disability, current or past drug and alcohol dependence, and brain injury. Some of the older residents had physical and mental difficulties and exhibited challenging behaviours. Nearly all residents were socially and economically disadvantaged. Many of those living with mental illness, had experienced difficulties associated with their illness for many years and lived with enduring disability. Mental illness may be episodic and involve times of stability as well as periods of relapse. Often, residents were ageing and as a result were progressively more physically, socially and emotionally disabled over time. Although care needs escalated, placement in a higher level of care facility was difficult due to lack of availability of nursing home beds.

There was no complete list or profile of residents of SRFs at the time this project was undertaken so the level of actual care provision was unable to be determined. However, it was clear that many residents with mental illness and drug and alcohol related problems provided profound and complex challenges to care. Short-term memory problems and disordered thinking often resulted in the individual requiring close monitoring and demanding creative approaches to care. Compounding these care challenges were socially difficult behaviours which, within a congregate care setting created significant problems.

Most SRF residents were paid some type of government pension or allowance and this was their sole source of income. People with long term mental illness often live in poverty, some have difficulty managing their money and therefore are vulnerable to being economically exploited (Burdekin, 1993). Their pension or government allowance paid for the accommodation, food and supervision with medication and personal care provided by the SRF. The little money that was left over after paying rent was usually allocated to the resident by the staff of the SRF on a daily basis.

Experiencing incontinence was just another of the complications of living in a SRF. For some residents, being incontinent meant finding accommodation that 'allowed' the inability to control one's bowel or bladder, as George described:

I got kicked out [of the SRF] because I wet the bed too much. I was wasting their money. I moved out of the next place too because of bed wetting. Now I'm happy because my current place... understand and help. They don't yell at me. The other places took cigarettes from me for wetting the bed. Here I get clean sheets and blankets ... I've got a continental quilt covered in plastic.

Whilst George had access to clean linen changes within his SRF; this was not so for Jack who was forced to remain soiled and wet for days, he reported:

Our place has locked up the linen cupboards. We used to be able to change our beds when we wanted to. We can't even get a towel to have a shower without asking a staff member. New management did this.

Although most residents were interested in eating healthily, this was not always possible. On the topic of eating a healthy diet, one resident said:

It's not always cooked properly. Potatoes you can't cut through them – not very appetizing.

Another was told by a manager:

If you don't like it [the food] then move out.

Stories of being neglected abound within the SRF setting, but, before we proceed, we should listen to the perspectives of staff and the managers.

The Perspective of Managers and Staff of SRFs

The research team all sought to understand the perspective of the managers and staff and arranged five group meetings. Managers and staff from eighteen SRFs were approached and provided information for this project.

Supported Residential Facilities are private businesses, hence profit was one motivation for managers and owners. One manager who was a Registered Nurse confided:

My daughter says I'm mad... she visited once with her small children but feels they are too young to be exposed to this type of environment.

Another manager suggested:

It's certainly not for the money

Some managers and staff appeared to have a wider social conscience beyond the need to make a profit.

I was determined to set up a home environment where residents could feel cared for and valued.

When asked what her motivation for working in the SRF was, one Manager responded:

I have no idea... my husband said 'buy this business... you'll only have to drop in a couple of times a week'... I'm here every day! I had to come in over the weekend recently because staff were sick and I had to do the cooking. I hate cooking!

Another manager said:

People ask me how I can do this sort of work... I've learnt not to judge people... when you see these people in the street you can get a very different impression from what they are really like... they are really quite nice people, although some can be awful.

One manager had lived in the SRF since childhood because his father owned the premises. He recalled that he would not bring friends home from school with him because others in the community had labelled it as 'The Mad House'. He added:

It's demanding... it's taken a toll on my private life. I'm 38 and not married. I had a girlfriend who lived here with me but it didn't last.

In addition to assisting residents with activities of daily living such as showering and dressing, staff of SRFs dealt with requests for personal assistance and the general organising of residents' daily lives such as making medical appointments, ensuring residents attended the appointments, communicating with relatives and government departments and providing emotional support. The nature of the mental illnesses endured by SRF residents often meant that significant staff time was engaged with negotiating everyday issues, resolving conflict between residents, managing behaviours (such as curbing a resident's demand for cigarettes from other residents or managing undesirable behavioural outbursts). Spending time in a SRF revealed a very busy, physically and emotionally demanding place to work. One manager said:

It is problem solving from morning to night!

Activities at SRFs

When visiting SRFs, we were struck by the inactivity of residents. Mostly, residents sat listlessly, inside or outside the SRF, smoking or sometimes watching television. Some residents walked to the local shops or around the district, others assisted preparing the meals in the kitchen. Generally, however, there was little recreational activity and minimal stimulation within the SRF environment. There were some outside community programmes, but these were not well attended or were attended by only a few. One manager reported:

...Only about three [residents] go to [the community programme].... most don't want to go... we had a music day but nobody came... they only want to smoke and drink coffee.

Managers tended to blame residents for their lack of initiative to become involved in activities. At the same time, SRF staff contended that there was little time to organise or supervise meaningful activities within the facility. Several residents who participated in this project revealed they did so because it gave them 'something to do'. Boredom was clearly part of life in an SRF.

Community Health Support

Community health support for residents was accessed from the community mental health services, the community health centre, the community nursing service and general practitioners. The local public hospital provided acute care services. The physical health of residents was neglected. We found during the project that several residents had untreated and uninvestigated symptoms of diabetes, pleural effusion and urethral stricture. Coghlan et al (2001) uncovered a scandalous neglect of the physical health of people with mental illness, revealing that people who use mental health services have a life expectancy in their 50s. Their death rate is twice as high as the rest of the Australian population.

Some residents had their own general practitioner (GP). However, it was not uncommon for one GP to service most of the residents of a single SRF, resulting in little or no choice of doctor. Some health providers can be prejudiced against people with mental illness because of difficult behaviours (Coghlan et al, 2001), thereby creating barriers to treatment for physical illness. One GP visited the SRFs fortnightly, reviewing participants, prescribing medication and ordering tests as required. Services for other health issues, such as dental services, seemed non-existent or unavailable due to extreme demand and excessively long waiting lists. Acute and chronic dental problems were obvious among many residents, causing constant pain and restrictions to dietary choices. The consumption of fresh fruit and vegetables was often prevented by dental problems.

Despite the network of community health support, managers expressed frustration that community services were inadequate:

They don't come when you call them...Most are bloody useless.

Several managers were concerned that mental health workers were only allocated to residents who were in crisis with their mental illness and other residents who would have benefited from the co-ordinated care of a community Mental Health Worker were unable to access one. The inadequacy of social supports available to people with mental illness was emphasised by Bachrach (1996: 235):

[People] require more than a mere residential assignment to overcome their disabilities and to cope with their problems in living; they also need an array of other services ranging from psychiatric and medical care, counselling and rehabilitative interventions to case management, social support, recreational opportunities and financial planning.

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Case Study: how do SRF managers manage incontinence?

In this section, we provide a case study showing the way in which SRF managers view their residents and some of the issues confronting them on a daily basis. Management of incontinence was the focus of the conversations, however several issues were highlighted:

The high cost of incontinence

The cost associated with incontinence was a major issue for managers of SRFs. Incontinence was not tolerated because it added to the already stretched budget and to the overall cost of caring for an individual, as the managers explained:

The cost issue also includes laundering – we wash clothes in-house but not sheets... there are the costs of electricity, labour, cleaning products et cetera.

We had one gentleman who would wet the bed every night and the pillows as well – you have to throw them away which is another additional cost. You can put plastic around the pillow but it's hard to find ones that last long without cracking.

The high level of caffeine intake among residents was identified as a significant issue, particularly from coffee or coke. Managers perceived that residents often had an excessive intake of caffeine because it helped them through the feeling of 'being in a cloud' that can be a side effect of their medications. Many residents only had a small amount of money so they did not feel that aids such as incontinence pads and urinals were among their priority purchases. As one manager explained:

Some residents are happy to spend their money on coke, coffee and cigarettes but are not so good at buying incontinent pads.

When does incontinence become a problem?

Managers were asked by the researchers 'who determines incontinence as a problem and when does it become a problem?' The response was that incontinence was deemed to be a problem when other residents were affected by it, when the individual was not attending to personal hygiene, or when incontinence was causing significant cost.

The issue of diversity of residents

Residents required varying levels of care within SRFs and the different reasons for residents experiencing incontinence were raised for discussion. Managers perceived that the reasons for incontinence ranged from the progression of dementia or other physical disabilities, to those who seem to lack the motivation to be continent. Managers perceived that for many people living with mental illness, that incontinence was behavioural.

Perceived lack of support

Managers contended that medical officers were uninterested in incontinence and generally did not perceive it to be an issue for them. Managers and staff of SRFs consequently felt they had little support when dealing with an incontinent resident.

Doctors do not see incontinence as a medical concern other than the writing out of prescriptions for antibiotics when a urinary tract infection is present. Medicos generally are not interested in managing incontinence.

There existed a reliance on the use of pads to contain urine from the perspective of SRF

Managers. The expense of pads however often precluded the use for some participants.

Inadequate levels of training in among managers and staff of SRFs

The responses from staff to incontinence suggested that health promotion has not been on the agenda in SRFs. Indeed most workers in this setting were not prepared educationally nor did they have the resources to implement health promotion strategies. Whilst several managers were Registered Nurses and, on a few occasions, enrolled nurses or qualified carers, most staff had no formal qualifications other than a first aid certificate and preparedness to work in SRFs. Very few staff had undertaken formal mental health training. In several SRFs, family members of the owner were the care providers. One manager suggested life skills were more important than formal qualifications:

I think that if you have raised children, you can do this sort of work because they are just like children.

In this way, infantilising residents was a strategy they used to make their lack of training appear less of a drawback.

Given that SRFs were required to provide only the basic needs such as accommodation, food and limited personal care, these levels of qualification might appear appropriate. The reality however, was that when the complexity of needs and behaviours of some of the residents of SRFs were considered, there was an urgent need for a structured and ongoing education program to support both staff and residents. Lack of education was an equity issue.

Incontinence as both a personal and political concern

Incontinence was personal for the individual living with it, but political because managers contended that the SRFs support some residents who require a higher level of care, such as a hostel but are unable (or unwilling) to move into the needed level of care. A current nursing home bed shortage has affected the levels of care available. The managers felt that if residents had existing accommodation in a SRF, it was perceived that there was not the

urgency to locate higher care accommodation for them.

With my particular gentleman, what if I can't look after him anymore because of the cost of pads and management – would he go to a nursing home? This would be a lot more expensive. He probably wouldn't be approved for a nursing home.

In SRFs, staff resources were not available to encourage continence promotion. For example, if residents were incontinent overnight, clean bed linen would not be available. SRFs generally only have passive caretakers sleeping on the premises over night, so outside of an emergency, assistance with activity or personal needs during the night was not available. In several SRFs, the proprietor's son was the overnight caretaker.

SRFs do not provide hostel or nursing home level of care. Managers revealed that one of the current issues when a Continence Nurse Advisor or community nurse reviewed a resident that often the strategies recommended were beyond the means of the staff of the SRF. Strategies such as regular toileting are considered a nursing home level of care, not the level of care provided in a SRF. It was important that the strategies to manage incontinent residents that were developed from this project could be implemented with minimal staff intervention because essentially there were few staff at SRFs able to implement them.

Discussion

Gathering the perspectives from the residents and managers of SRFs revealed that both parties were disadvantaged in terms of equity and social justice. The dependency of residents on SRF managers and staff can result in a relatively basic level of care and leaves residents open to the possibility of exploitation or harm. Provision of shelter is not enough. There was an absence of external support, relationships, planning and services for this group of people and their carers and although this dilemma were well recognised and documented by Burdekin (1993) more than a decade ago, little appears to have changed.

SRF managers were unable to offer support to residents that extended beyond the most basic of services that meet minimal human requirements. Often managers were forced to take on advocacy and *de facto* case management roles because government agencies and health care professionals had not addressed the basic needs of residents. Residents were mainly dependent on their supported residential facility to provide for their needs. In some instances, residents were totally dependent on the facility for all aspects of their care and daily life needs. Managers acted on their behalf and in most cases protected their interests.

SRFs are excluded from major government funding programs and are expected as private enterprises, to operate for profit. At the same time SRFs provide housing for some of our community's most vulnerable, disenfranchised and impoverished groups of people (Burdekin, 1993). Residents are largely hidden from the community and missing out on many services that other people with disabilities receive (Coghlan et al, 2001). The fragmentation of the public health system and limited access to appropriate level of care are barriers to people with mental illness obtaining treatment for physical illness (Coghlan et al, 2001; Koch et al, 2002). We contend that these are major social justice and equity issues.

In South Australia, residents of SRFs have largely been a hidden group in relation to service policy, planning and delivery. A system or sub-institution has developed where privately owned facilities are providing accommodation and care for people who had been moved into the community from psychiatric institutions. This model does not reflect contemporary approaches to the accommodation and care of people with disabilities and mental illness. In terms of social justice there exists a glaring absence of a comprehensive response to providing health care and disability support services. Herrman and Neil (1996: 254) called for a sustainable and coordinated response to adequate housing and community services for people with mental illness when they proposed that:

....the problems are compounded for people with a mental illness by the fact that government and community groups have never fully resolved the question of who has the ultimate responsibility for the accommodation of people with special needs.

More than a decade after Burdekin's (1993) damning report, we call for the development of a coordinated reform program (involving non-government organizations), to produce a range of options, which include sustainable new models to replace or support the services provided by SRFs. In addition, funding for Aged-care Facilities designed specifically for formerly homeless people with mental illness, intellectual disability or alcohol-related brain damage, and the provision of mental health Community Care Packages with an outreach component that would facilitate greater integration into the community.

Conclusion

Clearly, an integrated, well-resourced community mental health service as a promise of de-institutionalisation has not been realised. Whilst dealing with incontinence drew participants into this study, it was obvious that, beyond their needs for support in this area, this group of people were extremely disadvantaged socially, economically, and in the wider health arena. Many of the residents of SRFs are the disenfranchised of society. Residents lived with complex mental and physical health issues that were not adequately assessed or managed, and consequently, untrained SRF staff were left with the burden of addressing the complex needs of residents.

Following completion of this study, our response, driven by primary health care principles, was to initiate meetings with key stakeholders (services currently involved with this client group) to design, implement and evaluate an alternative model of health care delivery for the SRF population. These meetings continue in the effort toward developing a collaborative model of care for long term coordinated care for residents of SRFs.

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Acknowledgments

The authors thank the men and women who participated in the project and the members of the project team. The project was funded by the Australian National Continence Management Strategy, Commonwealth Department of Health and Ageing.

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