



From Psychiatric Hospital to Supported Housing

The Neami Community Housing Program,
Melbourne, Australia, 1995–2008

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INSTITUTE
FOR SOCIAL
RESEARCH

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Cover

Country Homestead, by Anthony Dowling
Acrylic on paper, 2006 (60 x 42 cm)
Courtesy of the artist and Neami Splash Art Studio

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Introduction

In 1995, a small non-government organisation called Neami was funded to provide housing and support for 30 former long-stay patients from a local psychiatric institution in Melbourne.¹ Aged between early 20s and early 50s and diagnosed with schizophrenia or related conditions, the patients had been assessed by clinical staff as being unable to cope in the community without intensive support. As the institution in which they had been inpatients was closing, new forms of supported housing had to be found. Thirteen years later, many of the people discharged in 1995 remain in the housing provided through this program.

The aim of this paper is to document the experience of the Neami Community Housing Program. The paper recounts how the program came about, describes the model it employs, and considers how its practice has changed over time. It then examines outcomes for clients at one year and twelve years after leaving hospital, and considers some implications for practice. The paper concludes by identifying characteristics of the Neami Community Housing Program model that have been critical to its success.

1 Background: the evidence on housing and support

A number of studies have considered the effectiveness of programs providing support for people living with disabilities associated with mental illness. However, it is difficult to make a critical reading of this research. Studies have examined programs that work with different client groups, offer different arrangements for housing, and provide differing arrangements for and levels of clinical and non-clinical support. The models considered may not be described clearly or named consistently in research reports, so comparing findings across studies is difficult (Arthurson and Worland 2007; Meehan et al. 2007).

Models of housing and support can be located on a continuum between *custodial housing*, in which clients live in quasi-institutional settings with high levels of control by staff, and *supported housing*, in which clients live alone or with others of their choosing, support is provided on an outreach basis, support varies as client needs

¹ The name 'Neami' originated as an acronym for North Eastern Alliance for the Mentally Ill. The organisation has been known as Neami since 1998.

change, and clients' entitlement to tenure continues in the long term irrespective of their support needs. *Supportive housing* sits between the *custodial* and *supported* housing models, providing self-contained accommodation in high-density settings with 24-hour on-site staffing (Gordon 2008). Examination of research across these models shows that programs that offer stable, affordable and long-term housing, relevant supports and risk management strategies, and some choice about where and with whom residents can live, can effectively sustain people with psychiatric disability in the community (Arthurson and Worland 2007).

The Neami Community Housing Program is one of several programs established in Australia to provide support through a supported housing model to people discharged from psychiatric hospitals. Those established in the 1990s include the Housing and Support Program (HASP) in Victoria, the Independent Living Program (ILP) in WA, and Project 300 in Queensland (Robson 1995; Smith and Williams 2007; Meehan et al. 2007). These were followed in 2003 by the Housing and Support Initiative (HASI) in NSW, and the Returning Home Program in SA in 2005 (Muir et al. 2007; Central Northern Adelaide Health Service 2006).

An evaluation of HASP in Victoria conducted in 1994-95 found that the program had been successful in enabling high-need clients to sustain tenancies in public housing (Robson 1995). Although agencies funded under HASP continue to report good outcomes, the program has not been evaluated since 1995. The WA Department of Housing has reported positive outcomes for clients supported through the ILP, although details have not been published (Smith and Williams 2007). The SA Department of Health is conducting a longitudinal evaluation of outcomes from the Returning Home Program.

The HASI and Project 300 programs have been the subject of substantial longitudinal evaluations. These evaluations used quantitative methods, taking outcomes such as hospitalisation rates and clinical measures as indicators of success. Findings show that although clients experienced no significant change in levels of clinical symptoms or degree of disability associated with mental illness, most succeeded in retaining their tenancies, and the number and duration of hospital admissions declined substantially (Meehan et al. 2007; Muir et al. 2007).

Program evaluations have rarely considered outcomes for clients through using qualitative methods that place clients' accounts of their own experience at the centre of concern. The study on which this paper is based is an exception. It uses qualitative methods to examine outcomes over twelve years for clients supported by the Neami Community Housing Program, and early outcomes for clients supported through the Returning Home Program in SA.² The present paper draws on data from clients in Victoria.³

2 The present study

Twenty-eight clients entered the Neami Community Housing Program in 1995, and of these, in 2007 fourteen remained in contact with Neami. All were invited to participate in the research, and eleven agreed. The author conducted face-to-face interviews with each client, asking open-ended questions that invited them to give an account in their own terms of their experience of being in hospital, leaving hospital and living in the community. Most interviews took place in clients' homes. With clients' consent, I interviewed their Neami support worker and sought information in writing from their clinical case manager and members of their family (not all clients consented to contact with clinical workers or family). Interviews were audio recorded (with two exceptions) and transcribed verbatim. Transcripts and survey responses, along with ethnographic notes made shortly after interviews, were coded according to themes and collated as case studies providing a variety of perspectives on the experience of each client.

In studies examining interactions in families, sociologists have used methods that engage multiple perspectives to look at a particular situation. These methods are useful for eliciting and understanding accounts from family members whose voices are likely to be overlooked in research that collects only a singular account of the family (Ribbens McCarthy et al. 2003; Carter 2004, 2006). They are particularly relevant to the present study, which is interested in the experience of people who because of their disabilities are more vulnerable than most to having their

² This is an Australian Research Council Linkage Project conducted by the Institute for Social Research at Swinburne University of Technology, with industry partners Neami and Supported Housing Limited. Additional funding was provided by the South Australian Department of Health. Chief investigators are Professor Terry Burke and Professor Sue Moore. The study received ethics approval from the Swinburne Human Research Ethics Committee, Austin Health Human Research Ethics Committee and Melbourne Health Research and Ethics Committee.

³ Outcomes for clients supported in SA are presented in the companion paper by Carter et al. (2008).

perspectives overlooked. Methods that use data from multiple perspectives provide an opportunity to place clients' views at the centre of concern, and take the views of workers and family members as an aid to interpretation of accounts created by clients.

In this study, client interviews were constructed as conversations, using open-ended questions without administration of clinical tests or measures. Similarly, interviews with workers and family members were designed to elicit accounts from respondents' perspectives of the client's experience of housing and support, and the respondents' experience of providing support to that client. In the cluster of stories around each client, we can see where the various accounts of the client's experience are consistent and where they differ.

Interviews with support workers included one clinical instrument completed in respect of the client: the Life Skills Profile (LSP) (Rosen et al. 1989, 2006).⁴ Scores against this instrument were available for nine of the eleven clients interviewed. Baseline data (collected in 1995, at or around the time of deinstitutionalisation) was available for five of these nine clients (total score only).

Clients interviewed in Victoria are among those for whom the program has worked well. From accounts of their experience we can identify the characteristics of housing and support provided through the program that enabled them to retain their tenancies and live independently in the twelve years since leaving hospital. The present paper draws on the eleven clusters of client interviews, supplemented by

⁴ The Life Skills Profile is a 39-item forced choice questionnaire about five areas (self-care, turbulence or anti-social behaviour, social contact, communication skill and responsibility). Neami workers completed the profiles on behalf of the clients, with their permission. For each of the 39 statements, case workers rated their client on a four-point scale ranging from 1 in which little difficulty with the skill is present or low/no levels of the anti-social behaviour are evident, to 4 in which there are extreme difficulties evident with the skill or high levels of the anti-social behaviour. Example items include *Is it generally difficult to understand this person because of the way he or she speaks (e.g. jumbled, garbled or disordered)? (Not at all difficult, slightly difficult, moderately difficult, extremely difficult)*, and *Is this person generally angry or prickly toward others? (Not angry at all, slightly angry, moderately angry, extremely angry)*. Item ratings are added to form a total score in which higher scores represent higher levels of disability. Scores can range from 39 to 156. Comparison with other studies and normative data requires caution as a range of scoring methods and versions of the LSP have been used, including scoring in the opposite direction (high scores representing lower disability), scoring 0-3 rather than 1-4 per item, using shortened versions (LSP-16 and LSP-20), and alternative names for the subscales (Rosen et al. 2006).

interviews with people who were involved in establishing the Neami Community Housing Program and have shaped its practice and development since then.⁵

3 How the Neami Community Housing Program happened and what it is

During the 1990s, reform of mental health services happened more quickly and more completely in Victoria than in other states, and by the end of that decade all stand-alone psychiatric hospitals had closed or were in the process of closing. In 1991 Victoria secured Commonwealth funding to support construction of new clinical facilities to replace the North Eastern Metropolitan Psychiatric Services (NEMPS) inpatient facility, located in the north-eastern suburbs of Melbourne, which made up one third of the state's psychiatric inpatient beds. Alternative services in the form of psychogeriatric nursing homes, acute-care beds in general hospitals and medium-stay beds in Community Care Units, and mobile community mental health teams were established and operating before the institutions were closed (Gerrand 2005).

A limited range of services was available to meet the need for housing and support for people with disabilities associated with mental illness. The Group Home Program provided long-term accommodation and disability support for people whose support needs were moderate, and the Residential Rehabilitation Program provided short-term and transitional accommodation linked with participation in rehabilitation programs for those whose support needs were greater. Some clinical services leased properties through the private rental market and managed these as 'treatment units' in which patients could learn skills required for domestic living. Several non-government organisations were funded to provide psychiatric disability support (later known as Psychiatric Disability Rehabilitation Support, or PDRS), in the form of home-based outreach and activity-based day programs, to individuals receiving clinical care outside the hospital system.

Closure of institutions put pressure on public housing by increasing demand for properties and increasing the number of tenants with high support needs. In 1992 the Housing and Support Program (HASP) was established to provide psychiatric

⁵ Key informants regarding the Program's establishment and history are Arthur Papakotsias (Chief Executive Officer, Neami), Glen Tobias (Victorian State Manager, Neami) and Joseph Connellan (Director, MC Two Human Services, formerly Chief Executive Officer, Supported Housing Limited).

disability support to public housing tenants. In contrast to the Residential Rehabilitation and Group Home programs, in which the agency that provided disability support was also landlord, under HASP, tenancy management and disability support were provided through separate agencies (Robson 1995).

Neami had been established in 1986 to address the housing needs of people leaving hospital by providing secure and affordable housing linked with psychiatric disability support. By the early 1990s it managed 20 properties, of which some were funded through the Group Housing Program, some through HASP, and some transferred from clinical services. Neami provided home-based outreach support to tenants and delivered a variety of day programs.

The Neami Community Housing Program came about as a result of entrepreneurship on the part of Neami. In 1994 the Victorian Office of Housing called for applications for funding under the Community Housing Program, an initiative established under the Commonwealth State Housing Agreement to develop the capacity of the community housing sector. Although this funding was identified specifically as ‘not for deinstitutionalisation’, Neami approached the Office of Housing to see whether an application might be considered if Neami was able to access funding through another avenue to provide support services to tenants (Papakotsias 2007). Neami then approached NEMPS with a proposal whereby patients affected by its institutional closure could be housed in properties obtained by Neami, if NEMPS was able to provide funding for Neami to provide psychiatric disability support. Neami’s proposal was viewed favorably by both parties, and the Neami Community Housing Program was established with funding from the Office of Housing of \$1.7 million for purchase of properties, and a commitment from NEMPS to provide both clinical support and ongoing funding for psychiatric disability support for 30 long-stay inpatients.

In order to separate the functions of tenancy management and disability support, Neami entered into an arrangement with a community housing agency, the Supported Housing Development Foundation (later known as Supported Housing Limited, or SHL).⁶ Neami transferred the \$1.7 million from the Office of Housing to SHL which used it to purchase three three-bedroom, seven two-bedroom and seven one-bedroom properties. This funding included no component for the cost of

⁶ Supported Housing Limited now operates as Housing Choices Australia, <<http://www.shl.org.au>>.

property management, maintenance or tenancy management, all of which was to be covered from revenue collected as rent.

Clinical staff from the psychiatric hospitals from which patients were discharged were nominated to 'follow' the thirty patients, forming community-based Mobile Support and Treatment Service. Funding for psychiatric disability support through Neami came from NEMPS' budget for clinical services. The decision by NEMPS to use its clinical services budget in this way was controversial among clinical staff, and the Neami Community Housing Program was established in an environment of industrial unrest.

A working group of staff from NEMPS and Neami oversaw initial implementation of the program, hosting forums for hospital staff, prospective tenants, and their families and carers, to inform them of the opportunities it offered. Potential tenants were identified by NEMPS from patients who were considered to require high levels of disability support over the long term. The number of eligible patients identified was less than had been anticipated and, of a planned 30, 28 people were discharged with support under the program (Cox 1996).

Hospital staff and Neami staff had different views about which patients would be suitable:

We were constantly locking horns with the staff at the hospital. They wanted to give us the easy people and we wanted more difficult clients. They continued to tell us that we didn't understand how disabled these people were, and we continued to tell them that in fact the most disabled people were on the streets already. We wanted to push the envelope and risk having some failures so that we knew that we were getting this service to the people most in need. We had some pretty heated discussions at the time (Tobias 2007).

In its design, the Neami Community Housing Program grew out of the supported housing model established through HASP. Tenants leased properties directly from SHL, with standard conditions under the Residential Tenancies Act. Rent was set at 25 per cent of the Disability Support Pension, with automatic payment made through Centrepay. Tenure was ongoing and did not depend on engagement with a specific program of rehabilitation or other support. Adopting the view that clustered housing

creates ghettos, properties were purchased in locations dispersed throughout the north-eastern suburbs (this was in contrast to HASP, in which properties – although not those supported through Neami – were sometimes built or purchased in clusters). All properties were located within walking distance of shops and transport, offering easy access to community facilities.

Clients rented houses as furnished. Rent collected by SHL included a levy of \$5 per week that was passed to Neami to use for maintenance and replacement of furniture and fittings as needed. SHL played no part in selecting or vetting potential tenants, instead seeing their role as to ‘work with whoever Neami decide. It’s their responsibility to make the support work’ (Connellan 2007). It was intended that most clients would share housing, in groups of two and three. Clients would select housemates from a pool of possible candidates, interviewing and choosing the ones they would prefer according to what one informant described as ‘the Readings window model’.⁷

Because the number of potential tenants was less than expected, clients had little choice about with whom they would share. Many households experienced difficulties with sharing. Support workers invested significant time in mediating disputes between tenants, and a number of clients relocated to other properties managed by Neami. Over time, Neami moved towards a policy of having no more than two tenants per property, adopting this position formally in 2002.⁸

Support provided by Neami is ‘client-directed’. The worker’s role is to support client empowerment, encouraging clients to form goals then helping to break large goals into small, achievable steps (Wissman 2003). Each client has a primary worker (known as a ‘keyworker’), as well as contact with the whole team, so they can contact a familiar person if their primary worker not available.⁹ Support workers have contact with clients’ family members and other people where clients wish this. Support plans are developed in co-operation with clinical case managers. In the

⁷ Readings is a Melbourne bookshop whose windows have for decades been used as notice-boards by people seeking accommodation in share houses, and people seeking housemates to live in vacant rooms.

⁸ At May 2008 two Neami properties remain occupied by groups of three people. Each of these was formerly a Group Housing Program property, whose residents have shared together since 1993.

⁹ In Victoria the title ‘keyworker’ refers to a person employed by a PDRS agency to provide psycho-social rehabilitation support. Although it is widely used in Victoria, the term can be misleading. In South Australia ‘keyworker’ refers to a clinician working as a case manager in a community-based clinical service.

Neami Community Housing Program, early support plans focused on ‘activities of daily living’ such as shopping, cooking, cleaning and self-care, then moved on to activities in the community and other goals. The nature of support provided changed as the clients’ needs changed (Cox 1996).

During the 1990s Neami operated a range of day programs, including drop-in and informal groups at Neami offices, an art studio and various outdoor recreational activities. Since 2003 Neami has stepped back from offering programs on-site, as they were seen to create an artificial community that acted to maintain separation from mainstream activities. As part of this change, clients were encouraged to join activities held in other venues, facilitated either by Neami or by other agencies (Elmer and Ronnau 2003; VICSERV 2006). Neami continues to deliver programs in locations outside its offices, for example, a drop-in group at a local cafe and a knitting group at a neighbourhood house. Participation is not restricted to Neami clients, with the result that clients enjoy activities with people outside the Neami circle (Tobias 2007).

The practice of support work has become more formalised over time. In 2000 Neami adopted the clinical instrument BASIS-32, which asks clients to indicate the extent to which they have been experiencing difficulty in a variety of domains, as an indicator of client outcomes; and in 2001 adopted the Camberwell Assessment of Need as a framework for development of Individual Support Plans (Trauer and Tobias 2004; Helyer et al. 2007). Practice is informed by an explicit consumer rights policy and code of ethics, and workers are supported through regular supervision, as well as induction and training programs (Neami 2007). In addition to in-house training, staff have access to resources and training through the PDRS peak body VICSERV (VICSERV 2008).

The PDRS sector in Victoria works from an explicit focus on rehabilitation and recovery, and attracts workers with qualifications in a broad range of disciplines (Wissman 2003). An increasing professionalisation of the sector is reflected in the language used to describe the work. In the early 1990s funding referred to ‘psychiatric disability support’. By 2000 this had changed to ‘psychiatric disability and rehabilitation support’ (Clanchy and Clarke 2002; Mental Health Branch 2003). Materials produced by VICSERV and by the funding body describe the work as

‘psychosocial rehabilitation support’ (Wissman 2003; Mental Health Branch 2003), and Neami currently refers to its work as ‘psychosocial rehabilitation support’ or ‘psychosocial health and rehabilitation support’ (Neami 2008).

A claim to professional status for PDRS work is more explicit in Victoria than in other states, where non-clinical support for people with disabilities associated with mental illness is characterised as ‘disability support’ (Meehan et al. 2007) or ‘accommodation support’ (Muir et al. 2007) and is more likely to be delivered by agencies whose previous work had been with intellectual or physical disabilities.

SHL regard their contribution as a specialist agency as critical to the success of the Neami Community Housing Program. Their expertise enables them to ‘navigate the cultures’ between the sectors involved, securing appropriate housing stock and dealing with clients whose support needs are high:

There’s a fundamental difference in culture between housing and support people. We can actually speak both languages. In the housing world they think we’re hippies, and in the support world they think we’re hard-nosed bastards (Connellan 2007).)

This informant described the model implemented by Neami as ‘probably the purest interpretation of community living’ for this client group. It is ‘a true mimicking of the environment out there where people rent from a real estate agent. Typically, community housing models evolve into a more structured staff-based system, but that hasn’t happened in this case.’

4 Outcomes for clients after twelve months

An evaluation commissioned by Neami in 1996 found that, of the 28 clients discharged from NEMPS with support under the program in 1995, all but one (nineteen men and nine women) remained with Neami. Several clients had had brief hospital admissions after joining the program, but only one (for a client who left the program) was regarded as ‘significant’. Neami staff attributed the low number of re-admissions to the responsiveness of clinical support available to clients (Cox 1996).

Of the eighteen clients interviewed for the 1996 evaluation, most reported feeling that they had no choice about joining the Neami Community Housing Program. One said,

'I couldn't stay in the hospital, they're knocking it down'. Clients were clear about the different roles of Neami and of their clinical case managers; as one put it, 'One's got no medication and they're both there to help you'. Most said they were happy with support they received from Neami, and identified social contact as the most valued aspect of this.

Clients' views about the support they received from clinical services were mixed, with some expressing unhappiness with the 'policing' of medication, and especially with clinical workers' practice of arriving at homes unannounced. One client said, 'They just show up. They should make times to come. It's like you're still in hospital' (Cox 1996: 33). Nine of the eighteen clients interviewed attended Neami day programs. Some clients said they had been forced to attend programs in hospital, and chose to avoid them now they were free to do so. Sixteen of those interviewed reported being happy with their Neami workers.

The most commonly reported problems were to do with sharing. Of the eighteen clients interviewed, twelve were sharing and six lived alone. Clients identified the advantages of sharing as enjoying company, sharing chores and costs, and sharing pets. Disadvantages included disputes about housework, and co-residents having incompatible views about social or sexual activities. Clients said their support workers had tried to help with problems associated with sharing, but interventions were not always effective. Some clients were waiting for an opportunity to move out of houses they were sharing, while others were living alone and waiting for an opportunity to move to a share house. Several said they would have liked to have more choice about who to share with, and more time to decide.

Most clients said they were happy with their housing, and would like to stay where they are living now; two said they wished to move to be closer to family and friends. Two that they would like to share with a partner at some time in the future. Most said the experience of leaving hospital had been better or much better than expected: one said, 'It gets better and better' (Cox 1996: 38). Clients identified the best thing about having their own homes as 'freedom', being able to go to bed when you like, get up when you like, and smoke and drink at home if you choose to. When asked to identify the worst thing about having their own homes, clients identified flatmates or visitors. Most identified all changes as positive, although 'at times it's still hard'.

The three parents who took part in the evaluation reported having been apprehensive about their daughter or son being discharged from hospital, but all said they had been well informed about what the process would entail. Their current concerns were about what would happen if support was reduced, the possibility of inadequate responses from the clinical team if there was a crisis, and issues to do with co-tenants. All said they had seen their child increase in independence (one said, 'He's just blossomed'), and all expressed hope for this to continue. Parents said support provided through the program was significant in relieving pressure on their family.

The evaluation noted that tensions existed between Neami and the Mobile Support and Treatment teams, reflecting differences in philosophy and expectations about their work:

The clinical role is defined by the professional status of the worker and carries with it an authority acknowledged by the client group. The disability support workers [begin] from a different starting point. The authority for their role is vested in the relationships they form with tenants, [which have] an emphasis on consumer control and choices. This difference has been a key source of conflict between the two teams. Whilst the teams share a commitment to empowerment, there are different understandings of the balance between 'rights' and 'duty of care' (Cox 1996: 47).

Relationships between the teams had improved over the twelve months, but 'there remains a clear desire by the Mobile Support and Treatment Service that Neami support workers give greater weight to their clinical judgement' (Cox 1996: 48). Instances of disagreement centred around a view held by Mobile Support and Treatment Service staff that Neami workers should use 'stronger intervention' in relation to house cleaning, diet and personal hygiene. Neami workers felt that support should focus on areas which clients identified as a priority for them and, if clients did not identify these areas as a priority, 'stronger intervention' was appropriate only if the situation was placing their health and safety at risk. In spite of these differences, staff from both services said outcomes for the clients had exceeded their expectations.

5 Outcomes for clients after twelve years

Of the 28 clients who entered the Neami Community Housing Program in 1995, fourteen were still in contact with Neami in 2007 and ten continued to receive home-based outreach support. Twelve remained in housing purchased under the Community Housing Program (six in share houses and six living alone), one lived in a property leased from the Office of Housing and one in a Supported Residential Service (SRS).¹⁰ Of those living in Community Housing Program houses, nine continued to receive PDRS support from Neami, two declined such support and found it elsewhere, and one no longer required support. The client who was living in a SRS was there as a result of a physical injury and hoped to return to independent housing, and continued to receive Neami support. The client who lived in an Office of Housing property was no longer in need of PDRS support.

Of the fourteen clients who were no longer in contact with Neami, all but one had moved away from the local area. Five had moved to independent housing in other areas, and of these, three were receiving support from other PDRS agencies and two no longer required PDRS support. Two were living in SRSs. There was no information available about the remaining seven clients who had moved away from the area covered by Neami.

The eleven clients interviewed comprised seven men and four women, ranging in age from 30 to 60. Most were in their 40s and 50s. Nine were born in Australia and two overseas. Of the clients for whom information about education was available, two had tertiary or TAFE qualifications, one had completed year twelve, two had completed year ten, and four had less than year ten. All clients received a Disability Support Pension, and most had their finances managed through the State Trustee.

Of the clients interviewed, prior to entering the Neami Community Housing program three had been in a psychiatric hospital for between ten and 20 years, five had had multiple admissions over a period of seven to eighteen years, and three had shorter admissions over periods of between eight and thirteen months. Nine had been diagnosed with schizophrenia, and two with schizo-affective disorder. According to

¹⁰ Businesses that are licensed to provide board and a basic level of care in return for payment equal to a percentage of each resident's pension income are known in Victoria as Supported Residential Services.

reports from workers, five of the clients showed no evidence of experiencing positive symptoms associated with mental illness, while six experienced ongoing symptoms.¹¹

Life Skills Profile data for the nine clients for which it was available indicated relatively low levels of disability across the 39 areas assessed. Greater levels of disability were demonstrated on items 26 (capability of working), 39 (making and keeping friendships), 20 (keeping active), 22 (attending social organisations), 15 (not neglecting physical health) and 16 (maintenance of adequate diet). On these items, the scores reflected moderate problems on average. Social isolation and lack of activity were also noted as issues of concern in case notes.

The statistical means for some items indicated that the group had very little problem in several areas, including items 18 (adherence to medication), 28 (destruction of property), 29 (offensive behaviour), 32 (invasion of others' space), 34 (violence towards others) and 36 (trouble with police). Again, case material supported the notion of few problems with violence or anti-social behaviour. For the five participants for whom scores were available in 1995 and again in 2007, four had improved their total score on the LSP and one had deteriorated, a finding supported by case material which indicated health and self-care difficulties were quite high for this particular individual.

Table 1 shows the item means for the five subscales of the LSP. The means reflect few problems with turbulence (anti-social behaviour and aggression) or with responsibility (mostly concerning responsibility for medications). There are, however, mild to moderate problems in self-care and social contact; the latter subscale also showing greater variation across clients than the other scales for which scores are relatively homogeneous.

¹¹ The DSM IV diagnostic criteria for schizophrenia classify the experience of voices, delusions and psychosis as 'positive symptoms', withdrawal and depressed affect as 'negative symptoms', and disorganised thoughts and memory problems as 'cognitive symptoms'.
<http://www.psychiatryonline.com/referral.aspx?gclid=CNykm_uYspMCFSMYagodIxumog>

Table 1: 2007 LSP data for Victorian sample (N=9)

Subscales (item mean)	Mean	SD
Self-care ¹	2.12	0.59
Non-turbulence	1.31	0.34
Social contact	2.22	1.01
Communication	1.70	0.56
Responsibility	1.24	0.30

Note: ¹ Score range = 1-4; lower scores represent higher functioning

All clients interviewed were living in housing that had been arranged through Neami. Nine were living in properties that had been purchased with Community Housing Program funding, one lived in a property leased directly from the Victorian Office of Housing, and one lived in a SRS. Five participants lived in share accommodation. All properties were ground floor units, semi-detached or detached, in blocks of various size, mostly four or less, some six or eight; one property had three bedrooms, five had two bedrooms and two had one bedroom. A couple of properties were of 1960s vintage and were, to my observation when I visited for interviews, rather tatty in appearance. Most were built in the 1990s and in reasonable to good condition, and some were almost new.

Of the eleven clients interviewed, eight receive home-based outreach support from Neami. Two had workers visit weekly, three had visits every two to three weeks, and three had monthly visits. All had additional telephone contact with Neami as needed. Two clients had decided many years ago that they did not wish to have support from Neami, but continued to live in their SHL property and had dealings with Neami in relation to maintenance of furnishings and fire safety equipment. One client had recently exited the program as he no longer needed support.

All clients had regular contact with clinical services. Two received daily visits from the Mobile Support and Treatment Service and three were visited fortnightly or monthly. Three had medication supervised through their local Community Mental Health Centre, and three were prescribed medication by their GP. Some clients received additional support in the form of meals on wheels, home-help to assist with cleaning, and visiting and transport provided through voluntary agencies.

In interviews, all clients described a regular routine of activities. Only one had paid work, and this was part-time, in a sheltered setting. Some reported attending group

activities and outings run by Neami or other agencies, and some took part in activities and voluntary work organised through local church groups. Many clients identified visits to shops and cafes in their local area as a regular activity. Some spent time with family members, visiting daily, weekly, or for weekends or holidays. Involvement with activities outside the home was reported by workers, clients and family to be declining among older clients. Three clients reported that their most significant activity was watching television or movies at home alone.

6 Themes from clients' accounts of their experience

Themes that emerged across client stories can be grouped around eight areas: family and personal history, how clients made sense of their experience of mental illness, problems with physical health, views about housing, views about support, experience of community, activities and goals, and challenges for the future.

*** 6.1 Family**

Most clients receive support from family, either parents or siblings. Some have parents who live in aged care facilities, or who because of illness associated with ageing are giving up driving, or will soon be obliged to leave the family home and move into care. For these clients, relationships are changing from one in which the parent is carer to the child, to one in which the child has responsibilities as carer to the parent.

Few of the clients interviewed have partners, and none have dependent children. Those who are parents reported having little or no contact with their children or with their former partners. The three clients who currently have partners receive (and give) substantial support from them. Many who do not have partners said they would like to have one in the future. For one client, involvement in the local church community provided support described as being 'like family'. No client reported having close friends who provided family-like support.

Family members of four clients took part in the research. All said that providing support to their disabled child or sibling is costly in terms of time, money and emotional energy. Family members see Neami support as underpinning client wellbeing, making it possible for the family to offer support in ways that are within

their means emotionally and in terms of time. Some expressed concern at what they saw as Neami support being diminished or withdrawn, either by a decrease in the frequency of visits from the keyworker or as a result of drop-in facilities and group activities that had been previously offered by Neami having been discontinued. The loss of group activities, in particular, was seen as being detrimental to the client.

In interviews I heard two conflicting accounts of changes that had occurred in Neami's delivery of group activities, and how these had affected clients. Some family members, some clients and a few Neami workers reported that activities previously offered by Neami had been discontinued, with the result that some clients now stayed at home all day rather than going out. Other Neami staff reported that although 'drop-in' no longer happened at the Neami offices, delivery of group programs in alternative venues had the effect of enabling clients to extend their social circle. My impression is that for those clients who made the transition to participating in groups outside of Neami settings, the change worked well. Other clients, declining to participate in activities delivered in an unfamiliar environment, found their circle of contacts and range of activities contracted rather than expanded by the change.

More than the delivery of structured programs, family members valued the security provided by an ongoing relationship between the client and a support worker, and with the agency more broadly. If this support is withdrawn, one mother said, 'I feel I have to know everything'. Family members were anxious to be reassured that support for their disabled child or sibling would be 'there for life'.

Families differ in the extent to which they are able or willing to provide support. Some clients receive from their families practical and emotional support in the form of help with shopping, cooking, and cleaning, regular visits to family homes, regular and extended family holidays, and family members responding to crises that happen out of hours. Many families provided material support. Some parents who have provided substantial and regular support are becoming less able to do so as a result of their own disability associated with ageing; the loss of this support and the activity and structure it provides will be significant for these clients.

* **6.2 Experience of mental illness and strategies for dealing with it**

Clients varied also in their experience of mental illness. As reported by support workers, some appeared to experience no positive symptoms of schizophrenia, while most experienced some symptoms. Symptoms most commonly reported were anxiety accompanied by delusions that, although odd, did not appear to create distress for the client and operated as a strategy to contain or deflect anxiety. Some clients experienced significant and ongoing symptoms that generate fear and distress for them. Some were conspicuous in appearance, becoming vulnerable to intimidation from community members who choose to single out those weaker than themselves: for these clients to experience anxiety about being in public is reasonable. Only one client was reported to regularly engage in behaviour that would provoke other people.

Many clients described living with fear, whether in an extreme form as paranoia, or as less intense but pervasive anxiety. They adopted various strategies for dealing with these fears. Some used strategies of avoidance, such as isolation, restricting activity, avoiding going out, and avoiding places and activities associated with anxiety. One client reported self-medicating with alcohol or valium as strategies to make it possible to moderate anxiety enough to go out. Several clients reported using strategies of distraction – leaving on a radio or a television whenever they are alone – as a way of living with voices that were not suppressed by medication.

Where client interviews contained content that had been identified by workers as ‘delusional’, this appeared to function as an explanatory story that enabled the client to make sense of their experience and offer hope. For example, one described being plagued by voices telling her repeatedly that she is no good. She said she knows who the voices are, and is able to live with them because she knows that one day a man will appear who will marry her, they will have many children and then the voices will cease.

Several clients used combinations of strategies in order to moderate and live with their ongoing symptoms. One had restricted the scope of his activity to repeatedly viewing a single series of movies and holding the world created in those stories as his reality. For this man, confining daily experience within the familiar territory of a limited genre enabled him to create a space of sanctuary. Adopting and sustaining his delusion was an effective way of keeping anxiety at bay. Living in his own home, in

which this behaviour was not criticised, has made it possible for him to sustain this strategy over a long period. Although his idiosyncratic interpretation of reality makes communication difficult, this client, like others, enjoys an easy relationship with support workers. One cost of this strategy is that isolation and inactivity have led to poor health.

Strategies used by clients vary in sophistication, just as clients vary in intellectual capacity and resourcefulness. Clients differ also in the extent to which they identified as having a mental illness. Some explained that they are careful to take their medication in order to stay well. Others rejected their diagnosis and will take medication only when supervised. A few saw their experience of mental illness as being in the past, and no longer part of the story of who they are.

* **6.3 Physical health**

Most clients experienced health problems associated with the combined effects of poor nutrition, lack of exercise, smoking and long-term use of prescribed drugs. Most were overweight, some had diabetes and some had diagnosed heart conditions. Some clients experienced seizures or dizziness resulting in falls, and several suffered from urinary incontinence. All but one smoke tobacco, most of them heavily. Few reported drinking alcohol. One client described himself as drinking sixteen cans of beer daily, 'but I'm not an alcoholic or anything'. No client reported (or was described by their worker as) using illegal drugs.

Clients were perceived by workers as being older than their years. One worker said, 'For these people, 52 is like 62'. Describing the daily routine of another client, a worker said, 'It's like he's 80'. Workers expressed the view that for some clients it becomes harder, with age, to sustain strategies that enable them to cope with their symptoms enough to go out.

* **6.4 Housing**

With the exception of the client who was living in a Supported Residential Service, all said they are happy with their housing. The location of properties close to transport, and to shopping centres where the people were friendly, was highly valued. Neighbourhood was important. Several workers identified the importance of locating properties in communities where people were accepting of diversity. One gave an

example of a client who, while housed temporarily in a property in a different suburb, was robbed and assaulted by local young people. This client did not feel safe again until he moved into a property close to the Neami office.

Sharing houses had worked well for a minority of clients. Several had shared with other clients in the early years of the program, and were now living alone. Three were living in share households, each of which had survived since the program was established in 1995. In these households, arrangements about housework were a potential area of conflict, just as they are in the wider community.

In one household, two clients lived together as a couple, providing support and occupation for each other. They reported sharing cooking and cleaning, and (according to my observation over two visits) their house was well kept and functional. Another household I visited was shared by two women clients. These tenants share cooking and cleaning but, although they have a cleaner who comes weekly, their house when I visited was messy and grimy to the point (in my view) of being a health risk. For these women, their longstanding arrangement for sharing had worked because one spent every weekday and all weekend at her mother's house nearby: they had devised a routine that enabled both to ignore the mess.

The third share household I visited was shared by two male clients, one of whom declined to participate in the research. The client I interviewed did not talk about domestic arrangements, but his support worker said this man did not know how to perform even simple housework tasks, and all the housework that happened is done by the resident whom I did not interview. The worker reported that their previous house, which these clients had recently left, had been dirty in the extreme but, as arrangements about sharing housework had not been identified as an issue in either client's support plan, the issue had not been addressed by their support workers.¹²

The strategies used by residents in these households to manage conflict around housework are familiar from previous research into how housework is negotiated in

¹² The worker who recounted this story in interview was a woman, and the client's previous worker had been a man. Arrangements around housework are more likely to be 'invisible' to workers who are male, young or single than to workers who are women who live with partners and kids (Carter 2008).

share households (Natalier 2003a, 2003b).¹³ The two same-sex share houses were the most messy of those I saw (or heard of) in the course of this research. In other properties I visited, the levels of mess were well within the common boundaries of 'normal', ranging from cluttered but functional to spare and neat.

Most properties were in good condition, described for example by a family member as 'better than public housing' and by a support worker as 'I'd be happy to live in it'. A couple of older properties were tatty and others were in need of maintenance, having worn carpets, broken blinds, and walls stained with nicotine. Several clients identified being able to smoke indoors as being very important to them, and representing 'freedom' in contrast to the constraints of hospital. Their exercise of this freedom had the effect, over time, of creating very dingy and smelly environments in their homes. Repairs were sometimes delayed because of the difficulty that would be caused to clients by disrupting their routine.

For some clients, the condition of their properties created risks to their health. Those who had been in the habit of cooking at home came to be at risk if their attention to kitchen hygiene declined. Clients who had experienced dizziness or seizures were at risk of falls, especially in the bathroom or when getting out of bed, or when moving through cluttered spaces. Some workers had arranged modifications to property fit-out as a response to Occupational Therapy assessments around these risks. All clients spoke positively about SHL as landlord, saying that they have responded quickly when any problems have arisen. Support workers and family members all spoke of housing as basic to clients' wellbeing, providing an 'oasis' in which they can be safe and in control of their environments.

* **6.5 Support from Neami**

Most clients spoke of relationships with their Neami keyworker and other staff as very important to them. Some have had dealings with individuals at Neami and SHL since 1995, and these relationships in particular were highly valued. Many spoke of Neami with a sense of ownership, expressing a feeling that the service is there for them, and they are comfortable and familiar with it. As noted above, some clients

¹³ In a study of all-male share households, Natalier (2003a) found that where only one person does housework this is experienced as a problem only by the man who's doing it all, and because the issue is seen to be trivial he is not entitled to complain about it.

who had been regular participants in group activities run by Neami were unhappy about these having been discontinued.

Although client support needs were identified through a standardised process using the Camberwell Assessment of Need, the skills and interests of the Neami worker appeared to have a significant influence on how needs were identified and support plans developed. These workers' backgrounds varied. Those interviewed had qualifications and experience in areas relevant to their current work, including social work, psychology, intellectual disability and aged care. Some had had previous careers in fields such as engineering or building construction. Some workers were very aware of issues around nutrition, or physical health care and ageing, or housing maintenance, while others were less so. Accounts from clients and workers indicated that, when a client changed worker, the focus of their support was likely to change as well.

One worker described walking a 'tightrope' between providing disability support and providing support that promotes rehabilitation. This worker argued that, as clients age, their capacities 'plateau' and they become less willing or able to manage challenges such as cooking fresh food and maintaining kitchen hygiene. In these cases, provision of disability support such as meals on wheels becomes appropriate where it would not have been so sooner.

Workers talked about the importance of continuing to support the client as they learn from their own mistakes, at their own pace, with progress measured if necessary in 'baby steps'. Clients identified as most important to them that their worker will 'always be there for me'. Having established secure housing and familiar and effective systems of support, some now require little in the way of ongoing disability support. Within the broader Neami client group, they are not 'squeaky wheels'. For these clients, workers need to be observant of the gradual changes associated with ageing, as support needs are likely to increase again with time.

* **6.6 Support from clinical services**

For most clients, the boundaries between support provided by Neami and that provided by clinical services is clear: clinical services provide support in relation to

medication and mental health, and Neami deal with other areas. In some instances, these boundaries were blurred.

For a few clients, clinical case managers do things that Neami would usually do. For example, two clients who do not wish to have support from Neami have daily visits from their clinical case managers who provide support in a variety of areas additional to those around medication. Two others, who have monthly visits from their Neami workers, said they have been on outings and shopping trips with their clinical case managers. For some other clients, Neami do things that would normally be done by a clinical worker. For example, one was encouraged by his Neami worker to seek advice about health problems, and this worker subsequently accompanied and advocated for him through a lengthy process of diagnosis and treatment.

In some instances, these variations around the boundaries between clinical and Neami areas of support reflect the client's choice, as in the case of the two who wanted nothing to do with Neami. In others, they may reflect the preferences of workers, as in the case of a man who had been known to clinical services as a 'difficult' client, but has had good relationships with his Neami workers. Clinical workers have higher caseloads and less capacity to do shopping and other activities than Neami workers, so their capacity to extend the boundaries of support they provide is limited. For the clients I interviewed, having some latitude about where to go for what kind of support worked well.

* **6.7 Support from other sources**

The majority of clients received support from sources in addition to Neami and clinical services. Several had a cleaner who came weekly, some had meals on wheels, and some had a gardener who took care of their unit's yard. Some clients had had support through PALS, a scheme whereby volunteers would regularly visit clients and accompany them on trips to the cinema or other activities. Some had support from volunteers who provided transport to medical appointments or shopping.

Workers noted that these extra supports are important for the relationships they enabled as well as for practical assistance. They provide what one worker describes as 'a benign repertoire of structure', an 'extra pair of eyes' that can alert the Neami

support worker if anything is amiss. For clients who had no regular contact with family, these additional supports were especially important.

* **6.8 Community**

For many clients, everyday interactions with neighbours and others encountered in the local area were very important. People working in the milk bar, chemist, fruit shop, op shop and Cash Converters were most frequently mentioned as being friendly and welcoming, for example, saying ‘You don’t have to buy anything, you can still come and say hello’.

Several clients had experienced bullying and exploitation in interactions with local people. For example, one was befriended by some young people who lived nearby, who then started to come into his house and steal things and bully him. Another had kids throwing things at his windows and turning on his garden taps. In both these cases, Neami intervention prevented the problem from escalating. Clients were also vulnerable to exploitation by marketers operating door to door and by phone. For example, one signed up to a contract with Foxtel that was later dissolved by the State Trustee, leaving the client with a considerable debt.

For most clients, Neami is central to their ‘personal community’ (Pahl and Devalin 2005; Pahl and Spencer 2006). Involvement with Neami has provided an avenue to develop relationships with individual keyworkers and with the support team, and participation in group activities, drop-in and camps has created a community of peers among service users. Several clients said they would like their support worker to visit more often, and these and other clients said they were unhappy about no longer going to groups and activities that had previously been run by Neami. Workers who supported these clients said they had become increasingly inactive since the delivery of groups had changed.

Some clients chose to reject association with a community based around PDRS services. In interviews they identified themselves as having a mental illness, but a community based around a common experience of mental illness was not something they wished to be part of.

* **6.9 Activities and goals**

Support plans developed in the early years of the program typically showed goals concerning domestic activities such as cooking, cleaning and shopping; then goals around using public transport, going to groups and other activities, and increasing fitness; and finally, goals about participation in study or work. By 2007, most goals around domestic activities had been achieved to a reasonable standard, and goals about getting out and engaging in activities were achieved well by some and less so by others. For many, goals around education or work had been 'let go' after several unsuccessful forays. One client said, 'Sometimes I think they want me to work more than I want to work'. Most clients said they were happy with their current level of engagement with activities outside the home. Those who expressed dissatisfaction said they would like to have more visits from their support worker, and more outings and activities with the worker and with Neami groups.

Some workers expressed the view that to persist in trying to get the client to engage in more activities is inappropriate. One said, 'I had to listen to his expressed wish not to be badgered'.

* **6.10 The future**

Workers and families expressed concern about changing needs associated with clients' ageing. Support provided through Neami needs to articulate with support provided through Aged Care programs, to enable clients to remain in their own homes while they wish to do so. Specialist psycho-geriatric beds are in short supply, and for some of these clients, living in a mainstream aged care facility would be intolerable.

7 Implications for practice

The experience of the Neami Community Housing Program has shown that some people who experience significant disability associated with mental illness can sustain tenancies and live in the community in the long term when provided with appropriate support. People who had been considered by their clinical workers and families to be unable to survive outside an institutional setting have not only 'made it', but have established activities, relationships and routines of their own choosing, and have flourished.

When the program was first established, clinical staff who had been previously based in hospital settings were uncomfortable with the client-directed approach adopted by Neami, and it took a substantial investment of time and effort for the two sectors to work effectively together. Although organisational relationships are well established and protocols are in place, issues still need to be worked through with each change of personnel in either team (Foulstone and Cornish 2007).

The client-directed nature of Neami support has led to disagreements with clinical staff, and sometimes with family members, in areas to do with house cleaning, nutrition and personal hygiene. There is a range of views in the broader community about what is an acceptable level of mess and what constitutes a health and safety concern, and these are reflected in views held by workers and family members.¹⁴ Some Neami workers have felt that families want them to ‘order the kids around’, to make sure their house is clean and tidy, while Neami maintains that if a client does not identify house cleaning as a priority, to live in mess is their privilege. Similarly, with regard to appearance and personal hygiene, some workers have felt that clinical staff expect them to make clients look middle-class and normal, where Neami’s position is that clients can make those choices for themselves. Support workers will give direct feedback to clients if they are smelly, and will advise and prompt around house cleaning if squalor becomes a risk to clients’ health or tenancy. Differences of opinion in these areas represent contested views about the boundaries of ‘acceptable risk’. Workers have different views about at what point the practice of client-directed support should meet its limit (Carter 2008).

Another area of ambiguity concerns the boundaries of the support worker role, and the extent to which PDRS support is ‘purchasing community’. While clients may see workers as their friends, workers are aware of professional boundaries by which relationships with clients are constrained. The stated objective of PDRS support is not to provide friendship or community, but to facilitate access to participation in activities and relationships beyond those provided by the support agency. Some clients achieve this kind of participation, taking Neami support as a starting point and moving on from there. For others, Neami is their community, and the activities

¹⁴ Guidelines produced by the NSW Department of Health provide a way of benchmarking this. See NSW Department of Ageing, Disability and Home Care (2005).

and networks Neami facilitates provide their occupation. These clients and their family members regret the loss of the group activities that acted to sustain this sheltered community. The change made by Neami in how group activities are delivered has been experienced in diverse ways by the people affected by it.

8 Conclusion

The Neami Community Housing Program has been effective in enabling a cohort of people who live with significant and ongoing disability associated with mental illness to sustain tenancies and live in the community over a period of twelve years.

It is fundamental to the success of the program that clients have access to housing that is affordable, located in close proximity to public transport and shops, and in communities that are accepting of diversity, and that they live only with companions of their choosing. When clients wished to move away from share arrangements, other suitable properties were found for them. Properties are dispersed throughout the local area and do not attract the stigma that may be associated with housing in clustered settings or housing that is co-located with support services. Clients sign a standard lease with a community housing agency that specialises in providing housing to people with disabilities. Clients know that their dwelling is their own, and that tenure will not be lost if their support needs change.

The flexibility and duration of support provided by Neami is critical to the program's success. Neami provides support that changes in response to clients' changing needs, and continues for as long as is needed. Support is directed by priorities identified by the client, enabling them to create their own recovery in their own way; clients are confident that support will 'always be there for me' when they need it. Clients have access to support from familiar and responsive clinical services when they need it. For clients to live successfully in the community, they need access to activities that enable them to form meaningful relationships with other people and to participate in various communities of interest in ways of their own choosing.

Implementing this model involves inherent tensions and ongoing negotiation between Neami support workers, clinical workers and clients' family members. As community standards about what is normal in domestic life and personal behaviour

are always shifting, judgements about the boundaries of ‘acceptable risk’ are continually being negotiated. The extent to which a PDRS agency should facilitate community among service users is another area of disagreement. Neami staff engage in ongoing discussion about appropriate ways to provide support to clients. Challenges for the future concern maintaining the integrity of the model in the face of resource constraints, and responding to changing needs that emerge as clients age.

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