

Healthy Home: Healthy Me

Review of the Northside Community
Service 2011 Severe Domestic Squalor &
Hoarding Pilot Project

Acknowledgements

We would like to acknowledge and thank the clients of Healthy Home Healthy Me who made themselves available to talk about their experiences of the program. Thanks also to the range of stakeholders who participated in the review.

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Foreword by Northside Community Service

'Healthy Home Healthy Me' was an 18 week pilot program that supported nine clients to reduce severe domestic squalor and chronic hoarding within Canberra's Inner North.

During 2009/10, the Aged and Disability Home and Community Care (HACC) program at Northside Community Service (NCS) had received a high number of referrals for people presenting with issues related to hoarding and/or squalor. Prior to the pilot program, all nine of the program participants initially received HACC case management as well as a range of other HACC services, such as domestic assistance, social support or transport, in an effort to address the presenting issues.

An initial one off episodic major clean was organized with some of these clients through another HACC-funded organization. However, it became quickly evident that mainstream HACC support was not sufficient to sustain lasting changes, and living conditions very quickly deteriorated.

NCS identified that this vulnerable group with complex needs required a program that went beyond basic domestic assistance. They also needed intensive case management to deal with a broad range of issues associated with hoarding and squalor, including chronic mental health conditions, relationship breakdowns, and insecure housing. No such program existed in the ACT.

In late 2010, ACT Health gave approval for NCS to use surplus HACC funds to deliver the pilot program 'Healthy Home Healthy Me', which was specially designed to address these needs.

This pilot program proved to be an extremely rewarding experience for staff and clients alike, as this report attests. NCS believes that there is merit in considering the development of such an initiative for the longer-term.

The Institute of Child Protection Studies was engaged to formally review the program in order to evaluate the effectiveness of the pilot. NCS hope that the results from this report will assist in developing future models in partnership with other community organisations and government agencies. The results of this report will be provided to ACT Health and Community Services Directorates.

My thanks to ACT Health for enabling this pilot project through innovative use of HACC funding, and to the Institute of Child Protection Studies for this thorough and informative report. Finally, I want to particularly acknowledge the NCS staff who saw this opportunity, developed it, and followed up with high quality services.

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Glossary

COTA	Council on the Ageing
CSC	Client Support Coordinator, Housing ACT
DSM-V	Diagnostic and Statistical Manual of Mental Disorders version 5
HACC	Home and Community Care
HHHM	Healthy Home Healthy Me Squalor Pilot Program
ICPS	Institute of Child Protection Studies
NCS	Northside Community Service
OCYFS	Office of Child, Youth and Family Support, ACT Government
SDS	Severe Domestic Squalor Project conducted in Sydney between 2008 and 2009

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Executive Summary

In 2011, Northside Community Service embarked on a project to support eight clients to reduce the severe domestic squalor within which they lived and to reduce its affects. The project, which engaged a specialised cleaning company, provided case management and living skills support, accommodation assistance and community engagement was the first of its kind and worked with clients to improve a broad range of outcomes. This report attempts to describe the *Healthy Home: Healthy Me* project and provides findings from a Review of the service conducted by the Institute of Child Protection Studies at the Catholic University.

Understanding Squalor

Domestic squalor is an under-researched issue which is understood differently within a range of contexts and disciplines, if understood at all. Although unrecognised as a specific mental health condition, the mental health literature links hoarding and domestic squalor to conditions including dementia, substance abuse and schizophrenia. The broader commentary considers them within the contexts of housing and care and protection.

There is some evidence to suggest that squalor and hoarding is best supported using intensive case management underpinned by a supportive, therapeutic alliance which allows clients to take control of their lives and sustain positive outcomes. In severe cases the engagement of forensic cleaning services and other forms of practical assistance have shown to be vital.

Review Approach

The Review of *Healthy Home: Healthy Me* was conducted between July and September 2011. During this period, five of HHHM's eight clients were interviewed by an experienced social worker who talked with them about their engagement with

the service, the important elements of the assistance provided and their perceived outcomes. Pre and post assessment program data were also reviewed. These interviews were complemented with interviews with key stakeholders from the housing, disability, Home Help, Care and Protection and alcohol and other drug sectors.

Findings

Overall, the Review showed that the HHHM project was successful in assisting clients living in domestic squalor to achieve positive outcomes. Some of the features of the HHHM were particularly appreciated by clients and other stakeholders and were considered vital in projects assisting those affected by squalor. These included:

- **The value of positive staff:** Clients highlighted the value of working with supportive staff who not only provided them with case management but also provided them with encouragement and were considered a trusted support. Clients valued assistance that was underpinned by:
 - **Genuine humanising relationships**
 - **Non-judgmental responsiveness to individual needs**
- **Domestic Assistance** Clients recognised the value of hands-on practical assistance which helped them address their living conditions.
- **Living skills:** Clients appreciated assistance in developing their living skills, particularly problem-solving, help-seeking and domestic care.

Some of the positive outcomes identified by clients and workers included:

- **More secure accommodation**
- **Increased social connectedness and community participation**
- **Greater confidence**

Some of the challenges or limitations that might be further considered when implementing a project like HHHM include:

- **Increasing the length of time of engagement:** There was an acknowledgement that for sustainable outcomes to be achieved and for clients to feel most comfortable, assistance might be required for some time. This reflects previous studies which suggest that projects are most effective when provided for a minimum of 18 months.
- **Increased service coordination and partnerships:** It was recognised that there was great value in identifying potential need early and responding to the needs of clients in a coordinated and collaborative way. This was in recognition of the fact that conditions for clients can deteriorate quickly and that intensive assistance is often required. To facilitate collaborative work, stakeholders recommended:
 - A panel model for identifying and responding to clients needs
 - The development of formal MOUs between service providers
 - The sharing of expertise amongst players
 - Access to ample brokerage funds

It was also suggested that the collection of data related to squalor across ACT agencies would assist government and local service providers better understand and respond to the specific needs of this client group.

Introduction

In 2011 Northside Community Service (NCS) carried out an intensive 18 week pilot program - *Healthy Home Healthy Me* – aimed at supporting eight clients to reduce severe domestic squalor and hoarding and its affects. The project was developed in response to needs identified through the work of its Aged and Disability Services program.

This report outlines the findings of an external review of the effectiveness of the NCS *Healthy Home Healthy Me* pilot program, conducted by the Institute of Child Protection Studies, Australian Catholic University. It examines the NCS intensive case management approach to addressing the complex needs and multiple barriers experienced by eight people living in severe domestic squalor. Severe domestic squalor poses many ethical dilemmas, and presents frontline human service agencies with a complex and overwhelming set of needs which may be extremely difficult to respond to and address.

Fundamentally, the review aimed to answer the following questions:

- What are the outcomes of the 18 week pilot project?
- What are the key elements of successful models of working with people who are in situations of squalor?
- What is the extent and nature of the problem through interviews with key stakeholders; ACT Housing, ACT Home Help, Child Protection, Mental Health, Drug and Alcohol services as well as program staff?
- What learnings can be applied to expand the focus of program to include families with children?

Understanding squalor

“Severe domestic squalor” or the term squalor is used in the limited literature to describe living conditions that may include: a dilapidated filthy house, living

conditions that are cluttered with rubbish, possible infestations of vermin, and where there may excrement and decomposing food strewn around the floors. This is a different set of issues to people who neglect self-care but keep their accommodation adequately clean and organised. “It contrasts, too, with cases where individuals hoard possessions excessively but in a reasonably organised way that still allows for clearing away of refuse” (Snowden, Shay and Haliday, 2006, p38). The term squalor is used to describe extreme household uncleanliness and hoarding, where the accumulation of material has led to the living environment being unclean, unsanitary or dangerous (e.g. conditions pose a fire or health risk) (PAH 2007).

Squalor by its very nature is a hidden and complex problem. People living in severe domestic squalor are highly likely to be extremely isolated, are more likely to be living alone (Snowdon et al, 2007) and face multiple barriers to accessing support services. Studies on squalor and hoarding tend to focus on the elderly, although it is increasingly being recognised that squalor affects people of all ages and walks of life. The child neglect literature does not use the term, although squalid living conditions are sometimes mentioned in the context of physical neglect.

The ‘Healthy Home Healthy Me’ pilot project

In 2011, NCS embarked on a project to respond to the needs of people living in squalor. Like other agencies, NCS had been grappling to understand how to best provide services to reduce severe isolation, improve safety, quality of life, functioning and access to adequate services, for people living in severe domestic squalor.

In 2010, Aged and Disability Services at NCS received 20 referrals for individuals or couples presenting with issues related to severe domestic squalor and/or hoarding. Youth and Family Services at NCS identified a further 5 referrals for families with children under 18 years where a major issue was severe domestic squalor.

In response to these requests, NCS had undertaken major cleans and provided some case management support for clients referred for severe domestic squalor. However they concluded that this did not adequately address the long-term needs of clients nor led to sustainable outcomes. Often the same person would return to the service within two years, presenting with the same problem. NCS argued that a service was required for these clients which provided more intensive and responsive support over a longer period; recognised the underlying mental health and health issues of clients and helped them develop life skills. It was also essential that such a program recognise and address the barriers this client group experience to meaningfully engage with services and to obtain help and support with a range of complex issues in their lives.¹

In light of this, NCS developed a pilot to respond to the challenges that they had encountered and reflected their commitment to support a very vulnerable and isolated client group. They aimed to reduce the risk of homelessness and eviction, premature admission into crisis and residential services, and reduce costs due to inadequately targeted resources.

The HHHM pilot was funded through the ACT Home and Community Care (HACC) program and specifically set out to:

- 1) Reduce squalor through provision of domestic assistance, including removal of rubbish and replacement of household items. A specialised contract cleaning company was used for major cleans and forensic cleaning.
- 2) Provide case management to sustain improvements in living conditions
- 3) Promote living skills including health and nutrition

¹ Nationally a number of important social policy initiatives are pertinent to the issue of squalor; the Social Inclusion agenda, a national focus on homelessness, a commitment to Family Support and child protection; and a commitment to funding programs which support people to maintain independence in their homes and prevent premature admission to residential care and crisis care.

- 4) Maintain secure accommodation
- 5) Encourage increased social contact and facilitate community participation.

Key factors in the NCS model included:

1) Case management

- Focus on engagement and trust building, consistent and humanising relationships
- Responsiveness and flexibility
 - Intensive long-term case management that included support and relapse prevention plans
- Skills – mental health training, non-judgmental, resilient
- Strong team work, supervision and support for staff

2) Domestic Support

- Links with ACT Home Help for ongoing domestic support

As the program was funded through HACC, only HACC eligible clients were able to participate. To be eligible for HACC services, a person must be a frail aged or be a younger person with a disability, or their carer. HACC services support people to be more independent at home and reduce the need for admission to residential care. Services typically include nursing care, meals, domestic assistance, personal care, home modification and maintenance, transport, respite care and counselling, support and information.

What is known about squalor: a review of the literature

The term 'severe domestic squalor' is used almost exclusively in Australia (McDermott & Gleeson, 2009). In the ACT the term is used primarily in the aged care and public housing sectors and although it is seen by some as a fairly negative emotive term, there does appear to be a shared understanding of what it means

across key agencies. In the Child Protection sector, squalor is understood as one of the eight domains of neglect.

Squalor and the aged care sector

The aged care sector has perhaps explored the issue of squalor more than any other sector, with an accompanying body of medical literature available. In the USA, the term 'self-neglect' is used to describe older people with serious social, functional or physical issues which in extreme cases lead to them living in squalor (Dyer et al, 2007). In the UK the medical condition *Diogenes Syndrome* is sometimes also known as senile squalor syndrome, messy house syndrome, social breakdown and senile breakdown. *Diogenes Syndrome* is a behavioural disorder of the elderly and is classically defined by extreme self-neglect, domestic squalor, social withdrawal, excessive hoarding (sylllogomania), and a lack of concern about one's living condition.

In Australia, and indeed internationally (Snowdon et al, 2007) very little has been written about service models for working with the complex issue of squalor. The only evaluation of a program available was conducted with the Severe Domestic Squalor Project in Sydney between 2008 and 2009 (McDermott & Gleeson, 2009).

Squalor and Hoarding

Hoarding features prominently alongside squalor and is understood to be a common though not universal feature in cases of severe domestic squalor (Snowdon et al, 2007) and is clearly mental health related. Hoarding as a Mental Health diagnosis does not currently exist, however a Diagnostic and Statistical Manual of Mental Disorders 5 (DSM-V) working group on Obsessive Compulsive spectrum disorders (Steketee, 2010) has recommended that hoarding be defined as a distinct disorder (the updated manual is to be published May 2013). Hoarding was one of the 9 diagnostic criteria for Obsessive Compulsive Disorder (OCD) in the DSM III. The definition of hoarding in the DSM-V is:

Persistent difficulty discarding or parting with personal possessions, even those of apparently useless or limited value....strong urges to save items, distress/indecision associated with discarding (Mogen, 2010)

Hoarding appears to be more prevalent in older than younger people and is reported to increase in severity with each decade of life. Other than dementia, hoarding may be the only psychiatric disorder that actually increases in severity and prevalence throughout the life course (Frost, 2010). Whilst a situation of severe domestic squalor may not necessarily involve hoarding and likewise, a situation of severe clutter and hoarding may not involve squalor, the two issues both need to be addressed and dealt with as part of any program targeted at squalor.

Neglect of children and squalor

In the child protection literature description of the physical domain of neglect includes a chronically unhygienic, unsafe, chaotic or cluttered environment, inadequate hygiene, inadequate nutrition and unreasonably unclean clothing (Lawrence and Irvine, 2004). Where one aspect of neglect is identified, there is the possibility that other domains of neglect and/or other forms of abuse are present. It is critical to understand that multiple forms of neglect and abuse often co-exist and are clustered. The state of the house therefore may be an important sign of families struggling and children being unsafe. There is only a limited literature on 'neglect' as a category of child abuse and even less said about the role squalor may play as an indicator of other underlying issues.

Underlying issues

Mental health, physical health & disability

National and international research suggests that more than two-thirds of people living in severe domestic squalor have an active mental illness (Halliday and Banerjee 2003). Studies show that dementia, substance abuse and schizophrenia are most

commonly identified, with physical and developmental disability and depression also highlighted. This is also consistent with the profile of clients in McDermott and Gleeson's Australian study (2009, p23) and with the profile of clients in the HHHM pilot.

Drug and Alcohol misuse

In a review of literature analysing 1100 cases of severe domestic squalor, abuse of alcohol was present in 27% of case reports (Snowdon et al, 2007). A further 10% of clients had a different substance use disorder. In the Sydney Severe Domestic Squalor Project, 11% of people accepted into the project and a further 19% of people referred but not accepted were identified as misusing drugs and alcohol.

Housing, insecure tenancy and risk of eviction

McDermott and Gleeson's Australian study (2009) on severe domestic squalor reported that clients living in public housing were over-represented in the group (54%) given that only 5% of the general population lives in public housing. They also reported that only 7% of clients lived in private rental compared with 20% in the general population. They conclude that *people living in squalor are more likely to experience housing insecurity* (2009, p 20) and found that this was true for 41% of clients in their study.

What is found to be effective?

Intensive case management

As stated above there is limited evidence on effective models of intervention with people who experience squalor. However the evidence base supporting the use of intensive case management models to improve outcomes with adults with serious mental health issues is well established both in terms of client outcomes and cost

effectiveness (Muesser, Bond et al. 1998); (Ziguras and Stuart 2000);(Smith and Newton 2007); Zigarus & Stuart, 2002).

Case management typically includes establishment of a working/therapeutic relationship of trust, assessment, goal setting, individual care planning, coordination, linkage and referral, core tasks and interventions on the client-level and systems-level including advocacy, supportive counselling and monitoring of the client's health and mental health and the care plan. Case management can be defined as: 'a collaborative process of assessment, planning, facilitation and advocacy for options and services to meet an individual's health needs through communication and available resources to promote quality cost effective outcomes' (CMSA, 2008).

The Severe Domestic Squalor project evaluation (McDermott & Gleeson, 2009) conducted in Sydney with 218 people referred to the project for assistance over a 12 month period strongly recommended that service models include:

- Case management
- Service coordination
- Flexible and individualised support,
- Ongoing support
- Holistic assessment
- Staff supervision
- Sharing of expertise and advice with others
- Sustainability

The evaluation also recommended five key service principles upon which successful interventions should be based:

- Respect for clients and non-judgemental attitudes
- Develop trust and rapport

- Move slowly and do not expect that living situations will change quickly. Short-term and quick fix solutions are usually unsustainable and can jeopardise relationships of trust
- Provide consistent, ongoing support
- Communicate regularly and honestly with all parties involved, including clients and other services (McDermott and Gleeson, 2009).

Building trust & relationship as the basis for intervention

The use of safe, nurturing and positive relationships as a basis for recovery and change with highly vulnerable people is recognised as an effective and essential ingredient of successful interventions in therapeutic literature (Perlman, 1979, Sudbery 2002, Trevithick, 2003, van der Kolk & MacFarlane 1996). In social work, psychology, nursing and medicine there is a large body of literature that points to the effect of the quality of the working relationship on outcomes, independent of the type of therapy (Lambert and Okiishi 1997; Horvath 2001). The SDS project evaluation conducted in Sydney highlighted the complex barriers experienced by the project clients. It concluded that a focus on long-term engagement through development of trust and rapport is pivotal to the success of any interventions with the client group. Building trust through relationships was considered a fundamental part of the HHHM program.

Forensic cleaning & practical assistance

The need for forensic cleaning services is an indicator of the severity and level of squalor (Halliday et al, 2000, Snowden et al, 2007). Major and forensic cleans are required when conditions have deteriorated to the extent that they seriously inhibit the tenant's ability to function, their health and the security of their tenure, pose serious fire risks and pose public health and safety risks as the squalor, accompanying hygiene issues and pest/rodent infestations spread beyond the walls

of the property and impact on neighbours. Major cleans and supports to sustain living conditions are expensive and time consuming and are considered a fundamental and important part of any program addressing severe domestic squalor. Squalor prevents clients from accessing services, creates a large number of very serious health and safety issues and exacerbates isolation and social exclusion. The SDS project (McDermott & Gleeson, 2009) mapped Primary Negative Consequences of Squalor and demonstrated a reduction over time in the severity of those consequences. Negative consequences included safety risks (trip, fall, and hazard), health risks, denial of access to services due to OH&S concerns, fire risks, risk of eviction, isolation, complaints from neighbours, legal issues, risk of homelessness, council orders and Consumer Tenancy Tribunal concerns.

Review approach

This review was undertaken in between July – September 2011 at the end of the *Healthy Home Healthy Me* pilot program. Ethics approval was granted by the University's Human Research Ethics Committee. Of particular concern was the need to ensure confidentiality of participants' identity and the vulnerability of the client group. For confidentiality reasons it was decided not to undertake a case study analysis of the five participating clients. A trained social worker carried out the interviews with clients to ensure follow up could be arranged if required.

The review aimed to answer the following questions:

- What are the outcomes of the 18 week pilot project?
- What are the key elements of successful models of working with people who are in situations of squalor?
- What is the extent and nature of the problem through interviews with key stakeholders; ACT Housing, ACT Home Help, Child Protection, Mental Health, Drug and Alcohol services as well as program staff?

- What learnings can be applied to expand the focus of program to include families with children?

Data sources

Clients

Five of the eight clients involved in the pilot project agreed to be interviewed and to provide feedback on the project and the model. A semi structured interview schedule was developed that included a retrospective pretest analysis.² Pre and post assessment data collected by NCS was also analysed. Very limited quantitative data was available. Pre and post assessment data for the 5 clients is examined, though its value for the purposes of this review is severely limited, both because of the small numbers and the short timeframe of the project. Assessments were originally planned as a way of providing regular feedback on progress and on specific areas requiring further attention. However they were not able to be used in the manner originally intended partly because of the time taken to build trust with clients, the intrusion of repeatedly revisiting the assessments, other needs taking priority for clients and the short timeframe of 18 weeks for the entire project.

Face to face interviews were carried out clients. With consent, interviews were taped and notes taken to record participants' views.

² A typical approach has been to use a pretest-posttest research design to document behavior change. However, in certain types of self-report program evaluation, pretest-posttest comparison results may be an inaccurate assessment of impact because participants may have limited knowledge or insight at the beginning of a program that prevents them from accurately assessing baseline behaviors. By the end of the program, their new understanding of the program experience may have an impact on the responses on their self-assessment. If a pretest was used at the beginning of the program, participants have no way to correct an answer at the end of the program if they made an inaccurate assessment in the baseline data. A retrospective pretest at the end of the program is more accurate because it's answered in the same frame of reference as the posttest (Rockwell and Kohn, 1989)

Stakeholder interviews

To ascertain broader views of the problem and pilot program 10 interviews were conducted with a total of 15 professionals from eight stakeholder agencies. Stakeholders were selected as key agencies likely to be working with or impacted by the issue of severe domestic squalor. Not all stakeholders had been involved in the HHHM pilot project, but all had grappled with the challenges and complexities of squalor and had expressed a strong interest in the issue. Stakeholders included ACT Home Help, Housing ACT (Northern and Central Regions Community Services Directorate), Karralika programs (drug and alcohol rehabilitation services), Child Protection (Community Services Directorate), the Health Services Directorate and former staff of the ACT Integrated Family Support Project. Representatives from ACT Mental Health services were also invited to participate, but were unable to do so. A range of NCS staff were interviewed: HHHM Case Managers and senior staff, the manager of NCS Aged and Disability Services and the manager of Youth and Family Services. Finally a representative from the Contract Cleaning Company which worked closely with NCS to undertake major cleans and forensic cleaning in the program agreed to participate in an interview.

Interviews with stakeholders were carried out either face- face or via the telephone.

Findings

The findings rely on three sources of data 1) client interviews, 2) program data; 3) stakeholder interviews. The findings are discussed in relations to the 5 outcomes NCS identified for the project.

This is followed by a discussion of key elements for a model required to address severe domestic squalor in the ACT. This discussion is based on the views of stakeholders, clients, and on the available literature.

What changed? Outcomes of the HHHM project

Clients' views on outcomes

The five clients interviewed reported very positive experiences of the HHHM program. They all commented that they would do the program again given the opportunity. They spoke very highly of the NCS staff and the project and gave specific examples of the approaches taken by staff which assisted them, discussed in detail below.

I'm happy about the learning, about getting to know people and it's helped my self esteem and confidence. I've started to learn how to keep things in order but there's still a lot more to learn. (Client 1)

I would encourage others to do the program. Not just because the staff are nice, but because it's helpful as well. (Client 1)

Interviews with clients indicate a movement towards positive change against all 5 outcomes. Feedback also pointed to two main areas of weakness in the pilot. Both areas of weakness were also identified by NCS as needing improvement in future programs. The first was sustainability of outcomes, specifically around the need for a longer time period for engagement and ongoing support. Two clients reported that the program had ended too soon, they needed a longer transition out of the program and that they were struggling to maintain the progress they had made. The second was the need for stronger links with other key support agencies. Both these issues are discussed in further detail later in the report.

Pre and post assessment tool results paint a more ambiguous picture of outcomes. Assessment results indicate substantial improvement for 2 clients out of the 5 and a slight decline against the assessment items for 3 out of 5 people. These findings are discussed in further detail below.

Domestic assistance

All clients commented on the importance of having hands-on practical help to address their living conditions. The 'boots and all' approach was appreciated and clients indicated that this worked well for them alongside case management. They particularly noted that case managers needed to be patient and flexible around domestic assistance and that they needed to understand that it could be a very challenging process for clients.

The practical help like cleaning and furniture was really important. They helped me get a new couch. That's the first time that's ever happened for me in my life. The fact that it was regular, that helped a lot with my memory problems. (Client 5)

The mess was overwhelming. We were unable to cope with it. We had no money and we were wondering what to do. The place was full of stuff and we didn't know what to do. Then NCS turned up and started to get organised and it was a dream the way they set it up for us. (Client 2)

And then a lot of the stuff got taken out of the house, remember they came here those 2 men and they worked really hard for a long time and it made a huge difference (Client 3)

She [NCS staff member] moved mountains, literally. (Client 4)

I wanted help, help to chuck out stuff, to box things up and organise. It has been a really good experience. (Client 1)

Clients also commented that the HHHM pilot project was enhanced by the services of the contract cleaning company who undertook forensic and major cleans. The company is run by a man with a social welfare background and a strong motivation to improve quality of life for clients. Stories describing how he went out of his way to assist clients, transport new furniture and devise strategies to help clients cope with the cleaning process, particularly during times of distress were volunteered by clients and stakeholders.

In contrast, the Sydney study (McDermott, 2009) highlighted instances with contract cleaning services and staff where clients were shocked, traumatised and very distressed, noting that on some occasions, "*significant tensions arose between clients and staff about what and how much clients are allowed to keep after a cleanup*"

(2009, p54). Both projects highlight some of the skills required to successfully engage and work with clients to address very personal issues related to their living conditions. They also demonstrate how important the role of the contract cleaner can be. Staff respect for client's possessions and recognition of their need to maintain as much control over the process as possible, needs to be skilfully balanced with health and safety issues.

Individual case management

Clients were individually case managed. All five commented on how important the consistent individual contact was for them. Home visits were undertaken as a matter of course and much of the work took place in people's homes.

I can't say enough for the girls who came. They understood the embarrassment and helped me overcome it and get through it. I think people who come to homes like mine need to be of that ilk. The whole program does. (Client 4)

Someone keeping in touch like that helps make me think about what I'm doing. For me the best thing about HHHM was the personal contact. (Client 5)

One client talked about how the HHHM worker connected her to other services she needed.

they were here one day and my feet were too sore to walk properly, she looked and said you need help with that foot, 'you need a nurse to look at it' and next thing you know there's a nurse at my doorstep. Ever since, 3 times a week the nurses have been here. They know what's going on, all the lovely stuff. You can feel quite relaxed and well looked after (Client 2).

Engagement & establishing trust

In the HHHM pilot, attention was given to engagement and establishment of trust with clients due to the extreme nature of their isolation and vulnerability. In most cases clients felt a strong sense of shame and embarrassment about their living conditions and had a history of distrust and reluctance to engage with services. Clients pointed out how important it was for them to develop trust in the workers and the service over time and that this was not an easy thing to do. Clients'

comments also reflect that NCS case managers were able to successfully engage and build trust and that this facilitated engagement with the program and resultant outcomes.

I've been quite isolated - I am not accustomed to giving my trust readily. My morale and self-esteem have been boosted through the program. It really helps you keep going. (Client 4)

Having contact, it helps, just talking to them about hard things and getting to know them. You've got someone willing to help you along and help your confidence and self-esteem and mental health and other areas as well. (Client1)

The calibre of the ladies who come here is incredible. They organised a whole range of service and assistance, they don't miss a trick. (Client 2)

We feel looked after. (Client 3)

What I liked was coming into contact with people and I was getting help... Programs like this are needed. I've had contact in the past with a few [programs] who didn't know where I was coming from and it didn't help. There are only a few people who understand and are really willing to help (Client 1)

The following example, illustrates the barriers to engagement experienced by some people living in severe domestic squalor. Prior to engagement in the program, an NCS case manager had built a relationship with one participant over a period of 9 months via telephone calls. Both the participant and the staff member concurred that those 9 months were necessary before the participant felt she could allow the case manager to visit her home.

I've become quite isolated...I am a very private person. I was terribly embarrassed by all the mess I was in. I said yes [to participating in the pilot] because of the way she [HHHM case manager] explained it. She understood my embarrassment, my need to do it my way. I knew them all [the staff] and I trusted them, which I don't do easily. It takes me a long time to trust people. At first I was reluctant and I nearly didn't participate. They were very understanding, very flexible, very patient. (Client 4)

Genuine humanising relationships

Clients also commented on the humanising effect of working closely and regularly with case managers whom they trusted. These helping relationships effectively communicated genuine interest and commitment to clients and helped to motivate them to take some steps to help themselves.

They were very friendly. They listened. I could tell that they genuinely cared about what was going on and that made a difference. Those little prods and pokes they were giving me to go in the right direction helped. I felt indebted to them. They would come and work really hard. I could see they genuinely cared and it gave me a bit of motivation. I didn't want to let them down next time they came (Client 5)

I come from of a background of severe depression so some days were harder than others. I coped on the hard days by talking to the workers. It helped doing that. On those days I didn't feel like doing things, going through things, but I had to get myself out of bed because I knew they were coming. (Client 1)

Non-judgmental responsiveness to individual needs

Clients commented on how important it was for them that the case managers were flexible, and that they varied the pace and content of the work according to what clients needed. Clients noticed and appreciated the efforts of case managers to ensure they were able to maintain as much control as possible over the process. The flexible, holistic nature of the case management helped them engage and stay engaged, even during difficult patches.

That's how they got my trust, was when they tried to do things the way I needed. They never judged or anything like that (Client 1)

She (HHHM case manager) understood my embarrassment, my need to do it my way. For example, I had lass from another service come along. She couldn't get her head around my need to do it my way, in a way that works for me. So I couldn't continue with her....I needed to be in control. The girls understood my need to take it slowly, to adapt, and to do it my way. I wanted to be the one who said 'yes you can take that away' (Client 4)

It was also really good that they were flexible, things weren't set in stone. (Client 5)

Living skills

Clients felt like they learned new skills and two commented that they felt they had just begun to learn what they needed through the program and would like to continue building on their living skills over a longer period.

One of the most important things was learning how to keep things in order. I need more time for this. We did a bit, but it's not enough. I do want to do the program for longer. It teaches me how to do this on my own and I'm not quite there yet. (Client 1)

One client commented that he had never used the stove in his home and that it was at least possible now as a result of the domestic support provided through the program. One of his goals was to plan a meal for himself and then follow through with shopping for the ingredients and cooking it. This was quite a challenge for him, and was something he had never done before, having been homeless or incarcerated for most of his adult life.

Developing help seeking skills and growing self-awareness

Clients indicated that the program helped them to recognise their need for help and develop some skills in seeking help. It also helped developed confidence and a greater level of self-awareness.

I realise because of this [program] that I probably do need professional help. I can't just do this on my own. I'm also more confident asking for help, although I don't feel I deserve it (Client 5)

I probably have more understanding now of where I can get help. The biggest learning was to speak things out. (Client 1)

Maintaining secure accommodation

Clients' comments indicate that their living conditions were becoming untenable prior to engagement in HHHM and in some cases that this was placing their accommodation and tenancy at risk. They also indicated that their squalid living conditions had a direct effect on their health and wellbeing and ability to function independently. This suggests that involvement in the HHHM project improved their ability to maintain secure accommodation.

We were at the end of our tether. The place was so full of stuff and everywhere things were going bad around us. (Client 3)

We would have been lost if it weren't for this. I don't know where we'd be – probably in some kind of institution (Client 2)

I'm more comfortable in my home now where it's clean and stable. It made my home a nicer place to be, and I can get out. (Client 1)

Increasing connectedness – social contact and community participation

Clients commented on an increased sense of confidence and connectedness as a result of the program.

This program helped with things outside the home as well, like Housing and Centrelink. I just couldn't do that on my own (C1)

It helped my confidence and it was good to have contact with people...it helped a lot getting out. I have been able to get out a bit and see some friends. (C1)

For me the best thing about it was being able to have the personal contact. A lot of the time I am really quite lonely... I've been stuck in a rut for a while (C5)

Others commented that they were still very isolated, but that the program had helped them to be more accountable and to open up new possibilities of engagement which they were beginning to consider.

I need regular contact with someone like the girls here [at NCS]. Someone keeping in touch helps make me think about what I'm doing. If they tell me I'm skinny or I'm looking bad – the feedback is important. I need to start going to professional counselling. (Client 5)

When asked about goals and plans, and what supports they needed in order to progress them, comments included:

I need support to set up a way and to be able to keep a daily record of what I'm doing. With my brain damage I forget a lot of stuff that's going on. Both short and long term memory are affected. (Client 5)

I want to study (Client 1)

I want to be able to call A [case manager] and say 'come over for a cuppa – no I don't need that help anymore' (Client 4)

Next thing you know they've organised and followed up the occupational therapist and now she's coming. Now we've already got the ramp and the bathroom is pending. We're delighted. We had no options ourselves, we'd nearly had it. (Client 2).

Retrospective analysis

A retrospective pre-test and post-test analysis (sometimes called then test) was conducted as part of the qualitative interview process with each of the 5 clients. All clients were asked to score themselves on a scale of 0 to 10 before commencement

with the program, immediately after completing the program and as part of the review, approximately 2 months after cessation the program. They were asked; *thinking back, how you would describe your life just before the program, at the end of the program and now. Rate it from 0 – 10 where 0 is the worst you could ever feel, and 10 is the best you could possibly feel’.*

For all 5 clients their sense of wellbeing had been low prior to commencement (average score of 2.1) and had improved markedly by the end of the 18 week program (average score of 6.8). For 4 out of 5, wellbeing had been maintained or improved 2 months later with an average score of 7.2. One client felt that two months later she was back where she’d started and that although she had improved from a 3 to an 8 by the end of the program, she was back at a 3 again.

All 5 clients indicated a marked improvement in scores between before and immediately after cessation of the program. One client indicated that improvements had been sustained at the same level two months later and three scored themselves even higher two months later.

I was miserable before, I was 0 out of 10. Now I’m a 7.5, I’m happy, learning, talking and getting to know people. My self esteem and confidence are up (Client 1)

Table 1 Retrospective pre and post analysis.

Client self- scores of wellbeing (0 = worst you could ever feel, 10 = best you could possibly feel)

CLIENT	COMMENCEMENT	END OF 18 WEEK PROGRAM	2 MONTHS AFTER CESSATION OF PROGRAM	CHANGE BETWEEN COMMENCEMENT & END
1	0	7.5	7.5	+ 7.5
2	2	6	9	+7
3	3	8	3	0
4	2	6	9	+7
5	3.5	6.5	7.5	+4

Program Pre and post assessments

In contrast the results of the pre and post assessment tools conducted by case workers and clients paint a different picture to the retrospective pre and post analysis conducted as part of this review. Three tools were utilised, each time as an assessment tool by the case manager and as a self-assessment tool by the participant. Clients and case managers completed the scales separately on commencement and on completion of the program. Clients with the worst overall scores showed the greatest change (improvement) in all 3 assessments.

Client self-perception of their living skills and household conditions varied markedly from those of the case managers. Clients also tended to self-assess quite positively on commencement of the program and their scores over time worsened. NCS attribute these overly positive scores on commencement to discomfort, fear and a sense of feeling threatened, likely to have been experienced by clients. Clients were less likely at this stage of the program to have the capacity and the rapport and trust built with workers which would enable them to undertake an honest assessment of their situation. Increased self-awareness and increased trust in staff over the

duration of program lead to increased awareness of the need for support and attention to specific issues (resulting in worsening scores in some scales). This phenomenon occurs quite commonly in evaluations with self-assessment tools and tends to reflect a growing awareness of the problem and recognition of the need for help on the part of the client. Most importantly, evaluation studies even when pretest-posttest information is obtained, actual changes in knowledge and behaviours may be masked if the participants overestimate their knowledge and skills on the pretest³. In this context a retrospective tool is likely to provide a clearer picture of change over time (Pratt, Mcguigan and Katzev, 2000).

In the Environmental Cleanliness and Clutter Scale (ECCS) 2 out of 5 clients recorded significant improvements in living conditions and 3 out of 5 clients recorded slightly worse scores at the end of the 18 weeks. Similarly in the Activities of Daily Living Scales, 3 out of 5 clients recorded slightly worse (higher) scores and in the Clutter Image Rating (CIR) 2 out of 3 clients had worse (higher) scores.

Environmental cleanliness and clutter scale

Higher scores in this scale reflect greater severity in issues such as accessibility, percentage of clutter covering floor, accumulation of refuse and cleanliness in various rooms in the house. According to scores, 2 clients improved markedly over time and 3 clients worsened slightly over time. These scores may indicate a growing recognition of the size of the problem at completion of the program and a continuing need for assistance.

³ This change in an individual's frame of reference because of program participation has been called the response shift bias (Howard & Dailey, 1979).

Table 2 Environmental cleanliness and clutter scale (eccs)

CLIENT	Client perspective at beginning of HHHM	Case Manager perspective at beginning of HHHM	Client perspective at end of HHHM	Case Manager perspective at end of HHHM	Differences/similarities in client and Case Manager (CM) scoring
1	12	18	13	11 (-7)	Client score worsened over time, case manager score improved over time
2	2	4	4	5 (+1)	Both client and CM scores worsened slightly over time
3	2	4	4	5 (+1)	Both client and CM scores worsened slightly over time
4	2	7	4	9 (+2)	Both client and CM scores worsened slightly over time
5	15	31	11	19 (-12)	Both client and CM scores improved (decreasing severity) over time

Activities of Daily Living Scales

Clients were asked to rate from 1 to 5 (5 being the highest) the degree of difficulty or problem they experience with 16 activities of daily living, 7 living conditions items

and 6 safety issues. The degree of difficulty had to be directly related to clutter or hoarding, rather than another issue such as physical injury or disability.

Scores assessed by clients and case managers follow similar trends in this assessment, though with differing levels of severity. Case managers assessments tended to rate the problem as higher than participants' self assessments did. Scores show that 2 clients improved over time (decreased in severity) and 3 worsened over time. These scores may indicate a growing recognition of the size of the problem at completion of the program and a continuing need for assistance. (High scores indicate a more serious issue)

Table 3 Activities of daily living scales

CLIENT	Client perspective at beginning of HHHM	Case Manager perspective at beginning of HHHM	Client perspective at end of HHHM	Case Manager perspective at end of HHHM	Difference & comments
1. Activities affected	14	25	19	17 (-8)	Client scores worsened, CM scores improved (decreased in severity) over time
2. Living conditions	8	13	9	8 (-5)	
3. Safety issues	8	13	7 (-1)	7 (-6)	
1. Activities affected	16	24	21	29 (+5)	Both client and CM scores worsened slightly over time
2. Living conditions	8	9	9	10 (+1)	
3. Safety issues	6	8	8	6 (-2)	
1. Activities affected	16	24	21	29 (+5)	Both client and CM scores worsened slightly over time
2. Living conditions	8	9	9	10 (+1)	
3. Safety issues	6	8	8	6 (-2)	
1. Activities affected	17	26	21	26 (0)	Both client and CM scores worsened
2. Living conditions	7	7	7	17 (+10)	

3. Safety issues	8	13	11	9 (-4)	slightly over time
1. Activities affected	20		19	21 (-13)	Both client and CM scores improved (decreased in severity) over time
	7		7	7 (-4)	
2. Living conditions	7		6	8 (-8)	
3. Safety issues					

Clutter image rating (CIR)

Clients were asked to select a photo for each room in their house which most accurately reflected the amount of clutter in the room. Each room was given a score between 1 and 9 with the worst and possible highest score being 9.

The results indicate that 2 clients experienced significant improvements between the beginning and the conclusion of the program and 1 client experience a smaller decline. Results for 2 other clients were not completed.

(Higher scores indicate a more serious issue)

Table 4 Clutter image rating (cir)

CLIENT	Client perspective at beginning of HHHM	Case Manager perspective at beginning of HHHM	Client perspective at end of HHHM	Case Manager perspective at end of HHHM	Difference & comments
1	66	106	69	69 (-40)	CM assess as marked improvement, client self-assesses slight decline
2	52	-	58	-	-
3	52	-	58	-	-
4	34	58	44	67 (+9)	Both client & CM think has declined
5	61	118	52	72 (-46)	Both CM & client assess as improved over time

Summary of assessment results

The apparent contradiction when comparing clients' verbal/qualitative feedback in interviews and in their self-rated retrospective post analysis with the 3 assessment tool results raises a number of issues. It may be that using these tools over a relatively short period of time with a small group of people is of little value for the purposes of evaluation and unlikely to yield useful results, though they may still have some value for the purposes of assessment. It may also point to inconsistent use of the scales, to difficulties carrying out assessments and to the limitations of scales in this context – *numbers cannot fully capture the complexity of situations of squalor (McDermott & Gleeson, 2009, p76)*. Further consideration needs to be given to the use of assessment tools in future squalor programs in order to obtain meaningful and useful data for the purposes of evaluation and service planning. This is a very small

sample and along with the issues with traditional pre and post design limited conclusions can be made. Although the interview data does indicate that clients regard the program as provide considerable improvement in their lives. See assessment tools in appendix.

Stakeholders' views

You can't just go in and fix it and walk away. It has to be sustained (Stakeholder 10)

Stakeholder agencies were invited to provide feedback on the HHHM program and to comment more broadly on key elements of a service model to address severe domestic squalor. Some stakeholders had not had any direct experience of the HHHM program as it was conducted over a short period of time, and so were not able to comment specifically on it. All agencies were invited to participate in the review because of their experience working with highly vulnerable clients and squalor.

Extent of the Need

Whilst agencies in the ACT use different terms to describe squalor, there is strong agreement amongst them that this is a hidden issue, that it involves some of Canberra's most vulnerable and isolated citizens many of whom are currently falling through the gaps. Across participants there was agreement that this issue is a high priority and that it requires a coordinated and adequately resourced response. In the ACT, agencies most directly impacted include the frontline agencies - community services, Mental Health services, Drug and Alcohol services, Child Protection, Family support services, Housing ACT and ACT Home Help.

Though methods of data collection vary between the stakeholder agencies interviewed, estimates for referrals related to severe domestic squalor range between 5% and 20%. Similarly to NCS, Housing ACT and ACT Home Help indicate higher estimated numbers of people seriously affected by squalor than other

agencies. This reflects their respective roles and greater likelihood of coming into contact with squalor as frontline agencies dealing with housing and domestic services.

The following discussion is based on participants' estimate of the extent of the problem. There was no analysis of agency records data and it would appear that referrals for squalor might be recorded differently across agencies, if at all. What is apparent across agencies is recognition of the time and intensity required for undertaking effective work with people living in severe domestic squalor. There is more work to be done than simply 'clearing up' the squalor.

A skip or disposal of rubbish is not going to fix the problem. The 'squalor' is part of neglect, it's a symptom. It has to be addressed through long term sustainable intervention and cannot be event based. (Stakeholder 8).

Northside Community Service

On average NCS estimate that they receive 2 referrals per month (approximately 5% of referrals) related to squalor or hoarding. About 10% of the current clients of the Aged, Disability, Homecare and Transport programs at NCS (around 55 people) are people being supported with issues of squalor and hoarding through domestic assistance, personal care and case management.

The majority of people living in squalor experience it over a very long time. The underlying cause is often mental illness, therefore programs need time...the need for ongoing casework is critical (Stakeholder 3)

Housing ACT

Housing ACT central region estimate they currently have 10 clients living in very extreme domestic squalor and a further 50-100 clients living with very serious domestic squalor. Around 20% of those instances involve children under 18 years of age, though Housing ACT find it most difficult to engage with and find support for single adults, due to a lack of appropriate services to refer to. The Northern region of Housing ACT estimate around 50% of their tenants affected by severe domestic

squalor are families with children and 50% are single adults of all ages ranging from 16 years to the elderly. It is likely that the much higher number of families of concern in the Northern region reflects the differences in housing stock in the 2 regions, with the central region containing a more complexes, bedsitters and single bedroom units which accommodate single adults. The Northern region has a higher number of houses, townhouses and aged person's units.

ACT Home Help

ACT Home Help is the agency in the ACT which provides domestic cleaning support for Home and Community Care (HACC) eligible clients who are unable to manage on their own. All clients in the HHHM project were able to transition to ACT Home Help for ongoing domestic support with the aim of maintaining the home in its improved condition, on conclusion of the program.

ACT Home Help estimate that at least 4 out of every 10 referrals they receive (40% or approximately 120 people per month) require level 4 cleans for high levels of squalor. Two out of every 10 referrals (20% or around 60 referrals per month) are for people living in very extreme squalor. Level 4 cleaning denotes forensic and heavy duty cleaning requiring specialised equipment and forensic cleaning skills and an enormous amount of work: as such they cannot be carried out by ACT Home Help staff. Level 4 cleans pose serious Occupational Health and Safety (OH & S) issues and are characterised by hygiene and other safety issues posed by animal and human waste, rotting garbage, filthy and extremely cluttered environments which are extremely difficult to move in. The cost associated with level 4 cleans can be as high as \$10,000, with a clean 'just touching on level 4' costing around \$1500.

Child Protection

Squalor is understood by the ACT Office of Child, Youth and Family Support (OCYFS) to be a symptom of child neglect and a very complex phenomenon. It is frequently

encountered. It can be very visual and confronting and sometimes overwhelming. It is regarded as a symptom which indicates the extreme vulnerability of children in situations where they are almost always isolated and where families by definition are disengaged. The term squalor is seldom used in the ACT Care and Protection context; however it is described under the physical domains of neglect (one of eight major domains) and reflects descriptions used by NCS and other agencies. Neglect is the major area of concern in approximately 50% of child protection cases referred to the OCYFS. There were no data readily available for the purposes of this review to enable analysis of the cross-over between child neglect and squalor. However it is recognised as a complex issue which points to the multiple disadvantages experienced by children and families in this situation and the huge cost to both individuals and society of its consequences. The need for a greater focus on neglect and squalor is apparent.

Drug and Alcohol services and Mental Health

Karralika Programs conduct a range of residential care and community based treatment for people affected by Alcohol and other Drug use. They do not currently collect data on squalor and it is not an explicit part of the assessment or referral process. Although a large component of their program is a therapeutic residential community where squalor is not a major issue, they recognise that squalor, alcohol and drug dependence and mental health frequently co-exist.

ACT Mental Health was contacted and an interview was requested as part of this review. Unfortunately, it was not possible to make contact with a representative from ACT Mental Health in the timeframe available. The views of Mental Health and Alcohol and other Drug services form a very important part of the picture of squalor in the ACT and should be included in any further discussion or planning.

The Model

As discussed above NCS model combined 2 main types of services – intensive holistic case management and domestic support. NCS report that a key to their approach was the combination of the ‘boots and all’ practical assistance with intensive case management. Housing ACT and other stakeholders agree that a hands on approach is vital for the success of any squalor program and that one without the other is likely to be unsuccessful.

Regular visits maintained over a long period of time create an informal accountability mechanism and also an opportunity for delivering skills and education respectfully and subtly (Stakeholder 1).

Factors raised by clients and NCS which would need further development in a longer term program include

- Partnerships, collaboration, networks. Factor in time needed to communicate effectively with other agencies and build constructive working relationships. Develop both formal (i.e. MOU’s, a connecting families style panel) and informal partnerships (sharing expertise and advise through networks)
- Length of time – service provision would need to occur over a much longer time period for sustainable gains to be achieved. Stakeholders and the literature suggest between 2 to 3 years is necessary. Clients certainly expressed a need for support for a longer period, to sustain improvements and changes and build on them.

Domestic support

Domestic assistance was tailored to meet the needs of clients and took the form of major or forensic cleans ongoing assistance and eventual referral to ACT Home Help for basic domestic assistance. As mentioned earlier, case managers worked individually with each participant pre and post cleaning to prepare them for major cleans, set goals and in some cases staged this cleaning over a period of time. They

recognised the importance of clients maintaining control over the process as much as possible - to empower and respect clients' rights, to enable continuing engagement, and to prevent unnecessary distress. Given the level of squalor present, domestic support was imperative. It was equally important to ensure sustainability of improvements through ongoing case management and domestic support. Clients all recognised that they needed assistance. Two clients reported feeling very relieved to have assistance to sort through and take away unnecessary items; however 2 others struggled with the challenge of allowing other people into their private homes to sort through their things and needed to maintain a strong sense of control.

I don't think it's just case management and support that's needed although that is a big part of it. I think it's also the hands on. Someone being there and sorting with the person and encouraging them right through it. The dirty work of getting it done and then maintaining that work over time and that's where we are really limited in what we can do (Stakeholder 10)

If you don't put case management in after the major clean, it doesn't matter how many cleans you do, it won't work. (Service Provider 2)

Case management

Engagement and trust building

Clients represent a highly vulnerable population with complex and multiple needs. All clients interviewed had multiple barriers to engagement with services, had experienced high levels of isolation, had serious current health and/or mental health issues and expressed a high level of distress about their living situation prior to engagement with the HHHM program. Their major needs included: major physical and mental health challenges/diagnoses, clients also experienced multiple other life challenges including, acquired brain injury, physical disability, frail physical health, full-time carer, threat of eviction due to living conditions (threat of eviction) substance abuse, extreme social isolation, debt (due to inability to contact agencies such as Centrelink and advocate for self, losing bills etc), unemployment and poverty, lack of social networks and little or no family support, attempted suicide,

lack of basic living skills, criminal history, history of long-term homelessness. Clients commented on their reluctance to trust services and gave examples of previous negative experiences with other services where they did not engage for a range of reasons. They also talked about the importance of taking time to build trust and safety:

That's how they got my trust, was when they tried to do things the way I need. They never judged or anything like that. (client 1)

It's very important when people come in to see you caught in the most awful mess. It's terribly embarrassing, regardless of the reason (Client 4)

NCS were all prepared to be flexible and to work with me, my way. It made me far more open. It's hard for me to achieve... they were very understanding and they found a way of making me feel less crummy, made me feel worthwhile. That's very important. (Client 4)

NCS staff reflected that successful engagement with this client group took time, patience and skill and that it was a high priority for the project.

I think the clients already trusted A [case manager] so we were able to get good results fairly fast, because she wasn't starting from scratch. It takes months to build that kind of trust. (Service Provider 1)

The importance of allowing time and a recognition of the level of skill required for the trust building process was also reinforced by stakeholders:

It's a slow laborious process of building trust before being invited into someone's home (Stakeholder 1)

There's a lot of skill involved in engagement and in maintaining a relationship. The biggest issues are engagement and recognising that it can take a really long time with no results and nothing happening but just doing that ground work and then you do get someone to engage. (Stakeholder 10)

Case managers outlined one situation where regular supportive phone calls with a client over a period of 9 months eventually led to the client accepting a home visit, which in turn led to her engagement in the pilot. NCS believe that their ability to engage with clients and build trust was pivotal to the outcomes of the project:

It takes several months to build trust with clients and the two case managers got to the point with clients where they were able to talk about really sensitive issues (Service Provider 2)

Responsiveness & Flexibility

NCS aimed to provide high-quality individualised and holistic support in the HHHM program. Individual needs and circumstances lead to variable pace and intensity of support. Similarly the content and nature of support was largely governed by individual needs. Stakeholders also recognised the importance of this flexibility, given the complex barriers faced by people living in severe domestic squalor. Clients commented on how vital it was for them, both in terms of staying engaged in the program and in influencing their openness to accept the support and services being offered:

I had moments when I thought 'I want to back out of this' but they spoke plainly with me. I could discuss my concerns, or if something irked me. They were very understanding, very good about it. (Client 4)

The worked with me the way I wanted to. The workers were all prepared to be flexible and worked with it my way. It made me far more open to their help and their suggestions....so the way they helped me was very important. (Client 4)

Intensive long-term case management

Low client to worker ratios were a key feature of the NCS model with 2 full-time case workers working together with 8 clients for around 3 to 4 hours per week. The regularity of contact was important for clients and it recognized the level of vulnerability and isolation experienced by clients:

Having regular contact with someone who can speak to me honestly about what they're seeing helped. (Client 5)

If the program were to be sustained over a much longer period both clients and NCS staff agreed that it would be possible and helpful for case management to be slightly less intensive, to give clients time to adjust to and integrate changes and to manage changes in circumstances and health and to allow more time for case managers to build strong relationships with other services and do more linking.

It felt rushed. It would be better if there was a longer time, more of a chance to get used to the changes and learn as you go. (Client 1)

Stakeholders consistently highlighted the need for long-term case management for this client group.

History has shown us that us going in and doing the clean is useless ...if you don't get help to work with the underlying issues, nothing we do is going to make a difference (Stakeholder6)

I have had to personally hire a skip and go over and help fill it up. That is a bandaid solution; it's not addressing the underlying problem, even if it does help to address some of the pressures in the short-term like if their tenancy is at risk (Stakeholder 1)

A strong case management focus is important and it has to address real and underlying issues, not just the need for cleaning. There are a whole range of issues and if they're not looked at and addressed, they will undermine the person's ability to engage successfully with the program (Service Provider 2)

Support plans and relapse prevention plans

Support plans were developed with each client. Goals were outlined and broken down into achievable steps. Plans were modified as needed and achievements and barriers noted. Exit and relapse prevention plans included a list of contacts and steps to undertake if feeling unwell or not managing.

Staff Skills & mental health training

Stakeholders and the service provider agreed that case managers need to be highly skilled and resilient. The importance of creating a very supportive and well-functioning team, well supported through training and supervision was also repeatedly pointed out. Teams of people working together were seen as essential as the nature of the work is too confronting, intense and at times unsafe for individual workers on their own to address.

Mental health skills and training were seen as very important, though staff do not necessarily have to have mental health qualifications. One client with serious mental health and physical health issues also a carer, commented on the skill of the workers:

I'm a very private person. I was terribly embarrassed with all the mess I'm in. I knew the staff and felt comfortable with all of them. I said yes because of the way [staff member] explained it. She understood my embarrassment, my need to do it my way. She patiently addressed my

concerns.... *If she hadn't been able to do that I wouldn't have been able to participate (Client 4)*

Issues

Clients raised two major issues which caused them distress or hampered the sustainability of outcomes for them. These issues were recognised by NCS as needing further development and also highlighted by other stakeholders as vital to the success of any program addressing severe domestic squalor.

Length of time of engagement

Based on the experience of stakeholders and the experience of the Severe Domestic Squalor (SDS) project (McDermott & Gleeson, 2009) a much longer program is needed for clients to be able make and sustain necessary changes. Initial periods of potentially lengthy and intense service delivery are to be expected. NCS recognised this is their May 2011 progress report;

It has become very clear that this client group require long term intense support in order to address all the issues that impact on their ability to live independent lives and be part of their community. The five months allocated to this program will not be enough to sustain the improvements...staff have only just scratched the surface (Aged and Disability Services, 2011).

The Sydney SDS project evaluation suggested a minimum of 18 months of intensive support is needed by many people (McDermott et al, 2009a). Housing ACT staff, Child Protection and Karralika (Drug & Alcohol rehabilitation services) also recognised the need for longer term engagement.

We are asking people to change significant and entrenched behaviour. And if we don't have the resources to support that we might be back at square one in 18 months looking at possible eviction. (Stakeholder 6)

Two out of five clients emphasised that the program had ended too soon for them. Those two clients also commented that they felt they had lost ground or that their situation had deteriorated in some way since cessation of the program, though one still rated their progress very highly:

It ended too soon, if it even went for a few months longer it would have made a lot of difference. I didn't cope with the program ending and with the transition very well (Client 1)

I could really do with that support again. Now, I know I'm in a pickle but I'm too tired to get out of it. I need support to sustain the changes. The program needs to be much longer. 18 weeks was good but not nearly long enough. I feel I've made some progress but there is still a long way to go. I do feel I've gone downhill again and haven't been able to maintain tidiness (Client 4).

One person felt that the program ended too suddenly and that this had precipitated a serious decline in her mental health when she was just beginning to make progress.

I still feel more confident but at the same time I sometimes still feel anxious. I haven't really been able to keep my house the way I want to. I need to learn more about how to keep things in order and stuff. On the program they did try to teach us to keep things in order but it was too short. Need that for longer. (Client 1)

Housing ACT also provided informal feedback from a participant who did not consent to be interviewed as part of this review. That client had also experienced a sharp decline in household conditions and was 'well on the way' to being back in a situation of squalor. The client did not cope well with the end of the program and the reduction in support, despite having known that this would occur from the outset. This demonstrates how important long term consistent engagement is and how difficult it is for people when they are finally successfully engaged and making some positive changes in their lives, to then have to cease or change their engagement.

Partnerships, Collaboration and Referrals

The second concern raised by clients, NCS and stakeholders centered on collaboration, partnerships and linking with other specialist support services. One client said she required support from Mental Health services and indicated that NCS had unsuccessfully tried to link her with an agency. NCS similarly identified that they had had limited success in linking clients with specialist agencies to enable ongoing sustainable support, particularly in the area of mental health and support with drugs and alcohol issues. Stronger partnerships would ideally facilitate warm and gradual referrals when needed and widen the support networks available to clients, a vital

avenue to address isolation and weak informal support networks. Partnerships may also be built so that they could accommodate the need for episodes of care, engagement and re-engagement.

Future directions

Views of service users and stakeholders largely concur around important features of the HHHM model for addressing severe domestic squalor. This review of the HHHM program indicates the potential for a high quality holistic, long-term, case management model coupled with domestic support to improve engagement and outcomes for a highly vulnerable client group living with multiple and complex needs. Though difficult to quantify, the need for such a service is clearly evident. The potential risks associated with not addressing severe domestic squalor through focused, adequately resourced and skilled service provision are many; increased risks of eviction and homelessness, premature admission into residential and crisis care facilities, increased fire and safety risks, infrastructure and renovation costs to Housing ACT, and very high costs to the safety, quality of life, health, mental health and wellbeing of those individuals concerned and their communities.

Service coordination and partnerships

NCS and stakeholders had a range of suggestions regarding partnerships to address squalor. The need to work on mechanisms to improve capacity for early intervention in situations of severe domestic squalor rather than later intervention at the point of complete breakdown or eviction was raised a number of times. Stakeholders and NCS also pointed out the potential for Housing ACT to act as the referral source and to provide the statutory motivation where necessary to increase engagement with support services. The HHHM and SDS experiences point to the utility of having a community or non-government agency engage in a more supportive 'boots and all'

role with clients whilst government agencies play a contractual and monitoring role. Community organisations also have the capacity if adequately funded to provide more intensive support than a government agency, partly due to client/staff ratios and partly due to the absence of the statutory or contractual role. This statutory role can create additional barriers to supportive engagement and create role confusion for both clients and staff.

Stakeholders identified that Housing ACT is often the first agency to become aware of squalor either through its annual (or sometimes more frequent) inspections or through complaints. Housing ACT is therefore more able than most other agencies to identify and monitor situations of potential and severe domestic squalor, though this identification and monitoring role is far from straight forward. There are many ways in which inspections can be hampered or delayed, however, Housing ACT as the Landlord are legally entitled to inspect their properties twice yearly. Annual visits are the usual practice unless there are concerns or a court order stipulating more frequent visits. Housing ACT have recourse through the Administrative Appeals Tribunal to gain temporary (usually a 4 hour period is granted) access to an 'inaccessible' property under certain circumstances.

Complaints also can indicate a situation of severe domestic squalor particularly when squalor has spread beyond the walls of the home and affects neighbours due to hygiene or safety issues, pest infestations, neglect of children, and ill-treatment of animals or build up of garbage. Housing ACT and other stakeholders all noted that squalid living conditions can rapidly deteriorate, so regular monitoring of complaints reports and the enhancement of referral and support mechanisms for Housing ACT staff to call on in situations of concern are important. In each of the 3 Housing ACT regions, Housing Managers and Client Support Coordinators are likely to become aware of situations of serious and severe domestic squalor and may be in a position to negotiate or via court order – necessitate referral and engagement to support

services. In order for this to work effectively, referral mechanisms, roles and responsibilities need to be explicit and agreed on.

Other considerations for referral and service coordination mechanisms suggested by stakeholders include;

- A panel model similar to the connecting families panel model currently used where there are child protection concerns
- Development of formal MOU's between service providers like NCS and Mental Health, Housing ACT, alcohol and drug services and child protection.
- Sharing of expertise and advice with others through informal and formal forums (i.e. networks, training, seminars, interagency meetings)
- Formal service partnerships such as a proposed partnership between NCS and ACT Home Help to better address the dual roles involved (case management and domestic support) – see appendices
- service coordination of multiple services through a lead agency
- access to brokerage funds for ancillary & support services (skips, major cleaning other interventions appropriate to individual client needs and support plans. Stakeholders commented that access to brokerage funds was vital to the success of the Integrated Family Support project.

Data Collection

Collection of data across a number of key agencies would help to clarify the extent of squalor, the current costs associated and help to identify areas of priority. Analysis of complaints to Housing ACT and reports by Client Support Coordinators which identify squalor as an issue would help to identify the number of ACT Housing clients affected by severe domestic squalor. Discussions between agencies such as Mental Health, drug and alcohol services and Child Protection and HACC funded services such as ACT

Home Help around data collection would also help to move towards a shared understanding and hopefully greater consistency in data collection, provide a clearer picture of the numbers of people affected by squalor and any demographic or geographic characteristics which would enable more effective planning and policy development.

Proposed NCS & ACT Home Help Squalor Model

Building on the experience of both agencies in working with people living in severe domestic squalor, NCS and ACT Home Help have begun discussions around a potential joint service model. The model is based on the HHHM pilot; however ACT Home Help would be engaged from the beginning with providing Domestic Support services in close cooperation with NCS Case Managers. Two NCS case managers and two ACT home Help domestic support workers would work closely together to provide the holistic services and support offered by the HHHM, in a more sustainable and ongoing project.

Conclusion

Despite the small size of the project, the HHHM pilot showcases a potentially effective model for working with people living in severe domestic squalor. The pilot also serves to highlight a gap in service delivery for a highly vulnerable client group with complex and unmet needs. Key services in the ACT identify a noticeable gap in services to meet the needs of this extremely isolated client group. Services concurred that the HHHM pilot model utilised important key features to be included in a service for people living in severe domestic squalor. Based on their experiences of working with this highly vulnerable client group, they agreed with NCS's emphasis on holistic, responsive, long-term case management linked with practical domestic support. In

conclusion, the issue of providing services for people living in severe domestic squalor in the ACT warrants further investigation and urgent attention.

References

- Aged & Disability Services (2011), "Squalor Management Program (pilot) Healthy Home Healthy Me- Independent Living Skills Program Submission", Aged & Disability Services, Northside Community Service, Canberra
- Case Management Society of America (CMSA), 2008 "What is a case manager?" see <http://www.cmsa.org>
- Dyer, C.B Goodwin, J.S., Pickens-Pace, S., Burnett, J., Kelly, P.A., (2007), "Self-neglect among the elderly: A model based on more than 500 geriatric patients seen by a geriatric medicine team", *Research and Practice*, 97(9), 1671-1676
- Frost, R. P. (2010) "Types of Hoarding." International OCD Foundation, <http://www.ocfoundation.org/hoarding/types.aspx>.
- Gershater-Molko, R. M., Lutzker, J. R., & Sherman, J. A. (2003). Assessing Child Neglect. *Aggression and Violent Behavior*, (8) 6, 563-585
- Halliday, G., Benerjee, S., Philpot, M., & MacDonald, A.(2000)" Community study of people who live in squalor". *The Lancet*, 355(9207), 882-886
- Halliday, G. and S. Banergee (2003). "Community Study of People Living in Squalor". *The Eleventh International Congress, International Psychogeriatric Association*. Chicago, USA, IPA.
- Horvath, A. (2001). "The Alliance". *Psychotherapy: Theory, research, practice, training*, 38(4), 365-372.
- Howard, G. S., Ralph, K. M., Gulanick, N. A., Maxwell, S. E., Nance, D., & Gerber, S. L. (1979). Internal invalidity in pretest-posttest self-report evaluations and the re-evaluation of retrospective pretests. *Applied Psychological Measurement*, 3, 1-23.
- Lambert, M., & Okiishi, J. (1997)." The effects of the individual psychotherapist and implications for future research". *Clinical Psychology:Science and Practice*, 4(1), 68-75.
- Lauder, W., Roxburgh, M., Harris, J. , Law, J., (2009) "[Developing self-neglect theory: analysis of related and atypical cases of people identified as self-neglecting](#)", *Journal of Psychiatric and Mental Health Nursing*, 16, (5): 447-454, June 2009
- Lawrence, R & Irvine, P., 2004, "Redefining fatal child neglect," *Child Abuse Prevention Issues*, Volume 21, <http://www.aifs.gov.au/nch/pubs/issues/issues21/issues21.html> [acc.08/01/2010]

Lutzker, J. R. (1990). Behavioral Treatment of Child Neglect. *Behavior Modification*, (14), 301-315

Halliday, G. and S. Banerjee (2003). Community Study of People Living in Squalor. The Eleventh International Congress, International Psychogeriatric Association. Chicago, USA, IPA.

Muesser, K. T., G. R. Bond, et al. (1998). "Models of community care for severe mental illness: A review on research on case management." Schizophrenia Bulletin **24**: 37-74.

PAH (2007). Guidelines for field staff to assist people living in severe domestic squalor, PAH (Partnership Against Homelessness).

Smith, L. and R. Newton (2007). "Systematic review of case management." Australian and New Zealand Journal of Psychiatry **41**(1): 2-9.

Ziguras, S. J. and G. W. Stuart (2000). "A Meta-Analysis of the Effectiveness of Mental Health Case Management Over 20 Years." Psychiatry Services **51**(11): 1410-1421.

Appendix

Questions for Qualitative Interviews with service users

1. How did you find out about the Healthy Home Healthy Me project?
2. What was the most helpful part of the Healthy Home Healthy Me project for you?
 - Can you give an example of something in your life that has changed since you participated in this project that you feel good about?
3. How did it help you?
 - Have there been positive changes in your life since participating in this project?
 - Have you been able to sustain those changes?
 - What help do you need to continue to sustain them?
 - Contact/referral to other services?
4. What did you like about the Healthy Home Healthy Me project?
5. What didn't you like?
6. What kind of help do you think people/families in your situation need?
7. What's next for you?

Questions for Qualitative Interviews with services/stakeholders

1. How many people, (individuals, families, people with children) does your service come into contact with living in squalor?
 - How many children who are neglected or at risk of neglect does your service come into contact with who are living in squalor?
 - What is your understanding of the links/relationship between squalor and neglect of children, if any?
2. Do you know about the Healthy Home Healthy Me pilot project?
 - How did you find out about it?
 - What is your perspective on the intensive case management model piloted by NCS?
3. What services does your organisation currently provide for people living with severe domestic squalor and chronic hoarding?
 - Are you able to address their needs?
4. What are the key needs of people living in squalor?
 - What are the needs of their children?
5. Referral processes and sources
 - How does your service come into contact with people living in squalor and who refers them?
 - Who do you refer to?
 - How do you work with other services to address needs?
6. What helps people living in squalor?
 - How might your service work with particular groups? (ATSI, CALD, mental health issues, drug and alcohol issues, Parents with young children)
7. What needs to be done to better address their needs?
 - What would help your agency to better address these needs?
 - Most important elements of a service model to address these needs
 - Service collaboration and networks
 - Programs
 - Policy