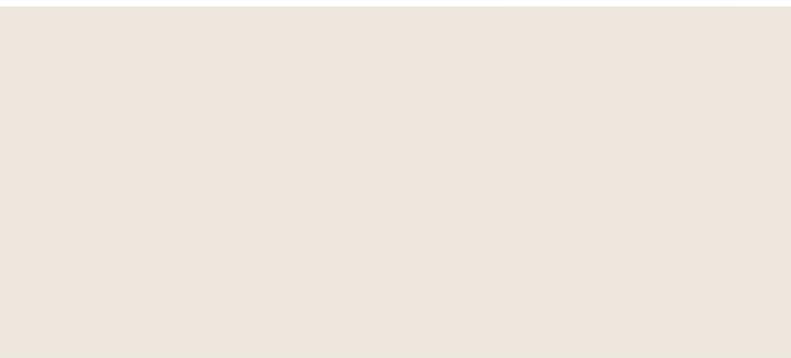




catholic community services

Evaluation of the Severe Domestic Squallor Project: Final Report



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Abbreviations

ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
CACP	Community Aged Care Package
COPS	Community Options Program
DADHC	NSW Department of Ageing, Disability and Home Care
DoCS	Department of Community Services
ECCS	Environmental Cleanliness and Clutter Scale
LGA	Local Government Area
OHS	Occupational Health and Safety
SDS	Severe Domestic Squalor Project
SPRC	Social Policy Research Centre
UNSW	University of New South Wales



EXECUTIVE SUMMARY

1. EXECUTIVE SUMMARY

1.1 Background

The Social Policy Research Centre at the University of New South Wales was commissioned by Catholic Community Services (a division of Catholic Healthcare) to evaluate the Severe Domestic Squalor Project (SDS). The Project aims to: facilitate holistic assessment and support for people who are living in squalor; foster sustainable solutions for clients; and to educate service providers working in the community about how to respond when situations of squalor are encountered. This report uses a logic model framework to assess the outcomes experienced by clients who have exited from the Project, learning outcomes from the service model, and compares the costs of the Project to the outcomes. A mixed method approach was used which included: an analysis of program data collected upon referral, entry into and exit from the Project; interviews with 12 stakeholders and eight clients; analysis of expenditure data; and an analysis of training evaluations. This is an important piece of research as it is the first in Australia to systematically collect evidence about the consequences associated with living in squalor, as well as the benefits of targeted support for people in these situations.

1.2 Key findings

Profile of referrals

SDS surpassed its commitment to DADHC to provide services to 157 clients during the one year pilot: 218 people were referred to SDS between 1 August 2008 and 31 July 2009. Analysis of the demographic profiles showed that:

- Referrals were 55 per cent male and 45 per cent female and were, on average, 62 years of age. A little over half of the referrals (58%) were younger than 65 years of age.
- Referrals were received from 12 services; the largest number of referrals was received from Housing NSW (20%), followed by Home and Community Care (17%), Community Mental Health (17%), and Community Health (12%). This reveals that situations of squalor are problematic for a diverse array of organisations.



- SDS received referrals from 17 local government areas. The highest number of referrals came from Sydney local government area (33%).
- People referred to the Project lived in a mix of public housing (54%), privately owned homes (39%) and rental accommodation (7%). The large proportion of people in public housing suggests that this is a complex group with multiple sources of disadvantage.
- Over one third (41%) of people referred to the Project lived in insecure accommodation as a result of living in squalor.
- Of the 218 referred clients, 208 were assessed by 31 July 2009 and 53 per cent (n=110) were accepted for further service. Of those who were not accepted, 18 per cent refused services and 13 per cent required immediate placement or hospitalisation.
- Clients accepted into the Project experienced a number of consequences associated with living in squalor: 85 per cent experienced safety risks, 71 per cent were unable to receive services, 54 per cent were isolated, and 41 per cent had an insecure tenancy.
- People who were accepted into SDS were more likely to experience safety, health and fire risks and to have an issue with hoarding. They were also more likely to be denied access to services due to OHS concerns.
- People who were not accepted were more likely to be over the age of 65, to have age related problems or cognitive impairments, as well as poorer physical and mental health. This indicates that people with these characteristics were less appropriate for SDS services, because it was felt that sustainable solutions could not be achieved where they currently lived. Even though they were not accepted, SDS was involved in organising other interventions for these people, such as guardianship or placement in more appropriate accommodation.

Client outcomes

SDS provides holistic assessments for people living in squalor. People who are willing to cooperate in the intervention and for whom a sustainable solution can be found are accepted for further intervention. Interventions are focused on three key areas: reducing the consequences associated with squalor; addressing any underlying impairments; and improving client's living conditions. As a result, clients are expected to experience positive changes in social contact and community participation. Baseline and exit information on these key indicators was available for 57 clients. The findings show that:

- As a result of their involvement with SDS, clients experienced a significant decrease in the number of consequences experienced as a result of living in squalor.
- They were significantly less likely to experience safety, health and fire risks and to be denied access to services due to OHS risks. They were also less isolated from the wider community, and had lower risk of being evicted from their current home. These outcomes are important given the current policy environment which emphasises homelessness prevention and social inclusion (NSW Government, 2009).
- SDS achieved greater involvement from agencies that can appropriately address underlying issues experienced by people living in squalor. Clients leaving SDS recorded higher levels of involvement across most service areas, particularly community services (21% increase) and aged care services (18% increase).
- Although service coordination is an essential element of fostering sustainable solutions, working together was impeded by conflicting definitions of risk and autonomy; strict service boundaries between human service agencies; and the time consuming and costly nature of interventions.
- Upon entry, client property conditions were extremely poor: 11 per cent of the sample did not have functioning running water and 16 per cent did not have functioning lighting.
- The living conditions of SDS clients at baseline were poorer than those of Aboriginal and Torres Strait Islanders, who are widely recognised as one of the most disadvantaged groups in Australia. The most comparable statistic to the

data collected by the Project is that of functioning kitchen facilities: five per cent of Indigenous Australians do not have working facilities for preparing food, as compared with 23 per cent of the SDS clients (Australian Bureau of Statistics, 2002; Australian Institute of Health and Welfare, 2004).

- Client living conditions improved significantly over the course of their involvement with the Project; clients had a significant decrease in global ECCS scores. They also experienced a 29 per cent increase in access to their kitchen areas, and 23 per cent increase in access to sleeping areas.
- As a result of the reduction in consequences associated with squalor, changes in living conditions, and increased service involvement, clients experienced other changes in their lives:
 - Social contact improved considerably for clients leaving SDS, of whom 81 per cent were reported to have a regular support network. This represents a 14 per cent increase on baseline measures.
 - Clients experienced a 21 per cent increase in employment related activities (to a total of 31% of the sample) and a 12 per cent increase in volunteering.

Community education

In addition to services provided to clients, SDS aims to educate the broader community about how to respond to situations of squalor by providing advice on a squalor hotline and running training sessions. SDS was contracted by DADHC to provide 30 training sessions for a maximum of 600 people.

From 1 August 2008 - 30 July 2009, the Project ran 32 training sessions for a total of 748 participants. Participants had largely positive responses to the training, and reported that the sessions were clear, well presented and relevant to participants' work. An estimated 1000 calls for advice was also received on the squalor hotline. This confirms that SDS provided a substantial amount of education to the community and exceeded its obligations to DADHC.

Service model

This section of the report draws on qualitative data from the 12 stakeholder interviews and eight clients to assess the benefits and limitations of SDS service model and the role SDS plays in the broader service system. Financial data also analysed and compared to the outcomes of the project to determine the costs and benefits of SDS. The analysis shows that:

- Benefits of the model include the provision of individual, flexible, holistic, ongoing and expert support. Another benefit is the development of partnerships with existing services.
- The Project was limited by a lack of resources. Furthermore, sustainable solutions could not be achieved for all clients because SDS could not link people in with the appropriate supports.
- Other challenges facing the Project centred on the degree of risk that is acceptable in situations of squalor. Further discussions within the broader community are required to gain consensus around whether living in squalor in the community constitutes an acceptable risk.
- All stakeholders and most clients believed the Project fills an important gap in the service system. Without it, stakeholders were concerned that people living in squalor will again be subject to short term, unsustainable interventions and that partnerships between services will be jeopardised.
- SDS support cost \$2427 per accepted client; each training session cost about \$700 per session. The expenditure has resulted in strong positive outcomes for clients of the Project.
- If the Project is refunded, it will require more sustainable staffing levels as the Project deals with some of the more complex situations in the community. For this reason, a baseline cost of \$4000 per client is both more realistic and still inexpensive for the government.

1.3 Recommendations

Service model

This evaluation has shown that people living in squalor can have complex issues and that the situations can result in difficult ethical dilemmas for professionals. Service models best suited to address situations of squalor should include the following elements:

- Case management;
- Service coordination;
- Flexible and individualised support;
- Ongoing support;
- Holistic assessment and support;
- Staff supervision;
- Sharing expertise and advice with others through both formal and informal approaches (e.g. training and telephone advice); and
- Sustainability.

Service principles

- Successful interventions in situations of squalor should be based on the following principles:
- Respect for clients and non-judgemental attitudes.
- Develop trust and rapport.
- Move slowly and do not expect that living situations will change overnight. 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.

The future of SDS

The prevention and reduction of homelessness is a current government priority and the NSW government has recognised that addressing severe domestic squalor is an important element of reducing tenancy evictions. SDS has been successful in reducing housing insecurity, linking clients with appropriate services, and improving living conditions. Without receiving recurrent funding it is unlikely that:

- Situations of domestic squalor in Sydney can be addressed sustainably;
- The implementation of the Severe Domestic Squalor Guidelines will be effectively achieved; and
- Evictions and housing insecurity in situations of squalor will be systematically reduced.

1.4 Conclusion

SDS not only met its contractual obligations to DADHC but provided high quality services to an underserved and vulnerable group of people. A commitment of further resources is needed to sustain the changes that have been measured in this evaluation and to provide others in the community with access to this unique service.



INTRODUCTION

2. INTRODUCTION

The Severe Domestic Squalor Project (SDS) is a one year pilot project run by Catholic Community Services and funded by the NSW Department of Ageing, Disability and Home Care (DADHC). The Project aims to provide support and assistance to people who are living in environments that are so unclean that their health, ability to receive services, or their ability to live independently in the community is jeopardised.

The Social Policy Research Centre (SPRC) was contracted by Catholic Community Services, a division of Catholic Healthcare, in 2008 to conduct an independent evaluation of SDS. The research aims to understand the outcomes experienced by clients as a result of their involvement with the Project, the effectiveness of the service model, and the extent to which the community training sessions met their stated aims.

This report provides a profile of all 218 people who were referred to SDS between 1 August 2008 and 31 July 2009, and assesses the outcomes experienced clients who had exited from SDS by the end of this period. The effectiveness of the service model, including changes that emerged in the wider service system as a result of the Project, is analysed, along with a comparison of the costs of the Project to the outcomes, and an assessment of the community education sessions. Finally, the report makes recommendations about the SDS service model and its future role in the service system.

2.1 Squalor within the broader context

The concept of domestic squalor is unique to the Australian context (Halliday et al., 2000) but it has considerable overlap with two other concepts that are used internationally: those of self neglect and Diogenes Syndrome. Self neglect is a term used in the US to describe "older persons with multiple deficits in social, functional and physical domains and who in extreme circumstances live in squalor" (Dyer et al., 2007: 1671). In 37 US states, self neglect is categorised as a type of elder abuse that professionals are mandated to report to their local Adult Protective Service organisation for investigation (Hailstones, 1992; Lustbader, 1996). In some of these states, criminal penalties can be enacted against professionals who fail to report (American Bar Commission on Law and Aging, 2005).

The term Diogenes Syndrome was coined in medical literature in the UK and is used to refer to older people living in the community who deviate from societal standards of cleanliness and hygiene. Some medical researchers have concluded that Diogenes Syndrome is a distinct medical syndrome (Clark, 1980; Clark et al., 1975; MacMillan and Shaw, 1966; Pavlou and Lachs, 2006; Pickens et al., 2006). Professionals in the UK are not mandated to report people who are believed to be suffering from Diogenes Syndrome, however professionals can use Section 47 of the National Assistance Act 1948 to compulsorily remove people who are older or physically incapacitated, living in unsanitary conditions and who are not caring for themselves from their homes (Forster and Tiplady, 1980; Shah, 1995b).

The Australian context differs from both the US and the UK. In Australia, discussions focus on squalor and hoarding rather than self neglect (McDermott, 2008). In addition, self neglect or squalor are not included as a form of elder abuse, which is defined as occurring within a relationship of trust (Hailstones, 1992; Kurrle and Sadler, 1994). In no cases can older people be removed from their homes against their wishes without first gaining a legal ruling that they are not capable of making decisions about their personal affairs (Bennett and Hallen, 2005). Shah (1995b) argues that some situations of squalor can be addressed through the use of legislation such as the state equivalent of the Mental Health Act or Public Health Act, however, these acts are not directly applicable to all circumstances of squalor.

Due to the growing frustration about the lack of a legislative framework to address these situations, professionals in many communities across Australia have begun to coordinate their responses to squalor. In NSW, service providers from a diversity of organisations such as DADHC, Housing NSW, local councils, and community health came together in Sydney in 2005 to develop guidelines about how to respond to severe domestic squalor (Partnership Against Homelessness, 2007; Snowdon et al., 2007). DADHC has incrementally increased its funding to support organisations that provide services to people living in squalor; in 2005, the Community Options Program (COPS) at the Benevolent Society in Sydney was provided funding to provide

case management and received additional funding in 2007 to provide cleaning services in these situations (McDermott et al., 2009b). In 2008, DADHC provided funding to Catholic Community Services to implement the pilot project that is evaluated in this report. They were contracted to provide services to 157 clients and 30 training events for groups of 8-20 people.

2.2 SDS role and service framework

SDS serves a large region, including the local government areas of: Ashfield, Botany Bay, Hornsby, Hunter's Hill, Ku-ring-gai, Lane Cove, Leichhardt, Manly, Marrickville, Mosman, North Sydney, Pittwater, Randwick, Ryde, Sydney, Warringah, Waverly, Willoughby, and Woollahra. SDS employs one manager and two case workers and is guided by a steering committee which is composed of professionals from various community organisations.

SDS has three primary objectives:

1. Facilitate assessment and support for people who are living in squalor;
2. Foster sustainable solutions for clients; and
3. Educate service providers working in the community and other gatekeepers (such as postal workers and meals on wheels) about how to respond to situations of squalor.

Project staff conduct a holistic assessment on each person who is referred to SDS. Assessments take into account the length of time people have been living in squalor; the structural integrity of the dwelling; health and safety risks for the client and other services; and the needs of neighbours and the wider community. The decision about whether to intervene and which intervention is most appropriate is made based on the person's level of cooperation, as well as their health, age, social support, future plans and financial circumstances. In addition, staff make decisions about the potential for interventions to be sustained into the future, which includes considering whether the environment can be consistently maintained by the client and/or mainstream support services over time; and whether



any underlying physical or mental health impairments that impair daily functioning can be sufficiently addressed. An important element of addressing any underlying impairments or outstanding problems people are experiencing as a result of living in squalor (such as eviction or legal action) is to build partnerships with other services in the community.

In addition to services provided to people referred to the Project and to clients, SDS aims to build community capacity about how to respond to situations of squalor. To this end, staff give advice to members of the community through a 1800 squalor hotline, which acts as a single point of access for enquires and referrals, and also present training sessions to organisations in the community that work with situations of squalor in their daily practice.

2.3 Methodology

The four specific aims of this evaluation are to:

1. Determine the outcomes for clients who are served by SDS;
2. Evaluate outputs and effectiveness of the training sessions held by staff at SDS;
3. Assess the service model implemented by SDS and identify the learning outcomes from this model; and
4. Identify good practice case studies of working with people who live in severe domestic squalor.

These aims were met through a mixed method approach which included analysis of program data collected upon referral, entry into and exit from the Project, interviews with 12 stakeholders and eight clients, analysis of expenditure data, and analysis of training evaluations. This is an important piece of research as it is the first in Australia to systematically collect evidence about the consequences associated with squalor, as well as the benefits of targeted support for people living in these situations. The methodology is described in further detail in Appendix A.



DEMOGRAPHIC PROFILE OF REFERRALS

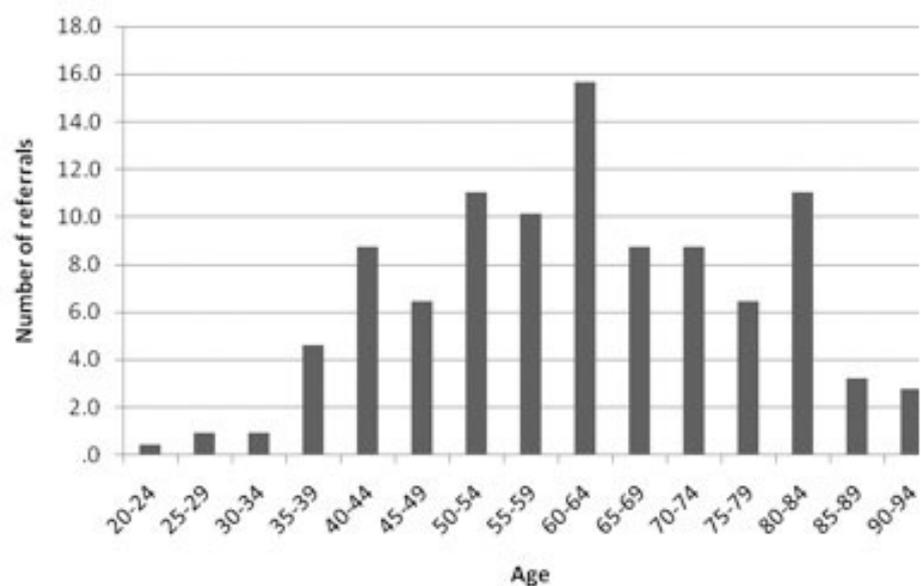
3. DEMOGRAPHIC PROFILE OF REFERRALS

A total of 218 clients were referred to SDS since the Project commenced in August 2008. This section examines the characteristics of all referrals and those who were accepted for further services. The aim of this section is to develop an improved understanding of the group of people who were referred to the Project.

3.1 Age and gender

Just over half of the referrals to the Project were male (56 per cent, n=121) and the average age was 62 years old. People referred to the Project ranged between 21 to 94 years of age, and a little over half (58%; n=168) were younger than 65 (Figure 3.1; data missing on one referral). This finding challenges literature from the United States, which argues that self neglect is more common among older people, and supports the conclusion that self neglect and squalor occur just as often in people under the age of 65 (Halliday et al., 2000; Shah, 1995a; Snowden, 1987).

Figure 3.1: Age Distribution of Referrals (n=217)



3.2 Referrals

SDS received referrals from a variety of government and non government organisations. Housing NSW made the largest number of referrals of any agency (20%) followed by Home and Community Care (17%), Community Mental Health (17%), and Community Health (12%) (Table 3.1). The high numbers of referrals that came from human service agencies suggests that situations of squalor are problematic for a diversity of organisations, and that the current service system is not coping well with the complexity that is inherent in situations of squalor. This is discussed more fully in Section 5.

Table 3.1: Client Referrals by Agency (n=218)

Agency	Number referred (n)	% of total referrals
Housing NSW	44	20
Home and Community Care	37	17
Community Mental Health	36	17
Community Health	25	12
Hospital inpatient services	21	10
Other Community Service*	20	9
Aged care package provider	10	5
Family	8	4
Self	7	3
General Practitioner	2	1
Neighbour	2	1
Rental Management	2	1
Not recorded	4	2
TOTAL	218	100

Source: SDS Project data

Notes: Agencies reporting no client referrals included; Police, EACH, Postal Workers, Fire Brigade, Ambulance Services

* Community/Neighbourhood Centres, Meals on Wheels

SDS received referrals from 17 of the 18 Local Government Areas (LGAs) that it covers. The largest number of referrals (33%) came from the Sydney Local Government Area (LGA) (Table 3.2). The spread of referrals demonstrates that squalor is an issue that has been encountered in most LGAs in the Sydney Metropolitan region.

Table 3.2: Client Referrals by Local Government Area (n=218)

Local Government Area	Referrals (n)	% of total referrals
Sydney	73	33
Warringah	17	8
Hornsby	16	7
Randwick	14	6
Ryde	13	6
Marrickville	12	6
Lane Cove	9	4
Waverley	8	4
Leichardt	8	4
Botany Bay	8	4
Manly	8	4
North Sydney	8	4
Mosman	5	2
Ku-ring-gai	5	2
Willoughby	5	2
Pittwater	4	2
Ashfield	2	1
Woollahra	2	1
Unknown	1	1
TOTAL	218	100.0

Source: SDS Project Data

Notes: No referrals were made from the Hunters Hill LGA

3.3 Housing and living situation

Upon referral to the Project, 54 per cent (n=118) of clients lived in public housing, followed by clients living in privately owned properties (39%; n=84). Only a small number of people referred to the Project lived in private rental properties (7%; n=16). This is a noteworthy finding, given that 20 per cent of the Australian population live in rental accommodation (Australian Bureau of Statistics, 2000). Furthermore, tenants of Housing NSW are over represented in the referrals, as only five per cent people in the general population live in public housing (Australian Bureau of Statistics, 2000). These statistics suggest that this is a complex group who have multiple sources of disadvantage and, as a result, are excluded from the private rental market. The stigma associated with living in squalor is likely exacerbated by lists of

bad tenants, such as the National Tenancy Database, which allows landlords to identify people who do not care for their properties or who are frequently in arrears. As a result of living conditions and other markers of disadvantage, people living in squalor are likely to experience housing insecurity. Indeed, 41 per cent of people referred to the Project (n=87) were rated by staff as having an insecure housing situation as a result of living in squalor.

Only 15 per cent of people referred to the Project lived with others, while the vast majority (85%; n=186) lived alone. There was no significant difference in the living situations of those under 65 (85% live alone) from those over the age of 65 (89% live alone). This mirrors some studies on self neglect in the US which suggest that this group of people are more likely than the general population to live alone (Byers, 1993; Clark et al., 1975; Dyer et al., 2007).

3.4 People who were not accepted to SDS

Out of 218 referrals, 208 clients had been assessed by SDS by 31 July 2009, and about half of people referred (53%; n=110) were accepted into the Project for further services (Table 3.4). People were most commonly not accepted because they refused services (18%) or required immediate hospitalisation or placement into an aged care home (13%).

Table 3.3: Client Selection Status (n=208)

Client selection	Number	% of assessed referrals
Accepted	110	53
Client refusal	37	18
Placement or hospitalisation required	27	13
Not squalor	16	8
Other service in-situ	16	8
Evicted	2	1
TOTAL	208	100

Source: SDS Project Data

Each referral involved a time consuming assessment process, which involved building trust with people who were referred so staff could determine whether they needed and would accept further services and, if so, to determine whether a sustainable situation could be reached. In many cases, building trust occurred over months and required multiple visits to client homes. Thus, SDS performed a valuable role even for those who were not accepted to the Project.

People who were accepted for further services differed in relation to their levels of cooperation; consequences experienced as a result of squalor; housing situation; contributing factors; and age. First, people accepted into the Project recorded substantially higher levels of cooperation with the intervention than those who were not; 65 per cent of clients accepted exhibited some or full cooperation compared with only 29 per cent of people who were not accepted. Apart from cooperation, people who were accepted experienced a higher frequency of adverse consequences as a result of living in squalor. Table 3.4 shows that clients of SDS were more likely than those not accepted to experience: safety, health and fire risks; isolation; and insecure tenancy; and were unable to receive services.

Table 3.4: Primary Consequence of Squalor against Acceptance (n=208), per cent

Primary consequence	Accepted (%)	Not accepted (%)
Safety risk (trip/falls/hazards)	85	70
Health risks	78	70
Unable to receive services*	71	55
Fire risk	65	57
Isolation	54	40
Eviction risk	45	38
Neighbour complaints	27	36
Consumer Tenancy Tribunal	12	12
Council orders	10	9
Legal issues	10	6

Source: SDS Project Data

Notes: Taken as a percentage of each category. Accepted (n=110), Not accepted (n=98)

Percentages equal more than 100 due to clients presenting multiple primary consequences of squalor

*As a result of Occupational Health and Safety (OHS) concerns

Those accepted to the Project were slightly more likely than those not accepted to occupy public housing and less likely to live in private residences (Table 3.5). This is likely because, unlike in privately owned accommodation, Housing NSW and private landlords have the direct authority to require their tenants to clean up.

Table 3.5: Type of Residence against Client Acceptance to SDS (n=208), per cent

Type of residence*	Accepted (%)	Not accepted (%)
Public housing	59	49
Private (owned)	36	42
Private (rental)	6	9
TOTAL	100	100

Source: SDS Project Data

*Taken as a percentage of their overall categories. Accepted (n=110), Not accepted (n=98)

The factors contributing to squalor also differed across the two groups. This measure is not based on a formal clinical assessment but was recorded by project staff. Thus, the measure is subjective, but it does provide an indication of the types of impairments experienced across this group. Clients who were accepted to SDS recorded higher levels of hoarding, mental health problems, and health impairments than people who were not accepted. People who were not accepted into SDS were more likely to have an age related and cognitive impairments (Table 3.6).

Table 3.6: Primary Contributing Factor to Client Squalor (n=208), per cent

Primary contributing factor	Accepted (%)	Not accepted (%)
Hoarding	58	43
Mental health problem	51	41
Health impairment	39	30
Age related impairment	16	21
Cognitive impairment	11	13
Drug and alcohol	11	19
Frontal lobe impairment	7	13
Disability	6	2
Unknown	5	6

Source: SDS Project Data

Notes: Taken as a percentage of their overall population categories.

Accepted (n=110), Not accepted (n=98)

Percentages equal more than 100 due to clients presenting multiple primary contributing factors of squalor

The health and mental health status of people referred to SDS was relatively poor (Table 3.7); 62 and 73 per cent of clients accepted to the Project were believed to have poor or very poor physical and mental health; these ratings were slightly worse for people who were not accepted, which may be reflective of the fact that 13 per cent required immediate hospitalisation after assessment.

Table 3.7: Physical and Mental Health Status against Acceptance (n=174), per cent

	Physical Health		Mental Health	
	Accepted to SDS (%)	Not accepted to SDS (%)	Accepted to SDS (%)	Not accepted to SDS (%)
Good/very good	37	37	27	31
Poor/very poor	62	63	73	69

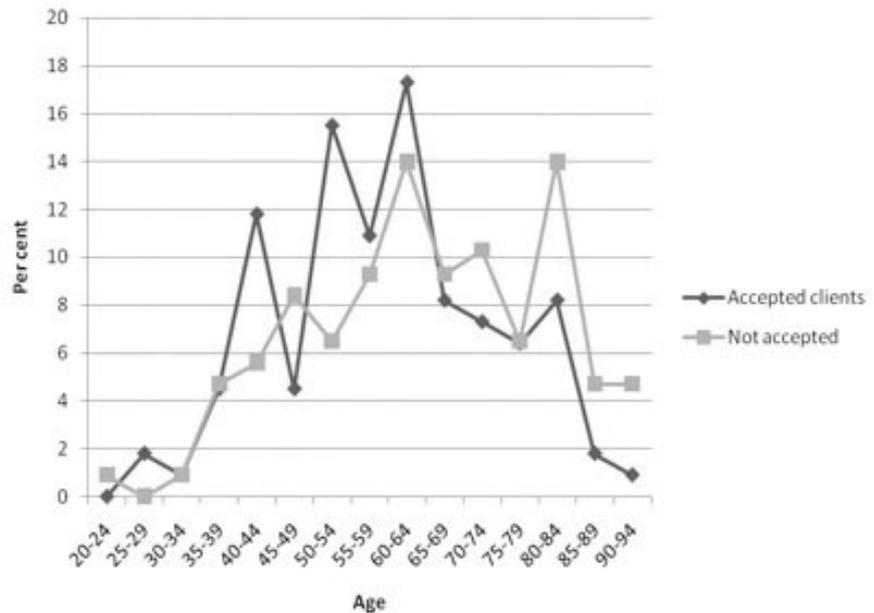
Source: SDS Project Data

Notes: Taken as a percentage of their overall categories. Accepted (n=93), Not accepted (n=81). 44 people were missing data on this measure.

This mirrors findings from the few empirical studies that have been conducted on self neglect and squalor which found that between 45% (Radebaugh et al., 1987; Wrigley and Cooney, 1992) and 70% (Halliday et al., 2000) of people have mental disorders or cognitive deficits. Most research has focused on the percentage of people who have poor physical and mental health, so it is interesting to note that one third to one quarter of people referred were believed not to be impaired by physical or mental health problems.

The final difference between people who were and were not accepted into the Project is the age distribution of each group; Figure 3.2 demonstrates that people over the age of 70 were less likely to be accepted into the Project than younger people. This suggests that people with these characteristics were less appropriate for SDS services, because it was felt that sustainable solutions could not be achieved where they currently lived. Even though they were not accepted, SDS was involved in organising other interventions for these people, such as guardianship or placement in more appropriate accommodation.

Figure 3.2: Age distribution, Accepted (n=110) Against Not Accepted (n=98), per cent



3.5 Conclusion

SDS surpassed its commitment to DADHC by assessing 218 people between 1 August 2008 and 31 July 2009. Referrals to SDS were more likely to be male and under the age of 65; most lived alone in either in public housing or privately owned accommodation, and more than one third had an insecure housing situation as a result of living in squalor. People who were accepted into SDS were more likely to experience safety, health and fire risks and the inability to receive services due to OHS concerns. They were also more likely to have hoarding and mental health problems. People who were not accepted were more likely to be older, to have age related problems or cognitive impairment, as well as poorer physical and mental health. The characteristics of the group are similar to research findings from other studies, which indicates that this group is representative of the broader population of people living in squalor. However, more research is done before this can be said definitively.

The next section assesses the outcomes experienced by a sample of 57 people who had entered and exited SDS by 31 July 2009.

3.6 Summary

- 218 people were referred to SDS between 1 August 2008 - 31 July 2009. The Project surpassed its commitment to DADHC to provide services to 157 people during the one year pilot.
- Referrals were 55 per cent male and 45 per cent female and were, on average, 62 years of age. A little over half of the referrals (58%) were younger than 65 years of age.
- Referrals were received from 12 services; the most referrals were received from Housing NSW (20%), followed by Home and Community Care (17%), Community Mental Health (17%), and Community Health (12%). This indicates that situations of squalor are problematic for a diverse array of organisations, and that the current service system is not coping well with the complexity of these situations.
- SDS received referrals from 18 local government areas. The highest number of referrals came from Sydney local government area (33%).
- People referred to the Project lived in a mix of public housing (54%), privately owned (39%) and rental (7%) accommodation. The large proportion of people in public housing suggests that this is a complex group with multiple sources of disadvantage.
- Over one third (41%) of people referred to the Project lived in insecure accommodation as a result of living in squalor.
- Of the 218 referred clients, 208 were assessed by 31 July 2009 and 53 per cent (n=110) were accepted for further service. Of those who were not accepted, 18 per cent refused services and 13 per cent required immediate placement or hospitalisation.
- Clients accepted into the Project experienced a number of consequences associated with living in squalor: 85 per cent experienced safety risks, 71 per cent were unable to receive services, 54 per cent were isolated, and 41 per cent had an insecure tenancy.

- People who were accepted into SDS were more likely to experience safety, health and fire risks and to have an issue with hoarding. They were also more likely to be denied access to services due to OHS concerns.
- People who were not accepted were more likely to be older, to have age related problems or cognitive impairments, as well as poorer physical and mental health. This suggests that people with these characteristics were less appropriate for SDS services, because it was felt that sustainable solutions could not be achieved where they currently lived. Even though they were not accepted, SDS was involved in organising other interventions for these people, such as guardianship or moving to more appropriate accommodation.



CLIENT OUTCOMES

4. CLIENT OUTCOMES

As stated in Section 2, SDS provides holistic assessments for people living in squalor, and accepts people into the Project who are willing to cooperate in the intervention and for whom a sustainable solution can be found. Interventions are focused on three key areas: reducing the consequences associated with squalor; addressing any underlying impairments; and improving client's living conditions. As a result of addressing the consequences, impairments, and living conditions, it is expected that clients will experience changes in social contact and community participation. This section examines the extent to which the Project has accomplished these aims. Analysis draws on data collected by Project staff on a sample of 57 clients who had exited SDS (spending an average of six months in the Project), and for whom there was a complete set of data at both entry and exit. Qualitative data from the interviews with stakeholders and clients is used supplement the quantitative analysis.

4.1 Primary consequence of squalor

Clients experienced an array of negative consequences as a result of living in squalor; these consequences provided the impetus for intervention in most situations.

Upon entry, clients experienced an average of five consequences associated with their living conditions, whereas upon exit, clients experienced less than one consequence. Table 4.1 shows that statistically significant decreases were recorded across seven areas so, upon exit, clients were significantly less likely to experience safety, health and fire risks, and were less likely to be denied access to services due to OHS concerns. Clients were also less isolated from the wider community, and had lower risk of being evicted from their current home. These outcomes are important given the current policy environment which emphasises homelessness prevention and social inclusion (NSW Government, 2009).

Table 4.1: Change in Primary Consequence of Squalor (n=57), per cent

Primary consequence	Entry	Exit	% change
Safety risk (trip/falls/hazards)**	81	9	-72
Health risks**	75	5	-70
Unable to receive services (OHS)**	72	9	-63
Fire risk**	60	9	-51
Eviction risk**	49	7	-42
Isolation**	51	11	-40
Neighbour complaints**	32	4	-28
Legal issues	14	0	-14
Risk of homelessness	12	2	-10
Council orders	9	0	-9
Consumer Tenancy Tribunal	12	5	-7

Source: SDS Project Data

Notes: Percentages equal more than 100 due to clients presenting multiple primary consequences of squalor

**p<0.05 (Chi-Square, Yates Correction for Continuity)

The majority of stakeholder and client interviews supported the changes that are described in Table 4.1. One client described the change he observed in his physical health as a result of the services provided by SDS: “My living environment’s a bit better. My health is a bit less threatened – it’s a slightly healthier place to live in because I’m not breathing in damp and fumes of that description”. Another client living in public housing who had formerly been at risk of eviction stated that the initial SDS cleanup in conjunction with the ongoing support provided had improved his housing security:

I showed them [SDS] the letters from the Housing NSW – I had to clean the flat or I would lose my housing... they talked to my ex case manager and figured out what was going on and I knew from then that everything was well under control. It made me feel relaxed and at peace was that I knew the problem with Housing could be solved.

Both the quantitative and qualitative data show that SDS has been successful in reducing the number of consequences experienced by clients.

4.2 Involvement of other services

In addition to reducing the consequences associated with squalor, SDS aims to address underlying issues that clients may be experiencing, such as mental health problems, cognitive impairments, or physical impairments. As it was not possible to include a clinical measurement of changes in underlying impairments, the evaluation measured the extent to which SDS was able to achieve greater involvement of the agencies that can appropriately address the underlying issues. Working with other agencies such as general practitioners; generic community based mental health services; psychologists and psychiatrists; allied health services; drug and alcohol services; and aged care services has been found to be crucial in promoting positive outcomes in situations of self neglect and squalor (Dong and Gorbien, 2005; Landau, 2000; Lauder et al., 2005; Snowdon et al., 2007).

Table 4.2 shows that clients leaving SDS recorded higher levels of involvement across most service areas, particularly community services (21% increase) and aged care services (18% increase). Small decreases in service involvement occurred in relation to clients who needed community mental health services and drug and alcohol services (Table 4.2). These reductions were small, but signify that SDS encountered some difficulties working with other services to address situations of squalor.

Table 4.2: Change in Involvement of Professional Support Networks, per cent

	Entry	Exit	% change
General Practitioner (n=57)	76	91	+15
Community Mental Health (n=51)	47	43	-4
Other mental health service (n=55)	36	42	+6
Other Community Services (n=57)	40	61	+21
Aged Care Services (n=27)	26	44	+18
Allied Health Services (n=49)	14	33	+19
Drug and Alcohol Services (n=26)	7	6	-1

Source: SDS Project Data

Notes: Percentages are derived from the number of clients in the Project who need the service (n=)

The qualitative data also supported the importance of working with others, particularly when the focus is on fostering sustainable, rather than short term, solutions. One stakeholder stated that working together with SDS was useful to encourage a client to accept services:

One of the things about her [the client] is that she is really resistant to anyone coming into her property and doing anything to get rid of her clutter. After SDS became involved and they involved me in the process there have been massive changes in how she welcomes me and welcomes the workers at SDS. She doesn't blame me any more for the problems that are happening in her life

The next quote further highlights the importance of working together to foster sustainability. This stakeholder shared a story in which SDS neglected to keep the referring agency involved when arranging ongoing services for one client:

I had arranged for the client to receive regular cleanups as a part of their SDS intervention plan. I had said at the time that I would need to speak to the client first in order to make them comfortable with the idea. This did not take place and the client refused the follow up cleaning. I was not informed about the refusal and I only found out after contacting the agency contracted to provide the cleaning. As a result the client has regressed into squalor.

Data collected at baseline showed that SDS had difficulty collaborating with other organisations over half of the time. The qualitative data pointed to two reasons for this. First, many services in the community are guided by strict eligibility criteria and boundaries around their particular areas of responsibility. Health and mental health services were reported to have particularly inflexible service boundaries, meaning that many workers in these organisations focus on health and mental health issues to the exclusion of all else. For example, a stakeholder who worked at a community health organisation stated, "In my role as a community nurse I am limited in how much I can address their squalor."

Stakeholders reported that some professionals, particularly from community health, community mental health and aged care assessment teams, do not believe living in squalor to be

problematic unless there is a clearly diagnosable health or mental health issue and the person is putting themselves and others at risk. In contrast, SDS staff and most of the interviewees strongly believed that squalor poses both health and safety risks and can result in other negative consequences. These participants believed that the risks confer upon them duty of care to intervene to protect clients as well as others affected by the squalor. An SDS staff member outlined the dilemmas that surround her duty to respect autonomy and to protect clients:

I see the question of squalor as one of a duty of care to these clients. It's well and good to say that we need to respect their autonomy, but if it gets to the extent where they are committing a type of suicide and are a danger to themselves and the community, I believe there is a duty of care to these people that goes above and beyond considerations of respecting privacy.

Because of the conflicting views about risk, SDS had difficulties engaging aged care and mental health services to work in partnership in some situations of squalor:

We need to get aged care and mental health to become more involved. They don't respond to some of the requests because they don't see the person as a danger to themselves or others. SDS on the other hand went out of their way to help to engage [this client].

Furthermore, when people living in squalor refused services, these organisations often declined to be involved unless the person was legally assessed to lack the capacity to make decisions. Workers at SDS, Housing NSW and Councils found this position to be frustrating because it ignores the consequences associated with the living conditions (as discussed in the previous section) as well as the implications for neighbours and others in the community.

The second element that limited service coordination in situations of squalor is that interventions are often costly and time intensive. Some situations of squalor require forensic cleaners because of the OHS risks involved, which makes hiring professional help prohibitively expensive. The cost of cleanups in situations of squalor and hoarding was particularly problematic for Housing NSW and local councils. Although



councils can recoup the cost of cleanups when private houses are sold, this is not the case for Housing NSW which has a limited budget to finance cleanups. In addition, SDS staff reported that it takes time to build trust with people who are living in squalor and, because there rarely are quick fixes in these situations, some clients need to be provided with case management for a lengthy period. The resource intensive nature of interventions in these situations precludes the ongoing coordination with agencies that do not have the time to sustain such relationships.

4.3 Living conditions

The third element of fostering sustainable solutions to situations of squalor is to facilitate improvements in client's living conditions. This section examines changes in the functioning and accessibility of client properties before and after exiting the Project as well as global changes in squalor as measured by the Environmental Cleanliness and Clutter Scale (ECCS).

Functioning and accessibility

The living conditions of the sample upon entry into the Project were extremely poor, to the extent that many of clients lacked access to the most basic household amenities. Upon entry into SDS, 11 per cent of clients (n=5) did not have functioning running water, 16 per cent did not have functioning lighting (n=7) and close to one quarter did not have functioning kitchen facilities (n=10; Table 4.3). These numbers are inordinately high compared with the general Australian population of which only 0.4 per cent does not have access to working kitchen facilities or a working bath or shower connection (Australian Bureau of Statistics, 2000).

Moreover, Table 4.3 indicates that the living conditions of SDS clients at baseline are poorer than those of Aboriginal and Torres Strait Islanders, who are widely recognised as one of the most disadvantaged groups in Australia. The most comparable statistic to the data collected by the Project is that of functioning kitchen facilities: five per cent of Indigenous Australians do not have working facilities for preparing food, as

compared with 23 per cent of the SDS clients (Australian Bureau of Statistics, 2002; Australian Institute of Health and Welfare, 2004).

Table 4.3: Change in Functioning of Basic Utilities (n=57), per cent

Functioning of...	Entry	Exit	% change
Running water	87	98	+9
Kitchen facilities	77	88	+11
Lighting*	84	97	+13

Source: SDS Project Data

Notes: *p<0.1 (Chi-Square, Yates Correction for Continuity)

Over the course of their involvement in the Project, clients experienced an improvement in the functioning of these basic utilities: there was a nine per cent increase in access to running water (to 98% of the sample), an 11 per cent increase in functioning kitchen facilities (to 88% of the sample), and a 13 per cent increase in functioning lighting (to 97% of the sample; Table 4.3). These changes indicate a movement towards the population norms. The Project benefited from having the flexibility to access donations and other funds to purchase replacement appliances and to bring in cleaning services when needed. One of the clients interviewed, for example, was assisted to reduce the amount of hoarded possessions in his flat and, once enough space was created, SDS purchased a new refrigerator for him.

In addition to poorly functioning household amenities, many clients were unable to access various parts of their homes due to the collection and storage of excessive amounts of items. Upon entry, almost 45 per cent of clients could not access their kitchen and another 36 per cent did not have access to their living area (Table 4.4). Consistent with the change in improved functionality of household utilities, clients leaving SDS recorded substantially increased levels of accessibility. In particular, there was a statistically significant increase in access to kitchen areas (29% increase) and sleeping areas (22% per cent increase; Table 4.4). Increased levels of accessibility are especially important for clients with mobility problems to enable safer passage to various parts of the house.

Table 4.4: Change in Accessibility of Basic Utilities (n=57), per cent

Accessibility to...	Entry	Exit	% change
Kitchen**	57	86	+29
Sleeping area**	71	93	+22
Living area	64	70	+6

Source: SDS Project Data

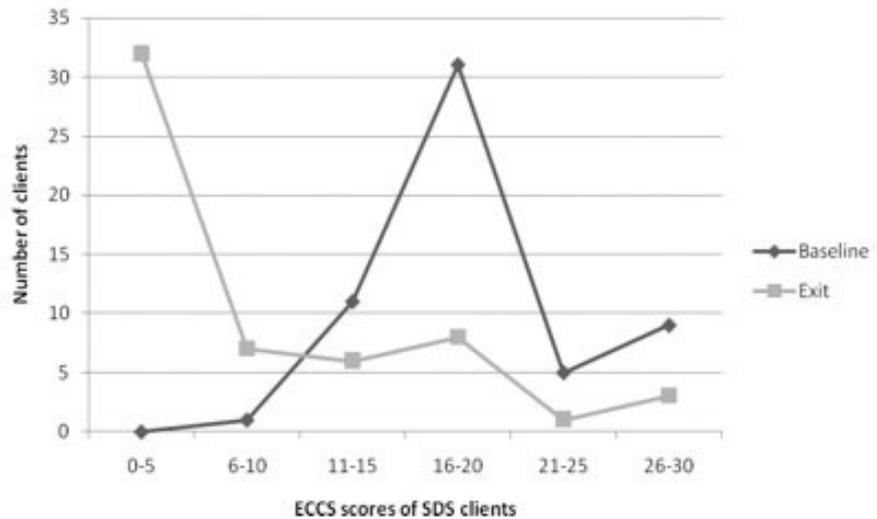
Notes: **p<0.05 (Chi-Square, Yates Correction for Continuity)

Changes in overall property condition

Changes in the overall condition of client properties was measured by the ECCS, a measure which combines a number of cleanliness and clutter domains to determine an aggregate score that is indicative of the level of squalor. The ECCS measures living conditions across six key domains: accessibility to parts of the property; accumulation of garbage and refuse; accumulation of items that have no obvious value; maintenance and upkeep required for property; personal cleanliness; and safety of the property. These domains are measured on a four point interval-ratio scale from '0' to '3', with any scores from '1' to '3' indicating some level of squalor, though the description of each score differs for each domain. The maximum aggregate score for the ECCS is 30.

The average aggregate ECCS score for the 57 clients upon entering the Project was 18.8 out of the maximum of 30, which indicates that clients were living in moderate to severe squalor (Halliday and Snowden, 2009); this decreased significantly for clients exiting the Project to 6.5 (p<0.05, Wilcoxon Signed Ranks test). Thus, client living conditions improved considerably from severe squalor at baseline to no squalor at exit. The distribution of the scores at baseline and exit is depicted in Figure 4.1.

Figure 4.1: Distribution of ECCS Scores on Baseline and Exit (n=57), per cent



Another way of contextualising the ECCS score is to look at changes experienced by exited clients across five key domains. Table 4.5 shows that, unlike in the general population, there were substantial issues with the quality of client dwellings upon entry. According to the 2006 Community Housing and Infrastructure Survey, 7.2 per cent of Indigenous dwellings were in such poor repair that they required complete replacement, and 23.4 per cent required major repair (Australian Bureau of Statistics, 2006). The 'maintenance and upkeep' item in Table 4.5 shows that SDS clients experience comparably poor housing quality: seven per cent of client homes required replacement and 26 per cent required major repairs.

Upon exit, there were considerable increases in '0' scores which indicates that, since being involved with SDS, clients experienced statistically significant changes regarding the accumulation of refuse, safety risk, property accessibility, personal cleanliness, and property maintenance.

Table 4.5: Change in ECCS Scores Between Entry and Exit (n=55), per cent

Accumulation of refuse or garbage**		None (0)	A little (1)	Moderate (2)	A lot (3)
	Entry	6	25	51	18
	Exit	65.5	17.2	8.6	8.6
	% change	+59.5	-7.8	-42.4	-9.4
Accessibility of property**		Easy to enter (0)	Somewhat impaired (1)	Moderately impaired (2)	Severely impaired (3)
	Entry	14.5	38.2	32.7	12.7
	Exit	57.9	17.5	12.3	12.3
	% change	+43.4	-20.7	-20.4	-0.4
Maintenance and upkeep required**		None (0)	Minor (1)	Major (2)	Replacement (3)
	Entry	3.6	63.6	25.5	7.3
	Exit	56.1	35.1	1.8	7
	% change	+52.5	-28.5	-23.7	-0.3
Personal cleanliness**		Clean and neat (0)	Untidy and crumpled (1)	Moderately dirty (2)	Very dirty (3)
	Entry	18.2	52.7	20	9.1
	Exit	54.4	38.6	7	0
	% change	+36.2	-14.1	-13	-9.1
Safety risk from squalor**		None (0)	Minimal risk (1)	Considerable risk (2)	Very unsafe (3)
	Entry	5.5	32.7	49.1	12.7
	Exit	57.9	15.8	14	12.3
	% change	+52.4	-16.9	-35.1	-0.4

Source: SDS Project Data

Notes: **p<0.05 (Pearson Chi-Square)

Changes in the ECCS scores were also reflected in qualitative ratings of the condition of client properties. Upon entry, a low percentage of clients were rated as having good or very good property condition (8%) as compared with 67 per cent of clients who exited from the Project (p<0.05). A stakeholder summed up the changes seen for one of her clients as follows:

On a physical level the place this client lives in is now amazing. He had a two bedroom unit that was quite in a state with pests and cockroaches. They helped keep everything that was important and get rid of all the rest. This client has come back from hospital and he almost broke down in tears [of joy] when he saw it clean and clear. It was just amazing.

Some clients interviewed for the evaluation also shared positive changes in their living conditions since being involved in SDS. One client's story is recounted in Case Study 1; this situation also highlights other consequences that can be associated with squalor as well as the impact it can have on neighbours.

Case Study 1

The place that I live in got kind of run down. That wasn't so much of a problem - it was the fact that I developed a plumbing problem in my flat and water leaked out all over the floor [over a two year period]. There was even an issue of damp in the wall and it affected the electricity as well. I was living in the worst shithole imaginable – it was like an underground water cavern. It was horrible. I didn't think about it, I just blocked it out. I just couldn't cope.

I didn't let people in until I had to. I had no other choice – I was getting into all sorts of trouble with the body corporate, and the council and the neighbours. That wasn't pleasant [and] it caused me a lot of stress. It got to the stage where the neighbor in the adjoining house complained because water was starting to leak into her property.

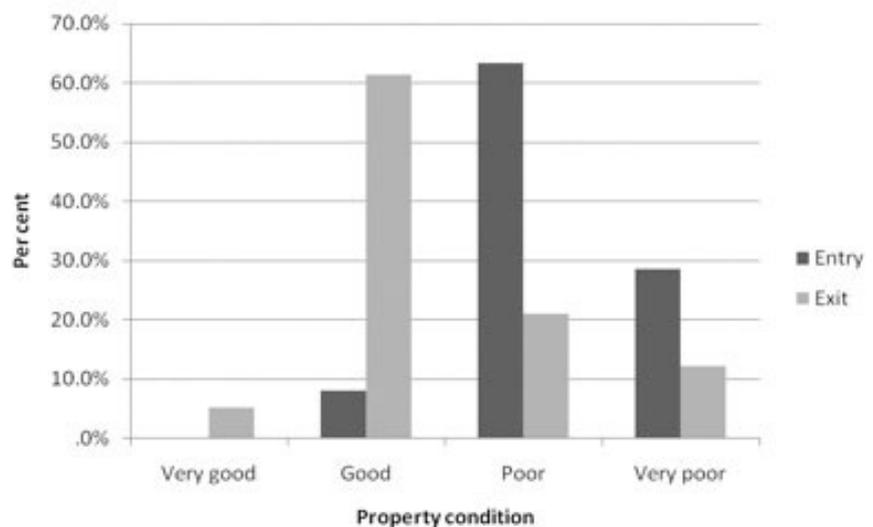
[When SDS became involved] they did quite a lot. They helped me get rid of a lot of old, damaged furniture. The carpet was damaged and soaked through. It stank like you wouldn't believe – it was rotting and it was affecting my health. It was starting to affect other people, especially the guy across the hall from me who was having health issues of his own. The whole place needed to be scrubbed down because there's trouble with insects as well – every building in this area has cockroaches but I had lots of small cockroaches and they're almost impossible to get rid of. Slowly things are getting done. It is a matter of survival.

While there was a considerable improvement for most clients, 33 per cent of clients still had poor or very poor property conditions upon exit. Staff reported this to be the case because most situations of squalor had developed over long periods of time, so it is unrealistic to expect that all clients have the desire and the capacity to change their living conditions quickly. For example:

There is another example of a client who had an initial cleanup done by SDS. There are still outstanding OHS risks, some services like HACC still can't go in, but private services now able to work with this client. She has also become a lot more cooperative with us and with other services.

Figure 4.2 shows the improvement in client property condition from entry to exit from SDS.

Figure 4.2: Client Property Condition on Entry and Exit (n=49)



While living conditions improved dramatically for most exited clients, some reported a difficult time accepting the loss of possessions that were disposed of during the clean ups. These clients mourned the loss of these items even though they recognised that the consequences associated with squalor had decreased. One female client who described herself as a hoarder stated:

Some good stuff went. Two video recorders went. I'm missing a lot of important documents because anything not nailed

down went. I really needed one of the things that has been thrown out for the court case but I can't do anything about that. So yeah, it was hard. Some of the things I had no feeling for but some of the things I'm still missing. They gave away my pots and pans but I insisted on keeping a couple.

This sentiment was shared by a few clients who were interviewed for the evaluation and reflects a common tension in these situations, which is that some professionals and community members believe living in squalor constitutes risks and negative consequences, but the people living in squalor disagree. This tension is discussed more fully in Section 6.

4.4 Social connections and community involvement

This section explores the extent to which the reduction of consequences associated with squalor, the increased involvement of other services, and the improvement in living conditions impacted on other aspects of client's lives, such as social connections and involvement in community activities.

As discussed in Section 4.1, one of the outcomes of the SDS intervention is that people experienced less isolation as a result of receiving services. This point is supported by data which measured the extent to which clients are supported by friends, neighbours or family. Social contact improved considerably for clients leaving SDS, of whom 81 per cent were reported to have a regular support network; this is a 14 per cent increase on baseline measures (Table 4.6). One male client interviewed for the evaluation stated that one of the most important aspects of the support provided by SDS is that it helped him to feel less isolated:

I certainly think the Project is helpful for people who are isolated and don't have contact with the outside world as far as associations with other people are concerned. This essentially happens in a lot of instances where hoarding and collection takes place.

Table 4.6: Change in Social Connections (n=51), per cent

	Entry	Exit	% change
Regular social contact	67	81	+14
Involvement in community activities	43	51	+8
Volunteering	5	18	+13
Education or training	10	6	-4
Employment related activity	10	31	+21

Source: SDS Project Data

Notes:

Employment related activity refers to participation in full time work, part time work, or looking for work

Over the course of receiving services from SDS, clients also increased their involvement in the community, as well as in education, volunteering, and work related activities. Clients had low levels of participation in these activities upon being accepted to the Project; this is particularly the case for economic participation, where only 10 per cent of clients under the age of 65 were involved in employment related activity. This figure is lower than the employment rate of the most disadvantaged group of people with disability – people with the highest levels of emotional or cognitive assistance – who have a labour force participation rate of 20 per cent (Australian Bureau of Statistics, 2003) as compared with only 10 per cent of this sample.

The number of clients participating in community activities, employment related activity, and volunteering increased upon exiting SDS. Of particular significance are the 21 per cent increase in the number of clients engaging in employment related activities (to a total of 31% of the sample) and the 12 per cent increase in the number of clients participating in volunteer work. The number of people participating in education and training decreased by four per cent, but this is an insignificant change given the small sample size.

It is important to exercise caution in attributing these changes solely to SDS interventions. For example, a client with schizophrenia who was interviewed for this research accepted assistance from SDS because he resumed taking his medication, which was the key contributing factor in his increased ability to interact with people in the community.

However, it is certainly the case that some of this change can be attributed to SDS and some stakeholders reported that the change in living conditions played an important role in improving these aspects of clients' lives. One stakeholder noted of her client who received services from SDS:

He used his hoarding as a way of almost building a barrier between himself and the outside world. People from the community would come and try to visit but he would feel like he had to hold them at bay at the door. He really isolated himself. Since the place has been cleaned he has been reaching out to the community and really become involved again. Just his physical surroundings have reflected his change in life.

4.5 Conclusion

This section has shown that SDS has promoted positive outcomes in client's lives through the reduction of the consequences associated with squalor, involving other services, and improving client living conditions. As a result, clients experienced increased social contact, strengthened connections to the community, and improved rates of participation in economic activity. It is too early to tell whether the Project has successfully promoted sustainable solutions in these situations over the longer term; further research and follow up is needed to make this determination.

4.6 Summary

- As a result of their involvement with SDS, clients experienced a significant decrease in the number of consequences experienced as a result of living in squalor.
- They were significantly less likely to experience safety, health and fire risks and to be denied access to services due to OHS risks. They were also less isolated from the wider community, and had lower risk of being evicted from their current home. These outcomes are important given the current policy environment which emphasises homelessness prevention and social inclusion (NSW Government, 2009).

- SDS achieved greater involvement of the agencies that can appropriately address any underlying issues experienced by people living in squalor. Clients leaving SDS recorded higher levels of involvement across most service areas, particularly community services (21% increase) and aged care services (18% increase).
- Although service coordination is an essential element of fostering sustainable solutions, working together was impeded by conflicting definitions of risk, and autonomy; strict service boundaries between human service agencies; and the time consuming and costly nature of interventions.
- Upon entry, client property conditions were extremely poor: 11 per cent of the sample did not have functioning running water, 16 per cent did not have functioning lighting. Close to one quarter of the SDS clients did not have functioning kitchen facilities as compared with five per cent of Indigenous Australians (Australian Bureau of Statistics, 2002; Australian Institute of Health and Welfare, 2004).
- Client living conditions improved significantly over the course of their involvement with the Project; clients had a significant decrease in global ECCS scores, and those exiting experienced a 29 per cent increase in access to their kitchen areas, and 23 per cent increase in access to sleeping areas.
- As a result of the reduction in consequences associated with squalor, changes in living conditions, and increased service involvement, clients experienced other changes in their lives:
 - Social contact improved considerably for clients leaving SDS, of whom 81 per cent were reported to have a regular support network. This represents a 14 per cent increase on baseline measures.
 - Clients experienced a 21 per cent increase in employment related activities (to a total of 31% of the sample) and a 12 per cent increase in volunteering.



TRAINING EVALUATION

5. TRAINING EVALUATION

Besides improving client outcomes, SDS aims to educate the broader community on squalor and how to respond to situations of squalor. To this end, Project staff provided advice on the squalor hotline and ran training sessions on:

- The complexity of the issues associated with squalor;
- Current research and legislation;
- The importance of working collaboratively to support people living in squalor; and
- Good practice interventions.

An estimated 1000 calls for advice and referrals were received on the squalor hotline and total of 32 training sessions were held between August 2008 and July 2009, with 748 recorded attendees over that period. The trainings were hosted by a number of agencies that come into contact with people living in squalor, such as Housing NSW as well as hospital and community based services. For evaluative purposes a sample of participants (n=89) were asked to complete a brief survey on their experience of the session, the quality of the information presented, and how relevant they found it to their interactions of people living in squalor. The survey questions were presented on five-point likert scales where respondents could rate the efficacy and relevancy of the training. The findings from the surveys are outlined in this section (see Appendix A for more information).

5.1 Satisfaction with training format and content

The majority of training participants (82%) were satisfied with the information provided in the training sessions and the quality of these sessions. 84 per cent of participants also reported that the training sessions were well sequenced and easy to understand. These overwhelmingly positive responses demonstrate that most participants believed that SDS provided proficient facilitation as well as information about squalor that was directed at the right level of knowledge.

5.2 Relevance and usefulness of training

Training sessions were directed at people in the community who face situations of squalor and who have struggled with the dilemmas that arise in these situations; 84 per cent of the sample reported that the information presented at the trainings was relevant to the situations of squalor that they encounter in practice. A similar percentage, 85 per cent, believed that the training would 'very much so' or 'mostly' help them to review and improve work practice when confronted with situations of squalor (Table 5.1).

Table 5.1: Impact of Training on Current Work Practices (n=89), per cent

Will the information assist you to review / improve your current work practices?	N	Per cent
Very much so	32	36
Mostly	44	49
Somewhat	9	11
Mostly not	3	3
Not at all	1	1
TOTAL	89	100

Source: Training Evaluation

Compared to the other domains assessed in the survey, a slightly smaller majority of respondents (79%) believed that they would use the content of the training in their day to day work (Table 5.2).

Table 5.2: Influence of Training Content on Day to Day Work (n=89), per cent

Will the content of the presentation influence/assist with your day to day work?	N	Per cent
Very much so	38	43
Mostly	32	36
Somewhat	16	18
Mostly not	3	3
Not at all	0	0
TOTAL	89	100

Source: Training Evaluation

Finally, participants expected the training to in result positive outcomes for the squalor clients they support. Table 5.3 illustrates that 81 percent of participants believed the information in the training would have a 'very' or 'mostly' positive impact on those they support, compared to four percent who believed it would have minimal impact.

Table 5.3: Benefits of Training for Clients Supported (n=89), per cent

Will the learning from this presentation have positive benefits for those you support?	N	Per cent
Very much so	39	44
Mostly	32	37
Somewhat	14	16
Mostly none	2	2
None at all	1	1
TOTAL	89	100

Source: Training Evaluation

The survey feedback from those who participated in the trainings was largely positive, and affirmed that the Project not only met its obligation to provide 30 trainings, but that it provided training with good quality facilitation and information. This was supported by a few interviewees who had participated in a training session. One person stated:

One of the most important aspects of the Project is the education. A lot of people [in squalor] live in complete isolation and educating people on how to be aware and to look out for this sort of thing is important. The hospitals need to be on the lookout, GPs need to be on the lookout, everyone needs to know and to be actively looking for it.

5.3 Conclusion

Besides improving client outcomes, SDS aims to educate the broader community on squalor and how to respond to these situations by providing advice on the squalor hotline and running training sessions. An estimated 1000 calls for advice and referrals were received on the hotline over the one year period, and total of 32 training sessions were held, with 748

recorded attendees. The data confirms that the Project not only met its obligations to provide 30 training sessions, but that the sessions provided relevant, well presented and easily disseminated information. Most of those who participated in the trainings believed the session would impact positively on current work practices and on individual squalor clients. Future evaluations could more thoroughly analyse the effectiveness of the trainings through the use of pre/post surveys that test participants' change in knowledge.

5.4 Summary

- SDS facilitated community education about squalor by fielding over 1000 calls on the squalor hotline and providing 32 training sessions for 748 people. Responses to these sessions were largely positive.
 - 82 per cent of the training participants were 'very' or 'mostly' satisfied with the presentation and facilitation of the training sessions.
 - 84 per cent of respondents believe the information was either easy to understand.
 - 84 per cent reported that the trainings are relevant to their work with people who live in squalor; 85 per cent believed the training would assist them to review and improve work practices in relation to squalor.
 - 79 per cent considered the information to be relevant to their daily work.
 - 81 per cent felt that the information provided in the training session would have benefits for the clients they support.



SERVICE MODEL

6. SERVICE MODEL

As stated in Section 2, SDS provides holistic assessments for people living in squalor that take into account: the needs and background of the individual; the consequences of squalor; underlying impairments; the person's capacity to make decisions; the extent to which the squalor is impacting on others in the community; and whether an intervention is feasible and sustainable. This section of the report draws on qualitative data from the 12 stakeholder interviews and eight clients to assess the benefits and limitations of SDS service model and the role SDS plays in the broader service system. Financial data is analysed at the end of this section and compared to the outcomes of the project to determine the costs and benefits of SDS and, finally, recommendations about the service model are made.

6.1 SDS service model

Stakeholders and clients reported a number of strengths associated with the SDS service model. All participants appreciated that the Project provides individual, flexible, and support that is not time limited. These characteristics ensure that the unique needs of each client can be appropriately addressed. One stakeholder noted:

The program has had a positive impact [on my clients]. It's responsive to the situations, so they take account the issues for Housing NSW and the tenant. They consider the whole picture.

One client noted that because SDS supports are flexible and ongoing, he was not pressured to make significant changes in his life in a short period of time. This was important for this client given his personal circumstances:

The main thing is they don't put a lot of pressure on me, which is helpful. I can't work under pressure any more. If it wasn't the case that they didn't allow for that I wouldn't have been in the Project for the same amount of time.

An additional benefit identified by stakeholders was that SDS provides support to clients beyond the initial cleanup. The ongoing and consistent nature of the support offered to clients is important to promote sustainability of the intervention. This

was furthered by the availability of other programs in Catholic Community Services that clients can receive services from once the OHS risks are reduced. A service provider stated:

For my clients the SDS intervention has been about more than just coming in and doing an initial cleanup. Two of the clients have regular fortnightly home support now, which helps with their cleaning and just gives them some company generally. It goes back to the fact that for some of these people there is no one off sustainable solution, and it's about getting the care that they need on an ongoing basis.

A few of the stakeholders interviewed reported that SDS had provided short, time limited interventions for a few of their clients rather than ongoing support. These interventions were not as successful because clients had a limited capacity to maintain their environment after the initial clean-up, and so the changes in the living environments were not sustained after people were exited from the Project. These comments affirm the importance of providing ongoing support, continually communicating with the referring agency, and also further educating the community about the types of support that are provided by SDS.

Stakeholders spoke highly of the expertise that SDS staff have when working with situations of squalor; participants reported a substantial lack of such expertise in the community. Interviewees affirmed that SDS staff are forthcoming with expert information on the causes, consequences and appropriate interventions in situations of squalor, that this expert knowledge has a positive impact on how they work with people living in squalor. Two stakeholders noted:

Formal conversations I've had with SDS have given me a lot of information on squalor: they explained the mental health issues behind domestic squalor and behind the habits that these people develop that I wasn't aware of.

Working with SDS to help this particular client has really helped me understand some of the bigger issues behind squalor. It's helped me to understand the emotional side of things, having experts there with that knowledge.

Some clients also appreciated the expertise that that Project staff had about how to reduce the consequences they had experienced as a result of living in squalor. One client stated:

The other thing I liked about the program is they knew when to start. I showed them the letters from the Department of Housing - I had to clean the flat or I would lose my housing. They not only knew what to do, but also when to do it. That was very impressive to me.

While the majority of the comments about the SDS service model were positive, two limitations were noted. First, some stakeholders reported that the Project was not always successful in promoting sustainable solutions to situations of squalor, meaning that some clients reverted back to living in squalor after they were exited from the Project. Situations of squalor are extremely complex, and so it is realistic to expect that sustainable solutions cannot be found for every client during their initial involvement with the service. However, it is important to be aware that the inability to provide ongoing support and to link clients in with appropriate services can have a detrimental impact on client outcomes. One participant stated that, to prevent clients from slipping back into squalor, the Project needs to:

Ensure first that clients have access to ongoing cleaning services; secondly that the cleaning service has the time and resources to place into building a rapport with the client; and finally that the cleaning service is trained in how to deal with squalor and that client eligibility.

The second limitation of the Project was that the funding was not sufficient to meet the demand for SDS services. The Project could only afford to employ three people full time to give advice (over 1000 telephone enquiries), assess 218 people, run 32 training sessions and manage over 50 ongoing clients at any given time. This workload is not sustainable and, even though there were support processes in place, there was concern that staff would become burnt due to the heavy workload and demanding cases. This can be a common occurrence amongst people working with situations of squalor (Cutler and Tisdale, 1992; McDermott, 2007).

Challenges facing the project

SDS continued to face two challenges throughout its operation. The first involved assessing the acceptability of risk and respect for autonomy. This was discussed in Section 4, but it is necessary to expand here on the ongoing challenges around these issues. The second challenge concerns respecting each client's understanding of his or her situation.

Risk acceptability and respect for autonomy

The focus on fostering sustainable solutions in situations of squalor meant that not all situations were assessed as being appropriate for receiving services from SDS; the most difficult decisions involved deciding whether people living in squalor had the capacity to remain living independently in the community. For example:

One client has interventions done previously and services have come in to clean up her living conditions. She is a woman in her 90s with a very poorly maintained house and poor health. There is a long history of elder abuse. Services were going in to make her food and clean up a little. They think they're helping, but to my mind they're actually band-aiding the situation. We were asked to come in by the council and we took a completely different approach, we involved the police as they have the authority to remove the woman from the situation.

The decision to employ more coercive interventions in situations that were thought not to be sustainable was contentious for some stakeholders who were concerned about respecting client autonomy. Project staff were also aware of the importance of respecting decisions made by clients, but felt that certain situations were so risky that they had a duty to intervene.

In professional ethics more generally, autonomy is the most strongly emphasised of all ethical principles and is used to refer to self-sufficiency, independence, and freedom from restriction (Collopy, 1988; Pojman, 2002). In the past decade, however, critiques of this conceptualisation of autonomy have emerged. Critics argue that, because humans are never fully self-sufficient, the concept of autonomy should incorporate

the notions of reciprocity, the need for relationships, trust, and dependence on others (Dekkers, 2001; Held, 1995; Verkerk, 2001). There is an ongoing debate to be had about what constitutes acceptable risk in situations of squalor. It is important that this debate consider the critique that autonomy cannot ignore the impact of individual decisions on the broader community, as people rarely, if ever, act outside of this context.

Respect for clients

The second challenge facing SDS was to demonstrate respect for clients; this was discussed by both staff and stakeholders as a crucial element of successful interventions in situations of squalor. Both Project staff and some clients discussed ways in which the SDS could be more mindful of being respectful to client property and to client's feelings. One staff member reflected on a learning experience early on in the Project:

There was such severe squalor in a residence that we needed to get forensic cleaners in. To respect the client's property, you need to be able to retrieve as much as you can for the client, but the forensic cleaners didn't do that. She had a coexisting mental illness that made the process very difficult for her, but at the time the cleanup was seen as an imperative by council so they were unwilling to wait until we could have the necessary mental health services in place. She was very traumatised after the cleanup.

A client also reflected on the difficulties that arose as a result of the cleanup that occurred in his home:

It was terrible. They threw out everything, saucepans, crockery, microwaves. They were perfectly good but they just threw everything. I wasn't involved at all in the cleaning, I just sat by. There were four or five of them and I asked them not to throw some of the things out, but they did. This all happened while SDS was involved but I didn't have any support people here at the time. I was very shocked.

There are significant tensions between clients and staff about what and how much clients are allowed to keep after a cleanup. These quotes provide a reminder that it is important to remain aware and sensitive of client feelings, and to ensure that all people who are involved in the cleanups are trained

about to consider the value of client possessions.

The difference of opinion between clients and staff about what constitutes squalor emerged in the interviews with clients, where seven out of the eight clients stated that they did not like the name Severe Domestic Squalor Project. These clients had particularly strong reactions against the word squalor, as demonstrated in the following quotes:

I think squalor is a degrading name. It describes conditions some people live in developing countries. Squalor was used in history books to explain the conditions people used to live in when they lived in poverty. It doesn't necessarily relate to filth, I think it relates more to density of population and poverty. Mismanagement is perhaps a better word because it means that you are not managing as expected.

You've gotta be very tactful when you label things. Squalor to me means nothing, I just laugh at it...I think [the Project needs to be called] something more pleasant. I don't think it applies in Sydney – there are probably other parts of the world that would be in squalor. I associate it with developing countries.

The label of squalor has been given to clients by professionals and academics, but it caused strong negative reactions for the majority of the clients who were interviewed. If the Project gets refunded it may be beneficial for staff to work with clients to find a name that is more inclusive of both professional and client views.

Good practice case studies

Quantitative and qualitative data strongly supported the service model implemented by SDS. The following case studies highlight the benefits that were described and how the service model has had a positive impact on people who are living in squalor:

Her ex partner was the primary hoarder and, due to the clutter and other issues, she had her children removed from her care by Department of Community Services (DoCS). SDS first came into contact with her through a DoCS referral. Since SDS has been involved there has been a gradual reduction in clutter, not yet to the extent that she can have

access with her children in her home, but that is a long term goal. Week by week the clutter is reduced with ongoing support. SDS has been great in helping her to realise how clutter impairs her long term goals and how improving her clutter can help her to achieve her goals. I believe there will continue to be improvements and that these will be sustainable.

I have a tenant who has hoarding issues and a bit of squalor. When I came along 12 months ago, she was resistant to services but she became agreeable to support services because her tenancy was at risk – we were about to make an application to the CTTT – and she was in danger of losing her kids. SDS became involved: a large dog was removed from the premises, they disposed of furniture, one of the kids tidied up the bedroom and bunk beds were provided for one of the rooms. The changes are gradual but, over time, there's been a huge difference. It's looking a lot more organised in the house and she's out in the community more. The kids are no longer in danger of being removed.

6.2 Importance of SDS in the broader service system

All 12 stakeholders interviewed for this research affirmed that SDS fills an important gap in the service system. Before SDS, participants reported that they often worked alone and had limited knowledge about the importance of fostering sustainable solutions in situations of squalor. Few services had the resources available to pay for forensic cleaning and replacing broken household appliances and requests for clients to purchase these items were often met with refusal. As a result, the majority of the interventions that occurred before SDS were lengthy, costly and unsustainable over the longer term.

SDS has worked to fill this gap in the service system by providing assistance, education and support to professionals who, before, had no choice but to address these complex situations alone. It provided specialised cleaning services in premises that most other services will not enter due to OHS risks and had the time and monetary resources available and to provide flexible, ongoing support to clients. According to both clients and stakeholders, the service provided by SDS is essential and,

without it, people living in squalor will again be subject to short term, unsustainable, and uninformed interventions. Furthermore, the partnerships that have developed between services will be jeopardised. Case Study 2 provides an example of the opinions voiced by most of the stakeholders interviewed for this research.

Case Study 2

When I dealt with situations of squalor before SDS I was isolated and it was very stressful. In the end, things would just get worse [for clients] and some of the outcomes weren't grand – there was no holistic change. Sometimes things would get totally out of hand – one the cases we had was on A Current Affair – so we've ended up with a high level of publicity which didn't help the clients or the community. We felt we weren't coping.

A coordinated, partnership approach is required in situations of squalor and hoarding because they are the most difficult cases that we deal with. We don't have the resources or expertise or time that these cases require to bring about effective change. We feel these situations also require specialist knowledge that we don't have, so all we end up doing is frightening people and stressing people – it doesn't help them to change and it only exacerbates the situation. It would be a backward step if SDS wasn't refunded.

Clients were also appreciative of the support provided by Project staff; they were particularly grateful for the sensitivity with which their individual circumstances were taken into account and the fact that SDS would help when no other service would. In the words of one client:

I'm very pleased. It's a very essential and important job. I mean the fact that it was so hard for us to get [a service] shows how important it is.

6.3 Economic evaluation

Expenditure data indicates that it cost \$288,005 to run SDS between 1 August 2008 and 31 July 2009. The recurring costs of

the Project are described in Table 6.1; this excludes the cost of the evaluation (\$45,000) as it is a non-recurrent expenditure.

Table 6.1: SDS Expenditure, 1 August 2008 – 31 July 2009

Item	Expenditure (\$)	Per cent of total budget
Salary and wages (3 full time employees)	161,376	56
Brokerage - internal (cost of running squalor hotline)	18,093	6
Brokerage - external (cost of cleaning, purchasing furniture and other equipment)	38,165	13
Administration (program support, HR, IT, office supplies)	35,572	12
Training (room rental and promotions)	12,996	5
Vehicle cost and expenses	21,803	8
TOTAL	288,005	100.0

The cost of administering the Project amounted to 12 per cent of the total budget; the remaining 87 per cent was spent on conducting training sessions for professionals in the community and providing direct services to clients. The cost of training sessions included room rental, promotion, and 0.15 of a worker, which totalled \$21,065. Given that 32 training sessions were held, the cost per session was about \$700. Direct services provided by SDS included: responding to enquiries from the squalor hotline; assessing the 218 people referred to the Project; providing ongoing case management to accepted clients; and supplying cleaning services to clients. Direct services accounted for two full time workers and .85 of a worker (\$153,307); internal and external brokerage (\$56,258); and vehicle costs (\$21,803). Including administration, the total spent on direct service provision was \$231,368, and the cost per accepted client was \$2427.

The cost of \$2427 per accepted client resulted in the following outcomes: improved living conditions; increased service access; reduced consequences of squalor; improved social relationships; improved community participation; increased employment related activities; and increased rates of volunteering. These benefits are quantified in Table 6.2.

Table 6.2: Summary of SDS Outcomes, per cent

Item	Description	Baseline	Exit	Implication	
Improved living conditions	Running water	87	98	11% increase in clients with running water. Moving towards population norm: 99.6% of Australians have access to bathing facilities	
	Functioning lighting	84	96	12 % increase in functioning lighting	
	Functional kitchen appliances	77	88	11% increase in kitchens with functional appliances; Some movement towards population norm: 99.6% of Australians have functioning kitchen appliances	
	Accessible kitchens	57	86	29% increase in kitchen accessibility	
	Accessible sleeping areas	70	93	23% increase in sleeping area accessibility	
	Accessible living areas	64	70	6% increase in living area accessibility	
	ECCS total score	19	7	12 point decrease in ECCS score measuring overall property condition	
	% with large amounts of refuse	69	18	51% decrease in the amount of refuse in client homes	
Involvement of other services	General Practitioner	76	91	Clients leaving SDS recorded higher levels of access across most service areas, particularly community services (21% increase) and aged care services (19% increase). The only decrease occurred in relation to clients needing community mental health services (4% decrease)	
	Other Community Services	40	61		
	Aged Care Services	26	44		
	Drug and Alcohol Services	7	6		
Consequences of squalor	Number of consequences	5	< 1	Clients experienced a reduction in the number of consequences as a result of changes in their living conditions	
	Safety risk	81	9		72% decrease in safety risk, 70% decrease in health risk, and 63% decrease in inability to receive services
	Health risks	76	5		
	Unable to receive services	72	9		
Social relationships	Regular social contact	67	81	14 % increase in regular social contact	
Community participation	Involvement in community activities	43	51	8% increase in involvement in community activities	
Employment related activity	Involvement in employment	10	31	21% increase in participation in employment	
Volunteering	Involvement in volunteering	5	18	13% increase in volunteering	

The benefits of the Project were summed up by one of the clients interviewed for the evaluation (Case Study 3).

Case Study 3

I have AIDS Dementia Complex. At the time I didn't know and this place turned into a nightmare and only later realized what had happened. It was horrible. The only skill that dementia didn't take from me was cooking but I couldn't clean so the kitchen turned into the biggest nightmare. I don't even want to think what it was like, it was so bad. There were pots and pans everywhere, I hadn't washed the floor in five years and everything was a nightmare. I was so overwhelmed that I didn't know where to start. I had no idea how to get it back to normal - I couldn't see a way out. When my case manager said there's a professional group that can help you I thought, 'oh wow, there are people who can exactly help me'. I didn't think anyone could ever help me.

These people [SDS] were so nice. They'd come every week, we'd get a coffee then we [cleaned up] room by room by room. I was so embarrassed and ashamed but they never made me feel like that ever. I was always thinking 'what are they going to think, I don't want them to see'. But they are the nicest mob. I really needed [their help]. I embraced it. It was exactly what I needed.

It is clear that SDS met its goals to improve client living conditions and to connect clients with other services. As a result, clients experienced fewer consequences as a result of living in squalor, increased social and community connections, and increased employment. This positive impact of the Project does not even begin to quantify any the broader service system and community impacts of SDS – for example, the Project may have indirectly improved the quality of life of people living next door to a person living in squalor. In comparison to other partnership programs that assist people with complex needs to live successfully in the community, the cost of \$2500 per client is inexpensive. For example, the Housing and Accommodation Support Initiative (HASI), aims to

assist people with severe mental health problems to maintain their tenancies; the lowest level of accommodation support for people in HASI costs approximately \$10,000 per annum (McDermott et al., 2009a). If the Project is refunded, however, SDS will require more staff to sustain the current level of activity (serving 110 complex clients per year, assessing referrals and continuing to provide advice and education to the community). For this reason, \$4000 per client is a more realistic cost.

6.4 Conclusion

The service model adopted by SDS promotes a flexible, holistic, and person centred approach to working with people in squalor. The Project also brings expertise about these situations into the service system. SDS experienced limitations due to resource constraints, and sustainable outcomes could not be achieved for all clients, but for the most part, stakeholders were positive about the structure and outcomes of the SDS service model. For a cost of \$2500 per client, the service itself offers an economical model of promoting positive outcomes for people with some of the most complex needs living in the community.

6.5 Summary

- Benefits of the model include: the individual, flexible, holistic and expert support that is provided. Support is ongoing and involves linking people up with mainstream services when possible.
- The Project was limited by a lack of resources and sometimes sustainable solutions could not be achieved because clients were not linked in with the appropriate supports.
- Other challenges facing the Project centred on risk acceptability and respect for autonomy. Further discussions within the broader community are required to gain consensus around whether living in squalor in the community constitutes an acceptable risk.

- All stakeholders and most clients believed the Project fills an important gap in the service system. Without it, stakeholders were concerned that people living in squalor will again be subject to short term, unsustainable interventions and that the partnerships between services that have developed will be jeopardised.
- SDS support cost \$2427 per accepted client; each training session cost about \$700 per session. The expenditure has resulted in strong positive outcomes for clients of the Project.
- If the Project is refunded, it will require more sustainable staffing levels as the Project deals with some of the more complex situations in the community. For this reason, a baseline cost of \$4000 per client would be more sustainable while remaining inexpensive.



RECOMMENDATIONS

7. RECOMMENDATIONS

7.1 Service model

This research has shown that people living in squalor can have complex issues and that these situations can result in difficult ethical dilemmas for professionals. It has found that service models best suited to address situations of squalor should include the following:

- **Case management:** This is ideally provided by a central organisation that has the knowledge, expertise and resources to appropriately address squalor.
- **Service coordination:** Involving other relevant agencies ensures that any underlying issues are addressed and avoids service duplication. Service coordination works best when one agency is given the responsibility and resources to drive partnerships.
- **Flexible and individualised support:** Workers must be given the time and resources to build trust and foster relationships with people living in squalor. While situations share similar characteristics, each requires an approach that takes into account individual circumstances.
- **Ongoing support:** Support that is not time limited and can be provided in an ongoing way will contribute to sustainable solutions to situations of squalor.
- **Holistic assessment and support:** Promoting sustainable solutions requires that services address the underlying issues and consequences associated with squalor along with living conditions.
- **Staff supervision and support:** Situations of squalor can be emotionally demanding on staff, so it is important to set up structures in which staff can be appropriately supported.
- **Expertise and advice:** There currently exists limited expertise in the community around squalor, so it is necessary to share existing expertise to build community capacity. This should be done through both a formal and informal capacity through, for example, running training session and providing advice over the phone.

- Sustainability: This is often overlooked in interventions, but it ensures that resources are not needlessly wasted. Sustainable solutions include attending to: any underlying issues, the consequences associated with squalor and living conditions. Support needs to be ongoing to ensure long term sustainability.

7.2 Service principles

Successful interventions in situations of squalor are based on the following principles:

- Show respect for other points of view, particularly those held by people living in squalor. A non-judgemental attitude, regardless of the lack of cleanliness, is essential to showing respect.
- Develop trust and rapport with each client.
- Move slowly and do not expect that living situations will change overnight. 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 and stakeholders.

7.3 The future of SDS

There is a growing recognition in the research literature that housing quality impacts on health outcomes and quality of life (Shaw, 2004; Wilkinson and Marmot, 2003). Furthermore, the prevention and reduction of homelessness is a current government priority and the NSW government has recognised that addressing severe domestic squalor is an important element of reducing tenancy evictions (NSW Government, 2009). To accomplish this, a partnership arrangement was formalised to implement the Severe Domestic Squalor Guidelines as part of the NSW Human Services Accord. The arrangement was made between three government

departments: Housing NSW (Central Sydney), DADHC (Metro South and Metro North), and NSW Health (Sydney South West Area Health Service, Northern Sydney Central Coast Area Health Service, and South Eastern Sydney and Illawarra Area Health Service). The document that formalised this partnership acknowledged the important role SDS has plays in coordinating services around the issue of domestic squalor in Sydney.

SDS has been successful in reducing housing insecurity, linking clients in with appropriate services, and improving housing quality. Without funding it is unlikely that:

- Situations of domestic squalor will be addressed sustainably;
- The implementation of the Severe Domestic Squalor Guidelines will be effectively achieved; and
- Evictions and housing insecurity in situations of squalor will be systematically reduced.



CONCLUSION

8. CONCLUSION

From 1 August 2008-31 July 2009, SDS received 218 referrals and accepted 110 people for further services. Those who were accepted for services tended to live alone and many lived in insecure accommodation. Data showed that squalor impacts on the whole community, from people living in Housing NSW to those who own their own homes. The low number of people referred to the Project who live in private rental accommodation indicates that this group suffers from a high level of disadvantage and are stigmatised due to their living conditions.

For the cost of \$2427 per client, the Project has successfully achieved its aim to of reducing the consequences of living in squalor, increasing service coordination, and improving living conditions. This has led to other benefits for clients such as improved social connections and increased community and economic participation. The overall success of the Project, and the recognised role of SDS in driving partnerships around situations of squalor, confirms the importance of making recurrent funding available to SDS. Furthermore, compared with other community programs that support people with complex needs to live independently in the community such as HASI, the cost of \$2427 per SDS client is inexpensive. If the Project were to be refunded it is important to recognise the service needs more staff to continue managing all aspects of the service, and so a more reasonable cost is about \$3000-\$4000 per client.

SDS not only met its contractual obligations to DADHC but provided high quality services to an underserved and vulnerable group of people. A commitment of further resources is needed to sustain the changes that have been measured in this evaluation and to provide others in the community with access to this unique service.

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Appendix A: Methodology

Although it is understood that situations of squalor present complex challenges for community organisations, minimal research has been conducted on service responses to situations of squalor. As a result, little evidence exists around best practice in these situations. This research aims to address this issue while also providing an evaluation of the SDS Project. The four specific research aims are to:

1. Determine the preliminary outcomes for clients who are served by SDS Project;
2. Assess the service model implemented by SDS and identify the learning outcomes from this model;
3. Identify good practice case studies of working with people who live in severe domestic squalor; and
4. Evaluate outputs and effectiveness of the training sessions held by staff at SDS.

These aims were met through a mixed method approach which included analysis of program data collected upon entry into and exit from the Project, interviews with key stakeholders and clients, cost data, and a survey that was conducted after training sessions.

Research questions

The research met these aims by addressing evaluation questions that relate to client outcomes, the service model, and the training sessions facilitated by SDS.

Individual clients:

- What are the characteristics of individuals who were referred and accepted to the Domestic Squalor Project?
- What outcomes were experienced for clients involved in this Project?

Model:

- What elements of the model adapted by the Domestic Squalor Project are effective/not so effective in developing service coordination in situations of domestic squalor?
- To what extent has the facilitation provided by Domestic Squalor Project assisted sustainable solutions in situations of squalor?
- What are the costs and outcomes of the Project?

Community education:

- What training events were held?
- To what extent were these training systems effective in increasing knowledge and understanding of domestic squalor?

The following table specifies the research methods that will be used to address each of the research aims.

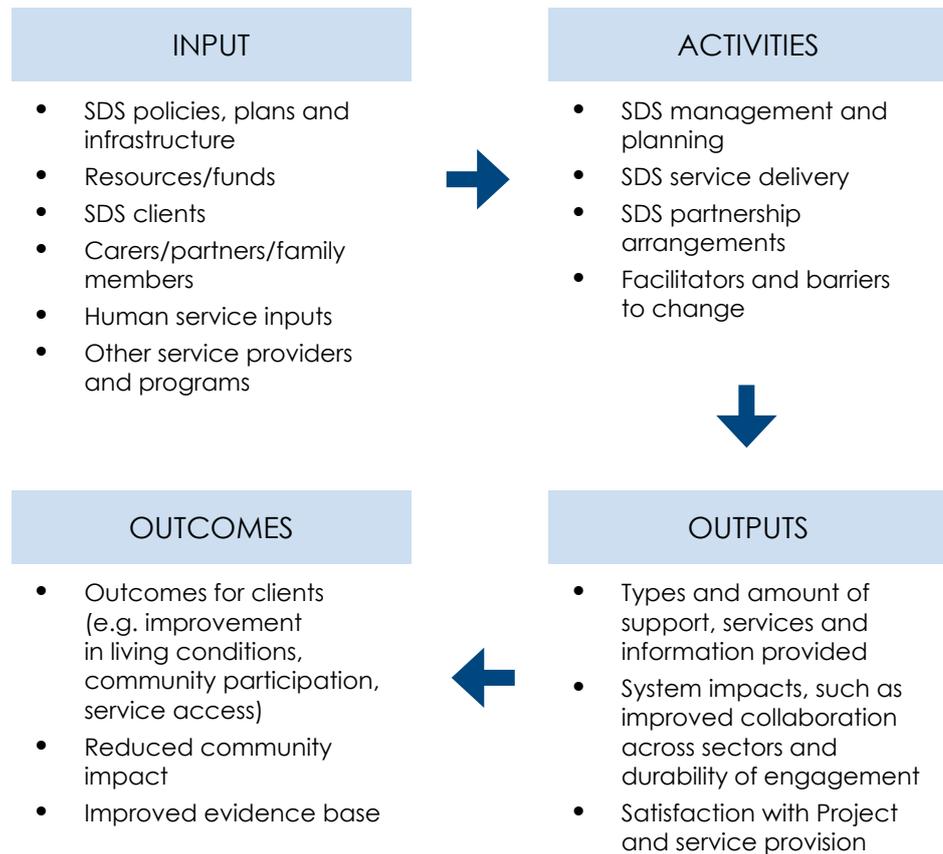
Conceptual framework

The research will involve interviews with key stakeholders, interviews with a small number of clients in SDS, and analysis of Project data (client database, training records and cost data). The information collected will be based on a theory approach, which identifies the:

- Inputs, including the human, organisational, and community resources invested in a program, so it can perform its planned activities;
- Activities, or what the program does with the inputs, including the processes, events and actions;
- Outputs of program activities, such as the volume of the work accomplished, the number of people reached; and
- Outcomes which includes the benefits or changes in the target population (Royce et al., 2006).

The way in which program theory is related to SDS is indicated in Figure A0.1:

Figure A0.1: Conceptual Approach for Evaluating SDS



Logic models are used to identify the intended relationships between resources, activities, outputs and outcomes and to measure the occurrence of each element (Savaya and Waysman, 2005). The elements of this model can be compared to data to determine whether what happens in practice is comparable to the intentions and objectives of the Project. It is also useful to understand the interactions between service provision, the individuals and other sources of support.

Methods

A mixture of quantitative and qualitative methods was chosen to answer the research questions, while also supporting the participation of clients of SDS. The methods - program data, qualitative interviews, training evaluation and economic evaluation - are outlined in detail overleaf.

Analysis of program data

This report provides longitudinal analysis on client data collected by SDS staff. The data includes information on client outcomes and demographics upon being referred to, assessed by and exiting the Project. The instrument used to collect data on client outcomes was developed in consultation with SDS staff and is based on considerations of data quality (what data is meaningful and captures intended change) and also practical considerations (data items needed to be simple and quick for Project staff to complete). Outcomes data has been collected on living conditions, physical and mental health, social connections, community involvement, and service access (Table A0.1).

Table A0.1: Measures of Effectiveness

Outcome	Comparison groups	Explanation
Change in living conditions	At baseline and on exit, SDS clients who leave the Project	Change in the living conditions rating scale on entry into the Project and on exit
Physical and mental health	At baseline and on exit, SDS clients who leave the Project	Change in health status during Project involvement
Employment, education, community participation	At baseline and on exit, SDS clients who leave the Project	Change in participation compared to baseline
Social relationships	At baseline and on exit, SDS clients who leave the Project	Change in relationships compared to baseline
Regular service access	At baseline and on exit, SDS clients who leave the Project, Population norm	Number of clients who have regular access to services

Analysis of the data is limited for a number of reasons. Firstly, SDS is the first Project to provide services to people living in squalor in the community. Most of the prior research has been done on people who have been referred to hospitals or Adult Protective Service organisations, and so previous research provides limited information about how this data can be interpreted. Secondly, numbers cannot fully capture the complexity of situations of squalor. These situations are recognised to pose complex legal and ethical dilemmas for

professionals and often the situations are problematic for long periods of time (McDermott et al., 2009b). Similar clients presented in the data with comparable interventions may vary markedly in the outcomes they experience as a result of these differences in context. Finally, the total number of clients accepted to the Project with available information upon exiting the Project is 57. As a result longitudinal analysis to detect change over time can only be conducted on these 57 cases, which makes for a small and potentially non-representative sample.

It is however worth noting that this database forms one of the more complete pictures of squalor that has been developed on individuals over time. It therefore provides a unique opportunity to understand situations of squalor in greater detail than before.

Qualitative interviews

Semi-structured interviews were conducted with stakeholders and clients of the Project to gain a greater understanding of the individual experiences of squalor, the SDS service model, and community education sessions. These interviews were essential for placing trends observed in the quantitative analysis in context. Table A0.2 identifies the number and type of interviewees who participated in the evaluation.

Table A0.2: Client and Stakeholder Interviews

Research stakeholder	Number of interviews
Clients	8
Housing NSW	4
Catholic Community Services	2
Brown Nurses	1
Community Support Network	1
Redfern Community Health	1
Local Council	1
COPS	1
St. Vincent's Hospital	1
TOTAL	20

Stakeholder interviews

A list of stakeholders from relevant agencies involved in SDS was provided by Project staff for the purposes of conducting interviews. From this list a total of 12 stakeholders were selected to participate in semi-structured interviews and were asked questions relating to their involvement in the Project, their observations of client change and outcomes, and how they think the Project can be better implemented. Interviews lasted roughly 30 to 45 minutes in length and supplemented other available quantitative and qualitative information. The interview schedule for stakeholders is included in the Appendix

Client interviews

Initial screening was conducted by SDS staff with current Project clients to determine which clients would be a suitable to participate in interviews. From this process a total of eight clients were recruited for the interview process, which like stakeholders involved a 30 to 45 minute semi-structured interview asking questions relating to their experience of the Project and their life and squalor history. The interview schedule for clients is included in the Appendix.

Given the small numbers it is difficult to make any generalisable conclusions from the data gained. However in combination with the client data, training and cost data analysis it assists in building a more complete picture of SDS and whether the Project has met its core aims of improved client life outcomes and service system education.

Training evaluation

As part of the Project, SDS aimed to educate professionals in the broader service system about the underlying causes of and ways to treat squalor and, in order to achieve this, training sessions were held with at various locations throughout the greater Sydney metropolitan area. The sessions focused on the causes and reasons for clients they have contact with living in squalor, treatment strategies for dealing with squalor and providing information to about the services that are available for people who are living in squalor.

To evaluate the training sessions, questionnaires were given to participants to complete in two separate phases. Initially,

questionnaire respondents were selected during the training seminar to complete the written survey. The survey presented a number of questions on a five-point likert scale asking respondents to rate how relevant and informative they believed the seminar was in relation to key areas of education identified by SDS staff. The survey also included a short answer section to capture any additional information not covered in the five-point questions (see Appendix).

For the second phase of the training evaluation, an online survey was distributed to a list of email contacts of seminar attendees. The purpose of this survey was to determine any significant differences between the first and second round of data collection for the training evaluation and to discover if service providers believed they had implemented any of the strategies or information learnt during the seminar. Similar to the original survey, questions were presented on a five-point likert scale and asked respondents to comment on various aspects of the seminar in addition to whether they believed they had found the information rendered as useful since attending (see Appendix).

There are limitations however in analysing the data collected from these training session evaluations. The first phase of data collection for the training session evaluation resulted in only 98 responses out of the comparably large number of service system professionals who attended. As a result it is difficult to consider any sole analysis based on this data as representative. The relevancy of the data gathered will increase however when triangulated with the stakeholder interview transcripts. The second phase of data collection encountered greater difficulty in terms of its validity. While there is consistency between the questions and measures used in both surveys, the response rate for the second survey was far lower (n= 4) so these results were excluded from the analysis.

Economic evaluation

A basic economic evaluation of the Project was also conducted; the budget for this evaluation was too small to conduct a full cost effectiveness or cost benefit analysis, so the evaluation involved collecting data on the program costs which were then compared against the outputs of the Project

and the outcomes for clients. The costs that were collected for evaluation purposes include the actual costs in the following categories:

- Staff costs: cost of salary and wages for program staff
- Management: cost of management positions that would not have been funded if SDS did not exist
- Administration: cost of staff development, insurance, administration, mileage
- Brokerage: cost of purchasing cleaning and other services for SDS clients
- Contract Centre Support: cost of running the 1800 squalor hotline

The cost analysis excluded:

- One-off costs of establishment and evaluation because these are not comparable to the operational systems in other community service programs;
- Costs incurred by other agencies that are not allocated in the SDS budget;
- Indirect costs to other stakeholders; and
- Non-financial costs, such as time, stress and impact on other service providers.

Costs were collected from 1 August 2008-31 July 2009 and are taken at the dollar value at the time of measurement. The cost data was then compared with the impact of the Project on clients, which was derived from the changes experienced by clients who left the Project, as well as qualitative data gathered from stakeholders and interviews with clients.

Appendix B: In-service Training Evaluation Questionnaire

INSERVICE EVALUATION

HR 33a



Location of Training: _____

Date: _____

Session Topic: **Severe Domestic Squalor**

Presenter: **Susan Graham**

Participant's Name (optional): _____

Participant's Position: _____

Rate the session by circling the number from 1 very satisfied to 5 not at all which best applies to your evaluation of the session.

1. Was the information relevant to your needs?
 very relevant **1** **2** **3** **4** **5** not at all

2. Was the information presented in a well sequenced, easy to understand format?
 very much so **1** **2** **3** **4** **5** not at all

3. Will the information assist you to review/improve your current work practices?
 very much so **1** **2** **3** **4** **5** not at all

4. How satisfied were you with the presentation/facilitation of the session?
 very satisfied **1** **2** **3** **4** **5** not at all

5. Will the content of the presentation influence/assist with your day to day work?
 very much so **1** **2** **3** **4** **5** not at all

6. Will the learning from this presentation have positive benefits for those you support?
 very much so **1** **2** **3** **4** **5** not at all

7. Please make any comments or suggestions about the session

Appendix C: Client Interview Schedule

Interview schedule - clients

First I'd like to ask you some questions about your involvement with Mercy Arms. Then I'd like to ask you a little bit about your life and your background. You are free not to answer any questions that you don't want to answer.

SDS

1. How did you become involved with SDS/Mercy Arms?
2. Is there anything you particularly like or dislike about being involved with SDS/Mercy Arms? How could the Project be improved?
3. How do you get on with the workers at Mercy Arms/SDS?
4. How has your life changed since being involved with Mercy Arms/SDS?
5. What is one thing that you would change about the Project?

History

6. Where are you from?
7. Who did you live with when you were growing up?
8. What was it like growing up where you did?
9. What were some of the struggles you experienced when you were growing up?
10. Did you work? What was that like?
11. What were your relationships like with your friends/family/partner?
12. How long have you been living here? What are some of your best memories in this house?
13. What goals do you have in life? How have you gone in fulfilling your goals?
14. What are your hopes for the future?

Appendix D: Stakeholder Interview Schedule

Interview schedule - stakeholders

1. What is your role/involvement in the Domestic Squalor Project?
2. What impact has the Project had on how you work with squalor clients?
3. In what ways do you think the Squalor Project works well?
 - Support provided to clients
 - Sustainable solutions to squalor
 - Service coordination
 - Education
4. What elements of the Squalor Project do you think are not working as well as they could? How have these barriers been overcome (refer to previous prompts)?
5. Is there a clear understanding of service providers' roles and responsibilities when dealing with situations of squalor?
6. Do you think the Squalor Project has had/will have an impact on service coordination around squalor clients?
7. What types of changes have you seen for clients involved in this Project?
 - Living conditions
 - Connection to services
 - Social connection
 - Community participation
8. Do you think these changes are sustainable? Why or why not?
9. Do you think the support provided by the Squalor Project works better for some clients than it does for others?
10. What do you see as the future of this Project?
11. Do you have any ideas about how the Squalor Project (or the model applied by the squalor Project) could be improved?
12. Do you have any further comments about the Squalor Project?

Appendix E: Environmental Cleanliness and Clutter Scale

ENVIRONMENTAL CLEANLINESS AND CLUTTER SCALE

To rate cleanliness of clients' accommodation

Developed by Halliday G, Snowden J (2008), and including items from Macmillan & Shaw (1966), Snowden (1987) & Samios (1996)

Initials of rater

Date of assessment

Initials of client

Client i.d. number

Raters should circle the box or number that best fits their observations in relation to the different items. These descriptions are meant to be indicative only, and raters may decide between one category and another based on aspects not mentioned in the boxes.

A.	REDUCED ACCESSIBILITY due to clutter (Note that reduction in floor-space due to excrement is not to be included in ratings or estimates of reduced accessibility):			
	0	1	2	3
	Easy to enter and move about dwelling.	SOMEWHAT IMPAIRED access but can get into all rooms.	MODERATELY IMPAIRED access. Difficult or impossible to get into one or two rooms or areas.	SEVERELY IMPAIRED access - e.g. obstructed front door. Unable to reach most or all areas in the dwelling.
	0-29%	30 to 59%	60 to 89%	90 to 100%
of floor-space inaccessible for use or walking across				

B.	ACCUMULATION OF ITEMS OF LITTLE OBVIOUS VALUE:			
	In general, is there evidence of accumulation of items that most people would consider are useless or should be thrown away?			
	0	1	2	3
NONE Rate 0 if only a small circumscribed part of the dwelling (e.g. a back-room) has been used or designated for storage of 'junk'.	SOME ACCUMULATION: but collected items are organised in some way and do not much impede movement or prevent cleaning or access to furniture and appliances.	MODERATE EXCESSIVE ACCUMULATION: Items cover furniture in most areas, and have accumulated throughout the dwelling so that it would be very difficult to keep clean.	MARKEDLY EXCESSIVE ACCUMULATION: Items piled at least waist-high in all or most areas. Cleaning would be virtually impossible: most furniture & appliances are inaccessible.	

PLEASE INDICATE TYPES OF ITEMS THAT HAVE BEEN ACCUMULATED :

Newspapers, pamphlets, etc Clothing Other items
what?

Electrical appliances Plastic bags full of items (If known,
what items?)

C.	ACCUMULATION OF REFUSE or GARBAGE			
	In general, is there evidence of excessive accumulation of garbage or refuse e.g. food waste, packaging, plastic wrapping, discarded containers (tins, bottles, cartons, bags) or other unwanted material ?			
	0	1	2	3
	NONE Scattered refuse and waste material (including cigarette butts) and/or up to 10 emptied containers scattered around.	A LITTLE Garbage and refuse piling up throughout dwelling.	MODERATE Accumulated bags, boxes and/or piles of garbage that should have been ejected.	A LOT Garbage & food waste piled knee-high in kitchen and elsewhere. Clearly no recent attempt to remove refuse & garbage

D.	CLEANLINESS of floors & carpets (excluding toilet & bathroom) :			
	0	1	2	3
	Acceptably clean in all rooms	MILDLY DIRTY Floors & carpets look as if not cleaned or swept for days. Scattered rubbish	VERY DIRTY Floors & carpets very dirty & look as if not cleaned for months. Rate 1 if only one room or small area affected.	EXCEEDINGLY FILTHY With rubbish or dirt throughout dwelling. Excrement usually merits a 3 score.

E.	CLEANLINESS of walls & visible furniture surfaces & window-sills			
	0	1	2	3
	Acceptably clean in all rooms.	MILDLY DIRTY Dusty or dirty surfaces. Dirt comes off walls on damp rag or finger. Few cobwebs.	VERY DIRTY Grime or dirt on walls. Cobwebs ++ & other signs of neglect. Greasy, messy, wet furniture.	EXCEEDINGLY FILTHY Walls, furniture, surfaces are so dirty (e.g. with faeces or urine) that rater wouldn't want to touch them.

F.	BATHROOM & TOILET :			
	0	1	2	3
	Reasonably clean.	MILDLY DIRTY Floor, basin, toilet, walls, etc. Toilet may be unflushed.	MODERATELY DIRTY Floor, basin, shower/bath, etc. Faeces and/or urine on outside of toilet bowl.	VERY DIRTY Rubbish &/ or excrement on floor & in bath or shower &/or basin. Uncleaned for months or years. Toilet may be blocked and bowl full of excreta.

G.	KITCHEN & FOOD:			
	0	1	2	3
	Clean Hygienic	SOMEWHAT DIRTY & UNHYGIENIC Cooktop, sink untidy & surfaces dirty, maybe with some spilt food. Refuse mainly in garbage bin. Food that could go off has been left uncovered & out of fridge.	MODERATELY DIRTY & UNHYGIENIC Oven, sink, surfaces, floor are dirty, with piles of unwashed crockery & utensils. Refuse/ garbage on surfaces/floors. Some rotten or mouldy food. Fridge unclean.	VERY DIRTY & UNHYGIENIC Sink, cook-top, insides of all cupboards filthy. Much of the food is rotten, putrid, covered with mould, unsafe to eat. Much garbage and refuse over surfaces & floor. Rate 3 if maggots seen.



H.	ODOR:			
	0	1	2	3
	Nil or pleasant	UNPLEASANT e.g. urine smell, unaired.	MODERATELY MALODOROUS. Stench (e.g. faecal/ putrid) but rater can stay in room.	UNBEARABLY MALODOROUS. Rater has to leave room very soon because of smell.

I.	VERMIN (Please circle: rats, mice, cockroaches, flies, fleas, other):			
	0	1	2	3
	None	A FEW Up to 10 live or dead insects. Don't rate cobwebs here.	MODERATE 11 to 30 live or dead crawling insects (exclude ants) or evidence of vermin in moderate numbers. Many flies, ants or fleas.	INFESTATION Vermin alive &/or dead in large numbers (e.g. >30 cockroaches). Two or more mice or rats. Lots of animal droppings, chewed articles.

J.	SLEEPING AREA:			
	0	1	2	3
	Reasonably clean & tidy.	MILDLY UNCLEAN Untidy. Bed unmade. Sheets unwashed for weeks.	MODERATELY DIRTY Bed sheets unclean & stained, e.g. with faeces or urine. Clothes &/or rubbish over surrounding floor areas.	VERY DIRTY Mattress or sleeping surface unclean or damaged. Either no sheets or (if present) extremely dirty bedding/linen. Surrounding area filthy.

Add up circled numbers to provide a TOTAL SCORE:

IS THIS PERSON LIVING IN SQUALOR?

- NO YES mild YES, moderate YES, severe

IS THIS DWELLING VERY CLUTTERED? YES NO



PERSONAL CLEANLINESS			
Describe the clothing worn by the occupant and their general appearance:			
0	1	2	3
CLEAN & NEAT. Well cared for.	UNTIDY, crumpled One or two dirty marks and in need of a wash	MODERATELY DIRTY, with unpleasant odour. Stained clothing.	VERY DIRTY, stained, torn clothes, malodorous.

MAINTENANCE, UPKEEP, STRUCTURE			
This rates the state of repair and upkeep by owner/landlord. If the accommodation was cleaned up as much as possible, to what extent would the dwelling require painting, refurbishment, structural repairs, etc before it would be reasonably habitable?			
0	1	2	3
None.	A LITTLE. Minor repairs & some painting.	A FAIR AMOUNT. Some structural repairs plus painting.	LOTS. Major structural repairs required, & then painting.

TO WHAT EXTENT DO THE LIVING CONDITIONS MAKE THE DWELLING UNSAFE OR UNHEALTHY FOR VISITORS OR OCCUPANT(S)?			
0	1	2	3
Not at all.	POSSIBLE RISK of injury e.g. by falling	CONSIDERABLE RISK of fire, injury or health problem	VERY UNSAFE The dwelling is so cluttered and unhealthy that people should not enter it, (except if specialists with appropriate clothing & equipment) and/ or there is a high fire-risk.



catholic community services

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