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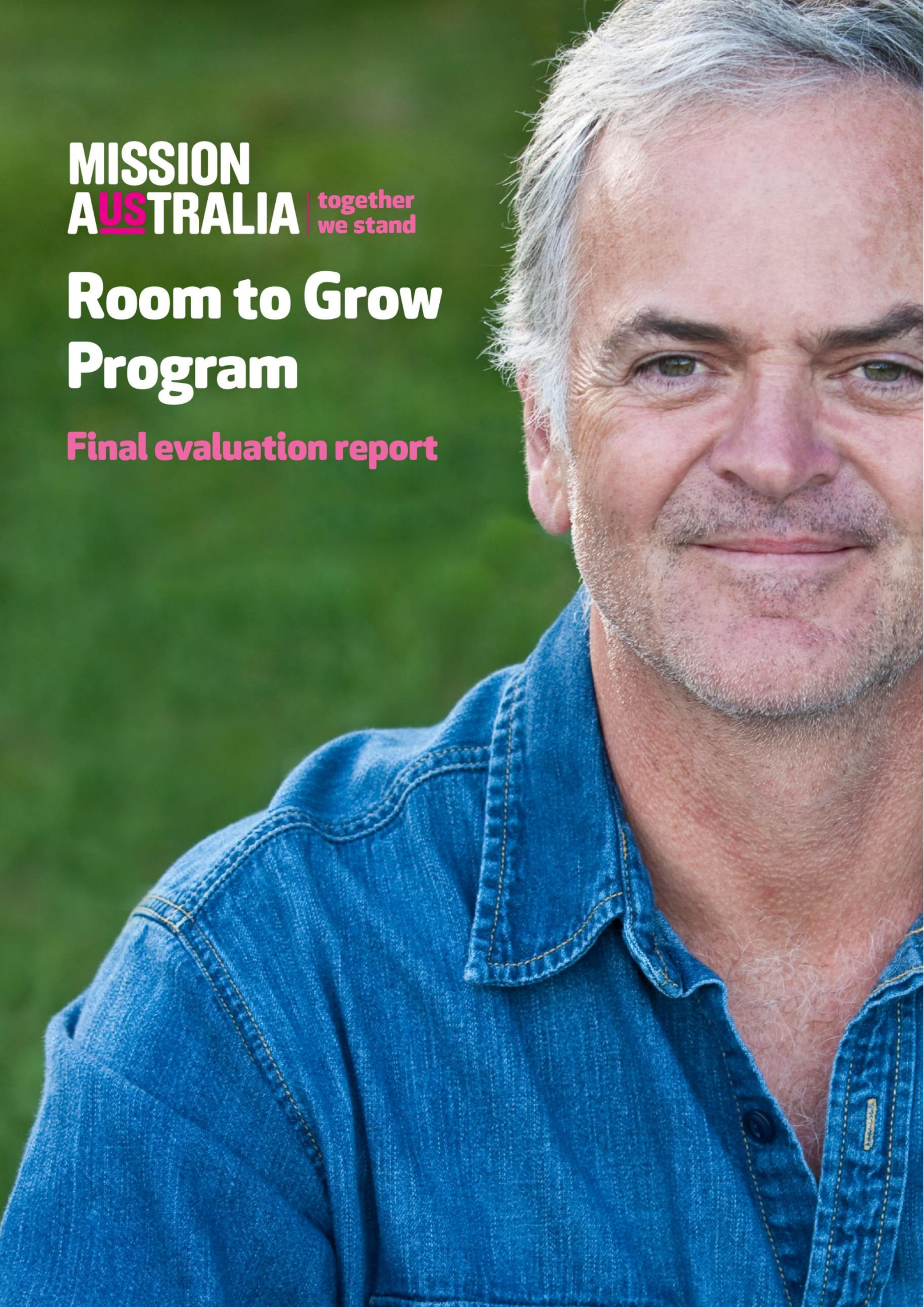
Room to Grow Program

Final evaluation report



Executive summary

Overview

There is a need for an integrated support program involving both psychological interventions and intensive case management for individuals experiencing hoarding disorder who are at-risk of homelessness through tenancy loss. MA developed a response which addressed this need through its Room to Grow pilot program. The service model which was developed and evolved throughout the duration of this pilot goes some way towards addressing the service gaps in this space. This service model also offers the potential for improved outcomes as evidenced through the significant improvements in home environments and wellbeing revealed through this evaluation and validated by program participants and staff throughout interviews and focus groups.

Background

From July 2015 to June 2016, Mission Australia (MA) implemented and evaluated an intervention for hoarding disorder and domestic squalor across the central and eastern Sydney region. This intervention was funded by the National Partnership Agreement on Homelessness (NPAH) through the NSW Department of Families and Community Services (FACS) with the aim of reducing the risk of homelessness due to issues associated with hoarding disorder and domestic squalor.

The Room to Grow pilot program aimed to address the physical, cognitive and psychological factors contributing to situations of severe domestic squalor and hoarding disorder, thereby reducing the risk of tenancy loss and homelessness.

Participants were referred to the Room to Grow program from MA's Common Ground Camperdown Support Service (CSS), Eastern Sydney Partners in Recovery (ESPIR) and the Sydney and South-East Sydney districts of Housing New South Wales (HNSW). The Room to Grow program took place over a 12 month period from July 2015 to June 2016, with service delivery running from September 2015 to July 2016. The service model embedded psychological and neuropsychological interventions within an intensive case management program.

Mission Australia's internal evaluation incorporated both an outcomes and progress evaluation to assess participant outcomes and to determine the successes and challenges faced throughout service implementation. Both quantitative and qualitative measures were used to analyse data and generate a strong evidence base for this unique program.

Recruitment

In total, 29 participants were enrolled in the Room to Grow program. Overall, eleven participants were referred through MA's Common Ground, thirteen were referred through HNSW (Sydney and South-East Sydney districts) and five were referred through ESPIR. All eleven participants from MA's Common Ground were formerly long-term homeless tenants supported through CSS. Following routine property inspections, a number of properties at Common Ground were assessed as being in various levels of disrepair, prompting their referral into the program. Similarly, client service officers from the Sydney and South-East Sydney districts referred participants living in HNSW properties identified as being at-risk of tenancy breaches or eviction due to issues related to domestic squalor or hoarding behaviours. ESPIR provided referrals for clients of their program identified as

experiencing significant issues with domestic squalor or hoarding behaviour. While all participants were required to consent to involvement in the program and did so voluntarily, participants from HNSW were encouraged to access the program to avoid tenancy loss or further NSW Civil and Administrative Tribunal actions.

Key findings

Demographics

There were 29 participants enrolled in the Room to Grow program. The majority (65.5%) were male and the mean age of participants was 52 years old.

Based on information taken from referral agents, the majority (82.8%) of participants were referred into the program with at least one form of existing professional support. Almost all (96.6%) participants were living alone on program entry. A significant majority (89.7%) of participants were identified with a pre-existing mental health diagnosis on referral and just over half (55.2%) of participants had current substance abuse issues, while one in ten (10.3%) presented with a physical disability. A minority of participants had an acquired brain injury (7.1%) or intellectual disability (3.4%). Close to half (44.8%) of participants were formally diagnosed with hoarding disorder on program entry by the consultant neuropsychologist.

The majority of participants were at-risk of homelessness on entry to the program, often due to issues related to their hoarding disorder and/or domestic squalor. Around one in four (24.1%) participants reported a history of Consumer, Trader & Tenancy Tribunal action in the last two years. Close to one in five (17.2%) participants had nuisance and annoyance complaints filed against them but only a small minority had experienced unstable housing over the last two years (6.9%).

Participant outcomes

Two waves of data collection took place throughout Mission Australia's outcomes evaluation. The first took place on program entry (July-August 2015), forming a baseline data set, and the second wave took place towards the end of service delivery (March-April 2016) to provide longitudinal data measuring change over time. Overall, statistically significant positive change was noted in the clutter and cleanliness of participants' living environments and their overall wellbeing, based on the Environmental Clutter and Cleanliness Scale (ECCS) and Personal Wellbeing Index (PWI) measures. Improvements were also seen in participants' subjective assessment of clutter in their homes, their capacity to complete instrumental activities of daily living and their overall cognitive functioning.

The mean PWI for the full cohort at wave one was 61, indicating that on average the wellbeing of participants in the Room to Grow program at entry was likely to be challenged or compromised. By wave two, after interventions had concluded towards the end of service delivery, the mean PWI rose to 68. While still in the range of 'challenged or compromised', this result indicated that the participant cohort had shifted closer to a 'normal' level of wellbeing.

Based on ECCS measure, moderate to severe squalor was indicated for the majority (67.9%) of program participants at wave one. By wave two, based on staff reports of participants' homes, moderate to severe squalor was indicated for less than one third of participants (29.6%). This represents a decrease in the mean ECCS score from 16.6 at wave one to 9.6 at wave two.

Out of a possible range of scores from 0-9, composite scores for the subjective Clutter Image Rating Scale (CIRS) were lowered between wave one and wave two, moving from 4.7 (significant clutter) to 3.7, just below the cut-off score of 4 for clinically significant levels of clutter, indicating a positive shift in perceptions of clutter.

Based on Lawton's Instrumental Activities of Daily Living Scale (IADLS) the majority of participants were assessed as high functioning at wave one with 57.7% of participants falling into this category. By wave two, the proportion of those assessed as high functioning had increased to 73.0%.

According to the Montreal Cognitive Assessment – Basic (MoCA-B), the average score for participants of the Room to Grow program at wave one was 23.8. By wave two this had increased slightly to 24.4.

All tenancies were maintained throughout service delivery. Considering the complexity of participants' history and the multiple issues faced by participants throughout the course of service support – including complex mental health issues and substance abuse – this is a substantial accomplishment for the pilot program.

Service implementation

Qualitative comments from participant interviews suggest that many participants experienced increased insight into the specific challenges presented by domestic squalor and/or hoarding disorder and the unique way each individual negotiated, managed and overcame these challenges throughout the duration of the program. Participants also highlighted a willingness to change and expressed an increased understanding of the processes required to enact this change in their living conditions and in their cognitions, emotions and behaviour. Service staff in focus groups identified a number of successes and challenges faced throughout service implementation. Overall, staff noted that the program provided an appropriate service model to address the needs of participants experiencing hoarding disorder and/or domestic squalor. However, staff also highlighted that some aspects of the service model presented limitations for service delivery, particularly in relation to program length, referral processes and staffing resources.

Benefits

Importantly, all participants highlighted the desire to form deeper connection with others, to repair their social networks and to reach out to others. Participants also related strong positive feelings with regard to others and towards the strong bonds that had formed throughout the group sessions of the program. This bond was so strong that some participants expressed the desire to remain in contact with other participants after the program ended, which led to the development of the 'Walk and Talk' peer support group. The therapeutic benefit of social interaction was clearly articulated by many in the group and for some this was stated as the main positive outcome from their involvement in the program.

The development of greater insight into the motivations behind their behaviour placed many participants in a position where they were able to begin questioning their behaviour and to start developing the routines and structure in which to challenge their previously well-established thought patterns and behaviours. Throughout the interviews, behaviour change was identified by some participants as one of the main goals they wanted to achieve through the program and many indicated that they had achieved this by the program's conclusion.

Challenges and limitations

In response to the interventions incorporated into the Room to Grow program, many participants reported feeling confronted by the realisation of how difficult it might be to start to shift long-held patterns of thought. Through increased mindfulness and insight, participants became aware of how cognitions and emotions could influence behaviour, while at the same time becoming increasingly aware of the difficulty they now perceived in needing to challenge these same thoughts and feelings. Despite the perceived difficulty of this process, the majority of participants felt positive about their ability to confront these challenges by the end of service delivery.

The anticipated 12 month duration of the Room to Grow pilot program was seen by program staff to be inadequate for the length of time required for many participants to achieve their program goals. This 12 month period did not reflect the need for the lengthy (3-6 month) period of rapport building to build trust or the timeframe required to address property condition – particularly for hoarding disorder where participants should ideally themselves organise and discard possessions. Further, the period was inconsistent with the long timeframe which some participants required to absorb and operationalise the skills needed to address emotions and cognitions associated with hoarding behaviour.

Finally, staff identified that a number of the participants referred into the program during the early stages of service delivery were unsuitable for the type of intensive case management and psychological interventions provided by the Room to Grow program. The majority of these referrals were for participants with issues related to low level domestic squalor. More targeted referral processes should be integrated into any future recruitment strategies for this program in order to better identify and refer participants experiencing the types of complex and challenging issues that this intensive service model was designed to support.

Recommendations

Best practice service model

- **Social interaction** should be central to program design in this space to address the long-term social isolation and other factors which prevent the formation of close social bonds experienced by many individuals with hoarding disorder and/or domestic squalor. The therapeutic value of social support and formation of new, supportive relationships between participants must not be underestimated.
- **Adapted Cognitive Behavioural Therapy (CBT) sessions** with a psychologist are highly recommended for those experiencing hoarding disorder. While recommendations for intervention length vary, at least 15 sessions is thought to be ideal, with a maximum length of 26 sessions.
- **Home visits** are generally considered essential for those with hoarding disorder and/or domestic squalor. It is important for individuals to have the opportunity of organising and discarding possessions in their own homes with the guidance of a case manager or support worker. Without such exposure it is less likely that skills learnt in CBT sessions will be effectively operationalized and internalised.
- **Participants must be centrally involved in all decision-making** regarding their properties, and any organisation, cleaning or discarding processes in their homes should be undertaken by the participant independently or at the very least led by the participant. Enforced cleans

are likely to lead to traumatisation and other negative outcomes – even with prior warning and consultation.

- Many participants of the Room to Grow program expressed the desire to continue receiving **ongoing support** and to meet on a regular basis with staff and other participants after the 'formal' interventions had concluded. Participants were concerned that, without some form of continued service contact, they would not be able to maintain the behaviour change developed throughout the CBT sessions. Ideally this continued support would take the form of a **peer support group** which may receive gradually lessening contact from service staff and become entirely peer-led without an exit date.

Program length and flexibility

- Due to the characteristics of those experiencing hoarding disorder and/or living with domestic squalor (e.g. histories of loss or trauma, long-term social isolation, anxiety sensitivity), a lengthy period of rapport and trust building between staff and participants is vital. This requires a long lead time built into anticipated program duration prior to intended 'interventions' such as CBT sessions or home visits. Ideally a period of 3-6 months may be required but actual timeframes should be led by the individual.
- There is no one-size-fits-all approach appropriate for individuals experiencing hoarding disorder and/or domestic squalor. It is important to use a nuanced approach which is flexible to the needs, capacities and goals of each individual.
- Ideally, service models operating in this space should be flexible enough to reflect input from program participants and to allow program staff to develop new initiatives which respond to the specific needs or goals of the group and/or the individual, while allowing the original service model to evolve throughout program implementation.

Inter-agency collaboration

- As hoarding disorder is a mental health diagnosis, it is vital to acknowledge this in any service response targeting these individuals. Inter-agency community responses must involve local health districts and community service organisations to incorporate case management and tailored psychological interventions such as 'Buried in Treasures' (BIT) workshops within an appropriate service response.
- To ensure the success of inter-agency collaboration, a strong governance structure must be established which utilises a facilitating/lead agency approach to manage referral, intake, brokerage and networking between the support services involved. The necessity of building strong relationships with external support services should be incorporated into the governance framework, encouraging relationships with and between other agencies.

Future directions

- Currently, there exists a service gap in the Sydney metropolitan region for a person-centred, recovery-oriented service model which embeds psychological interventions within a case management framework (including home visits and peer support facilitation) for individuals with complex comorbid issues who may be disengaged from service support and who are at risk of homelessness through tenancy loss or eviction due to issues related to hoarding disorder and/or domestic squalor.

- There exists an opportunity for government and local councils to partner with community services and mental health/allied health support services which can provide the intensive case management and psychological interventions (e.g. BIT workshops) which have the potential to make positive changes in the lives of individuals living with hoarding disorder and domestic squalor. These partners could ultimately support the transition of participants into a peer support model for long-term monitoring and broker funds for cleans, skip bins, trucks and other resources.
- Many participants from the Room to Grow program expressed interest in performing a community advocate or educator role engaging with individuals at an earlier stage of recovery. This suggests there may be an opportunity for service providers to draw on the lived experience and resources of individuals with hoarding behaviours after the conclusion of service delivery, potentially involving interested participants who have 'graduated' from the program in a peer support worker role.

Conclusion

This evaluation demonstrates the merits of intervening early to prevent tenancy loss and improve participant wellbeing and demonstrates the effectiveness of interventions addressing hoarding disorder and domestic squalor as a part of a comprehensive approach to preventing and addressing homelessness.

Introduction

From July 2015 to June 2016, MA ran and evaluated an intervention for hoarding disorder and domestic squalor across the central and eastern Sydney region. Participants included 11 clients of MA's Common Ground Camperdown Support Service (CSS), 5 clients of Eastern Sydney Partners in Recovery (ESPIR) and 13 tenants from Housing NSW (HNSW) properties who were identified as being at risk of homelessness due to issues related to hoarding disorder and domestic squalor.

This intervention was funded by the National Partnership Agreement on Homelessness (NPAH) through the NSW Department of Families and Community Services (FACS) with the aim of reducing the risk of homelessness for vulnerable individuals experiencing hoarding disorder and/or domestic squalor. The implementation and evaluation of the Room to Grow program were designed to address the core service responses of 'intervening early to prevent homelessness' and 'intensive responses for clients with complex needs'.

Originally titled the 'Hoarding and Squalor Intensive Treatment Program', it was re-titled 'Room to Grow' based on participant feedback. The pilot program aimed to address the physical, cognitive and psychological factors contributing to situations of severe domestic squalor and hoarding disorder, thereby reducing the risk of tenancy loss. The Room to Grow program incorporated an individualised case coordination plan which responded to the unique needs of each participant. Alongside this, participants were encouraged to access clinical interventions designed to assist in the management and improvement of hoarding behaviour, daily living skills and cognitive functioning.

The internal evaluation took the form of both an outcomes and progress evaluation. Firstly, MA aimed to determine the impact of the Room to Grow pilot program on a number of outcomes associated with domestic squalor, hoarding behaviour and property condition. Secondly, a progress evaluation was conducted to understand the successes and challenges faced throughout the service implementation of the pilot. Together, results from each evaluation type were used to generate a crucial evidence-base for the unique service model offered in the Room to Grow program – one which embeds psychological interventions within an intensive case management program alongside practical support and cleaning.

This report provides definitions of hoarding disorder and domestic squalor before presenting an overview of the service model, followed by a discussion of the cohort taking part in the program and levels of participation and engagement. The evaluation methodology will then be described, followed by a presentation of results from both the quantitative and qualitative analysis. Finally, this report will make recommendations for a best practice service model and future directions to be taken to address issues tied to hoarding disorder and domestic squalor in communities across Australia.

Definitions

While it has been found that one third of those living in severe domestic squalor exhibit hoarding behaviours[i], hoarding disorder and domestic squalor manifest in different subsets of behaviour and are caused by different physical, psychological and cognitive processes. As a result, each ought to be considered as a distinct and independent condition which requires a unique intervention and treatment.

Hoarding disorder manifests in the accumulation of personal possessions and a difficulty or refusal to discard these items.[ii] As a result, the living conditions of those with hoarding disorder often present health and safety risks and can reduce the accessibility and functionality of many living spaces.[iii] Severe domestic squalor refers to an environment in which the living conditions are so unhygienic and dirty that they would be considered unacceptable by those of the same culture and background.[iv] While there is some overlap between these experiences, accumulating items or waste because there is no motivation to discard or due to physical or cognitive impairment does not meet the criteria for hoarding disorder just as those who display hoarding behaviours may maintain clean and hygienic, though severely cluttered, living spaces.

At the onset of the Room to Grow program, participants were grouped according to the presence of hoarding behaviour and/or environments of domestic squalor. Each group presented with distinctly disparate behaviours, personal histories and clinical backgrounds and the property condition for each participant differed significantly between the groups.

Domestic squalor

Reference to 'domestic squalor' must be understood to refer to an environment rather than the occupant themselves or their behaviour. As mentioned, the term 'domestic squalor' is used in the Australian context when an occupant's home is considered so unhygienic and disorderly that extensive cleaning would be considered critical by a person of the same or similar culture and background.

Accessibility throughout the dwelling might be impeded by accrued waste material so that many rooms/utilities cannot be used for their original purpose and insects and other vermin are also likely to be present. Occupants may have a tendency to hoard other household items alongside accumulated waste materials, which may complicate or exacerbate their ability to manage the disposal of waste and the general cleanliness of the dwelling.[v]

The behaviour that leads to severe domestic squalor may be caused by mental health issues or may occur as a result of reduced cognitive or physical capacity.[vi] Those living in severe domestic squalor can present significant challenges to social services, health professionals and local councils as well as to their families, neighbours and to their own health and wellbeing. As it has been found that 1 in 1000 people aged over 65 in the Sydney metropolitan area live in moderate or severe domestic squalor,[vii] the burden placed on social and health services as well as the significant cost associated with the required cleaning and renovation warrants the development of timely and effective intervention for those living in these conditions.

In NSW, a severe domestic squalor reference group was set up with funding from the NSW government's Department of Ageing, Disability and Home Care (DADHC) to facilitate a review of services for people living in squalor. The final report was issued in 2007 and included guidelines for intervention which were ultimately approved by the then Partnerships Against Homelessness (PAH) Committee and are available online[viii]. These guidelines informed the service response developed in the Room to Grow pilot program.

Case management and interventions for participants of the Room to Grow pilot experiencing issues predominantly related to domestic squalor focused on improving living skills and cognitive functioning. This took place through intensive care coordination and regular ongoing cleans by

support workers who often cleaned with the participants. Participants were encouraged to access cognitive rehabilitation (CR) during the first six months of the program, in conjunction with an adapted cognitive behavioural therapy (CBT) program focussed on developing living skills and addressing any underlying psychological issues which may have contributed to the living environment. These participants were also able to access individual sessions with a psychologist if they were uncomfortable accessing psychological support in a group setting.

Hoarding disorder

In the latest edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), hoarding disorder has been included as a distinct disorder alongside those classified under 'Obsessive-Compulsive and Related Disorders'. Although previously the characteristics of hoarding disorder were included in the symptomology of Obsessive-Compulsive Disorder (OCD), recent research has shown that those meeting the criteria for hoarding disorder respond poorly to the medications and cognitive-behavioural therapy (CBT) used in standard OCD treatment. [ix,x] Evidence also suggests that hoarding disorder and OCD involve different neurological and biological functions.[xi] As a result, it is now understood that hoarding disorder requires specialised treatment options which respond more specifically to the characteristics of this issue.

Hoarding disorder is characterised by a number of intersecting behaviours, belief systems and cognitive processes. A cognitive-behavioural model of hoarding disorder has been developed to explain the mechanisms underlying the excessive acquisition and inability to discard which characterise hoarding behaviour.[xii,xiii] This model explains hoarding through three main factors:

1. *Information-processing deficits*: difficulties with organisation and categorisation of possessions, difficulties with decision-making about possessions and problems sustaining attention;
2. *Erroneous beliefs about, and emotional attachment to, possessions*: poor memory confidence, emotional attachment to possessions, inaccurate judgements about the importance and sense of responsibility for possessions, and need for agency over possessions;
3. *Behavioural avoidance and emotional distress*: erroneous beliefs can lead to heightened emotional distress (guilt, grief or anxiety) at, for instance, the prospect of 'losing' – either by not acquiring or discarding – a possession. This emotional distress triggers avoidance behaviours, designed so individuals can escape these intense feelings of loss and anxiety about decision-making.[xiv]

The service response for those experiencing issues related predominantly to hoarding disorder was led by psycho-education and an adapted CBT program based on the 'Buried in Treasures' (BIT) model developed by David Tolin, Gail Steketee and Randy Frost in the United States. The BIT workshops were run in tandem with a Cognitive Rehabilitation (CR) program to assist with improving cognitive functioning. Intensive case management also incorporated tools from the BIT model and built on skills participant's learnt in the BIT workshops. For this group, CR helped to build skills in executive functioning such as memory, attention, reasoning and problem solving which assisted with tasks undertaken throughout the BIT workshops, particularly with homework tasks.

Service model

Participant selection

Participants were referred to the Room to Grow program from MA's Common Ground Camperdown Support Service (CSS), Eastern Sydney Partners in Recovery (ESPIR) and the Sydney and South-East Sydney districts of Housing New South Wales (HNSW). CSS operates within Common Ground, a housing complex which provides housing for formally long-term homeless tenants, public housing and affordable housing tenants in Sydney's inner-city. CSS provides integrated service support for formally homeless tenants including case management, medical and psychological support.

Service delivery

The Room to Grow program took place over a 12 month period from July 2015 to June 2016, with service delivery running from September 2015 to July 2016. Within the program, participants progressed through an individualised case coordination plan with a number of potential referral pathways dependent on diagnosis, co-morbidities, living conditions and insight/motivation. Participants transitioned through a diagnostic/assessment phase, followed by a referral process to relevant services and encouragement to access these, proactive encouragement to engage with case management, access CR and/or CBT where appropriate, and to move through to final transition into ongoing case management and monitoring to prevent recurrence towards program exit. Participants joined a treatment plan determined by perception of property condition as determined by staff, group dynamics and participant behaviours.

Intensive case management

Participants had access to intensive case management involving the development of organisational and decision-making skills, assistance with activities of daily living and guidance with de-cluttering and discarding in the home where relevant. This intensive case management approach was delivered on a one-to-one basis for each participant. Participants with a cognitive impairment were supported to engage with and learn the skills taught throughout the program through involvement in the CR program (see below).

Adapted CBT – BIT workshops

Adapted CBT was run by two different psychologists over two separate programs of 12 sessions each. The first set of sessions were aimed at participants without a diagnosis of hoarding disorder and were focused on resolving underlying issues which impact on situations of domestic squalor (e.g. motivation or low mood) and eliciting behaviour change. The second set of sessions, the BIT workshops – were designed to address the cognitive, behavioural and emotional factors associated with hoarding disorder, in particular any emotional distress associated with acquiring or discarding possessions. In the BIT workshops, participants were first introduced to the concepts associated with hoarding disorder and then led to identify aspects of their own behaviour which may be reflected in this disorder. Finally, participants were supported to develop coping strategies which could allow them to appropriately manage their own emotional and cognitive response to acquiring and discarding possessions. Participants were encouraged to enact these strategies in their own home throughout organising and discarding activities. Case managers all read the BIT self-help book which accompanied the workshops and guided participants using the language and framework of the BIT model during home visits before, during and after the workshops.

As with intensive case management, participants with a cognitive impairment were supported to engage with and comprehend concepts explored through the CBT program through involvement in the CR program (see below). The adapted CBT program took place over a twelve week period, with a 90 minute session each week. Participants who were unable to attend group sessions (due to poor health, social anxiety, etc.) were offered individual sessions, covering the same content.

Cognitive rehabilitation

Cognitive rehabilitation has been trialled as an intervention in hoarding disorder with promising results[xv,xvi] . This intervention involves providing individuals with strategies to enhance functional cognitive skills, and practice of those strategies in order to improve cognition. The CR program included in the service model for the Room to Grow pilot involved twice weekly two-hour sessions over a period of six weeks. Each session comprised of cognitive strategy training, education about cognitive functioning and computer assisted practice. The CR program aimed to help strengthen under-functioning cognitive abilities to support participants to better engage with, comprehend and retain skills and strategies learnt throughout case management and/or the adapted CBT program.

Walk and talk peer support group

Towards the end of the final series of adapted CBT sessions, a group of participants stated that they would like to continue meeting with other participants in a group setting to continue with the social support and interaction gained in group sessions throughout the program. Due to the flexible nature of the service, program staff were able to develop a peer support group which responded to this request. All participants were invited to attend the walk and talk group and on average 8-10 participants attended each session. These relatively informal sessions were held once a week with group members deciding on a local park to meet at, walk through and catch up with one another. Case workers usually facilitated discussion of any difficulties faced or successes achieved in the previous week and encouraged those attending to reflect on experiences related to the program (organising, discarding, cleaning, etc.) and to ask questions of the group if needed. Transport was offered by program staff to and from the chosen location each fortnight. Twelve walk and talk peer support group sessions were held over the two month period from April – June 2016.

Staffing

At the onset of the program, the Room to Grow pilot was staffed with a program manager, one full-time and one-part-time case manager. Due to the complexity of the participant group and the often extensive travelling required to meet with participants across a large geographic area, it was felt that the caseload was too high for the number of case managers available. As a result, a further full-time case manager was recruited to cover this gap. Staff were trained through Lifeline Harbour to Hawksbury's hoarding and squalor training program.

Research methodology

Evaluation methods

Due to the complex histories of participants and the general paucity of current research in this space, the Room to Grow evaluation used a mixed methods approach collecting both qualitative and quantitative data. Hardcopy questionnaires were undertaken with the participants or by the case manager where relevant for each measure. Semi-structured interviews were conducted with

all participants in March 2016 and focus groups were conducted with MA program staff in September 2015 and March 2016.

The evaluation involved a full census of all program participants and staff, representing the experiences of all individuals involved in the program. All participants were encouraged to take part in the evaluation when they joined the program by their case manager and the program manager. As the first stage of the program predominantly involved rapport building alongside an initial assessment stage (to inform diagnosis), during this stage there was an opportunity for staff to inform the participants about the purpose of the evaluation and respond to any queries or reservations they may have had. Although the evaluation was presented as voluntary, all participants agreed to participate. Completion rates for each measure were high with the significant majority of participants attending their interview.

On intake, potential participants were asked to provide informed consent to be involved in the evaluation and were again asked for consent prior to taking part in the interviews. All quantitative data is de-identified and is presented only at aggregate level. Data from qualitative interviews has been de-identified and all quotes presented in this report are anonymous.

Measurement tools

This evaluation utilised several measurement tools recommended from the literature as valid and reliable measures of hoarding behaviour and living conditions which were sensitive to treatment effects. These measurement tools were used alongside participant interviews and staff focus groups to determine whether the program delivered the intended outcomes for participants and that all program components were able to be adequately implemented by staff (all tools included in Appendix A).

The measurement tools used in the evaluation have been listed below:

- *Clutter Image Rating Scale (CIRS)* – self-report pictorial rating system found to be a reliable and valid screening tool for detecting the presence of clinically significant hoarding symptoms. The CIRS has also been found to be sensitive to treatment effects.
- *The Environmental Cleanliness and Clutter Scale (ECCS)* – rating system designed to be filled by clinicians/staff found to be reliable for individuals living in severe domestic squalor. The scale relies on rating the living conditions of various rooms along with other indictors of squalor such as vermin and odour.
- *Montreal Cognitive Assessment (MOCA)* – internationally validated rapid screening instrument for mild cognitive dysfunction which is sensitive to treatment effects but not sensitive to age or education levels.
- *Lawton's Activities of Daily Living Assessment (IADL)* – validated rating scale to be completed by case manager for each participant to measure improvement in activities of daily living throughout the program.
- *Personal Wellbeing Index (PWI)* – an international validated measure of wellbeing which contains seven domains of satisfaction, each one corresponding to a quality of life domain including; standard of living; health; achieving in life; relationships; safety; community-connectedness; and future security.

Quantitative methodology

Data collection

Participants and staff were asked to complete a number of measures designed to capture different experiences and conditions connected with hoarding disorder and domestic squalor. These measures have now been captured longitudinally at both wave one and wave two, providing comparative analysis of results.

Wave one measures were taken, where possible, within the first 4-6 weeks of service delivery for each participant. While delivery of the Room to Grow program officially began in July 2015, referrals into the program were staggered over the first six months. This was due to the time required for different referrers across Sydney to identify and refer potential participants, for Mission Australia staff to meet with these participants and then for the Room to Grow assessment team to accept the referral.

As a result of this lengthy recruitment process, wave one measures were not completed for all participants until January 2016. In part due to this process, the decision was made to implement fixed data collection periods for the second wave rather than requiring service delivery staff to collect measures on an ongoing basic throughout the program's duration. The second wave of data collection was undertaken in April 2016.

Data analysis

First, descriptive statistics were used to explore the difference in the average scores across the CIRS, ECCS, LADLA, MoCA-B and PWI. Both individual items and the total scores were compared in each of these measures between the first and second waves of data collection.

Second, linear mixed models in SPSS were used to determine whether the Room to Grow program improved the CIRS, ECCS, LADLA, MoCA-B, PWI average scores, either by decreasing or increasing these means. Linear mixed models account for the similarity within a single participant's responses to the same measure over time when compared to the responses of other participants. As participants in the Room to Grow evaluation were asked to complete a set of measures twice over the duration of their time in the program (within-participant design), it was decided that a linear mixed model would best determine the effect of the program (the intervention) on participant's responses to each measure.

Linear mixed models examined whether the intervention had a significant effect on the mean scores of each measure from wave one to wave two. Linear mixed models were also used to determine whether there were any significant interactions between key demographic factors and the measures over time.

Qualitative methodology

Thematic analysis was used for participant interviews to identify themes described by participants and to capture the experience of those living with hoarding disorder or in environments of domestic squalor in the Australian context.

Thematic analysis involves the examination of qualitative information (in this case participant interviews) to identify, interpret and categorise meaningful patterns or 'themes' throughout the data. These themes generate an understanding of an experience or phenomenon, particularly

relevant where a strong evidence-base for such an experience has not yet been built. Themes are identified through an iterative process of data familiarisation, data coding, theme development and revision.

The evaluation sought to consider the reality of hoarding disorder and domestic squalor to the participants, the way the Room to Grow program was understood and interpreted with participants and ultimately, how participants perceived the impact of the Room to Grow program on their property and the behaviour, emotions and cognitions associated with hoarding disorder and domestic squalor.

Participants and procedure

Twenty-four semi-structured interviews were conducted by two Mission Australia research staff. Interviews took place at MA's Common Ground site in Camperdown, Sydney. Questions prompted a brief discussion of each participant's current and past property condition, including any personal history connected with this, followed by discussion of participant's experience in the program, its perceived strengths, weaknesses and suggested improvements for service delivery and reflections on the personal impact of the program.

Themes explored within the interviews were designed to allow the participant to describe the narrative of their own personal experience with hoarding disorder and/or domestic squalor and the place of the Room to Grow program within this. Participants were encouraged to clarify or reiterate issues they felt were significant to their personal narrative and to apply this to their interaction with the Room to Grow program. It was hoped that this would allow participants to provide an unbiased perspective of their experiences. As research staff from Mission Australia were known to be uninvolved in the service delivery, overall participants were very comfortable being critically reflective about the program.

Interview length was directed by the participant and resulted in interviews ranging from approximately twenty minutes to two hours. Interviews were transcribed and initial development of themes were validated with the Walk and Talk peer support group at their final meeting in late June 2016. This validation session took the form of an informal focus group and, in addition to the validation of themes, this session allowed participants who were engaged in the peer support group to provide final feedback about their experience of the final stages of the program. The decision to conduct this last session was led by the participants attending the Walk and Talk group who requested an opportunity to describe their final impressions of the Room to Grow program.

Thematic analysis

Data collected from the interviews was transcribed and initial impressions were noted. Following this, the recordings were again listened to, ensuring transcriptions matched recorded information and so that the principal investigator was able to guarantee full data immersion. Transcriptions and recordings were returned to multiple times during this stage to begin to build a complete picture of participants' experiences.

The first coding phase then took place. During this phase, each transcription was coded at the paragraph level to identify the key concepts being described by participants. Not all codes were

relevant to the evaluation questions but this level of coding provided context for codes identified as relevant and significant.

The second stage of coding involved reviewing codes for relevance and the early stages of identifying repeated patterns throughout the codes, this early pattern-identification provided scaffolding for the main themes and sub-themes categories in later stages. The first set of identified codes included both verbatim quotes felt to highlight significant concepts and interpretations of broadly described experiences from several participants. In both cases, these codes were felt to be representative of the general experience of all participants. These codes were then listed and organised together with codes thought to describe similar concepts or aspects of the data. These groupings were then labelled as the first 'themes'. The first themes were then listed again and these early themes were then organised into broader groupings again.

At this stage, as suggested by Braun and Clarke (2006), a thematic map was developed to help understand, organise and refine the relationship between themes and to start describing the relationship between main themes and sub-themes. The thematic map highlighted the relevance of certain themes over others and as a result some themes were discarded in place of broader or more conceptually relevant ones. The relevance and coherence of each theme was considered alongside all other themes and within the data set as a whole. This step was required to ensure each main theme and sub-theme accurately reflected the content of the full data set as well as ensuring that a coherent narrative was evolving within and between themes which contributed meaningfully to the key concepts being explored, i.e. participants experience with hoarding disorder and domestic squalor with reference to the impact of the Room to Grow program.

At this stage the original transcripts were again returned to, ensuring no content was missed and to add to and validate the new relationships between main themes and sub-themes. Lastly, the final labels of all main themes and sub-themes were chosen, highlighting the meaning encapsulated in each theme. Key quotes originally linked with early and developed themes were categorised and presented with detailed analysis of the content of each theme.

Results

Demographics

Demographic information was derived from referral information and internal Mission Australia data. There were 29 participants enrolled in the Room to Grow program. Of these participants, 65.5% were male while 34.5% were female. The mean age of participants was 52 years old.

Almost all (96.6%) participants lived alone and 20.7% of participants lived with a pet. Three participants were caring for children on a regular basis. Based on referral information, around one in five (24.1%) participants reported a history of Consumer, Trader & Tenancy Tribunal action in the last two years. As staff built stronger relationships with participants, it is now felt that the actual proportion with a history of Consumer, Trader & Tenancy Tribunal action would be higher. Based on referral information, 17.2% of participants had nuisance and annoyance complaints filed against them and 6.9% of participants had experienced a high turnover of housing in the last two years. The majority (82.8%) of participants came into the program with at least one form of existing

professional support, for most this consisted of a case manager, psychologist and/or community support worker.

Referring services indicated that around two thirds (65.5%) of participants had a history of hoarding on program entry, while 75.9% of participants had a history of domestic squalor. There was some overlap between histories of hoarding and squalor, with 68.4% of those with a reported history of hoarding also having a reported history of domestic squalor. On entry all participants were asked to attend an assessment with the neuropsychologist in part to determine whether they met the criteria for a diagnosis of hoarding disorder. Formal assessments have been provided for all 29 participants, with close to half 44.8% formally diagnosed with hoarding disorder.

A significant majority (89.7%) of participants were identified with a pre-existing mental health diagnosis on referral, although it is estimated that this has been underreported on referral forms and is likely closer to 100%. Aside from mental health diagnosis, the participant cohort for the Room to Grow program had experienced some complex co-morbid issues. Around half (55.2%) of participants had current substance abuse issues, one in ten (10.3%) presented with a physical disability, 7.1% had an acquired brain injury and 3.4% had an intellectual disability.

Some participants also presented with behaviours which required intensive staff support. One in five (20.7%) presented with current violence or aggression concerns, one fifth (17.9%) presented with current or previous self-harm or suicide attempts, 17.2% presented with current or previous risk-taking behaviour and 34.4% presented with other behavioural issues which may impact on service delivery, including memory difficulties, lack of motivation and anti-social or erratic behaviour. Complex presenting issues such as these necessitated the recruitment of an additional full-time case manager into the Room to Grow program staff.

Quantitative analysis

Descriptive statistics

Personal Wellbeing Index (PWI)

The PWI is a measure of subjective wellbeing designed to be sensitive to fluctuations in a person's circumstances. When circumstances become particularly difficult (i.e. if someone doesn't have housing, is being abused, etc.) a person's self-managing mechanism may be compromised and lower levels of wellbeing can result. In situations such as this, the PWI is a particularly sensitive instrument and if such difficult circumstances are addressed we might reasonably expect the PWI to pick up on improved levels of wellbeing. The PWI encompasses the constructs of satisfaction with the following domains: standard of living; health; achieving; relationships; safety; community; future security. It also includes a stand-alone question on satisfaction with life as a whole.

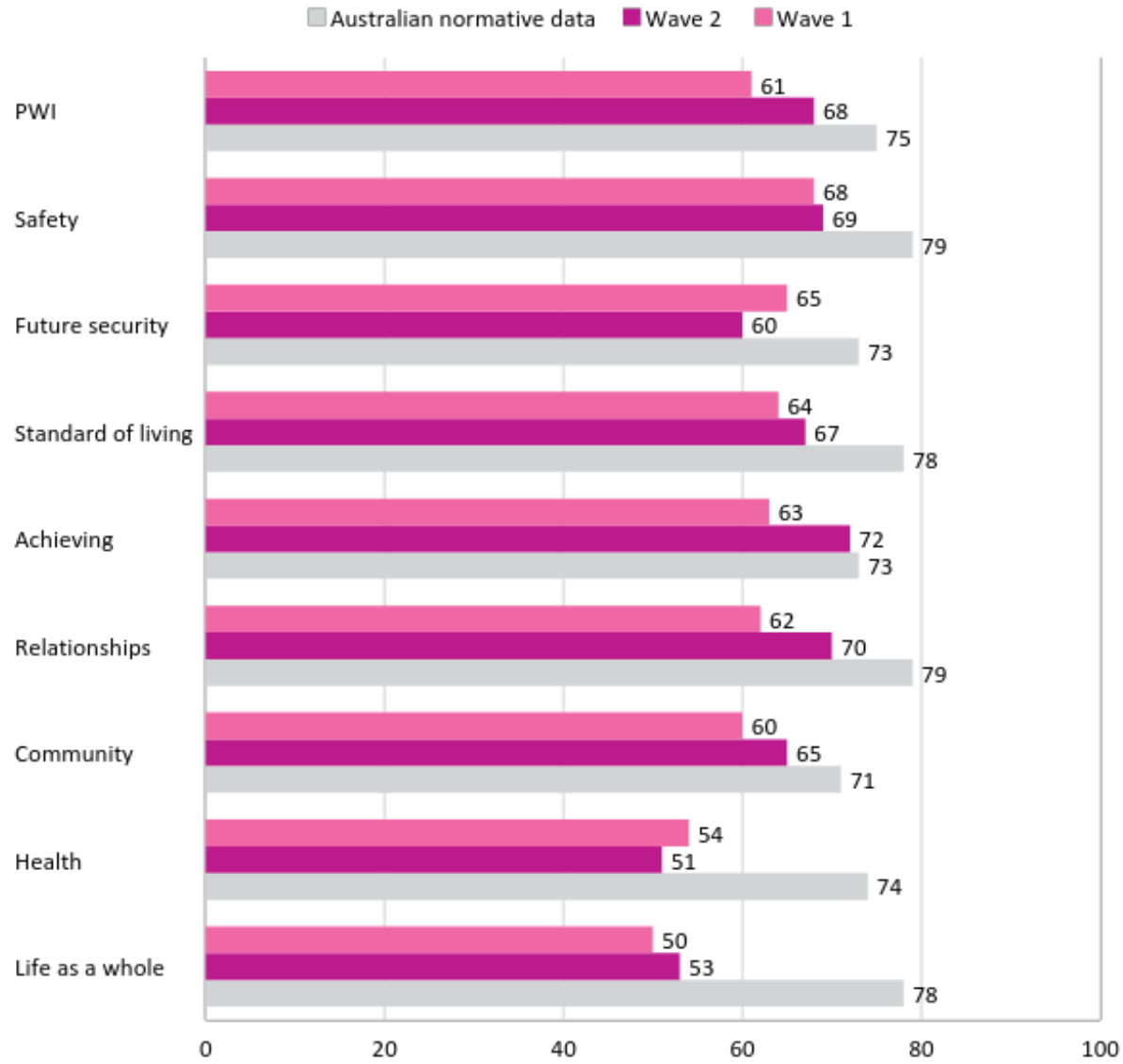
The survey participants are asked to rate their satisfaction with these domains on a scale of 0-10. The scores on these seven domains are averaged to form a single composite personal wellbeing score that is standardised onto a 0-100 point scale, where 0 is completely dissatisfied and 100 is completely satisfied. The following guidelines are given by the developers of the index for the interpretation of individual subjective wellbeing scores as measured by the PWI:

70+ points	'Normal': A person is likely to be experiencing a normal level of wellbeing

51-69 points	'Challenged': Personal wellbeing is likely to be challenged / compromised
<50 points	'High-risk': Very low personal wellbeing / strong likelihood of depression

In Australia, the average PWI is approximately 75. The PWI – Intellectual Disability format was used for participants of the Room to Grow program due to the anticipated high proportion of participants with complex needs which may impact on cognitive functioning. At wave one, 26 participants from the Room to Grow program completed the PWI measure. In Figure 1 below, the averages for each of the PWI domains have been compared between the wave one and wave two data collection periods. This table shows the change across time between measures for each of the domains compared with Australian normative data.

Figure 1 – Wave one and two PWI results, total cohort compared with Australian normative data[1]



[1] Cummins, R.A., Woerner, J., Weinberg, M., Collard, J. (2012) Australian Unity Wellbeing Index Survey 28.0, Report 28.0, Deakin University: Melbourne, Australia.

The mean PWI for the full cohort at wave one was 61, indicating that on average the wellbeing of participants from the Room to Grow program at wave one was likely to be challenged or compromised. At wave two the mean PWI rose to 68, while still in the range of 'challenged or compromised', this result indicated that the participant cohort had shifted closer to a 'normal' level of wellbeing. A number of life domains across the PWI rose between wave one and wave two, including pronounced improvements in the domains of 'achieving' and 'relationships'. The domains of 'health' and 'future security' show a small decrease in mean scores overall, although in the case of the 'health' domain this may be due to increased insight into participants overall physical health as a result of increased service support.

Environmental Cleanliness and Clutter Scale (ECCS)

The ECCS was developed to rate the degree and various aspects of uncleanliness in an individual's living area to both facilitate appropriate service support and provide a sensitive evaluation tool for research in this space. This tool has been found to be reliable and useful in rating cases where individuals are living in severe domestic squalor. A score of 12 or more was generally found to indicate moderate to severe squalor.

Staff from the Room to Grow program were asked to complete the ECCS after inspecting each participant's property. Overall, the items provide an overview of the environment in a person's home including accumulation of items, accessibility, the cleanliness of a number of rooms and areas throughout the home and the presence of factors associated with domestic squalor such as odour and vermin. There are ten items in total, listed below in Figure 2, each rated on a four-point scale from 0-3 with 0 indicating cleanliness or a lack of accumulation, odour or vermin and 3 indicating extreme uncleanliness, accumulation, odour or vermin.

Figure 2 below shows the mean score for each ECCS item from all participants at wave one (N=28) and two (N=27). A decrease in the mean score of all items can be seen between wave one and two, indicating an overall improvement in the environment of participant's homes. Particularly large reductions in mean score can be seen in the accumulation of refuse or garbage (wave one: 1.7; wave two: 0.9) and the cleanliness of floors and carpets (wave one: 1.9; wave two: 0.9).

Figure 2 – Wave one and two mean ECCS items

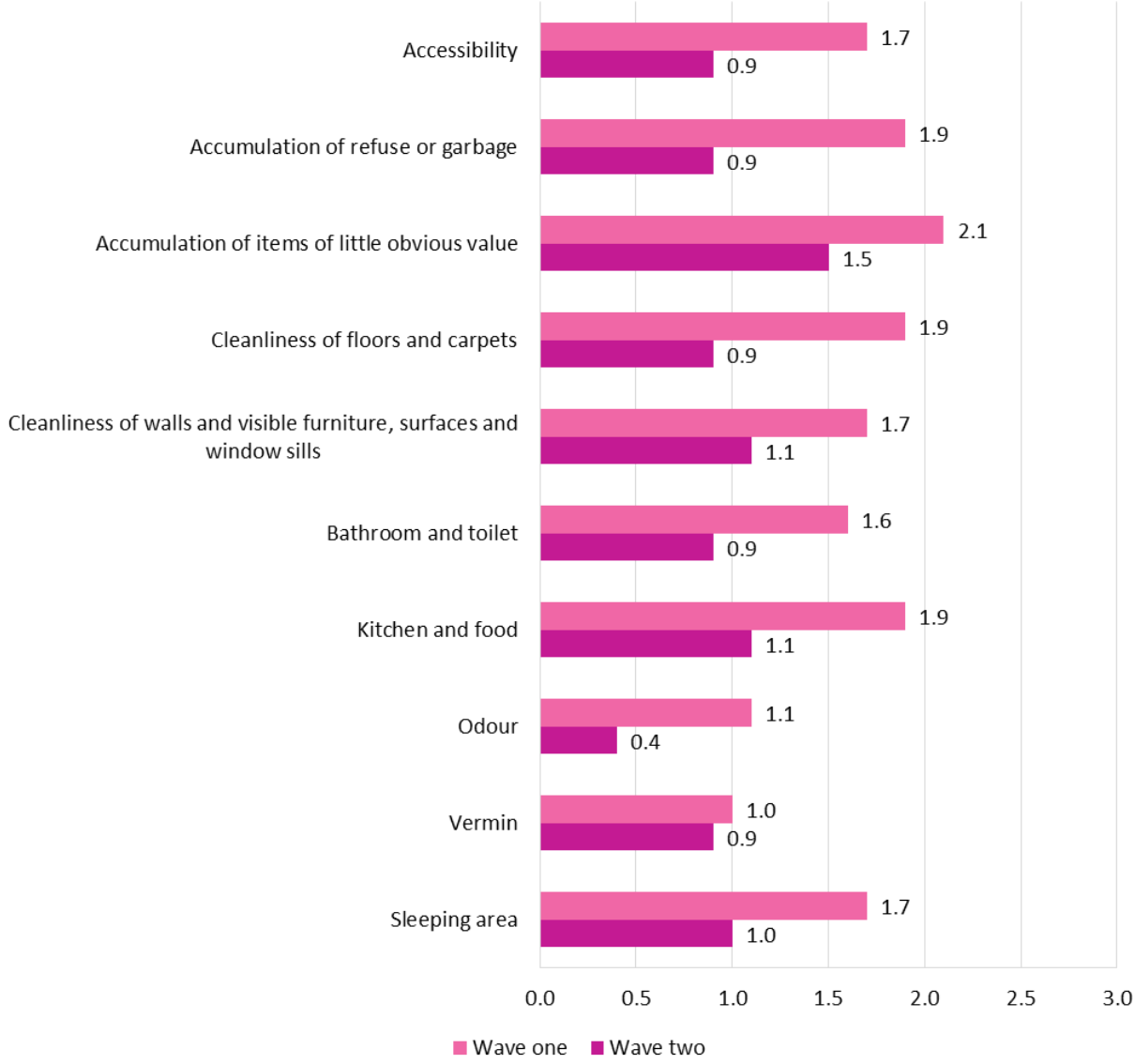
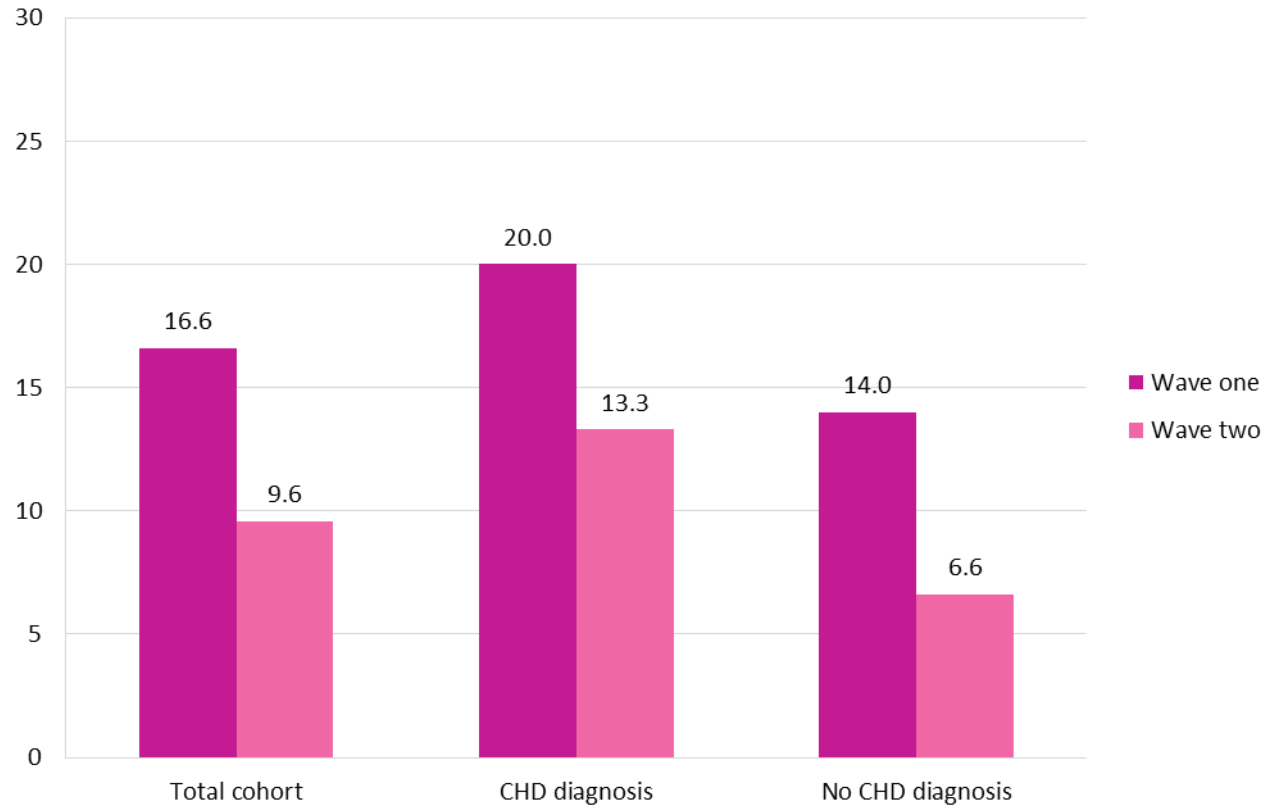


Figure 3 – Wave one and two mean ECCS scores



As can be seen in Figure 3, the mean ECCS score decreased from 16.6 at wave one to 9.6 at wave two. Similar decreases can be seen for both those with and without a diagnosis of CHD. Overall, participants without a diagnosis of CHD had the largest decrease in mean ECCS score between waves. This may be because the ECCS is more sensitive to changes in property condition in these cases and the prevalence of situations of domestic squalor was higher for participants without a diagnosis of CHD.

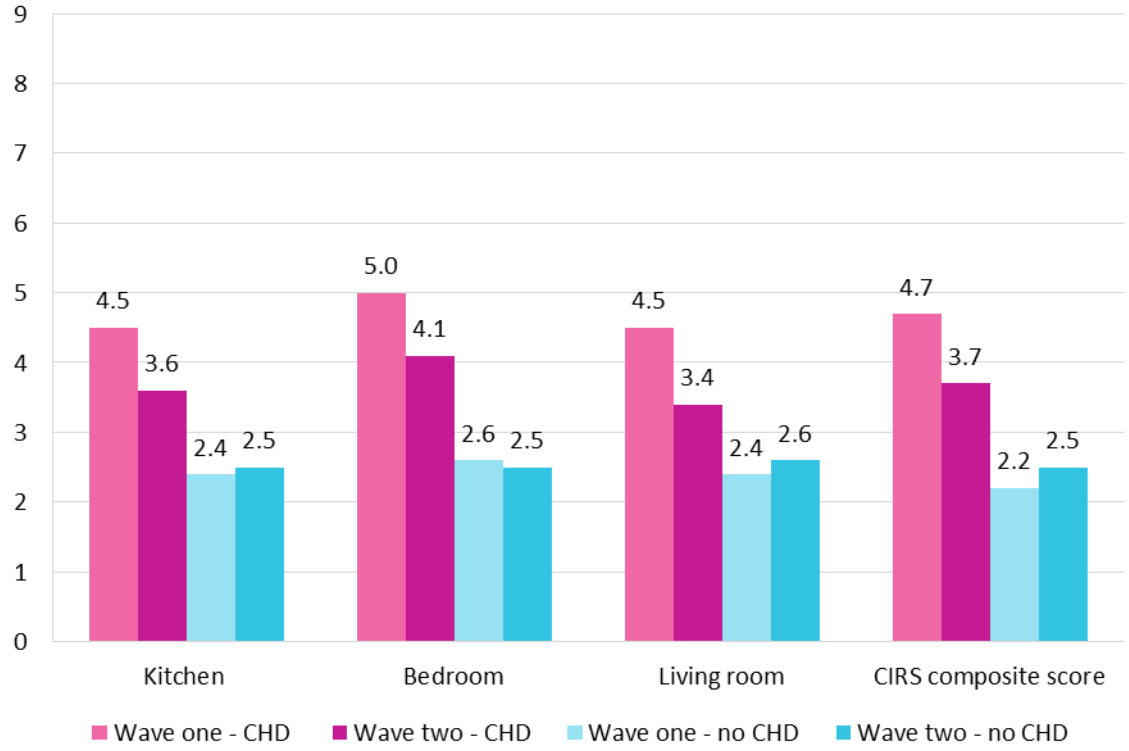
Clutter Image Rating Scale (CIRS)

The CIRS was developed to address the lack of available instruments for individuals to self-assess the severity of hoarding and clutter in their property. This assessment allows service providers to understand the clinical significance of hoarding symptoms and also provides a guide for the level of insight participants hold about the presence of clutter in their property. The CIRS is a pictorial scale containing nine equidistant photographs of severity of clutter within three of the main rooms in most people's homes, including the living room, kitchen and bedroom.

The CIRS has been found to have good test-retest reliability and strong inter-observer reliability, allowing the measure to be used multiple times within an evaluation model by participants to determine improvements in both insight and levels of hoarding symptoms/clutter over time. As the CIRS is a very brief measure (average completion time of less than five minutes) it can be useful in intervention contexts for measuring the clutter dimension of hoarding disorder and can easily take

place within the timeframe of an average case management session. A cut-off score of 4 or higher has been used as an indicator for significant clutter requiring clinical attention. Of the total participant cohort, 27 completed the CIRS at wave one while 25 completed the CIRS at wave two. Figure 4 below shows a comparison between the mean scores of those diagnosed with CHD and those without this diagnosis.

Figure 4 – Wave one and two mean CIRS scores, total cohort with and without CHD



The scores for those with a diagnosis of CHD are higher, above the cut-off for indications of significant clutter at wave one. However, mean scores are lower by wave two and the composite score moves from 4.7 (significant clutter) to 3.7, just below the cut-off score, indicating a positive shift in perceptions of clutter.

Unsurprisingly, those without a CHD diagnosis were well outside the cut-off for significant clutter during both wave one and two.

Lawton's Instrumental Activities of Daily Living (IADL) Scale

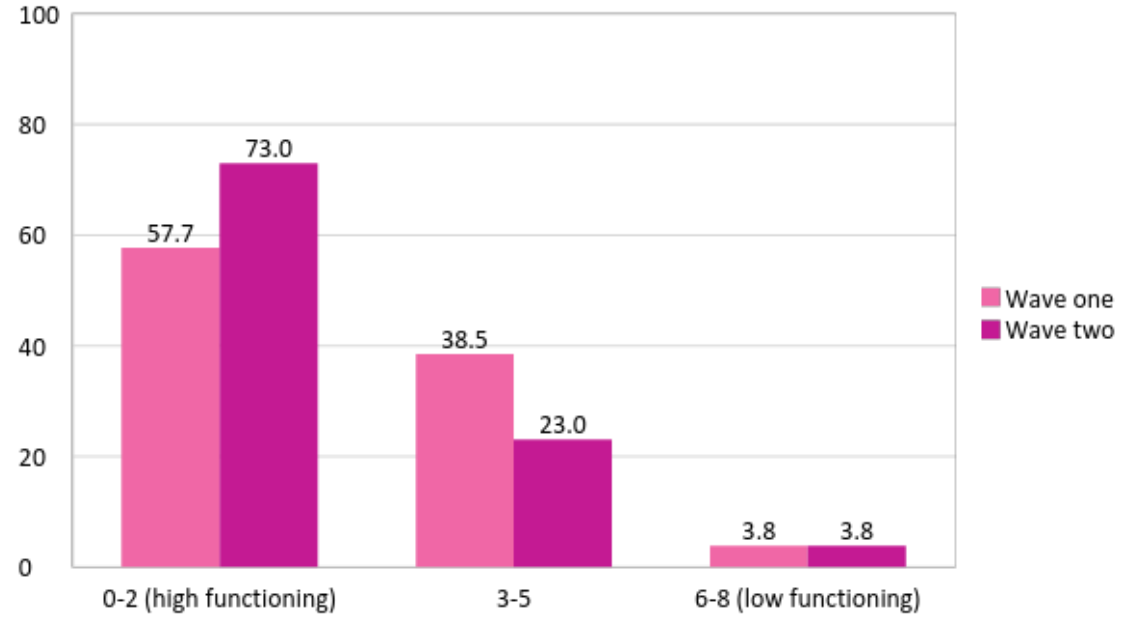
Lawton's IADL scale was developed to determine the level of functionality of participants in a number of more complex activities of daily living (instrumental activities of daily living) both in the home and in community settings. As instrumental activities of daily living (IADLs) require more complex functionality than activities of daily living, assessing IADLs can identify changes in functionality for individuals who are able to perform well with most daily tasks. In the Room to Grow program, the IADL scale was used both to identify participants who may be experiencing difficulties with daily tasks and to measure improvement or decline in participant's functionality with these tasks.

The IADL scale takes approximately 10-15 minutes to complete and is completed by staff with participants. The scale contains 8 items which are rated on either a four-point or three-point scale.

Points on the scale are then scored to indicate independence or dependency for each type of task. Participants are then given a summary score from 0 (high functioning) to 8 (low functioning)[2].

Of the total participant cohort, staff completed the IADL tool for 26 participants at both wave one and two. In Figure 5 below, the IADL scores for the total cohort have been presented for both waves. Scores have been grouped into three categories – 0-2, 3-5 and 6-8 – with 0-2 representing the highest functioning category and 6-8 the lowest functioning category.

Figure 5 – Wave one and two IADL scores, total cohort



At wave one the majority of participants were assessed as high functioning with 57.7% of participants falling into this category. Around one in four were slightly lower functioning with scores in the 3-5 range and 3.8% were assessed as low functioning. By wave two, the proportion of those assessed as high functioning had increased to 73.0% while the proportion with lower functioning decreased to just under one quarter (23.0%). Again, 3.8% of participants were assessed as low functioning in wave two.

Overall, the participant cohort from the Room to Grow program were relatively high functioning at wave one although on items measuring 'laundry', 'food preparation' and 'house-keeping', staff indicated that a low proportion of participants were able to complete these tasks *independently* (laundry: 50.0%; food preparation: 42.3%; house-keeping: 26.9%). The proportion of participants able to complete these same tasks independently had increased by wave two for each item, revealing increased independence in these instrumental activities (laundry: 73.1%; food preparation: 73.1%; house-keeping: 50.0%).

Montreal Cognitive Assessment – Basic (MoCA)

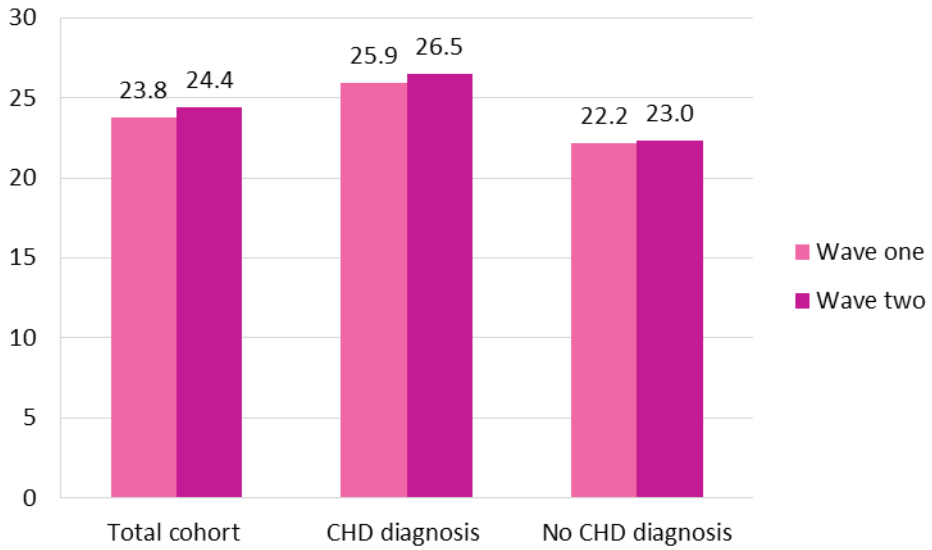
The MoCA is a concise, comprehensive cognitive screening tool designed to measure cognitive impairment and assess major cognitive domains such as attention and memory. The MoCA is

[2] The Lawton's IADL scale is typically scored with 0 indicating lower ability and 8 indicating higher ability. Throughout this evaluation the scale was scored in reverse, with 0 indicating higher ability and indicating lower ability.

sensitive to treatment effects and can detect mild cognitive impairment linked with degenerative conditions, substance abuse, schizophrenia and acquired brain injury (ABI). The Room to Grow program used the MoCA-Basic assessment as it has been specifically designed for subjects who may have low levels of education. Based on staff reports of participants from MA's Common Ground, from which the first participants were referred, it was anticipated that many participants may have incomplete or fragmented education, necessitating the MoCA-B.

At wave one, 23 participants were assessed with the MoCA-B, while 21 participants completed this measure at wave two. The MoCA-B is scored out of 30. The average score for normal controls is 27.4 with mild cognitive impairment detected within scores ranging from 18-26, moderate cognitive impairment within scores ranging from 10-17 and severe cognitive impairment scoring less than 10. The average score for participants of the Room to Grow program at wave one was 23.8.

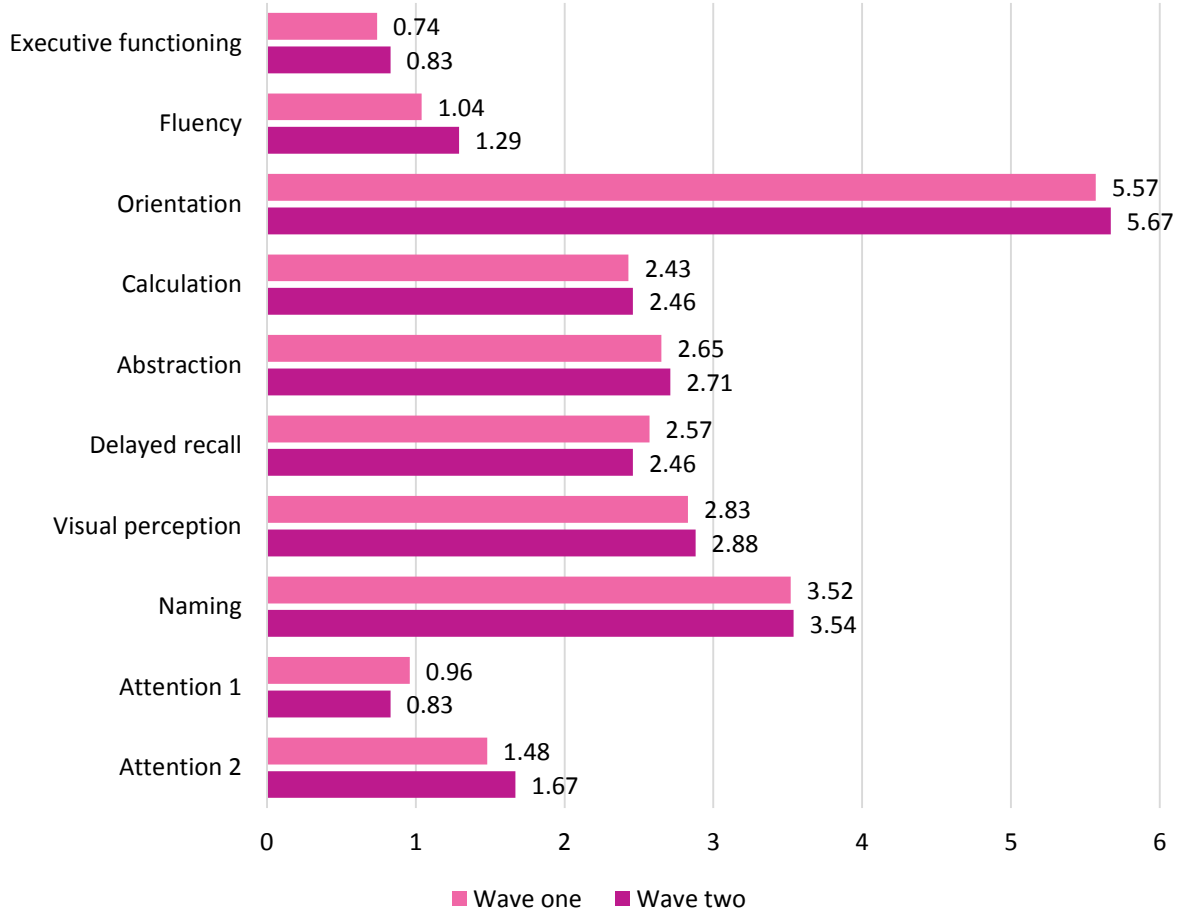
Figure 6: Wave one and two MoCA-B scores by CHD diagnosis



As can be seen in Figure 6, scores from all cohorts fell within the range for those with a mild cognitive impairment at wave one, with slightly higher average scores for those with a CHD diagnosis and slightly lower average scores for those without a CHD diagnosis. By wave two these results suggest that cognitive functioning has remained steady over the course of service delivery.

The mean scores for each item within the MoCA-B across both wave one and two have been outlined in Figure 7 below. The maximum possible score for each item is as follows: executive function: 1; fluency: 2; orientation: 6; calculation: 3; abstraction: 3; delayed recall: 5; visual perception: 3; naming: 4; attention 1: 1; attention 2: 2. Similar to the overall MoCA-B score, each individual item's score remained relatively steady over both waves, however for the majority of items there was a slight increase in the mean score between waves.

Figure 7: Wave one and two MoCA-B scores, all items



Neuropsychological testing

All 29 Room to Grow participants underwent neuropsychological testing on entry into the program. In the aggregate, scores on tests of attention, memory/new learning and executive functioning were in the average to low average range (generally at or below the 16th percentile).

Twenty-five of the 29 participants (86.2%) underwent post-intervention cognitive testing with an average retesting interval of 217 days. 17 of the 29 participants (58.6%) engaged in at least one session of cognitive rehabilitation. Of the 25 participants who had pre- and post- intervention test scores, 15 (60%) participated in at least one session of cognitive rehabilitation.

There were no overall significant changes in cognitive test scores for those that had two episodes of testing. However, nine individuals (36%) showed an improvement on standardised testing greater than one standard deviation. Six of the nine (66.6%) that showed such an improvement had undergone cognitive rehabilitation and three (33.3%) had not. Thus, twice as many participants improved on cognitive test scores if they had participated in CR than if they had not.

Linear mixed model analysis

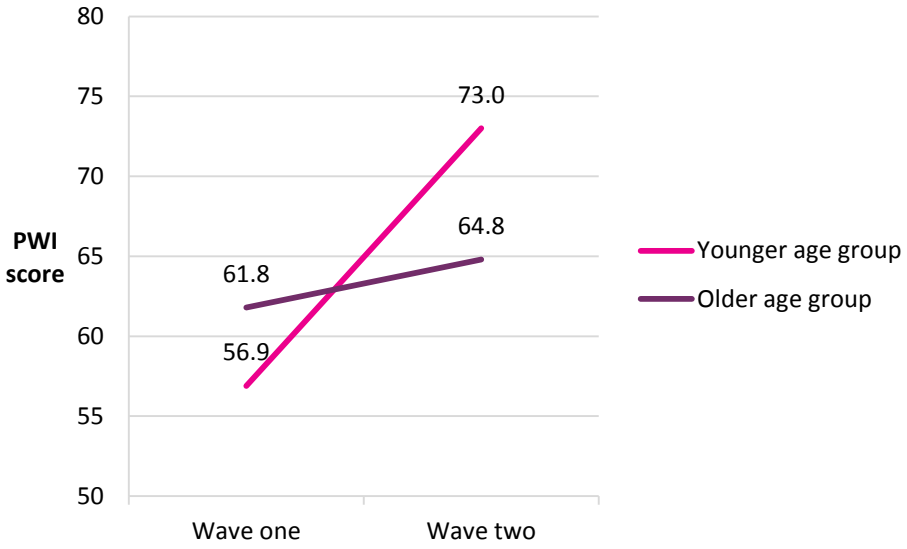
Linear mixed models (LMMs) were used to determine whether any statistically significant improvement had occurred between wave one and two in any of the measures recorded in this evaluation and to determine what, if anything, may be contributing to this improvement. Each LMM used a within-participant design with fixed and random effects. Statistically significant improvements were found for both the ECCS and PWI measures over time, ECCS: [β =7.0, t(26.0) = 5.2, p < 0.001]; PWI: [β =-7.9, t(24.4) = -2.1, p < 0.05].

Table 1: ECCS and PWI – LMM results

	Baseline mean (wave one)	Post-intervention mean (wave two)	β	t P value
ECCS	16.6	9.6	7.0	5.2 p<0.001
PWI	61	68	-7.9	-2.1 p<0.05

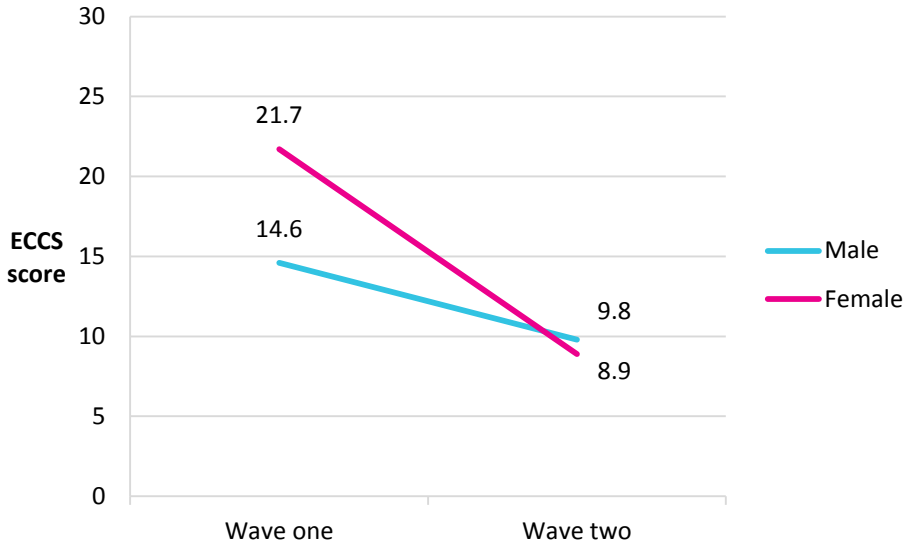
Significant interactions were also found between PWI and age and ECCS and gender. It was found that the change in PWI between waves was dependent on age, in that a younger age was associated with a greater increase in mean PWI score between wave one and wave two; [β =0.6, t(22.7) = 2.2, p < 0.05]. To illustrate this interaction, the scores over time for younger (1 standard deviation below the mean) and older (1 standard deviation above the mean) age groups were compared in Figure 8 below.

Figure 8: Interactions between PWI score and age between waves



It was also found that the change in ECCS over time was dependent on gender, in that females had a significantly greater reduction in ECCS score between wave one and wave two: [β =8.1, t(26.5) = 3.1, p < 0.005]. The scores for each gender between wave one and wave two has been described in Figure 9 below.

Figure 9: Interactions between ECCS score and gender between waves



Qualitative analysis

Overall, the themes which were developed throughout thematic analysis tended to cover two major areas of content. First, discussion around the role of the Room to Grow program in participant's lives - how it has impacted on their lives and how they have interacted with the program. Second, discussion of the contributing factors which participants believed led to their referral into the program.

Three overarching themes were elicited throughout discussions of each content area. Within discussions of the role of the Room to Grow program, the three overarching themes were 'awareness', 'questioning' and 'change'. Throughout discussion of the factors contributing to participant's involvement in the program, the three main themes were 'social isolation and connection', 'trauma and trust' and 'the overwhelming cycle'.

Each of the major themes categorised throughout thematic analysis in the interviews contained a number of sub-themes. The main themes and sub-themes have been described in Table 2 below.

Table 2: Main themes and sub-themes

	Main themes	Sub-themes		
Role of program	Awareness	Mindfulness	Insight	Confrontation
	Questioning	Getting the questions, knowing the categories	Structure	
	Change	Agency	Motivation	The intention to walk freely
Contributing factors	Social isolation and connection	I am the last person I know	A thread that runs through everybody	Reconnection
	Trauma and trust			
	The overwhelming cycle	When the building gets sad, everyone gets sad	Where am I going to start?	

It must be first noted that participants without hoarding behaviour who experienced predominantly domestic squalor were far more reticent during interviews when compared to those with hoarding behaviour. While this may be due in part to the individual characteristics of those who took part in this evaluation, program staff noted that overall the participants with hoarding behaviour were generally more forthcoming when describing their experiences. Knowing that the information given would inform this evaluation and thematic analysis, these participants were particularly keen to contribute. As a result, some of the themes developed through this analysis are more relevant for those experiencing hoarding behaviour. However, many themes were highlighted by all participants, particularly sub-themes within discussion of the underlying issues faced by participants.

Role of the program

Overall, the major themes which arose in discussions about the role of the program broadly describe the stages participants progressed through over the course of service delivery. While not all participants reported progressing through each stage in strictly consecutive order, it is useful to consider these themes as generally describing a progression from awareness, through questioning and arriving finally at change. The structure of these themes has been informed by Prochaska and DiClemente (1983) transtheoretical stages of change model, although the content is derived directly from interview data, with many participants describing themselves moving through one or more of the sub-themes within these stages over the course of the program.

Awareness

Many of the participants described situations relating to a greater awareness of their thoughts, emotions, motivations and responses when reflecting on the impact of the cognitive rehabilitation program. It was felt that this intervention allowed participants to develop a better understanding of how their minds worked which in turn led to the development of an enhanced awareness of mental activity. For many participants, this type of self-reflexivity and the depth and intensity at which they engaged, was a new experience or one which they had not engaged in since leaving formal education, which was many years prior for the majority of participants.

Mindfulness

While participants did not directly reference the practice of mindfulness, the comments throughout many of the interviews suggested that a process of greater mindfulness was occurring for many participants. Participants described a process of increasing concentration on thoughts and emotions as they arose in the present moment. This process was stimulated by the broadening of understanding of 'how the brain worked' as was taught through the psycho-education during cognitive rehabilitation sessions. Once participants gained this understanding and developed increased mindfulness, they saw that these activities had immediate application in the way they thought about their possessions, how they organised their homes, how they could motivate themselves and in their lives more generally. Some of the comments made during the interviews are as follows:

"Because you never give your mind a second thought, it's interesting to think about what motivates you because you can use that."

"Most things are automatic, you make mistakes because you don't put any of your thinking in before you do things."

"In my own day-to-day you can organise things better… and my personal life even."

Insight

Throughout the process of mindfulness and general awareness of emotions and cognitions, many participants noted that they had also begun to question the way they thought and how they responded emotionally to their experiences during this stage. This was also stated to be due to the lessons learnt throughout the CBT sessions or BIT workshop. As many participants had developed the behaviours which led to cluttered environments and/or situations of domestic squalor over a

lifetime of accumulated maladaptive thought patterns and emotional responses, they reported considering these thoughts and emotions as 'normal'. Many recognised that it would likely take time to continue to recognise and identify what might be helpful and unhelpful thoughts and emotions, but that ultimately this insight would be a useful tool which would allow them to better manage their homes and lives in general. Participants noted:

"You learn you have to deal with things better now that you have an understanding of how you function and the reason why, you know?"

"You treat [the way you think] as normal so you don't question your motivations or what you're thinking or why you do this or why you do that."

Confrontation

In response to both the cognitive rehabilitation and the CBT and BIT workshop, many participants reported feeling confronted by the realisation of how difficult it might be to start to shift long-held patterns of thought. Through increased mindfulness and insight, participants had become aware of how cognitions and emotions could influence behaviour, while at the same time becoming increasingly aware of the difficulty they were now perceiving in needing to challenge these same thoughts and feelings. Despite the perceived difficulty, many participants felt positive about their ability to confront these issues and to continue to 'rewire the brain'. However, it is important to note that almost all participants were not yet confident at the time of interview to be able to meet these challenges without the external support of the program staff, including both case management and psychological support in most cases. By the time of the final Walk and Talk group, the participants also still highlighted the importance of receiving continued support to manage this challenging process in an ongoing way. On this, participants noted:

"You just want to remove your brain."

"Hard for your brain to adjust to a change like that through repetitious…because...their system of repetition was meant to rewire the way the brain was supposed to think."

"You have to deal with the problems and analyse things, you know, you have to use your brain properly."

"Yeah, it was good. They made you sort of confront issues and that."

Questioning

As participants developed an awareness of the cognitions associated with hoarding behaviour and situations of domestic squalor they were able to begin challenging these, questioning the way they thought about their possessions and how and why they were motivated to behave in different ways. For those without hoarding behaviour this predominantly related to issues of motivation and the process involved understanding what motivated them, how to use this knowledge when dealing with the condition of their homes and finding the kinds of routines and structure to develop and sustain this motivation.

Getting the categories, knowing the questions

One important sub-theme that came out, particularly for participants with hoarding behaviours, was the importance of the categorisation process and the provision of formal questions to use when challenging aquisition and initiating discarding. Information-processing deficits have been found to be one of the main factors associated with hoarding disorder. These deficits typically take the form of a lack of confidence with memory - that you will be able to remember an important item and all of its relevant association when it is not visible - and difficulties with organisation and categorisation - having difficulty organising a pile of possessions into a system of categories (e.g. winter clothes, kitchen utensils, photographs). At the same time it has also been reported that people with hoarding behaviours often have a complex 'mental map' of the possessions in their homes, knowing exactly where to find a specific item or group of items despite the appearance of disorder from the outside. This suggests that while there is typically a strong awareness of the content in the homes of individuals with hoarding behaviour, the types of organisational systems often applied in domestic settings may not be seen as relevant or are not easily applied. For participants in the Room to Grow program, once these categorisation systems were re-introduced and made concrete through the BIT book and workshop, participants felt more confident in their ability to apply these systems in their homes. Participants stated:

"Keeping focused, getting it done, knowing how to organise with the categories and knowing what's going on in brain and different things."

"Going through that [BIT] book, getting the categories, knowing the questions…it has helped me so much."

"Using different categories, yeah. Ok, so if I'm sorting through stuff I might find a jacket – well, I'm going to put that with the winter stuff or I might have photographs, so I'm going to put my photographs here, put them into different categories."

Structure

Many participants noted the importance of routine and structure in the beginning to operationalise the knowledge learned throughout the program. As the amount and complexity of information was somewhat overwhelming for some participants, particularly those who had limited formal education, introducing some structure to the way this new knowledge was digested and operationalised was seen to be beneficial. Case managers were often seen as introducing or facilitating the development of such structure, allocating specific periods of time for organising possessions and working in the home, maintaining regular appointments and developing a plan to approach certain areas of the home led by the participant. In the early stages of beginning to work through possessions for those with hoarding behaviour, some participants noted that it was simply helpful to have someone there to confirm decisions with, adding a second opinion to the choice to discard an item as is described in the final excerpt below:

"Well, not having done any academic stuff for quite a long time it was a little bit laborious because it's so hard to focus when you haven't done it for a long time. I got over that but at first I was thinking, 'oh geez!', but yeah, I got over it"

"I did it on my own but I didn't have a formal 'how many of these do you have?', 'do you need it?', 'will you use it within the next year?'"

"I knew I needed to get through those boxes and there was probably no way I was going to be able to do it on my own. Without the organisation skills that they've given me now, you know with the categories and [my case manager] coming in and sorting out an area and getting my mindset with the papers, you know, knowing that I can toss this and I discard this and I can throw that, you know, that's my main problem"

Change

As has been described in the previous two main themes, awareness and questioning, the development of greater insight into the motivations behind their behaviour placed many participants in a position where they were able to begin questioning their behaviour and to start developing the routines and structure in which to challenge well-established thought patterns and behaviours. Throughout the interviews, some participants identified that one of the main goals they wanted to achieve through the program was behaviour change. This suggests that, for some, the insight and questioning was perhaps already present on program entry but that they still needed the additional motivation and support of the program to initiate and sustain that change. According to the stages of change model, it appeared that many participants at the time of interview were in the 'preparing' or 'action' stage, with many stating the need and desire to change, built on through the increased awareness and questioning, with some describing how they had begun to act out the changes they were seeking[xvii], as illustrated in the quote below:

"Well, I want a behaviour change that will have to result in a progression in domestic management for me"

Agency

For almost all participants, a sense of control over what took place in the program - what their goals were, how they interacted with the group and most significantly, what took place in their home - was central. In the case of activities completed in the home, this was likely influenced by the high levels of emotional regard attached to some participant's possessions which meant that many were extremely uncomfortable with others moving, organising or discarding their possessions. It is important to note here that this was only the case for individuals with hoarding behaviour, those experiencing predominantly domestic squalor often did not have the same degree of emotional attachment to or regard for their possessions and could be content to allow others to organise and discard items in their homes. However, for those with hoarding behaviour, all stated that it was very important for them to be the one to make decisions about what was kept or discarded, how to organise items and where to move these items to. Some participants preferred to make all decision and to also move the possessions themselves, preferring that the case manager assisting them was there to consult with and facilitate decisions rather than providing any physical assistance while others stated that while they preferred to be the decision-maker they were comfortable to receive physical assistance moving and discarding items, particularly where this was especially arduous or where the participant had physical limitations. Participants noted:

"I kind of designed my own goals, like I set out to [my case manager] what I wanted to focus on, no one told me what I should be focussing on, I kind of told them, told her."

"We had plans for people to come in and give me a hand but I found it hard to work with another person who isn't in the same…plan as what I've got"

"It's the logistics of it…and it's good to have a person there, I don't have a problem going through stuff and throwing it in the bin but it's taking it down to the rubbish bin"
"They've enabled me. It's made all the difference in the world. Not trying and take it out of my hands and decide for me, they've just enabled what I can do which, yes, let's get it out [of the house]. Wonderful."

Motivation

As previously stated, motivation was both the problem and the solution to responding to the environment in participant's homes. Many participants stated that they felt overwhelmed by the quantity of activity required to create a clear living space and, though this will be discussed in more detail in the following themes, feelings of depression and anxiety in response to the home environment led to an increased feeling of being overwhelmed which in turn increased feelings of depression and anxiety. Even for some participants with a strong desire to change, the strong sensation of being overwhelmed by the environment in their home made 'getting started' feel almost impossible. To break this cycle and challenge these feelings, many participants reported that simply knowing that their case manager was going to arrive on a particular day was the motivation they needed to confront both their home environment and the emotions bound up in it. For others, they reported that the presence of their case manager and the guidance that case manager provided in helping them to frame activities which could begin to 'make a dent' in the cleanliness or clutter in their home was the motivating factor. In either case, it was the presence of a regular, external support whose intervention - or indeed the prospect of their intervention - led to the development of the motivation needed to begin to make changes to their home, behaviour and psychological response to their home environment, as shown in participant's comments below:

"Getting started is the hardest part"

"I don't feel like they're imposing on me so that's good. It's a slow…so they're not pushing me which is good but they're still coming around because if they're not coming around then I'm not going to get on top of it and just to have a chat when they come to the door, it's good."

"…I think I've got the motivation because once I know my boys are out of there I've got that hour and I know if I don't get it in the first two hours and I sit there and veg out – some days don't work out better than others"

The intention to walk freely

The third sub-theme under the main theme of change, 'the intention to walk freely', is the description one participant gave during their interview when describing what they felt was the final stage of their behaviour change. While they had certainly made some significant changes already throughout the program, they felt that despite their 'intention' to continue to act out their

behaviour change, there were still occasions where they were tempted or relapsed into old behaviour patterns. However, the important change to note here is the presence of self-reflection and analysis which allowed this participant to recognise the temptation of relapse but also, and perhaps more importantly, the role their personal history has played in their current behaviour. As the participant in the second extract notes, the process of behaviour change is ongoing and will remain a challenge for some time into the future:

"For me, I think it's fairly extraordinary, in the last um, I would say in the last three or two months, some of the exercises in the program you know, being mindful and…the specifics in it…I have on one occasion recently, taken a walk you know really mindful of the intention to walk freely and not to avail myself [to acquire]… so I went up the hill, round the corner, there's a small gathering as if it was a garage sale, various people are collecting in this pile and I walked up… they're all examining this stuff and I had to stop, I had to notice and I don't dive into things, I used to, to an extent but usually if it's a surface attraction I will notice and I saw something and I picked it out… and I could not, I should not, I chose not to resist. So you know, there's…you're getting a sense of a little bit of where I have come from"

"It's going to be ongoing! I'm out there every single day and like I said I walked past the Vinnies the other day, I could've walked in and I said 'no!' I walked past and there was a cute little teddy bear in the tree and I just stopped and looked at him but I said 'no!' I'm going to stick him back in the tree and another week had gone by and I said to the group, I said 'he's still in the tree, I still didn't pick him up!' and they said [clapping] 'well good for you!'"

Contributing factors

There was a broad range of factors which participants described as contributing to hoarding behaviours and/or situations of domestic squalor. While there was a slight overlap between the contributing factors for both hoarding behaviour and domestic squalor, participants experiencing predominantly one or another of these issues described broadly distinct underlying issues which they felt had contributed to the current environment in their homes. Some of these issues seemed to have a cyclical or self-fulfilling quality; social withdrawal leading to greater isolation and increased withdrawal; previous trauma leading to a lack of trust; depression leading to a lack of motivation; and the internalisation of the home environment within leading to immobility.

Social isolation and connection

Almost all participants described periods of social isolation and withdrawal throughout their lives, including both participants with hoarding behaviour and those living in situations of domestic squalor. Importantly, this group of individuals all highlighted the desire to form deeper connection with others, to repair their social networks, to reach out to others and all related strong positive feelings with regard for others and towards the strong bonds that had formed throughout the group sessions of the program. This bond was so strong that some participants expressed the desire to remain in contact with other participants after the program ended, which led to the development of the 'Walk and Talk' peer support group. Some participants also formed friendships with others in the group and continued to meet up outside the program after the group sessions ended. The

therapeutic benefit of social interaction was clearly articulated by many in the group and for some this was stated as the main positive outcome to come from their involvement in the program.

I am the last person I know

For some the process of social withdrawal was a 'survival tactic' in response to a lack of trust felt towards others, for others is was due to loss of family or friends to old age and illness, a withdrawal into the home due to shame about their living environment or gradually 'shutting out' friends and neighbours for reasons some participants were unable to articulate during the interview. For those with hoarding behaviours, there was often a very limited number of people that participants felt comfortable allowing into their home, for some this was limited to only one other person, for others no one had been into their home for some months. The choice to allow such a select number of people into the home appeared to be a combination of shame and a lack of trust. The shame was focused on the home environment which many felt was in a condition they were not proud to reveal to others. The lack of trust was similar to the response related in the sub-theme 'agency', in that some participants allowed only those into the home with whom they had developed strong rapport and trust because otherwise their guest may interact with their possessions in a way which would make them uncomfortable, moving or discarding items without their knowledge or permission. Participants stated:

"Perfect would be where I could get my sister to come by and she'd like it…well organised, well kept. She's say it looked nice even if it didn't to make me feel better but I'd want her to think it instead of just saying it."

"Unfortunately all my family, or what's left of them live interstate or overseas. And of only one of them or two of them are still alive. The rest have died. So I've ended up being the last person that I know, so I need to make all new connections."

"Because I don't have the intermingling skills, one-to-one… it's a bit awkward for my age, for someone to discover."

A thread that runs through everybody

Many participants discussed the connection they felt with other participants taking part in the group sessions, stating that they felt they recognised a lot of their own behaviours, thoughts and feelings in the other participants. This was particularly the case when in some of the BIT workshop sessions participants were asked to share their stories and while some participants were initially cautious in revealing their experience to others, hearing that they were not the only ones having these experiences allowed them to 'open up' and to feel comfortable. Participants reported eventually sharing photographs with each other of their homes, allowing them to 'let others into their homes' without necessarily allowing them through the door - a first step for some in the pathway of their recovery. The sense of community was so strong for some participants that they reported feeling that the group had become 'like a family' by the end of the program:

"I'm sure you'd be aware of some differences between people who buy and people who hoard and everyone has their own – whatever it is – twist that is a self-identifier or something like that."

"I learnt that I wasn't on my own. I thought I was the only one that had this problem. And now I know that I'm not. The group...was really good. It involved a couple of people from in here, in this building and actually my main enemy in the building and I we got to talking and we kind of buried the hatchet. Yeah we got talking and I was quite stunned by some of the things he was saying – he gave me a lot of support for what I was going through at the time."

"There's a thread that runs through everybody…different scenarios but there was a thread that ran through all of us."

Reconnection

The goal of reconnection or rebuilding a social network was an important one for some participants, many of whom reported during the interviews that they felt the group programs had gone some way towards achieving this goal for them. The sense of similarity, recognition and community that participants were seeking appeared to perform an important role in their recovery journey, one which does not often receive as much attention in the current academic literature in this field. As many participants had experienced some form of trauma in their past, the ability to form meaningful connections with others was likely significantly challenged, yet the value of social interaction for this group is perhaps stronger than for the general population. It appears that the confidential nature of the group, the slow development of trust between group members and the sense of safety promoted in the group environment all contributed to the feeling of reconnection. Trust between group members may also help participants to extend this sense of connections to a broader circle of family and friends, albeit likely with continued support, into the future. Participants noted:

"Other people can see you as one…they can see you as a hoarder or see you as a collector or see you as this and that…but I didn't feel judged at all. I went in that room and, yeah, I've got problems, everyone's got problems in this group, that's why they're there. If somebody else has got the same situation or a little bit different, like if they can get into that group environment it can just give them that kick start and turn around…yeah, it's going to be hard for everyone, it's ongoing but I think if they can get into the group it can help them."

"Just connecting with other people in the room and knowing you're safe to say what you…and it's confidential and after you go out you can say what you want to say…but you're not going to be judged."

"…Once I came along to a group session I realised the benefit of also just the comfort of being in a room with other people with similar problems was really helpful."

Trauma and trust

Several international studies have supported a link between trauma and hoarding disorder, revealing that those with hoarding disorder reporting significantly greater traumatic life events than controls or those without hoarding difficulties[xviii,xix,xx]. Interviews and neuropsychological assessments conducted during this evaluation support this evidence, with some participants describing a history of traumatic events in childhood or early life. Due to the purpose and setting of the interviews, participants were not encouraged to disclose any information about their personal history and those

participants who did disclose this information did so unprompted. As a result, it is possible that the proportion of those with past trauma may in fact be in the majority.

For the participants in this evaluation, trauma most often expressed itself through the need for long periods of trust and rapport building between participants and staff and between participants themselves before they were comfortable enough to talk about their experiences, share their experiences more broadly, allow others into their home and finally, allow others to assist them with managing their home environment - whatever form this took:

"I was looking for someone I could trust. Knowing the way I am, they [the case managers] were able to sit down and talk to me."

"I didn't initially feel that comfortable, initially in the first couple of weeks, I was reticent to throw myself in because I thought…and as the weeks went on I appreciated that, yes, we are all in the zoo and I don't know if you want this deep shit but we're all whatever, with our own particular experiences and yeah, initially it was pretty confronting."

"Yeah, I mentioned to him that I had a person that I could trust to move in, give me a hand so…because…it isn't possible for one person to take on a problem like that…because you get too involved in the problem and it becomes out of control… like when you're thinking it, um…comes up…then the problem becomes a bigger problem…the more times that it comes up…and the other person…you can lean towards him. Not with a stranger, with someone you know. With a certain person – someone who thinks in the same way"

The overwhelming cycle

Many participants identified that the relationship between the condition of their home and their emotional and psychological state was often cyclical, with poor property condition causing feelings of anxiety and depression along with feelings of guilt, shame and of being overwhelmed. This in turn contributed to further deterioration in property condition and greater feelings of discomfort. Some participants specifically referred to periods of depression contributing to this cycle. For some the main contributing factor to uncleanliness or clutter in the home was perceived to be depression. Other participants stated that the condition of their home led to them feeling 'frazzled' and anxious. Based on these comments, it appears that living with clutter, mess or uncleanliness long-term often led to the onset or exacerbation of mental health issues which made any attempt to address the condition of participant's homes a greater challenge:

"It's a sort of depression; you get in kind of a state, living that way"

"I was in a really bad depression and [the hoarding] was part of the depression. I'd wake up and it would be like 'where do I start?'"

"When my place is a mess and I can't relax and I know I've got this excess nervous energy and it's to do with the house and it needs fixing and I can't get anyone to come around when it's looking the way it is… I know that's the catch thing"

When the building gets really sad, everyone gets sad

The majority of the participants in the Room to Grow program were living in public housing in locations across Sydney. For those living in public housing, a common theme that recurred was the low amenity of public housing properties, predominantly due to unresolved maintenance issues and poor building management. Participants described the often negative impact that the low levels of maintenance in their home and building had on their physical and emotional wellbeing. While all participants accepted responsibility for the condition of their home, they also highlighted the role that poor property maintenance and building management could have in contributing to the difficulties they faced in organising, cleaning and discarding items from their homes. As one participant relates in a quote below, when spaces such as the kitchen become difficult to use through a combination of clutter and non-functional appliances, people may stop using this space entirely for its intended purpose. Some participants hoped that there may be more opportunities in the future to advocate for improved conditions, not only as individuals but also through tenant advisory groups or tenant advocacy services:

"I don't have much bench space and the oven doesn't work properly…the oven works but the hot plate doesn't work; only one works and the grill plate doesn't work. And when it's a mess, when it's cluttered, it's not a real nice kitchen to be in. So you don't eat properly and that becomes a problem."

"Maybe if there were any suggestions that were put to [HNSW] they should at least take it on board? Because it's an overall…when the building gets really sad, everyone gets sad. When no one maintains the building it's like driving a car that's breaking down…"

"So when people give you the feedback – and I know they do – about 'housing doesn't respect you' I can only add to the list. Because you see there's an underlying deal with housing which is unspoken, which tells you, 'you be grateful, we've given you a roof over your head, you don't deserve any better, take what you're given'. And the people in housing just want to be treated like normal people… they don't respect you to tell the truth"

Where am I going to start?

Almost all participants stated that they felt confronted by the condition of their homes at times and often felt paralysed by the task of improving this. Many related that they didn't "know where to start" and that the "big picture" in their home was too overwhelming. To address this, participants stated that they had learnt to "take small bites" allowing living skills and organising/discarding skills to slowly develop, for example, at first simply cleaning a plate or hanging up clothes. Although each act may seem small, participants felt that together these acts contribute to a significant shift not only in the physical condition of their home but also in their psychological response to it. Many participants described greater motivation for action in the future and a strong sense of achievement. Participants felt that it was important to recognise that significant shifts in the mental processes tied to the condition of their home could be expressed though apparently minor physical differences and that those 'looking in from the outside' should appreciate these significant mental shifts without denigrating the seemingly less significant physical changes. Participants noted:

"It's good to have someone there to just let me help me understand I don't have to do it all at once or feel bad about it, which I do."

"It's overwhelming for me to go out and look at it but when I have the categories in front of me or I might have the book beside me and I can go 'well, that will go there' or…"

"…down the track, you know if [my case manager] texts me and says, you know 'how are you doing?' or 'can we meet up for 15-20 minutes?' even if it's…however long we've got… just to see how we're doing…just…to give me my motivation again. Just to check in"

Staff focus groups

Mission Australia's Research & Evaluation team led two internal focus groups with program staff involved in the Room to Grow pilot program. The first focus group was undertaken early in the service delivery period, in October 2015, to identify any early issues with program implementation and to ideally resolve any outstanding concerns. This group also allowed staff to comment on how effectively the service model was able to be operationalized 'on the ground' and to describe ways the model had evolved throughout actual service delivery. The second focus group was held towards the end of the service delivery period, in March 2016, to provide an opportunity for staff to review the program in retrospect and comment on challenges faced, suggested improvements and potential directions for future service delivery in this space. Additionally, Mission Australia's Room to Grow service staff increased over the pilot program and the second focus group offered an opportunity for new staff members to provide feedback.

Key recommendations and comments made by staff during both focus group sessions have been outlined below.

Referral

Staff identified that a number of the participants referred into the program during the early stages of service delivery were inappropriate for the type of intensive case management/psychological interventions provided by the Room to Grow program. The majority of these referrals were for participants with issues related to low level domestic squalor.

In part the inappropriateness of the referrals was due to participants living in relatively low levels of squalor (rubbish not thrown out/cigarette butts on the ground) which could be remedied with a series of ongoing cleans and case management rather than the intensive service model offered by the Room to Grow program. Staff recommended that the most appropriate service intervention for participants with low level domestic squalor would be the provision of proactive case management which would potentially address the factors leading to tenancy breaches.

Staff maintained that is was absolutely essential to conduct initial face-to-face assessments with potential participants in their homes. Meeting with potential participants in person and in their homes was seen to be an integral part of the initial referral, intake and assessment process. Staff felt that participants should ideally not be considered for program entry without undertaking this initial face-to-face assessment. This assessment allowed staff to meet, speak with and greet the person, introducing themselves and the program. This assessment also provided an opportunity to assess the behaviour, personality, capacity and motivations of the potential participant and to recognise

whether the potential participant was experiencing issues connected with hoarding or squalor or both. Finally, face-to-face assessments would allow staff to see the condition of the potential participant's property and to assess the appropriateness of their referral to the program. This information allows staff to project the form/scope of service delivery most appropriate for the person and provide insight into the best intervention to address the property condition.

Initial face-to-face assessments should ideally be conducted by a qualified intake and assessment team which would include staff members from the lead organisation and partner organisations at management level or above (i.e. not service-facing) to maintain neutrality.

Participant characteristics

Staff reported that participants experiencing predominantly hoarding disorder really enjoyed the CBT sessions and general participation in the program. This may be due to the social interaction and close personal bonds many participants formed with each other. Staff felt that these participants were learning and implementing practical activities in the home as a result of CBT, including improved insight into their emotions/cognitions, gaining an insight into the way their mind works, why they collect and why they find it difficult to discard. Staff felt that the CBT sessions which took place with predominantly participants experiencing hoarding behaviours were more successful due to the specific group. This group reported more consistent attendance rates, fewer absences due to substance abuse or behavioural issues/sickness with participants more often adhering to the schedule of sessions. Staff reported that overall the participants with hoarding behaviours appeared to be slightly more educated, with greater focus and greater insight than the group of participants experiencing predominantly domestic squalor. Comments from program staff concerning these topics have been provided below:

"The insight is a lot more, they know that they are hoarders or they see themselves as 'collectors'. They know that it is an issue and they're concerned about it."

"…They want to change and they're accepting of the help…rather than having to go [to CBT sessions] they want to go, they're so eager to learn and they always want knowledge, they want to learn about themselves as well as the condition…they're just completely different."

Disengagement

Some of the factors which contribute to situations of domestic squalor, most significantly substance abuse, also contributed to high levels of disengagement from the program. Disengagement was due to multiple factors for these participants, however disengagement predominantly took place during periods of hospitalisation for drug induced psychosis. Participants with substance abuse issues also required a greater amount of staff time to follow up and ensure they attended sessions, met case managers for appointments or to ensure they were present to productively work on the condition of their property.

Participants experiencing mental illness or who were otherwise under the influence of alcohol and/or drugs were more likely to damage their property in some way, contributing significantly to the likelihood of future tenancy breaches.

Staff engagement

In order to support participants to achieve the best outcomes in this space, all staff highlighted the importance of highly motivated, engaged and passionate service delivery staff who can operate well as a team.

It was noted that motivated and engaged staff supported participants to achieve better outcomes and it was felt that the greatest successes participants made were significantly assisted by factors such as teamwork and proactive case management. While all team members were alike in the high levels of motivation, engagement and energy used in case management, it was felt that having each staff member use different work approaches contributed greatly to positive outcomes for participants overall. This could mean one staff member using a more assertive approach, requesting home inspections and helping with physical maintenance and cleaning, while another uses a different approach, supporting the participant with living skills or engaging them with social outings at their request. While both staff are working towards the same end (sustained tenancy, improved property condition and improved quality of life) using different techniques and engaging in different activities with the participant allows them to feel fully supported by the program.

As staff have different strengths and approaches, the different dynamics fostered between staff and between staff and participants have worked very well within the program. The staff team was seen to be very connected, supportive and understanding of one another and this staff-level care, support and interconnection has flowed through into case management and participant contact.
Working with participants experiencing hoarding disorder and/or domestic squalor develops specialist staff experience, skills and understanding of the issues faced by these participants. This expertise is extremely valuable, however, there are very few staff with concentrated experience and engagement in this space. It is important to maintain the capacity of staff – where staff retention is lost, essential expertise is also lost.

Transport to and from sessions took up a significant amount of staff time. During the most intensive support periods, staff were transporting most participants to the three group sessions each week across greater metropolitan Sydney. At times all staff were engaged purely in transportation activities. Staff suggested that in the future brokerage money could be used to rent a vehicle and driver to provide transport services or that external support agencies, depending on available resources, could assist with some of the transport to take the burden off the lead agency.

Inter-agency collaboration

Early in service implementation, staff recognised that Mission Australia would need to perform the role of 'lead agency' or 'facilitating partner' to manage the broad network of support from multiple referring agencies, HNSW and service providers. Building relationships with external staff was seen as very important for staff within the lead agency.

Agencies who performed the role of 'landlords', including HNSW and Mission Australia Housing, were seen as highly supportive in providing referrals, connecting participants with relevant services and generally supporting Room to Grow staff with service delivery where relevant. Staff felt that this was due to these partners having an interest in assisting Room to Grow to maintain the participant's tenancy or improve the condition of their property because of their 'landlord' role. However, because Room to Grow staff were encouraging participants to address issues that have been

occurring long-term, this process was likely to be emotionally difficult and to potentially increase stress levels of participants during early service engagement. As a result some of the external support staff who had been connected with participants prior to their involvement in the pilot program at times inadvertently counteracted the aims of the program by reinforcing participant's negative perception of the activities undertaken throughout the Room to Grow pilot. While Room to Grow staff saw and understood the long-term benefits that would be brought by CBT sessions and home visits despite the initial feelings of stress, it was felt that external support staff did not always understand or appreciate these benefits or the role of the program.

Ideally, all support staff working with participants either internal or external to the program would be educated about the purpose of the program and the likely trajectory that participants would take throughout service delivery. This would ensure that all staff were able to work together to guide participants through any challenges they may face, assist them throughout their recovery process and encourage them to engage with and complete the program.

Due to the complexity of some participants (e.g. comorbid physical conditions, mental health issues or substance abuse) staff acknowledged that external support staff performed an incredibly important role as a part of the participants allied health team. At program entry many participants had not been connected with any additional support outside the Room to Grow program despite experiencing issues which placed their tenancy at severe risk. The majority of participants without support were successfully referred into a support program such as Partners in Recovery (Inner West Sydney) but staff commented that the waiting list could sometimes be lengthy, meaning that two to three participants received no external support for the majority of their time in the Room to Grow program, further extending the limited resources of internal service staff.

Finally, it was noted that the team leader should have a good service map and understanding of the geographic area in which they work. This would help facilitate appropriate referrals for participants, provide information for partners and other organisations with participants experiencing difficulties associated with hoarding disorder and domestic squalor, allowing Mission Australia to best act as the lead agency for the program.

Flexible and responsive support

It is vital for staff to have the time to build rapport and trust with participants. Staff must have the opportunity to have long periods of rapport building with participants before initiating activities which are designed to achieve program aims (e.g. property access for organising/cleaning). The importance of early engagement and rapport building should be incorporated into all service models and into the intended program duration. Each individual will require a different length of rapport building before trust is effectively built and the service design must reflect this.

Staff reported that participants were fairly comfortable discussing the condition of their properties when they realise that others are experiencing the same issues or have the same condition in their properties. However, some participants still felt uncomfortable inviting staff into their properties after three-four months of service delivery. Staff recognised that this was due to the high levels of trust required by these participants before they allow staff to access their property and acknowledged that it may not be possible to build this level of trust within the timeframe of the program. Staff who had worked previously with individuals with hoarding disorder reported that

sometimes it can take a full year to gain enough trust to enter a property. Staff stated they were uncomfortable to 'push' participants to allow them to access their properties before they had the opportunity to build sufficient trust and rapport as they felt this would negatively impact on their relationship and the program objectives.

Staff also felt that it was important to use nuanced approaches with participants that are flexible to the individual needs, capacity and personalities of each participant. Simply initiating the same one-size-fits-all approach with every participant was seen to be a highly unsuccessful approach for this cohort. This is especially the case when such an approach involves organising, cleaning and discarding items from the property without involving the participant in the decision-making process.

In cases of participants living with compulsive hoarding disorder, to suddenly 'gut' the property or undertake a forensic clean 'all in one go' would likely lead to traumatisation and other negative outcomes, even with prior warning and consultation. Staff saw that a much more sustainable and successful approach was to slowly support the participant to undertake any organisation, cleaning and discarding themselves, regardless of the timeframe this requires.

In the case of domestic squalor these considerations did not apply, these participants were mostly unfazed and in some cases keen to have someone come in and clean and discard items for them. Staff suggested that the most appropriate service response for those with low to medium levels of domestic squalor may include a higher number of contact hours to teach living skills through techniques such as 'errorless learning' which may take a high number of repetitions before skills are able to be repeated independently.

Program length

The 12 month duration of the Room to Grow pilot program was seen to be inadequate for the length of time required for many participants to achieve their program goals. Ideally, the duration should reflect the need for:

- a longer (3-6 month) period of rapport and trust building
- the lengthy timeframe required for addressing property condition – particularly for hoarding disorder where participant should ideally organise and discard themselves
- the long timeframe which some participants required to absorb and operationalise the skills needed to address emotions and cognitions associated with hoarding behaviour

Staff also repeated what many participants highlighted during interviews, underscoring that property inspections may not show noticeable change in property condition for a long period of time despite high levels of engagement from participants. This was usually due to participants slowly processing new skills learnt throughout CBT sessions and/or the long period of time required to begin organisation and discarding items in the home.

Staff felt that, in consultation with participants, they should have the autonomy to 'make the program their own', using what should be a relatively flexible service model to develop and evolve initiatives within the program which respond to specific needs, for example:

- Development of the peer support group;
- Social engagement with and among participants outside intervention sessions; and
- Monthly removal trucks.

Summary

This evaluation has found that Mission Australia's Room to Grow program made a statistically significant positive change in the clutter and cleanliness of participants living environments and overall wellbeing, based on the ECCS and PWI measures. Improvements were also seen in participant's subjective assessment of clutter in their homes, in participant's capacity to complete instrumental activities of daily living and in participants' overall cognitive functioning. Due to the small size of the cohort participating in this pilot project, qualitative data derived from participant interviews and staff focus groups provide important context/rich contextual information and should be considered alongside quantitative results. These qualitative findings highlight key features of the program experience from the perspective of participant's and strengths and weaknesses of the program design and implementation from program staff which offers important information for future service design.

Qualitative comments from participant interviews suggest that many participants experienced increased insight into the specific challenges presented by domestic squalor and/or hoarding disorder and the unique way each individual negotiated, managed and overcame these challenges throughout the duration of the program. Participants also highlighted a willingness to change and expressed an increased understanding of the processes required to enact this change in their living conditions and, more importantly, in their cognitions, emotions and behaviour.

Comments from program staff throughout focus groups highlighted the characteristics of the participant group, limitations of the service model and included discussion of future directions for service delivery in this space. Staff indicated that there were important differences between participants with hoarding disorder and those experiencing domestic squalor. These differences affected how participants accessed and interacted with the program, particularly through the relevance of some interventions (e.g. CBT sessions) and outcomes achieved. Service model limitations focused on program duration and referral processes. Future directions highlighted by program staff included the need for longer-term support and maintenance and more individualised interventions split between those with hoarding disorder and those experiencing domestic squalor.

Policy and practice recommendations

Based on the experience of implementing the Room to Grow pilot program, participants, service staff and local service managers provided a series of recommendations for best practice service delivery for individuals experiencing hoarding disorder and/or domestic squalor. An overview of these recommendations alongside broader recommendations from the sector has been presented below.

Program length and flexibility

- Due to the characteristics of those experiencing hoarding disorder and/or living with domestic squalor (e.g. histories of loss or trauma, long-term social isolation, anxiety sensitivity), a lengthy period of rapport and trust building between staff and participants is vital. This would require a long lead time built into anticipated program duration prior to intended 'interventions' such as CBT sessions or home visits. Ideally a period of 3-6 months may be required but actual timeframes should be led by the individual.

- There is no one-size-fits-all approach appropriate for individuals experiencing hoarding disorder and/or domestic squalor. It is important to use nuanced approaches which are flexible to the needs, capacity and goals of each individual.
- Strong relationships with external staff and support services take time to build and should be acknowledged in the expected timeframe of the program implementation, particularly for new programs or programs operating within a new or expanded region.
- Ideally, service models operating in this space should be flexible enough to reflect input from program participants and to allow program staff to develop new initiatives which respond to the specific needs or goals of the group while allowing the original service model to evolve throughout program implementation.
- As many participants had complex needs which were beyond the scope of internal program staff (e.g. physical and mental health issues, substance abuse), any additional support services not already in place should be identified early and appropriate referrals should be made within the first weeks of service delivery.

Inter-agency collaboration

- At the 2016 National Hoarding & Squalor Conference, many presenters highlighted the need for greater inter-agency collaboration between community service organisations, local council, local health districts, fire and rescue services and animal welfare agencies such as the RSPCA. A number of organisations and councils have begun to operate a 'hoarding and squalor task force' or 'inter-agency hoarding and squalor protocol' to effectively respond to cases of hoarding and/or squalor at the community level and further expansion of this collaboration across more regions would be ideal.
- Hoarding disorder is a mental health diagnosis and it will be vital to acknowledge this in any service response for this population. Inter-agency community responses must involve local health districts and community service organisations to incorporate case management and psychological interventions such as the Buried in Treasures workshops within an appropriate service response.
- To ensure the success of inter-agency collaboration, a strong governance structure must be established which utilises a facilitating or lead agency to manage referral, intake, brokerage and networking between the support services involved. The necessity of building strong relationships with external support services should be incorporated into the governance framework, encouraging relationships with and between other agencies.
- Ideally the lead agency or facilitating partner should undertake a service mapping exercise in the early stages of service delivery to understand the referral region and identify relevant resources and support services in the area.

Best practice service model

- **Social interaction** should be central to program design in this space to address the long-term social isolation and other factors which prevent the formation of close social bonds experienced by many individuals with hoarding disorder and/or domestic squalor. The therapeutic value of social support and formation of new, supportive relationships between participants must not be underestimated.
- **Adapted Cognitive Behavioural Therapy (CBT) sessions** with a psychologist are highly recommended for those experiencing hoarding disorder. While recommendations for

intervention length vary, at least 15 sessions is thought to be ideal, with a maximum length of 26 sessions.

- **Home visits** are generally considered essential for those with hoarding disorder and/or domestic squalor. It is important for individuals to have the opportunity of organising and discarding possessions in their own homes with the guidance of a case manager or support worker. Without such exposure it is less likely that skills learnt in CBT sessions will be effectively operationalized and internalised.
- **Participants must be centrally involved in all decision-making** regarding their properties, and any organisation, cleaning or discarding processes in their homes should be undertaken by the participant independently or at the very least led by the participant. Enforced cleans are likely to lead to traumatisation and other negative outcomes – even with prior warning and consultation.
- Many participants of the Room to Grow program expressed the desire to continue receiving **ongoing support** and to meet on a regular basis with staff and other participants after the 'formal' interventions had concluded. Participants were concerned that, without some form of continued service contact, they would not be able to maintain the behaviour change developed throughout the CBT sessions. Ideally this continued support would take the form of a **peer support group** which may receive gradually lessening contact from service staff and become entirely peer-led without an exit date.

Future directions

- Currently, there exists a service gap in the Sydney metropolitan region for a person-centred, recovery-oriented service model which embeds psychological interventions within a case management framework (including home visits and peer support facilitation) for individuals with complex comorbid issues who may be disengaged from service support and who are at risk of homelessness through tenancy loss or eviction due to issues related to hoarding disorder and/or domestic squalor.
- There exists an opportunity for government and local councils to partner with community services and mental health/allied health support services which can provide the intensive case management and psychological interventions (e.g. BIT workshops) which have the potential to make positive changes in the lives of individuals living with hoarding disorder and domestic squalor. These partners could ultimately support the transition of participants into a peer support model for long-term monitoring and broker funds for cleans, skip bins, trucks and other resources.
- Many participants from the Room to Grow program expressed interest in performing a community advocate or educator role engaging with individuals at an earlier stage of recovery. This suggests there may be an opportunity for service providers to draw on the lived experience and resources of individuals with hoarding behaviours after the conclusion of service delivery, potentially involving interested participants who have 'graduated' from the program in a peer support worker role.

Conclusion

There is a need for an integrated support program involving both psychological interventions and intensive case management for individuals experiencing hoarding disorder who are at-risk of

tenancy loss. Mission Australia's Room to Grow program attempted to develop a response which addressed this need. The service model which developed and evolved throughout the duration of this pilot goes some way towards addressed the service gap in this space and appears to do so effectively, as evinced through the significant improvements in home environments and wellbeing revealed through this evaluation and validated by program participants and staff throughout interviews and focus groups.

Mission Australia acknowledges that there are some important limitations to the Room to Grow service model (notably program length, referral processes and ongoing service support/maintenance) which should continue to be addressed or developed to more effectively respond to the needs of those accessing support. However, we believe that the Room to Grow model offers a strong blueprint for future service development in this space.

We recommend that FACS consider funding the Room to Grow program to fill the evident service gap with ongoing evaluative reflection to continue to improve on service design.

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Appendix A – Measurement tools

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First name: □ □ □ □ □ □
Last name: □ □ □ □ □ □
Birth month: □ □

Clutter Image Rating

People can have very different ideas about what it means to have a cluttered home. For some, a small pile of things in the corner of a clean and tidy room means it is seriously cluttered. For others, it may take large piles of clutter that make it hard to walk through a room before they think a room is untidy and cluttered.

To make sure we get a good idea of the amount of clutter in your home, we will show you some pictures of rooms with different levels of clutter – from completely clutter-free to very badly cluttered. Please pick out the picture on each page which comes closest to the clutter in your own living space, kitchen, and sleeping area. The picture doesn't have to exactly match what your home looks like but just choose the picture you think looks about the same. Put the number of the picture on the line next to the room type.

Room	**Number of matching picture**
Kitchen	_____
Bedroom	_____
Living room	_____

Clutter Image Rating Scale: Kitchen

Please select the photo below that most accurately reflects the amount of clutter in your room.


1


2


3

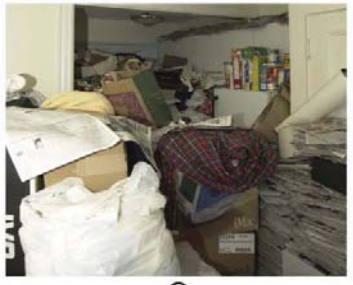

4


5


6


7


8


9

Clutter Image Rating: Bedroom

Please select the photo that most accurately reflects the amount of clutter in your room.

1

2

3

4

5

6

7

8

9

Clutter Image Rating: Living Room

Please select the photo below that most accurately reflects the amount of clutter in your room.

1

2

3

4

5

6

7

8

9

Environmental Cleanliness and Clutter Scale (ECCS)[1]

This form has been designed for service providers to respond to situations involving squalor. The form assists with rating the cleanliness of a person's accommodation.

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, but raters may decide between one category and another based on aspects not mentioned in the boxes.

Name of rater:	Date:

First name: □ □ □ □ □ □
Last name: □ □ □ □ □ □
Birth month: □ □

[1] Source: Halliday G, Snowdon J, 2006 Environmental Cleanliness and Clutter Scale (ECCS) based on the version devised by Snowdon (1986), which mostly used items listed by Macmillan & Shaw (1966). Some descriptions used by Samios (1996) in her adaptation of the scale have been included.

A	Accessibility (clutter)			
	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**, for example, obstructed front door. Unable to reach most or all areas in the dwelling.
	0-30%	30-60%	60-90%	90-100%
	% of floor space inaccessible for use or walking across			

B	**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	**Little** Bins overflowing and/or up to 10 emptied containers scattered around.	**Moderate** Garbage and refuse littered throughout dwelling. Accumulated bags, boxes and/or piles of garbage that should have been disposed of.	**Severe** Garbage and food waste piled knee-high in kitchen and elsewhere. Clearly no recent attempt to remove refuse and garbage

C	**Accumulation of items of little obvious value** In general, is there evidence of accumulation of items that most people would consider are of little use or should be thrown away?			
	0	1	2	3
	None	**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 and appliances are inaccessible.

Please indicate types of items that have been accumulated:

☐ Newspapers, pamphlets, and so on ☐ Clothing ☐ Electrical appliances

☐ Plastic bags full of items (If known, give examples of items_____)

☐ Other items (Please give examples_____)

D	Cleanliness of floors and carpets (excluding toilet and bathroom)			
	0	1	2	3
	Acceptably clean in all rooms.	**Mildly dirty** Floors and carpets look as if not cleaned or swept for days. Scattered rubbish.	**Very dirty** Floors and 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 and visible furniture surfaces and 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.	**Very dirty** Grime or dirt on walls. Cobwebs and other signs of neglect. Greasy, messy, wet and/or grubby furniture.	**Exceedingly filthy** Walls, furniture, surfaces are so dirty (for example, with faeces or urine) that rater wouldn't want to touch them.

F	Bathroom and toilet			
	0	1	2	3
	Reasonably clean	**Mildly dirty** Untidy, uncleaned, grubby floor, basin, toilet, walls and so on. Toilet may be unflushed.	**Moderately dirty** Large areas of floor, basin, shower/bath, are dirty, with scattered rubbish, hair, cigarette ends, and so on. Faeces and/or urine on outside of toilet bowl.	**Very dirty** Rubbish and/or excrement on floor and in bath or shower and/or basin. Uncleaned for months or years. Toilet may be blocked and bowl full of excreta.

G	Kitchen and food			
	0	1	2	3
	Clean and hygienic	**Somewhat dirty and unhygienic** Cooktop, sink untidy and surfaces dirty, maybe with some spilt food. Refuse mainly in garbage bin. Food that could go off (eg, meat, remains of meal) left uncovered and out of fridge. Rate 1 if no food, but fridge dirty.	**Moderately dirty and unhygienic** Oven, sink, surfaces, floor are dirty, with piles of unwashed crockery and utensils and so on. Bins overflowing. Some rotten or mouldy food. Fridge unclean.	**Very dirty and unhygienic** Sink, cooktop, insides of all cupboards filthy. Large amount of refuse and garbage over surfaces and floor. Much of the food is putrid, covered with mould and/or rotten, and unsafe to eat. Rate 3 if maggots seen.

H	**Odour**			
	0	1	2	3
	Nil. Pleasant.	**Unpleasant,** e.g., urine smell, unaired.	**Moderately malodorous:** bad, 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	**Few** (for example, cockroaches).	**Moderate:** visible evidence of vermin in moderate numbers for example, droppings and chewed newspapers.	**Infestation:** alive and/or dead in large numbers.

J	**Sleeping area**			
	0	1	2	3
	Reasonably clean and tidy.	**Mildly unclean** Untidy. Bed unmade. Sheets unwashed for weeks.	**Moderately dirty** Bed sheets unclean stained, for example, with faeces or urine. Clothes and/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.

Add up circled numbers to provide total score: _____

Do you think this person is living in squalor? (circle one)	**No**	**Yes**, mild – *not clutter*	**Yes**, moderate – *not clutter*	**Yes**, severe – *not clutter*
	Clutter – (lots), not squalor	**Yes**, mild + *clutter (lots)*	**Yes**, moderate + *clutter (lots)*	**Yes**, severe + *clutter (lots)*

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Lawton's Activities of Daily Living Assessment

First name: □ □ □ □ □ □
Last name: □ □ □ □ □ □
Birth month: □ □

General rating instructions

1. Rate what the person is currently capable of doing rather than what they actually do. In assessing capability, take into account not only physical function but also cognition (such as problems caused by dementia or an intellectual disability) and behaviour (such as unpredictable challenging behaviour). Consumers able to complete a task with verbal prompting should not be rated as independent (and therefore should be rated as a 2 or a 3).
2. In rating an item that is irrelevant (for example, the person does not have a phone or has no shops in the vicinity or does not use any medications), rate based on what the person would be capable of doing if the item was actually relevant to their situation.
3. When assessing issues such as whether diet is adequate or there are acceptable standards of cleanliness, take into account the person's social and cultural context. Rate based on what is adequate or acceptable in that context and not in your own.

No#	Item	Score	Task	Base-line	6 mths	12 mths
1	Telephone	1	Cannot use telephone at all			
		2	Can answer telephone but cannot dial			
		3	Can dial a few well-known numbers. Includes dialling only numbers that can be speed dialled.			
		4	Can operate telephone on own initiative - looks up and dials numbers etc. Includes use of TTY machine if no other assistance required.			
2	Shopping (do not include transport here –rate at item 6)	1	Completely unable to shop			
		2	Needs to be accompanied on any shopping trip			
		3	Can shop independently for small purchases			
		4	Can take care of all shopping needs independently			
3	Food preparation	1	Needs to have meals prepared and served			
		2	Can heat and serve prepared meals, or can prepare meals but not does maintain adequate diet (see note below)			
		3	Can prepare adequate meals if supplied with ingredients			
		4	Can plan, prepare, serve adequate meals independently			
4	House-keeping	1	Cannot participate in any housekeeping tasks			
		2	Can perform some light daily tasks but not at a level necessary to maintain an acceptable standards of cleanliness (see note below)			
		3	Can perform light daily tasks e.g. dishwashing, dusting			
		4	Can maintain house independently			

5	Laundry (excludes ironing)	1	All laundry must be done by others			
		2	Can launder small items - rinses socks, stockings etc.			
		3	Can do personal laundry but needs help with heavier items such as bedding and towels			
		4	Can do personal laundry completely			
6	Mode of Transport	1	Requires manual assistance from more than 1 person or does not travel at all			
		2	Travel limited to taxi or automobile with assistance of one other person			
		3	Can travel on public transportation when assisted or accompanied by another			
		4	Can travel independently on public transportation or can drive own car or can arrange own travel via taxi.			
7	Responsible for own medications	1	Is not capable of dispensing own medication			
		2	Can take responsibility if medication is prepared in advance in separate dosages			
		3	Can take responsibility for taking medications in correct dosage at correct time			
8	Able to handle finances	1	Incapable of handling money			
		2	Can manage day-to-day purchases, but needs help with banking, major purchases etc.			
		3	Can manage financial matters independently (budgets, writes cheques, pays rent, bills, goes to bank), collects and keeps track of income			

	Base-line	6 mths	12 mths
Total score (out of 30)			
Initials of rater			
Date assessed			

Personal Wellbeing Index – ID

First name: □ □ □ □ □ □
Last name: □ □ □ □ □ □
Birth month: □ □

Procedure and instructions:

Procedure: Show the 0-10 happiness scale and check that participant understands.

Instructions:

"*I am going to ask you a few questions about how happy you feel, using this Zero to 10 scale*"

"*This scale will be used to tell me how you feel about your life in a few different areas*"

"*Zero means you feel very sad*" [Point to the left side of the scale].

"*Ten means you feel very happy*" [Point to the right side of the scale].

"*And the middle of the scale is 5, which means you are neither happy nor sad*" [Point]

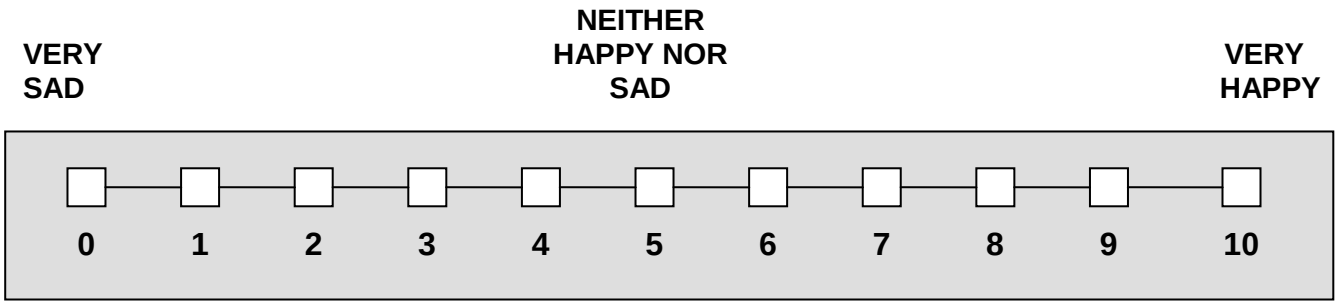
[Pointing to 8] "*How would you feel if you were an 8?*"

[Pointing to 2] "*How would you feel if you were a 2?*"

If necessary explain scale again and do a check with different numbers – avoiding 0, 5 and 10

"*Using this Zero to 10 scale….*" [Proceed to ask each of the test items below]

	Respondent's Rating
Part 1: Happy with life as a whole	**11-pt** (0-10)
"*How happy do you feel about your life as a whole?*"	☐
Part 2: Personal Wellbeing Index – ID	
"*How happy do you feel about…?"*	
1. the things you have? Like the money you have and the things you own?	☐
2. how healthy you are?	☐
3. the things you make or the things you learn?	☐
4. getting on with the people you know?	☐
5. how safe you feel?	☐
6. doing things outside your home?	☐
7. how things will be later on in your life?	☐


VERY SAD
NEITHER HAPPY NOR SAD
VERY HAPPY
0
1
2
3
4
5
6
7
8
9
10

MONTREAL COGNITIVE ASSESSMENT (MOCA-B)

BASIC

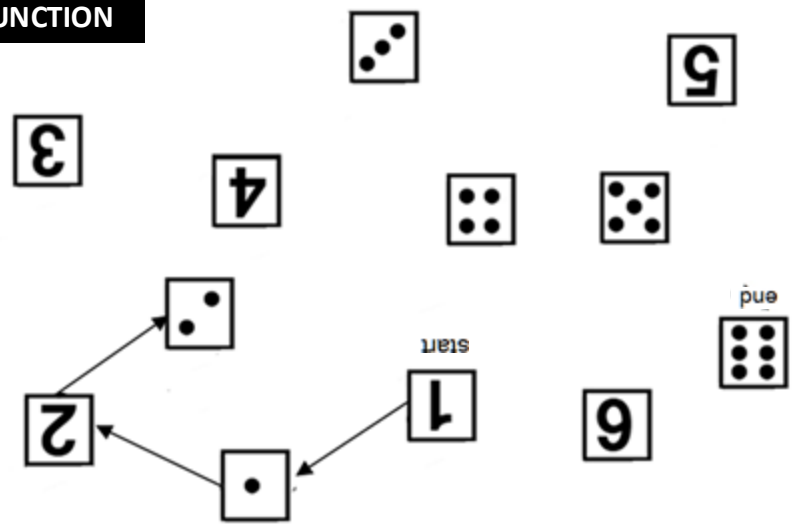
Client code

First name: □ □ □ □ □ □

Last name: □ □ □ □ □ □

Birth month: □ □

EXECUTIVE FUNCTION



SCORE

START TIME _____

(/1)

IMMEDIATE RECALL

Perform 2 trials even if 1st trial is successful

	ROSE	CHAIR	HAND	BLUE	SPOON
1st trial					
2nd trial					

No point

FLUENCY

Name maximum numbers of **FRUITS** in 1 minute

1..... 2..... 3..... 4..... 5..... 6.....

7..... 8..... 9..... 10..... 11..... 12.....

13..... 14..... 15..... 16..... 17..... 18.....

N items

2 points if N = 13 or more

1 point if N = 8-12

0 point if N = 7 or less

(/2)

ORIENTATION

[ ] time (± 2 hr) [ ] day [ ] month [ ] year [ ] place [ ] city

(/6)

CALCULATION

Provide 3 ways to pay using 1 dollar coins, 5 dollar and 10 dollar bills for an object that costs exactly **"13 Dollars"** (3 points if 3 ways, 2 points if 2 ways, 1 point if 1 way, 0 point if no correct way)

[ ] 1..... [ ] 2. ..... [ ] 3. .....

(/3)

ABSTRACTION

To what category these objects belong to ? (e.g. orange - banana = fruit)

[ ] train - boat [ ] north - south [ ] drum - flute

(/3)

DELAYED RECALL

Points are awarded for recall with No cue (1point for each item)

	ROSE	CHAIR	HAND	BLUE	SPOON
Recall with No cue	[ ]	[ ]	[ ]	[ ]	[ ]
Recall with category cue	[ ]	[ ]	[ ]	[ ]	[ ]
Recall with multiple choice cue	[ ]	[ ]	[ ]	[ ]	[ ]

(/5)

VISUOPERCEPTION

Identify drawings. No more than 60 seconds. See complementary sheet.

scissors	T-shirt	banana	lamp	candle
watch	cup	leaf	key	spoon

3 points if N = 9-10

2 points if N = 6-8

1 point if N = 4-5

0 point if N = 0-3

N __

(/3)

NAMING

Identify animals. See complementary sheet. [ ] zebra [ ] peacock [ ] tiger [ ] butterfly

(/4)

ATTENTION

Name the numbers in circles. See complementary sheet. 1 5 8 3 9 2 0 3 9 4 0 2 1 6 8 7 4 6 7 5

ERROR ___N

No point if 2 errors or more

(/1)

Name the numbers in circles & squares: 3 8 5 1 3 0 2 9 2 0 4 9 7 8 6 1 5 7 6 4

See complementary sheet. 1 5 8 3 9 2 0 3 9 4 0 2 1 6 8 7 4 6 7 5

ERROR ___ N

2 points if 2 errors or less

1 point if 3 errors

0 point if 4 errors or more

(/2)

END TIME _____

Adapted by : Parunyou Julayanont MD

Final Version June 04, 2014

TOTAL SCORE (/30)

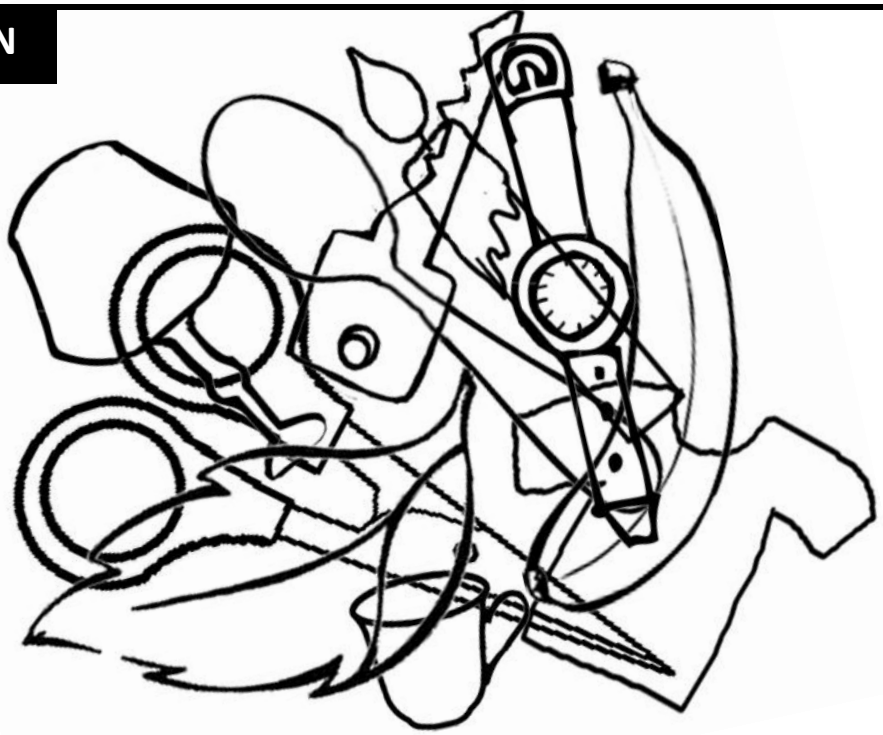
Add 1 point if education < 4 year AND add 1 point if illiterate

TOTAL TIME ____ min ____ sec

MONTREAL COGNITIVE ASSESSMENT (MOCA-B)

BASIC **COMPLEMENTARY WORKSHEET**

VISUOPERCEPTION



NAMING

ATTENTION

1 5 8 3 9 2 0 3 9 4 0 2 1 6 8 7 4 6 7 5

3 8 5 1 3 0 2 9 2 0 4 9 7 8 6 1 5 7 6 4

1 5 8 3 9 2 0 3 9 4 0 2 1 6 8 7 4 6 7 5

Room to Grow participant qualitative interviews – topic guide

Introduction

[To begin the interview, please follow the script below. It is not necessary to follow the script word for word, so it does not need to be memorised or read aloud. There are two main goals of the introduction. First, to relay important information which will ensure the participant understands the interview process; and second, to build rapport with the participant to ensure he feels at ease.]

My name is _____. I am a researcher at Mission Australia. I am involved in the evaluation of the Room to Grow program which is being conducted by Mission Australia. Room to Grow is the program through which you have been given help with your living situation.

Thank you for agreeing to take part. Before we begin, I want to explain what will be happening today and I also need to collect some administrative information.

The interview today should not take more than about one hour. The main purpose of the research is to find out how successful the Room to Grow program is in helping people to keep their tenancy, improving their living conditions and improving their lives generally. When we start I'll be asking some questions about how you have been going. Then I'd like us to talk about your involvement with Mission Australia and the Room to Grow program, if that's ok.

I want to emphasise that we are evaluating Mission Australia services, not you personally. You don't have to answer any question you don't want to. I'll ask you if you want a break somewhere in the middle, but if you would like a break at any time, just let me know. To compensate you for your time and effort, I will give you a $30 gift voucher at the end of the interview.

All the information you give me is strictly confidential. If you agree, I would like to record the discussion so that I can get a full and accurate record of what you have to say, but the recording and transcript will be stored securely and remain confidential. Only the researchers will have access to them. General feedback from the discussion today will be given to Mission Australia to enable them to review their services, but this is done on a confidential basis.

But there is a limit to confidentiality. If you tell me that you or someone you know is at risk of hurting themselves or someone else, or you know of specific details about a serious crime, then I am required by law to break confidentiality and report this information. But if I thought I had to report anything you said today, I would let you know.

I have a Participant Information Sheet and Consent Form. I'd like you to take a moment to read through these now. If you like, I can read it for you. Ask me any questions you have and if you are happy to, sign the consent form.

Please keep this copy of the Participant Information Sheet and Consent Form because it has contact numbers for members of the research team and the ethics committees involved, who you could contact if you had any questions or concerns later, or if you wanted to make a complaint.

Do you have any questions before we begin?

Introduction

Administrative information

1. Participant consents?

Yes – proceed with interview ☐

No – terminate interview and thank client ☐

3. Client code

List the 2nd and 3rd letters of the first name of the client and the 2nd, 3rd and 5th letters of the last name of the client. Indicate what month the client was born in. (Note: If client has a short name, instead of leaving a blank box write the letter "z") (Note: use numbers to record the birth month e.g. if the client was born in September you would write "09")

First name: □ □ □ □ □ □
Last name: □ □ □ □ □ □
Birth month:□ □

3. Do you consent for us to talk to your case worker [name] about how you're getting on?

Yes ☐

No ☐

4. Date of interview:

a. Date began?

DD MM YYYY

b. Date completed? (If different than the date above)

DD MM YYYY

5. Did the participant **NOT** complete the interview? (Tick if yes, and record the reason: a, b, c, d or e)

Yes □

Reasons for Non-Completion: □

a. Interview terminated by interviewer due to participant distress

b. Interview terminated by participant due to participant distress

c. Interview terminated by participant due to withdrawn consent

d. Interview interrupted and unable to be rescheduled

Topic guide

We are going to begin the interview now; I will make notes as we go along which you can see at the end of the interview.

1. Client's current circumstances

How are you feeling today? Are you ok about doing this interview?

Where are you living at the moment? What's it like? How are feeling about living there?

2. Involvement with Room to Grow program

What helped you to decide to take part in the Room to Grow program?

What goals or motivations did you have for being involved in the program? What did you hope to achieve? How far have you got with achieving these goals? What has helped most? What have been the barriers to meeting your goals?

How much do you feel the staff from the Room to Grow program have helped you to achieve your goals? Are you happy with what you have achieved in the program so far?

Is there anything you wish you had received more help with? This could be with your health, the way you feel, the way you learn or what's going through your mind

Did you feel supported throughout the program to access any extra support services you felt you needed?

How relevant did you feel the activities in the program were to helping you maintain your tenancy and improve your living conditions?

How much do you feel that the program is valuable to you in your life right now?

How much control do you feel you have had over your involvement in the program? Did you feel like you were able to make choices about what to be involved in? Did you feel able to make suggestions about how you might like things to be done differently?

3. Current accommodation and service support

You said earlier you were living at _____ at the moment. Could you tell me a bit more about this? Are you living on your own or sharing with other people?

Over the last 12 months, what kinds of services have you had access to? (I.e. psychologist, counsellor, health services, drug and alcohol services, other)

Since you started with the Room to Grow program, what other kinds of services have you been put in touch with? Have these been useful? How have they helped you?

How do you feel about the cleaning process (if one has occurred)? Did you feel that enough information was provided to you before, during and after this to explain what was happening? Did you feel able to make decisions with the cleaning service staff about your possessions? Why or why not?

4. Case management

Part of being involved in the Room to Grow program means having an extra case manager to support you and put you in touch with other services you need. How do find working with _____? Any problems?

In what ways has s/he helped you so far? Are there any other ways in which you'd like her/him to help?

5. Programs (CBT/CR/living skills)

Part of being involved in the Room to Grow program has meant that you can access extra programs to help support you to improve your living conditions. Which programs have you been involved in (CBT/CR)?

How do you find being involved in the CBT/CR program? Do you think the CBT/CR program is relevant to you? Any problems?

How supported do you feel to develop and use the skills you have learnt throughout the (CBT/living skills) program? How confident do you feel to begin to use these skills in your home? In your life in general?

Has anything changed throughout your involvement in the program to the way you think and feel about your living conditions/possessions? How has it changed?

6. Overall views on the Room to Grow program

Overall, do you think the Room to Grow program is an effective program for people who might be having trouble maintaining their tenancy because of issues with their living conditions (clutter/cleanliness)? Why or why not?

How happy are you with how clean and open your home is right now?

Because of your involvement in the Room to Grow program, do you feel able to start making changes in your home which could lead to cleaner, more open living spaces? (So that your home becomes closer to how you would like it to be) Why or why not?

What is the most important part of the program, for you? What is the least important part?

In your experience, how could the program be improved?

7. Final comments

Before we finish, is there anything else you'd like to add? Anything at all you think is important that I haven't already asked you about?

How do you feel about having been involved in this research? Has it been a positive or negative experience for you?

Mission Australia helps people regain their independence - by standing together with Australians in need, until they can stand for themselves.

Contact us

For further information please contact our **Research & Evaluation** team on:

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