

*“It’s like having a Coke but not being
able to drink it”*

A Report on the

**Sexual Health of
People Who Live in Boarding
Houses and Other Residential
Facilities
in the Western Region of
Adelaide**

Sally Gibson and Ralph Brew
SHine SA



**Funded by a Health Enhancement Research Grant
Department of Human Services**



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1999

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**SHine SA
17 Phillips St
Kensington
SA 5068**

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1.0 Executive Summary

This is a report on a qualitative research study into the sexual health of people who reside in boarding houses, mental health hostels and other Supported Residential Facilities in the western region of Adelaide¹. Most of these people have a mental illness, an intellectual disability or both. The research was undertaken by SHine SA (Sexual Health information networking and education SA) an agency which provides a broad range of sexual health education, counselling and clinical services to the South Australian community. SHine SA has 6 target communities one of which is people with a disability (intellectual, physical and those with a mental illness).

This research was funded by a Health Enhancement Research Grant from the Department of Human Services. The principal investigator for the research was Sally Gibson from SHine SA. Ralph Brew from SHine SA was the Project Officer for the research project and conducted most of the interviews. Murray Couch from the Australian Research Centre for Sex, Health and Society at La Trobe University was a consultant to the study.

Semi-structured interviews were conducted with 14 people who live or have recently lived in facilities. In addition, 2 owners of Supported Residential Facilities and 10 mental health and disability workers were interviewed to further develop an understanding of the sexual health experiences of people who live in the facilities.

A broad view of sexual health has been considered: from actual infection with sexually transmitted infections, knowledge of safe sex and contraception to the quality of sexual experiences and relationships that a person is able to enjoy. This view of sexual health is consistent with that adopted by the World Health Organisation which identified that sexual health is -

- *The capacity to enjoy and control sexual and reproductive behaviour in accordance with a social and personal ethic;*
- *Freedom from fear, shame and guilt, false belief etc which inhibit sexual response and impair socio-sexual relationships;*
- *Freedom from organic disorders, diseases and deficiencies that interfere with sexual and reproductive function.*

Consideration of sexual health issues is often absent from the response to people who have a mental illness or intellectual disability. This relates to the discourse around who are “fit” and proper people to have children which was originally fueled by the eugenics movement of the early 20th century and is reflected in the ongoing controversy around sterilisation of women with intellectual disabilities.

¹ In this report the term “residential facility” or “facility” will be used to cover *all* the different accommodation options such as mental health hostels, supported residential facilities as well as boarding houses and lodges. Some of the people interviewed were not sure what type of accommodation they lived in and often used the term hostel, lodge or boarding house interchangeably. However, all but one lived in licensed Supported Residential Facilities. There are differences in the legal status of these housing options and this is discussed further in section 4.

Although the de-institutionalisation movement of the 1960's and 70's brought about some reform, little attention was paid to the area of sexuality and relationships. The 1980's and 90's brought an increasing awareness about the importance of developing programs, which addressed safe sex and protective behaviours, so as to minimise the likelihood of transmission of HIV and other sexually transmitted infections.

People with a mental illness or intellectual disability may live completely independently and be able to manage their own affairs; however many will have some form of control over their affairs such as an administration order for their finances. People who live in a residential facility environment will not generally be under a full guardianship order and are considered to be competent enough to live in the community.

Many people with intellectual disabilities actively seek to form sexual and non-sexual relationships with other people. The current approach to the support of people with intellectual disabilities is to encourage and develop their independence and this will often include an acknowledgment of the sexual needs of the individual. The Intellectual Disability Services Council (IDSC) has a policy on sexuality and arranges for sexuality education for their clients. SHine SA is often involved in this educational work.

People with a mental illness may share some common concerns with people with intellectual disabilities but there are also significant differences. Many people with a mental illness may not experience the effects of their illness until later in their life which means that they often have a greater range of life experiences than people who have been born with an intellectual disability eg study, work, marriage, children. However some may experience severe mental illness from a young age and spend many years in institutions and be reliant on medication which can have a negative impact on the quality of their lives, including their sexual lives.

Research conducted in the USA with people who have been mentally ill since childhood or adolescence showed that they often experience severe difficulties in maintaining social and sexual relationships. Their sexual activities are also more likely to be impulsive, anonymous and coerced (Carmen and Brady 1990).

People with a mental illness who live in facilities often have been inpatients in psychiatric institutions and may move between facilities and hospitals. Some people are only in facilities a short time and move successfully into their own public or private housing although there are also some people who will live in facilities almost all their lives. Increasingly facilities are now seeing younger people and some with a history of offending which may or may not be related to their disability or illness. Some facilities also accommodate people with drug and alcohol dependency.

This research was successful in recruiting people with a mental illness but there were difficulties in securing interviews with people with an intellectual disability. This issue is discussed further in the section on methodology. While this means that some of the specific findings may apply more strongly to people with a mental illness who reside in facilities many of the themes that have been identified will apply to all people who live within such an environment.

The research took as its starting point the belief that the environment in which people live (in this case the facilities) will have a major impact on their sexual health. This environment is created by many different factors and people will relate to this environment according to their own attributes. For example a woman will have a different experience than a man, older and younger people may experience it differently and there will be variation according to the severity of disability. However it was expected that common themes would emerge from the interviews and this did occur.

The key finding from the research is that -

People who reside in supported residential facilities experience significant barriers to achieving healthy and safe sexual relationships. As a consequence they are at risk of sexually transmitted infections, coercive sex and negative outcomes associated with exploitative and unsatisfying relationships.

These barriers can be grouped under the following headings:

- 1. The physical and social context of the facilities**
- 2. The impact of illness and medication on sexual functioning and relationships**
- 3. The lack of support and education on sexual health issues**

These barriers are discussed in greater detail in section 5. However what is clear from the research is that it is a combination of all these barriers which leave the residents of facilities vulnerable to taking sexual risks and experiencing poor sexual health.

2.0 Summary of Recommendations

These recommendations relate to the findings outlined in section 5. They have been developed by the researchers in consultation with the reference group. Different people and agencies will have a responsibility to consider and take appropriate action on these recommendations and where these are clearly identified they have been named.

Recommendation 1

That guidelines and a resource kit on relationships and sexual activity be developed by the Supported Residential Facilities section of DHS and that these be distributed to all Facilities and the information in them conveyed to all residential facility residents.

Recommendation 2

That the Supported Residential Facilities Training plan include sexual health and sexuality education.

Recommendation 3

That when psychiatrists and general practitioners are considering prescribing drugs that have a negative effect on sexual functioning, their possible effects be discussed with clients and alternatives found where possible.

Recommendation 4

That the disability and mental health system support residents of facilities to attend regular social programs which enable clients to gather in safe informal surroundings during the evening.

Recommendation 5

That investigation take place about the viability of an all female residential facility in the western region of Adelaide.

Recommendation 6

That any guidelines developed (see Recommendation 1) also address harassment (sexual, racial, religious, sexuality) of residents by other residents and staff.

Recommendation 7

That education or support programs for residents, owners and staff of facilities (see recommendation 2) also address issues of homophobia and same sex relationships.

Recommendation 8

That the legal situation of workers who provide information about sex workers to clients be clarified.

Recommendation 9

That comprehensive sexual health and life skills education be implemented with residents of facilities and with those in more institutionalised settings.

Recommendation 10

That condoms and lubricant be made available in all facilities, drop-ins and inpatient facilities.

Recommendation 11

That the initial assessment process undertaken by both mental health and disability services involve an assessment of the sexual health needs of their clients. That there be a proforma developed to assist this process. That training be provided for staff to develop skills, knowledge and confidence in carrying out this part of their work.

Recommendation 12

That managers of facilities be encouraged to arrange regular guest speakers for the benefit of their residents. These speakers could cover a range of health and lifestyle issues.

3.0 Methodology

Qualitative research attempts to capture people's meanings, definitions and descriptions of events. (Minichiello et al 1997:9)

A qualitative research methodology was chosen as the researchers were interested in how people who lived in the facilities experienced their own sexual health. A literature search on sexuality and sexual health for people with disabilities revealed that little research has been carried out in this area, whilst that which has taken place has often reported on the results of educational work (Thompson and McCarthy 1993, Smith and Telford 1996) or has been survey based and concerned with knowledge of issues such as HIV/AIDS (Condon 1996).

It is rare for the "clients" of the mental health or disability sectors to be given the opportunity to contribute their perspectives on issues which affect their lives. The very circumstances which lead to their need to live in a hostel, means that they are often the most powerless people in the community. Providing a space for these people to articulate their experiences and desires around sexual health was considered to be a vital part of the research process. For this reason it was appropriate to attempt semi-structured interviews with clients, using the assumptions of "in depth" interviewing, "to understand the significance of human experiences as described from the actor's perspective and interpreted by the researcher." (Minichiello et al 1997:12)

To provide adequate contextual information for the understanding of the "client" interview accounts, it was decided to conduct focus groups with two categories: (1) people who own or manage hostels and (2) disability and mental health workers who provide services to the hostel residents. Obtaining the views of the owners and workers about the sexual health of hostel residents also contributed to ensuring that the findings of the research have greater plausibility in the sector as it enabled some verification from different points of view.

The value in the use of two qualitative methods in this way was the opportunity it provided for the useful application of "within methods" triangulation (Creswell 1994:174). Triangulation as used in this study was not so much in the classic sense of seeking convergence of results, but to allow overlapping and different facets, and contradictions and fresh perspectives of the experience being studied to emerge (Creswell 1994:175).

3.1 Research Process

Establishing a Reference Group

A reference group was established to provide a forum to discuss the research, emerging themes and to assist in strategies to recruit people to be interviewed.

Members of this reference group were:

- Sarah Burden: North Western Mental Health Service
- Jayne Wrigley: Supported Residential Facilities Unit, DHS

- Kath Vannan: Senior Social Worker, IDSC
- Sue Marshall: representative Supported Residential Facilities Association (SA Inc)
- Daniel Kean: consumer representative

Ethics Committee Approval

Ethics approval was sought and gained from the North Western Area Health Services. The committee requested some additional information in regard to consent and this was provided.

Development of an Interview Schedule, Protocol and Checklist

While the interviews were to be conducted as open ended it was recognised that many of the people interviewed would have difficulties with concentration and comprehension and may give very brief answers. To assist the interview process a standard set of questions was prepared which structured the interview but also maintained some flexibility (see Appendix 1 for interview schedule).

It was also recognised that there may be some disclosure of past or current sexual abuse and a protocol was developed which outlined how this would be managed by the researchers (see Appendix 2)

In addition a checklist was developed which was completed at the end of the interviews. This checklist included age, sex, income, type of accommodation, diagnosis, sexual orientation, numbers of children, numbers of sexual partners and frequency of screening for sexually transmitted infections. The interviewer completed this form after the interview based on the information that had been provided and asked the interviewee any questions for which the answer was not known (see Appendix 3 for checklist).

A schedule of questions was also developed for the focus groups for workers and owners (see Appendix 4).

Recruitment of Individual Interviewees

There were a number of issues to consider in recruiting residents from the facilities to be interviewed. People had to be able to understand what they would be interviewed about and be able to give their informed consent to be interviewed (see Appendix 5 for copy of the consent form). These criteria meant that some people with more severe disabilities who reside in facilities would not be interviewed.

In addition the fact that the interviews relied on a verbal interaction meant that some people with intellectual disabilities may have difficulty in understanding and responding to the questions. While the key interviewer was very experienced in working on sexuality issues with people with intellectual disabilities it was recognised that such an interview process, which essentially relied on a certain level of verbal skills, may not be appropriate to people with intellectual disabilities. This was a limitation of the chosen methodology.

The main recruitment strategies included leaving an information flyer (see Appendix 6) at places frequented by residents of facilities eg drop ins. A mail-out of this flyer was also done to the facilities in the western region of Adelaide and to key workers. The project officer also attended staff meetings of agencies to talk about the research. In addition the consumer representative told other residents about the research project and a limited form of snowballing took place with one resident being interviewed and then telling another person about it. The consumer representative and some mental health workers also invited the researchers to visit the St. Bedes drop-in and activities centre to take part in the social activities to establish contact and trust with consumers. These last two were the most effective recruitment strategies, with few people being interviewed only as a result of information from their workers.

The time set for interviews was between November 1998 and January 1999. While staff from IDSC showed considerable interest in the research some difficulties arose in using workers to assist with recruitment as December and January are times when many workers are on leave and the services are operating on a skeleton basis.

The recruitment process partially relied on the person making contact with the researchers by telephone. In these cases, they were then given the option of a pre-interview meeting to talk through what the research was about, or a firm time was made for the interview to take place. Often the pre-interview information was given over the phone. In order that anonymity and confidentiality be maximised, it was considered inappropriate to interview people where they lived. The researchers therefore arranged for interviews to take place in a private room at a local neutral venue; the Port Adelaide Community Health Service. In many cases, these visits also operated as a first introduction to the services on offer at that health service.

The male researcher interviewed men and the female researcher interviewed women. This was important particularly for the women who had all experienced sexual violence. The male interviewer was also able to establish good rapport with the men, which enabled explicit sexual discussion to take place comfortably.

The researchers picked the residents up and dropped them off after the interview, as people who live in the facilities have little money and their illness can make it hard to travel around. People received a payment of \$20 for participating in the interviews and this proved an important incentive for some people although many also expressed the view that they thought sexual health was an important area to be researched and were pleased to be able to give their views.

A target of 20 residential facility residents was set with 15 of these being men. The greater number of men reflects the fact that many more men reside in facilities. Initially it was planned to interview an equal number of people with intellectual disabilities and mental illness but this was not possible as people with intellectual disabilities did not make contact about being interviewed. Effort was made to have more contact with workers but it became evident that it would not be possible to interview many people who have intellectual disability as a primary diagnosis. The difference in response may also reflect the fact that people with intellectual disabilities may be less able to read a flyer and respond to it.

3.2 Demographic Details of the Residents Who Were Interviewed

The demographic information was provided by the interviewees.

Numbers of People Interviewed

A total of 14 people were interviewed (3 women and 11 men).

Age

Four were in the 17 -25 age range

Three were in the 26 - 30 age range

Three were in the 31- 35 age range

Two were in the 36 - 40 age range

Two were over 40 (one over 45).

The demographic profile of people who reside in facilities is not known. However it is likely that the people who were interviewed constitute a younger group than the overall population of people in facilities.

Disability

Twelve people had a primary diagnosis of a psychiatric disability with the most common illness being schizophrenia. One person had a dual psychiatric disability and intellectual disability and one person had a primary intellectual disability. All three women had a psychiatric disability.

Children

Four of the people interviewed had children. Two men had two children each, one woman had one child and another woman had two children. None of these people lived with their children although one woman had been with her children until recently when she was admitted to a psychiatric institution.

Ethnic and Socio-Cultural Background

Most people were from an Anglo-celtic background with two from a Southern European background. There was no Aboriginal person in the study. Most participants had lived all their lives in Adelaide although two people had come to Adelaide to leave difficult circumstances (such as domestic violence or family conflict), in other states.

Schooling Level

One person had attained University level education but the majority had taken their schooling no further than Year 11. Some had developed a mental illness early in life, which prevented them being able to go beyond Year 10. One was studying Year 12 subjects at the time of interview.

Accommodation

5 people interviewed lived in mental health hostels, 8 in other Supported Residential Facilities and 1 in a small private boarding house. There were no people interviewed who lived in larger boarding or lodging houses, although several participants lived in licensed facilities which still used these labels. (see section 4 for a discussion on the difference between these facilities)

Interviewees lived in a total of 8 separate accommodation facilities. All except one lived in the north-western coastal region of Adelaide which covers the areas of Peterhead, Largs Bay, Semaphore, Rosewater and Port Adelaide.

Sleeping Arrangements

4 people had their own room (one only temporarily until someone moved in)
7 people shared a room with one other person
3 people shared a room with 2 or more people.

Sexual Identity

All identified as heterosexual or “straight” although at least one of the men said he did have sexual interest in other men and pursued this when circumstances allowed. Two or three other people did mention times during either adulthood or childhood where same-sex activity was attempted or actually engaged in.

Relationship Status

3 people were currently in a relationship
3 people had not been in a relationship for months
1 person had not had a relationship for over a year
5 people had not had a relationship for years
2 people had never had a relationship.

It should be noted that what constituted a relationship was fairly fluid and does not necessarily equate to sexual activity. This is discussed further in section 5.

3.3 Focus Groups and Interviews with Owners/Workers

Letters were sent to owners and residential facility staff as well as workers in the disability and mental health sector. It was decided to hold separate focus groups given the different relationship which workers and staff have with residents in the facilities.

The response from owners and staff from facilities was poor. This may relate to the fact that facilities are generally run privately, are very busy and for staff to leave the residential facility a cost may be incurred through payment of replacement staff. Attendance of residential facility owners and staff at a consultation process to review the *Supported Residential Facilities Act* was also a problem as documented by Le Sueur in the report “*Evaluation of the Impact of the SRF Act on the Proprietors and Staff of Facilities* (June 1998). It may also have related to a perceived lack of relevance to the daily running of a residential facility. Some more assertive follow-up of letters could also have been carried out.

Two owner/managers did respond to the letter and were interviewed individually. These people had considerable experience in managing residential facilities and were very well informed on sexual health issues. Given the information provided by the residents of the facilities about the lack of support, or even restrictions placed on them, in regard to sexual activity, it is unlikely that these owners/managers are typical of the people who own and run residential facilities.

Only two people (one from the disability sector and one from the mental health sector) attended the first focus group for workers. This focus group provided valuable information and it was decided to make another attempt to run a second worker focus group. A second one was run at an IDSC office and was attended by eight workers from both the disability and mental health sectors.

3.4 Recording and Analysing of Data

Each interview or focus group was tape recorded and then transcribed by an experienced transcriber. All information was coded and stored in a locked filing cabinet and all identifying information was removed from the interviews. The interviews and focus groups were then loaded onto a computer using QRS NUD*IST software.

The data was coded and ordered under different headings. Themes were explored both by using NUD*IST and in a workshop conducted with the researchers by Murray Couch who had not been present in the interviews and so was able to provide an outside reflection on the main issues emerging from the data. These themes and issues were then discussed at meetings with the reference group.

4.0 Legislative Framework for Residential Facilities, Mental Health Hostels, Boarding Houses and People With Disabilities.

4.1 Historical Overview

It is now nearly five years since the *Supported Residential Facilities Act* was introduced in South Australia. This *Act* was stimulated by an accelerated change process in the boarding house sector which saw them increasingly providing limited personal care services in addition to meals. This was in response to a growing demand created by the policies of de-institutionalisation and normalisation which had been developing in the health and disability sectors since the mid 1970s. Adequate community accommodation and support services had not been otherwise arranged, particularly for people with intellectual disability and mental illness. In this context, standards of care were variable and several reports were presented to the government, outlining the problems which required some state intervention (SA Health Commission 1988, Chapman and Provis 1991).

The legislation provides for the regulation of Supported Residential Facilities and personal care services. It is now mandatory that where such services are offered to more than two residents, that the facilities be licensed and monitored and that they be obliged to follow a minimum standard of care.

A unit has been established to over-see the regulations under the *Act* and to act as a central contact point for local government officers who are authorised to monitor premises and care standards as well as make recommendations regarding the issuing or revoking of licenses. It also acts as a focal point for interaction between the state government and the association of licensed facilities, the SRFA. It produces a regular newsletter to keep stakeholders up-to-date with developments and events. The Supported Residential Facilities Unit (SRFU), is also responsible for coordinating reviews of the legislation and its regulations and making Annual Reports to the Minister for Human Services. In June 1998, a consultancy firm, Routley Consultancy, released an evaluation report on the impact of the *Act* on the Proprietors and Staff of facilities.

The *Act* covers a very broad range of facilities including those which self identify as Rest Homes, Hostels, Retirement Villages and Supported Accommodation, as well as those which previously identified as Boarding or Lodging Houses. Since the *Act* was introduced, many Boarding and Lodging Houses have upgraded their status by seeking licensing under the *Act* and are now operating as personal care providers to a variable proportion of their residents.

However, the presence of the *Act* does not preclude unlicensed Boarding House style facilities from continuing to operate, as long as they are not seen to be providing ongoing personal care services to more than two residents at any one time.

All but one of the facilities encountered through this research are in the Port Adelaide Enfield Council area. None of the persons interviewed lived in large unlicensed premises.

4.2 Licensed Premises (Supported Residential Facilities)

All group facilities which provide or wish to provide Personal Care services to more than two people are required to be licensed under the *Supported Residential Facilities Act*. Personal Care is defined as :

- provision of nursing care
- assistance with or supervision in; bathing, showering or personal hygiene
- toileting or continence management
- dressing or undressing
- consuming food
- direct assistance to people with mobility problems
- the management or assistance with the management of medication
- the provision of substantial rehabilitation or developmental assistance
- management of personal finances

Several of these facilities also continue to operate with an extra subsidy, which relates to their previous status as “Mental Health Hostels”. The Mental Health Service continues to administer this subsidy.

Some premises, which were unlicensed prior to the *Supported Residential Facilities Act*, are now licensed under the *Act*. These premises provide Personal Care Services to a far wider range of people than those with mental illness and do not attract that additional subsidy. These include people with Alzheimer's Disease, Korsakow's Syndrome, Brain Damage, Intellectual Disabilities and people who have been discharged from the Corrections system who also have a psychiatric disorder, or an intellectual disability or both.

The Evaluation of the Impact of the Supported Residential Facilities Act on Staff and Proprietors (Le Suere 1998) found that the economic margin for most facilities was not high. Special services and reduced fees were often requested for some residents but this had a negative outcome on staff resources and resource demand. It was also reported that increased charges in nursing homes and earlier discharge from hospital was resulting in admission of residents with high levels of “personal care needs” with a direct and significant effect on costs.

4.3 Unlicensed Premises (Boarding Houses & Lodges)

As stated above, under the *Act*, unlicensed premises generally may not provide Personal Care Services to more than 2 people. The residents of these facilities are generally only provided with a room to rent or co-rent as well as meals and the houses will have varying processes and expenses associated with provision of cleaning, personal hygiene and laundering. Historically, these unlicensed facilities would have been known as Boarding Houses or Lodges and many still are. Confusingly, several now licensed premises, retain the title of Lodge or Boarding House.

Given the unlicensed nature of these facilities, their obligations to the community and their residents are not as high. They are also under no special obligation to follow the principles of the *Act* as outlined below. They are covered by the *Residential Tenancies Act* and the *Equal Opportunity Act*, but neither of these *Acts* provide for inspection or intervention unless a resident is assertive enough to pursue a complaint themselves.

Generally speaking, the residents of unlicensed premises might be understood to be more able to manage their own affairs by their lack of “personal care” needs, as defined under the *Act*. It is also possible to speculate that proprietors could turn a blind eye to the narrowly defined care needs of some residents and therefore avoid the often prohibitive expense and trouble of gaining a licence and fulfilling the associated criteria in housing quality, service provision and so forth. Conversely, personal care services are legally provided by unlicensed facilities, where there has been an illness or accident, where someone is waiting to move into alternative accommodation or where seasonal shelter is sought by homeless people.

4.4 Authorised Officers

The Le Sueur Report highlighted the role of Authorised Officers, some of whom used "perfunctory inspections... [which were] ... unlikely to protect or benefit residents" and "concentrated purely on the physical requirements of the *Act* without appreciation of the overall environment provided" (Le Sueur 1998:11). Some of these workers come from a Social Work background, whilst others are from an Environmental Health background. Authorised Officers therefore probably tend to vary in how they interpret the regulations under the *Act* and have different levels of interest.

4.5 The Principles of the *Residential Facilities Act*

The Licensed Supported Residential Facilities are generally left to interpret the principles of the *Act* themselves. Under these principles, residents have the right to:

- High quality care, their own choice of doctor or other health provider, and the ability to make an informed choice about the services they wish to receive.
- Reasonable levels of nutrition, comfort, shelter and a home-like environment.
- A safe physical environment.
- Be treated with respect and dignity and their privacy being respected, to a reasonable degree.
- Independence and freedom of choice, including the right to choose friends of either sex, the right to practise their religion and cultural customs and the right to take part in activities of their choosing, so long as they do not infringe unreasonably upon the rights of others.
- Manage their own affairs wherever possible.

- Comment, either confidentially or publicly, about the residence in which they live, or the care they receive.
- Not be subjected to exploitation.

As will be seen later in this document, some major themes that emerge from those interviewed are those of privacy, the right to choose friends - and sexual partners - of either sex and the right to take part in activities of their own choosing.

Five of the people interviewed lived in Mental Health Hostels which are also licensed under the *Act* while eight other people lived in other Supported Residential Facilities. Only one person was in a small unlicensed boarding situation.

4.6 Involvement of the Guardianship Board

Most people living in a Supported Residential Facility, or even an unlicensed Boarding House, are under some kind of Order. Such orders are commenced by the Guardianship Board, upon application by anyone who can demonstrate a proper interest in the affairs of the client. Equally, anyone who can demonstrate a “proper interest” in the affairs of the client can also request discharge (cancellation) of an order.

In the case of:

- *Treatment Orders*; only a doctor is empowered to carry out the order;.
- *Detention Order*; a treatment team is empowered to carry out the order. (Not all mental health residents of Mental Health Hostels, other Supported Residential Facilities and Boarding Houses are under treatment orders).
- *Guardianship Order*; “an order may be made to give a person the legal right to make decisions for another person”. Here, the Guardianship Board may appoint the Office for Public Advocate if there is no-one else to take on the role.
- *Administration Order*; the Office of Public Trustee is instructed to handle the financial and other administrative affairs of the client. In this case, the Guardianship Board also appoints a liaison officer. The Guardianship Board prefers a family member to take on this liaison role, however, it is frequently the case that no-one in the family is willing to take the role on. In this case a professional such as a social worker, nurse or other worker will carry out the role.

At any one point in time, about one third of the mental health clients who live in the boarding house and SRF systems in the western area, are under administration orders (client records of North Western Area Mental Health Service). Sometimes this is for a temporary period, until their mental health stabilises or their general ability to manage their own financial affairs improves. Sometimes it remains a permanent arrangement. The ability to manage one’s own financial affairs is a significant status symbol for many and periods of time spent with money being managed by an institution contribute to feelings of powerlessness. There is a high level of resentment in many whilst others are grateful that during times of

instability, this is an area of their lives to which they do not have to pay attention. Past experiences of being destitute can mean external financial management is seen as necessary even if undesirable.

The *Supported Residential Facilities Act* also provides for the proprietors of these facilities to manage the personal finances of some residents. This can be particularly important in the context of large, busy group dwellings where movement of people through the residential facility is constant as is the desire to have more money. Security of money is often best handled through members of the staff. Not all individuals have to, nor do use such services and are well able to maintain control over their own finances.

5.0 Findings and Discussion

The following vignette is a schematic depiction of the lives of some of the people who reside in facilities. It is based on the material provided by the people interviewed but it is not possible to describe a universal experience of living in a facility as there is variation between how facilities are run and what they offer. For example one person interviewed lived in a residential facility where all people had their own single rooms but this was the exception.

After this vignette had been written it was given to a person who lived in a residential facility for his comment. He read it carefully, chuckling under his breath and then said “*This is what its like except that my hostel smells really nice. How did you know all of this?*”

What is it like to live in a residential facility or boarding house?

Your name is “Jim”. Each evening your meal arrives at about 5pm. It is likely to be a pizza or maybe sausages and potato. You eat at long tables in rooms that smell of old greasy food and cigarette smoke although nowadays no one is allowed to smoke inside. Still it’s hard to get rid of that smell which clings to the clothes and fingers of nearly everyone around you.

You try to stop smoking sometimes. Not because you think it is unhealthy, God knows the thought of dying of lung cancer in 30 years is the least of your health worries. But because it costs so much to smoke now. You have about \$30 a week left over after your room and board has been paid for and most of that goes on cigarettes. There are about 30 other people living in the residential facility and most share rooms with 2 other people. There are a few single rooms and you would like to have one but they cost \$30 more a week and this is impossible while you are still smoking. Maybe one day.

At night you sit in a room and watch television. If it’s a nice night you might go for a walk. You go outside a lot to the concrete to have a smoke and a chat. Some of the younger ones will be smoking marijuana and hoping that the owners don’t find out. You like that there’s people to chat with even if sometimes they annoy you. Sometimes someone will really go off and pick a fight. That’s when it’s important that the staff step in and manage it. A good residential facility is one where there is some order. It makes you feel safe, particularly when your illness makes you feel out of control and scared.

You would like to have your own place but this also scares you. You’re not sure if you could cope. You find it hard to plan your day. Maybe it’s the illness or maybe its the medication. How would you shop and cook and who would you talk with? You also want to have a relationship; settle down with someone and have your own place but you think now that this won’t happen as you don’t feel attractive and you don’t have money. Sometimes you can’t bear to even think about it as it fills you with too much grief.

But sometimes you think that Mary at the drop in fancies you and so you go there just to chat and spend time with her. Other people in the residential facility tease you and say that you have a lover and this makes you feel good. You arrange to visit her in the

residential facility and sit outside and have a smoke with her. You go for walks together. Maybe this will be enough. You don't want more than this as it becomes too complicated.

But maybe you want to have sex with her. You go for long periods of time when you think you won't have sex ever again. Sometimes you feel horny though and will wank quietly under the bed clothes hoping that the snoring coming from the other beds means they are asleep. You hear them though, "poor bastards" you think as they jerk themselves off getting one of the few free pleasures there is in life.

Sometimes you try to do it and nothing happens and instead of feeling good you feel really bad and even more hopeless. Now even that is letting you down. You don't know why you can't get it up or come and wonder if its the drugs you're on but how do you talk to the doctor about it? They don't tell you that you might not be able to have sex. They just say the drugs will make you feel better. Sometimes you wake up in the night and you hear someone in the showers. Then you realise its 2 men in the showers and wonder what they are doing having a shower at 2am in the morning.

You want to bring Mary home and lie in bed with her, touch her and maybe have sex. You know this is not allowed although you haven't been told this directly. The staff say to the women to keep out of the men's rooms. Sometimes they will go and bring them out and people have a good laugh about it. Once you found a woman in your bed but it was old Nancy and she was just confused about where she was. She thought she was Cleopatra sailing up the Nile and your bed was her boat.

The last time you had sex was when Flossie opened her door and said why don't you come in here. You didn't really fancy Flossie but it was something to do. You felt nervous that someone might see but it was very quick. Just put it in really and it was all over. Flossie kept hassling you after that and saying you were her boyfriend but then she did it with Ted and the owners asked her to leave.

Every so often you see your case manager. She talks with you about how you're going but you often think she doesn't really want to know. She helped you get on the disability pension and arranged for your rent to be paid directly from your bank account. You like the workers at the drop in as they spend more time with you and you get to make things. At least its something to do during the day and you can get a free coffee and tea there.

Mary's life is something similar but is also different. Although she's 30 she finds herself sharing a room with a woman who's 60 and has been in the residential facility for 20 years. This old woman is OK but doesn't like it if Mary has the radio on. Mary has a child in foster care. She hasn't seen him for 12 years and wonders how he is. She tells herself that living in a residential facility is only temporary and one day she will have her own home and her son will come and live with her.

Mary finds it hard to sit outside with the men and have a smoke. They often say things to her like "I'll give you a ciggie if you sit on my lap". A lot of them are real old blokes who smell and pace around. They scare her a bit and she tries to keep to herself. She does like a chat and a smoke though and sometimes its worth being felt up a bit to get some pot but she doesn't tell her worker this as she's not supposed to smoke if she's on medication.

Mary likes Jim. He talks with her and makes her feel special although lately he's been coming around every day and wants to keep kissing her. She feels suffocated by it and tries to tell him not to come as often but he has nothing else to do. Now the staff have noticed that Jim is around all the time and she worries what they will think. She's been asked to leave places before and doesn't want it to happen again. She just wishes that Jim would go away.

KEY FINDING

People who reside in Supported Residential Facilities experience significant barriers to achieving healthy and safe sexual relationships. As a consequence they are at risk of sexually transmitted infections, coercive sex and negative outcomes associated with exploitative and unsatisfying relationships.

These barriers can be grouped under the following headings:

- 1. The physical and social context of the facilities**
- 2. The impact of illness and medication on sexual functioning and relationships**
- 3. The lack of support and education on sexual health issues**

5.1 The Physical and Social Context of the Facilities

While there is variation between the facilities they all share the fact that a large number of adults are all living together in very close circumstances. This creates a number of stresses for people who live in the facilities and also for the people who own and work in the facilities. What is clear is that facilities are sexualised places. With usually 30 -50 adults living in close proximity it is to be expected that physical and sexual intimacy will be part of the environment.

Many residents spoke about either having sex in the facilities or observing sexual activity taking place. There was also acknowledgment that there were many people, usually the older residents, who didn't have sex and were not interested in it.

While some residential facility owners and managers acknowledge this in a positive way through discussion, education and support to engage in sexual activity in a safe and consenting way the majority of facilities were reported to try to ban it completely.

Some of the major issues relating to the physical and social context of the facilities are:

5.1.1 Privacy

Some people expressed their displeasure with sharing a room with other people all the time while for others it wasn't a problem. Often people shared with others who talked all night or paced around which they found annoying. A lack of privacy affects how sex takes place. It means that people have furtive and quick sex which is usually opportunistic and unplanned. An outcome of this is that condoms are rarely used.

“Well I’ve been living in a room with two other blokes for the past 3 years. And it’s a bit...there’s not much privacy, like I don’t ...I don’t have any sex, but I’ve got a lady friend there that I kiss, and she doesn’t mind kissing me and we just kiss and cuddle, you know ...not in my room. We’re not allowed in the rooms. I just kiss her out on the patio, where we sit.”

(Greg, 36 years old, shares room with two other men, no relationship for 2.5 years)

“Well I’ve learnt to live without a relationship. I suppose, um,... that if you’re given the opportunity to have sex with a female, that I mean, you obviously take it.”

(Gary, 29 years old, has his own room and has sex at least six times a year)

Another resident told how his occasional sexual experiences in the facility were never satisfactory because of the lack of privacy available to he and his partner.

Umm... We kissed for a little while and then... she wanted me to hurry up but I wanted to take my time... and we umm... it was sort of rushed sex, which I don’t like but err... I sort of think the sex that I had with the prostitute was nicer because we didn’t have to hurry, we had plenty of time, so \$500 and... and that lasted the whole night, so I had plenty of time. Whereas since then I’ve had to rush it.

(Michael, 25 years old, shares a room with one, no relationship for years and has casual sex about every month or two)

Another male told how he really wanted a single room for privacy, but that his access to it was limited.

I’ll be getting one of those rooms, single rooms. If I can get a single room, I’ll probably stick around for quite a while... They’re not there at the moment ‘cos well, I don’t really want to be nasty, but when one of the blokes die, I get the single room.

(Greg, 36 years old, shares room with two other men, no relationship for 2.5 years)

When questioned about whether having a private room would make a difference to his ability to bring home a sexual partner he replied, *It’s still gonna be the same. Yeah, still the same.*

The lack of privacy is often linked with the general culture of the facility environment, or to the state of mind or boredom of the other residents, and is not entirely dependent on the attitudes and practice of the owners.

Well the people that run the place, they think it’s fine. They think it’s good, er... my relationship with this lady. We complain about it, ‘cos people knock on the door at night, and some of them ask me for a cigarette or somethin’, and we can’t sort of have our privacy there, ‘cos the door gets knocked on at night. So it is a bit annoying, yeah.

(Hamish, 33 years old; in a relationship of 5 months duration, able to visit partner’s room)

Even on a basic level, sexual privacy was only available in very limited ways. One man shared a room with three other men. It was a fairly common occurrence for them to walk in on each other masturbating.

Yeah. I must admit we do spring each other... Well sometimes you can go into the showers and you know, wank off.

(Graham, 24 years old, shares room with three other males)

5.1.2 Group living

As well as lack of physical privacy, people also expressed some negativity about feeling watched all the time. Although they also participated in the gossip and chat, which comes from living with a lot of people, there was a sense that sometimes it is too much.

I'm in a boarding house...er... with lots of other people. You haven't got your freedom like you normally would have...living alone or anything like that, but you know... you keep to yourself, you don't bother anybody else, you do alright, I guess.

(Graham, 24 years old, never had a relationship)

I guess what I can see about the lives of our clients is that... they're grouped in accommodation settings where there's not a lot of individuality, the clients lose opportunity to be recognised as the individuals that they are, and I guess there's a sense of losing independence and motivation to do things for themselves.

(IDSC Worker)

Whilst workers thought that the group living was a negative experience for many of their clients they also said it suited some people. There were clear benefits to some people with mental illness who lived in group settings, even if it meant that they just had some company.

At the same time I think some of our clients really like the sort of lifestyle they get from a boarding house. It gives them freedom they can't experience in other places, it makes them feel part of a group, no matter how dysfunctional or functional that group is.

(Mental Health Worker)

However, to gain the full benefit, self-motivation and communication skills are definite advantage.

A: Yeah, it's better being in a room by myself where I can have conversations in the kitchen and lounge room when other people are there.

Q: Right. Yep. And how important is that do you think?

A: "Very important. Because um... if you haven't got conversations and ahh... rapport with people there, you're just left to yourself and ahh... and the things that happen to you that are very untoward and upset you. So you have to get out of yourself by having conversations with others there.

(John, 48 years old)

5.1.3 Rules about Sex

Ten out of the fourteen people interviewed thought that sex would not be allowed where they live. Few could recall this ever being explicitly stated but feared ejection from the residential facility if they had sex on the premises.

A: The rules are in that place you can't have it

Q: "mm What do you think about that?"

A: I think it stinks.....Its like, its like.....you bring a bottle of coke home and you can't drink it...you know what I mean.

(Greg, 36 years old)

Some other comments were –

There's just complete disapproval the whole time. They don't promote it, they denigrate it. They sort of try and push it the furthest away as possible, you know, sort of no mixed relations, kind of thing, you know, sort of no people after a certain hour...

... You couldn't bring visitors back um... to the place. Um... it was... if you did, you'd sort of more or less have to smuggle them in, so to speak. Um... and I mean half...it's not worth it in the long term, so you don't bother, you stay away from it.

(Gary, 29 years old, has his own room and has sex at least six times a year)

There's no sex at the boarding house. It's like, you know... the women are in different rooms, you know they're in different rooms to the blokes. So they're pretty strict, pretty strict

(Graham, 24 years old, shares a room with three other males, never had a relationship)

Well put it this way I don't know if they've got a rule about it but I swear that if you brought home a girl and started having sex with her in your bed and they caught ya, you'd be in trouble.

(Francis, 31 years old, never been in a relationship, no sex for many years)

You're not allowed to... If somebody comes in, they're going to say something to Christopher. Christopher will find out and then I get the boot or they do.

(Greg, 36 years old; no relationship for many years)

Another put the rules about sex in terms of the excitement and disruption that sex in the facility would cause the residents.

Ooh, nah, there'd be too many people chatter-bag... you know, too many people talking about it and they'll go to the boss, and then I'd be out of the hostel.

(Peter, 37 years old, no sex since he was in his early twenties)

The owners who were interviewed for this research did not ban sexual activity in their facilities and adopted a range of strategies to support safe and consenting sexual relationships. These included getting guest speakers in to talk about

sexual health and safe sex, giving out condoms and ensuring access to appropriate clinical services.

These owners did believe that sexual activity between residents was common and required careful management to ensure that sexual coercion was not taking place.

One owner commented -

Sometimes I do wonder why they have such strong sexual drive, I do. But then you and I and everyone else, our lives are filled with other things whereas their lives aren't filled with a lot of things.

It could be argued that owners and managers play a protective role as required under the *Supported Residential Facilities Act* and are trying to intervene to prevent sexual exploitation by predatory men. However, one male resident reported that it was not always approached in this way and instead intervention took place to stop any public expression of his consenting relationship.

It was actually said to me – I was walking down the road one day with Alexandra, holding hands, er... ‘We saw you down the street holding hands; some of the other residents might find that offensive.’ Well I said that I found that offensive because I’m still a human being, I’ve got feelings and if I was with this woman, I didn’t really see it was really any of his business. As far as I am concerned, I’m paying my rent, that should be the end of it...

(Ian, 42 years old)

Residents also described some owners as being supportive of them having sexual relationships.

Yes. Well the landlady said to me one day, you know, she said to me, ‘Look I have sex with my husband and I don’t see why, just because you’ve got a mental illness, you’re not allowed to have sex here’ and she said, ‘I think its fine, I think its natural and um...its healthy for the person’, and she wasn’t being um disgusting about it.

(Hamish, 33 years old, in a relationship of 5 months duration, able to visit partner’s room)

Others interpreted the silence by owners in relation to sexual activity as being tacit permission.

Well, by absence of any behaviour in respect to it. They don’t seem to do anything about it. Um... I mean if they ever talk about it, they say that’s your own private life.

(John, 48 years old; has sex about twice a year)

RECOMMENDATION 1

That guidelines and a resource kit on relationships and sexual activity be developed by the Supported Residential Facilities section of DHS and that these be distributed to all facilities and the information in them conveyed to all residential facility residents.

RECOMMENDATION 2

That the Supported Residential Facilities Training plan include sexual health and sexuality education.

5.2 The Impact of Illness & Medication on Sexual Functioning & Relationships

5.2.1 Masturbation

Most residents talked about the importance of masturbation as a sexual outlet. This was particularly true for the men. For some residents masturbation had assumed a high importance and was a major focus in their lives. This was easier for those who had their own rooms.

Q: Right, Okay, so if you were going to have sex it would need to be in a relationship, is that right?

*A: Yeah, In the meantime I just use Mrs Palmer and her five daughters.
(Graham, 24 years old, shares with three others, never had a relationship)*

Another man commented:

Q: How important is sex for you?

*A: Not at all. No I just...I just get a magazine now and masturbate every day. I almost try and... oh I wish I could kill my libido sometimes, you know.
(Francis, 31 years old, never been in a relationship, no sex for many years)*

Medication did interfere with sexual functioning and this was frustrating for some of the men. One man worked out which drug interfered with his sexual functioning and stopped taking it. He used to throw away these pills once they were given to him.

*Had a long break without... without... like I'd been on medication, and I couldn't ejaculate, and it frustrated me. So I started pocketing the ones that stopped me ejaculating, and I felt a lot better.
(Francis, 31 years old, never been in a relationship, no sex for many years)*

Another man prioritised the positive effect of the drug over the negative effects on his sexual performance.

*The tablets I take, Melleril, reduce my ability to ejaculate, so its a dry blow after efforts to masturbate, its not very good. I mentioned to the doctor that I couldn't ejaculate and he said 'oh', almost by the way... 'that's a result of taking Melleril'. He didn't tell me before that... Well Melleril helps me go to sleep at night and before I wasn't sleeping at all so I'm happy to forego the masturbation for sleep.
(John, 48 years old, no relationship for many years)*

RECOMMENDATION 3

That when psychiatrists and general practitioners are considering prescribing drugs that have a negative effect on sexual functioning, their possible effects be discussed with clients and alternatives found where possible.

5.2.2 Relationship to Their Own Bodies

In addition to the impact medication had on sexual functioning some people expressed feelings about their bodies which caused them distress. In particular one woman who had experienced past sexual abuse described her body as being unable to function sexually at all and this had led to her to have sex with someone as a way to test herself.

It was... see I'm impotent and um... I just wanted to see, you know, I'm missing a big part of my life, you know, my whole sexuality is... is gone and I couldn't ev...you know I still can't even achieve arousal, you know, and its like I just wanted to feel like a woman again. And I had this, you know...the first one... I chose for myself, but the second one he's pressuring and pressuring and it was like I wasn't going to do it, I had no intention and then I just, you know, I don't know why I did it, I just let myself, you know and it was the worst thing I ever did.

(Marie, 23 years old, no relationship for 1 year; had several sexual encounters in the last year)

Medication and a more sedentary lifestyle also meant that some people identified that they had put on weight and felt less attractive.

Its hard like I s'pose even like for people in boarding situation that when you don't have much self respect because you've lost even p'raps the things that I've lost, like through your family or friends or sort of everyone that's with you um...eating, like even with myself I'm putting on a lot of weight and starting to become a lot overweight sort of now. Its very hard to have the motivation to look good. If you look good, you do feel good... I mean there's truth in that. But when you're of limited income... and you can't afford to go out and have your hair done...

(Gary, 29 years old)

5.2.3 Establishing and Sustaining Relationships

Most people had some experience of relationships. Four people had been married or lived in defacto relationships where they had children. Some had never experienced a relationship which lasted more than a few months and two men had never had a relationship, although they had paid for sex with women. Some said they didn't want a relationship or else felt that they were not well enough to engage in a meaningful relationships and that this is something they just had to accept.

One man said –

I notice sometimes if you're deprived of something, you want it extremely badly, but the less you have of it, the less it becomes an issue to you. And I s'pose I'm in that category now. I um... I take it or leave it."

(Gary, 29 years old)

The lack of opportunities for relationships was a personal frustration for some people. One talked about the complete lack of experience of sexual relationships, casual or otherwise, among male residents he knew of. This came from a report of a rare experience of men sitting around talking honestly about their sex lives.

A: Well, I've had conversation at the house and we've um... some people that have sex, you know, our sexual lives and their sexual life comes up in conversation where we're just free-flogging the topics that we've shared in the past and that everyone shares.

Q: What are some of the stories you get to hear?

A: Mostly it's pretty sad, really, because most of them have had very few relationships... very few'd be long term, committed, with plenty of emotion to them. They hadn't had that, they've either had nothing or one night stand sort of thing. And I can think of one person there, he's hardly worked, he's 42 and he's never had a relationship, and that's very sad for him, he admits, and I can see this.

(John, 48 years old)

A few people strongly linked a sexual relationship with having children and felt that they shouldn't have sex because they were not in an emotional or financial position to have children.

Because if I had sex and had....there's child come by it, I'm gonna be more stressed out.

(Greg, 36 years old, no relationship for several years; has casual sex about twice a year)

There are many factors which make establishing and maintaining a relationship very difficult. Having a mental illness is one major barrier.

This relationship didn't last too long 'cos I couldn't understand the way her illness was going. She was manic depressive. And she couldn't understand the way I was going and talking and stuff like that. So ohh, we just split up. Its very hard to have a relationship, its very hard for a person who's got illness 'cos if they both clash a different way then it could be, you know that's it.

(Greg, 36 years old, no relationship for several years; has casual sex about twice a year)

One young man talked about a previous sexual relationship with an older woman, who also had a mental illness and an apparent lack of emotional coping mechanisms. An apparent power imbalance due to age difference as well their respective mental illnesses appeared to have triggered verbal abuse a violent argument, resulting in his injury. on his part is not out of the question.

Q: And why did she hit you across the head with a baseball bat?

A: Oh, because we had an argument afterwards, about her, because she keeps on whinging and complaining about things. But I've split up from her, and she got very angry and violent about it. We'd had sex just before that.

(Sam, 19 years old)

All the people interviewed socialised with people who either also live in the facilities or attend the drop in centres run by the mental health system. Everyone is on a very low income and this further limits any opportunity to meet people who are outside of this system. The effect is to create a sub-culture of people who move between facilities and seek potential partners from within that population.

Workers and residents both commented on the lack of social opportunities for people who live in facilities. Many would like to meet people outside the mental health system but also fear rejection by them. Most of the people interviewed expressed a strong desire for an intimate relationship with someone and this was associated with moving towards a more “normal” life.

One resident commented –

A: Well I think that romantic, romantic AND sexual relationship is quite important and they need it, they need to go to where they can meet people, where its affordable and within their budget...where they can meet people of the opposite sex or same sex or whatever. And um they can develop a relationship with someone like that. But there's nowhere to go to, they haven't got the clothes, the money to buy clothes to go to places where people are working go to.

Q: So it's not...is it purely the money?

A: Partly the money. Secondly it's the fact that... aaah... having mental problems brings social stigma. Um ... and thirdly the lack of opportunity means they don't get to practice social skills they could have practiced before.

(John, 48 years old)

RECOMMENDATION 4

That the disability and mental health system support residential facility residents to attend regular social programs which enable clients to gather in safe informal surroundings during the evening.

5.3 Support and Education on Sexuality and Sexual Health Issues

5.3.1 Gender Issues

Men interviewed for this research commented that owners gave serious attention to keeping women and men separate, particularly in the sleeping arrangements. Women appear to be constructed as the “sexual element” in a residential facility environment and questions about sex in a facility were often answered in relation to whether there were many women in the facility. Facilities are overwhelmingly a male environment and therefore the presence of a few women is noticeable. Women’s sexuality can be seen as a problem, because it is seen as destabilising for men and for the fact that they may get pregnant which would be an unwanted consequence for the residential facility owners.

The owner says “Don’t go to her, she’s an evil woman, or something like that, so we don’t go to her.

(Greg, 36 years old, no relationship for several years, but has casual sex about twice a year)

One owner commented that having women in the residential facility seems to motivate the men to dress more neatly and to cover their bodies carefully before moving from bedroom to shower.

I would say most of the chaps here respect all of them with the same respect. Actually they respect them very, very well. I think at this stage, there’s no sexual interaction between male and female clients.

There is evidence that sexual harassment of women is a common occurrence. One woman commented

The old men there, they’ll hit onto anyone, anything. You know... anything.

She also described the following experience;

The last boyfriend I had a couple of weeks ago when I was at the hostel, you know he’s pressuring me, he’s all over me, he’s grabbing my breast, taking them out in front of everyone and you know... it’s a horrible thing, it’s a horrible thing.

(Marie, 23 years old, no relationship for 1 year; had several sexual encounters in the last year)

Although the number of women interviewed for the research was small it should be noted that all had experienced considerable sexual violence in their lives which continued to cause them distress. These women were now living in residential facility accommodation where the majority of residents are men. All the women talked about how difficult it was for them with the constant pressure from men for sexual favours. One woman had a history of selling sexual favours although was not currently doing this.

Management of facilities often look out for women because of this pressure and yet this also served to reinforce that the problem was centred around the women rather than the behaviour of the men.

RECOMMENDATION 5

That an investigation take place about the viability of an all female residential facility in the western region of Adelaide.

RECOMMENDATION 6

That any guidelines developed (see Recommendation 1) also address harassment (sexual, racial, religious, sexuality) of residents by other residents and staff.

5.3.2 Same Sex Relationships

The tendency to depict “woman” as “sex” reflects a denial of homosexual behaviour in the residential facility environment and reinforces a construction of sexual activity as only penis-vagina intercourse. Responses to questions about sexual activity focussed primarily on experiences of intercourse although further questioning sometimes revealed a greater range of sexual activity. Three of the men talked about sexual experiences with men and transgendered women although all identified as heterosexual.

One man who had been sexually interested in men had been harassed and threatened with bashing by a man with whom he shared a room.

He just used to say to me ‘If you bring home any of your gay faggots, I’ll bash their friggin head in’

Far from being defended by the manager of the residence, this attitude was backed up by him.

At my last hostel the... owner didn’t mind me bringing home a girl but if I brought home a guy, they’d... he was even going to bash me so,... but that’s another reason why I wanted to leave.

(Michael, 25 years old)

There is evidence that sexual touching does take place between some men in the facilities but that it is very covert and not considered to be “sex” by owners or the residents. One owner who had worked in different facilities did believe sexual activity between men is common.

Q: So what were some of the things that you encountered? Can you describe...?

A: Oh everything from er... physical intercourse to um...oral sex to er... people just stripping, just mucking around, “general boy stuff” they were saying as a comment.

When asked how much he was aware of same-sex sexual interaction in his residence, given the general ban on opposite-sex sexual interaction, one resident commented:

Well I don’t know if they’re having intercourse in there or what they’re doing in there, but it’s just not normal for two blokes to be having a shower at 2 o’clock in the morning... Well, there’s some sort of homosexual activity

going on. I'm not a pervert. I won't go looking through the keyhole. If there was a man and a woman in the shower, I might have a look, you know cause I'm a bit of a voyeur.

(Ian, 42 years old, in a steady heterosexual relationship of several months duration)

Another resident commented

Well, it's... not visible. I mean it becomes... a secret society. You'd try, I presume, you'd try and hide it, you wouldn't want anyone to know. Um... you wouldn't tell anyone about it. Um... especially if you... if it was a guy that didn't consider himself, I s'pose homosexual, if he had an encounter with a bloke, I mean he wouldn't go telling the next fellow about it, he'd just keep it, it'd be... you'd want it to be very discrete, I'd imagine.

(Gary, 29 years old, identifies as *straight*)

Some workers and a female residents commented that they know of some lesbians who live in residential facilities. There were no references to sexual activity between women.

RECOMMENDATION 7

That education or support programs for residents, owners and staff of facilities (see recommendation 2) also address issues of homophobia and same sex relationships.

5.3.3 Sex Workers

The use of sex workers was cited by five of the men. For some men this had been their only sexual interaction with a woman and they saved up to use a sex worker once a year.

When asked if he had had any sexual relationships, one man replied:

Not one. Not one. All I've done... all I've done is gone to a brothel. And I've had about 40 brothel visits...

(Francis, 32 years old, no sexual activity with another person for several years)

The men said that they always used condoms with sex workers because the workers insisted on it. The use of sex workers is evidence that sexual interaction is important for many men particularly given the barriers to sex they experience in their lives. One of the men chose to go to sex workers, as they would let him perform certain sexual acts that other women wouldn't.

In between relationships, I regularly use the service of escort agencies, and I've got one prostitute that I've used in sort of the last years, and I only use that one particular prostitute because she lets me do... er what I want to do, without sort of flinching. A lot of prostitutes will only let you do certain things to 'em and my attitude is that... because I'm paying the money, I want certain services, and she provides those services.

(Ian, 42 years old, currently in a relationship)

One woman had done sex work while living in boarding houses and sometimes gave money from this to men who also lived in them. Her sex work was related to her drug use and she was actively trying to move away from this lifestyle with the support from a caseworker.

Discussing sex work is problematic for many workers. Many clients have their money managed by public trustee, so expenditure is scrutinized to some extent. Workers also feel reluctant to refer a client to a sex worker, as prostitution is illegal in South Australia, and yet know that some of the clients do use sex workers and that for some it is their only sexual outlet. This can also be beneficial as it is a practical reinforcement of safe sexual practices.

RECOMMENDATION 8

That the legal situation of workers who provide information about sex workers to clients be clarified.

5.3.4 Knowledge and Awareness of Sexual Health Issues and Services

All of the people interviewed had regular contact with the health system because of their mental illness or disability. Some of the facilities have a General Practitioner who visits each week and residents can raise any questions with the GP. However many people felt it would be too embarrassing to talk about anything sexual with the GP.

One man described it this way –

Q: What's the fear, what's the fear about do you think?

A: I suppose what they think of you... That'd be it in a nutshell – 'I saw this dirty bastard coming in, he's got warts all over his dick and I wonder who he's been rooting, a dog or something'; so that's how you feel...

(Gary, 29 years old, has sex between 6 and 12 times a year, often unprotected; tested for STI's once or twice before in his life)

Overall people showed very poor knowledge of sexually transmitted infections. Most people could only name a few diseases and were unsure of how you would know if you had a disease. Many thought there would be spots, rashes and pus. Some were judgmental of anyone who might have a STI.

Oh vaginal disease, you know VD... you go out with dirty women, you're going to get it, you know,...you're going to catch it.

(Peter, 37 years old; tested for STI's once or twice before in his life)

Er well... if I contracted a sexual disease, I wouldn't try passing it on. I wouldn't... and I wouldn't, I don't want AIDS either – I'm not going to fuck no sheila in the ass.

(Francis, 32 years old, never had an STI test, only sex has been with sex workers)

The above quote also illustrates misinformation about how HIV is transmitted as it indicates a belief that it is transmitted *only* through anal intercourse.

Some people had made use of community health clinics and one person named Clinic 275 as a place to go. The women had been supported by case workers to seek specialist assistance from women doctors in the western region. All of the women were up to date with their pap smears and were using contraception. None of the men had ever heard of testicular examination.

One woman was taking the pill just in case sex was forced on her, which further reinforces the perceived vulnerability of women in the facilities.

Q: And what about contraception. What sort of contraception have you used?

A: I'm just using the pill at the moment... Just in case I get jumped on or something...when walking down the street or something... It's not just your boyfriend, it could be some other guy... you know fights and stuff.

Q: Have you used any other forms of contraception?

A: No. Is there any others?

(Deborah, 34 years old, has not had sex for a year; screened for STI's once or twice in her life)

Men's knowledge of contraception was very poor and most identified that they left this to the woman. Some did express concern about making a woman pregnant and had been in this position.

Most people had been tested for HIV and Hepatitis as part of their involvement with the psychiatric system or criminal justice system in some cases. One person identified as Hepatitis C positive.

Overall knowledge and practice of safe sex was very poor although some people had reasonable knowledge and had received some special education. Most people defined safe sex as condom use but reported rarely using condoms when they had intercourse. Most said that they didn't use condoms because they didn't have them at the time sex took place. For example some people reported having sex while they were inpatient residents in hospitals and therefore could not access condoms.

Q: What do you know about the term safe sex?

A: Safe sex. That means... does that mean using a condom? Is that what you mean? Safe sex, using a condom, yeah I suppose that would be safe sex.

Q: Does it have any other meaning?

A: I never had... all the sex I had was... only once I had sex with a condom, that was with a prostitute. Every other girls... the other 13 or 14 women that I've made love to, always never had a condom.

(Peter, 37 years old, no sex and no sexual relationship for several years, tested for STI's once or twice ever)

Most residents also commented that they thought that people in the facilities didn't know much about safe sex or sexual health and never talked about these issues in the facilities or with their workers. Most relied on the sex education they had got at school for their basic knowledge about sex and safe sex, although

the men who had been with sex workers were experienced with using condoms. Women said they found it hard to get men to use condoms.

Q: So you've been on contraception all the time. Do you ever use condoms when you are having sex?

A: Sometimes. Yeah sometimes...not always

Q: How would it come about that you would use them, would you have condoms or would the guy have condoms?

A: Um... well they'd buy 'em.

Q: Yeah, So what do you think about using condoms?

A: Well most men don't seem to like 'em.

(Josie, 28 years old, has sex about every couple of months; gets tested for STI's every year)

Owners and workers expressed concern about the level of unsafe sex and did take some steps to address this. The owners gave condoms to residents when they felt they needed them. Condoms were also made available at a mental health drop in service. Owners also tried to work with case workers on education for a resident if they thought they were at risk.

I would like everybody to use them but they won't always. I have social workers too to teach those who I feel that don't even know how to use the... how to use them, particularly the women.

I would have to say most... most clients... unfortunately, even with most clients, practising safe sex isn't top of priorities, um...it's er. 'if they're there fine, I'll use them but if not, what the heck!'. I find that very, very common, but you know you've certainly got to try and prevent it as much as possible.

RECOMMENDATION 9

That comprehensive sexual health and life skills education be implemented with residents of facilities and with those in more institutionalised settings.

RECOMMENDATION 10

That condoms and lubricant be made available in all facilities, drop ins and inpatient facilities.

5.3.5 The Meanings of Relationships and Sex

The actual definition of a relationship varied between the people interviewed. Sex varied in importance for different individuals too.

One man talked about having a current “*non-sexual relationship*” with a woman, and yet upon further questioning, it became obvious that non-penetrative sexual activity was happening. He did not see what was occurring as “real” sex, even though it was a highly valued interaction and did appear to symbolise the strength and trust in their relationship.

Another young man (*Sam, 19 years old*) had an important “friendly relationship” with a woman of about his own age whom he had met through a community mental health service, but with whom there was no sexual play at all. They were just good friends who went out roaming around in the parklands having adventures together and smoking the occasional “joints of leaf”. “We had the best time down there”, he said about one incident.

Most of the women and men interviewed believed that a relationship was based more on the qualities of emotion, although the men tended to place more importance on actually getting sex, than the women. A desire for opportunities to meet new people and to get emotionally close to another person was expressed by all except one of the people interviewed.

The concept of courtship and building something together in the long term was also valued. When asked what a long-term relationship was, one man replied,

Oh, a few years, and you get married you know. That's a proper relationship, when you know your partner properly, you know, you marry her. That's the only way you're gonna be happy with a woman. You can't go out with a woman once a week, and say you're happy, just not on. You want... I want love and affection every day, you know.

(Peter, 37 years old)

Another man had more recent direct experience and did not feel that his long-term relationships were adequate.

My long-term relationships weren't very long-term. My first defacto lasted approximately 2½ years, my first marriage lasted 4 years, my second marriage lasted 5 years.

(Ian, 42 years old)

Several people represented their vision of relationships in very idealistic, perhaps unrealistic ways, usually outside the context of the mental health and residential facility systems. The general lack of support for relationships within the residential facilities seems to be a contributing factor. Being in a steady heterosexual relationship was given a status beyond the direct sexual and emotional benefits as it symbolises stability, normality and a potential path out of the system and the negative effects of mental illness.

One night stands' no good. I want a steady girlfriend, but they're hard to find, you know, because I'm getting older. Women, when they turn 30, they're thinking about marriage, you know. There're not many single women out there 35-45, you know. There is, but they're unmarried mothers, you know, they've got children. I don't want anything like that. I don't want... I want me own life, family.

(Peter, 37 years old, no relationship or sexual partners for many years)

5.3.6 Support for Healthy Sexual Relationships

As discussed, people who live in facilities talk rarely with others about their sexual lives and desires. Workers identified that unless a sexual issue was raised by the client they rarely initiated discussion about these issues. Workers in the disability sector said they used a comprehensive assessment tool but it didn't include sexual health issues.

I don't know that its part of our standard assessments... the real issues we haven't got there!... Its part of the questions that we ask about people's physical health needs. ie "Do you need a walking frame?"

One owner said he invited a guest speaker from a health agency into his facility to talk generally about sexual health issues. This enabled the issues to be raised in a safe way and afterwards people could go up and ask questions without fear of others finding out information about them.

RECOMMENDATION 11

That the initial assessment process undertaken by both mental health and disability services involve an assessment of the sexual health needs of their clients. That there be a proforma developed to assist this process. That training be provided for staff to develop skills, knowledge and confidence in carrying out this part of their work.

RECOMMENDATION 12

That managers of facilities be encouraged to arrange regular guest speakers for the benefit of their residents. These speakers could cover a range of health and lifestyle issues.

6.0 Conclusion

One of the aims of the introduction of the *Supported Residential Facilities Act* was to improve the quality of life for residents of the hostels. It is interesting to note that 13 out of the 14 people interviewed for the project lived in licensed facilities and yet the experiences they detail reveal that there are still considerable barriers to achieving a better quality of life.

Using the WHO definition of sexual health outlined in the executive summary; (capacity to enjoy and control sexual behaviour, freedom from fear, shame guilt and false belief, freedoms from organic disorders and diseases) it is clear that many of the residents in facilities are experiencing poor sexual health. It is also evident that the principles of the *Act* are not being consistently interpreted as extending to the creation of an environment which supports individuals to have safe and private sexual relationships. The outcome of this is that when sexual activity does take place it is quick, furtive and usually unprotected, which places people at great risk of sexually transmitted infections and unplanned pregnancy.

But it is not just physical infections and pregnancy, which can result from lack of attention to the sexuality of residents of the facilities. At an emotional level, people who have a long history of mental illness and who fail to receive education and information which may support them to have positive relationships, can experience an even greater sense of failure in their lives. While not all of the people interviewed for the project wanted a relationship, almost all did express this desire and yet felt unable to make this happen.

This research also highlighted many of the negative effects of grouped living situations which were well documented in the *National Inquiry into the Human Rights of People with Mental Illness* (Burdekin 1994). This inquiry found that ;

Living with so little personal space makes many residents feel aggressively territorial; the lack of privacy also produced sexual frustration. These factors contribute to erosion of self- esteem and loss of dignity, and result in a level of tension between residents which sometimes erupts into conflict. This atmosphere would be difficult for anyone to live in; for someone with a mental illness it is especially destructive (Burdekin 1994:389)

Many recommendations have been made in this report and it will require commitment and resources from owners of facilities, the disability and mental health sectors and other government and non government agencies to implement even some of these recommendations. Sexuality is often an overlooked issue. It is considered too private to talk about or less important than other issues such as the management of the mental illness or income or employment. This research has shown however that sexual health is a major determinant of a person's overall health and well being, and that to ignore this dimension of an individual's humanity is to severely limit people's potential to live emotionally and sexually, safe and satisfying lives.

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Appendix 1 Questions for Resident Interviews

Possible Themes:

- * Privacy * Desire for Relationships/Intimacy*
- * Lack of Desirability * Sexual Harassment *
- *Autonomy * Economics *
- *Importance given to sex and sexuality*

General Questions

1. tell me about your life?
2. where do you live - describe it?
3. how long have you lived there?
4. do you share a room?
5. what do you do during the day and at night?
6. are you in a relationship at the moment?
 - if so, who with and for how long?
 - if not, when was the last time and for how long?

I'd like you to tell me about your sexual history:

1. do you ever get to talk about sex and who would you talk about it with?
2. how did you become aware that people had sex?
3. what did you think about it?
4. where did you get your sex education, and how do you think about it now?
5. when did you become aware of masturbation?
6. do you think it is okay for people to masturbate?
7. how old were you when you first had sex, and who was it with?
8. how important is sex for you?
9. have you ever had sex when you didn't really want to?
10. how many sexual partners have you had?
11. were they male or female?
12. how many of them have been long term relationships?
13. what is a long term relationship?
14. what sort of sex do you like to have, where and with whom?
15. tell me about the last time you had sex?
16. where, who with, any drug or alcohol, consent, safety, condoms?

Knowledge:

1. what do you know about safe sex?
2. who do you think needs to have safe sex?
3. what can happen if you don't have safe sex?
4. what diseases do you know about?
5. how would a person know if they had a sexually transmitted disease?
6. what could they do, where would they go?
7. what do you know about contraception?
8. what contraception have you used, or are you using?

Health History:

1. have you ever:
 - had a sexually transmitted infection?
 - had a test for an infection such as HIV or Hepatitis?
 - been pregnant?
 - had an abortion?
 - had a miscarriage?
 - given birth to a child?
 - had a breast or testicular examination?
 - had a pap smear?
2. when was the last time you went to doctor about a sexual health problem?
3. how was it visiting the doctor about that?
4. where did you go to see the doctor?

Attitudes:

1. are there any sexual relationships which you think are wrong? e.g. same sex relationships, outside of marriage, young and old, same family, non-consent?
2. who's responsibility is it to use contraception, condoms etc.?
3. Is it ever all right to force another person to have sex?
4. where you live, do people have sex?
5. tell me how you know this and how it happens
6. how much do you think the other people you live with know?
7. should they know more?
8. what messages do you get about sex from the people that run the hostel/boarding house?

Final Questions:

1. If there was one thing about your life that you would change what would it be?
2. Is there anything else you would like to tell me?

Appendix 2 Protocol for Intervention

The project officer and any other person involved in the research project as an interviewer are not operating as service providers, but as researchers.

In this context, and in the context of working with people with disabilities, it is vital that the boundaries are defined and made clear at the beginning.

Where a discussion with a participant makes it evident that they would benefit from or be interested in being referred to an agency, then this referral can take place. If the participant agrees, the referral will also be taken through the participant's key worker, if they have one.

Where a referral is made to the researchers' own work base (SHine SA), then service delivery will be carried out by individuals other than the researchers.

If a research participant initiates contact with SHine SA themselves as a client, then the usual method of responding to and meeting their needs will be followed.

In the case of a disclosure of history of abuse and where this abuse is likely to continue, the participant will be referred to a SHine SA Sexual Health Counsellor. If it appears that the participant in the research is currently or has recently been abusing a minor then a mandatory report will be made to the Family and Youth Services.

In the case of an emergency, the researcher will lend personal assistance as required, directly call the emergency services on 000 and follow up with a phone call to the participants' home base. The researchers will also follow up with a call and an incident report to the appropriate service agency; i.e. IDSC or Western Adelaide Mental Health Service.

Appendix 3 Demographic Data Form

BH.....

Interviewer: 01/02
/

Date: /

Sex:

- Female
- Male
- Other

Age:

- 17-25
- 26-30
- 31-35
- 36-40
- 41-45
- over 45

Disability:

- Intellectual
.....
- Psychiatric
.....
- Dual Diagnosis
.....
- Don't Know
- Other
.....

Educational Background:

- Primary School
- Secondary School
- Apprenticeship
- College/University

Children:

- 0
- 1
- 2
- 3
- more than 3

Accommodation arrangements:

- Hostel
- Boarding House
- SRF
- Don't know
- Other

Sleeping Arrangements:

- Own Room,
- share with one
- share with more than one
- don't know
- other

Relationship Status:

- Never been in a relationship
- Haven't been in a relationship for..... years
- Currently in a relationship of

Sexual Partners :

- Female Only
- Female Mostly, Male occasionally
- Equal male and female
- Male Mostly, Female Occasionally
- Male Only
- Casual partners
- Relationship
- None

Sexuality Identity:

- Heterosexual
- Bisexual
- Lesbian
- Gay
- Don't Know
- None
- Other.....

Frequency of Sexual Activity:

- Never
- Not in last two years
- Once or twice a year
- Every month or two
- Every week
- Every day

Frequency of screening for sexually transmitted infections:

- Never
- once or twice,
- occasionally
- yearly
- quarterly

Current income:

- no income
- sickness benefits
- disability pension
- student allowance
- employed part-time
- employed full-time
- don't know
- other

Appendix 4 Questions for Service Provider Focus-Groups

1. What do you think life is like for your clients who live in boarding houses?
2. What is your perception of their sex lives?
3. How important is sex for them?
4. What do you think is the most important sexual health issue for them?
5. How do you know this?
6. Do you have any hopes and fears about sex and your clients/residents?
7. What perceptions do you have about sexual assault and sexual exploitation in your client group?
8. Where do you think people in this region would access sexual health services?
9. Do they access them?
10. What questions would you most like answers for, from the research?

Appendix 5 Consent Form



SHineSA COPY BH.....

I give my consent to be interviewed in the Boarding House Research Project which is being conducted by SHine SA.

By consenting to be interviewed, I understand that, that I will:

- be asked questions about my sexual health and private sexual life
- be recorded on tape and that this tape will be transcribed
- be able to stop the interview at any time
- be paid \$20 in cash at the end of the interview

I also understand that I will not be identified in the final report that is written after the project is complete. I understand that the tapes and the transcription of my interview will be kept secure in a locked cabinet and destroyed after the project is complete. My personal details and those of other people will not appear in the report.

I understand that if I would like to make any complaint about the project to someone who is not directly involved in it, then I can contact:

*Paul Miller
 Executive Officer
 Ethics of Human Research Committee
 North-Western Adelaide Health Service
 Telephone: 8222 6841*

Signature: Date:

✂-----



INTERVIEWEE'S COPY

I give my consent to be interviewed in the Boarding House Research Project which is being conducted by SHine SA.

By consenting to be interviewed, I understand that, that I will:

- be asked questions about my sexual health and private sexual life
- be recorded on tape and that this tape will be transcribed
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*Paul Miller
 Executive Officer
 Ethics of Human Research Committee
 North-Western Adelaide Health Service
 Telephone: 8222 6841*

Signature: Date:

Appendix 6 Flier

Do you live in a hostel or boarding house?

How would you like to get your voice heard about sexual health?

How would you like to talk about:

- your sexual experiences?
- your relationships?
- your hopes and dreams about these things?

What will happen to the information?

You will be interviewed for 1¹/₂ hours on tape. A report will be written which draws together all the stories. No one's story will be recognized. The information you provide will be confidential.

Why is this being done?

To get your voice heard about sexual health.
To plan better sexual health services.

Who is doing this?

SHine SA. We used to be called Family Planning SA. We provide sexual health services to all people in the Western Region.

When does this happen?

As soon as you want. Please call Ralph or Sally on 8431 5177 or get some help from a worker to arrange a time to meet and a time for the interview.

Equal Opportunity:

It doesn't matter if you are straight, lesbian, bisexual or gay, man or woman. Your story will be listened to. You will only be interviewed once.

Payment:

You will get paid \$20 in cash after the interview.