Anti-libidinal medication and people with disabilities –

long-term follow-up of outcomes following third party consent to medication for problematic sexual behaviour

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Chapter 1 - Introduction

Aim of the project

The aim of this project was to assess long-term outcomes for and characteristics of individuals with disabilities who had been prescribed anti-libidinal (sex drive reducing) medication for problematic sexual behaviour. In some cases, the New South Wales Guardianship Tribunal had conducted a hearing to consider third party consent to anti-libidinal medication, where the participant was incapable of giving consent himself or herself. The participants' sexual behaviour in some instances resulted in criminal charges against the individual, whilst in other cases, the behaviour placed the person at risk of being charged, or may have created other problems in their lives, such as jeopardising their accommodation. Attitudes, health, life history, life style, and behavioural outcomes for the individuals were assessed. Two comparison groups were used - individuals with disabilities who were not taking anti-libidinal medication, and people with disabilities who had been charged with non-sexual offences directed against other people, such as assault (people with intellectual disabilities who had been charged with offences that were not directed against another person, such as drug offences or shop-stealing, were not included in the comparison group).

Disabilities

People with various types of disabilities, including intellectual disabilities or other developmental disabilities, acquired brain injury, degenerative diseases of the brain, and dementia, may display problematic sexual behaviours, which can have serious consequences in their lives, as noted above. Difficulties may arise in relation to their treatment, especially when the individuals lack insight into their own behaviour, and may not be able to comprehend the nature and effect of any proposed treatments or therapies.

Some of the participants in this study were diagnosed as having an intellectual disability. Intellectual disability has been defined by the American Association on Mental Retardation (AAMR, 1992, p 1) as follows:

> ``*Mental retardation* [known in Australia as intellectual disability] refers to substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. Mental retardation manifests before age 18."

For practical diagnostic purposes, subaverage limitation in intellectual functioning is defined operationally as an Intelligence Quotient (IQ) or Standard Score (SS) of 70-75 or below, derived from performance on appropriate individual psychometric assessment instruments. Under no circumstances should a group test of intelligence be the sole determinant of IQ for a diagnosis of intellectual disability, according to the AAMR (p 25). The following four assumptions are essential to the application of this definition (AAMR, pp 6-7):

(1) Valid assessment considers cultural and linguistic diversity as well as differences in communication and behavioural factors.

(2) Limitations in adaptive skills occur within the context of community environments typical of the individual's age peers and are indexed to the person's individualised needs for support.

(3) Specific adaptive limitations often coexist with strengths in other adaptive skills or other personality capabilities, so that an individual may have abilities in relation to social skills, for example, while showing serious deficits in communication skills.

(4) With appropriate supports over a sustained period, the life functioning of the person with an intellectual disability will generally improve, and the person may become more independent, productive, and integrated into the community.

Under this new classification system, the terms ``mildly'', ``moderately'', ``severely'' or ``profoundly'' intellectually disabled are replaced with description of the level of support the person needs—intermittent, limited, extensive, or pervasive. The classifications, *mild, moderate, severe and profound*, are nevertheless still widely used in Australia and elsewhere, as described in Chapter 3 - Results.

Third party consent and the *Guardianship Act* 1987 (NSW)

This study included some participants with disabilities who displayed problematic sexual behaviours and who had been referred to the NSW Guardianship Tribunal for consideration of third party consent to prescription of anti-libidinal medication, because the person was thought to be incapable of consenting on their own behalf. In New South Wales, Australia, in the case of a person with a disability who demonstrates problematic sexual behaviours for which they may need treatment, and who may not be able to give consent to medication or some other forms of treatment, a referral is made to the NSW Guardianship Tribunal, under the provisions of the *Guardianship Act* 1987 (NSW) and *Guardianship Regulation* 2000. The R*egulation* states at section 7(b) that for the purposes of section 45 (3) (b) of the Act, the term “prescribed special treatment” includes any treatment that involves the use of androgen reducing medication for the purpose of behavioural control. The Tribunal considers an application for consent to special medical treatment for anti-libidinal and some other types of medication, and sometimes for behavioural interventions or other treatments for problematic sexual behaviours (see the *Act* for further details). Part 5 of the *Act* is relevant to medical and dental treatment, the objects of this Part being to ensure that people are not deprived of necessary medical or dental treatment merely because they lack the capacity to consent to the carrying out of such treatment, and to ensure that any medical or dental treatment that is carried out on such people is carried out for the purpose of promoting and maintaining their health and well-being. A person is incapable of giving consent to the carrying out of medical or dental treatment if the person is (a) incapable of understanding the general nature and effect of the proposed treatment, or (b) is incapable of indicating whether or not he or she consents or does not consent to the treatment being carried out. In considering an application the Tribunal shall have regard to the views of the patient, the person who is

proposing that the medical or dental treatment be carried out on this patient, and any persons responsible for the patient. In the case of "special treatment", which includes androgen reducing medication for the purpose of behavioural control, the Tribunal may give consent to the carrying out of the treatment if it is satisfied that (a) the treatment is the only or most appropriate way of treating the patient and is manifestly in the best interests of the patient, and (b) that in so far as the National Health and Medical Research Council has prescribed guidelines that are relevant to the carrying out of that treatment, those guidelines have been or will be complied with as regards the patient.

The ethical issues surrounding third party consent to controversial treatments for problematic sexual behaviour (PSB) are complex. One researcher, commenting on the fact that four states in the United States of America have passed laws requiring anti-libidinal medication as a condition of parole, states that "such laws are morally repugnant violations of offenders' constitutional rights to privacy, as well as physicians' ethics, because, in effect, they permit nonphysicians to prescribe medication for medically inappropriate purposes" (Miller, 1998). Whilst **mandated** use of anti-libidinal medication for sex offenders is not an issue in Australia, the general issues of prescription of medication for non-medical conditions, and potentially medically inappropriate purposes, are still relevant. These issues are of particular significance when the individual cannot consent on their own behalf to medication that may lead to behavioural change. The Guardianship Tribunal relies upon information from specialist medical practitioners, and usually one member of the Tribunal is medically qualified when such cases are under consideration. Nevertheless, non-physicians are involved in the decision-making, and the decision-making process itself is reliant upon information presented to the Tribunal. With these issues in mind, therefore, information about the implications of anti-libidinal medication, and the background characteristics of individuals with a disability and PSB who are considered for anti-libidinal medication, will greatly assist the NSW Guardianship tribunal and other bodies charged with making decisions about the most appropriate way of treating a patient.

Determining the person's capacity to consent can be a vexed question. In one research study, six independent estimates of the ability of people with intellectual disabilities to consent to medical and dental treatment were compared with assessments by the South Australian Guardianship Board (Tustin and Bond, 1991). The measures included a Consent Questionnaire (based on a definition of ability to give valid consent prepared by the Board), a biographical information checklist, opinions of residential managers, medical and dental officers ratings, adaptive functioning skills, and living situation. The best measure in this context was the Consent Questionnaire, which is based on a legal definition of informed consent. This finding indicates that the specific memory and judgement skills required to give informed consent may not be able to be evaluated effectively through environmental and observer avenues.

Legal requirements for obtaining third party consent and/or informed consent on the part of the client are not always observed, however. An Australian study of fertility control in young men who have an intellectual disability (Carlson, Taylor and Wilson, 2000) refers to reports of Androcur being prescribed by general practitioners, apparently without informed and legal consent. Reports were also received about surgical sterilisations being performed without informed consent or valid third party consent.

Defining problematic sexual behaviour (PSB)

The term "problematic sexual behaviour" (PSB) is used throughout this report because the sexual behaviour of the individual causes problems for them and others in their environment. The term "challenging behaviour" is not used; this term has been often used to describe unacceptable or difficult behaviours on the part of people with disabilities, but it is euphemistic and vague, and not well understood by those outside the field of intellectual disability. Furthermore, this term begs the question of who is challenged by the behaviour, the individual or those around him or her. "Sexually deviant" behaviour is not used because the term is judgmental; the behaviour may not be deviant, but could simply be normal or non-deviant behaviour in an unacceptable environment. For example, masturbation is not deviant sexual behaviour, but if performed in a public place by an individual with dementia, it becomes problematic. The terms "sex offences" and "sex offenders" are not used to describe all participants because some of the individuals with problematic sexual behaviour may not have been charged and may be unlikely to be charged, and therefore are not "offenders". (Police, professional staff caring for the individual, prosecutors, and friends or family members can all be involved in a decision not to charge an individual. Reasons for not charging the individual include the fact that his or her behaviour may not be occurring in a public place, but rather in a private space including a nursing home, group home or their family home; furthermore, the behaviour may not have a victim (as in the situation of public masturbation), or the behaviour may consist of minor nuisance acts. In addition, a decision not to proceed to charge the individual with an offence may be made because the individual performing the behaviour is likely to be found unfit to be tried in a court, or it could be foreseen that the charge would be dismissed because of their mental condition.) The terms "unacceptable sexual behaviour" and "anti-social sexual behaviour" are eschewed owing to the value judgments inherent in these phrases. Psychiatric terminology, such as "paraphilia" and "sexual disorder", is avoided because few of the participants have been diagnosed with any of these psychiatric conditions. Where the report refers to specifically to any of these categories, such as sex offenders or psychiatric disorders, for example, the term will be used in that limited context.

Problematic sexual behaviours and people with disabilities

Sex offenders

It is commonly assumed that sex offenders are mentally disordered, dangerous, and specialists in sex crimes, rather than generalist offenders involved in other criminal activities. However, Simon (2000) found that sex offenders and other violent offenders had extensive criminal involvement in other, non-sexual areas, the exception being child molesters who tended to specialise in sex offences and were less involved in other forms of criminality. Recidivism by sex offenders is a major concern, and probably under-reported because sex offenders tend not to be charged with all the offences they have actually committed (Ryan and Lane, 1997). Sex offenders who offend repeatedly are likely to commit both sexual and violent offences, reinforcing the evidence that suggests they do not commit only sex offences (Blackburn, 1993).

General overviews of sexual offending, characteristics of offenders, and the range and effectiveness of possible treatments and interventions can be found elsewhere (Grubin, Gudjonsson, Gunn and West, 1993; Blackburn, 1993).

People with intellectual disabilities and PSB

Methodological issues render it difficult to determine the prevalence of PSB amongst people with intellectual and other disabilities (Lindsay, 2002). In institutionalised or group home populations, PSB may not be reported or recorded in any valid or consistent way, and the individual may not be charged with an offence even when the PSB is serious. Rates of offending may bear little relation to rates of actual occurrence of PSB, therefore. Approaching the issue from another direction, there is no known research on the numbers of people with intellectual disabilities appearing before courts charged with sex offences, and no jurisdiction has been located in which intellectual disability is reliably or validly recorded at the court stage. Prevalence of sex offenders with intellectual disabilities located in prison populations is not an accurate measure of the numbers of people with intellectual disabilities who have been charged with this type of offence, because the accused person who has an intellectual disability may be diverted out of the criminal justice system at many points prior to imprisonment. Those who remain in the system and receive a custodial sentence are likely to be unrepresentative of the totality of the individuals who actually engage in PSB, or who are charged but diverted out of the criminal justice system. The incarcerated group may fall into one of two categories; they could be mildly, rather than severely intellectually disabled, and their impairment may not have been identified during their contact with the criminal justice system, or alternatively they may have committed serious offences that cannot be ignored, or dealt with through informal or diversionary measures.

Some research that has been located suggests that the rate of sex offending amongst the population of people with an intellectual disability may be slightly higher than for the general population, although there is a dearth of research in the area (Day, 1994). Whilst offenders make up a relatively small proportion of the general population of people with an intellectual disability in the community, within that offending sub-group, some studies have found that nearly half have been convicted of sexual offences, and recidivism rates are high (Lindsay and Smith, 1998; Law, Lindsay, Quinn and Smith, 2000). Conversely, other research has reported that people with intellectual disability are not over–represented in the sex offender population (Charman and Clare, 1992). People with disabilities who exhibit PSB are more likely to engage in nuisance behaviours including public masturbation, exhibitionism, voyeurism and sexual threats (Gilby, Wolf and Goldberg, 1989), whilst penetration of the victim and physical violence is less likely to occur when a person with an intellectual disability is the perpetrator.

Typical personal and social characteristics of sex offenders with intellectual disability include (Lindsay, 2002; Hayes, 1991; Hudson et al, 1999):

- a violent, neglecting and dysfunctional family background;
- educational, relationship and behavioural problems;
- psychiatric illness;
- delinquency;
- poor impulse control;
- low self-esteem;
- lack of personal power; and
- negative early sexual experiences, including the probability of being the victim of abuse.

Compared with adolescents with a history of non-sexual offending, sex offenders have been found to be more depressed, more hopeless, to have a more negative view of

themselves and the future, experience more loneliness, and report greater social avoidance and distress, although no differences were noted on the variables of general social skills functioning and attributional style (Napolitano, 1997).

A number of studies report that people with intellectual disabilities who exhibit PSB are likely to have been physically or sexually abused, in institutional or group home settings, or by family members or acquaintances, as well as by strangers. Balogh et al (2001) found that intellectually disabled sex offenders have previously been victims in over one-third of cases. Confirming this high prevalence, other research found that a history of having been the victim of sexual abuse occurred in 44% of sexual recidivists with intellectual disability, compared with 17% of non-recidivists (Morrison, 2002). Morrison reported that recidivists were non-specific in their sexual preference of the victim, victimising male and females, and adults and children, whereas non-recidivists in the same therapy group were more likely to concentrate on one category of victim. Despite the relatively high prevalence of having been the victim of sexual assault themselves, post-traumatic stress disorder (PTSD) symptoms following victimization are not frequently noted in this group, and do not appear to contribute to sex offending (Firth et al, 2001). A limitation of the latter study, however, was that all material was retrospectively derived from case notes, where the case interviews may not have routinely canvassed the symptoms of PTSD.

Glaser and Deane (1999) found few differences between sex offenders and non-sexual offenders with intellectual disability, indicating that the important characteristics for both groups were impulsivity and poorly controlled behaviour, rather than sexual deviation or focus. The only differences these authors found between the two groups were that fewer sex offenders had abused drugs or alcohol, or served prior terms in prison. Nevertheless, other researchers have found that recidivism in this group is associated with substance abuse, as well as with unemployment, and a history of psychiatric illness (Klimecki, Jenkinson, and Wilson, 1994). Research that compared a group of offenders with an intellectual disability with non-offenders found a possible link between substance abuse and offending behaviour, with the individual likely to be under the influence of alcohol or illicit drugs at the time of the offence (McGillivray and Moore, 2001). This study found that sexual and physical assault were not the most frequent offences reported for offenders with an intellectual disability, however; burglary, theft and armed robbery were the most common offences. Alcohol appeared to be a less important factor in cases of child sexual assault, compared with other offence categories, the authors speculating that this could be because children and alcohol frequently do not co-exist in the same environment. The three female offenders in McGillivray and Moore's study (N=30 offenders) were all heavy drinkers of alcohol and reported being intoxicated at the time of the offence, whereas the three females in the non-offender group reported no use of drugs or alcohol.

The results of these studies are often conflicting, possibly owing to differences in methodology and sampling; a clear picture of the profile of the individual with an intellectual disability and PSB has not yet emerged.

Elderly people with mental conditions

Few research studies have been located which study elderly people with PSB. Nursing home residents may present with hypersexuality or paraphilias, possibly arising as a result of progressing dementia or other neurological disorders, or as a side effect of medication for other conditions (Levitsky and Owens, 1999; Wiseman et al, 2000). Case

reports suggest that various pharmacological interventions may be useful for this population, but provide no comparative data and lack long-term follow up of outcomes and benefits, for both males and females. Wiseman et al's (2000) study found that a decrease in hypersexual behaviour amongst demented patients could be achieved with cimetidine alone or with a combination of cimetidine and other anti-androgen therapy, without serious side effects, although they acknowledged limitations in the methodology and suggested that prospective double-blind studies be undertaken. Levitsky and Owens (1999) commented that review of other medications that the patient may be already be taking must be undertaken, to eliminate medication-induced causes of PSB.

An Irish study found that sexually offensive behaviours (including indecent assault, public masturbation and lewd remarks) occurred in a sample of elderly people who had various diagnoses including vascular dementia, frontal lobe dysfunction, Alzheimer's disease, chronic schizophrenia, syphilis and depression; alcohol abuse was present in almost half of the cases (McAleer and Wrigley, 1998). Neuroleptics or anti-libidinal medications were used to treat 9 of the 13 cases, producing a good response in all cases.

People with acquired brain injury

Hypersexuality can be demonstrated by patients who have suffered acquired brain injury. Disinhibition, ranging from mildly inappropriate social/sexual behaviour to major behavioural disturbances, has been reported in patients with specific brain lesions (Starkstein and Robinson, 1997). Follow-up of a cohort of patients with traumatic brain injury indicated that 6.5% committed a sexual offence, a far higher proportion than those with a pre-injury history of sexual offending. The most common offences were "touching" offences, followed by exhibitionism and overt sexual aggression. The victims included staff members, members of the general public, and family members (Simpson, Blaszczynski, and Hodgkinson, 1999). The absence of pre-injury history of sexual offending indicated that the traumatic brain injury was a significant causal factor.

Other mental disorders

Finally, people with other forms of mental disorder, including psychiatric illness or substance abuse brain damage, may demonstrate inappropriate sexual behaviour (Hodgins et al, 1996). Mental disorder and acts of violence, including sexual violence, are particularly associated.

Baumbach (2000) found that about 50% of 415 individuals with foetal alcohol syndrome had repeated problems with inappropriate sexual behaviour or had been sentenced to a sexual offender programme. Whilst indicating that the contributing factors are complex and difficult to disentangle, Baumbach mentions unstable family background, environmental trauma, low intelligence, learning difficulties, impulsivity, and social problems. The protective factors preventing sex offending included early diagnosis and intervention services, stable home situation, no experience of being the victim of violence, and having basic needs met.

The perpetrator as victim

As mentioned above, the overlap between being a perpetrator and being a victim is an important factor in diagnosis and treatment of sex offenders. Research on convicted sex offenders indicated that 34% report having been abused as a child, and 27.1% indicated that the abuser was female (Pope, 2001).

Firth et al (2001) discuss three groups of models, derived from work with non-disabled individuals, that relate the experience of having been a victim of abuse to later becoming the abuser:

1. Trauma models that draw upon the abuse as traumatic, and relate later abusive behaviour to post-traumatic stress disorder.
2. Cognitive-behavioural reinforcement models in which the emphasis is on impulsivity and sexual gratification.
3. The abuse-reactive models which link the experiences as a victim to later actions as a perpetrator, especially though seeking control of others in situations provoking stress or anger.

Whilst linking post-traumatic stress disorder to later offending behaviour appears to be the least productive avenue according to Firth et al, the other two models offer useful frameworks for future research on sex offending and interventions in populations of people with disabilities.

Pharmacological treatment for problematic sexual behaviours

The available treatment options for sexual deviances include surgical castration, psychotherapy, cognitive and behavioural therapy, and pharmacological methods, including psychotropic medication, hormones and anti-androgens (Stone, Winslade and Klugman, 2000). Surgical castration reputedly has the lowest recidivism rate, although there are ethical considerations (Rosler and Witztum, 2000). With this method, extreme though it is, there nevertheless can be recurrence of the behaviours associated with the sex offending, even if arousal is almost obviated. Surgical castration does not entirely eliminate sexual functioning, and the effects can be reversed through taking testosterone; a proportion of castrates retain libido and the ability to have erections and sexual intercourse (Stone, Winslade and Klugman, 2000).

Research concerning the effectiveness of medication, including anti-libidinal therapy, for control of problematic sexual behaviours has been undertaken for several decades, yet has been plagued with limitations including:

- small sample sizes,
- self-report of compliance, side effects and effectiveness,
- the difficulty of obtaining valid data from individuals awaiting legal proceedings (Baron and Unger, 1977),
- the heterogeneous nature of the behaviours under study (Clarke, 1989),
- the short-term nature of most studies,
- observation and assessment of sexual behaviours in hospitals and other environments where risk of re-offending is minimal (Cooper, 1995), and
- absence of control or comparison groups.

Anti-libidinal hormonal medication

Prior to the 1970s, the pharmacological treatment of people with “deviant hypersexuality” was predominantly by way of oestrogens, administered orally or by implant. This treatment was moderately successful in suppressing inappropriate sexual behaviours; however, side effects such as feminisation, nausea, vomiting and breast cancer prompted experimentation with other drugs (Cooper, 1981). Anti-androgens, such as cyproterone acetate (CPA; Androcur), became available in Europe during the early

1970s, and were used intermittently during the following decade. This medication has not been available in the United States of America, where medroxyprogesterone acetate (MPA), a progestational agent, is used. In a study conducted by Cooper (1981), nine participants, none of whom had a mental illness or intellectual disability, were studied in a placebo-controlled trial of cyproterone acetate. Cyproterone acetate significantly reduced physiological sexual arousal, but had less impact upon psychological arousal.

Between the mid and late 1980s further research was performed on the effectiveness of anti-androgens for people with inappropriate sexual behaviours. This research was often conducted on people residing in psychiatric institutions, or repeat sex offenders and paedophiles. More recently, combinations of cimetidine with ketoconazole, spironolactone or both, have been used (Wiseman et al, 2000). A relatively new class of medication, gonadotropin-releasing hormone agonists, reportedly shows fewer side effects than MPA or CPA (Dickey, 1992; Krueger and Kaplan, 2001), although bone demineralisation can occur. CPA and MPA are effective in high doses, but the severe side effects limit their usefulness (Rosler and Witztum, 2000). MPA has been described as a "fairly weak antiandrogen, inadequate for preventing recidivism efficiently, and has many side effects" (Rosler and Witztum, 1998, p. 1923). These authors found that triptorelin (a medication that decreases testosterone levels) suppresses deviant sexual fantasies, urges and behaviour of men with paraphilias.

In their extensive review, Rosler and Witztum (2000) conclude that long-acting analogues of gonadotrophin-releasing hormone (GnRH) are more potent anti-androgens than CPA or MPA, abolish production of testosterone in a reversible fashion, have fewer side effects, and can be administered parenterally once every one to three months, thus reducing non-compliance. Whilst indicating that this is possibly the best option, the authors nevertheless stress the need for good methodological research using double-blind crossover studies and large sample sizes.

Psychotropic medication for anti-libidinal purposes

Psychotropic medications, including lithium carbonate, tricyclic anti-depressants, anti-psychotics (for example, Melleril and Modecate), selective serotonin re-uptake inhibitors (SSRI) and anti-epileptics have been used to treat sex offenders (Rosler and Witztum, 2000). This class of medication tends to be most effective with men whose disorder has obsessive-compulsive features. Undesirable side effects are reported, including dizziness, sleep disturbance, sore breasts, arrhythmia, dry mouth, blurred vision, galactorrhoea, miosis, nasal congestion, weight gain and fatigue (MIMS, 2002).

Anti-depressant medication

Anti-depressant medication has also been used, and has been found to decrease sexual fantasies, sexual urges, and associated masturbation (Stone, Winslade and Klugman, 2000). A small double-blind cross-over study of tricyclics found a beneficial effect (Kruesi et al, 1992).

The effectiveness of treatment of PSB with medication

Evidence concerning the effectiveness of pharmacological treatment for problematic sexual behaviours is contradictory and inconclusive. Some research indicates that the benefit of anti-androgen medication such as Depo-Provera is that it allows a "sexual vacation" from obsessions and dangerous behaviours, during which significant cognitive-

behavioural gains can be made (Robinson and Valcour, 1995). The environment of the treatment, and relatedly, compliance with treatment, are usually not taken into consideration. Administration of medication in a nursing home ensures compliance, even when side effects include nausea, arthralgia and headache (Wiseman et al, 2000), whereas such effects may affect compliance when self-administration occurs. Some researchers comment that "only a minority of subjects are likely to take an anti-androgen of their own volition" (Cooper et al, 1992, p 692).

Review of pharmacological research on the effectiveness of anti-libidinal medication illustrates the inappropriateness of generalising from research on people with mental illness and "paraphilia" to people with an intellectual disability. In particular, the parameters for success used in drug trials are often irrelevant to people with intellectual disabilities who have committed sexual offences, or who show sexually inappropriate behaviours. For example, complex self-insights or multi-faceted attitude change as measures of "successful outcome" are unlikely to be appropriate with participants with an intellectual disability. Furthermore, as much of the pharmacological research suggests, anti-androgens are primarily effective in reducing physiological arousal, as opposed to affecting sexual interest or direction of interest. A reduction in testosterone, for example, is arguably not directly related to sexual and aggressive behaviours, and not all individuals with high testosterone have high sex drives, or high levels of sexual aggression (Cooper, 1995). Physiological arousal can be peripheral to the motivations for inappropriate sexual behaviour in sex offenders, including those with an intellectual disability. One of the rare publications referring to research on medication for sex offenders with intellectual disability (Clarke, 1989) concluded that motivation for change and compliance with medication are stronger influences than intellectual ability, but this begs the question as to the extent to which people with an intellectual disability can develop and maintain motivation, and are able to comply with medication, as the latter process is a complex mixture of health beliefs, attitudes, and behavioural change. Clarke, in accord with other researchers, concluded that anti-libidinal medication "will reduce the intensity of sexual drive but will not alter its direction" (p. 143), and medication needs to be used in conjunction with psychotherapy and other interventions.

Whilst pharmacological treatment of the paraphilias is based mostly on the concept of sex drive suppression, little is known about the effect on behavioural change, and the extent to which sex drive suppression alone may alter the object of the individual's interest in offending behaviours. One study indicates that anti-social sexual expression can be normalised via artificial drive reduction, whilst supporting the notion that this kind of active intervention is appropriate only as an adjunct to psychotherapy and social interventions (Menghini and Ernst, 1991). This theme is echoed by other researchers who indicate that anti-androgen medications should never be used as exclusive treatment for paraphilic and aggressive sexual behaviours (Prentky, 1997), especially for offenders with intellectual disability (Cooper, 1995), and should only be used in conjunction with other therapies such as counselling and behavioural therapy. The effect of anti-libidinal medication plus imaginal desensitisation has been found to be no better that the desensitisation alone (McConaghy et al, 1988), although the same author maintains that there are benefits from the medication alone (McConaghy, 1998).

Some authors comment that deviant sexual arousal will never be completely eliminated, through any form of treatment (Wood, Grossman and Fichtner, 2000). Furthermore, reduction in assessed arousal (through physiological measures, self-report or

observation in a controlled environment) may not be related to non-offending behaviour after release from prison or another controlled environment.

Outcome measures used in research studies include recidivism rates and self-reports, as well as reports from third parties (including parents, parole officers, carers, school counsellors, and child protection agencies) (Camp and Thyer, 1993). Well-designed, controlled studies are rare, and little research effort has concentrated on identifying those components of treatment packages which are most successful (Camp and Thyer, 1993).

General health concerns about the use of medication to suppress sex drive in men have been raised, especially in regard to men with an intellectual disability. Disturbances of protein, calcium and phosphorus metabolism have been noted (Murray, 1987). Long-term consequences are not well-researched (Tancredi and Weisstub, 1986). Prescription of Androcur is inadvisable for men who are aged less than 18, those whose bone and testicular development is not complete, or who have delayed puberty (Hayes, 1991), all of which may well be the case for men with an intellectual disability. Furthermore, there are perils associated with prescription of medication for people with intellectual disabilities who may not be able to report side effects and bodily changes, and who may be taking multiple other medications that could result in drug interactions (Hayes, 1991). Attempts by men with an intellectual disability to communicate discomfort and side effects related to medication may be misinterpreted as challenging behaviour (Carlson, Taylor and Wilson, 2000).

Reviewers conclude that the area of effectiveness and success of prescription of anti-libidinal medication for PSB lacks a strong evidence base, and that large, well-conducted randomised trials of long duration are essential if the effectiveness of treatments is to be established ((White et al, 2000).

Non-pharmacological treatment for problematic sexual behaviour

As Clare (1993) aptly expressed the notion, whilst initially the main problem with sex offenders was that of deviant sexual arousal, increasingly “it was recognised that such a narrow approach failed to address the clinical evidence that sex offenders often had many different problems in their lives” (p. 167). Clare identified as difficulties the limited application of some assessment measures, the need for broad-based assessment of socio-sexual behaviour, the need for multi-disciplinary assessment, simplification of treatments, the importance of giving clear messages to people with intellectual disabilities, and a focus upon motivation as the important issue in evaluating and treating these sex offenders.

A major aim of non-pharmacological treatment for PSB is attitude change, particularly reduction of denial and minimisation of the consequences of the acts. Achievement of reduction in these crucial attitudes takes time, and research indicates that a two–year programme has significantly better results than a one-year programme in obtaining improvement in attitudes and reduction of incidents of re-offending (Lindsay and Smith, 1998).

A primary issue in treatment is the lack of motivation for change, and effort needs to be put into building up the cohesion of the treatment group and encouraging insight into the offending behaviour (Lindsay et al, 1999). Group treatments for non-disabled sex

offenders, based on a broad cognitive-behavioural model, have led to effective treatment programmes. The technique has been applied with success to sex offenders with learning disability (Sinclair and Murphy, 2000), over one year, during 50 sessions. Using baseline measures that included both mainstream sex-offender and specific intellectual disability measures, the results indicated that treatment was effective in impacting on cognitive and social skills measures. Cognitive behavioural therapy as a treatment option for offenders with learning disability was also used in the Brooklands Sex Offender Treatment Programme, which evolved from a collaboration between HM Prison Service, UK, and a team of health professionals who specialised in working with this type of offender (Hordell et al, 2000). The treatment programme consisted of 12 modules aimed at encouraging understanding of the offence cycle, and challenging cognitive distortions as well as addressing relapse prevention strategies. The results emphasised the continuing support needs of the men.

Innovative research (Brown and Stein, 1997) compared cases of sexual abuse of adults with intellectual disabilities perpetrated by men with intellectual disabilities, with those committed by other male perpetrators. Consistent with other research, this study indicated that men with intellectual disabilities offend against more male victims than non-disabled sex offenders and that their offences are somewhat less violent. The authors comment that "peer abuse" is a widespread problem, which service agencies have failed to address; repeated offences are frequent and lack of appropriate intervention is the norm. Therefore, in any programme for sex offenders with learning disability, one of the major aims must be to protect participants against abuse from other participants, or from other residents in living environments to which they may return.

Research about the most effective strategies for programmes aimed at sex offenders with learning disabilities is inconclusive, possibly owing in part to the diverse aetiology, and other methodological difficulties (Lindsay, 2002). It is clear that brief interventions are unlikely to be effective, that cognitive behavioural techniques are useful, and that a multi-disciplinary approach, and long-term support and follow-up are essential.

Some interventions target deviant sexual fantasies. Deviant sexual fantasies have been shown to be directly related to re-offending by committing further sexual crimes amongst juvenile sex offenders, and furthermore, cognitive distortions were indirectly related to recidivism through such fantasies (Kenny, Keogh and Seidler, 2001). In turn, learning problems and deviant sexual experiences (including sexual abuse, and/or exposure to models of sexual coercion, or pornography) were indirectly linked to recidivism through cognitive distortions or deviant sexual fantasies or both, according to these researchers. These authors state that the link between deviant sexual experiences and learning problems suggested that the adverse environments in which young people are subject to deviant sexual experiences may also have a detrimental effect on their learning, yet there is an alternative explanation, namely, that a higher proportion of young people with learning problems (which included those with intellectual disabilities in this study) were subject to sexual abuse. First and recidivist offenders differed in the degree to which the variables, which included social skill deficits, learning problems, deviant sexual experiences, deviant sexual fantasies and cognitive distortions, were present, rather than in the kind of variables that were of interest. Reviews of the literature related to recidivism (Hanson and Bussiere, 1998) indicate that recidivism in sexual crimes is predicted by early onset of offending, choosing males as victims, sexual interest in children, criminal lifestyle and number of prior offences. Level of libido is not mentioned in Hanson and Bussiere's meta-analysis.

A meta-analytic study of treatment effects (Dowden and Andrews, 1999) found that academic remediation, vocational skills training, employment, family supervision, management of anger and antisocial feelings, and development of self control were more strongly related to positive treatment outcomes than programmes that target self-esteem, personal problems or physical activity. Whilst self-control might be the only variable amongst these related to pharmacological interventions, this link would nevertheless need to be empirically demonstrated.

The consequences of problematic sexual behaviour (PSB)

Every individual who engages in PSB is vulnerable to the many negative outcomes that can occur. Criminal charges are the most obvious negative sanction, but other serious alterations to their lives can take place. Placement in high security living environments, expulsion from nursing homes, group homes or hostels, separation from family and friends, aversive therapies, or even physical or chemical restraint may occur. The task of the NSW Guardianship Tribunal and similar bodies in other jurisdictions is to evaluate whether administration of anti-libidinal medication is in the best interests of the individual, and is the most appropriate treatment. Whilst this decision is taken with the utmost care, based on the information and expert opinions available to the Tribunal, data about the characteristics and outcomes for these individuals is not available to the Tribunal, although this information may be of great value in assisting future decisions. In a more general crime prevention sense, the information about general life circumstances can provide vital clues to the prevention of further criminal or offending behaviour in this group, and the factors, both individual and environmental, which affect the outcomes, positively and negatively. Living environment, type and severity of disability, knowledge about and attitudes towards sexuality compliance with medication, type of medication, presence of other disabilities and symptoms, type and severity of PSB, age and gender are some of the major factors which were assessed in this study.

Chapter 2 – Methodology

Recruitment

The research aimed to obtain information about the histories, characteristics and long-term outcomes for people with disabilities for whom third party consent to anti-libidinal medication was considered by the New South Wales Guardianship Tribunal. The Tribunal agreed to be involved in the research, and arranged meetings with the NSW Office of the Public Guardian and the NSW Department of Community Services, because many of the individuals referred to the Tribunal were clients of these services. After lengthy negotiations and consideration of the research aims by both of these government agencies, they both decided not to participate in the research by referring clients. Subsequently, suitable participants who had no involvement with either of these government services were identified through the Tribunal. Other participants were recruited with assistance from both government and non-government mental health services, private clinics and services for people with intellectual disabilities. The project was approved by the Human Ethics Committees of the University of Sydney, and the Central Sydney Area Health Service. Staff at various centres and clinics were notified of the study by letter, and asked to contact clients who might be potential participants, to determine if they wished to participate. For those participants who could be enrolled through the Tribunal, that body contacted the individuals or their carers or family members, and to advise them of the study and ask for participation (see Appendices 1a, 1b, and 1c). Permission was obtained, where appropriate, from the individual, the guardian or "person responsible" (see Glossary) for participants to engage in the research. Once the individual, their person responsible or guardian had indicated their willingness to participate, with their consent their name was given to the Centre for Behavioural Sciences. Initial contact was by sending an information sheet from the Centre (see Appendix 2), inviting the individual to take part in the study, either at their home or at the Centre for Behavioural Sciences. A refusal form accompanied the letter of invitation (similar to the one sent out by the NSW Guardianship Tribunal), which participants could return, if they had changed their mind and were unwilling to participate in the study. Follow-up phone calls were made to participants who did not return a refusal form, and this procedure had been indicated to them in the initial contact letter. The follow-up call was made to determine whether they still wished to participate, or whether they had overlooked returning the refusal form. If they indicated that they no longer wished to participate, no further contact was made. Participants who were not taking anti-libidinal medication but who had demonstrated problematic sexual behaviour, and a comparison group with intellectual disability who had committed offences against a person which were not sexual offences, were also recruited through similar methods.

Participants who agreed to take part in the study signed a consent form, which was written in plain English, and which had been approved by the ethics committees and the Guardianship Tribunal (Appendices 2a and 2b). A carer or guardian witnessed the form. Persons responsible and guardians were provided an additional information sheet, accompanying the consent form. The consent form also provided information about confidentiality, the assessment time frame and schedule, and the purpose of the study. The consent form was read and explained to illiterate participants in the presence of a guardian or carer. The ability of participants to consent was further checked through an

"ability to consent" questionnaire, administered at the first time of personal contact between the participant and the researcher.

These procedures ensured the privacy and confidentiality of individuals who wanted to participate, as well as those who declined. Furthermore, the individual's ability to consent, and third party consent obtained from guardians or persons responsible, was scrupulously checked and re-checked.

The participant and their third party consent-giver were informed that participation could probably be of benefit to the participant, because they would take part in a full-scale psychological assessment, the results of which (with their informed consent) could be sent to service providers who might use those results to tailor a better service for the individual. This was a considerable incentive, because many participants had never undergone a full-scale psychological assessment, and waiting lists for such assessments through NSW government agencies were very long for those clients who were eligible for such assessments, whilst some clients were ineligible or there were no psychological services in their area. For the latter, the only alternative would be to pay for the assessment, and therefore the assessment for this study was seen by participants and their carers as beneficial and worthwhile. Feedback indicated that participants, their guardians and persons responsible viewed the process of the full-scale psychological assessment as very productive. Furthermore, feedback indicated that participants enjoyed the experience of undertaking the assessment, because for many it was a one-to-one interaction of the kind they seldom had, they enjoyed the opportunity to speak about their sexuality in a non-judgmental and non-threatening environment, and some asked for referral to agencies that could assist them with aspects of their sexual behaviour.

Assessment

Participants were given the option of undertaking the assessment in their home, or at the Centre for Behavioural Sciences, depending on the needs of the participant, and also taking into account possible safety issues for the research psychologist. The assessment was conducted over a maximum of three sessions, depending on the requirements for individual participants. Sessions rarely exceeded approximately 1-3 hours in length, depending on how many of the assessment instruments were suitable for individual participants. A detailed interview and assessment schedule can be found in Appendix 4. Participants who had recently undertaken any of the assessment instruments for other reasons were evaluated on alternative instruments where possible in order to avoid test familiarity and practice effect.

The general aim of the first session was to establish the participant's ability to consent, obtain a personal history, and assess intelligence quotient (IQ) and adaptive behaviour functioning. The second and third sessions (if a third session was required) involved exploration of participants' sexual attitudes and knowledge, level of victim empathy, moral judgement, and self-esteem.

Ability to consent questionnaire

This questionnaire was devised specifically for the study, based on the work of Morris et al (1993), and used the technique of explaining to the participant each of the concepts relevant to consent, then asking the participant to explain in return what was meant by each concept. The questions re-checked whether the participant was capable of giving

informed consent to participation in the study. If not, consent was sought from a guardian or person responsible.

Intelligence assessment

Assessment of intelligence was undertaken using either the Wechsler Adult Intelligence Scale – Revised (WAIS-R; Wechsler, 1981) or the Kaufman Brief Intelligence Test (K-BIT; Kaufman and Kaufman, 1990).

The WAIS-R is a set of standardised questions and tasks for assessing an individual's potential for purposeful and useful behaviour. It is composed of eleven tests, six verbal and five non-verbal. The verbal and non-verbal groups may be administered separately or together to yield, respectively, a verbal, performance, and full-scale IQ. The test takes up to an hour to administer. The individual tests are listed below, grouped according to the scale to which they are assigned. The Verbal, Performance and Full Scale IQ distributions were constructed to have means of 100 (which by definition is average IQ) and standard deviations of 15 IQ points. Subjects with an intellectual disability have IQ scores more than two standard deviations (SD) below the mean, on or below a percentile rank of 2, which means that 98 per cent of the population is performing better than this group on cognitive tasks.

VERBAL SCALE	**PERFORMANCE SCALE**
Information	Picture completion
Digit span	Picture arrangement
Vocabulary	Block design
Arithmetic	Object assembly
Comprehension	Digit symbol
Similarities	

The Kaufman Brief Intelligence Test (K-BIT) (Kaufman and Kaufman, 1990) is a brief, individually administered measure of the verbal and non-verbal intelligence of a wide range of children, adolescents and adults. It may be used for individuals aged between four and 90 years. The test is simple to administer and the Manual states that it may be given by non-psychologists, provided the administrators have appropriate background skills and training, although Australian test-suppliers require psychological qualifications on the part of the test purchaser. As with all other instruments in this study, the K-BIT was administered by a trained psychologist. The full test takes approximately 15 to 30 minutes to administer, and is composed of two subtests: Vocabulary (including expressive vocabulary and definitions) and Matrices. Vocabulary measures verbal crystallised thinking, based on school-related skills. The Matrices subtest measures non-verbal skills and the ability to solve new problems (fluid thinking) by assessing an individual's ability to perceive relationships and complete analogies. All Matrices items involve pictures or abstract designs rather than words. Age-based standard scores (SS) having a mean of 100 and a standard deviation of 15 are provided for the Vocabulary and Matrices sections, as well as an overall score known as the K-BIT IQ Composite. These scores are similar to the WAIS-R IQ scores, and were normed in parallel with numerous intelligence and achievement tests, permitting direct comparisons with global scores earned by an individual on the Wechsler Adult and Child Intelligence Scales, for example. The Matrices section only of the K-BIT may be administered in certain situations, for the following reasons:

- it is not dependent upon verbal skills or school-related learning, but rather demands non-verbal reasoning and flexibility in applying a problem-solving strategy. It tests fluid thinking, that is, the ability to be adaptable and flexible when encountering novel problem-solving situations; and
- because it is non-verbal, it can be administered to individuals of non-English speaking background, those from a different cultural background, hearing-impaired, illiterate, dyslexic, or speech and language disabled individuals.

Adaptive Behaviour

Vineland Adaptive Behavior Scales (VABS; Sparrow et al, 1984) were used to assess adaptive behaviour. The scales consist of semi-structured interviews conducted with a carer who is familiar with the day-to-day activities of the subject, or completed through direct and indirect observation of the client. The areas covered by the VABS for adults include:

- Communication – Receptive, Expressive and Written language
- Daily Living Skills – Personal, Domestic and Community skills
- Socialization – Interpersonal relationships, Play and leisure time, and Coping skills

As with the other tests, a composite score is achieved. The composite score and the domain scores can each be expressed as a standard score, which has an average standard score of 100, and standard deviations of 15.

Victim Empathy Scale (VES)

This questionnaire was developed by Beckett and Fisher (Beckett et al, 1994), and consists of 30 questions and statements, each rated by the test administrator on a 4-point scale (from 0=no, not at all, to 3=yes, very much). The original version was modified for respondents with an intellectual disability, to have fewer "reverse scoring" questions, and two items were omitted from scoring. The final score is expressed as a percentage of the maximum score for each participant, obtained by excluding items with a "Don't know" response. High scores reflect low victim empathy. The normal range is 8.4 - 27.6.

Quick Neurological Screening Test (QNST)

The QNST (Mutti et al, 1978) is a brief (approximately 20 minutes) individual test that assesses neurological integration related to learning. The test consists of a series of 15 brief tasks, adapted from paediatric neurological examination. The tasks include:

- Hand skill
- Figure recognition and production
- Palm form recognition
- Eye tracking
- Sound patterns
- Finger to nose
- Thumb and finger circle
- Double simultaneous stimulation of hand and cheek
- Rapidly reversing hand movements
- Arm and leg extension
- Tandem walk
- Stand on one leg

- Skip
- Left-right discrimination
- Behavioral irregularities.

The tasks are scored according to the instructions in the Manual. A high score (consistent with neurological damage) exceeds 50, a suspicious score is in the range 26-50, and a normal score is ≤25.

Sex Offenders Self Appraisal Scale (SOSAS)

The SOSAS consists of 20 statements to which the participant responds, on a 5-point scale, from "agree a lot" to "disagree a lot". The SOSAS was adapted from the Sex Offence Attitude Scale developed by the North Warwickshire NHS Trust in the United Kingdom, and has been used by Professor Glynis Murphy at the Tizard Centre, University of Kent at Canterbury, Canterbury, Kent, United Kingdom. Consistent with instructions, this instrument was administered using a series of five boxes which were labelled with "thumbs up" or "thumbs down" signs, two thumbs to indicate stronger response. The "in between" box was labelled with a sideways thumb illustration. The participant read each card with each statement written on it, or the tester read the statement aloud. The participant then "posted" the card into the box which represented their opinion. Some items are scored in the reverse direction, and one item is not scored. Scores are obtained for denial, blame, minimisation (of actions) reality awareness, social desirability motive, and victim blaming. High scores are consistent with high levels of the characteristic being assessed.

General questionnaire

The general questionnaire was developed by the researchers and canvasses issues including family history, residential situation, relationships during the developmental period, history of being the victim of abuse, relevant medical and psychiatric history, history of offences, educational background, substance abuse, and previous episodes of violence. The questionnaire outline can be found at Appendix 3.

Questionnaire about Attitudes Consistent with Sex Offences (QACSO)

The QACSO was developed by Professor William Lindsay at the University of Abertay Dundee, and has been used in collaborative research with Professor Glynis Murphy, at the Tizard Centre of the University of Kent at Canterbury. The QACSO is administered by asking the participant a question about sexual activity consistent with sex offending, and obtaining a response. Scores are derived for the areas of:

- Rape and attitudes towards women
- Voyeurism
- Exhibitionism
- Dating abuse
- Homosexual assault
- Offences against children
- Stalking and sexual harassment

Sexual Attitudes and Knowledge Scale (SAK)

The SAKS was obtained from Professor Glynis Murphy at the University of Kent at Canterbury, and can be used to evaluate the individual's attitudes, knowledge and skills in four areas

1. Understanding relationships
2. Social interaction
3. Sexual Awareness
4. Assertiveness

The participant is asked to respond to a series of questions, each accompanied by a picture. The question is read to the participant, and a score is derived for each of the four areas. The version that requires answers in an open-ended format was used. High scores are consistent with good levels of knowledge in each area.

Questionnaire on Moral Judgment

This questionnaire was based upon Kohlberg's work on moral reasoning (Kohlberg, 1981), and used the scenario developed by Kohlberg to pose ethical dilemmas. On the basis of the participant's responses, he or she was allocated to the pre-conventional, conventional or post-conventional level of moral reasoning.

Culture Free Self-Esteem Inventory (CFSEI)

The CFSEI is a series of self-report scales used to determine the level of self-esteem in children and adults (Battle, 1981; Battle, 1997; Battle, 2002). The CFSEI measures self-esteem in five areas: general, peers, school, parents, and lie (defensiveness) scales. The adolescent scales were used, to be consistent with the functional age of most participants. The CFSEI can be administered and scored in 15 to 20 minutes. Responses (yes/no answers) may be either written or spoken. Scoring was in accordance with the instructions in the Manual.

Chapter 3 – Results

In reporting the results, *PSB* refers to participants with problematic sexual behaviour, including those who were charged with a sexual offence. *Non-PSB* refers to participants who committed an offence against another person of a non-sexual nature (including non-sexual assault, for example). *Anti-libidinal medication* refers to any medication prescribed for the purposes of controlling the individual's problematic sexual behaviour, and includes some psychotropic medication as well as hormonal medication. The group who were prescribed medication specifically for control of sexual behaviours is referred to as the Anti-libidinal Medication group *(ALM)*, whereas those on medications for other purposes or on no medication are referred to as the No Anti-libidinal Medication group *(NALM)*. The numbers of participants in each of these groups is presented below, in the section entitled *Anti-libidinal medication*, in Table 4.

Levels of ability on tests of intelligence and adaptive behaviour are represented by standard scores, categorised as follows:

Level of ability	**Standard score (SS)**
Above average	110+
Average	90-109
Low Average	80-89
Borderline	70-79
Mild intellectual disability	50-69
Moderate intellectual disability	35-49
Severe intellectual disability	20-34
Profound intellectual disability	<20

These scoring categories were applied to intelligence and adaptive behaviour instruments.

Sample characteristics

A total of 38 participants, 35 males and 3 females, were included in the study; full data sets were not available for all, sometimes owing to the inability of the individual to respond the verbal questions, to their short attention span, or unwillingness to answer some items. No participant withdrew consent to participation during the assessment procedure, but some did not respond to certain items or tests.

Age and marital status

The age range was 15 to 86 years, the mean age being 31 years. Nearly three-quarters of the participants had never been married, and none was currently married, although three (7.9%) were in a de facto relationship (see Table 1). No significant differences were noted for marital status between the ALM and NALM participants.

1. **Marital status and gender**

Marital status	Gender				Total	
	Male		Female			
	N	%	N	%	N	%
Never married	27	71.1	1	2.6	28	73.7
Separated	4	10.5	0	0	4	10.5
Divorced	2	5.3	0	0	2	5.3
Widow/er	1	2.6	0	0	1	2.6
De facto relationship	1	2.6	2	5.3	3	7.9
Total	35	92.1	3	7.9	38	100.0

Ethnicity

For two-thirds of the participants, ethnicity could be determined, and the majority of males (61% of that group) and all the females were non-indigenous Australians. Amongst the other ethnic groups, 13% were Aboriginal, Torres Strait Islander, Maori or Pacific Islander, 13% from the Middle East and 9% were from Europe.

Employment

No differences between PSB and non-PSB, or ALM and NALM participants were found in place or type of employment. Most (53.1%) were unemployed and a further 9.4% worked in sheltered employment – the remainder held labouring or unskilled clerical jobs. Almost all those who were employed held casual positions and only three had been in the same position for more than one year.

Living situation

There was a significant difference in current living situation between the ALM and NALM groups (Chi-square significant at $p < .05$), although no significant difference was noted for residence at the time the problematic sexual behaviour took place. At the time of the assessment, most of the ALM group lived at home with parents or in a group/retirement home, which meant that they were probably under some form of supervision. The NALM participants were more likely to live in independent accommodation, alone or sharing, sometimes with a spouse or partner.

There were some slight changes in living situation between the time of the offence or the PSB and the time of the assessment, with two participants who lived on the street at the time of the offence obtaining accommodation, and some who had lived with parental family or with a partner moving into other accommodation, including boarding houses.

2. **Current and previous living situation**

Living situation		Medication purpose			Total
		ALM	Other reasons	No Rx	
Alone, own flat, house	Current	-	2	-	2
		-	5.3%	-	5.3%
	At PSB	-	1	1	2
		-	2.6%	2.6%	5.3%
Sharing, non-family	Current	-	-	2	2
		-	-	5.3%	5.3%
	At PSB	-	-	1	1
		-	-	2.6%	2.6%
With spouse/partner	Current	-	-	3	3
		-	-	7.9%	7.9%
	At PSB	-	2	4	6
		-	5.3%	10.5%	15.8%
With parental family	Current	5	7	5	17
		13.2%	18.4%	13.2%	44.7%
	At PSB	5	7	7	19
		13.2%	18.4%	18.4%	50.0%
Group/retirement home	Current	4	2	-	6
		10.5%	5.3%	-	15.8%
	At PSB	5	1	-	6
		13.2%	2.6%	-	15.8%
Caravan park	Current	-	-	1	1
		-	-	2.6%	2.6%
	At PSB	-	-	1	1
		-	-	2.6%	2.6%
No fixed abode	Current	-	-	-	-
		-	-	-	-
	At PSB	-	1	1	2
		-	2.6%	2.6%	5.3%
Other	Current	2	1	4	7
		5.3%	2.6%	10.5%	18.4%
	At PSB	1	-	-	1
		2.6%	-	-	2.6%
Total		11	12	15	38
		28.9%	31.6%	39.5%	100.0%

Education

Educational level was generally low, with nearly half the sample having only primary school education (see Table 3). Whilst there was no difference between the ALM and NALM groups, there was a trend for PSB participants to have slightly more education than non-PSBs (Chi-square significant at p<. 05).

3. **Educational level**

Educational level	Client category		Total
	PSB	Non-PSB	
Primary	4 12.9%	11 35.5%	15 48.4%
Year 10	6 19.4%	4 12.9%	10 32.3%
Year 12	- -	2 6.5%	2 6.5%
Trade, TAFE	1 3.2%	- -	1 3.2%
Could not recall	3 9.7%	- -	3 9.7%
Total	14 45.2%	17 54.8%	31 100.0%

Anti-libidinal medication

Eleven participants (28.9%), one female and 10 males, were prescribed some type of medication specifically for anti-libidinal purposes, which included assistance with PSB as well as other behavioural problems. Twelve males (31.6%) had been prescribed medication for another reason, and 13 males and 2 females reported no medication, a total of 15 (39.5%). As Table 4 shows, all of the participants who demonstrated PSB were taking anti-libidinal or other medication, whereas the majority of participants who had committed a non-sexual offences against the person were unmedicated (Chi-square significant at $p < .000$). Some participants (15.8%) with PSB had been prescribed medication for reasons other than reduction of libido, and a similar proportion were receiving medication for other reasons, amongst participants who had committed non-sexual offences against other people. Three ALM participants (27.2%) were taking one medication (Cogentin, anti-convulsant or hormonal medication), six took two medications (54.5%) and two took three medications (18.2%). Six had been prescribed hormonal medication specifically for PSB. Of these six, five were also prescribed another one or two medications, which included anti-convulsants, major tranquilliser, anti-psychotic, anti-depressant, and Cogentin. In contrast, the non-ALM group tended to take less medication – 51.8% took no medication, 25.9% were on one medication, 18.5% on two medications and 3.7% on three medications. Anti-convulsants, anti-depressants, and anti-psychotic medications were the most frequently mentioned, followed by tranquillisers, and Cogentin.

Only four could respond to questions regarding the effect of hormonal anti-libidinal medication. Of these, one reported no reduction in physiological arousal whilst the remainder reported significant reduction. Three reported mild reduction in behavioural arousal, and one reported significant reduction in this area of functioning. One participant reported all of the following symptoms – gynaecomastia, weight gain, drooling, and testes shrinkage.

4. **Presence of PSB and purpose of medication**

Client category	Purpose of medication			Total
	ALM	**Other reasons**	**No Rx**	
PSB	11 28.9%	6 15.8%	-	17 44.7%
Non-sexual offence against person	-	6 15.8%	15 39.5%	21 55.3%
Total	11 28.9%	12 31.6%	15 39.5%	38 100.0%

Participants with PSB who were taking hormonal anti-libidinal medication were significantly less likely to have engaged in numerous incidents of PSB, than those who were not taking this type of medication (Pearson Chi-square p< .02). They were more likely to be prescribed an anti-psychotic medication is addition to the hormonal medication (p< .05). No significant differences were found for levels of cognitive or adaptive functioning, or previous history of being the victim of abuse.

Comparison between PSB and non-PSB participants

A total of 17 out of 38 participants (44.7%) had demonstrated PSB. There was no significant difference in marital status between PSB and non-PSB, with most participants in both groups never having been married.

All of the PSB group had been prescribed some type of medication (see Table 4, Chi-square significant at p< .00), whereas 71.4% of the non-PSB group had no medication prescribed. Whilst there was some bias towards selection into the PSB on the basis of medication, 6 of the 17 had been selected on the basis of sexual offending and not because they were taking prescribed medication, especially anti-libidinal medication.

No significant differences were found between the two groups for prescription of anti-depressants, tranquillisers, anti-convulsants, anti-psychotics, or medication for movement disorders. There was a significant difference for anti-libidinal hormonal medication, as would be expected because some participants were invited into the study on the basis of anti-libidinal medication. Five of the PSBs were receiving hormonal medication to control sexual behaviour. Some participants were not prescribed anti-libidinal hormonal medication, but instead were receiving anti-psychotic, anti-depressant or other medication to control their PSB, giving a total of 11 who were specifically prescribed medication to address sexual behaviour, as noted in Table 4.

Family background

Until the age of 18, the majority of participants lived with or had frequent contact with their mother (90.7%) and father (77.4%), and/or stepmother (2.6%) or stepfather (5.3%). Most had siblings (76.3%), and 18.4% had stepsiblings. The majority were first or second born (58.3%). Most (73.0%) had not been in institutional care, whereas 4 were in care for less than a year and 3 for between 1-5 years; there were no significant differences on these variables between those in the ALM group and the NALM group. Generally, the family socio-economic status tended to be low, as was the parental

educational level and occupational status. Nearly 30% of families had undergone parental break-up, with no significant differences being noted between the groups.

In nearly one-third of families, no violence was reported, but for the remainder, verbal or physical violence had reportedly occurred.

For 14 participants for whom data were available, 50% reported moderate to severe alcohol abuse by their father; 15.4% reported the same for their mother (N=11). Drug abuse on the part of the father was reported by 8.3% of participants, but was not reported for any mothers. Rates of parental alcohol or drug abuse were not significantly different between ALM and NALM participants. Reported attitude of mother or father towards the participant was not significantly different between the two groups, although 18% of mothers and 20% of fathers were reportedly detached from or unaccepting of their offspring.

Suicide attempts on the part of the father were reported by 8.3% (N=12) and on the part of the mother by 7.7% (N = 13), and the same proportions reported psychiatric illness on the part of the parent.

History of abuse

Four participants indicated that they had been physically abused by their father or foster father, two had been abused by a brother (one being a case of sexual abuse), and three had been sexually abused by another family member. A total of nine participants (23.7%) reported abuse within the family situation.

Four participants reported physical abuse by a stranger, on three or more occasions, and nine reported sexual abuse by a stranger, six having been abused on three or more occasions. One reported physical abuse by a carer, and two reported sexual abuse by carers. A total of 42.1% reported extra-familial abuse, therefore.

A total of nine (23.7%) reported any physical abuse, and eleven (28.9%) reported sexual abuse from any source, with no differenced being detected between the ALM and NALM participants.

Intellectual disability

The mean scores for cognitive and adaptive behaviour functioning were in the range of intellectual disability, as would be expected in a group of participants selected for various types of impairment. As Table 5 shows, however, communication and socialisation scores were lower than scores on other sub-tests. Paired samples means t-tests between the adaptive behaviour scores were all significant ($p < .000$), indicating that each adaptive subtest differed significantly from the others. Verbal and performance intelligence test mean scores were significantly different ($p < .001$) from the means on the communication and socialisation domains, but not from the other intelligence sub-test score or from Daily Living skills.

5. **Scores on tests of intelligence and adaptive behaviour**

Standard Scores (SS)	N	Minimum	Maximum	Mean	SD
IQ verbal	30	40	91	67.1	13.2
IQ performance	30	42	99	65.4	15.3
IQ total	32	40	90	62.0	13.9
Communication	25	20	51	31.2	7.3
Daily living	25	22	106	65.8	20.7
Socialisation	25	20	72	48.3	12.5
Adaptive total	25	20	68	44.9	10.3

Table 6 shows the numbers of participants in each ability category, for the tests of intelligence and adaptive behaviour. Again, the greater level of impairment in Communication skills is illustrated, with 92% of the sample having scores placing them in the severe range of disability.

No significant differences were found between the means for the ALM and NALM groups on any of the sub-tests or total scores.

6. **Cognitive and adaptive skill levels**

Ability test	Severe	Mod.	Mild	Border-line	Low Av.	Av.	Total
IQ verbal	1 3.3	3 10.0	12 40.0	10 33.3	3 10.0	1 2.6	30 100.0%
IQ performance	0 0	5 16.7	16 53.3	4 13.3	2 6.7	2 10.0	30 100.0%
IQ Total	1 2.9	7 20.6	18 52.9	3 8.8	2 5.9	3 8.8	34 100.0%
Communication	23 92.0	1 4.0	1 4.0	0 0	0 0	0 0	25 100.0
Daily living skills	4 16.0	3 12.0	8 32.0	3 12.0	5 20.0	2 8.0	25 100.0
Socialisation	4 16.0	12 48.0	8 32.0	1 4.0	0 0	0 0	25 100.0
Adaptive Total	4 16.0	12 48.0	9 36.0	0 0	0 0	0 0	25 100.0

Psychiatric, neurological and other mental disorders

Psychiatric symptoms were derived from self-report, medical or psychological notes or reports from carers at the time of the assessment. No independent evaluation or diagnostic interview was undertaken. Depression was the most common psychiatric symptom, reported by 50% of the sample, followed by anxiety (39.5%) (see Table 7).

7. **Prevalence and severity of psychiatric conditions (N=38)**

Condition	None noted	Mild	Moderate	Severe
Depression	19 50.0%	6 15.8%	4 10.5%	9 23.7%
Delusions etc	30 78.9%	1 2.6%	7 18.4%	- -
Suicidal ideation	27 71.1%	3 7.9%	5 13.2%	3 7.9%
Post-traumatic stress disorder	31 81.6%	2 5.3%	3 7.9%	2 5.3%
Anxiety	23 60.5%	7 18.4%	5 13.2%	3 7.9%
Panic anxiety	30 78.9%	2 5.3%	3 7.9%	3 7.9%
Personality disorder	26 68.4%	3 7.9%	3 7.9%	6 15.8%
Dementia	37 97.4%	- -	- -	1 2.6%
Epilepsy	28 77.8%	8 22.2%	- -	- -
Autism	32 86.5%	3 8.1%	1 2.7%	1 2.7%

No psychiatric symptoms were reported by 9 (23.7%) of participants, and a further 7 (18.4%) reported one symptom, leaving 22 (57.9%) with two or more symptoms. Five participants revealed a history of one or more suicide attempts.

Chi-square analyses showed significant differences between the ALM and NALM participants for presence of delusions/hallucinations ($p < .05$; 45.5% of the ALMs, compared with 25% of those receiving medication for other reasons and none of the unmedicated group), and personality disorder ($p < .02$; 63.4% of ALMs compared with 33.3% of those receiving medication for other reasons and none of the unmedicated group).

Major life events

Whilst 77.8% (N=18) reported no major life events immediately prior to the offence or incident of problematic sexual or non-sexual behaviour, the remainder reported death of a significant person, change of employment or serious personal injury. No differences were noted between the ALM and NALM participants.

Quick Neurological Screening Test (QNST)

The QNST yields three ranges of scores on the 15 subtests:

- A *High* score of greater than 50 indicates learning difficulty
- A *Suspicious* score (26-50) results from one or more symptoms that may be developmental or neurological
- A *Normal* score of 25 or less is almost always achieved by persons who do not have a specific learning disability (Mutti, Sterling and Spalding, 1978)

Eighty-eight per cent of participants had scores indicating some form of neurological impairment, consistent with the presence of intellectual disability. Chi-square tests of significance examining differences between cognitive scores, adaptive scores and QNST scores yielded no significant differences, indicating that those participants with low cognitive or adaptive scores also tended to perform poorly on the QNST. However, correlation coefficients were significant only between QNST scores and the total adaptive score (-0.57) and daily living skills (-0.56) (both significant at p<. 05) (the negative direction of the correlation results from the fact that a high score on QNST indicates impairment whereas the reverse occurs for intellectual disability). No differences were found between ALM and NALM participants.

8. **Probability of neurological damage (QNST)**

Score	N	%
High >50	7	28.0
Suspicious 26-50	15	60.0
Normal 0-25	3	12.0
Total	25	1. 100.0

High scores on the QNST, consistent with brain damage, correlated significantly with low scores on sexual attitudes and knowledge (see Table 9).

9. **Correlation between Quick Neurological Screening Test (QNST) and Sexual Attitudes and Knowledge (SAK)**

Sexual Attitudes and Knowledge	Quick Neurological Screening Test Score
Understanding relationships	-.79**
Social interaction	-.80**
Sexual awareness	-.86**
Assertiveness	-.75**

** Correlation is significant at the 0.01 level (2-tailed).

Whilst the mean score for the QNST was higher for ALM participants (49.1 compared with 41.4), the difference was not significant. Furthermore, there was no significant difference between PSB and non-PSB participants.

Substance abuse

Substance abuse and other drug use were self-reported, and participants may have minimised their usage. A total of 17 participants (45.9%) reported drug or alcohol abuse in the past, whilst 9 (23.7%) reported current alcohol or drug abuse. Nine (24.3%) reported being under the influence of drugs or alcohol at the time of the offence. The number reporting drug or alcohol use at the time of the offence is lower than has been found in similar studies on offenders with an intellectual disability (Hayes, 1996), which may reflect a tendency to deny usage. Marijuana and alcohol were the substances most frequently reported.

10. **Substance abuse previously, at time of offence, and currently**

Substance abuse	None noted	Mild	Moderate	Severe
Drug use at offence/PSB	33 89.2%	- -	2 5.4%	2 5.4%
Drug use previously	26 70.3%	3 8.1%	4 10.8%	4 10.8%
Drug use currently	33 89.2%	2 5.4%	- -	2 5.4%
Alcohol abuse at offence/PSB	31 81.6%	- -	2 5.3%	5 13.2%
Alcohol abuse previously	24 63.2%	1 2.6%	2 5.3%	8 21.1%
Alcohol abuse currently	30 78.9%	1 2.6%	4 10.5%	3 7.9%

Moral reasoning

Of those participants for whom information about moral reasoning was available, three had reached the conventional stage of moral reasoning, whereas the remainder were in stages 1 or 2 of pre-conventional moral reasoning (see Table 11). The difference between the ALM and NALM groups was not statistically significant.

11. **Level of moral judgment**

Moral reasoning level	Medication		Total
	ALM	NALM	
Pre-conventional Stage 1	5 31.3%	1 6.3%	6 37.5%
Pre-conventional Stage 2	4 25.0%	3 18.8%	7 43.8%
Conventional Stage 3	1 6.3%	2 12.5%	3 18.8%
Total	10 62.5%	6 37.5%	16 100.0%

Pearson chi-square analyses produced significant differences between moral reasoning and the following variables:

- total time in institutional care (longer time in care was related to higher level of moral reasoning, $p<.04$)
- history of sexual abuse by a stranger (more frequent abuse was related to higher moral reasoning, $p< .05$)
- number of PSB incidents reported by the participant (greater number of PSB incidents was related to pre-conventional levels of moral reasoning, $p< .04$)
- results on the Victim Empathy Scales (lack of empathy was related to low levels of moral reasoning, $p< .00$)

No significant differences were noted when level of moral reasoning was cross-tabulated with intelligence or adaptive behaviour functioning, or with many variables that might

reflect attachment, including relationship with parents, family violence or conflict, substance abuse by parents, psychiatric illness of parents, history of the participant having been the victim of abuse by family members, number of non-sexual offences, violence or threats during the sexual offence, and self-esteem.

Problematic sexual behaviour (PSB)

Seventeen (44.7%) of participants reportedly had engaged in PSB, and for 13 of these, information was available about their age at the first incident of PSB. The following table shows the age at which the first incident of PSB occurred, according to the PSB participant or carer. The table also shows the ages of the first and second victims, as reported by the PSB group. Whilst the age range for the PSB groups' first incident is from 13-83, 61.5% reported that the first incident occurred before the participant was 27, and 84.6% by the age of 43. This indicates that late onset PSB, after the age of 30, tends to be not frequent in this sample.

In 73% of incidents, the first victim's age was 14 or less. Cross-tabulations indicate that the victim was almost always younger than the ALM participant, and in only one case was the first victim an age peer. The pattern was repeated for the second victim, and there was an age difference of at least five years even when the victim was another adult.

The majority of victims were female, a total of 16 females, and 8 males in all being reported as first or second victims. The participants in this study reported that they had been a sole perpetrator.

12. **Victim and perpetrator ages**

	N	Minimum	Maximum	Mean	Std. Deviation
Age at 1st. incident	13	13	83	32.08	19.87
Age of first victim	11	5	70	16.73	18.22
Age of second victim	6	8	68	26.00	23.45

In rank order of frequency, the offences took place in a public place (N=8), a common service setting (such as sheltered employment; N=7), victim's home (N=3), offender's home (N=2) or another place (N=1).

Up to six sexual offences or incidents were reported by the PSB sub-group, and the non-PSB sub-group reported up to 14 non-sexual offences. In this study, little overlap was noted between sexual offences and non-sexual offences against the person (as compared with offences which are not directed against the person, such as drug offences, or shop stealing). The non-PSB participants were included on the grounds that they had offended against the person in a non-sexual manner, so this is an expected result for this group. In the PSB group, three reported non-sexual incidents or offences in addition to sexual incidents.

13. **Problematic sexual behaviour related to being the victim of sexual abuse**

Number of instances of sexual abuse	Client category		Total
	PSB	Non-sexual offence against person	
0	8 21.1%	19 50.0%	27 71.1%
1	1 2.6%	- -	1 2.6%
2	1 2.6%	- -	1 2.6%
3	6 15.8%	1 2.6%	7 18.4%
4	1 2.6%	1 2.6%	2 5.3%
Total	**17** **44.7%**	**21** **55.3%**	**38** **100.0%**

Nine participants of the 11 who had been sexually abused also demonstrated PSB, whereas 2 of the participants who reported no history of being the victim of sexual abuse had committed non-sexual offences against other people. There is a trend, therefore, for prior sexual victimisation to be linked with PSB (Chi-square significant at $p < .05$).

Non-sex offenders were less likely to report symptoms of epilepsy or personality disorder (Chi-square $p < .00$ for both symptoms).

Culture-Free Self-Esteem Inventory (CFSEI)

Assessment is effected on the following 5 scales:

- Academic – self-esteem in academic pursuits
- General – an individual's perceptions of himself or herself as a person
- Parental/Home -the individual's perceptions of his/her abilities as they relate to the quality of interaction within the home or family unit
- Social – self-esteem in social situation and relationships with peers
- Personal – perceptions of anxiety and self-worth

Raw scores are converted to standard scores, which can then be summed and in turn converted to CFSEI quotients.

14. **Results on the Culture-Free Self Esteem Inventory (N=13)**

Scale	Min	Max	Mean	SD
Academic	6	13	10.0	2.4
General	2	13	6.0	3.3
Parental/Home	1	14	10.6	3.6
Social	1	7	4.8	2.2
Personal	7	14	11.5	1.8
CFSEI quotient	73	111	90.2	12.3

Generally, most participants indicated reasonable levels of self-esteem, the mean score being at the lower end of the average range. Lowest standard scores were obtained on the general self-esteem scale and the social scale. No significant differences in mean scores were noted between those on anti-libidinal medication, or other medication, or no medication. No significant correlations were found between self-esteem quotient and standard scores on adaptive or intelligence tests, or with results on any of the sexual knowledge or attitudes instruments.

A further scale, entitled the Defensiveness score, is a lie scale, indicating the degree to which the participant's responses are guarded. The cut off score for the lie scale indicated that seven (53.8%) of participants were more reluctant than most people to disclose their true feelings. No significant differences in the means of any of the scales, or in the CFSEI quotient were found between the lying and not lying groups. The ALM group was not more likely to lie on the scale than the NALM group.

Victim Empathy Scale (VES)

Ten respondents completed the VES, the scores ranging from 21-43, with a mean of 33.9 (SD = 7.9). Three were categorised as in the normal range, two were in the "lack of empathy" category and five were in the "severe lack of empathy" category.

Chi-square analysis showed no significant difference on victim empathy for ALM or NALM participants. No significant differences were found for history of physical or sexual abuse by family, or use of physical or verbal threats, or force during the assault that the participant perpetrated. Table 15 summarises the variables that were found to relate to lack of empathy.

15. **Variables associate with lack of empathy**

Variable	Chi-square level of significance	Lack of empathy associated with -
Level of moral reasoning	.00	Pre-conventional stage of moral reasoning
Father's attitude towards participant	.04	Father detached, unaccepting
Sexual abuse by a stranger	.04	No history of being abused by stranger
Understanding of interpersonal relationships	.05	High level of understanding of interpersonal relationships

Data analyses indicate that lack of empathy or severe lack of empathy tends to be associated with pre-conventional moral reasoning, lack of attachment to father, no history of having been a victim of sexual assault by a stranger, and a high level of understanding of interpersonal relationships, perhaps giving insight into ways in which individuals with PSB tend to "groom" the victim.

Sexual Attitudes and Knowledge Assessment (SAK)

This instrument yields four scores:

- Understanding relationships
- Social Interaction
- Sexual awareness
- Assertiveness

There were no significant differences between ALM and NALM participants on the scales of understanding relationships, social interaction and assertiveness. There was a small significant difference (p<. 05) on sexual awareness, with the medication group tending to be lower on knowledge of body parts. In general, however, the PSB group did not appear to have very low levels of sexual knowledge in any of the areas measured. More than two-thirds gained a score of 5 or 6 (out of a maximum of 6) for understanding relationships, over 90% scored 2 or 3 (out of 3) for social interaction, over 80% scored 28 or higher (out of 32) on sexual awareness, and 75% scored 7 or over (out of 10) for assertiveness.

No significant differences (using Pearson chi-square test) were noted for the four scores, when cross-tabulated with levels of cognitive or adaptive behaviour functioning.

Sex Offenders Self-Appraisal Scale (SOSAS)

The SOSAS assesses attitudes on the dimensions of denial, blame, minimisation, reality awareness, desirability, and victim blaming. The results shown in the table below indicate that while the means obtained for the PSB group are close to the median scores for each of the scales of blame, minimisation and reality, the mean derived on the denial scale was towards the high end of the scale, indicating strong use of denial. Pearson chi-square tests showed no significant differences on the scales when cross-tabulated with levels of cognitive or adaptive behaviour functioning. Furthermore, there were no significant differences noted (using the Pearson test) for the ALM and NALM participants, or for the various levels on the QNST. Analysis by psychiatric symptoms produced no significant differences.

16. **Range and means on SOSAS scales**

	N	Minimum	Maximum	Mean	Std. Deviation
Denial [5-25]	10	13	25	21.1	4.8
Blame [5-25]	10	5	25	15.3	7.6
Minimisation [5-25]	10	8	25	15.3	5.1
Reality [4-20]	10	4	20	15.3	5.0
Desirability [3-15]	10	3	15	10.7	3.9
Victim blaming [3-15]	10	3	15	8.0	4.6

Significant Pearson product moment correlations were found for the following variables:

- Social desirability and IQ performance score (r= -.75, p< .05)
- Culture-Free Self Esteem Inventory General score and Blame (r= -.76, p<. 01)
- Culture-Free Self Esteem Inventory Personal score and Reality (r= .74, p<. 02)
- Victim Empathy general score and Blame (r= .77, p< .01)
- Reality and number of sexual offences (r= -.85, p< .00)
- Social desirability and number of sexual offences (r= -.69, p< .04)
- Number of non-sexual offences and Blame (r= .77, p< .03)

Questionnaire on Attitudes Consistent with Sex Offences (QACSO)

The QACSO is scored as follows: 0 for a correct response, 1 for a partially correct response, and 2 for an abnormal response. Therefore a participant who has all correct responses would score zero.

T-tests for equality of means were performed for the ALM and NALM groups. A significant difference was found on the "Rape and attitudes towards women" scale, with the ALM participants having a lower mean score, consistent with more correct responses on the scale reflecting attitudes towards women and rape. This may indicate that they may be more likely to receive other types of intervention as well as the medication, which may have "educated" this group.

17. **QACSO scales - ranges and means for Anti-libidinal and Non Anti-libidinal Medication groups**

	Anti-lib. Rx	N	Mean	SD	SE
Rape, attitudes to women [0-52]	Yes	6	13.7*	4.03	1.7
	No	5	18.8	3.0	1.4
Voyeurism [0-26]	Yes	6	12.8	6.9	2.8
	No	5	13.2	5.2	2.3
Exhibitionism [0-26]	Yes	6	9.3	2.8	1.2
	No	5	11.8	6.3	2.8
Dating [0-20]	Yes	6	4.7	3.1	1.3
	No	5	4.0	3.2	1.4
Homosexual assault [0-24]	Yes	6	8.3	5.4	2.2
	No	5	10.0	2.4	1.1
Paedophilia [0-36]	Yes	6	5.5	3.6	1.5
	No	5	9.8	5.8	2.6
Stalking, sexual harassment [0-32]	Yes	6	8.2	8.3	3.4
	No	5	11.2	4.2	1.9

* T-test of means - difference significant at p < .05

When Pearson product moment correlations were performed between QACSO scores and adaptive behaviour domain standard scores, poor Communication was significantly correlated with attitudes consistent with voyeurism (r = -0.64, p< .04).

Number of instances of having been the victim of physical assault by any perpetrator was negatively correlated with homosexual assault attitudes (r= -.64, p< .04), indicating

that abnormal responses to the homosexual assault scale correlated with previously having been the victim of physical (not sexual) assault.

The QNST correlated significantly with the Paedophilia scale ($r = -.67$, $p < .03$), the negative correlation arising because a low score on the QNST represents a normal response. Therefore, neurological abnormality tends to be related to abnormal attitudes towards paedophilia.

Characteristics of the PSB incidents

There were no significant differences between ALM and NALM participants in terms of

- Coercion of victim
- Verbal or physical threats, or use of a weapon
- Aggressive behaviour prior to medication
- Self-injurious behaviour prior to medication

Changes as a result of medication

On the three parameters of aggressive behaviour, self-injurious behaviour, and oppositional-defiant disorder, there was a reported improvement after the prescription of psychotropic (not antilibidinal) medication, for all but one of the participants. Mostly, the symptoms changed from severe to mild, and there were some reports of change from moderate to mild, or moderate/mild to no symptoms.

Summary

A major finding of this research was that few differences emerged between the group who were prescribed some type of anti-libidinal medication and those who were not. Furthermore, leaving medication aside and comparing participants who had demonstrated some form of problematic sexual behaviour with those who had no history of PSB, there were again few differences noted.

18. **Characteristics differentiating anti-libidinal medication (ALM) sub-group, and problematic sexual behaviour (PSB) sub-group**

ALM sub-group compared with NALM
Significant differences found:
Living situation – more ALM resided in parental or group/retirement home
Delusions/hallucinations – more ALM reported these symptoms
Personality disorder – more ALM reported having been diagnosed with this disorder
Sexual awareness – ALM group had less knowledge of body parts
Rape and attitudes towards women – ALM groups had more correct responses on this topic
PSB Sub-group compared with non-PSB
Significant differences found:
Education - PSB participants had slightly more education than non-PSBs
Medication - PSB more likely than non-PSB offenders to be on medication

Chapter 4 – Discussion

The general aim of the research was to gather information about individuals with an intellectual or other cognitive disability who exhibited problematic sexual behaviour and who had been prescribed anti-libidinal medication, both hormonal or anti-psychotic medication specifically to address their sexual behaviours.

This research examined the cognitive and adaptive skills, psychological characteristics, family and social history variables, sexual attitudes and knowledge of various sub-groups of participants with intellectual or other cognitive disabilities. The major focus was upon participants who had been prescribed medication for problematic sexual behaviour, labelled the anti-libidinal medication (ALM) group. The ALM group formed part of a larger sub-group who demonstrated problematic sexual behaviour (PSB), some of whom had not been prescribed medication to address the behaviour. These two sub-groups were compared with a sub-group of participants with an intellectual disability who had a history of offences of a non-sexual nature against other people (non-PSB).

As noted above, for the purposes of this report, anti-libidinal medication includes some psychotropic medications as well as hormonal medications, prescribed specifically for the purpose of addressing PSB. Some participants received medication for other reasons, medical and psychological, whilst some participants received no medication.

Anti-libidinal medication

Nearly 30% of the participants were receiving anti-libidinal medication, either hormonal or psychotropic medication owing to PSB. Some demonstrated other behavioural problems in addition. An almost equivalent number of participants (31.6%) were prescribed medication for another reason, and 39.5% reported no medication. All of the participants who demonstrated PSB were taking anti-libidinal or another medication, whereas the majority of participants who had committed a non-sexual offences against the person were unmedicated. The non-PSB group had been included in the sample on the basis of their non-sexual offending behaviour, and not on the basis of being medicated or unmedicated, and therefore the finding that most of them were unmedicated may reflect upon the seriousness with which PSB is regarded, compared with non-sexual acts against other people. Of the four respondents who could articulate the effect of hormonal anti-libidinal medication, all reported a reduction in behavioural arousal while three reported reduction in physiological arousal. The results for this very small group tentatively indicate that anti-libidinal medication, by reducing the physiological drive, may provide a window of opportunity for intervening with other forms of treatment. One participant reported the following side effects gynaecomastia, weight gain, drooling, and testes shrinkage, however, which Is consistent with other research indicating that side effects are an important reason for non-compliance with medication (Rosler and Witztum, 2000). Other behaviours such as aggression, self-harm and oppositional-defiant behaviour also reportedly improved after prescription of psychotropic medication, for the majority of those receiving such medications.

The participants with PSB did not differ from the non-PSB sub-group in relation to receiving anti-depressants, tranquillisers, anti-convulsants, anti-psychotics, or medication for movement disorders. There was a significant difference for anti-libidinal

hormonal medication, as would be expected because participants were invited into the study on the basis of anti-libidinal medication.

Family background

Participants in the PSB/non-PSB or ALM/non-ALM sub-groups showed no differences on the variables of marital status (most were not married or in a relationship), unemployment, parental break-up or length of time in institutional care. Generally, the family socio-economic status tended to be low, as was the parent's educational level and occupation.

The prevalence of reported verbal or physical violence was high, occurring in 70% of families. Furthermore, nearly one in five mothers and fathers were reported as being detached or unaccepting of their offspring.

Hayes (2002) found that sex offenders with an intellectual disability were less likely to live at home with parents, or in their own home, and more likely to live in a boarding house or non-family situation. The current research found that the ALM group tended to live at home with parents or in a group/retirement home, which meant that they were probably under supervision. The NALM participants were more likely to live in independent accommodation, alone or sharing, sometimes with a spouse or partner. There had been some slight changes in living situation between the time of the offence or the PSB and the time of the participation in the research project, with two participants who lived on the street at the time of the offence since obtaining accommodation, and some who had lived with parental family or with a partner moving into other accommodation, including boarding houses. The commission of a sex offence or PSB, therefore, seems to result in some individuals moving into more supervised accommodation. The NALM sub-group was more similar to Hayes' (2002) other findings, that sex offenders lived in non-family situations.

History of abuse

A history of physical or sexual abuse was high, compared with the general population, for both ALM and non-ALM participants, with 23.7% reporting physical abuse from any source, and 28.9% reporting sexual abuse. No difference in prevalence was detected between the two groups of participants. A study of in-patients with intellectual disability aged between 9 and 21 years admitted to a specialist child and adolescent psychiatry department for young people with an intellectual disability (Balogh et al, 2001) found that 12.3% had been either a victim of sexual abuse, or victim/perpetrator, half having been abused by a member of their close or extended family. The higher prevalence in this study possibly reflects the more adult age range (that is, the older the participant, the more time had elapsed during which abuse could have occurred), and also differences in the nature of the samples. A study of 178 convicted child sex abusers in South East London found that almost half reported experiences of sexual victimisation in childhood (Craissati et al, 2002). Those who had been sexually victimised reported a significantly greater range of problems than those who had been physically or emotionally abused, including more psychological problems and self-harm, distorted offence attitudes, and difficulties with empathy, the latter not being replicated here.

A history of having been the victim of physical abuse as a child has been related to external rather than internal locus of control, whereas internal locus of control has been in turn related to positive treatment change (Fisher et al, 1998). The authors infer that

owning responsibility for actions is therefore an important component of treatment change. The finding that physical rather than sexual abuse relates to a more external locus of control is attributed to the possibility that sexual abuse victims often report feeling responsible for their abuse, whereas those who are physically abused can lay the blame externally. Further research on locus of control in people with intellectual disabilities who engage in PSB would be valuable.

Hayes (2002) found that sex offenders with intellectual disability were more likely than non-sex offenders to demonstrate inappropriate sexuality during their childhood, and to report that they were bisexual, or unsure of their sexual orientation. These results could be consistent with an early history of sexual victimisation, and lack of knowledge about sexuality. Early intervention at the first notification of PSB must be a priority.

Intellectual disability – cognitive and adaptive skills

The participants were selected into the research on the basis of some form of cognitive impairment or disability and this is reflected in the finding that the mean scores for cognitive and adaptive behaviour functioning were in the range of intellectual disability. Communication and socialisation scores were lower than scores on other sub-tests, however. The great majority of the participants obtained scores on the communication domain that placed them in the severe range of disability. No significant differences were found between the means for those on anti-libidinal medication, other medication or no medication on any of the sub-tests or total scores.

Talkington et al (1971) found increased aggression in association with communication deficits. Hayes (1999) found in a sample of Australian prisoners with intellectual disability that adaptive behaviour skills, especially the domains of communication and socialisation, were far lower than cognitive functioning. Indigenous prisoners, male prisoners and older prisoners were significantly more disabled in the area of adaptive skills than non-indigenous, female, and younger inmates. In another study, Hayes (2002) found that sex offenders with an intellectual disability were distinguished from non-sex offenders by severe deficits in communication skills, significantly lower levels of daily living skills, and poorer adaptive behaviour generally. These studies are correlational and not indicative of causality, which could be in either direction. Poor adaptive behaviour may result in social isolation and reduced opportunity for appropriate relationships and recreational/social activities, which may contribute to the likelihood of sexual offending behaviour. Alternatively, factors which contribute to deficits in adaptive behaviour that are greater than the impairments in cognitive functioning, such as impaired attachment related to previous victimization, may similarly contribute to the PSB. Longitudinal research is needed to tease out the impact of the various factors, and to enable better targeting of early intervention programmes.

Psychiatric, neurological and other mental disorders

Depression was the most common psychiatric symptom, reported by 50% of the sample, followed by anxiety (39.5%). More than half of the participants reported two or more psychiatric symptoms. Studies of prevalence of total psychopathology in people with intellectual disability yield rates of between 30-50% (O'Brien, 2002); major depression is reported at rates of 1-5%, up to three times the rate in the general population. Therefore, the group studied in the current research is reporting significantly higher rates of depression. No studies of the prevalence of anxiety have been located.

Significant differences were found between the anti-libidinal medication group and other participants for presence of delusions/hallucinations, and personality disorder. Whilst major psychotic symptoms are "relatively common" in people with intellectual disability (O'Brien, 2002), standard forms of diagnosis are difficult, especially when the client has communication difficulties. Halstead (1996) found a rate of 50% for major psychosis in a group of adults with intellectual disability in a secure facility.

The majority of participants in this study (88%) had scores indicating some form of neurological impairment, consistent with the presence of intellectual disability; those participants with low cognitive or adaptive scores also tended to perform poorly on the QNST. In addition, neurological impairment correlated significantly with low scores on sexual attitudes and knowledge. No differences were found between ALM and non-ALM participants. Consistent with research by Firth et al (2001), post-traumatic stress disorder arising from having been the victim of sexual of physical abuse does not appear to be a factor in PSB.

Substance abuse appeared to be less frequently reported than would be expected from the results of other studies, and participants may have minimised their usage (Hayes, 1996). Substance abuse and a history of psychiatric illness are associated with recidivism amongst sex offenders with an intellectual disability (Klimecki, Jenkinson, and Wilson, 1994; McAleer and Wrigley, 1998), suggestive of a poor prognosis for not engaging in PSB in the future for the participants in this study. Murrey et al (1992) commented that treatment models for sex offenders with intellectual disability tend to be based on extrapolation, without modification, of programmes for non-disabled offenders, despite differences in criminological profiles, a practice that may contribute to poor outcomes, especially for dually diagnosed individuals.

Moral judgment

Of those participants for whom information about moral reasoning was available, most were in stages 1 or 2 of pre-conventional moral reasoning (the basic levels of moral reasoning), but no statistically significant differences between the groups was found. Higher levels of moral judgment appeared to have resulted from "learning the rules" in institutional care. A history of being sexually abused by a stranger was also related to higher levels of moral judgment, perhaps through having to come to grips with relatively complex understanding of some interpersonal behaviours, or alternatively as a result of interventions which emphasised "right and wrong", following the abuse. A greater number of incidents of PSB and poor empathy were related to lower levels of moral reasoning. Moral reasoning has been a difficult area to research assess and address for many years (Hayes and Walker, 1986), and more research into the development of moral reasoning is required in order to determine whether this could be the basis of any productive intervention.

Problematic sexual behaviour (PSB)

The participants in this study tended to demonstrate PSB during their twenties or earlier, and victimised individuals who were younger than they were. The majority of victims were aged 14 or younger, and where the victim was another adult, the victim was at least five years younger than the perpetrator. Most victims were female, and in this research the perpetrators reported that they acted alone, a finding that has been confirmed elsewhere (Hayes, 2002). The offences mainly took place in a public place or a common service delivery setting such as a supported employment venue. No data

were available to indicate the proportion of victims who had a disability, and yet it is likely, given other research, that some victims were disabled (Brown and Stein, 1997), especially in common service settings. Two themes that emerge from this research are first, the importance of child and adult protection so that people with intellectual disabilities do not become the victims of abuse, and secondly, the need to break the cycle of abuse, so that the abused do not become abusers of others.

Attitudes and values

Whilst self-esteem has been found to be a relevant characteristic for sex offenders with an intellectual disability in other research (Hudson et al, 1999), no clear findings emerged in this study. Participants tended to respond to the CFSEI in an acquiescent manner, rather than by showing insight or demonstrating a realistic view of their own interactions with their environment. Other researchers have found significantly lower levels of self-esteem in child abusers (Fisher and Beech, 2002). Whilst low self-esteem is a concept that is often mentioned in relation to offenders with an intellectual disability, however, reliable and valid assessment of this variable using scales appropriate for this group is an area that needs further work.

Empathy emerged as an important variable. Lack of empathy was associated with low levels of moral reasoning, and feeling rejected by the father. Those who lacked empathy showed a good understanding of interpersonal relationships, however, possibly allowing the participant to get close to and "groom" their victim. Most participants seemed to have a reasonable understanding of relationships, social interactions, sexual awareness, and assertive behaviour. Some of this knowledge may have been acquired after the incident of PSB, during interventions to prevent repetition of such behaviour. The ALM group appeared to have lower levels of knowledge about body parts, however.

Participants tended to use denial strongly, which can interfere with successful interventions. Level of denial has not been shown to predict recidivism (Hanson and Bussiere, 1998), and reduction in level of denial does not appear to impact upon attitudes in other areas, such as towards the offence or the victim (Beckett et al, 1994), but most researchers and clinicians working in this area do not regard denial as irrelevant, because it is difficult to commence offence-related interventions if the client is not admitting to the offence (Fisher and Beech, 2002). Nevertheless, Fisher and Beech argue that offenders may use denial because they feel guilty and ashamed, and such individuals may be less at risk of recidivism than offenders who do not care about what they have done and openly admit to it. Therefore, denial may not always be related to a poor prognosis for rehabilitation.

Cognitive distortions are considered important variables for assessment relating to the circumstances of the PSB, and therapies and interventions (Lindsay, 2002). Lindsay states that "cognitive misconceptions may prompt the individual to commit offences and alterations of these misconceptions through cognitive restructuring may be a crucial aspect of treatment" (p.80). The ALM group had more correct responses to questions concerning rape and attitudes towards women; this may be a result of interventions after the incident of PSB. Poor communicators tended to express attitudes consistent with voyeurism, possibly indicating marginalisation and tentative social interactions because of their poor communication skills. Experience of having been the victim of physical abuse was related to abnormal attitudes on the homosexual assault scale. Neurological

damage was related to abnormal attitudes towards paedophilia, consistent with disinhibition that can occur with organic brain damage.

Directions for future research and implications for third party consent

Improved prediction of treatment outcomes

In a study of sexual abuse in young people with an intellectual disability, Firth et al (2001) hypothesised that abusive behaviour occurring as a coping response to victimisation would be associated with retribution, bullying or other attempts at control, younger victims, and denial of responsibility. On the other hand, these authors indicated that abusive behaviour with a primarily sexual motivation in impulsive individuals would be directed towards same-age victims, without bullying or retribution. Their distinction has important implications for treatment, because where abusive behaviour was based on themes of control and retribution, therapeutic progress was slow, especially when the clients significantly minimised the extent of their abusive behaviour. This type of perpetrator appeared to present the greatest long-term risk of recidivism, and were likely to abuse victims substantially younger than themselves. This research emphasises the need during intervention for extensive information about the individual exhibiting PSB, the victims' characteristics, and the response to previous treatment, to assist in making decisions about future treatment including the option of anti-libidinal medication. Future research into the type and extent of information that is predictive of treatment outcomes would be of assistance to third party consent givers such as guardianship tribunals, in their deliberations about whether to consent to anti-libidinal medication. This is a new direction for third party consent, which has tended to focus almost solely on the characteristics of the individual for whom consent is sought, without exploring the circumstances of the PSB. This avenue of risk assessment also emphasises the need for the deliberations of a guardianship tribunal to be informed by expert opinion about factors predicting recidivism.

Improving information concerning the likelihood that PSB occurred

Balogh et al (2001) draw attention to the importance of employing the gradation of the likelihood that sexual abuse has occurred, first proposed by Brown and Turk (1992). This gradation describes the likelihood of sexual abuse having occurred as:

1. Proven/highly probable – there has been a court case or admission with reliable witnesses
2. Probable – the grounds for suspicion are very high and there has been either:
    a. a disclosure coupled with either an investigation or access by a known perpetrator; or
    b. a retracted disclosure together with strong professional opinions that abuse has occurred.
3. Possible – there are strong suggestions that sexual abuse may have taken place, but there has been no disclosure and no indication of a particular perpetrator; there may be sexualised behaviour or a known perpetrator may have access to the victim.
4. Uncertain – there is professional suspicion, but no evidence of either an event or a possible perpetrator. There may be sexualised behaviour and/or an allegation, but suspicions that these are invalid.

Balogh et al (2001) indicate that positive confirmation is rare, and uncertainty about the severity and nature of the abuse is likely. This hierarchy of likelihood must be borne in mind when third party consent for anti-libidinal medication is being considered. Guardianship tribunals may be remote from the actual alleged events, and the information that they receive may be filtered through family members, carers, and various professionals, each with different perspectives and attitudes towards the alleged PSB. Guardianship tribunals would be assisted by research relating reporting of PSB to the actual likelihood that PSB has occurred, and by clear delineation the type of data that would be vital to the tribunal's deliberations, to make sure that PSB has occurred and is of sufficient gravity to warrant consent to therapeutic interventions, including anti-libidinal medication.

Improved prediction of risk

Johnston (2002) reports that attempts to improve risk assessment have mainly focussed upon the clinician's objectivity in administering standardised assessment guides that inform clinical decision-making, stating that "there is no research evidence to support the assumption that current forensic assessment tools are valid or indeed invalid in the population with ID" (p.52). Research into the validity of risk assessment tools for client populations with intellectual disability is clearly a priority that would assist in the decision-making surrounding third party consent to treatment for PSB (Prentky et al, 2000).

Summary

Pharmacological treatment for sex offenders, both those who have an intellectual disability and those who are non-disabled, has been considered one avenue of treatment for some decades. Such treatment can directly affect the hormonal levels of the client, attempting to influence sexual behaviour through reducing hormone levels associated with sexual urges. Alternatively, pharmacological intervention can target other patterns of behaviour considered to be associated with sex offending, including aggression and psychiatric disorders. Research tends to support the notion that hormonal medication may reduce the intensity of the sexual drive, but not its direction, and therefore needs to be used in conjunction with other interventions. Especially with sex offenders who have an intellectual disability, use of hormonal medication needs to be considered carefully, taking into account the other conditions that the client may suffer from, their physiological maturation and the possibility of drug interactions if they are prescribed medication for other reasons (Hayes, 1991; Lindsay, 2002).

The prescription of anti-libidinal medication, whether for hormonal change or psychological/behavioural reasons, is a significant decision for the prescriber and the client. A person with an intellectual or other cognitive impairment may not be able to understand the nature and effect of the proposed medication, and where the client cannot give informed consent, third party consent will be sought. In New South Wales, Australia, the Guardianship Tribunal must consider such cases and decide whether to consent or withhold consent.

A major finding in the research reported here was that individuals with cognitive disabilities who were receiving anti-libidinal medication were similar on most variables to those who were not receiving anti-libidinal medication or any medication at all, and also to those who had committed non-sexual offences against other people. Generally the PSB participants were not dissimilar to the non-PSB participants. An important difference was that the ALM participants were more likely to suffer from the major

psychiatric symptoms of delusions and hallucinations, and from personality disorder. These are significant psychiatric disorders, and probably could influence a decision to seek permission to intervene therapeutically with anti-libidinal medication, as well as influencing the third party consent giver to approve such intervention. Of significance, however, was the finding that the recipients of hormonal anti-libidinal medication were, with the exception of one case, all receiving one or two other medications, usually anti-psychotic or another mood altering or behavioural control medication. In view of the fact that other medication was the norm, the unique and significant input of the hormonal medication for sex drive control must be carefully evaluated.

Apart from these psychiatric symptoms there are no findings from the data that suggest that the ALM or PSB groups were more violent, aggressive, or dangerous than the comparison groups. The issue arises, therefore, as to why and in what circumstances the case was considered for anti-libidinal medication, especially in those instances where the individual cannot consent on their own behalf. A cautionary note must be sounded, focussing attention on the possibility that the individual's behaviour was not so extreme as to warrant the proposed intervention with anti-libidinal medication, but rather the circumstance of the residential or interpersonal environment were such that the behaviour could not be tolerated. Another possible explanation is that given the dearth of appropriate programmes to address PSB, pharmacological intervention may be considered as the only resort, rather than the last resort, which raises the issue of whether a guardianship tribunal can determine that the treatment is the only or most appropriate way of treating the patient and is manifestly in the best interests of the patient. If there is no other treatment available, an argument could be mounted that anti-libidinal medication is therefore the only way of treating the patient; however, medication should not be substituted for other appropriate therapeutic interventions, but rather should be an adjunct to other interventions.

A further area of difficulty is the need for a third party consent giver to determine that the individual actually has PSB. As mentioned above, Brown and Turk (1992) devised a scale for determining the probability that the sexual abuse took place, the gradings being "Proven/highly probable", "Probable", "Possible" and "Uncertain".

Establishing proven or probable PSB could be rare in matters requiring third party consent, because the PSB may be reported by a family or professional caregiver, and access to the victim may not be possible. Furthermore, charges may not have been laid, and a police or other investigation might not have taken place. In addition, carers may seek to prevent serious PSB, and want to intervene before harm has been done to the individual or a potential victim. Not only must extreme care be taken to ensure that the PSB has taken place or there is a high and real risk, and that the PSB is sufficiently serious to warrant anti-libidinal medication, but also the third party consent giver must be satisfied that the individual being considered for medication is the proven or probable perpetrator. Many of the other "witnesses" or possible victims are likely also to have a disability, with impaired or non-existent communication skills, and consequently the blame may have fallen on the wrong person. In extreme instances, a paid carer or family member may be a sexual predator within a residential environment, and be using one individual as a scape-goat to explain sexualised behaviour or distress on the part of other people with disabilities in the environment. The onus is on the third party consent giver to examine very carefully the evidence for PSB, in an area that is fraught with ethical difficulties.

The research reinforces the concerns expressed by other researchers (Clare, 1993, Lindsay, 2002) that a narrow focus on the problematic sexual behaviour and attempts to address this through reducing sexual drive by way of anti-libidinal medication fails to address the many different problems that people with intellectual disabilities and PSB have in their lives. In assessing whether anti-libidinal medication is in the best interests of the individual, this issue must be considered in the context of the person's environment (including their own safety from abuse), a broad-based assessment of psychiatric symptoms and socio-sexual behaviour by a multi-disciplinary team, assessment of the impact of other medications, and implementation of other interventions to address empathy, communication skills and adaptive behaviours, which appear to be strong concomitants of the problematic sexual behaviour.

Glossary of terms

Adaptive behaviour – "The quality of everyday performance in coping with environmental demands. The quality of general adaptation is mediated by level of intelligence; thus, the two concepts overlap in meaning. It is evident, however, from consideration of the definition of adaptive behaviour, with its stress on everyday coping, that adaptive behavior refers to what people do to take care of themselves and to relate to others in daily living rather than the abstract potential implied by intelligence" Grossman (1983, p 42).

ALM (Anti-libidinal Medication group) – participants who were prescribed anti-libidinal medication, including hormonal and other medication, specifically to treat their sexual behaviour.

Anti-libidinal medication - any medication prescribed for the purposes of controlling the individual's problematic sexual behaviour, and includes some psychotropic medication as well as hormonal medication.

Average ability – standard score 90-109 on a standardised test of intelligence or adaptive behaviour.

Borderline ability – standard score 70-79 on a standardised test of intelligence or adaptive behaviour.

Intellectual disability – substantial limitations in present functioning. It is characterized by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self-care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure, and work. The condition manifests before age 18. (AAMR, 1992).

Intelligence quotient (IQ) – "An index of rate of development in certain aspects of intelligence during childhood. Found by determining what percentage a child's mental age is of the chronological age. Among late adolescents and adults, it is an index of relative standing in similar aspects of intelligence, on a standard scale whose mean in the general population is 100 and whose standard deviation is approximately 16" (Stern in Grossman, 1983, p. 38).

Low average ability – standard score 80-89 on a standardised test of intelligence or adaptive behaviour.

Mild disability – standard score 50-69 on a standardised test of intelligence or adaptive behaviour.

Moderate disability – standard score 35-49 on a standardised test of intelligence or adaptive behaviour.

NALM (No Anti-libidinal Medication group) – those participants taking medications for other purposes than anti-libidinal, or on no medication.

Non-PSB - refers to participants who committed an offence against another person of a non-sexual nature (including non-sexual assault, for example).

Person responsible – term used in the Guardianship Act 1987 (NSW), section 33A(4) –
"There is a hierarchy of persons from whom the person responsible for a person other than a child or a person in the care of the Director-General under section 13 is to be ascertained. That hierarchy is, in descending order:

(a) the person's guardian, if any, but only if the order or instrument appointing the guardian provides for the guardian to exercise the function of giving consent to the carrying out of medical or dental treatment on the person,

(b) the spouse of the person, if any, if:

(i) the relationship between the person and the spouse is close and continuing, and

(ii) the spouse is not a person under guardianship,

(c) a person who has the care of the person,

(d) a close friend or relative of the person."

PSB - refers to participants with problematic sexual behaviour, including those who were charged with a sexual offence.

Standard score (SS) – score on a standardised test of ability.

Appendices

Appendix 1a – letter from the NSW Guardianship Tribunal to their clients (similar letter were sent by other agencies who participated through the Central Sydney Area Health Service)

Address of person

Dear [person]

The NSW Guardianship Tribunal is writing to ask you whether you would agree to be part of a research study conducted by researchers at the University of Sydney. The research study is about people who have had a Hearing before the Tribunal, regarding possible medication for problematic sexual behaviours. *(If you are the guardian or carer for the person to whom this letter is addressed, please read the letter.)*

We have attached a letter from the researchers which explains the study and asks for your consent. We have not given your name to the researchers at this stage. If you do not wish to be in the study, please return the attached refusal form to the Tribunal within two weeks. If we have not heard from you within that time, the researchers will contact you to ask you personally whether you will agree to be part of the study.

This letter from the Tribunal is simply asking whether you will be part of the study. The Tribunal is not conducting the research and will not see any information about you. The Tribunal will not give any information about you to the researchers without your consent.

The general results of the study will not identify anyone who participates in the study. The general report on the results will be valuable to the Tribunal for future Hearings because the Tribunal will have more information about what happens to people after a Hearing.

The letter from the researchers explains more about the study, and we would be pleased if you would take the time to read the letter.

Thank you very much.

Yours sincerely,

Nick O'Neill
President

Appendix 1b – Letter from the Centre for Behavioural Sciences, accompanying the letter from the NSW Guardianship Tribunal (the letter was printed on the Centre's letterhead)

[Date]

Dear [person]

Would you agree to be part of a research study?

This letter is to ask you whether you would like to be included in a research study about problematic sexual behaviours, and the usefulness of medication. The NSW Guardianship Tribunal had a Hearing concerning you, and you would be eligible to be included in the study, even if you do not take medication. Before you make up your mind, here is some information about the research. *(If you are the guardian or carer for the person to whom this letter is addressed, please read the letter.)*

Who is doing the research?

Researchers at the Centre for Behavioural Sciences, in the Department of Medicine at the University of Sydney are carrying out the study. The Guardianship Tribunal is contacting people who have had a Hearing about medication for sexual behaviours, but the Tribunal is not actually doing the research.

Why is this research being done?

The Guardianship Tribunal wants to know what happens to people who have a Hearing about medication for sexual behaviours, even if you do not take medication. You will not be identified personally, but all the information about people in the study will be put together so that the Tribunal can see which treatments help people and improve their lives, and which treatments do not help.

Is information about me confidential?

Absolutely. The Guardianship Tribunal is not giving anyone any information about you unless you agree to be in the study. The Tribunal has sent this letter to you because the Tribunal has your name and address on file, but the Tribunal has not given your name to us. If you send back the form saying you do not want to be in the study, we will not have access to your information, and will not contact you further. If you **agree** to be in the study, we will treat all of the information that you give us with great care, and everything will be confidential. The information will not go to anyone except us, the researchers. We will not give any information about you personally back to the Tribunal.

How will I benefit from being in the study?

The advantage of being in the study is that you will be able to have a psychological assessment by expert psychologists. This could be helpful to you or the professionals who are helping you at the moment, or to the people who care for you – but of course the information will not be given to anyone else unless you give consent. Another advantage is that you will find out more about yourself. We will spend time with you, asking you questions. You will be able to express your opinion about your medication (if you take

medication), and about what is happening in your life. And you will have the satisfaction of knowing that you are helping other people who might be in the same situation as you, because the final report (which will not identify you personally in any way) will be useful to the Tribunal and other professional who work in this area, by telling them what happens to people.

I would like to be in the research study – what do I do now?

If you want to be in the study, you don't need to do anything. In two or three weeks, we will contact you and arrange a time and a place to meet with you, and find out more about you. The interviews with you might take two sessions, because we do not want to tire you out. We will discuss all of this with you when we contact you.

I am the guardian or carer for the person to whom this letter is addressed – what do I do?

We would like you to consent of behalf of the person you are caring for, because the information will be of great importance. We might want to speak with you about the person you care for, and also assess how the person is going, and get their views. If that is all right with you, you can wait to be contacted, or you can phone us on 9351 2776 and speak to Professor Hayes or another researcher.

Can I refuse to be in the study?

Yes, you can refuse to be in the study – just send back the attached form to the Tribunal, and your details will not be passed on to us and we will not contact you further. There is no penalty if you do not want to be in the study. If you agree to be in the study and then you change your mind, you can tell us that, and we will destroy any information we have already collected about you. Again, there is no penalty if you decide you do not want to be in the study any longer.

Please feel free to contact us if you require any further information, or contact the Tribunal if they can be of any further assistance.

Yours sincerely,

Appendix 1c – Form for declining to be in the study

WITHIN 14 DAYS, PLEASE SEND THIS SHEET BACK IF YOU DO NOT WANT TO BE IN THE STUDY:

To: Mr Rodney Brabin
Registrar
NSW Guardianship Tribunal

I do NOT want to be in the study about medication for inappropriate sexual behaviours. Please do NOT give my details to the researchers at the University of Sydney.

SIGNED:_____

NAME (please print)_____

ADDRESS (please print)_____

_____ Postcode_____

IF YOU ARE A CARER OR GUARDIAN FOR THE PERSON TO WHOM THE LETTER WAS ADDRESSED:

SIGNED:_____

YOUR NAME (please print)_____

NAME OF PERSON YOU CARE FOR_____

RELATIONSHIP TO THE PERSON:_____

ADDRESS OF THE PERSON (please print)_____

_____

Postcode_____

Appendix 2a: Invitation letter following up clients of the NSW Guardianship Tribunal, and consent form (all letters were sent out on letterhead paper for the Centre for Behavioural Sciences) – similar letters were sent to clients of other agencies

INFORMATION STATEMENT

Following up people who have been prescribed medication for problematic sexual behaviours

Researchers from Behavioural Sciences in Medicine at the University of Sydney are undertaking a follow up study of people who had a Hearing before the NSW Guardianship Tribunal, concerning medication for problematic sexual behaviour. You will already have received a letter from the NSW Guardianship Tribunal asking you to participate. You told the Tribunal that you would participate, and the researchers are now asking you again, whether you are still willing to participate. If you agree, we will interview you about what has happened since the Hearing. We will ask questions about your experiences with the medication, and the good and not-so-good things which have happened in your life since then. The whole process will take about two hours.

This is not hazardous or uncomfortable. All we need is some of your time.

The information you give will be treated with the utmost confidentiality. The information will be stored at the University of Sydney in a locked cabinet. The data will be recorded on computer, but your name will not be on the computer, only an identification number. After the information is put onto the computer, your name will be deleted from the actual test forms.

What you tell us will not be reported back to the NSW Guardianship Tribunal or any other government department, in any way that could identify you.

If you agree to answer the questions, but then later decide that you do not want to participate, you can withdraw your consent at any time. If you decide now or later not to participate in the study, there will not be any penalty at all. The decision is up to you.

The Chief Investigator is Associate Professor Susan Hayes (telephone 02 9351 2776).

Any person with concerns or complaints about the conduct of a research study can contact the Secretary of the Human Ethics Committee, University of Sydney, on (02) 9351 4811.

Appendix 2b: Consent form for Participants

CONSENT TO BEING IN THE STUDY by the participant

I,_____, understand the purpose of the study about Problematic Sexual Behaviours, as explained to me by the Research Investigator. I consent to participate in the study. My consent is voluntary and I understand that all the information will be handled in the strictest confidence and that my participation will not be individually identifiable in any reports.

I understand I will be asked to answer some questions about my sexual behaviours and attitudes in the past and at present. I also understand that I will be given other psychological assessment. This may take 2 to 5 hours.

I understand these results will be seen only by researchers at Behavioural Sciences in Medicine at the University of Sydney, and will be used only in this project. Information which would identify me will be removed from the results at the University. No information about me will be given to any government department, or anyone else.

I understand that even after I have agreed to be in the study, I can decide at any time that I do not want to be in the study after all, and I can withdraw without any penalty. If I withdraw, any information about me will be destroyed.

Signed_____Witness' signature_____

Date_____

Name (Print)_____

CONSENT BY THE GUARDIAN OR PERSON RESPONSIBLE

I, _____, am the guardian/person responsible for

_____.

I have read the Information and the Consent Form for this study and I consent on behalf of this person.

Signed_____ Witness' signature_____

Date_____ Name (Print)_____

Date_____

Appendix 3: Questionnaire for Participants

General Information

Name/No……..
Date of Birth……/……/……Age…….
Sex: Male Female
Race/Ethnic background……..……...
First language……
Other language/s……..
Is the participant in contact with disability services? Yes No
Which?...…….
Does the participant have a case manager? Yes No …a counsellor? Yes No
Other?…….
General description of participant's behaviour

Disability

IQ Score…….Test……..……..……..Date……/……/……

Adaptive Behaviour Scale Score……...Test……..Date……

or

Level of Intellectual Disability as per case files:

Borderline Mild Moderate Severe

Record of psychiatric illness: Yes/No Type:
Record of physical illness: Yes/No Type:
Record of drug abuse: Yes/No Type/s of drug/s:
Record of alcohol abuse: Yes/No
History of suicide attempts: Yes/No Specify:

Vineland Adaptive Behavior Scales:
Communication score
Daily Living Skills score
Socialization Score
Adaptive Behavior Composite Score

or

Reference made to client level of social skills:
Very Good Good Neutral Poor Very Poor

Reference made to client participating and enjoying socializing activities: Yes/No

Reference made to client difficulty in establishing relationships with: Peers Opposite Sex Both

Reference made to client being withdrawn and experiencing social isolation: Yes/No

Reference made to client exhibiting violent behaviours: Yes No Specify

Reference made to client having verbal language skills:
Very Good Good Neutral Poor Very Poor

Family/Carer and Residential Issues

Is participant living with family? Yes/No State with whom:

Is participant living in a group home or supervised environment? Yes/No

Other place of residence: nursing home caravan prison institution hostel
Other, specify:

Age of parents at birth of participant: Mother: Father:

Parents' occupation: Mother Father

Parents' educational level: Mother Father

Brought up by both parents: Yes/No
No. of siblings
Participant's birth order

Brought up by foster-parents: Yes/No

Was participant in institutional care? Yes/No
From age of
For _____ years

Was participant brought up in a stable environment during developmental years? Yes/No

Socio-economic status of family:

Parental marital break-up: Yes/No DK
Age of participant at break-up

Presence of family violence: Yes/No DK
Presence of family conflict: Yes/No DK

Tick the appropriate corresponding box regarding the participant's relationships with others:

Participant's relationship with:	**Warm/ Affectionate**	**Detached/ indifferent**	**Conflictual**	**Other (Specify)**	**Not stated**
Mother/Step-mother					
Father/Step-father					
Sibling (Specify.					
Carer (Specify)					

Notes:

Tick the appropriate corresponding box regarding significant other's attitude toward the participant:

Attitude of:	***Mother/Step-mother***	***Father/Step-father***	***Carer (Specify)***
Caring			
Accepting			
Affectionate			
overanxious/overprotective			
detached/indifferent			
critical/disapproving			
Aggressive			
rejecting/abandoning			
unavailable (work/other commitments)			
Other (Specify)			

Notes

Tick the appropriate corresponding box regarding significant other's problems:

Problem	*Mother/* ***Step-mother***	*Father/* ***Step-father***	***Carer (Specify)***
Drug abuse by:			
Alcohol abuse by:			
Attempted suicide/suicide by:			
Suicidal ideation by:			
Neglect by:			
Psychiatric illness/disability of:			
Physical aggression by:			
Sexual offences by:			
Non sexual offences by:			
Incarceration of:			

Notes:

Victimization History (information to be gathered only through file-content or third-party reports)

Has the participant ever been physically abused? Yes/No

Has the participant ever been sexually abused? Yes/No

Physical abuse by parent/s: Yes/No Details:
.Age at which first abused:

Sexual abuse by parent/s: Yes/No Details:
Age at which first abused:
Physical abuse by sibling/s: Yes/No Details:
.Age at which first abused:
Sexual abuse by sibling/s: Yes/No Details:
Age at which first abused:
Physical abuse by relative: Yes/No Details:
Age at which first abused:
Sexual abuse by relative: Yes/No Details:
Age at which first abused:
Physical abuse by other known person: Yes/No Details:
Age at which first abused:
Sexual abuse by other known person: Yes/No Details:
Age at which first abused:
Physical abuse by stranger: Yes/No Details:
Age at which first abused:
Sexual abuse by stranger: Yes/No Details:
Age at which first abused:
Physical abuse by service provider: Yes/No Details:
Age at which first abused:
Sexual abuse by service provider: Yes/No Details:
Age at which first abused:

Has participant ever witnessed mother and father figure in reciprocally violent behaviour? Yes/No

Has reference been made to any one or more of the following in regards to the participant:

a) Perceived abandonment by primary care givers Yes/No
b) Difficulties in appropriately expressing anger Yes/No
c) Difficulties in appropriately expressing most emotions Yes/No
d) Being bullied (within the family) Yes/No
e) Frequent, unauthorized, non attendance at school/program Yes/No
f) Reckless/nuisance behaviour (e.g. walking in front of traffic) Yes/No
g) Other, specify

Exposure to sexually explicit material: Yes/No Age at 1st. exposure:
Notes:

Medical history

Aetiological diagnosis (if any):
Other significant pre, peri or post-natal traumas

Presence of neurological problems: Yes/No Type:

Current medication (other than anti-libidinal drug):

Type and dosage of anti-libidinal drug:

Commencement date/s

Suspension date/s

Level of motivation to anti-libidinal therapy:

1) Highly motivated (self-motivated)
2) Moderately motivated (motivated or influenced by others)
3) Not motivated (unwilling)
4) Incapable of giving consent

Compliance to anti-libidinal therapy:
1) Remembers and autonomously regulates drug intake
2) Must be reminded to take drug and others regulate intake; does not resist
3) Clearly refuses to take drug or resists

Educational history

Maximum grade/level of formal education ……
Year of discontinuation…….
Attended Special School/Classes? Yes/No Specify:

Number of schools attended

Post-scholastic courses attended: Yes/No Specify:

Specialist post-scholastic courses: Yes/No Specify:

General Scholastic Performance: Very Good Good Average Poor Very Poor

Disciplinary Problems: Yes/No
Expelled/Suspended? Specify:
Notes:

Typology of offence/s (information to be gathered only through file-content or third-party reports)

Was the participant charged with any offence? Yes No

Alleged sexual assault
Alleged paedophilic assault
Other (state)
General delinquent behaviour: Yes/No
Type:

a) Breaking and entering
b) vandalism
c) theft
d) arson
e) assault
f) abduction
g) other (Specify)

Age at 1st sexual offence

Type of incident
Gender of victim
Age of victim
Presence of recidivism: Yes/No
Number of incidents
Number of charges
If more than one victim, prevalent gender
prevalent age
Prevalent type of sexual offence/s
Was/were victims prevalently known to offender: Yes/No

Relationship between victim and participant who committed offence:

a) Brother/step-brother
b) Sister/step-sister
c) Father/step-father
d) Mother/step-mother
e) other relation
f) friend
g) acquaintance
h) stranger
i) co-resident
j) other, specify
k)

Setting:
a) home of victim b) home of offender c) public place d) common service setting e) other, specify
Were offences generally committed alone? Yes/No

Which of the following behaviours were used during the offence? Severity of offence?

Behaviour	***Severity (Scale 1-3)***
Consent not given by the victim and not required due to nature of offence (e.g. voyeurism)	
Consent given by the victim (no coercion required)	
Coercion (i.e. manipulation to consent)	
Verbal threats	
Verbal threats with a weapon	
Physical force (i.e. violence)	
Physical force with a weapon	

Code for Severity Scale: 1 = minor responsibility, coercion, threat, or force
2 = medium responsibility, coercion, threat, or force
3 = high responsibility, coercion, threat, or force

If a weapon was used, specify type:

Offender's occupation at time of offence:
a) school b) employment/vocational program c) none d) other, specify

Was the offender influenced by alcohol at time of offence? Yes/No

Was the offender influenced by drugs at time of offence? Yes/No

Is there evidence of a major life event preceding the offence? Yes/No Specify

Participant's primary caregivers at time of offence (tick):

	Mother figure	***Father figure***
Biological parent		
Step parent		
Adoptive parent		
Foster parent		
Other relatives		
Service carers		
Other person/people, specify		

Specify reaction of primary caregivers in response to offence

Services sought and provided to participant in response to inappropriate sexual behaviour: Yes/No

Specify type/s of services
Outcome of services

Running Chart of Participant's Inappropriate Sexual Behaviors or Offences

Date of Offence	***Type of Offence***	***Victim Age and Sex***	***Outcome***

Notes:

Appendix 4: List of instruments and questionnaires used in assessment

Activity	Approximate time required
Ability to Consent Questionnaire	10 mins
General Questionnaire	20 mins
Kaufman Brief Intelligence Test (K-BIT) or Wechsler Adult Intelligence Scale-Revised (WAIS-R)	40-70 mins
Vineland Adaptive Behaviour Scales (VABS)	90 mins
Vineland Maladaptive Domain	10 mins
Quick Neurological Screening Test (QNST)	30 mins
Sex Offender's Self-Appraisal Scale (SOSAS)	20 mins
Questions about Cognitions (QACSO)	20 mins
Victim Empathy Scale (VES)	20 mins
Sexual Attitudes and Knowledge Assessment (SAK)	20 mins
Questionnaire on Moral Judgement	20 mins
Culture Free Self-Esteem Inventory (CFSEI)	20 mins

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