

A Combined response to the Inquiry into the Involuntary or coerced sterilisation of People with disabilities in Australia

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General comments:

The terms of reference do not clearly define sterilisation. Sterilisation is usually considered as irreversible.

We urge the Inquiry to consider the broadest possible definition of reversible and irreversible sterilisation for both women and men with disabilities, including surgical and chemical suppression, full surgical and irreversible procedures, and future technologies.

We urge the Senate to acknowledge that sterilisation, forced or otherwise, is not an appropriate response for any person with disability. Sterilisation is a major and highly invasive action and as such would not be considered by people without disabilities unless as a last resort.

Including:

(a) the types of sterilisation practices that are used, including treatments that prevent menstruation or reproduction, and exclusion or limitation of access to sexual health, contraceptive or family planning services;

“the types of sterilisation practices that are used, including treatments that prevent menstruation or reproduction”:

- There is a lack of knowledge and training within health and disability sector about the sexual health of people with disabilities, which limits services provided in these sectors.

- The long term health effects of surgical and hormonal options are not well researched for women or men. Assumptions are made that there are few or no long term health effects. However what literature that is available indicates that there may be significant long term health effects, especially if sterilisation surgery occurs when the person is young (pre-adolescent, adolescent or young adult). The human and economic costs of these do not appear to be considered.

“exclusion or limitation of access to sexual health, contraceptive or family planning services”:

- Family Planning Queensland funding for information and support services for people with disabilities was recently cut – resulting in loss of workers and services
- This funding cut also resulted in decreased access to information about sexual health for people with disabilities (there is no well informed alternative source of this information in Queensland)

(b) the prevalence of these sterilisation practices and how they are recorded across different state and territory jurisdictions;

- There is no public recording or monitoring across state and territory jurisdictions of Family Court or tribunal sterilisation decisions, therefore prevalence information and reasons given by decision makers are not available.
- It would also be relevant to know how many requests for sterilisation are turned down by these decision making bodies and why.
- There is very little information available about the sterilisation of boys and men with disabilities for sexuality and fertility reasons.
- There is no information across Australia about how many men and women with disabilities have hormonal medication to suppress sexuality or menstruation and for what reasons.
- Although some men with disabilities as well as women are sterilised, it appears the attitudes of medical practitioners are more accepting of the sterilisation of females with intellectual disability.
- Are some sterilisation operations still being recorded as appendectomies (this practice was reported in the early 1990's)?

(c) the different legal, regulatory and policy frameworks and practices across the Commonwealth, states and territories, and action to date on the harmonisation of regimes;

(d) whether current legal, regulatory and policy frameworks provide adequate:

- (i) steps to determine the wishes of a person with a disability,
- Are all possible interpretations of a person’s non-verbal communications considered (eg it may be that the menstrual pads being used are uncomfortable for the girl/woman, rather than menstruation itself).

- Where a person lacks effective communication and even where people know the person well and can interpret on the person's behalf on other issues, there can be a concern that behaviour can be interpreted based on prejudicial attitudes about menstruation, sexuality or from attitudes influenced by the interests of others rather than the wishes of the person.
- If a person with a disability provides verbal consent to sterilisation, is this informed consent based on impartial information – there is a risk of coercion, (for example, that a couple will not be able to marry, or that services will be withdrawn, if sterilisation is not agreed to).

(ii) steps to determine an individual's capacity to provide free and informed consent,

- A person's abilities to provide consent should not influence the decision to sterilise (ie, just because a young woman has a disability and cannot communicate, should not mean that it is more acceptable to sterilise her than a young woman without a disability – this is disability discrimination).

(iii) steps to ensure independent representation in applications for sterilisation procedures where the subject of the application is deemed unable to provide free and informed consent, and

- What is meant by independent representation? –An independent representative should be fully informed about practical alternatives to sterilisation for people with disabilities?
- **Recommendation:** Disability advocacy services could provide informed and independent representation, but would need to be resourced appropriately in order to undertake this role.

(iv) application of a 'best interest test' as it relates to sterilisation and reproductive rights;

- Best interests of the girl/woman are subjective and open to wide interpretation. Sometimes it appears to be interpreted as the best interests of others/carers, with an element of convenience and an attitude that caring for a person with a disability are a burden. If someone is finding caring difficult, the focus should be on a lack of adequate resources for practical support rather than focussing on changing the physiology of the person with a disability.
- Sometimes sterilisation is considered to be in the person's best interests because services or resources are inadequate (e.g., a day service is unwilling or unable to provide staff to assist with changing menstrual pads). This is not acceptable. The service should be given information and support to find solutions to these support issues. For example, there are a range of educational and support strategies to assist a person to change socially inappropriate behaviours relating to sexuality or menstrual care.
- Best interests vary with attitudes (e.g., attitudes towards people with disability, towards menstruation, and towards the sexuality of people with disabilities).

- Temporary or permanent menstrual suppression through hormones or sterilisation reflects negative societal attitudes to menstruation. Menstruation is a healthy and normal part of female physiology. Assisting a girl or woman with menstrual care should be not different to assisting her with other personal care tasks (e.g., some women with disabilities who have been sterilised, already wear pads to incontinence reasons).
- The increased vulnerability of people with disabilities, who have been sterilised, to sexual abuse, does not appear to be considered. Abuse usually involves someone who knows the woman. The avoidance of unwanted pregnancies (which rarely occur for women with high support needs) seems to take precedence over the protection from sexual abuse that fertility may give a woman with a disability.
- A person with disability and their family may experience a range of issues (inadequate supports, isolation, etc) which lack a ready solution. It is necessary to guard against “best interests” assessments which propose sterilisation to a short term problem (e.g. difficulty learning menstrual management) because it is a “quick fix” to one aspect facing the individual/family – because other more pressing issues lack any “fix”. It must be recognised that in these circumstances, the issue of menstrual management is likely to be an indication of inadequate support or access to appropriate, timely professional intervention and practical support services rather than the primary cause of family distress.
- **Recommendation:** There should be a clear consistent test/set of criteria/checklist to enable decision makers to check that sterilisation is truly the last resort - all practical alternatives to sterilisation (such as education and support about relationships, how to accept menstruation as a healthy bodily function, how to change menstrual pads and manage discomfort, and contraception – if the woman is choosing to be sexually active), must have been genuinely tried (in a positive way, over a significant period of time). Observations by others about negative peri-menstrual changes/discomfort or cyclical epilepsy changes should be required to be recorded over a period of time, as sometimes impressions are inaccurate.

(e) the impacts of sterilisation of people with disabilities;

- Long term health effects (see above)
- The right to bodily integrity.
- Social and emotional effects of sterilisation also need to be considered
- While few studies have investigated the views and wellbeing of those with intellectual disability to determine these potential implications; a recent article regarding forced sterilisations for girls and women with intellectual disability included an interview with a young woman with mild intellectual disability who had undergone a hysterectomy when she was 12 while being told she was having her appendix removed (Osfield, 2012)¹. Years later during a pap smear, the young woman was informed by her General Practitioner that her uterus had been removed. She reported continued feelings of

¹ Osfield, S. (2012). Investigation: forced sterilisation. *Maria Claire Magazine*, June, 41–46.

anger, sadness and violation that “they had stolen something from my body” (Osfield, 2012, p.43). This example provides anecdotal support for the need to consider long term physical and mental health implications of sterilisation and also highlights the need for further investigation of these impacts and the views of individuals with intellectual disability who have been sterilised. These accounts challenge the unfounded assumption that sterilisation does not take anything of value to a woman who is presumed not to be planning to become a parent, or who due to intellectual disability is presumed to lack the same feelings or emotional needs as other women.

- **Recommendation** The senators should speak with women with disabilities who have been sterilised without giving informed consent about the impacts of this on their lives.

(f) Australia’s compliance with its international obligations as they apply to sterilisation of people with disabilities;

- In their 2012 shadow report to the United Nations, regarding Australia’s progress in meeting its commitments under the CRPD, Australian non-government disability organisations identified that the practice of non-therapeutic sterilisation continues for girls and women with intellectual disability (Australian Shadow Report Project, 2012²). The report requested that the Government prohibit this practice without full and informed consent of the individual with intellectual disability except in circumstances where there is a serious threat to health or life (Australian Shadow Report Project, 2012). This request has recently been supported by both the Australian Sex and Disability Discrimination Commissioners (Griffin, 2011³).

(g) the factors that lead to sterilisation procedures being sought by others for people with disabilities, including:

- (i) the availability and effectiveness of services and programs to support people with disabilities in managing their reproductive and sexual health needs, and whether there are measures in place to ensure that these are available on a non-discriminatory basis,
- All school students with disabilities should receive information about reproduction and sexual health

- (ii) the availability and effectiveness of educational resources for medical practitioners, guardians, carers and people with a disability around the consequences of sterilisation, and
- Information available to these groups is limited and often tends to focus on the range of surgical and hormonal options rather than educational and practical support options.

² Australian Shadow Report Project. (2012). *Disability Rights Now: Civil Society Report for the United Nations Committee on the Convention for the Rights of Persons with Disabilities*. Retrieved October 14, 2012, from <http://www.disabilityrightsnow.org.au/node/15>

³ Griffin, M. (2011, September 7). Call for ban on sterilising disabled. *Sydney Morning Herald*. Retrieved from <http://www.smh.com.au/national/call-for-ban-on-sterilising-disabled-20110906-1jvx8.html#ixzz25MQeFH00>

- Information should also be available which raises awareness of attitudes which can influence decisions (e.g., attitudes to people with disability and their sexuality, attitudes to women's health and to menstruation, attitudes to people with disabilities as parents, attitudes towards genetic research, attitudes towards dependence on others for self care)
- The Queensland Centre for Intellectual and Developmental Disability has a resource on its website (<http://www.som.uq.edu.au/research/research-centres/queensland-centre-for-intellectual-and-developmental-disability/resources/managing-menstruation-kit.aspx>).

(iii) medical practitioners, guardians and carers' knowledge of and access to services and programs to support people with disabilities in managing their reproductive and sexual health needs;

- In Australia, individuals with intellectual disability and their parents are directed to seek help with sexuality issues from their doctors as a first point of call (Centre for Developmental Disability Health Victoria, 2012)⁴.
- It has been documented that Australian GPs are often approached by parents and carers regarding sterilisation procedures for the individual with intellectual disability due to concerns about public masturbation, contraception, menstrual suppression and risk of sexual abuse (Eastgate, 2011)⁵.
- recent studies examining the views of medical professionals in their provision of health services to individuals with intellectual disability have identified barriers to quality health care including negative attitudes and stigma, difficulties in communicating with this cohort and a lack of training in intellectual disability, and intellectual disability and sexuality (Cook & Lennox, 2000⁶; Edwards, Lennox & White, 2007⁷; McCarthy, 2011⁸; Phillips, Morrison & Davies, 2004⁹). These barriers, reported by health professionals, along with the attitudes of parents and carers and contextual factors such as living arrangements are likely to impact on the reproductive health care of individuals with intellectual disability (McCarthy, 2011). It is important that health professionals, particularly GPs, are aware that their attitudes may impact on advice about sexuality to individuals

⁴ Centre for Developmental Disability Health Victoria. (2012). *Intellectual Disability*. Retrieved September 12, 2011 from http://www.betterhealth.vic.gov.au/bhcv2/bhcarticles.nsf/pages/Intellectual_disability

⁵ Eastgate, G. (2011). Sex and intellectual disability. *Australian Family Physician*, 40, 189–191.

⁶ Cook, A., & Lennox, N. (2000). General practice registrars' care of people with intellectual disabilities. *Journal of Intellectual & Developmental Disability*, 25, 69–77.

⁷ Edwards, N., Lennox, N., & White, P. (2007). Queensland psychiatrists' attitudes and perceptions of adults with intellectual disability. *Journal of Intellectual Disability Research* 51, 75-81.

⁸ McCarthy, M. (2011). Prescribing contraception to women with intellectual disabilities: General practitioners' attitudes. *Sexuality and Disability*, 29, 339–349.

⁹ Phillips, A., Morrison, J. & Davis, R. W. (2004). GP's educational needs in intellectual disability health. *Journal of Intellectual Disability Research*, 48, 142–149.

with intellectual disability and their family, and decisions about the desirability of sterilisation for this cohort.

A recent study examining attitudes towards the sexuality of individuals with intellectual disability amongst General Practitioners (GPs) in Queensland indicated that a large proportion view sterilisation as a desirable practice (Gilmore, 2010)¹⁰. In the follow up study, the attitudes towards the sexuality of individuals with intellectual disability of GPs in NSW were investigated. This study further examined the conditions under which doctors would view the sterilisation of individuals with intellectual disability as desirable. The study found that:

- The majority of doctors believe sterilisation is desirable in nine of the 12 conditions described in the questionnaire. These conditions encompass parenting issues, such as when the individual is considered unable to parent, or when the available parenting support is limited or costly to society; as well as health issues, including when there is a risk that the disability could be passed on to a child or when parenting or pregnancy presents a significant psychological or physical health risk to the individual with intellectual disability.
- The study speculated as to possible causes of these findings, such as doctors' training in the medical model of disability, or negative attitudes towards the notion of individuals with intellectual disability becoming parents.
- The results reveal factors that the majority of doctors view as reasonable grounds for sterilisation of women but to a much lesser extent for men. The majority of doctors indicated some level of agreement with sterilisation for women who were considered to be vulnerable to sexual abuse, who were unable to manage sexual hygiene without support, and who displayed hypersexuality. They may see these women as being at significant risk of pregnancy, yet unlikely to use contraception. Sterilisation, while preventing the most visible consequence of sexual activity, will not prevent abuse and, arguably, may even increase the incidence if potential offenders know that their abuse cannot be as easily detected because pregnancy is impossible.
- In regards to being approached and performing sterilisations - Most doctors reported they had not been approached to perform sterilisations.
- Only a small number reported that they had performed sterilisations but, in most cases, they did not provide information about how long ago these procedures were performed. The majority of approaches about sterilisation and actual sterilisations involved women, with inability to manage menstruation being the most common reason for the request or, less commonly, factors such as hypersexuality, residing in group homes, and incontinence.
- Only 12% believed medical practitioners receive sufficient training in the area of disability and sexuality.

¹⁰ Gilmore, L. (2010). *Attitudes of Medical Professionals Towards the Sexuality of Individuals with an Intellectual Disability*. Presented at the Australasian Society for the Study of Intellectual Disability (ASSID) Conference, Brisbane, 2010.

- **Recommendation:** Given their pivotal role, medical training and professional development for doctors is required focusing on accessibility of sex education for individuals with intellectual disability and alternatives to sterilisation.

(h) any other related matters.

- “It is illegal to have unlawful carnal knowledge of a person with an impairment of the mind” under Queensland Criminal Code. The act states that: “Any person who has or attempts to have unlawful carnal knowledge of a person with an impairment of the mind is, subject to subsection (3)(a) and (b), guilty of a crime, and is liable to imprisonment for 14 years.” This section of the Act is talking about the ability to consent, as it also examines issues with children and young people, and yet it may apply to people who cannot consent, not to people who may have an intellectual impairment, but do understand the nature and effect of the act and therefore can give consent. People who have intellectual impairment may well understand the nature and effect of the act and therefore can give consent, or negotiated consent.
- Women (with and without disabilities) and medical practitioners in Australia have limited knowledge of the functions of the female reproductive system and of long term effects of surgical removal of female reproductive organs. See **Appendix:** Comments from a listener to ABC Radio National Life Matters

Attachments:

1. Jeni Griffin, Glenys Carlson, Miriam Taylor & Jill Wilson (1994): An Introduction to Menstrual Management for Women who have an Intellectual Disability and High Support Needs, *International Journal of Disability, Development and Education*, 41:2, 103-116.
2. Glenys Carlson, Miriam Taylor & Jill Wilson (2000): Sterilisation, drugs which suppress sexual drive, and young men who have intellectual disability, *Journal of Intellectual and Developmental Disability*, 25:2, 91-104.
3. QAI Background Paper: Sterilisation of people with disability, November 2004.
4. Taylor Gomez, M., Carlson, G., & Van Dooren, K. (2012). Practical approaches to supporting young women with intellectual disability and high support needs with their menstruation *Health Care for Women International*, 33(8), 678-694.

Appendix - Comments from a listener to ABC Radio National Life Matters

In response to an ABC radio program about the Senate Inquiry into the sterilisation of girls and women with disabilities, a listener posted the following comment. This comment supports our concerns about the long term health effects of removal of the reproductive organs. This comment also indicates that the issue being investigated by the Australian Senate has relevance beyond people with disabilities as making decisions about the removal of reproductive organs is a difficulty for all Australian women. Australian women are not being fully informed about possible effects of the removal of reproductive organs by health practitioners, who in turn are not fully informed about these effects themselves.

ABC Radio Life Matters

Axelle : 11 Dec 2012 11:30:02am

My concern is connected to this topic [sterilisation of people with disabilities] but goes further to concern about the removal of reproductive organs from any woman, not just the disabled.

In talking to women friends, I have been dismayed by some of the responses I have received from many of them in regard to hysterectomy and castration. The one that shocked me was "Most older women have the uterus out because it isn't needed anymore" (regardless of whether it is causing problems or not). Such an attitude worries me, coming from anyone. I haven't heard any doctor, male or female, talk about the importance of a woman's reproductive system in providing hormones that the body needs up to the end of life, nor the many complications that can arise from removal of reproductive organs, some of which may be attributed to other causes, thus hiding the real cause of that ill-health.

... [some details about this person's health experiences have been deleted]

My point is that all Australian women need to be fully educated and informed about their reproductive system, not just in terms of sexual activity. Less drastic procedures than organ removal may well be available in Australia, but from what women have told me, they are not being informed of these alternatives at the time of consultation, so the women don't know about them.

There is no Australian literature criticising reproductive organ removal, yet there are studies available from Canadian, American and European sources that are very helpful. I have looked into many of these sources and found a wealth of information that just isn't available in Australia. I would recommend that women do their research before making any decision.

For me, my reproductive system is the physical expression of my innermost being and the essence of my identity that is central to my self-image.

Surely it reflects an attitude toward all women that their reproductive organs are held in little respect.

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An Introduction to Menstrual Management for Women who have an Intellectual Disability and High Support Needs

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An Introduction to Menstrual Management for Women who have an Intellectual Disability and High Support Needs

This paper describes a project researching the management of menstruation for women who have severe or profound intellectual disability (high support needs). Its mandate was to develop materials, processes and resources to support menstrual management for women who have high support needs. Intervention processes are described via an illustrative case study. The impact of care providers' attitudes on menstrual management for these women is considered. Partial participation in menstrual self-care is discussed. Reference is made to a ruling by the High Court of Australia which requires the consent of the Family Court of Australia for surgery resulting in sterilisation of young women under the age of 18 years.

The menstrual management project was set up to provide information and support to young women who have an intellectual disability and high support needs, and those providing them with personal assistance. The term, high support needs, is used in this paper when discussing people who have a severe or profound intellectual disability.

Four questions were addressed by the project:

1. Can women with high support needs learn menstrual self-care?
2. What makes menstrual self-care different from other aspects of a woman's self-care?
3. Are acceptance of menstruation, or partial menstrual skill development, appropriate goals for women who have high support needs?
4. What are some key factors to consider when developing either acceptance of menstruation, or menstrual skills for these women?

Ability of Young Women who have High Support Needs to Learn Menstrual Self-Care

For nearly three decades the literature has supported learning of self-care skills by people who have high support needs. Dressing was successfully taught

by Bensberg, Colwell, Cassel and Cassel (1965); Minge and Ball (1965); and Azrin, Schaeffer and Wesolowski (1976). A number of other researchers reported acquisition of other self-care skills such as face washing (Bensberg et al., 1965; Teffry, Martin, Samels, & Watson, 1970), toileting (Azrin & Fox, 1971; Bensberg et al., 1965; Heyward, 1988), and tooth-brushing (Snell, Lewis, & Houghton, 1989). Hamilton, Allen, Stephens and Davall (1969) suggested moderate self-sufficiency in toileting and dressing as indicators of similar success in menstrual pad management.

Very few investigators have addressed menstrual skill development for women who have high support needs. Approaches taken in reported studies included preparation of young women prior to menarche (first menstruation) (Dedrick, 1974; Demetral, Driessen, & Goff, 1983), detailed task analysis of target behaviours and simulation of menstrual flow (Dedrick, 1974; Demetral et al., 1983; Richman, Reiss, Bauman, & Bailey, 1984).

In a program aimed at preparing nine young women who had mild to severe intellectual disability for their menarche, Demetral et al. (1983) provided them with basic explanations about periods, and pad management practice with a "menstruating" doll. Seven of the participants learned pad management skills. Four of the young women generalised their skills from the simulated setting to their own menstruation with minimal prompting.

A number of programs have been developed in Australia to address menstrual management for young women with moderate support needs (Gray & Jilich, 1990; Jones, 1989; Telford & Smith, 1992). The applicability and relevance of goals and strategies suggested by these programs has not previously been investigated for women who have high support needs. Llewellyn-Scorey (1989) suggested both informal and formal approaches to menstrual management for these women. The strategies were trialled in an institutional setting with some success, but were not documented. The limited literature available suggests that women who have high support needs may be able to learn menstrual management skills. The effectiveness of approaches developed for women who have moderate support needs is not clear.

What makes menstrual self-care different from other aspects of self-care?

In a survey of textbooks which included skill development content for students with high support needs, Spinaze (1990) found that only one-third made any mention of menstrual management. A possible reason for this is the influence of societal attitudes towards menstruation. Hasleton (1989) and Gray and Jilich (1990) suggested that menstruation is a taboo subject in our society. This view was supported by a Victorian advocacy group who wrote:

Other people feel uncomfortable talking about sex and periods to disabled women so they don't. Other people's coyness about periods inhibits women getting clear information. (Strahan & Brudenell, 1990, p. 3)

A number of studies have focussed on societal attitudes towards menstruation. Scambler and Scambler (1985) and Hays (1987) found that approximately half of the women they surveyed felt negative towards menstruation. When asking young women about their experience of menarche,

Ruble and Brooks-Gunn (1982) found that while 72% regarded having their periods as a sign of maturity, 46% regarded periods as a "hassle." Attitudes towards menstruation have been reported to vary markedly between religious groups (Paige, 1973). One study suggested that men's perceptions of menstruation, and the impact it has on women's lives, differ significantly from those of women: men in the study perceived menstruation as more debilitating and disruptive than women (Brooks-Gunn & Ruble, 1986).

An Australian survey found that 80% of the young women interviewed thought of menstruation as an event that should only be discussed with their mothers or close female relatives. None mentioned their fathers as sources of information about menstruation (Abraham et al., 1985). In an American survey, young women who were not prepared for menstruation expressed less positive feelings about periods than those who were. The young women felt that their negative feelings were a reflection of their mothers' (Dashiff, 1986).

The literature suggests that menstruation is subject to strong societal taboos in our mainstream culture. It is not openly discussed, and may be regarded negatively and as "a women's issue." People who assist women with high support needs may hold varying attitudes to menstruation. They may feel uncomfortable discussing, or being involved in, menstrual management for women who have high support needs.

Acceptance of Menstruation and Partial Participation in Menstrual Care

Acceptance

Acceptance of menstruation for women who have high support needs does not seem to be a society norm. Squire (1989) reported that parents tended to see their sons and daughters with an intellectual disability as child-like and dependent: only half of parents surveyed valued education on topics like puberty and menstruation for these young people. In an Australian survey by Parsons (1989), 72% of parents said that they regarded sterilisation of people with intellectual disability as desirable practice. Hasleton (1989) suggested that in a society where technical fixes for unwanted or untimely bodily functions are approved, it is not surprising that caregivers may choose to "adjust" contraceptive measures to suppress menstruation.

In a recent study involving people who assist women with high support needs, half of the participants reported that most of the young women appeared to be either unaware of, or unconcerned about their periods (Carlson & Wilson, in press). Positive menstrual management experiences for these young women and those assisting them may result in greater acceptance of menstruation for women who have high support needs. One example of such an outcome was reported by Demetral et al. (1983).

The women clearly enjoyed the experience and the mothers/caregivers were delighted that they now had a way to manage this dimension of their daughter's life rather than fear it. (p. 44)

Partial participation

Partial participation has been an accepted programming option for people with high support needs for some time (England & Langton, 1983; NSW Department of Education, 1989). These people often have multiple impairments, which can include orthopaedic and sensory disabilities, chronic illness, and reduced or absent motor control (Sailor, Gee, Goetz, & Graham, 1988). Complete mastery of self-care tasks is often not possible.

Working with children who had cerebral palsy and high support needs, Snell et al. (1989) suggested partial participation in toothbrushing as a realistic and legitimate goal. Learning was focused on aspects of the task which were motorically feasible. The authors noted that the children seemed happier when assisting in dental routines than they had been when fully dependent.

Evans and Scotti (1989) supported the value of partial participation for people who have high support needs. They suggested the targeting of functional skills, that is, skills which achieve a critical effect for the person. It was their opinion that initiation or completion of tasks may give the person with a disability some control in situations where he or she would otherwise be passive. The authors emphasised the importance of choosing goals which are likely to result in positive emotional states for the person, like enjoyment and happiness.

Key Factors to Consider when Developing Either Acceptance of Menstruation or Menstrual Skills for these Women

Attitudes of care providers

Demetral et al. (1983) commented that the "myths and realities surrounding the onset of menstruation" often prevented parents from preparing their daughters who had an intellectual disability for physical and emotional changes that would occur. Parents and others who assist these women may hold attitudes reflective of societal trends: that menstruation is inconvenient and embarrassing, and that many would avoid it if safe, reversible methods were available (Abraham et al., 1985). Patullo and Barnard (1968) and Gray and Jilich (1990) explored the impact of people's feelings towards menstruation on attitudes of the young women they assist. It was suggested that fear or disgust about menstrual flow, and feeling that touching of sexual parts during hygiene routines is wrong, could be related to attitudes of those assisting these women with menstrual management.

Parents may have concerns about menstrual preparation for their daughters. Puberty and menarche, being developmental milestones for these young women, may act as triggers for episodes of recurrent grief among parents (Craft, 1985; Davis, 1987; Kratochvil & Devereux, 1988). This sense of loss may make the process of preparing their daughters particularly difficult (Gray, 1991). Other factors, including uncertainty about how much these young women can understand, the relatively low priority given to independence (Hammar & Barnard, 1966), and the stress and anxiety of an increasing burden of physical care (Adams, Wilgosh, & Sobsey, 1990), may also affect parents' receptiveness to acceptance of menstruation or menstrual skill development.

Teaching and residential staff may hold attitudes which do not support educational approaches to menstrual management. Tse and Opie (1986) reported that when considering menarche, school nurses perceived young women who had a disability as being less responsible for their behaviour than other young women. The authors suggested that further dependence might be fostered as a result of these expectations. In addition, staff may hold widely divergent views concerning sexuality and independence for women they assist (Craft, 1985). Such variation has implications for continuity of menstrual care for women who operate in more than one setting, or who are assisted by several people.

Gray and Jilich (1990) recommended that for successful outcomes, menstrual care should be provided by people who have positive, supportive attitudes. Increasing awareness of the range of possible feelings about menstruation, and encouragement of menstrual acceptance among those providing personal assistance, may be essential factors in menstrual management for women who have high support needs.

Establishing realistic goals

In *Guidelines for Menstrual Management*, developed for use with young women who have moderate support needs, Gray and Jilich (1990) identified the following goals: (a) recognition of sexual body parts, and awareness of their changes with puberty, (b) understanding that women menstruate—it is a universal experience, (c) knowing when a period is likely to occur, (d) knowing how and when to use pads, (e) understanding the socially private nature of menstruation, and (f) development of appropriate personal hygiene routines.

The relevance and feasibility of such goals for women who have high support needs has yet to be established. An important factor to consider is the heterogeneity of this group, who experience a great diversity of neurological and other disabilities (Evans & Scotti, 1989). Standardized, norm-referenced assessment procedures may be neither valid nor useful (Sigafos, Cole, & McQuarter, 1987). These facts, when combined, suggest that intervention for women with high support needs requires an individualised approach, based on information concerning both their abilities and deficits in function.

Partial participation in self-care has been suggested as an option for women who have high support needs. Where it allows a sense of control, or helps to reduce the amount of physical assistance required by a woman having her period, it may be seen to offer immediate benefits. Partial participation may produce changes in behaviour towards the women among people who assist them (Evans & Scotti, 1989). The avoidance of possible side-effects from medical or surgical procedures may also be seen as a gain.

A 1992 ruling by the High Court of Australia (*Secretary, Department of Health and Community Services vs JWB and SMB*, 1992) may change the degree of priority afforded educational and lifestyle approaches to menstrual management. This ruling states that consent for surgery resulting in sterilisation of a young woman under 18 years of age must be given by the Family Court of Australia. Before such consent, the Court may require evidence that approaches less intrusive than surgery have been thoroughly

investigated. Adoption of educative and supportive approaches may result in many more women who have high support needs being involved, at least partially, in their own menstrual management.

Illustrative Case Study

This case study illustrates the intervention process of the menstrual management project being described. There is particular reference to attitudes of people assisting this young woman, and choice of realistic menstrual management goals.

Approaches included provision of information and practical support; consideration of this young woman's abilities, as well as difficulties; and provision of opportunities for people assisting this young woman to examine their feelings about menstruation in a supportive and non-judgemental setting. These processes are consistent with perceptions of and preferences for service provision, expressed among parents (Baxter, 1989). Pseudonyms are used to maintain participants' confidentiality.

At the time of writing, Dorothy Green was 11 years old, and lived at home with her parents and younger sister. She attended special school in a metropolitan area. Teaching staff at Dorothy's school expressed interest in being part of the project and Mrs Green agreed to participate.

Baseline Questionnaire: February, 1992

This questionnaire was developed to indicate the actual or potential menstrual management skills of each woman. People familiar with each woman provided information in response to a structured interview format. An interview approach was chosen for collection of baseline information because of the difficulties posed by direct assessment among this population (Sigafoos et al., 1987). Klein-Parris, Clermont-Michel and O'Neill (1986) provided qualified support for the use of interview concerning people who have an intellectual disability: they recommended less complex items for greater accuracy.

Dorothy understood one-step requests and communicated her needs and preferences with single words, signs, and gestures. She had functional vision and no auditory impairment. These items suggested that Dorothy was able to both understand and communicate basic information, and that verbal, gestural and visual cues might be employed in learning situations.

Dorothy ate and drank independently. She used the toilet with verbal prompts, managing her pants independently. Dorothy walked with minimal assistance. These achievements demonstrated proficiency in motor control, balance and coordination. They indicated potential for menstrual tasks, such as pad management and disposal during toileting routines.

Information concerning current medical conditions was recorded. In Dorothy's case, despite encouraging results with toilet regulation, frequent urinary tract infections and a bowel disorder necessitated the use of incontinence pads. Her occasional experience of "thrush" was seen as a possible factor in the choice of appropriate incontinence/sanitary products.

At this time, Dorothy showed signs of physical maturity, but was not yet menstruating.

Care providers' attitudes towards menstruation

Questions from the Baseline Questionnaire and summarized responses were as follows:

"What do you think women in general feel about their periods?"

- Mrs Green: Am always glad to see mine as I'm diabetic. I get very moody. Some women get irritable, moody, and feel "unclean".
- School nurse: Most women probably see it as a natural part of life, and accept it.
- Present teacher: It varies tremendously. Still surrounded by myth, but not as much of a problem as it used to be.

"If a young woman has a disability, do you think that people's feelings about her menstruation are different?"

- Mrs Green: Yes, they might be different. Bleeding in public could occur—people will look, and the young woman may feel embarrassed.
- School nurse: Yes—it's a big concern for teachers. For some, dealing with menses is distasteful, abhorrent. They wonder how they're going to cope with menstrual flow as well as urine and faeces. Some people may also think that periods are unnecessary, as these young women will not be having children.
- Present teacher: Not in my experience, although some people may regard these women as a "race apart" who will not have periods.

Responses to these questions seemed to indicate an attitude of acceptance of periods for the general population, but some difficulties when considering menstruation among women who have high support needs.

Attitudes towards preparing Dorothy for her menarche

"Do you think it will be possible to prepare Dorothy in any way for her periods?"

- Mrs Green: No. She wouldn't be able to understand.
- School nurse: Yes. The possibility is there. Dorothy is aware of physical changes that have occurred. She may need preparation for the sight of blood on her pants.
- Former teacher: Yes. Dorothy may benefit from practising putting pads on and off. She likes her world to be very structured, so a definite routine would be best.

"What do you think might be realistic aims for Dorothy with her menstruation and her cycle in general?"

- Mrs Green: I'd like to see how she copes with it; see if she's a heavy bleeder. (It was reported that Mr Green was in favour of a hysterectomy for Dorothy.)
- School nurse: It would be great to have Dorothy assisting in some way. Perhaps she could help to put pads on, or to dispose of used ones. Family information and support may also be helpful.

- Former teacher: Dorothy could be encouraged to do a large part of pad management; she will need to be monitored for the start of her periods.

Responses to the last two questions indicated significant differences in attitudes and expectations. While Mrs Green planned to “wait and see how Dorothy would go” with her periods, she was not optimistic about the feasibility of either preparing Dorothy, or involving her in menstrual tasks. Teaching staff considered both of these goals to be attainable. They thought Dorothy would need others to monitor her menstrual cycles and prepare her for the likely onset of periods. They believed that she would be able to change and dispose of menstrual pads, if provided with a structured learning routine.

Information session for parents: February, 1992

This session was organised in response to requests from participants. Mrs Green and some other parents had indicated interest in meeting to discuss their concerns and feelings about menstrual management for their daughters.

Requests for information were also made. Topics included facts about menstruation, menstrual charting, suggestions for teaching menstrual skills, management of menstrual difficulties, and details of possible medical and surgical interventions. These and other information needs were addressed in a booklet titled *Managing Menstruation* (Taylor, Carlson, Griffin, & Wilson, 1993) prepared for use by parents and other people assisting women who have high support needs.

During the information session, several topics from the booklet were chosen for discussion, and opportunity for sharing of ideas occurred. Parents’ feedback about this session were positive. They found booklet information objective, detailed and realistic. They felt comfortable talking about their ideas and views in the informal setting. Their only difficulty was that of time: they would have preferred more opportunity for discussion.

Information exchange—Teaching staff: May, 1992

Dorothy’s teacher suggested that information sessions involving teaching staff might also be useful. An information exchange was attended by 15 staff members (both teachers and teacher aides) from Dorothy’s school, and the project team. This session focussed on feelings about menstruation, expectations for women who have high support needs, and examination of possible roles for school staff in relation to menstrual management.

Staff were asked to respond to a questionnaire concerning attitudes relevant to menstrual management. Questionnaire items included: (a) “What are some of the words or phrases that are used for, or used to describe, menstruation?” (b) “In what situations is it appropriate to refer to menstruation as a medical matter?” and (c) “What have been my experiences in the past with young women who have an intellectual disability, and are menstruating?”

In another exercise, two fictitious situations about young women experiencing menstrual difficulties were outlined. One young woman had high support needs; the other did not. Staff were asked to consider what approaches might be appropriate in these situations, and whether there would be any significant differences in approach for the two young women.

At around this time, school staff were considering how menstrual management might be incorporated into school goals and curricula. The team asked participating staff to rate in degree of relevance to the school, a number of possible menstrual management roles. Roles given higher ratings included: (a) facilitating the least restrictive approach to menstrual management, (b) assisting families to be informed about the full range of possible menstrual management approaches, and (c) offering practical support to families for menstrual management.

Feedback from this session indicated that staff found these exercises useful. Prioritisation of roles suggested that staff saw menstrual acceptance and skill development as potential menstrual management goals for their students.

Dorothy's Individual Education Plan: May, 1992

Following the information exchanges for parents and teaching staff, a project representative attended Dorothy's Individual Education Plan (IEP) meeting. She joined Mrs Green, Dorothy's teacher, and the school nurse to discuss Dorothy's educational needs. Menstrual management was identified as a priority.

Feelings about menstruation and disability seemed to be a strong influence on the way Dorothy's impending menstruation would be managed. During administration of the Baseline Questionnaire, some ambivalence in accepting Dorothy's menstruation had been evident: Mrs Green commented that she sometimes thought it was cruel to let disabled women have periods. Perhaps they should have hysterectomies before their periods began. Mr Green was understood to be in favour of a hysterectomy for Dorothy.

At Dorothy's IEP meeting, Mrs Green expressed the hope that Dorothy's experience of menstruation would be similar to that of other girls. She indicated interest in helping to prepare Dorothy for her periods. She thought ideas discussed might also assist her to prepare her younger daughter for menstruation. Mrs Green's receptiveness to such suggestions seemed to indicate a shift in attitude towards a greater acceptance of menstruation for Dorothy. Receptiveness towards menstrual preparation for Dorothy had not been evident in her earlier responses to the Baseline Questionnaire.

After discussion between those present two menstrual management goals for Dorothy were agreed upon—psychological preparation and physical comfort.

The first, preparation for menstruation, was stated this way: Dorothy would understand that her body was changing. She was "growing up." She would have periods. There would be menstrual flow. Strategies chosen to achieve this goal included (a) viewing of the video *Janet's Got Her Periods* (Gray & Jilich, 1990) by Dorothy, her teacher, mother and sister, both at school and at home (this video shows a mother and sister explaining about periods, and demonstrating pad use to a young woman who has an intellectual disability); and (b) charting of Dorothy's menstrual cycle (some cyclical changes appeared to be occurring) to assist Dorothy to be prepared for the likely onset of menstruation.

For Dorothy's physical comfort, the goal was that she would become accustomed to wearing sanitary pads. This was to be achieved firstly by

reducing problems with continence: investigating her bowel disorder, continuing medication for urinary tract infection, and provision of a high fibre diet. Success in this area might allow Dorothy to dispense with incontinence protection, and to use menstrual pads during her periods. (This might be more comfortable and less expensive than continuing the use of incontinence products.) Different menstrual pads were to be trialled, to establish which would be most comfortable for Dorothy.

Conclusions of the case study

This case study seemed to support what the literature suggested: that attitudes towards menstruation for women who have high support needs can be highly variable. Responses from people assisting Dorothy with her self-care demonstrated differing feelings and degrees of comfort with the idea of Dorothy menstruating. Their estimation of her potential menstrual management ability also varied considerably.

Following involvement in processes which addressed the influence of attitudes and experience on menstrual management, staff at Dorothy's school selected menstrual management roles which were compatible with development of menstrual skills and/or acceptance of menstruation for their students.

Subsequent to her involvement in a parent session, and access to a range of information Mrs Green appeared to modify her thoughts about menstruation for Dorothy. She seemed more accepting, and began to see preparing Dorothy for periods as feasible.

Menstrual management goals relating to psychological preparation and physical comfort were agreed upon as realistic. It was anticipated that pad management would be incorporated into Dorothy's IEP at a later stage: Dorothy's teacher hoped to include menstrual skills practice into existing toileting routines.

Discussion

Most young women in our society are prepared in advance for their menarche. Menstruation in our mainstream culture remains taboo, however: something to be discussed only among women, and to be hidden.

The situation is even more complex for women who have high support needs. Suppression or elimination of menstruation among women who have an intellectual disability seems to be widely accepted among people assisting them. Investigation of educational and lifestyle approaches to menstrual management has received relatively low priority.

Feelings people have about menstruation for a woman who has high support needs can affect choices they are likely to consider in response to her menstruation. Attitudes can reflect the devalued status of women who have an intellectual disability, as well as a societal taboo on menstruation. This taboo inhibits discussion, preparation and planning for menstruation.

Outcomes for Dorothy may assist with initial answers to questions addressed by the project.

1. *Can women who have high support needs learn menstrual skills?* Dorothy's teacher planned to incorporate pad management skills into her toileting routine. She and other school staff who knew Dorothy well were optimistic about Dorothy's potential for menstrual skill mastery.

2. *What makes menstrual self-care different from other self-care tasks?* The menstrual taboo and people's expectations for women who have an intellectual disability tend to inhibit discussion and realistic menstrual management planning. The influences of attitudes and expectations among people assisting Dorothy were noted in the course of their involvement with the project. Initial preferences for responding to Dorothy's menstruation differed: some were unsure about, or favoured hysterectomy, while others were confident that Dorothy could master at least some menstrual management skills. These differences did not continue after provision of relevant information, and a forum to share feelings and concerns.

3. *Are menstrual acceptance or partial participation in menstrual management appropriate goals for these women?* For Dorothy, both were considered realistic and important. Strategies to achieve menstrual acceptance were included in Dorothy's Individual Education Plan (IEP). Partial participation in pad management was seen as a realistic future goal.

4. *What are some key factors in developing acceptance of menstruation for women who have high support needs?* Dorothy's family and school were provided with information and practical support. Coupled with an examination of feelings about menstruation and their effects, these strategies allowed people assisting Dorothy to discuss and plan for her menarche in an open and coordinated way. For those assisting Dorothy, these processes seemed effective. Development of policy guidelines may assist in situations where conflict continues, even after employment of such strategies.

The impact of the 1992 High Court of Australia decision requiring consent of the Family Court of Australia for surgical sterilisation is not yet known. What is apparent is the need for practical assistance, such as educational and supportive approaches to menstrual management for women who have high support needs (Carlson & Wilson, in press).

In response to this need, the menstrual management project at The University of Queensland developed resources to assist families, educators, medical and residential staff with menstrual management for these women. The project involved approximately 30 women with high support needs: some were pre-menarchal, others already menstruating. It became apparent that needs for information and support similar to those outlined in Dorothy's case study have been common. Resources developed by the project include the booklet *Managing Menstruation* (Taylor et al., 1993), which provides a range of relevant information; a learning guide to assist people with the knowledge, attitudinal and practical challenges of menstrual management for these women; group processes with similar objectives; planners to identify realistic menstrual management goals and strategies; and a range of menstrual charting media, to facilitate the women's involvement in charting of their own menstrual cycles.

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Sterilisation, drugs which suppress sexual drive, and young men who have intellectual disability¹

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In 1992, the High Court of Australia ruled that all procedures involving the sterilisation of children (other than to treat some malfunction or disease) should be referred to the Family Court of Australia. There has been recent public debate about the sterilisation of young women who have intellectual disability. However, there appears to be very little known about the sterilisation of young men who have intellectual disability. Health Insurance Commission figures indicate that vasectomies and perhaps bilateral orchidectomies are occurring for some young Australian males under 19 years of age, some of whom are under nine years of age. In addition, the use of drugs to alter sexual behaviour in young men with intellectual disability remains controversial. Concerns include sexual behaviour, aggression and other aspects of human relationships of young men with intellectual disabilities. This paper reports on 51 responses to a request for information about sterilisation, drugs and young men who have intellectual disability in Australia. Several issues, including the influence of attitudes and the need for informed decision making are raised.

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INTRODUCTION

Sobsey (1994) has pointed out that people with developmental disabilities have often been targets of intervention that is intended to increase compliance or eliminate undesirable behaviour.

A range of reasons has been put forward to justify the high level of control exercised over people with intellectual disabilities relative to that exercised over people without such disabilities. These include a view that people with intellectual disability are a menace to society (Brown, 1994), a view Wolfensberger (1983) sees as based in society's fear of the unknown; the argument, based in eugenics, that intellectual disability can be controlled by eliminating the reproductive capacity of people with intellectual disability (Sobsey, 1994); and the view that people with intellectual disability are dependent and hence a burden to their families and society at large. These views conclude that it is legitimate to lighten this burden by measures such as sterilisation rather than by exploring lifestyle options (Parsons, 1989).

During research into the sterilisation of young women with intellectual disability (Carlson & Wilson, 1994a; 1994b), respondents provided anecdotes about the use of hormonal drugs and sterilisation among some young men with intellectual disability. These interventions were linked to concerns about anticipated or existing sexual behaviour. This paper reports on an exploratory study of 51 responses to questions about the forms of fertility control service providers were aware were being used with young men with intellectual disability.

The sterilisation of people with intellectual disability

Historically, the sterilisation of people with intellectual disability has been widely viewed as acceptable. For example, it is estimated that more than 70,000 people with intellectual disability were sterilised in the United States under the Buck v Bell legal precedent (Bates, 1987). Smith and Polloway (1993) reported that at a large residential institution in the state of Virginia 212, sterilisations (87 men and 125 women) occurred between 1969 and 1989. In another institution in the United States, 656 castrations (bilateral orchidectomies) were performed to stop the men masturbating (Maurer, 1991). The historical frequency of the sterilisation of people with disabilities in Australia remains unknown. However recent research in Queensland (Carlson, 1994; Carlson and Wilson, 1994a), found that sterilisation had occurred for 15 (50%) of a sample of 30 young women with intellectual disability and high support needs. The families of a further 10 (33%) of the young women had had their menstruation suppressed using hormones or were considering sterilisation surgery.

Reilly (1991), concluded that people who have intellectual disability are at risk of being sterilised for inappropriate reasons such as eugenics (the inaccurate and often ill-informed assumption that the disabled person's child will also have a disability). The acceptance of sterilisation operations in the past for people who have disabilities is sometimes used as an argument for its continuing social acceptability (Duncan, 1989). However, disability advocates are opposed to this argument (Parsons, 1989; Rioux & Yarmol, 1987) because it does not reflect changes that have occurred in recent decades in the educational options and lifestyle opportunities of people who have intellectual disabilities.

Nevertheless, when discussing current issues facing people living with an intellectual disability, Brown (1994, p. 142), stated that "living an ordinary life is a challenge but living an ordinary sexual life, in the sense of exercising rights over your own sexuality, is to live a life of defiance. As yet it is a life which services have done little to support".

Attitudes towards the sexuality of people with intellectual disability

Brown (1994) discussed fears and myths about the sexuality of people with intellectual disability, including stereotypes such as being asexual or sexually deviant. However, the evidence is that people with intellectual disability are more likely to be victims rather than perpetrators of sexual assault (Sobsey, 1994).

Parents and support workers are often concerned that giving knowledge about sexuality to a person or young adult with an intellectual disability will increase the likelihood of that person displaying inappropriate behaviours (Page, 1991). Squire (1989) noted that aspects of appearance, hygiene, health, and social behaviour were important to parents and staff, but not sexuality and personal issues. Similarly, Brown (1994) noted that fertility in people with disability is contentious. She suggested that there are generalised fears about the independence for people with disabilities because of their capacity for procreation, and therefore they are kept in suspended adolescence.

In seeking to clarify the issues encountered by young men with an intellectual disability and their families in relation to sexuality and fertility that may lead to sterilisation, it is important to understand the concepts, values, attitudes and beliefs relevant to intellectual disability, held by these young men, their families and service providers to understand how they influence decision making in this area. Shelton (1992) commented on the influence of personal attitudes, stating:

An individual who presents with sexually-related problems, eg. inappropriate masturbation, may be labelled by one staff member as challenging or as developing by another. It is important for people working with individuals with mental handicap to understand that their own personal, moral and behavioural codes ought to have little, if any, bearing on the way the individual's behaviour is viewed. (p. 81)

Sexual Behaviour

A New South Wales study found that, among prison inmates with intellectual disability 3.7% had committed a sex offence. This is slightly less than among prison inmates without intellectual disability, 4% of whom had committed a sex offence (Hayes & McIlwain, 1988). Characteristics of intellectually disabled sex offenders include poor self concept, poor peer relationships, limited sexual knowledge, a history of early sexual assault (Hayes, 1991). In contrast to sex offenders without intellectual disability, men with intellectual disability have fewer victims and offend against females less often than males (Hayes, 1991). Hayes (1991) noted that pharmacological interventions appear less effective than behavioural interventions for men with

intellectual disability, and stated that there is a dearth of treatment and management options for intellectually disabled sex offenders in Australia. She concluded that:

It is important...to recognise that deviant sexual behaviour by intellectually disabled clients may be a reflection of inappropriate role modelling (including having been sexually abused or exploited by family, care givers or peers), lack of information and education about sexual relationships and body parts, poor social skills, low self esteem, effects of institutionalisation, lack of appropriate sexual partners, lack of early intervention behavioural programs before criminality is reached and a dearth of training and resources. (p.225)

Current legal situation in relation to sterilisation for young men with an intellectual disability

The High Court of Australia decision known as *Re Marion* (1992), requires that all sterilisations of children (under 18 years of age) that do not involve the treatment of a malfunction or disease must be referred for approval to the Family Court of Australia. Since 1992, the only identified Family Court notification of a situation involving the sterilisation of a young man, related to vasectomy. This young man was 14 years old and the proposed vasectomy was for fertility and behaviour management reasons. This matter was diverted from trial under the Queensland Guidelines and Protocols for Special Medical Procedures for Children (Brady & Cooper, 1996), and the family chose not to proceed with the application for the vasectomy because this would not change his behaviour (personal communication, S. Brady, 23 June, 1997).

Decisions about surgical sterilisation and the use of controversial drugs by people with intellectual disability who are 18 years or over are required to be referred to the Guardianship Board or its equivalent in each Australian state or territory, according to local legislation (e.g. New South Wales, Disability Services and Guardianship Act, 1987).

Medical procedures to control fertility and their effects

Drugs used for temporarily controlling male sexuality include the use of Depo Provera and androcur. These drugs block male sexual hormones, reduce sexual drive and reduce sperm production.

Surgical sterilisation procedures for men include vasectomy and orchidectomy. A vasectomy is the surgical removal of a section of the ductus deferens (duct between testis and penis) so that sperm cannot pass out through to the ejaculatory ducts. The term vasotomy is used if the ductus deferens is only cut (Anderson, 1994). Vasectomies and vasotomies do not effect sexual drive. Orchidectomy (or orchiectomy) is the surgical removal of one or both testes. Bilateral orchidectomies (removing both testes), result in sterility and impotence (Anderson, 1994).

No research about the physical effects of sterilisation on young men with intellectual disabilities has been located. However, some physical effects of sterilisation on men

without disability have been documented. In addition, some information about the sexuality of men with intellectual disability and attitudes towards the sexuality of people with disabilities was found in the disability literature.

Physical effects of sterilisation surgery

Bilateral orchidectomy for men with prostate cancer leads to a generalised decrease in bone density, which may result in increased risks of bone fractures (Clarke, McClure, & George, 1993; Tuukkanen, Peng, & Vaananen, 1994). Only some studies into any association between vasectomy and prostate cancer have found an increased risk of developing prostate cancer after a vasectomy. In addition, some, but not all studies have observed increased risks in the man was under 35 years at the time of the vasectomy (Zhu, Stanford, Daling, McKnight, & Stergachis, 1996). Vasectomy has also been associated with chronic pain in one or both testes. Surgery on the nerves in the area is reported to be successful for the majority of men (Ahmed, Rasheed, Whit, & Shaikh, 1997).

Physical effects of drugs which suppress sexual drive

Drugs used to suppress sexual drive in men include Depo Provera, Androcur, stilboestrol (Honvan), goserelin (Zoladex) and some major tranquillisers. Some researchers report the successful use of drugs which suppress sexual drive in conjunction with behavioural intervention with men who commit sexual offences. For example, Gagne (1981) and McConaghy et al (1988) reported the successful use of psychotherapy with Depo Provera for sex offenders. Success is defined as the individual not further offending upon release to the community.

The use of Depo Provera (a progesterone-like drug), by men usually results in an inability to have an erection, reduction of semen production, and absence of orgasm (Murray, 1987). A range of side effects of Depo Provera in women has been recorded, including decrease in bone density and changes in fat metabolism (Cundy, Evans, Roberts, Wattie, Aimes, & Reid, 1991; Kauritz, 1994). Its use with men was not mentioned in the MIMS Annual, 1997. Research with male sex offenders indicated that weight gain and tiredness can occur, but that functioning of the reproductive organs may return to "normal" (Murray, 1987).

Murray (1987), also discussed the use of Androcur (which blocks male hormones) with men who have socially unacceptable sexual behaviour. Androcur reduces the intensity and frequency of sexual drive but does not change sexual orientation or direction. Short term effects can include breast development and breast pain (MIMS, 1997). Murray (1987) suggested that studies into long term effects of Androcur on men have not been undertaken. Hayes (1991, p. 224) stated that "[Androcur] should not be prescribed for men who are aged less than 18 or whose bone or testicular development is not complete, which may be the case in intellectually disabled men with particular syndromes, or delayed puberty".

Stilboestrol (an oestrogen like drug), is sometimes used in the treatment of prostate cancer. Its use has been associated with side effects including blood clotting,

headache, appetite loss, fluid retention, liver changes and change or loss of sex drive (MIMS, 1997). Reference to its use with young men with intellectual disability was not found in the literature, but was reported by a respondent in this study.

Goselerin is another drug used in the treatment of prostate cancer and which decreases sexual drive. It reduces testosterone levels to a range similar to that detected after orchidectomy (MIMS, 1997). Side effects may include hot flushes, breast development and discomfort, and long term health effects remain unclear (MIMS, 1997). One respondent referred to the use of this drug.

Antipsychotic (tranquillising) medications such as Melleril and Modecate, have also been used to reduce sexual drive in men who are sex offenders (Bancroft et al., 1974; Murray, 1987). These drugs may have a number of undesirable side effects including sleep disturbance, sore breasts, arrhythmia (changes in heart rate), increased body weight and tiredness (MIMS Annual, 1997).

Some general concerns about drugs which suppress sex drive in males have been raised. Murray (1987, p.107) suggested that these drugs should not be used with sexually immature males because "they disturb protein, calcium and phosphorus metabolism". Tancredi and Weisstub (1986, p. 268) stated that "We know little about the short-term effects of antiandrogens and long-term consequences may be even more problematic and pernicious. For example, it may take 15 to 20 years before one becomes aware of the long-term and possibly irreversible effects of the medication".

The following concern was raised in the literature specifically about drug effects on young men with intellectual disability. Hayes (1991) commented that young men with intellectual disabilities may not be able to report side effects and bodily changes, and some of their medications may interact with drugs which suppress sexual drive. Concern has also been expressed about the effectiveness of these drugs in eliminating unwanted sexual behaviour, especially if psychotherapy or behaviour support are not implemented concurrently (Murray, 1987; Hayes, 1991).

The Medicare data²

The Family Law Council of Australia (1994), noted that comprehensive national statistics on sterilisation are not available. However, Medicare claim statistics from the Health Insurance Commission of Australia, indicate that boys and young men are undergoing this type of surgery in Australia. From 1988-1994, an average of 27 vasectomies/vasotomies and 83 orchidectomies were undertaken annually on young men under 20 years of age in Australia (See Tables 1 & 2).

However the interpretation of these statistics is difficult because of a number of limitations. Firstly these statistics include only those services which qualify for Medicare benefit and for which a claim has been processed. Therefore, services provided by hospital employed doctors to public patients in public hospitals are not included. Secondly, individual characteristics such as intellectual disability are not recorded. Thirdly, due to Medicare recording procedures, it is not possible to ascertain how many of the surgical procedures were unilateral (which would not sterilise the person) or bilateral (which would sterilise the person). Despite these limitations,

²Medicare is Australia's national health system

Table 1**Orchidectomies* performed** Codes*** = 30638G + 30641S in Australia**

Years	Aged 0-9 years	Aged 10-19 years	Total 0-20 years
1988-1989	34	51	85
1989-1990	39	34	73
1990-1991	45	65	110
1991-1992	37	49	86
1992-1993 (not including code 30638)	28	42	70
1993-1994	35	41	76
Total Australia 1988-1994	218	282	500

*Orchidectomy is the surgical removal of one or both testes, and produces sterility and impotence (Anderson, 1994).

**These figures include only those services which qualify for Medicare benefit and for which a claim has been processed. These figures do not include services provided by hospital doctors to public patients in public hospitals.

***Indicate codes recorded on Medicare claim forms. The orchidectomy procedure is recorded as unilateral in the code. However, the Multiple Operation Rule applies to these codes. Health Insurance Commission statistics operate according to the Multiple Operation Rule (MOR), which means that if a procedure is bilateral, the item is recorded twice, but not as a separate code. The statistics therefore do not indicate the numbers of people but the number of item services performed (representative of the Health Insurance Commission, personal communication, 16 January 1995).

These figures have been obtained from the Australian Health Insurance Commission, 1995.

Table 2**Vagotomies/vasectomies* performed**Codes*** = 6249, 6253, 37622, 37623 in Australia**

Years	Aged 0-9 years	Aged 10-19 years	Total 0-20 years
1987-1988	35	11	46
1988-1989	16	10	26
1989-1990	12	17	29
1990-1991	11	7	18
1991-1992	8	19	27
1992-1993	9	12	21
1993-1994	7	15	22
TOTAL 1987-1994	98	91	189

*Vasectomy or vagotomy is a surgical procedure which severs the vas deferens so that sperm cannot pass to the ejaculatory ducts, without affecting potency (Anderson, 1994).

**These figures include only those services which qualify for Medicare benefit and for which a claim has been processed. These figures do not include services provided by hospital doctors to public patients in public hospitals.

***Indicate codes recorded on Medicare claim forms, unclear whether unilateral or bilateral.

These figures have been obtained from the Health Insurance Commission, 1995.

questions have been raised publicly on the basis of these Medicare statistics as to why boys of nine years of age or less would undergo a vasectomy, and whether any of these surgical procedures involve young men with disabilities (Family Law Council, 1994). The possibility of a discrepancy between the number of Family Court applications and Health Insurance Commission statistics was raised publicly on the *7.30 Report* (ABC Television, 22 April, 1997).

In summary, there appears to be a lack of documented information about the sterilisation of young men with intellectual disability in Australia. However, a number of potential concerns are raised in the literature, such as long-term health effects and inadequate support services to enable socially acceptable sexual expression to be learned, and the use of non-invasive methods of contraception. Therefore this research aimed to ascertain whether information relating to sterilisation or use of drugs which suppress sexual drive with young men with intellectual disability exists within Australia.

METHODOLOGY

Letters were sent to 81 individuals or organisations involved in the provision of services to people with intellectual disability, throughout Australia. These letters requested information about vasectomies, orchidectomies and the use of sex drive suppressing drugs with young men who have intellectual disabilities. This paper reports on the 51 responses provided in relation to these letters.

Qualitative analysis of the responses was undertaken. This involved categorising of the respondents into four occupational groups (see Table 3), summarising the information provided by the respondents in each area and identifying the range of emerging issues referred to within each group. Examples of specific information provided by respondents were selected to illustrate issues raised.

Table 3
Number of responses according to occupational groups

Occupational group	Response
Legal (e.g. individuals involved in state guardianship boards, including public advocates)	14
Educational (e.g. individuals working in state education departments)	4
Medical (e.g. individual medical practitioners and professional medical organisations)	11
Disability (e.g. individuals from direct support or advocacy services for people with intellectual disability)	22
Total	51

RESULTS

Respondents were involved in either legal, medical, educational or disability service provision. Their responses are outlined according to three groups: legal, medical, and educational/disability.

Legal respondents

Responses were received from staff of the Family Court of Australia, the Legal Friend in Queensland and staff associated with Guardianship Boards in Victoria, South Australia and Western Australia and the Adult Guardian in the Northern Territory. Redfern Legal Service also provided information. The Boards and Guardians all commented on a small number of situations that they had dealt with in this area. The reasons for sterilisation being requested in the total of seven situations that they reported included orchidectomy for cancer (two), and vasectomy contraception (six, including two disallowed). In the seventh situation an orchidectomy was sought by a transsexual man. The use of drugs to suppress sexual drive was mentioned in six situations all of which were associated with sex offences.

The Public Guardian of Western Australia outlined a number of anecdotal cases from the Public Guardian's archives and commented on the lack of processes for facilitating informed decision-making. One young man with Down syndrome was vasectomised to "protect against the possibility of getting a woman pregnant". His family were unaware of the generally low fertility of men with Down syndrome. The young man involved was not aware of the operation or of its effect. In a second situation, a young man was told that unless he agreed to vasectomy, he could not marry his fiancée. He did not give informed consent and was apparently coerced into the sterilisation. He was reportedly disturbed by the outcome and needed months of counselling. A third situation involved an orchidectomy after a severe injury to both of a young man's testes (personal communication, Public Guardian of Western Australia, 9 May 1995).

The Public Guardian of Western Australia also outlined records of the use of the drug stilboestrol with four young men with intellectual disability. The reasons for its use were unstated but whilst using the drug it is recorded that the men developed breasts and some lactated.

Medical respondents

Discussions with two paediatric surgeons (personal communications, 31 January 1995, 23 May 1995) suggested that there would be no therapeutic reason for performing a bilateral orchidectomy on a child or young man under 20 years of age. Bilateral orchidectomies are commonly performed on men over the age of 80 years who have advanced testicular or prostate cancers. Postpubertal unilateral orchidectomy (on one testis only) would be performed for cancer of the testis, for undescended testes which had been undetected until later years or, most commonly, for torsion or twisting in the testes. Paediatric surgery practice can involve prepubertal unilateral orchidectomy for torsion.

The respondent from the Australian College of Paediatrics (personal communication, 18 May 1995) stated:

Orchidectomy is usually performed for various disease states including torsion and tumour. Another indication could be to attempt to control rage attacks with aggressive sexual overtones, although this must be quite a rare indication. It would not be performed simply for fertility control.

There was a difference of opinion amongst medical respondents about whether or not the Medicare statistics for orchidectomy reflect the incidence of torsion and testicular cancer for men younger than twenty in Australia. Some indicated that these would all be accounted for by torsion. Others indicated that the figures probably exceed the incidence of torsion of the testes in this age range.

A representative of a Family Planning Association (personal communication, 20 April 1995) stated that it does not perform vasectomies on men under 25 years, nor does it provide Depo Provera, Androcur or goserelin to any men. The Association could not understand why vasectomy would be performed on pre-pubescent boys, as it is usually performed as a means of fertility control.

A representative of the Australian College of Paediatrics (personal communication, 18 May 1995) stated:

[Vasectomies] would be an appropriate form of fertility control in intellectually handicapped males who could complete intercourse. Needless to say, there needs to be an extended process examining the competence and potential competence of the individual and his ability to form relationships, together with the potential effect of infertility on that ability and his personal satisfaction with the relationship under those circumstances. If the intellectual handicap is based on an inherited disease, an additional factor may require consideration. If vasectomy was to be performed, effort should be made to collect and store semen prior to vasectomy for potential subsequent insemination.

Investigation of the incidence of, and ascertaining reasons for these surgical procedures, is difficult since the rationale for any of these procedures does not have to be recorded by the operating surgeon for Medicare Data, and the Health Insurance Commission is unable to assist researchers to contact the medical practitioners involved (representative of the Health Insurance Commission, personal communication, 8 July 1997).

The individual medical practitioners and representatives from medical associations who responded, made very few comments about the use of drugs with men. A representative from a Family Planning Association (personal communication, 20 April 1995) stated that Androcur or Depo Provera is used to treat hypersexuality in male sex offenders.

A representative from the Australian College of Paediatrics (personal communication, 18 May 1995) stated:

The use of hormonal drugs such as Depo Provera or Androcur would be less effective and less reliable methods of fertility control in men, and I have little information on its use in young men in this regard.

Educational/Disability service respondents

This group includes educational and advocacy services. It also includes support services for people with intellectual disability. Respondents from state government educational services indicated no knowledge in relation to the topic even though many of the young men involved would be attending schools. This may reflect a lack of centralised information, as any relevant information would apparently remain at a school level.

This pattern is similar for various state government intellectual disability services. At a central level there was relatively little information, though at a regional level more detailed, though anecdotal, information was forwarded. For example, a spokesperson for a State Government Disability Service (personal communication, 25 May 1995) commented on these issues being an "unknown" area. This organisation provides accommodation and support services to people who have intellectual disability and high support needs. A staff member from a region of the same organisation commented that "several" young men who lived in rented homes or in hostels were being given Androcur (personal communication, 16 May 1995). The reasons include sexually inappropriate behaviours and sexual offences. It is stated that Androcur in these situations is prescribed by general medical practitioners. Since these staff members made these comments, the organisation involved has included guidelines for staff in relation to sterilisation and the use of hormonal drugs in a Health and Well-Being Practice Manual (1996).

Similar information was provided by a manager of a non-government community based housing program. This respondent discussed a number of situations where young men have been prescribed hormonal drugs or surgically sterilised (personal communication, 2 May 1995). One young man, aged 24, was prescribed Androcur because his parents were concerned about the attention he was giving to young school girls. Consent was obtained through the office of the appropriate public guardian. The young man was not aware of the reasons for taking the drug. A second young man, aged 16, was prescribed Androcur in conjunction with sexual counselling following a sexual assault on his sister. A third young man, aged 19, was taken by a disability support worker to a general practitioner and was placed on Androcur. The medical practitioner told him that the pills would "slow him down from going out too often". The man was not aware of why he was on the drug. A fourth young man was placed on Androcur to suppress his sex drive. The family's general practitioner placed him on the drug as a result of a request from the young man's mother. This young man developed female characteristics, including breast enlargement, as a result of this treatment. A fifth young man, aged 14, had a vasectomy following an incident where he touched a young girl. His parents organised the procedure through the family's general practitioner.

Respondents from advocacy services for people with intellectual disability commented that they had very little documented information, although they could recount personal anecdotes of finding out indirectly about sterilisations of young men. Several advocacy services suggested that parents who used their services on many other occasions, did not approach them in relation to this issue because they suspected that the advocacy service would not support sterilisation decisions.

Given the apparent link between the sterilisation of young men who have disabilities and sexual offences, correctional and mental health services may also have relevant information. However, the mental health service approached did not reply and due to the limited scope of this study no correctional services were contacted.

DISCUSSION AND CONCLUSIONS

Unlike sterilisation or menstrual suppression in women, sterilisation or drugs with men may not be readily observed by carers. The above responses indicate that surgical sterilisation and the use of drugs to suppress sexual drive have occurred with boys and young men with intellectual disability in Australia. However, information about the incidence, the reasons for, and decision-making processes are not being collated by any person or organisation.

Some issues raised in the literature were reiterated by some of the respondents, for example, concerns about physical effects for the young men using the drugs. Similarly, for some men with intellectual disability, communicating post-surgical sterilisation discomfort and its location may be difficult and may be interpreted as challenging behaviour.

However, unlike the literature, none of the respondents directly commented on the influence of attitudes on sterilisation or drug decisions. However, attitudes towards the sexuality of people with an intellectual disability probably do influence the ways in which problems are defined and solutions are identified. For young men with an intellectual disability, the issue of their sexuality may be defined in terms of sexual deviance and controlled with surgery, drugs or imprisonment. As indicated by some of the respondents, drugs or surgery may be chosen even if a young man has shown no interest in sexual activity or has not harmed others in expressing his sexuality. In particular, vasectomies for prepubescent boys are questionable, given that they have not physically matured and have not established preferences for sexual expression. Sterilisation of postpubescent adolescent men is also questionable, given that it would not be considered for young men without disabilities of the same age.

An additional issue raised by some respondents was the need for informed decision-making. This included the inadequate nature of the involvement of the young man in some of the decisions. Informed decision-making by the young man and by substitute decision-makers would minimise irreversible decisions being made which are based on inaccurate assumptions that may be regretted at a later date. Education and disability services should ensure that human relations education and appropriate role models are available to all young people.

There appeared to be a gap in knowledge between centralised administrators of some services and the experiences of direct service providers. Consequently there was also a gap in knowledge about why decisions about sterilisation and drugs are being made, the characteristics of the young men for whom such decisions are made and whether they have consented to these procedures. The literature discusses young men with intellectual disability who commit sexual offences. Very little is documented about how the large majority of young men with intellectual disability experience their sexuality or exercise control over their fertility.

In conclusion, it is recommended that decision-making processes be investigated that involve young men with intellectual disability and substitute decision-makers, in relation to sterilisation and the use of drugs which suppress sexual drive. Secondly it is recommended that information about legal consent processes involving people with intellectual disability be publicised (perhaps repeatedly) through family, professional and disability networks. Finally it is recommended that services for people with disabilities identify and address gaps in policy and service provision relevant to this topic. For example, human relations education for young men, and relevant information and practical support for families should be readily available.

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BACKGROUND PAPER



Sterilisation of people with disability

**A paper relating to the development of a
position paper and policy statement by
Queensland Advocacy Incorporated**

November 2004

From United Nations Declaration of Human Rights

Everyone has the right to life, liberty and security of person. (Article 3.)

No one shall be subjected to torture or to cruel, inhuman or degrading treatment or punishment. (Article 5.)

All are equal before the law and are entitled without any discrimination to equal protection of the law. (Article 7.)

Motherhood and childhood are entitled to special care and assistance. All children, whether born in or out of wedlock, shall enjoy the same social protection. (Article 25.)

From United Nations Declaration on the Rights of Disabled Persons

Disabled persons shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature. (Article 10)

From UNICEF Convention on the Rights of the Child

States Parties shall take all appropriate legislative, administrative, social and educational measures to protect the child from all forms of physical or mental violence, injury or abuse, neglect or negligent treatment, maltreatment or exploitation, including sexual abuse, while in the care of parent(s), legal guardian(s) or any other person who has the care of the child. Such protective measures should, as appropriate, include effective procedures for the establishment of social programmes to provide necessary support for the child and for those who have the care of the child, as well as for other forms of prevention and for identification, reporting, referral, investigation, treatment and follow-up of instances of child maltreatment described heretofore, and, as appropriate, for judicial involvement (Article 19)

States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community. States Parties recognize the right of the disabled child to special care and shall encourage and ensure the extension, subject to available resources, to the eligible child and those responsible for his or her care, of assistance for which application is made and which is appropriate to the child's condition and to the circumstances of the parents or others caring for the child. (Article 23)

Contents

1.	Why are we writing this now?	4
2.	What are the historical conceptions and myths about people with disability that have led to their sterilisation?	5
3.	What recent significant milestones have led to the current legal position on sterilisation?	14
4.	What is the Australian and Queensland law relating to sterilisation?	24
5.	What happens when a girl or young woman is sterilised?	28
6.	What happens when a boy or young man is sterilised?	38
7.	What are the arguments and counter arguments central to sterilising people with disability?	40
8.	What are the arguments and counter arguments central to bodily integrity?	45
9.	What are some key systemic concerns which perpetuate the sterilisation of people with disability?	48
10.	A Final Word	49
	References	51

1. Why are we writing this now?

Sterilisation of people with disability has continued in Australia for many years. Common arguments for such invasive procedures to be carried out on girls, boys, women and men with disability have usually been related to others' concerns about their sexuality, their inability to cope and fear of menstruation and pregnancy. Such depictions have been common throughout history, with the expression of sexuality of people with disability being questioned and disfavoured. Despite great attitudinal and lifestyle gains for some people with disability in recent decades, this area has remained very contentious especially when significant disability or cognitive impairment is involved. Only as recently as March this year, photos of people with disability depicted in loving embrace have been condemned and withdrawn from public view here in Australia.

To probe further into this area of our national psyche raises many questions about far deeper attitudes and values about people with disability, way beyond those of sexual expression. Superficial analysis can fail to probe into much more entrenched beliefs that are held about people with disability, which lead to unnecessary violation of their bodies and their rights. By probing deeper, it is also difficult to ignore the intrinsic links between sterilisation and eugenic ideals which have continued to pervade our thinking over generations.

Since Australian legal precedent set in 1991, establishing the need to gain court authorisation for children, and later guardianship tribunal authorisation for people with impaired decision making capacity, the number of known sterilisations performed each year has fallen. However sterilisations are still being done without court or tribunal authorisation. (QAI; Brady, 2001) There is still evidence of young girls and boys, as well as young women and men being sterilised, although how many is questionable, given they may be confidentially arranged and be hidden from public scrutiny, given the legislative rulings.

Yet despite much debate, with efforts to legislate and have court processes setting legal precedents, we may be not much closer to attitudinal change or to definitive legislation and practices that will adequately protect people with disability from being sterilised. (Fellows, 2000) This is especially so for people with intellectual or other cognitive disability whose families have little information and practical support to reject such a solution.

This background paper explores what is known about sterilisation of people with disability to clarify the current situation. QAI plans to raise the profile of this issue and to influence good policy and practice, so that the people who have little voice in this debate and who are vulnerable to such practices can have proper protection and supports.

Sterilisation is still happening illegally at unknown levels, often with families having little information or support to reject such a solution

This paper clarifies the current situation, with QAI's intent being to raise the profile of this issue, to influence good policy and practice, and to protect those with little voice in this debate

2. What are the historical conceptions of people with disability that have led to their sterilisation?

Ancient Times

Biblical Times

Throughout the ages, people with disability have been caught up in the cruel and heartless historical events of their time. In order to understand current conceptions about people with disability, it is important to reflect upon the long-term collective consciousness that has been built up over millennia, perpetuated by societies, religions and civic leaders. Negative attitudes, myths and stereotypes have been reinforced over time so that ingrained beliefs are very much a part of our national psyche. Interestingly, such values have resulted in sterilisation being intrinsically linked with the death of people with disability in different eras.

In ancient times, in line with the linking of body and soul together, and the worshipping the body beautiful by the ruling classes of Ancient Greece and Rome, a vital society was seen to be one needing to weed out those who did not fit or could not contribute to such ideals. Aristotle and Plato pled for a law that no deformed child should live, advising parents to do away with an imperfect baby with clear conscience. Hippocrates posed the question about which children should be raised, and Soranus suggested that the art of childrearing included recognising which children were not worth bringing up. (Winzer, 1993)

Because children were seen as the property of the state, their fitness was monitored by elders who examined new born babies and watched their fitness, as well as their potential citizenship, breeding and warrior status, in order to protect the state. It was expected that Greeks took on the responsibility for the ensuing actions about their children, with fathers making the decision about whether a child was killed, exiled, or sold, based upon the perceived burden to the family and the state. (Winzer, 1993) Children with disability featured highly in these practices.

Spartans threw impaired children off cliffs and Athenians put them in jars by the temple where they starved to death. (BFI, 2003) Other European countries also practiced sacrificial burnings. Such practices reinforced the notion that good equals beautiful and disability or deformity equals bad, and that families and society were far better off without these imperfections.

In Biblical times, malevolence as well as benevolence was practiced. Reinforced by the scriptures, sinning was seen to be associated with impairment with the result that people with disability could not hold membership of religious congregations, being denied the opportunity to take communion or to become a priest. (Leviticus, Chapter 21) This was further reinforced by the notion that, if the person's sin were renounced they could 'take up thy bed and walk' (Luke, Chapter 5).

Biblical Times

Fontaine (1996) has put forward several ways that these Biblical notions were reinforced in the daily life of the times:

- Disability was presented as a potent reminder that woundedness and death was close for all, so close, that impaired people were seen to be experiencing a non-enviable death-in-life experience.
- Anything that threatened a woman's ability to be a fertile, able sexual partner was considered disastrous, denying her a rightful place in society, and not only that, she was rendered ritually impure by nature of her continuing to menstruate, making her a further object of pity and scorn.
- Malicious spirits or worship of other deities were seen to be responsible for the brokenness of the person with disability, setting the person apart as marked or cursed.
- Holiness could never be achieved by imperfect people, as the Lord had said to Moses 'None of your descendants throughout their generations who has a blemish may approach to offer the bread of his God' (Leviticus, Chapter 21), going on then to name blindness, lameness, mutilation of the face, limb too long, injured foot or hand, hunchback, dwarfism, sight defect, itching, scabs, and crushed testicles as examples of imperfection.
- Disability was seen as divine action to show off the power of God, so that if healing did not happen, the person with disability must be an agent of sin, or possessed by demons.

Disability was therefore associated with punishment from God, and could 'be cured if you sin no more,' (John, Chapter 9.) Such conceptions reinforced the idea that disability was retribution for a sinful life, with the person with disability playing the role of scapegoat in carrying the burden of sin and evil for all, often leading to death or banishment on the margins of the community.

The Middle Ages

At times of social upheaval, plague or pestilence during the middle ages, people with disability were also made scapegoats, being perceived as the sinners or evil doers who brought disasters upon the whole society. The horror of becoming disfigured or different was very powerful. At this time people without any disability would indulge in self-flagellation to become more holy by renouncing their sins. They believed that such penitence avoided their becoming sick or impaired.

An extension of this belief was later seen in the Inquisition and the witch hunts of the era. A most popular book of the day explained how to identify witches either by their impairments, or by their creation of impairments in other people, or by their having given birth to a child with disability. (BFI, 2003)

Millions of people, mainly women, were put to death throughout Europe at this time. Many who were sacrificed had some form of disability, or were a parent of a child with disability, or merely only had an association with a person with disability.

During the reformation, Martin Luther, the founder of the Protestant church, advocated that a changeling born with a disability be taken to the river and drowned to shun the evil forces that were felt to be ever-present and in possession of the child's body, in the place where his soul should be. (Scheerenberger, 1983) Around the same time in Holland, people with leprosy were shunned and an edict was passed that these sinful, evil people have all their worldly goods confiscated by the state, with the expectation that they be supported by the alms of those who were not stricken. The belief continued to perpetuate the idea that penitent sinners would gain reward in heaven, if, of course, they were humble enough.

For the next 500 years, the personifications of evil, moral weakness and powerlessness continued to be shown in literature as caricatures of people with disability. Many were also used as objects of ridicule and the butt of cruelty, being portrayed as freaks and fools to provide entertainment for the upper classes. Stories of the 'ship of fools' were rife at this time, whereby people with psychiatric disability were shipped from harbour to harbour to rid a city of their perceived menace and to provide entertainment for the masses when they arrived elsewhere. (Foucault, 1988)

As the industrial revolution loomed and productivity took on a new meaning, people with disability were rejected as part of the work force. At this time, they became increasingly dependent on the medical profession for fixes, cures, treatments and benefits, and the institution was born. However it was not long before the distinction between care and punishment became obliterated. (Clapton, 1999)

Towards the end of the 1800s a popular movement backed by scientists, writers and politicians began to interpret Darwin's theories of evolution and natural selection for what they saw as the common good of society. Active eugenicists set upon people with disability with the intent of their elimination, arguing that doing so was in line with natural selection and survival of the fittest.

Led by Galton, they believed that the quality of the human race could be improved by selective breeding and argued that impaired people, especially those who were born with disability, would weaken the gene pool and reduce the competitiveness of the nation. Again, defectiveness was something to be eliminated, or at least contained.

The Reformation

The Industrial Revolution

Social Darwinism

The Eugenics Movement

A key tenet of the Eugenics Movement was that the improvement of the race or breed could be managed by the control of human mating. This saw the rise of restrictive marriage and reproductive laws prohibiting sanctioned partnership or sexual intercourse involving anyone with intellectual disability or epilepsy, as well as other women of reproductive age with many other impairments. This resulted in compulsory, involuntary sterilisation, and institutional isolation with sexual segregation. (Sobsey, 1994)

Eugenicists at the turn of the century put forward the recommendation that children with intellectual disability should be detained for the whole of their lives, this being seen as the only way to stem the great evil of feeble-mindedness of a country. This was followed soon after by an International Congress outlawing sign language, as it was feared that deaf people would outbreed hearing people.

Hitler's Germany

The eugenics movement flourished even more at the time of European empire building and warfare, where the dominant belief was to create empires superior to those of other cultures and races. In wartime Germany, Hitler authorised a series of propaganda films to show how disabled people were useless consumers of the Nation's wealth and a burden on the state. (*Sins of the Fathers, Off the Path, All Life is a Struggle, What You Have Inherited, and Heredity.*) These documentaries plus the feature films, *I Accuse* and *Victims of the Past*, helped audiences to sympathise with this view and to justify compulsory sterilisation of people with disability and, later, what has euphemistically been called mercy killing. (BFI, 2003)

The assertion was two fold, in that sterilisation and mercy killing were being performed to benefit the victim, as well as for the well being of the nation as a whole. (Sobsey, 1994) The result was that 140,000 adults with physical and intellectual disability were murdered in 1939-40 at the hands of the doctors and further killing of over 100,000 children with disability continued until 1945.

Churchill's Britain

However eugenic conceptions were not isolated to Germany. Winston Churchill was a key supporter of the British Eugenics Society, as were Sidney and Beatrice Webb, founders of the English Labour Party, as well as many other influential intellectuals from both the left and right of politics in Britain. Churchill's infamous parliamentary speech indicates the feelings of the time about people with disability. "*The unnatural and increasingly rapid growth of the feeble minded classes, coupled with a steady restriction among all the thrifty, energetic and superior stocks, constitutes a race danger. I feel that the source from which the stream of madness is fed should be cut off and sealed up before another year has passed.*" (BFI, 2003)

The mid 20th Century continued the trend of increased institutionalisation and sterilisation of people with disability in developed countries. In Sweden, between 1935 and 1976 around two thirds of girls with intellectual disability were sterilised under the guidance of the National Institute for Racial Hygiene. The number has been estimated to be around 60,000 Swedes, with the ironic twist that Sweden was seen to be a country that was the stronghold of enlightenment and tolerance at this time. It appears that similar attitudes and values were held throughout Europe, with wholesale sterilisation practices being uncovered in Norway, France, Austria and Czechoslovakia. (Walsh, 1997)

In the USA, by the middle of the 20th century, thirty seven states had passed sterilisation laws, the first being in 1907. It has been estimated that 70,000 people with disability were sterilised by 1960 following a failed constitutional challenge in 1927 set by the legal case Buck v Bell. (Bates, 1987) The outcome of this case ensured that anyone residing in State Institutions having an intellectual disability, or anyone with a mental illness, or any woman who was congenitally deaf, would not be seen as eligible to reproduce. Such moves were supported by the Human Betterment Foundation with substantial support in California, where around 8,000 sterilisations happened within the first five years following the case. (Park and Radford, 1998) Later the pseudo scientific IQ tests were used as the basis for determining intellectual disability and deeming which people were eligible for sterilisation. (Bates, 1987)

Seventeen US states still retained sterilisation laws on their statute books as late as the 1980s. Between 1969 and 1989, in one institution in Virginia, 212 sterilisations were performed on 87 men and 125 women, (Smith and Polway, 1993) and in another institution in the US, 656 castrations were performed to stop men with disability from masturbating. (Mauer, 1991)

This situation also confirmed the belief that people with disability are morally defective. In fact this term was used to define those *'in whose case there exists mental defectiveness, coupled with strong vicious or criminal propensities and who require care, supervision and control for the protection of others'*. (BFI, 2003)

Although early Australian statistics are unknown, general knowledge about sterilisation of girls and young women with disability was commonplace. Between the two World Wars, sterilisation was supported by the medical profession as a prerequisite for discharge from hospital for women with intellectual or psychiatric disability. (Goldhar, 1991)

**Wide acceptance of
Eugenics**

**Institutionalised
responses**

**The mid
20th Century**

**The Australian
Scene**

Medical cooperation

Interestingly, Sobsey (1994) notes that no other profession has cooperated as enthusiastically with the notion and practice of sterilisation and eradication of people with disability than the medical profession. This appears to have been the case here in Australia.

Late 20th century Australia

In Queensland, as late as the 1970s, some young women with mild intellectual disability were institutionalised in Wolston Park and Challinor Centre or placed in church based homes for girls following pregnancy. Others who were deemed morally defective or in moral danger, were put into Karala House, a closed ward in the grounds of Challinor Centre, on their admission of sexual activity. (personal knowledge of author)

In moral danger

This label of 'in moral danger' was used with people with disability who showed any interest in sexual activity or who entered into a relationship, with the result being that they could be picked up by the police and detained. It seems that sometimes women were held long term at 'Her Majesty's Pleasure', a term used under the Mental Health Act to keep people incarcerated, especially if it were known that the woman had had a number of sexual partners.

One young woman who had post natal depression following the birth of her first child was admitted to a state institution for treatment. Following her release, she became pregnant again and was readmitted, deemed as being in moral danger. She never knew what happened to her children, lost contact with her family and was an isolated, lonely woman on her release back into the community in the late 70s, some two and a half decades later. (story known by author)

Sexual suppression

Men living in institutions at the time were also given bromide and other forms of sexual suppressants such as female hormones to avoid the likelihood of any sexual activity. One man, on visiting his psychiatrist ready for release from one local institution, was asked what he wanted to do with his life. He responded that he would like to find a good woman to marry so that he could have a sexual relationship. He was not released and was discovered several years later with large breast development following female hormone treatment that had never been reviewed. (personal knowledge of author)

Although there was no public admission of what went on behind the closed doors of institutions, some surgical sterilisation did happen, usually discovered only after the event. When one young woman with intellectual disability was found to be pregnant in the mid 1970s, she was whisked away to have an abortion and to be sterilised so that this situation would not happen again. The fact that she had been raped was not addressed. (story told to author)

It was also common knowledge in the 1970s and 80s that many teenagers with cerebral palsy, who were still at school and living in boarding or hostel facilities, had hysterectomies as standard procedure, often on the advice of the in house nursing and medical staff. This operation often happened at the same time as when they had their appendix out. These girls are still around to tell their story today. As mature women, some of whom have since formed intimate relationships, many are questioning the action of their parents, especially those who have had complications following surgery.

This situation also happened with other young girls who had a disability. As recently as the late 1980s, a university student with a heart condition was stricken to find out accidentally from her brother that she had had a hysterectomy in her mid teenage years when she had her appendix out. As she was in a relationship with another student, she had become very concerned about her lack of periods and what she should be doing about contraception. Her mother and doctor had apparently decided she should not have children and made the decision to do both operations together without her knowledge. To add insult to injury, everyone else in the family knew about her situation. (personal story told to author)

Prior to Marion's case in 1991, following which sterilisation could only be approved by tribunal or court, many families of young girls with disability would speak quite openly about the issue of sterilisation, some contacting professional staff to discuss the issues and to seek further advice. However since the landmark case requiring legal approval, there has been no real engagement around the issue, which appears to have gone underground. (statement from worker, 2004) Therefore it is difficult to know what the current situation actually is.

In the 1990s, Queensland researchers found that 15 of a sample of 30 young women with intellectual disability, who had high support needs, had been sterilised. A further 10 young women had their menstruation suppressed using hormone treatment with some of their families also considering sterilisation as an option. (Carlson and Wilson, 1994, b)

This showed that 83% of this sample of young women had some form of surgical or chemical intervention. An implicit assumption held by their mothers appeared to be that sterilisation was the accepted common practice when the person had high support needs. It appeared to be the natural thing to do, with the precedent being seen as a key argument for its continuity and social acceptability. (Carlson and Wilson, 1994, b)

Parents advised to sterilise girls with cerebral palsy

Appendectomy?

Marion's landmark case sent debate underground

83% of a sample of young women with intellectual disability with high support needs had surgical or chemical intervention

***500 castrations
and 189 vasectomies
on males under 20
years of age***

***17 sterilisations of
young girls and women
authorised out of the
small number known to
be recorded of 1,045***

Into the 21st Century

***The law fails to protect
vulnerable people and
the community aids and
abets the abuse***

Some Australian data is available about men and women who have been sterilised, although it is difficult to interpret.

Medicare claims between 1988 and 1994, showed 218 boys had their testes removed and 98 had vasectomies under nine years of age with a further 282 and 91 teenagers having had similar procedures aged between the ages of 10 and 19. (Carlson, Taylor and Wilson, 2000) Yet there would be few medical reasons, if any, as to why these procedures would happen to any male of this age.

Claims between 1992 and 1997, showed around 200 sterilisations of young girls were performed in Australian hospitals every year. During this time only 17 procedures had been authorised via court or tribunal hearings out of a total of the 1,045 recorded via Health Insurance Commission statistics. (Brady and Grover, 1997) This raises the question as to whether most of these were of healthy girls with intellectual disability, given there are very few therapeutic reasons as to why sterilisation should happen at this young age. Although this data was refuted by government, (Senate Report, 2000) the low alternatives put forward were equally as controversial, with codes open to interpretation, especially when claims are not kept after two years and anecdotal evidence does suggest otherwise.

By the end of the 20th Century, attitudes, practices and laws relating to the sterilisation of children and adults with disability have continued to vary widely. Canada has been seen to have the most restrictive laws and practices and New Zealand, the least. (Law Reform Commission of Western Australia, 1994)

Despite the legal precedents and new legislation here in Australia, the record suggests that unauthorised sterilisations have continued to be performed, albeit at unknown rates. Although official numbers have reduced further since 1997, unauthorised sterilisations still continue to be done into the 21st century. (Grover and Brady, in Skene and Nisselle, 2002) This has led to the suggestion that, despite such progress, the law has failed to protect vulnerable people with disability from sterilisation, with the community aiding and abetting this continued abuse by funding it through Medicare. (Brady and Grover, 1997) However now it is much harder to track, as the evidence has been well hidden and the debate about sterilisation has been silenced.

Recent international evidence supports this finding indicating that many young people with disability continue to face forced sterilisations world wide, with women with intellectual and learning disability having even greater chance of having forced sterilisation or abortions without proper consent. (la Rivière Zijdel, 2004)

Most women with disability also continue to be discouraged to become pregnant and to take on the role of mother. Evidence supports that they are given false information about their physical capabilities to bear children, with the medical world denying conception, and highlighting to potential mothers the criminal nature of their behaviour if they were to become pregnant.

Such situations have been seen to maintain the status quo in a modern context, whereby *the human beings who were once sterilised as threats to racial purity, burned as witches, or sent to the gas chambers in the past, are now being allowed to die for their own good, or to be sterilised for hygienic reasons, or the alleged inability to raise children in this era.* (la Rivière Zijdel, 2004)

The view of the person with disability as a menace to society and one to be feared continues to fuel those who hold similar beliefs to those of the old eugenics movement. The stereotype of sexual deviant still fits, with the view that eliminating people's capacity to reproduce will bring about a much better and safer society. (Wolfensberger, 1983) These commonly held, underlying beliefs, together with the alternative notion that people with disability are eternal children, asexual and dependent burdens to family and society, continue to legitimise the decisions to sterilise, rather than to explore what can be considered much more reasonable and practical options that relate to a valued person and their lifestyle.

Our historical record continues to build upon these myths with deep-seated beliefs played out by our service systems and communities today, overtly and covertly. The poor treatment of people with disability and the infringement of their human rights continues with responses that segregate and create institutional forms of care, where people with disability are still objectified and their basic dignity and humanity do not feature highly. These responses, and lack of support to community based alternatives, continue to be used to justify the high control over people with disability's reproductive capacity, with interventions that are intended to increase their compliance or to get rid of undesirable behaviours. (Sobsey, 1994)

However it has been suggested that deeper meaning can be attributed to these responses, whereby the basic presumption is that people with disability, especially those with intellectual or psychiatric disability, are actually seen to provoke and invite such abuse. The inability of the person with disability to comply with the prescribed social standards can be seen to be reason enough to elicit punishment, with abuse and violence to the person not only being legitimised, but also being condoned through the socially sanctioned, highly oppressive behaviour of others. (Waxman, 1991)

People with disability are now being allowed to die for their own good, or to be sterilised for hygienic reasons, or the alleged inability to raise children in this modern era

People with disability are still seen in stereotypes, either as a menace to society and to be feared or as an asexual, dependent burden

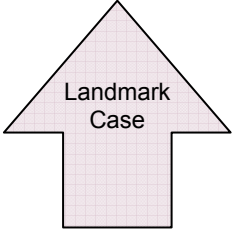
Should blaming the victim's inability to conform give others permission to despise, and condone violence and abuse?

3. What recent significant milestones have led to the current legal position on sterilisation?

In the late 1980s, a number of Australian court cases tested out the legality of decision making with regard to the sterilisation of young girls with disability. Two of the court decisions (*Re a teenager* and *Re S*) concluded that parental authority was sufficient in consenting to sterilisation. The other two decisions (*Re Jane* and *Re Elizabeth*) had the opposite finding, with the decision that court authorisation was required for any sterilisation procedure. The legal situation in Australia remained unclear until a landmark case that resulted in a High Court challenge in 1991. (*Re Marion*)

Early Court Cases Involving young girls with disability

1988	Re a teenager (13 FamLR 85)	Hysterectomy of a 14 year old girl was allowed, as it was submitted that menstruation would be likely to affect her development and quality of life because of her phobic reaction to blood.	Decided that the sanction of the court was not required where decisions were made about important medical treatment. Parents were deemed to be the best judges as to a child's welfare and could make such decisions.
1988	Re Jane (12 FamLR 662)	Hysterectomy was allowed as it was submitted that the child would have trouble in coping with menstruation, (although menses had not yet commenced) and she was also at risk of sexual assault and unwanted pregnancy.	Decided that any decisions were to be made in the child's best interests and that the child's welfare should be paramount. Parental consent was seen as insufficient when the medical procedure is to involve interference with a basic human right. Concern raised about the medical profession being able to protect the child by acting as a safeguard
1988	Re Elizabeth (13 FamLR 47)	Hysterectomy allowed	Decided that court approval was needed when an operation is non-therapeutic and involves the interference with a basic human right.
1989	Re S (13 FamLR 660)	Hysterectomy allowed	Decided that the rights of the parents as carers were paramount and as guardians, they did not have to seek the court's consent to carry out any medical procedure on a child, even if that entailed interfering with a basic human right or the main aim of the operation was non-therapeutic. Highlighted that an application to a court would involve additional financial strain.

1991	Re Marion (Secretary, Department of Community Services and Health v JWB and SMB, 1992 CLR 218)	Appeal to the High Court. Clarification of the issue of decision making: * The scope of the welfare power of the Family Court * The extent of parental responsibilities * The meaning and scope of the rights of the child * The impact of disability on the rights of the child. (Basser Marks, 1998) 	Decided that court authority (or tribunal) is required in cases of non-therapeutic sterilisation. Seen as unlawful for a doctor to perform a non-therapeutic sterilisation on a child. Parents or guardians can authorise the procedure if sterilisation is a by-product of surgery to treat a malfunction or disease. Sterilisation is to be differentiated from other medical treatment as it was deemed invasive and irreversible with constant risk of wrong decision making with particularly serious consequences. Authorisation only if sterilisation is in the child's best interests and a last resort after less invasive alternatives have been tried and failed or certain they won't work. Acknowledged the complexity of decision making and the risk of wrongful outcomes for the child given conflicting interests and the right to personal integrity.
1994	P v P (120 ALR 545)	High Court Addressed the issue of a possible conflict between individual State and Commonwealth legislation	Decided that the states can create additional legislation to authorise sterilisation but they cannot remove or alter the existing powers of the Family Court of Australia under the Family Law Act. Argued that without guiding principles and values to influence the decision making, idiosyncratic decisions that may not be in the best interest of the person would still be made.

Landmark cases setting the current legal precedents

Although these legal cases set precedents and expectations, it was clear that the processes for making decisions were quite inadequate, especially around what was regarded to be in the best interest of the young person. Opinion varied widely. In Marion's case, it was argued that precise rules and a hierarchy of values needed to be established to guide any decision making process, otherwise the best interests test would inevitably depend on the values of the decision-maker. Such decision making would also be fraught with conflicts of interest. (Fellowes, 2000)

**Australian Family Law
Council
Recommendations**

The Australian Family Law Council took on the task in 1994 to come up with recommendations to enable more consistent decision-making. They recognised that Commonwealth legislation was required for all Australian children to ensure that sterilisation of a child would only occur in exceptional and defined circumstances, using specific criteria.

They recommended:

- A new division in the Family Law Act, 1975, be created to regulate the sterilisation of young people
- The Family Court of Australia make the decisions about the sterilisation of minors
- Court hearings be the last resort and only when other options had failed to produce a satisfactory outcome
- Presiding judges be trained in the issues
- Specialist counselling and advisory services be made available
- Court costs be picked up by the Commonwealth Government
- The child have their own representative within the court during all proceedings related to consent for sterilisation to ensure that all options are presented
- Three stages be considered for the decision-making process.

The three stages relating to the decision-making process for legal authorisation of sterilisation were seen as follows:

Stage 1: Situations when sterilisation can never be authorised:

- 1. For eugenic reasons**
where the prime purpose is seen to prevent procreation (of people with disability at the expense of “superior stock”).
- 2. For purely contraceptive reasons**
where emphasis is on the word ‘purely’, for the prevention of pregnancy. (Although care must be taken that this primary motive may be disguised by other factors such as difficulty with menstrual management)
- 3. To conceal sexual abuse**
where emphasis is placed on the likelihood of others perpetrating the violation of the person’s rights. (Sterilisation may do nothing to help the woman or girl who is being sexually abused, and if anything, it can assist the abuser to feel safe, as no evidence would occur if the risk of pregnancy were removed. Of much greater concern are the welfare of the person who is being abused and who is suffering as a consequence, the cessation of the abuse and safeguarding against further abuse.)
- 4. Prior to the onset of menstruation**
based upon predictions about future problems that might arise.

**Situations when
sterilisation can never
be authorised**

Stage 2: Situations where, if sterilisation were not done, damage would be done to life or health:

- 1. To save life**
- 2. To avoid serious damage to physical or psychological health**

(In this situation they suggest that decision-makers have substantial discretion and that the danger of being ill-treated remains. Because of this, Stage 3 factors must be addressed.)

Stage 3: Situations where predetermined factors are explored to determine if serious damage to a person's physical or psychological health is likely:

- 1. Trials of other forms of contraception**
with other less restrictive and less permanent options being explored
- 2. Evaluation of the response to menstrual management**
with evidence of how training has progressed if this area is seen as a problem, and ensuring that decisions are not made pre puberty
- 3. Ensuring decisions made in the best interest of the person**
with the outcome that any sterilisation is only to be done as the last resort and only when less invasive procedures have been trialled. Such an approach has been justified by the recognition of the fundamental right to the inviolability and physical integrity of the person.

In seeking consent for sterilisation, the issue of best interest therefore remains paramount. The question about whether the consent should be based upon medical, legal, parental or social opinions must be raised here. This matter remains a difficult one, as it relates to the attitudes and values of the decision-maker and may rely on highly subjective judgement, as well as speculative prediction about what the future holds. (Brady and Grover, 1997)

As has been pointed out, the judiciary may have little experience or knowledge of disability. They have been far more likely to accept the expert evidence of doctors uncritically, rather than to acknowledge the recommendations of concerned others who work with and know the person's capabilities more intimately. They may also place greater authority on the concerns and wishes of parents. Yet parents too, may have little support and have difficulty in accessing information about menstrual and fertility management. Therefore they may have little knowledge of less restrictive alternatives to sterilisation or of its long term side effects. (Carlson, Taylor, Wilson and Griffin, 1994)

Situations where, if sterilisation were not done, damage would be done to life or health

Situations where serious damage to a person's physical or psychological health is likely

The concept of best interest

Practicality rather than values?

In much of the legal decision making, the concept of best interest has been understood within a utilitarian framework and has been interpreted around very practical daily life issues. For example, the overwhelming assumption is that hysterectomy appears to be the clear-cut therapeutic medical solution for difficulties with personal hygiene for girls and young women with intellectual disability. (Brady and Grover, 1997)

Common reasoning has been applied around the presumption that avoiding all typical life stresses is beneficial for any girl with disability. Sterilisation has been seen as the panacea to avoid menstruation, discomfort, mess, indignity, inconvenience, pain, premenstrual tension, sex education, or possible pregnancy, abuse, etc. Yet these are the same issues that all other girls and young women have to deal with, some needing more support than others.

Boys and young men as well as girls and young women

This issue does not only apply to girls and young women. The following UK landmark case highlights this issue.

A case about a young man with Down Syndrome was appealed in the UK with the judiciary holding that sterilisation on non-therapeutic grounds encompassed medical, emotional and all other welfare issues. His mother had sought sterilisation because of her concerns about his inappropriate behaviour at a day centre.

It was clear from the evidence of those who supported him that his support did not depend upon his fertility. The workers had considered ways to stop his inappropriate behaviour because it was conducted in a public place and, it would appear, that this would continue to need to happen whether or not he had the operation.

The judge put forward that social reasons for carrying out non-therapeutic invasive surgery were not part of the state of the law. He pointed out that if sterilisation did take place, neither would it save the young man from the possibility of sexual exploitation, abuse, and STDs, nor would it help him to cope with the emotional implications of any closer relationship that he might form. (UK Court Of Appeal, Civil Division, 2000)

Would this sterilisation be recommended if the person had no disability?

In addition, what may be seen as challenging by one person, eg menstruation or masturbation, may be seen positively or developmentally by another. One suggestion has been made that the way to decide the difference between therapeutic and non-therapeutic intervention would be to ask a very fundamental question about whether or not the sterilisation would be recommended if the person had no disability? (Brady and Grover, 1997)

Until recently, Queensland has had no specific legislation relating to the sterilisation of children with disability, with the Family Court of Australia holding jurisdiction in this area. However, Queensland did have the 1985 legislation of the Intellectually Handicapped, and later Disabled, Citizens Act, which applied to people with intellectual disability over the age of 18 with impaired decision making capacity.

In Queensland law, the importance of family members in the life of a person with disability was acknowledged, even in adulthood, especially when the person has high or complex support needs. Their commitment to the person, their expressed wishes, and the maintenance of existing relationships were to be taken into account in the decision making by the Legal Friend. The importance of family taking on formal roles in adulthood was strengthened when the Acts were changed to Guardianship legislation.

However Queensland law also recognised that certain special medical procedures could not be decided by parents alone. (Brady and Cooper, 1996) These were seen to be those which:

- Related to difficult ethical issues
- Required irreversible procedures
- Were life threatening situations
- Had treatment of significant risk
- Had disputed treatment.

Clearly sterilisation fell into several of these categories.

The first Australian protocols and practice guides for the decision-making processes around authorisation of sterilisation procedures for children were developed in Queensland in 1996. (Brady and Cooper, 1996) They included the need for court authorisation, consent by children, special medical procedures, guidelines and protocols, dispute resolution, the process of the Family Court, the legal process and the final hearing. These were very practical in nature, with implied rather than stated principles relating to their operation, giving direction to the various government departments that were involved at the time.

An attempt was made to secure ongoing supports especially for girls and their families. These alternatives included a range of supports typically used with other young women as well as specialist assistance and included:

- Using pain relief strategies or medication
- Prescribing contraception pills or injections
- Teaching strategies to cope with menstruation
- Giving support to families and carers

Early protection laws in Queensland

Special medical procedures needing authorisation

First protocols and guidelines developed in Queensland

Concern about unauthorised sterilisation remains

- Managing inappropriate behaviour
- Educating about protective behaviours
- Using support services. (Brady and Cooper, 1996)

Since then, the experience in Queensland has been seen to be a relatively positive one, with most of the known cases being diverted from the court. Ten of the eleven applications for special medical procedures filed in the Brisbane Registry of the Family Court were diverted, with procedures other than sterilisation agreed upon. (Murray, 1998) However it has been suggested that the success of these diversions would only be as good as the service landscape and the availability of support, knowledge and skill of those working with the young person and their family. (Brady, Briton and Grover, 2001)

Despite these moves forward, concern has remained about those unauthorised sterilisation practices that might still be happening. Justice Nicholson, the judge from Marion's Case, raised his concern that the need for authorisation for special medical procedures may not be as widely known by professionals or the community at large as it should be. (Brady and Cooper, 1996) Following the report detailing the numbers of illegal sterilisations happening in Australia (Brady and Grover, 1997), it became apparent that practices were still happening below the legal radar where they were not open to scrutiny.

In 1998, Elizabeth Hasting gave an impassioned speech putting governments and people involved in unauthorised sterilisations on notice. She asserted that *'a world in which government cannot be bothered to investigate potential illegal medical assault, in which those with no authority feel free to make decisions which are blatantly against the law and to carry out serious and irreversible procedures on those with little or no capacity to give or withhold consent, is a world in which people who have disabilities can have no certainty or confidence about their human being or their future'*. (Hastings, 1998)

Medical practitioners were reminded of the law

With increasing pressure from the sector about this issue, the Federal Attorney General wrote an open letter to the Australian Medical profession in 2000, reminding medical practitioners that they could be subject to criminal and civil and convictions if they go ahead with a sterilisation procedure without court or tribunal approval.

Doctors were reminded that:

- *It is unlawful throughout Australia to conduct a sterilisation procedure on a child that is not a by-product of surgery appropriately carried out to treat malfunction or disease (eg malignancies of the reproductive tract) unless legal authorisation has been obtained*

- *Practitioners are liable to be subject to criminal and civil action if such a sterilisation procedure is performed on a child under 18 years of age if it is not authorised by the Family Court of Australia or another court or tribunal with jurisdiction to give such authorisation.*
- *Parents or guardians have no legal authority to consent on behalf of children to such sterilisation procedures.*
- *Medicare Benefits are only payable for sterilisation procedures that are clinically relevant professional services as defined in Section 3 (1) of the Health Insurance Act, 1973.*

At around the same time, Guardianship legislation was finally introduced to Queensland to apply to people with impaired decision making capacity over 18 years of age. The scope of this legislation however, was extended to include special medical procedures for children. Guardianship operates in the context of legal tradition based on the common law protection of vulnerable persons, but it also incorporates modern notions of self-development and inclusion of people with disability in the life of their community. (Brady, Briton and Grover, 2001)

As with advocacy, there is tension between the promotion of rights and the protection of vulnerable people. Notions such as the least restrictive alternative and method of last resort have been used to help to guide decision-making. There have also been attempts to find solutions to the complex social problems often presented by recognising the need for having links with the service delivery system.

Currently all states have Guardianship legislation, but the laws are inconsistent, without any standard procedures or safeguards. (SCAG, 2004) The judiciary has questioned the suitability of guardianship tribunals to make decisions on sterilisation applications by pointing out that the expertise, procedures and requirements of such tribunals vary between states, leaving decisions at the mercy of the decision-maker's discretion, which inevitably includes personal value judgements. Yet difficulties with court procedures have also been identified. They have approved 90% of cases, compared with 53% by tribunal. (Brady and Grover, 1997) They are usually adversarial in their approach with the respective parties becoming locked into winning. This can mean that families do not have the opportunity to hear information which could under other circumstances, change their minds. (Brady, Briton and Grover, 2001)

The Human Rights and Equal Opportunities Commission has suggested that the best move would be for all the States to give jurisdiction to their respective guardianship tribunals.

Queensland Guardianship Legislation

***Tension between
rights and protection
of vulnerable people***

***Until now,
no standard procedures
and no safeguards***

Why guardianship tribunals are seen to be appropriate decision makers in relation to sterilisation

National Protocols for decision making established

Guiding Principles of the National Protocol

This direction was seen to be appropriate because guardianship tribunals: (SCAG, 2004)

- Have greater knowledge and experience of people with disability, and therefore greater expertise, than the Family Court
- Use enquiry based on a less formal approach compared with the adversarial nature of court proceedings
- Take a multi-disciplinary approach to the decision-making process
- Do not require legal representation
- Have no fees
- Have close links with local communities and service providers.

In an attempt to move the agenda forward, The Australian Guardianship and Administration Committee established a National Protocol For Special Medical Procedures (Sterilisation) which was introduced last year. (AGAC, 2003) Much of this Protocol is devoted to procedures, however it does include a framework for decision-making by including principles, guidelines about when sterilisation is appropriate, and the capacity of the adult or child to make their own decisions, or to have input into the questions before the Tribunal. (SCAG, 2004) The National Protocol encourages:

- **Same human rights**—*The right of all persons to the same basic human rights regardless of a particular person's capacity*
- **Individual value and autonomy**—*A person's right to respect for his or her human worth and dignity as an individual*
- **Maximum participation, minimal limitations**—*A person's right to participate, to the greatest extent practicable, in decisions affecting the person's life*
- **The expressed wishes of the person to be considered**—*In so far as the person is capable of expressing a wish*
- **Encouragement of self-reliance and self management**—*The importance of encouraging and supporting a person to achieve his or her maximum physical, social, emotional and intellectual potential, and to become as self-reliant as practicable*
- **The least restrictive alternatives**—*If there is a choice between a more or less intrusive and permanent form of treatment, the less intrusive way should be adopted unless it is, or would be, unsatisfactory.*
- **Maintenance of existing supportive relationships**—*Considering the views of and impact on the decision for the person's family and/or carers.*
- **Maintenance of cultural environment and values**—*The importance of maintaining a person's cultural environment and set of values, including any religious beliefs held by the person and/or the person's parents or care givers. (AGAC 2003/4)*

The Standing Committee of Attorneys-General Working Group, which has been considering what future direction should be taken, has recently released an issues paper for public discussion. (SCAG, 2004) They put forth the necessity to progress draft model legislation and guidelines for the authorisation of non-therapeutic sterilisation of children and to confer jurisdiction on State and Territory guardianship boards and tribunals for these decisions.

The paper and proposed legislation only focuses on non-therapeutic sterilisation of young girls and does not include the non-therapeutic sterilisation of young boys. The reason for this is said to be because of the strong gender bias relating to the issues, which results in the high frequency of requests to deal with the management of menstruation and unplanned pregnancy.

However the primary aim of any new legislation in this area was seen to be to protect the human rights of children with a decision-making disability. The working group agreed that:

- A nationally consistent approach to appropriate authorisation procedures was needed for the lawful sterilisation of children with a decision making disability
- The development of draft model State and Territory provisions by State and Commonwealth officers should happen, giving jurisdiction to guardianship or similar tribunals to authorise sterilisation procedures on children with a decision making disability, and operating concurrently with the Family Court of Australia and the Federal Magistrates Service
- In developing the draft model State and Territory provisions, officers should develop options for nationally consistent criteria for authorisation by guardianship or similar tribunals for further discussion. (SCAG, 2004)

Key questions that have been identified in their issues paper include:

- *To which group would the legislation apply in terms of age and impairment?*
- *How should non-therapeutic sterilisation be defined?*
- *What evidentiary and factual tests should the legislation impose? Examples of relevant tests include the 'best interests', 'last resort' and 'but for disability' tests*
- *What medical evidence requirements, if any, should be imposed?*
- *Should criminal penalties be imposed for the performance of an unauthorised sterilisation? If so, what penalty should be imposed?*
- *Should procedural requirements be included in the model Bill?*

Standing Committee of Attorneys-General Working group

What legislation hopes to achieve

Some key questions in drafting new legislation

4. What is the current legal situation regarding unauthorised sterilisation?

Queensland Law relating to an adult

The current legal situation in Queensland is governed by the *Queensland Guardianship and Administration Act, 2000*. This legislation not only covers adults with disability, but also covers children, giving jurisdiction for decisions about sterilisation to the Guardianship and Administration Tribunal.

Currently Queensland law states:

For an Adult:

(Queensland Guardianship and Administration Act 2000)

Definition: *Sterilisation is the health care of an adult who is, or is reasonably likely to be, fertile that is intended, or reasonably likely, to make the adult, or ensure the adult is, permanently infertile. Examples of sterilisation include endometrial ablation, hysterectomy, tubal ligation and vasectomy. Sterilisation does not include health care primarily to treat organic malfunction or disease of the adult.*

When consent can be given:

The tribunal may consent, for an adult with impaired capacity for the special health matter concerned, to sterilisation of the adult only if the tribunal is satisfied that:

- *one of the following applies:*
 - *the sterilisation is medically necessary*
 - *the adult is, or is likely to be, sexually active and there is no method of contraception that could reasonably be expected to be successfully applied*
 - *if the adult is female, the adult has problems with menstruation and cessation of menstruation by sterilization is the only practicable way of overcoming the problems*
- *the sterilisation can not reasonably be postponed*
- *the adult is unlikely, in the foreseeable future, to have capacity for decisions about sterilisation.*

When refusal is to be given:

Sterilisation is not medically necessary if the sterilisation is:

- *for eugenic reasons; (for improving the qualities of the human race, especially the careful selection of parent)*
- *to remove the risk of pregnancy resulting from sexual abuse.*

Aspects to be taken into account in decision making:

- *alternative forms of health care, including other sterilization procedures, available or likely to become available in the foreseeable future*
- *the nature and extent of short-term, or long-term, significant risks associated with the proposed procedure and available alternative forms of health care, including other sterilisation procedures.*

(based on SCAG, 2004)

In making the decision, the tribunal considers the following, some of which may be in conflict:

- *the principle of keeping treatment to the minimum necessary to preserve the adult's health and well-being*
- *the wishes of the adult and the adult's right to refuse treatment*
- *the views of any guardians appointed by the Tribunal*
- *the views of anyone appointed as attorney for the adult*
- *the views of the adult's statutory health attorney*
- *the adult's situation (including his/her medical condition)*
- *any alternative procedures that may be available in either the short or long term*
- *the general nature and effect of the alternative procedures*
- *the nature and degree of any risks .the reasons for proposing a particular procedure.*

For a Child:

(Queensland Guardianship and Administration Act 2000)

Definition: *Sterilisation is health care of a child who is, or is reasonably likely to be, fertile that is intended, or reasonably likely, to make the child, or to ensure the child is, permanently infertile. Examples of sterilisation include endometrial ablation, hysterectomy, tubal ligation and vasectomy. However, sterilisation does not include health care without which an organic malfunction or disease of the child is likely to cause serious or irreversible damage to the child's physical health. For example: If the child has cancer affecting the reproductive system and, without the health care, the cancer is likely to cause serious or irreversible damage to the child's physical health, the health care is not sterilisation.*

When consent can be given:

The sterilisation of a child with an impairment is in the child's best interests only if:

- *one or more of the following applies:*
 - *the sterilisation is medically necessary*
 - *the child is, or is likely to be, sexually active and there is no method of contraception that could reasonably be expected to be successfully applied*
 - *if the child is female—the child has problems with menstruation and cessation of menstruation by sterilization is the only practicable way of overcoming the problems*
- *the child's impairment results in a substantial reduction of the child's capacity for communication, social interaction and learning*
- *the child's impairment is, or is likely to be, permanent and there is a reasonable likelihood, when the child turns 18, the child will have impaired capacity for consenting to sterilisation*
- *the sterilisation can not reasonably be postponed*
- *the sterilisation is otherwise in the child's best interests.*

**Considerations by the
Guardianship and
Administration Tribunal**

**Queensland Law
relating to a child**

**Queensland Law
relating to a child**

When refusal is to be given:

Sterilisation is not in the child's best interests if the sterilisation is:

- *for eugenic reasons; or*
- *to remove the risk of pregnancy resulting from sexual abuse.*

Aspects to be taken into account in decision making:

In deciding whether the sterilisation is in the child's best interests, the tribunal must:

- *ensure the child is treated in a way that respects the child's dignity and privacy*
- *do each of the following:*
 - *in a way that has regard to the child's age and impairment, seek the child's views and wishes and take them into account*
 - *to the greatest extent practicable, seek the views of each of the following persons and take them into account:*
 - *any parent or guardian of the child*
 - *if a parent or guardian is not the child's primary carer, the child's primary carer*
 - *the child representative for the child*
 - *take into account the information given by any health provider who is treating, or has treated, the child*
- *take into account:*
 - *the wellbeing of the child*
 - *alternative forms of health care that have proven to be inadequate in relation to the child*
 - *alternative forms of health care that are available, or likely to become available, in the foreseeable future*
 - *the nature and extent of short-term, or long-term, significant risks associated with the proposed sterilisation and available alternative forms of health care*

Views of the Child:

The child's views and wishes may be expressed in the following ways:

- *orally*
- *in writing*
- *in another way including, for example, by conduct.*

(based on SCAG, 2004)

It is clearly illegal to sterilise a child, or an adult with limited decision making, without authorisation

The current situation is quite clear that it is not lawful to sterilise a person under or over the age of 18 with the consent of parents alone. Authorisation must be given by the Queensland Guardianship and Administration Tribunal.

Not only is it clear in the law, the Notes for Guidance in the Medicare Benefit Schedule have been amended to include the following guidelines for medical practitioners:

- *It is unlawful throughout Australia to conduct a sterilisation procedure on a minor which is not a by-product of surgery appropriately carried out to treat malfunction or disease (eg malignancies of the reproductive tract) unless legal authorisation has been obtained.*
- *Practitioners are liable to be subject to criminal and civil action if such a sterilisation procedure is performed on a minor (a person under 18 years of age) which is not authorised by the Family Court of Australia or another court or tribunal with jurisdiction to give such authorisation.*
- *Parents/guardians have no legal authority to consent on behalf of minors to such sterilisation procedures.*
- *Medicare Benefits are only payable for sterilisation procedures that are clinically relevant professional services as defined in Section 3 (1) of the Health Insurance Act 1973.*

If sterilisation is done without the tribunal's approval, then there is no lawful authority. The argument can be put that the medical practitioner, who should be well informed of his or her legal responsibilities, would be the primary offender if sterilisation were to be done illegally, whereas a parent, for example, would be aiding and abetting in the commission of the crime. (SCAG, 2004)

An unauthorised sterilisation procedure may then be seen as a civil trespass of treatment without consent. However, liability would need to be established by the court, proving that the procedure was performed without valid consent. The problem is, though, that few doctors would be found out, as neither they nor consenting parents would necessarily publicise the fact that a sterilisation procedure had happened. In addition, any doctor could use medical confidentiality as a protection.

If a charge of unlawful sterilisation were to be laid, because this would be civil proceedings, the doctor is not obliged to break patient confidentiality. If there were sufficient evidence, a search warrant could be issued, but it would be highly likely that the doctor would argue that the procedure was for therapeutic reasons. (Skene and Nisselle, 2002) To date there have been no cases and no doctor has ever been prosecuted.

Justice Nicholson (2003) has observed what he refers to as a *fair degree of antipathy in the medical profession* towards the concept of requiring approval for sterilisation procedures. He remains surprised by the limited number of applications made, which, in conjunction with anecdotal evidence, means that a large number of sterilisations must still be going on illegally. Sadly, there are no real means of knowing.

Notes for Guidance in the Medicare Benefit Schedule

***The current situation
regarding unauthorised
sterilisation***

***No doctor has ever
been prosecuted.***

5. What happens when a girl or young woman is sterilised

Concern about menstruation, protection and unplanned pregnancy

Accepted as the standard for menstrual management

Yet no-one suggests a colostomy for dealing with bowel incontinence

The doctor booked the 15 year old girl into hospital under her mother's name. *No one questioned me. No one, none of the nurses, no one. We were in a private room, we were on our own, and I stayed with her.* (King, 2003)

Sterilisation of girls and young women appears to be more widely accepted than for boys and young men, which puts a strong gender bias on the issue. This appears to be because of the added concern about dealing with menstruation, as well as the possibility of the responsibility of unplanned pregnancy.

Why then is a different thought process considered when a young woman has a disability? The answer could be seen as a complex interplay of thought processes involving discomfort about the overt expression of sexual maturity, the desire to protect the young person from sexual abuse, the fear of pregnancy and a lack of knowledge among parents, carers and health professionals about alternate strategies and resources available. (Henderson and Alphonso, 2003)

Other questions can also be raised. Why are we surprised that girls with disability go through the same physical and psychological changes of puberty and become sexually mature? Is pregnancy the only serious consequence of sexual abuse? Will sterilisation protect the young person concerned from sexual exploitation and abuse? Do we use sterilisation as a way of coping with a vulnerability to sexual exploitation in other population groups? The answers to these questions are not straightforward.

In the decades before sterilisation was publicly questioned, it appears that the accepted standard for menstrual management of girls and women with intellectual disability, especially those in institutional care, was to undergo surgical sterilisation or to administer drugs to stop periods as well as fertility. (Family Law Council, 1994) Often, families supported these procedures or asked for them to happen.

Even when training programs were in vogue in the 70s and 80s, little support was given to girls or parents to develop skills in managing menstruation as a normal part of life. This is interesting, because at the same time, huge efforts were being put into developing competencies in other areas of life for people with intellectual disability. One such area was toilet training where carers were prepared to invest much time and effort. No one ever considered surgery or bodily violation such as doing a colostomy or inserting a catheter as the answer to bowel or bladder incontinence, even when the consequences of smearing and other inappropriate behaviours are far more stressful and unhygienic for family members or for staff.

Driving many decisions about sterilisation may be the negative attitudes that many people hold towards menstruation, continuing the implicit belief that the menstruating woman is unclean. (Paige, 1973, Delaney et al, 1977) For most people there is some difficulty in having to deal with this private and personalised aspect of a woman's life in a public way. However sometimes this is used to justify sterilisation, as the following quotes from some Queensland mothers attest.

"She is like all of us, she doesn't like it."

"Normal people don't enjoy having periods."

"I'd get rid of my own periods if I could." (Carlson and Wilson, 1994 a)

In this particular study 73% of the mothers interviewed cited menstrual care as a reason for considering or deciding about sterilisation of their daughters.

For some parents, the indignity and distaste for having to deal with long term menstrual management and hygiene can be compounded by not knowing how to cope with the issues that arise. Sometimes parents acknowledged that fear of the unknown and of what might happen were actually much worse than how real life actually panned out. This is particularly concerning, given that many sterilisations happen before a child has reached puberty.

I was expecting the worst. I was dreading it. I was afraid. I didn't think we were going to cope at all, not just because of the menstruation, but because of her attitude towards blood. I was pleasantly surprised because it was nowhere near as bad as I had expected.

It was one of the biggest surprises with (my daughter). I thought she would be worried—What's happening?—Upset?—But she 100% accepted it as part of living.

When she first started menstruating she had some very heavy months...At that stage I took her to the (GP). We did discuss taking it further—even as far as a hysterectomy. Since then her periods have really settled down—over the last 6-7 months. (from Carlson, 1994)

Unfortunately many parents do not have access to information about ways that menstruation can be managed, or to ways of dealing with associated behaviour that is seen as challenging. Although less restrictive options than sterilisation are available, they are often not considered or trialled. Certainly it must be acknowledged that these do take extra time and effort, just in the same way as toilet training and learning about other aspects of daily life also take time and effort.

Negative attitudes to menstruation can fuel decisions

Fear of the unknown

Lack of information and support

Positive strategies take time and effort

Why loving parents consider sterilisation

Situations are difficult to cope with

Carlson (1994) also noted ways mothers supported their daughters:

When her daughter ignored menstruation by not wearing pads one mother described: *We showed her what would happen if she did not wear pads—it would be all in the pants and down the legs...It took a year before she perfected wearing them.*

I made special panties—had special lining and made them thick like a pad—and dark pants in winter so you can't notice too much if it did come through.

Other mothers also used massage and pain relieving medication to make their daughters more comfortable with painful periods.

As part of understanding the complexity of this issue, it is important to consider why very loving parents do seek non-therapeutic sterilisation of their daughters. Parents usually cite reasons relating to trying to manage menstruation in a dignified way, as well as the problems that contraception and unplanned pregnancy place on already heavily burdened family life. (SCAG, 2004) It is clear that many parents are trying to cope with a very difficult situation with inadequate supports. Some families recount stories of how undignified and complicated the situation could be for their daughters and also for themselves. Unfortunately these stories are usually told after an application for a sterilisation has been made, or post the event, when parents have become entrenched in their particular perspective and have been forced to justify their actions publicly.

I would go into my daughter's room and it was just horrific. Sometimes we would have blood everywhere and, you know, she did not know any better. Her mood swings were right up and down. She could be fine one minute and the next, be just uncontrollable, crying and sobbing. (Allen, 2003)

When she is menstruating, there is a total lack of dignity. There would be blood everywhere... There is no guarantee that she would not even suddenly decide to strip off in Woolies and throw pads all over the fresh fruit and vegetables. (Ferris, 2003)

These situations are difficult to cope with, but some stories about the indignity of 'blood everywhere' also can have an aside. Parents may state that the girl does not know what is going on, or does not realize the social significance of what they do, yet these same girls may already wear incontinence pads or pants and present no challenges in wearing or changing them. (Carlson, 1994) Even so, the decisions about sterilisation are never simplistic, nor are they taken lightly.

It was bad enough making that decision (about sterilisation) in the first place without feeling that you are almost a criminal by doing it. You get desperate; you are desperate to help your child. It is not something you take lightly. You go through another grieving process for your child when you make this decision, because you have to acknowledge that your child is so disabled that they cannot cope on their own with the menstruation.

No mother in her right mind would ever wish anything like this on their child, but it happened, and you can't live with rose-coloured glasses. It's life, and there's hard decisions and decisions you have to live with and I have no regret because what I see now is a happy, beautiful, vibrant little woman who's got a quality of life. (King, 2003)

Yet, despite such stories, research has shown that when parents are provided with information and the opportunity to explore other options, they rarely proceed with an application for sterilisation.

Some non-surgical alternatives include:

- Teaching strategies to cope with menstruation
- Supporting families in their coping with difficult situations
- Managing inappropriate behaviours
- Educating regarding appropriate protective behaviours
- Using pain relief strategies or medication
- Using contraceptive pills or injections
- Using support services. (Brady and Cooper, 1996)

Brady concluded that when families and children receive home-help, needs-based developmental programs, and supports that are external to home, it is much more likely that the girl will retain her bodily integrity. (Brady, 1998) The converse also applies. When families are not supported, or when children are not living with their families and are in grouped settings, the likelihood of fear and of choosing sterilisation as the first option are far more prevalent.

A recent study was carried out with 107 young women with significant intellectual disability and complex support needs, who had menstrual or contraceptive problems that could not be managed confidently or satisfactorily by the young woman, by her immediate carers or by her general practitioner. (Grover, 2002) All these young women were on the path towards sterilisation. The results were that 105 of these women and their families only required information, advice, or typical medical management, similar to what would be available to any other young women who did not have a disability. Only 2 of these young women's families continued on their path towards sterilisation and applied for legal approval.

Why the decision is so hard for parents

Alternatives to surgical sterilisation

Information, advice and medical management similar for all young women

Not necessarily by pragmatic ease or by individual choice

Sterilisation is not considered an appropriate option for girls or young women who do not have disabilities

It's part of being a woman, it's part of being an adult, and to take that away can be seen as a serious breach of human rights

When informed about alternatives, many parents, whose children also have significant disability, choose a very different path for their daughters. This path tends to be driven more by broader ethical and health considerations and concern for the well being of their daughters and not necessarily by pragmatic ease or by individual choice.

My daughter, in her early twenties, has in my view, the world's best and virtually pain-free periods which she manages extremely well now. However her response to them starts to give you some understanding of where the term 'the curse' came from. It has taken ten years to get to the stage of her very, very grudgingly accepting them as being part of being a woman. Her intense distress about this 'unfixable' problem sometimes made me wonder if I was doing the right thing by 'making' her persevere.

Given her views on periods and having babies (no thank you!!!) she would have probably opted to be sterilised the minute she turned 18, had she been presented with such a choice, and was not reliant on me for information and action on the subject.

However if she did not have an intellectual disability, I believe she would not have been presented with this choice and would have had problems in finding a doctor who was prepared to go ahead. Yet, if she did not live in the family home, it is quite probable that given institutional attitudes, she would have been sterilised. I took the view that the side effects of any drugs or surgery would be far more harmful and would be too high a price to pay for my daughter's interim sense of well being. (email to the author from a parent, 2004)

Certainly, sterilisation is not considered an appropriate option for girls or young women who do not have disabilities, who have difficulties with menstrual hygiene or painful menstruation, as a whole range of educational and therapeutic tools are available to assist them. Because diseases of the reproductive tract are very rare in girls and are no less rare in girls with intellectual disability, the vast majority of sterilisations of girls should not go ahead on any medical grounds, as there are almost always less invasive options to try. (Brady and Grover 1997)

It has been acknowledged that families must have dreadful problems in managing some of these issues on a day-to-day basis. However Grover (2002) believes that *'removing a healthy organ from someone and to remove, in essence, a function which is not just a messy and inconvenient function, it's part of being a woman, it's part of being an adult, and to take that away can be seen as a fairly serious breach of human rights'*.

Some family members argue that it can be equally invasive, perhaps even more so to have to take medication for years to stop menstrual bleeding. That also requires a lot of input from other people. (Ferris, 2003) The argument has also been put that the appointment of a guardian by the Guardianship Board to make such decisions concerning using medication to control fertility, suppress anti-social or nuisance sexual behaviour can also amount to sterilisation by stealth. (Dawes, 1998) Similarly the impact of the medication (eg Androcur and Depo Provera) accompanying temporary sterilisation renders it akin to sterilisation of a more permanent nature. (Murray, 1998)

The inherent risks of sterilisation at a young age cannot be overlooked. Particular concern has been raised about the long term effects of hysterectomy on young girls who are prepubescent, eg, the increased risk of early onset of menopause, decreased bone density, cardiovascular disease and thyroid disease. (SCAG, 2004) The following table is based on the work of Brady and Grover (1997), Centerwall (1981), Gary and Mooney (1995) and Turney (1993).

Surgical Intervention	Desired Effect	Known Side Effects
Partial hysterectomy (surgical removal of the body of the uterus, leaving the cervix, thus requiring regular pap smears)	<ul style="list-style-type: none"> • Permanent cessation of menstruation • Irreversible infertility 	<ul style="list-style-type: none"> • Hormone deficiency (prostaglandin) • Increased risk of atherosclerosis and cardiovascular disease • Possible bowel obstruction • Unknown long term consequences
Total hysterectomy (surgical removal of the whole uterus)	<ul style="list-style-type: none"> • Permanent cessation of menstruation • Irreversible infertility 	<ul style="list-style-type: none"> • Hormone deficiency (prostaglandin) • Increased risk of atherosclerosis and cardiovascular disease • Possible bowel obstruction • Unknown long term consequences
Total hysterectomy with ovaries (surgical removal of the uterus, cervix, fallopian tubes and both ovaries)	<ul style="list-style-type: none"> • Treatment of widespread cancer in reproductive tract or in post menopausal women • Cessation of hormone production • Permanent cessation of menstruation • Irreversible infertility 	<ul style="list-style-type: none"> • Hormone deficiencies • Early menopause • Osteoporosis • Increased risk of atherosclerosis and cardiovascular disease • Possible bowel obstruction • Unknown long term consequences

Are some alternatives sterilisation by stealth?

Side effects of sterilisation

Increased risk of early onset of menopause, decreased bone density, cardiovascular disease and thyroid disease

Some procedures are seen as less radical than others, yet still have significant side effects that are rarely explained

Surgical Intervention	Desired Effect	Known Side Effects
Endometrial ablation (laser surgery or diathermy to remove lining of the uterus)	<ul style="list-style-type: none"> • Treatment of very heavy bleeding in woman who do not wish to have further pregnancies • Permanent cessation of menstruation • Irreversible infertility 	<ul style="list-style-type: none"> • Almost 15% need a second operation • Hormone deficiency (prostaglandin) • Increased risk of atherosclerosis and cardiovascular disease • Unknown long term consequences
Bilateral Oophorectomy (surgical removal of both ovaries)	<ul style="list-style-type: none"> • Cessation of hormone production • Permanent cessation of menstruation • Irreversible infertility 	<ul style="list-style-type: none"> • Hormone deficiencies • Early menopause • Osteoporosis • Unknown long term consequences
Tubal ligation (surgical severance, tying, clipping or sealing of the fallopian tubes)	<ul style="list-style-type: none"> • Blocks eggs from moving to where it can be fertilised (still ovulate and menstruate) • Mostly irreversible infertility 	<ul style="list-style-type: none"> • Torsion and risk of fatality • Irreversible interference with endocrine system • Endometriosis • Chronic pain and gynaecological ill health • Premature onset of gynaecological cancer.

Concern has also been raised about the long term effects of the drug, depo provera which is used extensively with young women with intellectual disability.

Side effects of depo provera

Drug name and Use	Desired Effects	Known Side Effects
Depo provera (Banned in the USA for contraceptive purposes)	<ul style="list-style-type: none"> • Long term suppression of fertility 	<ul style="list-style-type: none"> • Lost bone density • Rapid weight gain • Tiredness • Depression • Kidney and gall problems • Haemorrhage

These long term physical consequences are rarely addressed medically with women with disability. In addition, women who have had hysterectomies say they also experience huge emotional consequences.

Women with disability who can express their feelings say that they feel very violated, lose their sense of identity as a real woman and feel very alienated from other women, as well as find that they have difficulty establishing relationships with men. Dowse (2003) has described these costs to women as enormous.

As Hastings (1998) pointed out, the key reason why sterilisation is carried out on girls and women with disability is *as a response, not to a clinical medical need, but to disability. It reflects persistent negative attitudes towards fertility, menstruation and menstrual management, especially in young women with an intellectual disability.*

The other key fear for families in their deliberations about sterilisation is that pregnancy will occur. However the issues are totally different for those young women with disability who are interested in forming consensual relationships with men, and those girls and young women who are taken advantage of, or are sexually abused or raped. Although contraception and sterilisation can prevent pregnancy, they will not, and do not, replace the need for a safe environment for these women.

A reason for the sexual abuse and the realistic fear of families in relation to unwanted pregnancy, is that their daughters are living in, or have the likelihood of living in, grouped residential arrangements where they or their family do not have choices about who lives with them or who assists them. In such a situation they may not be safe because the girl or woman lives and/or works with men and/or can have their personal care done by male attendants. These segregated lifestyles are often carried out behind closed doors and are not open to the scrutiny of others, including family members.

I suppose, in the back of our minds, pregnancy was always going to be a factor that we never wanted to face. We know somewhere down the track that we're not always going to be here, that she will have to go into care, and pregnancy would just be horrific. (Allen, 2003)

Unfortunately much research supports such fears about abuse in institutional settings. Extensive research in Canada (Sobsey, 1994), and in Europe (la Rivière Zijdel, 2004), has shown the high vulnerability of girls and women with disability. The recent European studies from six countries proved that nearly 80% of women with disability become a victim of various forms of sexual violence. This rate is far higher than the rate for non-disabled women or for disabled men. Here in Australia, young women with intellectual disability have been found to be 12.7 times more likely to be sexually assaulted as women in the general population. (Wilson and Brewer, 1992)

Sterilisation is mostly a response to disability not to a clinical medical need

Fear of unplanned pregnancy

Sterilisation does not stop sexual abuse especially in institutional care

The problem of high rates of sexual abuse

Abuse is often by men in paid positions

Perpetrators of such sexual abuse and violence with girls and women with disability are usually men, including men with disability, who are often inappropriately placed as cotenants with girls and women who are vulnerable.

However, for non-disabled women, family members score highest as perpetrators of sexual abuse, but for women with disability, the perpetrators are more often their service providers, doctors, psychologists, therapists, drivers, group leaders, personal assistants and others in positions of support and care. (la Rivière Zijdel, 2004)

Although sterilisation will stop pregnancy it will not stop sexual abuse or rape of girls and women with intellectual or physical disability. For perpetrators in paid support roles, their knowledge that the person has been sterilised can in fact add to the person's vulnerability to sexual abuse. Knowledge that the girl or woman with disability will not become pregnant can increase the likelihood and decrease the risk of detection.

Safeguards against sexual abuse are more important

Perhaps it is of far greater importance to have proper safeguards in place so that vulnerable people with disability are not in such situations, especially in living arrangements where they are left open to unscrutinised abuse in daily life. As a worst case scenario, if sexual abuse does happen, then women with disability must be able to have support and claim their right to justice.

About pregnancy and parenthood

The stereotypes of people with intellectual disability are of people who are incompetent, abusive and non-caring of the outcomes for their children. Yet ironically people who have significant intellectual and physical disability are far less likely to engage willingly in intimate relationships that result in pregnancy, particularly if they are not deemed capable of giving consent. The situation is more likely with people with mild intellectual disability who can enter into loving relationships, can understand the function of contraception and can manage pregnancy and parenting especially when supports are in place. (Llewellyn, 2000)

Often little assistance is in place to support the role of parent

People with mild intellectual disability often are forced to live on the margins of our communities with few support systems in place to model good parenting or to deal with unexpected contingencies that might arise. Research has shown that, when parents with intellectual disability get early access to support and when there is a supportive anchor in their lives, they and their children do well. (Llewellyn, 2000) Yet mostly they are left with inadequate supports with the solution being to sterilise rather than to put any supports and safeguards for living in place.

This sterilisation strategy again is fuelled by the myths that people with intellectual disability are ineffective parents, whose genetic contributions are less than desired. It is assumed that their children will also have an intellectual impairment, yet they can have children with average and above average intelligence. It is also assumed that they will have large numbers of children, that they will be inadequate as parents, and that they have an inability to learn. (McGaha, 2002)

Research suggests the lack of parenting skills is not the result of 'bad genes'. It is more likely to be the result of the developmental history of the individual. Without denying problems, mothers with intellectual disability can play a very positive role in their children's development, as can their fathers, with training at home in daily life being found to be particularly effective. (McGaha, 2002)

However the concern for many parents of women with disability is that they will be the ones who will have to look after their grandchildren, or at best be the main support of their daughter as a parent. This concern is not unrealistic, given the lack of support to people with disability to play typical valued life roles, including those of parenthood.

This situation not only applies to women with intellectual disability, but also to women with physical disability, who also face enormous pressure not to become parents, by their own parents, other family members and also by the medical profession. It is often wrongly assumed that they would not be able to care for a child, and that they might transmit impairment to that child and that this would be a terrible thing. It is asserted that the woman would not be able to continue to care for herself and would have a poorer life than she was having now, if she became pregnant and had a child. (Asch, 2001)

The assertion is also likely to be made that, as society is already spending so much money on her, it would be highly irresponsible for her to go ahead, knowing that more money would have to be spent to pick up the jobs that she would not be able to do in raising the child.

Women with disability are told *You use a wheelchair, how can you change a baby's nappy, how can you run after that toddler? You are deaf, how can you provide your child with ordinary language. You are blind, how can you see that medication that your child is going to open because only children can open child proof bottles of medication!* (Asch, 2001)

The same sentiment is often portrayed about continuing to menstruate, irresponsibly, with similar pressure being applied to get rid of periods permanently.

***Myths about women
with disability
as poor parents***

***Women with disability
face enormous pressure
not to have children***

***Coercion not to be
'irresponsible'***

6. What happens when a boy or young man is sterilised

Little known about the incidence or reasons

Sterilisation is rarely done, if ever, on boys without disability

Sterilisation of boys is happening

Victims more than perpetrators

The sterilisation of young boys is governed by the same 1992 court ruling that all procedures, other than those to treat malfunction or disease, are to be authorised by the court or appropriate tribunal. For boys and young men with impaired decision making capacity, any sterilisation or use of controversial drugs is required to be referred to the Queensland Guardianship and Administration Tribunal for authorisation.

Despite these legal rulings, no agency takes responsibility for collation of incidence, decision making or reasons as to why sterilisation might occur. Therefore very little is known about the current status of sterilisation of young boys or men with disability in Australia. An exception has been a small study by University of Queensland researchers. (Carlson, Taylor, and Wilson, 2000) They found, that vasectomies (surgical removal of the duct between the penis and the testes) and orchidectomies (castration by surgical removal of the testes) are still happening to young boys and men, as well as the use of drugs to suppress sexual drive.

Researchers found little therapeutic reason or support for vasectomies to be performed on prepubescent boys, or for the option of sterilisation for young men with disability, given it would never be considered for young men without disability of the same age. They also discussed medical evidence that indicated that removal of both testes would usually only be done on men over the age of 80 with advanced testicular or prostate cancer and tumours, and torsion in younger men would usually result in unilateral and not bilateral surgery.

Some interstate stories were cited where questionable sterilisations had taken place via tribunal authorisation. A young man with Down syndrome was sterilised to stop the possibility of pregnancy, yet his family was unaware of the low fertility of men with Down syndrome.

Another story was of a young man who was coerced into being sterilised before being allowed to marry. Some local stories have suggested that teenage vasectomies were also being carried out, and that general practitioners in Queensland, at the request of family members or support workers, were prescribing hormone-changing medications on a regular basis. (Carlson, Taylor, and Wilson, 2000)

Boys and men with intellectual disability are again the most at risk of being sterilised or to have their sexual desires suppressed. Yet, people with intellectual disability are more likely to be the victims of sexual assault than the perpetrators (Sobsey, 1994) and are also less likely to commit a sexual offence than other males in the general population (Hayes, 1991).

Interestingly, earlier research has indicated that behavioural interventions are much more effective than chemical interventions with men with intellectual disability who have committed a sexual offence. (Hayes, 1991) Yet despite this knowledge there is still a dearth of training, support and resources to enable young men to learn about appropriate sexual behaviour, deal with sexual feelings or to be protected from sexual abuse themselves.

The side effects of sterilisation procedures can have long term effects on men. (from Carlson, Taylor and Wilson, 2000)

Surgical Intervention	Desired Effect	Known Side Effects
Orchidectomy (castration by surgical removal of the testes)	<ul style="list-style-type: none"> • Permanent sterility • Loss of libido • Inability to perform sex 	<ul style="list-style-type: none"> • Decreased bone density • Risk of bone fractures
Vasectomy (surgical removal of the duct between the penis and the testes)	<ul style="list-style-type: none"> • Fertility control 	<ul style="list-style-type: none"> • Increased risk of prostate cancer • Chronic pain in the testes

The use of drugs can also produce chemical sterilisation with long term usage having marked side effects.

Drug name and Use	Desired Effects	Known Side Effects
Depo provera Cancer treatment (Banned in the USA for contraceptive purposes)	<ul style="list-style-type: none"> • Inability to have an erection • Reduction in semen production • Absence of orgasm 	<ul style="list-style-type: none"> • Lost bone density • Rapid weight gain • Tiredness, • Depression • Kidney, gall problems
Androcur Blocks male hormones	<ul style="list-style-type: none"> • Decreased sexual drive intensity and frequency 	<ul style="list-style-type: none"> • Breast development • Breast pain
Stilboestral Oestrogen like drug used for treatment of prostate cancer	<ul style="list-style-type: none"> • Loss of sex drive 	<ul style="list-style-type: none"> • Blood clotting • Headaches • Appetite loss • Fluid retention • Liver damage • Breast development • Lactation

Behavioural intervention more successful than chemical

Side effects of surgical sterilisation

Side effects of chemical sterilisation

Side effects of chemical sterilisation

Drug name and Use	Desired Effects	Known Side Effects
Goselerin Used for treatment of prostate cancer	<ul style="list-style-type: none"> Decreases sex drive Decreases testosterone production to castration levels 	<ul style="list-style-type: none"> Hot flushes Breast development Breast discomfort
Antipsychotic tranquillisers (eg Melleril, Modecate)	<ul style="list-style-type: none"> Decreases sex drive 	<ul style="list-style-type: none"> Sleep disturbance Breast pain Arrhythmia Weight gain Tiredness

Concerns about long term effects of these chemical interventions have been raised, especially when drugs are given to boys whose bone or testicular development is not complete, because of disturbance of protein, calcium and phosphorous metabolism. Also some men with disability may not be able to report the physical and chemical side effects that are happening to them following the use of these drugs, leaving them vulnerable to ill health.

7. What are the arguments for and against sterilising people with disability?

Polarised positions are not helpful

The arguments for and against sterilisation of people with disability can range from utilitarian responses of family members and carers who have, or fear having, considerable problems with fertility and menstruation, to philosophical beliefs about how people with disability are fundamentally no different from anyone else.

However it is important to point out, that the polarised positions of a purely utilitarian perspective or a purely rights perspective cannot be taken easily in this very complex matter. This is especially so when other options are available to support people with disability and their families with management of menstruation and fertility on one hand, and on the other hand, that sons or daughters often live in their parental home with family members or with other people who provide personal care, where they and their parents or support workers must co-exist in a social context where their rights may be not only interdependent but also may be quite conflicting. (Brady, Briton and Grover 2001)

In an attempt to summarise the arguments for and against sterilisation, the following analysis has been done, based on information from STAR, 1990, Sobsey, 1994, Brady and Grover, 1997, Tovey, 1999, Brady Briton and Grover, 2001, Manderson, 2002, and Henderson and Alphonso, 2003.

**Arguments for sterilisation
based in negative beliefs about people with disability**

- Suggest reproduction of impaired people, especially those who were born with disability, weakens the gene pool and reduces competitiveness by using up the nation's wealth and being a burden on the state
- Highlight negative perceptions and low value of the worth attributed to people with disability reinforced by the long established precedent of sterilisation over millennia
- Promote the asexual and an eternal child imagery of people with disability needing to be protected from becoming an adult sexual being.

**Counter-arguments to the negative beliefs
about people with disability**

- Reject eugenic beliefs about people with disability
- Emphasise the socio-political nature of the issues especially relating to the sterilisation of young women with intellectual disabilities
- Reject beliefs about eternal children and asexuality
- Reflect the changes in attitudes about the rights of people with disability
- Use other girls and young women as the yardstick, that is those without disabilities, where removing the womb and/or ovaries is only used to treat illness or disease.

Arguments based in concerns about menstruation

- Presume negativity and uncleanliness of menstruation
- Place high value on cleanliness and not having to worry about menstrual blood
- Deny information to girls about menstruation or learning about personal hygiene
- Eliminate the need to learn personal care skills associated with menstruation
- Eliminate expectation of experiencing any discomfort or inconvenience of monthly periods
- Remove extra personal care tasks associated with menstrual management by others

*Summary of
arguments around the
beliefs about people
with disability*

*Summary of
counter-arguments
around the beliefs about
people with disability*

*Summary of
arguments around
concerns about
menstruation*

Summary of arguments around concerns about menstruation

Summary of counter-arguments around concerns about menstruation

Arguments based in concerns about menstruation (continued)

- Remove expectation of having to cope with pain and physical discomfort such as cramps and heavy bleeding
- Lessen other medical conditions that might be effected by hormonal fluctuations such as epilepsy
- Remove the possibility of mood swings and behaviour thought to be associated with pre-menstrual tension and menstruation
- Eliminate the worry that menstrual blood will cause inappropriate behaviour and loss of dignity
- Remove emotional reactions to menstruation
- Eliminate difficult or inappropriate social behaviours associated with menstruation
- Remove the concern about coping with behaviour and situations that are new and likely to cause further difficulty
- Expect a cure-all for inappropriate behaviours, giving greater quality of life
- Eliminate the concern of families and personal carers about the handling of the practical aspects of menstruation.

Counter-arguments to concerns about menstruation

- Reject social taboos surrounding uncleanliness of menstruation and menstrual blood and see this as a normal function
- Question whose quality of life sterilisation is trying to maintain
- Argue that discussions about best interest are around the same issues that any other woman learns to cope with
- Acknowledge that heightened accountability in decision making around the notion of best interest requires a coordinated, experienced and multi-disciplinary approach
- Consider less invasive alternatives, including pain relief strategies and medications for menstrual discomfort, behaviour management strategies resolving inappropriate behaviours
- Reject the assumption that the person's skill development is nonexistent
- Reject that behaviour necessarily improves
- Reject that quality of life necessarily improves
- Consider that sterilisation is not a treatment of choice for girls who have epilepsy who don't have a disability.

Arguments based in fear about the safety of the person

- Assume the person is safer especially when they are in institutional care, living independently in community, living in mixed groups, or when males provide their supports
- Assume the risk of abuse or inappropriate sexual advances from others are removed or lessened
- Remove the necessity for a young woman to be informed about fertility or to learn protective behaviours, and to prevent pregnancy.

Counter-arguments to fear about the safety of the person

- Acknowledge that the actions of others make the person vulnerable
- Acknowledge sexual abuse is not stopped by the procedure
- Acknowledge that people with disability are far more likely to be the victims than the perpetrators
- Argue that sterilisation does not remove daily bowel and bladder functions or dressing which make the person equally open to sexual abuse via these other activities of daily life
- Put forth options that attempt to safeguard against sexual assault, personally and environmentally
- Argue that the procedure can lead to a more restrictive lifestyle and a cycle of neglect, with increased likelihood that sexual abuse will go undetected because of masking by isolation and no outward signs
- Take into account people's lifestyle options and opportunities to learn, and to safeguard against vulnerability
- Assumes sex education, personal support circles and other learning are viable
- Argues that not knowing what sexual assault is can make some people more vulnerable to rape or other forms of sexual abuse.

Arguments based in fear of pregnancy and the consequences

- Eliminate the fear of unwanted pregnancy and who will look after a child
- Remove the danger of pregnancy with all its accompanying pain and trauma
- Eliminate the fear of having to take on the parental role with grandchildren

Summary of arguments around the safety of the person

Summary of counter-arguments around the safety of the person

Summary of arguments around fear of pregnancy and the consequences

Summary of arguments around fear of pregnancy and the consequences

Summary of counter-arguments around fear of pregnancy and the consequences

Summary of arguments around lack of supports

Arguments based in fear of pregnancy and the consequences
(continued)

- Eliminate unwanted pregnancy if raped or sexually abused
- Eliminate the need for a possible abortion
- Remove the concern that a child may also have a disability.

Counter-arguments to fear of pregnancy and the consequences

- Argue that there is no data to substantiate pregnancy in the population of people with disability who are frequently sterilised
- Question the procedure with people with Down Syndrome as only 16 cases of pregnancy had ever been identified in international literature (personal communication with Lennox, in Brady and Grover, 1997)
- Put forth as alternatives, the typical responses such as the pill or other forms of contraception that are available and less restrictive to support young women who are sexually active
- Acknowledge the long term health consequences of sterilisation, in particular, early onset of menopause, decreased bone density, cardiovascular disease and thyroid disease
- Argue knowing about sex, pregnancy and childbirth can be a basis for learning about appropriate expressions of sexuality
- Argue learning about sexuality and life skills will increase a person's self-esteem and assist them with the development of healthy, safe and appropriate social and sexual behaviour.

Arguments based in lack of supports

- Ease 'the burden' on parents and carers by eliminating menstrual management and related personal care tasks
- Highlight the difficulties in gaining supports to assist with bodily and behavioural changes associated with growing up and developing adult relationships
- Highlight the lack of available education and supports for the practicalities of living as an adult sexual being
- Remove the need to try other ways
- Raise the concern that if supports for ordinary life are not achieved, then sexual safeguarding is even harder
- Highlight the importance of the rights of parents and carers in the debate and of the already difficult situation that they are facing.

Counter-arguments to lack of supports

- Gives serious attention to the array of services and support which may significantly enhance both the young person's quality of life and that of parents, siblings and carers
- Highlight that whilst families are prepared to spend years in toilet training they may have little inclination to do the same for menstrual management or other training around sexuality
- Consider and try to arrange supports and alternatives
- Argue that the procedure is never a solution for the scarcity of family support and resources
- Promote the illegality of the procedures if not authorised through the proper channels.

The notion of bodily integrity forms the basis of the laws of assault, whereby protection from the insult of bodily interference is upheld by the fundamental common law principle that every person has a right to bodily integrity. Any intervention that interferes with bodily integrity may be seen to constitute trespass upon the person, which is either deemed a crime that can be punished under State criminal law, or it can be civil wrong or tort for which the person can claim damages or compensation from the person who committed the assault. (Family Law Council, 1994)

As the law cannot draw the line between different degrees of violence, and therefore totally prohibits the first and lowest stage of it; if every person's body is considered sacred, then no other person has a right to meddle with it without the appropriate consent. The fact that the intervention is for a medical purpose is usually no defence to a prosecution or a civil action for assault. A surgeon who performs an operation without proper consent therefore commits an assault. (Circa, 2001)

This notion of bodily integrity is therefore seen as central to the arguments regarding sterilisation, as are other related universal Human Rights. Of special interest here are those of life, liberty and security of person, not being subjected to cruel, inhuman or degrading treatment or punishment, all being equal before the law and entitled without any discrimination to equal protection of the law, and motherhood and childhood being entitled to special care and assistance, with all children having the same social protection, whether born in or out of wedlock. (United Nations Declaration of Human Rights, 1948)

Summary of counter arguments around lack of supports

8. What are the arguments and counter arguments central to bodily integrity?

The laws of assault

Universal rights

***Compliance affirms
citizenship***

These rights are further strengthened by the Declaration of Rights of Disabled Persons (1975) and the UNICEF Convention on the Rights of the Child, Article 23, (1989) stating people with disability have the right to be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature.

By proclaiming that girls, women, boys and men who have a disability have these rights and are entitled to personal inviolability and bodily integrity, the law treats them as having equal value as other children and adults. Such a stance also affirms their inclusion as full citizens in the life of the community. (Brady, Briton and Grover, 2001)

The following analysis of the arguments for and against the use of the right of bodily integrity is based on information from George, 1996, Family Law Council, 1994, Myers, 1999, Tovey, 1999, Brady, Briton and Grover, 2001, and Nicholson, 2003.

Arguments in support of Bodily Integrity

- Give bodily integrity, without regard for its social context, the highest status of values, which means that the onus of proof is on demonstrating that some other value, intrinsic to the person concerned, is of higher value, and only then could sterilisation ever be approved as being in the person's best interests
- Question if there is no therapeutic need, no pathology or disease, nothing physiologically that indicates the need for bodily invasion by surgery, why would it be done?
- Suggest that surgery which purposefully destroys bodily integrity of a person must be condemned
- Regard the procedures as child abuse of the worst sort, by virtue of the assault and violation of the person's body and the denial of their future life as an adult
- Regard the action as criminal assault, which could give rise to actions for damages in future (as has happened in Sweden)
- Use the concept of disproportionate treatment, eg have pain during a period so sterilise to rid person of the pain
- Label sterilisation as another form of discrimination when the yardstick is different for others without disability
- Put forward that sterilisation is the point of last resort and proof is required that all other options have been exhausted
- Change the focus from the burden of care and parent's and carer's wishes to that of human rights, but emphasise the need to achieve those rights by providing information and supports to the people affected.

***Summary of
arguments in support of
bodily integrity***

Arguments against Bodily Integrity

- Put forward the right to maintain bodily integrity and personal inviolability is a matter for debate, not a basic human right
- View social integrity as more important than bodily integrity
- Regard the person as already deemed not to have standardised bodily integrity by the very nature of their disability
- Regard rights as being alongside responsibilities and that, as the person is deemed not to be responsible for managing the issues, then their rights are revoked
- Consider gender and discrimination issues in the context of hardships, and therefore overturn them with utilitarian arguments of the practicalities in everyday life
- See privacy and family autonomy as higher order values and therefore raise the reluctance to interfere with families' perceptions and decisions about this private area of life.

It is important to recognise that, although rights may demonstrate respect for the dignity and lives of people with disability, including their right to bodily integrity, they are not sufficient argument for obtaining the best interests of people in danger of being sterilised, no matter how vigorously they are fought for.

Like in Anti-Discrimination legislation, rights are usually trumped by claims of undue hardship. This notion of undue hardship acknowledges the person not only is a rights bearer, but also is enmeshed in a web of social relationships and circumstances (George, 1996)

Perhaps in deliberations, this point may be worth considering in a similar vein to Wolfensburger's well-known statement that *it is easy for someone to die with their rights on*. In this case, merely putting forward the rights argument will not necessarily bring about the desired changes that will stop senseless sterilisation of young people and afford them the dignity and opportunity to lead an adult life as a sexual being who is not vulnerable to sexual exploitation or abuse.

Rights do remain important, as they embrace the values that are to be held high and applauded. However, this argument would suggest that the purist rights approach may not be helpful in finding solutions to this dilemma around sterilisation. This is because rights arguments may not get to the cause of social distress or join with others in going beyond the causes to the discovery of genuine alternatives for people with disability and their families.

Summary of arguments against bodily integrity

Rights can be trumped by undue hardship

Rights are not enough to solve the dilemmas

9. What are some key systemic concerns which perpetuate the sterilisation of people with disability?

*Not taken seriously
Sanitised argument*

Extreme devaluation

*Power vested in
medical practitioners
legal decision makers*

*Speculative
decision making*

By individualising the issue of sterilisation and the process for authorisation, the wider social and systemic factors are never considered or dealt with, thus perpetuating the current attitudes and flaws in the system. In an interview for QAI, (2001) Susan Brady suggested the following systemic issues were central in maintaining the status quo with regard to young people being sterilised.

1. Lack of progress about the seriousness of the issue of sterilisation

Lack of progress has continued, not only socially and politically, but also personally, in terms of the lack of understanding about the gross intrusion and invasiveness that sterilisation has on a young person's body.

2. Neutral and benign language used to justify procedures

The same arguments are used around the *best interest of the individual* as were used around the *best interest of society* at the time of the eugenics movement, with the continued use of the same basic surgical responses to solve the reproductive and sexual health needs of young people with disability.

3. Extreme devaluation of people with disability especially girls and young women

The whole lack of respect for the humanity of these young people is shown by the devaluing burdensome language attributed to them and by the most restrictive responses as the first option, such as even by considering such unsuitable practices as a hysterectomy or vasectomy for any 10 year old child.

4. The power and authority vested in the medical profession as social arbitrators

The language and discussion is locked in medical discourse allowing medical approaches to be seen as taking the high moral ground or altruistic position, so that their subjective opinion and confidentiality are beyond question with the assumption that their procedures will address the child's and family's needs.

5. Speculative decision making by medical and legal decision makers

Decisions to sterilise are often based on unknown projections about the future, so that there is no reasoned argument to work through possible options and alternatives, which is highly dangerous when the removal of a body part and its consequences cannot be appealed against or altered by a later more informed decision.

6. The paradox of expected competency and maturity

Young women with intellectual disability are expected to manage menstruation instantly without the usual socialisation or opportunities to learn skills over time and are often described as stubborn, difficult and impulsive; terms which could relate quite easily to other teenage girls.

7. Hysterectomy as the vehicle for achieving quality of life

The operation is held up as the means of lifting burdens, enabling community inclusion and being the least restrictive option, which is similar to the eugenics argument that people were free to leave institutions if they were sterilised.

8. The conflicts between the rights of the family and the rights of the child

The issue is often portrayed in this way and if challenged can put the child at greater risk, with reluctance of families to use services that do not agree with their perspective, often leading to acceptance of services that would further isolate the child and where they are at much greater risk of abuse.

9. Hysterectomy as the safeguard for group living

Fear of workers and other residents sexually abusing women with disability has led to the expectation that hysterectomy is a prerequisite for some people going onto group living situations, this being fuelled by the statistics that at least 40% of women are sexually abused in care. Yet sterilisation does nothing to protect these people from sexual abuse.

10. Non-questioning of the illegality of sterilisation without authorisation

The question remains how so many girls and women could be illegally sterilised within the private or public hospital system without questions being asked by other specialists, theatre staff, nurses or hospital administrators, and how sterilisation could be performed under the guise of a differing medical procedure, when even to the untrained eye the differences between an appendix and a uterus are obvious. (Spicer, 1999)

These issues need to be brought out into the open, debated and addressed for any significant change to happen.

In deliberations about the rightness or wrongness of sterilisation of girls and young women, boys and young men, it may important to revisit how people with disability are usually caught up in the cruel and heartless historical events of their time, which can often be intrinsically linked with their death.

Unrealistic expectations

Conflicts between rights of parent or carer and rights of child

Irrational safeguards

Unquestioning and acceptance of illegality

10. A final word

The issue must be debated in the public arena and supports must be made available

Sterilisation is the most drastic action to take when we, at this time and age, have other less invasive and less harmful strategies to support people with disability, their families and their personal assistants, to get on with living life. Currently the issue of sterilisation is hidden, with silencing of all those involved, with little discussion happening, and scant empirical evidence being available.

Prevention and support are surely better than retribution following clandestine action. However for this to happen, the issue of sterilisation must be out in the public arena being debated, and supports to young people and their families must be developed and available, otherwise the practice will continue, whether illegal or not.

Perhaps, with these suggestions unheeded, the warning given to us by Elizabeth Hastings in her statement as Federal Disability Discrimination Commissioner in 1998 leaves us with serious food for thought:

A world in which government cannot be bothered to investigate potential illegal medical assault on its citizens, in which those with no authority feel free to make decisions which are blatantly against the law and to carry out serious and irreversible procedures on those with little or no capacity to give or withhold consent, is a world in which people with disabilities can have no certainty or confidence about their human being or their future.

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Queensland Advocacy Incorporated (QAI) is an independent, community based, systems advocacy organisation for people with disability in Queensland.

QAI's mission is to promote, protect and defend, through advocacy, the fundamental needs, rights and lives of the most vulnerable people with disability in Queensland.

QAI does this by engaging in systems advocacy work, through campaigns directed to attitude, law and policy change, and by supporting the development of a range

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Practical Approaches to Supporting Young Women With Intellectual Disabilities and High Support Needs With Their Menstruation

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Menstrual myths may influence decisions about menstrual and fertility management for women with intellectual disabilities and high support needs. We identify six myths (related to menstruation, menstrual management, communication, sexual feelings, menstrual difficulties, and surgical elimination) and the evidence that dispels these myths. We provide reflexive questions for practitioners to help them critically reflect on their own approaches to menstrual management. We encourage those supporting women with disabilities to consider the reflective questions we have provided and to strive to support informed decision-making about menstruation and the related areas of fertility and sexual feelings.

In a study undertaken by Carlson and Wilson (1996), some parents decided to use medical approaches to eliminate their daughter's menstruation and fertility (Carlson, 1995). All of these young women were identified as having intellectual disability. Menstrual myths—those negative attitudes and limited or inaccurate information about menstruation—may influence decisions about menstrual and fertility management for women with intellectual

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disability and high support needs. Some of these women may never be able to manage menstruation independently. Given that they are usually fully or partially supported with a range of other personal care tasks, however, they should also be supported in their menstrual management. Since little has been published in this area, we feel it is imperative to continue to provide practical information to practitioners and support workers about the full range of options for menstrual management and the related area of fertility management over a lifespan. In particular, we are concerned about the use of medical sterilization as an initial strategy for menstrual management, given that other potentially more appropriate and less invasive strategies exist. While little is known about the long-term impacts of medical sterilization, we have found that the strategies we outline in this article can be effective and empowering.

We identified many of these practical strategies from participant statements in our original study, when we worked with women to develop a *Menstrual Management Kit* (Carlson, Taylor, Griffin, & Wilson, 1992). Other strategies have been identified through our practical experiences with women since the original study was undertaken. While our practice is undertaken in Australia, we believe these strategies are useful to an international audience.

Sterilization in Australia

In 1992, the High Court of Australia ruled that parents as guardians could not lawfully authorize the sterilization of their daughter with intellectual disability under 18 years of age without an order from the Family Court of Australia. Before consent for hysterectomy is given, the Family Court of Australia will require evidence of the use of less invasive approaches to menstrual management. This ruling is applicable throughout Australia (Brady, 1998). If a woman is an adult, her legal guardian will not be able to give consent to medical procedures that involve sterilization. Sterilization is considered to be a “special medical procedure” and, as such, requires additional consent from a judicial body such as a state guardianship tribunal (Brady & Grover, 1997). No monitoring of the frequency or reasons for these decisions is occurring across Australian jurisdictions.

The Menstrual Management Kit: Participant Statements

While interviewing mothers of 30 young women with intellectual disability and high support needs, Carlson and Wilson (1996) found that for 14 of the young women, menstruation had been surgically eliminated. Menstrual cycles for another three young women had been hormonally suppressed (Carlson & Wilson, 1996). The most common reasons given for these decisions relate to fertility concerns and difficulties with menstrual discomfort,

flow, and cyclic emotional changes. Women with high support needs usually require ongoing support with day-to-day tasks in the area of self-care. Therefore, independent menstrual management may not be possible. Other mothers described successfully supporting their daughters to manage menstruation in practical ways. It appeared that menstrual management decision making on behalf of this group of young women was influenced by fertility considerations and was not based on a full range of information about other, potentially more appropriate, options.

In response to the conclusions arising out of this research, a menstrual management resource was developed in 1994 by a joint project between the Department of Social Work and Social Policy at The University of Queensland and the Division of Intellectual Disability Services in the Queensland Department of Family Services and Aboriginal and Islander Affairs, with original funding from the Commonwealth Department of Health, Housing and Community Services.

This Article

In this article, we aim to dispel commonly held menstrual myths relating to women with intellectual disability that may affect decision-making about menstrual management. We identify six myths (related to menstruation, management, communication, sexual feelings, menstrual difficulties, and surgical elimination) and the evidence that dispels these myths. We provide reflexive questions for health and other practitioners to help them critically reflect on their own approaches to the issues raised, including their personal responses to our proposed strategies.

A young woman's developing sexuality is also relevant to decision-making about menstrual management. While we refer to sexual feelings as they may impact on menstrual management (in our discussion below), a conversation about sexuality and women with intellectual disability, although critically important, is beyond the scope of what we could achieve here.

Myths About Menstruation

It is a myth that the menstrual flow of women with intellectual disability is "unclean" (Atkinson et al., 2003; Carlson & Wilson, 1996; Grover, 2002). The menstrual flow of women with intellectual disability is no different from that of other women.

Menstruation is a normal and natural function of most women's bodies. Many women with intellectual disability menstruate. Responses of family members, staff members, and friends toward menstruation can influence the reactions of a young woman with disability (Carlson & Wilson, 1996; Chou, Lu, Wang, Lan, & Lin, 2008).

Common issues for those supporting young women include the following:

- People assisting a young woman with menstrual management may be uncertain about how to explain menstruation to her and how to teach pad changing.
- Menstruation can be a reminder that the young woman may not experience adulthood in the way women without a disability might.
- The young woman may have physically grown, which can add to difficulties for people assisting with bathing, using the toilet, and changing menstrual pads.

Women's experiences of menstruation vary a great deal; for example, patterns of flow vary between women: what seems normal flow for one woman can be seen as heavy for another. Some women experience physical and mood changes around the time of menstruation. These changes can be positive or negative and can vary from cycle to cycle (Logue & Moos, 1986). Therefore, a woman's personal feelings about menstruation can be influenced by the people who support her, cultural attitudes, and personal experiences. In some cultures, menstruation is regarded positively and in others negatively. For example, in the Hindu culture a young woman's first menstruation is celebrated with new clothes, ceremonial baths, and feasting. Comparatively, in Western societies, menstruation is often regarded negatively and there is a strong social pressure to avoid any visual evidence of menstruation (Kelly & Gahagan, 2010). It is important to encourage people providing personal assistance, however, to have a positive and supportive outlook toward menstruation (Gray & Jilich, 1990). Consistency of approach between personal assistants and across environments is also a priority.

MYTHS ABOUT MENSTRUAL MANAGEMENT

It is a myth that women with intellectual disability cannot manage menstruation themselves or with assistance. Many can manage menstruation independently if given support to learn. Some can receive ongoing support in ways that are similar to other self-care tasks, such as using the toilet and bathing (Rodgers & Lipscombe, 2005).

Preparing for Menstruation

Unlike women in past generations, almost all young women today are informed and prepared for menstruation. If possible, preparation should be an ongoing process that begins early in life, so that menstruation is regarded as a normal part of life. Since menarche (first menstruation) begins at a different age for each individual, specific preparation for young women with

intellectual disability should probably begin around 9 years of age (Burke, Kalpakjian, Smith, & Quint, 2010). It should be remembered that some conditions and syndromes associated with intellectual disability, such as Marfan syndrome, can be linked with early menarche (Ejskjaer, Uldbjerg, & Goldstein, 2006; Mason & Cunningham, 2009; Yueh-Ching, Jane Zxy-Yann, & Cheng-Yun, 2009).

During the young woman's first 2 years of menstruation, there may be no pattern to the appearance and length of her periods. This is normal. It takes time for the body to settle into a menstrual cycle. It may be helpful to chart the young woman's cycle. A chart may prove useful in the management of menstruation by showing cyclical changes. For instance, a record could be made of the menstrual flow or signs of an approaching period such as swollen abdomen or changes in mood (Negriff & Dorn, 2009).

Providing information is an important part of effective preparation for menstruation (Swenson & Havens, 1987). Keep instructions easily accessible for the woman (e.g., on the toilet door or hanging beside the toilet roll). Even if you are not sure that the young woman will understand, it is important to give her basic explanations and reassurance about periods prior to menarche, for example, "Most girls menstruate"; "To menstruate means blood comes from inside your body and flows out through an opening between your legs"; "This opening is called a vagina"; "When you menstruate, you will need to use a pad"; and "You leave the pad in your pants" (Carlson et al., 1992).

When speaking about menstruation, the tone of voice, as well as the words used, will be very influential: if the person speaking is not comfortable, then the young woman is likely to be aware of this and react accordingly. It may be helpful to use anatomically correct dolls when providing explanations for some young women. Personalized books can be another useful approach; for those who may respond, photographs and/or familiar communication symbols could be used to assist with learning (Carlson et al., 1992).

When preparing for menstruation, care providers should be encouraged to model the following:

- avoid negative reactions to the sight of blood;
- respond calmly to menstruation;
- model modest behavior while bathing, dressing, and toileting;
- show affection appropriate to her age and interactions that recognize her approaching maturity; and
- ensure consistency of approach in menstruation between people who assist her and places where she regularly spends time.

"Practice periods" give young women opportunities to become familiar with routines and some sensations related to periods, for example, getting used

to the feel of wearing pads and spending time trying out pads of different sizes and shapes to find out which are most comfortable for her. Modeling by a mother or sister of what happens during periods can be of great benefit, as well as planning women's days or sessions when pads are worn during pleasant, "feminine" experiences like manicures, dressing up, hairstyling, and massage. The young woman could be involved in shopping for her own pads to help her to understand that menstruation is a natural part of her life. Importantly, young women who do not appear to have the ability to learn to manage any part of their menstruation still need preparation (Carlson et al., 1992).

Menstrual Pads and Incontinence Products

For women already using incontinence pads, factors to consider when choosing products for use during menstruation may include the following: absorbency, the woman's comfort, ease of use, cost per year, available sizes, ease of laundering (for reusable products), and impact on the environment (Carlson et al., 1992). Reusable products can be alternated with disposable products (e.g., women may use reusables at home, but use disposable products for school and outings). For women who do not already use incontinence pads, an additional consideration may be to ensure that the young woman has firm-fitting underpants, particularly cotton blends that may be better in warm weather and help to avoid vaginal infections and rashes.

Young women without disability who have not received preparation for their menstruation have been found to experience menstrual difficulties more frequently and more severely than young women who have received preparation. This may also be relevant for young women with intellectual disability (Kelly & Gahagan, 2010).

MYTHS ABOUT COMMUNICATION

It is a myth that a woman with intellectual disability will never understand or accept her own menstruation (Atkinson et al., 2003; Carlson & Wilson, 1996; Grover, 2002). With support and information, any woman can understand and accept menstruation as a natural part of life. Communication skills among women with high support needs can vary a great deal, both between individuals and at different times for the same woman. Differing approaches may also be needed to help each woman understand information and express herself. Possibilities for communication other than speech may include use of signing, a range of symbols, objects or object symbols, and augmentative language by those assisting them (Clegg, Sheard, Cahill, & Osbeck, 2001; Iacono & Johnson, 2004; Stephenson & Dowrick, 2005).

Some care providers are concerned about management of cyclic changes, such as discomfort or pain before or during menstruation. Use

preferred communication strategies to explain and to enable her to communicate her experiences and feelings:

- Keep a menstrual chart. Use a particular symbol to mark when the woman's next period is due. Involve her in her charting, so that both she and people who assist her are aware of when her period is due.
- Keep a list of activities or objects that each woman enjoys. Some of these can be planned for when she has her period. This may help her to associate periods with pleasant experiences. Enjoyable activities may also direct attention away from menstruation.
- It may be appropriate to assist the woman to start using pads a few days before her period is due. This may help to communicate to some women that menstruation will soon begin. A young woman may be already familiar with regularly wearing pads for continence reasons, so she won't have to get used to wearing them for menstrual reasons.
- Changes to the environment can signal to a woman that her period is due. Playing distinctive soothing music, burning a relaxing essential oil, or giving her a daily massage in the days before and during a woman's period may communicate to her in a pleasant way that her period is due (Carlson et al., 1992).

The possibility that a woman who has high support needs may experience pain or discomfort and be unable to communicate this can cause serious concern to those assisting her (Kyrkou, 2005). Even for those women least able to communicate clearly, it may be possible to evaluate their comfort; it is also possible to evaluate the effectiveness of strategies for easing discomfort by recording her nonverbal communications on a calendar. Discomfort is not inevitable.

ISSUES THAT MIGHT ARISE WITH MENSTRUATION

It is a myth that a woman with intellectual disability will inevitably have ongoing menstrual management difficulties such as discomfort or premenstrual stress (Atkinson et al., 2003; Carlson & Wilson, 1996; Grover, 2002). She will experience the menstrual cycle just as any other woman does, and her experiences may involve temporary or occasional discomfort.

Personal Hygiene

Bathing routines may need to be more frequent during periods, as both comfort and odor can cause difficulties for young women. A long shower hose to enable a quick rinse between the legs might provide relief. Ensure that pads are changed regularly and worn for no longer than 4 hours before

changing. As odor usually results from air mixing with menstrual blood, pads need to be kept close to the body, so underpants should fit snugly (Quint, 2008).

Habits

Some young women may develop inappropriate behavior habits that affect management of menstruation, including removal of pads in public or a tendency to handle the contents of their pads. It may help to use the young woman's preferred communication strategies to explain what is inappropriate and why this is so; diversion to another activity of interest to her may also be helpful (McVilly, 2002). Effective encouragement of appropriate behavior will support change (Carter, 2006; Kyrkou, 2005; Stone, 1999). To help improve understanding of spreading menstrual flow, have a washer ready and calmly, but firmly, state that the young woman can help to clean up. A young woman may try to remove the pad because she is uncomfortable. Comfort is important to all of us. Check for causes of irritation and try to find pads and clothing that she feels comfortable wearing. Are the pads too thick or not contoured? Is the fabric "scratchy"? Bicycle pants or gym shorts may help keep everything in place (Carlson et al., 1992).

Premenstrual Changes

Physical changes may include fluid retention, breast tenderness, headaches, acne, and general aches and pains. Other signs may include tension, anxiety, irritability, depression, anger, food cravings, increased appetite, and clumsiness. Some women may also experience a twinge or cramps in the lower back or abdomen or spotting when ovulation occurs—"Mittelschmerz" or "middle pain" (O'Herlihy & Robinson, 1980). Positive premenstrual and menstrual changes have also been reported by some women. These have included increased creativity, energy, and ability to relax (Logue & Moos, 1986). It is probable that many women do not notice premenstrual changes during every cycle. It has been found that physical discomfort and negative mood changes are often more noticeable during times of life stress or personal disruption. Premenstruation may be the only time when a woman lets off steam and expresses distress or irritability (Gurevich, 1995). By keeping a menstrual chart, the care provider may be more aware of premenstrual changes and give timely support to the young woman. Attention to diet, exercise, and sleep will often reduce the occurrence of premenstrual problems (Salamat, Ismail, & O'Brien, 2008). For example, eating lightly, increasing fiber, and drinking more water can reduce fluid retention. Complementary medicines have a range of products for reducing fluid retention and other premenstrual discomfort.

Discomfort

Most women say that despite premenstrual changes or menstrual discomfort they are able to continue with daily activities. Discomfort may include cramps, nausea, diarrhea, and headaches. For a young woman with high support needs, expressions of discomfort may range from “not being herself” to what is perceived as difficult to manage “behavior.” Ongoing period pain can sometimes be caused by physical conditions such as fibroids, endometriosis, or infection and should be investigated.

Charting the menstrual cycle can afford some insight into what is and is not normal for the young woman. During times of discomfort, try reducing activity expectations or provide a little extra pampering, like a bubble bath or a facial. Changes in positioning may help to reduce discomfort, and there are also gentle forms of exercise available. A hot water bottle, warm wheat pillow, or cold pack may be placed on her abdomen or lower back. Massage, relaxation, or acupuncture (Zhu, Proctor, Bensoussan, Wu, & Smith, 2008) may assist, as might leisurely exercise.

Epilepsy

Some women with epilepsy experience changes in epileptic seizures that are related to their menstrual cycle. These changes are not always severe and have been variously linked to alterations in hormone levels, fluid levels changes, and cramping. If these epileptic changes affect the woman's lifestyle, a review of medication could be initiated. Charting of seizures and menstrual cycles would be a first step in this review. Reducing fluid retention can reduce the chance of epileptic changes (Noe & Pack, 2010).

MENSTRUATION, SEXUAL FEELINGS, AND FERTILITY

It is a myth that young women who begin to menstruate do not experience normal sexual desires and feelings. How these desires and feelings are expressed varies with each woman.

Sexual Feelings

It is very individual. For some young women with intellectual disability, masturbation may be a way of expressing sexual feelings. Masturbation is a natural and healthy way of expressing sexuality (Elders, 2010).

Masturbation by a young woman with intellectual disability and high support needs may provide her with an outlet for tension, boredom, or curiosity (Noonan & Taylor Gomez, 2010). Problems arise when masturbation occurs in public, becomes distressing, or causes problems with the spread of menstrual fluid. In the past, people assisting a woman with high support needs may have focussed on trying to stop the young woman from

masturbating. It is now more likely that families and support workers may explore reasons and examine strategies for more appropriate masturbation. There are various approaches for a young woman to learn that masturbation in public is not socially acceptable, such as the use of rewards on initial short excursions or advice that it is a private activity best done in her bedroom (Walsh, 2000).

Fertility

Menstruation is a sign of fertility, which can be a source of concern for some families and staff members. For example, they may be worried about the risk of pregnancy through sexual abuse. Research suggests that an abuser is most likely to be a man who is known to the young woman: either a family member or a staff member. Much less commonly, a male who has an intellectual disability is involved (Reiter, Bryen, & Shachar, 2007). Risk of sexual abuse may be reduced by assisting the young woman to learn the basic ideas of protective behaviors (Mazzucchelli, 2001; Zwi et al., 2003).

If a young woman does not menstruate due to medical intervention, the risk of sexual abuse may increase because the abuser knows he is free to continue his abuse, since the young woman will not become pregnant (Brady & Grover, 1997). While contraception or sterilization may eliminate menstruation and fertility, they do not eliminate the risk of sexual abuse or sexually transmitted infections (STIs). *The Management Guidelines: Developmental Disability* (Lennox et al., 2005) suggest that, in addition to contraceptive advice, teaching about relationships and protection from STIs, especially the use of condoms, and education about the right to say or indicate “no” should occur. If a young woman with intellectual disability chooses to engage in consensual sexual activity, then there are a range of options for contraception to match her personal needs. There may be concern about young women with intellectual disability being parents. There appear to be very few recorded situations where women with intellectual disability and high support needs have become mothers (Starke, 2010).

MEDICAL APPROACHES

It is a myth that surgical elimination of menstruation and fertility does not involve risks to the woman’s long-term health.

Sterilization/Surgery That Affects Menstruation

Widespread sterilization of people with intellectual disability occurred in the nineteenth and twentieth centuries. As national legislatures around the world continue to debate the issue (Freckelton, 2007), publicly available data indicate that the rate of sterilization of people with intellectual disability has diminished (Spicer, 1999); however, many argue it should not be happening

at all (Servais, Leach, Jacques, & Roussaux, 2004). Sterilization should be considered an option of last resort (Grover, 2002). Some sterilizations of women with disabilities were hysterectomies (surgical removal of the uterus) to eliminate menstruation as well.

Research has indicated that women who have a hysterectomy between 39 and 60 years of age experience menopausal signs earlier than average, including hot flushes, osteoarthritis, constipation, depression, sexual problems, neurological problems, premature hormone changes, and vaginal dryness (Cosgrave, Tyrrell, McCarron, Gill, & Lawlor, 1999; Ejskjaer et al., 2006; Kalpakjian, Quint, Tate, Roller, & Toussaint, 2007). Research with women who have had hysterectomies in their late twenties or thirties indicates that for some women ovarian function can decline, leading to menopause several years earlier than average (Taylor Gomez, 2010). This may then lead to problems such as “brittle bones” (osteoporosis). Some researchers have found that women who have had a hysterectomy, even without the ovaries being removed, have a higher chance of developing heart-related (cardiovascular) disease (Lennox et al., 2005). The lining of the uterus (the endometrium) excretes substances called prostaglandins. These have been linked by some medical researchers to protect women from heart-related disease (Lennox et al., 2005). Prostaglandins have also been linked with menstrual “cramps.” The functions of prostaglandins, however, are not yet fully understood.

If a woman has a hysterectomy with ovaries removed as well as her uterus, she experiences instant menopause. Hormone replacement therapy is necessary immediately. The long-term use of hormone replacement therapy has been linked to an increased risk of breast cancer, cardiovascular events, and stroke. No monitoring of ovarian function after hysterectomy (ovaries not removed) in young women with intellectual disability appears to be occurring. In addition, emotional or mood responses to a hysterectomy may include depression and changed sexual response. These responses do not appear to have been monitored for women with intellectual disability (Atkinson et al., 2003; Grover, 2002).

Endometrial ablation (involving surgically scarring the lining of the uterus) can result in permanent cessation of periods; however, “break-through” menstrual flow may continue to occur. A second ablation may be necessary for some women. After endometrial ablation, the chances of becoming pregnant are greatly reduced. Problems that may occur during endometrial ablation include perforation of the uterus and damage to the bowel (Atkinson et al., 2003; Grover, 2002). The effects of eliminating the prostaglandins secreted by the lining of the uterus is unknown.

Contraceptives That Affect Menstruation

Women with intellectual disabilities are sometime prescribed contraceptive medications to reduce or suppress menstruation, rather than for fertility

management (Carlson 2002; Carlson et al., 1992; Carlson & Wilson 1996; Lennox et al., 2005).

The contraceptive pill (“the pill”) is widely used, particularly in Australia. According to the *MIMS Drug Manual*, possible short-term physical effects of the pill include sore breasts, abdominal cramps and swelling, headaches, nausea, weight changes, increased vaginal infections, tiredness, and depression. It is not stated how common these effects are, and they are certainly not experienced by all women.

Women taking the pill often have light and short periods during the “pill-free” week. Breakthrough bleeding or spotting between periods may occur while taking the pill, especially if one is taken late or missed. Possible long-term risk factors include blood clotting and heart and liver problems. There is strong evidence to suggest that oral contraceptive use is associated with venous thromboembolism, and the risk increases with age. More importantly, coincident disability health factors such as immobility, past cardiovascular accidents, and deep vein thrombosis may be a contraindications to the use of the pill (Lennox et al., 2005).

Bone density is especially important during adolescence (puberty until the ages of 18–26 years) because it increases the most during this time period. Research into the long-term effects of combined oral contraception on bone density in young women/adolescents is still limited, and the relationship remains unclear (Pitts & Emans, 2008).

The “continuous pill” is a term sometimes used to describe the use of the pill continuously without a monthly break, that is, without the use of “sugar pills” for a week. Some women use this occasionally to avoid the occurrence of menstruation during special occasions and sporting events. Women with disabilities may be given the pill continuously and indefinitely for its menstrual suppression effects. Effects experienced in addition to those of the the pill include the suppression of periods, although breakthrough bleeding (breakthrough menstrual flow) may occur. The continuous pill appears to be used by very few women on a long term-basis (Sexual Health & Family Planning Australia, 2008).

Progesterone-only contraceptives such as depot medroxyprogesterone acetate (DMPA) have been used to manage problems associated with menstruation in women with intellectual disability (Grover, 2002). Such problems include menorrhagia (heavy periods), irregular menses, and dysmenorrhea (painful periods). In the United Kingdom, McCarthy (2009) confirmed that the use of DMPA among women with intellectual disability represented a high proportion of users of DMPA when compared with the general population of women. Her study showed the extent to which women with intellectual disability to make “good” choices about their own reproductive health was limited. Women with intellectual disability currently receiving Depo-Provera injections did not understand how the contraception worked or the risks (adverse effects) of their contraception. In addition, McCarthy (2009) highlighted

the lack of choices women with intellectual disability are given when using DMPAs (McCarthy, 2009). A study by Cromer and colleagues (2004) showed that the bone mineral density in adolescent girls (aged 12–18 years) using DMPA was significantly reduced when compared with adolescent girls on oral contraceptive or no hormone treatment, over 12 months (–1.4% compared with 3.8% in nonhormone treatment; Cromer et al., 2004). The use of DMPA can cause reduced mobility through weight gain and thus increases the risk of osteoporosis in women who are already immobile (Albanese & Hopper, 2007).

REFLEXIVE QUESTIONS FOR PRACTITIONERS

Based on our strategies above, we have developed three key reflexive questions for practitioners that might help to integrate strategies into their existing practices or critically reflect on their current approaches.

1. Thinking about your own experiences and feelings about menstruation, and about your daughter/student/client, ask, “Are these affecting the way that you are feeling about her menstruation?”
2. If difficulties arise in menstrual management, consider who it is a problem for and what resources are need to solve the issue.
3. When deciding options for menstrual management and contraception for women with intellectual disability and high support needs, ask the following:
 - Is it “normal”?
 - Is it safe?
 - How will it affect her body?
 - How will it affect her long-term “quality of life”?

We encourage practitioners to engage in proactive discussions about these questions in a safe, supportive environment. In particular, discussion with colleagues, mentors, or other members of their community might open chains of communication, improve practice, and ultimately empower women with intellectual disabilities and high support needs in relation to their menstruation.

SUMMARY AND CONCLUSIONS

In this article, we have provided some background information about menstruation and women with intellectual disability. We advocate that menstrual elimination through medical interventions should be a last resort, as there is limited information about the long-term health effects. As alternatives, we have outlined a range of practical strategies (summarized in Table 1)

TABLE 1 Practical Strategies for Menstrual Management

Area of concern	Strategy
Communication	Use communication preferences of each woman to explain and reassure
Preparing	Try practice periods Give positive messages Model/demonstrate pad changing Have “women’s” sessions
Day-to-day	Go shopping together for menstrual pads Use visual instructions (e.g., in the toilet) on pad changing Check for signs of discomfort Use a consistent approach between care providers Continue to give positive messages Encourage modest behavior Keep a menstrual chart (involve her in this) Use pads a couple of days prior to when menstruation is due to start Support relaxation Include more bathing if needed Use firm fitting underwear Consider the woman’s preferences in menstrual products Pay attention to diet, exercise, and sleep Use pain management strategies if needed
Protective behaviors	Encourage understanding of the two basic messages of protective behaviors: <ul style="list-style-type: none"> • We all have the right to feel safe all the time. • There is nothing so awful that we can’t talk with someone about it.
Medical approaches	Try all other options first. Contraceptive medications or surgery to suppress or eliminate menstruation should be the least restrictive alternative Make sure long-term health effects are considered.

For further information, please refer to <http://www2.som.uq.edu.au/som/Research/ResearchCentres/qcidd/Pages/menstruation>

that have been useful in some situations. We encourage people supporting women with disabilities to consider the reflective questions we have provided and to strive to support informed decision making about menstruation and the related areas of fertility and sexual feelings. We are part of a culture that devalues people with disabilities (Block, 2000). We must increase the basic rights of women with intellectual disability to normal means of menstrual management and to live healthy lives as women (World Health Organization, 2001).

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