Feedback on the Draft Voluntary Sterilisation (Amendment) Bill to the Ministry of Health, Submitted in Response to the Public Consultation Launched on 4th June 2012

Date of this document: 2 July 2012

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Feedback on the Draft Voluntary Sterilisation (Amendment) Bill from the Association of Women for Action and Research (AWARE), submitted to the Ministry of Health

Key Points

1. AWARE welcomes the move to better safeguard the sexual and reproductive autonomy of persons with intellectual or developmental disabilities.

2. The proposed amendments, however, do not adequately protect people – especially women and girls – who lack mental capability.

3. Intellectually disabled women and girls face greater discrimination and violence than other women. This should be explicitly recognised in the new legislation.

4. If the intent of the amendments is to align the Voluntary Sterilisation Act with the Mental Capacity Act (2008), why is the MCA regime not adopted fully? We urge that voluntary sterilisation decisions be brought under the MCA.

5. AWARE is deeply disturbed to find that the Bill offers intellectually disabled people lower standards of protection when it comes to sterilisation than the MCA does for less weighty decisions, such as managing their finances.

6. In relation to the sterilisation of Minors, there should be a minimum age at which Minors are deemed capable of giving consent for sexual sterilisation (together with her parents / guardian). A court order or independent committee decision should be required for Minors below this age.

7. We believe that the decision to sterilise a person who lacks capacity (because of age or mental condition), except in emergency situations where the life or health of the person is threatened, should be made by a court of law or an independent committee.

8. Sterilisation should only be considered when less restrictive options are not available or have been exhausted. It should not be carried out for non-therapeutic reasons such as contraception.

9. More social support, respite care and training should be provided to the care-givers of persons with intellectual disabilities, including the management of their sexual and reproductive functions (such as menstruation), so that sterilisation is not seen as a method of care management.

10. AWARE requests for a meeting with MOH to discuss the above key issues.

Introduction

AWARE thanks the Ministry of Health for inviting views from the public on the Voluntary Sterilisation (Amendment) Bill (henceforth known as the "Bill"). We would like to commend the Ministry on its efforts to update the Voluntary Sterilisation Act (henceforth known as the "Principal Act") to align it with the Mental Capacity Act 2008 (MCA) and the UN Convention on the Rights of Persons with Disabilities (CRPD), which Singapore will soon be signing. This is a step in the right direction.

AWARE believes that every individual has the right to make informed and responsible decisions about their lives. The right of women to control their own bodies, particularly with regard to sexual and reproductive decisions, must be protected. These rights should apply regardless of one's disability or health status. AWARE is thus encouraged by the Ministry's proposal to better safeguard the sexual and reproductive autonomy of persons with disabilities, including persons with intellectual or developmental disabilities, health conditions such as mental illnesses or epilepsy, and/or hereditary illnesses, without assuming that they lack capacity based on these medical conditions.

However, AWARE is concerned that persons who lack mental capacity are left vulnerable even with the proposed amendments. Women and girls with intellectual disabilities experience discrimination and violence at a higher level than other women. AWARE believes it is important that the new legislation explicitly recognises this.

The government should also ensure that health providers and the general public are educated so that discrimination and violence are not carried out through the practice of sterilisation, where a woman with an intellectual disability might be sterilised because she is viewed as inferior.

One of the objectives of the Bill is to align it with the MCA. We support this objective completely and we are deeply disappointed that the Bill does not adopt the MCA regime in its entirety. We urge that voluntary sterilisation decisions be brought under the MCA.

In 2010, Dr Vivian Balakrishnan, who was then Minister of Community Development, Youth and Sports, noted that:

> "fundamentally, the Mental Capacity Act calls for a change in mindset. People who lack capacity are not simply human beings who have lost their right to dignity, autonomy and the fullest life possible. On the contrary, we are called to respect them as persons and act in their best interests."[1]

Singapore should approach sterilisation decisions in the same spirit.

AWARE is also concerned about the provisions in the Bill relating to the sterilisations of persons below 21.

AWARE's Concerns

Sterilisation is a major procedure that involves a violation of a person's physical integrity and the irreversible termination of a person's reproductive function. It often has profound physical and psychological effects on a person.

The question of who has the right to make this decision in the case of vulnerable adults and children is a complex matter and has been the subject of much debate in courts, including in Australia and Canada[2,3]. In these cases, the courts treated sterilisation as being in a different category from other medical procedures consented to by parents or guardians.

Sterilisation of Persons Lacking in Mental Capacity to Decide

Sterilisation is usually rationalized to be in the "best interests" of women or girls with intellectual disabilities. However, the reasons given often simply have to do with "social convenience"[4] such as menstrual management, hygiene, to prevent pregnancies or for eugenic purposes (which was more prevalent in the past).[5,6,7]

Female sterilisation is a highly intrusive and irreversible procedure,[8] and in line with the principles of the MCA, should not be permissible when there are less restrictive options available.[9]

In most cases, there will be less restrictive options. For example, the hygiene issues can usually be addressed by education or hormone manipulation. Where there is a compelling reason for contraception, there are many less invasive alternative solutions to sterilisation.

Moreover, sterilisation for contraceptive purposes does not prevent the transmission of sexually transmitted diseases.[10] Indeed, it may encourage sexual abuse when the perpetrator knows that a woman or a girl can no longer get pregnant.[11] Irreversible sterilisation violates the reproductive rights of women with intellectual disabilities.[12,13,14]

We recognise that caregivers of women and girls with intellectual disabilities are often overstretched and under-supported.[15] Adequate social support services must be set up, so that caregivers and medical practitioners will not decide on sterilisation as a solution to what is really a problem of poor social support.[16]

AWARE is deeply concerned that the Bill does not adopt all the standards, processes and protections of the MCA, despite the declaration that the amendments were made to "better align it with the MCA (2008)". The Bill has only adopted Part II of the MCA (sections 3 – 6). Furthermore, the MCA's Code of Practice is a very useful document with guidelines for laypersons and decision makers when dealing with tricky situations.[17] If VSA is separated from the MCA, it will not have the benefits of the Code of Practice.

It is a very grave matter for a caregiver to consent to the sterilisation of an intellectually disabled person. AWARE is thus deeply disturbed to find that the Bill offers intellectually disabled people lower standards of protection when it comes to sterilisation than the MCA does for less weighty decisions, such as managing their finances.

AWARE is particularly concerned that the Bill does not have the following parts of the MCA:

1. The legal infrastructure provided by the MCA regarding who is authorised to make decisions for intellectually disabled people.[18] In the Bill, as in the principal Act, a parent / guardian or spouse of such persons is authorised to provide consent on his or her behalf.

   The Bill concomitantly fails to provide safeguards against circumstances such as family disputes, which are recognised in the MCA Code of Practice as having potential negative impacts on the best interests of such people.[19]

2. The Bill does not incorporate Section 7 of the MCA. This section provides important protection for persons lacking in mental capacity by placing the burden on the medical practitioners involved in non-consensual sterilisation to take all reasonable steps that such sterilisation is in the best interests of the individual, including formal assessment of mental capacity.

3. The Bill does not incorporate Sections 21 to 23 of the MCA which empower the Court to give consent to the carrying out of a treatment by a health care provider.

AWARE believes that, given the major, irreversible and invasive nature of sterilisations, except in cases where the procedure is necessary to save the individual's life or to prevent serious damage to his or her health (hereinafter known as "Emergency Situations"), a court order should be a pre-requisite to the sterilisation.

If the MCA does not apply in full to sterilisation decisions, a conflict situation may develop between the parent or spouse (who, under the VSA, makes the sterilisation decision) and the deputy or donee appointed under the MCA (who makes all other decisions). The MCA has established a system for appointing persons who make particular substituted decisions. It does not make sense for the VSA to have a separate regime.

Sterilisation of Persons below 21

AWARE is concerned about the sterilisation of persons below 21 (or "**Minors**"). The Bill provides that this decision shall be made by the person and her parent or guardian.

Firstly, by providing for only one parent to make this decision, the Bill goes against the general law of guardianship that imposes both parents with joint guardianship responsibilities.

Second, while parents may have parental authority over their children for most decisions, courts in countries such as Australia and the United Kingdom have taken the view that there must be higher accountability for parents in consenting to sterilisation decisions, considering the serious and irreversible nature of such decisions.[20,21] AWARE wholeheartedly agrees with this view.

The same principle should apply to minors in determining capacity to consent as to adults. Being able to understand and weigh relevant information is a key part of possessing capacity to consent, and it is doubtful to what extent Minors, especially those who are younger, are able to understand the concept of sexual sterilisation.[22]

A distinction should be made between Minors who lack the capacity to understand the nature and implications of sterilisation and Minors who are mature enough to do so. The protections granted to adults lacking in mental capacity should be extended to the latter.

Compliance with International Conventions

The Bill falls short of standards set out in the CRPD. These standards include recognition of the disabled person's right to physical integrity (Article 17); as well as state obligations to safeguard the fertility of persons with disabilities on an equal basis with others, and to recognise their right to have families and bear children [Article 23(1)].

The Bill also fails to meet the standards required by the other international human rights instruments to which Singapore is a signatory. The Committee on the Elimination of Discrimination against Women (CEDAW) states that non-consensual sterilisation should not be permitted,[23] and that sterilisation should only be permissible where there is serious threat to life or health.[24] Further, the United Nations Special Rapporteur on violence against women has asserted that forced sterilisation is a method of medical control of a woman's fertility. It violates a woman's physical integrity and security and constitutes violence against women.[25]

The Committee on the Rights of the Child notes that it is "deeply concerned about the prevailing practice of forced sterilisation[26] of children with disabilities, particularly girls with disabilities." It says forced sterilisation seriously violates the right of the child to her or his physical integrity and results in adverse life-long physical and mental health effects.[27] Under the Convention on the Rights of the Child (CRC), States have an obligation to protect children from all forms of violence, and "an adult's judgment of a child's best interests cannot override the obligation to respect all the child's rights under the Convention."[28]

AWARE's Recommendations

Sterilisation of Persons Lacking in Mental Capacity to Decide

1. Given the extensive legal infrastructure already laid out in the MCA to safeguard the interests of persons who lack capacity, governance of the non-consensual sterilisation of persons lacking in capacity should be shifted from the principal Act to the MCA. This will ensure that the protections provided to persons lacking in mental capacity also cover non-consensual sterilisation.[29] To effect this, it will also be necessary to amend Section 26 of the MCA to delete the exclusion of voluntary sterilisations from the MCA.

2. The Bill should provide that in the case of persons who are not in a position to provide consent, such as persons who lack mental capacity, and children, sterilisation in their best interest should only be considered when less restrictive options are not available or have been exhausted. It should not be considered for non-therapeutic reasons, such as for contraceptive purposes.[30,31, 32]

3. In addition to the application of the MCA, the Bill should provide that except in the case of Emergency Situations, sterilisation of persons lacking in capacity and the question of their best interest should always be decided by a court or an independent committee.[33,34] A court decision is required in Australia, the United Kingdom[35], Croatia, Germany,

Slovenia and South Africa[36]. In Denmark, Iceland, Sweden and Norway, there needs to be approval by an independent committee[37].

4. If, for whatever reason, the authorities do not want the MCA to apply to decisions of sterilisation for persons lacking in mental capacity, the VSA should at least have a written requirement for the following:

    a. There should be a panel consisting of a psychiatrist, a medical practitioner who specialises in reproductive health, and a social worker, to decide on whether or not sterilisation is in the best interests of the person who lacks capacity.[38]

    b. To prevent conflict of interest, those sitting on the panel:[39]

        (i) Must not be related by blood or by law to the person consenting to sterilisation on the behalf of the person lacking capacity.

        (ii) Must not stand to benefit financially from providing the treatment for sexual sterilisation.

        (iii) Must not be involved in the routine care of the person lacking in capacity. Research done elsewhere suggests that often doctors talk primarily to the parents of an intellectually disabled person rather than to the person herself,[40] and this may result in a conflict of interest when parents seek sterilisation for their child.

    c. Regarding section 3(3) of the VSA, the information provided by medical practitioners in the process of ensuring full and informed consent should include that discussed in recommendations 6, 7 and 9 below.

5. The MCA Code of Practice recognises that the capacity to make decisions by persons with intellectual disabilities can increase if they are taught new skills.[41] Appropriate steps should be taken to develop the capacity of women with intellectual disabilities to understand matters relating to sex, sexuality and their reproductive rights and options. They should also be provided with information on motherhood and family planning in an appropriate manner.

    Relevant information on these matters should be communicated in ways that are comprehensible and appropriate to persons with intellectual disabilities. The appropriate and comprehensible communication of relevant information must thus be systematically developed (for example, Easy Read Guides[42]).

6. Women with intellectual disabilities should be informed of their rights to retain fertility and found a family on an equal basis with others, as per Article 23 of the CRPD. This should be communicated in language they can understand.

7. Parties deciding on sterilisation of a person lacking in capacity should be made aware of the rights of disabled women as laid out in the CRPD, including but not limited to Article 23.

8. Appropriate services should be put in place for women with intellectual disabilities to realise their right to motherhood.

9. Misconceptions exist about the experiences of sexuality, pregnancy and parenthood by women with intellectual disabilities. Caregivers of persons with intellectual disabilities, and the professionals who work with them, should be provided with information on this matter that is based on the self-reports by women with intellectual disabilities.[43,44] See the footnotes to this recommendation for examples of such literature.

10. More social support, respite care, and training should be provided to the caregivers of persons with intellectual disabilities, including the management of their sexual and reproductive functions (such as menstruation), so that sterilisation is not seen as a method of care management.

Sterilisation of Persons below 21

11. Similarly, there should be more protection for Minors. In particular,

    a. There should be a minimum age at which Minors are deemed capable of giving consent for sexual sterilisation (together with her parent / guardian). AWARE recommends that this be set at 18, the age of majority in most countries ("Minimum Age"). Many countries already have such minimum age requirements.[45]

    b. Generally, the decision should be made by both not one parent except in exceptional situations e.g. where one parent has abdicated his or her responsibility for the child or is unable to do.

    c. Except in the case of Emergency Situations, the sterilisation of persons below the Minimum Age should always be decided by a court or at least an independent committee (as proposed in Recommendation Point 4).

    d. It is noted that the MCA does not apply to such a case and the VSA should specifically provide for the MCA to apply to such Minors.

Proposed Meeting

AWARE seeks a meeting with the Ministry of Health on the following:

1. To understand the rationale for giving authority to parents/guardians and spouses of persons lacking in capacity to consent to sterilisation on their behalf.

2. To understand why the decision was made to not include sexual sterilisation of persons lacking in capacity amongst the decisions regulated by the MCA.

3. To discuss how Minors may be better protected, especially those that lack mental capacity and are specifically excluded from the application of the MCA.

It is imperative that legislation should be cognisant of the multiple levels of discrimination faced by women and girls with disabilities. Work to recognise the rights of these members of

society and reduce the discrimination and violence they experience must continue. AWARE hopes the Ministry will consider these recommendations. We look forward to collaborating with the Ministry to ensure the updated legislation represents global best practices.

[1] Vivian Balakrishnan, Opening Address, (official speech, Mental Capacity Act: Code of Practice Seminar, Singapore, May 21, 2010), accessed June 27, 2012, from http://app1.mcys.gov.sg/PressRoom/TheMentalCapacityActCodeofPracticeSeminar.aspx.
[2] E. (Mrs.) v. Eve, [1986] 2 S.C.R. 388, Supreme Court of Canada, accessed June 29, 2012, from http://scc.lexum.org/en/ 1986/1986scr2-388/1986scr2-388.pdf.
[3] Secretary, Department of Community Services and Health v JWB and SMB [1992] CLR 218 (Marion's Case), High Court, Australia, accessed June 29, 2012, from http://www.austlii.edu.au/au/cases/cth/HCA/1992/15.html.
[4] Human Rights Watch, "Sterilisation of Women and Girls with Disabilities: A Briefing Paper," *Human Rights Watch*, November 10, 2011, http://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities.
[5] Ibid.
[6] Veena Bharwani, "Doctors Differ on Sterilisation," *The New Paper*, Mar. 16, 2010. Accessed June 21, 2012, from http://www.asiaone.com/Health/News/Story/A1Story20100315-204803.html.
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[10] Loïse Conod, and Laurent Servais, "Sexual Life in Subjects with Intellectual Disability," *Salud Pública de México* 50, no. 2 (2008): 231, http://scielo.unam.mx/pdf/spm/v50s2/a17v50s2.pdf.
[11] Miriam Taylor, and Glenys Carlson, "The Legal Trends—Implications for Menstruation/Fertility Management for Young Women who Have an Intellectual Disability," *International Journal of Disability, Development and Education* 40, no. 2 (1993): 133-157.
[12] Lori Ann Dotson, Jennifer Stinson, and Leeann Christian, "People Tell Me I Can't Have Sex: Women with Disabilities Share Their Personal Perspectives on Health Care, Sexuality, and Reproductive Rights," *Women & Therapy* 26, nos. 3-4 (2003): 195-209.
[13] Rachel Mayes, Gwynnyth Llewellyn, and David McConnell, "Misconception: The Experience of Pregnancy for Women with Intellectual Disabilities," *Scandinavian Journal of Disability Research* 8 (2006): 120-131.
[14] E. (Mrs.) v. Eve, [1986] 2 S.C.R. 388.
[15] Leanne Dowse, "Sterilising by Stealth? Safeguarding the Human Rights of Girls with Disabilities in Australia," *The Australian Health Consumer* 3 (2004–2005): 5, https://www.chf.org.au/pdfs/ahc/ahc-2004-3-sterilising-by-stealth.pdf.
[16] Human Rights Watch, "Sterilisation of Women and Girls with Disabilities: A Briefing Paper," *Human Rights Watch*, November 10, 2011, http://www.hrw.org/news/2011/11/10/sterilization-women-and-girls-disabilities.
[17] Vivian Balakrishnan, Opening Address, (official speech, Mental Capacity Act: Code of Practice Seminar, Singapore, May 21, 2010), accessed June 27, 2012, from http://app1.mcys.gov.sg/PressRoom/TheMentalCapacityActCodeofPracticeSeminar.aspx.
[18] See parts IV and V of the MCA, and paragraphs 8.7, 9.5.6 and 9.7 of the MCA Code of Practice. Those authorised to make decisions do not necessarily include the parents/guardian or spouse of the person lacking in capacity. It should also be noted that the powers of deputies are limited [section 20(4)(b) *Mental Capacity Act*], and for some decisions, a decision by the Court is preferred [section 20(4)(a) Mental Capacity Act]. Those authorised to make decisions on behalf of persons lacking in mental capacity are also supervised by the Office of the Public Guardian.
[19] MCA Code of Practice, para. 9.5.8.
[20] Susan M. Brady, and Sonia Grover, "The Sterilisation of Girls and Young Women in Australia—A Legal, Medical and Social Context," report commissioned by the Federal Disability Discrimination Commissioner for the Human Rights and Equal Opportunity Commission, December 1997, http://www.wwda.org.au/brady.htm.
[21] Margaret Harrison, "What's New in Family Law? Parental Authority and its Constraints. The Case of 'Marion'," *Family Matters* 32 (August 1992): 10-12, http://www.aifs.gov.au/institute/pubs/fm1/fm32mh.html.
[22] Ibid. In *Marion's case*, the majority of the judges in the High Court of Australia "considered that, because of the difficulties associated with assessing the child's understanding and ability to consent, there is a significant risk that the wrong decision will be made."

[23] UN A/54/38/Rev.1, 1999, part 1, para. 22.
[24] CEDAW/C/AUL/CO/7, para. 43.
[25] E/CN.4/1999/68/Add.4, para. 51.
[26] Human Rights Watch defines "forced sterilisation" as occurring "when a person is sterilised after expressly refusing the procedure, without her knowledge or is not given an opportunity to provide consent." (Human Rights Watch, 2011). The MCA Code of Practice also recognises that in theory, carrying out the acts of care or treatment on persons who lack capacity involves acting without the person's consent. (See paragraph 7.1.1 of the MCA Code of Practice.) Non-consensual sterilisation can thus be interpreted as equating to forced sterilisation.
[27] CRC/C/GC/9, para. 60.
[28] CRC/C/GC/13, para. 61.
[29] Voluntary Sterilisation is not excluded from the UK Mental Capacity Act, which our Singapore MCA was modelled after.
[30] E. (Mrs.) v. Eve, [1986] 2 S.C.R. 388.
[31] Secretary, Department of Community Services and Health v JWB and SMB [1992] CLR 218 (Marion's Case), High Court, Australia.
[32] Margaret Harrison, "What's New in Family Law? Parental Authority and its Constraints. The Case of 'Marion'," *Family Matters* 32 (August 1992): 10-12, http://www.aifs.gov.au/institute/pubs/fm1/fm32mh.html.
[33] E. (Mrs.) vs. Eve [1986], Supreme Court of Canada. The Court ruled that "sterilisation should never be authorised for non-therapeutic purposes under the *parens patriae* jurisdiction. In the absence of the affected person's consent, it can never be safely determined that it is for the benefit of the person. The grave intrusion on a person's rights and the ensuing physical damage outweigh the highly questionable advantages that can result from it."
[34] The High Court of Australia ruled in *Marion's case* that the serious consequences of sterilisation "warrant the provision of non-medical as well as medical opinions, which court authorisation would ensure. According to the majority, court authorisation would also protect children from possible competing and perhaps even conflicting interests, such as those of the primary care-givers, as it is the child's interests (rather than the interests of a carer) which would be the primary consideration of the court." See Margaret Harrison, "What's New in Family Law? Parental Authority and its Constraints. The Case of 'Marion'," *Family Matters* 32 (August 1992): 10-12, http://www.aifs.gov.au/institute/pubs/fm1/fm32mh.html.
[35] Margaret Harrison, "What's New in Family Law? Parental Authority and its Constraints. The Case of 'Marion'," *Family Matters* 32 (August 1992): 10-12, http://www.aifs.gov.au/institute/pubs/fm1/fm32mh.html.
[36] EngenderHealth, *Contraceptive Sterilisation: Global Issues and Trends* (New York: EngenderHealth, 2002), http://www.engenderhealth.org/files/pubs/family-planning/factbook_chapter_4.pdf, pp. 91-93.
[37] EngenderHealth, *Contraceptive Sterilisation: Global Issues and Trends* (New York: EngenderHealth, 2002), http://www.engenderhealth.org/files/pubs/family-planning/factbook_chapter_4.pdf, pp. 93-94
[38] Adapted from Advance Medical Directive Act.
[39] Adapted from the Mental Health (Care and Treatment) Act, which governs the involuntary detention of persons in psychiatric facilities.
[40] Lori Ann Dotson, Jennifer Stinson, and Leeann Christian, "People Tell Me I Can't Have Sex: Women with Disabilities Share Their Personal Perspectives on Health Care, Sexuality, and Reproductive Rights," Women & Therapy 26, nos. 3-4 (2003): 195-209.
[41] MCA Code of Practice, para. 4.7.2.
[42] Disability Rights Commission, *How to use Easy Words and Pictures: Easy Read Guide* (Stratford upon Avon: Disability Rights Commission, 2006), FOCUS12/ER, http://www.equalityhumanrights.com/uploaded_files/how_to_use_easy_words_and_pictures.pdf.
[43] Lori Ann Dotson, Jennifer Stinson, and Leeann Christian, "People Tell Me I Can't Have Sex: Women with Disabilities Share Their Personal Perspectives on Health Care, Sexuality, and Reproductive Rights," Women & Therapy 26, nos. 3-4 (2003): 195-209.
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