

# Healthy Ageing - Adults with Intellectual Disabilities

## Women's Health and Related Issues

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## 1.0 Background

1.1 This report is concerned with issues which are important for the health of women with intellectual and developmental disabilities as they grow older and age. The specific focus on women's health is in no manner meant to be dismissive or designed to minimize concerns related to men's health issues. However, it is the position of the SIRG on ageing that women's health issues have not received appropriate and sufficient attention, that women as they age are subject to sex-related conditions and changes, and that in many instances the interests and needs of ageing women and women with disabilities are overlooked or neglected. Thus, this report is designed to explore factors related to well-being and quality of life for women, to examine and define sex-linked differences in their life experiences and opportunities and to define their distinctive vulnerabilities -including research on health status and access to health care.

## 2.0 Women's Health - a Global Perspective

2.1 The human rights of women and girl children are an integral part of universal human rights, according to the UN Vienna Declaration. Ensuring their full and equal participation in all aspects of life in society, without discrimination of any kind, is a priority objective for the international community. The United Nations Commission on the Status of Women promotes the well-being and education of the girl child as a priority for global action in its policy documents (1998). Further, the UN Standard Rules identify the availability of suitable medical and health care as an essential prerequisite if people with disabilities are to enjoy equal opportunities in the societies where they live (UN 1994).

2.2 Regional policies have adopted human rights as the basis for all actions related to the lives of persons with disabilities. Social policy within the European Union of 15 countries has replaced traditional care models of disability with a rights-based model. Human rights are expressed as equal opportunities for all citizens, particularly those with disabilities, to take part fully in all aspects of everyday life in their own societies (CEC 1996). A respect for human diversity should thus inform all aspects of social planning.

2.3. The WHO - Global Strategy on the promotion of women's health falls within this rights-based framework: The right of all women to the best attainable standard of health - as well as their right of access to adequate health services - has been a primary consideration of the World Health Organization (United Nations 1997b:10)

2.4 There have been dramatic increases in life expectancy during the 20th century, due chiefly to tremendous advances in medicine, public health, science and technology. However, the quality of human life is as important as its length - perhaps even more important. Today, individuals are concerned about their health expectancy - that is, the years they can expect to live in good health (WHO 1997). Inequalities exist, based on sex, region and social status. The poorest, least educated people live shorter lives with greater ill-health. Globally, while life expectancy increases, disability-free life expectancy seem to be stabilizing.

2.5 Priority areas for international action in health should be: a comprehensive chronic disease control package incorporating prevention, diagnosis; treatment and rehabilitation and improved training of health professionals; fuller application of existing cost-effective methods of disease detection and management, a global campaign to encourage healthy lifestyles; research into new drugs and vaccines and the genetic determinants of chronic diseases; and alleviation of pain, reduction of suffering and provision of palliative care for those who cannot be cured (WHO 1997:136).

### 3.0 Lifespan Perspective: Ageing and Health

Recently, more attention has been given to the personal and social development of girls and women with developmental disabilities throughout the lifespan. This approach attempts to understand their experiences and their engagement with the tasks considered appropriate in their family and culture at each transitional stage - infancy, childhood, adolescence, early - middle - and late adulthood, and old age. For example, young women in many industrialized societies typically complete formal schooling and/or vocational training, find employment, achieve full citizenship and build personal friendships and intimate relationships. Some may establish homes and start childbearing. Women in late adulthood who have been employed may retire from the active workforce, attend more to personal interests - depending on their income and talents - and perhaps devote themselves to grandchildren or other family concerns. And as they age, women and men increasingly value good health and the independence and mobility it brings.

3.1 Populations are ageing. The number of people aged 65 years and above account for 7% of the world's population: two-thirds (65%) of those aged 80 and above are female. Global strategies must take gender differences into account. A major challenge will be to develop innovative ways of tackling the special health and welfare problems of elderly women (WHO 1997:11). From the perspective of the WHO, healthy ageing is a global priority. The need to focus on promoting health and minimizing dependency of all older people is a principle of action common both to more developed countries - where 12.6% of the population is elderly - and to developing countries - where only 4.6% is elderly (WHO 1995:2).

3.2 Gender and health. The differential impact of gender on health is not static; rather it reveals itself as the individual grows and develops throughout his or her lifespan. Many risks to health are age-related: Men die earlier, while women experience greater burdens of morbidity and disability. Women constitute the majority of both the carers and the older users in the health sector. Supporting the female carers is a key health policy challenge (WHO 1995:6.1.5).

3.3 UN emphasis. The special situation of women is highlighted in current programs for older persons within development planning. 1999 was the International Year of Older Persons with the theme, "Towards a Society for All Ages." A society for all ages recognizes the rights and responsibilities of all age groups and makes it possible for older persons to live healthy, productive, economically secure lives (UN 1997a: SG/SM/6339 OBV/11).

3.4 Gender is recognized as a determinant of health. A gender approach to health includes an analysis of how different social roles, decision-making power and access to resources affect health status and access to health care. The special needs of women and current inequalities in delivery of health care are apparent. The WHO has targeted increasing its efforts towards: (1) advocacy for women's health and gender-sensitive approaches to health care delivery and development of practical tools to achieve this; promotion of women's health and prevention of ill-health; (2) making health systems more responsive to women's needs; (3) policies for improving gender equality; and (4) ensuring the participation of women in the design, implementation and monitoring of health policies and programs, in WHO and within countries (WHO 1997:83).

3.5 Health status. Data gathered about the health of women living in developed nations indicate that while these women live on average up to about 80 years, many die prematurely before the age of 65 due to accidents or diseases which could largely be avoided by healthier living or early detection. Special health issues are important to women at different stages of their lives. Eating disorders have serious consequences for younger women, adult women confront

health problems related to HIV and AIDS, and among elderly women, the rising incidence of osteoporosis has become a chief concern for women (CEC 1997:8). In contrast, the health status of adult women in the developing nations is often compromised, resulting in shorter life expectancies, greater rates of illness or disability-related conditions. poorer nutrition, and a greater incidence of problems more related to earlier life stages.

3.6 Policy focus on women's health. Policy-makers may embed the distinctive health needs of women throughout the lifespan in national health strategies. For example, in Ireland, the Department of Health formed a plan for women's health in consultation with many individual women and women's groups throughout the country. The plan, which is in keeping with WHO targets for the health of women, recognizes that some groups of women - those with disabilities, for example - face particular challenges to maintaining good health. Lack of information, lack of access to services and special difficulties related to advice about sexual and reproductive health were identified. The Irish Government document recommends direct consultation with women who have disabilities themselves in order to develop appropriate services (Government of Ireland 1997:63).

#### **4.0 Health, Ageing and Intellectual Disabilities : Cross-Cultural Contexts**

4.1 Increased longevity and improved services of all kinds have led to an unprecedented growth in the population of persons with intellectual disabilities. It is estimated that as many as sixty million persons in the world may have some level of intellectual disability (WHO 1997). Older people with intellectual disability have significant physical health needs (Cooper 1998; van Schrojenstein Lantman-de Valk 1998, inter alia). The health of individual men and women with disabilities as they grow older will reflect the social and economic circumstances shaping their daily experiences. Their fortunes may be especially at risk relative to those of their peers or family members. "It is in situations of dire poverty that household members are subjected to neglect, and people with disabilities are particularly vulnerable (Whyte and Ingstad 1998: 43).

4.2 Access to health care. Informants from developing, rural or remote regions report that greater access to health care, information, proper treatment protocols, and the like, would all greatly enhance longevity. Many individuals with more severe disabilities do not survive the early childhood years. There may be no surgeons, or no facilities for neonatal care, and poor health outcomes for the elderly. In the Pacific region, for example, diseases such as measles, and dengue fever may be lethal. Given generally poor access to health resources, the population of people with intellectual and developmental disabilities is more likely to be stricken and affected by threats from disease. Cultural differences also influence health care across the lifespan. Local healers and natural medicines may be a mainstay for a community. Further, cultures vary in their understanding of, and attitudes toward, elders, as well as toward women. Such attitudes may influence the availability and accessibility of health care for older women.

4.3 Socioeconomic contexts. Thus, healthy ageing does not arise and maintain itself in a vacuum. Social, political and economic environments interact with the daily lives and experiences of individuals in a given society. Efforts to promote their health and well being reflect this complex interaction. The quality of daily life experienced by individuals both reflects and contributes to the quality of the society in which they live. Providing political environments which foster healthy social relationships, trust, economic security, sustainable development and other factors related to advancing the health and well-being of citizens has been identified as a priority for governments. The quality of social relationships in a society has been documented as part of health outcomes: healthier communities with greater social cohesion produce healthier citizens (Lomas 1997). These and other factors make up a country's social capital, an essential

factor if states are to achieve the priorities for effective health promotion which are listed in the Jakarta Declaration, such as increased investment in health development particularly for needy groups (Cox 1997:3).

## **5.0 Health and Ageing: Women's Health and Related Issues**

5.1 In preparing this report, two key questions were posed in order to inform those charged with implementing global, regional and national health strategies including the needs of women with intellectual disabilities. These questions were (1) What is the current knowledge base about the health of women with intellectual disabilities across the lifespan, especially among older women? (2) What are the practices most effective in promoting good health and satisfaction with services among women with intellectual disabilities?

Three kinds of evidence were used to compile this report. First, information about global and regional trends, demographic patterns and socio-economic indicators were drawn from a range of policy and research documents published by bodies such as the World Health Organization and other groups (Sections 2,3 and 4). Second, research literature in scientific publications was reviewed and three summaries were prepared: these appear in Sections 6.1, 6.2 and 6.3. Third, colleagues in many countries contributed background information about local conditions in their parts of the globe. Qualitative data were yielded by focus groups and other consultative meetings of women with intellectual and developmental disabilities, their families, advocates and professional workers in many countries. The themes which emerged about their experiences of health care and promotion appear in Section 7.

The final section of this report, Section 8, includes recommendations for research, policy and practice.

## **6.0 Summary Reviews Of Literature**

Research summaries related to women's health and ageing are organized across four topic areas and appear in the following three sections. The editors' initials appear in parentheses. The first section (6.1) reviews evidence about cancer and sexual health (H. van S L- de V) and reproductive health (NS). The second (6.2) focuses on promoting health among ageing women with intellectual disabilities (TH), and the third section (6.3) addresses the social, economic and cultural contexts of health (PNW).

### **6.1 Physical Health And Ageing**

#### **6.1.1 Menstruation**

6.1.1.1 Among women with intellectual disabilities, the average age at onset of menarche is similar to that of women in the general population. Most appear to have regular menstrual cycles. Recent studies of gonadal function in women with Down syndrome have found distributions of age at menarche and frequencies of women with regular menses that are much closer to those found in the general population than had been presumed from earlier studies (mostly of institutionalized women). Between 65% and 80% of women with Down syndrome have regular menstrual cycles, while 15 to 20% have never menstruated.

6.1.1.2 Methodological problems in studies of hormonal status during menstrual cycles in women with Down syndrome and other intellectual disabilities include small sample sizes, sampling of only a few cycles, and lack of control for the stage of menstrual cycle at which the

blood sample was drawn. Nonetheless, international studies have generally supported the conclusion that most cycles show evidence of ovulation and formation of a *corpus luteum*, suggesting that gonadal endocrine function is within normal ranges in the majority of women with intellectual disability.

6.1.1.3 Many women with intellectual disability are treated with psychotropic medication and/or anti-epileptic drugs (AEDs). Psychotropic medications can interfere with a number of hormonal and metabolic functions. A common finding is hyperprolactinemia in association with neuroleptic drug use. Prolonged elevations in prolactin can lead to declines in follicular (FSH) and luteinizing hormone (LH) release, leading to declines in ovarian function. Reduced gonadal function may lead, in turn, to menstrual disturbances, including amenorrhea or infertility and reduced estrogen release which may increase risk of age-related disorders associated with reduced estrogen levels. Seizures and AEDs may also influence memory and cognition through changes in neuroendocrine function. Elevated levels of sex-hormone binding globulin, FSH and LH have been described and long-term AED therapy has been associated with primary gonadal dysfunction and increased risk of polycystic ovarian syndrome.

## 6.1.2 Sexual Health

6.1.2.1 Women with intellectual disability have the same sexual needs and rights and responsibilities as do other women. However, care personnel and other carers are not always adequately educated on this issue and may seek to limit opportunities for sexual activity. Older parents may tend to ignore the sexual needs of their children. In many societies, general attitudes toward persons with disabilities and toward women specifically may further serve to deny or trivialize sexual health concerns. Unfortunately, such attitudes may also carry over to women of older age and thus deny access to health services related to gynaecological concerns and functions and may lead to a dearth of health professionals who are willing or trained to address reproductive health issues.

6.1.2.2 People who are sexually active are prone to sexually transmitted disease (STDs). Education on symptoms of STDs and early treatment is necessary to avoid further transmission and development of late-stage complications of the infection. Some STDs are characterized by chronic pelvic pain, vaginal discharge and abdominal pain, but other STDs may be present without clinical manifestations (e.g., 65% of Chlamydia infections). However, even when they are symptom-free, infected women may transmit their infections and, untreated, may develop severe complications. Infection with the HIV virus and development of AIDS is of special concern. Currently, in countries from which information is available, it appears that HIV in persons with intellectual disability is mainly spread by men who have sex with men. However, because many of these men also have sex with women, heterosexual spread of HIV may be increasing, following the pattern seen in the general population.

6.1.2.3 Women with intellectual disabilities need to be educated about safe sexual practices. Line drawings or pictures, or other effective teaching materials, may be helpful in presenting safe sex precautions and in initiating discussion about sexual activity in persons with limited conceptual or verbal capacities. Women with intellectual disabilities may have poor skills in negotiating safe sex even if they are motivated to practice safe sex to avoid sexually transmitted diseases. Women with intellectual disabilities are subjected to the same power discrepancies as women in the general, and requests for safe sexual practices (e.g., condom use) may be difficult to impose. Furthermore, many women with intellectual disability have low self esteem, making negotiations surrounding sexual activity more difficult. Practical skills may also be a problem. Many persons with intellectual disabilities have motor problems which limit their ability to use

condoms effectively, as well as poor understanding of their proper use. Sexual education needs to include practice in condom diaphragm/pill use with instruction adapted to the capacity of this population. It is crucial to recognize profound cultural differences in sensitivity to the content of such education for women and in recruiting and preparing care staff and instructors.

### 6.1.3 Vulnerability and Protection

6.1.3.1 In addition, both men and women with intellectual disability are more often victims of sexual abuse than are persons in the general population. Most offenders are known to their victims and may include care personnel and other carers, family members or fellow residents who take advantage of the person's inability to defend themselves or their lack of knowledge about their sexual rights. Because of poor communication skills and lack of knowledge about their rights, people with intellectual disabilities make also experience difficulty in telling carers about the abuse. Such abuse may continue for years before any signs are given. Education about sexual abuse should take place in settings provided by carers who are familiar and respectful of the person with an intellectual disability and who can encourage full and frank discussion about abuse (see: McCarthy and Thompson 1998).

### 6.1.4 Fertility and Contraception

6.1.4.1 In a number of countries, women with intellectual and developmental disabilities are as likely to marry and to bear children as are their peers. While little research has addressed fertility in women with intellectual disability, it is reasonable to assume that most adults are fertile unless they have a disorder that affects genital organs or brain regions responsible for hormones that regulate ovarian function. For example, only a few births to men and women with Down syndrome have been documented. In addition, in some countries a majority of women with intellectual disabilities use some form of contraception. Oral contraception is preferred, with low dose combinations of progestins and estrogens. Depot progesterones are also widely used as contraceptives. Their advantage stems from the fact that they need to be administered only four times a year. However, irregular vaginal bleeding ("spotting") and effects on cholesterol metabolism that might increase risk for coronary heart disease need to be considered.

### 6.1.5 Therapeutic Amenorrhea

6.1.5.1 Therapeutic amenorrhea may be used in women with intellectual disability who are unable to manage menstrual hygiene effectively or in women who show self-injurious behavior related to menstruation. The most common form of therapeutic amenorrhea is suppression of menstrual cycles with lynestrenol. In one report, a Finnish gynaecologist noted that 66% of his patients with intellectual disabilities had been prescribed lynestrenol at some time in their life. Alternatively, endometrial ablation, abrasion of the inner layer of the uterus, may be used to suppress menstruation and establish therapeutic amenorrhea. More radical procedures, such as hysterectomy (removal of the uterus) may also be used to prevent pregnancy. In the past, sterilization was widely used to prevent pregnancy, often without the consent of the person with an intellectual disability. In more developed countries, guidelines for sterilization now require extensive documentation of the medical rationale for the treatment, including documentation of informed consent procedures.

6.1.5.2 Endometrial ablation, hysterectomy and sterilization, while effective, are irreversible, raising legal and ethical concerns about these procedures. Determination of the perceived problems surrounding management of menstruation and/or fertility should be medically documented and should be undertaken as much for the information of the women herself as for

the convenience of the carer.

#### 6.1.6 Menopause

6.1.6.1 Very little is known about menopause in women with intellectual disability. Limited studies have reported on the median age at menopause and no study has systematically tracked changes in hormones and ovarian function with age in a large group of women with intellectual disabilities. Thus, there is very little information on how decreases in hormones after menopause may affect health and cognitive ability. Studies of menopause have found that the median age at menopause was 3 to 5 years earlier in women with intellectual disability compared with women in the general population. Women with Down syndrome and women with Fragile X appear to have especially early onset of menopause.

#### 6.1.7 Age-Related Health Problems

6.1.7.1 *Osteoporosis*. Osteoporosis is considered to be characteristic of disorders that increase after menopause and are related to estrogen loss. In addition, long-term use of anti-convulsants is a risk factor for osteoporosis. In women with osteoporosis bone mass slowly declines over the years to produce thinner and more porous bones, which are weaker than normal bones. Post-menopausal bone loss is associated with wrist fractures in about 15% of women and with spine fractures in 20-40%. The most serious complication of osteopenia is hip fracture, which occurs in 15% of older fair-skinned women and causes high rates of morbidity and mortality. Clinical trials of estrogen and bone density have consistently shown that estrogen prevents or delays bone loss when taken within 5 years of surgical or natural menopause. Osteoporosis and an increased risk for fractures was also found in younger women with intellectual disabilities who had either hypogonadism, a small body size, or Down syndrome.

6.1.7.2 *Breast Cancer*. Risks for breast cancer and cervical cancer also increase with age. Whether or not women with intellectual disabilities have the same risk for these cancers as women in the general population is still being debated, and further research is needed to address this question. Women who have never been pregnant - including many women with intellectual disabilities - may be at higher risk and thus screening is especially important (M. Vink: personal communication). But screening for these cancers may present special problems. Current guidelines for screening for breast cancer recommend regular mammography in women over 50 years of age (every 1 to 2 years). Problems for effective participation in screening programs among women with intellectual disability include difficulties in understanding and co-operating with the procedures, problems of transportation to screening sites and, often, musculoskeletal problems which make accommodation to the mammography machines an uncomfortable and fearful experience. Most physicians experienced with mammography in women with intellectual disability emphasize that health and nursing personnel need to take sufficient time for women to familiarize themselves with the machines and with the procedures to participate effectively. However, economic pressures under extant proprietary or national health care systems in certain nations may limit the willingness of physicians and their staff to provide the necessary time and training to achieve successful levels of co-operation. In the Netherlands, all women within a municipal administration system are invited by postal code and birth date for breast cancer screening, but illiteracy and poor literacy may limit participation. In other countries, the screening program does not include women who are not able to pay for the procedures. In general, women with intellectual disabilities receive fewer opportunities for screening for breast cancer than do women in the general population. This may be particularly insidious in nations that have no systematic screening procedures as women with intellectual disabilities may be at particular risk since most may have limited access to available health practitioners, and if access is not

available, such screenings may never be carried out

6.1.7.3 *Cervical cancer.* Guidelines for screening for cervical cancer recommend screening by cervical smear testing once every 2 to 5 years for women between the ages of 30 and 60 years. Sexual activity is associated with increased risk for cervical cancer, so that women with intellectual disability who have no experience of sexual activity may possibly be excluded from screening programs. Poor receptive and expressive language, discomfort and fear may create difficulties in achieving co-operation in pelvic examination and obtaining cervical smears in some women with intellectual disabilities. In some nations, lack of available female physicians may further limit such examinations as societal mores proscribe such contact by male physicians. Further, given sensitivities to genital contact, and lack of familiarities of such procedures by women with disabilities under these circumstances, no such screenings may ever be undertaken in certain nations, further increasing risk.

6.1.7.4 *Heart disease.* The frequency of heart disease is lower in menstruating women than in men of the same age, but after menopause the frequency of heart disease is the same in women as in men. Many studies have shown that the risk of a coronary event is reduced by about 50% in postmenopausal women using oral estrogen compared with women not taking oral estrogens. It is thought that this decrease in coronary heart disease is related to the ability of estrogen to prevent coronary artery disease and prevent the build-up of some types of cholesterol in the bloodstream. Other age-related conditions that appear to occur with increased frequency in women with intellectual disability are thyroid problems, sensory impairment, heart rhythm disorders and musculoskeletal disorders.

6.1.7.5 *Alzheimer's disease.* Ovarian hormones such as estrogen are also important to maintain brain function in regions of the brain affected by Alzheimer's disease. Some scientists have suggested that the loss of estrogen after menopause may increase risk for the cognitive declines associated with Alzheimer's disease, although this is still controversial. Several studies have found that women who took estrogen after menopause had a decreased risk and later age at onset of Alzheimer's disease. Epidemiological studies on the sex-linked prevalence of Alzheimer's disease are equivocal, with some showing a higher rate among women with Down syndrome, and others showing no discernible patterns between men and women with intellectual disabilities of other etiologies.

6.1.7.6 *Menopause.* Women with intellectual disabilities may have an earlier age of menopause which may place them at increased risk for these estrogen-related disorders. In addition, the frequency of estrogen or hormone replacement therapy is much lower in women with intellectual disabilities than in women in the general population, so that they do not receive the same degree of preventive and therapeutic intervention as women in the general population.

6.1.7.7 *Psychiatric illnesses.* Older women in general are reported to often experience more instances of depression and other life stressor-related reactive behaviors indicative of psychiatric difficulties. As reported by the WHO/IASSID's report on *Biobehavioural Issues*, this is often the case among older women with intellectual disabilities as well. This paper should be accessed for a more detailed explanation of this problem area.

## 6.2 Health Promotion

6.2.1 Health care paradigms are expanding from an historical emphasis on treatment of disease conditions to a more expansive focus on health promotion through healthy lifestyles, preventive health care, and positive environmental conditions. There is a growing body of research

associating successful ageing and disease prevention with health behaviors and environmental conditions. Among women with disabilities health promoting activities and settings can lead to enhanced useful functioning, prevention of secondary disabling conditions, and an increased quality of life. Researchers have only recently begun to explore the conditions promoting optimum health among older persons with intellectual disabilities, and even less among women with intellectual disabilities. In a national survey conducted in the United States, the most common chronic health problems noted for older adults with intellectual disabilities were high blood pressure, osteoarthritis, and heart disease. Women with intellectual disabilities who survive into old age are most likely to die of heart disease. Older women with intellectual disabilities, particularly women who have a lifelong history of anti-epileptic medicine may be more susceptible to osteoporosis than the general population.

6.2.2 Proper nutrition, exercise, and access to preventive health care can increase health and longevity. Yet women with intellectual disabilities receive less preventive health care than women generally and have highly sedentary lifestyles. Among adults with intellectual disabilities obesity and cholesterol levels are higher than for the general population. This is particularly true for women and for adults living in independently. Among adults with Down syndrome, a United States study reported that nearly half of the women and nearly one third of the men had morbid obesity. A study of women with intellectual disabilities living in residential facilities found that women were more likely than men to have malnutrition or obesity. Data from the United States tells us that older adults with intellectual disabilities living at home exercise less frequently than other older adults. In addition to the negative effects on health, the high levels of obesity and the low levels of physical activity reported among adults with intellectual disabilities can create barriers to successful employment, participation in leisure activities, and performance of daily living activities. Other health behaviors, in addition to diet and exercise, which have been shown to affect health among the general elderly population, such as smoking, alcohol use, medication management, and stress management, have been rarely studied among women with intellectual disabilities.

6.2.3 Access to preventive health care varies widely by country. Data from the United States indicates very low levels of health screenings for older women with intellectual disabilities, including mammograms, breast examinations, and pap smears, particularly for women living in the community. Reasons for lack of preventive health care include lack of private insurance, attitudinal barriers of health care professionals, insufficient health education, and fear of examinations, and communication difficulties experienced by women with intellectual disabilities.

6.2.4 To promote healthy behaviors and preventive health care among older women with intellectual disabilities, health education is needed for the women with intellectual disabilities and for health professionals. Women with intellectual disabilities may lack basic knowledge about their bodies and about health and ageing. They may be unaware of how their current lifestyles and behaviors can have an effect on their overall health and well-being. Also, health professional often do not communicate effective strategies for health promotion to women with intellectual disabilities or their carers.

### 6.3 The Context Of Healthy Ageing

6.3.1 The socio-economic context - for example, level of income, employment status and family circumstances - and also the cultural environment in which individuals develop and age influence health outcomes. Differences in life expectancy, income and access to health care are conspicuous when outcomes for women in developing countries are compared to those in the less

developed countries - where the majority of all persons with intellectual and developmental disabilities live. While these topics have been explored among the general population to some extent, little empirical research is available concerning women with intellectual disabilities.

6.3.2 Very few women with intellectual disabilities marry, even in the more developed countries, and few will have the opportunity to experience gender roles which are typical in their cultural settings. Few bear children. As a consequence, in later life they lack key sources of informal support and care. The importance of the role played by brothers and sisters in the development and well-being of adults with intellectual disabilities across the lifespan has been recognized. Yet the extent and function of such relationships have only recently been studied empirically. Women with intellectual disabilities are also less likely to become primary family carers, although increasingly those who become middle-aged may be called on to care for an elderly or frail parent who has heretofore provided care for them. Some questions remain: for example, can respite care - an important element in formal care - help to maintain or promote health and well-being among women with intellectual disability, either directly or through its impact on family members?

6.3.4 While it is recognized that friendships and social networks contribute to the health and well-being of women in the general population, the specific elements of this contribution in the lives of women with intellectual disability is less well understood. Adults with intellectual disability tend to name significantly fewer individuals and to have more dense social networks than other adults. Those who receive formal services describe social networks filled largely by members of staff. In addition, their networks include more family members than friends - although men with intellectual disabilities are likely to include fewer friends. Adults also tend to name family friends as their own. While empirical evidence suggests that adopting multiple social roles may help to protect women from threats to their well-being, women with intellectual disability are much less likely to have such varied life opportunities.

6.3.5 The favorable impact of employment on the well-being of employees in terms of income, personal satisfaction, esteem, friendships and health has been well-documented in the more developed countries. Less is known about the impact of employment status on the health and well-being of adults with intellectual disabilities, although this has been recognized as an important area for continued research.

6.3.6 The day-to-day experiences of women in the workplace, as well as the expectations of supervisors, employers and co-workers have been explored in a few recent studies. It has been reported in Australian and North American studies that women with intellectual disabilities in community employment are more lonely at work than men. Initial findings of a longitudinal study being carried out in France (GRADIOM) suggests that staff members and medical personnel in sheltered workshops appraise women with intellectual and developmental disabilities as being old some years in advance of the men of similar age with whom they work. Whether this perception is due to cultural factors or to differential working conditions or access to health care has not yet been determined. In general, the uptake of employment, patterns of occupation, and benefits of employment among women with intellectual disabilities across the lifespan have not been investigated systematically and across cultures.

6.3.7 It is not known, for example, whether in developing countries women with intellectual disability share in the "feminization of the work force" trend which has been apparent in more industrialized countries, notably among women with disabilities. Some findings suggest that patterns of employment and employment outcomes differ for women with intellectual disability. Less is known about the employment experiences of women in developing countries, where a priority is to acquire skills so as to contribute to family - and thus, their own - livelihood.

6.3.8 While employment may bring benefits in terms of income, self-esteem and community participation, it may not be without hazard. Because of the generally unskilled nature of the occupations assigned to women with disabilities who may be employed, they are more likely to be exposed to occupational hazards and toxic substances. Many occupational diseases can be prevented through improvements to the work environment and reduction of harmful exposure to toxins and other substances. For example, silicosis is common in many dust-generating activities such as ceramics production, prompting a joint IL-WHO initiative planned to eliminate this disease. The long-term impact of these occupational hazards on the health of women with intellectual or other developmental disabilities who are in the labor force has yet to be investigated.

6.3.9 Although, it is likely that women with intellectual disabilities who have achieved employment in the regular labor force subsequently take a more active part in society, outcomes for them in terms of greater social inclusion - a core social policy within the European Community, for example - have yet to be determined. Accordingly, there is little evidence to indicate how their health and well-being may be promoted through wider participation in society.

## **7.0 Qualitative Information**

This section presents a summary of key issues identified during a range of focus group data collections, as well as at a variety of meetings or consultations carried out with women with intellectual disabilities, their family members, advocates and friends. While the procedures varied slightly, some commonalities emerged when data from all the groups were explored. The issues which arose in several different sites have been blended here, partly to protect the individuals who offered their assistance so readily. The findings appear under five headings selected because they reflect the emergent concerns of the women informants: ageing and disability (7.1), treatment (7.2), training for professional workers (7.3), health promotion (7.4), and personal and practical supports (7.5).

### **7.1 Ageing and Disability**

7.1.1 Determining one's age is often difficult for persons with limited experiences or with intellectual disabilities. For example, only half of the participants in one group could tell their current age. Thus, self-defining ageing over the life course may be a difficult skill. Life course changes, such as acknowledgment of the basic physical changes that take place over time, from baby to girl to teenager to woman, such as the body growing bigger as a person gets older and girls getting periods as a teenager; concern over changes in family relations and issues related to ageing parents as they get older - sometimes mostly sad experiences (e.g., grief over death of a loved one and negative changes in relationships with family members) can be difficult without outside validation. To some persons with intellectual disabilities, "getting old" evokes notions of becoming sick and dying. However, some adults do recognize that not to do so depends on a person's health status and how often she visits the doctor. In many of the focus groups, there was generally a lack of appreciation of anything that would be considered "good" about growing older.

7.1.2 A related perception emerged in one group, which found that often there is a lack of self-identification among older women as being someone with a disability, or a negative perception of people with disabilities. The desire to bear a child, but a child without any disabilities, was apparent for some women. Another group found that many older women with intellectual disabilities have previously been institutionalized for years. They have grown up with poor diets

and a lack of exercise, thus increasing their risk of osteoporosis.

## 7.2 Medical Procedures and Treatment

7.2.1 Giving consent to undergo medical procedures or treatment raises complex issues which differ from country to country. Consent issues for procedures such as a breast biopsy are a major problem for women who may have difficulty understanding the procedures themselves or the relative merits and disadvantages of a particular form of treatment. Mental health issues in relation to sexual abuse of women are still untreated or under-rated. Alcohol and drug dependence and disorders such as depression among women living alone or with their families tend to be treated as behavioral disorders. As a result, appropriate treatment is not provided. There still is a tendency by doctors to apply a "band-aid" approach - such as prescribing a calming medication - rather than address the underlying problems. Equipment for mammograms and other tests that are recommended for the general population are often not suitable for women with physical disabilities such as spina bifida or for women with disabilities who are very short in stature, who have contractions or similar conditions. Even the examination tables are not accessible for many women with physical disabilities or who are afraid of the examination process.

7.2.2 Dental care for women with disabilities was reported as an issue by a number of groups. Few dentist offices are accessible and the equipment is rarely suitably adapted for adults with physical disabilities. There is also still a fear of the dental process among many women. Care personnel report an increase in swallowing disorders, seizures, asthma, reflux, and functioning loss in older women. These phenomena have only been observed and there is a need for studies to determine whether these observations accurately reflect prevalent health conditions. Little is known about osteoporosis in women with disabilities and little is known whether certain medications such as steroids and epilepsy medications can increase the risk of osteoporosis. Focus groups report a need for training on sexually transmitted disease, especially AIDS.

7.2.3 Complex issues such as estrogen replacement are still controversial for the general population of women: it is even more difficult to determine appropriate treatment recommendations for individual women. There is still a tendency to perform possibly unneeded hysterectomies, sterilizations, and procedures such as dilatation and curettage when there is no one to advocate or advise the woman with a disability. Much of the research available has been based on populations of men rather than women - for example, studies on heart disease. It is difficult to monitor and advise women with disabilities or to make decisions about health when the information is not available. Studies are few that involve women themselves and the information from those that are conducted needs to be made available widely for women with disabilities.

7.2.4 Decisions related to pap smear tests include an assumption that women who appear to have been sexually inactive have no need for tests. And yet, who is to decide whether the woman has ever been active or may have been sexually abused in the past? The need for information related to HRT - hormone replacement therapy - including risk factors, cost of ongoing treatment, types of HRT available (e.g., tablets, patches, implants). Women who have been sterilized at an early age (parents have been able to give consent for minors under 18 years of age to have a hysterectomy) may have different needs in older age than women who may choose to be sterilized at a later age.

7.2.5 It is helpful if older women with intellectual disabilities can recognize the differences between women and men in terms of different body parts (including genitalia); that menstrual periods are something only women have; and that menopause is a time when a woman's period

stops. Often, older women do not understand why the menopause takes place. Others may lack a way to describe common physical changes that women experience related to menopause<sup>1</sup>, such as hot flashes and irritability, or to understand what is involved taking medication such as HRT. Generally, women with intellectual disabilities experience an overall discomfort about, and reluctance to discuss, traditionally taboo subjects, such as sexuality, and in general talking about their own bodies.

### 7.3 Training for Professionals

7.3.1 Physicians and their staff do not often understand disabilities or have any education on disabling conditions. Community health professionals may not have experience in health care and concerns related to people with developmental disabilities in general, and older women in particular. The offices where medical care is provided are often rushed with little time spent explaining the service system, health issues and other matters. Many women in the focus groups reported that there is not enough time in the office preparing women with disabilities for examinations and helping each woman understand health related issues. Even family members are rushed through visits to physicians.

7.3.2 Training for health professionals, staff and families on how to better communicate health issues to women with intellectual disabilities was urged by a number of groups. This was defined further as training for health professionals that will sensitize them to the concerns expressed by many of the women with intellectual disabilities (i.e., painful or uncomfortable exams and procedures) and how to facilitate more positive health experiences for them.

7.3.3 There are often many unanswered questions regarding the purpose of having medical examinations, such as ophthalmic, dental and pelvic exams, and mammograms. Many women reported feeling discomfort or pain during mammograms or pelvic exams. They reported being accompanied to physician visits by care personnel, but often the care personnel were not helpful in explaining the physical procedures.

7.3.4 Women in the focus groups noted that health examinations can be made more pleasant, by doing such things as controlling their own behavior (lying still, holding breath), but many were less certain of how the physician or other medical personnel might help. There were mixed reactions on how physicians treated women: some reported that physicians and other health professionals were nice to them, while others disagreed.

### 7.4 Health Promotion

7.4.1 Focus groups often emphasized the need for prevention of onset or worsening of a disease or condition among women with intellectual disabilities. Proactive lifestyle changes can provide health benefits for women with intellectual disabilities who have not led healthy lives, even at a later age. The systematic use of periodic screening checklists for women has been found to be of benefit to general practitioners.

7.4.2 When health services are available, women often report that they experience general confusion over what procedures physicians would do during both regular and specialized exams, and what was the purpose the different types of examinations. In some nations, aid in preparing for medical examinations is provided by care personnel. In the United States, for example, such personnel -often nurses - help to prepare women for medical examinations and other treatments. This is often the case if the woman is enrolled in a residential or day services program. However, it has been noted that if the woman is living on her own in the community, there is no one who

takes responsibility for this training or advocacy.

7.4.3 Wellness as a lifestyle was often discussed. Participation in a exercise regime and recognition of the importance of regular exercise for staying healthy as they get older was an apparent need. Many women knew that is important to eat the right foods in order to stay healthy, but were not aware that many of the foods that they currently eat would not fit the model of a "healthy" diet. Efforts to encourage women to understand that smoking can cause cancer and that it is not a healthy behavior were recommended. The fact that older women (and men) with intellectual disabilities are less likely to engage in active sports was noted .

7.4.4 Education for women with intellectual disabilities was recommended, including topics concerning women's health issues and general age-related changes, as well as about specific health issues related to their disability and/or to ageing. Many of the women reported watching and/or listening to television and radio. Given this, it was agreed that appropriate health information could be developed utilizing a variety of materials, including audio-visual and related computer-based multimedia - for example, WEB-TV.

7.4.5 Access to health promotion may be constrained if women do not have suitable support. Generally, women who are not affiliated with (service) agencies do not have anyone to help them negotiate the complex health system and payment processes.

## 7.5 Personal and Practical Supports

7.5.1 Women capable of occupation or employment should be assisted to achieve or maintain optimal functional and employment capacity. With regard to employment and access to health care, women with disabilities should be able to work without compromising their entitlement to health services. To help in managing work assignments, personal assistance services should be provided.

7.5.2 Medical services for women with intellectual disabilities should be provided consistent with current standards of practice and such medical services should be sufficient to achieve their purpose. When income is used to determine eligibility or degree of medical service receipt, medical services for which individuals may be eligible should be provided at no expense or at minimum on a sliding fee scale. Further, with regard to medical services, a patients' bill of rights which addresses the needs of people with disabilities should be available. Person-centered, holistic approaches to health care need to be adopted.

7.5.3 Supports for women with intellectual disabilities are important so that they might be encouraged to explore perceptions of themselves as women and their personal issues related to sexuality in a way that is respectful and breaks the apparent "taboo" surrounding these discussions. They may gain support, further, by learning ways to communicate their concerns, including an understanding that they have the right to express feelings of discomfort and/or to ask questions of health professionals. Finally, women with intellectual disabilities should be helped to understand more fully and develop more positive perceptions about being a women, having a disability, and getting older.

7.5.4 Although some areas on the world are comfortable exploring the myriad of women's issues, others are not There are many important matters related to women's health care that need to be discussed. One is that access to health care is often arbitrary. Even when it is allocated, the requirements of special groups of women with intellectual disabilities may be poorly understood, placing them at a disadvantage. Women with multiple disabilities may have even less access to

health care than their peers with minimal disabilities, especially to reproductive health care. Professionals may have had little contact with women who have profound disabilities and little sensitivity to their needs throughout the lifespan and those of their family carers. Often, women with physical or multiple disabilities and their advocates spoke of their distress when they encountered various medical investigations and procedures, and the resulting distress which could prevent them from receiving appropriate treatment.

7.5.5 Ethical issues related to informed consent to medical treatment are far from uniform. Both good and poor practices may be found in all regions. Advances in professional training and adequate financial resources do not guarantee good practice. Too often, prevalent is the belief that women of reproductive age should be sterilized routinely in order to prevent transmission of conditions giving rise to disabilities.

## **8.0 Policy and Service Recommendations**

A number of recommendations related to women's health policy and practices in health and health-related services are proffered:

### **8.1 Sterilization**

In some nations, sterilization is used to control a woman's sexuality or for the benefit of carers and not with regard to the woman's preferences or health. Each nation should adopt guidelines regarding the sterilization for women with intellectual disabilities, especially addressing the issue of informed consent to this procedure. Sterilization should never be applied as a broad social policy and without the woman's consent.

### **8.2 Evaluating Health Status**

Service providers should determine how the health status and health care practices of parents and carers may be associated with those of women with intellectual disabilities so as to evaluate their health needs and plan appropriate interventions within a family context.

### **8.3 Adopting Health Promotion Strategies**

Health promotion strategies which recognize the cultural and social context and which are sensitive to the needs of women with an intellectual disability throughout their lives should be developed in consultation with them. At the same time, a greater understanding of age-related changes should be advanced.

### **8.4 Training Health Providers**

Health care professionals should receive training in order to deal sensitively and effectively with women's health needs. Training should be targeted according to local conditions. In some countries, primary health care workers should be trained to offer essential information and guidance if physicians or other professionals working in health care systems are unable to do so.

### **8.5 Inclusive Communities**

Supports for living and working in the community should take account of the distinctive characteristics and needs of women with intellectual disability at different stages in their lifespan.

## 9.0 Research Priorities

Several important areas of research in sexual and reproductive health are suggested. In many instances, these inquiries should be undertaken within the context of large scale multinational studies.

### 9.1 Menstruation

This topic has received scant research attention and many questions remain unanswered, including: How many women with intellectual disabilities have regular/irregular and fertile/infertile menstrual cycles? How do risk factors such as having Down syndrome, short stature and hypogonadism - and maybe other risk factors- influence this? To what extent do anticonvulsants and neuroleptics influence these?

### 9.2 Menopause

Life stage related changes affect women with intellectual disabilities in the same manner as they do other women. Yet, little research has been directed toward these critical transition stages. Many questions remain, such as: How many women with intellectual disabilities have an earlier onset of menopause? What are risk factors for that?

### 9.3 Sexually Transmitted Diseases

STDs are a public health problem at any age. Women with intellectual disabilities are no less vulnerable to them. Yet, research has been negligent in addressing the particular issues related to STDs and women with intellectual disabilities. It is necessary to know more, for example: What are effective strategies for educating women with intellectual disabilities on sexually transmitted diseases?

### 9.4 Reproductive Health

The area of reproductive health, particular in regard to what practices may affect women as they age is virtually untouched in the literature on women and intellectual disabilities. An important question is, Are women with intellectual disabilities more or less at risk from certain forms of cancer? More information is needed, such as: How can women with intellectual disabilities be guided on making their own choices in having children and/ or using contraceptives? What are the rights and responsibilities of guardians in supporting the choice process?

### 9.5 Training of Medical Practitioners

In a number of countries, medical personnel are trained to become specialists in the area of intellectual disabilities, yet practically none have emerged as leaders in the area with regard to women's health. The dearth of trained practitioners who can serve as leaders in women's health is an impediment to realizing many health targets. Universities, medical training institutions and other settings should expand their focus in this area, particularly expanding their research efforts. There is a need to know more about how to more effectively deliver services to women with intellectual disabilities. For example: What training packages are effective in educating physicians, and especially gynaecologists on the special needs of women with intellectual disabilities?

## 9.6 Prevention

What is an appropriate strategy for making PAP smears in women with intellectual disabilities? Are there groups of women with intellectual disabilities who need not to be invited for this preventive measurement? What is known about the prevalence or course of cervical cancer in this population?

## 9.7 Disease Impact

Research must help to determine the incidence and impact of osteoporosis and osteoarthritis among ageing women with disabilities, notably in terms of their social inclusion and general well-being.

## 9.8 Lifespan Effects

Long-term effects on health should be investigated among ageing women. How diet and nutrition of women with disabilities relate to the incidence of heart disease, and the interface of longitudinal drug therapy with lifelong health are two such areas.

## 9.9 General Life Status

Overall, to date there have been few empirical studies investigating the impact of their employment status or levels of social inclusion on the health and well-being of women with intellectual disability at different stages in the lifespan, and across different social and cultural settings. Further, no research has been conducted on how to integrate women's health issues into the medical practice of nations where women have a devalued status. This is an important, if often complex, area for continued research.

## 9.10 Socio-Economic Status and Health

Women with an intellectual disability are generally of low socio-economic status. Research should be undertaken to determine the special needs of such women that need to be met in order for them to achieve an equivalent level of physical and subjective well-being to non-disabled women and men living in similar circumstances.

## 10.0 Summary

Promoting women's health across the lifespan may be seen as part of global strategy. Three major themes arise in this report.

First, our understanding of the distinctive needs, vulnerabilities and sources of well-being for women with intellectual disabilities must be addressed vigorously. There are compelling research priorities in the areas of reproductive and sexual health, and in health promotion practices, if health strategies founded on scientific evidence are to be pursued. Research questions of great importance to the health and ageing process among women generally have not been investigated among women with intellectual disabilities.

Second, a notable feature of WHO policy is the direct involvement of women themselves in informing, shaping and evaluating health interventions. This report offers examples of how women with disabilities may be directly involved as full partners in the formation of health strategies and interventions, and thus as contributors to their own well-being as they age.

Third, it is evident that health resources are finite. The distinctive health care needs and also the relatively low socio-economic status of women with intellectual disabilities must be understood in order to inform the allocation, or the re-allocation, of scarce resources at global level.

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