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## Healthy Ageing - Adults with Intellectual Disabilities

### Summative Report

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## Executive Summary

Awareness of the increasing number of ageing persons with intellectual disabilities led the World Health Organization (WHO) and two international organizations concerned with scientific inquiry and advocacy, the International Association for the Scientific Study of Intellectual Disabilities and Inclusion International, to examine the general health status of adults with intellectual disabilities, identify the conditions that support their longevity and promote healthy ageing, and propose health and social inclusion promotion activities that would universally foster sound health and improve quality of life.

The increased longevity of persons with intellectual disabilities in many of the world's nations is the direct result of medical and social advances which have also extended the longevity of the general population. Yet, the WHO is aware that people with intellectual disabilities are still generally regarded as a devalued class and often disadvantaged when attempting to access or secure social and health services. With this in mind, and recognizing that scientific and medical advances can benefit people with lifelong disabilities, this report encapsulates the major findings and conclusions of the WHO sponsored inquiries and summarizes the proposals for universal health promotion activities. These findings and conclusions are drawn from four special reports prepared for the WHO by the IASSID (physical health, women's health, biobehavioral, and ageing and social policy).

Key issues underlying the reports are:

- There is generally a lack of organized public or private sector systems designed to address the needs of persons with intellectual disabilities.
- Public attitudes need to be modified, both to create positive and valued status for persons with intellectual disabilities and to improve public support for specialty services that are designed to aid adults with intellectual disabilities.
- There is a need for supportive services, health surveillance and provision, and family assistance for person with intellectual disabilities.
- Women with intellectual disabilities often find themselves a disadvantaged class and little is done universally to address their specific health and social needs.
- While intellectual disabilities may have a biological, genetic, or environmental basis, in some nations, they are still not distinguished clearly from mental illnesses.
- Health practitioners generally fail to recognize special problems experienced by persons with lifelong disabilities who are ageing.

Disadvantaged subgroups of ageing adults with intellectual disabilities are at particular risk. In many nations, older adults with severe and profound impairments are disregarded or institutionalized. Housing is often inadequate and health provision neglected. Older adults with mild impairments are often marginalized and not provided with minimal supports needed to be productive members of their societies. Rehabilitative services, vocational opportunities, and quality old-age services are not provided. In many nations, older women with intellectual disabilities experience challenges that are particular to their sex. Their specific needs are often overlooked or dismissed. Older adults with co-morbid conditions experience particular problems and their compound physical and/or mental health conditions not addressed.

Across the world, national health provision schemes are often inadequate and do not recognize the special needs of adults with intellectual disabilities and as they age, their health needs are not attended to in a manner equivalent to that of the general population. Health care provision may also be sketchy at best and specialty services for people with intellectual disabilities are not available, further compromising their health and potential longevity. In addition, lifestyle choices and inadequate personal skills may have a major impact on their health and well-being. Sensory and mobility impairments, morbid obesity, poor oral hygiene, sexual behavior, and other lifestyle or personal attributes can also contribute to difficulties.

Yet, exemplary government policies and practices in health surveillance, provision and promotion, and formal schemes for social and family supports, as well as rehabilitative, training, and personal supports do exist. National health and social policies that are inclusive of people with intellectual disabilities and provide for special supports and assistance into old age are much needed – as are education and training initiatives in diagnostic procedures, presentation of interventions, and provision of supports. Only with special supports for families, adequate health care, housing, occupational opportunities, and inclusion in daily life open to all other older people, will the goals of universal healthy ageing and increased longevity for adults with intellectual disabilities be attained. ❖

## Purpose

The International Association for the Scientific Study of Intellectual Disabilities (IASSID), a non-governmental organization associated with the World Health Organization (WHO), was invited by the WHO to prepare a report on health related aspects and the ageing of persons with intellectual disabilities. The goal of this effort was to identify key features of health and social policy and practices that would improve the longevity and lead to the healthy ageing of persons with intellectual disabilities throughout the world. The IASSID, through its Special Interest Research Groups on Aging and Health Issues, prepared a series of draft reports, and discussed them in conjunction with representatives of Inclusion International at a specially convened meeting at the WHO headquarters in Geneva, Switzerland on April, 20-23, 1999. Representatives of these two organizations then redrafted and submitted the revised reports to the WHO for worldwide distribution. These four reports are cited at the back of this document.

This report, prepared conjointly with Inclusion International, provides a summary of the main issues put forth in the three main reports on physical health, women's health, and biobehavioral issues affecting adults with intellectual disabilities, as well as the report on concerns related to social and ageing policy. Included in this summary are the main recommendations from the four reports for improving health and longevity among persons with intellectual disabilities. Subsidiary recommendations are contained in each of the four reports.

## Introduction

The World Health Organization takes a broad view of health, stating that *"health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity."* In doing so, it draws attention to the need to view health as the outcome of influences in addition to biomedical health care and management. Such a view is equally applicable to people with intellectual disabilities.

A number of terms are used for intellectual disability with varying levels of acceptability across disciplines and professions. These terms include "intellectual handicap", "intellectual retardation", "mental retardation" and "mental handicap". WHO's International Classification of Diseases (ICD-10) uses the term "mental retardation", although it is recognized that some groups of professionals have serious reservations in using this term. In the current series of documents the term "intellectual disability" has been used, since it has the highest extent of acceptability among the organizations that have collaborated on preparation of this series.

This report recognizes that there are many myths or misconceptions about intellectual disabilities and ageing among persons with lifelong disabilities, including that people with intellectual disabilities are mentally ill, that people with intellectual disabilities do not survive to old age, that disabilities are the result of some wrongful behavior on the part of parents, that adults with intellectual disabilities can only be cared for in institutions, and that they are incapable of learning everyday skills, being educated, or of working. Nothing could be farther from the truth. Their intellectual disability is not necessarily a disease. They are not mentally ill. Nor were they born with a disability due to some wrongful behavior on the part of their parents. In many countries, people with intellectual disabilities live to old age, attend schools, work, and live independently in and contribute to their communities.

Whilst no one definition of intellectual disabilities has gained universal acceptance, it is generally accepted that the term intellectual disabilities encompasses any set of conditions, resulting from genetic, neurological, nutritional, social, traumatic or other factors occurring prior to birth, at birth, or during childhood up to the age of brain maturity, that affect intellectual development. These conditions result in a lifetime of lower than average overall capability for self-determination and general independent functioning and performance in vocational, social, and personal functions. In some instances these conditions may occur in conjunction with physical, sensory or psychiatric impairments of varying degree. Such conditions have variable impact on the individual, from minimal to severe. They can be compensated for by a variety of interventions, enrichments, training and/or special assistance or supports in all spheres of life.

Underlying all of the reports is the recognition that ageing is a lifelong process and that there is no generally accepted age which defines exactly when people become old. For the purpose of the collective reports, the sixth decade, when people with intellectual disabilities are in their 50s, was chosen as the chronological point for determining age-related change. However, this is often complicated by the occurrence of what appears to be premature ageing and shortened life expectancy in some individuals with intellectual disabilities, particularly in persons with profound and multiple disabilities and frequently those with Down syndrome. Life expectancy may also be compromised by poor health status and living conditions.

Nations vary in their recognition of and provision for adults with intellectual disabilities. In many cultures, persons with disabilities may not hold a valued status in societal terms. Consequently, they may have reduced access to the basic necessities of life, including housing, work opportunities, nutrition and health care, that are associated with ageing in good health. Barriers to the acceptance of persons with intellectual disabilities can include prejudicial beliefs about the nature and causes of disability, poorly organized services or a lack of governmental policies favoring supports for persons with disabilities, inadequate health and social services, and poorly trained professionals or practitioners. Poor health status and unfavorable economic conditions affecting the entire national population may also be barriers. Such barriers can be overcome with enlightened public policies, educated professionals and carers, determined advocacy, and other special compensatory efforts.

## **Background**

There were dramatic increases in life expectancy during the 20th century, due chiefly to advances in medicine, public health, science, education, and technology. Globally, while life expectancy increased, disability-free life expectancy seemed to be stabilizing. Increased longevity and more readily available services of all kinds have led to an increase in the population of persons with intellectual disabilities in the developed nations of the world. It is estimated that as many as sixty million persons may currently have some level of intellectual disability and that this figure will rise in the coming years.

Major inequalities do exist, however, depending on sex, region and socio-economic status. The poorest, least educated people live shorter lives with greater ill-health.

In nations with established market economies, most adults with intellectual disabilities who live past their third decade are likely to survive into old age and experience the normal ageing process. Numerous adults are surviving into late old age, with some surviving to become centenarians. In spite of gradual declines in various functions, they can have active and varied lifestyles with an excellent quality of life.

Like other people, older people with intellectual disability may have significant physical health needs, reflecting the social and economic circumstances which have shaped their daily lives. Environments which foster healthy social relationships, trust, economic security, sustainable development and other factors related to advancing the health and well-being of citizens have been identified by governments as priorities. Healthier communities with greater social cohesion produce healthier citizens. Further, the effect is cumulative and lifelong, with good health in childhood affecting and contributing to good health in older age.

In some nations people with intellectual disabilities may not constitute a priority given the wider social problems that are to be faced. In general, they may have restricted social roles and more limited social networks than people without disabilities, and thus may have fewer opportunities to benefit from many common experiences open to those without disabilities. Poor social networks reduce the likelihood of survival into old age.

In considering initiatives to improve the quality of old age in both developing and developed regions, it is clear that realization must reflect regional and cultural differences. The *UN International Plan of Action on Ageing* asserts that each country must respond to demographic trends and the resulting changes *"in the context of its own traditions, structures and cultural values . . ."* This view is equally applicable to older people with intellectual disabilities. Focusing on ageing *and* intellectual disability implies that all policies affecting people with intellectual disabilities are developed in such a way as to maintain, if not improve, their situation as they age.

What follows is a summary of the main issues, considerations, and recommendations related to physical health, women's health, and mental health, as well as service provision. By necessity there may be some overlap in the discussions as each section examines common concerns from its particular perspective.

### **Physical Health Concerns**

The majority of people, including people with intellectual disability, live in non-developed market economy countries. Because of a persistent scarcity of information regarding the status and needs of persons with intellectual disabilities in less developed countries, it is difficult to make statements that are universally applicable regarding the "healthy ageing" of all people with intellectual disabilities. The highest priorities for the majority of people with and without intellectual disabilities in less developed countries generally include basic health care, adequate nutrition and housing, education, human rights, and political, social and economic stability.

An international perspective on healthy ageing for persons with intellectual disabilities must acknowledge that the available literature is strongly dominated by the experiences of clinicians and researchers in developed countries, and that it probably does not reflect everyday realities in countries with lessor economic status.

The developed countries are definitely witnessing an increase in the longevity of adults with intellectual disabilities and an overall increasingly greater number of such older persons. As more people with intellectual disabilities attain older age, it is important to note that additional functional impairment, morbidity, and even mortality can result from the consequences of early age-onset conditions, through their long-term progression or interactions with older age-onset conditions. In addition, the long-term consequences of therapeutic interventions need to be considered -- examples are movement disorders that may result from the prolonged use of neuroleptic medications, and bone demineralization that may occur secondary to the chronic use of certain anticonvulsants.

On the other hand, it is important to underline the fact that many ageing persons with intellectual disabilities may be just as healthy as other older persons without life-long disabilities. This can be attributed to a quality lifestyle. It may also be due to "differential mortality" – the tendency for healthier people to live longer. Thus, older cohorts may actually be healthier in many domains than younger groups of persons with intellectual disabilities, and show greater functional abilities until the oldest ages. In order to ensure that all people with intellectual disabilities have an equal opportunity to achieve old age, access to adequate health care and social supports throughout the life-span is of prime importance.

### *Health risks*

Certain people with intellectual disabilities have particular health risks. They may be defined by the presence of specific syndromes (hence termed *syndrome-specific*), or by the extent of the central nervous system compromise that has caused the intellectual disabilities (leading to *associated developmental disabilities* such as autism, cerebral palsy, epilepsy, head injury, and sensory impairments). They may be defined by their living conditions, such as living on their own or with their families; in specialty rehabilitative or small residential programs; or in hospitals or large, general purpose institutions. The resulting lifestyle and environmental issues and health promotion/ disease prevention practices may directly cause, or interact with, hereditary factors. They may also be defined by age as when increased longevity of persons with intellectual disabilities leads to the definition of populations by chronological older age -- and a subsequent increased risk of acquiring adult and older-age associated conditions.

Persons with specific syndromes constitute an important segment of the adult population with intellectual disabilities. These syndromes can be caused by toxins, injuries, infections, and genetic/metabolic disorders which affect the central nervous system and, in some cases, other organ systems, during the developmental period. The residuals of such syndromes can become manifest at different stages of the lifespan.

*Fragile X syndrome* is the most common inherited disorder associated with intellectual disabilities. Older adults with Fragile X syndrome exhibit relatively high rates of mitral valve prolapse, musculoskeletal disorders, early menopause, epilepsy and visual impairments.

*Down syndrome* is a relatively common chromosomal disorder that, in addition to causing intellectual disability, results in a relatively high risk for a number of conditions. Throughout the lifespan, persons with Down syndrome manifest higher risks for specific endocrinological (especially hypothyroidism), infectious, dermatological, oral, cardiac, musculoskeletal and other organ system disorders. In addition, they exhibit high rates of impaired vision and hearing. Older

adults with Down syndrome are at increased risk for early development of age-related visual and hearing disorders, epilepsy, and Alzheimer's disease. Their longevity is generally some 10 to 20 years less than that of the broader population of people with intellectual disabilities.

Other syndromes (e.g., Prader-Willi syndrome) may not be as common or easily identifiable as the above; however, the same principle of knowledge of syndrome-specific issues may permit better functional and health status.

### *Lifestyles*

As adults with intellectual disabilities, particularly those with milder cognitive impairments, are offered more lifestyle choices, there is the potential that some of these choices may result in long-term risks that have not necessarily been anticipated. Adults with intellectual disabilities living in the community may be exposed to tobacco use, substance abuse, violent behavior and high-risk sexual activity (including the risk of AIDS). Older adults living in congregate care settings may encounter the same risks, in addition to being exposed to neglect and contagious diseases.

Passive lifestyle factors may also pose risks. A sedentary lifestyle, for instance, presents consequent risks of physical deconditioning. Obesity-related diseases such as coronary artery disease, hypertension, and diabetes affect those who are chronically over-weight. For adults with intellectual disabilities living in independent or semi-independent settings, targeting lifestyle may result in substantial gains in longevity, older-age quality of life, and functional capability.

The cumulative research in developed countries suggests that adults and older persons with intellectual disabilities have rates of adult and age-related conditions that are comparable to the rates for the general population, though in some instances the rates are higher. For many people with intellectual disabilities, the interaction between biological, psychological and social aspects of ageing remains the most important factor in the later years of life. The risk of chronic diseases acquired during adulthood reflects the same interplay between hereditary predisposition and environment that is present in the general older population.

### *Health assessments*

Physical and functional decline in older age warrants careful evaluation. A decline in functional status should not be peremptorily attributed to behavioral issues or pathologies, such as dementia. Comprehensive evaluations of older persons with intellectual disabilities experiencing changes often show high rates of concurrent treatable conditions. Examples include affective disorders, sensory impairments, delirium, and previously undiagnosed medical conditions. Such disorders may be expressed atypically. Communication difficulties arising from intellectual disabilities or associated motor impairments may serve as barriers to accurate medical evaluation or health services provision.

The medical history is in many cases derived from carers' observations, who should be able to recognize signs of distress in adults even those with severe cognitive impairment. Health care providers depend on the verbal or written reports of carers who know the person. Adults with intellectual disabilities can benefit from training of carers in health-related issues – particularly basic assessment skills. At the same time, adults who have basic communication skills need to be educated in the effective communication of pain or distress. Even in optimal circumstances

– when the ill person with an intellectual disability is accompanied by knowledgeable carers – informant- based medical history taking requires time.

Behavioral issues constitute another potential barrier. Adults with intellectual disabilities may have difficulty cooperating with examinations and procedures. Health care providers should be educated regarding the confusion, fear, and frustration experienced by many persons with an intellectual disability when they attempt to access health care services. Extra time may be necessary to reassure the person and help him or her acclimate to the medical or examination setting. In some situations, safe, conscious sedation is appropriate for adults with intellectual disabilities. In others, general anesthesia may be necessary to enable safe and thorough health maintenance exams and procedures.

Behavioral issues can also play an important role in successful rehabilitation after disease or injury. Also, teaching adults with intellectual disabilities how to use assistive or prosthetic devices, such as canes, walkers, wheelchairs, braces, dentures, eyeglasses and hearing aids, is useful, but may require time and special techniques.

Health care providers need to address the issue of health care – not just in terms of healthy living, but also by increasing understanding and confidence in using health services.

#### *Obtaining health services*

For many adults with intellectual disabilities living where health services in the community are readily available, case complexity can be a significant important barrier to effective medical care.

Whilst older adults are able to access a variety of health care professionals (such as medical subspecialists, dentists, audiologists, mental health providers, and others) such multidisciplinary expertise demands case management. Administrators and policy makers need to understand that, in some cases, clinically indicated and relatively expensive techniques and expertise, while requiring careful management, will prove cost-effective in the long-term.

However, access of persons with intellectual disability to primary health care provision may be restricted by a wide range of factors, among them:

- lack of training on intellectual disability itself,
- lack of training on health issues relative to older persons with intellectual disabilities,
- lack of pertinent information on the medical history of the individual,
- difficulties in undertaking medical examination because of communication problems or behavior problems,
- absence of specialized back-up for complex medical conditions, and
- lack of understanding on the physician's part concerning informed consent issues.

In addition, access barriers may also result from prevailing community values, where the devalued status of persons with intellectual disability can influence the willingness of carers to pursue health care, especially if they have to contend with material barriers such as distance and financial costs beyond their means. Yet, when cultural attitudes are not a barrier, even when health services are available, costs and travel time to seek health or specialty rehabilitative services can be prohibitive. Such barriers may deter many low income, otherwise willing, families from seeking help.

Access to health care for older persons with intellectual disabilities can be further compromised if family carers (who are likely to be elderly) do not themselves receive adequate health care or are generally inexperienced with health care systems. Not knowing what may be needed or available can be particularly problematic and a deterrent to aggressive health services advocacy.

### *Consent*

A further issue is the agreement or consent to treatment. The rights guaranteed to persons without lifelong disabilities must be respected when health care professionals approach persons with intellectual disabilities. Adults with disabilities should always be informed of any medical procedures or treatments proffered and their consent obtained. Providers are under special obligations to ensure that there is a clear understanding of the parameters of consent and the nature of the medical treatment to be undertaken. If the person is not in a position to consent, consent or authorization shall be obtained in the manner prescribed by law, guided by the person's best interest.

Given all of the above, it is imperative that health and social services personnel receive training and support in identifying the specific social support and health care needs of adults and older persons with intellectual disabilities and that government and other administrators are alert to the specific legislative, regulatory, and budgetary enablements for provider organizations to deliver such services. Further, it is important to expose health care staff and administrators to sound community support models that enrich older age and sustain healthy ageing.

### **Women's Health Concerns**

Just as greater awareness is needed for the needs of girls and women throughout the world, more attention is needed for the personal and social development of girls and women with intellectual disabilities. It is important to understand their experiences and roles, as considered appropriate within their family and culture at each transitional stage throughout the life span.

For example, in many developed nations young women with intellectual disabilities complete formal schooling and/or vocational training, find employment, achieve citizenship and build personal friendships and intimate relationships. Like other women, older women with intellectual disabilities who have been employed may transition from the active workforce and attend more to personal and social interests. Yet, most may be discouraged from marriage, establishing independent homes, and bearing children.

In developing countries, women with intellectual disabilities may not have the same vocational and lifestyle freedoms as in those living in developed nations, but may not necessarily be excluded from family or community activities, or from marriage and childbearing. Yet, because they may have more sheltered lives, their exposure to available health care or social services may be seriously limited. It is essential to be attentive to health care concerns related to the lives of all women with intellectual disabilities as women, wives and mothers.

### *The main issues*

There are a number of issues which are important for the health of women with intellectual disabilities as they grow older:

- Among women with intellectual disabilities, the average age at onset of menarche appears similar to that of women in the general population; most appear to have regular menstrual cycles.
- Little is known about menopause in women with intellectual disability. Limited studies have reported on the median age at menopause for women in developed countries, but no studies have systematically tracked changes in hormones and ovarian function with age in a large group of women with intellectual disabilities.
- Although little research has addressed fertility in women with intellectual disabilities, it is reasonable to assume that most mature women are fertile unless they have a disorder that affects genital organs or brain regions responsible for hormones that regulate ovarian function.
- Osteoporosis, considered to be characteristic of disorders increasing after menopause (or as a result of long-term medication), may lead to increased risk for fractures.
- Therapeutic amenorrhea may be induced in women with intellectual disability who are unable to manage menstrual hygiene effectively, who show self-injurious behavior related to menstruation, or who risk pregnancy. The most common form of therapeutic amenorrhea is suppression of menstrual cycles via medication.
- Given their relative inability to defend themselves and/or a lack of knowledge about their rights, women with intellectual disabilities are often victims of physical and sexual abuse. Offenders are probably known to their victims and may include care personnel and other carers, family members or fellow residents of living settings. In some countries women with intellectual disabilities may be prime candidates for prostitution.
- Women with intellectual disability who are treated with psychotropic medication and/or anti-epileptic drugs may see such medications interfere with hormonal and metabolic functions, which may have long-term effects on their health.
- Women with intellectual disability may be subjected to irreversible medical procedures, such as endometrial ablation, hysterectomy and sterilization, with or without their consent. Such procedures raise important legal, ethical and bioethical issues.
- Just as in the general female population, risks for breast cancer and cervical cancer increase with age (whether or not women with intellectual disabilities have the same risk for these cancers as other women is still subject to debate).
- Poor receptive and expressive language, discomfort, and fear may create difficulties in achieving cooperation in gynecological procedures. Pelvic examinations and cervical smears may present particular problems, as may the relative lack of female practitioners with whom contact may be easier. Thus, women with intellectual disabilities may be at greater risk of certain diseases than other women.

In both women and men, proper nutrition, exercise, and access to preventive health care can increase health and longevity. Yet women with intellectual disabilities generally receive less preventive health care than women generally, just as women receive less preventive health care than men.

Among adults with intellectual disabilities in developed countries, obesity and cholesterol levels are generally higher than for the general population and women are more likely than men to be affected by obesity. In part, this may be due to women with intellectual disabilities having comparatively more sedentary lifestyles. In developing countries, women with intellectual disability may be affected more frequently by malnutrition than are men.

### *Special concerns*

Access to health care varies widely by country. Data from developed nations indicate low levels of specific health screenings targeting older women with intellectual disabilities, including mammograms, breast examinations, and pap smears. Reasons for the lack of such preventive health care include unequal health insurance coverage, attitudinal barriers in health care professionals, insufficient health education, fear of examinations, communication difficulties, and inaccessible examination setups for women with concurrent physical disabilities (i.e., inadequately designed examination tables and equipment for mammograms).

Certain medical procedures or treatments raise particular issues, the tenor of which may differ from country to country. For example, procedures such as a breast biopsy are a major problem for women who may have difficulty understanding the procedure itself or the relative merits and disadvantages of a particular form of treatment for themselves. Sometimes the problem is legal as well as ethical; for instance, sterilization which may or may not be legally validated by the community, regardless of whether or not the woman herself has given conscious assent.

Mental health issues in relation to sexual abuse of women are often poorly understood and underrated. Serious reactive disorders, such as acting out or depression among women living alone or with their families, tend to be treated as behavioral disorders and underlying causes go uninvestigated. As a result, appropriate interventions or treatments are not provided.

### *Health education*

Women with intellectual disabilities should be able to recognize the differences between women and men in terms of different body parts, understand that menstrual periods are something which occur only in women, and understand that menopause is a time when menstrual periods cease. Often, older women do not understand why the menopause takes place. Others may lack the means to describe common physical changes related to menopause (such as hot flashes and irritability). Those who may benefit from hormone replacement therapy (HRT) may not understand what is at stake in taking such medication.

Supports for sensitive topics among women with intellectual disabilities are important inasmuch as they may encourage women to explore perceptions of themselves and the issues related to their sexuality in a way that is respectful and breaks what appears to be "taboo." Women with intellectual disabilities may moreover gain support by learning ways to communicate their concerns, including an understanding that they have the right to express any feelings of discomfort and/or to ask questions of health professionals.

It is important to help all women, and in particular women with intellectual disabilities, develop more positive perceptions about being a woman and growing older, as well as putting her disability and its possible effects on her ageing in a context.

## **Biobehavioral and Mental Health Concerns**

*Mental disorders* are those that can be classified by diagnostic systems such as the WHO's ICD-10. Biological, psychological and social factors disorders may all contribute to their expression. *Behavioral disorders*, conversely, are patterns of maladaptive behaviors (usually as perceived by an informant) that interfere with typical life functioning. They may be related to another mental disorder in the individual, to biological vulnerability, to long-standing learned behaviors, or to a mismatch between environmental expectations and resources with respect to the individual's capabilities and wishes.

Although less common than behavioral disorders, major mental disorders still occur in older adults with intellectual disabilities with an overall prevalence of about 10%. Some disorders, such as dementia, increase with age. Dementia occurs at about the same rate as in the general population, except that it appears at a greater rate (and at a younger age) in adults with Down syndrome. As in the general elderly population, psychotic disorders may also increase with age (although psychoses which appeared in youth may stabilize). They are, however, less frequent than mood and anxiety disorders.

### *Impact of everyday stressors*

Social, cultural, environmental and developmental factors can have significant impact on the expression of both psychiatric and behavioral disorders in older people with intellectual disabilities. Stressors may be multiple, and include separation from or bereavement as the result of the death of a parent, other relative, or friend; loneliness; or sudden relocation. Though much remains to be clarified as to quantifying specific influences on age-related changes in persons with intellectual disabilities, the general consensus is that perceived symptoms need to be evaluated in a broader context, and not necessarily attributed to one individualized factor. They should be explored as part of a complex interaction of the individual with his or her environment.

### *Biological factors*

Biological contributions to mental and behavioral disorders are also important. Major mental disorders in older people with intellectual disabilities may have considerable negative impact on cognitive, affective and general functioning, as well as overall quality of life. Examples include sensory loss, depression, dementia, nutritional abnormalities, and chronic medical conditions provoking chronic pain and discomfort.

Mental disorders such as schizophrenia or bipolar disorders continue to be as present in old age as in the general population. It is important therefore to detect and optimally treat these. Diagnosis is more difficult in older people in general due to higher rates of comorbidity,

polypharmacy and a reduced tendency to express psychological complaints (as compared to physical complaints). This is magnified in adults with intellectual disabilities, particularly among those adults with the most severe impairments.

The presence of seizure disorders further complicates the assessment of mental functioning (although this may be more pronounced in younger multiple disabled adults than in older adults). Generally late onset seizures signal an emerging problem, such as Alzheimer's disease. Other challenges include communication barriers, baseline behavioral abnormalities (secondary to brain abnormalities, learned maladaptive behaviors, and environmental deprivation) overlapping with core mental disorders and more florid stress-related decompensation.

Pharmacotherapy used in severe, potentially harmful behavioral syndromes or in the more biologically driven mental disorders, must be tailored to age-related vulnerability. Medication pharmacokinetics, including drug volume of distribution, protein-binding factors, hepatic metabolism and renal clearance need to be considered in formulating psychotropic regimens.

Treatment response time often lengthens with old age, and unfamiliar environments may result in significant stress that makes the assessment of change difficult. In addition, some older adults with intellectual disabilities may be receiving medications for chronic medical conditions, and the potential for drug interactions should be carefully considered. Thorough knowledge of the biomedical state of each older adult, as well as close coordination with primary health care providers, is necessary for the safe prescription of any medication. Adverse effects of psychotropic medications, such as sedation, increased confusion, constipation, postural instability, falls, incontinence, weight gain, sex steroid dysregulation and other

endocrinologic or metabolic effects, and movement disorders must be minimized.

### *Prevention strategies*

Practitioners dealing with behavioral and mental disorders should first consider prevention strategies which can intervene at different times. *Primary prevention* strategies are implemented to anticipate and prevent occurrence of the problem. *Secondary prevention* is early treatment of an emerging problem to prevent its full expression, and *tertiary prevention* strategies minimize functional impairment once the problem is firmly established.

Primary prevention strategies for behavioral and mental disorders are not well analyzed, but some issues related to lifestyle and supports are known to be associated with prevalence. Decreased use of large institutions can reduce the frequency of a variety of maladaptive behaviors and infectious diseases, as well as mitigate poor social and emotional development. In developed nations, polypharmacy (which is responsible for many other secondary adverse effects) may also occur, specially in large institutions.

Increased work on communication skills and identification of sensory deficits can encourage adaptive behavior. When trained to understand and deal with the emotional needs and stresses of adults, staff can provide more emotionally supportive environments that minimizes the occurrence of challenging behaviors or the perception of the person as "a problem."

Secondary prevention of mental and behavioral disorders involves appropriate early detection, assessment and treatment of the designated problem by careful orchestration of biological,

psychological and social interventions. Whenever feasible, all persons involved (the adult, professional staff, family and friends from the community) should be involved. Training and information should be provided to allow non-professional carers to continue effectively aiding after professional involvement has ceased. Modifications may be necessary in the home and work environments as well as in staff approaches to the person. Needs that are expressed through maladaptive behaviors must be met more productively, and alternate expressions taught to all concerned.

In more sophisticated environments, supportive therapy, individual or group behavioral therapy, family therapy and social skills training may all be of help, as may be the involvement of spiritual elders or healers, depending on the cultural milieu.

### *Training and education*

Often making a reasoned assessment of mental status is fraught with difficulties. Health care providers who are not familiar with intellectual disabilities may experience difficulty in making accurate mental health assessments. Carers who are most able to report changes in usual functioning generally do not have the necessary knowledge of mental disorders. Records of previous levels of functioning or personal histories may be unavailable or unreliable.

Unfortunately there are few clinicians (even in the developed nations) who possess the skills necessary for bridging such gaps, or for undertaking appropriate interventions for behavioral difficulties experienced by adults with intellectual disabilities. There are fewer still who are aware of the psychological issues or dynamics related to functional decline, grief secondary to loss of family or friends, and other life changes that take place as people age.

Cultural perspectives on normative behavior may further color how seemingly "deviant" behavior (which may be attributed to intellectual disabilities) is perceived. Ideally, there should be a core of professionals and clinicians with specialized training in intellectual disabilities. Mental health, psychiatric, neurological, and psychogeriatric professionals or clinicians should receive training in intellectual disabilities. Such training must stress the differentiation of intellectual disabilities from mental illnesses and the differentiation of psychopathologies from behavioral and reactive disorders. Furthermore, specialized resource centers should be available to which clinicians, workers, families and other carers can turn to seek information and referral.

### **Service Concerns**

People with intellectual disabilities living in developed countries generally have access to essential services. However, countries vary in their models of care provision. Thus, it is worth noting the general barriers that exist in providing social supports and health care to people in general and to those with intellectual disabilities. It is important that health care providers and policy makers acknowledge that many people with intellectual disabilities have special needs which may require modification of standard health care practices and service models.

Specific services providing physical and mental health care for persons with intellectual disabilities, regardless of their age, are not necessarily available throughout the world. Services that specifically provide care to older people with intellectual disabilities are extremely rare. Moreover, in some regions basic life necessities, let alone physical or mental health delivery, are

barely available for the general population. Persons with intellectual disabilities are often the last to benefit when basic health or mental health services are made available. In these situations, service provision, such as basic supports, needs to be adapted to best deal with the local environment.

The overriding goal in the development of any specialty services, is to include the acceptance of basic principles, which include maintenance of respect for the individual and his or her family, inclusion of the person's needs and wishes in any support plan, and development of support plans that are minimally restrictive, culturally sensitive, and which foster the growth and autonomy of the person.

Outcomes that serve as a basis for demonstrating the social value of intellectual disability services may include:

- Practical, leisure, or life enhancing skills (such as those involved in self-determination and those which allow a person to access common opportunities offering enduring benefits);
- Improved or maintained dietary and general health status that prevents physical health factors from hindering typical activity;
- A varied rhythm of life
- Recognition that challenge and productivity must continue throughout old age;
- An increased and well-established social network; and
- Participation on a regular basis in the general life of the community, with friends and acquaintances of one's preference.

In implementing such objectives, consideration must be given to several underlying problems. One is that health care systems do not necessarily distinguish between people with mental illness and people with intellectual disabilities. Another is that the prevalent literature comes from developed nations where the longevity of adults with intellectual disabilities is more pronounced and has become a normative phenomenon. To what extent this same longevity and population profile is generalized to all nations, including those with developing economies, remains to be seen. Data from developed nations may not be easily translated to everyday realities in other countries. Yet another is fiscal realities. From a policy perspective, developing nations may have to choose between allocating limited resources to such practices as diagnosis and treatment of psychiatric and behavioral disorders in persons with intellectual disabilities and improving the nutritional and health status of the general population, or prevention of specific causes for intellectual disabilities.

However, any given culture may have its own valued means of improving the health and quality of life of its members, including ways that have only recently attracted the interest of developed societies. Consistent with the *UN Standard Rules for Equalization of Opportunities for Persons with Disabilities*, recognition should be given to the value of persons with intellectual disabilities and resources should be provided to improve their general health status so that longevity consistent with that of the general population becomes the norm. Nations should devote resources to treatment of physical, psychiatric and behavioral disorders that impede or distort

normal ageing in this population. However, in order to do so, nations will have to adopt beliefs that value the lives and the productivity of persons with intellectual disabilities.

In developed nations, ageing-supportive social and health policies should be focused on promoting productive or successful ageing for all. In developing nations age-supportive public policies should be focused on basic functions, such as promoting healthy ageing and encouraging survival into old age. Once such basics are achieved, then the goals of productive or successful ageing can be universally incorporated into national public policy structures.

It is unrealistic in the context of developing services for older people to split this emerging population off from the wider field of ageing. The need is to develop infrastructures for health and ageing which can be accessed by older people with intellectual disabilities. In this way, natural inclusion can be facilitated, supported by relevant training for both professionals and the wider public. Further, specialized resource centers need to be available to which clinicians, families and carers can seek information, referral and training.

In every country, there have been long-standing difficulties for people with intellectual disabilities in accessing services for physical restoration or rehabilitation, sensory (hearing, vision) impairments, and dental care, as well as other health-related services. These difficulties are exacerbated in developing regions where access to such services is limited for the entire population. Lack of services to address these needs often allows easily remedied conditions to become barriers caused by disabilities and reduces the participation of people with intellectual disabilities in daily life. Also, the need for health-related services may increase as people with intellectual disabilities age.

Some nations have relied on institutional settings, but most rely on families to provide care. As the life expectancy of persons with intellectual disabilities increases, families are under new pressures to maintain care over a longer period of time. Safety nets must be provided to ensure that, in the absence of family support, persons with intellectual disabilities do not find themselves abandoned to starve or condemned to poorly organized and inadequate services. Decisions about when to maintain in-home care or to plan for transitions to out-of-home living situations should be guided by considerations of service needs, consumer choice, service availability, current and future health needs and the potential consequences of transitions.

Families who continue to provide lifelong care require appropriate supports. Although in some instances there may be a decreasing number of older adults still living with their families, often, in many regions of the world, long-term family caring remains the norm. The extent of support for such families depends upon the kind of service provision available in the society, as well as cultural attitudes toward family responsibility. Where family care continues, then the social and health needs of carers should be viewed as a priority and met through appropriately focused services.

In most nations, the family provides the main informal supports for a person with an intellectual disability. However, in the absence of such family supports or mechanisms for supporting the families who are the carers, the lack of safety nets can result in extreme outcomes, such as starvation, further impairment, or even greater marginalization. Thus, nations with poorly organized or non-existent mechanisms for family supports may place their citizens with disabilities in jeopardy.

While the family constitutes a key element in the social networks of people with intellectual disabilities, such networks are typically restricted to family members, service providers and peers with intellectual disabilities. The value of these relationships should not be underestimated or undervalued. However, the desirability of extending networks to include other adults, both younger and of similar age, is widely recommended. Such an extension has the potential for enriching the lives of people with intellectual disabilities and increasing social participation, as well as enhancing the life of the wider community.

At the heart of an inclusive policy is acknowledgment of the rights of the person to live in a dwelling appropriate to her or his culture in the mainstream of that society. As noted in the *UN International Plan of Action on Ageing*: "Housing for the elderly must be viewed as more than a mere shelter. In addition to the physical, it has psychological and social significance." Thus, in developed regions this may typically involve an ordinary house or apartment in an urban setting, often with some degree of independence. In developing regions, life in a rural setting may be the more typical dwelling place, with conditions greatly dependent upon the status and economic conditions of the family. In either setting, whenever possible, institutional care should be avoided, as should be dwellings isolated from the main community. Where isolated, segregated facilities exist, policies leading to transition of older as well as younger persons with intellectual disabilities toward community settings should be the objective.

In nations with undeveloped social and vocational training services and where enriched opportunities for health and development are only provided in segregated facilities, policy should mandate the involvement of each person within the greater community and the freedom to return to their community once training or other supports have achieved their goals.

Support in individual homes should be related to the level of dependency of the person and should be sensitive to, and accommodate, age-related changes. Personal choice with respect to lifestyle should be central to the home's ethos as this will determine in a significant way the person's quality of life. In addition, suitable adaptations to enable the person to cope with functional difficulties arising as they age should be available.

Both the general public, policy makers and front-line service providers require information to better understand older people with intellectual disabilities. The *UN International Plan of Action on Ageing* urges governments and international organizations to educate the general public with respect to ageing and the ageing process. Such education needs to encompass older people with intellectual disabilities and to work against the compound negative stereotypes associated with older people and those adults with intellectual disabilities.

Staff in such settings may require training to integrate age-related information and practice into their existing practices. Progression toward the integration of older people with intellectual disabilities into generic elderly services requires that staff in those services receive training with respect to both intellectual disability and age-related issues. Indiscriminate aggregation of impaired elderly and younger disabled persons should be avoided and specialty services for older persons used only when they provide exceptional social and personal benefit to older adults with intellectual disabilities.

## Recommendations

Over their life-span, adults with intellectual disabilities should maintain the same array of preventive health habits and receive the same protective health services as those offered to the general population. To achieve this goal:

*Health care providers throughout the world, caring for people with intellectual disabilities of all ages, should adopt a life-span approach that recognizes the progression or consequences of specific diseases and therapeutic interventions.*

Functional decline in adults and older persons warrants careful medical evaluation. Since undiagnosed mental health and medical conditions can have atypical presentations in people with limited language capabilities, regular screening for physical and sensory impairments should be implemented during particularly sensitive moments in the life cycle, such as childhood and the late-adulthood years. In promoting general well-being:

*Adults with intellectual disabilities and their carers need to receive appropriate and ongoing education regarding healthy living practices in areas such as nutrition, exercise, oral hygiene, safety practices, and the avoidance of risky behaviors such as tobacco use and substance abuse.*

Health care providers serving adults and elders with intellectual disabilities should recognize that adult and older-age onset medical conditions are common in this population, and may require a high index of suspicion for clinical diagnosis. Thus:

*Nations should ensure that there are sufficiently educated and trained medical and health personnel to provide appropriate preventive and treatment-oriented health and social services.*

Promoting women's health across the life-span needs to be seen as part of a global strategy, and the vulnerabilities and sources of well-being for women with intellectual disabilities must be addressed vigorously. Research questions of significance to the health and ageing process among women should receive special attention. Since it is WHO strategy to directly involve women in informing, shaping and evaluating health interventions which concern them directly, women with disabilities and/or representatives of relevant disability organizations should be involved as partners in the formation of health care interventions. Thus:

*The distinctive health care needs and relatively low socio-economic status of women with intellectual disabilities should be recognized and services provided to help overcome these distinctions.*

Promoting sound mental health involves improving the detection and holistic assessment of both reactive behaviors attributable to life stressors and to more problematic mental health disorders such as depression, anxiety and dementia in older people with intellectual disabilities. To this end, WHO and nations should work earnestly to increase the mental health knowledge and skills in professionals, carers, and families of older people with intellectual disabilities.

With this in mind:

*National preventive health strategies should include ways to promote mental health and minimize negative outcomes of mental health problems in older people with intellectual disabilities and to improve the quality of life in older people with intellectual disabilities.*

Where a policy of integration with generic elderly services is undertaken, preparation should involve staff training with respect to management of the process of integration and the nature and needs of older people with intellectual disabilities. Hence:

*National public policies should recognize the contribution of adults with intellectual disabilities to the greater population, and when appropriate, specialized services and assistance should be provided, and equitable access to generic services should be ensured.*

A detailed program of research that takes into account the respective economic and cultural contexts of developing and developed regions needs to be promoted and implemented. The research and informational needs of developing countries should be defined and their technical and financial requirements worked out in order to ensure that appropriate goals are met. To this end, governments and the academic community should undertake a course of research that will help further expand knowledge of the ageing process among older adults with intellectual disability. Included among these efforts should be studies of:

*Structural practices endemic to developing nations that successfully promote longevity and healthy ageing of persons with intellectual disabilities, as well as practices that promote successful and productive ageing of persons with intellectual disabilities in developed and developing nations, and the educational and training needs of those providing services to older people with intellectual disabilities to ensure that quality of life is maintained at the highest possible level.*

*Morbidity and mortality studies of older people with intellectual disabilities in developing nations and the conditions under which the health and social needs of older people with intellectual disabilities can be met within the context of generic services, and the extent to which special provision is required.*

*Evaluation of programs aimed at maintaining functional abilities, extending competence in later life and in general enhancing quality of life and factors which lead to increased inclusiveness in society with respect to both age-peers and intergenerational solidarity.*

*Cross-cultural studies that will ensure that common aspects of quality provision are identified as well as specific cultural influences of significance and cultural and economic factors that support family caring.*

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### **Links to Main Documents**

1. Evenhuis, H., Henderson, C.M., Beange, H., Lennox, N., Chicoine, B., & Working Group. (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Physical Health Issues*. Geneva, Switzerland: World Health Organization.
2. Walsh, P.N., Heller, T., Schupf, N., van Schrojenstein Lantman-de Valk, H., & Working Group. (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Women's Health Issues*. Geneva, Switzerland: World Health Organization.
3. Thorpe, L., Davidson, P., Janicki, M.P., & Working Group. (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Biobehavioral Issues*. Geneva, Switzerland: World Health Organization.
4. Hogg, J., Lucchino, R., Wang, K., Janicki, M.P., & Working Group (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Ageing & Social Policy*. Geneva: Switzerland: World Health Organization.

All the above documents are available from the following IASSID web site:  
[www.waisman.wisc.edu/IASSID/SIRGAID](http://www.waisman.wisc.edu/IASSID/SIRGAID)