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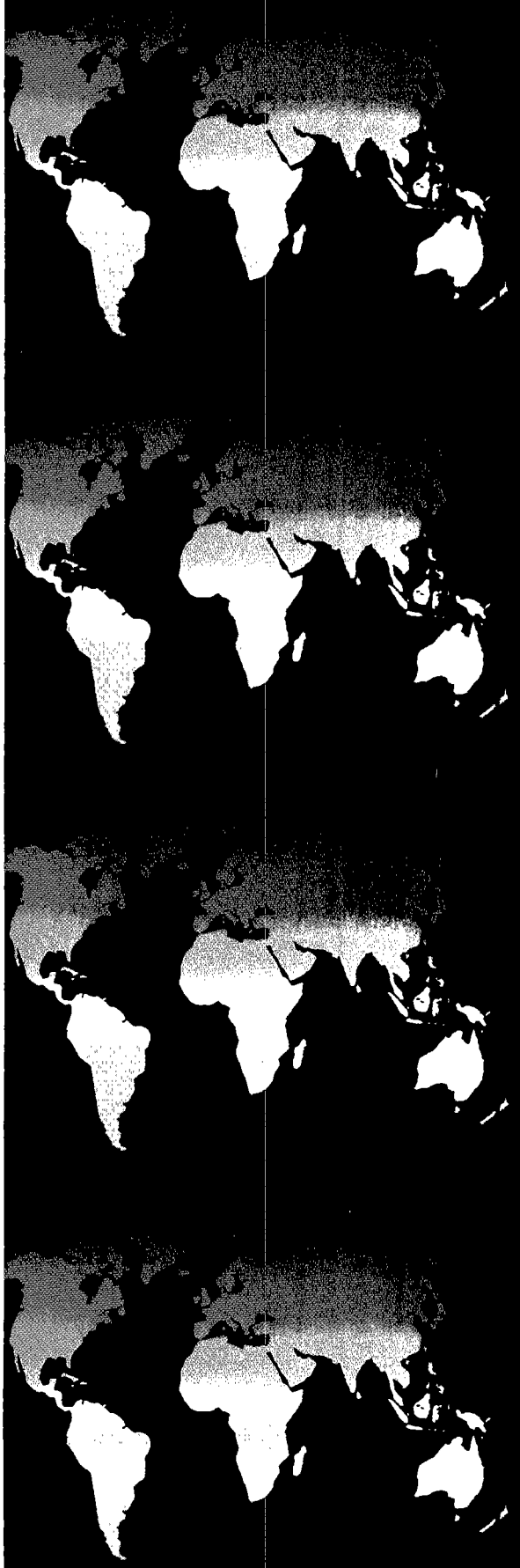

AGEING AND INTELLECTUAL DISABILITY

Improving Longevity and Promoting Healthy Ageing

Summative Report

Department of Mental Health
and Substance Dependence
World Health Organization

International Association
for the Scientific Study of
Intellectual Disabilities

WHO Global
Movement for
Active Ageing

Inclusion
International

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Healthy Ageing - Adults with Intellectual Disabilities

Summative Report

Department of Mental Health and
Substance Dependence
(attention: Dr S. Saxena)
World Health Organization
20 Avenue Appia
CH-1211 Geneva 27

IASSID AGING SIRG
Secretariat
c/o 31 Nottingham Way South
Clifton Park
New York 12065-1713
USA

or E-Mail: sirgaid@aol.com

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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