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Launching of the Global Movement for Active Ageing and the International Day of Older Persons

Statement by

Dr Gro Harlem Brundtland Director-General

Geneva, 2 October 1999



World Health Organization



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Vladimir Petrovsky, Mary Robinson, Guy-Olivier Segond, Excellencies, Dear guests and friends,

It is a great privilege and pleasure for me to be here today on the occasion of the International Day of Older Persons and the UN Open Day.

For the entire history of the United Nations, Geneva has been its host. This relationship is so old and close that one rarely thinks about the one without the other. Thousands of UN employees, past and present, have enjoyed the hospitality of the Swiss-Romands and the beauty of the city. Millions of others have fond memories from visits to this city while they attended meetings at the UN. It is a small but heartfelt gesture for us to open up our doors and show you how this large family of organizations works.

Almost exactly one year ago, I spoke in this Assembly Hall. Together with many of you in this audience and on this podium today, we launched the International Year of Older Persons 1999.

Much has been said during this past year about the ageing of the global population. So you know very well that rapid population ageing is triggered when people live longer and longer, and fewer and fewer children are being born.

Population ageing is occurring not just in the industrialized countries but also in virtually the whole of the developing world. Today, 60% of people over 60 live in developing countries and in 25 years that proportion will exceed 75%.

There have been many shrill voices warning of a "Grey Dawn", of the breakdown of welfare and health systems under the weight of this new wave of elder persons, too old to work and too ill to manage on their own. We are headed for a catastrophe, some of these prophets warn.

Such potential trends are of course of great concern to the World Health Organization. If our health systems are under threat of breaking down in the decades to follow, we all need to do something about it. And what have we done?

We have arranged a walk.

Since the sun rose over the Pacific Ocean more than twenty hours ago, millions of people - old and young alike - have walked together, in New Zealand, in the Philippines, in Tanzania and in almost every country in-between.

What we have seen here at the Palais des Nations this morning is our contribution to what is to my knowledge the biggest health promotion event by and for older people ever held. It has been called "the Global Embrace", and it is exactly what its name implies: a 24-hour walk and health promotion event, as well as a celebration, starting in the Pacific and continuing around the world through

Active Ageing makes the difference

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Global Movement for Active Ageing

In a society for all ages Active Ageing makes the difference

n 1999, during the International Year of Older Persons, WHO launched a new campaign highlighting the benefits of Active Ageing. This was in perfect harmony with the slogan for the International Year "Towards a Society or All Ages" as Active Ageing highlights the importance of social integration and health throughout the life course.

The campaign started on World Health Day 1999 when Dr Gro Harlem Brundtland, Director General of WHO, stated "there is much the individual can do to remain active and healthy in later life. The right life style, involvement in family and society and a



supportive environment for older age all preserve well being. Policies that reduce social inequalities and poverty are essential to complement individual efforts towards Active Ageing."

The Active Ageing campaign culminated in a "Global Embrace" on 2 October 1999 which consisted of a chain of celebrations and walks circling the globe during a 24-hour period.

The Global Embrace aimed to:

- inspire, inform, and promote health
- provide enjoyment to all generations
- draw attention to the public health benefits of Active Ageing.



The Global Embrace:

- linked local project leaders to a global community from all over the world
- mobilised volunteers and funding at the local level
- served as the launch of the Global Movement for Active Ageing, a new WHO initiative, to ensure that the momentum of 1999 will continue in the new century.

Achievements of the Global Embrace:

Well over one million people in 97 countries in both the developing and the developed world participated.

Organisers in developing countries responded with particular enthusiasm as little attention had previously been given to health promotion for older people. "The Global Embrace 1999 was an event Trivandrum will never forget."

Jothydev K., Trivandrum, India





New partnerships were forged: service providers and medical centres linked with clubs and associations of older people, multisectoral NGOs linked with local government.

In addition to walks and celebrations, the events offered: blood pressure screenings, eye examinations and practical advice on nutrition and physical activities.

Many older people with disabilities participated highlighting that Active Ageing applies to all, including those that experience functional limitations.

Broad-based coalitions of international NGOs participated (e.g. HelpAge International, Rotary International, International Sports for All Association, International Council of Nurses, International Osteoporosis Foundation, International Federation of Medical Students' Associations and others) disseminating news about the Global Embrace to their national affiliates.

The media played an important role in the Global Embrace

According to a survey evaluating the outcome of the Global Embrace, eighty-four percent of the events had media coverage in local and national radio, TV and newspapers.

The Internet was used extensively to reach a global public.

An interactive Website was opened for a 24-hour period which allowed participating cities to report "live" on their events.

"Older people are a human treasure and a precious capital for our countries and our cultures."

Ministry of Health, Chad

The Global Embrace 2000

You are invited to join the Global Embrace 2000, a walk event and a celebration for Active Ageing on Sunday, 1 October 2000.

By walking and celebrating with young and old, the Global Embrace 2000 affirms the importance of staying active and healthy. Health at older ages concerns everyone. Healthy older people are a resource to their communities and families.

We urge cities, organisations and individuals all around the world to join the Global Embrace 2000 and to encircle the globe on 1 October, the International Day of Older Persons. It is your contributions, ideas and cultural perspectives, that will make this event unique. The growing numbers of older persons in the world's population in the 21st century should be celebrated as an achievement for all of humanity.

Local partnerships for Active Ageing are key for planning and implementing a successful event. Now is the time to build networks based on local priorities in the area of ageing. Walking, dancing, gymnastics and other activities that promote health can all be part of your event. See our Website for starting your media campaign. It also contains other useful tools, including the Active Ageing logo which you may wish to use for your promotional materials. "We stretched, we walked and we talked. All are eager to repeat the event in 2000."

Barbara Forbes & Jacqueline Goffaux, Nashville, USA

"Let us take steps forward into the next century, towards a happy and healthy ageing society."

1999 Global Embrace participants, Nagano, Japan



The Global Movement for Active Ageing

Do you want to know more about Active Ageing? Are you interested in the latest research results or in what your colleagues — researchers, practitioners and community activists — are doing in various parts of the world? The Ageing and Health Programme of WHO maintains a database of organisations interested in promoting information on Active Ageing programmes. It is also collecting information about project outcomes, new research and innovative policies on Active Ageing. The data will be made available on the Website. Tell us about your projects and join our network.

Join us by registering through our Internet site or return the attached response coupon by mail.

Ageing and Health, World Health Organization 20, avenue Appia, 1211 Geneva 27, Switzerland Phone: +41 22 791 3486 Fax: +41 22 791 4839 E-mail: activeageing@who.ch http://www.who.int/ageing/global_movement "It was very stormy and rainy in the Netherlands but over 10,000 walkers participated in the Global Embrace 1999."

Dutch Committee International Year of Older Persons, Netherlands

"We inspired people of different ages."

Heini Parkkunen, Turku, Finland



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Healthy Ageing – Adults with Intellectual Disabilities

Biobehavioural Issues





International Association for the Scientific Study of Intellectual Disabilities



WHO Global Movement for Active Ageing



Department of Mental Health and Substance Dependence World Health Organization

Healthy Ageing - Adults with Intellectual Disabilities

Biobehavioural Issues

Authors

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This report has been prepared by the Aging Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) in collaboration with the Department of Mental Health and Substance Dependence and The Programme on Ageing and Health, World Health Organization, Geneva and all rights are reserved by the above mentioned organization. The document may, however, be freely reviewed, abstracted, reproduced or translated in part, but not for sale or use in conjunction with commercial purposes. It may also be reproduced in full by non-commercial entities for information or for educational purposes with prior permission from WHO/IASSID. The document is likely to be available in other languages also. For more information on this document, please visit the following websites: http://www.iassid.wisc.edu/SIRGAID-Publications.htm and http://www.wo.int/mental_health, or write to:

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1. Background

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. As in the general elderly population, in spite of gradual declines in a variety of domains, they can still have active and varied lifestyles with an excellent quality of life. Age associated, functional declines must be separated from specific losses due to physical illness, dementia, depression, sensory loss, and social and environmental factors The interaction between biological, psychological and social aspects of ageing remains the most important factor in the functional outcome of a person with intellectual disabilities

Very little empirical data exists about normal psychological functioning developmental processes throughout the life-span in people with intellectual disabilities. Seltzer (1993) presents the best model, linking behavioural. cognitive and affective outcomes to the negotiation of developmental tasks of ageing in the context of a variety of interacting individual, social and environmental antecedent conditions, such as intellectual ability, social competence, personality, physical condition, environment and learning history. Every person has his/her own individual set of antecedent conditions, and has different opportunities to successfully negotiate the developmental tasks of ageing.

Goal 1 To improve the understanding of normal psychological functioning throughout the life-span of people with intellectual disabilities

People with intellectual disabilities in general have restricted social roles and more limited

social networks, and thus fewer opportunities to experience and learn from some of the tasks commonly experienced by those without intellectual disabilities, particularly those who have spent considerable time in more restricted institutional environments. Mid to older life changes such as bereavement may thus have a greater impact, and with a greater likelihood of adverse functional outcome. The acceptance of mortality for example, which is an integral part of ageing in people without intellectual disability, is often hindered by a lack of exposure to rituals such as funerals in an attempt to shield the person from unpleasant events.

Furthermore, the magnitude of individual adverse reactions to stressors may be accelerated because of cognitive impairment (pre-existing and/or degenerative, as in the dementias), poor self-esteem and poor perception of self-competence due to repeated adverse life experiences over the life-span, and poor social support.

Goal 2 To improve knowledge and awareness of age-related stressors and their impact on older people with intellectual disabilities

2. Mental and behavioural disorders

For the purpose of this paper we have defined mental disorders as disorders that can be classified into diagnostic systems such as the ICD10. Biological, psychological and social factors disorders may all contribute to their expression. Behavioural disorders on the other hand 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, biological vulnerability, longstanding learned behaviors,

WHO/MSD/HPS/MDP/00.4 Page 2

or a mismatch between environmental expectations and resources with the individual's capabilities and wishes: for example, a behavioural problem such as wandering in a demented person may be maladaptive if the individual lives in an open facility close to a busy highway, but contribute to the maintenance of physical abilities in a well-designed dementia unit due to regular exercise.

Major mental disorders, although less common than behavioural disorders, are still fairly frequent in elderly people with intellectual disabilities. Day and Jancar (1994) reviewed this topic and found an overall prevalence of about 10%. Some disorders such as dementia increase with age. which is particularly noticeable in those with Down Syndrome (DS). As in the general elderly population, psychotic disorders also increase with age, but are less frequent than mood and anxiety disorders. Interestingly, due to "differential mortality" or the tendency for healthier people to live longer, older cohorts may actually be healthier in many domains than younger cohorts (Janicki, Dalton, Davidson & Henderson, 1999), and show greater functional abilities than the young until the oldest ages.

Most studies find that, compared to the general population, behavioural disorders are more common in people with intellectual disabilities at all stages of the life span. There seems to be an association with age mostly in those individuals that have dementing disorders (Moss & Patel, 1995).

3. Etiology

Social, cultural, environmental and developmental factors and stressors have significant impact on the expression of both psychiatric and behavioural disorders in older people with intellectual disabilities (Day & Jancar, 1994). Stressors may be multiple, and include separation from or death of a parent, loneliness and sudden relocation. Unfortunately, little is known about quantifying these influences on age-related changes in persons with intellectual disabilities. However, the general consensus of clinicians in the field is that all perceived symptoms need to be evaluated in a broad context, and not necessarily attributed to one individualized factor but explored as part of a complex interaction of the individual with the environment.

To understand and appreciate Goal 3 the social. cultural environmental and developmental context of behaviors and their functions people in older with intellectual disabilities

Biological contributions to mental and behavioural disorders are also important, and often increase with age. Examples include sensory loss and dementia in DS, feeding abnormalities in those with cerebral palsy due to reflux, and a variety of other behavioural changes related to chronic medical illnesses (Lantman de Valk et al., 1998; Davidson et al., 1995). Of course, genetic risk factors for the major mental illnesses such as schizophrenia or bipolar disorders continue to be present in old age as in the general population, and specific behavioural clusters associated with developmental syndromes may persist from younger years into old age.

4. Detection and assessment of mental disorders

Major mental disorders in older people with intellectual disabilities may have considerable negative impact on cognitive, affective and general functioning as well as on the quality of life of the person. It is important therefore to detect and optimally treat these, especially treatable disorders such as depression. However, diagnosis is already more difficult in older people in general due to higher rates

of comorbidity, polypharmacy and a reduced tendency to voice psychological compared to physical complaints, and this is magnified in the intellectual disabilities group, particularly in the most disabled segment. The presence of seizure disorders and their treatments additionally complicates the assessment of mental functioning, although this may be more pronounced in younger age groups that tend to be more multiply disabled. Other challenges in the intellectual disabilities group include communication barriers, baseline behavioural abnormalities (secondary to brain abnormalities, learned maladaptive behaviors. and environmental deprivation) overlapping with core mental illness symptomatology, and more florid stress related decompensation.

Health care providers that are not familiar with intellectual disabilities have difficulty making accurate mental health assessments. yet carers that are most able to report changes in the usual functioning generally do not have the necessary knowledge of mental disorders. Unfortunately, in most parts of the world there are few specialists with both intellectual disabilities and psychogeriatric expertise that would be able to bridge that gap. Cultural perspectives on normative behavior may further color how seemingly "deviant" behavior, which may be attributable to intellectual disabilities, may be perceived. Tests and assessment instruments are often not available in local languages.

In many cases the combination of the above individual, environmental and care system difficulties leads to a lack of differentiation between mental illness and intellectual disability, with both over and under diagnosis of mental illness, each of which can lead to adverse consequences. Although florid and disruptive behaviors are likely to come to the attention of mental health services, milder symptoms such as early depression and cognitive impairment may be missed, whereas there may be an overdiagnosis of disorders like schizophrenia due to the diagnosticians' unfamiliarity with the presentation of older people with intellectual disabilities and stress decompensation, for example.

Ideally, assessment of biobehavioural issues involves interviewing the person as well as their carers, and exploring the environment as a potential contributor to the symptoms. Interactions between the older person's cognitive, affective and general functional abilities with the environment and care system must be explored. Frequencies of symptoms possible correlation and to other environmental events can be analyzed by charting identified behaviors and symptoms. A thorough medical evaluation, including visual and auditory assessments should precede a final mental health diagnosis.

Screening instruments exist for various mental disorders in intellectual disabilities, but must he developmentally and culturally appropriate. General instruments include the Psychopathology Instrument for Mentally Retarded Adults (PIMRA; Matson), and the Reiss screen (Reiss, 1987). The Mini-PAS-ADD (Prosser et al., 1997) and the PASS-ADD Checklist (Moss et al., 1998) have been developed specifically to improve case recognition in this population. These instruments are not sufficiently specific or sensitive to make a diagnosis, but are useful to indicate the need to obtain further mental health assessment

Instruments designed for specific disorders, such as the Beck Depression Inventory (Beck, Ward, Mendelson, 1961) and the Zung Self-Rating Depression Scale (Zung, 1965) have been adapted and simplified for use in intellectual disabilities by Kazdin and associates (Kazdin, Matson, Senatore, 1983). These, as well as others such as the Hamilton Rating Scale for Depression (Hamilton, 1960) have been used successfully to assess depression in people with intellectual disabilities and mental disorders.

WHO/MSD/HPS/MDP/00.4 Page 4

The diagnosis of dementia in intellectual disabilities has been discussed at length, as people with DS are at very high risk of developing this. The instruments used in the general population are difficult to use due to floor effects, and furthermore, baseline abilities in intellectual disabilities are so varied that only repeated measures over time are likely to result in an accurate assessment of dementia. It is suggested that behavioural measures should be repeated at set intervals after age 40 in DS, and after age 50 in others with intellectual disabilities to detect functional changes, which can then be further evaluated clinically. The IASSID/AAMR practice guidelines give more detail on assessment and care management in dementia (Janicki et al. 1996).

Auxiliary diagnostic tools such as computerized tomography (PCT), positron emission tomography (PET), single photon emission computerized tomography (SPECT) and magnetic resonance imageing (MRI) may be helpful diagnostically, and might eventually become more routinely used, at least in developed nations.

- Goal 4 To improve the detection and holistic assessment of mental disorders such as depression, anxiety and dementia in older people with intellectual disabilities.
- Goal 5 To increase mental health knowledge and skills in professionals, carers and families of older people with intellectual disabilities.

5. Interventions

Interventions in general must incorporate the best information from two separate bodies of evidence: the mental health-intellectual disability (dual-diagnosis) literature, and the psychogeriatric literature. Data from the psychogeriatric literature is important as it considers physical and mental changes developing longitudinally with the ageing from Data the mental process. health-intellectual disability literature is important because it identifies issues specific to or more prevalent in people with intellectual disabilities, and focuses on interventions that have particular use in this area. Both fields are now starting to address the role of autonomy and choice-making by adults in the development and treatment of mental health symptoms.

Ideally, interventions for behavioural and mental disorders should first consider prevention: primary. i.e., strategies implemented to prevent all occurrence of the problem; secondary, i.e., early treatment of a problem to prevent its full expression; and tertiary, i.e., strategies to minimize functional impairment due to the problem once firmly established. (It should be remembered that the "problem" referred to is not necessarily only directly related to the older person with an intellectual disability, but is really the interaction of multiple variables as described earlier, culminating in the perception of their being a "problem" by some person, usually in the care system or the community.)

Primary prevention strategies for behavioural and mental disorders are not comprehensively understood, but some issues are known to be associated with a reduced prevalence. Decreased use of large congregate care such as institutions reduces the frequency of a variety of maladaptive behaviors, infectious diseases as well as polypharmacy, which is responsible for many other secondary adverse effects. Increased work on communication skills and identification of sensory deficits often reduces the development of maladaptive behaviors such as aggression, and increases adaptive behavior. Increased availability of

rewarding activities, and increased provision for autonomous choice making in various domains is also associated with positive behavioural outcomes, although systematic studies are difficult to perform. Humane, non-abusive living environments sensitive to the needs of their older residents with intellectual disabilities are likely also to foster reduced development of maladaptive behaviors. Finally, staff that are trained to understand and deal with the emotional needs and stresses of their residents will better provide an emotionally supportive environment that will minimize the occurrence of challenging behaviors or the perception of the person as "a problem."

Primary prevention of the major mental disorders such as schizophrenia is less likely, as there is a large biological and genetic component to most of these. However, the recurrence of individual episodes of illness can be minimized by reducing stressors if possible, providing sensitive support for those that do occur, and ensuring appropriate medication use.

Goal	6	To develop living environments that are responsive to the mental health needs of older people with intellectual disshifties
		health needs of older people with intellectual disabilities.

Secondary prevention of mental and behavioural disorders involves appropriate early detection, assessment and treatment of designated problem, by careful the involvement of biological, psychological and social interventions. It is crucial to involve the persons themselves, staff, family and community in the holistic treatment planning process, and provide sufficient training to allow carers to continue therapeutic any professional interventions after involvement has ended. Modifications may need to be made to the home and work environment and/or staff approaches to the

person. Needs that may be expressed in a maladaptive behavioural way must be met more productively, and alternate expressions taught. Supportive therapy, individual or group behavioural therapy, family therapy and social skills training might all be of help, as might be the involvement of spiritual elders or healers, depending on the cultural milieu. Unfortunately, there are too few clinicians, even in the developed world, who have the skills to undertake psychotherapy for individuals with intellectual disabilities. There are fewer still who are aware of the psychological issues related to functional decline, grief secondary to loss of family or friends, and other life changes that take place as people age.

Pharmacotherapy is most often used in the most severe, potentially harmful behavioural syndromes or in the more biologically driven mental disorders, and must be tailored to age vulnerability. Medication related pharmacokinetics, including drug volume of distribution. protein-binding. hepatic metabolism and renal clearance need to be considered in formulating psychotropic regimens. Treatment response time often lengthens with old age, and strange environments such as inpatient settings 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 psychotropic medications. Adverse effects such as sedation, increased confusion, constipation, postural instability, falls, incontinence, weight gain, sex steroid dysregulation and other endocrinologic or metabolic effects, impairments of epilepsy management, and movement disorders must be minimized.

WHO/MSD/HPS/MDP/00.4 Page 6

There must always be the awareness of risk and benefit calculations that require detailed knowledge of the specific adverse effects and drug interactions of each particular agent. The potential for acute and long term adverse effects should be determined and discussed with adults and carers at the time of initial prescription and during regularly scheduled psychotropic medication reviews.

Tertiary prevention, or the treatment of established disorders with the goal of minimizing further functional disabilities. becomes more important with the increasing age of the person. Although older people, as do young people, have the right to safe, effective treatment, at times the ageing process has brought about so many changes that a realistic goal becomes modified from cure to maximization of overall psychosocial outcomes. The maintenance of mobility, the preservation of meaningful social interaction. and the maximizing of cognitive and affective functioning becomes paramount. Possible hazards and unpleasant side effects of treatments must balance the reasonable likelihood of positive response, resulting in difficult end-of-life decision making for the person and significant caring others.

> 7 To promote mental health and minimize negative outcome of mental health problems in older people with intellectual disabilities

6. Service provision

Goal

Formal services that specifically provide mental health care to older people with intellectual disabilities are minimal to nonexistent throughout the world. Service provision needs to be adapted to best deal with the local cultural and health care environment, and this is very variable. In some areas basic life necessities, let alone mental health delivery to the general

population are not yet available, and the disabled population is often last to benefit when this does come about. The primary need may be basic supports in these areas. whereas in other more privileged areas sophisticated education about the assessment and treatment of behavioural and mental disorders to care providers may be a An overriding goal. reasonable goal. however, in the development of any of these diverse services is to include the acceptance principles. These include of basic maintenance of respect for the individual and their families, involvement of the person's own needs and wishes in any treatment plan. and finally development of treatment plans that are minimally restrictive, culturally sensitive, and that foster the growth and autonomy of the person. All treatment programs should be broadly based with biological, psychological and social components.

Goal 8 To increase mental health services and supports in their own communities for older people with intellectual disabilities.

Goal 9

To collaborate with older people with intellectual disabilities and their support system in developing culturally sensitive, humane, and least restrictive mental health interventions with an integrated bio-psycho-social orientation.

7. Quality of life issues

During the past decade there has been increasing concern regarding the outcomes of treatment and involvement in intellectual disability services in the assessment of the social value of services. A similar shift has also occurred in other sectors, such as child and adult social services, public health, youth corrective activities senior services and mental health. This type of reorientation in most sectors represents a substantial change in how the benefits of human services and other public or humane enterprises are gauged. The intended end result is tailoring of the services and supports to each individual in ways that encourage and promote the participation of that particular person with an intellectual disability in valued social roles. This is achieved by focusing the benchmarks for effective services upon outcomes with evident lifestyle impacts.

These desirable lifestyle impacts are usually embodied by the expression"quality of life," but are informed by philosophical implications of human and disability rights developments in many nations. From this standpoint, the value of professional services delivered in a high quality manner, the effects of those services, and the efforts of social groups, service groups, and advocates are ascertained with regard to impacts on lifestyle and related personal and social opportunity.

Valued outcomes that serve as a basis for demonstrating the social value of intellectual disability services, but which may vary in their particulars within different cultures, may include: (1) Increased practical, leisure, or life enhancing skills, such as those involved in making choices between alternative activities, and those which allow a person to access community opportunities (e.g., work or retirement activities), including enduring benefits; (2) Improved or maintained dietary and general health status that prevents nbysical health factors from becoming an untoward hindrance on typical activity; (3) A varied rhythm of life involving preferred activities and recognition that challenge and productivity must continue throughout old age; (4) Participation on a regular and full basis in the general life of their community and with friends and acquaintances of one's preference; and (5) An increased and well-established social network of acquaintances, friends and valued social amenities.

With increasing age, gerontological research has validated the expected belief that engagement and minimization of life stressors have preventive value and can lead to prolonged life and stable health status. Life factors that provide for sound nutrition, access to valued activities, safe and pleasant domicile, and intellectual challenge can minimize stress, organic or environmentally derived psychopathology and reactive behaviors. A quality old age among persons with intellectual disabilities will be based on the same factors that provides for a quality old age among other persons.

Goal 10 To improve the quality of life in older people with intellectual disabilities and mental health problems

8. Research

Most research in the area of mental or behavioural disorders or problems has had treatment as its focus. Much less has been done about the causes and risk factors of such disorders and their prevention. Almost all of the data available comes from populations of persons with intellectual disabilities from nations with established market economies, where research funding has been most available and there has been a critical mass of workers who specialized in this field. For instance, prevalence data for psychiatric and

WHO/MSD/HPS/MDP/00.4 Page 8

behavioural disorders may differ between nations with established market economics and developing nations and treatment outcomes may vary where the cultural ethos may inhibit referrals and special resources or services are limited. Improved health status and prevention in developing nations, the principal goal of WHO, must depend on identification of special issues pertaining to developing nations and application of techniques that permit information to be gathered free of cultural or other restraints.

Well-controlled research in mental and behavioural disorders as they occur in persons with intellectual disabilities is limited. Most of the work over the past 30 years addresses treatment issues; fewer focused on diagnosis or etiologic factors, or prevention. Only a small number address basic mechanisms. These disappointing data probably reflect several things, including a well-known lack of a research focus or funding. As a consequence, there are limited numbers of scientists in the field and a lack of programmatic efforts in research centers addressing any relevant issue related to intellectual disabilities. Without specific attention from health planners and ministerial level policy makers, as well as a critical mass of investigators working on a common problem in programmatic ways, little converging data can emerge and, quite likely, few if any major discoveries will appear quickly.

Promising lines of inquiry relate to both treatment strategies and biological determination and regulation of behavior. Rigorous methodologies are available to undertake controlled or randomized clinical trials for behavioural and pharmacologic interventions. Recent advances in molecular genetics and neuropharmacology provide new opportunities for linking severe behavioural psychiatric disorders and to brain neurochemistry. The field must move toward a research focus that includes a better balance of studies of basic mechanisms, translational and clinical outcome studies.

Goal 11 To develop a research agenda that will provide evidence concerning each goal for all nations.

9. Conclusions

Ageing issues in older persons with intellectual disabilities still remain to be appropriately identified, assessed and resolved. The complex interaction between biological, psychological and social aspects is arguably the most important area of need at the start of the next millennium. Psychiatric and behavioural disorder prevalent among adults with intellectual disabilities may be both transnational and culture bound. The prevalent literature is based in the nations with established market economies where the longevity of adults with intellectual disability is more pronounced and has become a normative phenomenon. To what extent this same longevity and prevalence of psychiatric and behavioural disorders is shared among nations, other than those with established market economies is unknown.

The analyses in this paper rely heavily on research results from nations with established market economies. For developing countries, sufficient medical systems or well-trained physicians may be limited. Also, health care systems in developing countries often do not sharply distinguish between people with mental illness and people with intellectual disabilities. Thus, data from nations with established market economies may not be easily translated to social policy in other countries. From a policy perspective, developing nations may have to choose between allocating limited resources to such practices as diagnosis and treatment of mental and behavioural disorders in persons with intellectual disabilities and improving the 2)

nutritional status of the general population, perhaps preventing some types of intellectual or developmental disabilities. Establishing reliable diagnostic practices that might permit effective treatment and tracking people with mental illness and people with intellectual disabilities may require resources beyond the indigenous capabilities of some developing nations.

Consistent with the Standard Rules of the United Nations, if recognition is to be given to the value of persons with intellectual disabilities and to the provision of resources to improve their general health status so that longevity becomes a norm, nations will also have to devote resources to aiding in treatment of mental and behavioural disorders that impede or distort normal ageing. However, first nations will need to internalize beliefs that value human life and the productivity of persons with intellectual disabilities. With valued status, resources will aid in promoting sound practices in ameliorating psycho-geriatric issues prevalent in the population. To this end, at minimum, there should be a core of professionals and clinicians with specialized training in intellectual disabilities and all mental health, psychiatric, or psycho-geriatric professionals or clinicians should also receive training in intellectual disabilities. Such training must stress the differentiation of intellectual disabilities from mental illnesses. Further, specialized resource centers need to be available to which clinicians, families and other carers can seek information and referral. Two main aspects to any new service focus on this subject are - information and the appropriate training of practitioners.

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WHO/MSD/HPS /MDP/00.4 Page 11

10. Future goals developed at the 10th International Roundtable on Ageing and Intellectual Disabilities

- To improve the understanding of normal psychological functioning throughout the life-span of people with intellectual disabilities.
- To improve knowledge and awareness of age-related stressors and their impact on older people with intellectual disabilities.
- To understand and appreciate the social, cultural environmental and developmental context of behaviors and their functions in older people with intellectual disabilities.
- To improve the detection and holistic assessment of mental disorders such as depression, anxiety and dementia in older people with intellectual disabilities.
- To increase mental health knowledge and skills in professionals, carers and families of older people with intellectual disabilities
- To develop living environments that are responsive to the mental health needs of older people with intellectual disabilities.
- To promote mental health and minimize negative outcome of mental health problems in older people with intellectual disabilities.
- To increase mental health services and supports in their own communities for older people with intellectual disabilities.
- To collaborate with older people with intellectual disabilities and their support system in developing culturally sensitive, humane, and minimally restrictive mental health interventions with an integrated biopsycho-social orientation.
- To improve the quality of life in older people with intellectual disabilities and mental health problems.
- To develop a research agenda that will provide evidence concerning each goal for all nations.

WHO/MSD/HPS/MDP/00.7 Page 22

6.3 Health personnel in developing regions

Health and social service personnel in developing regions require training and support in identifying the specific social support and healthcare needs of older people with intellectual disabilities. In particular, it is important to alert staff to the specific conditions that may affect older people with intellectual disabilities and ensure appropriate treatment. Further it is important to expose staff to sound community support models that enrich older age and sustain productive ageing. Bv highlighting people with intellectual disabilities, the pool of personnel who are knowledgeable and sympathetic both towards those with intellectual disabilities and their families may be increased.

Recommendation 20 [Education & Training (6)]

20a Public awareness of the nature and needs of older people with intellectual disabilities must be raised through channels appropriate to the particular society or culture.

20b Staff working with people with intellectual disabilities require training to respond to age-relate needs.

20c Where a policy of integration with generic elderly services is being undertake, part of the 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.

7.0 Research and Evaluation: Scant Information and the Need for Research

The UN International Plan of Action on Ageing gives high priority to research related to the developmental and humanitarian aspects of ageing. It urges research at the local, national, regional and global levels with a special emphasis on cross-cultural studies and interdisciplinary work. Among the research topics identified four are of particular relevance to health and social policy:

- the use of skills, expertise, knowledge and cultural potential of older people
- the postponement of negative functional consequences of ageing
- health and social services for the ageing as well as studies of coordinated programmes
- · training and education

The specific agendas for research with older people with intellectual disabilities in each of these four areas may be derived from the previous sections 4 to 6. In broad terms, research is called for into:

- Structural practices endemic to developing nations that can more successfully promote longevity and healthy ageing of persons with intellectual disabilities.
- Practices that promote successful and productive ageing of persons with intellectual disabilities.
- Morbidity and mortality studies of older people with intellectual disabilities.
- 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 additional specialist provision is required.
- Evaluation of programmes aimed at maintaining functional abilities and extending competence in later life.
- Factors which lead to increased inclusiveness or exclusion in society

Healthy Ageing - Adults with Intellectual Disabilities: Ageing & Social Policy

WHO/MSD/HPS/MDP/00.7 Page 23

with respect to both age-peers and intergenerational solidarity.

- 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.
- Cross-cultural studies that will ensure common aspects of good quality provision are identified as well as specific cultural influences of significance.

Cultural and economic factors that support family caregiving.

Recommendation 21 [Research and evaluation (7)]

21a A detailed programme of research that takes into account the differing scientific base and cultural contexts of developing and developed regions needs to be formulated.

21b The research and informational needs of developing countries should be defined and the technical and economic requirements worked out in order to ensure that workers in developed countries can assist in meeting these goals.

8.0 Future Action

The UN International Plan of Action on Ageing describes in some detail the rôle of international and regional co-operation with respect to implementation of the plan. This encompasses direct assistance - both technical and financial - co-operative research and the exchange of information and experience. A wide range of agencies and mechanisms for such co-operation are indicated. It is hoped that in raising the profile of older people with intellectual disabilities in this and the accompanying WHO documents, consideration of the ways in which health and social policies can be improved will benefit from the same support as that to be offered to their peers without intellectual disabilities.

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World Health Organization Ageing and Health Programme



The Role of Physical Activity in Healthy Ageing

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TABLE OF CONTENTS

1.	AGEING	1
2.	AGEING AND FUNCTIONAL HEALTH	1
3.	FUNCTIONAL HEALTH IN EVERYDAY LIFE 3.1 Coping with the everyday 3.2 Experiences of coping in everyday life 3.3 Social implications of maintaining functional ability	3 3 3 3
4.	PHYSICAL ACTIVITY AND ITS BENEFITS FOR AGEING PEOPLE	4
5.	RESEARCH EVIDENCE ON THE BENEFITS Introduction 5.1 Mobility 5.2 Cardiovascular disease 5.3 Osteoporosis 5.4 Falls 5.5 Glucose metabolism (diabetes)	4 5 6 6 7
6.	PHYSICAL ACTIVITY AND MENTAL HEALTH Introduction 6.1 Depressive symptoms 6.2 Anxiety	7 7 8 9
7.	WHAT KIND OF PHYSICAL ACTIVITY?	10
8.	WALKING	10
9.	HOW TO ENCOURAGE PHYSICAL ACTIVITY IN DAILY LIFE	11
10.	LIFE AS A PROJECT 10.1 What kind of exercise?	12 13
RE	FERENCES	14

The Role of Physical Activity in Healthy Ageing

1. AGEING

Ageing is an integral, natural part of life. The way in which we grow old and experience this process, our health and functional ability all depend not only on our genetic makeup, but also (and importantly) on what we have done during our lives; on what sort of things we have encountered in the course of our lifetime; on how and where we have lived our lives. Lifespan is defined as the maximum survival potential for a particular species. In human beings, the lifespan is thought to be about 110 to 115 years (Matteson 1997). Life expectancy, then, is defined as the average observed years of life from birth or any stated age.

Despite recent developments, the basic biological mechanisms involved in the ageing process remain largely unknown. What we do know is that:

- 1) ageing is common to all members of any given species;
- 2) ageing is progressive; and
- ageing involves deleterious mechanisms that affect our capacity to perform a number of functions.

Ageing is a highly complex and variable phenomenon. Not only do organisms of the same species age at different rates, but the rate of ageing varies within the single organism of any given species. The reasons for this are not fully known. Some theorists argue that individuals are born with a particular amount of vitality - the ability to sustain life - which continually diminishes with advancing age. Environmental factors also mediate the length of life and time of death (Dychtwald 1986).

With the process of ageing, most organs undergo a decline in functional capacity and in their ability to maintain homeostasis. Ageing is a slow but dynamic process which involves many internal and external influences, including genetic programming and physical and social environments (Matteson 1997). Ageing is a lifelong process. It is multidimensional and multidirectional in the sense that there is variability in the rate and direction of change (gains and losses) in different characteristics for each individual and between individuals. Each period of life is important. Thus it follows that ageing should be viewed from a life course perspective.

2. AGEING AND FUNCTIONAL HEALTH

With the continuing growth of elderly populations in modern societies, it has become a matter of increasing urgency to look for ways to maintain and improve the functional abilities of ageing people, to help them cope independently in the community and ultimately, to raise the quality of their lives. The incidence of many chronic illnesses and disabilities increases with age. In Jyväskylä, Finland, among those aged 75 and over, only about one-tenth has no clinically diagnosed disease (Laukkanen et al 1997). However, people adapt: almost half of these elderly people describe their own health as good. Usually people assess their health status by comparing it with that of their peers, so self-reported health assessment may be described as "age-adjusted". Disability-free life expectancy varies between countries and cultures. The health of older people should not and cannot be examined simply from the vantage-point of disease prevalence or the absence of illness. Even when they do have illnesses, large numbers of older people feel

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perfectly healthy because the illnesses do not have major adverse effects on their everyday lives.

Research on ageing has traditionally been concerned with health, but recently the concept of functional capacity has also been attracting growing attention. Although the significance of function in health and illness has long been appreciated, it was not until the 1950s that its importance was recognized as the numbers of older and disabled persons grew and the prevalence of chronic disease increased (Katz and Stround 1989). The importance of function was affirmed by the US Commission on Chronic Illness and the World Health Organization, which fostered the development of a scientific base for measuring functional status. Further theoretical research and instrument development examined key constructs of functional health: activities of daily living (ADL), instrumental activities of daily living (IADL) and psychological and social variables. The functional ability of elderly people is crucial to how well they cope with activities of daily living, which in turn affects their quality of life.

Functional status can be defined as a person's ability to perform the activities necessary to ensure well-being. It is often conceptualized as the integration of three domains of function: biological, psychological (cognitive and affective), and social. Thus, functional assessment is derived from a model which observes how the interrelationship of these domains contributes to overall behaviour and function. In older persons, adaptive responses to stressors in each of these domains assume increasing importance. Although developmental and ageing processes can cause wide variations, measures of physical health attempt to ascertain overall health and fitness levels. Commonly-used indicators of physical health include diagnoses and conditions present, symptoms, handicaps, categories of drugs taken, severity of illness, and quantification of medical services utilized - for example, number of hospital days per year, or days unable to perform usual activities per year (Kane and Kane 1981, Kane 1984). Self-ratings of health and disability may also be included in such measures. Scales of functional status address activities of daily living (bathing, dressing, feeding, transfers, continence and ambulation) and those instrumental activities of daily living (housekeeping, shopping, taking medicines, using transportation, using the telephone, cooking and managing money) which are usually necessary for independent living.

Functional competence has also been defined as the degree of ease with which individuals think, feel, act, or behave in congruence with their environment and the expenditure of energy. Functional health has also been associated with quality of self-maintenance, quality of role activity, intellectual status, emotional status, social activity and attitudes towards the world and self.

Health and functional ability are crucially important to the quality of people's social lives: level of functional ability determines the extent to which they can cope independently in the community, participate in events, visit other people, make use of the services and facilities provided by organizations and society, and generally enrich their own lives and those of the people closest to them.

Population groups within the same country often remain divided by significant disparities in morbidity, mortality and functional ability. The research evidence indicates that length of education is a major factor in determining health disparities between

population groups. Education, in its turn, is closely linked to income, life-styles, work, working conditions, housing conditions, and opportunities at large. A major determinant of people's life chances is their financial situation.

3. FUNCTIONAL HEALTH IN EVERYDAY LIFE

3.1 Coping with the everyday

Assessment of functional ability often includes an evaluation of the individual's ability to carry out various activities of daily living. The ADL scales that have been developed over the past few decades now have a more or less standardized content and format consisting of items relating to Physical Activities of Daily Living (ADL), and Instrumental Activities of Daily Living (IADL). The former address various self-care activities such as eating, dressing, personal hygiene, and moving about in and outside the house (Katz et al 1963, Kane and Kane 1981, Wiener et al 1990), while IADL functions are related to household management, running errands outside the home, use of public transport, cooking meals, etc. (Lawton and Brody 1969, Fillenbaum 1985, Laukkanen et al 1994).

The research evidence indicates that almost all home-dwelling people aged 75-80 can cope with ADL. Problems occur more frequently with IADL tasks. The "cultural" differences in coping with everyday activities are most clearly reflected in the differences between men and women's abilities to perform everyday chores (Laukkanen et al 1994). Rogers and Miller (1997) suggest that it may be possible to limit the number of ADL questions to a 3-item index. The basic activities would then be walking across a room, dressing and bathing.

3.2 Experiences of coping in everyday life

Coping in everyday life is an integral part of measuring functional health. One of the clearest indicators of lowered functional health is a sense of fatigue (Avlund 1995). Researchers have pointed out that it is important to take this feeling seriously and respond accordingly. People should talk to health care staff about fatigue, especially if it persists without an obvious explanation, as it may be a sign of illness or the onset of decline in functional health.

3.3 Social implications of maintaining functional ability

Every community of human individuals involves, by definition, different kinds of relationships which bind people together both within and across generations.

Autonomy is frequently cited as something that helps improve quality of life. The debate on autonomy has tended to emphasize independence, the ability to cope alone, of people having control over their lives (Heikkinen 1997). Although dependence is a possibility at any point in life - and it can be short-term or long-term, partial or overwhelming - everything converges on the maintenance and/or improvement of functional ability, on the individual being instrumental in improving his own quality of life. Independence is important for everyone but so, given human societal structures, is interdependence. In "ageing well", perhaps the best goal that can be set is to look after oneself and others. An important part of this is safeguarding functional ability and health (Heikkinen 1997).

4. PHYSICAL ACTIVITY AND ITS BENEFITS FOR AGEING PEOPLE

An international consensus statement regarding physical activity, fitness and health (Bouchard et al 1994) identifies six areas affected by physiological effort: body shape, bone strength, muscular strength, skeletal flexibility, motor fitness and metabolic fitness. Additional areas that benefit from physical activity are cognitive function, mental health and social adjustment. Exercise has been defined as a regular, patterned time activity pursued to achieve desirable fitness outcomes, such as an improved level of general health or physical performance (Bouchard and Shephard 1994). Fontane (1996) describes physical activity as a continuum of physical behaviour: 1) activities of daily living; 2) instrumental activities of daily living; 3) general activity and exercise; 4) fitness exercise and 5) exercise training. Those who start physical exercise early in life tend to continue it later. So what a person does with leisure seems to shape and develop leisure itself (Mobily 1987, Mobily et al 1991, Mobily et al 1993). In 1995, a WHO expert group underlined the positive health effects of physical exercise by saying that physical inactivity is an unnecessary waste of human resources. A passive, mainly sedentary lifestyle, the expert group pointed out, is known to be an important risk factor for poor health and reduced functional ability.

The lowered level of physical activity and the growing number of chronic illnesses that often follow with increasing age, frequently create a vicious circle: illnesses and related disabilities reduce the level of physical activity, which in turn has adverse effects on functional ability and exacerbates the disabilities caused by the illnesses. A greater degree of physical activity can help to prevent many of the negative effects ageing has on functional ability and health. Physical activity is also the best way to break the vicious circle and move on to a path of progressive improvement. This, ultimately, helps elderly people to and increases their independence.

The benefits to be gained from sensible physical exercise considerably outweigh the potentially adverse effects. These benefits include improved functional ability, health and quality of life, with a corresponding decrease in costs of health care, both for the individual and for society at large. Physical activity involves no immediate drawbacks, although excessively intensive exercise may cause injuries and/or illness and subsequent costs. This kind of cost-benefit analysis provides a useful basis for evaluating campaigns that encourage physical activity as a path to better health.

5. RESEARCH EVIDENCE ON THE BENEFITS

Introduction

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The research results indicate that as well as increasing muscle capacity, physical activity can help to improve stamina, balance, joint mobility, flexibility, agility, walking speed and overall physical coordination. Physical activity also has favourable effects on metabolism, the regulation of blood pressure, and the prevention of excessive weight gain. Furthermore, there is epidemiological evidence that regular vigorous exercise is related to a decreased risk of cardiovascular diseases, osteoporosis, diabetes and some forms of cancer.

5.1 Mobility

One of the most crucial factors determining functional capacity is mobility. As the musculoskeletal system deteriorates with increasing age, mobility problems increase. This is one of the most significant changes that adversely affects the ability of older people to cope independently in their communities and to have contacts with other people. Impaired mobility also greatly increases the need for different kinds of services.

The capacity of the human body to make use of muscle strength peaks between ages 20 and 30 and from there on steadily declines with age, most significantly between ages 50 and 60. In a recent study, some 30% of men and 50% of women aged 65-74 years did not have sufficient muscle strength to lift 50% of their weight (Ashton 1993). At age 70, males are usually capable of exerting about 80 % and women around 65 % of the maximum muscle strength of young people aged 20. These changes are the result of a reduction in the size and number of muscle cells. Leg muscle strength is particularly important in walking, negotiating stairs and maintaining general mobility. Stairclimbing is one way in which leg muscle strength can easily be improved. Any similar type of exercise will sooner or later have a positive effect on the quality of everyday life.

Buchner and de Lateur (1991) argue that there is a threshold relationship between muscle strength and certain functional abilities such as the ability to climb stairs. This means that normally, adults have much more strength than is needed to perform basic daily activities. Thus, if policy makers, when trying to assess reductions in mobility, depend upon people recognizing their own functional limitations, the amount of impaired mobility in the population as a whole (including older people) is likely systematically to be underestimated.

The first age-related changes that can affect mobility are anthropometric changes, Crosssectional studies have shown that stature and range of motion in the joints tend to decline with age (Schultz 1992). People between 65 and 74 years of age are approximately 3 per cent shorter than people between 18 and 24; this is thought to be due primarily to the shortening of intervertebral disc spaces and associated kyphosis. Cross-sectional studies of differences in joint range of motion have shown a general decrease with advancing age among healthy elderly people, although the amount of decline varies substantially with the group of individuals studied and the joint measures. In addition to age-related changes in anthropometrics, joint range of motion and strength, age-related decline in postural balance, gait and ability to transfer from one surface to another may underlie reduced physical mobility. Extensive studies of agerelated changes in postural balance show age-related decrements in the sensory-motor systems that underlie postural control, even in the absence of awareness of difficulty. Gait disturbances have been documented extensively among older people, including shorter step and stride length and decreased ankle extension and pelvic rotation. However, it is controversial whether these changes are due to a normal ageing process or whether they are pathological changes accompanying old age. Gait speed is related to aerobic capacity (Cunningham et al. 1982), muscle strength (Bassey et al. 1988), presence of other chronic diseases (Bendall et al. 1989), ability to rise from a chair (Friedman et al. 1988) and cognition (Visser 1983). Recently Tinetti and colleagues (1994) began research on confidence in mobility as a factor that may independently affect mobility.

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There are also some findings which indicate that difficulties in moving about indoors and outdoors, reduced walking speed and reduced muscle strength all were associated with an increased risk of death during the five-year follow-up period (Laukkanen et al 1995).

5.2 Cardiovascular disease

Cardiovascular disease is the leading cause of death in many countries. There are several risk-factors associated with atherosclerotic heart disease such as smoking, obesity and high blood pressure. There is strong epidemiological evidence that regular vigorous physical activity is related to a decreased risk of cardiovascular disease (Kannel and Sorlie 1979; Kottke, Puska, Salonen et al 1985; Barry 1986; Donahue, Abbot, Reed et al 1988; Berlin and Colditz 1990). The contribution of exercise to reducing morbidity and mortality is apparent in many ways:. positive changes can be seen, for instance, in cardiovascular efficiency, blood lipids, blood pressure and thrombotic tendency.

5.3 Osteoporosis

Loss of bone mineral density, and the directly-related increased risk of bone fracture (Cheng et al 1997), has considerable socioeconomic implications in western societies. Age-related osteoporosis begins at around age 40 and continues for the rest of the individual's life-span. Because of their more dramatic hormonal changes, osteoporosis is more common in women than in men. Exercise has a role in treating osteoporosis. The general trend of most published study findings is so consistent that the use of weightbearing exercise is considered a standard treatment for osteoporosis (Krolner et al 1983; Chow et al 1987). The role of exercise in prevention of osteoporosis is less clear, however (Elward and Larson 1992). Findings from existing studies are compromised by the lack of control for diet, weight and behavioural changes. There are also limitations in measurement techniques (Elward and Larson 1992). It seems likely that exercise does not strengthen all types and locations of bone but rather affects those areas actually used during the exercise.

5.4 Falls

Exercise can also help to reduce the frequency of falls, which are a major cause of broken bones and which predict difficulties not only in activities of daily living but also in the whole life (Rivara et al 1997). Falls more frequently have more serious consequences for elderly people than for those who are younger. It is estimated that every person aged over 65 suffers at least one fall each year, while the number of falls among those of 85 years and over is about eight times greater than in the age group 65-69. About one-third of those who fall suffer fractures as a consequence. Cheng et al (1994) showed that falls are common among elderly people, but it can be assumed that only those persons who have low BMD values frequently develops fractures. A fall was the main reason for fractures in the age-group studied (75 and 80 year-old men and women). Evidence is increasing that factors other than osteoporosis are important in the pathogenesis of common fractures. Ninety per cent of hip fractures in elderly people seem to be the result of falls (Grisso, Kelsey, Strom et al 1991).

Dargent-Molina et al (1996) maintain that factors such as muscle strength, neuro-

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muscular coordination, postural stability, steadiness of gait and the structural properties of bone all influence fall frequency. Referring also to Tinetti et al (1988) and Nevitt et al (1989), they stated that performance-related measurements of physical capacity (particularly measurements of balance and gait impairments) are strong predictors of risk of falling among elderly individuals. The findings further suggested that neuromuscular impairment may play two distinct roles in the occurrence of hip fractures: it may not only increase the risk of falling but also influence an individual's speed, coordination and protective responses during a fall. Another important finding was that visual impairment is an independent risk for hip fracture. These findings suggest that intervention programmes to prevent hip fractures should target both fall-related factors and the maintenance of bone mass (Dargent-Molina et al 1996).

In everyday life, the combination of reaction speed, coordination and strength is the key factor in carrying out tasks. Rivara et al (1997) mention that the most important risk factors for falls and fall-related injuries among older people are a history of one or more prior falls, cognitive impairment, a low body-mass index, female sex, general frailty, use of diuretics, use of psychotropic drugs and hazards in the home. In their review article related to physical exercise, they mention weight-bearing exercise, physical exercise combined with balance training and multimodal programmes (Province et al 1995; Tinetti et al 1994) as being effective preventive measures.

Limitations in joint range of motion often mean that ageing individuals have to give up a number of activities.

5.5 Glucose metabolism (diabetes)

Type II (maturity-onset) diabetes usually occurs after the age of 40 and is strongly associated with obesity (Ashton 1993). Glucose tolerance deteriorates with increasing age. Regular moderate exercise appears to reduce the risk of developing Type II diabetes in both normal and obese middle-aged people (Ashton 1993). Later-stage diabetes is associated with many disorders (such as blindness and neuropathy which can lead to the amputation of extremities), each of which has its own substantial impact on function and quality of life. It is known that exercise improves the physiological control of glucose metabolism and evidence does exist which suggests that regular aerobic exercise of at least 30 minutes' duration three or more times a week offers potential benefits to those elderly people with glucose intolerance or overt diabetes (Harris 1984; Tonino 1989).

6. PHYSICAL ACTIVITY AND MENTAL HEALTH

Introduction

The connections between physical activity and mental health have been studied quite extensively in young and middle-aged people, but not in older people. Physical activity is most typically described in terms of a specific type of physical exercise. Most work in this field to date has taken the form of intervention studies aimed at preventing or resolving mental health problems by means of exercise programmes. At the population level there has been very little research on the possible effects on mental health of lifelong regular exercise. The focus of earlier research was on the indirect effects of physical exercise. Most studies found a positive correlation between exercise and mental health, albeit an ambiguous one: it is not known which influences the other or in what direction the influence operates. Furthermore, the correlation is not normally particularly strong, nor does it not show up in all studies. The most common positive effects of physical exercise on mental health are reduced depression and anxiety, better tolerance of stress and improved self-esteem (Brannon & Feist 1992).

The research evidence on the connection between physical activity and mental health is not conclusive as far as the intensity of this connection is concerned. Some researchers maintain that the evidence points at a causal link between physical exercise and mental health (e.g. Brannon & Feist 1992), while others indicate that they have only been able to demonstrate that there is a correlation (e.g. Sime 1990). In most cases, the evidence does not warrant conclusions of a causal link: the effects have been short-term and have not necessarily shown any connection to physical exercise. According to Berger (1989), the mental health benefits of physical activity are equally wide-ranging among both older and younger people. From the gerontological research and studies carried out in the field of physical activity in the tinter distribution activity and exercise help to maintain and improve the functional ability, health and mental wellbeing of older people (Ruuskanen & Ruoppila 1995).

Ojanen (1994) proposed a number of hypotheses with regard to the connections between physical activity and mental health. Although his studies focused on young and working-age people, it is possible to extract from Ojanen's work research hypotheses that concern elderly people as well and take into account physical activity as a whole. Follow-up research is now needed at population level to establish exactly how physical activity and mental health are connected to each other. A simple intervention study within a selected sample is not enough to test the hypotheses and obtain relevant data at the population level.

A baseline assumption which can be made about the connections between physical activity and mental health in elderly populations is that physical activity as a whole and taking physical exercise are associated with mental health. Mental problems have adverse effects on the level of physical activity: on the other hand, moderate regular physical activity may reduce the emergence or existence of mental problems. The intensity and regularity of physical activity is connected with mental health. Health and functional ability, as well as socio-economic factors, influence the connections between physical activity and mental health (McAuley & Rudolph 1995; Clark 1996).

6.1 Depressive symptoms

A connection between physical exercise and depression has been reported both for young and middle-aged people (Brown 1990; Brannon & Feist 1992; Ojanen 1994; McAuley & Rudolph 1995) and for older people (Berger 1989; O'Connor et al. 1993; Ruuskanen & Ruoppila 1995). Despite their various shortcomings, these studies generally support the conclusion that physical activity and exercise reduce depression. Although people who exercise frequently suffer from depression less often than others, it has been impossible to establish the direction of the causal link. Regular aerobic exercise shows the clearest connection with reduced depression. According to Brown (1990) ())))

physical activity may be used to help prevent or alleviate mild or moderate depression. There also seems to be a link between a low level of physical activity and high depression scores, but no causal connection has been established. O'Connor et al. (1993) suggest that physical activity may reduce depression through a cognitive rather than a social mechanism, meaning that elderly people who can cope independently with physical activities by virtue of an exercise programme, for instance, will see their selfesteem and confidence increase, which in turn may also contribute to reducing depression.

6.2 Anxiety

Physical exercise has been successfully prescribed as a treatment for anxiety (Berger 1989; Brown 1990; Brannon & Feist 1992; Ojanen 1994). At the same time as it reduces anxiety and muscle tension, exercise helps to reduce and prevent stress. The best remedy for stress is regular physical activity (Brannon & Feist 1992), while for anxiety it is aerobic exercise (Ojanen 1994). Brannon and Feist (1992) suggest that aerobic exercise is most effective in the treatment of state anxiety but may also help with trait anxiety.

There are connections between physical activity and mental health in areas other than those discussed above, but they have not been researched in any depth. These areas include improved self-esteem and self-confidence, greater overall life-satisfaction and general well-being (Berger 1989; Brannon & Feist 1992; Morris 1992; Ruuskanen & Ruoppila 1995; US Department of Health and Human Services 1996). No clear connection has been established with psychotic disorders (Ojanen 1994). Tuson and Sinyor (1993) observe that change in mood is predicted by self-perceived meaning of physical exercise and other physical activity, as well as by the duration of exercise taken.

Positive expectations, commitment and the conviction that physical activity has beneficial effects, all strengthen the favourable impact exercising has on mental health (Oianen 1994). It seems that continuous, intensive physical exercise is the most effective (Kaplan et al. 1993; Ojanen 1994; Shephard 1994; Clark 1996). The longer the individual has exercised, the stronger the link between physical activity and mental health (McAuley & Rudolph 1995). In elderly people, moderately intense physical activity is usually sufficient to maintain physical and mental capacity, although Clark (1996) argues that three-quarters of elderly people in the United States do not take regular moderate exercise. Follow-up studies in Jyväskylä (Oinonen et al. 1997; Hirvensalo et al. (1998) found that one-third of the elderly population goes for walks several times a week. A high level of participation in other forms of exercise such as callisthenics, cross-country skiing and swimming was also reported. It seems that people who most need physical exercise are precisely those for whom participation is most difficult. The positive effects of physical exercise on mental health may be undermined by adverse environmental factors as well as by excessively intensive exercise (Berger 1989).

In the light of the latest research results, it seems that physical exercise and other forms of physical activity are the most significant means whereby individuals can influence their own health and functional ability, and accordingly maintain a high quality of life into old age.

7. WHAT KIND OF PHYSICAL ACTIVITY?

Any form of physical exercise is suitable for anyone at any age, provided that it is not excessive in terms of general or local stress loads. The structures and functions of the human body usually adapt to the loads imposed upon them, whether these increase or decrease. When exercise is discontinued and the stress loads disappear, the changes created in the body will also disappear. This applies to all the effects of physical exercise, although the rate at which they disappear varies considerably from a few hours to months. The results achieved can be maintained even if the duration is reduced, provided that the intensity of training remains at the same level.

Age is not, in itself, an obstacle to physical exercise. Indeed, exercise can contribute to positive changes and increase physical performance in older people just as it does in younger people. Improvements in muscular strength are particularly interesting. For example, training can help to improve considerally the strength of the lower limbs within a matter of months (Fiatarone 1990). The most crucial issue is the extent to which physical activity can be incorporated into ageing people's lifestyle.

It is known from earlier research that the most common form of physical activity for older people is walking: for example, around two-thirds of the elderly population in Jyväskylä, Finland regularly go for walks. Around one-third does callisthenic exercises at home. It seems that both these forms of exercise remain popular as people get older: it is only in the age group over 80 that the number of people engaging in these activities clearly begin to decline. Cross-country skiing, cycling and swimming are comparatively rare forms of physical exercise for older people, even in Nordic countries. Factors which influence the level of involvement include culture, age cohort, income level, and the availability of public services (Heikkinen et al 1990).

Many older people enjoy different forms of so-called utility exercise such as gardening and other outdoor jobs around the house. It is also quite common for older people to decide to walk to the shops or do their errands on foot, simply in order to get some exercise and fresh air. Men engage in heavy keep-fit exercise more often than women, but otherwise there are no major differences between men and women.

8. WALKING

Walking is the most natural, the most "everyday" form of movement human beings undertake. It starts very early in life and continues, for the most part, until the very end. It is an activity common to everyone except the seriously disabled or the very frail (Morris and Hardman 1997). No special skills and/or equipment are required. Walking is convenient and may be included in occupational and domestic routines. It is selfregulated in intensity, duration and frequency and, having a low ground impact, is inherently safe (Morris and Hardman 1997).

Walking is a year-round, readily repeatable, self-reinforcing, habit-forming activity and the main option for increasing physical activity in the sedentary population (Morris and Hardman 1997). For ageing and elderly people, walking is an ideal way to start exercising more. A low level of walking is the major factor in the current widespread waste of potential for health and well-being that is due to physical inactivity. The reason for walking is usually the need to get from place A to place B to do an errand, but it can also be to clear the brain. Walking is such a natural way of moving that it is not even perceived as a separate activity, unless problems occur (Morris and Hardman 1997).

A normal middle-aged person should not be aware of any major physical changes, but around the age of 50 it becomes desirable to set goals for maintaining the physical self: for instance, consciousness of posture, speed of movement, sprightliness, and weight.

As individuals begin to grow older and their levels of physical activity begin to decline, their bodies begin to regress. Pain, illness or an injury may also affect the permanence of physical skills. Ageing in itself changes the way people move: they begin to walk more slowly, posture may change, stride gets shorter. Walking is an all-encompassing activity which requires not only muscle strength but also balance, a skill learned very early in life. During a walk, as in other forms of aerobic exercise which use the body's large muscles (e.g. swimming or cycling), there are important changes in cardiovascular and respiratory functions. Controlled trials involving both men and women have shown that fast walking (i.e.at faster than normal pace) improves fitness.

Even though walking is the most common method of getting about, it also offers a variety of ways - such as walking with someone else or walking in demonstration for a common cause - to break loose from everyday routines.

Fitness gains from walking are particularly valuable for elderly people and proportionately can be as significant as those benefits enjoyed by younger age groups. Leg muscle strength (which has already been mentioned on several occasions in this paper) is particularly important in minimizing immobility, thus in turn contributing to the maintenance of independence in older people. Weakness makes it difficult to support bodyweight and stand up from a low chair or toilet seat, to climb stairs or mount a bus.

The importance of observing an older person's gait cannot be overemphasized. Direct observation of walking gives the health care professionals useful screening data about mental status, muscle strength, joint range of motion, motor planning skills, ability to concentrate, sitting and standing balance and potential to rehabilitation.

The scope of people's existence is directly related to how much and in what way they engage in physical activity (Heikkinen 1995). Not only does mobility favour contact with other people; it is the best guarantee of retaining independence and being able to cope.

9. HOW TO ENCOURAGE PHYSICAL ACTIVITY IN DAILY LIFE

Earlier in the history of humankind, mobility was an essential part of survival: hunting for food, avoiding dangers, self-defence - all involved and required movement. Today, most daily activities have been delegated to machines: the length of the stride required today is shorter than it used to be, the amount of strength required in hands and arms is less. A number of things which previously obliged people to go out - shopping or paying bills, for example - can today for who and the comfort of the home. There are fewer things in everyday life which necessitate physical activity. However, since it is

recognized that some activity is nonetheless necessary, some people try to meet this need through organized exercise. This sort of "artificial" activity does not appeal to all. Some people feel it is awkward and not worth the trouble; others feel they do not have the time to spare.

10. LIFE AS A PROJECT

Most people's lives are oriented towards the future (Merleau-Ponty 1962,Heikkinen 1995). In a normal life course, the future perspective is one of ageing. Ageing is often marked by concerns about independence, coping, health and functional ability. Sometimes such concerns lead to situations in which everyday life is increasingly structured within a medical framework. This in turn may become a source of anxiety.

Individuals are always bound to a certain extent by the conditions of their lives and environments. The degree to which they succeed depends largely on functional ability. The better their functional health, the greater their functional freedom within the confines of their life-situations. There is no doubt that physical activity is a crucial factor in maintaining functional health throughout the life span.

It is important to become conscious of the messages that the body sends. As mentioned in the discussion on walking, people do not normally pay attention to their bodies. With increasing age, however, more ailments and pains begin to make themselves felt, even if the individual is not actually ill. This is a sign that functional health has started to deteriorate. In this situation, everyday actions, and life in general, become increasingly difficult (Heikkinen 1995). However, by moving more than previously and by exercising, it is possible to induce positive changes. Such changes can help to reinforce people's belief in the value of continued physical activity for maintaining well-being.

Individuals need to register both negative and positive experiences, as this helps maintain a mental balance and eventually facilitates adaptation to the changes that inevitably occur with time.

The key to maintaining physical activity and functional ability lies within each individual, although immediate surroundings, significant others and family also play a crucial role in creating and maintaining a positive, active approach to life. People can resort to past experiences for inspiration, to push themselves forward both mentally and physically. It is not easy to develop effective strategies to promote exercise or physical activity in ageing people. Shephard (1986) has shown that the idea of "training" is difficult for elderly people to appreciate, and may even be intimidating. The benefits of exercise may be easier to accept if ageing people can perceive them, for instance, in terms of having more or better time with loved ones or not being dependent on others in later life.

The way in which people experience their bodies is also a cultural phenomenon, bound to a particular cultural context. In many cultures the training of the body is recognized as crucially important to mental pursuits as well. The Western tradition, which makes a distinction between the physical and the mental, complicates the natural relationship between these two planes of human existence.

10.1 What kind of exercise?

Physical activity and exercise should meet the individual's current needs. It is important that health care personnel explain why it is necessary, useful or beneficial to engage in physical exercise. Initially it may be very difficult to convince older people to adopt more mobile and active ways of life. They may need to be persuaded that age is no obstacle to physical activity and that the more they invest in maintaining their capacity to move, the more they will enjoy physical independence and interaction with others. Practical examples can be used to illustrate the daily possibilities for increasing physical activity - e.g. climbing the stairs instead of taking the lift - and highlighting the concrete benefits that this will have. Another good way to encourage exercise is to find forms of physical activity that have interested the individual earlier in life. In the presence of a specific problem such as an illness, it must be explained why certain types of physical activity are recommended, while others - which may be too demanding - should be avoided. Ageing well - to which physical activity can make a substantial contribution - is a challenge that brings its own rewards to those who are prepared to face it.

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WORLD HEALTH ORGANIZATION GENEVA 1997

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TABLE OF CONTENTS

- Migration and urbanisation: Table 1: The Total Elderly Population and percentage of World Population by Gender and Region.
- 2.2 The ageing population:
- 2.3 Natality and mortality:
- 2.4 Rural segregation: Table 2: Estimated and Projected Urban/Rural Distribution of African Population Aged 60 Years and over in 1980 and 2000 (in thousands).

- 5.1 Women:
- 5.2 Elderly refugees:
- 5.3 The AIDS Pandemic:
- 6.1 Research needs, information gaps and advocacy.
- 6.2 Africa's need for an intergenerational approach to social welfare.
- 6.3 Ageing makes a women's world: the gender approach
- 6.4 Developing an indigenous approach to ageing: training requirements.

APPENDICES

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1. INTRODUCTION: KEY CONCEPTUAL CONSIDERATIONS

Aging may be defined as the survival of a growing number of people who have completed the traditional adult role of making a living and child rearing. At this stage, there is a substantial change in an individual's capacity to contribute to the work and protection of the group. In biological terms, however, aging may refer to the increasing inability of a person's body to maintain itself and to perform its operations as it once did (Vatuk, 1980). There are many theories which attempt to explain the why and when of aging. The social psychological literature of aging depict two general view points with regards to optimum patterns of aging. Both views are based on the observation that as people grow older, their behavior changes, their activities become curtailed and the extent of their social interactions decrease (Cumming and Henry, 1961). The activity theory of Havinghurst (1968) and others whilst disagreeing with the 'disengagement theory' stress the inevitable changes in biology and health. In their view, the decreased social interaction that characterises old age results from the withdrawal of society from the aged person and that the decrease in interaction proceeds against the desires of most aging persons. Although they lack consensus as to which if any, theory of aging is best defined, certain factors are generally agreed upon to play a role in determining how long a person can expect to live and at what crucial period a person can be thought of as having aged. Factors such as activity level, social roles and social attitude are prominent. It is generally accepted that in old age, the loss and decline be it physiological, psychological, economic or social are greater than at any other stage in a person's life. Such losses, however, are not always due to biological factors but might also be due to social, economic and environmental and cultural factors (Derricourt and Miller, 1992). Aging therefore can best be understood when viewed as a continuous process of progressive change in all structures and functions of the body: the impact of such changes on a person's quality of life is largely dependent on the social and cultural milieu (Ageing International, 1995). Precisely, these set of issues were discussed at the African expert meeting on aging in Senegal (ICSG, 1985) and the African Gerontological Society (AGES) in Ghana in 1995.

'Aging involves not only losses but also gains' (ICSG, 1985)

In writing this report we keep in mind the definition which best describes those segments of the population beyond their middle years of life encompassing several stages of lifespan with a vast range of differences. However as cross national age data has become more available, researchers have had to use chronological age to provide an operational definition of old age (Pilai and Abane, 1995; International Federation of Ageing, 1985). Thus statistical definition of old age has come to be recognised as the official retirement age of a given country, which in Africa ranges from 55 -65 years of age. This defined category is incongruent with African life experience for in Africa only a small percentage of people are engaged in the formal sector with appropriate retirement provisions. Other than the Republic of South Africa and Namibia where there are operative whole sale old age retirement arrangements, there is nothing like "retirement" from work for the vast majority of aging Africans who work in the informal sector except at the age at which age or ill health makes it impossible to be active.

On the other hand many an old African sees aging as work related (Apt, 1996: Apt et al, 1995). Inability to work appears to be the cut off point to aging: 'I am old, I can no

-1-

longer work on my farm 'or I am now useless I can no longer work as I used to'. The message is repeated again and again in African surveys of older persons (Marzi, 1994). Many Africans societies generally recognise distinct age stages to which are ascribed roles and patterns of human activities. These are childhood, adolescence, adulthood and old age. To these age categories are ascribed specific roles and responsibilities, defining and limiting the nature of inter-connecting rules and with differential role expectations. The Akans (Ghana) for example, perceive aging from a biological perspective, beginning from adolescence through parenthood and advancing with grand-parenthood status (Apt van Ham, 1989; Apt, 1996). Thus in many African societies, the timing of social role transitions such as becoming a parent, grandparent and losing the ability to reproduce are used as a mark of old age (Tout, 1989; 1990).

Traditional African words used to describe an old man or an old woman are neither demeaning nor derogative. Literal translations of old age in many African languages define it synonymously with wisdom. Common expressions in West African languages like 'elder' 'he or she who knows' 'he or she who has vision' and simple addresses like 'grandpa' 'grandma' even to the non-kin older person, clearly reveal the respect and honour accorded to old age in traditional Africa. The Malians for example perceive the tree as a symbol of old age; a mighty tree with deep spreading roots which cling to the ground with its shadegiving branches of leaves spreading high to the sky. This same symbolism is reflected in Zimbabwe's Ndebede people's reference to the elderly as "shade of the children" (Cox and Mberia, 1977). Furthermore, the symbolism in the languages of Africa painstakingly codify the aging process and accords old people a place in the daily life of family and community. In the social life of a family, everybody recognizably contributes; no one is left out.

This document examines the aging experience in Africa. It provides a description of the demographic context in which the people of Africa experience aging. The document further examines the aging experience in the African modern environment, the effect of culture contact and the emerging patterns of attitudes and behaviors relative to the elderly. The report contrasts the modern experience of aging in Africa with the traditional experience within the framework of the African value systems which give credence to the place and role of the elderly in the social environment.

2. DEMOGRAPHIC CHANGE AND OTHER SPECIFIC DEMOGRAPHIC CONSIDERATIONS: THE AFRICAN SITUATION.

Demographic aging of the African population can better be appreciated if the factors most relevant to the aging process in the continent are placed on a global context first. Following Hauser and Duncan (1959:31) demography may be defined as the study of the size, territorial distribution and composition of population, changes therein and the components of such change which may be defined as natality, mortality, territorial movement and social mobility". With the exception perhaps of natality, demographic studies of the aged population have been conducted along all these dimensions. One of the most important findings of these investigations relates to the increasing size in both absolute and relative terms of the aged population in many if not all of the countries of the world. Data from the United Nations (United Nations, 1990) may be used to illustrate this point. In 1960 there were, across the world, approximately 158 million people who were 65 years and over and in 1980, the number was estimated at 258 million, an increase of 63 percent. The 151

16

population 65 years and over is estimated to have increased by approximately 140 million in the following 14 years, much of such increase took place in the poorer nations of the world.

2.1 Migration and urbanisation:

Migration and urbanisation have both separately and jointly been assessed as contributing to the destabilization of the traditional African values that in the past sustained elderly people in a closely knit age integrated society (Vatuk, 1996; AGES, 1995). Africa has a long history of migration within countries and across borders within the continent. Although sub-Saharan Africa even now is overwhelmingly rural, the rapidity with which populations mostly young people are moving from rural areas into towns and cities surpasses all else in the history of the developed world. Young people with some education move in large numbers from the rural areas to towns and cities in search of opportunities for earning a good income.

Region	Total Population 60 & over	Percentage	
Africa			
Total	18,825,313	6.1	
Male	10,149,311		
Female	8,676,002		
North America			
Total	8,446,002	8.9	
Male	4,486,336		
South America			
Total	20,738,538	8.0	
Male	3,960,606		
Female	11,076,726		
Asia			
Total	199,567,198	6.1	
Male	97,763,881		
Female	101,803,317		
Oceania			
Total	268,081	7.2	
Male	128,233		
Female	139,848		

Table 1: The Total Elderly Population and percentage of World Population by Gender and Region

Source: United Nations, 1990

Linked to migration is urbanisation. Between 1970 and 1982, African urban populations on the average grew by almost 6 percent a year, more than twice the overall rate of population (Goliber, 1985). In 1960, about 11 percent of the African population lived in urban areas and 22 years later the population had nearly doubled to about 21 percent. In this year, only seven cities in the African region had more than half a million residents but by 1980, the figure was up to 35 of which nine were in Nigeria alone. Along with rapid growth of towns and cities, the development of single dominant metropolitan areas is another characteristic feature of the regions urbanisation. Thus in 1980, in West Africa, 50 percent of Togo's urban population were concentrated in the capital, Lome, 57 percent of Kenya's urban population could be found in Nairobi and 50 percent of Zimbabwe's in Harare, the capital (Goliber, op cit). Migration creates emotional distance between family members particularly between the young and the old. While most migrants in Africa attempt to do the best of their ability to fulfil their filial duties to parents left behind, many older people suffer material hardships as well as physical and social deficits due to the absence of younger generation. Besides, the burden of agriculture is left to the very old. The problems facing older persons whose children have migrated are similar to those facing others in the community who are childless or whose children are unable or unwilling to provide support and care (Vatuk, 1996). Policy frameworks for supportive measures should encompass both these categories of older persons who bear the burden of infrastructural deficits (the need to carry water, fetch firewood, dispose of refuse, transport household provisions in the absence of affordable motorised transport) without the support of compensating social relations for undertaking these tasks (Grieco, Apt and Turner, 1996).

-4-

2.2 The aging population:

Although sub-Saharan Africa's elderly population is not as large in size as in other regions of the world, it must still be considered as a potential cause of concern since the largest increase in the number of elderly in the world between 1980 and 2000 will occur in Asia and Africa. The number of Africans 60 years and over will grow from 22.9 million in 1980 to 101.9 million in 2025. (See Appendix 2). This is an increase by a factor of 4.4 whereas,the elderly population in developed countries will increase by a factor of only 2.1 (Habte-Gabr et al, 1987).

The proportion of Africa's elderly population 65 years and over on average stands at about 3.0 per cent. It is the lowest of any world region. Nevertheless the proportion of the age group 65 years and older is expected to increase enormously by 2025. Thus during the last two decades of the twentieth century, sub-Saharan Africa's elderly population will increase by about 82 percent and between 2000 and 2020, it is expected to increase by 93 percent (Adamchak, 1989). The most rapid growth is expected in Western and Northern Africa whose elderly populations are projected to increase by a factor of nearly 5 between 1980 and 2025. In Western Africa, the Ivory Coast's older population is expected to increase by a factor of 5.4 and Cape Verde by a factor of 5.3 during this period. Of relative grow at a very fast rate. Consequently, between 1980-2025 the 75 years and over age group will increase by 434 percent in East Africa, 385 percent in Middle Africa, 427 percent in Northern Africa and S45 percent in Western Africa. Nigeria, in West Africa, 427 percent in Morthern Africa and S45 percent in Western Africa. Nigeria, in West Africa, years and over age group will increase by Africa and S45 percent in Western Africa. Nigeria, in West Africa, 421 percent in Northern Africa and S45 percent in Kestern Africa. Nigeria, in West Africa, 421 percent in Northern Africa and S45 percent in Cane S45 percent in S45 percent in Middle Africa, will be among the countries in Africa that will experience very large increases in this group.

Another unique feature of the Africa region is that almost half of its population is in the age range of 14 years and under (See Appendices 1 & 3). In some countries, such as

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Kenya, more than half of the population is in the age range of under 15 years. This is in contrast to the developed world where just under a quarter of the population are in that age category. The implication of this discussion is that for nearly all African countries the elderly population is statistically insignificant whereas it is youth which constitutes the bulk of dependency. The youthful character of the African population results in the demand for an exceptionally large share of development resources to meet the immediate needs of the young. Education for instance commands about 25 to 35 percent of recurrent government expenditures in many African countries and little part of such education expenditures are allocated to the educational needs of the old despite the clear existence of their lifetime education requirements in societies which are under dramatic change through the processes of modernisation and communication technology developments.

2.3 Natality and mortality:

The combination of natality and mortality profiles in Africa result in the elderly constituting a low percentage of the total population. Africa has the world's highest crude birthrate at 46.0 births per thousand which is double the average world crude birthrate. Almost all countries of Western Africa, have birth rates over 45 and total fertility rates over 6. In Eastern Africa, the estimated birth rate in 1984 for Kenya was 55 and the current estimated fertility rate for women in Kenya average 8.1 birth per woman over the course of her reproductive years. On the other hand, the crude deathrate in Africa is the world's highest and life expectancy at birth (around 49 years in 1990) consequently the lowest. These features explain why the proportion of the older age is low in Africa. As Africa's substantial declines in fertility and birthrate is expected to make an impact on the region's substantial declines only after the year 2000, the proportion of the young age group (0-14) will remain almost constant at about 44 percent between 1980 and 2000 and drop to 34 percent by 2025 while the working age group (15-59) accounting for an almost stable 50 percent of the total population in this period will jump to 59 percent by 2025 (United Nations 1985, 105-106).

2.4 Rural segregation:

A large proportion of the elderly people in Africa live and work in the rural areas. Table 2 provides comparative numbers of urban and rural elderly in Africa (1980 to 2000). By the year 2020, rural segregation will become a fact and the elder segment of the population will be concentrated primarily in rural areas. By then, approximately 64 percent of Africa's elderly will live in areas defined as rural (United Nations, 1982).

 Table 2:
 Estimated and Projected Urban/Rural Distribution of African Population Aged 60 Years and Over in 1980 and 2000 (in thousands)

And the second second second second	1980		2000		
	Males	Females	Males	Females	
Africa					
Urban	2,480	2,947	6,852	8,200	
Rural	8,014	9,495	12,795	14,881	

Source: United Nations, 1985

In summary, the aging process in Africa will get underway at the turn of the century, in the sense that the population as a whole will be getting older only after 2025. By the beginning of the century the ageing trend will become manifest in the increasing relative weight of the elderly segment of the population as a result of the decline in both crude birth and death rates anticipated in all African countries. By the year 2000, expectation of life at birth in African countries sill be reaching the age of 60 years and having reached that age, live longer than in former times, has a host of economic and social implications for policy planning, a fact that African governments cannot ignore (Apt and Grieco, 1994).

-6-

3. CRISIS AND ADJUSTMENT: AFRICA'S ECONOMIC CONTEXT AND ITS IMPLICATIONS FOR OLDER PERSONS

African countries are hard hit by economic crisis and face a number of daunting problems. Notable among these is the mounting debt burdens and the threat of economic stagnation and decline. The rapid population growth of 3.0 percent per annum and an economic growth rate of 2 percent per annum has resulted in inadequate financial resources for socio-economic development. Other aspects of the crisis lie outside the sphere of this macro-economic environment. War, civil strife, disease and widespread environmental degradation have had a devastating effect. In an effort to combat these problems, African countries have adopted economic reform policies that include structural adjustment programmes that entail cut backs in national expenditures in particular to the basic services that include health and education. The cumulative effect has been a rapid deterioration of education and health and other social services in Africa. Starting with the 1980s, there has been a reversal of the progress made in basic education and health maintenance in the 1960s and 1970s.

At the beginning of the 1980s Africa's external debt stood at less than \$50 billion. In 1991 Africa's debt burden was estimated at over 300 billion dollars. During this same period, investment fell from 25 percent to only 15 percent of Gross Domestic Product (GDP). Africa's debt burden is in itself the most serious constraint on realising the goals of Education and Health for All. Whilst the bulk of policy attention has been on simple debt forgiveness, there is a need for some part of such debt forgiveness to be converted into investment in social expenditure (Voices from African Women, 1996). These situations are cause for concern and deserve close attention by African nations, as they constrain efforts to meet the basic needs of people in the region, and most particularly vulnerable groups such as the elderly.

There are widespread unemployment and under-employment in Africa. In Eastern Africa, countries like Kenya and Burundi, for example, have about 30 percent rural workers under-employed. In 1993, the Economic Commission for Africa (ECA) estimated that 40 percent of sub-Saharan Africa's entire labour force - about 64 million workers - is affected by rural unemployment. In the urban areas there are large numbers of workers in poorly paid jobs for which a majority are over-qualified and a number of urban workers are forced to make their living through the streets of Africa's capital cities and large towns selling small items, carrying loads and shining shoes. All these factors affect cost and standard of living and are worth considering in Africa in view of young people having to care for themselves, their own children and their elderly relations. Supporting elderly relations in the urban environment is no easy task for populations who find their main source of livelihood in the poorly remunerated activities of Africa's informal sector.

Africa's economic circumstances require the older person to remain economically active until a greater age than his or her counterpart in the West. The working old of Africa are a routine and widespread feature of economic life. In urban West Africa, the reduction in an older women's physical strength does not signal the end of her economic activity: she simply moves her place of trading from the market to the doorstep of her family home (Grieco, Apt and Turner, 1996). Equally, in the rural areas, older women typically continue to farm until great age (Apt, 1996). The same economic circumstances which necessitate the continued economic activity of the older person in Africa also restrict the access of the majority of Africa's older persons to credit and other micro finance facilities. Little attention has been paid to, and no provision made for, appropriate micro-finance facilities for the older person which permit their continued economic activity on a more secure and remunerative base (Grieco and Apt, 1996).

4. TRADITION AND CHANGE: THE AFRICAN SOCIAL CULTURAL CONTEXT.

For a long time, the myth has prevailed that the extended family in Africa, with its structures and patterns of family solidarity and blood ties would render the problems of aging virtually insignificant. But Africa, like the rest of the world is growing old and the increase in numbers of aging people resident on the continent who will require care in order to achieve an acceptable quality of life is occurring at the same time as the traditional welfare system, the extended family has begun to disintegrate. The social forces of African societies have been affected by internal and external forces of change. New ideas have impinged upon African systems and ways of doing things and people moving from rural to urban areas in search of better life have had drastic consequences on the family structure and intergenerational supports. Urbanisation and the modernisation of economies have placed great strains on the extended family system and the signs are that this traditional welfare system, and in fertility rates have and sex differentials, in birth and death rates, in morbidity pattern, and in fertility rates have and will continue to have repercussions on the place and the role of the older person in African societies.

Until recently, the social arrangements of traditional Africa were, in the main viewed simply as a barrier to economic development: the imperative was for modern social behaviour and values as the necessary pathway to economic success. In this overly simple tale of what was required for the future of Africa, the positive economic functions of the African family system were forgotten. Nevertheless, the African extended family system operated as a social welfare system, a social welfare system which had been hidden from history by intellectual and colonial stereotyping which viewed the traditional in any form whatsoever as a barrier to economic and social progress. A consequence of this cultural

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16

blindness has been the failure to realise that the destruction of traditional relationships will result in the destruction of the operating welfare system.

- 8 -

The family has been the cornerstone of social welfare arrangements in Africa; contemporary policy making must recognise this legacy and seek to incorporate it in the development of the national social welfare programmes which are increasingly becoming necessary as Africa experiences a social welfare crisis.

With regard to the structure of the extended family and its role as a social welfare agency, the current orthodoxy is that family size should be drastically reduced within the developing countries. However, this understanding fails to appreciate that where the family is the major social welfare agency a reduction in family size necessarily reduces the number of social linkages to sources of material support. Put simply, the larger the family the greater the probability that one member of the family will find a source of income generating employment other things being equal. To advocate a reduction in family size where there is little chance of receiving social welfare support from any other agency is problematic. This relationship between family size and access to avenues of social support are clear: more members means more labour and more labour means greater flexibility in terms of meeting the need for personal care of both younger and older members of the family. Extended families are better at caring for the elderly and are necessary to the caring for the elderly in contexts where public social welfare arrangements are not available.

Whereas in rural areas the elderly live with their kin, in urban areas of Africa the elderly are beginning to live separately from their offspring (Apt, 1996). Separate accommodation for older and younger generations breaks with the traditional intergenerational arrangements of Africa in which the old not only received but also provided substantial services to the household. The autonomy or independence of the older person was embedded in the patterns of interdependence which existed between the old, the child bearing and young generations. In Africa, such interdependence takes many forms: ritual obligations, inheritance structures, economic linkages, personal and child care, all enter the pattern of exchange between the generations within the framework of the household, the kin system and community. In traditional Ghanaian society, the old were greatly valued for their role in symbolic life - the old were central to the performance of religious and social rituals. In many African communities, historically, the elderly had control over critical household assets which preserved their social and economic inclusion in the set of multi-generational exchanges of the extended household. The control over ancestral property, ancestral lands and socially sanctioned control over the labour and marriage of children (Apt, 1995), all enabled the elderly to protect their welfare. It was out of these patterns of interdependence that the centrality and autonomy of the older person was constructed. Modern developments, such as legislative reform of inheritance customs designed to produce social equity, weaken the ability of the elderly to make the same strategic use of inheritance options in ensuring that their daily welfare is taken care of (World Bank, 1994).

The monetising or modernising of African society can, if left to itself, produce a fundamental alteration in these relationships of interdependence between the generations. A reduction in the mutual interdependence of the generations of African society reduces the very resources which older Africans frequently need to shape their independence and autonomy. Perceptions of the traditional and sacred as inappropriate to monetised, modern

society cut at the very heart of the customary resources of the older person. Similarly longer life expectancies associated with the modernising of society produce an aging society - a society in which great age is no longer an infrequent event and therefore no longer a scarce resource. It is the scarce resource which achieves the status of the sacred or valued: in a society with increasing numbers of older persons, great age is less likely to be valued and, in as far as it is associated with diminished economic and social functions, it is increasingly likely to be viewed as both a societal and familial burden.

In this context, it is important that policy makers carefully consider how to preserve and extend the life of existing indigenous inter-generational patterns of social exchange. To summarise, traditionally the older person was seen as occupying a clear productive role within the household and community an important component of which was the ceremonial and symbolic function: currently, this particular role is subject to erosion.

5. PRIORITY AREAS FOR ACTION:

5.1 Women:

The single most important demographic fact about aging is that the aging society is a female society. Women in most parts of the world are the survivors of the century although only a hundred years ago many died in childbirth. Due to improved medical science and preventive medicine, life expectancy of women is now about 10 percent greater than that of men, a trend which is becoming visible even in the less developed regions of the world.

Longevity in itself is not necessarily desirable for women. The fact that a woman may live longer does not in any case indicate that a woman is healthier than a man or that the woman has a more qualitative existence. As a matter of fact extra years can disadvantage women. Older men by comparison are more frequently cared for by a wife. In African societies often by wives much younger. The phenomenon of female longevity definitely has implications for policy planning and social service delivery to the elderly. Besides, the imbalance in members between the sexes among the elderly population in the world has very serious social and psychological implications, namely, the presence in the population of a large number of single females who are in the main, widows.

The impoverishment of Africa means the deterioration of living conditions particularly of women who in major regions of the continent, bear the triple responsibility of raising a family, working to bring home income and upholding community structures. Generations of African women are assigned to the role of homemaker from a very young to a very old age. Mothers and their daughters have been entirely responsible for the care of the home and the preparation of food. In rural areas the latter entails carrying of water, growing and purchasing of food and the provision of fuel. Even in old age, women must continue to be economically productive until they are physically or mentally incapacitated and unable to continue their homemaker's tasks. Africa is the region where the largest number of old people are forced by economic and family circumstances to work well beyond the age of sixty five (Brown, 1984; Okraku, 1985). ILO studies of labour force participation of older persons across the world (1993) shows that in at least 20 African countries, between 74 and 91 percent of persons 65 and over continue to work. Many of these older workers are women. The problems of survival that they face leave them little opportunity to develop energies of their own for qualitative living. In the African region, the poor health status of elderly women begins in childhood, continues throughout her life and is culturally inspired. Inequality among male and female children is widespread in Africa. Occupational socialisation begins very early for girls: Girls must work with mothers and boys can play but boys need their energy so they must eat more and so on and so forth - with girls frequently leaving school to work in order to pay for the education of their brothers. Some girls must go through the agony of circumcision with all that it entails in terms of health, for the sexual benefits of their future partners. Many girls enter the reproductive age without the physical and social maturity needed for the task of child bearing and parenthood.

Some girls are forced into marriages with partners three to four times their age and reluctantly become parents. Others in fact are married off even before they are born. Besides, the girl child who survives the drudgery and the pain of infancy must still face the challenge posed by long term implications of the risk factors a woman faces especially in a developing region like Africa. Existing and emerging factors such as maternal anaemia and malnutrition, drug abuse, sexually transmitted diseases most especially now, HIV infection and AIDS and of course repeated pregnancies which threaten women's health are all widespread in Africa. There are many health concerns which are specific to women and which are age specific. For example, vaginal infections, infertility, cancers of the reproductive organs and fibroids, to name a few have a direct effect on women's morbidity and mortality levels and have increasingly cumulative effects on elderly African women's already weakened health through excessive child childbearing. The environment where men are preferenced over women in the allocation of resources and where women carry a greater burden of tasks than men has its consequence for the health status of older women. Throughout their life time they have poor access to resources with the cumulative effect that in their old age they have insufficient resources for a decent quality of life: their task overload throughout their life also takes its toll on their health.

Many elderly African women need to work physically harder to survive after their childbearing and childrearing years and after they become widowed and/or divorced. While older men in Africa can expect to receive care and attention from wives, the female cannot hope for similar attention from a husband since she is most likely to outlive them or end up divorced. Yet elderly women in Africa have more health problems (Pappoe et al ,1990), and much of it is stress related (Apt, 1994). The health of older women can be directly affected by her circumstances as indeed they do in Africa: the pressures of bereavement and hostile cultural practices which affect older women's self-esteem and self image. The health problems of the older African woman is linked especially to economic insecurity and social rejection often as a witch after many years of hard work to cushion her family. An area of concern therefore is marriage norms and unfavourable cultural practices against women.

Effective solutions tailored to their situations, interests and needs should be designed in collaboration with them. Elderly women in the region contribute to their own welfare as well to that of their households well into their 70s or longer (Khasiani, 1991). As Africa's development implementers consider the best and the most efficient options of providing care for the current and future generations of older women, it is important to note that assistance should be provided in ways which show sensitivity to the different capacities and needs of older women. Recognition that women in Africa are both receivers and providers of care will lead to more meaningful programmes.

Over the last two decades attempts have been made by many African governments to raise the quality of life for women. While no doubt some progress has been made in certain key areas in many countries (most specifically in Ghana and Uganda), structural relationships of inequality between men and women (manifested in labour markets and in political structures as well as in households) woefully lag behind. There is the need for African governments to rethink 'development' in a broader framework which enables women to be fully integrated in economic, political and social decision-making processes, to enable a healthy survival of women. Here we infer that participation in economic, political, cultural and community life is closely related to maintenance of the health and self-esteem of older women. While physical disabilities are often cited as the primary reason for decreased quality of life in old age, it is increasingly apparent that many factors, such as mental health, retirement policies, social expectations and family structure, have a great impact on whether older individuals are able to maintain a productive and meaningful place in society. The improvement of the quality of life for older women therefore can only be achieved through the understanding of the relationships among biology of aging, age related conditions and social characteristics.

Presently in Africa, many women in old age are already afflicted with chronic conditions or will develop them in the near future. But many women continue to function in spite of chronic conditions in supportive roles themselves.

83 year old widowed Akan (Ghana):

.... I also look after my daughters' children when I am healthy. (Apt et al, 1995).

Older women provide very important services such as health experience, social knowledge and child care. Many act as economic anchors holding the fort while young parents work or even adding through unpaid work to the household budgets of the young as illustrated by the voices of the following Ghanaian women traders (Apt et al, 1995).

* 67 year old married Ewe trader:

.... I help my daughters by doing the cooking while they are away from home and take care of their children.

* 62 year old divorced Nzema trader:

..... I also take care of her (daughter) children for her and do some of the cooking.

To summarise, the relationship between gender and aging is of particular significance in Africa and social policy development whether by donors or governments must explicitly concern themselves with this issue.

5.2 Elderly refugees:

Africa has experienced an unprecedented proliferation of tensions arising from new ideologies of African governments, greed and political mismanagement, social and ethnic discrimination and terror tactics of dictators (Blavo, 1995). These and economic hardships have caused millions of Africans to flee their countries and presently African refugees top the list in the world. Elderly persons have special difficulties coping with the hazardous and stressful journeys and are overwhelmed with the process of adjustment to new life. Many who choose to remain behind suffer much hardship as there is hardly anyone left young enough to cultivate food and provide care and protection. To be a refugee is distressing enough but to be an elderly refugee is double agony, the most tragic fate imaginable (Blavo, ibid). Their problems are principally social and emotional, rather than material although the latter may also be present (Vatuk, 1996). Their plight needs special attention. Of particular importance is the need to target older persons in refugee circumstances for help in adjustment to the new situation, reconcile them to their losses and enable them to revitalise their traditional knowledge and cultural resources to help build family and community and retain continuity in the past (Blavo, ibid; Vatuk, ibid).

5.3 The AIDS Pandemic:

AIDS deserve special attention because failure to control the epidemic will result in very costly consequences in the future for society and especially the elderly. Currently, WHO estimates that about 14 million people are infected with the virus worldwide and more than 8 million of these infested cases are estimated to be in sub- Saharan Africa. Of the 700,000 AIDS cases that have been officially reported worldwide, 250,000 have come from the Africa region. It is estimated that one in forty adults in sub-Saharan Africa is already infected and in certain cities of Africa, the prevalence of infection is as high as one in three (Antwi, 1995). AIDS, because it affects mainly people in economically productive adult years has enormous implications for the elderly family member. Many elderly people will lose their economic support with the death of their adult children and as well many grandparents will be left burdened with the care and maintenance of young children. A classical example is to be found at Kakuutu country in Uganda, close to the Northern Tanzania border post at Mutukula where estimates indicate a gloomy situation with almost half the adult population being said to have died of AIDS related causes. District statistics for 1994 put the total number of orphaned children at 60,000 but aid workers put current estimates to be close to 100,000 as the epidermic continues to take its toll (Ojulu, 1996). Many of these orphans prefer to stay with their families who no doubt will be older than their parents. AIDS has further implications with regard to health of the elderly themselves due to added stresses as heads of households and ill health of infected adult children, the cost of health care which will also have to be borne by the elderly. In Tanzania, clinicians estimate that on the average, an HIV infected adult suffers 17.5 episodes of HIV related illness prior to death.

6. SUGGESTED POLICY ACTIONS.

The list of policy actions that need to be taken in respect of aging and Africa is a lengthy one, with many local specificities requiring to be addressed nation by nation and region by region: here our intention is to provide a broad indication of the first and foremost steps to be taken to address aging and Africa in a progressive and appropriate way.

6.1 Research needs, information gaps and advocacy.

There are many gaps in the existing information on aging and Africa. As Mamo (1996) notes:

"Perhaps the greatest obstacle facing developing countries with respect to planning for ageing is the general lack of a 'culture for research' which is applicable to other areas of planning and policy making. Not only are funds generally lacking, but whenever resources are made available, there is a general tendency across many countries...to consider research as superfluous and wasteful," He suggests that a more holistic approach to understanding the demands of an aging society is necessary:

"Several areas of research deserve to attain higher priority in order that a more general view of aging can be sought. Such themes as attitudes to aging (which tend to evolve continuously); family structures, individual roles and expectations; life quality of older persons; and subjective well being tend to be neglected areas. These themes and others relating to a more holistic approach, as opposed to the more subject-limited traditional topics for research, address the inter-relationship between economy, community and family networks and assess more broadly the contributions of the various partners of care. Qualitative as well as quantitative approaches need to be adopted and incorporated together." (Mamo, 1996)

The resource constraints experienced in Africa make it imperative that networks of policy makers and researchers be formed to develop continental policies on aging. Networks are key to reducing research costs and to ensuring the efficient and inexpensive transmission of new policy approaches and developments.

6.2 Africa's need for an intergenerational approach to social welfare.

The traditional form of African society was strongly intergenerational in its functioning. The resource base of Africa precludes the possibility of government operating as the primary or even a substantial funding agency for the social welfare of the elderly in the near future. Correspondingly, responsibility for the welfare of the older African person will either be located with kin or with older persons themselves or some mix of the two. It is therefore appropriate that policy makers and professionals undertake the development of inter-generational social policies which integrate and not isolate the old. Tax breaks for those taking care of their older relatives, housing designs which permit multi-generational living, social facilities which can be used as meeting places or clubs by the older person: each of these simple measures could play its part in sustaining the environment condusive to intergenerational solidarity.

In giving specific consideration to Africa, it must be recognised that older persons will continue for the foreseeable future to be economically active until a late age and that this requires an appropriate micro-financial structure. Already in Africa alternative models exist for providing for older persons welfare by extending to them access to the financial services which enhance profitability of economic activities: in Shama in Ghana, older women have got together to obtain finance from an outside agency to recapitalise their trading activities and those of others in their community. They were not looking for grants but an opportunity to gain the capital to strengthen their own and their community's economic activity. They have been successful and generated an African model which can usefully be adopted elsewhere. Supporting the elderly in economic activity permits the older persons to continue in the inter-generational social exchange which is customary in Africa.

Most importantly the formal education system should incorporate the older person in the training of the young. Older persons could participate in the education of the young by imparting traditional skills within the schoolroom. This would be consistent with tradition and would contribute towards the continued social and self esteem of the elderly, self esteem which has very real health benefits.

6.3 Aging makes a women's world: the gender approach.

There is a growing recognition of the gender dimension of aging amongst policy makers but the drawing up and implementing of policies which resolve the problems has been much slower. There are many options which could be considered; three key ones are:

a) Given the smaller life time access to financial resources experienced by women, programmes for the recapitalising of older women so as to enable them to continue in economic activities such as trading should be considered. Micro finance programmes rarely consider the specific needs of the older woman within their framework: this should be corrected.

b) There is a need for specific attention to be paid to the particular health needs of older women. For example, reproductive health campaigns normally exclude older women but should not: health education should be provided on a life long basis.

c) Knowing that it is women who are likely to end up unresourced and unpartnered at the older cohorts, it is important that support networks which provide sociability opportunities for the partnerless cohorts be developed. Providing meeting places for older women and ensuring the political empowerment of elderly women in community decision processes are key actions which can be taken.

6.4 Developing an indigenous approach to aging: training requirements.

Traditionally in many African communities, elderly women played a key role in the initiation rites of girls. Although there is now widespread recognition that many of the particular practices adopted are harmful both to women's health and self-esteem, traditionally this was a source of great honour. In many communities where harmful initiation rites are practiced, the barrier toward better and safer reproductive health for women is located with these esteemed female elders. In order to retain this esteem and change towards safer practices, there is a need to produce modern viable substitute rites which incorporate these women. For example, these elders can be exposed to and trained in knowledge on AIDS; be assisted in developing a ritualised form which allows for the effective transmission of this knowledge (and in so doing preserving the basis of their esteem); and be encouraged to impart within this ritual arrangement modern health knowledge. In case this seems far fetched, it is already the case that such training of traditional healers on aids is already taking place in a number of locations in Africa.

Within the modern sector, there is a need for the training of professionals in gerontological knowledge. Nurses, doctors, social workers, housing officers and other welfare personnel need to be better informed on gerontology in general and the specific features of aging in Africa and in their locality.

Finally, there is a need for cross-African cooperation and interaction on gerontological training: the exchange of personnel concerned with the aging issue between institutions and countries, the sharing of training programmes amongst countries, the development of African training materials, each of these measures would make a contribution to filling the current policy void.

If Africa's tradition of respect for age is not to disappear, then policy makers and professionals must act soon. The comparatively low percentage of older persons should not be allowed to generate complacency: the real number of older Africans is growing and in order to meet their needs, action is needed now. In line with African culture, the 'shade' should be preserved.

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APPENDIX I

ESTIMATED AND PROJECTED POPULATION IN THE MAIN FUNCTIONAL AGE GROUPS OF TOTAL POPULATION IN AFRICA, 1980, 2000 AND 2025

(Percentage of total population)

	Africa	Eastern	Middle	Northern	Southern	Western
		Africa	Africa	Africa	Africa	Africa
<u>1980</u>						
0 - 14	44.9	45.8	43.5	43.2	42.1	46.4
15 - 59	50.2	49.4	51.3	51.5	51.6	49.3
60 and over	4.9	4.7	5.2	5.3	6.3	4.3
2000						
0 - 14	43.9	46.0	43.4	39.1	41.0	46.1
15 - 59	51.1	49.4	51.4	55.0	52.6	49.5
60 and over	5.0	4.6	5.2	5.9	6.4	4.4
2025						
0 - 14	34.1	36.3	34.7	28.4	32.1	35.7
15 - 59	59.2	58.0	58.7	62.4	59.8	58.6
60 an over	6.6	5.7	6.6	9.2	8.1	5.7

Source:	Demographic	indicators of Countries: Estimates a	and
	Projections	as Assessed in 1980 (United Nations	
	Publication.	. Sales No. E. 82. XIII.5)	
APPENDIX II

PROJECTED GROWTH IN 60+ POPULATION (IN THOUSANDS)

	<u>1980</u>	2000	<u>2025</u>	Overall factor <u>of</u> <u>change</u>
Africa	22,934	42,726	101.962	4.4
Eastern Africa	6,320	11,495	27,215	4.3
Middle Africa	2,756	4,783	10,631	3.9
Northern Africa	5,763	10,918	27,164	4.7
Southern Africa	2,086	3,680	8,124	3.9
Western Africa	6,011	11,851	28,829	4.7
Total African 46	9,982	852,885	1,541,702	3.3

Absolute increase in 1980-2025 period (60+ population)

Africa	79.0	million
Eastern Africa	20.9	million
Middle Africa	7.9	million
Northern Africa	21.4	million
Southern Africa	6.0	million
Western Africa	22.8	million

Source: <u>Demographic Indicators of Countries: Estimates and</u> <u>Projections as assessed in 1980</u> - Document ST/ESA/SER.A/82, United Nations, 1982.

Appendix II shows the rapid increases in number of persons aged 60 and over projected for the period 1980 - 2025.

APPENDIX III

ESTIMATED AND PROJECTED POPULATION OF ALL AGES AND POPULATION AGED 60 AND OVER, FOR REGIONS AND COUNTRIES OF AFRICA, 1980, 2000 AND 2025.

	<u>A. T</u>	otal Popul	ation_	B. Pop and	60years		
	1980	2000	2025	1980	2000	2025	
Africa	496 98:	2 852 885	1 541 702	22 934	42 726	101 962	
Eastern Afric	a						
a/	133 50	1 250 029	477 919	6 320	11 495	27 215	
Burundi	4 243	7 207	13 310	228	378	824	
Comoros	35	8 620	1 016	16	29	73	
Ethiopia	31 46	3 54 666	93 633	1 336	2 440	5 766	
Kenya	16 46	5 37 138	82 343	724	1 319	3 497	
Madagascar	9 74	2 15 208	26 438	472	91	3 1 799	
Malawi	6 162	12 014	22 997	253	492	1 247	
Mauritius b/	959	1 248	1 568	60	104	264	
Mozambique	10 473	18 701	36 260	567	994	2 116	
Reunion	525	685	825	31	63	162	
Rwanda	4 797	9 333	19 566	218	398	970	
Somalia	4 637	7 156	13 418	285	402	723	
Uganda	13 201	25 396	51 888	660	1 148	2 973	
United Republ: of Tanzania	ic 17 934	34 031	63 598	894	1 649	3 859	
Zambia	5 766	11 276	21 777	247	485	1 213	
Zimbabwe	7 396	14 726	28 435	326	648	1 680	
Middle Africa	53 093	91 445	162 170 23 643	2 756 353	4 783 615	10 631 1 323	
Angola Cameroun	8 444	13 937	23 421	548	847	1 725	

3

Central Afric	can											
Republic	-	2 294	3	914	7	399	1	27		201		398
Chad	4	455	7	063	12	195	25	59		392		785
Congo	1	537	2	717	5	204		83		147		313
Equatorial Guinea		363		616	1	129	2	24		37		73
Gabon		548		754	1	172	5	51		68		108
Zaire	28	291	49	982	87	935	1 3	06	2	472	5	895
Northern Africa d/	109	017	186	160	295	916	57	63	10	918	27	164
Algeria	18	919	37	041	62	880	1 0	29	1	693	4	621
Egypt	41	963	64	421	94	933	2 3	84	4	635	11	025
Libvan Arab												
Jamahiriya	:	2 978	6	077	10	934	1	12		288		763
Morocco	20	296	36	509	59	297	9	84	1	921	5	135
Sudan	18	371	32	328	54	435	8	70	1	641	3	863
Tunisia	6	354	9	556	13	072	3	79		728	1	721
Southern Africa	32	998	57	981	100	553	2 0	86	3	680	8	124
Botswana		807	1	597	3	432		35		51		161
Lesotho	1	341	2	222	3	732		90	:	144		297
Namibia	1	009	1	822	3	266		54		98		226
South Africa	29	285	51	320	88	260	18	81	3	336	7	326
Western Africa e/	141	372	267	271	505	144	6 0	11	11	851	28	829
Benin	3	530	6	756	13	927	1	60		300		714
Burkina Faso	6	908	11	895	20	465	3	30	:	576	1	293
Cape Verde		324		427		824		18		35		95
Gambia		603	1	046	1	970		28		50		112
Ghana	11	679	22	348	42	007	5	24		999	2	465

5	014	8	823	16	841		247		454			979
	573		839	1	432		42		61			103
8	034	14	775	26	727		272		743		1	681
1	967	4	002	7	897		82		166			439
6	940	12	620	24	979		313		561		1	298
1	634	3	022	6	074		73		129			326
5	318	10	045	20	516		227		405			982
77	082	149	965	285	479	3	117	6	361		16	053
5	661	9	747	16	771		270		471		1	060
3	474	6	090	10	675		185		319			707
2	625	4	844	8	854		121		226			540
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Source: Demographic Indicators of Countries

Note: Figures for individual countries may not add to subregional totals as the population of additional territories may be included in the totals

- a/ Including British Indian Ocean Territory, Djibouti and Seychelles.
- b/ Including Agalega, Rodriques and St. Brandon.
- c/ Including Sao Tame and Principe.
- d/ Including Western Sahara.
- e/ Including /St. Helena.

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Healthy Ageing – Adults with Intellectual Disabilities

Physical Health Issues





International Association for the Scientific Study of Intellectual Disabilities



WHO Global Movement for Active Ageing



Department of Mental Health and Substance Dependence World Health Organization

Healthy Ageing - Adults with Intellectual Disabilities

Physical Health Issues

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This report has been prepared by the Aging Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) in collaboration with the Department of Mental Health and Substance Dependence and The Programme on Ageing and Health, World Health Organization, Geneva and all rights are reserved by the above mentioned organization. The document may, however, be freely reviewed, abstracted, reproduced or translated in part, but not for sale or use in conjunction with commercial purposes. It may also be reproduced in full by non-commercial entities for information or for educational purposes with prior permission from WHO/IASSID. The document is likely to be available in other languages also. For more information on this document, please visit the following websites: http://www.ussid.wisc.edu/SIRGAID-Publications.htm and http://www.who.int/mental_health, or write to:

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1. Introduction: A lifespan, developmental perspective on healthy ageing and intellectual disability

The majority of people, including people with intellectual disability, live in the world's less developed countries. Because of the paucity of information regarding the health status and needs of persons with intellectual disabilities in less developed countries, it is hard to make universal statements regarding "healthy ageing" for people with an intellectual disability. The highest priorities for the majority of people with intellectual disabilities in all countries are likely to include basic health care adequate nutrition and housing, education, civil rights, and political, social and economic stability. An international perspective on healthy ageing for persons with intellectual disabilities must acknowledge that the available literature largely reflects the experiences of clinicians and researchers in industrialized countries. Nelson and Crocker in 1978 called for affiliations between academic developmental physicians and physicians serving persons with intellectual disabilities in large institutions. A current high priority should be the development of alliances between policy makers, advocacy groups, physicians, educators and other professionals serving people with intellectual less developed disabilities in and industrialized countries (for an example, see Helm, Crocker & Rubin, 1999).

Recommendation 1

To develop a worldwide perspective on healthy ageing and intellectual disabilities through affiliations between interested parties in industrialized and developing countries that promote advocacy, trans-cultural and costeffective clinical practices, research, and the exchange of information and expertise.

Although there is more information regarding the health status of people with intellectual disabilities in industrialized countries, it remains difficult to make general statements regarding strategies for healthy ageing, Large, industrialized countries- such as the USA- may exhibit profound regional differences in the prevalence rates for intellectual disabilities (MMWR, 1996), These differences reflect socioeconomic factors differences in the definition of intellectual disabilities, and case-finding techniques (Schrojenstein Lantman-de Valk, 1997). People with intellectual disabilities constitute a heterogenous population. The "two group" model is an attempt to point out that people with mild cognitive impairment may have different etiologies and clinical issues than people with more severe cognitive impairment (who may be more likely to have associated syndromic conditions and other developmental disabilities) (Capute & Accardo, 1990), Furthermore, industrialized countries exhibit variations in the way that health care and other services are organized and delivered to people with (and without) an intellectual disability, and these pre-existing differences in service delivery have an impact on the relevance of specific strategies to promote healthy ageing.

Industrialized countries are witnessing an increase in the longevity of adults with an intellectual disability (Janicki et al, 1999). As more people with intellectual disabilities attain older age, it is important to note that excess functional impairment, morbidity, and even mortality can result from the

consequences of early age-onset conditions, through their long-term progression or their interactions with older age-onset conditions. An example of the potential consequences of long-term progression is the high incidence of esophageal reflux in children with cerebral palsy and severe motoric compromise. If childhood-onset esophagitis is not identified and treated, it can lead to high rates of esophageal stricture or cancer in adulthood (Roberts et al, 1986; Bohmer et al 1996, 1997a,b; Cook, 1997). An example of the interaction of early-age onset and later-age onset conditions is, in persons with Down syndrome, the superimposition of adult-onset sensorineural hearing loss on childhoodacquired conductive hearing loss resulting from inadequately treated middle ear infections (Evenhuis, 1995a,b). The long-term consequences of therapeutic interventions also need to be considered- examples are movement disorders that may result from the prolonged use of neuroleptic medications (Haag, Ruther & Hippius, 1992; Wojcieszek, 1998), and bone mineralization disease that may occur secondary to the chronic use of certain anticonvulsants (Bikle, 1996; Phillips, 1998). Although more research needs to be done, it is apparent that healthy ageing for people with an intellectual disability requires a dynamic, lifespan clinical approach.

Recommendation 2

Health care providers caring for people with intellectual disabilities of all ages should adopt a <u>lifespan approach</u> that recognizes the progression or consequences of specific diseases and therapeutic interventions.

2. Special issues in health care, healthy ageing, and intellectual disability

indicates that specific Research populations of people with intellectual disabilities have particular health risks. These populations may be defined by the presence of specific syndromes (hence termed syndromespecific), or by the extent of the central nervous system compromise that has caused intellectual disability (leading to the associated developmental disabilities such as epilepsy, cerebral palsy, and some forms of visual impairment). In addition, populations may be defined by their placement within specific habilitative and residential programs and access to basic health care services. The resulting lifestyle and environmental issues and health promotion/disease prevention practices may directly cause, or interact with, hereditary factors, to protect against or confer specific health risks. Finally, the increased longevity of persons with intellectual disabilities in industrialized countries leads to the definition of populations by chronological older age- and a subsequent increased risk of acquiring adult and older-age associated conditions.

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3. Syndrome-specific conditions

Persons with specific syndromes constitute a clinically and numerically important portion of the population with an intellectual disability. 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. Moreover, these effects can become manifested, and clinically anticipated, at different stages of the lifespan. Down syndrome is a relatively common chromosomal disorder that, in addition to

causing an intellectual disability, results in a relatively high risk for a number of conditions. In the neonatal period, Down syndrome can be associated with congenital defects of the heart, gastrointestinal tract, eyes, and other organs (Pueschel & Pueschel, 1992). Throughout the lifespan, persons with Down syndrome manifest higher risks for specific endocrinological (especially hypothyroidism), infectious, dermatologic, oral health, cardiac, musculoskeletal and other organ system disorders (Murdoch et al. 1977: Sare et al. 1978; Dinani & carpenter, 1990; Pueschel & Pueschel, 1992; Song, Freemantle & Selicowitz, 1993: Marino & Pueschel, 1996). In addition, they exhibit high rates of disorders of the special senses of vision (Pires da Cunha & Belmiro de Castro Moreira, 1996) and hearing (Strome & Strome, 1992; Roizen et al. 1993). Older adults with Down syndrome have an increased risk of the early development of age-related visual and hearing disorders (Buchanan, 1990; Evenhuis et al. 1992), epilepsy (McVicker, Shanks & McCleeland, 1994) and dementia (Wisniewski et al. 1985: Lai & Williams, 1989; Evenhuis, 1990: Burt et al, 1995; Zigman et al, 1995; Devenny et al, 1996). Adults with Down syndrome have decreased longevity compared to the general population of people with intellectual disabilities (Janicki et al., 1999). Fragile X syndrome is the most common inherited disorder associated with an intellectual disability. People with Fragile X syndrome exhibit relatively high rates of mitral valve prolapse (Loehr et al, 1986; Sreeram et al, 1989), musculoskeletal disorders (Davids, Hagerman & Eilert, 1990), early female menopause (Conway et al, 1998; Murray et al, 1998), epilepsy (Ribacoba et al. 1995) and visual impairments (Maino et al, 1991). Adults with Prader-Willi syndrome are prone to high rates of cardiovascular

disease and diabetes arising from morbid obesity (Greenswag, 1987; Lamb & Johnson, 1987). Other syndromes may not be as common or easily identifiable as Down syndrome, Fragile X syndrome, or Prader-Willi syndrome; however, the same principle of knowledge of syndrome-specific issues may lead to the enhanced functional and health status of persons who have them. Examples are the deafness and eye ahnormalities that occur in people with intrauterine toxoplasma, cytomegalovirus infections or foetal alcohol syndrome (Evenhuis & Nagtzaam, 1998).

Knowledge of the specific age-related health risk factors associated with Down syndrome and other syndromes can lead to enhanced prevention or early diagnosis of potentially impairing conditions and, possibly, increased life expectancy. Other relatively common syndromes associated with an intellectual disability that can have an impact on health status across the lifespan include Williams syndrome, Angelman syndrome, and tuberous sclerosis.

In addition, prenatal medical practices (such as the prevention of premature delivery) and the early identification of metabolic syndromes through neonatal screening (such as those that detect phenylketonuria or congenital hypothyroidism) have already led to treatments that can *prevent* or mitigate intellectual disabilities. Genetic counseling also helps to prevent inherited disorders that are associated with intellectual disabilities. In the future, the field of biomolecular genetics may provide further advances in the prevention or treatment of intellectual disabilities and other impairments that are caused by genetic/metabolic syndromes.

WHO/MSD/HPS/MDP/00.5 Page 4

Recommendation 3

Children presenting with intellectual disabilities should have thorough diagnostic searches for etiologies and syndromes to optimize their current and future health care.

4. Associated developmental disabilities arising from central nervous system compromise

A significant number of persons with intellectual disabilities do not have specific syndromes. but exhibit associated developmental disabilities that reflect central nervous system compromise. These associated developmental disabilities may result in both primary and secondary diseases or impairments; they constitute a large component of mortality during childhood (Boyle, Decoufle & Holmgreen, 1994), An important example is cerebral palsy (Rosen & Dickinson, 1992). Children and adults with intellectual disabilities and cerebral palsy with severe motoric and functional impairments have decreased life expectancies compared to the general population (Evans, Evans & Alberman, 1990; Crichton, Mackinnon & White, 1995; Strauss & Shavelle, 1998; Strauss. Shavelle & Anderson, 1998). In addition to these motoric impairments that can adversely affect speech, mobility, and survival, children with intellectual disabilities and cerebral palsy present with high rates of strabismus and cerebral visual impairment (Schenk-Rootlieb et al, 1992; Erkkila, Lindberg & Kallio, 1996) and bladder dysfunction (Boone, 1998). Spasticity may require medical or neurosurgical treatment to alleviate pain, prevent deformities, and enhance function (Russman & Romness 1998); orthopedic surgery may also be required (Renshaw et al, 1996). Children and

adults with intellectual disabilities and cerebral palsy also exhibit a high risk for a number of secondary disorders. Upper gastrointestinal dysmotility, resulting in dysphagia, esophageal reflux and gastric emptying disorders, may lead to dental esophagitis, anemia. feeding erosion. problems, aspiration and pneumonia (indeed. respiratory disease is the leading cause of death in people with cerebral palsy and severe motoric impairments) (Reilly & Skuse, 1992; Arvedson et al, 1994; Mirrett et al, 1994; Rogers et al, 1994; Böhmer et al, 1997b. Shaw, Wetherill & Smith, 1998). People with intellectual disabilities and cerebral palsy are prone to lower gastrointestinal also dysmotility; this may cause constipation and fecal impaction (Cathels & Reddihough, 1993), and death due to bowel obstruction and intestinal perforation (Jancar & Speller, 1994). Bone demineralization with consequent fractures and decubitus ulcers may occur secondary to long-standing immobility and nutritional deficiencies (Brunner & Doderlein, 1996; Wagemans et al. 1998). Children and adults with cerebral palsy and severe or multiple impairing conditions require multidisciplinary care (Lowes & Gries, 1998). In later life, the chronic abnormalities of muscle tone may lead to chronic myofascial pain, hip and back deformities (including degenerative vertebral spine disease that may cause myelopathy); worsening bowel and bladder function is also seen (Harada et al, 1996; Mikawa Y, Watanabe R & Shikata J, 1997:Turk et al, 1997; Saito et al, 1998). The optimization of function and survival for people with cerebral palsy throughout life depends on the anticipation and identification, and prevention or treatment, of both primary and secondary disorders

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People with intellectual disabilities and epilepsy have other health risks. Children with intellectual disabilities and intractable epilepsy present with higher rates of cerebral palsy, visual impairment, and severe cognitive impairments (Steffenberg et al, 1995). In addition to the risk of status epilepticus (which is more common in children with coexisting neuro-impairments such as cerebral palsy), epilepsy is associated with injuries such as fractures (Desai, Ribbans & Taylor, 1996; Jancar & Jancar, 1998). People with intellectual disabilities and epilepsy have an increased mortality due to sudden death. aspiration episodes, and pneumonia (Forsgren et al, 1996). Unrecognized or inadequately treated seizures can impair cognitive function (Aldenkamp, 1997). Epilepsy syndromes associated with an intellectual disability (Dulac & N'Guyen, 1993: Ohtsuka, 1998) may prove difficult to treat and lead to a worsening of seizure control (Udani et al. 1993; Branford, 1998) and progressive cognitive impairment (Oka et al, 1997). However, some people with an intellectual disability and epilepsy exhibit a remission of the enilensy in later life- the need for anticonvulsant medication needs to be regularly reappraised (Goulden et al, 1991; Brodtkorb, 1994). A coordinated and comprehensive approach to the management of epilepsy in people with intellectual disabilities may result in optimal management (Coulter, 1997)- health care service models do not always foster this type of approach.

Other examples of associated developmental disabilities that can result from central nervous system compromise, with obvious health status and functional repercussions, include autism, mental health issues, and some disorders of vision.

Recommendation 4

Persons presenting with an intellectual disability should have expert care to identify and treat associated developmental disabilities such as cerebral palsy, epilepsy, autism, and disorders of vision.

5. Conditions related to lifestyle and environment and health promotion/disease prevention practices

Industrialized countries have varying habilitative and residential philosophies and practices for persons with intellectual disabilities. In the North America, Australia, and in many European countries, governments have implemented measures to close large publically -operated institutions and move residents into a variety of small communitybased settings. Other countries have opted to modify the institutional model. In addition, countries exhibit wide variation in expenditures for supports and services for people with intellectual disabilities (for USA, see Braddock et al, 1998). It is important to note that, throughout the industrialized world, many people with intellectual disabilities have experienced or continue to experience placement in large institutions. Previous or current residence in large institutions place many people with intellectual disabilities at risk for past or present exposure to a number of infectious diseases, including tuberculosis (Lemaitre et al, 1996), hepatitis B (Hayashi et al, 1989; Stehr-Green et al, 1992; Cramp et al, 1996), and Helicobacter pylori (Bohmer et al, 1997).

WHO/MSD/HPS/MDP/00.5 Page 6

Recommendation 5

People with intellectual disabilities with current or previous histories of life in large institutions should be evaluated for evidence of infectious diseases such as tuberculosis, hepatitis B, and Helicobacter pylori.

As people 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 a higher potential for risky behaviors and conditions that result from the lifestyle choices, or the interaction of lifestyle and hereditary factors. People with intellectual disabilities living in the community may engage in tobacco use (Burtner et al, 1995; Hymowitz et al, 1997; Tracey and Hoskin, 1997), other substance abuse (Westermeyer, Phaobtong & Neider, 1988; Moore & Posgrove, 1991; Christian & Poling, 1997), violent behavior (Pack, Wallander & Brown, 1998), and high-risk sexual activity (Cambridge, 1996). Behavioral factors of people with intellectual disabilities. and their carers contribute to the high rates of peridontal disease noted in people with intellectual disabilities (Beange, McElduff & Baker, 1995; Lucchese & Checchi, 1998; Scott, Marsh & Stokes, 1998). A sedentary lifestyle, with consequent risks of deconditioning, obesity, (and diseases related to obesity including coronary artery disease, hypertension and diabetes) has been noted in people with intellectual disabilities in a variety of residential settings (Rimmer, Braddock & Marks, 1995; Beange, McElduff & Baker, 1995; Fujiura, Fitzsimmons, Marks & Chicoine, 1997). For people with intellectual disabilities, targeting lifestyle issues (Turner & Moss, 1996) may result in substantial gains in longevity and older-age quality of life and functional capability. Special programs that target healthy behaviors

such as safe sex practices (Ager & Littler, 1998), avoidance of tobacco and other harmful substances (Tracy & Hosken, 1997), good oral hygeine (Nicolaci & Tesini, 1992), optimal exercise and dietary habits (Pitetti, Rimmer & Fernhall, 1993, Golden & Hatcher, 1997), and fire safety education (Janicki & Jacobson, 1985; MacEachron & Krauss, 1985), ned continued development.

Recommendation 6

People with intellectual disabilities, and their carers, need to receive appropriate and ongoing education regarding healthy living practices in areas such as nutrition, exercise, oral hygeine, safety practices, and the avoidance of risky behaviors such as substance abuse and unprotected or multiple partner sexual activity.

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Presently, however, there is no research to suggest that preventative health practices that are recommended for the general population, throughout the lifespan, should be withheld from people with intellectual disabilities. Standard immunization schedules and age-appropriate screening protocols for conditions such as dental disease, sensory impairments, various forms of cancer (with the possible exception of PAP smears in women who have no history of sexual activity), glaucoma, hyperlipidemia, and hypertension, should be offered to people with intellectual disabilities.

Recommendation 7

People with intellectual disabilities should receive the same array of lifespan preventative health practices as those offered to the general population.

6. Older age-related conditions

A number of recent studies have addressed the health status of middle-age and older adults with intellectual disabilities. These studies vary in methodology, and include longitudinal residence carers surveys (Anderson, 1993), interviews with subjects with intellectual disabilities and their carers (Cooper, 1998), carers interviews combined with medical chart reviews (Kapell et al. 1998), health status questionnaires of physicians providing care to subjects (Hand, 1994), questionnaires of direct care staff and physicians (Schrojenstein Lantman-de Valk et al. 1997), comprehensive medical assessment of subjects by a developmental physician (Beange, McElduff & Baker, 1995), and comprehensive and longitudinal assessment of subjects by a developmental physician (Evenhuis, 1995a,b; Evenhuis, 1997a), Only one of these studies attempted to identify subjects who were not previously registered or residing within the intellectual disabilities service system, resulting in a 15% segment of the older population with an intellectual disability (Hand, 1994). It is significant that the study that utilized comprehensive medical assessment by a developmental physician (of subjects who were being managed by community-based primary care physicians) uncovered a high number of previously undiagnosed conditions (Beange, McElduff & Baker, 1995). The cumulative research suggests that older adults with intellectual disabilities have rates of common adult and older age-related conditions that are comparable to or even higher than that of the general population (Minihan & Dean, 1990; Anderson, 1993; Hand, 1994; Beange, McElduff & Baker, 1995; Evenhuis, 1997: Schrojenstein Lantman-de Valk et al 1997; Kapell et al, 1998; Cooper, 1998). For many people with intellectual disabilities, the risk of a variety of chronic diseases that are acquired

during adulthood, and that are associated with older-age morbidity or functional impairment. reflects the same interplay between hereditary predisposition and environment that is present in other older persons. However, as discussed above, factors related to syndromes. associated developmental disabilities, and lifestve and environmental issues, may account for higher rates, compared to the population without intellectual disabilities, for a number of conditions. Previously noted examples include obesity, dental disease, gastroesophageal reflux and esophagitis. constipation, and deaths due to bowel obstruction and intestinal perforation and gastrointestinal cancer. Other examples include non-atherosclerotic heart disease (Kapell et al. 1998; Cooper, 1998), mobility impairment (Kearny, Krishnan & Londhe, 1993; Evenhuis, 1997), thyroid disease (Kapell et al. 1998), osteoporosis (Center, Beange & McElduff, 1998) psychotropic drug polypharmacy (Tu, 1979; Gowdy, Zarfas & Phipps, 1987: Schrojenstein Lantman-de Valk et al. 1997), and deaths due to pneumonia (O'Brien, Tate & Zaharia, 1991; Janicki et al, 1999).

Recommendation 8

Health care providers serving older adults 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.

Sensory impairments appear to constitute an area of special vulnerability for older adults with intellectual disabilities (Warberg M & Rattleff J, 1992; Wilson & Haire, 1992; Schrojenstein Lantman-de Valk et al, 1997). Although causes of visual and hearing loss may be present in rates similar to those in the general population (presbyacusis, cataract,

WHO/MSD/HPS/MDP/00.5 Page 8

presbyopia, macular degeneration, glaucoma, diabetic retinopathy), the resulting impairment may be more severe because of pre-existing, childhood onset visual and auditory pathology (Schrojenstein Lantman de-Valk et al, 1994; Evenhuis, 1995a,b).

Functional decline in older adults with intellectual disabilities warrants careful evaluation: a decline in functional status should not be peremptorily attributed to behavioral issues or dementia (Prasher & 1998). Chung 1996 Burt et al. Comprehensive evaluations of older adults presenting with changes in state or functional decline and intellectual disabilities have vielded high rates of (often-concurrent) treatable conditions. Examples include affective disorders, sensory impairments, delirium, and undiagnosed medical conditions (Evenhuis, 1997b; Evenhuis, 1999; Thorpe, 1999; Chicoine, McGuire & Rubin, 1999; Henderson et al. in press). It is important to note that, because of communication difficulties, medical and mental health disorders may present atypically. Even people with an intellectual disability and dementia may have a relatively high burden of treatable medical conditions that may have an additive effect on disability (Cooper, 1999). The reversal of functional decline should be sought for people with intellectual disabilities of all ages, and not solely for functional or quality of life issues- severe functional impairment is related to decreased life expectancy in people with intellectual disabilities of all ages (Eyman et al, 1990).

Recommendation 9

Functional decline in older adults with intellectual disabilities warrants careful medical evaluation; undiagnosed mental health and medical conditions can have atypical presentations in people with limited language capabilities. Regular screening for visual and hearing impairments should be implemented for people with intellectual disabilities during the childhood and late-adulthood vears.

7. Barriers to health care services in healthy ageing and intellectual disabilities

In theory, people with intellectual disabilities living in industrialized countries have equal access to essential health care services. As mentioned previously, countries (and regions within countries) vary in their models of health care delivery for people with intellectual disabilities. However, it is worth noting the general barriers that exist in providing care to people with intellectual disabilities (see Seltzer & Luchterhand, 1994), although the significance of these barriers may vary by region and type of health care system. It is important that health care providers and policy makers acknowledge that many people with intellectual disabilities have special needs that may require modification of standard health care practices and service models

Communication difficulties arising from intellectual disabilities or associated motor impairments can serve as barriers to accurate medical evaluation. The medical history, in many cases, is derived from carers observations. In these cases, the health care provider is dependent on the verbal or written reports of carers that know the patient. People with intellectual disabilities can benefit from the training of carers in health-related issuesparticularly basic assessment skills (Crocker & Yankauer, 1987). There is evidence that, in places where deinstitutionalization has led to placement of people with intellectual disabilities in the community, health care has deteriorated because carers were not familiar with the individuals (Linaker & Nottestadd, 1998). Carers need to be able to recognize

signs of distress in persons with severe cognitive impairment (LaChapelle, Hadjistavvropoulos & Craig, in press); at the same time, individuals who have notential communication skills need to be educated in the effective communication of pain or distress (Bromley, Emerson & Caine, 1998). In addition, unresolved concerns about informed consent for or refusal of health services may, at times, prove to be a barrier for some people with intellectual disabilities (O'Donnell, 1994). Even in optimal circumstances- when the ill person with an intellectual disability is accompanied by knowledgeable carers- informant-based medical history taking takes time. Concepts of health care productivity need to be altered when considering the population of people with intellectual disabilities and significant communication difficulties.

Physical barriers may constitute a problem for many persons with intellectual disabilities and other disabling conditions. Older women with cerebral palsy, with and without an intellectual disability, have reported difficulties obtaining dental and gynecologic care because of accessibility problems (Turk et al, 1997). Health care facilities should be easily accessible to persons with an intellectual disability who may have a variety of physical and sensory impairments.

Behavioral issues constitute another potential barrier. Persons with intellectual disabilities may have difficulty cooperating with examinations and procedures. Health care providers need to be educated regarding the confusion, fear, and frustration that many people with intellectual disabilities may experience when they access health care services. Again, more time may be necessary to reassure someone with an intellectual disability. Habilitative programs or health care providers should address the issue of health care- not just in terms of healthy living, but also by increasing understanding and confidence in using health services (McRae, 1997; Lunsky, 1999). Protocols for safe conscious sedation may be helpful for some people with an intellectual disability. In other cases, 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 acute rehabilitation after disease, insults or injury. Also, teaching persons with an intellectual disability how to use assistive or prosthetic devices, such as canes, walkers, wheelchairs, braces, dentures, eveglasses and hearing aids, may require more time and special techniques.

For many people with intellectual disabilities, the most important barrier to effective medical care is case complexity. People with intellectual disabilities may access a variety of medical subspecialists, dentists, audiologists, mental health providers, and other health care professionals. Case management is crucial for the optimal utilization of health care services for people with intellectual disabilities who have complex needs requiring multidisciplinary expertise (Walsh, Kastner & Criscione, 1997).

It is worth noting that, in some countries or states, health care rationing or reimbursement schedules may constitute barriers to basic health services. In addition, administrators and policy makers need to understand that, in some cases, clinically indicated and relatively expensive techniques and expertise may prove cost-effective in the long-term.

Recommendation 10

Health care providers and policy makers need to eliminate attitudinal, architectural

WHO/MSD/HPS/MDP/00.5 Page 10

and health care reimbursement barriers that interfere with the provision of high quality health services for people with intellectual disabilities.

Recommendation 11

Carers need training in assessing and communicating the basic health status of the adults with intellectual disabilities.

Recommendation 12

Health care case management should be available to adults with intellectual disabilities who have complex needs.

8. The role of the physician in healthy ageing and intellectual disabilities: Primary care and developmental physicians

Physicians can play a pivotal role in the functional attainments and quality of life of many persons with intellectual disabilities. However, successful habilitation and community placement may depend on the prevention or identification of a variety of health issues. Accordingly, the physician is one member of a health care team. Other important team members include nurses. audiologists, nutritionists, dentists, mental specialists, and rehabilitation health specialists. An interdisciplinary approach may be required for a number of health issues, including visual and hearing impairment (Evenhuis, 1995a,b), swallowing disorders (Kennedy et al, 1997), urinary incontinence (Bradley, Ferris & Barr, 1995), dental care (Editorial, 1998), and geriatric assessment (Carlsen et al, 1994).

Many adults with intellectual disabilities do not need special medical attention. It is important for primary care physicians to recognize that, in general, adults and older persons with an intellectual disability have the same needs for disease prevention, diagnosis, and treatment as other members of the population. For routine care, health status can improve by ensuring regular encounters with primary care physicians (Martin, Roy & Wells, 1997), and through 'opportunistic' health assessment at the time of encounters (Jones & Kerr, 1997). However, some persons with intellectual disabilities and specific issues, associated developmental disabilities, and complex neuropsychiatric conditions) may require regularly scheduled, easily administered screening protocols (Cohen, 1997; Piachaud, Rohde & Pasupathy, 1998).

It is noted that, in many countries, the relatively frequent contact between adults and older persons with an intellectual disability and primary care physicians based in the community is a new and largely unplanned phenomenon arising from the deinstitutionalization and increased longevity of persons with intellectual disabilities. Evidence suggests that community-based primary care physicians in some regions may not provide access or have the expertise or professional back-up to care for people with intellectual disabilities who have severe or complex impairments (Strauss & Kastner, 1996; O'Brien & Zahari, 1998; Strauss et al, 1998). Primary care physicians need to be able to get access to information through a variety of means: formal consultations, telephone consultation systems, internet communication, clinical guidelines, training seminars, and written materials such as texts (see Lennox, 1999). In complex cases, established referral paths to developmental physicians and other specialists with intellectual disabilities expertise can be crucial

Developmental physicians, trained with a lifespan approach to developmental disabilities, can provide valuable expertise to

primary care physicians and other health care providers serving people with intellectual disabilities. The influence of this specialty can range from preparing written guidelines and training programs for primary care physicians and other health care providers, to providing formal and informal consultation services for complex patients. In addition, they can provide leadership in the area of clinical research.

Health care providers need evidencebased practice standards (Lennox & Kerr. 1997), similar to the international guidelines for the screening and diagnosis of visual and hearing impairments in persons with intellectual disabilities, recently developed by the IASSID Special Interest Research Group on Health Issues (Evenhuis & Nagtzaam, 1998). Comparable standards need to be developed for other specific interventions. conditions, diseases, and syndromes. Most important is a need for leadership to more fully introduce people with an intellectual disability of all ages- who comprise a substantial portion of the human populationand postgraduate medical into basic education.

Lastly, there is a need for medical specialists with interest and expertise in intellectual disabilities. Psychiatrists, neurologists, physiatrists, otolaryngologists, ophthalmologists and other specialists with intellectual disabilities knowledge can be enormously helpful to colleagues in their own disciplines, as well as to primary care specialists and developmental physicians.

Recommendation 13

An interdisciplinary approach is required for a variety of clinical issues involving people with intellectual disabilities.

Recommendation 14

Health care systems need to provide educational and clinical practice supports for primary care physicians caring for people with intellectual disabilities.

Recommendation 15

The development of the discipline of lifespan developmental medicine is necessary to provide medical education, practice standards, clinical expertise, research, and professional leadership regarding the special needs of people with intellectual disabilities of all ages.

9. Conclusion: Areas for future research

The development of research to enable healthy ageing in persons with intellectual disabilities represents a new and complex area. Previously mentioned is the need to provide evidence-based practice standards to enhance health status, longevity, functional capability, and quality of life. Other high priority research areas include:

•The acquisition of additional clinical and epidemiological knowledge regarding specific syndromes, with linkages to basic science research in biomolecular genetics and metabolism.

•The development of adapted diagnostic and therapeutic methods for people who have difficulties with cooperation or communication.

• The development and evaluation of interdisciplinary interventions for complicated conditions (e.g. sensory impairment, dysphagia, communication, and functional decline).

WHO/MSD/HPS/MDP/00.5 Page 12

 The development of clinimetric measures in a number of areas -functional capability, quality of life, mental health, pain assessment, and clinical diagnosis- that are sensitive and specific, easy to administer, and applicable to persons with a wide range of mental and physical capabilities.

•The evaluation of clinical guidelinesincluding referral protocols- to support community-based primary care physicians, within specific health care systems, to care for people with intellectual disabilities.

 The evaluation of the applicability of a new discipline of lifespan developmental medicine to lead in interdisciplinary care, health care education, service delivery, and research for people with intellectual disabilities.

•The development of the knowledge base regarding the health status and needs of people with intellectual disabilities living in less developed countries.

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Recommendation 1

To develop a worldwide perspective on healthy ageing and intellectual disabilities through affiliations between interested parties in industrialized and developing countries that promote advocacy, trans-cultural and costeffective clinical practices, research, and the exchange of information and expertise.

Recommendation 2

Health care providers caring for people with intellectual disabilities of all ages should adopt a <u>lifespan approach</u> that recognizes the progression or consequences of specific diseases and therapeutic interventions.

Recommendation 3

Children presenting with intellectual disabilities should have thorough diagnostic searches for etiologies and syndromes to optimize their current and future health care.

Recommendation 4

Persons presenting with an intellectual disability should have expert care to identify and treat associated developmental disabilities such as cerebral palsy, epilepsy, autism, and disorders of vision.

Recommendation 5

People with intellectual disabilities with current or previous histories of life in large institutions should be evaluated for evidence of infectious diseases such as tuberculosis, hepatitis B, and Helicobacter pylori.

Recommendation 6

People with intellectual disabilities, and their carers, need to receive appropriate and ongoing education regarding healthy living practices in areas such as nutrition, exercise, oral hygeine, safety practices, and the avoidance of risky behaviors such as substance abuse and unprotected or multiple partner sexual activity.

Recommendation 7

People with intellectual disabilities should receive the same array of lifespan preventative health practices as those offered to the general population.

Recommendation 8

Health care providers serving older adults 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.

Recommendation 9

Functional decline in older adults with intellectual disabilities warrants careful medical evaluation; undiagnosed mental health and medical conditions can have atypical presentations in people with limited language capabilities. Regular screening for visual and hearing impairments should be implemented for people with intellectual disabilities during the childhood and late-adulthood years.

Recommendation 10

Health care providers and policy makers need to eliminate attitudinal, architectural and health care reimbursement barriers that interfere with the provision of high quality health services for people with intellectual disabilities.

Recommendation 11

Carers need training in assessing and communicating the basic health status of the adults with intellectual disabilities.

Recommendation 12

Health care case management should be available to adults with intellectual disabilities who have complex needs.

Recommendation 13

An interdisciplinary approach is required for a variety of clinical issues involving people with intellectual disabilities.

Recommendation 14

Health care systems need to provide educational and clinical practice supports for primary care physicians caring for people with intellectual disabilities.

Recommendation 15

The development of the discipline of lifespan developmental medicine is necessary to provide medical education, practice standards, clinical expertise, research, and professional leadership regarding the special needs of people with intellectual disabilities of all ages.



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Healthy Ageing – Adults with Intellectual Disabilities

Women's Health and Related Issues





International Association for the Scientific Study of Intellectual Disabilities



WHO Global Movement for Active Ageing



Department of Mental Health and Substance Dependence World Health Organization

Healthy Ageing - Adults with Intellectual Disabilities

Women's Health and Related Issues

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This report has been prepared by the Aging Special Interest Research Group of the International Association for the Scientific Study of Intellectual Disabilities (IASSID) in collaboration with the Department of Mental Health and Substance Dependence and The Programme on Ageing and Health, World Health Organization, Geneva and all rights are reserved by the above mentioned organization. The document may, however, be freely reviewed, abstracted, reproduced or translated in part, but not for sale or use in conjunction with commercial purposes. It may also be reproduced in full by non-commercial entities for information or for educational purposes with prior permission from WHO/IASSID. The document is likely to be available in other languages also. For more information on this document, please visit the following websites: http://www.iassid.wisc.edu/SIRGAID-Publications.htm and http://www.who.int/mental_health, or write to:

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This report was developed as a draft and circulated to both Health Issues and Aging SIRG working group members and selected others for commentary and amendments. The amended document became part of the working drafts circulated to delegates at the 10⁶ International Roundtable on Ageing and Intellectual Disabilities in Geneva in 1999, and was discussed and amended further at this meeting. A set of summative broad goals was developed by the group and appears in this paper, which itself became part of the comprehensive WHO document on ageing and intellectual disability (WHO, 2000). The primary goal of this paper is to organize information on women's health issues in older women with intellectual disabilities, and to present broad summative goals to direct further work in this area.

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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 sexrelated 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 wellbeing 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

The human rights of women and girl 2.1 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 wellbeing 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 perquisite 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.

Priority areas for international action 2.5 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).

Healthy Ageing - Adults with Intellectual Disabilities: Women's Health and Related Issues

WHO/MSD/HPS/MDP/00.6 Page 2

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).

Gender is recognized as a determinant 3.4 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 m

Healthy Ageing - Adults with Intellectual Disabilities: Women's Health and Related Issues

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 osteoprorsis 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-CulturalContexts

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).

42 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 tiself 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.

WHO/MSD/HPS/MDP/00.6 Page 4

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 recommenda-dations 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

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Healthy Ageing - Adults with Intellectual Disabilities: Women's Health and Related Issues

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, disturbances. including to menstrual 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 Clamydia 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.,

WHO/MSD/HPS/MDP/00.6 Page 6

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 nerson'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. vaginal However. irregular bleeding ("spotting") and effects on cholesterol metabolism that might increase risk for coronary heart disease need to be considered.

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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 selfinjurious 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. Postmenopausal 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

WHO/MSD/HPS/MDP/00.6 Page 8

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 are 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.

6175 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/ASSID's report on *Biobehavioural Issues*, this is often the case among older women with intellectual disabilities as well.

Healthy Ageing - Adults with Intellectual Disabilities: Women's Health and Related Issues

WHO/MSD/HPS/MDP/00.6 Page 9

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 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 wellbeing. Also, health professional often do not communicate effective strategies for health promotion to women with intellectual disabilities or their carers.

WHO/MSD/HPS/MDP/00.6 Page 10

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 wellbeing, 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 welldocumented in the more developed countries. Less is known about the impact of employment status on the health and wellbeing 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 skill 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 dustgenerating 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 ones 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

WHO/MSD/HPS/MDP/00.6 Page 12

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 hat 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, 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 the care personnel were not helpful any hybridian to helpful any 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 dice to them, while others disarreed.

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 computerbased 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 manageing 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. Personcentered, 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. WHO/MSD/HPS/MDP/00.6 Page 16

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 factorsinfluence 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 in 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 wellbeing for women with nitellectual 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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Healthy Ageing - Adults with Intellectual Disabilities: Women's Health and Related Issues

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"HOT TO KEEP STALL KOUNG ANEN NHEN YOU ARE GETTING OLD" KAEPING HAALANK A GUIDE FOR SENIORS

. 10 1:

11

A: SINCOMES RESULARLY : .

The anount of Exercise you need is "a little more than you" did yestarday".

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00. 10

Falling is a good exercise, especially if you have not been excercising regularly.

You may even try biking, hiking or even swimming.

Wise your judgement about what pace to sat for yourself. Listen to your body. Ask your doctor for advice if your are unsure.

If you cannot talk while you are exercising because you one too short of breath, you are probably aportoing it.

deercise daily or, at least, every other day.

Relaxed, steady regular exercises is much better than intermittent exhaustive work out.

You will soon notice increased energy, limberness and firmness.

It is important to move your joints. Falking is good for this purpose, but you can also keepyour joints supple by flexing your arms, shrugging your shoulders or even stretching your legs. Such everoise holps prevent stiffness.

3: EAT RIGHT 1

Choose your food from each of the following four main groups every day 1

 Fruits and Vegetables - sat four or five servings everyday.

2. Dairy products - including milk, cheese or ics cream.

.....2

3. Meats - Four to Standard and read or the equivalent each form. An average service of white ownes, the following road provide the equivalent of three space of meat. The eggs, one and of baked beans or four table spaces of versuo burder.

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4. Breads and Gereals, including rice and points - fibre from whole grain bread, three to five slices each day, is highly beneficial.

Concentrate on Calcium intake to promote healthy bones. Two glasses of milk each day are enough, but three glasses are better. If you do not like milk the following foods contain the same amount of Calcium as same amount is in one glass of milk. Two slices of cheese, one cup of yogurt, or four table spoons of skimmed milk powder.

Eat planty of fibre, whole grain bread is a good fibre source bran, beans, fruits and vegetables also provide fibre. C: <u>AVOID AQOIDENTS</u>.

Look for danyors inside and outside. Wake modification (such as ramps, railing, supports) if nocessary.

If your balance is poor, seek advice from your doctor. Use assistive devices such as a Cane or Walker. Plan your activities for safely.

If you fail, think about how it happened and determine how it could be prevented in the future. Tell your doctor about it.

Do not go out alone.

Do not rush especially at night and in bad weather.

D: KEEP INVOLVED :

Keep informed about the news.

Nake an effort to visit your friends and make new friends, If you are alone, keep yourself busy in various activities visit other senior citizens, or visit temples, or visit home for "HO<u>R FO KEAF STILL YOUNG SYEN MHEN YOU ARE BEFTING OLD"</u> KAEPIN<u>A HAALTAY</u> A GUID<u>E FOR SBUIDES</u>

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A: ATTROISS MEDLARLY :

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Choose your food from each of the following four main groups every day !

1. Fruits and Poyotables - out four or five servings everydaus

2. Dairy products - including Hilk, chocse or ice cream.

.....2

3. Seats - Four to Six ounce of meat or its equivalent each day. An avorage serving is three ounce. The following food provide the equivalent of three ounce of meat. Two eggs, one cup of baked beans or four table spoons of peanut butter.

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Do not rush especially at night and in bad weather.

D: KEEP INVOLVED :

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Sake an effort to visit your friends and make new friends.

- 2 -

E: KNOW YOUNSELF :

You know if you are overweight or smoke or drink too much. .idmit your meakness and work to improve them. Your health is your responsibility.

- 3 -

It is nover too late for you to benefit from cutting back on encess or stop smoking.

F : SHE TOUR FAMILY PHYSICIAN :

Your family physician is trained to help maintain your health.

Four family physician will check your blood pressure, perform cancer screening checks look for "hidden illnesses", you may not be aware of, identify factors that increase your succeptibility to cliness and take measures to ensure your good health.

See your family physician at least once a year. <u>ACMERAL NAPORT - SYMPTOMS</u> :

You must report any mental or physical problems to your doctor. Wany older persons unnecessarily live with excessive stiffness, shortness of breath, tiredness insomnia, or even incontinence because of the misconception that is "Just Old Age".

Also be sure to report symptoms even if they mildly ... inconvenience you, such as swelling, changes in bowel habits, tered appetite, weight change, or altered sleeping pattern's.

These symptoms should be evaluated by your family physician. Early treatment of such problems before they become more difficult to resolve will aid in maintaining your best possible health.

The yoal of treating the elderly is not always to prolong their life - But add LIFE to their years and - Not years to their Life.

Verbal Autopsy Questionnaire - Adults

(Above 15 years of age)

1. Preliminary Information

a. b.	Name of the deceased: Age in years at time of deal	h:	Date of interview:
c. d.	Sex: if Female-	Male/Female Pregnant / Lactating/ Neither Age of eldest living child	
d. e.	Marital status * Married * Unmarried Address:	* Widowed *Divorced	* Separated

f. Name of the informant(s)

- g. Informant's relation to the deceased -
- h. Who, among the informants, was present at the time of the fatal illness?
- i. Occupation (give details of type of work) ____
 - i) Working person, active till death
 - ii) Working person, stopped working for some period before death (specify period)
 - iii) Not working person
- j. Family structure Nuclear / Joint

Total No. of Members Male adults Female adults

Children

k. Income and food supply: (Relates to the family)

Agriculture:

Total Land owned

Irrigated land owned

Crop from last harvest was sufficient to adequately feed the family till which month -

Wages:

Work as agricultural labour - No. of days in last 6 months	
Work on Govt. relief works No. of days in last 6 months	
Work outside the village- No. of days in last 6 months	

Daily Wage-Daily Wage-Daily Wage-

Any other source of income:

Has the total income during last six months been sufficient to adequately feed all family members? Were all the family members eating usual quantity and quality of food at the time of death of the deceased person?

If there was a decrease in the dietary intake, what was the approximate proportionate decrease (proportion of usual)? -

Which items in the diet specifically were decreased -Foodgrains (Maize, Wheat, Jowar, Rice etc.) Pulses Vegetables Oil, milk etc. Meat, eggs, fish etc.

In the last six months relating to the deceased and family -

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Were any unusual or 'famine' foods being eaten (roots, tubers, leaves etc.) Any substances being eaten to suppress hunger? Was the family purchasing PDS rations ? Was the family availing of drought relief ? If so in what form? Any other deaths in the family in the past one year? Deaths of eattle or other animals Distress sale of eattle, vessels, implements and other belongings to obtain food Borrowing or begging food from neighbours, relatives or others

No

No

- I. Personal habits
 - Smoking Yes
 If yes
 Duration
 Bidi / cigarette per day
 Alcohol Yes
 If yes
 Duration
 Quantity per day
- m. Date of death Day Month Year
- Weather at the time of Death: Extreme cold / Extreme heat / Neither
- o. Place of Death
 - i. Home
 - a. Staying alone / With family
 - b. Families in immediate neighborhood: Yes/No
 - ii. Lack of access as being trapped, lost etc
 - iii. Health centre / F c spital
 - iv. On the way to Health Centre/Hospital
 - v. Any other
- p. Whether Death Certificate Available
 - i. Yes/No
 - ii. If not why
 - iii. If yes

Mention Cause of Death as certified

2. Medical history related to death

2.1 Was the deceased seeing a health care provider before death: 1.yes 2.no

2.2	lt	yes.	specify	y (na	ume,	prote	ssion,	address.):
2.3 F	or how long	:					years	
2.4		For	wi	nat	compla	int		(specify):
2.5 V	Vas the dece	ased taking an	y medication: 1.	yes 2.no				_
2.6	If yes	specify	(ask for	remaining	containers	/	unused	medicines):
2.7 V	Vas the dece	ased hospitaliz	ed before death:	Lyes 2.no				
2.8	Iſ	yes	s, spe	cify	where	(1	name,	address):

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2.9 For how long;	davs	
2.10 When did the deceased leave hospital (before de	ath):	
days		
2.11 Did the deceased undergo any surgical operation	during this hospitalization: 1.y	cs 2.no
2.12 If yes, when (before death):		days
2.13 Do you know what was the operation: Lives 2.nd		
2.14 If	ycs,	specify
2.15 Was the deceased or any member of the family e	ever told the nature (the diagnos	sis) of the illness:
1. yes 2.no		
2.16 If yes, what was it	(specify as clearly	y as possible):
Was there any accident / poisoning / bite / burn or oth	er unnatural event shortly befo	ore death-
1.yes 2.no		
2.17.1 If yes, whi	at was	the accident:
2.17.2 If yes, specify hours / days before death:		
2.18 Where accident occurred: 1. at work 2. road	l (vehicular accident) 3. at h	ome 4. other (specify):
2.19 Organs/part of body injured during accident		
2.20 Other unnatural events-		
 Drowning 		
Poisoning		
 Hanging 		

- · Bite by snake or other venomous animal
- Burns
- Violence
- · Any other (specify)

How long before the death did this event take place? (Hours /days)___

Details of the event (in case of poisoning, what agent was used; in case of violence, what type of violence etc.)

3. Specific disease related information

3.0 Open ended question about the illness -

According to what you know what did the deceased die of and how? Please narrate.

(All questions in the sections below pertain to the illness immediately preceding death unless specified otherwise)

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3.1 Cardiovascular system

3.1.1 Did the deceased ever complain of unusual breathlessness? : 1.yes 2.no

If yes, was it on:

3.1.1.1 Exertion: 1.yes 2.no

If yes, how much exertion: 1. Walking on level surface 2. Walking up an incline 3. Climbing stairs

3.1.1.2 Breathlessness while lying down flat: 1.yes 2.no

3.1.1.3 At night, relieved by sitting up in bed: 1.yes 2.no

3.1.2 Did the deceased ever complain of chest pain: 1.yes 2.no

If yes:

3.1.2.1 Was it persistent for several hours: 1.yes 2.no

3.1.2.2 Was it relieved by rest: 1.yes 2.no

Was it accompanied by excessive sweating: 1. Yes 2. No

3.1.3 Did the deceased ever complain of cyanosis on the lips, fingers or nails: 1.yes 2.no

3.1.4 Did the deceased ever complain of swelling on the body (the lower limbs, foot and leg, eyelids, abdomen, back) especially if lying down: 1.yes 2.no

3.1.5 Did the deceased ever complain of an episode of palpitations (sudden rapid heart beats for one hour or more): 1.yes 2.no

3.1.6 Did the deceased ever complain of recurrent sore throat, joint pain and inflammation (migrating, fleeting and affecting several joints):

1.yes 2.no

3.2 Respiratory system

3.3 Digestive system

Did the deceased ever complain of: 3.3.1 Abdominal pain 1.yes 2.no If yes, since when ? was the pain: 3.3.1.1 Persistent: 1.yes 2.no 3.3.1.2 Localized over one area: 1.yes 2.no If yes: 3.3.1.2.1 Central abdomen: 1.yes 2.no 3.3.1.2.2 Kight upper abdomen 1.yes 2.no 1.yes 2.no 3.3.1.2.3 Lower abdomen 1.yes 2.no 1.yes 2.no 3.3.1.2.3 Lower abdomen 1.yes 2.no 1.yes 2.no 3.3.1.2.3 Lower abdomen 1.yes 2.no 3.3.1.2.3 Lower abdomen 1.yes 2.no 3.3.1.2.4 Loin radiating to the groin (inguinal region) and / or the testicle of same side : 1.yes 2.no 3.3.1.2.5 Relieved by meals (food): 1.yes 2.no 3.3.1.2.5 Relieved by meals (food): 1.yes 2.no 3.3.1.2.6 Mearwarded by meals (food): 1.yes 2.no

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3.3.2 Persistent heartburn: 1.ves 2.no 3.3.2.1 Was it sometimes accompanied by water brash (belching of sour fluid in the mouth : 1.yes 2.no

3.3.3 Diarrhoea: 1.yes 2.no If yes, was it: 3.3.3.1 Acute (less than 15 days) 3.3.3.2 Chronic (more than 15 days) 3.3.3.3 Accompanied by blood 1.yes 2.no Alternating with constipation: 1.yes 2.no

3.3.4 Vomiting blood: 1 If yes: 3.3.4 1 Was the blood:	.yes 2.no							
3347 Did this vocatir	1.3.4.1 was used of the stand of blood last until death 1 yes 2 no							
3.3.4.3 For how long before death:								
								romiting blood: 1.ves 2.no
If yes:								
3.3.4.5 What was it								
3.3.5 Normal stools with	h bloed in the stools: 1.yes 2.no							
If yes:								
3.3.5.1 Was the blood:	Lred 2.dark brown							
3.3.5.2 Did the sympto	ms last until death: 1.yes 2.no							
If yes:								
3.3.5.2.1 For how long	before death:	month(s)						
3.3.5.3 Was the deceas	ed or any member of the family inform	ed of the nature or cause:						
1.yes 2.no								
If yes:								
3.3.5.3.1	What	was						
3.3.6 Jaundice: 1.yes 2	.no							
If yes:								
3.3.6.1 For how long b	efore death:	days						

3.3.6.2 Did jaundice last until death: 1.yes 2.no 3.3.6.3 Was the deceased or any member of the family told of its nature or cause: What

D'd the patient receive any injection or blood transfusion in the six months prior to developing jaundice?

was

it:

it:

3.3.7 Persistent vomiting: 1.yes 2.no If yes: 3.3.7.1 Did it last until death: 1.yes 2.no

days

3.3.7.1.1 What was the duration: (before death): days

3.4 Urinary system

1.yes 2.no If yes: 3.3.6.3.1

Did the deceased ever complain of one of the following symptoms: 3.4.1 Pain in the loin radiating to groin (see abdominal pain, 3.3.1): 1.yes 2.no

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3.4.2 Blood in urine: 1.yes 2.no If yes: 3.4.2.1 Did blood in urine last until death: 1.yes 2.no 3.4.2.1.1 For how long (before death): ______ month(s) 3.4.2.1.2 Was Blood in urine ever associated with pain: 1.yes 2.no 3.4.2.2 Mas blood in urine:

1.persistent 2.intermittent

3.4.3 Problems in urination: 1.yes 2.no If yes:

3.4.3.1 Decreased volume of urine: 1.yes 2.no

3.4.3.2 Complete retention of urine lasting for more than a few hours:

1.yes 2.no

If yes:

3.4.3.2.1 Was this retention:

1.recurrent 2.transient

3.4.3.2.2 Did this retention last until death:

1. yes 2. no

3. 5 Infectious diseases

3.5.1 Did the deceased ever complain of fever in the month prior to death:

1. continuous 2. intermittent 3. never complained

If continuous or intermittent:

3.5.1.1 Did fever last until death: 1. yes 2. no

If yes:

3.5.1.1.1 For how long before death: ____

Was the fever on alternate days or every day at a fixed time?

Were there chills / rigors accompanying the fever?

Was there continuous fever for more than one week?

3.5.1.2 Was the deceased or any member of the family ever informed of the nature of the diagnosis of this fever: 1.yes 2.no

days

If yes:

3.5.1.2.1 What was it:

3.6 Reproductive mortality

If the deceased is a female aged 12-50 years:

3.6.1 If married and living with her husband OR separated, divorced, or widowed for less than 3 months, did she complain before she died of: 3.6.2.1 Continuous fever: 1 yes 2, no

3.6.2.1 Continuous lever: 1 yes 2. no

3.6.2.2 Vaginal bleeding: 1. yes 2. no

3.6.2.3 Abortion (up to 42 days (6 weeks) before death): 1. yes 2. no

3.6.3 Was she pregnant and delivered before her death (up to 6 weeks before death) regardless of gestation age: 1, yes 2, no

If yes:

3.6.3.1 Where did the delivery take place: 1, hospital 2, home 3, other (specify)

Any significant symptoms or events related to the pregnancy or delivery

- · Unusually large amount of vaginal bleeding before / during / after delivery
- Convulsions
- · Inability to deliver within 24 hours of onset of labour

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- · Severe continuous pain in the abdomen during labour
- · Pain in lower abdomen with fever / foul discharge after delivery

3.7 Malignancies

Did the deceased ever complain of:

3.7.1 The presence of any mass or turnour in any part of the body: 1.yes 2.no

If yes:

3.7.1.1 Where: (specify, if a woman emphasize mass in breast)

3.7.1.2 Did this tumour persist until death: 1.yes 2.no

3.7.2 Continuous loss of weight with no apparent reason 1.yes 2.no

3.7.3 Abnormal vaginal bleeding aside from the menstrual cycle especially after menopause

3.7.4 Lump in the cheek / tongue

3.7.5 Was the deceased or any member of the family ever informed of the possible existence of a malignant tumour or growth: 1.yes 2.no

If yes:

3.7.4.1 Where in the body (specify as clearly as possible) :

3.7.4.2 What was the outlook for the patient: 1.not mentioned 2.good 3.reserved 4.bad (fatal)

3.8 Other

Did the person have obvious loss of weight in the three months prior to death?

Did the person have paralysis / extreme weakness on one side or a particular part of the body? Did s/he have severe continuous unremitting headache ? If yes, was there accompanying fever and inability to bend the head forwards?

Did s/he have convulsions? If yes, did these last until death?

Was the body stiff/ arched back for some hours or days before death?

Was the person unconscious before death? if so, for what duration?

4. Specific information related to malnutrition / starvation

4.1 Food intake (semi-quantitative) – here the interviewer has to estimate the caloric intake if possible based on detailed dictary history.

Daily intake during the week prior to death Moming Noon Afternoon / evening Night Other meals / snacks (Quantify exact amounts of roti, rice, ghat / rabdi (porridge), dal etc. as far as possible)

Daily intake during the month prior to death Morning Noon Afternoon / evening Night Other meals / snacks

Any abnormal or unusual foods being consumed:

 Water intake – Normal / reduced / do not know b. Source of Water - \Comp4\d\VerbAutopsy-Badwani\VA-Adult1.doc



p. Behavioral changes: None /Muttering or irrelevant talk / Unconscious

5. Presumed cause of death

5.1	Fre	m	death	certificate		iſ	available:
5.2		From	1	verbal	auto	opsy	form:
	5.21	Imn	nediate	cause	1	of	death:
	5.22 Underlying cause(s) of death						
	5.23	Contr	ibutory	cause(s)		of	death:

Questionnaire modified from - Mortality and causes of death in Jordan 1995-G:assessment by werbal autopsy S.A. Khoury, D. Massad, T. Fardous, Bulletin of the World Health Organization, 1999, 77 (8)

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GER-1. Page 1 of 3

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3:02

Minutes

Community Health Cell

From:	"American Academy of Anti-Aging Medicine" <newsletter@a4m.org></newsletter@a4m.org>
To:	<chc@sochara.org></chc@sochara.org>
Sent:	Saturday, June 19, 2004 7:20 AM
Subject:	BioTech E-Newsletter
pecial Co	onference Hotel Rates at the Chicago Anti-Aging Expo
4M has secure	a special rate at the Hyatt Regency Downtown. Once these rooms are gone, you will miss out on the opportunity to
ay at the even	nt hotel. Neighboring hotels 2 or 3 blocks away are approximately \$100 per night more. Lock in savings and
phyenience for t	he most comprehensive worldwide conterence in Anti-Aging this year by registering today.
ome About A4	M Membership Anti-Aging Library Directory Store What's Hot? Newsletter Media Site-map Contact

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BIOTECH E-NEWSLETTER Issue June 16, 2004

Compiled by WorldHealth.net N OHS WEEKS HEAGHINES

+ Umbilical cord blood transplants, bone marrow transplants save lives

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"Nursing Home Residents with Alzheimer's Disease Benefited from Continuous Treatment with ARICEPT® (donepezil HCI tablets)

*A small portion of dark chocolate a day keeps heart attacks and strokes awav

+ FAT INTO BRAIN Stom cells from pudge could regenerate nervous system

+ METABOLIC AGING : Theory Turned Upside Down

Seven-year study in mice suggests that longer life comes from higher metabolism, not lower

American 54 Board of AntiAsias 2KAMAR



+ Cause of Aging Confirmed Mitochondrial DNA findings suggest that reversing damage in cellular power plants could increase iongevity Hormone Therapy: Not So Bad After All?

Variations in estrogen and progestin drugs may explain negative findings

+ Scientists smuggle drugs into tumors

· Cigarette smoke transforms healthy saliva into a deadly cocktail that can accelerate mouth cancer

A state of the state A Comparison of the second s

Dr. Nicholas Perticone, MD, FACN

Micholas Penicone, MD, FACN, is a board certified clinical and research dermatologist. A brilliant scholar, Dr. Perricone completed medical school in were in orresponse or different scholar, bit, ernerniss compared Maddat Scholar in Declarities at VyVV Motical Scholar of his Demotelyay Residency at Ford Madical Carter //r. Periona is regarded na tha Father of the Inflammation Theory of Aging H is the author of the two New York Time at 1 sets Sellers; The Parricong Prescription, A Physician's 20 pay Program for Total Body and Face Rejuvekation, (HarperCollins Aug 2020) and The Writhle Cure (Wamer Books.) Dr/Perricone's also hosts a series of award-winning Public Television specials airing nationally on PBS-TV. In September 2003, Dr. Perricone launcheal the Ache Prescription on the loday Show. His next book, the Perricohe Promise, will be published by Werner Books in October 2004.

A thit bledical Advisors



W THIS WEEKS HEADUNES Umbilical cord blood transplants, bone marrow transplants save lives Umbilical cord blood and bone marrow transplants at Loyola University are curing or slowing the progression of many cancers originating in the bone marrow (i.e., leukemia, myeloma) or lymphatic system (lymphoma).

More than 106,000 people in the US each year are diagnosed with these life-threatening diseases.

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6/21/04

Page 2 of 3

Schart Goldman DbG

even il otter destinents nave produced no results, a done marrow dansplant may save the patients

FAASP, DO, FADASIDA Chainman Adda



Repaird State MP 100 President Add

Contact Internation American Academy of Anti-Aging Medicine 1510 West Montana St. Chicago, IL 60614 113-528-1000

Continuous Treatment with ARICEPT® (donenezil HCI tableta) Las Vegas, NV - May 18, 2004 - A new retrospective analysis reported that Alzheimer's patients in nursing homes who were treated with ARICEPT® for at least six months showed greater benefits in cognitive and functional status than patients who discontinued therapy.

+Nursing Home Residents with Alzheimer's Disease Benefited from

The findings, based on data obtained from an assessment tool used nationally by nursing homes, were presented at the American Geriatrics Society Meeting (AGS) today, ...more

- A small portion of dark chocolate a day keeps heart attacks and strokes away

Transplant Program at Loyola University Medical Center, Maywood, iii. ...inore

If you eat a small portion of dark chocolate each day you reduce your risk of getting a heart attack or stroke, say US scientists in a new study.



The researchers found that dark chocolate is high in flavenoids. Flavenoids come from plants and are commonly found in dark chocolate. Flavanoida improve the function of blood vessels and prevent the build up of cholesterol (the bad cholesterol),more

+ FAT INTO BRAIN

Stem ceils from pudge could regenerate nervous system.

Adult stem cells from fat can be turned into fully functioning brain cells suggesting a new approach to treating nervous system diseases.



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which there to could got Mare

Researcher Henry Rice and colleagues at Duke University Medical Center in Durham, North Carolina may have found a way to provide researchers with a virtually limitless supply of stem cells to treat a number of nervous system disorders. ...more



+ METABOLIC AGING : Theory Turned Upside Down Seven-year study in mice suggests that longer life comes from higher metabolism, not lower.



Mice with a high metabolism live longer than their low-metabolism counterparts, a finding that conflicts with a long-held theory of aging and suggests new approaches to extending lifespan.

The findings come from a seven-year study of mice by UK researchers from the University of Aberdeen, the Rowett Research Institute and the Medical Research Council in Cambridge ...more



+ Cause of Aging Confirmed: Mitochondrial DNA findings suggest that reversing damage in cellular power plants could increase longevity Stopping the clock: Genetic mutations in cell power plants appear to speed aging, suggesting that reversing the damage could increase longevity.

Genetic mutations that accumulate in the DNA of mitochondria-the power plants in cells-determine the lifespan of mice, confirming a cause of aging and suggesting ways to slow it down



The findings, by researchers at the Karolinska institute in Stockholm, Sweden, reveal a fundamenta biological mechanism underlying the aging process. ...more

+ Hormone Therapy: Not So Bad?

Pills popped? Drugs such as Premarin have been found risky, but a new study supports other types of hormone therapy.

Differences in estrogen and progestin drugs mean that women should not rule out harmone therapy after menopouse despite highly publicized



6/21/04

Page 3 of 3



nive repuits, a new study suggests.



+ Scientists smuggle drugs into tumors

Disguising a molecule to get it past the body's immune system could greatly enhance the success of a groundbreaking new therapy, Cancer Research UK scientists report in the British Journal of Cancer"(1) this week.

directly to tumors. But because the therapy uses an enzyme*(3) not neturally found in humans, a patient's immune system can recognize and reject the enzyme before it can do its job. ...more + Cigarette smoke transforms healthy saliva into a deadly cocktail



Contact Dave Deterat al 113-108-0/90 renditivertitievents net



Cigarette smoke transforms healthy seliva into a deadly cocktail that can accelerate mouth cancer, according to new research in the British Journal of Cancer.

Normally, saliva provides a protective buffer between toxins and the ining of the mouth because it contains important enzymes that fight and naturalize hermful substances ...more

0/21/04

22

MP XYES + I laneef Alibhai M.D., Medical Director, MD Cosmetic & Laser Clinic, Abboteford, BC, Canada + Mitchell Chen, D.O., Ph.D., Medical Director of Florida Institute of Health, Clearwater, FL + Michael Klentze, M.D., Ph.D., Medical Director, Klentze Institute of Anti' Aging, Munich, Germany

- * Petrick Quillin, Ph.D., DR, CNA, Clinical Nutritionist, Center for Advence Medicine, San Diago, CA + Fred Vegnini, M.D., F.A.C.S., Clinical Assistant Professor of Surgery, Cornell University, NY
- * Nick Martin, M.D., Lancester Family Health Center, KY * Michael Breen, M.D., Principal, Dr. Michael Breen Assoc, Winnetka, II
- * Ed Lichten, M.D., Clinical Instructor, Wayne State College of Medicine, Detroit, MI
- * Charles Simone, M.D. Director, Simone Protective Cancer Center, NJ

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- * Office lasers / Fillers / Botox
- + Stem Cell Research
- * Regenerative Medicine
- + Nutrition & Concer Prevention
- + Latest Cosmetic / Derm Procedures
- + Diahetes / Metabolic Syndrome X
- + Bio-identical HRT
- + Medical Spas
- + Growth Hormone Therapy
- + DNA & Mitochondrial Repair
- + Obesity Drugs, Bariatric Surgery

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Community Health Cell

From:	Dr. Natz <event@worldneaitn.net></event@worldneaitn.net>
To:	<chc@sochara.org></chc@sochara.org>
Sent:	Thursday, April 15, 2004 6:37 AM
Subject:	Personal from Dr. Klatz

Dear Colleague,

TH

I read of your work on the Internet and I believe you will have interest in advanced biotechnology for the intervention of disorders of human aging. Our medical society will be hosting the International medical events of the year with the 12th Annual worid congress on Anti-Aging Medicine in Chicago, August 20-23, at the Hyatt Regency, and again in Las Vegas at the Mandalav Bay Resort, December 3-5. This is my personal invitation to you.

The A4M is a nonprofit organization of physicians and scientists from over 70 countries worldwide and have grown from just 12 members in 1993 to over 12,500 members today. Our reach is wide as we now provide educational seminars, training, and advanced notcer information to over 100,000 featificare protessionais.

For your convenience Twe included links to the following important resources

- 12th Annual World Congress on Anti-Aging Medicine flier, speakers, topics, and registration. http://www.worldhealth.net/event/
- Our latest Biotech E-Newsletter of breakthrough technologies for aging interventions. http://www.worldheakth.nd/cbn/a4m_040406.html
- Our Society's official web site, <u>www.woriafieatin.net</u>: The #1 source for anti-aging medical information. You can
 ind application information for our society as well as board certification information and requirements for the
 American Roard of Anti-Aeine Medicine.

Thanks for taking the time to review this correspondence. We look torward to working with you, and hope you will join us at our August conference in Chicago. If you have no interest check here and I will remove you from my personal orivate mailing list.

Best Professional Regards, Dr. Ronald Klatz MD, DO, FAOASM President of the American Academy of Anti-Aging Medicine

- Sebrary - Appeing + Headle

Community Health Cell

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	From:	"Network: TUFH Secretariat" <secretariat-network@network.unimaas.nl></secretariat-network@network.unimaas.nl>	
	To:	<hlt-net@nic.surfnet.nl></hlt-net@nic.surfnet.nl>	
	Sent:	Monday, June 21, 2004 5:27 PM	
	Attach:	GI IET9FellowshipApplication.doc	
	Subject:	Fellowship opportunity: Community Based Care for the Elderiv	
	> < <ghet< td=""><td>TSFellowshipApplication.doc>></td><td></td></ghet<>	TSFellowshipApplication.doc>>	
	> Dear Coll	leagues,	
	>		
	> GHETS is	is very pleased to announce the availability of fellowships to	
	> support th	he development of the Network TUFH Elderly Care taskforce at The	
	> Network:	TUFIPs annual conference in Atlanta, Georgia, USA, from October	
	> 6-10, 200	04. This year, GHETS is offering partial fellowships to support	
	> travel to t	the Network: TUFH conference for colleagues in developing	
	> countries	with a demonstrated commitment to community based care for the	
	> elderly an	ad an interest in participating in and leading the activities of	
	> the Netwo	ork: TUFH elderly care taskforce.	
	>		
	> The numb	ber and amount of fellowships awarded by GHETS will be determined	
	> according	to criteria established by the Executive Committee of the	
	> Network:	TUFH Elderly Care Taskforce. Please be aware that applicants	
	> from high	income OECD countries are not eligible for GHETS fellowship	
	> runding.		
	>		
	> To be con	nsidered for a GILFTS fellowship, applicants must	
	> 1. Suoma	and receive approval for an abstract describing their work in	
	> communit	ty based care for the elderly. Abstracts must be submitted on-mite	
	> at <u>http://t</u>	to the attached application (2 page) and rature to CHETS	
	> 2.Comple	ident@abate ara) no later than Thursday, July 1, 2004	
	>2 Submit	all conviced supporting documentation including a signed letter	
	> of gunn	and an institutional latterhead from the leadership of the	
	> anniicante	s institution by July 1 2004	
	> approxima	a matterior by sury 1, 2004.	
	> Applicatio	ons should be submitted via fax (270-514-1741) or email	
	> (bridget(a)	shets org) by July 1, 2004. Fellowship recipients will be	
	> notified by	v nid-July.	
	>	,,	
	> Please not	te that elderly care fellowship funds are extremely limited. The	
	> Executive	Committee anticipates that awards will only partially cover the	
	> expense o	of attendance at the Network: TUFH annual meeting. Applicants are	
	> encourage	ed to seek other sources of support, including their institutions,	
	> for conter	rence-related expenses, and to base estimated expenses on the	
	> most cost-	effective arrangements available. Cooperation in keeping	
	> fellowship	p funding requests as low as possible is greatly appreciated, and	
	> will allow	CHETS to support as many qualified applicants as possible.	
	>		
	> Please und	dertake the following steps as soon as possible:	
	> * Registe	er for The Network: TUTTI 2004 annual conference in Atlanta,	
	> Georgia, (USA, and make your notel booking, see	
	> <u>http://ww</u>	wille-fielworktuin.org/conterence/registrationition.asp. Fieldse be	
	> aware that	t a latter from The Network: TIFFH to support your visa application	
	> hu confer	ning your registration for the conference: see	
	> http://www	my the networkfully org/conference/information.asp and click on	
12	~ Mica Anal	listion	
v	> + Anniv to	or a US visa if required: see	
	> www.trav	el state gov/visa services html for visa application information	
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 > (this process should be started as soon as possible) > "Make airline reservations > > If you have any questions about the application process, please contact > the GHETS office at bridget@ehets ore. We look forward to welcomine the > future leadership of the Network: TUFU Elderly Care Taskforce in Atlanta > this October. > > Sincerely, ~ > Dr. Larry Chambers > Chair, Network: TUFH Elderly Care Taskforce > Élisabeth Bruyere Research Institute, Ottawa, Canada > > Dr. Abraham Joseph > Past Chair, Network: TUFH Elderly Care Taskforce > Director, Schieffiein Leprosy Research & Training Ctre > Karagiri, Vellore District, India 1 > Jessica Greenberg > Coordinator, Network: TUFH Elderly Care Taskforce > Executive Director, Global Health through Education, Training and Service > (GHETS) > > Bridget Canniff Fellini > Coordinator, Network: TUFH Elderly Care Taskforce > Director of International Programs, Global Health through Education, > Training and Service (GHETS) You have received this message because you are subscribed to HLT-NET, an email list for The Network: Towards Unity for Health

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This festival rekindle many memories of A Happy Divali



Dear Friends,

Diwali is here, the brightest day of the year. A time for radiance, generosity and goodwill, a time when we count our blessings, and spare a few thoughts for those less fortunate than us.

It does not take much to make a difference. A small contribution from you will go a long way to spread joy and happiness in the lives of the destitute elderly, by supporting :

- Cataract Operation, thereby giving precious gift of sight.
- Our Adopt-A-Gran Programme, thus ensuring that their basic necessities are provided for.
- Our Mobile Medicare Programme, whereby we provide free medical treatment to the poor eld'orly living in slums and villages all over the country.
- Our Cancer Detection and Care-giving Programme for the poor suffering community to ensure timely support for the victims.
- Our Counselling / Training for the Care-givers of the Alzheimer patients.
- Our Day Care Centres, Old Age Homes and Home Care Initiatives.

As the sparkles come out on the eve of Diwali, let us also send rays of kindness into the twilight of veteran lives.

Once again we wish you A Happy Diwali.

Yours sincerely,

Mathew Cherian Director General

(Since 1993, all donations to HelpAge India are 100% TAX Exempt under section 35AC and 80GGA of Income Tax Act, 1961 for projects covering medical care to old persons, leprosy and cancer patients, provision of homes to old persons, rehabilitation of old women and conducting eye camps. Our application for renewal is pending with the Govt. of India) Yes, I want to make a difference and see a smile on ageing faces this Diwali. Please accept my contribution of: Bs.2,500/-Bs. 1.500/-Bs. 2.000/-U Others Rs. Bs. 1000/-Cheque / DD No..... Name..... Address Tel · For payment by Credit Card Credit Card No. Name of Card......Cardholder's Signature..... CVV No. (Last three digits of the number at the reverse of your credit card..... (for Diners card only) Master Card/Visa card/American Express/Diners Card only. HelpAge India



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C-14, Qutab Institutional Area, New Delhi-110 016 Tel.: 51688955 - 59, Fax : 91-11-26552916 E-Mail : helpage@nde.vsnl.net.in ND/D/04



Florida that had been largely reported by an uncredited intern. Brage further enraged the newsroom when he claimed that *Times* national reporters did things like that all the time. When Raines issued a mild and tardy response, many of his people felt he had sold them out.

The Bragg case caused a minor public flap compared with Blair's, but it was ulti-

> LELYVELD The interim edite

BLAIR

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mately more damaging to Raines. Journalists started giving anti-Raines quotes to competitors; they ranted against Bragg and Times management on a popular website for journalists. It didn't help that when Sulzberger went to the Times Washington bureau for a brown-bag lunch, an employee said, "he got a harsher message than he expected."

Some have speculated that his family, particularly his father, pressured him to act, but Sulzberger says that although he talked with family members, he made the decision to accept Raine's resignation himself. He also insists that he did not order the editors to quit. There was no single 'ahi' moment.

There was a sense from the two of them that the hill that they had to elimb was becoming too steep. And that the cost of that to the institution was becoming too great," says Sulzberger, "And, sadiy, I had to agree."

Sulzberger named Joseph Lelyveld, Raines' predecessor-a measured manager, liked in the newsroom - to be the interim executive editor while a replacement search is under way. Sulzberger tells TIME he's looking for a "great journalist" who is "an effective leader and a manager"-which, in the wake of the Raines war, may be more than mere corporate-speak. "If employees are happy and fulfilled," he says, "generally what they produce is good," Times employees say they are relieved to have a respite from the turmoil with Lelyveld, who addressed the newsroom Friday, ending with four simple words: "Let's go to work." -Reported by Amanda Bower, Jodie Morse and Andrea Sachs/ New York and Viveca Novak/Washington



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nobilized the staff for all-out at the heads of the Times's titonally had leeway in detories to cover, and as the crid Raines' top-down crisis ame business as usual, it bethe shook up the staff, givsignments to cronies. He was domineering, Hel aunched a st the Augusta National golf on of women and then was at esponsible for spiking two ns that didn't square with the

, many successful leaders are s-your boss, perhaps. But med Raines' leadership into a sue. That Blair, a smooth talkated himself with Raines and long uncaught despite warnsloppy work was blamed on 1g favorites and his unwillingTHE END OF RAINES' REIGN: The former executive editor, left, says goodbye, as Sulzberger, center, and Boyd, far right, look on

ness to listen to others. "This was very quickly not about Jayson Blair," says a *Times* staff member, "but about Howell and the star system he created. The level of anger was just out of control."

Sulzberger, who often tells interviewers about the importance of making mistakes in life, stood by his editor when the crisis broke, saving he would not accept Raines' resignation. But Sulzberger also took an aggressive role in trying to gauge newsroom discontent, including holding a meeting of hundreds of employees in a Times Square movie theater-which made it clear that Raines and Boyd needed to act very fast to fix morale. Among other things, the paper appointed a committee to make management suggestions-and began looking for other Blairs. Then came a second scandal: Rick Bragg, a Pulitzer prizewinning feature writer, was suspended after he filed a story about oystermen in

THEALTH THEAGE OF ARTHROUGH OF THE SEARCH WHAT YOU CA

WE'RE HEADED FOR AN EPIDEMIC OF JOINT DISEASE. WHAT YOU CAN DO TO PROTECT YOURSELF

By CHRISTINE GORMAN and ALICE PARK

THE FIRST SIGN IS OFTEN A TWINGE IN YOUR KNEE OR YOUR BACK or some stiffness at the base of your thumb. Or maybe you're getting out of the car and a sharp pain shoots down your leg from your hip to your calf. "Nothing serious," you think. "I must have just strained something. I'm too young to have arthritis."

Think again. If you are within even shouting distance of middle age, chances are you have osteoarthritis, a degenerative disorder in which the cartilage—the natural shock absorber that cushions the insides of your joints—begins to break down. Doctors used to think of it as a disease of old age, but they new believe that this form of arthritis, the most common of about 100 types, begins its relentless, initially painless course when you're still in your 30s, 20s or even younger. Most of the time you won't suspect anything is wrong until you're in your 40s or 50s and begin to feel those telltale twinges, signs that the disorder may be starting to affect your bones. By then the damage has been done, and even the best treatments can't do much more than ease the pain and try to maintain the status quo in what are already degenerating joints.

KNEE

New studies show that runners are at no greate risk of arthritis, as long as thei joints are properly aligned

RHEUMATOID ARTHRITIS

The Other Crippling Joint Disease

A stebilitating as osteoanthrilis can be, it at least develops gradually. That may not seem like much consolation uniti you consider the other arthritis—freumatoid anthritis (RA)—which in severe cases hits like a freight train. "People who are jogging one day." says Dr. Stanley Cohen of Dallas" St. Paul Medical Center, "can't get out of bed two weeks later."

Although the symptoms can be similar, the diseases are very different. Osteoarthritis is focused on a particular joint; RA is a systemic disease—an autoimmune disorder in which the body's defense system attacks the joints through the thin layer of cells called the



COPINC: Renoir kept painting only by tying a bursh to his gnarled hand synowum that line and lubricate the joints. The runaway immune response clogs the synowium with infection-fighting calls that release proteins calls due to the sense are compounds that hell enginged with new block vessels and begins to grow, kudu-like, penetrating and further dramaging cartilage and born.

The most visible symptoms of RA are swollen joints and cripping stiffness, particularly of the hands and feet. It can cause fatigue, fever and loss of appetite. It can also affect the heart and lungs and their surrounding membranes. The disease, which afflicts 2.5 million people in the U.S., usually hits between ages 30 and 50, but it can strike at any age, including childhood. It is three times as common in women as in men and can shorten life by a decade.

When RA was given its name in the 19th century, those who suffered from ti--including impressionist master Pierra-Auguste Renoil--had little to look forward to beyond life in a wheelchair. Even in the 1950s, says Cohen, few treatments were available other than signin or contissen, a powerful antiinflammatory with severe side effects when used a thijd hosages. Tojections of gold saits also provided some reliab attrabudg no concerliably says of the attrabudg no concerliable says of t

> "if we treat early and we treat aggressively." Dr. Anand Malaviya, India's foremost expert on the disease, warns that in Asia this is a complicated order. In India alone, he says, there are some 10 million people with RA. Roughly 70 000 specialists would be needed to treat them all: India has between 50 and 100. "The shortfall is staggering" and the consequences of misdiagnosis severe. "Giving patients some sort of alternative herbal cure or therapy, or even magic, can be disastrous. It can kill a natient " Malaviva adds

Today the most effective treatments are combination therapies, Methotrexate, a cancer drug that has been used to treat RA for 30 years, is augmented by other drugs, including the new but costly "biologics" such as etanercept (Enbrel) infliximab (Remicade) or anakinra (Kineret). These are genetically engineered versions of naturally occurring molecules that bind or block the activity of cytokines. Also in early development are drugs designed to reduce the formation of the blood vessels that feed the growth of the synovium.

Researchers have discovered a genetic marker that is often associated with RA's earliest onset and most severe cases. Yet not all RA sufferers have the marker (and vice versa), which makes scientists wonder whether RA is a single disease. Environmental factors might also play a role, although no one knows whether the trigger is a virus. a bacterium or something else Autoimmune diseases are always tricky, But even if RA doesn't yield to a simple fix, it is becoming easier to manage for those who can get proper treatment -By David Bierklie



BY 2020, SCIENTISTS EXP ECT SOME 40 MILLION AMERICANS WILL SUFFER FROM OSTEOARTHRITIS

The situation with arthritis is about to get worse-a lot worse-and very soon. It's almost as if we were watching the formation of an epidemiological perfect storm. Across Asia, as across the world, you have an ever-expanding population that's living longer than ever before. You have old cultural and societal habits (squatting, praying) and newer ones such as high-impact exercise and video gaming that are adding more and more stress onto the body, essentially putting a down payment on pain and discomfort later in life. Top it off with a generation of Asians who are heavier than previous ones and whose weight is literally squeezing the life out of their joints. All this on a continent where education about arthritis is limited, as is the expertise needed to treat a surging demand.

NECK

Arthritic joints might produce bony spurs that press on nerves, leading to numbness or weakness in an arm or a leg appointed, scientists are starting to gain the kind of insights that can lead to more effective treatments and better strategies for heading off trouble before it begins.

How complex a process are we talking about? Doctors used to think that cartilage was the beginning, middle and end of the osteoarthritis story. Now they know that cartilage is important, but so is everything that surrounds it–muscles, bones, tendons and ligaments. The damage caused by wearing ill-fitting shoes, suffering a football injury or spending day after day stooped over in a field can certainly give rise to arthritic joints. But the worst problems often stem from basic differences in the body's biochemical makeup. For example, some people's cartilage seems to resist damage better than others. In addition.

HEALTH

In the U.S., estimates show there are 20 million people with arthritis, a number projected to grow to 40 million by 2020. Getting a statistical measure across Asia is more difficult. And other, more deadly diseases tend to grab more attention. But when you consider the estimates that do exist for Asia's arthritis victims-150 million in India, at least 65 million in China. 10 million in Japan, 1.6 million in Taiwanalong with unanimous testimony from doctors that the number of arthritic patients is rising significantly, it creates a picture that, for Asia's nations and healthcare budgets, looks a lot like arthritis itself: painful in the short term, potentially crippling down the line.

¹What's more, many would-be patients don't know that something can or needs to be done, or they don't have enough information to make an informed (and asde) decision about their care. ²Arthritis is a huge problem in our society.³ says Dr. Koh Wei Howe, president of Singapore's Rheumatoid Arthritis Society. ³There are many sufferers out there who are not avare of the available treatments. Some dont even recognize that they have arthritis.³

There exists, however, the possibility of some relief amid all the aches and pains. Researchers are paying a lot more attention to osteoarthritis these days. They have discovered that what they thought was a fairly straightforward mechanical breakdown of the joints is a much more complicated process with lots of component parts. Although this means that patients hoping for a quick fix are likely to be dis-

38
ANATOMY OF A BREAKDOWN

Arthritic

knee

Doctors used to think that failing cartilage caused osteoarthritis. Now they know it is a complex process involving muscles, tendons, bones-even genes



A HOST OF CULPRITS

CARTILAGE: Made up of water, proteins and sugars, cartilage is the body's shock absorber. Injury. age and many other factors can cause cartilage to break down, but the end result is the same: without its cushion, bones start to grind against one another

MUSCLES: These support the ints. The quadriceps, for ample, are responsible for holding up the knee and relieving some of the stress of walking and running. Weak guads can put too much strain onto the joint, leading to tears in the tendons

BONE: While bone normally responds to eroding cartilage by sending out spurs and other odd growths, sometimes it's the other way around: changes in bone structure that affect the shape of a joint can trigger a breakdown in the cartilage

TENDONS AND LIGAMENTS: By connecting and anchoring muscles and bones, these provide support or the joint. If they are torn in an jury or weakened from lack of use, the cartilage in the knee is forced to bear more weight, hastening its collapse

INFLAMMATION: As cartilage degrades, immune cells swoop in to engulf and destroy the dying tissue. In their zeal, they even attack healthy tissue. The debris, including toxic enzymes, can build up in the fluid of the joint, causing painful swelling

GENES: More than half of arthritis sufferers are born with mutations in their genes that control cartilage formation and destruction. These aberrations can result in cartilage that is weaker to begin with or that degrades faster than it should

HEALTH

researchers have discovered an array of | bones begin to grind against one another. biochemical messages that are traded between bones, muscles and other parts of the body and play a key role in keeping joints healthy. "Ultimately, we think it's the biochemical approach that's going to solve the riddle of arthritis," says Dr. Mitchell Sheinkop, an orthopedic surgeon at the Rush-Presbyterian-St. Luke's Medical Center in Chicago. "Someday you may pop a pill and your cartilage will continue to grow, but that's 10 years away-at least." Until then, what doctors would like to

have is some kind of test that will identify people in the earliest stages of osteoarthritis before too much damage has occurred That way their treatments might stand a better chance of arresting the degenerative process before disability sets in Unfortunately, conventional X rays, which give very detailed pictures of bone, don't provide very good images of cartilage. And researchers haven't vet discovered any biological markers in the blood that reliably tell them, "Hey, this person's cartilage is starting to fall apart. Do something!"

To understand the latest insights and where they might be leading, it helps to know a little bit about how a joint is put together, and there's no better place to start than with the cartilage. Like so many tissues in the body, cartilage is composed mostly of water. Indeed, you can think of it as a damp sponge. The spongy part contains several important components, including the chondrocytes-cells that generate new bits of cartilage-and various molecules that give the "sponge" its structure and help hold it together.

With every step we take, our moving body puts pressure roughly equal to three times our weight on the knees and hips. As that pressure is distributed across those joints, cartilage is compressed, absorbing most of the load. And, as you might expect with something that resembles a damp sponge, water is squeezed out of the cartilage into the space between the bones. Once the pressure is released, the water flows back into the cartilage, carrying with it nutrients that were picked up from the synovial fluid, which fills the joint. This constant fluid exchange is critical to maintaining healthy, pliable cartilage and explains why joint-moving exercises-such as walking-help delay the progress of osteoarthritis.

Sometime between ages 40 and 55, the activity of the chondrocytes starts slowing down and the cartilage takes longer and

This is a normal consequence of aging, but aging isn't the only culprit. Something as simple as falling on an jey sidewalk or putting on some extra weight can increase your risk of osteoarthritis, Anything that puts extra stress onto the joints will wear out the cartilage that much faster.

Now the first wrinkle: "It appears that not all cartilage is created equal." says Dr. Roland Moskowitz, president of the Osteoarthritis Research Society International in Washington, D.C. Ankles, for example, bear the same loads as knees and hips. Yet most people, unless they're ballet dancers, don't get osteoarthritis of the ankle. Similar discrepancies exist in non-weight-hearing joints as well. The wrist, for instance, is much less prone to



osteoarthritis than the joint at the base of the thumb. It could be that ankles and wrists have some mechanical advantage that protects them from osteoarthritis. But preliminary evidence suggests that the real advantage, at least for ankles, is biochemical: there is something in their composition that allows them to bear greater loads and respond to changes in the joint without breaking down

Some evidence for this somes from related research on hones. Most people think of bones as inert objects whose only job is to keep our bodies from collapsing into a puddle of flesh. But bones are actually quite active tissues, constantly building and rebuilding themselves from the inside out. If you break a hone, the body produces repair proteins that direct cellular activities as the bone knits itself together. When investigators take these so called osteggenic proteins and sprinkle tham on lah samples of damaged and lags, he canha longer to replenish itself. As the cushion of | lage begins to repair itself. "Now here cartilage grows progressively thinner, the | comes the interesting part," says Dr. Klaus

WHAT YOU CAN DO

You don't have to suffer. There are many ways to find relief

DRUGS

There is still no cure for arthritis but many medications can relieve the nain in stiff joints = OVER THE COUNTER PAINKILLERS. For mild pain acetaminophen should be your first choice, as it relieves discomfort without damaging the digestive tract. If pain persists, your doctor might recommend aspirin or ibuprofen, which can reduce the swelling and damage due to inflammation: anti-inflammatory drugs, however, can be harsh on the stomach

COX-2 INHIBITORS: These newer analgesics tend to cause fewer stomach problems than traditional anti-inflammatories. But they are expensive, and recent studies have linked them to heart problems TETRACYCLINES: These

antibiotics were designed to kill germs, but they can also slow erosion of the cartilage HYALURONIC ACID:

Injections of this natural lubricant particularly in the knee, can ease pain for as long as a year

EVENTION

While there is no guarantee that anything you do will prevent osteoarthritis, here are some steps you can take to keep your cartilage as healthy as possible

Kuettner, professor of biochemistry at Rush-Presbyterian-St. Luke's, "The ankle joint responds better than the knee joint to osteogenic proteins." Is that why the ankle rarely gets osteoarthritis? "We don't know." he says, "but it's a hint in that direction."

Another hint comes from the observation that women with strong, healthy bones-the kind least susceptible to the



CORTICOSTEROIDS: Shots BONE FUSION: Fusing hones of steroids, which reduce inflamtogether with pins or plates can mation, can provide a short-term eliminate the pain caused by a fix for joint pain. Continued badly damaged joint: the joint. injections, however, can worsen however, will never bend again a damaged joint by masking JOINT REPLACEMENT: When discomfort and enabling you to the bones in a joint are damaged continue destructive activities, beyond repair, a substitute joint Recause their pain is limited to can in some cases be fashioned specific joints, osteoarthritis out of plastic or metal. Total hip sufferers don't need the widerreplacement is the most common. ranging effects of but almost any joint, including the knee, thumb, elbow and corticosteroid pills



If nain nersists surgery can either relieve the pressure on joints or replace

them altogether ARTHROSCOPY: In this minimally invasive procedure. doctors clear away dying cartilage and smooth out rough joint connections through slit-size incisions A recent study suggested that in some cases, arthroscopic surgery was no better than sham surgery-it seems to

WATER WORKOUTS: The buoyancy of water can help you work best when the joint is move stiff joints without gravity's still mechanically sound weight-bearing pressure

shoulder, can be replaced

or rin away from

bones, requiring

EXERCISE

Moving arthritic

but if you don't

ioints might hurt.

exercise them regularly they

can permanently freeze up

or repair them

surgery to reattach

TISSUE REPAIR: Failing joints

can cause surrounding muscle,

ligaments and tendons to tear

KEEP MOVING: Flexing joints lubricates and protects them, so exercise regularly. But avoid high-stress activities that pound on knees or hips STAY SLIM: Carrying too much weight

puts extraordinary stress onto the knees,

brittleness of osteoporosis-are at greater risk of developing osteoarthritis. Again, doctors suspect a complex interplay of mechanical and biochemical factors. Healthy bones can support heavier loads. They also tend to replace old bone cells with new bone cells at a pretty fast clip. But somehow the biochemical signals responsible

TIME, JUNE 16, 2003

RECUMBENT BICYCLE: The reclining position takes the

hurden off such susceptible joints as the knees and hips WALKING: If it doesn't hurt too much, walking is one of the best ways to keep joints-from the ankles to the shouldersfrom seizing UD

LOW-IMPACT AEROBICS Any exercise that doesn't put nounding pressure on the joints can help build up muscle and keen ligaments and tendons flexible enough to give the joints the support they need

ALTERNATIVE THERAPIES

If taking standard pain-relies medications makes you uncomfortable, you may want to consider some of these alternative remedies ACUPUNCTURE: The Chinese traditionally believed it relieves pain by realigning of (life energy). Western doctors think the judicious placement of needles might actually work by stimulating the release of endorphins, the body's own painkillers

GLUCOSAMINES: Preliminary evidence suggests that these supplements. derived from lobster and crab shells. might help relieve arthritic pain possibly by encouraging cartilage growth CHONDROITIN SULFATES Chondroitin is believed to help keep cartilage from

breaking down; many arthritis sufferers take it with glucosamines -- By Alice Park

hips and ankles. Shed excess pounds to take a load off the joints BUILD MUSCLE: Joints need a strong support system; maintaining muscle tone will help stabilize knees. hips and shoulders

ger even greater damage to the cartilage. Or is it the other way around? Is it damaged cartilage that gets the process started , by sending aberrant signals to the bone? "At this point, it would be a mistake to fight bitterly over whether osteoarthritis starts in the bones or cartilage, because in the end there may be different forms of the disfor the bone's increasing turnover rate trig-for the bone's increasing turnover rate trig-

HEALTH

at Harvard University. "In some cases, it may start in the bone. In others, it might start in the cartilage

In a 10-year study of American families that include members who have developed osteoarthritis in their 40s and 50s. Olsen's group has identified at least three genetic variations that make the cartilage of these patients more susceptible to overloading Other scientists have found at least a dozen cartilage-disrupting enzymes that annear to be overactive in osteoarthritis. Yet even the interaction between hones and cartilage doesn't tell the whole story. You also need to take into account the ligamentsthose tough bands of tissue that connect mes to bones-and the muscles that surmd and stabilize the joints. Ligaments can get stretched or torn, and muscles can atrophy from underuse, disrupting a joint's finely tuned mechanism. Take, for example, the quadriceps, the

large muscles on the front of the

thighs that help raise and lower the legs. "It's common knowledge that patients with os- teoarthritis of the knee will have weakness in the quadriceps." says Dr. Kenneth Brandt, a rheumatologist at Indiana University in Indianapolis. For a long time, physicians assumed this was because their patients' pain prevented them from exercising. But five years ago, Brandt and his colleagues began studying a group of 400 elderly people livin central Indiana and disered, much to their surprise, that weakness in the quadriceps in some cases preceded the advent of osteoarthritis It makes sense. The stronger

the muscles, the greater the load

they take off the joint thus limiting damage to the cartilage. Brandt's group is trying to determine whether healthy seniors who strengthen their quads by doing exercises with elastic bands can delay, or possibly prevent, the disabling consequences of osteoarthritis in their knees, Professor Mohd Farooque, former head of orthopedics at the All India Institute of Medical Sciences in New Delhi, says this is particularly applicable in Asia; "In the West, arthritis is seen much more in the hip, but here it is much more in the knee. This is because we sit like Buddha, we squat on the toilet, we kneel to pray, and it puts the knee under extreme stress. If it's a daily activity, the muscles and joints adjust. But if people, say, don't pray as often as they might, then it can do a lot of damage."

started, the damage to the joint eventually begins to grow. That's when the body's immune system gets into the act. White blood cells rush into the joint and release destructive proteins that chew up the pieces of damaged tissue. This so-called inflammatory process, which is often but not necessarily accompanied by swelling. works well when the body needs to fend off an acute attack, say, from invading viruses or bacteria. But when the problem is chronic, as in osteoarthritis, the white blood cells might overreact, repeatedly releasing so many "monping up" proteins that even healthy tissue is laid waste. In rheumatoid arthritis, the immune-system response is particularly aggressive.

So what can you do? The first step for most patients is to try to get some immediate relief. About 15% don't seem to experience inflammation; for them, over-the-

HANDS Osteoarthritis of the fingers and the base of the thumb Soaking the fingers in warm water often helps

counter painkillers like acetaminophen (Tylenol) are often all that's necessary to control their symptoms. Things become more complicated when inflammation is involved. Western standbys like aspirin or ibuprofen are pretty good antiinflammatories, but long-term use can trigger dangerous side effects such as internal bleeding. Traditional remedies abound as well: acupuncture, massage, hot-spring baths, herbal ointments and more targeted (and dubious) palliatives such as sour plum juice (in Taiwan) or deer horn and tiger's penis (in China). Newer drugs, such as COX-2 inhibitors Vioxx and Celebrex, tend to be more effective but aren't vet available in all Asian countries. Some researchers believe there is too

However the arthritic process gets | much emphasis on drug treatments for osteoarthritis "There are other things that can improve symptoms as much as nills." says Indiana University's Brandt, Losing weight as little as 4.5 kilos can make a difference, for example, as can strengthening the muscles that surround a joint. Certain exercises, such as tracing circles in the air with the arms, have also proved helpful at keeping the joints from stiffening and losing mobility. Many arthritis sufferers swear by the dietary supplements glucosamine and chondroitin. Preliminary studies suggest they might relieve pain, but the jury's still out on whether they actually promote the growth of new cartilage.

> Sometimes surgery is unavoidable. Each year doctors in the U.S. perform 270,000 knee replacements and 170,000 hip replacements. In Asia, countries like Singapore and Japan-where medical care is sophisticated and patients are relatively

wealthy-lead the way. But the number of surgeries performed is rising all across Asia.

No single approach works best for everyone. As with any chronic condition, there are always some things you can't control. But there's still a lot you can do for yourself. That's the lesson Kazuko Havashi, a 71-year-old housewife from the city of Kamakura, west of Tokyo, has learned. She has osteoarthritis in both knees. When the pain started, at the age of 60, she figured it was a by-product of her youthful days of competitive volleyball and swimming, "I thought it was an old people's disease," she savs, "but I see many younger people having the same problem." Her doctor recommended knee re-

placement surgery, but she's hoping to avoid it, opting instead for three sessions a week of electromagnetic therapy and massages. For exercise, she walks in a swimming pool, and she's trying to shed six kilos. Hayashi is also waiting for the day researchers know enough about what triggers osteoarthritis to come up with more effective treatments. There is a surgery to remove wrinkles: there must be a good treatment being developed for arthritis. I should live long and wait for it." Everybody else should pay attention to those twinges. -With reporting by Joyce Huang/Taipei, Huang Yong/Beiling, Noah Isackson/Chicago, Alex Perry/New Delhi, Constance E. Richards/Asheville, Sean Scully Los Angeles, Nolly Sindayen/Manila, Hiroko Tashiro/Tokyo and Sophie Taylor/Hong Kong

By MATTHEW FORNEY BEIJING

HE BABY WASN'T AS LUCKY AS MY OWN infant son. Both were born in 1995 more than two months prematurely. After gazing at Boy in his incubator in the neonatal intensive-care unit of Peking Union Medical College Hospital in Beijing, I strolled past a row of bassinets containing other newborns. At the end lay a child with seaweed-colored skin stretched tight over his skull. I motioned to the young attending doctor, figuring she hadn't vet noticed his death. She had. The child's lungs were underdeveloped, she explained, and lack of oxygen at birth meant he would suffer severe mental and physical handicaps. The parents, preferring not to raise a disabled boy, asked the doctor to handle the matter. The physician, whose care for my own child had been exemplary, did so by withholding treatment and nourishment from this baby until he died.

Clearly upset by the incident, the doctor told me she had little choice in the matter. China's one-child policy encourages families to raise the best little emperors they can: doctor-aided euthanasia is not uncommon when children are born with birth defects. Infanticide is just one of the many ethical compromises forced upon China's doctors by an authoritarian government. Obstetricians under orders from bureaucrats perform late-term abortions, and psychiatrists commit sane political dissidents to mental institutions. In March and April, hundreds of doctors knew that Party officials were risking lives by denving the scope of the same epidemic. Only one, 71-year-old military doctor Jiang Yanyong, went public with damning information. His colleagues, meanwhile, abetted a scheme to hide SARS patients in Beijing from World Health Organization inspectors. "Medicine is supposed to be the most ethical profession," says Oiu Renzhong, a medical ethicist at the Chinese Academy of Social Sciences, "but Chinese doctors work in the most unethical environment."

Even if the county's physicians subscribed to the Hipporatic odth, the ancient moral dictum that guides Western medical workers, they would have to violate it. In Ghina, doctors serve the al-powerful state, and when a professional code of conduct conflicts with the Party line, the latter often holds sway. 'Of course it's an ethical problem,'' says a doctor who participated in Beijing's saks cover-up. 'We want to be honest, but if we don't go along, we cant exist.'

Shanghai doctor Zhang Shuyun discovered the perils of following her conscience after exposing abuses at Shanghai's main or-



China's physicians must make life-and-death decisions the Party's ethical compass-and death wins far too often

arty's ethical compass—and death wins far too often

ORPHANS Dr. Zhang Shuyun's revelations of fatal neglect at a Shanghai orphanage exposed widespread abuses in institutions across China



SARS Delitag utilitary

surgeon and Party member Hang Yanyong exposed government secrecy over the true extent of the outbreak

HEALTH

phanage in the early 1990s. For years, the orphanage cleared room for new children by neglecting existing charges until they died, often emaciated and lashed to their cots. Shanghai officials fired Zhang for demanding an investigation. She fled to England with a suitcase full of documents and photographs that became the basis for a chilling 1996 Human Rights Watch report called Death by Default. Her actions helped clean up the orphanage, but today Zhang fears she has sent the wrong message to colleagues back home. She must live in exile. but the man whom Human Rights Watch blamed for covering up the scandal. Wu Bangguo, is No. 2 in the Politburo. "Other doctors will learn from my experience and keep their mouths shut," Zhang says.

The roots of complicity go beyond the fear of being ostracized. In China, required reading for every medical student is On the Absolute Sincerity of Great Physicians, a 1.400-year-old treatise by Sun Simiao that Hippocrates would appreciate. But traditional ethical tracts never addressed the greater role that doctors play as guardians of public health. Confucian Emperors were suspicious of physicians; books published in the Song dynasty encouraged self-diagnosis among citizens. This contrasts with the evolution of Western medical ethics, which stemmed from the pragmatic realization among 18th century European powers that strong armies and workforces depended on good public health, necessitating standard qualifications for doctors, regular hospital inspections and vaccinated conscript pools. But "Chinese physicians developed no group identity of safeguarding the entire population or, if the government goes in the wrong direction, of voicing criticism," says Paul Unschuld, an expert on Chinese medical history at the University of Munich. Today, only half of China's medical

schools offer ethics courses. When such classes are provided, they suggest that thorny issues can always be resolved by adhering to government policy-and that individuals' health and welfare come second. One text, Analyzing Ethics in Clinical Cases, neatly files down the horns of a familiar dilemma. On page 24, the authors present the case of a seven-month-pregnant peasant woman who is forced by family-planning officials to abort. She submits, but the baby survives. When the woman refuses to let the doctors "dispose" of her infant son, the book says practitioners should "act according to the one-child policy land) point out that because medical abortions can affect a child's normal development, she should abandon" her protests and allow euthanasia. If that doesn't work, the authors say, "let the family-planning office decide." Of course, that office ordered the abortion in the first place.

The government ensures that doctors remain powerless by controlling medical societies, which in other countries help set ethical norms. The Chinese Medical Association is run by Zhang Wenkang, the former Health Minister who was sacked in April for covering up sass. In 1999, legal reformers pushed through a law calling for the formation of a truly independent organization, the Chinese Medical Doctors Association. It was established last year-headed by retured officials from the Health Ministry.

Still, there are signs of protest, if not change, Huang Shurong, a peasant from the northern province of Heilongjiang, was committed by psychiatrists to a mental institution five times from 1998 to 2002 for complaining that local officials had taken her best farmland. A website run by the Procuratorial Daily, the newspaper of China's prosecutor's office, last year published a review of her case in which doctors were warned not to comply with police seeking expedient ways of incarcerating undesirables, "Medical staff are an essential link in the chain of evil that produces these abuses, and this should not be forgotten when allocating blame and punishment," the review stated. So far, no punishment has been allocated. Late last month, the World Psychiatric Association took China to task in an unusual statement calling on the country to allow international experts to investigate allegations that psychiatry is used as a political tool.

Meanwhile, Jiang Yanvong, the military doctor who exposed the government's SARS cover-up by publicly accusing the Minister of Health of lving about the capital's outbreak, has become a local hero. The China Women's News ran his photo ahead of those of government officials in a front-page piece headlined HONOR ROLL OF SARS FIGHTERS. Although Jiang has been told not to give interviews, he seems to have escaped retribution. Partly that may be because, as a top surgeon who has saved the lives of military leaders, he could count on protection. In an earlier interview with TIME, he acknowledged that his position allowed him to speak out. Others doclined to take such risks, he said, because "China's system is not built for people to say no."

Inspired by Jiang's courageous stand, more Chinese physicians may begin saying no. I believe the doctor who helped deliver my son, and who couldn't look me in the eye as she explained what she'd done with the other baky, hopes that day will come soon.

45

FOR CENTURIES, PEOPLE HAVE DREAMED OF HARNESSING THE POWER **OF OCEAN TIDES, HAS A** COMPANY IN WALES MADE THE DREAM COME TRUE?

By KATE NOBLE

TIME N

1

SURFING

HE WATER COMES IN, THE WATER goes out, propelled by the perpetual engine of the sun and moon. With 70% of the earth's surface covered by the restless tides and currents of the oceans, the idea of harnessing that movement to serve the planet's energy needs is too tempting to ignore.

Since the Middle Ages people have built tidal mills, trapping an incoming tide in a storage pond to turn a wheel as the water ebbs. But the dream has always been to tap the power of the ocean itself-to harness the force of tides mighty enough to erode and shift entire coastlines. And so later this year a small South Wales company called Tidal Hydraulic Generators (THG) plans to lower a steel frame supporting five 6-m diameter tur-bines to the floor of the Severn Estuary. The tubes will translate the power of the tide as it ebbs and flows into one megawati of electricity, enough to power about 500 homes. The project will be a test run for much larger rigs, with up to 50 turbines apiece, that could produce

enough electricity for a small town. The inspiration for the turbines came on a calm day in 1997 when Richard Ayre, managing director of THG, was working for the marine national park in

44The energy here is absolutely

astronomical.77 -Richard Ayre, managing director, THG

St. Bride's Bay, Pembrokeshire. Trying to ical," thought Ayre, who started won-dering how to generate power from it construction of the five-turbine unit in the Bristol Channel

Because water is 800 times more dense than air, tide power is a more productive energy source than wind power. now commonly used throughout the developed world. Where a wind turbine may be up to 80 m in diameter, a tidal stream turbine need be only 10 m across to produce 50% more energy. Though the blades turn slowly, just 10 revolutions per minute, the rotation generates a great deal of torque-a force that causes an object to rotate. That is then turned into energy via a hymotor that drives the gener-ator. David Bard, managing director of Babte, the engi-neering group that is working with Ayre, thinks tidal stream power have by future. Twice a day the North Sea drains in and out of the Fentland Frich, he says. We estimate that Using fidal stream generators we could meet all or the renewable energy needs of the UK. The Severn Estuary was chosen to bet the new technology because it ho

test the new technology because it has the world's highest

range between high and low tides, around 12 m, and during the

FROM CURR **TO ELECTRIC**

A South Wales comp called THG has desig tidal turbine system. what it will look like

Each blade set can rotate through 180°, seeking the ebb and flow of the tide to provide near continuous energy

INCOMING TIDE

GEN-3-

World Bank Reprint Series: Number Sixty-two

ICDARY

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(continued on inside back cover)

Basic Needs: Premises and Promises

Paul P. Streeten,* World Bank

The objective of a basic needs approach is to provide opportunities for the full development of the individual. It focuses on mobilizing particular resources for particular groups, identified as deficient in these resources. It is contrasted with the income and employment approaches, which neglect important features of meeting basic needs. The essence of the case for the basic needs approach is that the gap between requirements and actual living levels can be filled sooner, and with fewer resources. that by alternative routes. After a discussion of the value and factual premises underfying this approach and of the political and administrative constraints, the problem of a possible trade-off between basic needs and growth, and between basic needs and the New International Economic Order is discussed, and the case for additional aid, in order to make a substantial step towards meeting basic needs by the year 2000, is argued.

OBJECTIVES

The objective of a basic needs approach to development is to provide opportunities for the full physical, mental, and social development of the individual. This approach focuses on mobilizing particular resources for particular groups, identified as deficient in these resources, and concentrates on the nature of what is provided rather than on income. It is, therefore, a more positive and concrete concept than the double negatives like "eliminating poverty" or "reducing unemployment." If does not replace the more aggregate and abstract concepts which remain essential to measurement and analysis; it gives them content. Nor does it replace concepts that are means to broader ends, like productivity, production, and growth, but it calls for changing the composition of output, the rates of growth of its different components, and the distribution of purchasing power.

In addition to the concrete specification of human needs in contrast to *absrace* concepts. and the emphasis on *ends* in contrast to *means*, the basic needs approach encompasses "nonmaterial" needs. They include the need for selfdetermination, self-reliance, political freedom and security, participation in decision making, national and cultural identity, and a sense of purpose in life and work. While some of these "nonmaterial" needs are conditions for meeting the more "material" needs, there may be conflict between others, such as meeting basic material needs and certain types of freedom. For other sets of needs, there may be neither complementarity nor conflict. 'Finally, meeting specific priority

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¹ The notion "basic" does not preclude possibilities of conflicts and trade-offs: since not all needs can be met at once, their hierarchy manifests itself as a succession in time.

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BASIC NEEDS

needs has an appeal to donors and to those taxed, which income redistribution lacks.

INCOME VERSUS BASIC NEEDS APPROACHES

The income approach recommends measures that raise the real incomes of the poor by making them more productive, so that the purchasing power of their earnings (together with the yield of their subsistence production) is adequate to enable them to buy the basic needs basket. The basic needs approach, in the narrow sense, regards the income-orientation of earlier approaches as inefficient, or partial, for several reasons:

(1) There is some evidence that consumers are not always efficient optimizers, especially concerning nutrition and health, or when changing from subsistence farmers to cash earners. Additional cash income is sometimes spent on food of lower nutritional value than that consumed at lower levels, or on items other than food.

(2) The manner in which additional income is earned may affect nutrition adversely. Female employment, for example, may reduce breast feeding and, therefore, the nutrition of babies, even though the mother's income has risen, or more profitable cash crops may replace "inferior" crops grown at home.

(3) There is maldistribution within households, as well as between households; women and children tend to be neglected in favor of adult males. Points (1), (2), and (3) raise difficult and controversial questions about free choice and society's right to intervene, and about effective methods of aiding choice and strengthening and reaching the weak.

(4) Perhaps twenty percent of the destitute are sick, disabled, aged, or ophaned children; they may be members of households or they may not; their needs have to be met through transfer payments or public services, since, by definition, they are incapable of earning. This group has been neglected by the income and productivity approach to poverty alleviation and employment creation. Of course, this situation raises particularly difficult problems of implementation, not only in poor societies.

(5) Some basic needs can be satisfied effectively only through public services, subsidized goods and services, or transfer payments. The provision of public services is of course, not a distinct feature of a basic needs strategy. Emphasis is placed, rather, on investigating why these services so often fail to reach the groups for whom they were intended and on ensuring that they do.

(6) The income approach has paid a good deal of attention to the choice of technique, but has neglected the need to provide for appropriate products. In many developing societies, the import or domestic production of over-sophisticated products, transferred from relatively high-income, high-saving economies, has frustrated the pursuit of a basic needs approach by catering to the demands of a small section of the population, or by preempting an excessive slice of the low incomes of the population, or by preempting an accessive slice of the low incomes of the population, or by preempting and a more even income distribution, which in turn generates the demand for these products, is an essential, disturt feature of the basic needs approach.

(7) Finally, as already mentioned, the income approach neglects the importance of "nonmaterial" needs, both in their own right and as instruments of meeting some of the material needs more effectively and at lower costs. This point becomes particularly relevant if the nonsatisfaction of nonmaterial needs increases the difficulty of meeting basic needs despite income growth.

The selective approach makes it possible—and sooner—to satisfy the basic human needs of the whole population at levels of income per head substantially below those that would be required by a less discriminating strategy of allaround income growth. This point is crucial. Fewer resources are *required*, or the objective can be achieved soner, because a direct attack on deprivation eliminates spending on resources that do not contribute to meeting basic need, among which are: (1) the non-basic-needs items in the consumption expenditure of the poor: (2) part of the nonincentive consumption expenditure of the better off; and (3) investment expenditure, to the extent that its reduction does not detract from constructing the sustainable basic for meeting basic needs.²

In addition, these fewer resources needed show a higher "productivity" in meeting their objective. A combined operation for meeting an appropriately selected package of basic needs economizes in the use of resources and improves the impact, because of linkages, complementarities and interdependencies among different sectors.³

Finally, concentrating efforts on infant mortality, women's education, and even the apparently purest "welfare" component (provision for old age and disability) should reduce desired family size and fertility rates more speedily and at lower costs than raising household incomes.⁴ The causal nexus has not been established beyond controversy, but it presents one of the hypotheses of the basic needs approach.

For these three reasons—saving resources on objectives with lower priority than basic needs, economizing on linkages, and reducing fertility rates (and, on certain assumption, population growth)—a basic needs approach economizes in the use of resources or in the time needed to satisfy basic needs.

A basic needs approach will also tend to make more domentic resources available (1) The output needed to satisfy basic needs is likely to be laborintensive. In countries with high unemployment, this will raise both employment and production. (2) Attacks on malanutrition, disease, and illiteracy result not only in longer life spans and improved quality of life, but also in improved quality of the labor force³ (3) The removal of motives for having large families by an attack on the "correlates of fertility decline" mentioned in the previous

² To the extent that meeting basic needs covers provision for the victims of natural disasters special arrangements are required and the argument of the text applies with less force.

³ Very low fertility rates are registered in countries with low infant mortality rates and high life expentancy.

⁴ Cassen (1976) emphasizes the complex processes connecting these "correlates of fertility decline," with other aspects of development, including income and fertility. Morawetz (1978) confirms statistically the link between basic needs and fertility decline.

³ It is, however, an open question whether the returns to this form of human investment are higher, at the margin, than those from more conventional investment in physical capital.

BASIC NEEDS

paragraph can be (alternatively) regarded as a factor reducing the required resources or as one increasing the available resources. (4) A basic needs approach that harnesses local labor will mobilize and increase incentives for higher production.

More resources may also become available internationally because the pledge for meeting the basic needs of the world's poor as a first charge on our aid budgets has stronger moral and political appeal than most other schemes advanced for the promotion of international assistance. There can be no certainty about this, but it is already clear that the concept has international appeal and may help to overcome the present aid faigue by defining new forms of international cooperation and commitments.⁶

It remains to be investigated how a basic needs approach is likely to affect specific resource constraints—foreign exchange, administrative skills, etc. It might be thought that such a strategy would reduce exports, but it would also tend to reduce import requirements. It would certainly call for more administrative skills, but if local energy can be harnessed, motivation for raising the supply of these skills would be strengthened and the skills are not of a very hier order.

In brief, therefore, a basic needs approach—because it saves resources, mobilizes more resources, and makes these resources more productive—achieves an agreed priority objective sooner than a solely income-oriented approach, even if the latter is poverty-weighted. The "resource gap" is narrowed or closed from both ends.

Two crucial questions remain: one of value and one of fact. The *value* assumption underlying the above argument is that lower weight is attached to the uses of resources that do not meet basic needs. One may object that governments and people who do not accept this value judgment will reject the whole approach, and those that accept it will not need it. But if aid agencies adopt the approach, they may be able to push the unconvinced in the direction of accepting the value judgment.

The crucial factual assumption is that leakages or "trickle-up" effects in a selective system are smaller than in a general system. If the benefits do not effectively reach the needy, the "wastage" of the basic needs approach may be as large as, or even larger than, that of the income-oriented, nonselective approach. This is an important area for operational research and experimentation.

BASIC NEEDS AND GROWTH: A TRADE-OFF?

Critics of the basic needs approach have often stated that such an approach sacrifices savings, productive investment, and incentives to work for the sake of current consumption and welfare.

Basic needs and growth are not strictly comparable objectives. Growth emphasizes annual increments of production and income, and concern for the

⁶ Since food is an important element in a basic needs strategy, and since, given the distribution of votes in Western democracies. food aid is politically easier than finance, properly channelled food aid can make an important international contribution to meeting basic needs.

future. A basic needs approach must also contain a time dimension. It proposes a set of policies that increasingly meets a dynamic range of the basic needs of a growing population.

If basic needs and growth are to be compared at all, the question should be: Does meeting basic needs imply sacrificing certain components of current output or certain components of current incomes? Such a sacrifice then may reduce aggregate growth of income per head by raising the capital/output ratio and/or lowering the savings ratio, and/or raising population growth.

Four types of trade-off can be envisaged:

- between benefits to higher income groups in favor of benefits to lower income groups;
- (2) between non-basic-needs goods and services consumed by all income groups, including the poor, in favor of basic needs goods and services consumed by the poor;
- between activities that create incentives for larger savings and efforts to work in favor of current consumption;
- (4) between goods and services which make a larger contribution to future production in favor of those that make a smaller contribution or none.

All these policies have certain distributional dimensions, in both space and time; they imply decisions about how goods and services are distributed. The concern of those who suzget that basic needs involves a trade-off with growth is that the children and grandchildren of those whose basic needs are met now would have to accept lower levels of living than if the present generation were asked to tighten its bell more [or higher prosperity later.

Ignoring for the moment problems of measurement, the options can be illustrated by four paths. In Fig. 1 we trace the log of consumption per head of the poor on the vertical axis and time on the horizontal axis. Path 1 shows at first lower levels of consumption but, as a result of better incentives and productive



Fig. 1. Comparison of the effects over time of four approaches to consumption by the poor.

BASIC NEEDS

investment, overtakes path 2 at some point $\{\overline{T}_i\}$ and. for ever after, the consumption of the poor is higher. Path 2 starts with higher consumption by the poor but, by neglecting incentives, private and public savings, and productive investment. falls behind path 1 after a certain date, \overline{T}_i . This is how the option is often presented.

It should be clear that sound policies should rule out path 3, which is an efficient way of meeting the needs of the poor.

The rationale behind basic needs, however, is path 4. High priority is given to some components of current consumption by the poor which may then, for a while, fall below the consumption levels that could have been attained by the two other paths. When the present generation of children entering the labor force begins to yield returns, (T_2) , the growth path is steeper than it would have been under 1, and overlakes first the welfare path 2 and later the growth path 1.

Stalinist forced industrialization and the industrial revolution in England followed path 1. Taiwan, Korea, and perhaps Japan followed path 4. Jayng in earlier years the runway for future "take-off into self-sustained growth" by meeting certain basic needs through land reform and massive investment in human capital, especially education. Critics charge that STL Lanka and Tanzania may be following path 2 and Burma path 3. though these experiences have not yet been fully analyzed.

In comparing growth paths, it is important that growth and its components are correctly measured. Basic needs are measured, in the first place, in terms of psysiological needs and physical inputs, and financial costs are calculated from these. Growth, on the other hand, is an aggregate in which the existing, often very unequal, income distribution determines purchasing power, and with it the price weights. A ten percent increase in the income of someone earning \$10,000 is weighted a hundred times more than a ten percent increase in the income of someone earning \$100. Ahluwalia and Chenery (1974) have suggested a modification to the conventional growth measure, which weights initial shares of each income group by their share in the national income, so that the weight of the poorest is the smallest and that of the richest the largest. One possibility is to weight each group equally, according to the number of people (or households, allowing for size and age distribution), so that a one percent growth of the poorest 25 percent has the same weight as a one percent growth of the richest 25 percent. An even more radical system of weighting would attribute zero weights to the growth of income of all income groups above the poorest 25 or 40 percent. and a weight of unity to those below the poverty line. Whatever method is chosen, any discussion of the "trade-off" between basic needs and growth ought to specify what weights it attaches to income growth of different income groups. This would bring out clearly the value judgements underlying the strategy.

The relative importance of different items in the consumption basket is normally determined by their relative prices. We register growth when the consumption of whiskey has risen, even though the consumption of milk may have declined. This is not because we regard whiskey consumed by the rich as more important than milk consumed by the poor, but because the higher incomes of the rich determine the relatively high price of whiskey, while lack of purchasing power of the poor is reflected in the low price of milk. In societies with unequal income distributions, the standard measure for GNP growth, therefore, gives accessive weight to the growth of non-basic-needs goods and deficient weight to basic needs goods.

Having specified the particular resources needed for the particular target groups, and having defined a time profile for meeting the basic needs of a growing population on a sustainable basis, growth will turn out to be the *result* of a basic needs policy, not its objective. Growth is not normally something that has to be sacrificed, "traded-off," in order to meet present needs. On the contrary, in the light of the above considerations, a basic needs approach may well call for higher growth rates than a so-called "growth' strategy. But the time path composition and the beneficiaries (and the measure) of such growth will be different from those of a conventional high-growth strategy.

THE POLITICS OF BASIC NEEDS

It is sometimes argued that basic needs is an ideological concept that conceals a call for revolution. Such an interpretation can be justified neither historically nor analytically.⁷ It is evident that a wide variety of political regimes have satisfied basic needs within a relatively short time. Options for the future are even wider than the limited experience of the past twenty-five years.

It is, of course, frue that the success of different political regimes in meeting basic needs cannot be attributed to their having written basic needs on their banner. Most share certain initial conditions and sets of policies that present important lessons for others attempting to meet basic needs. By starting from a base at which some basic needs were already satisfied, they reduced the time required for meeting other needs, both directly, and through the indirect effect on the quality and motivation of the labor force.

If some political regimes have succeeded in satisfying basic needs within a short period without adopting a basic needs approach as an explicit policy instrument, others have paid lip service to the objective, without succeeding in implementing it. The reasons for this gap between professions and practice are, ultimately, political.

If the failures of certain strategies are due to political obstructions, it is then essential to show how these forces can be key in check. For example, measures to meet basic needs can be implemented by a reformist alliance, in a peaceful manner. Some of these measures, like the cradication of communicable diseases or the preservation of social peace, are clearly in the narrow self-interest of the dominant groups. Others are in the longer-term interest of some groups who could mobilize support for gradual reform.⁸

⁷ Even if justified, it would still require a "delivery system" for revolution.

⁸ In 19th century England, the rural rich campaigned against the urban rich for factory legislation, which improved the condition of the poor, while the urban rich campaigned against the rural rich for the repeal of the Corn Laws, which reduced the price of food for the poor.

BASIC NEEDS

BASIC NEEDS AND THE NEW INTERNATIONAL ECONOMIC ORDER

Developing countries are apprehensive lest a basic needs approach adopted by donors implies sacrificing features of a New International Economic Order (NIEO). But the conflict can be avoided. The differences between the two approaches point to the need to advance on both fronts simultaneously. The NIEO is concerned with formulating a framework in institutions, processes, and rules that would correct what developing countries regard as the present bias of the system against them. This bias is thought to be evident in the structure of certain markets, where a few large and powerful buyers confront many weak. competing sellers; in discrimination in access to capital markets and to knowledge; in the present patent law and patent conventions; in the thrust of research and development and the nature of modern technology; in the power of the transnational corporations: in discriminatory restrictions on migration: in international monetary arrangements: etc. A correction in the direction of a more balanced distribution of power and access to power would enable developing countries to become less dependent and more self-reliant. But the NIEO by itself is no guarantee that the governments of the developing countries would use their new power to meet the needs of their poor.

A basic needs program that does not build on the self-reliance and self-help of governments and countries is in danger of degenerating into a global charity program. A NIEO that is not committed to meeting basic needs is liable to transfer resources from the poor in rich countries to the rich in poor countries.

It is easy to envisage a situation in which the benefits of international basic needs assistance are more than wiped out by the damage done by protectionisi trade measures, by an unequal distribution of the gains from trade and foreign investment, by transfer pricing practices of transnational corporations, by the unemployment generated by inappropriate technology. by brain drain and restrictions on migration of unskilled workers, or by restrictive monetary policies which inflict unemployment. The global commitment to basic needs makes sense only in an international order in which the impact of all other international policies—trade, foreign investment, technology transfer, movement of professionals, migration, money—is not detrimental to meeting basic needs.

The NIEO is a framework of rules and institutions, regulating the relations between sovereign nations: and basic needs is one important objective which this framework should serve. The way to make the institutions accept this objective is to strike a bargain: donors accept leatures of the NIEO if, and only if, developing country governments commit themselves to poverty eradication.

There are those who maintain that integration into *any* international economic order in which advanced capitalist economies dominate is inconsistent with meeting the basic needs of the poor. Pointing to the People's Republic of China (at least until recently), they advocate "delinking" in order to insulate their society, or a group of like-minded societies. from the detimental impulses propagated by the international system. Policies derived from such a view of the world order do not depend, of course, on wringing concessions from rich countries, but can be pursued by unilateral action. On the other hand, those who think that the international system has benefits to offer if the rules are reformulated and the power relations recast, will not opt for complete delinking but for restructure.

A more specific question is how an international basic needs approach is to be implemented in a manner consistent with the spirit of the NIEO. The governments of developing countries are anxious to preserve their full sovereignty and autonomy and do not wish to have their priorities laid down for them by donors. Donors, on the other hand, wish to make sure that their contributions reach the people for whom they are intended. The solution is to be found in the strengthening of existing institutions and the evolution of new ones that are acceptable to both donors and recipients and that ensure that international aid reaches the vulnerable groups. Such buffer institutions and buffer processes would combine full national sovereignty with basic needs priority. They would be representative, independent, and genuinely devoted to the goals of international cooperation.

DEVELOPMENT ASSISTANCE REQUIREMENTS FOR FINANCING BASIC NEEDS

Provisional estimates indicate that a basic needs program would call for an annual investment of \$20 billion over a twenty-year period (1980-2000) at 1976 prices. If recurrent expenditures are added, the annual total costs would amount to \$45-60 billion. If programs are implemented only in the poorest countries, annual investment and recurrent costs are estimated to be \$30-40 billion. This would be 12-16% of these countries' projected GNP and 80-100% of their projected gross investment. Assuming the OECD countries concentrate their effort on the poorest countries and contribute about 50% of the additional costs of these programs, this would call for \$15-20 billion official development assistance (DDA) flows per vera over twenty vears.

At present, ODA flows from OECD countries amount to about 514 billion a year. Of this, the poorest countries receive only about \$6 billion. Only a part of his assistance is now devoted to meeting basic needs, and the resource calculations are based on additional requirements. Nevertheless, it might be asked why the whole of the assistance should not be switched to what is agreed to be a priority objective, so that additional requirements could be greatly reduced. Moreover, if some ODA now going to middle-income countries could be redirected to the poorest countries, requirements could be further reduced.

Such redirection would, however, be neither desirable nor possible. Middleincome countries have a higher absorptive capacity and tend to show higher returns on resource transfers. They, too, have serious problems of poverty. Moreover, a reallocation of ODA flows is politically much easier if it is done out of incremental flows than if existing flows to some countries have to be decreased. The legacy of past commitments and the expectations that they have generated cannot be discarded in a few years.

There are three reasons why additional resources of about \$20 billion per year are needed in order to make a convincing international contribution to basic

144

BASIC NEEDS

needs programs in the poorest countries. First, twenty years is a very short time for a serious antipoverty program. It calls for extra efforst both on the part of developed and developing countries. The domestic effort—economic, administrative and political—required from the developing countries is formidable. At the same time, while the figures for ODA seem large, total ODA flows that would rise year by year by \$25 billion between 1980 and 2000 (averaging \$20 billion per year for the entire 20 years) would still be only 0.43% of the GNP of the OECD countries in the year 2000, substantially below the agreed-upon target of 0.7%. The acceleration (from the present 0.34%) is certainly within the power of the developed countries.

The second reason for additional resources is the fact that the change from present policies to a basic needs approach creates formidable problems of transition. Investment projects that have been started cannot studdenly be terminated. An attempt to switch to basic needs programs while the structure of demand and production has not yet been adapted to them is bound to create inflationary and balance-of-payments pressures. This might result in capital light and added brain drain as local groups anticipating being hurt attempt to safeguard their interests. Strikes from disaffected workers in the organized industrial sector might occur. Unless a government has some reserves to overcome these transitional difficulties, the attempt to embark on a basic needs program might be doomed from the beginning.

The third reason is tactical and political. It is well known that the developing countries are suspicious of a basic needs approach. One reason is that they believe that pious words conceal a desire to opt out of development assistance. And there is no doubt that the pronouncements of some people in the developed world justify such suspicion. If an international commitment to meet basic needs within a short period is to be taken seriously by the developing countries, the contribution by the developed country must be additional and substantial. The essence of a global compact, as announced by Robert S. McNamara in Mania in 1976, is that both developed and developing countries should reach a basic understanding to meet the basic needs of the absolute poor within a reasonable period of time. Such a compact would be a sham if it did not involve substantial additional capital transfers.

FURTHER RESEARCH: TOWARDS A COUNTRY TYPOLOGY

An important conclusion from having identified the distinct features of a basic needs approach is the need for a redirection of research. It is in the areas of the technology of public services, development administration, and development pohitics that future work is likely to yield promising results, although economists as such have little to contribute to some of the principal problems, except work on linkages and externalities. The work should start from an appropriate country twolowy that distinguishes:

(1) between countries with relatively high average incomes per head, in which an emphasis on redistribution of income and assets and a redirection of social services can make a substantial contribution to meeting basic needs, and those with very low incomes, in which growth is an essential condition for meeting basic needs:

(2) between countries whose political system encourages self-reliance and local mobilization and those that will depend heavily on external assistance;

(3) between countries with high population density and little cultivable land, in which land redistribution holds out limited scope, and those with abundant cultivable land in relation to their population;

(4) between smaller countries that can hope for growth in employment opportunities from labor-intensive exports and larger countries in which foreign trade plays a relatively smaller role;

(5) between countries in which a large proportion of the population live in the countryside and where rural development has greater importance and those with a large proportion of urban population.

Different political regimes and different administrative, technological, and ecological conditions are also relevant.

Work will also be needed on the development of systems of monitoring basic needs. Social indicators, methods of developing composite or integrated indicators (such as an extension of life expectancy to comprise the dimensions of basic needs) and their correlation with economic indicators are prerequisites for analysis and policy. Once these are available, we can assess the impact of policies on meeting basic needs.

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146

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DEPARTMENT OF MENTAL HEALTH

EDUCATION IN PSYCHIATRY OF THE ELDERLY

A TECHNICAL CONSENSUS STATEMENT





WORLD HEALTH ORGANIZATION

WORLD PSYCHIATRIC ASSOCIATION GENEVA

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EDUCATION IN PSYCHIATRY OF THE ELDERLY

A TECHNICAL CONSENSUS STATEMENT

This document is a technical consensus statement jointly produced by the Geriatric Section of the World Psychiatric Association and WHO, with the collaboration of several NGOs and the participation of experts from different Regions.

It is intended to provide a basic guide for all those involved in the development and implementation of education in the fields of mental health and mental health promotion for older persons.

KEY WORDS: psychogeriatrics / elderly people / training / health education / mental health care.

DEPARTMENT OF MENTAL HEALTH WORLD HEALTH ORGANIZATION

WORLD PSYCHIATRIC ASSOCIATION

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WHO/MNH/MND/98.4 Page I

CONSENSUS STATEMENTS ON PSYCHIATRY OF THE ELDERLY

The publication of this document represents the culmination of three years of work jointly developed by WHO and WPA, particularly through its Geriatric Psychiatry Section. Of course we are very proud of it and hope it Ill receive the same attention and have the same impact as those of the first consensus statements.

The innovative operational model through which this document was arrived at is indeed already interesting on its own. Although an initiative primarily from WPA, several other NGOs, some of the most relevant ones to the area of Psychiatry of the Elderly were also involved, thus setting a standard which cannot be ignored in future similar exercises. In addition, the meetings for deliberations were hosted by the Psychogeriatric Services of the University of Lausanne, which is a WHO Collaborating Centre for Research and Training in Psychogeriatrics. The private sector was also involved, since it was financially supported by a generous grant from Pfizer Pharmaceuticals, Pfizer, Inc.

We would like to express our gratitude to all institutions involved as well as to those who participated in the conference, and who are named in Annex. Our particular appreciation goes to the two Co-Chair of the meeting, Prof. J. Wertheimer and Prof. T. Arie and to the Co-Rapporteurs, Dr N. Graham and Prof. C. Katona.

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WHO/MNH/MND/98.4 Page ii

FOREWORD

Psychiatric troubles are particularly frequent in old age. They are becoming predominant with demographic aging and raise important questions in terms of public health policies. The challenge is already of concern in developed countries since several decades. It is starting to be so also in developing ones, with life expectancy incresing progressively.

Psychiatric problems in the elderly have very complex causes and consequences, implicating among others, brain and physical diseases, personality factors, social situation. They are matter of prevention, treatment and rehabilitation. They are found both in the community and in initiations (general and psychiatric hospitals, long stay facilities, outpatient departments, day care centres, etc.) They consequently concern a wide range of persons including, apart from patients, the public in general, relatives, professionals involved and political and administrative representatives.

Two previous consensus statements produced guidelines on Psychiatry of the Elderly and on the Organization of Care in Psychiatry of the Elderly. This third one focuses on Education. This point is evidently crucial for the dissemination of knowledge, experience and practice in this field. The topic is diverse, going from biology of aging to clinical aspects and to sociological considerations. The public varies from lay people to professionals from different horizons. The aim is to propose wide guidelines favouring an education of good quality, taking into account the complext) of the subject to teach and of the public concerned. This consensus statement reflects the views brought by representatives of the main international associations involved in psychiatry of the elderly.

> Professor J. Wertheimer Chairman - Geriatric Psychiatry Section World Psychiatric Association

1. INTRODUCTION

The World Health Organization and the World Psychiatric Association have recently published two consensus statements on the scope of psychiatry of the elderly and organization of services in psychiatry of the elderly.

The first consensus statement described the specialty of psychiatry of the elderly and made several recommendations with regard to aning and education (1).

- The specialty of psychiatry of the elderly requires a grounding in general psychiatry and in general medicine as well as training in the specific aspects of both psychiatric and medical conditions as they occur in older people. Psychiatry of the elderly should be taught in the variety of settings in which it is practised.
- Training schemes for all health and social care workers should include a component on mental health care of older people. Training in mental health care of older people should be offered at both undergraduate and postgraduate level and also during continuing professional development.

 Education and information about mental health care of older people should be offered to the general public and to carer groups. The development of appropriate training manuals with culturally appropriate material should be achieved for all groups of professionals and carers.

The second statement described the organization of services in psychiatry of the elderly and emphasized the need of all concerned for appropriate education, training and information (2).

WHO/MNH/MND/98.4 Page 2

Both Statements take account of pronouncements by the United Nations and the World Health Organization bearing on health and access to health care (3-6).

This third statement explores educational issues in greater detail. Its objectives are to :

- promote development and action on these issues at every level (local, regional, national and international) for all those concerned;
- promote an understanding on these issues and encourage positive attitudes;
- describe an approach to, and a core content for educational programmes;
- indicate the variety of groups to whom education should be offered;
- encourage the evaluation and continuous updating of all these activities.

2. PRINCIPLES

Education in this field should follow modern principles of adult education. It should:

- offer clear learning objectives centred on the learner's needs;
- ensure that learners are actively involved in their learning;
- address attitudes and skills as well knowledge;
- be appropriate for the context and culture of the learner;
- be systematically evaluated;
- be ready to challenge assumptions and acknowledge controversy where it exists;

1

 respect the spirit of the relevant recommendations from the UN and the WHO.

3. NEEDS

It is necessary to consider to whom education should be offered, what should be taught and teaching methods.

Education for whom:

- health and social care professionals undergraduate, post-graduate and continuing education;
- health and social service managers;
- other care workers who constitute the bulk of care staff, especially in longer-stay institutions, community and primary health care;
- family carers, neighbours and others;
- voluntary workers;
- people in professions not specifically related to health but on whose work the mental disorders of old people impinge (e.g. lawyers, policemen, journalists, clergy, architects and designers);
- public policy makers;
- the general public.

What to teach?

The people concerned with this field range from professionals (generalists and specialists) to the lay public. It is obvious, therefore that the needs and levels of different groups will vary widely. Nevertheless there is basic information which is common to the needs of all. What follows is a core curriculum primarily derived from the learning needs of health professionals. Attitudes, knowledge and skills are embodied in different degrees in each of the items on the following list.

WHO/MNH/MND/98.4 Page 4

- The processes of ageing in individuals.
- Demography, economics and politics of ageing societies.
- Epidemiology, pathology, clinical features, assessment, diagnosis, treatment and management of the mental disorders of old age emphasizing the features which differ from similar conditions in younger people.
- The physical disorders and impairments of function which commonly occur in old age.
- The special significance in old age of the interdependence of mental physical and social factors.
- Prevention and health promotion including recreational and spiritual issues.
- Ethical and legal issues.
- Planning, provision and evaluation of services in different settings.
- Carers: needs and support.
- End of life issues.
- Multidisciplinary team work.
- Interviewing and communication skills.
- Fostering of positive attitudes, insight into the reasons for negative attitudes, and realistic expectations.

Teaching methods

Guiding principles:

 Many who work with the elderly do so under pressure and may feel they have no time to teach. Every activity of a service is a fluiful educational opportunity, ranging from a visit to old persons in their own homes to a meeting of a service planning committee.

10

 Formal education should fit with different learning styles. The best way of accomplishing this is to make a variety of different teaching formats available for learners. These may include large and small group teaching, tutorials and seminars.

Carers and users of the service can make a significant contribution to multidisciplinary groups.

- Education for multidisciplinary groups can facilitate team work and dispel inter-professional misperceptions.
 - Teaching thrives on association with research and encourages critical thinking in learners. Where appropriate, learners should themselves participate in research.

Media (radio, television, newspapers, etc.) - including materials which range from documentaries to dramas - are excellent ways to educate patients, caregivers, the public and professionals groups. Already available information and educational materials which are culturally appropriate should be used and further developed.

Information technology offers innovations such as distance-based education, video conferencing, internet, CD ROM programmes and computer teaching modules. These are also useful.

Evaluation

Evaluation of teaching is always desirable and depends on prior setting of learning objectives. Accepted methods of evaluation need to be applied. Aspects for evaluation may include:

- Satisfaction of the learners with the teachers and the course content.
- Measurable change in knowledge, skills and attitudes.
- Improvement in patient outcomes.

WHO/MNH/MND/98.4 Page 6

4. CONCLUSIONS

There has been considerable growth in awareness worldwide of the importance of the mental health of older persons, especially in countries experiencing rapid population ageing. In some countries psychiatry of the elderly is a recognised specialty.

The importance of effective education for all those involved with the care of older persons with mental disorders is now widely acknowledged. While a great deal has already been achieved including the development of excellent teaching resources, there remains a pressing need in many situations for the establishment and implementation of teaching programmes. Improved access to existing resources should be facilitated through international exchange and continuing research.

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WHO/MNH/MND/98.4 Page 8

ANNEX

Consensus Meeting on Education in Psychiatry of the Elderly Organized by the World Psychiatric Association, Section of Geriatric Psychiatry Co-sponsored by the World Health Organization Hosted by the Lausanne University Psychogeriatrics Service Lausanne, 14-16 May 1998

List of participants

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WHO/MNH/MND/98.4 Page 9

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