Healthy Ageing - Adults with Intellectual Disabilities

Ageing & Social Policy

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Thorpe, L., Davidson, P., Janicki, M.P., & Working Group. (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Biobehavioural Issues*. Geneva, Switzerland: World Health Organization (WHO/MSD/HPS/MDP/00.4).

Evenhuis, H., Henderson, C.M., Beange, H., Lennox, N., Chicoine, B., & Working Group. (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Physical Health Issues.* Geneva, Switzerland: World Health Organization (WHO/MSD/HPS/MDP/00.5).

Walsh, P.N., Heller, T., Schupf, N., van Schrojenstein Lantman-de Valk, H., & Working Group. (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Women's Health and Related Issues.* Geneva, Switzerland: World Health Organization (WHO/MSD/HPS/MDP/00.6).

Hogg, J., Lucchino, R., Wang, K., Janicki, M.P., & Working Group (2000). *Healthy Ageing - Adults with Intellectual Disabilities: Ageing & Social Policy*. Geneva: Switzerland: World Health Organization (WHO/MSD/HPS/MDP/00.7).

1.0 Background: Ageing and Social Policy - Barriers and Goals

1.1 *Perspectives of International Organizations*

1.1.1 *The International Plan of Action on Ageing* was the first international instrument on guiding the formulation of policies and programs on ageing throughout the world, most recent update [1]. It was endorsed by the United Nations General Assembly in 1982 (resolution 37/51). The resolution set out to strengthen the capacities of Governments and society to deal strategically with ageing populations and to address the developmental needs of older people themselves. In 1991, the United Nations General Assembly adopted the *United Nations Principles for Older Persons* (resolution 46/91), the eighteen principles of which fall into five clusters concerning their status:

independence

participation

care

self-fulfilment

dignity

1.1.2 Support for these principles has been given added impetus in the proposal for 1999 as the *International Year of the Older Person*. The United Nations has urged the adoption by member states of the basic principles set out in the 1982 resolution, in order to ensure that policies are designed in such a way that they address the needs of older people.

1.1.3 It is intended in the above documentation to include all people as they age, and implicitly those with intellectual disabilities should benefit equally as age-related policies and practices evolve. Older people with intellectual disabilities should therefore have equal entitlement to medical treatment for both physical and mental disorders and good quality social provision as their peers within the society of which they are members. To ensure that such development is explicit in future work, delegates meeting recently in Cyprus, (29 March 1998), urged:

(i) that the Secretary General of the United Nations, within the framework of the *1999 International Year of Older Persons*, encourage the inclusion of older persons with intellectual and developmental

disabilities, and

(ii) that national and international organizations across the world advocating for persons with intellectual and developmental disabilities communicate their support for such a resolution to the Secretary General of the United Nations.

*"The Larnaca Resolution" Journal of Intellectual Disability Research, 1998, **42**(3), p.262.*

1.1.4 The fundamental principle underlying this resolution is an emphasis on the *inclusion* of older persons with intellectual disabilities in both health and social services and the wider life of the community in which they live. Such a view is entirely consistent with the progress towards inclusion that is being made for all people with intellectual disabilities across the lifespan, but requires special consideration in relation to the later years of life.

1.2 *World Health Organization Initiative*

1.2.1 The World Health Organization, in collaboration with the International Association for the Scientific Study of Intellectual Disabilities (IASSID) and Inclusion International, has developed a summative paper on the health needs of people with intellectual disabilities, together with recommendations for effective intervention to improve the health status of such older adults.

1.2.1 Four Working Groups were established concerned with Ageing & Social Policy, Physical Health & Impairment, Biobehavioural Issues and Women's Health & Related Issues. The present report should be seen as providing the wider context in which the specific health and biological issues dealt with in these papers have relevance, and in which women's needs in particular require consideration. Similarly, issues of health and well-being must be located in the wider comprehensive social framework of community care in which people lead their lives and are offered suitable support.

1.3 *Inclusion International and the Ageing Initiative*

1.3.1 Working cooperatively with the IASSID and the WHO to accommodate this global policy issue, Inclusion International (II) (formerly known as the International League of Societies for Persons with Mental Handicap) has also formulated a formative statement on the inclusion of older persons with intellectual disabilities within the fabric of their society (57). It recognizes that the variations among the countries of the world pose the most significant obstacle to establishing universal principles that address ageing and intellectual disabilities. It also recognizes the cultural gulf between and within industrialized societies and developing countries, but affirms that respect and dignity are the rights of all human beings and pursues four elemental guiding principles: inclusion, full citizenship, self-determination, and family support. These guiding principles define good ageing, social and health public policies and practices and provide a standard for all nations in their activities related to the ageing of people with intellectual disabilities. They also form the standard for the recommendations found in this report.

1.4 *Ageing, Social and Health Policy*

1.4.1 The present paper is concerned with the first of these issues, ageing, social and health policy as it affects people with intellectual disabilities as they get older and live into old age. Here we consider the necessary policies and practices conducive to ensuring that older people with learning disabilities are treated in a manner that is acceptable to them *and* is compatible with the *International Plan of Action on Ageing*.

1.4.2 During the course of the paper reference will be made to the five areas dealt with in the UN statement noted above, i.e., *Independence*, *Participation*, *Care*, *Self-fulfilment* and *Dignity*.

1.4.3 Implicit in the philosophy underlying this paper is the view that ageing is a life long process. There is no fixed cut-off point at which people with intellectual disabilities become old, and the studies on which this report draws vary considerably with respect to the lower age-band defining their study populations. Typically, however, consideration of ageing takes the sixth decade when people are in their 50s as a starting point for determining age-related change. This picture is complicated by the occurrence of premature age in some individuals with intellectual disabilities, most obviously those with Down syndrome. The present report, therefore, uses the expression "older people with intellectual disabilities" refer to people in the 50s through to 'old-old' age. With age 60 years as a somewhat arbitrary but necessary marker. We are also mindful that biological ageing may pre-date this age and social ageing occur later than it.

2.0 Ageing in the Developing and Developed World: Myths, Cultural Stigma Vs. Human Rights and Valued Status

2.1 Throughout both the developing and developed worlds, improved health and social care have led to dramatic increases in the life expectancy of both men and women. In some western countries life expectancy has doubled during the 20th Century while those surviving to 65 years do so in better health than in the past [2]. It is estimated in the *UN International Plan of Action* that between 1975 and 2025 world population will double, with a 224% increase in the number of people over 60 years of age. By that date, it is estimated that 72% of over 60s will live in developing regions, and the proportion of over 60s in those regions will by then approximate levels observed in developed regions in the 1950s.

2.2 Several studies have indicated an increased incidence of intellectual disability in developing relative to developed regions, in some cases double of more. For illustrative studies see: [3] with reference to Bengal and Bangladesh and also: [4] in Pakistan. In combination with an increasing life expectancy, prevalence rates of intellectual disability are high in developing regions. In considering policy and programs in developing and developed regions, therefore, it is clear that the need for positive initiatives is and will increasingly be equally pressing. While the basic principles already noted will also be just as relevant, it is clear that their realization will have to reflect regional and cultural differences. The *UN International Plan of Action on Ageing* asserts that each country must respond to demographic trends and the resulting changes: *"In the context of its own traditions, structures and cultural values..."*. This view will be equally applicable to older people with intellectual disabilities, though for some regions people with intellectual disabilities may not at present constitute a priority given the wider social problems some communities face. In focusing on *ageing* and *intellectual disability*, therefore, it is important to ensure that policies affecting *all* people with intellectual disabilities are developed in a positive way as a background to improving their situation when they pass 60 years.

2.3 We must also at the outset caution against any implication that issues and models of services evolved in developed countries are naturally translatable to developing regions. The failure of Western models of rehabilitation to take root in developing regions has been reported by [5] where it is noted that they are often not sustainable economically and are essentially urban-based. This last point is of particular importance as 70-80% of people in developing regions live in rural settings. In addition, both the health and economic conditions in some societies are far removed from those in the affluent developed regions. Endemic diseases and epidemics present enduring problems in such regions and a focus for health and social services. Poor neonatal facilities and lack of adequate services for older people mean that vulnerable individuals with disabilities will have high mortality and will not live to later life. A direct concern with older people with intellectual disabilities may therefore be peripheral to efforts to improve health and social care for the wider population of all ages.

2.4 Bearing the foregoing in mind, the position adopted in the present paper is that each country must develop strategies for older people with intellectual disabilities that are commensurate with its stage of social and healthcare development, and which reflect wider demographic factors. However, the argument is also advanced that those who are older and have intellectual disabilities should be included within policies and approaches designed for the betterment of the older population generally, and should receive whatever additional support they require to lead a healthy and fulfilled life.

2.5 In evolving inclusive policies in developing regions it is crucial to acknowledge the wider social context in which disability and poverty can go hand in hand. In the absence of family support, the lack of safety nets can result in extreme outcomes such as starvation, See [6] and [7]. In addition, further barriers may be presented by myths related to disability and cultural stigma attached to people with disabilities, as well as overall poor health status in the population as a result of inadequate health services. In many cases, these wider influences will have led to poorly organized or non-existent mechanisms for supporting people with intellectual disabilities.

2.6 In a broad sense, in developed nations, ageing-supportive social and health policies should be focused on promoting productive or successful ageing (58). Whilst, in developing nations ageing-supportive public policies should be focused on more basic functions, such as promoting healthy ageing and encouraging survival into old age. Once such basics are achieved, then the higher level goals of productive or successful ageing should also be incorporated into the national public policy structure. Similar processes should apply to how nations construct their public policies involving the ageing of adults with intellectual disabilities.

3.0 Ageing and Intellectual Disability: Health & Social Systems - Lack of Speciality Input and Improving Quality of Life

3.1 *Longevity and intellectual disability in developed regions*

3.1.1 The social and medical factors leading to the increase in longevity described above have also significantly increased the life-span of people with intellectual disabilities in both developed and developing countries [8]. Increased longevity among people with intellectual disabilities has been reported in European countries including Austria, Germany and Switzerland [9], Denmark [10], France [11], Netherlands [12], and Ireland [13] and the United Kingdom [8] as well as in the United States [14] [15] and Australia [16]. While there is documentation that people with severe or profound intellectual disability, multiple disabilities (e.g. cerebral palsy, epilepsy, severe motor handicap, inborn heart defect), and persons with Down syndrome [17]; [18]; [19] still have a reduced life expectancy, age-specific mortality rates among people with mild intellectual disability and adults within the general population in developed countries are comparable [20]; [21].

3.2 *Longevity and intellectual disability in developing regions*

As noted above (Section 2.2) increased incidence of intellectual disability coupled with greater life expectancy will result in a growing population of older people with intellectual disability in developing regions. Nevertheless, population data from developing regions comparable to that available in developed regions are typically lacking e.g. [22].

With respect to policy and planning, it is unrealistic in the context of developing services for older people to split this emerging population off from the wider field of ageing. The need is to develop infrastructures for health ageing which can be accessed by older people with intellectual disabilities. In this way, natural inclusion can be facilitated, supported by relevant training for both professionals and the wider public.

Finally, any given culture may have its own valued means of improving the health and quality of life of its members, including ways that have only recently attracted the interest of developed societies. These may include the use of local healers and medicinal plants and may offer approaches quite distinct from those familiar to western advisors.

3.3 *The relevance of data on the older population*

3.3.1 In proposing the development of positive programs for older people generally, the *UN International Plan of Action on Ageing* asserts that: *"Data concerning the older sector of the population -- collected through censuses, surveys or vital statistics systems -- are essential for the formulation, application and evaluation of policies and programs for the elderly and for ensuring their integration in the developmental process."* Such data bases will deal with the 60 years plus population and will entail data collection specifically relevant to planning both health and social services. Governments and organizations in a position to undertake such data collection are urged to do so. However, it is also acknowledged: *"In some developing countries, the trend towards a gradual ageing of the society has not yet become prominent and may not, therefore, attract the full attention of planners and policy makers who take account of the problems of the aged in their overall economic and social development planning and action to satisfy the needs of the population as a whole."*

3.3.2 Both the requirement to collect data and the constraints on undertaking such an exercise are clearly of equal relevance to older people with intellectual disabilities. Such surveys need to be carried out within the cultural framework of the society which itself will influence the definition and perception of intellectual disability. It is unlikely that a common scientific framework of criteria defining the population on an international scale will prove feasible. It is essential, however, that data collection is formally tied into service planning and development [23]. It should also be noted that evidence exists from developing regions that more reliable data can be achieved once services are established [24].

While use of international classification systems should be considered, it may well be that criteria for inclusion will be determined more by administrative and service-based criteria in the first instance. However, a review of such procedural issues is called for and noted in the following recommendations:

Recommendation 1

[Establishing data bases (3.1-3.3)]

1a Governments should be encouraged to include older people with intellectual disabilities as part of any surveys of their ageing populations.

1b International and governmental agencies in developed regions should be encouraged to provide technical support to developing regions on the type of data needed on this population which will inform the setting up of appropriate services.

1c Attention should be given by relevant international agencies to developing compatible methodological and practical approaches with respect to such data collection in order to enable the development of an international database.

3.4 *Increasing awareness of ageing and intellectual disability*

3.4.1 Professionals, policy makers and academics working in the field of intellectual disability in developed regions have become thoroughly aware of the issues involved in demographic changes associated with intellectual disability. Awareness is also increasing in developing regions, particularly

in urban areas where economic pressures are making it more difficult for younger family members to sustain older members with intellectual disabilities. However, wider acknowledgment of the challenges arising from such demographic change by significant agencies is limited. The *UN International Plan of Action on Ageing* draws attention to the role of governments in developing short-, medium- and long-term action to implement the *Plan of Action* as well as the role of international and regional co-operation. Technical co-operation, the exchange of information and experience, and the formulation and implementation of international guidelines are proposed. Such strategies have equal relevance to older people with intellectual disabilities and their encouragement is suggested in the following recommendations:

Recommendation 2

[Increasing awareness of ageing and intellectual disability (3.4)]

2a WHO, IASSID, and II, together with other relevant international organizations should collaborate in arranging and supporting technical assistance for providers and practitioners addressing the service needs of older persons with intellectual disabilities in developing regions.

2b Formal presentations should be made to governments and the relevant service commissioners by professionals from their respective countries and by outside representatives on the need to include the assessment of older people with intellectual disabilities on policies on ageing.

2c IASSID and II, together with its relevant working parties and committees, should explore opportunities for global co-operation in enhancing the quality of life of older people with intellectual disability through the development of informed policies and programs.

2d IASSID and II should give technical assistance to providers and practitioners in developing regions.

3.5 *Ethnicity, culture and ageing*

3.5.1 While the foregoing deals essentially with an international continuum of regions defined with respect to economic development, it is important to bear in mind two further issues that extend these considerations with respect to both *ethnicity* and *culture*:

3.5.1.1 Most developed countries have ethnically diverse populations which have increasingly become the focus of social gerontologists. Issues of ethnicity have already been identified as highly relevant to a consideration of ageing and intellectual disability [25]; [26].

3.5.1.2 The social context in which people age is not only diverse across cultures, but is also subject to change, not least with respect to family structure [27], a situation of considerable importance with respect to continued family caregiving.

Recommendation 3

[Ethnicity, culture and ageing (3.5)]

3a In suggesting policies and programs to different governments on issues related to ageing and intellectual disability, full cognisance must be taken of ethnic and cultural differences both within and across regions that affect attitudes to older people generally, and those with intellectual disabilities in particular

3.6 *Health problems in older people with intellectual disabilities*

The chance of people with intellectual disabilities being affected by health problems is higher than that in people without intellectual disability. Indeed, some conditions may be related to the aetiology of a person's cause of intellectual disability. As people age, "normal" ageing problems add to these congenital disorders [28]. As in older citizens in general, prevalence is increasing in older age groups for some disorders such as visual and hearing disorders, dementia, affective disorders, hypertension and other cardiovascular disorders [29]. Older age, however, is clearly not the only risk factor for contracting disease in people with intellectual disabilities. People with more serious levels of intellectual disability and people with Down syndrome are at a higher risk for some chronic conditions than those with a milder level of intellectual disability and those with intellectual disability resulting from causes other than Down syndrome. When considering prevalence, the significance of morbidity, and the possibility of early detection and treatability [30], some disorders have priority above others [29].

Recommendation 4

[Screening for health problems (3.6)]

4a The following disorders should be considered when developing screening instruments and procedures: visual and hearing problems, gastro-intestinal disorders, dementia, depression and hypothermia.

4b While conditions such as hypertension, diabetes and chronic urinary tract infections may proceed symptom-free into old age in people who have difficulty in verbalizing their health problems, timely and adequate assessment and treatment should prevent secondary conditions

4.0 Access to Health Services: Improving Poor National Health Status Through More Responsive Systems and Better Training

4.1 Central to the policies and programs referred to above is the need to ensure that older people with intellectual disabilities have access to health services that include health promotion and support services that will guarantee the greatest possible health quality of life as they age. This will be dependent upon their inclusion within existing systems of health service provision, and will also be heavily influenced by the quality of such provision in their region. Marked differences in such quality be found along the continuum of regional development. Access to health services by people with intellectual disabilities can present problems in both developed and developing regions. Common to both are the difficulties arising from the responsibility of family and professional carers to access health services on behalf of the person with intellectual disabilities. Other barriers also have to be overcome, however.

4.1.1 *Primary healthcare provision: Developed regions*

Because of "cohort" and "healthy survivor" effects many of the older adults with intellectual disability tend to be more able and in better health than is the case for children with intellectual disability. Contrary to the wealth of evidence pointing to the existence of age-related adaptive decline in adults with Down syndrome, data regarding similar decline in intellectually disabled adults without Down syndrome are less conclusive [21]. Advancing age of persons with intellectual disability is no reason to exclude them from community integrated health service provision by supplying specialized residential health care.

Access to primary health care provision in the community is still a problem for young *and* old persons with intellectual disabilities. Such difficulties may be particularly in evidence where significant deterioration is observed in chronic diseases of old age, particularly where dementia is suspected.

In many countries there is a tendency towards community living of older persons with intellectual disability and to separate living arrangements from institutional care provision. Big residential facilities are being divided into smaller decentralized units, which are quite often located in populated areas. People living is such settings should be on the list of general practitioners with an active consultation attitude and health screening policy [31]; [32]. Adequate in-home services for both nursing care and assistance in activities of daily living and management of household activities, should be offered to let them stay as long as they wish in their original living environment.

In developed regions, however, access to primary healthcare provision in the community is restricted by a wide range of factors [33].

4.1.1.1 lack of pertinent information on medical history

4.1.1.2 lack of training concerning the health issues relative to older person with intellectual disabilities

4.1.1.3 difficulty in undertaking medical examination because of communication problems or in some instances, behavior problems

4.1.1.4 absence of specialized back-up for complex medical conditions

4.1.1.5 lack of understanding on doctor's part of informed consent issues

4.1.1.6 difficulty in dealing with sexual issues related to contraception.

The above problems will continue to be present as consultation on age-related medical problems is sought. Such difficulties may be particularly in evidence where significant deterioration is observed, particularly where dementia is suspected.

Despite the above difficulties a policy of inclusion requires that conditions that encourage access to generic health services, information and education is put in place. Specific recommendations to achieve this (again drawing on [33]) include:

Recommendation 5

[Primary healthcare provision in developed regions (4.1.1)]

5a Clarify the "information problem" and develop guidelines in pamphlet form for carers to ensure they provide adequate medical history information

5b Make available to health professionals information on specialists in aspect of intellectual disability that may require referral.

5c Establish continuing medical education programmes related to behavioural difficulties, use of psychotropic medication, specific syndromal issues.

5d Under the auspices of WHO, prepare easily translatable protocols and education material for physicians and other health care providers in developing countries.

5e Provide information on informed consent by patients with intellectual disabilities.

5f Develop common health care protocols on common disorders applicable to all individuals and identify areas of health maintenance and promotion and alternative programmes that are developed jointly by primary health care teams and the relevant social agencies.

More generally, the inclusion of issues related to ageing and intellectual disability in the curricula of primary healthcare professionals is called for with respect to physicians, therapists and nurses as well as providers of social services.

4.1.2 *Primary healthcare provision: Developing regions*

In developing regions the issue of accessibility relates to wider issues to do with access to food, clean water and acceptable shelter, as well as good quality healthcare for the whole population, See [5]. General shortcomings in healthcare systems will be accompanied by an absence of specialist intellectual disability practitioners such as nurses, therapists and physicians.

Against this background, inclusion of older people with intellectual disabilities in primary healthcare and habilitation services must be viewed in the context of the inclusion of all people, regardless of age, in the wider service framework. To achieve this the following steps should be taken as health services for the whole population are progressively developed:

4.1.2.1 screening from infancy onwards to establish the nature of individuals' disabilities and determination of the ways in which these can best be met

4.1.2.2 surveillance across the life course with respect to conditions associated with specific risk factors

4.1.2.3 development of provision within evolving health and social services that will facilitate access of people with intellectual disabilities

4.1.2.4 in-service training of relevant professionals and aids to meet these needs in inclusive services including specialist information on ageing and intellectual disability, medication and specific syndromal issues

4.1.2.5 support for family and other caregivers to identify the healthcare needs of those for whom they provide to ensure appropriate referral

4.1.2.6 information to carers on special concerns with respect to ageing of person with Down syndrome or cerebral palsy

Recommendation 6

[Primary healthcare provision in developing regions (4.1.2)]

6a Governments and service planners in developing regions should be encouraged to consider service design and structures that will optimise the inclusion of people with intellectual disabilities in mainline health and social services

6b IASSID make available to governments and national and local service planners information and advice that will facilitate such inclusive policies

4.2 *Premature ageing among people with intellectual disabilities*

While people with Down syndrome shown earlier decline in abilities than their non-Down syndrome peers [39],[40], it is important to emphasise that since the 1950s the longevity of people with Down syndrome has increased dramatically. Appropriate healthcare and social support to enhance quality of life from 40 years onwards has therefore become a key element in service provision for this population.

Clearly, where premature ageing is possible, age-related support needs to be put in place well in

advance of conventional chronological age. Medical surveillance of people with Down syndrome from 40 years onwards will ensure that intervention and support is offered with respect to specific areas of decline at the earliest possible time. Briefing for staff in immediate contact on anticipated difficulties will increase the probability of intervention at the earliest possible time.

Though premature ageing in people with Down syndrome has been distinguished from the on-set of dementia, it is known that individuals with this condition are particularly at risk for dementia. Guidelines for health and social care management over the course of this illness, applicable to both people with and without Down syndrome, are available [41].

Recommendation 7

[Premature ageing among people with intellectual disabilities (4.5)]

7a In developing health services for older people with intellectual disabilities, policy makers and providers should take into account the probability of premature ageing in people with Down syndrome and cerebral palsy and include them in ageing population data bases.

7b Staff and families supporting people with Down syndrome require specific information and/or training to enable them to identify areas in which premature decline is occurring.

7c Physical and mental health surveillance relevant to older people in the general population should be considered for people with Down syndrome from 40 years onwards.

7d Policies should be implemented to diagnose Alzheimer dementia accurately in the general population with the inclusion of individuals with developmental disabilities and employ suitable care management practices.

7e In line with the overall policy of inclusion in mainstream services advocated in this document, consideration should be given to the inclusion of Down syndrome individuals with dementia in services for people with dementia in the wider population.

4.3 *Additional medical and social support*

In every country, there have been long standing difficulties for people with intellectual disabilities in accessing services for hearing, vision, and dental care, as well as other health-related services. These difficulties are exacerbated in developing regions where access to such services are limited for the entire population. Lack of services to address these needs often allows easily remedied conditions to increase barriers posed by disabilities and reduces the participation of people with intellectual disabilities in daily life. Also, the need for these vision, hearing, dental and other health-related services remains and may increase as people with intellectual disabilities age. Attention to the need for such services for people with intellectual disabilities must be included in the training of general physicians, and the development of generic health and health-related services. Moreover, the needs of the ageing person with intellectual disabilities must be taken account of in the preparation of dentists, audiologists, ophthalmologists, chiropodists and other health related service personnel in developed regions. Such needs must also be addressed in the assessment, planning, training and education and supportive services and their delivery in developing regions.

Recommendation 8

[Additional medical support (4.3)]

8a Where appropriate and possible health and social service providers in a given administrative area should audit the extent to which general health care, for example dental, chiropody and sensory deficit

services are meeting the needs of older individuals with intellectual disabilities within the generic ageing services provision.

8b The extent to which generic dental, chiropody and sensory deficit services have the expertise to meet the needs of older people with intellectual disabilities should be determined and steps taken to increase the inclusiveness of such services.

4.4 *Care and age-related difficulties*

Age-related decline and the development of chronic and acute illnesses characterise ageing in general as well as people with intellectual disabilities as in the wider population. The latter typically use a number of different types and sources of care simultaneously [34], and opportunities for those with intellectual disabilities to access these services in the same way are required. The continuum of care should embrace preventative measures as well as acute services (typically involving nursing care), while post-acute care will require recuperative support and possibly rehabilitation services. With respect to the latter, specialist gerontological services, including relevant therapies, will be required. Long term care will involve enduring provision in a managed setting or family home.

Of equal importance is appropriate social provision, typically involving long term caregiving and/or support in community settings. In later life these will be managed settings, e.g. group homes or supported living, with an important, but decreasing number of older adults still living with family carers. The extent of both types of support will depend upon the kind of service provision available in the society, as well as cultural attitudes towards family responsibility. Where family care continues, then the social and health needs of caregivers should be viewed as a priority and met through appropriately focused services.

Recommendation 8

[Care and age-related difficulties (4.4)]

8a Older people with intellectual disabilities with chronic and often multiple medical problems are entitled to the full continuum of acute and long term care as the rest of the population

8b Older people with intellectual disabilities should be entitled to specialist services where their condition requires such input

8c The contribution of good quality social and community support provision to quality of life should be acknowledged and met through appropriate support and services.

4.5 *The medical consequences of significant life transitions*

Older adults with intellectual disabilities are likely to face major transitions in their living situations as they and their families age. For adults who live with family members, death or frailty of parents or age-related changes of the person with a disability can necessitate a move to a different setting. For adults who live in out-of-home residential settings, both changes in social policy and changes in their own health can result in relocation to other settings. In the developed world over the last three decades thousands of older adults with intellectual disabilities have been moved from institutions to community placements [35]. This has been in response to shifting ideologies of care which now emphasise community inclusion over previous more segregated approaches. The major life transition of moving from one setting to another can have significant health consequences for adults who move [36].

When people are relocated, increases in morbidity and mortality are a concern. This phenomenon,

termed "transfer trauma" has been noted among people in nursing homes and in facilities for those with intellectual disability. In particular it is a concern for persons in frail health. However, research in the fields of both ageing and intellectual disabilities has indicated that these transitions can be successful with proper attention to the relocation process and to the quality of care provided in the new residence [37]; [38]. To promote better socio-emotional outcomes, there is a need for psychological preparation, attention to self-determination and individual preferences, and continuity in friendships and caregivers. To better meet the medical needs of older adults experiencing residential transitions it is important to ensure sufficient access to medical care, transmission of relevant medical information, and seamless continuity of treatment.

Recommendation 9

[The medical consequences of significant life transitions (4.4)]

9a Prior to a change in living setting, attention needs to be paid to psychological preparation for the change and to consideration of the individual's preferences.

9b Prior to a change in living setting , a full assessment of the current and anticipated medical needs and of the future healthcare network's ability to meet medical needs should be determined and well documented. This information should follow the adult into the new setting.

9c Intensive monitoring should be undertaken in the period following relocation.

9d Continuity in treatment and in personal relationships with friends, families, and carers can help ease transitions.

9e New settings need to have sufficient access to health and social care and front line staff need to be adequately trained in emergency medical procedures.

4.4.1 More recently there has been concern to facilitate transitions for individuals living at home to similar community settings, both to expand their independence and community participation. This transition can also prepare the person and the family for new challenges concerned with the ageing process. Although greater emphasis is now being placed on greater participation in decision-making for such persons, the reality is that these transitions are often imposed without consideration for the person's wishes or future health needs. It is important that in considering such transitions their impact on the health of the individual is paramount, whatever the ideological viewpoint driving such service developments.

Some developing regions have relied on institutional settings but most, in the absence of resources, rely on families to provide care. As the life expectancy of persons with intellectual disabilities increases, and new resources must be identified to support in-home and community based care. Decisions about when to maintain in-home care or to plan for transitions to another setting should be guided by considerations of cultural factors, service needs, consumer choice, service availability, current and future health needs and the potential consequences of transitions.

4.6 *Healthcare education*

4.6.1 Increase in health risks in community settings have been reported [42]; [43]. These relate to both the less restrictive ethos of many community settings involving greater exercise of choice and in some cases increased disposable income. Specifically increased smoking, alcohol consumption, poor diet and lack of food and inadequate physical exercise all pose health risks. Community life is also likely to increase risk of sexually transmitted diseases and HIV/AIDS regardless of the whether the person is living independently, in a managed setting, or in the family home.

4.6.2 There is a need, therefore, to develop health education programmes which will compensate for risks associated with poor health habits. In particular, improved nutrition and dietary habits require attention. There is a need to inform health education programmes for older people with intellectual disabilities by drawing on the wider literature on health education. However, individual choice as to whether to engage in such education remains the right of the individual, as in the wider population of older people.

4.6.3 In developing regions, the health risks listed above, particularly with respect to nutrition, will be considerably greater than in developed regions. Here improvement will only occur to a significant degree as the wider condition of the society improves. This issue of personal choice may here be of less relevance than ensuring that older people with intellectual disabilities gain from wider public health improvements to the same extent as their peers without intellectual disabilities.

Recommendation 11

[Healthcare education (4.6)]

11a Health education and preventative intervention programmes should be available to older people with intellectual disabilities and to their families to the same extent as they are for the wider population.

11b All health education programmes should include people with intellectual disabilities.

11c Health education information should be designed to be intellectually accessible to older people with intellectual disabilities and their families.

11d Strategies for intervention should draw on the wider literature on behavioural and cognitive programmes with this population.

5.0 Health, the Social Context: Short Comings in State Input and Improving

Social Support

5.1 An individual's health extends beyond biomedical explanations that relate to the physical body [44]. The World Health Organisation [45] stated a well known and much broader view indicating *"health is a state of complete physical, mental and social well-being and not merely the absence of disease and infirmity."* Although such a position has been criticised as being idealistic, it draws attention to the need to view health as the outcome of influences in addition to biomedical health care and management. Such a view is equally applicable to people with intellectual disabilities. Without an acceptable individual and social quality of life the healthcare recommendations noted above are unlikely to contribute fully to realising the principles described in the *UN International Plan of Action on Ageing* in this or the wider population.

5.2 While the framework set by the UN is equally applicable to older people with and without intellectual disabilities, it is important to attend to some of the special needs of the former within the wider agenda. Before dealing with these it will be helpful to note the UN's social agenda for older people:

"Policies and action aimed at benefiting the ageing must afford opportunities for older people to satisfy the need for personal fulfilment, which can be defined in its broadest sense as satisfaction realised through the achievement of personal goals and aspirations, and the realisation of potentialities. It is important that policies and programmes directed at the ageing promote opportunities for self-expression in a variety of roles challenging to themselves and contributory to

family and community. The principal ways in which older people find personal satisfaction are through: continued participation in the family and kinship system, voluntary services to the community, continued growth through formal and informal learning, self-expression in arts and crafts, participation in community organisations and organisations for older people, religious activities, recreation and travel, and participation in the political process as informed citizens."

5.3 Consistent with the point made in Section 1 (above), all of these activities entail inclusion in the wider society, and equally represent aspirations of, and for, older people with intellectual disabilities. For the present purpose we will consider the activities under four broad headings: the family (5.4 and 5.5), leisure and learning (5.6), income security and employment (5.7) and community inclusion (5.8).

5.4 *The family and friendship*

While there is now an extensive literature on the family care of people with intellectual disabilities in the developed regions, such information is generally not available for their developing counterparts. A similar situation holds true for information on friendship. Most of what follows, therefore, is derived from studies in developed countries. Complementary information from developing countries will in future make an important contribution to the emergence of good quality services for older people with intellectual disabilities.

5.4.1 The *International Plan of Action on Ageing* acknowledges the family as the fundamental unit of society, despite its ever changing nature and widely differing cultural conditions. Its rôle in caring for older people is acknowledged, as is the family's right to support for undertaking such care. The presence of a family member with intellectual disabilities does not lessen the ties within a family. Indeed, it is clear that regardless of the level of ability or behavioural difficulties, or where a person with intellectual disabilities lives, family members go to considerable trouble to main active contact. For many parents, particularly mothers, *"non-normative"* caring extends well into adult life [46]. Thus, as the person with intellectual disabilities ages, she or he continues in the family home of an ageing parent. Though the percentage of people with intellectual disabilities living at home declines with advancing years, there remains a small percentage who still live with parents who are themselves over 60 years, some in their 90s.

5.4.2 While research shows that most parents find extended caring very fulfilling, the experience has definable stresses and with advancing age becomes in practical terms increasingly difficult. Service providers are often unaware of this situation and their response can be unacceptably slow [47]. In addition, the interests of the adult with intellectual disabilities and family carers may be in conflict. Here the philosophy and rôle of person-centred planning provides a way forward by making values and processes explicit in decision making [48].

5.4.3 Research studies in developed regions have considered many facets of family caring and it is possible to draw the following conclusions:

5.4.3.1 Family caregivers of adults with intellectual disabilities represent a unique (non-normative) group of caregivers.

5.4.3.2 Family caregiving is a valued activity for the mother or other relative involving both satisfaction and stress.

5.4.3.3 For the majority of family caregivers their rôle is fully accepted by them and is not seen merely as an unavoidable option.

5.4.3.4 A variety of stresses have been demonstrated that increase the burden of care, and some of

which are specifically linked to the ageing of the caregiver and her adult child.

5.4.3.5 Services to reduce stress and hence the burden of care do contribute positively, but not optimally, and are often insufficiently tailored to individual need to do so.

5.4.3.6 Service providers fail to understand and appreciate the nature of long term family caregiving for adults with intellectual disabilities.

5.4.3.7 There are important cultural differences in attitudes to family care and what motivates it, of which service providers needs to be acutely aware. In particular in some ethnic minority groups in developed regions and in families in developing regions, continued family caregiving rather than the "launch" of the person into the wider community remains the norm.

5.4.3.8 In the same way that it has been emphasised that adults with intellectual disabilities are *people first*, so caregivers must be considered *people first*, and consideration given to their full identity and multiple rôles.

5.4.3.9 There are marked individual differences among caregivers in their willingness to plan for the future. While the natural familial commitment to caregiving can make them reluctant to plan, this situation is exacerbated by the inadequate response of service providers to their needs.

5.4.3.10 There are cultural differences in attitudes to future planning which must be understood if appropriate assistance is to be given to family caregivers.

5.4.3.11 Adults living at home with ageing caregivers can in their own right become significant resources for their caregiver.

5.4.3.12 Adults living at home may have different views regarding their future from those of their caregivers, raising complex issues for mediators. The approach of person centred planning provides a philosophy and context in which the interests of the older person with intellectual disabilities can be realised.

5.4.3.13 The wider social and economic context in which caregivers provide has an important bearing on their well-being, over and above the specific satisfactions and stresses of caring.

5.4.4 Comparable studies are called for in developing regions in order to determine how family values and attitudes influence caregiving to adults with intellectual disabilities.

5.4.5 Within the wider framework of policy on ageing it is clearly important to see these older family carers as intrinsic to the development of policy and programmes in the same way as are their daughters and sons. In addition, as a significant resource for and influence on their adult children, they contribute directly to her or his well-being.

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

5.4.7 When a person with intellectual disabilities moves from one setting to another, for example relocation from an institution to the community or to another neighborhood due to the death of a parent, longstanding friendship networks can disrupted or lost. Service planners should be mindful of

this undesirable outcome of a change which is otherwise beneficial.

Several recommendations follow from this perspective:

Recommendation 12

[The family and friendship (5.4)]

12a Policies should be developed to provide or expand support for family and community carers in such a way that it is sensitive to their own cultural and age-related needs.

12b While all policy development and service proposals should be developed in consultation with family members and the individual with intellectual disabilities, all those individuals who are informally involved should be consulted.

12c Support for future planning should be responsive to the particular readiness of the parental carer and not be driven from the outside.

12d In developing services for older people with intellectual disabilities attention should be paid to offering opportunities to extend the friendship network of the person and maintain existing friendships even where significant residential changes occur.

5.5 *Cultural influences on family caregiving*

Recently, service providers and researchers in developed countries have begun to recognise the impact of culture and ethnicity on both the willingness of people with intellectual disabilities and their families to seek and accept the services they need, and the perceived and actual openness of service systems to provide services in an equitable and welcoming manner. Developing regions also have cultural and ethnic variations and the dominant service systems and philosophies offered by developed regions reflect none of them. Slavish adoption of American, Western European, or other developed region models for services for ageing persons by developing regions will not succeed. Models must be built anew that reflect the values and cultures of people with intellectual disabilities and their families in those regions. Equally, developed regions must be open to modifying service models and philosophies to reflect, welcome and respect the values and cultures of people traditionally under- served in their countries. Particular efforts are needed to welcome and reach out to immigrant communities.

Recommendation 13

[Cultural influences on family caregiving (5.5)]

13a Planning for individuals with intellectual disabilities must consider and be sensitive to cultural and ethnic influences that condition attitudes to family caring.

13b Where cultural attitudes are negative concerning these individuals, programmes should be developed to modify such beliefs and attitudes towards a more positive approach to family support

5.6 Learning and leisure

The *UN International Plan of Action on Ageing* urges the concept of lifelong education as promulgated by the United Nations Educational, Scientific and Cultural Organization (UNESCO). Specifically, informal, community-based and recreation-orientated programmes for ageing people should be promoted with the aid of national governments and international organisations. Recent years have seen an emerging acknowledgement of the importance of education and leisure in the lives

of older people with intellectual disabilities [49]. *The Plan* draws attention particularly to greater participation in leisure activities and creative use of time, both aspirations now widely accepted in the field of intellectual disability. Policy should therefore be directed to the development of programmes of learning and leisure for older people with intellectual disabilities in inclusive community settings, in contrast to segregated activities or essentially passive pursuits such as watching television.

Recommendation 14

[Learning and leisure (5.6)]

14a Programs actively encouraging and supporting integrated and active learning and leisure engagement should be promoted with appropriate support for both older people with intellectual disabilities and those providing these services.

14b Programs providing leisure for the general ageing population should be inclusive for older individuals with intellectual disabilities.

14c Leisure education programmes should set out to enhance psychosocial inclusion as well as well physical integration.

5.7 *Employment and Income Security*

5.7.1 *UN International Plan of Action on Ageing* draws attention to the global contrasts in income security and employment: *"Major differences exist between the developed and the developing countries and particularly between urban, industrialised and rural, agrarian economies -- with regard to the achievement of policy goals related to income security and employment. Many developed countries have achieved universal coverage through generalised social security systems. For the developing countries, where many, if not the majority of persons live at subsistence levels, income security is an issue of concern for all age groups. In several of these countries, the social security programmes launched tend to offer limited coverage; in the rural areas, where in many cases most of the population lives, there is little or no coverage."*

5.7.2 While there is little specific information on how this global situation affects older people with intellectual disabilities, it is anticipated that the disadvantages affecting some developing regions, particularly in rural settings, will affect equally and to an increasing extent individuals in this population.

5.7.3 *UN International Plan of Action on Ageing* urges equality of employment opportunities for older people generally, though attention has been drawn to a global decline in the proportion of older persons, especially men, in the work force [2]. The situation is more serious for older people with intellectual disabilities. International studies in developed countries indicate that less than 1 in 10 older people with intellectual disabilities over 50 years are in full-time employment, the ratio for part-time employment being even lower. This ratio drops still further when the over-60s are considered. Only a small proportion of those who are able to work have a demonstrated track-record of being in employment. It is clear, therefore, that these issue of employment of older people with intellectual disabilities must be seen in the context of much earlier opportunities for people with intellectual disabilities to have work. While work for the first time in later life should not be excluded as a possibility, longer term improvement is likely to come through more comprehensive employment developments.

5.7.4 The situation in many developing regions is even graver, where 70-80 per cent of people with and without disabilities live in rural areas, and where income for the employed is extremely low.

Self-employment is here the norm, with farming, fishing, selling and handicrafts the predominant, local activities. It is in this context that employment for people with disabilities, including older people with intellectual disabilities needs to be developed, rather than in specialist, segregated settings [50]. Examples of such initiatives which encourage and support such employment are available from a number of developing regions [50]; [7]. The explicit extension of such schemes to older people with intellectual disabilities has yet to be documented, however.

Recommendation 15

[Employment (5.7.1 - 5.7.4)]

15a In developing policies to increase income security in the wider population of older people, older people with intellectual disabilities should be included in planning with a view to their enjoying similar security to their peers without intellectual disabilities.

15b Employment initiatives should adopt a long term view aimed not only at improving employment opportunities for younger people with intellectual disabilities, but with ensuring extension of employment into later life where this is the individual's choice.

15c Support is required to facilitate local employment initiatives in developing regions which are integrated into the local economy and reflect the indigenous pattern of economic activity.

5.7.5 *Social security*

In developed regions there is usually universal social security support for those who have retired, are unemployed, or are precluded from employment because of job availability for people with disabilities. In developing regions such support may be minimal or non-existent, and indeed, [50] and [7] both place the emphasis on the availability of loans to develop employment opportunities rather than social security.

Recommendation 16

[Social security (5.7.5)]

16a In countries where universal or limited social security benefits apply, older people with intellectual disabilities should be included within the social security system available to their peers without disabilities.

16b In developing regions, countries introducing limited or comprehensive benefit s for older people should ensure that older people with intellectual disabilities are included from the outset.

5.7.6 *Retirement options*

In developed regions retirement from services is a relatively new phenomenon and is not necessarily associated the availability of a retirement pension, particularly in the absence of a universal health or social policy. Retirement policies in relation to older people with intellectual disabilities in developing countries have typically been established with respect to the transition from a day service to non-involvement, or a different type of involvement, in that service. Reference has been made to *"supplemental retirement programs"* in such settings and positive outcomes reported [51]. Such initiatives are to be contrasted with the use of the concept of *"retirement"* as a means of discharging a person from a service without offering further support for constructive engagement in new activities. Systematic pre-retirement programmes with older people with intellectual disabilities draw attention to attitudinal similarities with their peers without intellectual disabilities [52]. These and other authors urge the need for proper preparation for retirement, a recommendation directly in line with that of the

UN International Plan of Action on Ageing : *"Governments should take or encourage measures that will ensure a smooth transition from active working life to retirement . . . ".*

In developing regions, retirement for older people with intellectual disabilities, in the absence of day service provision or employment opportunities, may be even less clear cut. Where self-employment of the kind referred to in 5.7.4 (above) has been successfully achieved, retirement may be dictated by the ability or motivation of the person to continuing working, or by cultural norms related to age and active engagement in work. However, the development of formal retirement policies consistent with those in place for the wider population of older people should be encouraged. In many countries the concept of "the pensioner" is alien, and progress towards pension rights can only be achieved in step with the development of pension policy in the wider population.

Recommendation 17

[Retirement (5.7.6)]

17a Where an older person with intellectual disabilities is leaving an existing service, providers should ensure that age-appropriate, fulfilling alternatives are made available in line with the person's own choices and preferences.

17b Where retirement from paid part-time or full-time employment is involved, pre-retirement preparation conducted to the standards deemed appropriate for the wider population of retirees should be offered to the person.

17c In developed regions where the rights of the older person to retirement with a pension is available, older people with intellectual disabilities should be included in these arrangements.

17d In developing regions any retirement policy that has been adopted should be equally applicable to older people with intellectual disabilities.

5.8 *Community inclusion*

5.8.1 Much of the preceding is concerned with community inclusion in both health and social settings. At the heart of an inclusive policy is acknowledgement of the rights of the person to live in a dwelling appropriate to her or his culture in the mainstream of that society. As noted in the *UN International Plan of Action on Ageing*: *"Housing for the elderly must be viewed as more than a mere shelter. In addition to the physical, it has psychological and social significance..."*. Thus in developed regions this may typically involve an ordinary house or apartment in an urban setting, but in some developing regions a life in a rural setting in a typical dwelling place. Congregate care, i.e., the grouping of a large number of people outside the expected range of people living together should be rejected, as should dwellings isolated from the main community. Where isolated, segregated facilities exist, policies leading to transition to community settings are called for. In nations with undeveloped social and vocational training services and where enriched opportunities for health and development are only provided in segregated facilities, then policy should mandate the involvement of each person within the greater community and the freedom to return to their community once training or other supports have achieved their goals.

5.8.2 Support in the person's home should be related to the level of dependency of the person and should be sensitive to, and accommodate to, age related changes. Personal choice with respect to lifestyle should be central to the home's ethos as this will determine in a significant way the person's quality of life [53]. Indeed the *UN International Plan of Action on Ageing* emphasises that ageing

people should be involved in housing policies and programmes for the elderly population. In addition, suitable adaptations to enable the person to cope with functional difficulties arising as they age should be available.

Recommendation 18

[Community inclusion (5.8)]

18a A person's home should be in a situation typical for members of the community in which the person lives or has originated from.

18b Support in the home and community should be sensitive to the person's level of dependency and should adjust to age-related changes.

18c The ethos of domestic settings should be one of personal choice for the resident(s).

18d Enriched residential settings, providing remedial or habilitative services, should permit the person to remain attached to their community and in contact with family and friends.

18e Old-age housing should only be used if it provides for a more enriched quality of life than the person's normal habitat.

5.9 *Intergenerational solidarity*

5.9.1 A further aspect of inclusiveness that has received considerable attention is that of *intergenerational solidarity*. This is advocated as a principle that will ensure social cohesion and reduce the isolation of ageing people, at the same time facilitating their contribution to the lives of younger people. The strength and nature of intergenerational contact varies from country to country, and may be weakened by a variety of demographic and sociocultural trends. In developed regions the suggestion that cross-generational contact has weakened in recent decades has been challenged with respect to people without intellectual disabilities [54]. However, we know less about trends in the population of people with intellectual disabilities than we do in the wider field. Certainly the removal of the institutional option for children with intellectual disabilities and their continued life in the community has meant greater contact with both parents, and increasingly with grandparents.

5.9.2 In addition, intergenerational solidarity between younger and older people with intellectual disabilities must be encouraged where this is of mutual benefit. The segregation of older people with intellectual disabilities from younger peers can lead to double segregation by age and disability, cutting people off from valued contact.

Recommendation 19

[Intergenerational solidarity (5.6)]

19a Policies aimed at encouraging intergenerational solidarity between younger and older people in the wider population should extend to the full age spectrum of individuals with intellectual disabilities.

19b In developing services responsive to the specific age-related needs of older people with intellectual disabilities, care must be taken not to segregate them from their younger peers.

6.0 Training and Education: Promoting Social Inclusion Through Training

Both the general public, policy makers and front-line service providers require information the better to understand older people with intellectual disabilities. The *UN International Plan of Action on*

Ageing urges governments and international organisations to educate the general public with respect to ageing and the ageing process. Such education needs to encompass older people with intellectual disabilities and to work against the dual stereotypes associated with both older people and those with intellectual disabilities.

Staff working specifically with people with intellectual disabilities are increasingly confronting this emerging population and require training to integrate age-related information and practice into their existing practices. With the progressive movement towards the integration of older people with intellectual disabilities into generic elderly services, staff in those services require training with respect to both intellectual disability *and* age-related issues in this population. The experience of such integration has provided a rich base for undertaking such training [55]; [56].

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. By highlighting people with intellectual disabilities, the pool of personnel who are both knowledgeable and sympathetic 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 co-ordinated 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 disabilties.

- 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 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.

9.0 References

1. United Nations, *International Plan of Action on Ageing*. 1998, United Nations/Division for Social Policy and Development: New York.

2. Kinsella, K. and Y.J. Gist, *Older Workers, Retirement and Pensions: A comparative international chartbook*. 1995, Washington DC: Bureau of the Census.

3. Miles, M., *Mental retardation and service development: Bengal and Bangladesh.* Behinderung und

Dritte Welt, 1997. **8**(1): p. 25-32.

4. Yacob, M., A. Bashira, K. Tareen, K.H. Gustarson, R. Nazir, F. Jalil, U. VonDöben, and H. Ferngren, *Severe mental retardation in 2 to 24-months-old children in Lahore, Pakistan: A prospective cohort study.* Acta Paediatrica, 1995. **84**: p. 267-272.

5. McConkey, R. and B. O'Toole, *Towards the new millennium,* in *Innovations in Developing Countries for People with Disabilities*, B. O'Toole and R. McConkey, Editors. 1995, Lisieux Hall: Chorley, Lancs. p. 3-14.

6. O'Toole, B., *Mobilizing communities in Guyana*, in *Innovations in Developing Countries for People with Disabilities*, B. O'Toole and R. McConkey, Editors. 1995, Lisieux Hall: Chorley, Lancs. p. 85-104.

7. Neufeldt, A., *Self-directed employment and economic independence in low-income countries*, in *Innovations in Developing Countries for People with Disabilities*, B. O'Toole and R. McConkey, Editors. 1995, Lisieux Hall: Chorley, Lancs. p. 161-182.

8. Hogg, J., S. Moss, and D. Cooke, *Ageing and Mental Handicap*. 1988, London: Croom Helm.

9. Wieland, H., *Geistig behinderte Menschen im Alter: Theoretische und empirische Beitrage zu ihrer Lebenssituation in der Bundesrepublik Deutschland, in Osterreich und in der Schweiz*. 1987, Heidelberg: Ed Schindele.

10. Dupont, A., M. Vaeth, and P. Videbech, *Mortality, life expectancy, and causes of death of mildly mentally retarded in Denmark.* Upsala Journal of Medical Sciences, 1987. **44 (Supp)**: p. 76-82.

11. Reboul, H., P. Comte, M.-C. Jeantet, and J. Rio, *Les Handicapes Mentaux Vieillissant: A la recherche de solutions adaptees, individuelles, collectives*. ND, Vanves: Centre Technique National D'Etudes et de Recherches sur les Handicaps et les Inadaptations.

12. Maaskant, M.A., *Mental Handicap and Ageing*. 1993, Dwingeloo: Kavanah.

13. Mulcahy, M. and A. Reynolds, *Census of Mental Handicap in the Republic of Ireland*. 1984, Dublin: Medico-Social Research Board.

14. Janicki, M.P., *Aging and new challenge.* Mental Retardation, 1988. **26**: p. 177-180.

15. Janicki, M., A. Dalton, M. Henderson, and P. Davidson, *Mortality and morbidity amoung older adults with intellectual disabilities: Health services considerations Disability and Rehabilitation.* in press.

16. Ashman, A.F., J.N. Suttie, and J. Bramley, *Employment, retirement and elderly persons with an intellectual disability.* Journal of Intellectual Disability Research, 1995. **39**: p. 107-115.

17. Eyman, R.K., T.L. Call, and J.F. White, *Mortality of elderly mentally retarded persons in California.* Journal of Applied Gerontology, 1989. **8**: p. 203-215.

18. Eyman, R.K., T. Call, and J.F. White, *Life expectancy of persons with Down syndrome.* American Journal of Mental Retardation, 1991. **95**: p. 603-612.

19. Haveman, M.J., M.A. Maaskant, and F. Sturmans, *Older Dutch institutionalized residents with and without Down syndrome: Comparisons of mortality and morbidity trends and motor/social functioning.* Australia and New Zealand Journal of Developmental Disabilities, 1989. **15**: p. 241-255.

20. Eyman, R.K., H.J. Grossman, G. Tarjan, and C.R. Miller, *Life expectancy and mental retardation*. 1987, Washington DC: American Association on Mental Retardation.

21. Zigman, W.B., G.B. Seltzer, M. Adlin, and W.P. Silverman, *Physical, behavioral, and mental health changes associated with aging*, in *Aging and developmental disabilities: Challenges for the 1990s*, M.P. Janicki and M.M. Seltzer, Editors. 1991, Special Interest Group on Aging, American Association on Mental Retardation: Washington DC. p. 52-75.

22. Lianta, D., *An Indonesian perspective*, in *Aging and Developmental Disabilities: Perspectives from nine countries*, S. Moss, Editor. 1992, University of New Hampshire: Durham NH. p. 53-58.

23. Khatleli, P., L. Mariga, L. Pachaka, and S. Stubbs, *Schools for All: National planning in Lesotho*, in *Innovations in Developing Countries for People with Disabilities*, B. O'Toole and R. McConkey, Editors. 1995, Lisieux Hall: Chorley, Lancs. p. 135-160.

24. Saunders, C. and S. Miles, *The Uses and Abuses of Surveys in Service Development Planning for the Disabled: The case of Lesotho*. 1990, London: SCF.

25. Heller, T. and A. Factor, *Permanency planning among Black and White family caregivers of older adults with mental retardation.* Mental Retardation, 1988. **26**: p. 203-208.

26. Heller, T., R. Markwardt, L. Rowitz, and B. Farber, *Adaptation of Hispanic families to a member with mental retardation.* American Journal on Mental Retardation, 1994. **99**: p. 289-300.

27. Moss, S., *Conclusion*, in *Aging and Developmental Disabilities: Perspectives from nine countries*, S. Moss, Editor. 1992, University of New Hampshire: Durham NH. p. 85-89.

28. Welsh Health Planning Forum, *Protocol for Investment in Health Gain, Mental Handicap (Learning Disabilities)*. 1992, Welsh Office: Cardiff.

29. Van Schrojenstein Lantman-de Valk, H.M., M. Van den Akker, M.A. Maaskant, M.J. Haveman, H.F. Urlings, A.G. Kessels, and H.F. Crebolder, *Prevalence and incidence of health problems in people with intellectual disability.* Journal of Intellectual Disability Research, 1997b. **41**: p. 42-51.

30. Patterson, C. and L.W. Chambers, *Preventive health care.* Lancet, 1995. **345**: p. 1611-1615.

31. Kerr, M., F. Dunstan, and A. Thapar, *Attitudes of general practitioners to caring for people with learning disability.* British Journal of General Practice, 1996. **46**: p. 92-94.

32. Van Schrojenstein Lantman-de Valk, H.M., J.F. Metsemakers, M.J. Soomers-Turlings, M.J. Haveman, and H.F. Crebolder, *People with intellectual disability in general practice: case definition and case finding.* Journal of Intellectual Disability Research, 1997a. **41**: p. 373-379.

33. Minihan, P.M., D.H. Dean, and C.M. Lyons, *Providing Care to Patients with Mental Retardation: A survey of physicians in the State of Maine*. 1990, Joint Community Health Project: Boston MA.

34. Kane, R.L. and R.A. Kane, *Healthcare for older people: Organizational and policy issues*, in *Handbook of Ageing and Social Sciences*, R.H. Binstock and L.K. George, Editors. 1990, Academic Press: New York. p. 415-437.

35. Emerson, E. and C. Hatton, *Moving Out: The impact of relocation from hospital to community on the quality of life of people with learning disabilities*. 1994, London: HMSO.

36. Strauss, D., R. Shavelle, A. Baumeister, and T.W. Anderson, *Mortality in persons with developmental disabilities after transfer into community care.* American Journal on Mental

Retardation, 1998. **102**: p. 569-581.

37. Heller, T., *Residential relocation and reactions of elderly retarded persons*, in *Aging and developmental disabilities: Issues and approaches*, M.P. Janicki and H.M. Wisniewski, Editors. 1985, Brookes: Baltimore MD.

38. Conroy, J.W. and M. Adler, *Mortality among Pennhurst Class members, 1978 to 1989: A brief report.* Mental Retardation, 1998. **36**: p. 380-385.

39. Maaskant, M.A., M. Van den Akker, A.G.H. Kessels, M.J. Haveman, H.M. Van Schrojenstein Lantman-de Valk, and H.F.J. Urlings, *Care dependence and activities of daily living in relation to ageing: Results of a longitudinal study.* Journal of Intellectual Disability Research, 1996: p. 535-543.

40. Devenny, D.A., W.P. Silverman, A.L. Hill, E. Jenkins, E.A. Seren, and K.E. Wisniewski, *Normal ageing in adults with Down's syndrome: A longitudinal study.* Journal of Intellectual Disability Research, 1996. **40**: p. 209-221.

41. Janicki, M.P., T. Heller, G. Seltzer, and J. Hogg, *Practice Guidelines for the clinical assessment and care management of Alzheimer and other dementias among adults with mental retardation*. 1995, Washington, DC: American Association on Mental Retardation.

42. Rimmer, J.H., D. Braddock, and B. Marks, *Health characteristics and behaviours of adults with mental retardation residing in three living arrangements.* Research in Developmental Disabilities, 1995. **16**: p. 489-499.

43. Turner, S. and S.C. Moss, *The health needs of adults with learning disabilities and the Health of the Nation Strategy.* Journal of Intellectual Disability Research, 1996. **40**: p. 438-450.

44. Siddell, M., *Health in old age: Myth, mystery and management*. 1995, Chichester: Wiley.

45. WHO, *Alma Ata 1978 Primary Health Care*, . 1978, WHO: Geneva.

46. Hong, J. and M.M. Seltzer, *The psychological consequences of multiple roles: The nonnormative case.* Journal of Health and Social Behavior, 1995. **36**: p. 386-98.

47. Walker, C. and A. Walker, *Uncertain Futures: People with learning difficulties and their ageing family carers*. 1998, Brighton: Pavilion Press.

48. Sutton, E., T. Heller, H.L. Sterns, A. Factor, and A. Miklos, *Person Centered Planning for Later Life: A curriculum for adults with mental retardation*. 1994, Chicago: University of Illinois, Akron OH.

49. Hogg, J., *Leisure and intellectual disability: The perspective of ageing.* Journal of Practical Approaches to Developmental Handicap, 1994. **18**: p. 13-16.

50. Campos, M., *Developing livelihoods*, in *Innovations in Developing Countries for People with Disabilities*, B. O'Toole and R. McConkey, Editors. 1965, Lisieux Hall: Chorley, Lancs. p. 71-84.

51. Seltzer, M.M. and M.W. Krauss, *Aging and Mental Retardation: Extending the continuum*. 1987, Washington DC: American Association on Mental Retardation.

52. Laughlin, C. and P.D. Cotton, *Efficacy of a pre-retirement planning intervention for ageing individuals with mental retardation.* Journal of Intellectual Disability Research, 1994. **38**: p. 317-328.

53. Heller, T., A.B. Miller, and A. Factor. *Environmental characteristics of residential settings and*

well-being of adults with intellectual disabilities. in *International Association for the Scientific Study of Intellectual Disabilities*. 1998. Cambridge, England, March 1998.

54. Bengston, V., C. Rosenthal, and L. Burton, *Families and aging: Diversity and heterogeneity*, in *Handbook of Aging and Social Sciences*, R.H. Binstock and L.K. George, Editors. 1990, Academic Press: London. p. 263-287.

55. LePore, P. and M. Janicki, *The Wit to Win: How to integrate older persons with developmental disabilities into community aging programs* (3rd rev). 1997, Albany NY: New York State Office of Mental Retardation & Developmental Disabilities.

56. Janicki, M.P., *Building the Future: Planning and Community Development in Aging and Developmental Disabilities: Second edition*. 1993, Albany NY: New York State Office of Mental Retardation & Developmental Disabilities.

57. Inclusion International. Extending Lives - Extending Opportunities: Report of Inclusion International's Open Project Group on Needs and Appropriate Supports for Ageing People with Mental Handicap/Intellectual Disability. 1998. Ferney-Voltaire, France: Inclusion International.

58. Rowe, J.W., and Kahn, R.L. *Successful Aging*. 1998. New York: Pantheon Books.