

Healthy Ageing - Adults with Intellectual Disabilities

Physical Health Issues

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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. 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 disabilities in less developed and industrialized countries (for an example, see Helm, Crocker & Rubin, 1999).

Recommendation 1

To develop a worldwide perspective on healthy ageing and intellectual disability, 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

disabilities through affiliations between interested parties in industrialized and developing countries that promote advocacy, trans-cultural and cost-effective 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.

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 childhood-acquired 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 & Hippus, 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 lifespan approach that recognizes the progression or consequences of specific diseases and therapeutic interventions.

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

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

Research indicates that specific populations of people with intellectual disabilities have particular health risks. These populations may be defined by the presence of specific syndromes (hence termed *syndrome-specific*), or by the extent of the central nervous system compromise that has caused the intellectual disability (leading to *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.

3. Syndrome-specific conditions

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 & McClelland, 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 abnormalities 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.

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

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

erosion, esophagitis, anemia, feeding 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 also prone to lower gastrointestinal 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 (Lowe & 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.

addition to the risk of status epilepticus (which is more common in children with co-existing 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 epilepsy 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

As people with intellectual disabilities, particularly those with milder cognitive impairments, are offered more lifestyle

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 community-based 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).

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*.

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 periodontal 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 hygiene (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), need continued development.

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

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 hygiene, safety practices, and the avoidance of risky behaviors such as substance abuse and unprotected or multiple partner sexual activity.

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

(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; Schroyenstein 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 lifestyle 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,

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 & Chung, 1996; Burt et al, 1998).

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, Zarfes & Phipps, 1987; Schroyenstein 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; Schroyenstein 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 (presbycusis, cataract, presbyopia, macular degeneration, glaucoma, diabetic retinopathy), the resulting impairment may be more severe because of pre-existing, childhood onset visual and auditory pathology (Schroyenstein Lantman de-Valk et al, 1994; Evenhuis, 1995a,b).

Comprehensive evaluations of older adults presenting with changes in state or functional decline and intellectual disabilities have yielded 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 years.

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 issues- particularly 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 & Nottestad, 1998). Carers need to be able to recognize signs of distress in persons with severe cognitive impairment (LaChapelle, Hadjistavropoulos & Craig, in press); at the same time, individuals who have potential 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, eyeglasses 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 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 health specialists, and rehabilitation 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 health risks (because of syndrome-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 evidence-based 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 population-

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:

into basic and postgraduate medical education.

- 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).

- 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 guidelines-including 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.

References

- Accardo PJ & Capute, A J (1990). Mental retardation. In: AJ Capute, & PJ Accardo, (Eds.) *Developmental Disabilities in Infancy and Childhood*, pp. 431-440, Baltimore: Paul H. Brooks.
- Ager J & Littler L (1998). Sexual health for people with learning disabilities. *Nursing Standard* 13, 34-9.
- Aldencamp AP (1997). Effect of seizures and Arvedson J et al (1994). Silent aspiration prominent in children with dysphagia. *Internat Journal Pediatr Otorhinolaryngol*, 28, 173-81.
- Beange H, McElduff A & Baker W (1995) Medical disorders of adults with mental retardation: a population study. *American Journal Mental Retardation*, 99, 595-604.
- Böhmer CJM, Niezen-de Boer MC, Klinkenberg-Knol EC et al. (1996). The prevalence of gastroesophageal reflux and reflux esophagitis in severely mentally handicapped. *Gastroenterology*, 110, A66.
- Böhmer CJM, Klinkenberg-Knol EC, Niezen-de Boer MC & Meuwissen SGM (1997). The age-related incidences of oesophageal carcinoma in intellectually disabled individuals in institutes in the Netherlands. *European Journal Gastroenterol*, 9, 589-92.
- Böhmer JJM, Niezen-de Boer MC, Klinkenberg-Knol EC et al (1997). Gastro-oesophageal reflux disease in intellectually disabled individuals: leads for diagnosis and the effect of omeprazole therapy. *American Journal Gastroenterol*, 92, 1475-9.
- Böhmer CJM, Klinkenberg-Knol EC, Kuipers EJ et al (1997). The prevalence of Helicobacter pylori infection among inhabitants and healthy employees of institutes for the intellectually disabled. *American Journal Gastroenterol*, 92, 1000-4.
- Boone TB (1998). The bladder and genitourinary tract in the cerebral palsies. In G Miller & GD Clark (Eds.) *The Cerebral Palsies: Causes, Consequences and Management*, pp. 299-307, Boston: Butterworth-Heinemann.
- Boyle CA, Decoufle P & Holmgren P (1994). Contribution of developmental disabilities to childhood mortality in the United States: a multiple cause of death analysis. *Pediatric & Perinatal Epidemiology*, 8, 411-22.
- Braddock D, Hemp R, Parish S & Westrich J (1998). *The State of the States in Developmental Disabilities 5th Edition*. Washington DC: American Association on Mental Retardation.
- Branford, D, Bhaumik S, Duncan F & Collacott RA (1998). A follow-up study of adults with learning disabilities and epilepsy. *Seizure*, 7, 469-72.
- Brodtkorb E (1994). The diversity of epilepsy in adults with severe developmental disabilities: age of onset and other prognostic factors. *Seizure*, 3, 277-85.
- Bromley J, Emerson E & Caine A (1998). The development of a self-report measure to assess the location and intensity of pain in people with intellectual disabilities. *Journal of Intellect Disability Research*, 42, epileptiform discharges on cognitivefunction. *Epilepsia*, 38, S52-5.
- Anderson DJ (1993). Health issues. In: E. Sutton, AR Factor, BA Hawkins, T Heller & GB Seltzer (Eds.) *Older Adults with Developmental Disabilities: Optimizing Choice and Change*, pp. 23-60, Baltimore: Paul H Brooks. 72-80.
- Brunner R & Doderlein L (1996). Pathological fractures in patients with cerebral palsy. *Journal of Pediatric Orthopedics*, 5, 223-4.
- Buchanan LH (1990). Early onset of presbycusis in Down's syndrome. *Scandin Audiology*, 19, 103-10.
- Burt DB, Loveland KA, Chen Y, Chuang A, Lewis KR & Cherry L. (1995). Aging in adults with Down syndrome: report from a longitudinal study. *American Journal on Mental Retardation*, 100, 262-70.
- Burt DB, Loveland KA, Primeaux-Hart S, Chen YW, Phillips, NB, Cleveland, LA, Lewis, KR, Lesser J & Cummings E (1998). Dementia in adults with Down syndrome: diagnostic challenges. *American Journal on Mental Retardation*, 103, 130-45.
- Burtner AP, Wakham MD, McNeal DR & Garvey TP (1995). Tobacco and the institutionalized mentally retarded: usage choices and ethical considerations. *Special Care in Dentistry*, 15, 56-60.
- Cambridge P (1996). Men with learning disabilities who have sex with men in public places: mapping the needs of services and users in south east London. *Journal of Intellect Disability Research*, 40, 241-251.
- Carlsen WR, Galluzzi KE, Forman LF & Cavalieri TA (1994). Comprehensive geriatric assessment: applications for community-residing, elderly people with mental retardation/developmental disabilities. *Mental Retardation*, 32, 334-40.
- Cathels BA & Reddihough DS (1993). The health care of young adults with cerebral palsy. *The Medical Journal of Australia*, 15, 444-46.
- Center J, Beange H & McElduff A (1998). People with mental retardation have an increased incidence of osteoporosis: a population study. *American Journal on Mental Retardation* 103,19-28.
- Chicoine B, McGuire D & Rubin SS (1999). Specialty Clinic Perspectives. In: MP Janicki & AJ Dalton (Eds.) *Dementia, Aging and Intellectual Disabilities: A Handbook*, pp.278-93, Castletown NY: Hamilton Printing.
- Christian L & Poling A (1997). Drug abuse in persons with mental retardation: a review. *American Journal on Mental Retardation*, 102,126-136.
- Cohen WI (1996). Health care guidelines for individuals with Down syndrome (down syndrome preventative medical checklist). *Down Syndrome Quarterly*, 1, 1-10.
- Conway GS, Payne NN, Webb J, Murray A & Jacobs PA (1998). Fragile X premutation screening in women with premature ovarian failure. *Human Reproduction*,

- 13, 1184-87.
- Cooke LB (1997). Cancer and learning disability. *Journal of Intellect Disability Research* 41, 312-6.
- Cooper SA (1998). Clinical study of the effects of age on the physical health of adults with mental retardation. *American Journal on Mental Retardation* 106, 582-89.
- Cooper, SA (1999). The relationship between psychiatric and physical health in elderly people with intellectual disability. *Journal of Intellect Disability* Cramp ME, Grundy HC, Perinpanayagam RM & Barnado DE (1996). Seroprevalence of hepatitis B and C virus in two institutions caring for mentally handicapped adults. *Journal of Royal Society of Medicine*, 89, 401-2.
- Crocker AC & Yankauer A (1987). Basic issues (in providing community-based health care). *Mental Retardation*, 25, 227-32.
- Davids JR, Hagerman RJ & Eilert RE (1990). Orthopedic aspects of fragile-X syndrome. *Journal of Bone & Joint Surgery*, 72, 889-96.
- Day KA (1987). The elderly mentally handicapped in hospital: a clinical study. *Journal of Mental Deficiency Research*, 31, 131-46.
- Desai KB, Ribbans WJ & Taylor GJ (1996). Incidence of five common fracture types in an institutional epileptic population. *Injury*, 27, 97-100.
- Devenny DA, Silverman WP, Hill AL, Jenkins E, Sersen EA & Wisniewski KE (1996). Normal ageing in adults with Down's syndrome: a longitudinal study. *Journal Intellect Disability Research*, 40, 208-21.
- Dinani S & Carpenter S (1990). Downs syndrome and thyroid disorder. *Journal of Mental Deficiency Research* 34, 187-93.
- Dulac O & N'Guyen T (1993). The Lennox-Gastaut syndrome. *Epilepsia*, 34, S7-17.
- Editorial (1990). Growth and nutrition in children with cerebral palsy. *Lancet*, 1253-4.
- Editorial (1998). A position paper from the Academy of Dentistry for Persons with Disabilities. Preservation of quality oral health services for people with developmental disabilities. *Special Care in Dentistry*, 18, 180-2.
- Erkkila H, Lindberg L & Kallio AK (1996). Strabismus in children with cerebral palsy. *Acta Ophthal Scandinavica*, 74, 636-8.
- Evenhuis HM (1990). The natural history of dementia in Down's syndrome. *Archives of Neurology*, 47, 263-7.
- Evenhuis HM, Zanten GA van, Brocaar MP & Roerdinkholder WHM (1992). Hearing loss in middle-age persons with Down syndrome. *American Journal Mental Retardation*, 97, 7-56.
- Evenhuis HM (1995). Medical aspects of ageing in a population with intellectual disability: I. Visual impairment. *Journal Intellect Disability Research*, 39, 19-26.
- Evenhuis HM (1995). Medical aspects of ageing in a population with intellectual disability: II. Hearing impairment. *Journal Intellect Disability Research*, 39, 27-33.
- Evenhuis HM (1997). Medical aspects of ageing in a population with intellectual disability: III. Mobility, internal conditions and cancer. *Journal Intellect Disability Research*, 41, 8-18.
- Evenhuis HM, Oostindiër MJ, Steffelaar JW & Coebergh JWW (1996). Incidentie van kanker bij mensen met een verstandelijke handicap; mogelijk verhoogd risico op slokdarmkanker (Cancer incidence in people with intellectual disability: increased risk of oesophageal cancer?). *Ned Tijdschr Geneeskd*, 140, 2083-6.
- Evenhuis HM, (1997). The natural history of dementia in ageing people with intellectual disability. *Journal of Intellectual Disability Research*, 41, 92-6.
- Evenhuis HM, Mul M, Lemaire EKG & de Wijs JPM (1997). Diagnosis of sensory impairment in people with intellectual disability in general practice. *Journal of Intellectual Disability Research*, 41, 22-9.
- Evenhuis HM & Nagtzaam LMD (Eds.), (1998). *Early identification of hearing and visual impairment in children and adults with an intellectual disability. IASSID International Consensus Statement. SIRG Health Issues.*
- Evenhuis HM (1999). Associated medical aspects. In: MP Janicki & AJ Dalton (Eds.), *Dementia, Aging and Intellectual Disabilities: A Handbook*, pp. 103-118, Philadelphia: Brunner-Mazel.
- Eyman RK, Grossman HJ, Chaney RH & Call TL (1990). The life expectancy of profoundly handicapped people with mental retardation. *New England Journal of Medicine*, 323, 584-9.
- Forsgren L, Edvinsson SO, Nystrom L & Blomquist HK (1996). Influence of epilepsy on mortality in mental retardation: an epidemiologic study. *Epilepsia*, 31, 956-63.
- Fujiura GT, Fitzsimmons N, Marks, B & Chicoine, B (1997). Predictors of BMI among adults with Down syndrome: the social context of health promotion. *Research in Dev Disabilities*, 18, 261-274.
- Golden E & Hatcher J (1997). Nutritional knowledge and obesity of adults in community residences. *Mental Retardation*, 35, 177-84.
- Goulden KJ, Shinnar S, Koller H, Katz M & Richardson SA (1991). Epilepsy in children with mental retardation: a cohort study. *Epilepsia*, 32, 690-7.
- Gowdy WC, Zarfes DE & Phipps S (1987). Audit of

- psychoactive drug prescriptions in group homes. *Mental Retardation*, 25, 331-34.
- Greenswag LR (1987). Adults with Prader-Willi syndrome: a survey of 232 cases. *Developmental Medicine & Child Neurology*, 29, 145-52.
- Haag H, Ruther E & Hippus H (1992). *Tardive Dyskinesia*. WHO Expert Series on Biological Psychiatry, Seattle: Hogrefe & Huber.
- Hayashi J, Kashiwagi S, Noguchi A, Nkashima K, Ikematsu H, Kajiyama, W & Nomura H (1989). Hepatitis b infection among mentally retarded patients in institutions, Okinawa, Japan. *Fukuoka Igaku Zasshi*, 80, 436-40.
- Helm, D., Crocker, A. & Rubin, L. (1999). A case study in international cooperation for children with developmental disabilities: The Republic of Armenia. *Abstract of Proceedings: AAMR 123rd Annual Meeting*. May 1999.
- Henderson CM, Janicki MP, Ladrihan P & Davidson PH (In press). Comprehensive adult and geriatric assessment for persons with ID. *Community Supports for Older Adults with Lifelong Disabilities*, Baltimore: Paul H. Brookes.
- Hymowitz N, Jaffe FE, Gupta A & Feuerman M (1997). Cigarette smoking among patients with mental retardation and mental illness. *Psychiatric Services*, 48, 100-2.
- Jacobson L (1988). Ophthalmology in mentally retarded adults. A clinical survey. *Acta Ophthalmol*, 66:457-62.
- Jancar J (1990). Cancer and mental handicap. A further study (1976-85). *British Journal Psychiatry*, 156, 531-3.
- Jancar J & Jancar MP (1998). Age-related fractures in people with intellectual disability and epilepsy. *Journal of Intellectual Disability Research*, 42, 429-33.
- Jancar J & Speller CJ (1994). Fatal intestinal obstruction in the mentally handicapped. *Journal of Intellectual Disability Research*, 38, 413-22.
- Janicki, MP & Jacobson JW. (1985). Fire safety, self-preservation, and community residences for persons with mental retardation. *Fire Journal*, 79(4), 38-41, 82-86.
- Janicki MP, Dalton AJ, Henderson CM & Davidson PW (1999). Mortality and morbidity among older adults with intellectual disability: health services considerations. *Disability and Rehabilitation*, 21, 284-294
- Jones RG & Kerr MP (1997). A randomized control trial of an opportunistic screening tool in primary care for people with intellectual disability. *Journal of Intellectual Disability Research*, 41, 409-15.
- Kapell D, Nightengale B, Rodriguez, A, Lee, JH, Zigman WB & Schupf N (1998). Prevalence of chronic medical conditions in adults with mental retardation: comparison with the general population. *Mental Retardation*, 36, 269-79.
- Hand, JE (1994). Report of a national survey of older people with lifelong intellectual handicap in New Zealand. *Journal of Intellectual Disability Research*, 38, 275-87.
- Harada T, Ebara S, Anwar MM, Okawa a, Kajura I, Hiroshima K & Ono K (1996). The cervical spine in athetoid cerebral palsy. A radiologic study of 180 cases. *Journal of Bone and Joint Surgery*, 78, 613-19.
- Kearny GM, Krishnan VHR & Londhe RL. (1993). Characteristics of elderly people with a mental handicap living in a mental handicap hospital: a descriptive study. *British Journal of Development Disability*, 76, 31-50.
- Kennedy M, McCombie L, Dawes P, McConnell KN & Dunnigan MG (1997). Nutritional support for patients with intellectual disability and nutrition and dysphagia disorders in community care. *Journal of Intellectual Disability Research*, 41, 430-36.
- Lai F & Williams RS (1989). A prospective study of Alzheimer disease in Down syndrome. *Archives of Neurology*, 46, 849-53.
- LaChapelle DL, Hadjistavropoulos T & Craig K (In press). Pain measurement in persons with intellectual disabilities. *The Clinical Journal of Pain*.
- Lamb AS & Johnson WM (1987). Premature coronary artery atherosclerosis in a patient with Prader-Willi syndrome. *American Journal Medical Genetics*, 28, 873-80.
- Lennox, N (Ed.), (1999). *Management Guidelines. People with Developmental and Intellectual Disabilities*, Melbourne: Therapeutic Guidelines.
- Lemaitre N, Sougakoff W, Coetmeur D, Vaucel J, Jarlier V & Grosset J (1996). Nosocomial transmission of tuberculosis among mentally-handicapped patients in a long-term care facility. *Tubercle & Lung Disease*, 77, 531-6.
- Linaker OM & Nottesstad JA (1998). Health and health services for the mentally retarded before and after the reform. *Tidsskr Nor Laegeforening*, 188 (3), 357-61.
- Loehr, JP, Synhorst, DP, Wolfe, RR & Hagerman, RJ (1986). Aortic root dilatation and mitral valve prolapse in the fragile X syndrome. *American Journal of Medical Genetics*, 23, 189-94.
- Lowes LP & Greis SM (1998). Role of occupational therapy, physical therapy, and speech and language therapy in the lives of children with cerebral palsy. In: G Miller & GD Clark (Eds.) *The Cerebral Palsies: Causes, Consequences and Management*, pp. 333-46, Boston: Butterworth-Heinemann.
- Lucchese C & Checchi L (1998). The oral status in mentally retarded institutionalized patients. *Minerva Stomatologica* 47 (10), 499-502.
- Lunsky, Y (1999). Women with developmental disabilities: collaborative strategies for providing GYN care. *Abstract of Proceedings: AAMR 123rd Annual Meeting*, May 1999.
- Maaskant MA & Haveman MJ (1989). Aging residents

- in sheltered homes for persons with mental handicap in the Netherlands. *Australia & New Zealand Journal Development Disabilities*, 15, 219-30.
- Maaskant MA & Haveman MJ (1990). Elderly residents in Dutch institutions for people with mental handicap. *Journal Mental Deficiency Research*, 34, 475-82.
- MacEachron AE & Krauss MW (1985). Self preservation ability and residential fire emergencies: Martin DM, Roy A & Wells MB (1997). Health gain through health checks: improving access to primary health care for people with intellectual disability. *Journal of Intellect Disability Research*, 41, 401-408.
- McRae D (1997). Health care for women with learning disabilities. *Nursing Times*, 93, 58-9.
- McVicker RW, Shanks OEO & McClelland RJ (1994). Prevalence and associated features of epilepsy in adults with Down's syndrome. *British Journal Psychiatry*, 164, 528-32.
- Mikawa Y, Watanabe R & Shikata J (1997). Cervical myelo-radiculopathy in athetoid cerebral palsy. *Archives of Orthopedics & Trauma Surgery*, 116, 116-18.
- Minihan PH & Dean DH (1990). Meeting the needs for health services of persons with mental retardation living in the community. *American Journal of Public Health* 80, 1043-48.
- Mirrett PL et al (1994). Videofluoroscopic assessment of dysphagia in children with severe spastic cerebral palsy. *Dysphagia*, 9:174-9.
- Moore D & Posgrove L (1991). Disabilities, developmental handicaps, and substance abuse: a review. *Intl Journal of the Addictions* 26, 109-23
- Morbidity and Mortality Weekly Report (1998). State-specific rates of mental retardation —United States, 1993. 45, 61-65.
- Murdoch JC, Ratcliffe WA, McLarty JC, Rodger JC & Ratcliffe JG, (1977). Thyroid function in adults with Down syndrome. *Journal Clin Endocrin Metabolism*, 44, 153-8.
- Murray A, Webb J, Grimley S, Conway G. & Jacobs P. (1998). Studies of FRAXA and FRAXE in women with premature ovarian failure. *Journal of Medical Genetics*, 35, 637-40.
- Nelson RP & Crocker AC (1978). The medical care of mentally retarded persons in public residential facilities. *New England Journal of Medicine*, 299, 1039-44.
- Nicolaci AB & Tesini DA (1982). Improvement in the oral hygiene of institutionalized mentally retarded individuals through training of direct care staff: a longitudinal study. *Special Care Dentistry*, 2, 217-21.
- O'Brien KF, Tate K & Zaharia ES (1991). Mortality in a large southeastern facility for persons with mental retardation. *American Journal on Mental Retardation*, 95, 397-403.
- O'Brien KF & Zaharia ES (1998). Recent mortality patterns in California. *Mental Retardation*, 36, 372-79.
- replication and criterion-validation study. *American Journal of Mental Deficiency*, 90, 107-10.
- Maino DM, Wesson M, Schlange D, Cibis G & Maino JH (1991). Optometric findings in the fragile X syndrome. *Optometry and Visual Science*, 68, 634-40.
- Marino, B & Pueschel, SM (Eds.), (1996). *Heart Disease in Persons with Down Syndrome*. Baltimore: Paul H. Brooks.
- O'Donnell J (1994). Dental care for special needs individuals: a new barrier to access. *Special Care in Dentistry*, 14, 178-79.
- Ohtsuka Y (1998). West syndrome and its related epileptic syndromes. *Epilepsia*, 39, 30-7.
- Oka E, Sanada S, Asano T & Ishida T (1997). Mental deterioration in childhood epilepsy. *Acta Medica Okayama*, 51, 173-8.
- Pack RP, Wallander JL & Brown, D (1998). Health risk behaviors of African American adolescents with mild mental retardation: prevalence depends on measurement method. *American Journal on Mental Retardation*, 102, 409-420.
- Phillips J (1998). Complications of anticonvulsant drugs and ketogenic diet. In: J Biller (Ed.) *Iatrogenic Neurology*, pp. 397-414), Boston: Butterworth-Heinemann.
- Piachuad, J, Rohde J & Pasupathy A (1998). Health screening for people with Down syndrome. *Journal of Intellect Disability Research*, 45, 341-45.
- Pires da Cunha R & Belmiro de Castro Moreira D (1996). Ocular findings in Down's syndrome. *American Journal Ophthalmol*, 122, 236-44.
- Pittetti KH, Rimmer JH, & Fernhall B (1993). Physical fitness in adults with mental retardation. An overview of the current research and future directions. *Sports Medicine*, 16, 25-56.
- Prasher VP & Chung MC (1996). Causes of age-related decline in adaptive behavior of adults with Down syndrome: differential diagnosis of dementia. *American Journal on Mental Retardation*, 101, 175-83.
- Pueschel SM & Pueschel JK (Eds.) (1992). *Biomedical Concerns in Persons with Down Syndrome*, Baltimore: Paul H. Brooks.
- Reilly S & Skuse D (1992). Characteristics and management of feeding problems of young children with cerebral palsy. *Devel Med Child Neurol*, 34, 379-88.
- Renshaw TS, Green NE, Griffin PP & Root L (1996). Cerebral palsy: orthopedic management. *Instructional Course Lectures*, 45, 475-90.
- Ribacoba MR, Salas PJ, Fernandez TJ & Moral RM (1995). Fragile X syndrome and epilepsy. *Neurologia*, 10, 70-5.
- Rimmer JH, Braddock D & Fujiara G (1994). Cardiovascular risk factors in adults with mental retardation. *American Journal on Mental Retardation*, 98, 510-18.

- Rimmer JH, Braddock D & Marks B (1995). Health characteristics and behaviors of adults with mental retardation residing in three living arrangements. *Research in Developmental Disabilities*, 16, 489-99.
- Roberts IM, Curtis RL & Madara JL. (1986). Gastroesophageal reflux and Barrett's esophagus in developmentally disabled patients. *American Journal Gastroenterol*, 81, 519-23.
- Rogers B, Stratton P, Msall M, Champlain M, Koerner P & Piazza J (1994). Long term morbidity and Russman BS & Romness M (1998). Neurorehabilitation for the child with cerebral palsy. In: G Miller & GD Clark (Eds.) *The Cerebral Palsies: Causes, Consequences, and Management*, pp. 321-32, Boston: Butterworth-Heinemann
- Saito N, Ebara S, Ohotsuka K, Kumeta H & Takaoka K (1998). Natural history of scoliosis in spastic cerebral palsy. *Lancet*, 351, 1687-92.
- Sare Z, Ruvalcaba RHA & Kelley V (1978). Prevalence of thyroid disorder in Down syndrome. *Clinical Genetics*, 14, 154-8.
- Schenk-Rootlieb AJ, Nieuwenhuizen O van, Graf Y van der, Wittebol-Post D & Willemse J (1992). The prevalence of cerebral visual disturbance in children with cerebral palsy. *Dev Medicine and Child Neurology*, 34, 473-80.
- Schrojenstein Lantman-de Valk HM van, Metsemakers JF, Soomers-Turlings MJ, Haveman MJ & Crebolder HF (). People with intellectual disability in general practice: case definition and case finding. *Journal Intellect Disability Research* 41, 373-9.
- Schrojenstein Lantman-de Valk HMJ van, Haveman MJ, Maaskant MA & Kessells AG (1994). The need for assessment of sensory functioning in ageing people with mental handicap. *Journal of Intellectual Disability Research*, 38, 289-98.
- Schrojenstein Lantman-de Valk HMJ van, Akker M van den, Maaskant MA, Haveman MJ, Urlings HFJ, Kessells AGH et al (1997). Prevalence and incidence of health problems in people with intellectual disability. *Journal of Intellect Disability Research*, 41, 42-51.
- Scott A, Marsh L & Stokes ML (1998). A survey of oral health in a population of adults with developmental disability: comparison with a national oral health survey of the general population. *Australian Dental Journal*, 43, 257-61.
- Seltzer G & Luchterhand C (1994). Health and well-being of older persons with developmental disabilities: a clinical review. In MM Seltzer, MW Krauss & MP Janicki (Eds.) *Life Course Perspectives on Adulthood and Old Age*, pp. 109-141, Washington DC: American Association on Mental Retardation.
- Shaw L, Weatherill S & Smith A (1998). Tooth wear in children: an investigation of etiologic factors in children with cerebral palsy and gastroesophageal reflux. *ASDC Journal of Dentistry for Children*, 65, 484-6.
- management strategies of tracheal aspiration in adults with severe developmental disabilities. *American Journal on Mental Retardation*, 98, 490-98.
- Roizen NJ, Wolters C, Nicol T, Blondis TA (1993). Hearing loss in children with Down syndrome. *Journal Pediatrics*, 123, S9-12.
- Rosen MG & Dickinson JC (1992). The incidence of cerebral palsy. *American Journal of Obstetrics & Gynecology*, 167, 417-23.
- Song F, Freemantle N, Selicowitz M (1993). A five year longitudinal study of thyroid function in children with Down syndrome. *Developmental and Child Neurology*, 35, 396-401.
- Sreeram N, Wren C, Bhate M, Robertson P & Hunter S (1989). Cardiac abnormalities in the fragile X syndrome. *British Heart Journal*, 61, 289-91.
- Steffenburg U, Hagberg G, Viggedal G & Kyllerman M (1995). Active epilepsy in mentally retarded children. 1. Prevalence and additional neuroimpairments. *Acta Paediatrica*, 84, 1147-52.
- Stehr-Green P, Wilson N, Miller J & Lawther A (1991). Risk factors for hepatitis B at a residential institution for intellectually handicapped persons. *NZ Medical Journal*, 105, 514-6.
- Strauss D & Kastner T (1996). Comparative mortality of people with developmental disabilities in institutions and the community. *American Journal on Mental Retardation*, 101, 26-40.
- Strauss D, Anderson TW, Shavelle R, Sheridan F & Trenkle S (1998). Causes of death of persons with developmental disabilities: comparison of institutional and community residents. *Mental Retardation*, 36, 386-91.
- Strauss D & Shavelle R (1998). Life expectancy of adults with cerebral palsy. *Dev Medicine & Child Neurology*, 40, 369-75.
- Strauss DJ, Shavelle RM & Anderson TW (1998). Life expectancy of children with cerebral palsy. *Pediatric Neurology*, 19, 243-44.
- Strauss DJ, Shavelle RM, Baumeister AA & Anderson TW (1998). Mortality in persons with developmental disability after transfer to community care. *American Journal on Mental retardation*, 102, 569-581.
- Strome SE & Strome M (1992). Down syndrome: an otolaryngologic perspective. *Journal Otolaryngol*, 21, 394-7.
- Thorpe L (1999). Psychiatric disorders. In: MP Janicki MP & AJ Dalton AJ (Eds.) *Dementia, Aging and Intellectual Disabilities: A Handbook*, pp. 217-230, Philadelphia: Brunner-Mazel.
- Tracy J & Hosken R (1997). The importance of smoking cessation and preventative health strategies for people with intellectual disability. *Journal of Intellect Disability Research*, 41, 416-21.
- Tu JB (1979). A survey of psychotropic medication in mental retardation facilities. *Journal of Clinical*

- Psychiatry*, 40, 125-128.
- Turner S & Moss S (1996). The health needs of adults with learning disabilities and the Health of the Nation strategy. *Journal of Intellectual Disability Research*, 40, 438-450.
- Turk MA, Geremski CA, Rosenbaum PF & Weber RJ (1997). The health status of women with cerebral palsy. *Archives of Physical Medicine & Rehabilitation*, 78, S10-17.
- Udani VP, Dharnidharka V, Nair A & Oka M (1993). Difficult to control epilepsy in childhood- a long term
- Warberg M & Rattleff J (1992). Treatable visual impairment. A study of 778 consecutive patients with mental handicap placed in sheltered workshops. In: J Roosendahl (Ed.) *Mental Retardation and Medical Care*, pp. 350-56, Zeist: Uitgeverij Kerkebosch.
- Warburg M (1994). Visual impairment among people with developmental delay. *Journal Intellectual Disability Research*, 38, 423-32.
- Westmeyer J, Phaobtong T & Neider J (1988). Substance use and abuse among mentally retarded persons: comparison of patients and a survey population. *American Journal of Drug & Alcohol Abuse*, 14, 109-23.
- Wilson DN & Haire A (1990). Health care screening for people with mental handicap living in the community. *British Medical Journal*, 301, 1379-81.
- Wilson D & Haire A. (1992). Health care screening for people with mental handicap in the United Kingdom. In: J Roosendahl (Ed.) *Mental Retardation and Medical Care*, pp. 58-67, Zeist: Uitgeverij Kerkebosch.
- Wisniewski KE, Dalton AJ, Crapper-McLachlan DR, Wen GY, Wisniewski HM (1985). Alzheimer's disease in Down's syndrome: clinicopathologic studies. *Neurology*, 35, 957-61.
- Wojcieszek J (1998). Drug-induced movement disorders. In: J Biller (Ed.) *Iatrogenic Neurology*, pp. 215-230, Boston: Butterworth-Heinemann.
- Zigman WB, Schupf N, Sersen E, Silverman W (1995). Prevalence of dementia in adults with and without Down syndrome. *American Journal on Mental Retardation*, 100, 403-12.
- study of 123 cases. *Indian Pediatrics*, 30, 199-206.
- Wagemans AMA, Fiolet JFBM, Linden ES van der, Menheere PPCA (1998). Osteoporosis and intellectual disability: is there any relation? *Journal of Intellectual Disability Research*, 42, 370-4.
- Walsh KK, Kastner T & Criscione T (1997). Characteristics of hospitalizations for people with developmental disabilities: utilization, costs, and impact of care coordination. *American Journal on Mental Retardation*, 100, 505-20.

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 cost-

effective 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 lifespan approach 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 hygiene, 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.