

Healthy Ageing – Adults with Intellectual Disabilities: Physical Health Issues

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Introduction: a life-span, 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 healthcare, 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 & Crocker (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 (e.g., see Helm *et al.* 1999) (Box 1).

Box 1. Recommendation 1.

To develop a world-wide 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.

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 1998). These differences reflect socio-economic factors, differences in the definition of intellectual disabilities, and case-finding techniques (Schrojenstein Lantman-de Valk *et al.* 1997a). People with intellectual disabilities constitute a heterogeneous population. The ‘two group’ model is an attempt to point out that people with mild cognitive impairment may have different aetiologies and clinical issues than people with more severe cognitive impairment (who may be more likely to have associated syndromic conditions and other developmental disabilities) (Accardo & Capute 1990). Furthermore, industrialized countries exhibit variations in the way that healthcare and other services are organized and delivered to people with (and without) an intellectual disability, and these pre-existing differences in service delivery have an impact on the relevance of specific strategies to promote healthy ageing.

Industrialized countries are witnessing an increase in the longevity of adults with an intellectual disability (Janicki *et al.* 1999). As more people with intellectual disabilities attain older age, it is important to note that excess functional impairment, morbidity, and even mortality can result from the consequences of early age-onset conditions, through their long-term progression or their interactions with older age-onset conditions. An example of the potential consequences of long-term progression is the high incidence of oesophageal reflux in children with cerebral palsy and severe motoric compromise. If childhood-onset oesophagitis is not identified and treated, it can lead to high rates of oesophageal stricture or cancer in adulthood (Roberts *et al.* 1986; Evenhuis *et al.* 1996; Böhmer *et al.* 1996, 1997b, c; 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 *et al.* 1992; Wojcieszek 1998), and bone mineralization disease that may occur secondary to the chronic use of certain anticonvulsants (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 (Box 2).

Box 2. Recommendation 2.

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

Special issues in healthcare, 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 programmes and access to basic healthcare 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.

Syndrome-specific conditions

Persons with specific syndromes constitute a clinically and numerically important portion of the population with an intellectual disability. These syndromes can be caused by toxins, injuries, infections, and genetic/metabolic disorders which affect the central nervous system and, in some cases, other organ systems, during the developmental period. Moreover, these effects can become manifested, and clinically anticipated, at different stages of the life-span. 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 life-span, 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 *et al.* 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 *et al.* 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 *et al.* 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 life-span 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 counselling 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 (Box 3).

Box 3. Recommendation 3.

Children presenting with intellectual disabilities should have thorough diagnostic searches for aetiologies and syndromes to optimize their current and future healthcare.

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 *et al.* 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 *et al.* 1990; Strauss & Shavelle 1998; Strauss *et al.* 1998a, b). 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 *et al.* 1996) and bladder dysfunction (Boone 1998). Spasticity may require medical or neurosurgical treatment to alleviate pain, prevent deformities, and enhance function (Russman & Romness 1998); orthopaedic 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, oesophageal reflux and gastric emptying disorders may lead to dental erosion, oesophagitis, anaemia, feeding problems, aspiration and pneumonia (indeed, respiratory disease is the leading cause of death in people with cerebral palsy and severe motoric impairments) (Editorial 1990; Reilly & Skuse 1992; Couriel *et al.* 1993; Arvedson *et al.* 1994; Mirrett *et al.* 1994; Rogers *et al.* 1994; Böhmer *et al.* 1997b; Shaw *et al.* 1998). People with intellectual disabilities and cerebral palsy are also prone to lower gastrointestinal dysmotility; this may cause constipation and faecal impaction (Cathels & Reddiough 1993), and death caused by bowel obstruction and intestinal perforation (Jancar & Speller 1994). Bone demineralization with consequent fractures and decubitus ulcers may occur secondary to long-standing immobility and nutritional deficiencies (Brunner & Doderlein 1996; Wagemans *et al.* 1998). Children and adults with cerebral palsy, and severe or multiple impairing conditions require multidisciplinary care (Lowes & Greis 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 *et al.* 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.

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 (Steffenburg *et al.* 1995). In addition to the risk of status epilepticus (which is more common in children with coexisting neuro-impairments such as cerebral palsy), epilepsy is associated with injuries such as fractures (Desai *et al.* 1996; Jancar & Jancar 1998). People with intellectual disabilities and epilepsy have an increased mortality caused by 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 *et al.* 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) – healthcare 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 (Box 4).

Box 4. 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.

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

Industrialized countries have varying habilitative and residential philosophies and practices for persons with intellectual disabilities. In North America, Australia and in many European countries, governments have implemented measures to close large publicly-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 variations in expenditures for supports and services for people with intellectual disabilities (for the 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.* 1991; Cramp *et al.* 1996), and *Helicobacter pylori* (Böhmer *et al.* 1997a) (Box 5).

Box 5. Recommendation 5.

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

As people with intellectual disabilities, particularly those with milder cognitive impairments, are offered more lifestyle choices, there is the potential that some of these choices may result in a higher potential for risky behaviours 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 & Hoskin 1997), other substance abuse (Westermeyer *et al.* 1988; Moore & Posgrove 1991; Christian & Poling 1997), violent behaviour (Pack *et al.* 1998), and high-risk sexual activity (Cambridge 1996). Behavioural factors of people with intellectual disabilities and their carers contribute to the high rates of periodontal disease noted in people with intellectual disabilities (Beange *et al.* 1995; Lucchese & Checchi 1998; Scott *et al.* 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 (Beange *et al.* 1995; Rimmer *et al.* 1994; Fujiura *et al.* 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 programmes that target healthy behaviours such as safe sex practices (Ager & Littler 1998), avoidance of tobacco and other harmful substances (Tracy & Hosken 1997), good oral hygiene (Nicolaci & Tesini 1982), optimal exercise and dietary habits (Pittetti *et al.* 1993; Golden & Hatcher 1997), and fire safety education

(Janicki & Jacobson 1985; MacEachron & Krauss 1985) need continued development (Box 6).

Box 6. 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 behaviours 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 life-span, 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 cervical smears in women who have no history of sexual activity), glaucoma, hyperlipidemia, and hypertension, should be offered to people with intellectual disabilities (Box 7).

Box 7. Recommendation 7.

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

Older age-related conditions

A number of recent studies have addressed the health status of middle-aged and older adults with intellectual disabilities. These studies vary in methodology, and include longitudinal residence carers surveys (Anderson 1993), interviews with subjects with intellectual disabilities and their carers (Cooper 1998), carers interviews combined with medical chart reviews (Kapell *et al.* 1998), health status questionnaires of physicians providing care to subjects (Hand 1994), questionnaires of direct care staff and physicians (Schrojenstein Lantman-de Valk *et al.* 1997), comprehensive medical assessment of subjects by a developmental physician (Beange *et al.* 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 *et al.* 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 (Maaskant & Haveman 1989, 1990; Minihan & Dean 1990; Anderson 1993; Hand 1994; Beange *et al.* 1995; Evenhuis 1995a,b, 1997a,b; Schrojenstein Lantman-de Valk *et al.* 1997a,b; Cooper 1998; Kapell *et al.* 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, gastro-oesophageal reflux and oesophagitis, constipation, and deaths caused by bowel obstruction and intestinal perforation and gastrointestinal cancer. Other examples include non-atherosclerotic heart disease (Evenhuis *et al.* 1996; Böhmer *et al.* 1997b; Jancar 1990; Cooper 1998; Kapell *et al.* 1998), mobility impairment (Kearny *et al.* 1993; Evenhuis 1997a,b), thyroid disease (Kapell *et al.* 1998), osteoporosis (Center *et al.* 1998) psychotropic drug polypharmacy (Tu 1979; Gowdy *et al.* 1987; Schrojenstein Lantman-de Valk *et al.* 1997), and deaths caused by pneumonia (O'Brien *et al.* 1991; Janicki *et al.* 1999) (Box 8).

Box 8. Recommendation 8.

Healthcare 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 (Jacobson 1988; Warberg 1992; Wilson & Haire 1990; Warburg 1994; Schrojenstein Lantman-de Valk *et al.* 1997). Although causes of visual and hearing loss may be present in rates similar to those in the general population (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 (Schrojenstein Lantman-de Valk *et al.* 1994; Evenhuis 1995a,b).

Functional decline in older adults with intellectual disabilities warrants careful evaluation; a decline in functional status should not be peremptorily attributed to behavioural issues or dementia (Prasher & Chung 1996; Burt *et al.* 1998). 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; Chicoine *et al.* 1999; Evenhuis 1999; Thorpe 1999; Henderson *et al.* Year?). 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) (Box 9).

Box 9. 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.

Barriers to healthcare services in healthy ageing and intellectual disabilities

In theory, people with intellectual disabilities living in industrialized countries have equal access to essential healthcare services. As mentioned previously, countries (and regions within countries) vary in their models of healthcare 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 healthcare system. It is important that healthcare providers and policy makers acknowledge that many people with intellectual disabilities have special needs that may require modification of standard healthcare 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 healthcare 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, healthcare 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 *et al.* Year?); at the same time, individuals who have potential communication skills need to be educated in the effective communication of pain or distress (Bromley *et al.* 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 healthcare 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 gynaecological care because of accessibility problems (Turk *et al.* 1997). Healthcare facilities should be easily accessible to persons with an intellectual disability who may have a variety of physical and sensory impairments.

Behavioural issues constitute another potential barrier. Persons with intellectual disabilities may have difficulty cooperating with examinations and procedures. Healthcare providers need to be educated regarding the confusion, fear, and frustration that many people with intellectual disabilities may experience when they access healthcare services. Again, more time may be necessary to reassure someone with an intellectual disability. Habilitative programmes or healthcare providers should address the issue of healthcare – not just in terms of healthy living, but also by increasing understanding and confidence in using health services (McRae 1997; Lunskey 1999). Protocols for safe conscious sedation may be helpful for some people with an intellectual disability. In other cases, general anaesthesia may be necessary to enable safe and thorough health maintenance exams and procedures. Behavioural 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 supportive 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 healthcare professionals. Case management is crucial for the optimal utilization of healthcare services for people with intellectual disabilities who have complex needs requiring multidisciplinary expertise (Walsh *et al.* 1997).

It is worth noting that, in some countries or states, healthcare 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 (Boxes 10–12).

Box 10. Recommendation 10.

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

Box 11. Recommendation 11.

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

Box 12. Recommendation 12.

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

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 healthcare 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 (Wilson & Haire 1990; Evenhuis 1995a,b, 1997c; Evenhuis & Nagtzaam 1998), swallowing disorders (Kennedy *et al.* 1997), urinary incontinence (Bradley *et al.* 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 *et al.* 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 1996; Piachaud *et al.* 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 life-span approach to developmental disabilities, can provide valuable expertise to primary care physicians and other healthcare providers serving people with intellectual disabilities. The influence of this specialty can range from preparing written guidelines and training programmes for primary care physicians and other healthcare providers, to providing formal and informal consultation services for complex patients. In addition, they can provide leadership in the area of clinical research.

Healthcare 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 – into basic and postgraduate medical education.

Lastly, there is a need for medical specialists with interest and expertise in intellectual disabilities. Psychiatrists, neurologists, physiotherapists, 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 (Boxes 13–15).

Box 13. Recommendation 13.

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

Box 14. Recommendation 14.

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

Box 15. Recommendation 15.

The development of the discipline of life-span 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.

Conclusion: areas for future research

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

- The acquisition of additional clinical and epidemiological knowledge regarding specific syndromes, with linkages to basic science research in biomolecular genetics and metabolism.
- The development of adapted diagnostic and therapeutic methods for people who have difficulties with cooperation or communication.
- The development and evaluation of interdisciplinary interventions for complicated conditions (e.g. sensory impairment, dysphagia, communication, and functional decline).
- 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 healthcare systems, to care for people with intellectual disabilities.
- The evaluation of the applicability of a new discipline of life-span developmental medicine to lead in interdisciplinary care, healthcare education, service delivery, and research for people with intellectual disabilities.
- The development of the knowledge base regarding the health status and needs of people with intellectual disabilities living in less-developed countries.

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comprehensive WHO document on ageing and intellectual disability (WHO 2000). The primary goal of this paper is to organize information on physical health issues in older people with intellectual disabilities, and to present broad summative goals to direct further work in this area.

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