Healthy Ageing - Adults with Intellectual Disabilities

Physical Health Issues

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

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

Industrialized countries are witnessing an increase in the longevity of adults with an intellectual disability (Janicki et al, 1999). As more people with intellectual disabilities attain older age, it is important to note that excess functional impairment, morbidity, and even mortality can result from the consequences of early age-onset conditions, through their long-term progression or their interactions with older age-onset conditions. An example of the potential

consequences of long-term progression is the high incidence of esophageal reflux in children with cerebral palsy and severe motoric compromise. If childhood-onset esophagitis is not identified and treated, it can lead to high rates of esophageal stricture or cancer in adulthood (Roberts et al, 1986; Bohmer et al 1996, 1997a,b; Cook, 1997). An example of the interaction of early-age onset and later-age onset conditions is, in persons with Down syndrome, the superimposition of adult-onset sensorineural hearing loss on 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 & Hippius, 1992; Wojcieszek, 1998), and bone mineralization disease that may occur secondary to the chronic use of certain anticonvulsants (Bikle, 1996; Phillips, 1998). Although more research needs to be done, it is apparent that healthy ageing for people with an intellectual disability requires a dynamic, lifespan clinical approach.

Recommendation 2

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

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

Persons with specific syndromes constitute a clinically and numerically important portion of the population with an intellectual disability. These syndromes can be caused by toxins, injuries, infections, and genetic/metabolic disorders which affect the central nervous system and, in some cases, other organ systems, during the developmental period. Moreover, these effects can become manifested, and clinically anticipated, at different stages of the lifespan. Down syndrome is a relatively common chromosomal disorder that, in addition to causing an intellectual disability, results in a relatively high risk for a number of conditions. In the neonatal period, Down syndrome can be associated with congenital defects of the heart, gastrointestinal tract, eyes, and other organs *(*Pueschel & Pueschel, 1992). Throughout the lifespan, persons with Down

syndrome manifest higher risks for specific endocrinological (especially hypothyroidism), infectious, dermatologic, oral health, cardiac, musculoskeletal and other organ system disorders (Murdoch et al, 1977; Sare et al, 1978;Dinani & carpenter, 1990; Pueschel & Pueschel, 1992; Song, Freemantle & Selicowitz, 1993; Marino & Pueschel, 1996). In addition, they exhibit high rates of disorders of the special senses of vision (Pires da Cunha & Belmiro de Castro Moreira, 1996) and hearing (Strome & Strome, 1992; Roizen et al, 1993). Older adults with Down syndrome have an increased risk of the early development of age-related visual and hearing disorders (Buchanan, 1990; Evenhuis et al, 1992), epilepsy (McVicker, Shanks & McCleeland, 1994) and dementia (Wisniewski et al, 1985; Lai & Williams, 1989; Evenhuis, 1990; Burt et al, 1995; Zigman et al, 1995; Devenny et al, 1996). Adults with Down syndrome have decreased longevity compared to the general population of people with intellectual disabilities (Janicki et al., 1999). Fragile X syndrome is the most common inherited disorder associated with an intellectual disability. People with Fragile X syndrome exhibit relatively high rates of mitral valve prolapse (Loehr et al, 1986; Sreeram et al, 1989), musculoskeletal disorders (Davids, Hagerman & Eilert, 1990), early female menopause (Conway et al, 1998; Murray et al, 1998), epilepsy (Ribacoba et al, 1995) and visual impairments (Maino et al, 1991). Adults with Prader-Willi syndrome are prone to high rates of cardiovascular disease and diabetes arising from morbid obesity (Greenswag, 1987; Lamb & Johnson, 1987). Other syndromes may not be as common or easily identifiable as Down syndrome, Fragile X syndrome, or Prader-Willi syndrome; however, the same principle of knowledge of syndrome-specific issues may lead to the enhanced functional and health status of persons who have them. Examples are the deafness and eye 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 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 (Lowes & Gries, 1998). In later life, the chronic abnormalities of muscle tone may lead to chronic myofascial pain, hip and back deformities (including degenerative vertebral spine disease that may cause myelopathy); worsening bowel and bladder function is also seen (Harada et al, 1996; Mikawa Y, Watanabe R & Shikata J, 1997;Turk et al, 1997; Saito et al, 1998). The optimization of function and survival for people with cerebral palsy throughout life depends on the anticipation and identification, and prevention or treatment, of both primary and secondary disorders.

People with intellectual disabilities and epilepsy have other health risks. Children with intellectual disabilities and intractable epilepsy present with higher rates of cerebral palsy, visual impairment, and severe cognitive impairments (Steffenberg et al, 1995). In addition to the risk of status epilepticus (which is more common in children with 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 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.

As people with intellectual disabilities, particularly those with milder cognitive impairments, are offered more lifestyle choices, there is the potential that some of these choices may result in a higher potential for risky behaviors and conditions that result from the lifestyle choices, or the interaction of lifestyle and hereditary factors. People with intellectual disabilities living in the community may engage in tobacco use (Burtner et al, 1995; Hymowitz et al, 1997; Tracey and Hoskin, 1997), other substance abuse (Westermeyer, Phaobtong & Neider, 1988; Moore & Posgrove, 1991; Christian & Poling, 1997), violent behavior (Pack, Wallander & Brown, 1998), and high-risk sexual activity (Cambridge, 1996). Behavioral factors of people with intellectual disabilities and their carers contribute to the high rates of peridontal disease noted in people with intellectual disabilities (Beange, McElduff & Baker, 1995; Lucchese & Checchi, 1998; Scott, Marsh & Stokes, 1998). A sedentary lifestyle, with consequent risks of deconditioning, obesity, (and diseases related to obesity including coronary artery disease, hypertension and diabetes) has been noted in people with intellectual disabilities in a variety of residential settings (Rimmer, Braddock & Marks, 1995; Beange, McElduff & Baker, 1995; Fujiura, Fitzsimmons, Marks & Chicoine, 1997). For people with intellectual disabilities, targeting lifestyle issues (Turner & Moss, 1996) may result in substantial gains in longevity and older-age quality of life and functional capability. Special programs that target healthy behaviors such as safe sex practices (Ager & Littler, 1998), avoidance of tobacco and other harmful substances (Tracy & Hosken, 1997), good oral hygeine (Nicolaci & Tesini, 1992), optimal exercise and dietary habits (Pitetti, Rimmer & Fernhall, 1993, Golden & Hatcher, 1997), and fire safety education (Janicki & Jacobson, 1985; MacEachron & Krauss, 1985), need continued development.

Recommendation 6

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

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

Recommendation 7

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

6. Older age-related conditions

A number of recent studies have addressed the health status of middle-age and older adults with intellectual disabilities. These studies vary in methodology, and include longitudinal residence carers surveys (Anderson, 1993), interviews with subjects with intellectual disabilities and their carers (Cooper, 1998), carers interviews combined with medical chart reviews (Kapell et al, 1998), health status questionnaires of physicians providing care to subjects (Hand, 1994), questionnaires of direct care staff and physicians (Schrojenstein Lantman-de Valk et al, 1997), comprehensive medical assessment of subjects by a developmental physician (Beange, McElduff & Baker, 1995), and comprehensive and longitudinal assessment of subjects by a developmental physician (Evenhuis, 1995a,b; Evenhuis, 1997a). Only one of these studies attempted to identify subjects who were not previously registered or residing within the intellectual disabilities service system, resulting in a 15% segment of the older population with an intellectual disability (Hand, 1994). It is significant that the study that utilized comprehensive medical assessment by a developmental physician (of subjects who were being managed by community-based primary care physicians) uncovered a high number of previously undiagnosed conditions (Beange, McElduff & Baker, 1995). The cumulative research suggests that older adults with intellectual disabilities have rates of common adult and older age-related conditions that are comparable to or even higher than that of the general population (Minihan & Dean, 1990; Anderson, 1993; Hand, 1994; Beange, McElduff & Baker, 1995; Evenhuis, 1997: Schrojenstein Lantman-de Valk et al 1997; Kapell et al, 1998; Cooper, 1998). For many people with intellectual disabilities, the risk of a variety of chronic diseases that are acquired during adulthood, and that are associated with older-age morbidity or functional impairment, reflects the same interplay between hereditary predisposition and environment that is present in other older persons. However, as discussed above, factors related to syndromes, associated developmental disabilities, and lifestye and environmental issues, may account for higher rates, compared to the population without intellectual disabilities, for a number of conditions. Previously noted examples include obesity, dental disease, gastroesophageal reflux and esophagitis, constipation, and deaths due to bowel obstruction and intestinal perforation and gastrointestinal cancer. Other examples include non-atherosclerotic heart disease (Kapell et al, 1998; Cooper, 1998), mobility impairment (Kearny, Krishnan & Londhe, 1993; Evenhuis, 1997), thyroid disease (Kapell et al, 1998), osteoporosis (Center, Beange & McElduff, 1998) psychotropic drug polypharmacy (Tu, 1979; Gowdy, Zarfas & Phipps, 1987; Schrojenstein Lantman-de Valk et al, 1997), and deaths due to pneumonia (O'Brien, Tate & Zaharia, 1991; Janicki et al, 1999).

Recommendation 8

Health care providers serving older adults with intellectual disabilities should recognize that adult and older-age onset medical conditions are common in this population, and may require a high index of suspicion for clinical diagnosis.

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

because of pre-existing, childhood onset visual and auditory pathology (Schrojenstein Lantman de-Valk et al, 1994; Evenhuis, 1995a,b).

Functional decline in older adults with intellectual disabilities warrants careful evaluation; a decline in functional status should not be peremptorily attributed to behavioral issues or dementia (Prasher & 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; 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 & Nottestadd, 1998). Carers need to be able to recognize signs of distress in persons with severe cognitive impairment (LaChapelle, Hadjistavvropoulos & Craig, in press); at the

same time, individuals who have 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- into basic and postgraduate medical education.

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

Recommendation 13

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

Recommendation 14

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

Recommendation 15

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

9. Conclusion: Areas for future research

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

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

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

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

●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.

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Recommendation 1

    To develop a worldwide perspective on healthy ageing and intellectual disabilities through affiliations between interested parties in industrialized and developing countries that promote advocacy, trans-cultural and 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 <u>lifespan approach</u> that recognizes the progression or consequences of specific diseases and therapeutic interventions.

Recommendation 3

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

Recommendation 4

    Persons presenting with an intellectual disability <u>should have expert care to identify and treat associated developmental disabilities</u> 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.