Addressing Health Disparities Through Promoting Equity for Individuals with Intellectual Disability

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ABSTRACT

Intellectual disabilities (ID) are conditions originating before the age of 18 that result in significant limitations in intellectual functioning and conceptual, social and practical adaptive skills. IDs affect 1 to 3% of the population. Persons with ID are more likely to have physical disabilities, mental health problems, hearing impairments, vision impairments and communication disorders. These co-existing disabilities, combined with the limitations in intellectual functioning and in adaptive behaviours, make this group of Canadians particularly vulnerable to health disparities. The purpose of this synthesis article is to explore potential contributory factors to health vulnerabilities faced by persons with ID, reveal the extent and nature of health disparities in this population, and examine initiatives to address such differences. The review indicates that persons with ID fare worse than the general population on a number of key health indicators. The factors leading to vulnerability are numerous and complex. They include the way society has viewed ID, the etiology of ID, health damaging behaviours, exposure to unhealthy environments, health-related mobility and inadequate access to essential health and other basic services. For persons with ID there are important disparities in access to care that are difficult to disentangle from discriminatory values and practice. Policy-makers in the United States, England and Scotland have recently begun to address these issues. It is recommended that a clear vision for health policy and strategies be created to address health disparities faced by persons with ID in Canada.

MeSH terms: Health; health care access; policy; disabled persons; mental retardation

La traduction du résumé se trouve à la fin de l'article.

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> "Compared with other populations, adults, adolescents, and children with [*intellectual disability*] experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care…many health care providers and institutional sources of care avoid patients with this condition. Without direct clinical experience, health care providers may feel incapable of providing adequate care. They may not value people with [*intellectual disability*] and their potential contributions to their own health and to their communities."[1]

These words, from the U.S. Secretary of Health and Human Services in "Closing the Gap, A National Blueprint to Improve the Health of Persons with Mental Retardation", echo the concerns of families of persons with intellectual disability (ID) and the clinicians, caregivers and researchers trying to serve this most vulnerable segment of our population here in Canada. Not only do individuals with ID have more health concerns than those without intellectual challenges, but differences in the causes of health problems, the presence of functional limitations, communication difficulties (by the individuals themselves, as well as interpretations by care providers), and barriers to access to care contribute to their vulnerability. This article will review issues related to the extent of health problems experienced by persons with ID, the pathways leading to vulnerability, as well as health policies and programs that have been put into place to address some of the factors contributing to vulnerability. The article will conclude with a discussion of what needs to be done to make opportunities for good health equitable for persons with ID. The challenges are great, but so are the possibilities for improving the health, well-being and quality of life for members of this highly vulnerable population.

Intellectual disability

An intellectual disability (ID) is defined as a significant limitation in both intellectual functioning and conceptual, social and practical adaptive skills, originating before the age of 18.[2,3] This disability manifests as a lowered ability to cope with common life demands and to meet the standards of per-

sonal independence expected for the individual in at least two of the following domains: communication, self-care, domestic skills, social skills, self-direction, community, academic skills, work, leisure, and health and safety. The World Health Organization has estimated that almost 3% of the world population has some form of ID.[4] Individuals with ID make up 1-3% of the population in Canada (i.e., 300,000-900,000 individuals).[5-8] Since ID is a lifelong disability, the cost of care for this group is significant. In the Netherlands, ID accounts for 9% of the total disease-specific costs, making it the most costly diagnostic category.[9] Therefore, appropriate use of our health care resources to best meet the needs of individuals with ID and their families must be considered a priority.

Individuals with ID are more likely to have physical disabilities (~30%), mental health problems (~30%), hearing impairments (~10%), vision impairments (~20%), and communication disorders (~30%) than individuals in the general population. These co-existing disabilities, combined with the limitations in intellectual functioning and in adaptive behaviours, make this group of Canadians particularly vulnerable to health disparities.

Health disparities

Health disparities are simply population-specific differences in health indicators. Such differences may or may not be inequitable. While not all differences in health can be eliminated, health disparities can be reduced by promoting equity. Whitehead defined health inequities as "differences in health that are unnecessary, avoidable, unfair and unjust".[10] Health inequities can therefore be defined as the presence of disparities in health and in its key demographic, social, economic, and political determinants that are systematically associated with social advantage/disadvantage. The inclusion of social determinants of health in the concept of inequity emphasizes that equity in health means equal opportunity to be healthy for all population groups.[11] It is therefore important to examine not only differences in health but also the causes or determinants of such differences. Not all determinants of differences are indicative of health inequities. Specifically, differences in health due to natural, biological variations; health-damaging behaviours that are freely chosen; or a transient health advantage may not be avoidable and unjust. In contrast, differences in health due to (a) health-damaging behaviours in which the degree of choice of lifestyles is severely restricted; (b) exposure to unhealthy, stressful living and working conditions; (c) inadequate access to essential health services and other basic services; or (d) natural selection or health-related mobility* can be said to be avoidable and unjust and hence indicative of inequities.[10] These considerations are important in addressing health disparities by promoting equity for individuals with ID.[12]

The findings described in this article reflect an extensive review of the literature including peer-reviewed articles, textbooks and government documents. Much of the published research concerned with the health status of persons with ID and their utilization of health services has been conducted in the United States (US), the United Kingdom (UK), the Netherlands, Australia and New Zealand. Unpublished thesis manuscripts based on research conducted in Canada are included in the review to reflect the consistency of findings across jurisdictions. While the Canadian-based research is scant, the similarities noted across the various countries, together with our experiences working with individuals with ID and their families, lead us to suggest that much of the findings are relevant to Canada.

Health disparities and intellectual disabilities

Life Expectancy and Mortality

The life expectancy of people with intellectual disabilities is shorter than that of the general population, and this is especially true for persons with severe ID.[13,14] Studies have demonstrated that the increased mortality occurs in the earlier years (up to age 40 or 50).[15,16] However, life expectancy of the ID population is increasing in parallel with the general population. This is seen most dramatically in individuals with Down syndrome, where the mean age at death increased from 26 years in 1983 to 49 years in 1997.[17] A significant proportion of the excess mortality seen in the ID population is related to a combination of associated co-morbidities (severe mobility impairments, seizure disorders, vision impairments, hearing impairments and an inability to feed oneself resulting in reliance on enteral feeding) which together are indicative of medical fragility; that is, susceptibility to infection and other medical complications.[14-16,18-20] Another factor associated with increased mortality is race; or more precisely, the social and economic disadvantage commonly experienced by certain groups. A recent study of persons with Down syndrome found increased mortality among Blacks and other races compared to Caucasians with Down syndrome in the US.[17] In Australia, increased mortality was found among individuals with ID of Aboriginal descent.[13]

Morbidity

As a group, individuals with intellectual disabilities have a greater variety of health care needs compared to those of the same age and sex in the general population. Medical conditions that are found at higher rates in this population include psychiatric,[21-23] seizure and gastrointestinal disorders.[24,25] Some infectious diseases such as tuberculosis, hepatitis B and helicobacter pylori are also more common in this group.

In the Netherlands, adults with ID were found to be 2.5 times more likely to have diagnosed health problems than patients without ID.[24] An Australian study showed that 95% of adults with ID had health problems. Specialist care was considered necessary for 74% of these conditions (819 conditions among 202 adults studied).[25]

Both malnutrition[26] and obesity are common clinical problems for individuals with ID. Prevalence estimates for obesity in this population range from 29.5-50.5% or twice as high as that in non-ID populations.[27-31] As in other groups, obesity in persons with ID is related to serious medical conditions such as coronary heart disease, hypertension and diabetes.[32] Cardiovascular disease is one of the most common causes of death among individuals with ID.[27]

* Health-related mobility refers to the advantages conferred by good health such as higher education and income. It contributes to health disparities in that the healthier one is, the more likely one is to remain healthy or be able to improve one's health through lifestyle choices, environmental protections, and access to health care.

Persons with ID have poor dental health.[33] There is an increased incidence of gum disease, with gingivitis being 1.2 to 1.9 times higher than in the general population.[27] In 2002, the International Association for the Scientific Study of Intellectual Disabilities (IASSID) reported that periodontal disease, oral mucosal pathology, and moderate to severe malocclusion occurred at rates seven times higher in the ID population than in the general population.[34] A recently published Canadian study revealed that dental procedures make up 40% of day surgery visits by people with ID in Ontario.[35]

Among individuals with ID, aging is associated with decreased mobility and higher levels of osteoporosis and fractures.[36,37] The prevalence of both hearing and visual loss, which are higher among individuals with ID than in the general population,[38-40] also increase significantly with age,[41,42] as does the risk of experiencing abuse. Major mental disorders are frequent in elderly persons with ID;[43] in particular, there is a higher prevalence of dementia.[36,44] Premature aging has also been reported in individuals with Down syndrome. Several women's health issues have yet to be studied thoroughly in an ID population, though some studies report that women with ID experience menopause three to five years earlier than women without ID.[45]

Health problems secondary to medication use are significant in persons with ID. Due to their propensity for co-morbid disorders and the common use of medications, the prevalence of polypharmacy is high.[46,47] More than 15% of individuals with ID take two or more psychotropic medications concurrently.[48,49] Polypharmacy increases the risk for drug interactions, leading to sedation, increased confusion, constipation, postural instability, falls,[50] incontinence, weight gain, sex steroid deregulation, endocrinologic or metabolic effects, impairments of epilepsy management, and movement disorders such as tardive dyskenisia.[43] For example, oral contraceptives are a common method of birth control for women with ID; however, psychoactive and anticonvulsant medications reduce the efficacy of such oral contraceptives and the fluid retention associated with their use can precipitate seizures.[51]

Psychotropic medications are often administered to persons with ID to treat behavioural, emotional or cognitive problems. Pyles reviewed the use of psychoactive medications and found that 26-40% of persons with ID in the community and 35-50% of those living in institutions had current prescriptions.[52] Branford examined medication use by 1,510 persons with ID and found that 23% were taking antipsychotics and 29% were taking antiepileptics.[49] Given the high use of psychotropic medications with their significant side effects – including effects on memory and learning – incorrect diagnoses and inappropriate treatments can have a devastating effect on health, well-being and quality of life in this population. The use of such medications among persons with ID can also result in serious complications including osteoporosis,[45] fractures, decreased mobility,[36] serious injuries,[50] primary gonadal dysfunction, and increased risk of polycystic ovarian syndrome.[45]

There is also a high risk for drug-nutrient interactions, since drugs can deplete nutrient or mineral absorption, cause gastrointestinal problems or affect the taste of food, thereby lessening the desire to eat.[26] Medications can increase the excretion of nutrients or the action of enzymes that break down vitamins, and they can even be life-threatening. In some cases, medications will have a longer half-life because of decreased lean body mass which is common in persons with ID.[26]

Uptake of Health Promotion/Disease Prevention Activities

Several studies have confirmed that individuals with intellectual disabilities do not engage in health promotion and disease prevention activities to the same extent as the non-ID population.[25,53-57] This is particularly notable in the areas of physical activity, oral health, screening and immunization.

Adults with ID tend to lead sedentary lives. Only about 24% participate in regular exercise 3 to 4 days per week, compared to 51% of the general population.[25,57-61] Knowledge about dental hygiene is often poor, with 22% reporting that they do not brush their teeth daily.[33] A New Zealand study found that 73% of individuals with ID needed follow-up interventions, with the majority being health promotion activities. The six most common activities that were neglected were: 1) health protection, such as vaccination, regular checks for existing conditions and smoking cessation; 2) referral to an optician for sight testing, glaucoma and cataracts; 3) hematological testing, medication levels, cholesterol, blood sugars and hepatitis testing; 4) weight, obesity or underweight management; 5) ENT services, such as hearing tests, aids, wax, speaking and swallowing aids/treatment and lumps behind the ear; and 6) gynecological and other women's health concerns, such as menstruation, cervical smears, mammography, breast lumps, and uterine tumors.[54]

One study reported that only 39.1% of women with ID had had a Pap smear within the past three years, a finding significantly lower than for the comparison group of women without ID.[47] Women with ID are also less likely to perform breast self-examinations.

It is recognized that uptake of health promotion and disease prevention activities is not a simple lifestyle choice. Mitigating factors include education, income, self-efficacy and physical limitations. For individuals with ID who rely on caregivers to assist in such activities, the caregivers' attitudes, knowledge and skills further influence the decision to participate in health promoting activities. These and other factors contributing to disparities in health are outlined below.

Pathways and mechanisms leading to vulnerability

For persons with intellectual disabilities, the factors leading to vulnerability are numerous and complex. They include, first and foremost, the way society has viewed ID; the etiology of ID; health damaging behaviour in which the degree of choice of lifestyles is severely restricted; exposure to unhealthy, stressful environments; health-related mobility; and inadequate access to essential health services and other basic services. The pathways are complex because the mechanisms are interrelated. For example, as will be shown, the value society has placed on persons with ID has contributed to disinterest in understanding the various etiologies of ID and their health consequences, which has led to inadequate access to needed care. The following section highlights some of the specific con-

tributors to vulnerability in this population beginning with a review of the historical policy context.

Historical Policy Context

To be adequately understood, health differences and the mechanisms contributing to health disparities faced by persons with ID must be considered in light of the socio-cultural, historical and policy context in which they have developed and continue to exist.

> "Intellectual disability is primarily a socioculturally determined phenomenon that has been apparent since the dawn of man. The impact of disability, however, has varied with the needs of society, its expectancies and social consciousness."[62]

The nature of the environment of care for persons with ID in Canada is influenced by our common societal values, as translated into legislation and policy.[63] Public policy ultimately defines the environment in which service providers deliver their care to individuals with ID. This care includes services provided by both health and social services, and the education sector in the case of children.

In order to understand and appreciate the current realities for persons with ID and their families, including the practice of health care provision, it is necessary to consider how disability policy has developed over the past 150 years, and particularly in the last 50 years.

Prior to the 1870s, there were no systematic procedures for caring for persons with ID. Some were cared for at home by family members; others lived on their own, in insane asylums, or in prisons. The lack of access to medical care meant that life expectancy was short, with infant mortality being very high. Health care provision was generally minimal.

The need for specialized care for persons with ID (as opposed to the generic care given to individuals with ID in psychiatric hospitals and prisons) was eventually recognized. As a result, policy-makers in the US, Western Europe and Canada created special institutions for persons with ID, where there was more consistent medical care. This marked the beginning of the "asylum era".[64] Although the original intent was to provide care that led to rehabilitation, this rarely occurred. The asylums became permanent places of residence for these individuals, who usually received minimal care or education. This model of care continued into the 20th century.

The second half of the 20th century saw a major shift in the provision of services to individuals with ID. Institutions, which were previously seen as providing the best approach to care, became overcrowded and had lengthy waiting lists. Moreover, research began to indicate that community-based alternatives were associated with more positive outcomes.[65] During the 1950s and 1960s, parents and advocacy groups complained about the conditions in institutions for the "mentally retarded" and their voices began to be heard. As a result, in 1958 the Canadian Association for Community Living was founded by parents of children with ID who wanted support and services within the community instead of in institutions.

South of the border, President J.F. Kennedy, who had a sister with an ID, formed the President's Committee on Mental Retardation in October 1961. The President's Committee made 112 recommendations that created a wave of community-based services, deinstitutionalization and research in the field of ID. Moreover, specific federal funds were earmarked for the care of persons with ID. In Canada, a federal-provincial conference on mental retardation was held in 1964, and this led to the creation of the National Institute on Mental Retardation (NIMR) at York University in 1967. NIMR's role was to provide information and carry out research related to ID.

The transition from institutional settings toward a more community-based setting for persons with ID has been guided by the normalization principle, a Scandinavian concept introduced by Bengt Nirje, which argues that the lives of individuals with disabilities should be as normal as possible.[66] This principle was introduced to North America by Wolf Wolfensberger, and subsequently widely applied to services for persons with ID. Normalization, as defined by Wolfensberger, recommended the utilization of means which were as culturally normative as possible in order to establish and/or maintain personal behaviours and characteristics which were as close to the norm as possible.[67]

The philosophy of normalization was widely adopted across Canada throughout the 1980s. Its influence is reflected in the deinstitutionalization movement that led to the closure and downsizing of institutions, and the development of community-based accommodation and services for both children and adults with ID. Currently, increasing numbers of persons with ID are being integrated into the community, the educational mainstream and supported employment. It has been estimated that in 2000, 89% of all individuals with ID in the US were living in the community (i.e., not in private or public institutions); of these, 61% resided in settings for six or fewer individuals.[68]

A serious challenge throughout this evolution has been to provide appropriate health care to persons with ID. Prior to the normalization movement in the 1970s, IDs were considered medical conditions requiring constant professional care, much of which occurred in institutional settings. Normalization introduced a dramatic shift in the philosophy of care.[67] However, medical – and particularly specialized psychiatric – care became less of a priority and medical care for persons with ID became known as the "Cinderella of psychiatry" in Canada.[69] As institutions closed, individuals with co-existing ID and psychiatric disorders (referred to as having a dual diagnosis) were forced to access generic mental health services, but appropriate structures were not in place to allow them to do so easily. These systemic problems led to misdiagnoses, inappropriate treatments and over-reliance on psycho-pharmacological interventions. Researchers in the UK and the US have concluded that "attempts to provide for mental health needs of people with [intellectual disabilities] within generic psychiatric services, whether by design or default, have been obviously unsuccessful".[70]

Individuals with mental health problems and ID experience a "double stigma." The presence of mental disorders in people with ID is "one of the main reasons for the breakdown of community placements and retention in residential environments that are more restrictive than otherwise required".[71] Behaviours that were acceptable in institutional environments are not tolerated in community settings, posing a threat to community inclusion for these

individuals. Persons with ID and mental health issues are often considered inappropriate for traditional ID community integrated services because of their psychiatric difficulties but are also considered inappropriate for usual mental health services because of their low IQ. Adding to this stigma is the lack of knowledge of mental health professionals with regard to this population because of deficiencies in training and the existing barriers to practice in this area.[72-74]

Prior to deinstitutionalization, in some institutions professionals with specialized knowledge of the medical and psychological needs of these individuals ensured proper care and contributed to the training of the next generation of health care practitioners.[75] Ironically, part of the evils of the institutional system – the rigidity of the medical model and social marginalization – can be viewed retrospectively as having had some positive effects on the provision of health care to persons with ID. For example, the dietary needs of individuals with phenylketonuria were easier to control in institutional settings where dietitians and nurses could closely monitor a person's progress. Furthermore, much of the research leading to advances in our understanding of the medical disorders and complications associated with specific ID-related syndromes was carried out in institutions around the world.

Canada has evolved dramatically in its philosophical values regarding the care of individuals with ID: "Canada has moved from seeing segregation and institutionalization of persons with disabilities as desirable outcomes to believing in the value and promise of a fully inclusive society."[76] While such changes in philosophical orientation have benefited persons with ID over the past 30 years, they have had major implications for families, on whom the burden of care is often placed.

Today, for many individuals with ID, family is the sole source of social support. As individuals with ID are frequently unable to access supports themselves, families, as their key social network, play a critical role in securing needed care. In an attempt to access adequate health care services parents often take on an advocacy role, becoming the spokesperson for their family member, regardless of the latter's age. In addition to their many other responsibilities, parents often become heavily involved in information seeking, problem solving and educating themselves and others, including health care professionals and politicians, about their child.[77] In the process, they spend significantly more time interacting with professionals than do parents of children without disabilities.[78] Parents provide the necessary transportation and are the source of information about health and behaviour concerns, providing assistance in the medical setting.

The burden of caring for a child with ID in the community has been the focus of many studies.[79-82] The results highlight the many challenges facing families across the life span. Stress varies according to the age of the child, the type of disability and the degree of disability.[79] It is generally agreed that families experience particularly stressful times during periods of transition. For example, when a child with ID enters school, parents are often faced with the difference between their child and other students without disabilities of the same age. In addition, parents often are forced to advocate in order to obtain an educational assistant or other supports for their child in the classroom.[77,83] Other concerns frequently arise in adolescence when individuals with ID may become interested in sexual activity. Sex education and social skills training geared to the needs of teens with ID are not always readily available and parents are often concerned that their child continues to be vulnerable to abuse despite such training.[84] After the ages of 18 or 21, employment or productive day activities may not be available for individuals with ID[77,83] and day-to-day care and supervision of adults with ID becomes increasingly stressful for many parents as they themselves age. Finding ongoing care, accommodation and meaningful activities for adults with ID, as well as setting up trusts and guardianships, are major concerns for many older parents.[85] In addition, there are often ongoing concerns regarding behavioural challenges, explaining the child's disability to others, meeting personal needs and those of other family members, and respite care.[77,86] In the US, it is estimated that 61% of individuals with ID live with a family caregiver, and 25% of these caregivers are aged 60 or older.[68]

While important steps have been taken in order to integrate persons with ID into the community, they have been regrettably segregated once again by a failure to address their specialized medical needs. Although the aspect of social marginalization is being addressed by a shift to community care, planners have largely overlooked the development of adequate medical care for this population in community settings.

The health disparities faced by persons with ID are indicative of a complex interplay of various factors, including policy. The following sections examine the contributions of: etiology of an ID; individual behaviours; environments; health-related mobility; and barriers to access in the creation and maintenance of the disparities in health in the current policy context of community living for persons with ID.

Etiologies of Intellectual Disabilities

The cause of intellectual disability is unknown in a large proportion of cases. Some common causes for ID include Down syndrome; Fragile X syndrome; TORCH infections; prenatal insult; structural brain anomalies; and single gene, metabolic or neuromuscular disorders. Less common causes include rare genetic disorders. Several clinical series suggest that a diagnosis or cause of ID can be identified in 40-60% of all patients undergoing neurodevelopmental evaluation.[87-89]

As we learn more about the etiologies of all common disorders, it is increasingly evident that genetic factors play a significant role in the etiology of ID at all IQ levels.[90,91] It is also clear that the current exponential growth in genetic information will ultimately lead to improved diagnosis and understanding of the causes, treatment and prevention of ID.[92] When a genetic cause is known and understood, it can facilitate medical care for the person with ID as related complications can be anticipated and even prevented. It is therefore critical to attempt to determine the cause of the ID.

The main genetic causes of ID are chromosome abnormalities, small chromosome deletions and duplications, and single gene mutations. The following review illustrates the potential contribution of genetic testing to reducing health disparities faced by persons with ID.

Chromosome abnormalities are the most common cause of congenital mental dis-

ability.[87] Data from 16 worldwide-published studies show that chromosomal abnormalities are found in 4-34.1% of individuals with ID.[93] The best-known example of a genetic imbalance compatible with life is Down syndrome, caused in the majority of cases by trisomy of chromosome 21, and present in 1 in 700 newborn children.

Relatively small chromosomal deletions or duplications can also result in ID. Well-known microdeletion syndromes include Williams-Beuren syndrome, Prader-Willi syndrome, Angelman syndrome, Wolf-Hirschhorm syndrome, and DiGeorge/Velocardiofacial syndrome. As shown in Table I, the manifestations of these and other syndromes associated with ID include specific health problems.

Standard cytogenetic analyses are often not sensitive enough to detect the small chromosome rearrangements causing these and other disorders.[94] In recent years, the development and application of various sophisticated methods that combine DNA technology with cytogenetics have led to the discovery of many chromosomal rearrangements involving the otherwise almost indistinguishable ends of chromosomes.[95] Recent reports suggest that such sub-microscopic abnormalities lead to gene-dosage imbalance and represent a significant cause of ID with or without congenital anomalies.[95-99] Since the ends of human chromosomes are thought to be the most gene-rich regions of the genome, such gene-dosage imbalance is expected to have a disproportionately greater clinical significance than similar abnormalities in other regions of the chromosomes.[100]

Many disorders associated with ID are due to single gene mutations. Classical examples include phenylketonuria and other inborn errors of metabolism, Smith-Lemli Opitz syndrome, Noonan syndrome, Sotos syndrome, as well as numerous forms of x-linked mental retardation including Fragile X syndrome (see Table I for a list of significant health problems associated with these syndromes).

Despite the frequency and tremendous impact of ID on society, there exist no generally accepted guidelines for clinical and laboratory investigations directed at understanding its causes. This is unfortunate, because having a diagnosis can lead to better managed care and cost savings because of reduced numbers of unnecessary tests.[87] One of the key needs of families living with ID is to understand the disorder's long-term impact on the affected individual's development and future health. Families are understandably anxious to know the cause of ID in their relative, as are referring physicians, social agencies and therapists. Families feel that a diagnosis brings relief from uncertainty, allows refinement of prognosis and recurrence of risks, assures identification with an appropriate support group, and enables funding of special services. However, an incorrect diagnosis can lead to inappropriate counselling, stigmatization and labelling that can continue for years even after a diagnosis is invalidated or changed.[87]

Moreover, genetic forms of ID often exhibit distinctive natural histories in which the evolution of symptoms and disabilities offers opportunities to develop prospective health management templates.[101] Therefore, it is possible to develop specific templates of anticipatory health guidance for different forms of ID that include a combination of active intervention (as in screening for visual impairment or hearing loss), comprehensive diagnostic screening tests (e.g., laboratory or neuroimaging studies), parent and/or physician alerts for particular signs or symptoms, and a consistent strategy of ongoing functional assessment that reflects potential variations in the expected natural history.

There are presently many examples of health supervision guidelines that have been developed for specific genetic syndromes of ID, with the best model for preventative management being devised for Down syndrome, such as the early checklist by Dr. Mary Coleman as adopted by Cohen and the American Academy of Pediatrics.[102,103] Guidelines for the management of other syndromes, including Fragile X syndrome, achondroplasia, neurofibromatosis-1 and Marfan syndrome have been devised by the American Academy of Pediatrics; there are now more than 30 checklists for common congenital

TABLE I

Well-known Syndromes Associated with Intellectual Disabilities

Genetic Cause	Syndrome	Clinical Features
Chromosome Trisomy	Down (Trisomy 21)	Characteristic facies, cardiac and gastrointestinal anomalies, growth retardation, conductive hearing loss, risk of leukemia and Alzheimer disease
Contiguous Gene Microdeletion	Williams-Beuren	Supravalvular aortic stenosis, multiple peripheral pulmonary arterial stenoses, unique facies, mental and statural deficiency, characteristic dental malformation, and infantile hypercalcemia
	Prader-Willi	Obesity, muscular hypotonia, mental retardation, short stature, hypogonadotropic hypogonadism, and small hands and feet
	Angelman	Severe motor and intellectual retardation, ataxia, hypotonia, epilepsy, absence of speech, and unusual facies
	Wolf-Hirschhorm	Severe growth retardation and mental defect, microcephaly, unusual facies, and closure defects such as cleft lip or palate, coloboma of the eye, and cardiac septal defects
	DiGeorge/ Velocardiofacial	Hypocalcemia arising from parathyroid hypoplasia, thymic hypoplasia, cleft palate, cardiac anomalies, typical facies
Single-gene mutation	Phenylketonuria	Deficiency of phenylalanine hydroxylase, unusual odour, light pigmentation, peculiarities of gait, stance and sitting posture, eczema and epilepsy
	Smith-Lemli Opitz	Deficiency of 7-dehydrocholesterol reductase with multiple congenital anomalies including microcephaly, ambiguous genitalia, genitourinary and cardiac anomalies, polydactyly and syndactyly
	Noonan	Hypertelorism, low-set posteriorly rotated ears, short stature, a short neck with webbing or redundancy of skin, cardiac anomalies, deafness, motor delay, and a bleeding diathesis
	Sotos	Excessively rapid growth, advanced bone age, acromegalic features, and a non-progressive cerebral disorder
X-linked (trinucleotide repeat)	Fragile X	Macroorchidism, large ears, long facies, prominent jaw, large stature, autism spectrum disorder and hyperactivity

anomalies or syndromes.[89,101,104-108] Such preventative management approaches and guidelines to genetic disorders of ID may offset the negative consequences that may be perceived to arise from diagnostic labels.[109,110]

The early detection of phenylketonuria through newborn screening, with the prevention of severe cognitive and developmental delay by early dietary restriction of phenylalanine, is one of the most successful programs aimed at reducing ID in individuals at risk.[111] Another example is Down syndrome, where adoption of the health checklist for children with Down syndrome by the American Academy of Pediatrics in 1994 has led to far better outcomes for children with this syndrome.[103,112] With the recognition of a substantial risk for Alzheimer's disease and heart and eye disease in older individuals with Down syndrome, these concerns can now be addressed in a timely manner.[87,108] Similar approaches are being developed for a large number of other genetic causes of ID.

Thus, while the differences in health related to a genetic cause of ID may at first seem unavoidable, with an accurate early diagnosis of such genetic disorders and the provision of appropriate anticipatory care, some health problems can be avoided or their consequences minimized.

Health-damaging Behaviours/Lifestyles

Individual behaviour as a health determinant for persons with intellectual disabilities is complicated by their inherent limitations in adaptive functioning in areas such as self-care, communication and literacy. Because of their disabilities, individuals with ID are frequently dependent on others (family members or paid caregivers) to assist them in making healthy choices. In many cases, health-damaging behaviours in this population may be best understood in the context of health-related mobility discussed in a later section.

In addition to poor nutrition and low levels of physical activity, smoking, alcohol and caffeine consumption are behaviours of concern. Smoking occurs at higher rates in the ID population than in the general population, with those living in the community generally having a higher use of cigarettes, alcohol and caffeine than those living in institutions.[27,36,44,59] In many instances, initiation of smoking and caffeine consumption are behaviours modeled after caregivers. Historically, cigarettes have been used as rewards for good behaviour in institutions.

While many benefits have come from the closure of institutions for persons with ID, movement into community life has generally been associated with an increased risk for poor diet.[44] A study examining lifestyle practices of adults with ID found that the participants from group and family homes had higher body weight, higher percentage body fat, and higher cholesterol levels than participants from institutions.[59]

Research aimed at identifying and reducing barriers to choosing a healthy lifestyle among persons with ID is scarce. Individuals with ID often do not participate in physical activities because they lack either motivation or the opportunities to become involved in fitness programs.[113] One study suggested these may require adaptation and specialized training for persons with ID, in order to achieve goals such as increased cardiovascular fitness.[114] A survey of caregivers concluded that physical exercise programs that are not adapted to the needs and abilities of individuals with ID, or that are not located in nearby facilities, bar people with ID from enjoying the benefits of these services.[61] Special Olympics offers a segregated competitive sports program for individuals with ID, meeting the physical fitness needs of those with greater athletic abilities. Much more research is needed to determine how to ensure that non-competitive, leisure, recreation and sporting activities, and fitness programs are equally accessible to individuals with ID.

Exposure to Unhealthy, Stressful Environments

Previous or current residence in large institutions places persons with intellectual disabilities at risk for past or present exposure to a number of infectious diseases including tuberculosis, hepatitis B and *Helicobacter pylori.*[46,115,116] This is exemplified by an Ontario-based study examining the prevalence and screening methods for *Helicobacter pylori* among adults with ID. It revealed that 80% of study participants who had formerly been institutionalized suffered from the infection – which, untreated, has been associated with peptic ulcers and gastric cancer deaths.[36,117] This rate was three to four times higher than in adults with ID who had never been institutionalized.[118] While few individuals continue to live in large institutions, many adults live and/or work in smaller congregate settings where exposure to infectious agents and stressful environments remains a concern.

Health-related Mobility

Health-related mobility refers to the advantages conferred by good health such as higher education and income. It contributes to health disparities in that the healthier one is, the more likely one is to remain healthy or be able to improve one's health through lifestyle choices, environmental protections and access to health care.

Several studies have demonstrated that persons with ID are more likely to experience poverty than the general population[119] and that they have among the highest poverty rates, lowest average incomes, and highest out-of-pocket expenses of all population groups.[120] In the US, households with an individual with ID are larger, more likely to subsist below the poverty line, and are more likely to be dependent on means-tested income support.[121] The financial instability of this group threatens their access to nutrition, medical care and other resources.[120,122,123] Multiple conditions requiring additional and more comprehensive services add to personal health care expenses and can strain economic resources.[124]

Adults with ID tend to have limited education and levels of literacy, thereby limiting their access to health promotion literature and a myriad of health promotion activities. The education and literacy levels achieved by individuals with ID reflect both limitations inherent in their disability and the inadequacies of the education they receive.

Large-scale health promotion campaigns (e.g., anti-smoking, healthy eating, regular physical activity, sun protection and health care screening messages) frequently require a level of literacy or abstract thinking that renders them inaccessible to many individuals with ID. Few resources are available for persons with ID that describe the dangers of excessive alcohol, tobacco and caffeine consumption in terms that enable

them to make informed decisions about such use. Thus, research on how low literacy impacts indirectly on health by contributing to poverty, stress, unhealthy lifestyles, low self-esteem, dangerous work environments and inappropriate use of health services is needed for this population.

More direct impacts of low literacy on health have been noted by the National Literacy and Health Program.[125] That program cited the incorrect use and mixing of medications and increased safety risks, such as home and workplace accidents, as major contributors to poor health in individuals with low literacy. In addition, language used in pamphlets to explain various medical conditions is often incomprehensible to persons with ID.

The ability to know when and how to access health care is critical to ensuring one's health. Currently, systems of health care rely on an individual's ability to recognize the need for care, to seek care, and to coordinate the provision of care. However, self-referral for consultation is rare in this population[44,126] and, in general, persons with ID are less likely to voice psychological complaints.[43] Since people with ID often lack the ability to recognize health problems,[127] it is important for caregivers and health care professionals to recognize signs of distress.[46]

Inadequate Access to Essential Health Services and Other Basic Services

In general, health screening for persons with ID requires significant improvement.[47] Since this population experiences health-related problems at similar or higher rates than the general population, individuals with ID should receive the same array of preventative health practices throughout their lifespan.[32,46] When comprehensive assessments are undertaken, they often reveal high rates of concurrent treatable conditions.[32]

An Australian study of adults with ID revealed that an average of 2.3 conditions per person were unrecognized prior to a comprehensive assessment and an additional 2.7 conditions per person were considered unmanaged.[25] Other studies identified high rates of previously unrecognized or poorly managed co-morbidity in this population. Such conditions include hypertension, obesity, congenital heart disease, abdominal pain, respiratory disease, cancer, gastrointestinal disorders, diabetes, chronic urinary tract infections, oral diseases, musculoskeletal conditions and osteoporosis, thyroid disease, hypothermia, pneumonia, vision impairment and hearing impairment.[36,44,46,127-132] A recent study examining the hospitalization of persons with ID living in Ontario noted high rates of admission for ambulatory sensitive conditions.[133] These admissions, also known as "preventable admissions", are due to conditions such as diabetes, asthma and hypertension, which are expected to be managed by patients outside an in-patient setting. They are used as a marker of access to appropriate primary care.

Other barriers to receipt and use of appropriate health care include characteristics of the individual (e.g., communication disorders, motor impairments), and features of the health care system (e.g., poor physical accessibility, health-care provider ignorance and discontinuity in care).

Communication difficulties

Communication difficulties are a major problem for both persons with intellectual disabilities and their health-care providers, and are more common in individuals with ID than in the non-disabled population.[134-137] A study conducted in Ottawa, Ontario found that 27% of adults with ID were identified by caregivers as needing speech, language and audiology services.[138] There is a wide range of communication deficits in persons with ID: some have difficulty understanding spoken language; others are non-verbal with no intentional communication; others use a small number of single words or single manual signs in specified situations or augmentative communication systems (e.g., pictures, assistive devices); a smaller proportion have extensive vocabulary and are able to communicate using long sentences. Language is often socially inappropriate and/or contains speech or grammatical errors.

The inability or unwillingness of others to adapt appropriately to the poor communication skills of many individuals with ID results in maladaptive behaviours that pose additional challenges for health professionals and parents. Such behaviours contribute to diagnostic overshadowing, with symptoms related to physical problems being misinterpreted as being attributable to ID. The inability to effectively communicate one's distress or discomfort makes the recognition, diagnosis and treatment of health problems challenging for individuals with ID, caregivers and health-care providers.[36,43,44,46,126,139,140] Language and cultural differences compound this issue.[139] Recently, the English National Board for Nursing identified insufficient communication skills training for health care professionals dealing with person with ID as contributing to their poor health.[58] The need for communication skills training has been emphasized in both nursing and medicine, with effective communication between health care professionals and patients being an important variable in patient satisfaction and compliance.[141-145]

Communication difficulties also have an impact on the availability of research specific to the treatment of health problems among persons with ID. Research is often limited to individuals who are able to consent to participating in research. The purpose of this requirement is to avoid taking advantage of persons who are unable to consent but who might reject such participation if they understood the full consequences of participation. Unfortunately, however, this also means that individuals who are not able to consent (or are deemed unable to do so) do not benefit from participating in research that might lead to better treatments or cures. Since drug interactions are common, the assumption that what works in a non-ID population will work similarly in an ID population is not necessarily so.

Despite the increased prevalence of communication difficulties in individuals with ID and the implications of such difficulties, many do not have access to services needed to diagnosis and respond to these problems. An Ontario-based study reported that only 35% of adults with ID who were identified by caregivers as needing speech, language and audiology services were actually receiving these services.[138]

Motor impairments and poor accessibility

These are barriers to appropriate care, especially since physical access to clinics and treatment centres is a first step towards consultation.[46] With respect to women's health care needs, medical procedures, such as mammograms and cervical cancer screening, are not always possible because

persons with ID often have musculoskeletal problems that prohibit them from using standard equipment and examination tables.[146,147]

Service delivery restrictions

In a review of the health care literature, Beange and Lennox identified poor compliance to treatment management plans, poor continuity of care, inadequate knowledge of services and resources, and little time for examination/consultation as posing limitations to adequate care provision.[36] Almost three quarters of general practitioners surveyed indicated that time restrictions during consultations limit the quality of care they are able to provide to people with ID.[36] In Canada, fee-for-service remuneration of physicians does not include allowances for the additional time required to adequately assess the needs and manage the care of individuals with ID. Some jurisdictions have developed remuneration schemes that take into account the increased time demands on physicians for meeting the health care needs of special populations such as the elderly.

Knowledge and attitudes of health-care providers

Many physicians do not recognize the health needs of this population and therefore overlook potential health complications. The Surgeon General's Report noted reluctance on the part of general practitioners to "get to the bottom" of the problem, investigate, review and refer.[1] In a survey of general practitioners in Australia, 80% said they found it harder to provide good quality health care to patients with ID than to non-disabled patients.[54]

Voelker explains that the lack of standards of care and best practices for the ID population, and information on differences in the manifestation of symptoms, can cause coexisting syndromes to be misdiagnosed or missed completely.[129,140] Although emotional, behavioural, and psychiatric disorders are three to four times more common in people with ID, these symptoms in persons with mild disabilities and rare conditions are often overlooked and assumptions regarding treatment are often made prematurely.[43,129] Alcohol, drug dependency and depression are likely to be regarded as behaviour problems and there is often a lack of differentiation between mental illness and ID.[43,45] Horwitz and colleagues identified two major challenges to diagnosing mental health conditions in persons with ID: 1) that providers are often reluctant to diagnose mental health conditions in persons with ID and 2) that there are often difficulties in identifying symptoms.[27] Symptoms are frequently attributed to the disability rather than evaluated as potentially separate conditions (i.e., "diagnostic overshadowing"). This is not limited to issues of mental illness. It is often wrongly assumed that women with disabilities are not at the same risk for developing breast and cervical cancers as the general population, and therefore few women in this population have access to screening for these conditions.[45,147]

Parents of individuals with ID often become frustrated with health-care professionals who they see as being uninformed about ID.[77,148] Parents often describe physicians as being aloof and insensitive when providing diagnostic information, or not wanting to take the time to listen to their concerns, or being unreceptive to their suggestions.[77,148] Many parents feel that they have had to educate first themselves and then their physicians and other health care professionals about ID. As a result, interactions between parents and professionals can become strained. Parent advocates and professionals who are also parents of individuals with ID have emphasized the need for more collaborative parent-professional relationships.[149] Although parents participating in an Ontario study indicated that attitudes and the general level of awareness among health professionals about ID had improved in recent years, they felt that more exposure to persons with ID, education around specific health concerns for persons with ID, acknowledgement of the special needs of such individuals, and more compassion in general would improve physicians' relationships with families.[77]

Two recent Canadian studies considered the adequacy of psychiatry training in ID in our country.[72,150] A survey of training programs revealed, "inadequate training opportunities exist in many of the residency programs, particularly those involving adults and adolescents"[72] (p.138). The authors concluded that: "[a]cross Canada, there have been insufficient advances in clinical training and service developments to meet the needs of individuals with [intellectual] disabilities and comorbid mental health disturbances."[72]

In a survey of 60 senior psychiatry residents from across Canada, only half indicated they had received training in ID in their undergraduate medical education and 85% of them felt that more training was needed. Almost 90% of residents who had not received undergraduate education on ID responded that they would have benefited from such information. Eighty-five percent of respondents reported that they had some education regarding dual diagnosis in their residency program but most (59%) felt that more information and training was needed. These concerns, reported by senior medical residents, support the need for curriculum enhancements that experts in ID have long recommended.

A recent study showed that general practitioners typically do not see themselves as the most appropriate professionals to provide health care to people with disabilities, and that their general lack of knowledge of health needs and specialized diagnostic procedures places them at a disadvantage when dealing with such patients.[126] This uneasiness stems from the fact that in most programs, disability issues represent only a small portion of medical education curricula, and that continuing medical education is usually not geared towards disability-related issues. Similarly, a survey of dental schools indicated that 47% of schools had 8 or fewer didactic hours on the treatment of individuals with ID, and 65% had 10 or fewer hours on clinical activities associated with this population.[151] This lack of training and experience likely influences providers' willingness to provide treatment to individuals with ID.[27]

Initiatives to reduce inequities

In Canada, public policy development is influenced by the constitutional division of powers and budgets between the federal and provincial levels of government.[63] The provinces have traditionally had jurisdiction over matters pertaining to education, health and social services. The federal government often assists in running various programs through cost-sharing arrangements and transfer payments to the provinces in order to promote its national

policies. The federal government makes many of its commitments to Canadians through federal budget speeches and Speeches from the Throne. The most recent speeches have mentioned persons with disabilities specifically, and this group has been singled out as a key priority for the current government.

> "These federal commitments, however, do not fit easily within the structures of the federal government. They cut across departmental lines, they affect the operations of many agencies and they are intimately interwoven with the jurisdiction of the provinces and territories as well as the voluntary and private sectors. This means that no one jurisdiction – let alone one federal department – can control decisions, resources and activities. Success depends on developing and sustaining a common vision of outcomes, objectives and lines of accountability."[152]

Protection for persons with intellectual disabilities is also specifically included under the equality rights section of the *Charter of Rights and Freedoms* of the Canadian Constitution. It guarantees persons with ID the right to equality before the law and to equal protection and benefit of the law without discrimination.

The Canadian government has become increasingly concerned with the needs of Canadian citizens with disabilities, in part because of our aging population. Although the federal government does not yet have a national policy concerning the care of individuals with disabilities or, more specifically for persons with ID, it has been moving in this direction.

In the last 10 years, the Government of Canada has organized task forces, governmental subcommittees and reports looking at the needs of individuals with disabilities. In doing so, "Canada has gradually developed a framework of legislation to protect those rights of persons with disabilities that are within the Government of Canada's jurisdiction. As well, a number of important initiatives have helped bring a sharper focus to the Government's efforts to make progress on disability issues."[76]

For example, in 1999 the Government of Canada released its disability agenda, entitled *Future Directions to Address Disability Issues for the Government of Canada: Working Together for Full Citizenship.*[153] The *Future Directions* document built on the framework introduced in 1998 by *In Unison,* the federal, provincial and territorial vision of full inclusion for persons with disabilities.[154] Although not specifically speaking to the needs of individuals with ID (but disabilities in general), *Future Directions* identifies seven key actions needed to help people with disabilities achieve full inclusion:

1. increase accountability and improve policy and program coherence;
2. build a comprehensive base of knowledge;
3. build the capacity of the disability community;
4. address the acute needs of Aboriginal people with disabilities;
5. improve access and remove barriers to disability supports and income;
6. enhance employability of persons with disabilities; and
7. reduce injury and disability rates by prevention and health promotion.

In 2000, the Canadian government made another important step towards defining public policy for individuals with disabilities in general, with the publication of the report on the *In Unison* vision.[155] This report on *In Unison* aimed "to provide Canadians with a broad view of how adults with disabilities have been faring in comparison with those without disabilities, using both statistical indicators and examples of personal experiences".[155] The report built upon common identified objectives and proposed a "Canadian approach" based on the *In Unison* framework for the development of disability supports. It focussed primarily on issues of individual accessibility and portability.

In December 2002, the Canadian government released its first comprehensive report on disability in Canada, *Advancing the Inclusion of Persons with Disabilities.*[76] The report, issued by the Minister of Human Resources, describes where Canada had made progress, how the Government of Canada had contributed, and where work remained to be done. As part of this important effort, the Canadian government was concerned about the different definitions that various government departments were using to determine eligibility for provincial and federal programs. Consequently, the Standing Committee on Human Resources Development and the Status of Persons with Disabilities, specifically asked the Canadian government to study the harmonization of disability definitions in federally administered programs. The Office of Disability Issues was commissioned to study and unify existing definitions of disability, in order facilitate understanding of the notion of disability across programs.

The resulting report was published by the Office for Disability Issues, Human Resources Development Canada, in late 2003. The report thoroughly examined disability definitions in the various provinces and territories, and defined disability on a federal-program basis. Unfortunately, this was not done from an ID perspective. The report also studied definitions of disability that exist worldwide. Although it did not position itself on the adoption of any one definition, it concluded that "[d]isability is a multidimensional concept with both objective and subjective characteristics. A single harmonized 'operational' definition of disability across federal programs may not be desirable or achievable. And, the scope of solutions to address the broader issues identified go beyond definitions." The authors went on to suggest:[156]

> "This report is not an end in itself. It does not resolve the tensions mentioned earlier but provides, for the first time, a shared information base to allow Government of Canada departments to provide a more coherent picture of its disability policies and programs and to continue a dialogue with all stakeholders…. In addition to the actions identified above, the report confirms the need for further examination of the complexities associated with disability definitions and eligibility criteria." (p.48)

While great strides have been made in Canada in the area of disability policy, the health needs of persons with intellectual disabilities have been largely overshadowed by issues of accessibility, employment equity and income security for persons with disabilities, without recognition of the specific vulnerabilities to poor health faced by persons with ID. As a result, Canada does not have a national policy concerning the health needs of persons with ID; nor do we have national statistics that provide us with a portrait of their vulnerability to experi-

ence health disparities. The Canadian situation is in contrast to developments in other countries such as the US, England and Scotland where a commitment has been made by governments to adopt an agenda for change which promotes equity by addressing health disparities faced by persons with ID.

In the United States and the United Kingdom, separate budgets, governmental committees and research institutes have been established nationally in order to improve the health of individuals with ID. During the last few years, important documents were written which reflect the current state of health and health care for persons with ID in the US, England and Scotland. These reports describe the need for "closing the gap", "valuing people" and "promoting health, supporting inclusion".[1,157,158] The themes and conclusions in these reports are the same: persons with ID are a marginalized group in society, partly because of their dependence on others for their care, partly because we do not know how to appropriately assess their health care needs, and partly because most health care professionals are ill-equipped to communicate and treat persons with ID. The policy documents outline similar objectives in caring for persons with ID.

Closing the Gap summarizes the six goals and action steps that form the US' National Blueprint to improve the health of persons with ID, i.e., to ensure that:

1. health promotion is extended to individuals with ID;
2. information is gathered about the health needs of persons with ID;
3. the quality of health care is improved;
4. health-care providers are appropriately trained;
5. sufficient funding is available to meet the health-care needs of persons with ID; and
6. there are increased numbers of providers of care to persons with ID.

In England, where government spending on individuals with ID surpassed £3 billion in 1999-2000 (or roughly $6.7 billion Canadian), the government's priorities concerning individuals with ID include: "[t]o enable people with [intellectual] disabilities to access a health service designed around their individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary", and "[t]o ensure that social and health care staff working with people with [intellectual] disabilities are appropriately skilled, trained and qualified, and to promote a better understanding of the needs of people with [intellectual] disabilities among the wider workforce."[157]

Priorities for Scotland are aimed at reducing inequities by targeting five areas for action. New developments and interventions are being undertaken relating to:

1. leadership and accountability;
2. infrastructure, including a program of research focused on health improvements for persons with ID and database development;
3. specific interventions, such as health screening program specifically for persons with ID;
4. information; and
5. education, including initiatives pre and post registration/graduation for health professionals.[158]

In the US and many parts of western Europe, there has been a long tradition of education in the field of ID. In the US, the aforementioned President's Committee on Mental Retardation made many recommendations that included (a) the importance of interdisciplinary training, (b) best-practice in services for individuals and their families, (c) advancement of scientific understanding, and (d) coordination between universities and state agencies to survey the personnel needs in the field. These recommendations led to the passing of an American public law specifying that

> "…grants were authorized to assist in the construction of public or non-profit clinical facilities associated with a university that would both provide services and aid in clinical training. This idea was 'an active, reciprocal exchange of information and resources between communities and universities that would benefit persons with ID through improved systems of service and personnel preparation.'"[159,160]

The initiatives, which have been or are being implemented in the United Kingdom, the US and Scotland are urgently needed in Canada in order to improve the health and well-being of Canadians with ID.

In November 2000 and April 2002, researchers in the field of ID in Canada met in Kingston and Vancouver (respectively) because of the "urgent need to develop training programs for health professionals who care for people with [intellectual] disabilities."[65] For the first time in Canada, this effort constituted an opportunity for educators, practitioners and community leaders to convene at national symposia in order to strategically address gaps in current education on ID in Canada. From these meetings came clear priorities for Canadians that included:

1. the need to lobby for a federal point of responsibility within Health Canada;
2. the desirability of epidemiological data regarding ID collected consistently across all provinces and territories;
3. endorsement and publication of a consistent definition of intellectual disability across Canada, including standardization of the assessment description and measures;
4. establishment of focal points in universities and colleges for the coordination and collaboration in ID studies; and
5. the creation of a national association for intellectual disability.[161]

Since these meetings, two organizations have been formed to respond to these priorities. The first is the HEIDI program (Healthcare Equity for Intellectually Disabled Individuals); a group of researchers looking at addressing health disparities faced by individuals with ID (www.heidiresearch.ca). The second organization is CARE-ID (Canadian Association for Research and Education in Intellectual Disabilities); an association striving to increase the number of researchers and educators in the field of intellectual disabilities.

CONCLUSIONS

> "Good health is essential to quality of life, and the health and well-being of its people are essential to the strength of the Nation…. Yet there is a segment of our population that too often is left behind as we work to achieve better health for our citizens. Americans with [intellectual disability], and their families, face enormous obstacles in seeking the kind of basic health care that many of us take for granted."[1]

Our review suggests that for Canadians with ID, the situation may not be very dif-

ferent. Persons with ID do not receive the services that their health conditions require. Limitations in domains such as self-care, literacy and communication are important barriers to accessing preventative and restorative health care. Furthermore, the inadequate efforts by governments and communities to accommodate these limitations place individuals with ID at an increased risk for poverty, physical inactivity, poor nutrition and greater stress. Barriers to health for this population are evident at various levels, including inaccessible health promotion messages, undiagnosed and untreated medical problems, and the lack of access to knowledgeable and sensitive health-care providers. These issues deserve serious attention as persons with ID are at greater risk for health problems than the general population and receive less preventative care. Furthermore, for persons with ID there are important disparities in access to care that are difficult to disentangle from discriminatory values and practices (such as reliance on caregivers, lack of training of health-care professionals, undiagnosed conditions, and other institutional discriminations which make even the recognition of the need to access care problematic in this population).

Achieving health for all means that public health practice and research must not ignore this segment of the population. It is recommended that a clear vision for health policy and strategies to address health disparities faced by persons with ID in Canada be created. Such a vision should include attention to the following areas:

1. enhanced research in genetics, medicine and health services aimed at ensuring accurate diagnosis, dissemination of guidelines for clinical and laboratory investigations directed at understanding etiology, and the development of specific health care watches for management;
2. monitoring uptake of health services by persons with ID and reasons for discrepancies;
3. developing a greater understanding of differences in manifestation and treatment of health problems in persons with ID;
4. training professionals in the different and special needs of persons with ID, including how to communicate with persons with ID and their caregivers;
5. public awareness campaigns and health promotion activities that include persons with ID.

Canada does not currently have a policy document such as England's *Valuing People White Paper*,[157] the US Surgeon General's *Closing the Gap*,[1] and Scotland's *Promoting Health, Supporting Inclusion*,[158] which concern individuals with ID specifically. There is no major public policy document from a federal branch of government that promotes society's values and goals for Canadian citizens with intellectual disabilities. We need to follow the lead of these countries and develop a national agenda that addresses health equity for persons with ID. To facilitate this, we need a national voice, a forum where researchers, families, individuals with ID and support agencies can work together to ensure the best quality of care for persons with ID. It is through this forum that national policies can be developed to secure the rights of this vulnerable population to the excellence in health care expected for all citizens of Canada.

> "To be disabled does not mean to be sick. An individual may have a disability and be healthy; however, to be healthy, like other individuals, individuals with disabilities need information and options that are accessible and useable."[162]

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RÉSUMÉ

Les déficiences intellectuelles (DI) sont des affections qui apparaissent avant l'âge de 18 ans et dont la conséquence est une limitation significative du fonctionnement intellectuel ainsi que des capacités conceptuelles, sociales et d'adaptation. Les DI touchent entre 1 et 3 % de la population. Les personnes atteintes présentent généralement des déficiences physiques, des problèmes de santé mentale, des troubles de l'audition ou de la vue, et des problèmes de communication. Ces incapacités concomitantes, combinées aux limitations du fonctionnement intellectuel et du comportement adaptatif, rendent ce groupe d'individus particulièrement vulnérable à des disparités sur le plan de la santé. Le but de cet article de synthèse était d'examiner les facteurs qui contribuent éventuellement à rendre vulnérables sur le plan de la santé les individus atteints de DI, de préciser l'ampleur et la nature des disparités auxquelles est en butte cette population et d'analyser les initiatives qui permettraient de s'attaquer à ces différences. Selon cette revue, les personnes atteintes de DI s'en tirent moins bien que la population en général sous l'angle de certains indicateurs clés de la santé. Parmi les facteurs de vulnérabilité, nombreux et complexes, mentionnons l'attitude de la société devant les DI, l'étiologie de ces déficiences, les comportements dommageables sur le plan de la santé, l'exposition à des environnements malsains, les problèmes médicaux de mobilité, et l'accès inadéquat aux services essentiels de santé et autres services de base. Dans le cas des personnes atteintes de DI, on note d'importantes disparités quant à l'accès aux soins de santé, disparités qu'il est difficile de distinguer des valeurs et des pratiques discriminatoires. Aux États-Unis, en Angleterre et en Écosse, les décideurs ont récemment commencé à se pencher sur ces questions. On recommande de se doter d'une vision claire en matière de politique et de stratégies sur le plan de la santé afin de s'attaquer aux disparités que subissent les personnes atteintes de DI au Canada.