Improving Health Outcomes for Children and Youth with Developmental Disabilities

A literature review in the health status of children and youth with developmental disabilities within a population health framework.

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Table of Contents

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Introduction

The health of our children is a major concern to us as parents, to our society and to our governments. Care and attention coupled with timely investments are needed to support healthy growth and development and the last decade has seen a number of initiatives at the federal, provincial and municipal levels dedicated to this agenda. While coalitions, councils and networks on children's health are proliferating it is apparent that many if not most of them are not thinking about, talking about, or planning for the needs of children with developmental disabilities. It is of concern that a segment of the child population in Ontario which has known health risk factors appears to be absent from mainstream child health initiatives. This concern has prompted the writing of this paper with the hope that improved understanding will result in more being done to address the challenges facing these children in experiencing good health during early and adolescent years and growing into healthy adults.

The purpose of this paper is to inform and educate the reader about developmental disabilities, to consider the health status of children with developmental disabilities within a population health framework, and to identify some of the key issues that emerge from an examination of the current literature. The literature review examined formal research studies published primarily from 1995 to 2007, international, national and provincial reports (policy documents, guidelines, reviews) as well as websites of service and advocacy organizations for specific types of developmental disabilities. One of the challenges of undertaking this review is the limited amount of research on children with developmental disabilities undertaken in Ontario. Where there was insufficient material in particular related to the health needs of children, the review extended to include international research and relevant articles on adults with developmental disabilities. Although this is less than ideal, examining the health issues faced by adults with developmental disabilities helps us to better understand the needs and identify the possible interventions for children.

Many other papers that consider the status of children with disabilities in our society have been written over the years including those that focus on inclusion and citizenship such *as Enabling Citizenship: Full Inclusion of Children with Disabilities and their Parents* (Valentine, 2001). While other approaches provide important ways of viewing and understanding the needs of children, good health is integral to their being able to participate in and experience the richness of life as it is for all children; yet many children with developmental disabilities face health disparities stemming from the very nature of their disability. These are health problems that may adversely affect their well being and set the stage for life as an adult that may be further, and perhaps unnecessarily, compromised. Some evidence of these health problems for adults with a developmental disability is provided by the European Union Pomona Project (van Schrojenstein Lantman-de Valk, Linehan, Kerr, Noonan-Walsh, 2007):

- Developmental disabilities-related morbidity includes neurological and sensory disorders (van Schrojenstein Lantman-de Valk et al., 2000).
- Mental health problems in people with developmental disabilities may remain undetected and/or may be misinterpreted as behaviour disorders (Salvador-Carulla et al., 2000). Signs of physical discomfort such as head banging that may be due, for example, to toothache may be misinterpreted as challenging behaviour instead of a sign of pain and a demand for help.
- There is a high use of psychotropic medication amongst people with developmental disabilities (Stolker, Koedoot, Heerdink, Heufkens, & Nolen, 2000). Life-long medication intake necessary for epilepsy and/or psychiatric disorders may have undesirable side effects, such as osteoporosis and a lower level of consciousness leading to falls, fractures and other incidents (Wagemans, et al., 1998).
- People with developmental disabilities are also at risk for lifestyle-related co-morbidity (Messent, et al., 1999). The inability to read written health promotion materials may result in, for instance, a lower participation in breast cancer screening through mammography (Jones & Kerr, 2007; Sullivan et al., 2003). However, it should be noted that personal risk-taking health behaviour such as smoking and

excessive alcohol intake can be reduced in this population (Lawrenson, et al., 1994; Robertson et al., 2000).

- People with developmental disabilities are socially and economically disadvantaged: generally they have low incomes, small social networks without many friends and a weak representation at the policy level (Yamaki & Fujiura, 2002).
- Their access to essential health services and other basic services is limited, and they are exposed to unhealthy, stressful living and working conditions (Drum, et al., 2005; Ouellette-Kuntz, 2005).

More specifically in reference to children, recent UK research (Emerson & Hatton, 2007) noted that children with developmental disabilities were significantly more likely than those without developmental disabilities to:

- Be boys;
- Have been exposed to a greater variety of adverse life events (e.g., abuse, serious accidents, bereavement, domestic violence);
- Be brought up by a single parent (nearly always a single mother);
- Live in poverty;
- Live in a poorly functioning family (e.g., one that is characterized by disharmony);
- Have a mother who is in poorer health;
- Have a mother who has mental health needs;
- Live in a family with lower educational attainments and higher rates of unemployment; and
- Have fewer friends.

As an approach, population health focuses on the interrelated conditions and factors that influence the health of populations over the life course, identifies systematic variations in their patterns of occurrence, and applies the resulting knowledge to develop and implement policies and actions to improve the health and well-being of these populations.

A population health approach:

- Addresses the determinants of health recognizing that they are complex and interrelated;
- Focuses on the health of populations;
- Invests upstream (prevention and early intervention);
- Bases decisions on evidence;
- Applies multiple strategies to act on the determinants of health;
- Collaborates across levels and sectors;
- Employs mechanisms to engage citizens; and
- Increases accountability for health outcomes.

The Canadian Population Health Framework proposes that the healthiness of a population is shaped by the complex interactions between 12 determinants of health including factors such as income level, education and the physical environment. These 12 determinants will be explored later in the paper along with information obtained from the review of the literature that provides evidence regarding the healthiness of children with developmental disabilities.

Before considering the health status of children with developmental disabilities it is important to understand what is meant by developmental disabilities, their causes and common conditions. The first section of this document provides background on clinical and administrative definitions of developmental disabilities; some of the causes and representative types of developmental disabilities and estimates of their prevalence. The second section presents the twelve inter-related determinants of health from the Canadian Population Health Framework and summarizes current literature for each determinant pertinent to the health of children with developmental disabilities and their families. The final section of the paper identifies some of the key issues arising from this review. This document intends to educate and inform but most importantly, to stimulate discussion on the very pressing health needs of these children and the strategies that can be taken up locally and provincially to address them.

PART 1: BACKGROUND ON DEVELOPMENTAL DISABILITIES

What is currently meant by the term developmental disabilities in Ontario? What is being learned from the latest research about the causes of these disabilities and their prevalence? In this Background section, the findings from the literature are reviewed with respect to various types of definitions currently in use; what is now known about developmental disabilities in general and several specific presentations.

Definitions and Prevalence: A Brief Overview

The language of disability is shifting. In the United States, the term "mental retardation" is gradually being replaced by "intellectual disabilities". The literature in most European Union countries, Australia and from international sources uses the term "intellectual disabilities". The United Kingdom (UK) appears to be unique in having adopted the term "learning disability" to refer to people with mental retardation (unlike the use of the term in North America to refer to those experiencing specific difficulties in learning).

Within Canada, the use of the term "mental retardation" became pejorative over the last decades, and the terms "developmental disability" and/or "intellectual disability" are now often used more or less synonymously. In many instances these terms are used to refer to the diagnosis of mental retardation as defined by the DSM-IV (that is including an IQ below 70 along with limitations in adaptive functions and onset before the age of 18), but not always. Sometimes developmental disability may include conditions that do not have mental retardation as a component; or, it may be used to refer to conditions that may cooccur with mental retardation but not in all instances. This, in brief, is the challenge of the current language; there is confusion about what is or is not included with different descriptors.

The literature review examined two types of definitions of developmental disabilities: clinical and administrative. Some brief information is provided below with more detailed information on definitions available in Appendix 1 and 2.

The most prevalent clinical definitions in use, which provide classification systems and criteria used for diagnostic purposes, are found in the following four documents (see Appendix 1 for full descriptions):

- The ICD 10 (World Health Organization, 1992) classification;
- The DSM-IV (The Diagnostic and Statistical Manual of Mental Disorders published by the American Psychiatric Association, 1994) criteria;
- The International Classification of Functioning, Disability and Health (ICF, 2001) classification; and
- American Association on Intellectual and Developmental Disabilities (the AAIDD, formerly the American Association on Mental Retardation) 2002 definition.

Service providers and governments describe the population for which their service is intended and in doing so create an additional layer of administrative or eligibility definitions of developmental disabilities usually intended to demarcate those who can from those who cannot access services. Administrative descriptions are provided for several government ministries in Ontario that have some service responsibility for this population along with descriptions used by several other provincial governments in Canada (see Appendix 2 for several examples).

The variation in definitions and descriptions demonstrates the confusion that inevitably exists because of our lack of shared language and understanding. For the purposes of this review, the term developmental disability rather than mental retardation will be used throughout this document wherever possible; it will be assumed to include diagnoses of mental retardation as well as some other developmental disorders, which are not linked to a specific range of IQ, but all share adaptive functioning deficits.

The ***prevalence*** of a condition refers to how many people in a defined population have a specified condition at a specific point in time. ***Incidence*** is how many new cases of a condition appear within a defined population over a specified period of time; for example, the number of

newborns who were diagnosed with Down syndrome in Canadian hospitals in 2006. This incidence rate is then usually compared with the incidence of Down syndrome in another timeframe to assess whether there has been an increase or decrease.

The World Health Organization estimates that the prevalence of developmental disability is between 13% of the population**.** The report acknowledges, however, that "[T]he prevalence figures vary considerably because of the varying criteria and methods used in the surveys, as well as differences in the age range of the samples" (World Health Organization, 2001, p. 35).

One important distinction is the difference between true prevalence and administrative prevalence which defines the number of people in the population based on those who use services. If in a particular geographic region services are limited or service utilization rates are low then "administrative" prevalence rates will be equally low and likely underestimate the true prevalence of the condition. Few jurisdictions have undertaken broad population surveys as the basis for determining prevalence and therefore often rely on service prevalence data or the generally accepted prevalence rates for specific conditions.

A critical review of prevalence studies concluded that the prevalence of severe developmental disabilities among 5 to 19 year olds was stable across populations in developed countries at 0.3 to 0.4%. In contrast, the prevalence of mild developmental disabilities varied greatly with an average 'true' prevalence of 3% and 'administrative' prevalence of 0.5% (Roeleveld, Zielhuis & Gabreels, 1997). Horwitz and colleagues (2000) report that in the USA, the "administrative" prevalence amongst children ranges from 0.3% to 3.1% in different regions of the country, with a national average of 1.1%. Ouellette-Kuntz and Paquette (2001) confirmed this conclusion in a county in Ontario where they estimated that the 'administrative' prevalence for all levels of developmental disabilities was 0.8 to 0.9%.

Perspectives of Parents and Children with Developmental Disabilities

To a parent, family or caregiver, a child is first and foremost an individual human being with strengths and abilities. He or she is a full citizen with rights, who needs "assistance" to achieve full inclusion and engagement in society. The nature of the "assistance" required varies from child to child and from family to family; it varies from community to community (with significant differences in rural versus urban environments); it changes over time; and changes as society (attitudes, values, environment, technology, knowledge) itself evolves. To be born, to grow up and to live your life to your fullest potential in Ontario in the 21st century is very different from what constituted living well at any other point in history.

Rights of Children and Youth with Disabilities

There is a strong international movement to improve the life circumstances of all people. The current perspective is that people with developmental disabilities should not just live in society, but also be valued, accepted, respected and involved. They should be a vital part of the community – not simply reside in it. Inclusion of people with developmental disabilities in all aspects of community living is the overarching vision of the future.

Canada is a signatory to the *UN Convention on the Rights of Children*, which recognizes the rights of children with disabilities. The Convention recognizes the child's right to:

- protection and promotion of equality;
- special care, including family support, early education, child care and early intervention;
- access services, including education, employment training, health care and rehabilitation; recreation and play.

nicef.org/crc

In 2007 the Government of Canada signed on to the UN Convention on the Rights of Persons with Disabilities (December 2006). Although core UN human rights treaties already guarantee human rights and fundamental freedoms to all persons, including persons with disabilities most do not specifically prohibit discrimination on the grounds of disability. This gap in the international human rights system, coupled with growing recognition in the international community that persons with disabilities are subject to systemic and widespread human rights abuses, was the rationale for the

Convention. The Canadian *Charter of Rights and Freedoms* has guaranteed equality rights for people with disabilities since its enactment in 1982.
http://laws.justice.gc.ca/en/charter/index.html

- In 1998, the federal and provincial/territorial Ministers of Social Services released *In Unison: A Canadian Approach to Disability Issues,* a vision paper that provides a blueprint for policy development for adults with developmental disabilities. The paper:
- makes a commitment to "full citizenship" for people with disabilities; and
- identifies building blocks to guide policy development (disability supports, income supports and employment supports).
http://socialunion.gc.ca/pwd/unison/unison_e.html

In follow up to *In Unison* the Social Service Ministers commissioned an analysis of needs in order to determine whether persons with disabilities in Canada have adequate access to the supports and services they require for full inclusion. This report *Supports and Services for Adults and Children aged 5 – 14 With Disabilities In Canada: An analysis of data on needs and gaps (2004),* provides one of the few Canadian examinations specifically of children with disabilities.
http://socialunion.gc.ca/pwd/gapsreport2004.html

Causes and Presentations

The causes of developmental disabilities are varied and remain unknown in a large proportion of cases. Even in cases of known etiology the line between "cause" and "effect" is not always clear leading to challenges in efforts to categorize causes. It is nonetheless important to seek to establish the etiology of the disability; not merely as an academic exercise or to provide a label, but because known specific causes and their consequences (e.g., distinct syndromes) frequently provide a guide to prognosis and to effective intervention, as well as to chances of recurrence. For the purposes of this paper the known causes can be grouped in two broad albeit not mutually exclusive, categories:

- **Genetic** which includes harmful particular individual genes and aberrant chromosomes as well as deleterious polygenic influences.
- **Environmental** which includes particular physical hazards before, during and after birth as well as adverse domestic and social circumstances (Berg, 1985).

Genetic Causes

Specific gene defects and microscopically visible chromosome variants (e.g., duplications, deletions, translocations) may arise anew or be transmitted in characteristic ways. These and related genetic causes of developmental disabilities have been receiving a great deal of attention from researchers in recent decades particularly in the sphere of molecular biology. Among other developments in these regards are:

- new knowledge from the Human Genome Project,
- use of new, more sensitive and more powerful testing technologies such as array-based comparative genomic hybridization (aCGH) and advanced neuroimaging techniques,
- availability of significantly more research funds through such vehicles as the Combating Autism Act of 2006 in the USA,
- the 67 University Centres of Excellence in Developmental Disabilities (UCEDD) each of which is affiliated with a major research university and serves as a resource for all people in the areas of education, research and service relative to the needs of people with developmental disabilities.
http://www.aucd.org/template/page.cfm?id=24
- The National Institute of Child Health and Human Development coordinates the efforts of scientists and program staff from several National Institutes of Health organizations in the Down Syndrome Working Group. In September 2007 the working group released its draft research plan with input from the outside scientific and family communities. The plan focuses specifically on genetic and neurobiological research relating to the cognitive dysfunction and the progressive late-life dementia associated with Down syndrome.
http://www.nichd.nih.gov/news/releases/upload/DRAFT_NIH_Down_Syndrome_Plan_2007.pdf
- Collaboration amongst families of children with developmental disabilities and researchers is illustrated by The Autism Genome Project (AGP) Consortium, a public-private collaboration involving more than 120 scientists and 50 institutions in 19 countries.
http://www.nimh.nih.gov/science-news/2007/largest-ever-search-for-autism-genes-reveals-new-clues.shtml

Environmental Causes

There is an increased interest in environmental factors as a potential cause of some types of developmental disabilities including:

- *Problems During Pregnancy* – Use of alcohol or drugs; malnutrition; infections and certain environmental toxins. Fetal alcohol spectrum disorders (see next section) and mother's use of drugs during pregnancy has received considerable research attention over the last decade.
  http://www.hc-sc.gc.ca/ahc-asc/media/nr-cp/2001/2001_51_e.html
- *Problems At Birth* – Prematurity and difficulties in the birth process (such as temporary oxygen deprivation or birth injuries).
- *Problems After Birth* – Childhood diseases such as whooping cough, chicken pox, or measles that may lead to meningitis and encephalitis: injuries such as a blow to the head or near drowning. Lead, mercury and other environmental toxins can cause damage to the brain and nervous system.
- *Poverty and Cultural Deprivation* – Children growing up in poverty are at higher risk for malnutrition, childhood diseases, and exposure to environmental health hazards; and in addition they may receive inadequate health care. These factors increase the risk of developmental disability, as well as increased risk for concurrent mental health problems. Children in is advantaged areas may be deprived of many common cultural and educational experiences provided to other youngsters. Under-stimulation of infants and toddlers (neglect and abuse) also has a negative impact on the development of intellectual and adaptive functioning. As noted by the Toronto Board of Health in 2006, children living in low income families or neighbourhoods have worse outcomes on average than other children on a range of key health indicators such as infant mortality, low birth weight, respiratory conditions, obesity, injuries, and developmental outcomes. Children who experience deep and persistent poverty in the earliest years of their lives are most at risk. Health improves with each step up the socioeconomic ladder.
  http://campaign2000.ca/rc/pdf/OntarioReportCard2006.pdf
- The family environment, and more specifically, the mother-child interaction, is the focus of much research. Studies such as Ontario's Early Years Study and Early Years 2 have integrated new knowledge from neurobiological and neurogenetic research to increase public and service provider understanding of the importance of the mother-child attachment in the early years and its effect on healthy brain development. These research findings have increased public awareness of, and interest in, healthy parenting and early childhood development, much earlier identification of developmental concerns, and a number of new types of intervention strategies.
  http://www.founders.net/ey/communities.nsf/cl/fn-com-15
  http://www.children.gov.on.ca/mcys/english/resources/beststart.asp

Common Conditions

A review of any textbook on developmental disabilities will demonstrate that there are many conditions associated with delays in adaptive functioning and intellectual ability. In the following section a brief description of five conditions commonly associated with developmental disability is provided. The first two conditions were chosen as they are, respectively, the most common genetic and inherited forms of developmental disabilities. The latter three conditions are also common but can present with or without a concomitant delay in intellectual ability.

1. Down Syndrome
2. Fragile X Syndrome
3. Fetal Alcohol Spectrum Disorders
4. Cerebral Palsy
5. Pervasive Developmental Disorders

Down Syndrome

Down syndrome is the most common known genetic cause of developmental disability. People with Down syndrome have extra chromosome 21 material often referred to as trisomy 21. According to a report released January 6, 2006 by the Centers for Disease Control (CDC), the occurrence of Down syndrome in the United States may be more common than was often thought, estimated at one case for every 733 live births. Until then the US National Down Syndrome Society had used the estimate of one in every 800-1,000 live births, which was reported in past studies based on data from states, hospitals and other sources. Prevalence of the condition in the large majority of cases is linked with ages when mothers have children, with the chances of having an affected child increasing as maternal age advances. However, no child-bearing age is immune and many children with Down syndrome are born to young mothers.

Early intervention is extremely important in the first 6 years, as cognitive and communication skills lag behind personal-social and adaptive skills. Intervention improves the style of mothers' interaction, which in turn benefits the child's receptive language. Because sign,

picture communication and reading fall into the visual domain and are relative strengths, they need to form the focus in intervention.

There is evidence of increased risk for a variety of developmental and medical conditions including congenital heart disease (50%); gastrointestinal disorders, including celiac disease (7 to 16%); hearing loss (75%); otitis media (50-75%). A number of skin and eye conditions are common. Hypothyroidism occurs in 16-20% of individuals with Down syndrome and is caused by a deficient production of thyroid hormone. Type II diabetes is more prevalent in people with Down syndrome than the general population. Blood disorders such as leukemia occur 10 to 30 times more frequently in children with Down syndrome than typically developing children. Screening for atlantoaxial instability (cervical spine X-ray) is recommended by most authorities. Obstructive sleep apnea is also common and prevalence varies from 40-50%. Neurological disorders in children with Down syndrome include hypotonia (reduced muscle tone) and seizures. Children and adolescents with Down syndrome are also at increased risk of developing behavioural and psychiatric disorders such as attention deficit hyperactivity disorder (ADHD), autism, depression and obsessive compulsive disorder (Van Cleve & Cohen, 2006).

Virtually all individuals with Down syndrome over the age of 40 years have microscopic changes in the brain that are very similar to changes seen in Alzheimer disease. Occasionally family members or health professionals attribute behavioural changes in young persons with Down syndrome to possible onset of Alzheimer disease. Other possible causes such as depression, hypothyroidism or celiac disease may account for these changes and should be evaluated because there is no documented case of Alzheimer disease in young persons with Down syndrome and its clinical manifestations are now viewed as occurring much less frequently than earlier reports had claimed (Van Cleve et al., 2006). With medical and social interventions the life span of individuals with Down syndrome has increased significantly in recent years.

http://www.ds-health.com

Fragile X Syndrome

Fragile X syndrome (FXS) is the most common known hereditary form of developmental disability worldwide although downward revision of prevalence estimates from 80 per 100,000 has taken place since precise identification of the fragile X gene in 1991 to 16-25 per 100,000 affected males and about half that for affected females (Saul & Tarleton, 2007). Associated cognitive, behavioural and morphological symptoms of FXS are highly variable (Belmonte & Bourgeron, 2006). Approximately one-third of all children diagnosed with FXS also have some degree of autism. FXS is one of a very small number of conditions that are known single gene causes of autism (The National Fragile X Foundation).

www.Fragile.org

Males with fragile X syndrome typically are cognitively impaired and need specialized help at school, supported employment and assistance with community living. They frequently have behavioural problems. Affected females, by contrast, usually have milder learning difficulties and fewer obvious clinical features. They may have learning difficulties, anxiety and shyness, and some physical features that become more evident with age.

The nature of this inherited condition is such that some individuals can be affected with a lifelong developmental disability, while other family members who are premutation carriers of the fragile X gene are unaffected. Unaffected family members who carry the gene mutation can have affected children.

Fetal Alcohol Spectrum Disorders

Fetal alcohol spectrum disorders (FASDs) is an umbrella term used to describe the range of physical, cognitive, behavioural and/or learning disabilities with possible life-long implications that are caused by prenatal exposure to alcohol. FASDs are caused by a woman drinking alcohol at any time during her pregnancy and are therefore entirely preventable. There is currently no evidence of a "risk-free" drinking level during pregnancy. The term "spectrum" is used as an individual with FASD may have a wide range of physical and mental challenges that vary in degree from mild to severe. Fetal Alcohol Syndrome (FAS) is the most severe presentation of FASD and

is the leading nongenetic cause of developmental disabilities in the western world (Brown & Percy, 2007).

The prevalence of FAS in the United States has been reported as 1 to 3 per 1000 live births and the rate of FASD as 9.1 per 1000 live births. However, diagnosis may often be delayed or missed entirely. There are no national statistics on the rates of FASD in Canada, although studies have estimated its prevalence in small populations. In an isolated Aboriginal community in British Columbia, FASD prevalence was 190 per 1000 live births. In north-eastern Manitoba, an incidence of about 7.2 per 1000 live births was found. In another Manitoba study in a First Nations community, the prevalence of FAS and partial FAS was estimated to be 55-101 per 1000 (Chudley et al., 2005). Within a First Nation community in New Brunswick, one recent study identified a total prevalence rate in the community's elementary school of 19.25 per cent or 193/1000 children (Cox, 2007).

According to the FASD Canadian Practice Guidelines (2005), the risk factors for prenatal alcohol exposure include higher maternal age and lower education level, prenatal exposure to cocaine and smoking, custody changes, lower socioeconomic status and paternal drinking and drug use at the time of pregnancy; and reduced access to prenatal and postnatal care and services, inadequate nutrition and a poor developmental environment (e.g., stress, abuse, neglect).

The main effects of FASD in infancy and early childhood are: physical and cognitive developmental delay; and behavioural and learning problems. Secondary disabilities include mental health disorders (attention-deficit hyperactivity disorder, conduct disorder) disruptive school experiences, trouble with the law, confinement (inpatient treatment for mental health problems and alcohol/drug problems, or incarceration for a crime), inappropriate sexual behaviour, alcohol and drug problems, dependent living and unemployment. In a recent study only 34% of those with FAS had an IQ below 70, the cut-off point determining eligibility for special services in most jurisdictions though they clearly had specific intellectual and academic problems and adaptive behaviour deficits (Clarke, Lutke, Minnes & Ouellette-Kuntz, 2004).

Cerebral Palsy

Cerebral palsy (CP) is defined as a group of non-progressive, but often changing, motor impairment syndromes secondary to lesions or abnormalities of the brain arising at any time during brain development. The impairment of motor function may result in paresis, involuntary movement, or poor co-ordination. It does not include motor disorders that are transient, that result from progressive disease of the brain, or that are due to spinal cord abnormalities or injuries. In developed countries, the prevalence is estimated to be 1.2 to 2.5 per 1000 children (Kuban & Leviton, 1994; Murphy, Yeargin-Allsopp, Decoufle & Drews, 1993).

CP is a commonly used term that refers to a group of motor disorders. The five main features of CP are:

- Onset that is before, during or after birth (usually before 5 years of age);
- Motor difficulties that are secondary to brain damage;
- Abnormal muscle tone and impaired control of movements with poor motor coordination, balance, or abnormal movements and postures (or a combination of these features);
- A disorder that is non-progressive, but permanent; and
- It is often accompanied by disturbances of sensation, cognition, communication, perception and/or behaviour and/or by a seizure disorder (Brown & Percy, 2007, p. 279).

People with CP vary from being completely independent to being very dependent. The degree of independence often relates to the motor control they are able to develop in their hands. Speech/language development in children with CP varies from being able to speak fluently, to having some difficulties in articulation; or being unable to speak because of motor problems.

Most children with CP have intelligence levels in the normal range, but some also have a developmental disability or a learning disability. Reported rates of slower intellectual development associated with CP vary from 30-60% (Evans, Evans & Alberman, 1990).

People with CP are at risk for medical complications including seizures (seen in approximately 20-30%), visual impairment, strabismus (turning in or out of the eye), hearing loss; dental cavities, drooling, swallowing difficulties, poor growth/nutrition, aspiration pneumonia, reflux, constipation, and orthopaedic complications. Life expectancy can be reduced in individuals with CP. However, the majority of individuals will survive long into adulthood.

Pervasive Developmental Disorders (PDD)

The DSM-IV (1994) introduced a new category for long-term disorders with relatively poor prognosis for improvement – the Pervasive Developmental Disorders (PDDs). The DSM-IV recognizes five sub-sets within the PDD category:

- Autistic Disorder;
- Asperger Disorder;
- Childhood Disintegrative Disorder (CDD);
- Rett Disorder; and
- PDD-Not Otherwise Specified (PDD-NOS).
- After the DSM-IV classifications three of the above disorders were grouped together and called the "Autism Spectrum Disorders" (ASD). ASDs are characterized by impairments in social interaction and communication, and the presence of restricted activities and interests. Symptoms typically appear in early childhood with social-communication difficulties and/or delayed developmental milestones. Recent studies have shown that the deleterious developmental and behavioural sequelae of ASDs can be minimized in a proportion of children through intensive behavioural intervention. It is clear from sibling, twin and family studies that genetic susceptibility plays a large role in the etiology of ASDs. However, exogenous factors are also believed to play a role in their onset, although no such factors have been elucidated.
- There is no clear consensus on the prevalence of ASDs. Published studies over the last ten years have found prevalence proportions ranging from 16.3 to 67.4 per 10,000 children. Large increases in the proportion of children diagnosed with an ASD have also been reported over the last few decades. A comprehensive review of studies published since 1966 found that the prevalence of ASDs climbed from
- 7.8 per 10,000 to 67.4 per 10,000, while a UK study reported that the incidence among children 1 to <5 years increased from 3.5 per 10,000 per year in 1991-92 to 13.1 per 10,000 per year in 1995-96. The age-adjusted incidence of ASDs among persons under the age of 22 years in Olmsted County, Minnesota also increased from 5.5 per 100,000 between 1980 and 1983 to 44.9 per 100,000 between 1995 and 1997. It is unclear, however, whether these findings reflect a true increase in incidence, or whether they are due to changes in diagnostic and referral patterns. Wing and Potter and Fombonne conclude that the increases in prevalence are largely attributable to changes in diagnostic criteria and increasing recognition of ASDs; others believe that there is a true increase in the occurrence of ASDs.
- Large increases in the prevalence and/or incidence of autism and related disorders have also been detected in trend studies. Analysis using BC Ministry of Education data indicates that between 1996 and 2003 the proportion of school children assigned the special education code for autism increased from 12.3 to 42.4 per 10,000 (Ouellette-Kuntz et al., 2007).
- Autism is associated with developmental disability in about 70% of the cases and is overrepresented amongst males (with a male/female ratio of 4.3:1) (Fombonne, 2003).

It is now believed that most children with ASD are probably born with it, and that a preliminary (or "suspected") diagnosis can be made well before the age of three, with some researchers suggesting that it can be diagnosed at 14 months, and other researchers predicting that there may soon be biological or genetic markers that could lead to a test being administered to newborns.

Asperger disorder tends to be diagnosed at a later age than Autistic disorder. An individual with Asperger disorder does not possess a significant delay in language development; however, he or she may have difficulty understanding the subtleties used in conversation, such as irony and humour. Also, while many individuals with Autistic disorder have a significantly below average IQ, a person with Asperger disorder possesses average to above average intelligence (Autism Society of America, 1995). Challenges facing children, youth and adults with Asperger disorder include anxiety and depression; attention difficulties; tics or Tourette syndrome; gross

and fine motor deficits; and poor organizational skills (The Asperger's Society).

www.aspergers.org

When children display similar behaviours but do not meet the specific criteria for autistic disorder (or the other three PDDs listed earlier), they may receive a diagnosis of Pervasive Developmental Disorder Not Otherwise Specified, or PDD-NOS.

Rett disorder or syndrome is a neurological and neurodevelopmental disorder resulting from a genetic mutation that has been found in more than 95% of those meeting criteria for typical Rett disorder and more than 50% meeting those for atypical Rett disorder (International Rett Syndrome Association). Rett disorder is extremely rare and is most often misdiagnosed as autistic disorder, cerebral palsy or nonspecific developmental delay. Swedish studies suggest that prevalence is between 1 in 10,000 to 1 in 12,000 females but the Texas Rett Syndrome Registry has identified 1 in 22,800 females age 2-18 years (International Rett Syndrome Association).

Initially, it was thought to occur only in females and to be fatal for male foetuses. It is now known that variations of the disorder can be found in males who have mutations of MECP2, with some overlap in the symptomatology observed in girls and a wide range of severity (Schwartzman et al., 1999; Schanen, Kurczynski, Brunelle, Woodcock, Dure, & Percy, 1998).

Children with childhood disintegrative disorder develop a condition which resembles autism but only after a relatively prolonged period (usually 2 to 4 years) of clearly normal development. Although apparently rare, the condition probably has frequently been incorrectly diagnosed. More boys than girls appear to be affected. Childhood disintegrative disorder is perhaps 10 times less common than more strictly defined autism (Volkmar, 1992).

Health Issues in Children with Developmental Disabilities

People with developmental disabilities often have co-existing or concurrent health conditions. Research shows that this population tends to have more medical problems than the general population. Rates of morbidity are substantially higher than that of the general population, and a large proportion of medical conditions that go unrecognized are treatable and/or preventable. Three conditions which affect children with developmental disabilities are discussed; dual diagnosis, epilepsy and complex care. Dual diagnosis (mental health disorder and a developmental disability) and epilepsy have been selected because of their relatively high co-occurrence with a developmental disability and complex care, which is not specifically a health condition, is also included because of the significant challenges in supporting children with complex health care needs.

Dual Diagnosis

Dual diagnosis was defined jointly by the Ontario Ministries of Health and Long-Term Care (MOHTLC) and Community and Social Services (MCSS) in 1997 to refer to individuals who have a diagnosed emotional/psychiatric disturbance as well as a diagnosed developmental disability. In a meta-analysis (a process which collects and synthesizes results from individual studies to estimate an overall effect size) of all studies, Reiss (1993) found rates of mental health problems of 15 to 50% in adults with developmental disabilities. He noted that low prevalence rates were generally found in surveys that relied on retrospective review of case files, while higher rates were found in surveys using professional interviewers and more elaborate scientific methods.

There is now a clear acknowledgement that children with developmental disabilities can develop the full range of psychiatric illnesses and that they have a higher rate of mental health disorders than the general population (Emerson, 2003; Hudson & Chan, 2002; Cooper et al., 2007). In Great Britain, the Office of National Statistics undertook surveys in 1999 and 2004 of children and youth. From these surveys 3.5% of the children surveyed were identified as having a developmental disability and of those children, 36% were also found to have a diagnosable psychiatric disorder (Emerson & Hatton, 2007). In this study the authors noted that children and adolescents with developmental disabilities are over six times more likely to have a diagnosable psychiatric disorder than their peers without developmental disabilities. They also noted that young people with developmental

disabilities are poorer, live in more challenging family circumstances and have fewer friends; all of which are known to be associated with an increased risk of mental health problems.

According to this key study, the increased risk of having a mental health problem cuts across all types of psychiatric disorders. The study found that children with developmental disabilities are:

- 33 times more likely to have autism spectrum disorder;
- 8 times more likely to have Attention Deficit Hyperactive Disorder;
- 6 times more likely to have a conduct disorder;
- 4 times more likely to have an emotional disorder; and
- 1.7 times more likely to have a depressive disorder.

They are also significantly more likely to have multiple disorders. The study describes three main reasons which appear to account for the high rates of mental health problems in this population. First, the intellectual impairment associated with a developmental disability reduces the child's capacity for finding creative and adaptive solutions to life's challenges. Second, these children are at increased risk for exposure to poverty and social disadvantage. They also have higher rates of stressful life events such as abuse than children without developmental disabilities. Third, some particular causes of developmental disability predispose children to particular types of mental health problems.

While several studies suggest that there are no gender differences in the overall presence of psychopathology, there are some noted differences within certain types of disturbances; for example, antisocial behaviour in the post-school period occurs significantly more often in males whereas emotional disturbances occur more frequently in females (Borthwick-Duffy, 1994).

Epilepsies

The epilepsies are a group of neurological disorders, characterized by the occurrence of seizures. Seizures are more common in individuals with a developmental disability and the incidence of seizure activity generally increases with the severity of the developmental disability. The most common therapy for epilepsy is treatment with anticonvulsant medications. They do not cure epilepsy; they simply suppress seizures on a temporary basis. In about 60% of cases, medications control the seizures; in 20%, the seizures are only partially responsive to medications.

Seizures often occur with other disorders. Epilepsy Ontario notes the following for examples:

Epilepsy and Down Syndrome – Seizures occur in 5% to 10% of persons with Down syndrome, which is several times the expected frequency in the general population. The high frequency of seizures is likely due to a combination of inherent physiological and structural anomalies and common medical complications of the syndrome. Also, there is an age-related incidence of epilepsy in Down syndrome, peaking in the first year, and again in the fourth and fifth decades of life. Current research suggests that approximately 75% of older individuals with Down syndrome develop seizures.

Epilepsy and Tuberous Sclerosis – Tuberous Sclerosis is a genetic multi-system neurocutaneous disorder with clinical characteristics frequently including epilepsy, developmental disability (to varying degrees), and retinal and skin lesions. Recurring seizures usually begin by the middle of the first year of life. It is reported that as many as 92% of persons with Tuberous Sclerosis have seizures.

Epilepsy and Autism – Approximately 20% to 35% of individuals with autism have a seizure disorder. About one in four autistic individuals begin to have seizures during puberty. The exact reason for the onset of seizures is not known, but some researchers believe that it may be due to hormonal changes. Sometimes these seizures are noticeable, (associated with convulsions); but, for many, they are small, sub-clinical seizures, and are typically not detected by simple observation. Some possible signs of subclinical activity include the following: exhibiting behaviour problems, such as aggression, self-injury, and severe tantrums; making little or no academic gains after doing well during childhood and pre-teen years; and/or losing some behavioural and/or cognitive gains. People with autism are at a higher risk for seizures if they have certain specific neurologic conditions, such as tuberous sclerosis, neurofibromatosis or untreated

phenylketonuria. As well, infantile spasms (sudden generalized muscle contractions, usually beginning between ages 3 and 8 months) do occur in association with autism. Other forms of epilepsy, such as complex partial epilepsy, generalized tonic-clonic epilepsy and absence seizures, may also occur in children with autism.

http://www.epilepsyontario.org

In March 2007, a team of US scientists in 13 epilepsy centers received a grant of $15 million dollars over the next five years to study the complex genetic factors that underlie some of the most common forms of epilepsy. The study, known as the Epilepsy Phenome/Genome Project (EPGP), is being funded by the National Institute of Neurological Disorders and Stroke, and brings together over 50 researchers and clinicians from 15 medical centers around the country.

http://www.epgp.org/Pages/Default.aspx

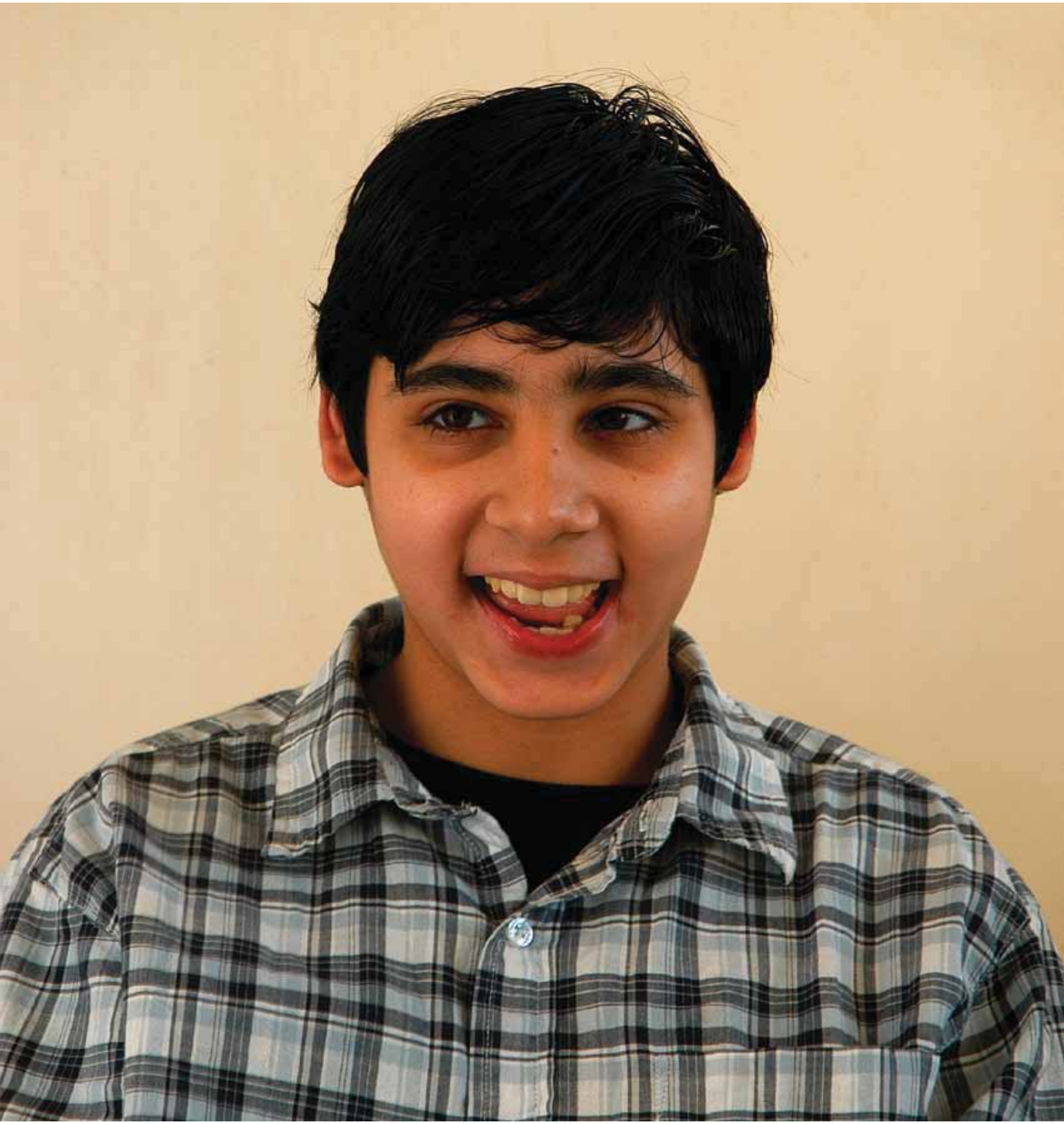
Complex Care

Advances in neonatal intervention and the treatment of childhood diseases have resulted in a relatively new category of children with disabilities: these children who require complex care are medically fragile and may also be technology-dependent. This is an administrative description rather than a diagnostic category or cause of developmental disability. Ontario's Ministry of Children and Youth Services has broadly defined these complex care children for program eligibility purposes as "children who need intensive care and constant monitoring on a 24-hour basis". The definition is applicable to children/youth whose condition is assessed to be such that if the required intervention is not provided, the child's condition will deteriorate to the point where permanent and irreversible damage is likely to occur. Examples of children/youth deemed to require complex care include those who:

- are medically fragile and/or technologically dependent;
- have severe physical disability requiring a high level of support;
- have developmental disabilities which are profound or severe and further complicated by other diagnoses (e.g., children with autism spectrum disorder and dual diagnosis; children with developmental disabilities who are also self-injurious or pose a risk to caregivers or other family members);
- live in communities where local services have been incapable of responding to the complexity or intensity of supports needed; or cases where interventions have been unsuccessful; and
- are exposed to parental/family exhaustion and/or isolation.

The vast majority of these medically fragile children who have complex special health care needs are being cared for by their families in the community. Caregivers face numerous and complex tasks related to the care of their children with periodic or episodic support from health care institutions, health care professionals, and occasional access to respite services (Mentro, 2004). Caring for a child with complex care needs at home is an extraordinary challenge, requiring commitment and strength on the part of the caregivers. In addition to being highly motivated and well organized, families also must have adequate financial resources, and be well connected to readily accessible community supports when crises occur.

Child welfare services in Ontario (Toronto; London & Middlesex) have reported a sharp increase in the last decade in the number of complex care children being referred to them for placement because of diminished parental coping capacity. It is difficult for child welfare agencies to find placements for these children. Many of these children remain in foster care for extended periods. There are concerns that children requiring complex care are placing an enormous strain on the resources of child welfare agencies.



PART 2: UNDERSTANDING THE HEALTH OF CHILDREN

Before examining the Canadian Population Health Framework, this review will discuss briefly how researchers have in the past few years attempted to shed light on the differences in health and health status experienced by individuals with developmental disabilities. The work to date has not been specific to children. However, understanding the health status and risks for adults provides an opportunity to identify and target "up stream" health promotion strategies.

Pomona Project: The EU Health Promotion Framework

The European Community Action Programme (2005) has an objective of health promotion through addressing health determinants. People with developmental disabilities are less healthy than their peers of the same age (U.S. Department of Health and Human Services, 2002). Health differences amongst people arise naturally because of biological variations; however, some health differences are avoidable and may be amendable to intervention.

Concerns about the health disparities among people with developmental disabilities led to cooperation between the WHO and the International Association for the Scientific Study of Intellectual Disabilities (IASSID) to study and report on the healthiness in people with developmental disability in the European Community (Janicki et al., 1999; WHO, 2001). Subsequently, "Health Disparities" was the theme of an international meeting in 2005 which initiated a process of identifying the various determinants that play a role in the health of people with developmental disabilities and disparities in their health care.

In its extensive literature review the Pomona Project references an Australian study (Lennox et al., 1997) that provides further insight into health disparities. The authors of this study note that because of limited verbal capacities, people with developmental disabilities experience problems in communicating with health care professionals, both in verbalizing complaints and in providing their medical history.

A further difficulty may arise in understanding diagnosis and treatment options. Medical personnel are often not trained to communicate using nonverbal strategies such as gestures, pictures, pictograms, and other illustrative materials.

The Pomona Project has recently developed a set of 18 health indicators specifically for people with developmental disabilities (van schrojenstein Lantman-de Valk, Linehan, Kerr, & Noonan-Walsh, 2007). These include:

- Demographics (prevalence; living arrangements; daily occupation; income/socio-economic status; and life expectancy);
- Health status (epilepsy; oral health; body mass index; mental health; sensory capacities; mobility);
- Determinants of Health (physical activity; challenging behaviour; psychotropic medication use); and
- Health systems (hospital and contact with health care professionals; health check; health promotion; and developmental disabilities specific training for physicians).

The second phase of the Pomona project (POMONA II 2005-2008) is measuring the extent of health disparities or inequalities of people with developmental disabilities against each of these 18 health indicators in these countries: Austria, Belgium, Finland, France, Germany, Ireland, Italy, Lithuania, the Netherlands, Norway and Romania.

http://www.pomonaproject.org

Health Disparities Framework

In September 2003, the Canadian Institutes of Health Research (CIHR) International Think Tank on "Reducing Health Disparities and Promoting Equity for Vulnerable Populations" examined current knowledge about disparities or inequities in the health of specific populations, including disabled people. A multidisciplinary team of researchers and clinicians with experience in developmental disabilities prepared a synthesis paper specific to this vulnerable group for the think tank (Ouellette-Kuntz et al., 2005). The authors conclude that it is currently difficult to confirm the extent to which premature mortality or excess morbidity in individuals with developmental disabilities compared with the general population is avoidable. However, observed disparities in intake

of health promotion/disease prevention activities and health care access, utilization and quality are almost certainly avoidable. They conclude that these disparities are likely "unjust".

Ouellette-Kuntz (2005) identifies the following as modifiable factors that should be part of a framework for the study of health inequities based on intellectual impairment:

- Lifestyle factors/behaviours;
- Social networks (particularly the critical role of caregivers in facilitating access to care and lifestyle choices);
- Living and working conditions (including community attitudes and access to services and facilities);
- Wider structural determinants of health (economics, policies); and
- Constraining and enabling social structures and mechanisms contributing to inequity.

Canadian Population Health Framework

In 1986 the Federal Government began an exploration of the broader social, economic and environmental factors that affect the healthiness of Canadians. In 1989, the Canadian Institute for Advanced Research (CIAR) introduced the population health concept, stressing that the individual determinants of health do not act in isolation from one another. It is the complex *interaction* amongst determinants that can have a synergistic effect on healthiness.

In the same way, children with developmental disabilities are not simply coping with a lifelong health condition. Children – and their families, friends, schools, playgrounds, recreational facilities, libraries, neighbourhood – are impacted when their healthiness and capabilities are not optimized.

In January 1997, the Federal, Provincial and Territorial Advisory Committee on Population Health (ACPH) prepared "Strategies for Population Health – Investing in the Health of Canadians". This paper, presented to the Ministers of Health was prepared to advise the Conference of Deputy Ministers on national and interprovincial strategies that should be pursued to improve the health status of the Canadian population and to provide a more integrated approach to health. The paper set out the proposed framework for a population health approach. The ACPH defined population health as referring to the health of a population as measured by health status indicators and as influenced by social, economic and physical environments, personal health practices, individual capacity and coping skills, human biology, early childhood development, and health services. As an approach, population health focuses on the interrelated conditions and factors that influence the health of populations over the life course, identifies systematic variations in their patterns of occurrence, and applies the resulting knowledge to develop and implement policies and actions to improve the health and well-being of those populations.

http://www.phac-aspc.gc.ca/ph-sp/phdd/pdf/e_strateg.pdf

In the second report of the ACPH, "Toward a Healthy Future – Second Report on the Health of Canadians" (1999), a consensus emerged on the twelve key determinants of health that will be Canada's focus for the coming decades. The twelve determinants of health are:

1. Income and Social Status
2. Social Supports Networks
3. Education
4. Employment/Working Conditions
5. Social Environments
6. Physical Environments
7. Personal Health Practices and Coping Skills
8. Healthy Child Development
9. Biology and Genetic Endowment
10. Health Services
11. Gender
12. Culture

http://www.phac-aspc.gc.ca/ph-sp/phdd/pdf/toward/toward_a_healthy_english.PDF

APPLYING THE POPULATION HEALTH FRAMEWORK

Each of the determinants is introduced with a **background** section that provides an overview of the underlying premises developed by the Public Health Agency of Canada for the determinant as well as evidence on the health of Canadians from *Strategies for Population Health – Investing in the Health of Canadians (ACPH 1997). This is followed by* **evidence of the health of children with developmental disabilities** that provides a review of the literature on each determinant. One of the challenges in applying the

framework is the lack of Canadian data or research specific to developmental disabilities in general and children with developmental disabilities, more specifically. In instances where data are available for adults with a developmental disability it is included as it provides insight into the experiences of children that could contribute to their status as adults.

KEY DETERMINANT 1 – INCOME AND SOCIAL STATUS

Background

Higher income and social status improve health status. Higher income determines living conditions such as safe housing and ability to buy sufficient good food throughout life, including during pregnancy. The degree of control that people have over life circumstances, especially stressful situations, and their discretion to act are key influences. Higher income and status generally results in more control and discretion. The biological pathways for how this could happen are becoming better understood. A number of recent studies show that "limited options" (stemming from low income status and poverty) combined with poor coping skills for dealing with *stress* increase *vulnerability* to a range of diseases through pathways that involve the immune and hormonal systems.

Evidence of Health of Children with Developmental Disabilities

Child Poverty – According to a number of reports, children in general are at risk due to the frequency of those that are living in poverty. Statistics Canada data (Campaign 2000, 2006), reveals the following:

- One child in every six in Ontario is in a family that lives below the poverty line (measured by the Low Income Cut-off) – that is currently 478,480 or 17.4% of Ontario's children and youth under 18.
- Poverty rates are significantly higher among vulnerable social groups. Just over half (54.6%) of low income children in Ontario live in female single-parent families.

http://campaign2000.ca/rc/pdf/OntarioReportCard2006.pdf

Recent research in Niagara Region (Arai & Burke, 2007) examined the breadth and depth of poverty and why it is not possible to address child poverty independent of poverty among families. The report notes that Canada has not seen any significant decreases in child poverty rates in 30 years despite government commitments to eliminate poverty. In 1989, when members of the House of Commons voted unanimously to end poverty by 2000, child poverty rates were at 15.1%. By 2003, they had risen to 17.6%. The study examined poverty in disadvantaged groups including people with disabilities. Poverty can impact access to social support networks, access to social services, children's health outcomes, an individual's coping skills, as well as educational outcomes. The authors note that poverty can also be defined in terms of the individual's experience of powerlessness, voicelessness and social exclusion. The report concludes that one of the strategies that should be used to mitigate the negative effects of low income on children and youth is to provide them with more opportunities to access programs and services, such as enriched early child development, child care, recreational programs, and other community supports.

http://www.regional.niagara.on.ca/living/saeo/reports/default.aspx

Children with a Disability and Family Income – Using data from the National Population Health Survey (NPHS) (1996-97), the Roeher Institute (Roeher Institute, 2000) suggests that, while Canadian children with disabilities live in families of various economic circumstances, these children are more likely to be poorer than other children. The analysis of the NPHS data revealed Children with disabilities are more likely than other young people to be in families at the lower end of the income scale – 28.8% of children with disabilities live in households where the total income is in the lower-middle and lowest income quintiles, compared with 17% of children without disabilities. The Report suggests that this data could be interpreted to mean that children who live in low income households are 2.5 times more likely to have a problem with vision, hearing, speech or mobility than are children in high-income families.

http://roeher.ca/comersus/subject.htm

Research from the UK (Emerson & Hatton, 2007) indicates that of the children in Britain with developmental disabilities and a mental health disorder:

- 53% are living in poverty compared to 30% for all

children; and

- 38% are living in families in which no adult has paid employment compared to 15% for all children.

Costs of Care Giving – Parent(s) of a child with disabilities face unique financial challenges and, for most, making financial ends meet is difficult. The costs of care giving are often incurred in two forms:

1. From reduced income and benefits due to lost time from paid employment; and
2. From the additional out-of-pocket expenses incurred to meet the daily needs of their child, such as transportation, special clothing, and assistive devices.

Caregivers of children with disabilities are forced into hard choices. They must often choose between employment and caring for their children because affordable child care and other services are not available. The lack of income support involves choices that affect other children in the family as well, who will also live in poverty when family income is inadequate. In the long run, parents may be mortgaging their own future as well as that of their children, both those living with disabilities and those who are not (Valentine, 2001).

The economic costs of caring for, nurturing and supporting the healthy development of capabilities in a child with a developmental disability is very high. The vast majority of these extraordinary expenses are family responsibility. Families face extraordinary costs associated with caring for children with lifelong health needs and uncertain employability prospects. Multi-disabled children and medically fragile children put enormous financial pressures on even moderate income families. Recent Canadian research notes that only one-half of children with disabilities have the assistive devices they need (Hanvey, 2002).

http://www.nationalchildrensalliance.com/nca/pubs/reports_date.htm

Adults with Developmental Disabilities and Poverty – Families of children with developmental disabilities face lifelong financial stresses and the future financial prospects for their children are poor. The Canadian Association for Community Living (CACL) estimates that 77% of adults with a developmental disability live in poverty. Most adults with a developmental disability who do not live with their parents have an income of less than $11,000 per year – insufficient to secure even a reasonable quality of life. Those who live in supported independent living situations receive $112 per month comfort allowance or $1,344 per year. Persons with a dual diagnosis [developmental disability and mental health disorder] are a high-risk group for living in poverty (Canadian Mental Health Association, Ontario Division, 1998).

http://onterio.cmha.ca/admin_ver2/maps/98_17.pdf

KEY DETERMINANT 2 – SOCIAL SUPPORTS NETWORK

Background

Support from families, friends and communities is associated with better health. Such social support networks could be very important in helping people solve problems and deal with adversity, as well as in maintaining a sense of mastery and control over life circumstances. The caring and respect that occurs in social relationships, and the resulting sense of satisfaction and well-being, seem to act as a buffer against health problems. Some experts believe that the health effects of social relationships may be as important as established risk factors such as smoking, physical activity, obesity and high blood pressure.

Evidence of Health of Children with Developmental Disabilities

The healthiness of children with a developmental disability is significantly impacted by two types of social supports:

1. Informal social supports (primarily family, friends, neighbours, and the community); and
2. Formal social supports (such as health and social service providers; self-help groups; professional associations and advocacy groups).

Rehabilitation professionals agree that families can

be the most powerful and enduring influence in the lives of persons with developmental disabilities (Krauss & Seltzer, 1994; Cook & Ferritor, 1985; Kelley & Lambert, 1992). The life expectancy of individuals with developmental disabilities has been increasing for several decades (Janicki & Wisniewski, 1985; Waltz et al., 1986). In a North American context, demographic shifts and changes in care giving suggest that the family will continue to be an important context for children with developmental disabilities as they reach adulthood. Over a decade ago, American researchers predicted that the vast majority of people with developmental disabilities would live with their parents for their entire life (Krauss & Seltzer, 1994). It has been estimated that, in the USA, 80 to 85% will live with their parents, typically until the parents' health declines or they die (Heller, 1993). Aging caregivers is a current concern in the literature. American sources estimate that 70% of adults with disabilities are living with parents who are now 60 years and older. However, research in South Eastern Ontario indicates that of the individuals with developmental disabilities known to service providers, 94% of children live with their parents, this drops to 45% for 18 to 44 year olds and to 12% for those over the age of 45 (personal communication, Helene Ouellette-Kuntz, March 2008).

While the strength of family supports is critical to the healthiness of children, Valuing People notes that many of these children lack the other critical component of a social support network, namely friends. People with developmental disabilities can be among the most disadvantaged of an already disadvantaged group. Often people with developmental disabilities live isolated lives, knowing only their family and other people with disabilities. Research published in 1999 in the UK found that only 30% had a friend who was not either developmentally disabled or part of their family, or paid to care for them. Over two-thirds of people with developmental disabilities had no 'outside' friends. In the same report, Prime Minister Tony Blair wrote: "People with learning (developmental) disabilities can lead full and rewarding lives, as many already do. But others find themselves pushed to the margins of our society. And almost all encounter prejudice, bullying, insensitive treatment and discrimination at some time in their lives. Such prejudice and discrimination – no less hurtful for often being unintentional – has a very damaging effect. It leads to your world becoming smaller, opportunities more limited, and a withdrawal from wider society so time is spent only with family, carers or other people with learning (developmental) disabilities."

http://valuingpeople.gov.uk/dynamic/valutingpeople8.jsp

Social isolation is often reported by families of children with developmental disabilities. According to UK research (Emerson & Hatton, 2007) less than one in three care givers of children with dual diagnosis report that they turn to family and friends for advice about their child's emotions, behaviour or concentration difficulties.

KEY DETERMINANT 3 – EDUCATION

Background

Health status improves with level of education. Education is closely tied to socioeconomic status, and effective education for children and lifelong learning for adults are key contributors to health and prosperity for individuals, and for the country. Education contributes to health and prosperity by equipping people with knowledge and skills for problem solving and helps provide a sense of control and mastery over life circumstances. It increases opportunities for job and income security and job satisfaction. It improves people's ability to access and understand information to help keep them healthy.

Evidence of Health of Children with Developmental Disabilities

Parents, professionals, and researchers have been concerned about the most appropriate school placement for children with developmental disabilities. Special education seems to offer small class size and specially trained teachers while advocates for integration suggest that greater achievement is possible through exposure to non-disabled peers in regular class-room settings. A review of 36 U.S. studies on the social and academic achievement of school-age children with developmental disabilities was undertaken to explore this issue further (Freeman, 2000).

Acknowledging many limitations, the author concludes that integration works in part for improvement in academics and social competence, especially at the younger age groups, but not for social acceptance. Moreover, full integration yields more positive results than does partial integration, especially for younger children. Analysis of the research studies suggests that:

- The greater the degree of integration, the more positive the academic results; children with milder levels of disability achieve more positive results in the integrated classroom than do their counterparts in the segregated classrooms.
- Although children with developmental disabilities might not be as socially competent as typically developing children in the general education program, they are more socially competent than children with developmental disabilities who are integrated only part time or are segregated.
- The placement of children with developmental disabilities in the general education classroom might not improve their social status among typically developing peers. A partial explanation may be found in the desire of children to associate with others who are like themselves. Thus it is not surprising that children with developmental disabilities do not achieve the same levels of acceptance as their nondisabled peers in the general education classroom, but are well accepted in the special education classroom, where their peers are similar to them.
- Children who are older suffer the most from partial integration. Children seem to have enough difficulty being part of the group even if they have no apparent disability; secondary school children with disabilities may be even more likely to feel unaccepted.

In December 1980, the Education Amendment Act (Ontario) required all schools to provide special education and services for all children. No child could be excluded on the grounds of a handicapping condition. In 1998, the Ontario Ministry of Education adopted new regulations requiring school boards to ensure that all 12 categories of exceptional pupils have an Individual Education Plan (IEP); developmental disability and is one of the 12 exceptionalities.

In Ontario in 2005-06, approximately 15% of elementary students received Special Education services (compared to 10% in 2000-01). The percentage of students receiving Special Education supports varies by region: 12.8% Greater Toronto Area; 17.1% Southwestern Ontario; 16% Northern Ontario; 17% Eastern Ontario; and 16% Central Ontario.

The Ministry's "Education for All" initiative (Ontario Ministry of Education, 2005) acknowledges that "fairness is not sameness". Universal design and differentiated instruction are new approaches being introduced in Ontario which allows teachers to enhance the learning of all students by adapting content to the needs and abilities of each student. In 2003-04, there were 43,000 students (of all disabilities) on waiting lists for Special Education assessment; an Identification, Placement, and Review (IPR) process; and placement. In 2005-06, the waiting list was reduced to 38,000 students (People for Education, 2006).

http://www.peopleforeducation.com/tracking/topic/elementary/elem_bytopic.html

In Ontario the Working Table on Special Education was established by the former Minister of Education in May 2005 to reform how students with special needs receive support in school. The Working Table, bringing together representatives from the education community including educators, administrators, parents, special education support staff and students, provided recommendations to the Special Education Transformation Report of the Co-Chairs (Bennett & Wynne, 2006). The report notes that there continues to be philosophical differences about what is meant by "inclusion". "There is a school of thought that would move the system as quickly as possible to a pure inclusion model – a model that would still allow for transitional congregated placements and withdrawals. Another school of thought argues that for the foreseeable future, and perhaps ideally, there would continue to be a range of placements for students with special education needs. The Working Table acknowledges that the regular classroom should continue to be the placement of first choice but that a range of placements may at times be necessary for practical reasons."

http://www.edu.gov.on.ca/eng/document/reports/speced/transformation

The key issues for children with a developmental disability would appear to be that they are likely under-identified;

they wait too long for assessment and placement and so are not getting the kind of intervention they require to benefit from the school setting.

Adolescents with developmental disabilities face unique challenges in transitioning from elementary and secondary school settings to the adult education settings. Many benefit from the extra years they may stay in school (until they are 21) and leaving school earlier than 21 may negatively impact an already disadvantaged teenager.

The transitioning issue is of considerable concern to parents, but to date, there does not appear to be any plans in place to make concerted efforts to improve this process within school settings. Further, there is very little research regarding approaches and practices that result in optimal transition outcomes for young people with developmental disabilities.

KEY DETERMINANT 4 – EMPLOYMENT / WORKING CONDITIONS

Background

Unemployment, underemployment, and stressful or unsafe work are associated with poorer health. People who have more control over their work circumstances and fewer stress-related demands of the job are healthier and live longer than those in more stressful or riskier work activities. Employment has a significant effect on a person's physical, mental and social health. Paid work provides not only money, but also a sense of identity and purpose, social contacts and opportunities for personal growth. When a person loses his/her benefits, the results can be devastating to both the health of the individual and his or her family. Unemployed people have a reduced life expectancy and suffer significantly more health problems than people who have a job. A major review done for the World Health Organization found that high levels of unemployment and economic instability in a society cause significant mental health problems, and have adverse effects on the physical health of unemployed individuals, their families and their communities.

Evidence of Health of Children with Developmental Disabilities

Adolescents with developmental disabilities not only experience difficulty transitioning from school to work, but also experience extreme difficulty in securing attachment to the paid labour force. As part of the transition process into the labour force, they need assistance from agencies with specialized skills and programs to help assess their abilities, provide work skill development, and assistance with a job search. Since 1990, the provincial government in Ontario has had a policy of *supported employment* defined as "paid employment in an integrated, competitive work setting where on-going, individualized training and support is provided to a person with a disability". Supported employment programs help a person find a job and then they provide the training and support that is necessary to ensure success. There is an expectation that a support worker will be knowledgeable about the abilities of an individual and will be able to work with an employer to tailor-make a job for him/her.

Studies of supported employment programs in Ontario (Dale, 2002; Pedlar et al., 1989) and in the U.S. (Moseley, 1988; Wehman & Kregel, 1994) generally indicate that successful supported employment programs have made a significant difference in the lives of many people with developmental disabilities. People are proud of working in the community, enjoy the work they do, and get along well with their co-workers. Many prefer working in the community to working in a sheltered workshop. Employers who have hired people with developmental disabilities usually say that they are good workers: they work hard, learn new skills, are well liked, and are an asset to the workplace. Some employers have observed that when co-workers become involved in supporting a person with a developmental disability, this sometimes carries over to other relationships at work; people may become more supportive of one another – not only supportive of the person with the disability. Finally, many employers take great pride and derive great personal satisfaction from having had such a positive impact on the life of a person with a developmental disability (Sandys, 2003).

However, the supported employment model has not resulted in large numbers of young adults with developmental disabilities attaching securely to the labour force, in part because the level of support that some need is often intense and ongoing. Sheltered workshops continue to exist, and self-employment and worker co-ops are other models that are producing what some have characterized as negligible results. Some people are now questioning whether alternatives to work (non-vocational alternatives) should receive more attention and whether it is timely to consider acceptance of a wider variety of means of living in society (largely based on feminist theories of "choice"). Alternatives to work might include intensive daytime activities to enable community integration and improved quality of life, focussing on literacy training, cooking classes, computer classes, art classes, recreational activities, volunteering and community outings.

One of the major challenges facing young adults transitioning from school is the significant waiting lists that exist in most Ontario communities for supported daytime activities, whether they are employment-related or more developmental/leisure oriented. Families are often not prepared for the outcome, and the secondary effect of no post-school activity can be loss of individual skill and reduced employment for the primary caregiver who has to provide additional daytime supports. As noted in the section on family income, 38% of children with dual diagnosis in a UK study (Emerson & Hatton, 2007) were living in families in which no adult had paid employment compared to only 15% of their non-disabled peers.

Federal/Provincial/Territorial Labour Market agreements have been established to create an inclusive labour market by maximizing the participation of those currently employed, under-employed, or unemployed, through the removal of barriers and the enhancement of opportunities for skills development. More specifically, the labour market agreement proposes to provide incentives to employers to hire more young Canadians with all types of disabilities (including but not specifically focussed on developmental disabilities) and to provide support for transition to jobs. As noted in the 2004 report, a disproportionately high number of people with disabilities in Ontario, as in the rest of the country, have no employment earnings. In 2003, 63 per cent of people with disabilities in Ontario reported earnings as a result of employment, while 85 per cent of non-disabled individuals did report such earnings. For those who do work, average earnings are lower among people with disabilities as compared to the rest of the population. The average earnings of people with disabilities in Ontario who are employed are $31,800 while non-disabled people average $38,300 (Canada Ontario Labour Market Agreement for Persons with Disabilities 2004).

http://www.accesson.ca/NR/rdonlyres/4B678FE9-F2F6-46DC-98DE-6A95508E8720/97/LabourMarketAgreement1.pdf

Advocates continue to promote enhanced levels of workplace integration and workforce inclusion for people with developmental disabilities, but it is acknowledged that there are public and employer attitudinal barriers to be overcome. Understanding the views of the general public is an important factor.

A telephone survey of 680 people in Ontario in 2006 (Burge, Ouellette-Kuntz, & Lysaght, 2007), provides the following evidence:

- 65% of respondents viewed integrated employment as best for most adults with developmental disabilities;
- the majority of respondents believed that most persons with developmental disabilities should work in integrated employment settings did not perceive potential problems to be likely with respect to safety, productivity, or company image; and
- • only 34% believe that segregated employment is most appropriate for persons with developmental disabilities.

KEY DETERMINANT 5 – SOCIAL ENVIRONMENTS

Background

The importance of social supports also extends to the broader community. Civic vitality refers to the strength of social networks within a community, region, province or country. It is reflected in the institutions, organizations and informal giving practices that people create to share resources and build attachments with others. Social stability, recognition of diversity, safety, good working relationships and cohesive communities provide a supportive society that reduces or avoids many

potential risks to good health. A healthy lifestyle can be thought of as a broad description of people's behaviour in three interrelated dimensions:

- individuals;
- individuals within their social environments (family, peers, community, workplace); and
- the relationship between individuals and their social environment.

Social or community responses can add resources to an individual's repertoire of strategies to cope with changes and foster health.

Evidence of Health of Children with Developmental Disabilities

The healthiness of children with developmental disabilities in relation to their social environment is negatively impacted by two key factors:

Societal Attitudes – Societal attitudes towards people with developmental disabilities are poor. Acceptance of disability and difference is slowly improving. The National Longitudinal Study of Children and Youth noted, however, that the experience of disabled children with respect to bullying and aggression by other children in school settings was several percentage points greater than that of children without disabilities. Children with developmental disabilities are reported in the literature to experience a high level of verbal abuse.

Risk of Abuse – Child maltreatment increases the risk of developmental disabilities because victims can be exposed to physical trauma, neglect, and various emotional and psychological effects, all of which may result in developmental disability. The risk of abuse for individuals with development disabilities may be as much as ten times greater than the risk for persons without a developmental disability (Randall, Parilla, & Sobsey, 2000). Compounding this serious issue, among children with developmental disabilities, abuse may be both under-diagnosed and under-reported (Brown & Percy, 2007). The Canadian Incidence Study of Reported Child Abuse and Neglect (2003) examined a total of 103,298 child investigations in Canada (excluding Quebec). Of all the child investigations undertaken, children with developmental disabilities made up 11% of the investigations for physical abuse and 15% of the investigations for neglect.

In one study using the data collected by the Canadian Incidence Study of Reported Child Abuse and Neglect (CIS) (Schormans & Brown, 2002) it was noted that children with developmental disabilities are more likely to experience multiple incidences of abuse over a period of time than their non-disabled peers. The perpetrators of maltreatment of children are most likely to be a biological parent, sometimes in combination with another caregiver. Caregivers in this study were rated for seven functioning concerns and those caring for children with a developmental disability were four times more likely to have cognitive impairments that might impact upon the quality of care giving in the households; significantly more were reported to have mental health issues and a higher rate of criminal activity.

Perpetrators of maltreatment of children with developmental disabilities are less likely to be criminally charged, tried or convicted than might be expected (Brown & Percy, 2007). Data from the CIS indicated that 11.9% of alleged perpetrators continued to live with children without a developmental disability compared with a rate of 34.9% for children with developmental disabilities.

Access to Supports – Valentine (2001) notes that that while our view of disability has shifted from a deficit model children with disabilities are still not full and active members of our communities and their needs have been neglected as gains have been made on the side of adults with disabilities. The current situation faced by children with developmental disabilities and the parents who care for them falls far short of full citizenship. In particular, the community supports that most children with disabilities and their families need are not yet understood to be a central component of citizenship rights. Families often have to struggle and fight to get the necessary supports so they and their children can live an active and full life in the community. The supports he suggests that families require to achieve positive outcomes for their children include:

- • out of home supports;
- respite care;

- education supports;
- assistive devices; and
- supportive societal attitudes.

Places to Socialize in the Local Community – Children, teenagers and young adults with developmental disabilities need opportunities for social interaction within their local communities. Far too often, this does not happen at all or only within segregated environments. As indicated previously, many people with developmental disabilities have few or no friends, beyond their own families, other children with developmental disabilities and paid caregivers.

From a positive standpoint, children with developmental disabilities in many communities in Ontario are able to receive support and encouragement from such sources as self-help groups, professional associations, advocacy groups, and dedicated recreational groups, etc. These affiliations are often a lifeline and may, in many instances, be the primary contacts that these children (and their caregivers and siblings) have with the social environment.

KEY DETERMINANT 6 – PHYSICAL ENVIRONMENT

Background

The physical environment is an important determinant of health. At certain levels of exposure, contaminants in our air, water, food and soil can cause a variety of adverse health effects, including cancer, birth defects, respiratory illness and gastrointestinal ailments. In the built environment, factors related to housing, indoor air quality, and the design of communications and transportation systems can significantly influence our physical and psychological well-being.

Evidence of Health of Children with Developmental Disabilities

Notwithstanding more than 25 years of Canadian experience in addressing barriers in the built environment, many issues still remain. The Council of Canadians with Disabilities, Canadian Association for Community Living, and the Canadian Association of Independent Living Centres are collaborating in advocacy efforts in building an inclusive and accessible Canada.

http://www.endexclusion.ca

Their efforts include addressing shortcomings in the built environment, as well as encouraging improvements in public transportation and transportation for people with special needs.

Within their homes, many people with developmental disabilities need modifications and adaptations to meet their needs. According to a report prepared at the request of Ministers of Social Services (Fawcett et al., 2004), only 4% of children with disabilities in Canada (6,600 children) require special features to go in and out of their home, and a similar number require special features for use inside their home. However, amongst these children there is a high degree of unmet need for all of these requirements. About three in five children requiring some type of specialized feature to get in, around, or out of their home have an unmet need. Cost is the main reason listed for these unmet needs. Family poverty results in limited ability to choose living and/or recreation spaces that are physically adequate – safe, free from exposure to environmental irritants and toxins. It is also important to note, however, that over a third of these families report that they do not know where to look for help.

KEY DETERMINANT 7 – PERSONAL HEALTH PRACTICES AND COPING SKILLS

Background

Personal health practices and coping skills refer to those actions by which individuals can prevent diseases and promote self-care, cope with challenges, and develop self-reliance, solve problems and make choices that enhance health. Definitions of lifestyle include not only individual choices, but also the influence of social, economic, and environmental factors on the decisions people make about their health. There is a growing recognition that personal life "choices" are greatly influenced by the socio-economic environments in which people live, learn, work and play. These influences impact lifestyle choice through six areas:

- personal life skills;
- stress;
- culture;
- social relationships;
- belonging; and
- a sense of control.

Interventions that support the creation of supportive environments will enhance the capacity of individuals to make healthy lifestyle choices in a world where many choices are possible.

Through research in areas such as heart disease and disadvantaged childhood, there is more evidence that powerful biochemical and physiological pathways link the individual socio-economic experience to vascular conditions and other adverse health events.

Evidence from Investing in the Health of Canadians (1994) suggests that coping skills, which seem to be acquired primarily in the first few years of life, are also important in supporting healthy lifestyles. These are the skills people use to interact effectively with the world around them, to deal with the events, challenges and stress they encounter in their day to day lives. Effective coping skills enable people to be self-reliant, solve problems and make informed choices that enhance health. These skills help people face life's challenges in positive ways, without recourse to risky behaviours such as alcohol or drug abuse. Research indicates that people with a strong sense of their own effectiveness and ability to cope with circumstances in their lives are likely to be most successful in adopting and sustaining healthy behaviours and lifestyles.

Evidence of Health of Children with Developmental Disabilities

No children's literature in this respect was found; however, a number of sources provided information on the "lifestyle" patterns of adults with a developmental disability. The adult references used here point to the need to inform, educate and support patterns of activity at a much earlier age that will result in healthier adult behaviour. v

Personal Health Practises. Fitness levels of persons with developmental disabilities are much lower than those of the general population (Pitetti & Campbell, 1991; Pitetti, Rimmer, & Fernhall, 1993). Their ability to run, jump, swim, climb stairs, lift weights, play golf or do anything that is physical in nature is inferior to the rest of the population. Most individuals with development disabilities get very little physical activity and carry high amounts of body fat, particularly women and persons with Down syndrome (Rimmer, Braddock, & Fujiura, 1993). These traits do not develop from their condition, but rather from their lifestyle.

Rimmer notes: "If you look around the general fitness and recreation community, you'll notice that there aren't many people with disabilities, including developmental disabilities, participating in physical activity. How many people with developmental disabilities do you see performing step aerobics in a local health club? Or going for walks after dinner with their friends? Are they on the starting line of a weekend road race or a benefit walk? Are they hiking in Yellowstone? Skiing in Vail? For the most part, they are conspicuously absent from the physical culture of our society. And as they grow older, it is likely that a greater number of them will fall victim to disease and disability at an earlier rate than the general population."

http://www.ncpad.org

Research by Pitetti and Campbell (1991) notes that adults with developmental disabilities can be considered a high-risk group for developing secondary conditions; for example:

- Adults with developmental disabilities age earlier and have a higher mortality rate than the general population.
- Young adults with developmental disabilities living in community residences have cardiovascular fitness levels representative of a sedentary lifestyle.
- Significantly more cardiovascular disorders are seen among individuals with developmental disabilities than in the general population.

Obesity rates are also high among persons with developmental disabilities in particular those with Down syndrome (Pomona Project 2004; Pitetti et al., 1993).

In addition, in an era of deinstitutionalization, it is alarming to note that people with developmental disabilities living in smaller, less supervised settings

(group homes and family settings) have a significantly higher rate of obesity compared to those living in institutionalized settings, which suggests that there is an environmental influence at play (Rimmer & Yamaki, 2006).

Family/Child Coping Skills. The coping skills of parents of children with developmental disabilities are critical to healthy child outcomes. Many researchers have noted the high stress level and prodigious amount of time, energy and patience required to successfully parent a child with a developmental disability.

Participants at a Canadian Policy Research Networks Roundtable noted that parents of children with disabilities often feel blamed by society for their child's disabling condition. Negative attitudes towards parents of children with developmental disabilities further exclude families who are, in many instances, already experiencing social isolation and exclusion (Valentine 2001).

Caring for any child involves considerable resources, but the demands are often increased when caring for a child with disability. A study of the health of primary caregivers of children with cerebral palsy (CP) compared with that of other Canadian caregivers (Brehaut et al., 2004) produced the following results:

- Caregivers of children with CP had lower income than did the general population of caregivers, despite the absence of any important differences in education between the two samples.
- Caregivers of children with CP were less likely to report working for pay; less likely to be engaged in full-time work; and more likely to list caring for their families as their main activity.
- Measures of support showed no difference in reported social support or family functioning between the two samples, although the CP caregiver sample did report a statistically greater number of support contacts.
- Measures of psychological health showed greater reported distress, chronicity of distress, emotional problems, and cognitive problems amongst caregivers of children with CP.
- CP caregivers also reported a greater likelihood of a variety of physical problems, including back problems, migraine headaches, stomach-intestinal ulcers; asthma; arthritis/rheumatism; and experience of pain, as well as a greater overall number of chronic physical conditions.

Although many families cope well, the study findings suggest that the demands of their children's disabilities can explain differences in the health status of parents. Mothers of children with CP are more likely to have a variety of physical and psychological health problems.

The relationship between autism and parenting stress has been compared against the stress experienced by parents of children with other types of special health needs. Parenting a child with autism with recent special service needs seems to be associated with unique stresses (Schieve et al., 2007).

Social skills in children reflect their ability to cope through the ability to actualize appropriate behaviours (Heiman, 2001), yet many children with developmental disabilities experience greater difficulty in finding, making and keeping friends. As noted by Emerson and Hatton (2007):

- 33% find it "harder than average" to make friends (compared to 9% in non-disabled children);
- 25% find it "harder than average" to keep friends (compared to 5% in non-disabled children);
- 14% have no friends (compared to 1% in non-disabled children); and
- 43% cannot talk to a friend when they are worried (compared to 20% in non-disabled children).

KEY DETERMINANT 8 – HEALTHY CHILD DEVELOPMENT

Background

Recent evidence on the effects of early experiences on brain development, school readiness and health in later life has sparked a growing consensus that early child development is a powerful determinant of health in its own right. At the same time, we have been learning more about how all of the other determinants of health affect the physical, social, mental, emotional and spiritual development of children and youth. For example, a young person's development is greatly affected by his or her housing and neighbourhood, family income, level of parents' education, genetic makeup and access to nutritious food, physical recreation as well as dental and

medical care.

From the Second Report on the Health of Canadians (1999):

- Experiences from conception to age six have the most important influence of any time in the life cycle on the brain's neurons. Positive stimulation early in life improves learning, behaviour and health into childhood.
- A loving, secure attachment between parents/caregivers and babies in the first 18 months of life helps children to develop trust, self-esteem, emotional control and the ability to have positive relationships with others in later life.
- Infants and children who are neglected or abused are at higher risk for injuries, a number of behavioural, social and cognitive problems later in life, and death.

From Investing in the Health of Canadians (1994):

- A low weight at birth links with problems not just during childhood, but also in adulthood. Research shows a strong relationship between income level of the mother and the baby's birth weight. The effect occurs not just for the most economically disadvantaged group. Mothers at each step up the income scale have babies with higher birth weights, on average, than those on the step below. Problems are not just a result of poor maternal nutrition and poor health practices associated with poverty, although the most serious problems occur in the lowest income group. It seems that factors such as coping skills and sense of control and mastery over life circumstances also come into play.

Evidence of Health of Children with Developmental Disabilities

All young children require environments and early experiences that support their healthy growth and development and optimize their potential for the future. This is particularly true for children with a developmental disability where early intervention has the potential to mitigate the impacts of conditions that leave these children at risk for delayed development. The first step to successful early intervention is universal screening programs that identify children at risk and through coordinated community services, direct the child and family to the appropriate support.

In a paper looking at services for school-age children, child and youth development strategies and the potential of integration initiatives linked to schools, the authors (Brown et al., 2001) refer to the description provided in Developmental Health and the Wealth of Nations (Offord et al., 1999) regarding the distinction between universal and targeted programs and clinical interventions.

> Universal programs apply to the general public or a whole population group that is not identified on the basis of individual risk factors. Individual families do not seek help and the children are not singled out for intervention. All children in the group (e.g., a school) receive the intervention. Universal programs are non-stigmatizing and everyone benefits. They may have a broad effect across a large population of children, but are less likely than targeted programs to be intensive enough for some children who are at risk for serious problems.
>
> In targeted programs families don't seek help, but certain children are singled out for intervention, not necessarily because they already have a disorder but because they are at high risk for developing one. Targeted programs are more likely to reach a higher proportion of high-needs children, based on knowledge of risk factors, and provide them with more intensive help. However in terms of total population, their impact is limited in that the largest number of children with problems is in the generally untargeted middle-income group.
>
> Clinical or treatment services are provided directly to the individual child with a disorder. But they only reach a small number of families. There are limited resources. And the intervention tends to occur after a problem has become aggravated. At that point, the young person may be taken out of the mainstream and put into a specialized service stream.

[1] Two-generation initiatives are based on the premise that changing vulnerable children's developmental trajectories requires addressing the multiple issues contributing to their vulnerability and that this necessitates providing services to both the child and the parents.

Offord and colleagues suggest that an optimal mix of universal, targeted and clinical programs is needed and the nature of the combination will change as knowledge accumulates. They also suggest that there will always be trade-offs among the three approaches. The authors conclude that a strategy of concurrent steps includes:

- Effective universal programs;
- First-stage screening (high sensitivity, low cost) to identify children who are not being helped enough by the universal program;
- More intensive, targeted intervention for those children;
- Later-stage screening that is more specific (and more expensive); and
- Clinical services for children who are not affected by the other programs.

http://www-fhs.mcmaster.ca/slru/documents/Convergence_01.pdf

In the ongoing debate about the need for a pan-Canadian early childhood education and care (ECEC) system, one of the arguments often raised is that available public resources should instead be targeted to children most in need. However, little is known about the effectiveness of the targeted initiatives currently in place. In a recent paper, Doherty (2007) examines 13 Canadian early-intervention programs for children vulnerable to poor developmental outcomes. In commenting on the impact of these programs the author questions whether they provide the highest social return in terms of public investment and whether a universal or targeted approach in ECEC is the best way to ensure that all children have the best possible start in life is then explored. The paper assessed programs that were parent-focused, child-focused and two-generation1 against a number of common factors including their relative effectiveness in terms of child development. The author notes that:

- Initiatives that target children directly with structured and centre-based programs have the most positive effect on vulnerable children's development.
- Although parent/family-focused interventions that attempt to improve parenting skills, education and/or employability may benefit parents by, for example, increasing their self-confidence, their effect on children's development is generally negligible.
- The effectiveness of group programs depends on their quality – that is, having well-trained staff, effective programming and appropriate staff-child ratios.
- The effectiveness of group programs also depends on the duration of intervention.

Given the lack of school-readiness of approximately 25 percent of five-year-olds, the relative ineffectiveness of targeted ECEC programs and the limited availability of high-quality child care services, a change of strategy is required. As Doherty points out, vulnerability to poor developmental outcomes occurs across all income levels, and there are no easily observable markers to identify all vulnerable children. Therefore, if the goal is to reach as many vulnerable children as possible, then ECEC programs must be universally available to all families who wish to use them. A non-targeted, evidence-based, cost-effective strategy and the necessary government funding and resources to make it work are what is needed.

http://www.irpp.org/fasttrak/index.htm

As noted in *The Early Years Study 2: Putting Science into Action* (McCain, Mustard and Shanker, 2007, p. 46):

> "Vulnerable children are found in all socio-economic status (SES) groups but populations are not evenly distributed between groups. The largest numbers of children overall are found in the middle groupings. The lowest SES group has a greater percentage, but a smaller number, of vulnerable children. Conversely, children in the middle SES groups are less likely to be vulnerable, but because of the size of the group, this is where the most vulnerable children are found. Restricting programs to vulnerable children in the low SES group therefore misses the majority of children experiencing difficulties."

McCain, Mustard and Shanker suggest that those who provide services for at-risk families walk a fine line. Families can be stigmatized and humiliated by singling them out for service, or they can be missed by offering a service to everyone that does not take into

account barriers to participation for disadvantaged families. According to the authors, research indicates the most successful early year's strategies provide service within a universal context. Programs implemented for all children with provisions to include those with special needs due to income, race, language or disability promote inclusion by providing equitable opportunity.

> "Advances in child development suggest children, with and without developmental challenges, benefit from participation in inclusive programs. "Inclusive" means including children with disabilities in the same programs they would attend if they did not have disabilities. Inclusive programs not only accept children with disabilities, but also they facilitate their full participation". (McCain, Mustard and Shanker, 2007, p. 108).
>
> http://www.councilecd.ca

An example of an Ontario initiative reflecting the intentions noted by the authors of the above papers is the Healthy Babies, Healthy Children (HBHC) Program. The Ministry of Health and Long-Term Care launched Healthy Babies, Healthy Children in 1998. The program offers all families with new babies information on parenting and child development and delivers extra help and support to those families who would benefit. Delivered by the province's 37 public health units, Healthy Babies, Healthy Children provides:

- Screening/assessment for pregnant women (through prenatal programs or by their doctors), for all new mothers (by nurses in hospital or by midwives); and for families with children up to age six (by the parents themselves or by their doctors).
- A phone call from a public health nurse to every new mother shortly after her baby is born, offering information and a home visit.
- Home visiting services by a public health nurse or lay home visitor for families who would benefit.
- Referrals to services in their communities, such as breastfeeding, nutrition and health services, play and parenting programs, and child care services, for all families with children up to age six.

HBHC was designed as a universal prevention/early intervention program to improve the well-being and long-term prospects of Ontario children. It uses a communitywide planning and implementation process that involves most or all organizations and agencies that serve families and children (prenatal to age six). HBHC helps to ensure an effective system of prevention, screening, and early intervention services. It emphasizes the early identification and prevention of problems and builds on the strengths of families and community members. The HBHC program is intended to complement other human service initiatives. The stated goals for HBHC are:

- To promote optimal physical, cognitive, communicative and psychosocial development in children.
- To act as a catalyst for a coordinated, effective, integrated system of services and supports for healthy child development and family well being through the development of a network of service providers and participation in community planning activities.

KEY DETERMINANT 9 – BIOLOGY AND GENETIC ENDOWMENT

Background

The basic biology and organic make-up of the human body are a fundamental determinant of health. Genetic endowment provides a predisposition to a wide range of individual responses that affect health status. Although socio-economic and environmental factors are important determinants of overall health, in some circumstances genetic endowment predisposes certain individuals to particular diseases or health problems.

From the Second Report on the Health of Canadians (1999):

- Studies in neurobiology have confirmed that when optimal conditions for a child's development are provided in the investment phase (between conception and age 5), the brain develops in a way that has positive outcomes for a lifetime.
- Aging is not synonymous with poor health. Active living and the provision of opportunities for lifelong learning may be particularly important for maintaining health and cognitive capacity in old age. And studies on education level and dementia suggest that exposure to education and lifelong learning may create reserve capacity in the brain that compensates for cognitive losses that occur

with biological aging.

Evidence of Health of Children with Developmental Disabilities

Many children with developmental disabilities, like others, have a genetic predisposition to certain conditions and diseases, and initiatives to better meet their primary health care needs are critical. Identifying and diagnosing these conditions from a health perspective sets the stage for understanding what clinical approaches or treatments may be most appropriate. This may in some instances be contrary to the expressed preferences of families or organizations who advocate for no labelling from a value-base perspective. In addition to distinct physical features, some specific developmental disability syndromes, for instance Prader-Willi syndrome, and fragile X syndrome, also have characteristic behaviours, commonly referred to as behavioral phenotypes. This latter term has been described as the heightened probability or likelihood that people with a given syndrome will exhibit a constellation of behavioral or developmental sequelae relative to those without the syndrome (Hodapp et al., 2003). The authors suggest, as do other clinicians and researchers in the field, that understanding the etiology of the developmental disability does matter and may lead to more precise, targeted forms of early intervention.

It appears that biological differences may contribute to health disparity in relation to life expectancy and mortality. Children born with more severe forms of disabilities including major physical, sensory and neurological disorders continue to have a lower life expectancy while those individuals with milder forms of disability are experiencing dramatically increased life expectancy (Eyman et al., 1993). A study in the US (Yang et al., 2002) found that life expectancy in persons with Down syndrome almost doubled from 1982 to 1997, the average age at death increasing from 25 to 49 years.

KEY DETERMINANT 10 – HEALTH SERVICES

Background

Health services, particularly those designed to maintain and promote health, to prevent disease, and to restore health and function contribute to population health. The health services continuum of care includes treatment and secondary prevention.

From the Second Report on the Health of Canadians (1999):

- Disease prevention activities in areas such as immunization and the use of mammography are showing positive results. These activities must continue if progress is to be maintained.
- There has been a substantial decline in the average length of stay in hospital. Shifting care into the community and the home raises concerns about the increased financial, physical and emotional burdens placed on families, especially women. The demand for home care has increased in several jurisdictions, and there is a concern about equitable access to these services.
- Access to universally insured care remains largely unrelated to income. However, many low- and moderate-income Canadians have limited or no access to health services such as eye care, dentistry, mental health counselling and prescription drugs.

Evidence of Health of Children with Developmental Disabilities

The Surgeon General's Report (U.S. Department of Health and Human Services, 2002) noted that persons with developmental disabilities grow up, grow old, and need good health care services in their communities. They and their families report exceptional challenges in staying healthy and getting appropriate health services when they are sick. As noted in the report people with developmental disabilities often feel excluded from public campaigns to promote wellness. They also describe shortages of health care professionals who are willing to accept them as patients and who know how to meet their specialized needs.

In 2000, Special Olympics commissioned a full review of literature examining the current health status of people with developmental disabilities (Horwitz, et al., 2000). The report identifies these disparities or inequities experienced by young adults with developmental disabilities across a range of health areas:

- Obesity;

- Cardiovascular fitness levels;
- Vaccination levels of 77% for those with developmental disability are lower than those reported for the general population at 91%;
- Mental health disorders among those with developmental disability are reported to occur at a rate 3-6 times higher than in the general population;
- The proportion of missing teeth to filled teeth is cited as being higher among individuals with developmental disability when compared to the general population, suggesting that extraction, rather than restoration, is the preferred choice of treatment; and
- Despite the increased prevalence of certain health conditions among people with developmental disability, evidence suggests that these individuals generally do not receive preventative screening.

At the time of the Surgeon General's report, 50% of dental students in the U.S. reported no clinical training in the care of patients with special needs and 75% reported little to no preparation in providing care for these patients (Waldman & Perlman, 2006). The authors note that it took a full two years of concentrated efforts and advocacy to have the Commission on Dental Accreditation adopt a standard requiring graduates of dental schools and schools of dental hygiene to be competent in assessing the treatment needs of patients with special needs.

In a very recent paper presented to the 7th Congress of the International Dental Ethics and Law Society in Toronto (Schwartz, 2007) the author proposes 10 recommendations that, if taken up by North American dentists, will make a difference in access to dental care. Included among these is mentoring new dentists by showing an active commitment in providing dental care for the needy, disabled and elderly on a regular basis.

Ouellette-Kuntz (2005) examined the health disparities and inequities for adults with developmental disabilities and notes that health disparities are more likely to occur in people with developmental disabilities for the following reasons:

- The impact of a developmental disability on one's ability to enjoy the same opportunities for good health and health care as non-disabled individuals. Specifically, limited levels of education and literacy impact directly on access to health promotion literature and activities.
- The contribution of historical and current models of support to the health of individuals with developmental disabilities. Specifically, 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.
- Knowledge, skills and attitudes of physicians regarding developmental disabilities. Specifically, many physicians do not recognize the health needs of this population and therefore overlook potential health complications.
- This paper examined the health disparities for people with developmental disabilities in the following areas:
- *Life Expectancy:* Life expectancy of individuals with developmental disabilities is shorter than that of the general population; this is especially true for persons with severe developmental disabilities.
- *Morbidity:* Individuals with developmental disabilities have a greater variety of health care needs, compared to those of the same age and sex in the general population, including psychiatric disorders, poor dental health, obesity and premature aging.
- *Uptake of Health Promotion/Disease Prevention Activities:* Individuals with developmental disabilities do not engage in health promotion and disease prevention activities to the same extent as the general population.

Health care access, utilization and quality also show disparities. Access to preventative care is reduced; rates of undiagnosed medical problems are higher; and there are differences in hospital inpatient utilization. Studies conducted in Ontario confirmed a greater likelihood of admission to hospitals for dental procedures, for ambulatory-care sensitive conditions, and for mental disorders (Balogh et al., 2005), conversely there are fewer admissions for hip or knee replacements. Adults with developmental disabilities in Kingston, Ontario admitted for psychiatric care tend to have longer hospitalizations (Saeed et al., 2003).

As noted in the *Consensus Guidelines for Primary Health Care of Adults with Developmental Disabilities* (Sullivan et al., 2006), people with developmental disabilities have complex health issues, some differing from those of the general population. Adequate primary

health care is necessary to identify these issues and to prevent morbidity and premature death. Physical, behavioral, and mental health difficulties should be addressed, and primary health care providers should be particularly attentive to the interactions of biological, psychological, and social factors contributing to health, since these interactions can easily be overlooked in adults with developmental disabilities. In an effort to improve access to and quality of primary health care, the guidelines were developed in Ontario using a "best available evidence" standard. The guidelines address:

- General issues in primary care;
- Physical health guidelines; and
- Behavioural and mental health guidelines.

Ontario Ministries of Health and Long-term Care and Community and Social Services sponsored a training initiative to teach these guidelines to primary care providers in four regions of Ontario, in the fall of 2006.

KEY DETERMINANT 11 – GENDER

Background

Gender refers to an array of society-determined roles, personality traits, attitudes, behaviours, values, relative power and influence that society ascribes to the sexes on a differential basis. Gendered norms influence the health system's practices and priorities. Many health issues are a function of gender-based social status or roles.

From the Second Report on the Health of Canadians (1999):

- Men are more likely to die prematurely than women, largely as a result of heart disease, fatal unintentional injuries, cancer and suicide. Rates of potential years of life lost before age 70 are almost twice as high for men than women and approximately three times as high among men aged 20 to 34.
- While women live longer than men, they are more likely to suffer depression, stress overload (often due to efforts to balance work and family life), chronic conditions such as arthritis and allergies, and injuries and death resulting from family violence.
- While overall cancer death rates for men have declined, they have remained persistently stubborn among women, mainly due to increases in lung cancer mortality. Teenage girls are now more likely than adolescent boys to smoke. If increased rates of smoking among young women are not reversed, lung cancer rates among women will continue to climb.

Evidence of Health of Children with Developmental Disabilities

In the study of prevalence in Lanark County (Ouellette-Kuntz & Paquette, 2001) the male to female ratio for those with a developmental disability was approximately 1.4:1. The Health and Welfare report (1988) reviewed studies over a previous 20 year period; noting that developmental disability is consistently found to be more prevalent in males, the report cited ratios of 1.27:1 and 1.37:1. The report also noted that ratio differences are more marked at the mild level of developmental disability rather than the severe and may also be more reflected in biology-based causes.

Health threats to males with developmental disabilities are similar to those of males in the general population; however, males with developmental disabilities are more likely to require health services related to:

- Mental health problems;
- Sexual counselling; and
- Nutritional counselling.

Children with developmental disabilities of both genders are at increased risk for sexual assault; however the rate is somewhat higher in girls.

As indicated previously, child maltreatment is at heightened risk for both males and females with developmental disabilities.

KEY DETERMINANT 12 – CULTURE

Background

Some persons or groups may face additional health risk due to a socio-economic environment, which is largely determined by dominant cultural values that contribute to the perpetuation of conditions such as marginalization, stigmatization, devaluation of language and culture and lack of access to culturally appropriate health care and services.

From the Second Report on the Health of Canadians

(1999):

- Despite major improvements since 1979, infant mortality rates among First Nations people in 1994 were still twice as high as among the Canadian population as a whole and the prevalence of major chronic diseases, including diabetes, heart problems, cancer hypertension and arthritis/rheumatism, is significantly higher in Aboriginal communities and appears to be increasing.
- In a comparison of ethnic groups, the highest rate of suicide occurred among the Inuit, at 70 per 100,000, compared with 29 per 100,000 for the Dene and 15 per 100,000 for all other ethnic groups, comprised primarily of non-Aboriginal persons.
- The 1996/97 National Longitudinal Survey of Children and Youth found that many immigrant and refugee children were doing better emotionally and academically than their Canadian born peers, even though far more of the former lived in low-income households. The study suggests that poverty among the Canadian-born population may have a different meaning than it has for newly arrived immigrants. The immigrant context of hope for a brighter future lessens poverty's blows; the hopelessness of majority-culture poverty accentuates its potency.

Evidence of Health of Children with Developmental Disabilities

American literature identifies some prevalence data suggesting higher rates of mild mental retardation amongst black African-American males. British government reports (Valuing People, for example) suggest that Asians have a higher incidence of developmental disabilities. Some references are made in Canadian literature to the particular challenges faced by First Nations/Aboriginal parents of children with developmental disabilities, primarily with respect to low income families and parenting stresses.

A recent US study (Day, et al., 2005) reported racial or ethnic differences in mortality in Down syndrome. Citing from earlier research the authors of this study note that the median age at death among blacks with Down syndrome was significantly lower than that of whites. In Western Australia significantly poorer survival was found among Aboriginal children than among non-Aboriginal children, mirroring the pattern in the general population in Australia. In the US rates of Down syndrome births among different racial groups was significantly different (i.e., a higher rates in Hispanics compared with whites at maternal ages under 40 years), even after controlling for prenatal diagnosis and elective abortion. Consistent with these earlier studies, the authors also found higher mortality in blacks than whites – a pattern consistent with that of the general U.S. population. Ontario is a diverse society, and children and youth with developmental disabilities (and their families) need culturally sensitive services. The cultural factors that affect assessment and intervention include: communication; cultural norms; behavioural norms; and cultural values and beliefs; patterns of thinking; and styles of communication. The assessment of a child requires the examiner (or the team) to be culturally competent. The professional must be perceived as a credible deliverer of a valued service.

Issues with respect to delivering culturally sensitive services include: second language and translation issues; measurement issues (whether North American norm-referenced tests are appropriate for another culture); and terminology acceptability (being sensitive to the use of labelling terminology that may cause offence or embarrassment).

PART 3: ISSUES SUMMARY

This review of the literature points to a number of issues affecting the lives of children with a developmental disability many of which touch on the theme of universal or targeted approaches. The history of the supports and services has been one of targeted interventions and investments. Over the last 10 years that focus has become increasingly narrowed as fiscal constraints prompted a "most in need" strategy for service and investments. Taking a population health approach to viewing the health status of these children is an effort to broaden that focus and bring the response to their needs back into the mainstream perspective. The issues faced by many children and their families may be bettered or worsened by society's response and the quality of its support systems; however, it is important to acknowledge that while many of their issues and needs may change, they will not necessarily lessen over time. Unlike the intention of "make better" and "whole again" implicit in the word "rehabilitation", the focus is more one of "habilitation" which takes a long term approach to facilitating connections and relationships, maximizing independence, enhancing self worth, encouraging self-determination and enhancing physical and emotional well being. The issues described below will require further attention if this habilitation path is to be there for children with developmental disabilities.

Understanding the Language of Disability: Definitions and Terminology

There is a significant variation in terms and language from those descriptions used to diagnose developmental disability and those that define developmental disability for the purposes of clarifying eligibility for services and supports. Some of the descriptions are focussed more specifically on individual impairments (ICD and DSM IV) whereas others approach this from the needs of the individual (sometimes taking a more "strengths-based" approach) and the individual in the context of his/her environment (AAIDD, ICF, Ministry of Education).

The value of more "impairment" specific definitions would appear to relate to defining very specific sub-groups because there are some targeted treatments for these groups. On the other hand, if services are intended to be more inclusive, then specific criteria or cut-off (IQ level) may serve to disentitle some groups to services. The definitions and eligibility criteria reviewed would all appear to be grappling with the extent to which the definition of developmental disability includes children with learning problems and impairments in adaptive functioning who have higher overall IQ (such as some children with Fetal Alcohol Spectrum Disorder and Pervasive Developmental Disorder) than those in the traditional mental retardation category.

In Ontario, there is no standard definition of "developmental disability". Developmental disability and intellectual disability are used more or less synonymously to refer to the diagnosis of mental retardation as defined by the DSM-IV, although the terms are not completely interchangeable. Virtually everyone with mental retardation has a developmental disability, but not everyone with a developmental disability has mental retardation. Different terminology is used by different governmental departments to determine eligibility for supports (see Appendix 2).

Notwithstanding past efforts to improve access to supports through the Making Services Work for People (MCSS, 1997), parents of children and youth with developmental disabilities continue to experience barriers in access to needed services. In the field, however, service providers may not use or apply a definition to a child and/or the family, but may be more likely to simply respond to needs as presented by a child and/or his or her parent or caregiver. Some service agencies may require that a child has a formal diagnosis of developmental disability, but some may not, possibly because it is acknowledged in the field that there are lengthy waiting lists for appointments with professionals qualified to provide a diagnosis.

There are a number of issues emerging from lack of consistent terminology and definitions:

- Because different terms are used in different

contexts it is difficult to identify the population as they move from one system to another. For example, because of definitional difference between the Ministries of Education and Community and Social Services there are challenges in identifying those who may use services as they prepare to leave school. Further, the definition establishes the scope of those who are potentially included or excluded for service

- – for example, does a child with above IQ 70 and Asperger syndrome have access to all services for children with a developmental disability?
- The gap between diagnostic tests and functional assessments (generally of adaptive behaviour) adds to the confusion regarding definitions and labelling, contributing to ambiguities regarding eligibility for services.
- Tension continues to exist regarding the practice of "defining" children based on disability setting the potential benefit of diagnostic-specific interventions against the value-based approach of non-stigmatizing labelling.

Knowing the Population: Data on Developmental Disabilities

The administrative prevalence of moderate to profound developmental disabilities is fairly consistent across jurisdictions; however the data are likely not reflective of the true prevalence rates of mild developmental disability. As noted in the literature review, there are very few prevalence studies of children (Bradley in Ontario being one of the few exceptions) and definitional ambiguities confound efforts to undertake this kind of review; if children with pervasive developmental disorders (PDDs) and fetal alcohol spectrum disorders (FASDs) are included, one could anticipate a significant difference in prevalence. The lack of comprehensive data (administrative or population-based) about children with developmental disabilities makes it difficult to assess prevalence, and to understand, predict and/or plan for the service requirements of the population locally and/or provincially. For example, the lack of data impedes efforts to understand incidence and confirm the speculation that incidence of FASDs and PDDs are increasing dramatically. Comprehensive data would create the ability to identify specific population segments and target investments where they have the greatest potential for impact. Competing demands for limited dollars requires funders to make thoughtful expenditure decisions; the availability of data could mean that not all future investments will continue to reflect the "most in need" orientation of the last 10 years.

An increasingly complex world regarding privacy of information would appear to challenge efforts to gather more comprehensive data such as that done by the Center for Disease Control's Metropolitan Atlanta Developmental Disabilities Surveillance Program (MADDSP), in Atlanta Georgia. In Ontario the Ministry of Community and Social Services is currently developing a single application for service in the adult system which at full implementation has the potential to provide a new and rich source of data on the status and needs of this population. However, it is unclear to what extent there is interest in pursuing a similar strategy in the children's system.

Availability of and Access to Supportive Environments

Caregivers/parents are generally stronger and more physically and psychologically resilient than might be expected, but mental health issues (anxiety, depression, addiction) of caregivers living in poverty may be underreported or not captured in the literature. Caregivers (almost always mothers) spend 50-60 hours per week on personal care, advocacy, coordination of services and transportation directly related to their child's disability (Roeher Institute, Beyond the Limits: Mothers caring for their children with disabilities 2000). Mothers report that the source of their stress is lack of support, not their child. Dealing with and navigating "the helping system(s)" is stressful, confusing, and energy draining.

Parents who are attempting to enrich the life of a child with developmental disabilities, and prepare youth to fully participate as an adult living independently in the community require new knowledge and skills. Some families cope admirably, but others may need access to non-programmatic family supports such as networking, peer supports, and assistance in particular, through times of transition. Self-support and "family-to-family"

support strategies may require start-up operating funds and perhaps staffing, to avoid further depleting family energy. Other approaches to support families include:

- Internet/self-help (a good example are short videos on www.autismspeaks.org which demonstrate normal child development and videos of autistic "red flag" behaviours);
- Peer groups;
- One-to-one ongoing supports (Family Support Workers); and
- System navigators (Service/case coordinators).

Circles of Support and other models that build caring relationships around a person with a developmental disability are effective ways to extend the social sphere of the child and family and to involve others in care/support considerations. However, for the past decade, resources have tended to be invested in delivering services to those "most in need". As a result little public funding has gone into upstream investments to build the types of innovative family supports that could support caregivers and prevent problem situations. Building the capacity of families to exchange knowledge and build networks of support is a means of building the capacity of communities and a civil society.

Supportive community environments must provide full access and participation for all children including those with disabilities. Involvement in community activities such as child care and local recreation has a number of positive benefits for young people with developmental disabilities:

- Their presence in the community serves to challenge the values and beliefs of others by informing and enlightening regarding the strengths, gifts and challenges of people with disabilities.
- Active citizenship and social inclusion require an on-going presence in the community.
- Participation in these inclusive environments increases the self-esteem of the children.
- Participation in recreation in particular is vital for improving physical health as noted by the report from Special Olympics (US).

Barriers to social inclusion and engagement for people with developmental disabilities include physical accessibility, cost of service and in particular, transportation. Families will often report that even when services are accessible and available they can't make use of them because of the lack of transportation; this can mean the lack of public and specialized transportation and/or the prohibitive cost associated with purchasing transportation.

Too often these areas of support and development are not available to children with developmental disabilities and their families, despite evidence that attitudes are changing quite rapidly amongst young adults who attended schools with children with developmental disabilities and amongst politically powerful allies such as Baby Boomers who are themselves experiencing exclusionary issues as they develop physical or mental health issues.

The Impact of Income and Social Status

While developmental disabilities affect children living in families across the socioeconomic spectrum, a disproportionate number are born into, grow up in, and as adults continue to live in poverty. An adequate family income is needed to enable positive outcomes in all children and many families of those with developmental disabilities experience excessive financial burden. The gradual move from universal to more targeted strategies has resulted in increased stringency in "income testing" and "claw backs" from multiple benefits; for example the current Assistance for Children with Severe Disabilities (ACSD) is a much more targeted and limited benefit than its earlier incarnation (Handicapped Children's Benefit). Some efforts have been made to recognize the costs for all lower income families in raising children such as the National Child Benefit and the 2007 Federal Budget initiatives including the Registered Disability Savings Plan (RDSP), and Working Income Supplement. Recent change to the Ontario Child Benefit is a positive step in recognizing that families often are penalized rather than aided by the provision of new or expanded benefits. However, it would appear that more is still required.

There does not appear to be a unified advocacy voice for children with developmental disabilities (there are several organizations advocating regarding child poverty) or a well documented Canadian study of the

unique financial needs of families raising children with developmental disabilities or of people living with disabilities throughout their (now extended) lifespan.

Taking a Life-Span Approach

Ontario continues to have an artificial divide between services for children and services for adults, which is particularly confounding because developmental disability is a life-long condition. Parents must navigate health-funded services; child-funded services; children's mental health services; child welfare services; – and many other "silos" – to obtain the services they need to help their child develop to his/her fullest potential. Access to a wide range of seamless supports and care (such as primary health care; mental health care; recreation supports; employment supports) that crosses sectors and ministry responsibility is needed to ensure that children are healthy as they grow to adulthood and that they maintain their health as they age. As well, system navigation support is needed to ease the burden placed on parents of children with developmental disabilities to locate and access the resources they need.

A more comprehensive systems approach is needed to facilitate smooth life transitions:

- From birth or infancy to early identification and appropriately intensive intervention services;
- From community-based early intervention services into the Special Education component of the education system (kindergarten/Grade 1);
- From elementary school into high school Special Education; and
- From high school to adult education, employment and/or community inclusion and participation.

One of the challenges in achieving this "seamless" approach is the current policy void regarding children with developmental disabilities. MCYS has been focussed almost exclusively on children with autism and while MCSS historically has had the lead responsibility for this policy area, over the last 3 years their efforts have been focussed on the transformation of the adult service system. The result has been minimal financial investment in this area and an eroding of the current service base as older children "age out" in their children's services because of an inability to "transition" to the appropriate adult service. Policy ambiguities have compounded investments in some core service areas such as out-of-home residential placement. The specialized system is diminishing and the mainstream system has not stepped up to the plate in many key areas of support affecting the health and development of these children. A policy agenda is needed.

Early Intervention Strategies

A wealth of information in the last 10 years has pointed to the benefit of universal programs that optimize the developmental potential of all children and in particular create the potential to reach those who are at greater risk for delayed development (for example due to socio-economic or mental health status). Universal programs (such as Healthy Babies, Healthy Children and Early Years' Centres) to support early identification and intervention in Ontario are valuable upstream investments. However, children with developmental disabilities whose risks are clearly identified by virtue of their disabling condition, have special needs and often require types of intensive supports that are not always adequately addressed through these more universal strategies. As noted in the literature the tension between universal and targeted interventions will continue; finding the right balance that provides for appropriate investment of resources into both ends of the continuum is still required.

Moving from Education to Employment

There seems to be limited literature examining the educational outcomes of children with developmental disabilities. More specifically in Ontario, the extent to which the Individualized Education Plan/transition plan (required at age 14 in Ontario) is producing positive outcomes for students is yet to be researched. There is a need to examine the extent to which this process is effective in planning for the post-education needs of the student and determining the appropriate educational interventions that will equip the students with the knowledge and skills needed to:

- move from high school to higher education;
- use new technology;

- securely attach to the new Ontario job market;
- live a health promoting and abuse-averse lifestyle; and
- live independently and participate as adult citizens in the community.

It is the responsibility of the school principal to ensure that there is compliance with provincial policy regarding transition planning. In reality the practise is highly variable across Boards of Education and even from school to school. Families are often not aware of the transition planning requirements and miss an opportunity to become full participants in this process. Educating parents about their rights and finding ways for school and community to work together are needed to improve outcomes for children as they prepare to leave school.

Waiting lists for access to Special Education in schools in Ontario were considerably reduced in 2005/06, but the shortage of skilled professionals to provide assessment services continues to be an issue. The educational placement strategy for children with developmental disabilities appears to be reflective of the individual capacity of boards of education and/or the value-based advocacy of the child's parents rather than an approach that is guided by evidenced-based understanding of what promotes the best academic and social outcomes for children.

Adults with developmental disabilities in Ontario continue to have a high unemployment rate. There is evidence that the majority of Ontario citizens are supportive of integrating people with developmental disabilities in the workforce, but there is no reported improvement in labour force participation despite a booming economy. Recent changes in the Employment Supports component of ODSP provide greater flexibility in extending supports but no data are available regarding the impact this is having on employment retention. Adults with developmental disabilities, who do not want to work, face a lack of alternatives-to-work options that could support other life goals or choices.

Targeted strategies are required to:

- Reduce the high-school drop-out rate of children with developmental disabilities;
- Implement effective cross-sectoral transition processes;
- Ensure secure attachment to the labour force; and
- Explore the possibility of developing an organized approach to alternatives-to-work.

Access to Health Services and Strategies

Health Promotion – While progress has been made in Ontario on prevention of developmental disability, there has been no overall strategy for thinking about the health status and needs of children with developmental disabilities. As a result, virtually no investments have been made in developing health promotion strategies that reach out to people with developmental disabilities, in particular while they are children and illness prevention is possible. Contrast this with other health promotion/intervention initiatives such as those related to HIV and the efforts of Cancer Care Ontario.

More needs to be done to improve the engagement of children and families in health promotion activities (such as managing weight, and exercise). Supports to children and adults with developmental disabilities have largely been developed within the "specialized service system" where dollars are limited and the focus for some years has been on the "most in need". As a result the specialized system has not been able to focus on more "up-stream" interventions; at the same time mainstream programs for children (often provided by municipalities) have limited capacity to accommodate. Hence, little has been done in some key areas that are known to improve health such as recreational programs that target and prevent obesity and sex education for adolescents.

Primary Care – Access to appropriate primary health services is fundamental to all children yet those with developmental disabilities face unique challenges in securing appropriate diagnostic tests and interventions. The prevailing attitude is that the needs of children and adults with developmental disabilities are primarily a social service issue. While for many this is true, the literature clearly documents that the health care of this population needs urgent attention. The US Surgeon General (Closing the Gap: Report of the Surgeon General's Conference on Health Disparities and Mental Retardation) the EU Pomona Project, and the US Special Olympics have

reported on the differential treatment of people with developmental disabilities. Ontario research has provided evidence of the similar inequities faced here. In the health service system children are less likely to get specialized care; for example, there is no service base for children with dual diagnosis and access to specialized dental clinics is highly limited. The outcome of these barriers to health services is more preventable health conditions which begin in childhood and are notably worse by adulthood.

The development of consensus guidelines on primary care of adults with developmental disabilities in Ontario is an excellent start, but a long-term plan to ensure that these guidelines are applied is needed and similar efforts need to be directed at children.

Dual Diagnosis – The literature now provides solid evidence that children, youth and adults with developmental disabilities can and do experience mental health problems at an alarmingly high rate (close to one-third). Ontario has research (on adults) which documents the extent to which tertiary care psychiatric hospital beds are being utilized by people with dual diagnosis who could be better managed in the community. While some limited supports are available for adults there is no current service base for children. Access to appropriate dual diagnosis management and treatment services for children with a dual diagnosis in Ontario is a critical need. As noted by some parents, their limited capacity to cope is often stretched to the breaking point when school is no longer able to cope with challenging behaviours and sends the child home for lack of appropriate programming and specialized supports.

Capacity and Excellence in Professional Support

The shortage of professionals with skills and expertise to work with people who have developmental disabilities is a critical concern. This shortage includes front-line support staff in the specialized service system as well as primary care professionals and specialized professionals in the health system. Children with more complex needs such as dual diagnosis face even more significant challenges in getting access to a professional who understands their needs and is able to diagnose and provide appropriate interventions. The Ontario chapter of the National Association on Dual Diagnosis has been championing this issue and recently completed a literature review of education and training strategies for staff working in developmental disabilities.

For the government funded social service system there continues to be difficulty in retaining staff due to wage disparities with other sectors (children's mental health, education), poor career path options and fragmented training strategies. Primary care health providers (doctors, dentists) require both the educational/clinical exposure during training and a combination of directives and incentives (for example, practice requirements and fee schedules) to encourage their willingness and capacity to serve this population. Building the necessary corps of specialized health providers is a longer term multi-sectoral strategy that needs to be undertaken urgently as the replacements for those who are about to retire are not evident in the numbers needed to provide essential support.

To attract people to work and remain in this field, a long-term investment is required that includes changes to post-secondary education curricula, increased research opportunities, and improved training strategies.

Appendix 1 - Clinical Definitions

ICD 10: The International Classification of Diseases and Related Health Problems (1992)

The World Health Organization ICD 10 (1992) offers a taxonomy of diseases and health problems. It uses the term intellectual disability for which it provides a four-level severity classification:

ICD 10 F70 Mild Intellectual Disability – Ability to use speech in everyday situations; usually full independence in self care; IQ range 50-69. Difficulties in identification of this population arise, as those with borderline disability may not be in contact with service providers.

ICD 10 F71 Moderate Intellectual Disability – Slow in comprehension; supervision of self care, retarded motor skills; IQ between 35-49.

ICD 10 F72 Severe Intellectual Disability – Marked impairment of motor skills; clinically significant damage to Central Nervous System; IQ between 20-34.

ICD 10 F73 Profound Intellectual Disability – Severely limited understanding; immobility or restricted mobility; incontinence; requires constant supervision; IQ less than 20; usually organic aetiology.

www.who.int/mental_health/media/en/69.pdf

DSM – IV: Diagnostic and Statistical of Manual Mental Disorders, 4th Edition (1994)

The DSM-IV uses the term mental retardation and outlines the following diagnostic criteria and five degrees of severity of intellectual impairment:

a. Significantly sub-average intellectual functioning: an IQ of approximately 70 or below on an individually administered IQ test (for infants, a clinical judgement of significantly sub-average intellectual functioning).

b. Concurrent deficits or impairments in present adaptive functioning (i.e., the person's effectiveness in meeting the standards expected for his or her age by his or her cultural group) in at least two of the following areas: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction functional academic skills, work, leisure, health and safety.

c. The onset is before 18 years.

Severity of intellectual impairment:

317 Mild Mental Retardation (IQ level 50-55 to approximately 70)

Mild Mental Retardation is roughly equivalent to what used to be referred to as the educational category of "educable". This group constitutes the largest segment (about 85%) of those with the disorder. As a group, people with this level of Mental Retardation typically develop social and communication skills during the preschool years (ages 0-5), have minimal impairment in sensorimotor areas, and often are not distinguishable from children without Mental Retardation until a later age. By their late teens, they can acquire academic skills up to approximately the sixth-grade level. During their adult years, they usually achieve social and vocational skills adequate for minimum self-support, but may need supervision, guidance and assistance, especially when under unusual social or economic stress. With appropriate supports, individuals with Mild Mental Retardation can usually live successfully in the community, either independently or in supervised settings.

318.0 Moderate Mental Retardation (IQ level 35-40 to 50-55)

Moderate Mental Retardation is roughly equivalent to what used to be referred to as the educational category of "trainable". This outdated term should not be used because it wrongly implies that people with Moderate Mental Retardation

cannot benefit from education programs. This group constitutes about 10% of the entire population of people with Mental Retardation. Most of the individuals with this level of Mental Retardation acquire communication skills during early childhood years. They profit from vocational training and with moderate supervision, can attend to their personal care. They can also benefit from training in social and occupational skills but are unlikely to progress beyond the second-grade level in academic subjects. They may learn to travel independently in familiar places. During adolescence, their difficulties in recognizing social conventions may interfere with peer relationships. In their adult years, the majority are able to perform unskilled or semiskilled work under supervision in sheltered workshops or in the general workforce. They adapt well to life in the community, usually in supervised settings.

318.1 Severe Mental Retardation (IQ level 20-25 to 35-40)

The group with Severe Mental Retardation constitutes 3%-4% of individuals with Mental Retardation. During the early years, they acquire little or no communicative speech. During the school-age period, they may learn to talk and can be trained in elementary self-care skills. They profit to only a limited extent from instruction in pre-academic subjects, such as familiarity with the alphabet and simple counting, but can master skills such as learning sight reading of some "survival" words. In their adult years, they may be able to perform simple tasks in closely supervised settings. Most adapt well to life in the community, in group homes or with their families, unless they have an associated handicap that requires specialized nursing or other care.

318.2 Profound Mental Retardation (IQ level below 20 or 25)

The group with Profound Mental Retardation constitutes approximately 1%-2% of people with Mental Retardation. Most individuals with this diagnosis have an identified neurological condition that accounts for their Mental Retardation. During the early childhood years they display considerable impairments in sensorimotor functions. Optimal development may occur in a highly structured environment with constant aid and supervision and an individualized relationship with a caregiver. Motor development and self-care and communication skills may improve if appropriate training is provided. Some can perform simple tasks in closely supervised and sheltered settings.

319 Mental Retardation, Severity Unspecified

The diagnosis of Mental Retardation, Severity Unspecified, should be used when there is a strong presumption of Mental Retardation but the person cannot be successfully tested by standardized intelligence tests. This may be the case when children, adolescents, or adults are too impaired or uncooperative to be tested or, with infants, when there is a clinical judgement of significantly subaverage intellectual functions, but the available tests (e.g., the Bayley Scales of Infant Development, Cattell Infant Intelligence Scales, and others) do not yield IQ values. In general, the younger the age, the more difficult it is to assess for the presence of Mental Retardation except in those with profound impairment.

http://psyweb.com/Mdisord/jsp/menret.jsp

International Classification of Functioning, Disability and Health, 2001(ICF)

The ICF classifies functioning and disability associated with health conditions. In the belief that everyone at some time suffers from some degree of disability, this new classification system is designed to emphasize health strengths, rather than deficits. The ICF enables clinicians to examine the presence and severity of "functioning" at three levels:

- Body functioning (physiological and psychological aspects; as well as body structure elements; and impairments that are significant deviations or loss);
- Individual functioning (activities or tasks/actions by an individual; activity limitations – difficulties an individual may have in executing activities; and participation restrictions – problems an individual may experience in involvement in life situations; and
- Societal functioning (environmental factors that make up the physical, social and attitudinal environment in which people live and conduct their lives).

It is important to point out that this definition is not used to diagnose a developmental disability but may be used in a complementary manner to understand individuals in their life context.

www.who.int/classifications/icf/en

American Association on Intellectual and Developmental Disabilities Definition

AAIDD suggests that, "Mental retardation is not something you have, like blue eyes, or a bad heart. Nor is it something you are, like short or thin. It is not a medical disorder, not a mental disorder. Mental retardation is a particular state of functioning that begins in childhood and is characterised by limitation in both intelligence and adaptive skills. Mental retardation reflects the "fit" between the capabilities of individuals and the structure and expectations of their environment."

AAIDD's previous definition from 1992 was the same as that found in the DSM IV. However, the updated 2002 definition is as follows:

> "Mental retardation is a disability characterised by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practice adaptive skills. This disability originates before age 18."

The following five assumptions are essential to the application of the definition:

3. Limitations in present functioning must be considered within the context of community environments typical of the individual's age, peers and culture.
4. Valid assessment considers cultural and linguistic diversity as well as differences in communication, sensory, motor and behaviour factors.
5. Within an individual, limitations often co-exist with strengths.
6. An important purpose of describing limitations is to develop a profile of needed supports.
7. With appropriate personalised supports over a sustained period, the life functioning of the person with mental retardation will generally improve.

http://www.aamr.org/Policies/faq_mental_retardation.shtml

Appendix 2 - Administrative Definitions

The definition of developmental disabilities in relation to eligibility for specific services is explored by briefly noting several descriptions from provincial governments/authorities responsible for service provision.

Ontario – Ministry of Children and Youth Services (MCYS)

MCYS provides services and supports to children who have a developmental disability using this definition in the Child and Family Services Act:

> "A development disability is a condition of mental impairment, present or occurring during a person's formative years that is associated with limitations in adaptive behaviour".

The Assistance for Children with Severe Disabilities (ACSD) program, formerly known as the Handicapped Children's Benefit (HCB), provides help to parents to assist with some of the extra costs of caring for a child who has a disability. The purpose of the benefit is to help children who have disabilities live as normal

a life as possible at home and in the community. In order to quality for this program, both the following financial and medical criteria must be met:

- Child must be under 18 years of age and live at home with a parent or a legal guardian.
- Income of a family will be evaluated to determine qualification.
- The child must have a severe disability that results in a functional loss.
- Extraordinary costs must be present which are incurred directly as a result of disability.
- The application for ACSD must be accompanied by a diagnosis of the disability provided by a paediatrician, a family physician, or a registered psychologist.

The regulations governing this program (Ontario Disability Support Program Act, 1997, Ontario Regulation 224/98, Assistance for Children with Severe Disabilities) do not define the basis on which "severe disability" will be assessed and determined.
http://www.children.gov.on.ca/mcys/english/programs/needs/index.asp

Ontario – Ministry of Community and Social Services (MCSS)

In the Developmental Services Act, developmental disability means "a condition of mental impairment present or occurring in a person's formative years that is associated with limitations in adaptive behaviour." The Ministry is currently undertaking a review of the eligibility criteria and definitions which may result in changes to the legislation and/or regulations.

The Ontario Disability Support Program which provides income support for a broader group of adults with disabilities defines its eligibility criteria as:

- "The person has a substantial physical or mental impairment that is continuous or recurrent and expected to last one year or more;
- The direct and cumulative effect of the impairment on the person's ability to attend to his or her personal care, function in the community and function in a workplace, results in a substantial restriction in one or more of these activities of daily living; and
- The impairment and its likely duration and restriction in the person's activities of daily living have been verified by a person with the prescribed qualifications."

While the Act defines who can provide a disability determination it does not define in more detail than the above description, the basis on which that determination should be made.

Ontario – Ministry of Education

Ontario Ministry of Education uses the following categories to group students with exceptionalities.

> "A student – defined as 'exceptional' through the Identification, Placement and Review Committee (IPRC) process because their educational needs cannot be met through regular assessment and instruction resulting from the presence of exceptionality in one or more of:
> - behaviour,
> - communication,
> - intellect,
> - physical status, or
> - multiple exceptionalities."
>
> http://www.edu.gov.on.ca/eng/general/elemsec/speced/speced.html

The exceptionality of "intellect" includes gifted, mild intellectual disability and developmental disability.

The latter two terms are defined as follows:

Mild Intellectual Disability **A learning disorder characterized by:**

- an ability to profit educationally within a regular class with the aid of considerable curriculum modification and supportive service;
- an inability to profit educationally within a regular class because of slow intellectual development; and
- a potential for academic learning, independent social adjustment, and economic self-support.

Developmental Disability **A severe learning disorder characterized by:**

- an inability to profit from a special education program for students with mild intellectual disabilities because of slow intellectual development;
- an ability to profit from a special education program that is designed to accommodate slow intellectual development; and
- a limited potential for academic learning, independent social adjustment, and economic self-support.

British Columbia

In 2007, BC Ministry of Health developed guidelines

intended to support the planning and development of mental health and addiction services for children, youth and adults with developmental disabilities and co-occurring mental health disorders in British Columbia (Byrne, Hurley, & James, 2007).

http://www.health.gov.bc.ca/mhd

The BC planning guidelines acknowledge that the term "developmental disability" is evolving, has only appeared in use within the last decade, and it is not a diagnostic medical term with a consistent definition. By contrast, MR, as defined in the DSM-IV-TR, is a defined medical term.

The BC Community Living Authority Act (July 2005), is the legislation which provided for the transfer of responsibility for services to people with developmental disabilities from the province to the new crown corporation. Community Living British Columbia (CLBC) is mandated under the provisions of the Community Living Authority Act to provide supports and services to individuals with 'developmental disabilities'. "Developmental disability" as defined in the Community Living Authority Act means: 'significantly impaired intellectual functioning that:

- manifests before the age of 18 years,
- exists concurrently with impaired adaptive functioning, and
- meets other prescribed criteria' (as of the date of this policy, no further criteria have been prescribed)

To be eligible for CLBC services, an individual must meet all the requirements of developmental disability as defined above in the Act. Individuals and children requesting services from CLBC due to the presence of a developmental disability must provide initial confirmation of developmental disability from a registered or certified psychologist. In assessing the elements of developmental disability, registered or certified psychologists apply the "Diagnostic Criteria for Mental Retardation" including the criteria for age of onset, intellectual functioning and adaptive behaviour as cited in the DSM IV.

http://communitylivingbc.ca/publications_and_resources/documents/EligibilityforCLBCSUPPORTSANDSERVICES.pdf

Alberta

Alberta's Ministry of Health and Wellness developed the Persons with Developmental Disabilities (PDD) program using a community governance model in 1998. A policy framework defines developmental disability using the following description with no specific reference to IQ level: A state of functioning that began in childhood and is characterized by significant limitations in both intellectual capacity and adaptive skills. The following criteria are used to make the determination of developmental disability for PDD Program purposes:

- Significant limitation in intellectual capacity;
- Onset prior to age 18; and
- Significant limitation in adaptive skills in two or more of the following adaptive skill areas: communication, home living, community use, health and safety, leisure, self-care, social skills, self-direction, functional academics, work.

http://www.pdd.org/docs/prov/CISF_FW_Jan_2007.pdf

The policy also describes a range of processes that can be used to determine eligibility moving from informal to more formal (psychological testing) assessments. The legislation governing this program (The Persons with Developmental Disabilities Community Governance Act) provides authority for regulations to be developed to define developmental disability more specifically but these regulations have not been enacted as yet. Work is currently being done on regulations which are expected to define "significant intellectual limitation" as two standard deviations below the mean IQ as determined by a psychologist through formal testing.

Appendix 3 - Prevalence

In the 2001 study "The Prevalence of Childhood Disability" (Missiuna, Smits, Rosenbaum, Woodside, & Law, 2001, CanChild), the authors argue that this information is crucial as "Governments must be aware of incidence and prevalence information for each distinct type of childhood disability in order to plan efficiently, evaluate effectively, and provide funding for appropriate services for these children and their families."

The prevalence and incidence of some childhood disabilities are easier to assess than others. Developmental disabilities are one of the more difficult to assess because of several key factors:

- **Lack of a Clearly Defined Condition**. To be able to design a study to measure prevalence, one must set parameters on which conditions to include or exclude from the analysis. As indicated

previously, there is no consensus on the definition of developmental disabilities which hampers the ability to study prevalence.

- **Timing of Diagnosis**. Some developmental disabilities are diagnosable at or before birth; while others cannot be diagnosed with confidence until children reach school-age or later. Some disabling conditions only become apparent when children fail to meet critical milestones. Study designs which focus exclusively on children 0-5 will not capture the prevalence of conditions (or needs) which may not be diagnosed until much later.
- **Dynamic Environment**. The severity of intellectual impairment can be measured using quantifiable test instruments, but functionality is more subjective and may be open to interpretation. A child with developmental disabilities often has capabilities/disabilities which vary with the environmental context (including societal attitudes and values; the functioning of the family or caregivers at a point in time; access to supports; services available from the local educational system, recreational system, or other supports; transportation accessibility; the state of the labour market economy; technology changes) – and capabilities/disabilities vary over time. A child with developmental disabilities in Ontario in the 21st century is living in a rapidly changing environment and this has a powerful influence on his/her functional capabilities or limitations at any point in time. The ability to spell, for example, was of far greater importance before the invention of Spell Check on computers. Technological changes can open as well as close doors for children with developmental disabilities. The environmental context for the client (and his/her caregivers) is dynamic, but prevalence surveys are by nature static instruments in that they capture and report on functioning at a fixed point in time.
- **Concurrent or Successive Disorders**. Children with developmental disabilities often have several functional limitations which co-exist or are concurrent, such as mental health problems. Unless very carefully designed, prevalence studies may not adequately capture the extent of these concurrent disorders and therefore under-report the need to plan for additional supports and services. The primary diagnosis may be mental retardation, but secondary co-morbid health conditions may be of greater concern to clients, caregivers or systems with which the child interacts.

Canada

Prevalence studies in Canada reflect many of the same methodological challenges faced elsewhere. One earlier review of prevalence studies in Canada conducted by a Working Group on the Epidemiology of Mental Retardation in Canada (National Health and Welfare 1988) acknowledged challenges with definitional and identification criteria while noting prevalence rates for mild developmental disability that ranged from 1.7 to 3.8/1000, rates for moderate developmental disability that ranged from 1.7 to 2.84/1000 and rates for severe developmental disability that were similar to those in the mild group. A study conducted in Niagara region of children aged 14-20 known to the service system to have developmental disability, identified a total of 255 youth of whom 171 (67%) participated in the study (Bradley, Thompson, & Bryson, 2002). The key findings from that study were:

- An overall prevalence for mental retardation of 7.18/1000.
- For mild MR, that is IQ = 50-75, prevalence of 3.54/1000 which is in the lower end of the range established in previous studies. This rate is more reflective of rates found in Sweden and in stark contrast to the much higher rates found in United States.
- For severe MR, that is IQ <50, prevalence of 3.64/1000 which is consistent with previous studies in Canada and elsewhere.

The authors concluded that, while prevalence rates for severe MR are relatively stable across geographic locations, rates for mild MR vary for several factors including prevailing philosophies of care and integration, as well as resources available to implement these philosophies. The low prevalence of mild MR may be attributed to the policies of integration in Ontario over the past 3 decades that may have made persons with mild MR less visible.

In a study of prevalence in one county in Ontario (Ouellette-Kuntz & Paquette, 2001) the authors used an agency survey process in an effort to compare local data to the rate for administrative prevalence of .6% that had been used by the Ministry of Community and Social Services. When these data were considered in the context of their examination of international studies of prevalence, both "true" and administrative, and the Ministry's analysis for administrative data they concluded that there was no evidence basis on which to presume that "true" prevalence of developmental disabilities in Ontario was less than 3%

and that the administrative prevalence is significantly less than 1%. As further noted in the Colloquium on Primary Health Care for Adults with Developmental Disabilities (Sullivan et al., 2006), the current evidence is not conclusive but would appear to suggest that administrative prevalence figures may be capturing only half the population affected by these disabilities. Further research is needed to clarify what prevalence rate would make an adequate base for future planning of services and supports for a highly vulnerable population (McCreary, 2005).

U.S.A.

In the USA, developmental disability is not always defined in the same way across research studies or service agencies, even within the same state. Some diagnoses rely exclusively on IQ scores; or adaptive behaviours only; and others use a combination of the two. No registry or comprehensive national survey exists in the USA and studies of prevalence of developmental disability vary considerably in their estimates.

The Metropolitan Atlanta Developmental Disabilities Surveillance Program used a multiple-source methodology to study the prevalence of mental retardation, cerebral palsy, hearing impairment, and visual impairment among school-age children. This population-based study, which used only IQ scores as the criterion, found an overall prevalence of mental retardation of 0.9% in children who were 10 years of age between 1985 and 1987 and whose mothers were residents of five Georgia counties at the time of the child's birth (Bhasin et al 2006).

Australia

The Australian operational definitions and estimates of prevalence have been affected by the selective use and periodic revisions of definition and classification systems. Most Australian institutions have adapted the AAIDD definitions and classifications to define intellectual disability whereas the Australian Bureau of Statistics (ABS) national disability and health surveys (the only existing national data containing valid and reliable information about the population with disability) have adapted the WHO ICIDH and ICD-9 concepts.

In "*The Definition and Prevalence of Mental Retardation in Australia*" (1997), Wen presented a number of estimates of national prevalence of intellectual disability derived from the three ABS disability surveys (1981, 1988, 1993), depending on the methods and assumptions used in estimation. The results showed a range of national estimates of prevalence (derived from self-reported information in ABS surveys), from 0.65% of the total population with their conditions identified before age 18 to 1.86% of the total population with intellectual disability, either as the primary disabling condition or an associated condition. Wen concluded that the existing variety of data suggests a need to improve the consistency of concepts and definitions for intellectual disability and to increase the comparability of data collections for different purposes.

United Kingdom

In "Valuing People: A New Strategy for Learning Disability for the 21st Century" (Great Britain, 2000), it is noted that "The prevalence of severe and profound developmental disability is fairly uniformly distributed across the country and across socio-economic groups. Mild to moderate learning disability, however, has a link to poverty and rates are higher in deprived and urban areas. The number of people with severe and profound learning disabilities in some areas is affected by past funding and placement practices, especially the presence of old long-stay patients and people placed outside their original area of residence by funding authorities."

With respect to the future, Valuing People states "Evidence suggests that the number of people with severe learning disabilities may increase by around 1% per annum for the next 15 years as a result of:

- Increased life expectancy, for example among people with Down syndrome;
- Growing numbers of children and young people with complex and multiple disabilities who now survive into adulthood;
- A sharp rise in the reported numbers of school age children with autistic spectrum disorders, some of whom will have learning disabilities; and
- Greater prevalence among some minority ethnic populations of South Asian origin. A study by the Centre for Research in Primary Care at the University of Leeds published alongside Valuing People revealed that the prevalence of learning disability in some South Asian communities can be up to three times greater than in the general population."

http://www.doh.gov.uk.learningdisabilities/strategy.htm

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