



**CORE**

Public Health Functions for BC

**Evidence Review:**  
**Prevention of**  
**Disabilities**  
**(Congenital & Genetic)**

**Population Health and Wellness**  
**BC Ministry of Health**

*This paper is a review of the scientific evidence for this core program. Core program evidence reviews may draw from a number of sources, including scientific studies circulated in the academic literature, and observational or anecdotal reports recorded in community-based publications. By bringing together multiple forms of evidence, these reviews aim to provide a proven context through which public health workers can focus their local and provincial objectives. This document should be seen as a guide to understanding the scientific and community-based research, rather than as a formula for achieving success. The evidence presented for a core program will inform the health authorities in developing their priorities, but these priorities will be tailored by local context.*

*This Evidence Review should be read in conjunction with the accompanying Model Core Program Paper.*

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Population Health and Wellness, Ministry of Health (February 2007)

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## EXECUTIVE SUMMARY

The following table provides a summary of the domains and evidence reviewed in this paper. The evidence is divided into two categories:

- α** Evidence is based on meta-analysis, systematic review and/or one or more randomized controlled trials.
- β** Recommendation is based on expert opinion, non-randomized studies or program evaluations.

Domain	What is Known	Evidence of Prevention Interventions Found for This Review
<b>Prevention of Congenital Anomalies</b>		
<ul style="list-style-type: none"> <li>▪ Prevention of conception: Genealogy/Family History</li> </ul>	Some diseases and congenital anomalies are inherited.	<ul style="list-style-type: none"> <li><b>α</b> Evidence-based guidelines for genetic screening and counselling for people with a higher risk of congenital anomalies have been published (e.g., Ashkenazi Jews).</li> <li><b>β</b> A large online program for people to track the genealogy of their family with respect to disease is currently under evaluation in the United States.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Pre-conception programs</li> </ul>		<ul style="list-style-type: none"> <li><b>α</b> Pre-conception programs can prevent birth defects and low birth weight through targeting smoking cessation, pregnancy intervals, folic acid supplementation and interventions with women with diabetes to improve control of blood sugar levels.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Folic acid intake</li> </ul>	<ul style="list-style-type: none"> <li><b>α</b> Taking folic acid at the time of conception reduces the risk of neural tube defects.</li> <li><b>α</b> Folic acid intake may be less than recommended at the time of conception.</li> <li><b>α</b> The uptake of folic acid supplementation is at best 50 per cent of women of childbearing age.</li> <li><b>α</b> Women with less education and other social and economic challenges are less likely to use folic acid supplements.</li> <li><b>α</b> While fortification of wheat products has increased folic acid consumption, it appears that folic acid supplementation is still necessary to reach the recommended daily dose to prevent neural tube defects.</li> </ul>	<ul style="list-style-type: none"> <li><b>α</b> Pre-conception visits, including education about folic acid, can improve uptake of folic acid.</li> <li><b>α</b> Public awareness programs can increase uptake of folic acid.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Early detection and pregnancy termination through prenatal screening</li> </ul>	<ul style="list-style-type: none"> <li><b>α</b> Maternal serum screening (MSS) and ultrasound can detect some congenital anomalies.</li> <li><b>α</b> A large proportion of women are choosing termination following positive screening tests.</li> <li><b>α</b> Disparities may exist in accessing MSS and termination with respect to education and culture.</li> </ul>	<ul style="list-style-type: none"> <li><b>α</b> Routine ultrasound and Maternal Serum Screening can reduce the number of births with congenital anomalies in the presence of access to elective termination.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Management of diabetes</li> </ul>	<ul style="list-style-type: none"> <li><b>α</b> Women with diabetes are at increased risk for congenital anomalies.</li> </ul>	<ul style="list-style-type: none"> <li><b>α</b> Improving glycemic control of diabetic women during pregnancy can reduce birth defects.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Prevention of complications due to BMI &gt; 30</li> </ul>	<ul style="list-style-type: none"> <li><b>α</b> There are increased risks of congenital anomalies for women with BMI &gt; 30.</li> </ul>	No clinical trials were found that tracked birth outcomes following weight management programs.
<ul style="list-style-type: none"> <li>▪ Exposure to Environmental risks</li> </ul>	<ul style="list-style-type: none"> <li><b>α</b> There is evidence of increased risk of congenital anomalies and low birth weight for babies born to women exposed to higher than normal levels of some environmental contaminants.</li> </ul>	<ul style="list-style-type: none"> <li><b>β</b> Attention to the level of contaminants by monitoring water, air, industrial and waste sites, and occupational exposure is warranted.</li> <li><b>β</b> Pesticide exposure in agricultural communities, and in agricultural workers and their families, merits monitoring.</li> </ul>

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Domain	What is Known	Evidence of Prevention Interventions Found for This Review
<b>Prevention of Disabilities</b>		
<ul style="list-style-type: none"> <li>▪ Reducing transmission of infectious diseases to fetus/newborn</li> </ul>	<ul style="list-style-type: none"> <li>α HIV, rubella, hepatitis B, chicken pox, herpes and syphilis can be transmitted to the fetus and can result in mental retardation and other disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>α Immunization reduces transmission of infections to the fetus.</li> <li>α Routine Screening for HIV, hepatitis B, syphilis, rubella and asymptomatic bacteriuria decreases transmission to the infant.</li> <li>α Selective serotesting for chicken pox for unexposed women is cost-effective.</li> <li>α Treatment of pregnant women with antiretrovirals reduces HIV transmission and reduces prematurity and low birth weight.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Reducing risks of low birth weight due to smoking</li> </ul>	<ul style="list-style-type: none"> <li>α Smoking is a major factor in low birth weight.</li> <li>α Low birth weight babies have a higher rate of disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>α Smoking cessation programs can be effective in reducing the incidence of low birth weight.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Reducing risks for preterm birth</li> </ul>	<ul style="list-style-type: none"> <li>α Babies born prematurely have a higher incidence of disabilities.</li> </ul>	<ul style="list-style-type: none"> <li>β Periodontal therapy has not been proven to decrease the risk of preterm birth, but more research may be able to show some effect.</li> <li>α Corticosteroids are the only proven intervention to prevent preterm birth.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Occupational factors</li> </ul>		<ul style="list-style-type: none"> <li>β A policy of maternity leave benefits can reduce the incidence of preterm births especially with women who stand for long periods of time at work.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Reducing exposure to alcohol</li> </ul>	<ul style="list-style-type: none"> <li>α Fetal Alcohol Spectrum Disorders (FASD) are preventable.</li> <li>α Alcohol consumption, especially binge drinking is the principal risk factor for FASD.</li> <li>α The threshold for risk of FASD seems to increase with the dose of alcohol.</li> <li>α Moderate alcohol consumption is widespread in women of childbearing age.</li> <li>α There is a small percentage of women who drink alcohol at levels that puts their fetus at risk for FAS.</li> <li>α Long-term outcomes of babies with FAS are poor.</li> </ul>	<p><b>Population Level</b></p> <ul style="list-style-type: none"> <li>α Limiting the availability of alcohol can reduce use of alcohol.</li> <li>α Warning labels and posters can decrease the use of alcohol.</li> <li>α School and community programs can reduce substance use.</li> <li>β The “Strengthening Families Program” offers promise in prevention of alcohol abuse.</li> <li>β A long-term comprehensive system-wide program can reduce the incidence of FAS.</li> </ul> <p><b>Primary Care</b></p> <ul style="list-style-type: none"> <li>α Alcohol dependence assessment instruments can detect high-risk drinkers.</li> <li>α Brief interventions can reduce substance use.</li> </ul>
<b>Early Detection of Disabilities and Early Intervention</b>		
<ul style="list-style-type: none"> <li>▪ Newborn screening</li> </ul>	<ul style="list-style-type: none"> <li>α A number of disabling conditions can be detected at birth.</li> <li>α Early detection can improve later outcomes.</li> <li>α Treatments are known and available for some conditions (e.g., PKU).</li> </ul>	<ul style="list-style-type: none"> <li>α 27 conditions have been recommended for newborn screening, while only 4 are screened in BC. These additional 23 screening tests could lead to earlier detection and treatment of some rare genetic conditions.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Developmental and behavioural screening and follow-up</li> </ul>		<ul style="list-style-type: none"> <li>α A program of developmental screening in primary care can increase the number of children screened.</li> <li>β Early detection of some disabilities may improve later functioning.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Developmental and behavioural screening and follow-up of very low birth weight babies</li> </ul>	<ul style="list-style-type: none"> <li>β Systematic follow-up of low birth weight and preterm infants may improve later functioning by early detection and intervention of developmental delays.</li> </ul>	<ul style="list-style-type: none"> <li>β Adoption of proposed standards for follow-up of very low birth weight infants may improve outcomes, but monitoring of the outcomes of screening and follow-up programs is needed.</li> </ul>
<ul style="list-style-type: none"> <li>▪ Early detection of autism</li> </ul>	<ul style="list-style-type: none"> <li>α Early detection of autism improves functioning.</li> </ul>	<ul style="list-style-type: none"> <li>α Standardized screening tools are available for use by parents or health professionals and are effective in detecting autism.</li> </ul>

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Domain	What is Known	Evidence of Prevention Interventions Found for This Review
<ul style="list-style-type: none"> <li>▪ Early intervention programs</li> </ul>	<ul style="list-style-type: none"> <li>α Home visiting by a nurse has shown to have little or no effect on children’s development.</li> </ul>	<ul style="list-style-type: none"> <li>α Validated screening tools for use by parents to screen for developmental delays are effective at case finding.</li> <li>α Early childhood education improves outcomes, especially in academic achievement for disadvantaged children as well as those at low risk.</li> <li>α Early intervention programs by parents have been show to improve outcomes of low birth weight children.</li> </ul>

## **1.0 OVERVIEW/ SETTING THE CONTEXT**

In 2005, the British Columbia Ministry of Health released a policy framework to support the delivery of effective public health services. The *Framework for Core Functions in Public Health* identifies prevention of disabilities as one of the 21 core programs that a health authority provides in a renewed and comprehensive public health system.

The process for developing performance improvement plans for each core program involves completion of an evidence review used to inform the development of a model core program paper. These resources are then utilized by the health authority in their performance improvement planning processes.

This evidence review was developed to identify the current state of the evidence-based on the research literature and accepted standards that have proven to be effective, especially at the health authority level. In addition, the evidence review identifies best practices and benchmarks where this information is available.

### **1.1 An Introduction to This Paper**

The research questions guiding this review were:

- What types of conditions should be included in the review?
- What conditions have potential for prevention?
- What types of programs have been shown to reduce the risk factors or the incidence, prevalence or severity of birth defects and disabilities?

Outcomes of interest in interventions reviewed:

- Incidence and prevalence of a condition as a result of an intervention.
- The number of premature births or low birth weights.
- Long-term child development outcomes:
  - The age at which a condition is identified, if that affects prevention of disability.
  - Long-term neurobehavioural outcomes.
  - School achievement.
  - Long-term physical disability.
  - IQ.
  - Use of special education.
- Maternal outcomes
  - Alcohol consumption.



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- Smoking.
- Interval between pregnancies.
- Use of screening tests.
- Terminations of pregnancy for detected abnormalities.
- Knowledge and adoption of folic acid supplementation.
- Percentage of pregnancies that are planned.
- Provider outcomes
  - Health care provider behaviour and knowledge.
  - Adoption of clinical practice guidelines and/or screening and assessment tools.

## **2.0 METHODOLOGY**

### **2.1 Evidence Standards and Grading**

The primary sources of evidence used for this review are graded reviews of the evidence, graded clinical practice guidelines, systematic reviews, meta-analyses and randomized controlled trials. Reviews use different grading systems. Studies that do not meet the gold standards for A grade evidence are graded at B, C or D as shown in Table 1. A discussion of the merits and weakness of an evidence basis for public health planning is outside of the scope of this report. However, a recent article by Kemm (2006) summarizes the limitations of traditional evidence grading in public health. The science of grading is still in development and there has been no consensus on best methods although there have been efforts to establish a consensus (Guyatt et al. 2006). Guyatt et al. suggests the following grading model:

High:	Further research is very unlikely to change our confidence in the estimate of effect.
Moderate:	Further research is likely to have an important impact on our confidence in the estimate of effect, and may change the estimate.
Low:	Further research is very likely to have an important impact on our confidence in the estimate of effect, and is likely to change the estimate.
Very Low:	Any estimate of effect is very uncertain.

It is helpful to view the evidence in the paper in the context of Guyatt's model.

Selection of the evidence for this review was based on the criteria below:

- Available on the Internet.
- Used a grading system to rank the evidence.
- Included citations to the original research.
- Were published by an “authority” (professional, academic or government agency).
- The evidence or guidelines were created in western countries with a universal health care system.
- The population is similar in ethnic and socio-economic status to Canada.<sup>1</sup>
- The evidence is within the scope of public health, which is broadly defined as primary and secondary prevention of birth defects and disabilities, regardless of type of intervention. In some cases this includes primary care (physicians).
- Where no graded review was available, systematic reviews or meta-analyses are used as the source of evidence.

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<sup>1</sup> American evidence is included, but caution is needed in assessing if the evidence would apply to a Canadian setting, due to differences in access to health care.

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- Where no systematic reviews or meta-analyses were available, the evidence is based on clinical trials.
- Where no clinical trials were found, the evidence is based on other types of studies and/or expert opinion.
- Many population-level strategies (e.g., media campaigns or legislation) have not been subject to clinical trials, but they are included if there are pre- and post-measures or a comparison group.

Coding of the evidence in this review follows the categories in column 1 below. However, the categories in column 2 are also used if the original review already graded the evidence following this coding. While this creates some confusion about the grading systems, it is outside of the scope of this review to recode existing reviews.

**Table 1: Definitions of Types of Studies Reviewed and Grading**

1		2	
Coding used in this review		Some evidence in the review will be coded by these categories	
		Grading system used by the Canadian Task Force on the Periodic Health Examination (CTFPHE 1994).	Grade of evidence used by the National Collaborating Centre for Women’s and Children’s Health (2003 SR G)
MA	Meta-analysis	Ia	A
RCT	Randomized controlled trial	Ib	A
SR	Systematic review	Ia	A
SR G	Graded systematic review	Ia	A
CCS	Case-control study	IIa	B
CCT	Controlled clinical trial	II	B
COH	Cohort study	IIa	B
COM	Comparative study	III	C
CPG or G	Clinical practice guidelines	IV	D
R	Review (non-systematic or not Cochrane)		
<b>Studies methods without grading</b>			
OB	Observational study		
PP	Pilot project		
PS	Prospective study		
XS	Cross-sectional study		
FUS	Follow-up study		
CT	Clinical trial		
PE	Program evaluation		

## **2.2 Methodological Limitations**

- Good evidence is often available for single, targeted initiatives, such as smoking cessation; however, larger community- or population-wide programs do not include a control group, so evidence is limited.
- Outcomes of some promising programs were not found on the Internet. More information might be found by contacting the programs directly. It is possible that more evidence exists in unpublished sources.
- There are many studies that can point to an association between maternal and paternal risk factors and birth defects and disabilities, but this does not infer causation.
- This evidence review is not systematic and may have omitted some important research.
- Many clinical guidelines are often summaries, not linked to primary research or lacking the grading of the evidence.
- Reviews miss a large amount of detail about program components that may have been critical to the success of the program.

## **2.3 Exclusions to the Review**

The Ministry of Health has developed a number of other evidence reviews at the same time as this review. This review excludes topics included in those other reviews, such as the prevention of disabilities due to unintentional injuries, violence and abuse. Other topics briefly covered in this review are prevention of disabilities as a result of substance abuse, lifestyle, dental health, infectious diseases and exposure to air, water and other environmental exposures; these topics are covered in more detail in other reviews. The reviews of reproductive health and healthy infant and early childhood development cover some of the same content as this review; however, this review includes a greater focus on the prevention of birth defects and disabilities within the context of public health. Interventions in primary care are included if the intervention is “population-wide” or “high-risk” screening, or if the intervention is preventive. Finally, this review excludes clinical interventions such as labour and delivery and treatment of conditions and screening outside the scope of public health or primary care. Primary care in Canada has a long history of preventive care as part of the role of family physicians (CTFPHE 1994).

## **2.4 Search Methods**

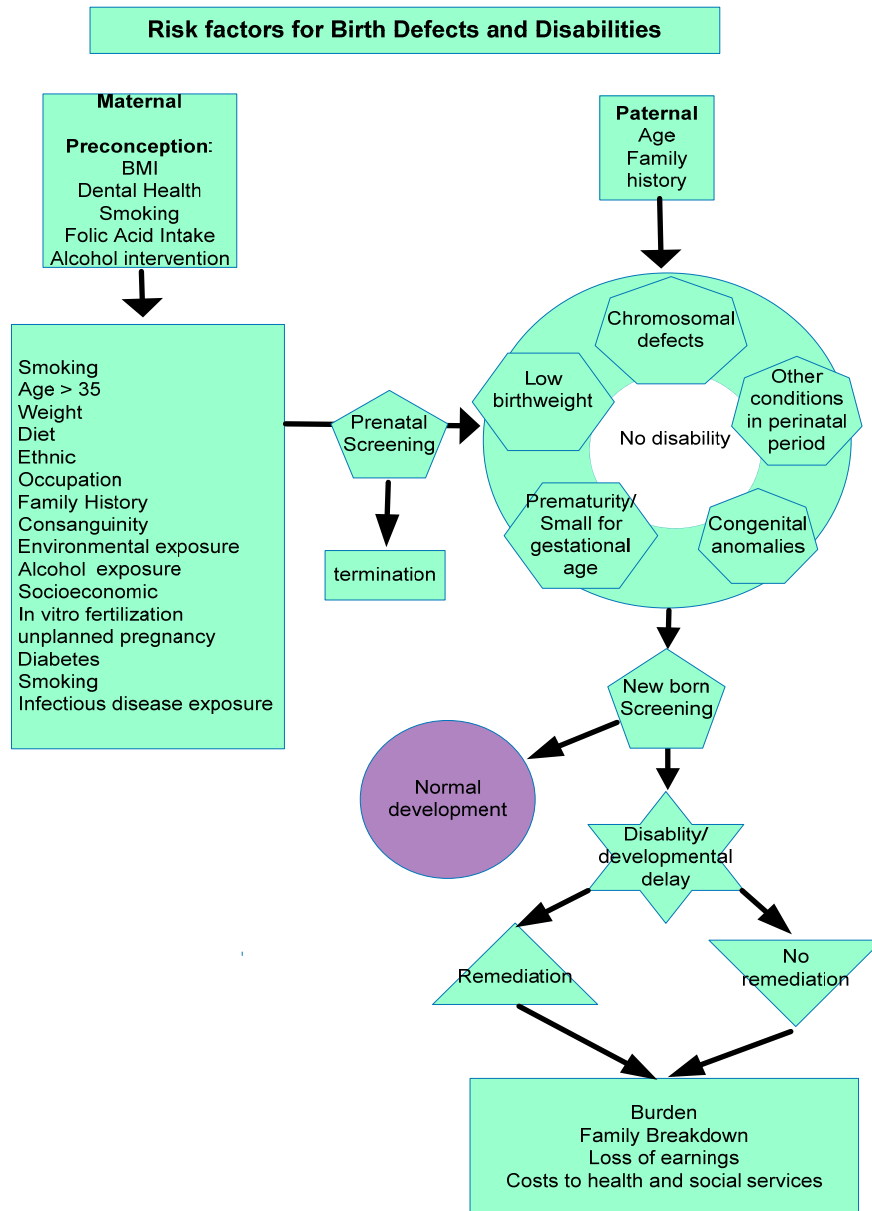
The first searches for this review were of websites about birth defects and developmental disabilities, followed by Medline, the US CDC and the Cochrane Collaboration, medical speciality web sites such as American College of Obstetrics and Gynaecology (ACOG), the Society of Gynaecologists and Obstetricians of Canada (SOGC) and the National Institute for Clinical Excellence (NICE) United Kingdom site. Then references in papers were reviewed if relevant. An extensive list of websites is included in Appendix 1.

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Where no reviews were available, the most recent and best quality single studies are reported. If more recent randomized controlled trials have been published since a major systematic review or meta-analysis, and it contributes new evidence, it has been included.

Figure 1 illustrates a model designed for this project for identifying factors associated with the prevention of congenital anomalies and disabilities. It is not an exhaustive list, but is meant to illustrate the synergy among factors that are included in the review.

**Figure 1: Project Model**



### 3.0 INCIDENCE, PREVALENCE, RISK FACTORS AND TRENDS

#### 3.1 Incidence and Prevalence

This section is included to provide an introduction to the different kind of birth defects and disabilities included in this report, and to give an overview of the incidence and prevalence of different birth defects and disabilities. More detailed reports on incidence, prevalence and trends are reported in the citations included in this section. Estimating prevalence of disabilities is often confusing due to different definitions used by different agencies that report the statistics. Further confusion also results from the reporting of disabilities versus the number of people with disabilities.

Selected counts and disability rates in BC are reported in Table 2. The data is as reported from the Participation and Activity Limitation Survey (PALS) (Statistics Canada 2002) and the BC Health Status Registry Report (British Columbia Vital Statistics Agency [BCVSA] 2005). The PALS survey codes disability by “function”, while the Health Status Registry reports by “diagnosis” (ICD-10 coding). Further details on the types of disabilities can be found in Appendix 2 and in the Glossary.

**Table 2: Summary of Prevalence of Birth Defects and Selected Disabilities in Children, BC.**

	Age Range	Cases	Percentage of Age Group in Column 2	Year
<b>BC Health Status Registry Report*</b>				
1. Congenital anomalies (see Table 3).	Births	1,855	0.05%	2002
2. Inherited or chromosomal disorders diagnoses (see Appendix 3, Table A for examples).	<15	3,588	0.4%	2002
3. Other selected disabilities (see Appendix 3, Table B for examples).	<15	16,295	2.3%	2002
Mental retardation	< 15	1,221	N/A	2002
Developmental delays and stuttering.	< 15	2,800	N/A	2002
Autism.	< 19	550	N/A	2004
4. Fetal alcohol spectrum disorders.**	N/A	167	N/A	2001-2003
<b>Participation and Activity Limitation Survey (PALS) BC sample***</b>				
	Age Range	Number of Disabilities Reported	Percentage of Population < Age 15 with Disability	Year
Total Disabilities	< 15	25,040	3.5 %t	2001
Disabilities Moderate/Mild	< 15	15,180	2.1 %	2001
Disabilities Severe	< 15	9,850	1.4 %	2001

**Notes:**

\* The BC Health Status Registry Report is produced by the British Columbia Vital Statistics Agency. There is voluntary reporting of a list of conditions by health care agencies and providers. See Appendix 3 for a detailed list of conditions.

\*\* Fetal alcohol syndrome is not reported routinely and the criteria for reporting are not standardized. The number quoted may underestimate the number, and no ages were reported. See the BC Health Status Report for details on reporting (BCVSA 2005).

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\*\*\* See Figure 2 and definitions in Appendix 2. The Participation and Activity Limitation Survey (PALS) is a post-censal survey that collects information about persons whose everyday activities are limited because of a health-related condition or problem. The last wave was 2001. The data reported here is from the sample reported in BC.

**3.1.1 Congenital Anomalies**

Congenital describes something that was acquired while the individual was still developing in the uterus. For example, a congenital defect is a defect that is not found in the individual's genes, but developed for some other reason while the individual was a fetus (<http://www.thebiotechdictionary.com/term/congenital>). The causes of most human congenital malformations cannot be determined. One review suggests that the cause is unknown for approximately 60 per cent of malformations (Kalter and Warkany 1983a and 1983b). The causes that are known can be classified into certain groups. Congenital malformations that are caused by a single major mutant gene are thought to account for approximately 7.5 per cent of all congenital malformations. Chromosomal abnormalities are estimated to be the cause of 6 per cent of all malformations. Congenital malformations can also be caused by an interaction between genetic and non-genetic factors, as seen with Down's syndrome, which becomes more common as maternal age increases. It has been suggested that such interactions account for 20 per cent of malformations (Kalter and Warkany 1983a and 1983b).

As well as genetic factors, there are specific environmental factors that have been found to cause congenital malformations. These may include maternal infections such as rubella; maternal illness such as diabetes; environmental substances such as mercury; teratogenic agents taken by the mother (drugs or chemicals that can cause congenital malformations); and nutritional deficiencies such as a lack of folate. Maternal illness and teratogenic drugs are thought to account for approximately 5 per cent of all congenital malformations (Al-Yaman, Bryant and Sargeant 2002).

A total of 1,855 births were identified with one or more congenital anomaly in 2002 in BC. The most common deformities are congenital musculoskeletal deformities, followed by anomalies of the heart. Table 3 presents rates for selected congenital conditions (BCVSA 2005).

**Table 3: Congenital Anomaly Rates, BC, 1997–1999 (3-Year Rate)**

	Rate per 1,000 Total Births		
	BC	Canada	Cases (3 years)
Cleft lip with or without cleft palate	1.78	1.07	230
Down's syndrome	1.69	1.40	218
Cleft palate (CP)	0.85	0.7	110
Neural tube defect (NTD)	0.77	0.64	100
Spina bifida	0.59	0.45	76
Limb reduction defect (LRD) rate	0.43	0.40	55
Hypoplastic left heart syndrome (HLHS) rate	0.22	0.28	28
Anencephaly rate	0.14	0.10	18

**Note:** Total births = 129,230

**Source:** Canadian Congenital Anomalies Registry.

### 3.1.2 Inherited or Chromosomal Abnormalities

This category includes a diverse range of conditions (See Appendix 3, Table A for list of conditions and the number of cases reported for those under 15). Haemophilia and other coagulation defects were the most frequently reported conditions. A genetic condition of interest is cystic fibrosis (CF), a recessive disorder characterized by chronic airway infection. There were 215 cases of CF reported in those under 15.

### 3.1.3 Other Selected Disabilities

A third group of disabling conditions which generally manifest in childhood is now reported by the BC Health Status Registry (See Appendix 3, Table B for a list of conditions). Blindness and visual impairments, other than retrolental fibroplasia, were the most commonly reported conditions. Epilepsy was the second most frequently reported condition and developmental delay was the third.

### 3.1.4 Fetal Alcohol Spectrum Disorders

The incidence of Fetal Alcohol Spectrum Disorders (FASD) varies among populations, partly as a result of different screening tools, definitions of FASD and patterns of alcohol use. It is likely that a large number of cases remain unreported in BC as there is no systematic reporting system. Guidelines have recently been published on criteria for diagnosis in Canada (Chudley et al. 2005).

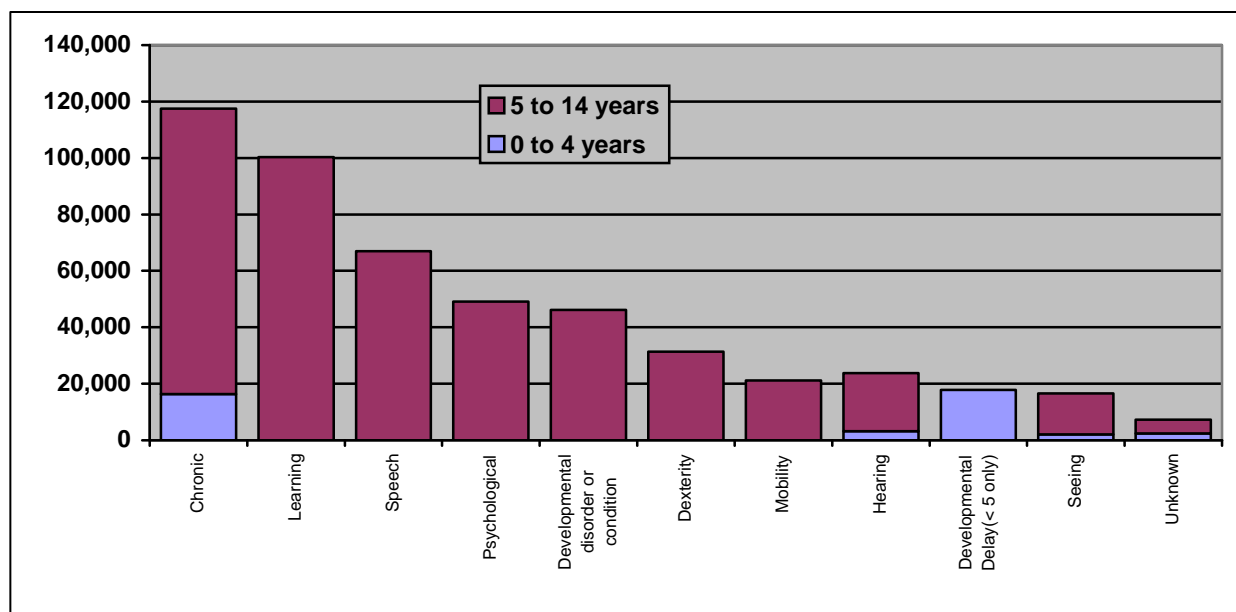
Birth rates of infants affected by FAS vary from 0.2 cases per 1,000 live births in the general obstetric population to 4.3 per cent among “heavy” drinkers in the United States (Centers for Disease Control and Prevention [CDC] 2002a; Abel 1995). The incidence in low socio-economic status, African American or Native American populations is about 10 times higher (2.29 cases per 1,000) compared to sites with a predominantly middle/upper socio-economic status and Caucasian background (0.26 per 1,000) (Abel 1995). Prevalence has been estimated at 180 per 1,000 children in Aboriginal communities in Canada (First Nations Centre 2005). See the definition of fetal alcohol syndrome in the Glossary, for an explanation of the range of FASD conditions.

### 3.1.5 PALS Grouping of Disabilities

The Participation and Activity Limitation Survey (PALS) categorizes disabilities by functional limitations regardless of origin. Figure 2 shows the distribution of types of disabilities in children in Canada. (See Appendix 2 for the definition of categories).



**Figure 2: Type of Disabilities Among Children Aged 0 to 14 Years with Disabilities, by Age Groups, Canada, 2001.**



**Note:** See Appendix 2 for definitions. Due to the fact that some disabilities are not reported until children enter school, the category of development delays represents a “catch-all” category of disabilities for children 0-4 years.

### 3.2 Risk Factors for Birth Defects or Disabilities

The precise causes of congenital abnormalities are not known for 50-60 per cent of cases. Multifactorial etiology accounts for 20-25 per cent of all abnormalities, 6-8 per cent are monogenetic (caused by mutation of a single gene), 6-8 per cent by chromosomal abnormalities and 6-8 per cent by other external factors such as maternal illness, infections, drugs, radiation, ethnic background, diabetes, maternal age, obesity, epilepsy, alcohol consumption and occupational or environmental exposure (e.g., lead, hazardous waste sites) (Eurocat 2003 **R**).

- Infertility and/or assisted reproductive technology (ART) are associated with increased risk of congenital anomalies (Zue et al. 2006; Hansen et al. 2005 **SR MA**; McDonald et al. 2005 **SR MA**; Rimm et al. 2004 **MA**).
- Women of First Nations origin are at increased associated risk of a neural tube defect (NTD)-affected pregnancy in Ontario, compared to Caucasian women (Ray et al. 2004), and for oral facial defects in BC (Uh et al. 2006).
- The increase in women over 35 having children has not increased the live birth rates of Down’s syndrome in European countries where screening and termination is available (Dolk et al. 2005).
- Prevalence of risk factors in the pre-conceptual period is high. 54.5 per cent of women reported one or more of 3 risk factors (frequent drinking, current smoking and absence of an HIV test), compared with 32.0 per cent of pregnant women ( $p < .05$ ) in the United States Behavioural Risk Factor Surveillance System (Anderson et al. 2006).

### 3.2.1 Diabetes

- Babies born to women with diabetes are at increased risk for congenital malformations (cardiac, renal and neurological) in many western countries (Macintosh et al. 2006; Evers, de Valk and Visser 2004; Anderson et al. 2005; Schaefer-Graf et al 2000 **CH**).
- 1.8 per cent of births in BC were reported to have complications related to diabetes in pregnancy (2,450 births 1999-2003) (BCVSA 2005).
- Women with diabetes who have unplanned pregnancies are at greater risk for congenital anomalies (12 per cent) compared to women with diabetes who planned their pregnancy (4.2 per cent) (Evers et al. 2004).

### 3.2.2 Obesity

Obesity represents one of the most prevalent risk factors for congenital anomalies. Congenital anomalies associated with maternal obesity include: neural tube defects (Cedergren and Kallen 2003; Anderson et al. 2005), other birth defects (Queisser-Luft et al. 1998), spina bifida, omphalocele, heart defects, multiple anomalies, heart defects and multiple anomalies (Watkins et al. 2003 **CCS**). The increased risk for congenital anomalies associated with higher maternal body weight does not appear to be modified by folic acid supplementation and may be associated with glycemic index or hyperinsulinemia (Anderson et al. 2005; Carmichael et al. 2002).

**Table 4: Females Body Mass Index, 2000–2005, BC (Self-Report Percentage of Age Group, Excluding Pregnant Women)**

		2000/2001	2005
25 to 34 years	Overweight, self-reported adult body mass index 25.00 to 29.99	19.3	17.1
25 to 34 years	Obese, self-reported adult body mass index 30.00 or higher	8.3	10.3
35 to 44 years	Overweight, self-reported adult body mass index 25.00 to 29.99	19.6	21.7
35 to 44 years	Obese, self-reported adult body mass index 30.00 or higher	11.3	9.6

**Source:** (Statistics Canada. 2005).

### 3.2.3 HIV/AIDS

There were 2,206 infants identified as perinatally exposed to HIV born between 1984 and 2005 in Canada. The number of HIV-exposed infants reported per birth-year has increased steadily from 87 infants in 1993 to 173 in 2005. The proportion of HIV-exposed infants whose mothers' HIV status was attributed to heterosexual contact was 70.7 per cent, and 27.5 per cent were attributed to injection drug use. Although the number of HIV-exposed infants has increased for each birth-year, the proportion of infants confirmed to be HIV-infected has decreased from 39.5 per cent in 1994 to 4 per cent in 2005. Correspondingly, the proportion of HIV-positive mothers receiving antiretroviral therapy in Canada has increased steadily, reaching a high of 89 per cent in 2005 (Public Health Agency of Canada 2006).

### 3.2.4 Prenatal Alcohol Exposure

Drinking at a level to cause harm is common in women of childbearing age in BC. The Canadian Community Health Survey reported that 2.2 per cent of women in BC are alcohol dependent, or about 37,780 women of all ages (Cartar et al. 2004). The 2004 Canadian Addiction Survey

reported that 33 per cent of women age 19–24 consume alcohol at a level of risk for harm, compared to 19 per cent of women age 25–39 and 10 per cent of women age 40–45 (Stockwell, Sturge and Macdonald 2007). The First Nations Longitudinal Health Survey reported that 24.7 per cent of women of all ages had 5+ drinks once a month and 5.2 per cent once a week (First Nations Centre 2005).

Risk factors for prenatal alcohol exposure include higher maternal age, lower education level, cocaine use, smoking, custody changes, lower socio-economic status, reduced access to prenatal and postnatal care, inadequate nutrition, poor developmental environment (e.g., stress, abuse, neglect), mental health concerns, social isolation and a history of severe childhood sexual abuse (Astley et al. 2000a; Mengel, Searight and Cook 2006; Bingol et al. 1987; Sood et al. 2001).

The impact of alcohol exposure varies with the timing of exposure during fetal development and the pattern of consumption (e.g., binge drinking: 4 or more drinks per occasion) (Stratton, Howe and Battaglia 1996; Maier and West 2001). Unplanned pregnancies may occur when these women are drinking and do not use effective birth control (Project CHOICES Intervention Research Group 2002). Up to 50 per cent of women who become pregnant will not realize they are pregnant until after their sixth week of pregnancy, exposing their fetus to alcohol at a particularly vulnerable time (Floyd, Decoufle and Hungerford 1999). This fact is especially important because 1 in 8 women of childbearing age report binge drinking in the past month (Tsai and Floyd 2004). When women drink, they are more likely to participate in risky behaviour, including having multiple sexual partners and engaging in unprotected intercourse, increasing the likelihood of an alcohol-exposed pregnancy (Wechesler et al. 1994).

It is possible to identify women at risk for alcohol abuse by past history of health behaviour. In surveys of women aged 18–44 years from 6 settings, including an urban jail, a drug/alcohol treatment facility, a gynecology clinic, two primary care clinics, and a response to a media solicitation in the United States. 12.5 per cent met the *a priori* definition of "at risk" for an alcohol-exposed pregnancy. Stepwise logistic regression showed that the following were significantly correlated with being at risk:

- Recent drug use (odds ratio [OR]=3.1; 95 per cent confidence interval [CI]=2.1-4.4).
- Having smoked more than 100 cigarettes (OR=1.9, 95 per cent CI=1.3-2.7).
- A history of inpatient treatment for drugs or alcohol (OR=1.8, 95 per cent CI=1.3-2.4).
- Inpatient mental health treatment (OR=1.6, 95 per cent CI=1.1-2.3).
- Having multiple sex partners (OR=1.7, 95 per cent CI=1.2-2.2)
- Recent physical abuse (OR=1.5, 95 per cent CI=1.1-2.0) (Project CHOICES Intervention Research Group 2002).

Although the Institute of Medicine and United States Preventive Services Task Force (USPSTF) advocate routine alcohol screening for pregnant women, recent estimates suggest that only one-third of pregnant women are assessed for alcohol use during routine prenatal care in the United States (USPSTF 2004; Chang et al. 2000). When screening does occur, it is frequently confined to the initial prenatal visit, rather than at every prenatal visit.

### 3.2.5 Low Birth Weight as a Risk Factor for Disabilities

Extremely or Very Low Birth Weight (VLBW) infants are at increased risk of neurological abnormalities, developmental delays and educational, psychological and behavioural problems (Tanner, Sabine and Wren 2005; Mikkola et al. 2005). Visual impairments are common, and their prevalence increases with decreasing gestational age (Victorian Infant Collaborative Study Group 1997; Vohr et al. 2000). VLBW infants also have an increased risk for hearing loss (Cole, Hagadorn and Kim 2002; Hack and Fanaroff 2000) and speech and language delays (Cole et al. 2002; (Hille et al. 2001). Approximately 6 to 20 per cent of VLBW children have cerebral palsy and related neurologic disability, compared with normal birth weight children (Cole et al. 2002; Hack, Klein and Taylor 1995). Even VLBW children who seem “healthy” in childhood may have greater limitations in activities of daily living during adolescence (Hille et al. 2001), lower mean IQs, lower academic achievement scores, higher neurosensory impairment rates and subnormal height, compared with normal birth weight peers (Hack et al. 2002).

#### *Prematurity*

Prematurity is also a risk factor for disability and commonly a cause of low birth weight. Of babies born at 23–24 weeks, 20 to 35 per cent will have some disability and 10 per cent will have a severe disability. Of babies born at 25 weeks, 10 to 25 per cent will have some disability. At 28–32 weeks, 10 to 15 per cent will have some disability, and at 33 weeks, about 5 per cent will have some disability (Maternal Newborn Early Child Development Resource Centre et al. 2002). Common outcomes of prematurity are cerebral palsy (Elliot et al. 2005), failure to catch-up on growth, increased disease and re-hospitalizations, underweight and shorter than expected height and educational, psychological and behavioural problems (Bhutta et al. 2002 **MA**). Six percent of deliveries in BC in 1999–2003 were premature (8,600 deliveries) (BCVSA 2005).

A number of risk factors for low birth weight (LBW)/small for gestational age (SGA)<sup>2</sup>/prematurity fall within the domain of public health, while some are within the domain of primary and acute care.

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<sup>2</sup> Small for gestational age (SGA) is defined as birth weight less than the 10<sup>th</sup> percentile.

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**Table 5: Risk Factors for Prematurity**

Public Health	Primary or Acute Care	Other Factors
<ul style="list-style-type: none"> <li>Maternal malnutrition</li> </ul>	<ul style="list-style-type: none"> <li>Previous history of preterm/LBW births</li> <li>Bacterial vaginosis</li> <li>Urinary tract infection</li> <li>Placental factors</li> <li>Multiple births</li> </ul>	<ul style="list-style-type: none"> <li>Race/ethnicity</li> <li>Extremes of maternal age</li> <li>Low socio-economic status</li> <li>Occupational factors</li> <li>A short (&lt;18 months) and a long (&gt;60 months) birth interval</li> </ul>
Heavy alcohol use Cocaine use Passive smoking/environmental tobacco smoke exposure Violence/abuse Antenatal care Chronic stress HIV infection Tobacco use		

Sources: (City of Toronto 2002 **R**; Kharrazi et al. 2004 **COM**; Croteau, Marcoux and Brisson 2006 **CCS**; Luke et al. 1995).

**3.2.6 Environmental Risks**

Vrijheid, Loane and Dolk (2003) carried out a systematic review of environmental risks for congenital abnormalities (see Table 6<sup>3</sup> for a summary of the review). In summary, exposure to environmental contaminants in the air and water and at work can be a risk factor for congenital defects and low birth weight. The evidence is very specific regarding the type of environmental exposure (e.g., type of pesticide and degree of exposure). The topic of pesticide exposure merits a review by itself. It is strongly recommended that any health region review the full report in order to assess the relevance of the findings for their own region. Monitoring and surveillance for clusters of congenital anomalies continues to be an important public health strategy.

**Table 6: Environmental Pollution and Congenital Anomalies**

	Quality of Evidence (Good vs. Poor)	Number of Studies in Review	Risk of Congenital Anomalies	Risk of Low Birth Weight, Stillbirth or Preterm Birth
1. Heavy Metals				
1.1 Lead (water, smelter, industrial, residential)	Good.	10	No difference in women with occupational exposure to lead (Gump et al. 2005 <b>COM</b> ).	No difference in women with occupational exposure to lead (Gump et al. 2005 <b>COM</b> ).
1.2 Mercury		6	Confirmed teratogen.	Lacking evidence.
1.3 Cadmium		8	Lacking evidence.	Lacking evidence.
1.4 Arsenic		11	Lacking evidence.	Possible.

<sup>3</sup> The summary in Table 6 provides a simplified view of what is a complex body of evidence. Over 350 studies were cited in this review, and many were judged to be poor quality as a result of possible recall bias and/or retrospective methods.

**Core Public Health Functions for BC: Evidence Review**  
**Prevention of Disabilities (Congenital & Genetic)**

	<b>Quality of Evidence (Good vs. Poor)</b>	<b>Number of Studies in Review</b>	<b>Risk of Congenital Anomalies</b>	<b>Risk of Low Birth Weight, Stillbirth or Preterm Birth</b>
1.5 Chromium		2	Lacking evidence.	Lacking evidence.
1.6 Nickel		1	Lacking evidence.	Lacking evidence.
2. Organic solvents	Large body of research.	44	Higher risk (occupational).	None reported in review.
3. Vinyl chloride and styrene		13	Higher risk (occupational).	None reported in review.
4. Polychlorinated biphenyls (PCBs)*	Multiple chemical exposure at the same time.		Confirmed teratogen. Minor defects.	Mixed results.
5. Dioxins and phenoxy herbicides		19	Lacking evidence.	Possible higher risk for low birth weight Possible higher risk for early spontaneous abortion, paternal exposure.
6. Pesticides	Extensive number of studies but exposure hard to measure; many different pesticides.	37	Evidence is mixed. Possible effect and paternal exposure possible effect. Possible higher risk in areas close to agriculture.	None reported in review.
7. Air pollution (carbon monoxide, nitrogen oxides, sulphur dioxide)	Few studies on congenital anomalies; studies in highly polluted areas.	12	None reported in review.	Probable higher risk.
<b>8. Drinking water</b>				
8.1 Water pollution Chlorinated and aromatic solvents		14	Good evidence of higher risk in well-designed studies.	None reported in review.
8.2 Drinking water pollution Chlorination by-products e.g., trihalomethanes	Extensive number of studies but exposure hard to measure	17	Good evidence of higher risk in well-designed studies.	Probable higher risk for spontaneous abortion.
8.3 Water hardness		17	Mixed results. Possible lower risk with higher magnesium levels.	
<b>9. Hazardous waste sites</b>				
9.1 Single-site studies		18	25 per cent increase in incidence in Sydney, Nova Scotia compared to the rest of Nova Scotia..	Very strong evidence of higher risk of spontaneous abortion, low birth weight and preterm birth.
9.2 Multi-site studies		9	Increased risk 12 to 33 per cent.	None reported in review.

**Core Public Health Functions for BC: Evidence Review**  
**Prevention of Disabilities (Congenital & Genetic)**

	Quality of Evidence (Good vs. Poor)	Number of Studies in Review	Risk of Congenital Anomalies	Risk of Low Birth Weight, Stillbirth or Preterm Birth
10. Smelters		12	None reported in review.	Higher risk of spontaneous abortion. Non-significant reduction in intra-uterine growth retardation (Trail).
11. Incinerators	Few studies	3	Lacking evidence.	None reported in review.
12. Residence in contaminated areas		3	None reported in review.	Possible higher risk of low birth weight in industrial areas.
13. Endocrine-disrupting chemicals (e.g., PCBs)		16	Mixed evidence.	None reported in review.

**Note:**

\* PCBs have been banned since the 1970s in Canada and the United States.

**Source:** (Vrijheid et al. 2003).

### 3.2.7 Lead Exposure

Until the 1980s, the two main sources of lead exposure for Canadians were leaded house paints and emissions from leaded gasoline. In 1983, Canada initiated a phase-out of leaded gasoline, and in 1990, implemented regulations limiting the use of leaded gasoline. Lead concentration in urban air decreased from about 0.55 micrograms per cubic metre in 1975 to less than 0.05 in 1990, a drop of more than 90 per cent (Health Canada 2002).

Blood-lead levels (BLL) in children have been monitored in the United States, and it is assumed data in the United States would be similar to Canada, although the age, condition and quality of housing stock may be different. Blood-lead levels declined 41 per cent between 1988 and 2002 in the United States. In 1991 to 1994, the overall mean BLL for the American population aged 1-year-old and older was 2.3 microgram/dl, with 2.2 per cent of the population having levels  $\geq 10$  microgram/dl, the level of health concern for children. Among American children aged 1–5 years, the mean BLL was 2.7 microgram/dl, and 890,000 of these children (4.4 per cent) had elevated BLL (Pirkle et al. 1998 **COM**). The prevalence of elevated BLL among children living in homes in the United States built before 1946 was 5 times higher than that among children living in homes built after 1973 (most of which do not have leaded paint) in the 1991 to 1994 survey (Pirkle et al. 1998 **COM**).

In the past, the risk of health effects of exposure to lead has been pegged at  $BLL > 10 \mu\text{g/dL}$ . In 2005, the Centers for Disease Control and Prevention issued recommendations for prevention of lead exposure in children, targeting  $BLL < 10 \mu\text{g/dL}$ . Their recommendations are based on an evidence-based review of the literature (CDC 2005). The available evidence supports an inverse (negative) association between BLLs  $< 10 \mu\text{g/dL}$  and the cognitive function of children, as well as other health effects (CDC 2005). Higher BLL are significantly associated with both myocardial infarction and stroke mortality, and the association is evident at levels ( $\geq 2 \mu\text{g/dL}$ ), much lower than previously reported (Menke et al. 2006).

### 3.2.8 Occupational Factors

In a recent case control study in Quebec, it was found that an increased risk for having a small for gestational age infant was significantly associated with an irregular or shift-work schedule alone or at with least two of the following: night work, irregular or shift-work schedule, standing posture, lifting loads, noise and high psychological demand combined with low social support. The elimination of these occupational conditions by preventive measures taken before 24 weeks gestation brought workers risks close to those of the women who were not exposed to these conditions (Croteau et al. 2006 CCS).



## **4.0 PRE-CONCEPTION**

There is increasing evidence that pre-conception counselling and care can reduce maternal and fetal morbidity and mortality, including congenital malformations. Since 1987, several reviews of published reports have assessed the evidence and documented the effectiveness of specific pre-conception interventions (Moos and Cefalo 1987; Jack and Culpepper 1990). One systematic review found new evidence of effectiveness for screening women who are seeking family planning for risk conditions; providing dietary folate supplements; and providing nutrition services to women affected by certain metabolic conditions (diabetes and hyperphenylalanemia) (Korenbroet et al. 2002 **SR**).

The effectiveness of several interventions that address risk factors preconceptually for adverse outcomes have been documented, including

- Folic acid supplementation (see Section 4.3).
- Management of diabetes (see Section 4.4).
- Control of alcohol consumption (see Section 7.0).

This chapter is drawn from the document *Recommendations to Improve Pre-conception Health and Health Care—United States*, published in April 2006 by the Centers for Disease Control and Prevention (CDC 2006 **G**). Since pre-conceptual care is in the early stages of development, the body of research is not large. Interventions that address multiple pregnancy-related risk behaviours simultaneously have not been systematically evaluated and are less commonly delivered.

### **4.1 Pre-conception Programs in Other Countries**

In France, pre-conception care has focused on good glycemic control prior to conception. Tertiary perinatal centres began offering pre-conception care in an attempt to reduce the level of adverse pregnancy outcomes of diabetic mothers (Boulet et al. 2006). Services included risk assessment of potential diabetic complications, education on nutritional and glycemic self-monitoring and optimization of insulin treatment regimens as directed by treatment guidelines. Data from a cross-sectional study of 12 perinatal centres in France indicate that nearly half of all women with Type 1 diabetes received pre-conception care during 2000 and 2001, as compared to 24 per cent of women with Type 2 diabetes. Because rates of adverse outcomes among infants of diabetic mothers were similar to those during 1986 to 1988, it was concluded that more effort was needed to achieve the targets.

In 1989, Hungary established the Optimal Family Planning Service (OFPS) under the direction of the World Health Organization (WHO) Collaborating Centre for the Community Control of Hereditary Diseases. The OFPS was comprised of 32 regional health care centres providing periconceptional care free of charge. In 1996, the Hungarian government increased the number and scope of the centres to incorporate these services within primary health care. Assessments of various indicators in Hungary 10 years after the creation of the OFPS indicate that the rates of major congenital anomalies decreased and that the use of protective factors such as folic acid supplementation, rubella vaccination, and infection screening increased. The Hungarian model

was based on three steps: check-up of reproductive health (i.e., pre-conceptional screening), the three-month preparation for conception and better protection in early pregnancy. The periconceptional care model is effective for the introduction of periconceptional folic acid/multivitamin supplementation and for the reduction of smoking and alcohol consumption. The rate of major congenital abnormalities (20.6 per 1,000) was significantly lower than expected (35 per 1,000), although these rates are substantially higher than those seen in Canada (Czeizel 1999 **RCT**).

In the US, there is a modest system of pre-conceptual services. Boulet et al. (2006) has summarized periconceptional activities in 22 states, including a sample of performance measures and priorities. Freda, Moos and Curtis (2006 **CPG**) summarized the pre-conceptual activities of the principal maternity care providers in the United States, including standards and scope of each professional organization.

## **4.2 Recommendations by the Centers for Disease Control and Prevention (2006)**

### **4.2.1 Recommendation 1. Consumer Awareness.**

*Increase public awareness of the importance of pre-conception health behaviours and pre-conception care services by using information and tools appropriate across various ages; literacy, including health literacy; and cultural/linguistic contexts.*

### **4.2.2 Recommendation 2. Preventive Visits.**

*As a part of primary care visits, provide risk assessment and educational and health promotion counselling to all women of childbearing age to reduce reproductive risks and improve pregnancy outcomes.*

A prospective study of the impact of pre-conception health promotion in a family planning clinic revealed that women who had received the intervention (22 per cent) were more likely to report intended pregnancies (Moos et al. 1996 **CCS**).

### **4.2.3 Recommendation 3. Interventions for Identified Risks in the Pre-conception Period.**

*Increase the proportion of women who receive interventions as follow-up to pre-conception risk screening, focusing on high priority interventions (i.e., those with evidence of effectiveness and greatest potential impact).*

## **Risk Factors for Adverse Outcomes**

- **Isotretinoin.** Use of isotretinoin (e.g., Accutane<sup>®</sup>) in pregnancy to treat acne can result in miscarriage and birth defects (CDC 2000a).
- **Recreational drug use.** Further research is needed on preconceptual care for recreational drug users. See the evidence review on the *Prevention of the Harmful Effects of Substance Use*.

- **Anti-epileptic drugs.** Certain anti-epileptic drugs are known teratogens (e.g., valproic acid). Recommendations suggest that before conception, women who are on a regimen of these drugs and who are contemplating pregnancy should be prescribed a lower dosage of these drugs (Barrett and Richens 2003 **R**; Crawford et al. 1999 **CPG**).
- **Folic acid deficiency.** Daily use of vitamin supplements containing folic acid prior to pregnancy has been demonstrated to reduce the occurrence of neural tube defects (Lumley et al. 2001 **SR**; Williams et al. 2005; Robbins et al. 2005 **RCT**; Czeizel, Dobo and Vargha 2004 **CCS**). Strategies to increase the uptake of pre-conceptual folic acid are discussed in Section 4.3.
- **Diabetes (pre-conception).** The three-fold increase in the prevalence of birth defects among infants of women with Type 1 and Type 2 diabetes can be substantially reduced through proper management of diabetes in the pre-conception period (American Diabetes Association 2004; McElvy et al. 2000; Jovanovic and Nakai 2006; Ray, O'Brien and Chan 2001 **MA**). See Section 4.4.
- **Infectious Diseases.** See prenatal guidelines for screening for infections in Section 5.1.
- **Hepatitis B.** Vaccination is recommended for men and women who are at risk for acquiring hepatitis B virus (HBV) infection. Preventing HBV infection in women of childbearing age prevents transmission of infection to infants and eliminates the risk to the woman of HBV infection and sequelae, including hepatic failure, liver carcinoma, cirrhosis and death (Mast et al. 2005).
- **HIV/AIDS.** If HIV infection is identified before conception, timely antiretroviral treatment can be administered, and women (or couples) can be given additional information that can help prevent mother-to-child transmission (CDC 2002d **G**; Brocklehurst 2006 **SR**).
- **Rubella seronegativity.** Rubella vaccination provides protective seropositivity and prevents congenital rubella syndrome (CDC 2001 **G**; American College of Obstetricians and Gynecologists [ACOG] 2003 **G**).
- **Sexually Transmitted Diseases (STDs).** *Chlamydia trachomatis* and *neisseria gonorrhoeae* have been strongly associated with ectopic pregnancy, infertility and chronic pelvic pain. STDs during pregnancy might result in fetal death or substantial physical and developmental disabilities, including mental retardation and blindness. Early screening and treatment prevents these adverse outcomes (CDC 2000b).
- **Hypothyroidism.** The dosages of Levothyroxine<sup>®</sup> required for treatment of hypothyroidism increase during early pregnancy. Levothyroxine<sup>®</sup> dosage needs to be adjusted for proper neurological development of the fetus (ACOG 2002 **CPG**; American Association of Clinical Endocrinologists 2002 **CPG**).
- **Maternal phenylketonurea (PKU).** Women diagnosed with PKU as infants have an increased risk for delivering neonates/infants with mental retardation. However, this

adverse outcome can be prevented when mothers adhere to a low phenylalanine diet before conception and continue it throughout their pregnancy (ACOG 2001a **G**).

- **Obesity.** Adverse perinatal outcomes associated with maternal obesity include neural tube defects, preterm delivery and diabetes, as previously described in Section 3.2.2. A comprehensive review of obesity and reproduction, including recommendations, has been published (Association of Maternal and Child Health Programs 2006), along with an extensive list of recommendations about approaches to a healthy weight.
- **Oral anticoagulant.** Warfarin, which is used for the control of blood clotting, has been demonstrated to be a teratogen. To avoid exposure to warfarin during early pregnancy, medications can be changed to a non-teratogenic anticoagulant before the onset of pregnancy (ACOG 2001b **G**).
- **Smoking.** The Cochrane Review of smoking cessation in pregnancy provides substantial evidence about the effectiveness of smoking interventions in pregnancy, which could potentially be applied to pre-conception programs (Lumley et al. 2006 **SR**). Smoking cessation has been included in the evidence review on Healthy Living (Tobacco Control).
- **Alcohol misuse.** Prevention of alcohol use in the pre-conception period can result from any general community-based alcohol prevention program, including programs targeting young women, and screening and counselling programs in primary care (Floyd et al. 2005 **CPG**; Ingersoll et al. 2003 **PP**; Whitlock et al. 2004 **R**; Floyd et al. 1999). Further details can be found in Section 3.1.4, and in the evidence review on *Prevention of the Harmful Effects of Substance Use*.

#### 4.2.4 Recommendation 4. Interconception Care.

*Use the interconception period to provide additional intensive interventions to women who have had a previous pregnancy that ended in an adverse outcome (i.e., infant death, fetal loss, birth defects, low birth weight, or preterm birth).*

Experiencing an adverse outcome in a previous pregnancy is an important predictor of future reproductive risk (Klerman, Cliver and Goldenberg 1998; Mercer et al. 1999 **PS**; Surkan et al. 2004). Short interpregnancy interval can also result in poorer outcomes.

#### 4.2.5 Recommendation 5. Pre-pregnancy Checkup.

*One pre-pregnancy visit for women and their partners planning pregnancy should be offered as a component of maternity care.*

#### 4.2.6 Recommendation 6. Public Health Programs and Strategies.

*Integration of components of pre-conception health into existing local public health and related programs, including emphasis on interconception interventions for women with previous adverse outcomes is recommended.*

The CDC makes 44 recommendations about service integration that are available in the full report.

One example of integration is a multi-strategy approach to the integration of services in North Carolina, involving primary care and departments of health and mental health. Interventions focused on the delivery system within the physician's office, and the use of teamwork and data in an "office systems" approach. The home-visiting intervention involved teams of nurses and educators and involved two to four visits per month through the infant's first year of life. Visits provided education on fetal and infant health and development, informal support systems, linkages with health and human services, training in injury prevention and child discipline and assisted mothers in obtaining care from primary care offices.

The results of this approach included the following:

- Intervention group women were significantly more likely to use contraceptives (69 per cent versus 47 per cent), not smoke tobacco (27 per cent versus 54 per cent) and have a safe and stimulating home environment for their children.
- Intervention group children were more likely to have had an appropriate number of well-child care visits (57 per cent versus 37 per cent) and less likely to be injured (2 per cent versus 7 per cent).
- Intervention mothers also received Aid to Families with Dependent Children for fewer months after the birth of their child (7.7 months versus 11.3 months) (Margolis et al. 2001 **OB**).

### **4.3 Folic Acid**

While the evidence of prevention of neural tube defects by folic acid has been established, evidence of the effect of folic acid and other vitamin supplements on birth defects has been growing. Recently, a systematic review and meta-analysis was conducted to evaluate the protective effect of folic acid-fortified multivitamin supplements on other congenital anomalies (Goh et al. 2006 **MA**). Use of multivitamin supplements provided was reported to be associated with consistent protection against neural tube defects, cardiovascular defects limb defects, cleft palate, urinary tract anomalies and congenital hydrocephalus. a protective effect of large doses of folic acid (approximately 6 mg/d) and iron (150-300 mg/d of ferrous sulfate) during the first gestational month against Down's syndrome (adjusted odds ratio 0.4, 95 per cent confidence interval 0.2 to 0.7 for both). In general, folic acid and iron were used together, so it was difficult to separate these effects, due to the limited number of subjects and controls (Czeizel and Puho 2005 **CCS**). The Society of Obstetricians and Gynaecologists of Canada has published recommendations on folic acid consumption based on the evidence (Table 7).

**Table 7: Folic Acid Recommendations (Society of Obstetricians and Gynaecologists of Canada)**

	Level of Evidence
Women in intermediate- to high-risk categories for neural tube defects (NTDs) (NTD-affected previous pregnancy, family history, insulin-dependent diabetes, epilepsy treatment with valproic acid or carbamazepine) should be advised that high-dose folic acid supplementation is recommended (4.0 mg to 5.0 mg daily). This should be taken as folic acid alone, not in a multivitamin format, due to risk of excessive intake of other vitamins, such as vitamin A.	(I-a)
Women who could become pregnant should be advised to take a multivitamin containing 0.4 mg to 1.0 mg of folic acid daily.	(II-1a)
Women in the reproductive age group should be advised about the benefits of folic acid supplementation during wellness visits (birth control renewal, Pap testing, yearly examination), especially if pregnancy is contemplated.	(III-a)
A three-generation pedigree on the families of both the pregnant woman and the biological father should be obtained to identify increased risk for congenital birth defects (e.g., NTD, cardiac, chromosomal, or genetic defects).	(III-a)
Women should be advised to maintain a healthy nutritional diet, as recommended in <i>Canada's Food Guide to Healthy Eating</i> (good or excellent sources of folic acid: broccoli, spinach, peas, Brussels sprouts, corn, beans, lentils, oranges).	(III-a)

Source: (Wilson et al. 2003).

#### 4.3.1 Impact of Folic Acid Fortification in Canada

Evidence regarding the relative impact of food fortification versus supplementation suggests that both strategies have contributed to reducing NTDs, but the impact has varied by geographic area. Maternal serum screening and termination may also have been responsible for downward trends in NTDs.

Most of Canada's cereal grain products were fortified with folic acid by January 1998, providing an additional 0.1 to 0.2 mg per day of dietary folate to the Canadian population. The effect of supplementation on the prevalence of open neural tube defects was measured before and after fortification. The total annual incidence of NTDs in Newfoundland fell by 78 per cent after the implementation of folic acid fortification, from an average of 4.36 per 1,000 births during 1991–1997 to 0.96 per 1,000 births during 1998–2001 (RR 0.22, 95 per cent CI 0.14-0.35,  $p < 0.0001$ ). In this study, it was not possible to determine the contribution of supplementation versus fortification to the trend in NTDs (Public Health Agency of Canada 2003; House et al. 2006 **XS**).

In Nova Scotia and Ontario, fortification seemed to have more of an effect than supplementation. In Nova Scotia, in the period after supplementation but before fortification, the incidence of open NTDs did not change significantly: After fortification was implemented, the incidence of open NTDs decreased by more than 50 per cent: the mean annual rate was 2.58 per 1,000 births during 1991–1997 and 1.17 per 1,000 births during 1998–2000 (RR 0.46, 95 per cent CI 0.32–0.66) (Persad 2002). Among women in Ontario undergoing maternal serum screening, the prevalence of open neural tube defects declined from 1.13 per 1,000 pregnancies to 0.58 per 1,000 pregnancies after fortification (prevalence ratio 0.52, 95 per cent CI 0.40-0.67,  $p < 0.0001$ ) (Ray et al. 2002).

4.3.2 Strategies to Increase Uptake of Recommendations

The strongest predictor of folic acid supplementation is consultation with a health care provider before becoming pregnant (De Jong-Van den berg et al. 2005 CCS) or hearing about it from a physician or anyone else in the health care system (Feldkamp, Friedrichs and Marti 2002). Other strategies that have been effective are mass media campaigns on periconceptional folic acid use (See Table 8). The campaign in the Netherlands seems to have been the most effective, but needs to be viewed in the context of the extensive use of midwives for prenatal care in the Netherlands, as well as campaigns directed at health professionals.

**Table 8: Comparative Rates of Periconceptional Folic Acid Tablet Supplement Use Before and After the Introduction of Public Folic Acid Awareness Campaigns.**

Description of Campaign	Number (Per cent) Periconceptional Folic Acid Vitamin Tablet Use*		Rate Ratio (95 per cent CI)**
	Before campaign	After campaign	
<b>1996 Health Education Authority campaign in UK</b> (Sillender and Pring 2000)* To increase public and professional's awareness of, and access to folic acid-fortified foods and supplements. Use of television and magazine announcements.	71/262 (27 per cent)	36/75 (48 per cent)	1.8 (1.3–2.4)
<b>1995 campaign in Netherlands</b> (van de Pal-de Bruin et al. 2000 COM). Aimed at women wishing to conceive (“planners”), and their health care professionals. Subsequently aimed also at women who might want to become pregnant, though not immediately (“future planners”). Use of media aimed at public and professionals. Personal letters sent to health care professionals.	78/1636 (4.8 per cent)	339/1612 (21 per cent)	4.4 (3.5–5.6)
<b>1994–1995 “Folate Before Pregnancy” campaign in South Australia</b> (Chan et al. 2001) Use of telephone messages, leaflets, messages in newspapers and occasional television announcements.	50/187 (27 per cent)	77/167 (46 per cent)	1.7 (1.3–2.3)
<b>1995 campaign in Netherlands</b> (de Walle, Cornel and de Jong-van den Berg 2002). Use of mass media. Special attention paid to women of lower socio-economic status.	17/342 (5.0 per cent)	161/452 (36 per cent)	7.2 (4.4–11.6)

**Notes:**

\* Considers folic acid vitamin use before conception and in the early first trimester of pregnancy.

\*\* Compares rate after folic acid campaign with rate before campaign.

**Source:** (Ray, Singh and Burrows 2004).

The results of the United Kingdom’s 1995–1998 folic acid campaign (Sillender and Pring 2000) showed that

- 24 per cent of pregnant and recently pregnant women claim to have taken folic acid when planning for a baby; 54 per cent during the first 12 weeks of pregnancy and 73 per cent at some time during pregnancy (1997).

- In 1997, 71 per cent of health professionals spontaneously identified that folic acid advice should be given to women planning a pregnancy, compared to 55 per cent in 1996.
- In 1997, 49 per cent of health professionals who had seen campaign information claimed to have changed their practice as a result.
- The range of fortified products and supplements increased. For example, the number of brands of bread that included folic acid increased from 8 to 20.
- Availability, sales and prescribing of folic acid supplements changed during the campaign. During the campaign, one more single folic acid supplement gained a medicinal license. The number of unlicensed supplements increased from 9 in 1996 to 17 in 1998. Eight months after the launch of the consumer campaign, sales of folic acid were on average 40 per cent higher than at the start of the campaign. Prescription rates for folic acid were 55 per cent higher in the third quarter of 1997 than at the start of the campaign.

## **4.4 Diabetes**

A meta-analysis of the effect of pre-conception care in reducing congenital malformations in women with diabetes mellitus has shown that the pooled rate of major anomalies was lower among pre-conception care recipients (2.1 per cent) than non-recipients (6.5 per cent) In nine studies, the risk for major and minor anomalies was also lower among women who received pre-conception care (RR 0.32, 95 per cent CI 0.17–0.59), as were the early first-trimester mean glycosylated haemoglobin values (pooled mean difference: 2.3 per cent, 95 per cent CI 2.1–2.4) (Ray et al. 2001 **MA**).

With the results of the Diabetes Prevention Trial showing that both metformin therapy and intensive lifestyle intervention reduced the risk of developing diabetes (by 31 per cent and 58 per cent, respectively, in comparison with placebo, age 30+) there is potential for pre-conception screening for impaired glucose tolerance in women with risk factors (Ratner 2006 **RCT**). Prevention trials have demonstrated that Type 2 diabetes and its complications can be prevented or at least delayed through healthful dietary practices, regular moderate physical activity, weight loss and medication use (Diabetes Control and Complications Trial Research Group 1993 **RCT**; Diabetes Prevention Program Research Group 2002 **RCT**). Estimates of the cost and benefits of pre-conception diabetes care have shown potential benefits since the early 1990s (Scheffler, Feuchtbaum and Phibbs 1992 **CCS**; Elixhauser et al. 1993). However, guidelines have only recently been developed. Guidelines for pre-conception care in diabetes have been published by the CDC in 2006. These guidelines include increased training for health care providers, an expanded community assessment and education program, increased surveillance as well as other health care system enhancements (Owens, Kieffer and Chowdhury 2006). New guidelines on pre-conception and diabetes are under development by the National Institute for Clinical Excellence (NICE) organization in the United Kingdom, and are due November 2007.

### **4.4.1 Prevention of Diabetes**

A systematic review and meta-analysis has shown evidence of prevention or delay of the onset of diabetes, although none of the studies were specific to pregnancy or pre-conception. Twenty-one



trials met the inclusion criteria, of which 17, with 8,084 participants with impaired glucose tolerance, reported results in enough detail for inclusion in the meta-analysis. From the meta-analysis the pooled hazard ratios were 0.51 (95 per cent CI 0.44 to 0.60) for lifestyle interventions versus standard advice, 0.70 (0.62 to 0.79) for oral diabetes drugs versus control, 0.44 (0.28 to 0.69) for orlistat versus control, and 0.32 (0.03 to 3.07) for the herbal remedy jiangtang bushen recipe versus standard diabetes advice. These correspond to numbers needed to treat for benefit (NNTB) and harm (NNTH) of 6.4 for lifestyle (95 per cent credible interval, NNTB 5.0 to NNTB 8.4), 10.8 for oral diabetes drugs (NNTB 8.1 to NNTB 15.0), 5.4 for orlistat (NNTB 4.1 to NNTB 7.6), and 4.0 for jiangtang bushen (NNTH 16.9 to NNTB 24.8). Overall, the studies showed that lifestyle and pharmacological interventions reduce the rate of progression to Type 2 diabetes in people with impaired glucose tolerance. Lifestyle interventions seem to be at least as effective as drug treatment Gillies et al. 2007 **MA**).

## **4.5 Other Pre-conception Interventions.**

### **4.5.1 Adolescent Health**

The American College of Obstetricians and Gynecologists (ACOG) reaffirms its recommendation that teenage girls first visit an ob-gyn between the ages of 13 and 15 (ACOG 2006) This initial reproductive health visit will help teens develop a relationship with their ob-gyn before they need to seek care for a specific health issue.

### **4.5.2 Family History**

The United States Surgeon General has launched a national public health campaign to encourage all American families to learn more about their family health history. The use of family history as a public health tool in chronic disease prevention has been reviewed by Yoon et al (2001); Yoon, Scheuner and Khoury (2003); and Yoon et al. (2002). Application to birth defect prevention would be a natural fit with this strategy. Cystic fibrosis is one example where prenatal genetic testing is being considered. The Surgeon General has created a new web-based tool to make it easy to create a portrait of a family's health (<https://familyhistory.hhs.gov/>).

### **4.5.3 Genetic Testing**

The Society of Obstetricians and Gynaecologists of Canada (SOGC) recommends carrier screening for Tay-Sachs Disease in Ashkenazi Jewish couples (TSD) (*II 2a*); Canavan disease and familial dysalutonomia screening should also be offered to Ashkenazi Jewish couples (*III a*). Carrier screening for other disorders should also be done for other conditions with increased frequency in Ashkenazi Jews: Bloom syndrome, Fanconi anemia, Gaucher disease, glycogen storage disease type (*Ia*), mucopolysaccharidosis type IV, Niemann-Pick disease (*Ia*), and cystic fibrosis, when there is a positive family history. When only one member of the couple is an Ashkenazi Jew, screening should be offered for TSD only (*II 2a*). When both partners are carriers of the same autosomal recessive condition, they have a 25 per cent risk of having an affected child. They should be referred for genetic counselling before conception (Langlois and Wilson 2006; Leib et al. 2005; ACOG 2005).

## **5.0 PRENATAL INTERVENTIONS**

This section includes extracts from prenatal guidelines from the United Kingdom and additional evidence from other sources such as the Society of Obstetricians and Gynaecologists of Canada and the Cochrane Reviews. The focus is on interventions during the prenatal period within the scope of public health and/or primary care that may have an impact on the prevention of birth defect or disabilities, and/or low birth weight or prematurity.

### **5.1 Prenatal Care**

This section summarizes guidelines for antenatal care as graded by NICE, in conjunction with the Royal College of Obstetricians and Gynaecologists. These guidelines were chosen because they:

- Covered all aspects of routine maternity care in one document.
- Used a systematic review.
- Graded the evidence.
- Were recent.
- Used primary research sources and linked the citations to the recommendations.
- Were based on a population from ethnic groups similar to Canada.
- Were based on a universal health care system.<sup>4</sup>

<b>Level of Evidence/References</b>	
<p><b>Gestational age assessment: last menstrual period and ultrasound</b>                      Pregnant women should be offered an early ultrasound scan (before 16 weeks) to determine gestational age (in lieu of last menstrual period for all cases) and to detect multiple pregnancies. This will ensure consistency of gestational age assessments, improve the performance of mid-trimester serum screening for Down’s syndrome, and reduce the need for induction of labour after 41 weeks.</p>	<p><b>A</b>                      (Neilson 2000 <b>SR</b>)</p>
<p><b>Nutritional supplements</b>                      Pregnant women (and those intending to become pregnant) should be informed that dietary supplementation with folic acid, before conception and up to 12 weeks’ gestation, reduces the risk of having a baby with neural tube defects (anencephaly, spina bifida). The recommended dose is 400 micrograms per day. See Section 4.3 for more information on folic acid.</p>	<p><b>A</b>                      (Czeizel 1999 <b>RCT</b>)                      (Wald et al. 2001 <b>CT</b>)                      (Czeizel 2004)</p>

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<sup>4</sup> Further details on the guidelines can be found at <http://www.nice.org.uk/page.aspx?o=cg006fullguideline>.

**Core Public Health Functions for BC: Evidence Review**  
**Prevention of Disabilities (Congenital & Genetic)**

	<b>Level of Evidence/References</b>
High levels of preformed vitamin A during pregnancy are considered to be teratogenic. From the epidemiological evidence, it is not possible to establish a clear dose-response curve or threshold above which vitamin A intake may be harmful during the first trimester (considered to be the critical period for susceptibility). A dose between 10,000 and 25,000 IU of vitamin A may pose a teratogenic risk. The intake of vitamin A during pregnancy should be limited to the recommended daily amount. As liver and liver products contain variable and sometimes very high amounts of vitamin A (10,000–38,000 mg per typical portion size of 100g), these should be avoided in pregnancy. The consumption of liver and liver products by pregnant women (and moreover the intake of greater than 700 µg) is associated with an increase in the risk of certain congenital malformations.	<b>C</b> (Rothman et al. 1995 <b>PS</b> )
<b>Scuba diving in pregnancy</b> Pregnant women should be informed of the potential dangers of certain activities during pregnancy, especially scuba diving, which may result in fetal birth defects and fetal decompression disease.	<b>D</b> (Camporesi 1996)
<b>Smoking in pregnancy</b> Pregnant women should be informed about the specific risks of smoking during pregnancy (such as the risk of having a preterm baby and low birth weight baby). The benefits of quitting at any stage should be emphasized. Women who smoke or who have recently stopped should be offered smoking cessation interventions. Interventions that appear to be effective in reducing smoking include advice by physician, group sessions, and behavioural therapy (based on self-help manuals).	<b>A</b> (Lumley et al. 2006 <b>SR</b> ) (Wyszynski, Duffy and Beaty 1997 <b>MA</b> )
<b>Screening for haematological conditions - Blood grouping and red cell alloantibodies</b>	(Modell et al. 1997)
Women should be offered testing for blood group and RhD status in early pregnancy.	<b>B</b>
It is recommended that routine antenatal anti-D prophylaxis be offered to all non-sensitized pregnant women who are RhD negative.	NICE 2002 Technology Assessment
Women should be screened for atypical red cell alloantibodies in early pregnancy and again at 28 weeks, regardless of their RhD status.	<b>B</b>
Pregnant women with clinically significant atypical red cell alloantibodies should be offered referral to a specialist centre for further investigation and advice on subsequent antenatal management.	<b>D</b>
If a pregnant woman is RhD-negative, consideration should be given to offering partner testing to determine whether the administration of anti-D prophylaxis is necessary.	<b>CPG</b>
<b>Screening for structural anomalies</b> Pregnant women should be offered an ultrasound scan to screen for structural anomalies, ideally between 18 and 20 weeks gestation, by an appropriately trained sonographer and with equipment of an appropriate standard.	<b>A</b> (Bricker et al. 2000 <b>SR</b> ) (Whitlow et al. 1999) (Saari-Kemppainen et al. 1994 <b>COM</b> )

**Core Public Health Functions for BC: Evidence Review**  
**Prevention of Disabilities (Congenital & Genetic)**

<b>Level of Evidence/References</b>	
<p><b>Screening for Down’s syndrome and neural tube defects</b></p> <p>Pregnant women should be offered screening for Down’s syndrome with a test that provides the current standard: a detection rate above 60 per cent and a false-positive rate of less than 5 per cent. The following tests meet this standard:</p> <ul style="list-style-type: none"> <li>• From 11 to 14 weeks <ul style="list-style-type: none"> <li>• Nuchal translucency (NT).</li> <li>• The combined test (NT, hCG and PAPP-A) (MSS).</li> </ul> </li> <li>• From 14 to 20 weeks <ul style="list-style-type: none"> <li>• The triple test (hCG, AFP and uE3) (MSS).</li> <li>• The quadruple test (hCG, AFP, uE3, inhibin A).</li> </ul> </li> <li>• From 11 to 14 weeks and 14 to 20 weeks <ul style="list-style-type: none"> <li>• The integrated test (NT, PAPP-A + hCG, AFP, uE3, inhibin A).</li> <li>• The serum integrated test (PAPP-A + hCG, AFP, uE3, inhibin A).</li> </ul> </li> </ul> <p>By April 2007, NICE recommends that screening for Down’s syndrome be enhanced to provide a detection rate above 75 per cent and a false-positive rate of less than 3 per cent. The following tests currently meet this standard:</p> <ul style="list-style-type: none"> <li>• From 11 to 14 weeks <ul style="list-style-type: none"> <li>• The combined test (NT, hCG and PAPP-A).</li> </ul> </li> <li>• From 14 to 20 weeks <ul style="list-style-type: none"> <li>• The quadruple test (hCG, AFP, uE3, inhibin A).</li> </ul> </li> <li>• From 11 to 14 weeks and 14 to 20 weeks <ul style="list-style-type: none"> <li>• The integrated test (NT, PAPP-A + hCG, AFP, uE3, inhibin A).</li> <li>• The serum integrated test (PAPP-A + hCG, AFP, uE3, inhibin A).</li> </ul> </li> </ul> <p><b><u>Abbreviations</u></b>  <i>AFP maternal serum alpha-fetoprotein (screens for neural tube defects)</i>  <i>MSS = maternal serum screening</i>  <i>hCG =human chorionic gonadotropin</i>  <i>A (PAPP-A) -pregnancy associated plasma protein-</i>  <i>NT - nuchal translucency</i>  <i>uE3 - unconjugated estriol</i></p>	<p><b>B</b>  (Dick 1996)  (Wald et al. 2003)  (Smith-Bindman et al. 2001 <b>MA</b>)  (Conde-Agudelo and Kafury-Goeta 1998 <b>MA</b>)  (Bindra et al. 2002 <b>PS</b>)</p>
<p>Pregnant women should be given information about the detection rates and false-positive rates of any Down’s syndrome screening test being offered and about further diagnostic tests that may be offered. The woman’s right to accept or decline the test should be made clear.</p>	<p><b>D</b></p>

**Core Public Health Functions for BC: Evidence Review**  
**Prevention of Disabilities (Congenital & Genetic)**

<b>Level of Evidence/References</b>	
<b>Screening for infections</b>	
<p><b>Hepatitis B virus</b>            Serological screening for hepatitis B virus should be offered to pregnant women so that effective postnatal intervention can be offered to infected women to decrease the risk of mother-to-child-transmission.<sup>5</sup></p>	<p><b>A</b>            (Xu et al. 1985 <b>RCT</b>)            Wong et al. 1984 <b>RCT</b>)            (Sehgal et al. 1992)            (Nair et al. 1984 <b>RCT</b>)</p>
<p><b>HIV</b></p> <ul style="list-style-type: none"> <li>Pregnant women should be offered screening for HIV infection early in antenatal care, because appropriate antenatal interventions can reduce mother-to-child-transmission of HIV infection.</li> </ul>	<p><b>A</b>            (Brocklehurst 2006 <b>SR</b>)            (Mandelbrot et al. 1998 <b>PS</b>)            (Kind et al. 1998 <b>PS</b>)            (European Model of Delivery Collaboration 1999 <b>RCT</b>)</p>
<ul style="list-style-type: none"> <li>A system of clear referral paths should be established in each unit or department so that pregnant women who are diagnosed with an HIV infection are managed and treated by the appropriate specialist teams.</li> </ul>	<p><b>D</b></p>
<p><b>Rubella</b>            Rubella-susceptibility screening should be offered early in antenatal care to identify women at risk of contracting rubella infection, and to enable vaccination in the postnatal period for the protection of future pregnancies.<sup>6</sup></p>	<p><b>B</b>            (Miller, Cradock-Watson and Pollock 1982 <b>PS</b>)</p>
<p><b>Syphilis</b></p> <ul style="list-style-type: none"> <li>Screening for syphilis should be offered to all pregnant women at an early stage in antenatal care because treatment of syphilis is beneficial to the mother and fetus.</li> </ul>	<p><b>B</b>            (Alexander et al. 1999 <b>PS</b>)            (Walker 2001 <b>SR</b>)</p>
<ul style="list-style-type: none"> <li>Because syphilis is a rare condition and a positive result does not necessarily mean that a woman has syphilis, clear paths of referral for the management of women testing positive for syphilis should be established.</li> </ul>	<p><b>GPG</b></p>
<p><b>Toxoplasmosis</b>            Pregnant women should be informed of primary prevention measures to avoid toxoplasmosis infection.</p>	<p><b>C</b>            (Foulon et al. 1999)            (Gilbert et al. 2006)</p>

<sup>5</sup> Hepatitis B immunization was implemented at the Grade 6 level in BC in 1992.

<sup>6</sup> Rubella immunization is routinely offered to children in BC, so few women who attended school in Canada should need immunization.

**Core Public Health Functions for BC: Evidence Review**  
**Prevention of Disabilities (Congenital & Genetic)**

<b>Level of Evidence/References</b>	
<p><b>Asymptomatic bacteriuria</b>  Pregnant women should be offered routine screening for asymptomatic bacteriuria by midstream urine culture early in pregnancy. Identification and treatment of asymptomatic bacteriuria reduces the risk of preterm birth.</p>	<p><b>A</b>  (United States Preventive Services Task Force 1990) (Smaill 2002 <b>SR</b>) (Villar, Lydon-Rochelle and Gulmezoglu 2001 <b>SR</b>) (Centers for Disease Control and Prevention 2002 <b>CPG</b>)</p>
<p><b>Herpes</b> (not included in NICE Antenatal Guidelines)  All patients and their partners should be asked about a history of genital and orolabial herpes simplex virus (HSV) infection. Those with an HSV-positive partner should consider abstinence, condom use, antiviral therapy in the HSV-positive partner, and avoidance of oral-genital contact if the partner has orolabial HSV infection. Women with recurrent HSV infection should be counselled about the use of acyclovir (Zovirax) at term to decrease the risk of caesarean delivery, the role of caesarean delivery in decreasing vertical transmission, and avoiding postpartum transmission to the infant through direct contact.</p>	<p>(Sheffield et al. 2003 <b>SR</b>) (Royal College of Obstetricians and Gynaecologists [RCOG] 2002 <b>CPG</b>)</p>
<p><b>Varicella Zoster Chicken Pox</b> (not included in Nice Antenatal Guidelines)</p> <ul style="list-style-type: none"> <li>• Screening: All women of childbearing age should be asked about their history of chicken pox. Women with no history of exposure can have serologic testing for varicella zoster IgG to determine immunity (80 to 90 per cent of these women are found to be immune). If testing is done in the pre-conception period, women can be offered two doses of varicella vaccine at least one month apart. Pregnancy should be delayed one month after vaccination. Varicella vaccine is contraindicated in pregnant women.</li> <li>• Immunization: Women found to be non-immune during pregnancy should be counselled to avoid exposure to chicken pox and to report exposure immediately. Susceptible pregnant women who are exposed are candidates for varicella zoster immune globulin. Non-immune women should be offered postpartum varicella vaccination. The vaccine is considered safe in breastfeeding women. Immunization should be delayed for three months in women who have received RhoD immune globulin (Rhogam).</li> </ul>	<p>(National Advisory Committee on Immunization 2004) (CDC 1999 <b>G</b>) (Canadian Task Force on Preventive Health Care 2005 <b>SR</b>)</p>
<p><b>Hepatitis C High-risk screening</b>  Hepatitis C antibody screening should be offered to women with risk factors (e.g., prison inmates, injection drug users, women exposed to blood or blood products, HIV-positive women, women with elevated aspartate transaminase levels, multiple sexual partners, or tattoos). Vertical transmission of hepatitis C is estimated to be 8 percent. Aside from vertical transmission, there does not appear to be an increased risk of adverse pregnancy outcomes in women infected with hepatitis C.</p>	<p><b>B</b>  (Boucher and Gruslin 2000 <b>CPG</b>) (CDC 2002c <b>CPG</b>)</p>

**Core Public Health Functions for BC: Evidence Review**  
**Prevention of Disabilities (Congenital & Genetic)**

<b>Level of Evidence/References</b>	
<b>Recommendations against universal screening</b>	
<p><b>Hepatitis C virus</b>            Pregnant women should not be offered routine screening for hepatitis C virus because there is insufficient evidence on its effectiveness and cost-effectiveness.</p>	<p><b>C</b>            (Whittle et al. 2002)            (Okamoto et al. 2000)            (Tajiri et al. 2001)            (Ketzinel-Gilad et al. 2000)</p>
<p><b>Asymptomatic bacterial vaginosis</b>            Pregnant women should not be offered routine screening for bacterial vaginosis because the evidence suggests that the identification and treatment of asymptomatic bacterial vaginosis does not lower the risk for preterm birth and other adverse reproductive outcomes.</p>	<p><b>C</b>            (McDonald et al. 2003  <b>SR</b>)            (Brocklehurst, Hannah and McDonald 2000  <b>SR</b>)            (Flynn, Helwig and Meurer 1999 <b>MA</b>)            (Gratacos et al. 1998)</p>
<p><b>Chlamydia trachomatis</b>            Pregnant women should not be offered routine screening for asymptomatic chlamydia because there is insufficient evidence on its effectiveness and cost-effectiveness. However, this policy is likely to change in the United Kingdom with the implementation of the national opportunistic chlamydia screening program.</p>	<p><b>A</b>            (Preece et al. 1989)            (John Hopkins Study of Cervicitis and Adverse Pregnancy Outcome 1989)            (Preece, Anderson and Thompson 1989)            (Brocklehurst and Rooney 2000 <b>SR</b>)            (Ketzinel-Gilad et al. 2000)</p>
<p><b>Cytomegalovirus</b>            The available evidence does not support routine cytomegalovirus screening in pregnant women.</p>	<p><b>C</b>            (Peckham et al. 1983  <b>PS</b>)</p>
<p><b>Group B Streptococcus (GBS)</b>            Recommendations on screening for GBS vary among different organizations. The CDC, ACOG, SOGC, the Canadian Task Force on Preventive Health Care, and the BC Reproductive Care Program recommend that all women be offered GBS screening at 35 to 37 weeks' gestation and that colonized women be treated with intravenous antibiotics at the time of labour or rupture of membranes. The United Kingdom guidelines recommend against routine antenatal screening for GBS because evidence of its clinical effectiveness and cost-effectiveness remains uncertain.</p>	<p><b>C</b>            (Smaill 1999 <b>SR</b>)            (CDC 2002b)            (Schrag et al. 2002)            (Money and Dobson 2004)            (Benitz, Gould and Druzin 1999 <b>R</b>)</p>
<p><i>Canadian Task Force on Preventive Health Care Recommendation:</i>            There is fair evidence (level II-1 and II-2) that universal screening for GBS colonization at 35 to 37 weeks' gestation, followed by selective intrapartum chemoprophylaxis (IPC) given to colonized women who have risk factors, reduces the incidence of colonization and early-onset infection in neonates.</p>	<p><b>B</b>            (Canadian Task Force on Preventive Health Care 2002 <b>CPG</b>)</p>

<b>Level of Evidence/References</b>	
There is insufficient evidence to evaluate the effectiveness of IPC given on the basis of risk factors alone.	<b>C</b>
<b>Gestational Diabetes</b> <sup>7</sup> The evidence does not support routine screening for gestational diabetes mellitus.	<b>B</b> (Scott et al. 2002 <b>SR</b> ) (Jensen et al. 2000) (Wen et al. 2000) (Perucchini et al. 1999 <b>PS</b> )

## 5.2 Dental Interventions

Of the over 660 studies identified in a systematic review of periodontal interventions to prevent preterm or low birth weight (PT/LBW), 12 met inclusion criteria and were included in a systematic review. While several studies implicated periodontal disease as a risk factor for PT/LBW, few assessed the impact of the prevention and treatment of periodontal disease on outcomes. Several epidemiologic studies did not support periodontal disease as a risk factor for PT/LBW.

The conclusions reached by the reviewers included:

- Periodontal disease may be a risk factor for PT/LBW.
- Additional longitudinal, epidemiological and interventional studies are needed to validate this association and to determine whether it is causal.
- It is not yet clear whether periodontal diseases play a causal role in adverse pregnancy outcomes.
- Preliminary evidence to date suggests that periodontal intervention may reduce adverse pregnancy outcomes (Scannapieco, Bush and Paju 2003 **SR**).

Dental health is covered in a separate evidence review.

## 5.3 Screening and Management of Diabetes

### 5.3.1 Screening for Gestational Diabetes

A Cochrane review in 2003 determined there was not sufficient evidence to justify screening for gestational diabetes (Tuffnell, West and Walkinshaw 2003 **SR**). However the same author called for universal screening in an editorial in the British Journal of Obstetrics and Gynaecology in 2006 (Tuffnell, West and Walkinshaw 2006), following a clinical trial that showed improved outcomes of mothers and infants with intensive treatment for gestational diabetes (Crowther et al. 2005 **RCT**). Although screening has been recommended in Australia it is not clear if it has been adopted in practice (McIntyre et al. 2005 **CPG**). Recent clinical trials have shown that improved diabetic management improves outcomes for all types of diabetes (McElvy et al. 2000; Jovanovic and Nakai 2006; Ray et al. 2001 **MA**).

<sup>7</sup> Screening for gestational diabetes was done routinely by 94 per cent of American physicians in 1996, but only by 16 per cent of physicians in the United Kingdom.



**Core Public Health Functions for BC: Evidence Review**  
**Prevention of Disabilities (Congenital & Genetic)**

A large prospective study, the Hyperglycaemia and Adverse Pregnancy Outcome (HAPO) study is currently underway, which will help establish whether screening for and treating gestational diabetes improves pregnancy outcomes (HAPO Study Cooperative Research Group 2002 PS). The results of this study are due to be available in 2007 and will provide standards for screening.

Each of the following approaches is acceptable screening protocol according to the SOGC guidelines (Berger, Crane and Farine 2002):

Guideline	Evidence Grade
<ul style="list-style-type: none"> <li>• Routine screening of women at 24–28 weeks of gestation may be recommended with the 50 g glucose challenge test (GCT), using a threshold of 7.8 mmol/L (140 mg/dL), except in those women who fulfill the criteria for low risk</li> <li>• The diagnostic test can be the 100 g oral glucose tolerance test (OGTT), as recommended by ACOG, or the 75 g OGTT, according to the American Diabetes Association (ADA) criteria.</li> </ul>	<b>(III-C)</b>
<ul style="list-style-type: none"> <li>• A small but significant number of Canadian obstetricians and centres have a policy of non-screening for gestational diabetes mellitus (GDM). Until evidence is available from large randomized controlled trials that show a clear benefit from screening for glucose intolerance in pregnancy, the option of not screening for GDM is considered acceptable. Conversely, there are no compelling data to stop screening when it is practiced.</li> </ul>	<b>(III-C)</b>
<ul style="list-style-type: none"> <li>• Women considered at high-risk for GDM should undergo a diagnostic test as early in pregnancy as possible and that testing should be repeated at 24 to 28 weeks if initial results are negative.</li> </ul>	<b>(III-C)</b>
<ul style="list-style-type: none"> <li>• If GDM is diagnosed, glucose tolerance should be reassessed with a 75 g OGTT 6 to 12 weeks postpartum in order to identify women with persistent glucose intolerance.</li> </ul>	<b>(III-C)</b>

**5.3.2 Management of Women with Pre-existing Diabetes**

Pregnancy outcomes in women with pre-existing diabetes are highly correlated with the level of blood glucose control immediately before and during pregnancy, and the achievement of tight blood glucose control (i.e., blood glucose and HbA1c levels within the non-diabetic range) before and during pregnancy improves outcome (Hadden and Traub 1998; Scottish Programme for Clinical Effectiveness in Reproductive Health 1999; Suhonen, Hiilesmaa and Teramo 2000 PS). Regular assessment of fetal well-being during the third trimester reduces the risk of perinatal mortality (Harman and Menticoglou 1997).

Clinical practice guidelines on management of diabetes in pregnancy have been developed by a number of organizations, including the British Columbia Reproductive Care Program (BCRCP 2001). The BCRCP guidelines include detailed clinical practice guidelines for testing and treatment of Type 1, Type 2 and gestational diabetes, which are considered outside the scope of public health recommendations. Additional guidelines and recommendations on diabetes in BC can be found in the 2004 Provincial Health Officer’s (PHO) report *The Impact of Diabetes on the Health and Well-being of People in British Columbia* (PHO 2005).

## **5.4 Interventions to Prevent Low Birth Weight and Small for Gestational Age**

- Smoking cessation remains the principal prevention strategy to reduce low birth weight (LBW), and quitting smoking during pregnancy can reduce the risk of LBW (Delpisheh et al. 2006; Dubois and Girard 2006; Steyn et al. 2006).
- Colorado's Prenatal Plus program targeted prenatal risk factors (smoking, inadequate weight gain during pregnancy, and psychosocial problems). An intervention that included care coordination, nutritional counselling, or psychosocial counselling showed that women who quit smoking had a LBW rate of 8.5 per cent, compared with an LBW rate of 13.7 per cent among women who did not. Women with adequate weight gain had a LBW rate of 6.7 per cent, compared with 17.2 per cent among women with inadequate weight gain. Women who resolved all of their risks had a LBW rate of 7.0 per cent, compared with a rate of 13.2 per cent among women who resolved no risks. Women who had at least 10 Prenatal Plus visits were more likely to resolve their risks than were women who had fewer visits (Ricketts, Murray and Schwalberg 2005 **PE**).
- A risk assessment and educational model of intervention resulted in a decline in rates of LBW births in public and private patients, and for very LBW births in private patients (Meis et al. 1987).
- The Healthy Families<sup>8</sup> (HFNY) program in New York uses intensive home visitation services. Specially trained paraprofessionals are assigned to the participating families to deliver home visitation services until the child reaches five or is enrolled in Head Start or kindergarten. Home visitors provide families with support, education, and referrals to community services aimed at addressing the following goals: 1) to promote positive parenting skills and parent-child interaction; 2) to prevent child abuse and neglect; 3) to ensure optimal prenatal care and child health and development; and 4) to increase parents' self-sufficiency. HFNY mothers experienced better childbirth outcomes than mothers in the control group. The study used low birth weight as one of the outcomes. Control group mothers were significantly more likely to deliver LBW babies than were HFNY group mothers. The mean LBW rate was 2.5 times higher for the control group (8.3 percent) than for the HFNY group (3.3 percent) controlling for other factors including race, age, depression, marital status, social support and economic hardship. The cost per family ranges from \$3,000 to \$3,500 per year (Scholl, Hediger and Belsky 1994 **MA**).
- The City of Toronto published an evidence-based review of the literature on low birth weight in 2002 (City of Toronto 2002 **R**). The review suggested a balanced, nutritious diet as having a beneficial effect in reducing small for gestational age births. The review also suggested that supplements such as iron, calcium, magnesium and zinc have shown improvement in physiological parameters and a trend towards a reduced rate of either preterm or LBW births.

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<sup>8</sup> <http://www.promisingpractices.net/program.asp?programid=147>.

- The Montreal Diet Dispensary sponsored an early nutrition program for women in poverty to reduce the risk of LBW babies. It provided nutritional counselling and support, group activities, home assessment and follow-up visits. A study of 522 siblings over a 16-year period showed a reduction in LBW of 50 per cent in sibling pairs (Higgins et al. 1989 **PE**).
- In the United States, the federally funded Special Supplemental Food Program for Women, Infants and Children provides nutrition education and food vouchers for poor families. The evaluations have been mixed, but in general they show a reduction in LBW babies (Devaney, Ellwood and Love 1997 **R**; Devaney 1992).

Interventions that have improved outcomes of LBW infants include:

- Intensive postnatal home visits (Vermont Intervention Program for Low Birth Weight Infants) (Achenbach et al. 1990).
- Home visits with center-based educational interventions (Infant Health and Development Program) (McCormick et al. 1993).
- Clinic services to adolescent mothers (Comprehensive Perinatal Services Program) (Perkocha et al. 1995 **PE**).
- A volunteer program targeted at adolescent mothers and their children (Barnet et al. 2002 **RCT**).
- A public health nursing early intervention program for adolescent mothers (Koniak-Griffin et al. 2000 **RCT**).

An experiment conducted in Gary, Indiana, raised incomes to the poverty line and tracked birth weight. Increased income resulted in increases of between 0.3 to 1.2 pounds for babies in families of the income-supplemented group, due to improved nutrition for their mothers (Kehrer and Wolin 1979 **COM**).

## **5.5 Interventions to Prevent Prematurity**

A review of the literature by the City of Toronto (2002 **R**) on prevention of LBW/preterm birth found some evidence of interventions to prevent preterm births, although the quality of the evidence was not graded. The conclusions of the review by the City of Toronto suggested the following interventions have the potential to prevent prematurity.

- Smoking cessation and relapse prevention.
- Treatment of infection (See guidelines on screening for infections in Section 5.1).
- Screening mothers with previous history of preterm/LBW births for infection.
- Promotion of balanced nutritious diet for pregnant women.
- Administration of glucocorticoids to mothers with threatened preterm labour to reduce subsequent complications in the newborn infants.

A reduction in preterm births has been observed in Haguenau (Eastern France) during a 12-year intervention study with a program for prevention of preterm deliveries. The Perinatal Study of Haguenau was an observation tool used in a stable population, and it allowed measurement of the way women have progressively responded to the new proposals in prenatal care. It also allowed measurement of the results of the interventions: low birth weight (less than 2,500 g) and preterm birth rates (less than 37 weeks of gestation) among single live births.

The total duration of the study was divided into three periods of four years (1971 through 1974, 1975 through 1978, and 1979 through 1982), for which the numbers of single live births were 5,763, 4,957 and 5,919, respectively. For the same periods, the LBW rates, 4.6 per cent, 4.0 per cent and 3.8 per cent, respectively, showed a significant decrease (P less than .001). Following a similar pattern, the rates of preterm birth were 5.4 per cent, 4.1 per cent and 3.7 per cent (a significant reduction with P less than .001). These improvements in pregnancy outcome do not disappear after standardization of mother's age, high blood pressure, or social class distribution. These findings, which concur with the results of others, enhance the hypothesis of a direct relationship between a prevention program and a reduction in preterm birth rates (Papiernik and Goffinet 2004; Papiernik et al. 1985).

#### 5.5.1 Management of Preterm Labour

Prompt recognition of the signs and symptoms of preterm labour (secondary prevention) is essential if treatment with corticosteroids (tertiary prevention) is to begin early enough to have optimum effect. A discussion of preterm labour and birth should occur early in pregnancy. This will allow women who develop preterm labour at an early gestational age (22 or 23 weeks) to benefit from the information. Counselling should occur at the 18- to 20-week visit.

Women are able to identify symptoms of preterm labour. One study interviewed 107 women with preterm labour, 102 women with premature rupture of the membranes (PROM) and 106 normal pregnant women to ascertain the frequency of each of 8 warning symptoms of preterm labour. Preterm labour patients were distinguished from both normal women and amniorrhexis (rupture of the amnion) patients by a greater frequency of painful and painless contractions. Menstrual cramps, backache, and increased vaginal discharge, symptoms often said to be normally present in pregnancy, were also significantly more common in preterm labour patients than in women with preterm membrane rupture and in normal subjects (Katz, Goodyear and Creasy 1990 **COM**; Iams et al. 1990).

Prevention of preterm labour is primarily in the domain of primary and acute care. Clinical guidelines on management of preterm labour have been published by the Ontario Clinical Preterm Labour Practice Guidelines (Maternal Newborn Early Child Development Resource Centre 2002) and the BCRCP (2005b **CPG**). The Ontario guidelines have graded the evidence on the management of preterm labour. Selected evidence from the Ontario guidelines is cited below.

*Best Practice Guideline*

- Universal counselling and education to take place at the 18- to 20-week primary care prenatal visit, to ensure that all women receive information about premature labour (A III).
- Encourage the woman experiencing signs and symptoms of preterm labour to go to the hospital (or nursing station in remote areas) because: (A III)
  - The only way to diagnose preterm labour is by a physical assessment and this is not possible over the telephone.
  - Early assessment and treatment can make a difference in the outcome for the baby.
  - Timing is critical.
  - It is better for the woman and her baby to be assessed and sent home rather than wait too long to start appropriate treatment.

*Treatment to Delay Labour*

One full course of corticosteroids given to the mother antenatally is the one intervention known to make a difference in neonatal morbidity and mortality for infants of 24–34 weeks gestation (Vause and Johnston 2000; Leviton et al. 1995). Implementation of standards of treatment with corticosteroids has been slow by physicians (Erickson et al. 2001). Although sudden unexpected events may preclude treatment with antenatal corticosteroids, it is also possible that improved prenatal care and better community health care provider awareness and compliance with consensus practice guidelines may increase the incidence of treatment with antenatal corticosteroids (Chien et al. 2002).

*Fetal Fibronectin*

Fetal fibronectin (fFn) shows evidence of effectiveness when used as a diagnostic tool to assess risk of preterm birth in women at higher risk of preterm labour. Absence of fetal fibronectin can prevent unnecessary treatment. The BCRCP (2005b **CPG**) recommends testing with fetal fibronectin for women at risk for preterm delivery living in communities distant from a special care nursery, as a means to screen out women who should not be transferred, based on a negative fFn (Watson, Kim and Humphrey 1998; Goldenberg et al. 2000).

**5.5.2 Nutritional Supplements**

There has been a growing number of studies on the use of omega-3 fatty acids to prevent preterm birth (Oken et al. 2004 **PS**; Olsen 2004 **RCT**; McGregor et al. 2001; Helland et al. 2001 **RCT**; Facchinetti, Fazio and Venturini 2005). Five trials showed an association between fish oil supplementation and length of gestation and four trials did not show an association. One study showed shorter gestation and fetal growth with higher fish or omega-3 intake (Oken et al. 2004 **PS**). Another study found neonates with a high concentration of docosahexaenoic acid (fish oil) in umbilical plasma phospholipids had longer gestational length than neonates with a low concentration (Helland et al. 2001 **RCT**). It is worthwhile to follow the research on this area in the future.

There has also been a study of pre-conceptual multivitamin supplements and reduction of preterm births. The Pregnancy, Infection, and Nutrition Study recruited women at 24–29 weeks of pregnancy from 4 prenatal care clinics in North Carolina from August 1995 to June 2000. For women who took multivitamins prior to pregnancy, compared with non-users, the adjusted risk ratio was 0.50 (95 per cent CI: 0.20, 1.25) for delivering preterm (< 37 weeks). In contrast, prenatal and periconceptional use, compared with non-use, were not related to preterm birth, with adjusted risk ratios of 1.1. Pre-conceptional multivitamin use was inversely associated with both early (<35 weeks; adjusted odds ratio = 0.59, 95 per cent CI: 0.12, 2.76) and late (35-36 weeks; adjusted odds ratio = 0.40, 95 per cent CI: 0.12, 1.40) preterm birth; findings were based on only 2 and 3 exposed cases, respectively. These results suggest that, compared with non-users, women who take multivitamin supplements prior to conception may have a reduced risk of preterm birth, but further studies are needed with a larger sample of pre-conceptional users (Vahratian et al. 2004).

### 5.5.3 Occupational Interventions

France has had a long history of programs to prevent prematurity. The proportion of deliveries before 37 weeks declined from 8.2 per cent in 1972 to 4.9 per cent in 1988. The French program focussed on:

- Early and equal access to prenatal care for all women.
- Provision of information that would convince women to change their lifestyles.
- Recognition, during prenatal care, of warning signs of increasing risk of preterm birth.
- Appropriate use of maternity work leave and reduction of physical activity.

The French national perinatal surveys show that this principle of providing early and adequate care for pregnant women has been achieved. For instance, the proportion of pregnant women with 7 or more prenatal visits was at 22.2 per cent in 1972, 33.9 per cent in 1976, 54.9 per cent in 1981 and 90.5 per cent in 1995. The proportion of pregnant women without any prenatal visit during the first trimester was at 3.6 per cent in 1976 and 2.4 per cent in 1981. A comparison with other European countries shows that France is one of the more successful among its European neighbours in ensuring timely access to medical care during pregnancy (Papiernik and Goffinet 2004; Papiernik et al. 1985).

In 1972, France established a policy for identification of risk factors or exposure to hard work conditions. For those women with identified risk factors, a reduction in physical effort or medically prescribed work leave was prescribed. Salary replacement for maternity leave at 100 per cent plus sick leave benefits began in 1972. In 1972 12 per cent of pregnant women took Medically Prescribed Work Leave (MPWL) in the first trimester, increasing to 23 per cent in 1981. In the third trimester, 24 per cent took MPWL in 1972 and 40 per cent in 1981. Hard work as a risk factor for preterm delivery has disappeared in France but remains a risk factor in other European countries with shorter work leaves. However, since 1988, the rate of preterm births has increased in France, and this has been attributed to the increasing use of ultrasound to detect fetal growth restriction and the increase in multiple births.

Other studies in Canada support the evidence of the effect of occupation on preterm birth. A recent study in Halifax found that restriction of maternal activity and self-palpation of uterine contractions was associated with a marked reduction in the risk of preterm birth (OR .20; 95 per cent CI .08-.50), which supports the results of the French approach of activity limitations (Croteau et al. 2006 CCS).

## **5.6 Medication Use During Pregnancy**

The Centers for Disease Control and Prevention have published a call for action on medication use during pregnancy (Lagoy et al. 2005).

Unfortunately, there is little experience with the use of most medications in human pregnancy and lactation at the time they are marketed. Even when information is available, it may not be readily accessible to women and health care providers. In addition, almost half of pregnancies in the United States each year are unintended, and medication exposures may occur in the early weeks of gestation before a pregnancy is recognized. For these reasons, it is critical that up-to-date information about the effects of medication use during pregnancy and lactation and the management of maternal conditions be available to women and health care providers. A comprehensive, coordinated public health approach that builds on and expands existing activities is needed to generate information about medication use, make that information readily available, and translate it into safe and effective health care.

The article also lists websites and telephone help lines to access information. There is a website that has a searchable database for possible risk factors for fetal development (<http://www.safefetus.com/>). The MotherRisk website (<http://www.motherisk.org/women/drugs.jsp>) also provides a web page on 15 drugs that are known to affect fetal development.

## **6.0 NEWBORN AND CHILDHOOD INTERVENTIONS**

This section includes evidence about programs shown to reduce the severity of disabling conditions either by screening, early detection and treatment and/or early intervention or early childhood education. Screening programs include newborn screening, universal developmental screening, screening for autism and screening and follow-up for LBW infants. Interventions include home visiting by nurses or others, infant development programs, early intervention programs, early childhood education programs, programs targeted at families and income and financial assistance programs. The evidence suggests that the following interventions can improve outcomes of children born with birth defects or disabilities.

- Newborn testing for rare disorders.
- Validated screening tools used by parents to screen for developmental delays.
- Screening for autism and early intervention.
- Screening, follow-up and timely access and quality care for VLBW children.
- Early childhood education for disadvantaged children, as well as those at low risk (the evidence of impact on children with disabilities needs further investigation).
- Early intervention programs by parents.
- Screening for FASD using standardized tools.

Early intervention is covered in the evidence review on Healthy Infant and Child Development.

### **6.1 Newborn Screening**

The United States Maternal and Child Health Bureau commissioned the American College of Medical Genetics (2006 G) to outline guidelines for state newborn screening programs. The expert panel identified 29 conditions for which screening should be mandated. The list of conditions and the number of screened cases reported in the United States is listed in Appendix 4. The number of cases screened is small, with congenital hypothyroidism being the most common condition.

The current status of screening across Canada varies by province, according to a recent survey by the Canadian Paediatric Society (Sheinkopf and Siegel 1998). The number of diseases screened varies from 3 to 28. Nine provinces/territories have a centralized computer system for tracking positive cases. Only five provinces/territories have adequate personnel and resources for follow-up and treatment. Treatment costs are only partially covered in most jurisdictions. Five provinces/territories have formal advisory committees with official mandates. Treatment products for adults with inherited metabolic diseases are available in six provinces/territories.



## **6.2 Developmental Screening**

### **6.2.1 Screening by Health Professionals**

In 2001, the American Academy of Paediatrics made recommendations about universal developmental screening in primary care (2001 **CPG**). They recommended that screening tests be administered at 9, 18 and 24 or 30 months. The policy statement included lists of specific screening tools that had been tested for psychometric properties. Despite the publication of guidelines and assessment tools only 23 per cent of pediatricians used standardized tools to assess pediatric development. The evidence suggests that standardized tests by health care providers may not improve screening (Sand et al. 2005).

The Assuring Better Child Health and Development (ABCD) Project in North Carolina was set up to implement a screening program in primary care. The number of children screened increased from 47 per cent to 68 per cent in over 4 years. Those involved with the North Carolina project have been contacted by other states with an interest in establishing a similar initiative. Although there are features of the project that are unique to North Carolina, there are also elements that are transferable to any practice or state interested in integrating child development services (Earls and Hay 2006).

Elements for a successful state project include:

- Identify a physician champion to lead project activity.
- Direct the activity from a local level rather than at the state level.
- Pilot the activity before replicating.
- Replicate activities after data are collected and shared.
- Develop policies for “best practices” in well-child care, on the basis of the experience of local activity.
- Align goals with collaborating partners to help ensure active participation from partners.
- Identify care management resources in local communities to support the practice and family rather than hiring additional staff.

Practical tools for the practice and family developed by the ABCD Project include:

- Office resource guide (research and how-to's for implementation in the office).
- Curricula and workbooks (eligible for continuing medical education).
- Anticipatory guidance by well-visit (available in English and Spanish; can be personalized to the practice).
- Talking guides for clinicians (steps in discussing developmental screening with families).
- Posters for the examination and waiting rooms (encourages families to request developmental screening and promotes awareness of early intervention).

- Video and companion workbook for practice teams (rationale, billing, performance measurement and a view into the office process).

### 6.2.2 Screening by Parents

Several studies have shown that parental reports of the child's current skills are predictive of developmental delay (Doig et al. 1999; Tervo 2005; Bricker and Squires 1999). This has led to the development of parental report instruments, which have been tested in diverse populations and provide accurate information about development. Parental concerns about language, fine-motor, cognitive, and emotional-behavioural development are highly predictive of true problems (Dulcan et al. 1990; Glascoe 1998; Glascoe and Dworkin 1995). Glascoe and Dworkin (1995) have shown that by asking about developmental concerns systematically, the physician can screen for developmental delays as effectively as by using formal developmental screening tools that require developmental examination of the child. Parent report instruments, such as the Parents' Evaluation of Developmental Status (Glascoe 1998), Ages and Stages Questionnaires (Bricker and Squires 1999), and Child Development Inventories (Ireton 1992), have excellent psychometric properties, and have the advantage of requiring much less time from the physician than instruments that require direct examination.

## 6.3 **Autism Screening and Early Intervention**

This section provides recommendations on the general approach for identifying children with developmental problems, particularly autism, at an early stage, from review of the evidence from the New York State. Their recommendations have been graded (New York State Department of Health 1999).

- It is important to identify children with autism and begin appropriate interventions as soon as possible, since early intervention may help speed the child's overall development, reduce inappropriate behaviours, and lead to better long-term functional outcomes. It is often possible to recognize autism within the first three years of life [A]. Other sources suggest it can be recognized at age two.
- It is important for professionals and parents to recognize that there are several ways that children with autism are first identified. These ways include:
  - A parent's or professional's concern that some aspect of the child's development is delayed or something is abnormal about the child's behaviour.
  - A health care provider's or other professional's concern about possible autism either at the time of a periodic health exam, or when the child is being evaluated for some other health problem (such as a possible hearing loss) or developmental problem (such as a delay in talking or does not talk, does not make eye contact) [D2].
- Developmental surveillance done routinely at specific age points is important for all young children. Health care providers or other professionals can provide such surveillance and can facilitate the identification of developmental problems as early as possible [D2].

- The periodic exams at 15, 18 and 24 months are particularly useful in providing information about possible autism, since this condition can often be identified within the first 3 years of life [D2].
- Studies suggest there are approximately 1 to 2 children with autism for every 1,000 children in the general population. Since autism is relatively rare, it is usually not practical to screen the general population of young children for autism using any specific screening test for autism [D2]. A more useful approach for identifying children with possible autism is to:
  - Look for "clinical clues" of possible autism.
  - Follow-up with appropriate screening tests and further assessment if heightened concerns or clinical clues of possible autism are identified [D2].

Numerous studies on early intervention in autism have shown the benefits of early identification and intervention for children with developmental disabilities and, particularly, for those with autism spectrum disorders (Dawson and Sterling 1997; Committee on Educational Interventions for Children with Autism 2001 **R**). Evidence exists for the benefits of intensive behavioural programs for young children with autism spectrum disorders, although the precise teaching strategies and curricula content are often a topic of debate (Lovaas 1987; Ozonoff 1998, as cited in Rogers 1998). While the components of intervention programs are often a source of controversy, it is generally agreed that program intensity combined with early diagnosis and intervention can lead to substantial improvement in child functioning (Sheinkopf and Siegel 1998). A substantial benefit of early intervention is the positive impact on the family's ability to interact in a developmentally appropriate manner with their child and to have a greater understanding of the disability and how it interacts with family life (American Academy of Pediatrics [AAP] 1994 **CPG**). Early identification and diagnosis enhances the opportunity for effective educational and behavioural intervention; reduction of family stress by giving the family specific techniques and direction; and access to medical and other supports (Cox, Klein and Charman 1999). In the end, early intervention improves the quality of life for the individual and his/her family, and is cost-efficient for the human service delivery system (Jacobson, Mulick and Green 1998).

#### **6.4 Follow-up of Very Low Birth Weight Children**

Wang et al. (2006) describe the development of a set of quality-of-care indicators for the neurodevelopmental follow-up care of very low birth weight (VLBW) children. This set of indicators focuses specifically on the neurodevelopmental follow-up of VLBW infants and is not meant to cover all aspects of follow-up care. Most of the evidence in the table of indicators (Appendix 5) was level III evidence (i.e., based on opinion or descriptive studies).

The Vermont Oxford Network (VON) developed a NICU database that contains detailed, uniform, clinical and treatment information on all infants who have birth weights of 401 to 1500 g and are born at member institutions or admitted within 28 days of birth (Rogowski, Staiger and Horbar 2004). An expanded VON or development of parallel networks could provide a platform

for monitoring follow-up care and assist in compiling information on the quality of care that is delivered. A similar network has been developed in Canada—The Canadian Neonatal Network.<sup>9</sup>

## **6.5 Early Intervention and Early Childhood Education Programs**

Considerable work has been done on estimating the costs and benefits of early childhood education by the Committee for Economic Development. The review by Belfield (2005) concludes that the benefits accrue to high-risk children as well as to low-risk children, and the benefits of universal versus targeted programs favour universal programs. These assessments are all based on long-term outcomes regarding functioning in society.

A recent systematic review demonstrates the effectiveness of early childhood development programs in improving functioning of children in a number of different domains (Anderson et al. 2003 **SR**). More than 70 per cent of the effects reported were in the cognitive domain, with limited evidence available for health screening and social and family outcomes. Within the cognitive domain, consistent improvements were found in measures of intellectual ability, standardized academic achievement tests, standardized tests of school readiness, promotion to the next grade level, and decreased placement in special education classes because of learning problems. The programs were all in the United States, and the study populations were disadvantaged<sup>10</sup> preschool children. It is not clear if these programs have had an impact on children with disabilities, or if children with disabilities were included in the programs. The review included the High/Scope Perry Preschool Study in Ypsilanti, Michigan, and the Carolina Abecedarian Project, as well as 14 other programs, including Head Start.

The United States is home to two heavily cited preschool demonstration projects, the Carolina Abecedarian Project<sup>11</sup> (Campbell and Ramey 1994 **FUS**) and the High Scope Perry Preschool Study (Schweinhart n.d.; Schweinhart, Barnes and Eikart 1993). Several centres in the federally funded Head Start program have also been evaluated (Devaney et al. 1997 **R**). The evaluations of these preschool centre-based educational interventions demonstrate increased cognitive and socio-emotional development for children in the groups compared to those in control groups. These projects were included in some of the reviews above.

### **6.5.1 The Carolina Abecedarian Project**

The Carolina Abecedarian Project was a carefully controlled scientific study of the potential benefits of early childhood education for poor children. Children from low-income families received full-time, high-quality educational intervention in a child care setting from infancy through age 5. Each child had an individualized prescription of educational activities. Educational activities consisted of "games" incorporated into the child's day. Activities focused on social, emotional, and cognitive areas of development, but gave particular emphasis to language. Children's progress was monitored over time, with follow-up studies conducted at ages 12, 15 and 21. The young adult findings demonstrate that important, long-lasting benefits were associated with the early childhood program.

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<sup>9</sup> <http://www.canadianneonatalnetwork.org/index.shtml>.

<sup>10</sup> Disadvantaged is the term used to describe economic disadvantages.

<sup>11</sup> <http://www.fpg.unc.edu/~abc/>

*Major Findings*

- Children who participated in the early intervention program had higher cognitive test scores from the toddler years to age 21.
- Academic achievement in both reading and math was higher from the primary grades through young adulthood.
- Intervention children completed more years of education and were more likely to attend a four-year college.
- Intervention children were older, on average, when their first child was born.
- The cognitive and academic benefits from this program are stronger than for most other early childhood programs.
- Enhanced language development appears to have been instrumental in raising cognitive test scores.
- Mothers whose children participated in the program achieved higher educational and employment status than mothers whose children were not in the program. These results were especially pronounced for teen mothers.

**6.5.2 Interventions Targeted at Low Birth Weight and Preterm Infants and Children**

Another systematic review of early intervention programs targeted families from deprived environments with multiple risks, premature or LBW infants, or psychosocial or psychiatric risks (Dumaret 2003 **R**). Programs resulted in variable degrees of positive influences on children's cognitive, behavioural and social development. The most remarkable results concerned school attendance and school performance. Positive effects were also recorded in specific populations (adolescent mothers, mentally retarded mothers). Nevertheless, the efficacy of some programs remained limited and mainly dependent upon parents' motivation and involvement and concurrent family risk factors.

The programs targeting preterm and LBW children reported by Scarr-Salapatek and William (1973) showed improvements in IQ, and the studies by Field et al. (1980) and Ross (1984) showed improvements in behaviour.

Timely access and quality of care are especially important for VLBW children. One example of a successful follow-up program was the Vermont Intervention Program for Low Birth Weight Infants. The intervention involved seven hospital sessions and four home sessions in which a nurse helped mothers adapt to their LBW babies. The findings suggest that the intervention prevented cognitive lags among LBW children, and that this eventually had a favourable effect on academic achievement, behaviour and advancement in school. The progression from no significant differences between experimental and control children on early cognitive and achievement scores, to significant and pervasive differences in later functioning, argues for long-term follow-up periods to properly evaluate the power of behavioural interventions to compensate for biological risks (Achenbach et al. 1990; Achenbach et al. 1993 **RCT**).

A prospective follow-up of the Infant Health and Development Program at 8 sites reported on results for LBW infants. Comparison groups were the heavier low birth weight (HLBW; 2001-2499 g) and lighter low birth weight (LLBW  $\leq$  2000 g) at 18 months and 3 years. Differences favouring the 3-year follow-up group were seen on the Tests of Achievement in math, behaviour and vocabulary in the HLBW youth. In the LLBW youth, the achievement in reading was higher in the 18-month follow-up than in the 3-year follow-up group. The findings in the HLBW 3-year follow-up group provide support for preschool education to make long-term changes in a diverse group of children who are at developmental risk. The lack of observable benefit in the LLBW group raises questions about the biological and educational factors that foster or inhibit sustained effects of early educational intervention (McCormick et al. 1993; McCormick et al. 2006 **RCT**).

## **6.6 Parent Intervention Programs**

In one parent intervention group, parents were taught to carry out the 0–2 year intervention program, which included motor, cognitive, speech development and social behaviour. Intelligence tests at the age of 1½ and 2 years of age showed that the average mental development index (MDI) in the intervention group was 13.8 and 14.6 higher than in the conventional care group, and the differences were significant. The psychomotor development index (PDI) was 5.2 and 4.7 higher but the differences were not significant. The MDI and PDI in the intervention group and normal control were quite close, but at 2 years of age, the MDI and PDI in the intervention group were 5.7 and 7.3 higher than those in the normal control, and the differences were significant ( $p < 0.05$ ). Compared with the normal control, the MDI in the conventional care group at 1½ and 2 years of age were 11.5 and 8.9 lower. The difference was very significant. There were four cases of mental retardation, whose mental development index (MDI) was less than 70 in the conventional care group, but none in the intervention group. To conclude, early intervention can promote intellectual development of premature infants and may be beneficial to the prevention of mental retardation. Early and intensive intervention can produce better results. Bringing parents' initiative into full play through deepening their understanding of the importance of early intervention is the key to success (Bao, Sun and Wei 1999).

Another program evaluated the effects of an early post-discharge developmental mother-child intervention program on neurodevelopment outcome at 36 months in VLBW infants. At 36 months of chronological age, as compared to controls, children in the intervention group exhibited higher scores in personal-social subscales (mean = 101.4 versus 92.9,  $P = 0.02$ ), eye-hand coordination (92.7 versus 87.1,  $P = 0.041$ ) and practical reasoning (98.6 versus 89.4,  $P = 0.01$ ). Development Scales were 97.6 and 92.4 respectively, in the intervention and control groups ( $P = 0.074$ ). To conclude, early post-discharge developmental mother-child intervention programs may have a positive effect on the later neurodevelopment outcome of VLBW children (Gianni et al. 2006 **RCT**).

## **6.7 Home Visiting by Nurses**

An extensive evaluation of home visiting programs targeting children and families has been published on the Future of Children website (Gomby, Culross and Behrman 1999). Results are mixed and, where positive, are modest in magnitude. Studies have revealed some benefits in parenting practices, attitudes and knowledge, but the benefits for children were more elusive.

Only one program model revealed marked benefits in the maternal life course. When benefits were achieved in any area, they were often concentrated among particular sub-groups of families, but there was little consistency in these sub-groups across program models or, in some cases, across sites that implemented the same program model, making it difficult to predict who would benefit most in the future.

The programs reviewed were: the Nurse Home Visitation Program (NHVP); the Comprehensive Child Development Program (CCDP); and Parents as Teachers (PAT).

There were no improvements in immunization rates, the number of well-child visits, the number of medical or dental visits, or children's development and achievement. Only very young teens and smokers in Elmira, New York, demonstrated reductions in preterm births and in the percentage of LBW babies. Only the Elmira NHVP assessed behaviour more than a few years after the end of program services. Teens who had been born to poor, unmarried women who had been home visited showed benefits over the control group in fewer instances of running away, fewer arrests and convictions, fewer cigarettes smoked per day, fewer days having consumed alcohol in the last six months and less lifetime promiscuity. Parents also reported that their children had fewer problems related to drug or alcohol use.

In sum, benefits to children's development have not been demonstrated reliably in randomized trials of home visiting programs, although methodologically weaker studies have reported favourable outcomes. When benefits have occurred in randomized trials, they have usually accrued to only some of the participating children, and have been small. Of the two programs that assessed changes in children's behaviour, only NHVP demonstrated benefits.

In the Elmira program site, poor unmarried women who had been home visited had fewer subsequent pregnancies and births, were more likely to defer their second births, spent fewer months on welfare or receiving food stamps, had fewer problems resulting from substance abuse and had fewer arrests than their counterparts in the control group. These were large differences: 60 versus 90 months on welfare, for example, and 65 versus 37 months between first and second births. A 1998 RAND Corporation study indicated that these changes in maternal life course among high-risk mothers were primarily responsible for the program's \$18,611 net savings to government (Karoly et al. 1998). In the NHVP, the linchpin finding appears to be the reduction in the rate of subsequent births, which the authors believe led to positive changes for parents and children later in life.

## **6.8 Programs in Canada**

The most comprehensive and researched early childhood development program in Canada is the Better Beginnings Better Futures Project in Ontario in the 1990s. Extensive tracking of outcomes have been done and reported on the [Better Beginnings](#) website (Better Beginnings Better Futures 2005). Two program models were developed in the Better Beginnings program. In the first, prenatal/infant development programs for children from birth to age four link up with preschool programs. The second model targets children aged four to eight and integrates preschool programs with primary school programs. The communities served are low-income. An interim report shows positive child outcomes in the areas of emotional, behavioural and social functioning. Families reported reduced domestic violence and smoking. Neighbourhood

outcomes show increased safety, satisfaction with housing and use of recreational facilities, and a reduced number of students requiring special education (Peters et al. 2000).

## **6.9 Interventions to Control Environmental Exposure to Chemicals and Metals**

### 6.9.1 Monitoring

The Second National Report on Human Exposure to Environmental Chemicals provides population serum, blood and urine levels for 116 environmental chemicals over the years 1999 and 2000, with separate analyses by age, sex and race/ethnicity for the United States. A new biomonitoring assessment of the exposure of the American population will be released every 2 years. These reports will include the current 116 chemicals and any new chemicals added, to monitor priority exposures of the population (Pirkle et al. 2005).

Health Canada enacted legislation in 1976 to restrict the lead content of paints and other liquid coatings to 0.5 per cent by weight, on furniture, household products, children's products, exterior and interior surfaces of any building frequented by children. To reflect current scientific and medical knowledge, amendments to these regulations to reduce the lead content of paints and other liquid coatings from 0.5 to 0.06 per cent by weight are currently being prepared by Health Canada.

The United States Environmental Protection Agency (EPA 1998) reviewed studies on reducing lead exposure in housing. These studies showed that among children with baseline blood-lead levels (BLL) greater than about 25 µg/dL, measures to remove or repair nonintact leaded paint were followed by declines in BLL of 20 per cent to 30 per cent over the following year. Recent longitudinal studies have evaluated leaded paint abatement programs that combined multiple lead hazard control methods (Aschengrau et al. 1998; Farfel, Chisholm and Rohde 1994; National Center for Lead-Safe Housing 1998; Rhoads et al. 1999 **RCT**; United States EPA 1997). In these studies, benefits of environmental interventions have generally been modest—BLL reductions in the range of 10 to 30 per cent.

The release of lead from bone might also reduce the impact of environmental interventions. By one estimate, an intervention reducing total lead exposure by half for a 5-year-old child would cause the child's BLL to decline by only 25 per cent after 1 year due to release of lead from bone (Rust et al. 1999).

The United States recommendations include: screening of high-risk children, follow-up services, taking an environmental history, educating parents about lead, and conducting follow-up blood lead monitoring, removing lead in housing, reducing non-essential exposure (e.g., lead-toys, ceramics), surveillance and regulations (CDC 2005).

One example of an intervention to reduce elevated blood levels occurred in Trail, BC. Elevated BLL due to lead exposure from the smelter, have declined. BLLs fell to 5.9 µg/dl in 1999 with average rate of decrease from 0.6 µg/dl per year (1989 to 1996) to 1.8 µg/dl per year (1997 to 1999) (Hilts 2003). This accelerated reduction was attributed to the introduction of the new lead smelter in May 1997. Mean air levels of lead fell from 1.1 µg/m<sup>3</sup> in 1996 to 0.28 µg/m<sup>3</sup> in 1998,



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and lead concentrations in outdoor dust, street dust and indoor dust decreased by 50 per cent. Since 1998, yearly ambient lead levels have been substantially below guideline levels (PHO 2004).

## **7.0 FETAL ALCOHOL SPECTRUM DISORDER AND ALCOHOL CONSUMPTION**

Guidelines for assessment and treatment, evaluation, research and planning activities regarding fetal alcohol spectrum disorder (FASD) have increased in number and level of quality in the past five years. Narrowing down material for a short review means a substantial amount of valuable information is omitted. The most promising interventions appear to be

- Reduction in alcohol use by:
  - Brief interventions.
  - The Strengthening Families Program.
  - Community-wide awareness.
  - Supply/pricing control programs.
  - Long-term, multi-strategy, system-wide interventions, including legislated programs.
- Improvement in the quality of diagnostic techniques for FASD, including research on biomarkers and brain function tests, may improve early detection and case finding.

### **7.1 Guidelines**

There has been substantial work done on developing guidelines on FAS by multiple organizations. The following agencies have all published guidelines or recommendations on FASD and alcohol use: the Royal College of Obstetricians and Gynecologists (2006), the United States Surgeon General (2005), Health Canada (Chudley et al. 2005), the Public Health Agency of Canada (2005), the BCRCP (2005a) and the Ministry of Children and Family Development (2003). There have been differences in recommendations on the safety of alcohol ingestion during pregnancy. Those suggesting a moderate level of alcohol is safe include the United Kingdom Guidelines on Routine Antenatal Care (National Institute for Clinical Excellence 2003) (one “standard unit” per day), and the Royal College of Obstetricians and Gynecologists (2006), who conclude that “there is considerable doubt as to whether infrequent and low levels of alcohol consumption during pregnancy convey any long-term harm, in particular after the first trimester.”

A graded review of best practices regarding all aspects of surveillance, detection, screening, prevention and treatment of Fetal Alcohol Syndrome was done for Health Canada by Roberts and Nanson (2000 **G**). Evidence from the Roberts and Nanson review has been excerpted in the sections that follow.

## 7.2 Community-level Interventions

<b>Level of Evidence/Reference</b>	
A brief intervention with college-level, high-risk women can reduce alcohol intake.	Ingersoll et al. 2005 <b>Ib</b> Grossberg, Brown and Fleming 2004 <b>RCT</b>
Life skills and multi-component, school-community substance use prevention programs can reduce substance use problems among adults.	<b>B</b> Botvin et al. 1995 <b>RCT</b> Murphy-Brennan and Oei 1999 Pentz et al. 1989 <b>RCT</b> Paine-Andrews et al. 1996
Measures to limit the availability of alcohol, such as bans on sales and importation that are broadly supported by the community, or price increases, can reduce alcohol use by pregnant women.	<b>C</b> Douglas, Narbonne-Fortin and Lauzon 1997 Lauzon et al. 1998 Abel 1998a <b>R</b> Abel 1998b <b>R</b>
Warning labels and posters can increase awareness and effect short-term behaviour change regarding alcohol use among low-risk women. However, women who drink heavily during pregnancy do not appear to be affected by warning labels.	<b>B</b> Casiro et al. 1994 Abel 1998b <b>R</b> Hankin et al. 1996a Hankin et al. 1996b
Intensive case management or coordination services that advocate for women can be effective in promoting family planning, access to substance abuse treatment, retention in treatment, reduced consumption and connections to community services for high-risk pregnant women.	<b>A</b> Laken and Ager 1996 Egelko et al. 1998

## 7.3 Interventions Aimed at Young People

<b>Level of Evidence/Reference</b>	
The Cochrane review of psychosocial and educational interventions aimed at the primary prevention of alcohol misuse by young people found that the Strengthening Families Program (SFP) <sup>12</sup> showed promise as an effective prevention intervention. The Strengthening Families Program was found effective in a National Institute on Drug Abuse (NIDA) research grant in the early 1980s, and more than 15 subsequent independent replications have found similar positive results with families in many different ethnic groups. Both culturally adapted versions and the core version of SFP have been found effective with African-American, Hispanic, Asian, Pacific Islander and American Indian families. The original SFP for families with children ages 6 to 11 has now been joined by versions for families with both younger children and early teens. This program is currently being implemented by the BC Ministry of Children and Family Development in at least one region of BC.	<b>A</b> Foxcroft et al. 2006 <b>SR</b>

<sup>12</sup> <http://www.strengtheningfamiliesprogram.org/>.

## 7.4 Interventions Targeting Pregnant Women

	<b>Level of Evidence/Reference</b>
Use of the T-ACE and TWEAK alcohol dependence instruments identify women who would benefit from intervention for their alcohol use during pregnancy.	<b>B</b> Mengel et al. 2006 Bradley et al. 1998 <b>R</b> Chang et al. 2005 <b>RCT</b>
A drug education program among pregnant adolescents attending prenatal clinics has been shown to reduce substance use	<b>C</b> Sarvela and Ford 1993.
Multi-component, community-wide initiatives as a means of increasing awareness generally can reduce consumption by pregnant women, and promote referrals. However the Cochrane Review in 2006 did not find evidence to support community interventions targeted at young people in non-school settings.	Ingersoll et al. 2003 <b>PP</b> Abel 1998a <b>R</b> Gates et al. 2006 <b>SR</b>
Combining prenatal care with other services, including substance abuse treatment, shows positive outcomes for women with substance use problems and their newborn children.	<b>B</b> Egelko et al. 1998
A single point of access addressing the range of social and health needs of pregnant women with substance use problems (e.g., assistance with transportation and child care, education, vocational training, job placement, housing, getting food, income support and help in accessing health care and mental health services), through collaboration between relevant service providers, are effective in engaging and retaining women in treatment.	<b>C</b> Whiteside-Mansell, Crone and Connors 1999

## 7.5 Brief Interventions

	<b>Level of Evidence/Reference</b>
A brief intervention with college-level, high-risk women can reduce alcohol intake.	<b>A</b> Ingersoll et al. 2005 <b>Ib</b> Grossberg et al. 2004 <b>RCT</b>

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<b>Level of Evidence/Reference</b>	
<p>There is good quality evidence that brief physician intervention successfully reduces alcohol.</p> <p>Brief interventions for alcohol abuse have been classified into 3 types: 1) very brief (one 5-minute session); 2) brief (one session up to 15 minutes duration); 3) multi-contact brief sessions (an initial session of up to 15 minutes followed by several time-limited contacts, either by telephone or in the clinic). These brief treatments are often equally effective as longer-term therapy. When compared with "usual" care, multiple contact brief interventions lead to 10 per cent to 19 per cent of patients changing to recommended or safe drinking levels. The overall absolute risk reduction associated with brief treatments is 10.5 per cent.</p> <p>Although brief alcohol intervention has a reasonable evidence basis, there are only limited investigations involving pregnant patients. The Trial for Early Alcohol Treatment (Project TrEAT) involved 4, 2-minute to 15-minute office counselling sessions and a self-paced workbook directed toward women of childbearing age. The intervention led to a 48 per cent reduction in average alcohol intake with 25 per cent fewer women engaging in binge drinking. Although Project TrEAT's benefits were still pronounced at 48 months, the largest decline in alcohol use occurred within 6 months after the intervention.</p>	<p>Fleming et al. 1997  <b>RCT</b>            Bertholet et al. 2005  <b>SR MA</b>            Chang et al. 2000  <b>RCT</b>            Moyer et al. 2002  <b>MA</b>            Poikolainen 1999  <b>MA</b>            Manwell et al. 2000  <b>RCT</b></p>

## 7.6 Motivational Interviewing

<b>Level of Evidence/Reference</b>	
<p>A counselling model developed for health risk behaviour, has also demonstrated success in reducing prenatal alcohol use—particularly among heavier drinkers.</p>	<p><b>A</b>            Handmaker, Hester and Delaney 1999  <b>RCT</b></p>
<p>A more intensive intervention, Project CHOICES, targeted women at-risk for an alcohol-exposed pregnancy. Risk status included a week of low-level, daily drinking and/or a binge episode in the past 3 months, recent sexual activity, and no or ineffective contraception. Women participated in 4 motivational interviewing sessions and received individualized information about their risk of an Alcohol-exposed pregnancy (AEP). Risk reduction included decreased alcohol use (18 per cent), effective contraception (34 per cent), or both (48 per cent) with 68 per cent of the participants reducing their risk of an AEP. In a further analysis comparing only education about drinking during pregnancy with education plus counselling, 54.8 per cent receiving education alone reduced their risk of an AEP with a 68.9 per cent risk reduction for education with added counselling.</p>	<p><b>A</b>            Project Choices Intervention Research Group 2003</p>

## 7.7 Infancy and Early Childhood Interventions

<b>Level of Evidence/Reference</b>	
<p>A longer-term, stable living environment contributes to more positive outcomes for children affected by alcohol in utero. This may be facilitated by family-centred substance abuse treatment, respite care and other support services, and FAS-specific information and training for birth, foster and adoptive parents.</p>	<p><b>C</b>            Streissguth et al. 2004</p>
<p>A single point of access, combining services for the mother with attention to the developmental needs of the child, can improve outcomes for the child.</p>	<p><b>C</b></p>

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Level of Evidence/Reference	
Early educational interventions may contribute to improved outcomes for children affected by prenatal alcohol use.	<b>C</b> Coles and Platzman 1992 Streissguth et al. 1996 Astley and Clarren 1999 Streissguth et al. 2004

**7.8 Interventions with Health Care Providers**

Level of Evidence/Reference	
There have been a number of strategies targeted at physicians that have been found to be effective. Providing physicians with alcohol screening results (CAGE questionnaire responses, alcohol consumption and readiness to change) and recommendations for their patients can reduce alcohol intake.	Saitz et al. 2003 <b>RCT</b>
A three-hour training module aimed at assisting implementation of alcohol screening and brief intervention services in the primary care setting can reduce the number of high-risk drinkers.	Babor et al. 2004
Telemarketing and academic detailing (personal visits) can increase acceptance of a brief intervention program.	Funk et al. 2005 <b>PP</b>
A 20-minute videotape on motivational interviewing showed significant differences in motivational interviewing skills between the experimental and control groups. Obstetric care practitioners who viewed the training video were rated as showing greater empathy, minimizing patient defensiveness and supporting women's beliefs in their ability to change.	Handmaker et al. 1999 <b>RCT</b>

Health Canada (2003) has done a survey to assess knowledge of the risks of alcohol in pregnancy in the general public and health professionals. The results of the survey of the general public showed a high degree of knowledge of the risks of alcohol but still some areas of misunderstanding and ambiguity. The report recommends:

- Improvements in the use and implementation of standard screening tools for alcohol use among pregnant women.
- Better implementation of the existing clinical practice guidelines recommending that no alcohol be consumed during pregnancy.
- Improvements in information exchange between health care professionala and patients on some key health issues.
- Better training on the diagnostic features of FAS.
- Improved professional preparedness to care for alcohol-dependent/abusing pregnant women and individuals with FAS.

## 7.9 System-wide Interventions

Washington State instituted two major clinical/research programs that have made significant contributions over the past three decades to screening, diagnosis, education and prevention of FASD (Clarren and Astley 1997; Streissguth et al. 1981 **PS**). Washington State prevention efforts have reflected the full continuum of strategies from public health education and training to direct intervention with high-risk women (Little, Streissguth and Guzinski 1980; Albert 2002; National Institute on Alcohol Abuse and Alcoholism 1987; Hankin 1994; Greenfield and Kaskutas 1998; LaDue and Hartness 2000). Although prevention efforts have been ongoing since the early 1970s, a substantial increase in effort began in 1992 with the implementation of FAS prevention projects sponsored by the Centers for Disease Control and Prevention (Astley et al. 1997; Olson et al. 2002; Astley et al. 2000b), establishment of the Parent-Child Assistance Program (State of Washington 1995) and a legislative mandate in 1995 for statewide expansion of the FAS program and establishment of the Fetal Alcohol Syndrome Interagency Work Group to ensure coordination of efforts across key state agencies, including family advocacy groups.

A cross-sectional study in Washington State was conducted to determine whether the prevalence of fetal alcohol syndrome among children in a foster care population decreased with the documented decrease in prevalence of maternal use of alcohol during pregnancy from 1993 and 1998. The prevalence of maternal drinking during pregnancy in Washington State declined significantly ( $P < 0.001$ ) in that time period, as did the prevalence of fetal alcohol syndrome among foster children born between 1993 and 1998 ( $P < 0.03$ ). For example, women reporting  $< 14$  drinks a week in the 3 months prior to pregnancy declined from 4.9 per cent to 0.7 per cent between 1993 and 1998. These observations support the likelihood that fetal alcohol syndrome prevention efforts in Washington State are working successfully (Astley 2004).

## 7.10 Interventions Where There is no Evidence of Effectiveness

<b>Level of Evidence/Reference</b>	
The Cochrane Collaboration has reviewed home visit programs, prevention programs in non-school settings and AA type programs and found no evidence of effect on alcohol use.	<b>A</b> Gates et al. 2006 <b>SR</b> Doggett, Burrett and Osborn 2005 <b>SR</b> Ferri, Amato and Davoli 2006 <b>SR</b>
A systematic review was done of nursing interventions to prevent secondary disabilities in Fetal Alcohol Spectrum Disorder included referral and follow-up, case management, delegated functions, screening, surveillance, teaching and consultation. The majority of the evidence was graded at the level of opinion of authorities with no evidence-based studies published.	<b>A</b> Caley et al. 2006 <b>R</b>

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## **GLOSSARY AND ABBREVIATIONS**

### **GLOSSARY**

#### **Anencephaly:**

A congenital malformation characterized by the total or partial absence of the cranial vault, the covering skin, and the brain missing or reduced to small mass. Include craniorachischisis. Include infants with iniencephaly and other neural tube defects as encephalocele or open spina bifida, when associated with anencephaly. Exclude acephaly, that is, absence of head observed in amorphous cardiac twins.

#### **Autism spectrum disorders (ASD):**

A family of developmental disorders most commonly associated with autism. Also known as pervasive developmental disorders.

#### **Asperger 's Syndrome:**

A form of ASD characterized by normal intelligence and language development, as well as autistic-like behaviours and marked deficiencies in social and communication skills.

#### **Attention Deficit Hyperactivity Disorder (ADHD):**

A neurobehavioural disorder characterized by difficulties in staying on task, following instructions, paying attention to detail and sitting still.

#### **Birth Defect:**

Also described by the term *congenital*, a birth defect is a structural, metabolic or functional abnormality that is present at birth, detected before birth, during the infant's first year of life or even later in life.

A structural, functional or metabolic abnormality present at birth that results in physical or mental disability or is fatal. There are more than 4,000 known birth defects, which may be caused by genetic or environmental factors. About 150,000 babies are born each year with birth defects.

#### **Cerebral Palsy:**

An umbrella term for a series of chronic disorders in which motor control is impaired by damage to certain parts of the brain.

#### **Cleft Lip (with or without cleft palate):**

A congenital malformation characterized by partial or complete clefting of the upper lip, with or without clefting of the alveolar ridge or the hard palate. Excludes midline cleft of upper or lower lip and oblique facial fissure (going towards the eye).

#### **Cleft Palate (without cleft lip):**

A congenital malformation characterized by a closure defect of the hard and/or soft palate behind the foramen incisivum without cleft lip. Includes submucous cleft palate.

Excludes cleft palate with cleft lip, cleft uvula, functional short palate and high narrow palate.

**Confidence interval (CI):**

The 95 per cent confidence interval (or 95 per cent confidence limits) would include 95 per cent of results from studies of the same size and design in the same population. This is close but not identical to saying that the true size of the effect (never exactly known) has a 95 per cent chance of falling within the confidence interval. If the 95 per cent confidence interval for a relative risk (RR) or an odds ratio (OR) crosses 1, then this is taken as no evidence of an effect. The practical advantage of a confidence interval (rather than a P value) is that they present the range of likely effects.

**Congenital:**

Describes something that was acquired while the individual was still developing in the uterus. For example, a congenital defect is a defect that is not found in the individual's genes but developed for some other reason while the individual was a fetus.

**Developmental Disabilities:**

A cognitive, intellectual or behavioural impairment that presents itself during childhood.

**Disabilities:**

This varies with who is creating the definition. Several definitions are used in this review. The categories of disability used by the BC Health Status Registry are based on a grouping of conditions by their presumed cause. The Participation and Activity Limitation Survey (PALS) uses the World Health Organization's (WHO) framework of disability, provided by the International Classification of Functioning (ICF). This framework defines disability as the relationship between body structures and functions, daily activities and social participation, while recognizing the role of environmental factors. For the purposes of PALS, persons with disabilities are those who reported difficulties with daily living activities, or who indicated that a physical or mental condition or health problem reduced the kind or amount of activities they could do. The respondents' answers to the disability questions represent their perception of the situation and are therefore subjective.

**Down's Syndrome:**

A congenital chromosomal malformation syndrome characterized by a well-known pattern of minor and major anomalies and associated with excess chromosomal 21 material. Include trisomy mosaicism and translocations of chromosome 21. Down's syndrome, also known as Trisomy 21, and characterized by an extra chromosome 21, is the most common chromosomal birth defect.

**Dyslexia:**

Dyslexia, a learning disability, is a language-based disorder that affects reading.

**Fetal Alcohol Syndrome (FAS) and Fetal Alcohol Syndrome Disorders (FASD):**

Refers to a constellation of physical, behavioural and cognitive abnormalities. In addition to the classic dysmorphic facial features, prenatal and postnatal growth abnormalities and mental retardation that define the condition, approximately 80 per cent of children with

FAS have microcephaly and behavioural abnormalities. As many as 50 per cent of affected children also exhibit poor coordination, hypotonia, attention-deficit hyperactivity disorder, decreased adipose tissue and identifiable facial anomalies, such as maxillary hypoplasia, cleft palate and micrognathia. Cardiac defects, hemangiomas and eye or ear abnormalities are also common

There are a number of subtypes, including full-blown fetal alcohol syndrome (FAS), and the less noticeable, but sometimes equally serious, possible fetal alcohol effects (PFAE). The latter is also known as prenatal exposure to alcohol (PEA) or alcohol-related neurodevelopmental disorder (ARND).

Features of FASD may include facial deformities, stunted physical and emotional development, memory and attention deficits, a tendency to impulsive behaviour, inability to reason from cause to effect, a failure to comprehend the concept of time, difficulty telling fantasy from reality, inability to control sexual impulses and an apparent lack of remorse. Secondary disabilities such as mental illness and drug addiction are also likely to develop. Unlike the primary disabilities, these do not reflect central nervous system damage, but instead develop because the child has difficulty adapting to his environment (Impact-RSV Study Group 1998).

**Genetic Diseases, Inborn:**

Diseases that are caused by genetic mutations present during embryo or fetal development, although they may be observed later in life. The mutations may be inherited from a parent's genome or they may be acquired in utero.

**Hereditary:**

A condition that was passed on from parents through genes, chromosomes and/ or DNA.

**Intellectual Disabilities:**

Intellectual disabilities, often referred to as mental retardation, are a cognitive disability characterized by significantly below-average intellectual functioning (generally regarded as an IQ below 70), combined with impairment in carrying out functions of daily life such as caring for oneself, communicating and interacting socially.

**Learning Disability:**

A learning disability is distinct from mental retardation in that a diagnosed individual may have normal or above-average intelligence, but has difficulty acquiring new skills or information.

**Minor Malformations:**

The terms includes malformations that are not life-threatening, and for which minor surgery can remove the malformation or no intervention is needed. This can also include behavioural delays.

**Odds ratio (OR):**

One measure of treatment effectiveness. It is the odds of an event happening in the experimental group expressed as a proportion of the odds of an event happening in the control group. The closer the OR is to one, the smaller the difference in effect between



the experimental intervention and the control intervention. If the OR is greater (or less) than one, then the effects of the treatment are more (or less) than those of the control treatment. Note that the effects being measured may be adverse (e.g., death or disability) or desirable (e.g., survival). When events are rare, the OR is analogous to the relative risk (RR), but as event rates increase the OR and RR diverge.

**Perinatal Conditions:**

This includes a wide range of conditions in the perinatal period as coded by the ICD-10. It includes conditions relating to gestational age and birth weight.

**Phenylketonuria (PKU):**

A condition in which the body cannot process a protein found in many foods; it can be treated through specialized diets.

**Randomized Controlled Trial (RCT):**

A trial in which participants are randomly assigned to two or more groups: at least one (the experimental group) receiving an intervention that is being tested and another (the comparison or control group) receiving an alternative treatment or placebo. This design allows assessment of the relative effects of interventions.

**Relative Risk (RR):**

The number of times more likely ( $RR > 1$ ) or less likely ( $RR < 1$ ) an event is to happen in one group compared with another. It is the ratio of the absolute risk for each group. It is analogous to the odds ratio (OR) when events are rare.

**Spina Bifida:**

A family of congenital malformation defects in the closure of the spinal column characterized by herniation or exposure of the spinal cord and/or meninges through an incompletely closed spine. Include meningocele, meningomyelocele, myelocele, myelomeningocele and rachischisis. Spina bifida is not counted when present with anencephaly. Excludes spina bifida occulta, and sacrococcygeal teratoma without dysraphism.

**ABBREVIATIONS**

AAP	American Academy of Paediatrics
ACOG	American College of Obstetricians and Gynecologists
BCRCP	BC Reproductive Care Program
CDC	Centers for Disease Control and Prevention
CPS	Canadian Paediatrics Society
LBW	low birth weight
NTD	neural tube defects
RCOG	Royal College of Obstetricians and Gynecologists
SGC	small for gestational age
SOGC	Society of Obstetricians and Gynaecologists of Canada
VLBW	very low birth weight

## **APPENDIX 1: RELATED WEBSITES**

### **Maternal Child Health**

- The Hospital for Sick Children–Motherisk: <http://www.motherisk.org/prof/index.jsp>. A comprehensive site with up-to-date research, recommendations and patient information on pregnancy.
- Maternal Child Health: <http://www.mchlibrary.info/>. A portal to a wide selection of the scientific literature on maternal child health.
- Foresight – the Association for Pre-conceptual Care: <http://www.foresight-preconception.org.uk/>. Patient information (United Kingdom).
- Healthy Beginnings - A must have for mothers to be (Society of Obstetricians and Gynaecologists of Canada): <http://www.sogc.org/healthybeginnings/>.
- University of North Carolina Chapel Hill. Public Health: Key Health Campaigns: Overview: <http://mombaby.org/index.php?c=4&s=47>. The website has an integrated approach to clinical care and public health in the field of maternal child health and links to public health sites related to Maternal Child Health.

### **Clinical Practice Guidelines**

- Guidelines and Protocols Advisory Committee (BC): <http://www.health.gov.bc.ca/gpac/index.html>.
- BC Reproductive Care Program: <http://www.rcp.gov.bc.ca/guidelines/Obstetrics/Master%20OB2A%20PTL%20March%202005.pdf>.
- Canadian Pediatric Society: <http://www.cps.ca/english/publications/FetusAndNewborn.htm>.
- Society of Obstetricians and Gynaecologists of Canada: [http://www.sogc.org/guidelines/index\\_e.asp](http://www.sogc.org/guidelines/index_e.asp).
- Canadian Medical Association: <http://mdm.ca/cpgsnew/cpgs/search/english/quicksearch.asp>.
- Royal College of Obstetricians and Gynaecologists (United Kingdom): <http://www.rcog.org.uk/index.asp?PageID=3>.
- Cochrane Collaboration: <http://www.cochrane.org/index.htm>.

### **Birth Defects and Genetics**

- **Birth Defects – MEDLINEplus:** <http://www.nlm.nih.gov/medlineplus/birthdefects.html>. Provides links to sites about specific birth defects and disorders, screening, treatment, and self help organizations.
- **Genetics Home Reference (National Library of Medicine):** <http://ghr.nlm.nih.gov/handbook/testing?sessionid=3273CCC675A662BD29E3AE07361C9AFF>. Provides consumer information about genetics, genetic conditions and the genes or chromosomes responsible for those conditions.
- **Genetic Disorders & Birth Defects Info Center:** <http://geneinfo.medlib.iupui.edu/>. A comprehensive site with both professional and public level information on specific disorders and the genetic research currently under way on specific disorders.
- **GeneTests:** <http://www.geneclinics.org/>. Clinical genetic information with concise descriptions of inherited disorders and current information on the role of genetic testing in the diagnosis, management, and genetic counselling of patients; also includes a database of US and international clinics providing genetic counselling.
- **Genetic Alliance:** <http://www.geneticalliance.org/>. International coalition that supports individuals with genetic conditions and their families, educates the public, and advocates for consumer-informed public policies.
- **Birth Defect Research for Children:** <http://www.birthdefects.org/>. Non-profit organization providing parents and expectant parents with information about birth defects and support services. Has a parent-matching program which links families who have children with similar birth defects. Also sponsors the National Birth Defect Registry.
- **March of Dimes:** <http://www.marchofdimes.com/>. Supports research and provides information on the four major problems affecting the health of America's babies: birth defects, infant mortality, low birth weight, and lack of prenatal care.
- **National Organization for Rare Disorders:** <http://www.rarediseases.org/>. Federation of more than 140 non-profit voluntary health organizations serving people with rare disorders and disabilities. Includes a searchable Rare Disease Database, which offers free access to abstracts. Full reports can be ordered for a small charge.
- **National Down Syndrome Society:** <http://www.ndss.org/>. Information on Down's syndrome. This site is dedicated to education, research and advocacy, and has information for family, friends, and community professionals and organizations.
- **Cleft Palate Foundation:** <http://www.cleftline.org/>. The foundations' website provides information on improving the quality of life for people with facial birth defects.
- **Spina Bifida Association of America:** <http://www.sbaa.org>. A resource website with information about prevention and advocacy.
- **Attention-Deficit/Hyperactivity Disorder (CDC):** <http://www.cdc.gov/ncbddd/adhd/default.htm>.

- **National Institute of Mental Health, Autism Spectrum Disorders (Pervasive Developmental Disorders):** <http://www.nimh.nih.gov/publicat/autism.cfm>.
- **Welcome to EUROCAT:** <http://eurocat.ulster.ac.uk/>. A European network of population-based registries for the epidemiologic surveillance of congenital anomalies.
- **National Library for Health (United Kingdom) – Screening:** <http://www.library.nhs.uk/screening/>. A comprehensive site with reviews of all screening tests.

### **Infant Development and Early Intervention.**

- **National Center on Birth Defects and Developmental Disabilities:** <http://www.cdc.gov/ncbddd/>. Produced by the Centers for Disease Control and Prevention to prevent birth defects and to enhance the quality of life among those with disabilities. Has links to other high quality information resources.
- **Developmental Disabilities (CDC):** <http://www.cdc.gov/ncbddd/dd/default.htm>.
- **The Future of Children:** <http://www.futureofchildren.org/info-url2815/info-url.htm>. Seeks to promote effective policies and programs for children by providing policy-makers, service providers and the media with timely, objective information based on the best available research.
- **Developmental Pediatrics Online:** <http://www.dbpeds.org/>.

### **Fetal Alcohol Syndrome**

- **Canadian Pediatric Society Statement on Fetal Alcohol Syndrome:** <http://www.cps.ca/english/statements/II/ii02-01.htm>.
- **Canadian Addiction Survey (Centre for Addictions Research of BC):** <http://www.carbc.uvic.ca/alcoholbulletin2005.pdf>.
- **BC Reproductive Care Program Guidelines:** [http://www.rcp.gov.bc.ca/guidelines/Substance\\_Use/Alcoholguideline.pdf](http://www.rcp.gov.bc.ca/guidelines/Substance_Use/Alcoholguideline.pdf)
- **Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy (Health Canada):** [http://www.hc-sc.gc.ca/ahc-asc/pubs/drugs-droques/best\\_practices-meilleures\\_pratiques/index\\_e.html](http://www.hc-sc.gc.ca/ahc-asc/pubs/drugs-droques/best_practices-meilleures_pratiques/index_e.html).
- **Fetal Alcohol Syndrome Multimedia Guide:** <http://fas.academicedge.com/index.html>.
- **Fetal Alcohol Syndrome (CDC):** <http://www.cdc.gov/ncbddd/fas/>.
- **National Institute on Alcohol and Alcohol Abuse:** <http://www.niaaa.nih.gov/>.
- **FASD Center for Excellence (Substance Abuse and Mental Health Services Administration):** <http://www.fascenter.samhsa.gov/>.

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- **Agency for Health Care Research and Quality, Preventive Services:** <http://www.ahrq.gov/clinic/prevenix.htm>.
- **FASD Connections:** <http://www.fasdconnections.ca/index.htm>.

**Environmental Links**

- **National Environmental Education Foundation (US):** <http://www.neefusa.org/about/>.
- **Centre for Research on Occupational and Environmental Technology (CROETWeb), Workplace Safety and Health Resources:** <http://croetweb.com/index.cfm>.
- **National Pesticide Information Center:** <http://npic.orst.edu/>.
- **Pesticide Illness and Injury Surveillance (National Institute for Occupational Safety and Health):** <http://www.cdc.gov/niosh/topics/pesticides/>.

**Research Links**

- **The Canadian Neonatal Network™:** <http://www.canadianneonatalnetwork.org/abstractor-login.php>.
- **Human Early Learning Partnership (HELP):** <http://www.earlylearning.ubc.ca/>.

## **APPENDIX 2: TYPES OF DISABILITIES AMONG CHILDREN**

The Participation and Activity Limitations Survey (Statistics Canada 2002) questions allow the identification of the following types of disabilities among children under 15:

- **Hearing** (applicable to all children under 15).
- **Seeing** (applicable to all children under 15).
- **Speech** (applicable to children aged 5 to 14).
- **Mobility** (applicable to children aged 5 to 14): Difficulty walking. This means walking on a flat firm surface, such as a sidewalk or floor.
- **Dexterity** (applicable to children aged 5 to 14): Difficulty using hands or fingers to grasp or hold small objects, such as a pencil or scissors.
- **Developmental delay** (applicable to children under 5): Child has a delay in his/her development, a physical, intellectual or another type of delay.
- **Developmental disability or disorder** (applicable to children aged 5 to 14): Cognitive limitations due to the presence of a developmental disability or disorder, such as Down's syndrome, autism or mental impairment caused by a lack of oxygen at birth.
- **Learning** (applicable to children aged 5 to 14): Difficulty learning due to the presence of a condition, such as attention problems, hyperactivity or dyslexia, whether or not the condition was diagnosed by a teacher, doctor or other health professional.
- **Psychological** (applicable to children aged 5 to 14): Limited in the amount or kind of activities that one can do due to the presence of an emotional, psychological or behavioral condition.
- **Chronic condition** (applicable to all children under 15): Limited in the amount or kind of activities that one can do due to the presence of one or more chronic health conditions that have lasted or are expected to last six months or more and that have been diagnosed by a health professional. Examples of chronic conditions are asthma or severe allergies, heart condition or disease, kidney condition or disease, cancer, epilepsy, cerebral palsy, spina bifida, cystic fibrosis, muscular dystrophy, fetal alcohol syndrome, etc.
- **Unknown** (applicable to all children under 15): The type of disability is unknown if the respondent answered YES to the general questions on activity limitations, but did not provide any YES to the questions about type of disability that followed.
- **Under age 4:** hearing, vision, chronic health conditions, developmental delay, and disability of an unknown nature.
- **Children 5 and over:** speech, mobility, dexterity or a psychological condition, as well as learning disabilities and developmental disability. Some types of disabilities are not identified before age 5.

### **Scoring of Severity of Disability**

An index measuring the severity of the disability (Participation and Activity Limitations Survey) was constructed based on the answers to the survey questions. Points were given according to the intensity and the frequency of the activity limitations reported by the respondent. A single score was computed for each type of disability. Each score was then standardized in order to have a value between 0 and 1. The final score is the average of the scores for each type of disability.

Since the survey questions differ depending on the age of the respondent, a different scale was constructed for adults (15 years and over), for children under 5 and for children aged 5 to 14. Each scale was then divided into different severity levels. The scale for adults and for children aged 5 to 14 was divided into four groups (that is, mild, moderate, severe and very severe), while the scale for children under 5 was divided into two groups (that is, mild to moderate and severe to very severe).

**APPENDIX 3: HEALTH STATUS REGISTRY REPORT – SELECTED CONDITIONS AND DISABILITIES**

**Table A: Counts of Individuals Living with "Other" Genetic and Acquired Conditions by Age Group, 2002, BC.**

<b>Conditions</b>	<b>&lt;15</b>
Hereditary haemolytic & aplastic anemias	599
Hereditary disturbance in tooth structure	501
Disorders of mineral metabolism	446
Haemophilia and other coagulation defects	390
Disorders of protein metabolism	312
Cystic fibrosis	251
Other extrapyramidal diseases	188
Other and unspecified disorders of metab.	185
Other myopathies	176
Muscular dystrophy	97
Hypopituitarism (includes dwarfism)	78
Disorders of carbohydrate trans/metab.	78
Other disorders of amino-acid metabolism	66
Phenylketonuria (PKU)	57
Hyperpituitarism & other pituitary disorder	49
Hereditary peripheral neuropathy	49
Anterior horn cell diseases (excl. ALS)	37
Acromegaly/gigantism	16
Congenital syphilis	12
Huntington's chorea	1
<b>Total Diagnoses</b>	<b>3,588</b>
<b>Total Cases</b>	
<b>Diagnoses less tooth disorders</b>	<b>3,087</b>

Source: Health Status Registry Report.

**Table B. Children (Less than 15 yrs.) with Selected Disabilities and Handicapping Conditions, 2002, BC.**

<b>Disability</b>	<b>&lt; 15</b>
All other visual impairments/ blindness	7,430
Epilepsy	3,784
Stuttering and specific developmental delays	2,800
Abnormal auditory perception and deafness	1,428
Infantile cerebral palsy	1,249
Mental retardation	1,221
Hyperkinetic syndrome	1,185
Diabetes mellitus	1,094
Hemangioma and lymphangiona	1,075
Other acquired deformities of limbs	585
Childhood cerebral degenerations and acquired hydrocephalus	546
Retrolental fibroplasia	357
Hemiplegia	323
Other paralytic syndromes	275
Curvature of spine	273
Osteochondropathies	218



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<b>Disability</b>	<b>&lt; 15</b>
Disorders of muscle, ligament and fascia	208
Tourette's syndrome	201
Rheumatoid arthritis	160
Disorders of adrenal glands	142
Neurofibromatosis/ von Recklinghausen's	105
Quadriplegia	73
Retinoblastoma	39
Paraplegia	35
<b>Total Diagnoses</b>	<b>24,806</b>
<b>Total Cases</b>	<b>16,295</b>

Source: Health Status Registry Report.

**APPENDIX 4: LIST OF CONDITIONS RECOMMENDED FOR SCREENING  
(UNITED STATES)**

**List of Top-Ranked Conditions Recommended for Newborn Screening.**

Condition	Ranking	Current BC Children's screening	US Screening 2000(cases)*
Medium-chain acyl-CoA dehydrogenase deficiency	1	Yes	
Congenital hypothyroidism	0.99	Yes	Yes (1,601 cases)
Phenylketonuria	0.98	Yes	Yes (193 cases)
Neonatal hyperbilirubinemia (kernicterus)	0.96		
Biotinidase deficiency	0.95		24 states (8 cases)
Sickle cell anemia (hemoglobin SS disease)	0.94		Yes (832 cases)
Congenital adrenal hyperplasia (21-hydroxylase deficiency)	0.93		24 states (79 cases)
Isovaleric acidemia	0.89		
Maple syrup disease	0.89		22 states (8 cases)
Very long-chain acyl-CoA dehydrogenase deficiency	0.89		
Classic galactosemia	0.88	Yes	Yes (60 cases)
Hemoglobin S/ $\beta$ -thalassemia	0.87		Yes (93 cases)
Hemoglobin S/C disease	0.86		Yes (380 cases)
Long-chain L-3-hydroxyacyl-CoA dehydrogenase deficiency	0.84		
Glutaric acidemia type I	0.83		
3-Hydroxy-3-methylglutaric aciduria	0.82		
Trifunctional protein deficiency	0.81		
Multiple carboxylase deficiency	0.80		
Benign hyperphenylalaninemia	0.78		71 cases
Methylmalonic acidemia (mutase deficiency)	0.77		
Homocystinuria (attributable to cystathionine $\beta$ -synthase deficiency)	0.76		17 states (5 cases)
3-Methylcrotonyl-CoA carboxylase deficiency	0.75		
Hearing loss	0.73		
Methylmalonic acidemia (Cbl A,B)	0.72		
Propionic acidemia	0.71		
Carnitine uptake defect	0.69		
Glucose-6-phosphate dehydrogenase deficiency	0.67		
Galactokinase deficiency	0.69		
$\beta$ -Ketothiolase deficiency	0.66		
Citrullinemia	0.65		
Argininosuccinic acidemia	0.64		
Tyrosinemia type I	0.63		4 states (0 cases)
Short-chain acyl-CoA dehydrogenase deficiency	0.61		
Tyrosinemia type II	0.60		
Glutaric acidemia type II	0.59		
Medium/short-chain L-3-hydroxyacyl-CoA dehydrogenase deficiency	0.58		
Cystic fibrosis	0.57		7 states (79 cases).
Variant hemoglobinopathies (including hemoglobin E)	0.55		Yes
Human HIV infection	0.54	?	

**Note:**

\* National Newborn Screening and Genetics Resource Center 2003.

**Source:** American College of Medical Genetics 2006.

**APPENDIX 5: FOLLOW-UP FOR LOW BIRTH WEIGHT INFANTS**

Table codes

Type	function	Modality	Strength of Evidence
Pr preventive; A- acute; C- chronic;	S- screening; D- diagnosis; Tr- treatment; F- follow-up;	H- history; Ph- physical examination; T- tests; I- interventions/medication; R- return/referrals;	1- randomized- controlled trial; 2- nonrandomized- controlled trial- cohort or case control study- or multiple time series; 3- descriptive study or expert opinion.

Applicable Age, y	Indicator Number	Indicator	Type	Function	Modality	Strength of Evidence
<b>A General Care</b>						
0-1	1	A copy of a summary of the patient's neonatal hospital course should be in the patient's primary care provider's medical record.	Pr	F	H	2
	2-17	Summary of the neonatal hospital course should include:				
0-1	2	Gestational age at birth	Pr	D	H	3
0-1	3	Birth weight	Pr	D	H	3
0-1	4	Discharge weight	Pr	D	H	3
0-1	5	Discharge head circumference	Pr	D	H	3
0-1	6	Days on supplemental oxygen or gestational age off oxygen	Pr	D	H	3
0-1	7	Date and results of last metabolic screen	Pr	D	H	3
0-1	8	Date and results of last hearing screen	Pr	D	H	3
0-1	9	Date and results of last retinal examination	Pr	D	H	3
0-1	10	Date and results of last cranial imaging	Pr	D	H	3
0-1	11	Date and result of worst/significant abnormality in cranial imaging	Pr	D	H	3a
0-1	12	Date and results of last hematologic assessment	Pr	D	H	3
0-1	13	Dietary intake at discharge (i.e., breast milk or formula; other nutritional supplements)	Pr	F	H	3a
0-1	14	Immunization status	Pr	F	H	3
0-1	15	Problem list (diagnosis, medication [including oxygen], and referrals)	Pr	D	H	3a
0-1	16	Palivizumab (Synagis) date(s)	Pr	F	H	3a
0-1	17	Psychosocial history	Pr	S	H	3a
0-2	18	Head circumference should be measured and plotted at every health maintenance visit up to the visit at age 2	Pr	S	Ph	2
0-6	19	Height and weight should be measured and plotted at every health maintenance visit.	Pr	S	Ph	3a

**References:**

Van Walraven et al. 2002 **III**; AAP 2000 **G**; AAP 1998 **CPG**; Hack et al. 1991; Green 1994 **IV**

Applicable Age, y	Indicator Number	Indicator	Type	Function	Modality	Strength of Evidence
<b>B. Physical Health</b>						
	20-21	Parents of all VLBW infants should be counselled regarding:				
0-1	20	Sleep position in the prevention of SIDS within 1 mo of discharge from the nursery, unless the infant is discharged after 6 mo adjusted age	Pr	S	I	2a
0-1	21	Hazards of environmental tobacco smoke within 2 mo of discharge from nursery	Pr	S	I	2a

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Applicable Age, y	Indicator Number	Indicator	Type	Function	Modality	Strength of Evidence
0-2	22	Children who are younger than 2 y as of November 1 and have required medical therapy (supplemental oxygen, bronchodilator, diuretic, or corticosteroid therapy) for CLD after May 1 should receive appropriate doses of palivizumab (Synagis) with the first dose given before November 1	Pr	Tr	I	1a
	23-26	Children who have CLD and are discharged on supplemental oxygen should have the following assessments performed at least monthly until they are off supplemental oxygen:				
0-1	23	An interim history	C	F	H	3a
0-1	24	Measurement of weight	C	F	Ph	3a
0-1	25	Pulse oximetry reading at rest	C	F	T	3a
0-1	26	Pulse oximetry reading during feeding	C	F	T	3a
0-1	27	Children who show poor weight gain (average of <20 g/d) during the first month after discharge from the nursery should have a specific follow-up plan documented in the chart.	Pr	F	I	3a
0-1	28	All VLBW infants should receive supplemental iron (as an iron supplement or iron-fortified formula) starting by 2 mo of age.	Pr	Tr	I	3a

**References:**

The Impact-RSV Study Group 1998; Blair et al. 2006 CCS; Meissner and Long 2003 R; Green 1994 IV; AAP 1985 CPG; Kotecha and Allen 2002

**Vision, Hearing, and Speech and Language**

Applicable Age, y	Indicator Number	Indicator	Type	Function	Modality	Strength of Evidence
<b>C. Vision, Hearing and Speech and Language</b>						
0-1	29	Findings of the ophthalmologic examination for ROP should be recorded using the International Classification of ROP.	Pr	D	H	3
0-1	30	The discharge summary should include the schedule for the first post discharge pediatric ophthalmologic follow-up, if indicated.	Pr	F	H	3a
0-1	31	The primary care provider should document whether the first ophthalmologic follow-up visit occurred on schedule.	Pr	F	H	3a
0-3	32	If on a routine clinic visit between birth to 3 y of age any ophthalmologic morbidity is documented, then the patient should be seen by an ophthalmologist within 1 mo.	A	Tr	R	1
0-6	33	The primary care provider should document whether children who receive a diagnosis of a vision problem are receiving appropriate interventions.	Pr	F	H	3a
	34-37	An ophthalmologic examination should be performed at least:				
1-2	34	Once between ages 1 and 2 by an ophthalmologist	Pr	S	T	3b
3-4	35	Once between ages 3 and 4	Pr	S	T	3
4-5	36	Once between ages 4 and 5	Pr	S	T	3
5-6	37	Once between ages 5 and 6	Pr	S	T	3
	38-41	In the absence of a formal developmental evaluation, the assessment of speech and language development as defined by a developmental screening test should be documented at least:				
1-2	38	Once between ages 1 and 2	Pr	S	T	3
2-3	39	Once between ages 2 and 3	Pr	S	T	3
3-4	40	Once between ages 3 and 4	Pr	S	T	3
4-5	41	Once between ages 4 and 5	Pr	S	T	3
0-3	42	For children who are younger than 3 y and have suspected language developmental delay, a specific intervention (watchful waiting with re-evaluation, hearing assessment, and/or specific speech and language testing, or a specific intervention program) should be started within 2 mo of the suspect or abnormal finding.	Pr	D	I	3

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**Prevention of Disabilities (Congenital & Genetic)**

Applicable Age, y	Indicator Number	Indicator	Type	Function	Modality	Strength of Evidence
0-1	43	For all infants who have risk factors for hearing loss <sup>89</sup> and passed the inpatient universal newborn hearing screen, a diagnostic hearing test should be performed by 12 mo of chronological age.	Pr	D	T	3
0-1	44	For infants who did not pass the inpatient universal newborn hearing screen, a hearing diagnostic should be completed within 3 mo of the failed screen.	A	D	T	3
0-1	45	For infants who did not receive inpatient universal newborn hearing screen, a hearing diagnostic should be completed within 1 mo of discharge from the nursery.	Pr	D	T	3
0-1	46	For infants with a diagnosis of a nonconductive hearing loss, rehabilitation should be started by 6 mo of chronologic age.	A	Tr	I	3

**References:**

Committee on Practice and Ambulatory Medicine et al. 2003 **IV**; Prasad and Chudley 2002; Green 1994 **IV**; AAP 2001; AAP 1998 **CPG**; American Academy of Audiology et al. 2000 **CPG**

Applicable Age, y	Indicator Number	Indicator	Type	Function	Modality	Strength of Evidence
<b>D. Developmental and Behavioural Assessment</b>						
	47-48	For children between ages 0 and 3, a formal developmental evaluation should be performed at least:				
0-2	47	Once between 9 and 15 mo corrected age	Pr	D	T	3a
1-3	48	Once between 21 and 30 mo corrected age	Pr	D	T	3a
0-3	49	For children between ages 0 and 3, a formal developmental evaluation should be performed within 2 mo of a suspect or abnormal developmental screening test (e.g., abnormal Bayley Infant Neurodevelopment Screener)	A	D	R	3a
	50-55	In the absence of a formal developmental evaluation, the presence or absence of parental concerns and a multidimensional developmental screening test should be documented using standardized instruments at least:				
0-1	50	Once during the first 6 mo	Pr	S	T	3a
0-1	51	Once during the second 6 mo	Pr	S	T	3a
1-2	52	Once between ages 1 and 2	Pr	S	T	3a
2-3	53	Once between ages 2 and 3	Pr	S	T	3a
3-4	54	Once between ages 3 and 4	Pr	S	T	3a
4-5	55	Once between ages 4 and 5	Pr	S	T	3a
	56-60	A structured, age-appropriate neuromotor assessment should be performed by corrected age at least:				
0-1	56	Once during the first 6 mo	Pr	S	Ph	3
0-1	57	Once during the second 6 mo	Pr	S	Ph	3
1-2	58	Once between ages 1 and 2	Pr	S	Ph	3
2-3	59	Once between ages 2 and 3	Pr	S	Ph	3
4-5	60	Once between ages 4 and 5	Pr	S	Ph	3
0-5	61	If the structured neuromotor examination or the formal developmental evaluation is suspect or abnormal, then a specific intervention (watchful waiting with re-evaluation, specialist consultation, or a specific intervention program) should be started within 2 mo of the suspect or abnormal finding.	A	F	R	3
0-6	62	If a professional who is performing the neuromotor examination recommends physical therapy or occupational therapy for the patient, then interventions should be started within 2 mo of the recommendation.	C	Tr	I	3
0-6	63	If parents express concerns about their child's behaviour, then a specific intervention (watchful waiting with re-evaluation, primary care management, referral to a specialist, or referral to a specific intervention program) should be started within 2 mo.	C	F	R	2

**Core Public Health Functions for BC: Evidence Review**  
**Prevention of Disabilities (Congenital & Genetic)**

Applicable Age, y	Indicator Number	Indicator	Type	Function	Modality	Strength of Evidence
3-5	64	Children who are born <1000 g and/or <28 wk gestation should be referred to the school system or a child developmental specialist for a psychoeducational assessment between ages 3 and 5, unless it has already occurred.	Pr	S	R	3a
4-6	65	By the next health maintenance visit after referral of a child for psychoeducational testing, the primary care provider should document the result of the referral and/or assessment and any planned intervention(s).	Pr	F	H	3

**References:**

Green 1994 IV; Glascoe 1997; AAP 2001 CPG

Applicable Age, y	Indicator Number	Indicator	Type	Function	Modality	Strength of Evidence
<b>E. Psychosocial Assessment</b>						
	66-68	The following family demographic characteristics (maternal age, marital status, health insurance information, education, number of children in the household, and child's primary care giver) should be noted in the chart at least:				
0-1	66	Once in the first year	Pr	S	H	3a
1-3	67	Once between ages 1 and 3	Pr	S	H	3a
3-5	68	Once between ages 3 and 5	Pr	S	H	3a
0-3	69	Family psychosocial evaluations including the presence or absence of substance abuse should be noted at least once by age 3.	Pr	S	H	3a
0-5	70	For families with social risk(s) as defined by psychosocial indicators 66-69, a specific intervention (re-evaluation, primary care management, referral to a specialist, or referral to a specific intervention program) should be started within 1 mo of the psychosocial assessment.	C	F	R	3

**References:**

AAP 1998 CPG