

**ETHICAL ISSUES RAISED  
BY PRENATAL SCREENING  
FOR DOWN SYNDROME  
(TRISOMY 21) IN QUÉBEC**

LITERATURE REVIEW

DOCUMENT PREPARED AS PART OF THE  
CONSULTATION ON THE SCREENING FOR  
DOWN SYNDROME IN QUÉBEC

THE HEALTH AND WELFARE COMMISSIONER

JUNE 2008

The Health and Welfare Commissioner was established by a law in June 2005. The Commissioner is responsible for assessing the results achieved by the health and social services system taking into account the range of systemic factors that interplay within the system, and for providing the public with the necessary background for a general understanding of the actions undertaken by the Government to address the major issues in the health and social services arena.

The Commissioner has a Consultation Forum composed of 27 members, including 18 citizens from each of the regions of Québec who do not represent a special interest group and nine other persons with special expertise in the field of health and social services.

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## INTRODUCTION

The Ministère de la Santé et des Services sociaux is considering putting in place a prenatal screening program for Down syndrome, also called trisomy 21, which would eventually be accessible throughout Québec. Since this project raises important ethical and social issues, over which a number of organizations have expressed concerns, the Minister of Health and Social Services, Mr. Philippe Couillard, asked the Health and Welfare Commissioner to hold a consultation on the subject.<sup>1</sup>

Under section 15 of *An Act respecting the Health and Welfare Commissioner*, the government or the minister can entrust the Commissioner with any special mandate within the Commissioner's competence. However, in no case may such a mandate take precedence over the other functions assigned to the Commissioner under its empowering legislation.

This literature review, prepared as part of the Commissioner's consultation mandate, provides a survey of the ethical and social issues related to Down syndrome screening. The information it contains should be food for thought for people interested in this matter and for the members of the Consultation Forum who will participate in deliberations on this subject. This Forum is made up of citizens from every region of Québec as well as experts.

The document first addresses Down syndrome, the technical questions related to its screening and diagnosis, and the current situation with regard to prenatal Down syndrome screening in Québec. It then presents the main ethical and social issues related to Down syndrome screening, as identified in the literature. The quantity and nature of the issues raised are intended to reflect their relative importance in the literature.

**The arguments presented have not been supplemented by the other parts of the Commissioner's consultation, such as targeted calls for papers or online consultations. Therefore, this is not a statement of position by the Commissioner or the result of consultations on this topic. These will be presented in the Commissioner's report issued in the fall of 2008.**

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<sup>1</sup> The information contained in this document regarding the Québec Down syndrome screening program was drawn from a discussion paper obtained by the Health and Welfare Commissioner from the Ministère de la Santé et des Services sociaux in January of 2008.



## 1. DOWN SYNDROME (TRISOMY 21)

Down syndrome was first described in detail in 1866 by the British doctor John Langdon Down, whence its name (Costa, Delatour *et al.*, 1998).

In general, at the clinical level the syndrome is characterized by developmental delays, a characteristic morphology of the face and other health problems (Kohut, Rusen *et al.*, 2002, p. 1).

More specifically, people with Down syndrome have the following physical characteristics to some degree. The skull is small, the nape of the neck is flat and wide and the face is round. The eyes are slanted and the nose is short and sometimes flat. The mouth is small, which causes people with Down syndrome to frequently stick their tongues out of their mouths. People with Down syndrome are short, and their limbs and fingers are short. They grow slowly, but age rapidly (Rapin, 1992).

People with Down syndrome may also have specific health problems. For example, they are at risk of skeletal malformations. Heart problems can also accompany Down syndrome. They are also at risk of gastrointestinal obstructions, poor functioning of the thyroid gland, cataracts and deafness. They run a greater risk of developing leukemia than the general population and show early neurological changes similar to those of Alzheimer's (Kohut, Rusen *et al.*, 2002, p. 2).

People with Down syndrome are mentally retarded. The degree of mental retardation observed varies, from mild to more extreme (AETMIS, 2003), and cannot be evaluated through a screening<sup>2</sup> or diagnostic<sup>3</sup> process (Pratte, 2003, p. 21).

According to a study conducted in Europe, most children with Down syndrome are toilet trained and able to feed and clothe themselves with a little help as of age five. However, they take longer to learn to walk and talk (Shojai, Boubli *et al.*, 2005, p. 516).

The integration of these children in special schools allows some of them to learn to read and write and develop their socialization skills, in terms of language and psychomotor behaviour (Shojai, Boubli *et al.*, 2005, p. 516).

While cases of severe intellectual disability are rare, many adults with Down syndrome live in assisted living environments (Kohut, Rusen *et al.*, 2002, p. 2).

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<sup>2</sup> Screening: "Techniques offered to pregnant women to identify those with a high risk of carrying an affected child" [courtesy translation] (Forest, Blouin, *et al.*, 2004, p. 27).

<sup>3</sup> Diagnosis: "Techniques to confirm the diagnosis among pregnant women identified as being at high risk of carrying an affected child" (Forest, Blouin *et al.*, 2004, p. iv).

In Québec, various rehabilitation services are offered to people with intellectual disabilities such as those mentioned by the Fédération québécoise des centres de réadaptation: access to services, evaluation and orientation; adaptation and rehabilitation of the person; adaptation/ rehabilitation for integration to the living environment, the working environment and the community; specialized educational assistance to families and loved ones; specialized support to partners (Cloutier and Wilkins, 2006, p. 13-15). This federation underlines the “need to support parents and provide them the assistance required to support, as effectively as possible, the development of their child and to support them in their many efforts to obtain services from the health and social services, educational, municipal, socio-economic and community networks” [courtesy translation] (Cloutier and Wilkins, 2006, p. 7).

The incidence of Down syndrome “in the population is 1 per 770 live births, or 1.3 per 1,000 live births.” (AETMIS, 2003, p. vii). If we compare the rate of prevalence of Down syndrome around the world, it is clear that easier access to and increased use of prenatal screening and diagnostic tests, as well as pregnancy interruption services, explain the differences observed: “the most significant decreases in the birth prevalence of Down syndrome occurred in countries or regions which had the highest rates of terminations” [courtesy translation] (Kohut, Rusen *et al.*, 2002, p. 5). The observation of the evolution of the prevalence of Down syndrome in France also shows that when the rate of prenatal detection of Down syndrome increases, the prevalence of the syndrome at birth is reduced (Khoshnood, Vigan *et al.*, 2004).

The prevalence of Down syndrome increases with the age of the mother. This increase is gradual up to age 35 and is particularly marked thereafter<sup>4</sup> (AETMIS, 2003; Roizen and Patterson, 2003, p. 1281; Kohut, Rusen *et al.*, 2002, p. 2).

The progress of medical care has made it possible to reduce the mortality and morbidity associated with Down syndrome at birth and during childhood. For example, multidisciplinary care can improve the chances of survival of infants with cardiac problems, and early medical intervention can reduce the risks of complications (Kohut, Rusen *et al.*, 2002, p. 2). Furthermore, the life expectancy of people with this syndrome has improved: in 1997, their average age in the United States was 49 (Kohut, Rusen *et al.*, 2002, p. 1).

## 1.1 Screening for and diagnosis of Down syndrome

In 1959, Jérôme Lejeune and his team discovered the connection between Down syndrome and the presence of a third chromosome 21 (Lejeune, Gautier *et al.*, 1959), one of the structures that contain our DNA and our genes and found in each of our cells. Normally, human beings have 46 chromosomes, but people with Down syndrome have

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<sup>4</sup> The probability of having a trisomic child at 35 is 1 per 260 births and at 44 is 1 per 30 (www.fetalmedicine.com).



47; they have three 21st chromosomes rather than two. This is the origin of the other name of Down syndrome: trisomy 21. The third 21st chromosome appears most often upon ovulation or at the beginning of conception. Down syndrome is therefore not hereditary, although genetic material is involved, because it is very rarely transmitted from one generation to the next (Pratte, 2003, p. 6).

Since the discovery of the connection between Down syndrome and the presence of the third 21st chromosome, Down syndrome screening and diagnosis have been possible.

### 1.1.1 Prenatal screening

The Society of Obstetricians and Gynaecologists of Canada (SOGC) present the options for prenatal screening for Down syndrome currently available (see table 1):

“Currently available non-invasive<sup>5</sup> screening options include maternal age combined with

1. first trimester screening (FTS) (nuchal translucency<sup>6</sup>, maternal serum biochemical markers<sup>7</sup>);
2. second trimester serum screening; or
3. a two-step integrated screening, which includes first and second trimester serum screening with or without nuchal translucency (IPS, Serum IPS, contingent and sequential).” (Summers, Langlois *et al.*, 2007, p. 162).

**It is necessary to distinguish Down syndrome screening and diagnosis.**

#### *Screening*

Screening is aimed at a population. Screening tests make it possible **to assess the probability** for a mother to carry a child with Down syndrome. With our current state of knowledge, they are non-invasive<sup>4</sup> and present no physical risk for the fetus or the mother aside from those related to anxiety and stress. Screening tests do not confirm a diagnosis (Summers, Langlois *et al.*, 2007).

#### *Diagnosis*

Diagnostic tests are aimed at a patient. Unlike screening tests, diagnostic tests make it possible to **determine whether a fetus has Down syndrome**. The diagnostic tests currently available are invasive (Ogilvie, 2003; Summers, Langlois *et al.*, 2007) and present risks for the mother and the fetus. These risks include the loss of a fetus (+/- 0.6% to 1%) (Wilson, Langlois *et al.*, 2007).

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<sup>5</sup> Invasive: “involving the introduction of instruments into the body” (*The Canadian Oxford Dictionary*) as opposed to “non-invasive” which does not involve such an introduction. According to the classification of the SOGC, a blood test is not considered to be an invasive intervention even if it involves passing through the skin surface.

<sup>6</sup> Nuchal translucency: “Subcutaneous space located between the skin and the spine of the fetus,” [courtesy translation] in the neck (Forest, Blouin, *et al.*, 2004, p. 27) that can be seen and measured by ultrasound between the 11th and 14th week.

<sup>7</sup> Maternal serum biochemical markers: Factors (proteins, hormones) found in the mother’s blood that can be measured through lab analysis to determine certain characteristics of the fetus.

Screening tests performed obtain results in the form of risks (probability) of the fetus presenting an anomaly. Depending on the screening technique used, results can be obtained for different anomalies. For example, certain tests can screen for, in addition to Down syndrome, trisomy 18 and neural tube anomalies. Useful information for case management for the mother and the child can also be obtained through the analysis of markers in the blood, such as the risk of puerperal toxemia and growth delays. Each technique has its own degree of reliability (Pratte, 2003, p. 28). If a risk beyond a predetermined threshold is identified through the screening, the parents would be offered a diagnostic test to confirm whether or not the anomaly is actually present.

### 1.1.2 Prenatal diagnosis

Prenatal diagnosis based on chromosomal analysis has been available since the 1960s (Ogilvie, 2003, p. 156). Down syndrome is the most common clinical observation (Ogilvie, 2003, p. 156).

**Table 1: Main options currently available for screening for and diagnosing Down syndrome\***

Screening options

- Screening using maternal serum markers (blood tests)
  - First trimester
  - Second trimester
- Screening via ultrasound<sup>10</sup>
  - First trimester (nuchal translucency)<sup>6</sup>
  - Second trimester
- Combined (serum markers and first trimester ultrasound)
- Integrated (serum markers during the first and second trimester with or without ultrasound)

Diagnostic techniques

- Chromosomal analysis
  - Sampling through amniocentesis<sup>8</sup>
  - Chorionic villi sampling (CVS)<sup>9</sup> or chorion biopsy

Other related techniques

- Ultrasound for dating<sup>10</sup>

\* The different screening techniques used separately do not meet current clinical standards (for example, blood tests during the first trimester or nuchal translucency). The screening options using different techniques—combined, integrated—are the only ones that respect current clinical standards.

The Society of Obstetricians and Gynaecologists of Canada (SOGC) therefore presents the options for prenatal diagnosis of Down syndrome that are currently available (see table 1) and recommendations as to their use:

“Invasive prenatal diagnosis would be limited to women who screen above a set risk cut-off level on non-invasive screening or pregnant women who will be 40 years at time of delivery who, after counselling, chose to go directly to amniocentesis<sup>8</sup>/chorionic villi sampling<sup>9</sup> (CVS).” (Summers, Langlois *et al.*, 2007, p. 162).

Thus, the SOGC recommends: 1) that invasive diagnostic tests that present risks for the mother and the fetus tests be offered only following a screening test that shows that the patient presents a high risk of carrying a fetus with Down syndrome, and 2) that in the absence of screening, diagnostic tests be offered to women over 40.

In other countries, such as the U.K. (Ogilvie, 2003, p. 157) and France (Pratte, 2003, p. 42), it is also recommended that invasive diagnostic tests be offered only to women with a high risk of carrying a fetus with Down syndrome.

It is important to underline that the techniques for diagnosing Down syndrome are evolving to be more targeted and to reduce waiting time for results.

The ultrasound for dating<sup>10</sup>, used during the first trimester as a related technique, rounds out these screening and diagnostic techniques (see table 1). The ultrasound for dating is used to accurately date the pregnancy. It also allows for “the detection of twins, the diagnosis of *in utero* death and other complications of pregnancy” [courtesy translation] (Forest, Blouin *et al.*, 2004, p. 9). The precise dating of the pregnancy takes on increased importance in screening processes in that the screening tests are reliable at specific moments during a pregnancy.

## 1.2 Options following the Down syndrome screening and diagnosis process

In most cases, the result of the screening and prenatal diagnosis processes is negative (Pratte, 2003, p. 19). In cases where the result is positive, i.e. where a fetus is indeed

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<sup>8</sup> Amniocentesis: “the sampling of amniotic fluid by insertion of a hollow needle to determine the condition of an embryo” (*Canadian Oxford Dictionary*).

<sup>9</sup> Chorionic villi sampling (CVS) or chorion biopsy: “Prenatal test that involves taking a small sample of cells from the membranes around the fetus. These cells are used to perform a genetic analysis, i.e., an analysis of the fetus’s genes” [courtesy translation] (CORAMH, 2002).

<sup>10</sup> Ultrasound: 1) “an esp. diagnostic procedure using echoes of ultrasonic pulses to delineate objects or areas of different density in the body”; 2) “an image of a subject produced by such a procedure” (*Canadian Oxford Dictionary*). By extension, an ultrasound for dating makes it possible to establish the date of the pregnancy.

diagnosed with Down syndrome, the future parents have the following options: voluntary termination of pregnancy or preparation for the arrival of the baby. Parents can prepare by ensuring that special medical supervision will be available during delivery and that specific medical care will be provided during and after delivery; they can also explore the particular choices open to them with regard to the newborn's future life, including identification of specific resources, adoption or placement in a foster family (Pratte, 2003, p. 20).

### **1.3 The various types of Down syndrome screening in Québec**

Screening can take on various forms, each of which has its own defining characteristics. For example, screening can be systematic or not, or mandatory or not.

Screening is considered systematic if every member of a population undergoes the process. It is considered systematically offered if the entire population has access to it. Opportunistic screening is offered following a request from the individuals to whom the process would apply, or on a non-systematic basis. These three situations are different and must be presented as such.

Furthermore, screening can be “mandatory if it is imposed by a law, an organization or an institution, or optional if a person freely consents to submit to a given test, agrees to undergo a test (offered screening) or requests a test of his or her own accord (requested screening)” [courtesy translation] (Melançon, Leclerc *et al.*, 2001, p. 265).

### **1.4 Screening and prenatal diagnosis in Québec**

Down syndrome screening developed in the United Kingdom during the 1980s following certain local initiatives, and was introduced without any prior in-depth analysis of the ethical and social issues that could arise from this practice (Reynolds, 2003). Down syndrome screening in Québec has developed in a manner comparable to that in the United Kingdom. Indeed, ethical reflections have been led independently but without the framework of a provincial program.

Prenatal diagnosis of Down syndrome by chromosomal analysis and amniocentesis is currently offered to women aged 35 and over in Québec through the public health and social services system and has been for about 20 years.

In addition, an ultrasound during the second trimester of pregnancy is offered to all pregnant women in Québec. This ultrasound makes it possible to visualize the fetus, measure its vital signs, and identify certain signs that could indicate a problem during pregnancy. However, nuchal translucency cannot be measured during this ultrasound as the procedure is performed too late in the pregnancy.

In Québec, prenatal Down syndrome screening is currently offered in various forms, and its availability is variable, both in the public health care system and in the private sector (AETMIS, 2003). It is offered only in a certain number of regions, based on local initiatives, without any standards or mechanisms to control either quality or practice (Forest, Blouin *et al.*, 2004). To our knowledge, there is no directory of the easily accessible services currently offered. It should be noted that Down syndrome screening programs exist in many countries and several Canadian provinces, for example, Ontario, Manitoba, and Newfoundland and Labrador (Forest, Blouin *et al.*, 2004).

### **1.5 What would the implications of implementing a provincial Down syndrome screening program be?**

The main objective of the program that the Ministère de la Santé et des Services sociaux (MSSS) plans to implement would be to offer prenatal Down syndrome screening through the public health and social services system to all pregnant women, regardless of their age, and couples in Québec who wish to avail themselves of this service. The screening would therefore be systematically offered. A prenatal Down syndrome screening program would make this service available to all women and couples able to have children and thereby let them know the risk of having a child with Down syndrome.

Participation in the program planned by the MSSS would be based on free and informed consent. It would be preceded by the presentation of complete, non-directive information by the health care professional responsible for monitoring the pregnancy or another dedicated professional. Pregnant women would receive information regarding the significance of the results. If a woman's results indicated a high level of risk, she would be sent for diagnostic testing after being asked to freely give her informed consent for the procedure. Finally, if a woman's diagnostic test results indicated that the fetus had Down syndrome, she would have access to genetic counselling<sup>11</sup>.

With regard to the screening technique to be used, the expert panel set up by the MSSS has recommended the technique of integrated serum screening (measurement of the serum markers in the mother's blood during the first and second trimesters of pregnancy), with a dating ultrasound.

Implementing such a program would require a certain restructuring of the manner in which health care professionals monitor pregnancies, given that, among other things, certain tests would have to be performed quite early in the pregnancy, depending on the

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<sup>11</sup> Genetic counselling provides individuals and families with information about the nature, the mode of transmission and the implications of a genetic anomaly in order to help them make an informed decision, both medically and personally. Genetic counselling also makes it possible to guide patients through discussions concerning, among other things, interpretation of test results, prevention, medical aspects, options regarding prenatal diagnosis and available resources (Canadian Association of Genetic Counsellors, 2006).

selected technique. Once the diagnostic test confirmed the presence of Down syndrome, the woman or couple would have to decide whether to terminate the pregnancy or keep the fetus with the syndrome.

## 2. ETHICAL AND SOCIAL ISSUES RAISED BY DOWN SYNDROME SCREENING (TRISOMY 21)

The legitimacy of a screening program depends on several implementation conditions. In particular, the context and methods that are established must enable all pregnant women and couples to make a **free, informed** decision with regard to procreation. In addition, the decision that is presented to the parents must be based on **real options**. These conditions are difficult to put in place. But what is the **current situation** in Québec?

### 2.1 What is the current situation in Québec?

In response to various ethical concerns (e.g. equity, information, monitoring, risk reduction, service quality, etc.), several people maintain that it is important to implement Down syndrome screening programs that are monitored and evaluated.

The absence of a provincial screening program does not imply a total absence of screening practices. In effect, various screening practices are currently employed in Québec. As we have seen, in Québec, the availability of screening tests varies depending on the region, the institution and the professional (AETMIS, 2003) (Forest, Blouin *et al.*, 2004). Tests with varying degrees of reliability are offered in certain public institutions and regions of the province, without any provincial assessment or quality control mechanisms in place. Private companies also offer these tests to women and couples who are willing and able to pay for them. Availability of tests in the private sector can also vary according to place of residence. In situations where tests are not offered through the public system, access depends entirely on the parents' initiative.

#### 2.1.1 Equity with regard to service offerings

Parents' chances of gaining access to screening services vary according to their financial means, the information that they have on the subject, and their understanding of this information. This situation raises an important issue with regard to equity. For example, in the private sector, the cost of services comparable to those offered as part of the proposed program for the general population could add up to around a \$1000 (dating ultrasound, serum tests during the first and second trimesters or the equivalent, amniocentesis and genetic counselling).<sup>12</sup>

This inequality with regard to access created by uncoordinated services for couples expecting a child is an important argument in favour of universal availability of the test (Bassett, Lee *et al.*, 2004). In this regard, some contend that there is "an urgent need to set guidelines and thus ensure a certain standardization in the practice" of prenatal screening [courtesy translation] (Pratte, 2003, p. 197).

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<sup>12</sup> Based on the prices in effect at PROCREA Cliniques in May 2008.

### 2.1.2 Guidance and standardization of information given to parents

As previously pointed out, the current situation is characterized by a lack of trained health care professionals who can provide information regarding the screening process. The implementation of a screening program for the general population would prove beneficial by providing professionals with guidance, standardizing the information given to parents and making it possible to assess the practices in order to ensure quality.

Based on the principle that reproductive decisions should be made by the parents, it is necessary to ensure not only that they receive accurate, balanced information about the actual consequences of the birth of a child with Down syndrome, but also that this information is offered equally to all parents, regardless of their social status, level of education or place of residence. The same goes for information about testing options that make it possible to offer parents this reproductive choice by evaluating the risk of Down syndrome and ultimately confirming its presence or not. Currently, the availability of tests to assess the risk of having a child with Down syndrome in Québec varies according to the financial means of the parents and local resources, which means that not everyone has access to the same information or to the tests.

### 2.1.3 Decreased risk of fetal loss

Given the higher risk that pregnant women aged 35 and over have of carrying a fetus with Down syndrome, amniocentesis is systematically offered to these women. It bears repeating that the risk of having a child with Down syndrome increases dramatically starting at age 35. However, this diagnostic test presents a significant risk of fetal loss (in the region of 0.6% to 1%) (Wilson, Langlois *et al.*, 2007). This fetal loss also includes healthy fetuses that could have been born alive and in good health if the diagnostic test had not been performed. By screening women before the diagnostic test, it is possible to identify those whose risk of carrying a fetus with Down syndrome is low, thereby eliminating the need to perform an amniocentesis and avoiding the risk of fetal loss associated with the procedure (Aymé, 1996; Bassett, Lee *et al.*, 2004, p. 109).

This risk has led researchers to suggest new diagnostic avenues. For example, some researchers have been trying to develop techniques that would make it possible to establish a diagnosis by analyzing fetal cells or DNA found in the mother's blood (Audibert, 2006). In Québec, research in this area is ongoing (Krabchi, Gadjji *et al.*, 2006; Gravel, 2008).

### 2.1.4 Demand

In Canada, the Royal Commission on New Reproductive Technologies produced a report in 1993 which included a survey on the use of prenatal diagnostic testing (Royal Commission on New Reproductive Technologies, 1993). Based on an analysis of the results obtained, the vast majority of respondents (pregnant women and couples expecting a child) would be prepared to use prenatal diagnosis services and would



support termination of pregnancy as an option available after results are obtained (Bassett, Lee *et al.*, 2004, p. 109). A certain number of people (18%) were opposed to the use of these services (Bassett, Lee *et al.*, 2004, p. 109).

Some parent testimonials confirm this desire to have access to prenatal screening tests, insofar as they enable parents to obtain information about the condition of the fetus and make decisions accordingly.

“Everything that you can explore in advance is positive. It reduces uncertainty and increases your certainty. Then you know at least that there is no sign of any abnormality.” (Gottfredsdottir, Sandall *et al.*, 2008, p. 6)

“For us, this was just straightforward. We did not talk about it, it just was there, it was something we were going to do. Because we have this opinion you see, to get information of possible inherited diseases, which you can diagnose early in pregnancy, then it is just fine to do it. Then you have a choice.” (Gottfredsdottir, Sandall *et al.*, 2008, p. 8)

Similarly, in the United Kingdom, Down syndrome screening is considered to be acceptable by the general public insofar as the vast majority of people use the services available (Reynolds, 2003, p. 269).

Certain activist groups that defend the rights of persons with disabilities are aware that prenatal screening will continue to evolve. However, these groups are concerned that this service will be left to the private sector, which would reduce their influence over the information given to women and health care professionals (Bassett, Lee *et al.*, 2004, p. 111).

### 2.1.5 Compliance with good medical practice

Physicians must offer their patients the best existing medical services. In the case of prenatal Down syndrome screening, parents' right to be offered screening and diagnostic testing options that meet clinical guidelines is recognized by law. Parents who are not offered such tests and who give birth to a child with Down syndrome when they would have decided to terminate the pregnancy had they been informed of such a possibility through screening and diagnostic testing can sue the health care professional involved (Bassett, Lee *et al.*, 2004, p. 107).

### 2.1.6 What is done elsewhere

For various reasons mentioned above as well as others, several countries and Canadian provinces have decided to implement a prenatal Down syndrome screening program (Forest, Blouin *et al.*, 2004). In British Columbia, for example, a health technology assessment concluded that, at the very least, decision-makers have the obligation, as in all health services, to offer equitable access to prenatal genetic testing and ensure the

quality of such testing (Bassett, Lee *et al.*, 2004, p. 108). However, the evaluators concluded that the province would have to establish socially acceptable mechanisms to regulate the use of future prenatal testing, both in the public health care system and in the private sector. In addition, they concluded that the decision-makers must balance the support given to women who wish to use screening and diagnostic testing services, and eventually pregnancy termination services, with equal support to women and families who choose to welcome a child with disabilities (Bassett, Lee *et al.*, 2004, p. 108).

### 2.1.7 Economic considerations

Economic analyses have shown that the costs associated with the care of persons with Down syndrome are greater than the cost of screening programs (Bassett, Lee *et al.*, 2004, p. 111).

This economic argument, considered independently of any other factor, could be used by some as an argument in favour of the implementation of a prenatal Down syndrome screening program. Nevertheless, as some authors point out, the value of a life, whether the individual is handicapped or not, cannot be calculated solely in terms of debits and credits (Bassett, Lee *et al.*, 2004, p. 111). This warning points to the importance of considering other ethical and social concerns associated with prenatal Down syndrome screening.

## 2.2 Within the framework of a screening program, does reproductive choice really exist?

Beyond concerns regarding implementation of a government-run program, the notion of screening for Down syndrome touches on fundamental social and ethical issues. For some, screening would inevitably raise the question of “a life worth living,” inasmuch as the primary options consist of terminating the pregnancy or keeping the affected fetus, since the condition currently has no cure.

These questions are currently being posed with regard to the Down syndrome screening and diagnostic testing available, and could become more insistent following implementation of a government screening program.

### 2.2.1 Pregnancy termination as the primary option

Since Down syndrome screening and diagnostic testing provide results regarding a condition for which no medical solution currently exists, pregnancy termination is presented as the sole action possible (Kohut, Rusen *et al.*, 2002, p. 5). Is this a true reproductive choice?

In Canada, abortion is no longer illegal since 1969 (Pratte, 2003, p. 72), and the moment of its practice is not restricted (Doucet, Létourneau *et al.*, 2007, p. 31).

Pregnancy can be terminated in various ways, depending on the stage of the pregnancy, the services available at the institution in question, and the preferences of parents and medical staff.

One type of procedure consists of administering medication (consisting of single or combined products) orally, vaginally, intramuscularly or in the amniotic fluid (Boudreault, Boudreault *et al.*, 2003; Minnick, Kathleen J *et al.*, 1994, pp. 40–42).

Another procedure known as “dilation and evacuation”<sup>13</sup> is either carried out under local anaesthetic or under general anaesthetic in the operating room, depending on the case (Boudreault, Boudreault *et al.*, 2003, p. 5).

The decision to terminate a pregnancy and the procedure used to do so are sources of stress and anxiety (Pratte, 2003, pp. 29–30). Terminating a pregnancy can be a heart-breaking decision that entails a period of mourning, since it signals the termination of a dream for many of the women and couples concerned.

The prenatal screening and diagnosis services currently available as well as proposed testing under the provincial Down syndrome screening program in Québec could lead to late pregnancy terminations. A late diagnosis can ensue from any number of factors, including testing late in the pregnancy, delays imposed by waiting for test results, the availability of different professionals or the time for reflection needed by the couple.

It should be noted that, based on recommendations from the Canadian Paediatric Society (CPS) and Society of Obstetricians and Gynaecologists of Canada (SOGC), Québec obstetrics and neonatal practitioners have set the fetal viability threshold at 24 weeks (Doucet, Létourneau *et al.*, 2007, pp. 19–20). In rare cases, pregnancies can be terminated when the fetus is viable, i.e. when it “has the potential to survive outside of the mother’s body, with or without intensive neonatal support” [courtesy translation] (Doucet, Létourneau *et al.*, 2007, p. 12). The guidelines for voluntary termination of pregnancy developed by the Collège des médecins du Québec stipulate that the rare cases of pregnancy termination after 23 weeks of gestation are reserved for serious congenital anomalies or exceptional clinical circumstances (Collège des médecins du Québec, 2004, p. 12). Can Down syndrome be considered a serious congenital abnormality? The question remains, whether or not a population screening program is instigated.

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<sup>13</sup>“Dilation and evacuation” consists of dilating the cervix to surgically extract the content of the uterus (Boudreault, Boudreault *et al.*, 2003, p. 5).

For some, pregnancy termination is simply not an option. For others, the fact that the pregnancy termination constitutes the main available option following Down syndrome screening is problematic inasmuch as the process involves a judgment about which lives are worth living.

### 2.2.2 Pressure from the environment and society

Procreation is considered part of the private sphere, and the existing offer of services is based on individual freedom of choice. Nonetheless, a couple's reproductive decisions have a reciprocal relationship with society: influenced by the social context in which they are made, they also have an impact on society and general perceptions on the value of human life. Considered as a whole, such decisions are a reflection of social currents—for example, society's attitude toward persons with disabilities and its notion of “normalcy.”

The perceptions of future parents are influenced by the perceptions of society at large (Shojai, Boubli *et al.*, 2005, p. 515). According to Pratte, “maternal serum analysis and prenatal diagnostic testing in general occur within a context of social pressure that can restrict parental freedom of choice to a significant degree” [courtesy translation] (Pratte, 2003, p. 56). Various studies have shown that the social contexts of screening and prenatal diagnosis—particularly those prevalent in certain Western countries in recent years—can foster selective abortion (Pratte, 2003, p. 57).

Implementing a screening program entails the preliminary assumption that terminating a pregnancy or bringing to term a Down syndrome fetus both represent reasonable choices in our society. This also presupposes that everyone is neutral and equal in facing this choice. However, parents' perceptions can be coloured by any number of factors that extend from culture to religion, sexual orientation and past experience. Because of this, terminating a pregnancy is not an option for some people.

Additionally, the subjective interpretation of the diagnosis results, the level of risk, the implications of Down syndrome and the available options are all determinants that help define a “good choice” (Shojai, Boubli *et al.*, 2005, pp. 514–515). For instance, some parents consider the risk of amniocentesis-related miscarriage as more acceptable than the risk of not having the screening and possibly bringing to term a child with Down syndrome.

### 2.2.3 Normalcy, difference and the search for the perfect baby

While parental autonomy for reproductive decisions is not in question, it is important to realize the extent to which the social context can affect the decision-making process. For instance, individual perception of “normalcy” is highly affected by the society in which one lives. What is a “normal” child? Those whose lives are perceived as being worth living? (Pratte, 2003, p. 61; FQPN, 2007). And what is a life worth living? A productive life, or one in which the quality of human relationships takes on its full meaning? According to Jean Vanier, one who is deemed “intellectually disabled,” though lacking a

“consciousness of power,” is gifted with a more immediate awareness of love than other humans; a consciousness that “is as evolved as the consciousness of power is dormant” [courtesy translation] (Vanier, 1974, p. 61).

Current screening takes place in a medical, public health and social context that places ever-greater importance on genetics (Pratte, 2003, pp. 2–3; Cambon-Thomsen, 2004). While offering new possibilities for diagnosis and treatment, this new area of knowledge brings with it a host of questions and concerns (Pratte, 2003, p. 196). “Geneticization”—the tendency to believe that genetics underlies everything, and which is associated with the determinist standpoint that posits genetic mutation as an error rather than a variation on a theme—raises the question of “normalcy” with greater insistence as it fuels the search for the perfect child. Though this search exists independently to the science of genetics and its new applications, it is intensified by the apparent availability of means (genetics) with which to obtain such “perfection,” even if only at a perceptual level.

#### 2.2.4 Perception and integration of persons with disabilities

The arrival of an intellectually disabled child is often experienced as a negative event (Shojai, Boubli *et al.*, 2005, pp. 516–517). However, it has been shown that families can weather the arrival with serenity, that Down syndrome children can integrate positively into the school environment and that they and their families can enjoy rewarding lives (Lippman, 2002; Shojai, Boubli *et al.*, 2005, pp. 516–517). The following testimonial from the parent of a child with Down syndrome expresses this reality:

“If you don’t directly experience a child’s disability or illness, you tend to think that parents who are called upon to face this reality are courageous, strong and determined. ‘How do they do it?’ you wonder. ‘I could never do what they do: it’s too hard.’ I understand, because it’s what I myself thought before this birth. Today I understand that we are no more courageous, strong or determined than any other parent. If we are able to act as we do, bear our problems and forge ahead, it’s because of our love for our child. There’s nothing exceptional about how we deal with Laurence. It’s simply that, because we love her unconditionally, we are ready to do anything for her. It’s true that our love sometimes has to take a different and sometimes less direct route. But at the end of the day, isn’t it often repeated that we are all of us different to one another? This applies no less to my daughter. Parents share the same concerns: Will my child grow, develop, blossom? Will she be happy and healthy? We all worry about our children in the same way, like any sensitive and loving parent regarding his or her child.” [courtesy translation] (Regroupement pour la trisomie 21, 2007a).

How are those born with Down syndrome received in our society? Are they seen as an economic burden, or accepted as important members of the community (FQPN, 2007)? If deficiency and disability are seen as undesirable and incompatible with leading a rewarding life (Taylor and Mykitiuk, 2001), won’t disabled persons be seen as

“individuals who should not exist, and who wouldn’t have existed if they had been ‘caught’ in time” [courtesy translation] (Roy, Williams *et al.*, 1995, p. 204)? Instigating a screening program carries the risk of increasing our society’s intolerance toward disabled persons by exposing them and their families to discrimination.

Québec is seen by the World Health Organization as a leader in the social integration of persons with disabilities (World Health Organization, 2004; World Health Organization, 2007). Nonetheless, even if it can be considered progressive in this respect, Québec exists within a broader social context of low tolerance for the disabled (Pratte, 2003, p. 57) (Favre, 2006). One possible interpretation of the available statistics posits a low degree of social acceptance for trisomy 21, based on the levels of pregnancy terminations and abandonment at birth (Shojai, Boubli *et al.*, 2005, pp. 516–517). Some authors suggest that the difficulties linked to the life of a disabled person arise more from discrimination than from the deficiency itself—that, in fact, social obstacles are what have created the disability (Lippman, 2002).

### 2.2.5 Eugenics, discrimination and stigmatization

Certain scientific and economic discourses imply that pregnancy termination is the best solution for dealing with a fetus showing a congenital anomaly (Chang, 2006; Chen, Qian *et al.*, 2008; Hurlimann, 2008). According to some authors, the spectre of eugenics<sup>14</sup> looms when public funding for prenatal screening devalues groups with certain characteristics or increases their stigmatization (Lippman, 2002). A jurisdiction that would prompt a prenatal screening program based on the expected social benefits of terminating pregnancies whose fetal anomalies had been identified through the very same screening program would be strongly criticized as an endorsement of eugenics (Bassett, Lee *et al.*, 2004, p. 107).

Even through the end result of a Down syndrome screening program may not be pregnancy termination, in some countries, mass screening has translated into a decrease in the number of children with the syndrome (Kohut, Rusen *et al.*, 2002, p. 5; Shojai, Boubli *et al.*, 2005). For this reason, some consider that universal access to screening and diagnostic testing can lead to eugenic practices (FQPN, 2007). While the individual decision to resort to abortion does not in itself constitute eugenics, the cumulative effect of these individual decisions on society raises the question (Roy, Williams *et al.*, 1995, p. 203).

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<sup>14</sup> “Any initiative that aims to influence the transmission of hereditary characteristics in order to improve the human species” [Courtesy translation] (Goffi, 2001).

According to some authors, parents who make different choices themselves risk discrimination in such a context:

“In a prevailing context of submission to the norm, couples who choose not to terminate a pregnancy involving a ‘different’ fetus are increasingly misunderstood. This affects the assistance and support that these couples are entitled to expect from society. The couples also run the risk of being condemned as ‘irresponsible’ and becoming themselves the target of discrimination.” [courtesy translation] (CCNE, 2001).

### 2.2.6 From systematized screening availability to systematized testing

Women’s reproductive capacities have always had social and political implications. The medical control of maternity, from conception through birth, occurred gradually over the 20th century (Baillargeon, 1999). While 47.8% births occurred in hospitals in 1950, by 1970, this had become true of practically all births (99.7%). The shift in birthing location was accompanied by a significant drop in maternal and perinatal deaths in the same period. If, in 1950, the maternal mortality rate was 15.3 for every 10,000 live births, it had dropped to 0.9 by 1975. Perinatal mortality also fell significantly during this time, going from 45.8 per 1,000 births in 1950 to 15.2 in 1975. While the medicalization of childbirth has certainly contributed to this decrease, it is not the only factor. Maternal and perinatal mortality has been on the wane since 1930<sup>15</sup> (Laurendeau, 1983).

Many authors feel that medical intervention in the birthing process has modified the social order as it relates to the experience of giving birth, as well as society’s perception of this natural event. Starting in the 1950s, home birthing came to be seen as outmoded and dangerous for mother and child. Hospital birthing, which became standardized with the advent of hospital insurance in Québec, gave rise to a process of childbirth control, described as an attempt to regulate an experience once considered unique and unpredictable. This technical slant refined the detection of mothers most liable to experience childbirth difficulties and the knowledge of complications, from whence came the notion of the high-risk pregnancy. In the aim of reducing the risks for mother and baby, technical interventions regarded as necessary, like Down syndrome screening and diagnostic testing, are increasingly practiced.

The medicalization of maternity has been denounced by feminist groups in particular as a way of depriving women of the natural experience of maternity (Laurendeau, 1983; Rothman, 1994). Critics of the medical model of birthing care advocate for a more holistic, multi-disciplinary and human approach to pregnancy and childbirth (Déchamp-Leroux, 2003).

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<sup>15</sup> Since this time, a number of factors have contributed to the improvements in general health. The use of sulfa drugs and other antibiotics led to a significant reduction in puerperal septicemia, one of the primary causes of maternal mortality. Improvements to socio-sanitary conditions and the baby’s environment also helped diminish the number of deaths attributed to infectious diseases, respiratory system failure, constitutional disorders, malformations and some accidents (Laurendeau, 1983).

However, it is important to point out that a large part of the population sees the medical procedures related to childbirth as a means of ensuring a safe and healthy pregnancy. The constant rise of interventions like Caesarean sections and labour induction stands as proof (Health Canada, 2003).

### 2.2.7 Resources available to future parents

The social context strongly influences the resources available to couples who give birth to a “different” child. Parental freedom of choice depends on the existence of a financial and psychological support system for handicapped persons, along with the presence of appropriate infrastructures (Pratte, 2003, p. 197). These resources are not always available and, in certain contexts, prenatal diagnosis can take precedence over the provision of support for persons with Down syndrome (Favre, 2006).

The fact that more resources are put into screening than, for example, into caring for disabled persons or searching for treatment is cause for concern (FQPN, 2007; Shojai, Boubli *et al.*, 2005, p. 514). In France, it has been shown that the financial resources injected into Down syndrome screening and related research fail to be matched by an equivalent investment into therapeutic research for cardiac and other health problems prevalent among persons with Down syndrome (Shojai, Boubli *et al.*, 2005, p. 518). Similarly, research into screening and diagnosis has been prioritized over research into the association between Down syndrome and Alzheimer’s or cardiac problems (Roizen and Patterson, 2003, p. 1281). This results in rising numbers of detectable conditions as well as increasing numbers of women who are offered prenatal screening and diagnosis, without a corresponding development of therapeutic solutions (Pratte, 2003, pp. 49–50); (Lippman, 2002). As a result, persons with Down syndrome and their families are subject to growing marginalization (Shojai, Boubli *et al.*, 2005, p. 518). Social priorities regarding the distribution of resources therefore serve to significantly limit individual choice in matters of procreation. Effectively, if support for the outcome of a choice is not made available to those who make that choice, can they truly be said to have any options?

### 2.2.8 Messages conveyed by a screening program

The implementation of a public screening program and the manner in which it is conducted is an expression of societal choices. A program carries political legitimacy when it is funded, supervised and sometimes evaluated by the State. An example of the legitimacy such a program can enjoy can be seen in the results of a study carried out in France in 2003-04, where it is reported that “a non-negligible number of women believe that this test is mandatory and that in the event of a positive result, termination of pregnancy is in order” [courtesy translation] (Favre, 2006).

Moreover, the fact that the State ensures the efficient operation of a screening program sends a powerful message in terms of the priority given to individual autonomy when it comes to reproductive decisions. The very establishment of a systematic screening program creates tension between the principles of respect for individual autonomy



regarding reproductive decisions and the value of the lives of vulnerable persons such as those with disabilities.

In this regard, some wonder whether a State can “truly promote the integration of and respect for persons with cognitive impairments while instituting a so-called ‘public health’ policy which implies that it is reasonable and even desirable to ‘prevent’ their birth” [courtesy translation] (Hurlimann, 2008).

### **2.3 Can reproductive decisions within the framework of a screening program be well informed?**

To promote the autonomy and freedom of choice of individuals regarding their reproductive decisions, comprehensive, unbiased and balanced information must be provided to parents on screening processes and the consequences of related decisions.

Information pertaining to the repercussions of keeping a child with Down syndrome is important, as different genetic conditions lead to highly variable consequences in terms of the quality of life of the child and his or her entourage. Depending on the condition’s severity, a person afflicted with Down syndrome can either lead a relatively autonomous existence with help for everyday life or be compelled to live in an environment for non-autonomous persons (Shojai, Boubli *et al.*, 2005, p. 516; Kohut, Rusen *et al.*, 2002, p. 2). Can Down syndrome be compared to other severe genetic diseases that threaten the life of the unborn child and/or condemn it to great physical distress, such as lactic acidosis, for example? As one author points out:

“The future availability of non-invasive prenatal testing for increasingly numerous genetic conditions will translate into significant progress for the many families that are clearly at risk of severe genetic disease. Yet, at the same time, this availability will raise difficult ethical issues by potentially increasing the number of abortions for highly variable genetic conditions.”  
[courtesy translation] (Audibert, 2006)

In a study testing the judgment of ethics committee members, it was shown that prenatal screening was deemed acceptable for conditions threatening the life of an unborn child, but deemed unacceptable for other, less serious conditions (Reynolds, 2003, p. 270). Members’ responses depended a great deal on the description of the condition to be screened.

The Royal Commission on New Reproductive Technologies drew the same conclusion in its analysis of a survey of Canadians in 1993: the majority of people supported the use of screening services and recourse to pregnancy termination when a serious disease is detected, with such support hinging on the severity of the disease (Royal Commission on New Reproductive Technologies, 1993).

Furthermore, screening tests, whatever they may be, are subject to technical limitations: they can lead to false positives<sup>16</sup> or false negatives<sup>17</sup> (Julian-Reynier, 2002). Technical limitations of various types are identified according to the screening techniques used: the circumstances of the examination, the measuring technique, the software used to calculate risks, the expertise and experience of the health care personnel, the false positives and negatives, etc. (Scott, 2007, p. 1; Summers, Langlois *et al.*, 2007).

On the other hand, technical possibilities are constantly growing and already allow for testing for various conditions such as trisomy 18 and neural tube anomalies based on a single sample (Julian-Reynier, 2002). Informed consent requires that these diagnostic options be addressed with the parents.

To ensure that the information provided to the parents is truly accurate and balanced, a certain number of conditions must be met. For example, the nature and quality of the information conveyed to the parents influence their decision-making. The golden rule when it comes to addressing these concerns is that every effort should be made to provide comprehensive information, thereby fostering individual autonomy. However, some question the practical feasibility of this idea (FQPN, 2007), particularly regarding the requirement of trained personnel and the likelihood that the parents will be able to understand the results.

### 2.3.1 The requirement of trained personnel able to transmit information

The current situation is marked by a shortage of professionals specifically trained to transmit information to the future parents, as well as a lack of uniformity in their training (Pratte, 2003, p. 55). While implementation of a screening program would organize the practice, it would also increase the need for trained and competent personnel to ensure the quality of the information given for the purposes of informed consent.

### 2.3.2 Understanding the results' implications

Achieving patient autonomy in decision-making partly depends on an understanding of the results' implications, particularly in terms of risks (probabilities). Studies in Europe reveal that the content of the information conveyed, which varies from one site to another, influences the parents' choice (Shojai, Boubli *et al.*, 2005, p. 518). Other studies show that in some prenatal screening programs, the explanations given by health professionals were considered inadequate, unclear or insufficient by the mothers, and that the latter's understanding of certain aspects of the process was deficient (Shojai, Boubli *et al.*, 2005, p. 518), even in contexts where an organized screening program had been in place for many years (Favre, 2006).

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<sup>16</sup> “False positives denote the results of tests that are ‘positive’, i.e. that detect the presence of an anomaly, though there is in fact no anomaly at all. False positives, which can never be completely eliminated, are an intrinsic feature of any biological test” (Julian-Reynier, 2002).

<sup>17</sup> Conversely, false negatives denote the results of tests that are “negative”, i.e. that do not indicate any anomaly, though an anomaly does in fact exist (Julian-Reynier, 2002).

The perception of the future parents is also influenced by the views of the health care personnel who provide the information. It appears that these professionals' areas of specialization, area of practice, religion, sex, number of children and ethnic origin could have a bearing on the information they impart and, consequently, on the choices offered to the parents (Shojai, Boubli *et al.*, 2005, p. 517; Pratte, 2003, p. 53).

The complexity of genetics coupled with that of the notion of risk makes the information provided even more difficult to understand for the parents, especially when they are vulnerable and anxious in the face of a delicate reproductive decision. The waiting period prior to obtaining the results and the uncertainty regarding the results themselves, in addition to other uncertainties related to the screening process such as the syndrome's severity and the unborn child's quality of life, are a source of stress and anxiety for the future parents (Pratte, 2003, p. 4 and pp. 29–30; Ogilvie, 2003, p. 158).

For some, this complexity and the social pressures exerted on parents who are struggling with these decisions cast doubt on the merits and feasibility of the principle of non-directivity in genetic counselling (Pratte, 2003, p. 55).

## **2.4 Some wider considerations**

Other, more general questions concern screening programs and programs for the screening of Down syndrome in particular, as well as the options they offer.

The issue of the rights of persons with disabilities comes into play. In commenting on the International Convention on the Rights of Persons with Disabilities, which lays down the specific rights to which such persons should be entitled in the signatory countries, some people affirm that the current, more general standards are insufficient to guarantee the rights of these persons (Arbour, 2006; MacKay, 2006). In the light of certain concerns relating to the voluntary nature of screening programs for Down syndrome, it is relevant to ask how they affect the integration of persons with disabilities into our societies and the services offered to them.

On a different subject, to the extent that there are a host of chromosomal or genetic anomalies affecting persons with disabilities and that genetic testing seems likely to become increasingly available, we are faced with the fact that tests could become available for a growing number of conditions, such as heart diseases, for instance (Bassett, Lee *et al.*, 2004, p. 111). How far should we go?

The finding that test availability is currently inconsistent also begs the more general question of the introduction of new technologies into our society and health and social services system.

The technosciences involve standards, guidelines and a legacy of knowledge that transform human experience. This form of science encompasses a number of values often related to progress and the achievement of well-being (Koninck and M.-H.Parizeau, 1994). Questioning the relevance or necessity of this new technical and scientific knowledge can be perceived as an inability to adapt to, or a refusal to face, change or progress (Laurendeau, 1983; Doré, 1998). The introduction of these new techniques leads to questions about what approach should be adopted and what behaviours should be tolerated or rejected. Questions related to the impacts of a practice generally arise once the process or technology is developed or implemented (Doré, 1998). These types of technological innovation which result in new practices therefore “generate a new normativity” (Rocher, 1994). For example, the development of techniques to monitor pregnancy and the screening of genetic anomalies leads to a radical transformation in the experience of pregnancy (Tymstra, 1991). This technologization is accompanied by greater accountability on the part of the woman and the couple, since both will have a role to play in regard to the pregnancy and will also take part in defining humanitarian criteria that are constantly questioned and redefined as a result of technical advances (Mehl, 1999; Déchamp-Leroux, 2003). What prompts the introduction of a particular technology rather than another? What interests underlie their development, introduction and utilization? Should these processes be given a framework? What are their ethical and social consequences?

## **CONCLUSION**

In conclusion, there are numerous ethical and social issues related to the screening and diagnosis of Down syndrome. Such concerns vary in nature: the relevance of having a universal program; the manner in which this universal program would be implemented; the quality and type of care offered to pregnant women; the fairness of this service offer; the requirement of free and informed consent and the support given to future parents struggling with difficult decisions; the place and support our society gives to persons with disabilities and what this implies in terms of our sense of what constitutes normality; the value of a human life; the introduction of new technologies into our health and social services system and technical and scientific developments in our societies.

The advocacy of positions for and against population screening characterizes much of the debate and attests to the complexity of the associated issues. Arguments based on the logic of reducing risks and promoting health clash with other arguments that are just as powerful and which are grounded in reflections on what it means to be human, the dignity of a human being and the contribution to society made by persons with disabilities, who remind us of the fragility and beauty of the human spirit. Rationality, charity, efficiency, health—these are just some of the concepts that we must all consider as we work together to define a society in which we can flourish, find fulfillment and happiness, and discover a meaning to our life.

Our society is faced with choices that have to be made according to collective values and priorities. There is no perfect solution. The central issue consists of our individual and collective capacity to develop the ability to listen to and accept divergent viewpoints and interests, so that we can better understand the motivations behind them. It is up to us to seize this opportunity to find a middle ground on which we can work together to build the society of tomorrow.



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