

THE INFLUENCE OF DOWN SYNDROME RELATED INFORMATION ON ATTITUDES
TOWARD SELECTIVE REPRODUCTION

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Abstract

The aim of the current study was twofold: first, to examine the relationship between participants' attitudes and their decisions about selective reproduction; second, to examine the influence of information about Down syndrome (DS) on these same decisions. As a preliminary step in investigating the influence of attitudes and information presentation on selective reproduction decisions, the current study examined the hypothetical decisions of female undergraduate students. Although presenting more positive information about DS did not appear to influence hypothetical decisions about selective reproduction, participants' attitudes were related to these decisions. Specifically, attitudes toward persons with DS were related to decisions about prenatal screening. For decisions about prenatal testing and selective abortion, though, perceptions of parenting a child with DS mediated the relationship between attitudes and reproductive intentions. These findings suggest that women may be more likely to personalize their decisions about prenatal testing and selective reproduction by considering their perceptions of parenting a child with DS. These findings also suggest that informed decision making may require the inclusion of different information at the different decision stages (i.e., screening, testing, and selective abortion). In order to facilitate informed decision making, and in an attempt to ensure that attitudes toward persons with DS are informed by multiple perspectives, expanded information about DS should be included in prenatal screening protocols. Similarly, because perceptions of parenting appear to play a role in later decisions, information about raising a child with DS should be included in prenatal testing and selective abortion counselling sessions.

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Dedication

I would like to dedicate my thesis to my immediate and extended family. My mom and dad, Lyn Robinson and Terence Maton, supported and encouraged me from the beginning. It is because of them that I first started university. Ken and Yvette Shynkaruk have loved and encouraged me, even when teasing me about my university education.

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1. Introduction

Prenatal diagnostic procedures are often promoted as enhancing reproductive choice for pregnant women and their families (Bryant, Green, & Hewison, 2001; Parens & Asch, 2003). As such, prenatal screening and testing are becoming routine parts of prenatal care around the world. This trend continues in Canada, where new medical guidelines suggest that all pregnant women should be offered prenatal screening, regardless of their risk status (SOGC, 2007). One implication of these guidelines is that pregnant women will have to make a number of decisions in a very short time: whether or not to participate in prenatal screening, whether to have further diagnostic testing if increased risk is found, and what to do if a fetal abnormality is detected (Santalahti, Hemminki, Latikka, & Ryyanen, 1998). Because there are no available treatments for most of the genetic conditions detected, pregnant women receiving a positive diagnosis must then decide between aborting the affected fetus and giving birth to a disabled child.

The Canadian guidelines for prenatal diagnosis state that informed choice should be a general principle for all prenatal diagnosis programs (SOGC, 2001). Because the prenatal screening guidelines focus particularly on the detection of Down syndrome (DS), disability advocates have expressed concern about the DS-related information provided to pregnant women facing these decisions. Specifically, Parens and Asch (2003) state that people's lack of knowledge about disabilities like DS may contribute to uninformed choices about prenatal screening and testing. Although prenatal protocols could be revised in order to address this concern, information about the reality of raising a child with DS is currently lacking (Grant & Flint, 2007). Therefore, the current study is a preliminary investigation of the influence of presenting information about DS on decisions about prenatal screening, testing, and selective abortion, using hypothetical scenarios.

1.1 Prenatal Screening and Prenatal Diagnostic Testing

Prenatal screening and prenatal diagnostic testing (PDT) can provide women with important information about the health of their fetus, can improve their chances of having healthy offspring, and can increase bonding with their future child (Kolker & Burke, 1994). These procedures can also have negative effects, primarily due to inadequate information being provided (Gekas, Gondry, Mazur, Cesbron, & Thepot, 1999; Goel, Glazier, Holzappel, Pugh, & Summers, 1996). Many women feel that they have received insufficient information about prenatal screening and PDT (Gekas et al., 1999), the reality of living with a disabled child

(Moyer et al., 1999), and the effects of DS (Gekas et al., 1999). Prenatal screening may also introduce worry about fetal defects not previously thought about (Kidd, Cook, & Marteau, 1993; Moyer et al., 1999), cause anxiety in women receiving a result indicating increased risk, and provide false reassurance in women receiving a normal result (Dick, 1996; Goel et al., 1996).

1.1.1 Prenatal screening. Prenatal screening is a process of identifying pregnant women with an increased probability of congenital disorders (e.g., DS, trisomy 18, neural tube defects). The increased probability must be sufficiently high to justify the subsequent invasive prenatal diagnostic tests, which are more expensive and pose physical risks to the pregnant women and the fetus (Canick, Saller, & Lambert-Messerlian, 2003). Increased probability is determined when the chance of carrying a fetus with a serious abnormality is equivalent to or higher than the chance of complications from the testing procedure (Markens, Browner, & Press, 1999). Traditionally, increased probability was based on maternal age and hereditary factors. More recently, increased probability has been calculated by examining a number of factors including maternal age, maternal health, health of previous pregnancies, and history of hereditary disorders (Canick et al., 2003), along with detailed ultrasounds and maternal serum screening (MSS).

Detailed ultrasounds are used to accurately date the pregnancy and to identify major structural abnormalities. MSS is a blood test measuring the levels of alpha fetoprotein (AFP) present in the mother's bloodstream, and is offered to women between their 15th and 18th weeks of pregnancy (Maternal Serum Screening Steering Committee, 2001). AFP is a substance which is naturally produced by the fetus and excreted through the amniotic fluid into the mother's blood (Blatt, 1988). Levels of AFP are adjusted for factors such as gestational age, maternal weight, maternal ethnic origin, and diabetic status (SOGC, 2001). An abnormally high amount of AFP indicates an increased chance of a neural tube defect such as anencephaly. An abnormally low amount of AFP indicates an increased chance of DS (Kolker & Burke, 1994).

Along with AFP, MSS now also examines unconjugated estriol, human chorionic gonadotrophin, and dimeric inhibin-A. Unconjugated estriol has been found to be decreased in women carrying a fetus with DS while human gonadotrophin and dimeric inhibin-A are twice as high in these women (Canick et al., 2003). When combined with age-related probabilities, this resulting quad screen is expected to have a detection rate for DS of 82%, with a false-positive rate of 3% to 5% (SOGC, 2007). Because prenatal screening cannot definitively identify fetal abnormalities, the results are presented in terms of the probability of having an affected baby

(e.g., risk of 1/250).

1.1.2 Prenatal diagnostic testing. When a prenatal screening test is positive¹, indicating that a woman's chance of congenital disorders is above a designated probability cut-off, the pregnant woman is given the option of proceeding with PDT. PDT can include detailed ultrasounds, amniocentesis, and chorionic villus sampling (MSSSC, 2001). Current techniques also include percutaneous umbilical blood sampling, fetal tissue sampling, and embryoscopy, although these methods are not used as frequently (SOGC, 2001). Other than detailed ultrasounds, these diagnostic techniques are invasive procedures that remove a sample of tissue from the fetus or its surroundings (Kolker & Burke, 1994); as such, they carry a risk of fetal loss ranging from 0.5% to 1.0% (Canick et al., 2003).

The purpose of these diagnostic tests is to confirm initial unfavourable results of MSS. The majority of positive prenatal screening tests are found to be false positives, such that over 98% of women tested ultimately learn that their fetus is not affected (Kolker & Burke, 1994). When unfavourable screening results are confirmed, however, pregnant women must decide between preparing for a life with a child with an untreatable condition like DS or terminating the pregnancy.

1.2 Prenatal Decision-Making

More women than ever will be facing the decisions associated with prenatal screening due to recent Canadian medical guidelines recommending that all pregnant women should be offered prenatal screening as part of their prenatal care (SOGC, 2007). While this "screening for all" policy is promoted as offering wider reproductive choices to more women (Bryant, Green, et al., 2001), it also increases the number of decisions that will need to be made by pregnant women. Pregnant women will first have to decide whether they will participate in prenatal screening. If an increased probability of fetal abnormality is found, they then have to decide whether or not to proceed with PDT.

The invasive PDT procedures present pregnant women with a particularly difficult decision. They must examine the chance of having a baby with a serious abnormality and the risk of fetal loss from the diagnostic procedures (Kolker & Burke, 1994). If PDT confirms the

¹ A positive screening result indicates that a woman has an increased chance of a fetal abnormality; a negative screening result indicates that a woman does not have an increased chance. Because these terms are counterintuitive and can cause confusion (i.e., a positive screening result is a negative event for women), the terms "favourable result" and "unfavourable result" will be used in the remainder of this document.

presence of a fetal abnormality, they must again decide how to proceed. Although many genetic abnormalities can now be detected in developing fetuses, there are no available treatments for most of the detectable conditions. In the majority of instances, therefore, abortion is the only available intervention in the event of an unfavourable diagnosis.

1.2.1 Factors influencing testing decisions. When pregnant women are asked about their reasons for accepting MSS², three themes are common: (a) the test is a routine part of prenatal care, (b) the test offers reassurance that the pregnancy is going well, and (c) the test provides valuable information and knowledge (Green, Snowdon, & Statham, 1993; Press & Browner, 1993; Press & Browner, 1997; Verjaal, Leschot, & Treffers, 1982). The fact that so many women feel as though MSS is a routine part of prenatal care has led some authors to suggest that when women agree to MSS, they are not truly making a decision (Browner & Press, 1995; Chiang, Chao, & Yuh, 2005; Press & Browner, 1997; Santalahti et al., 1998). When asked to explain why they agreed to be tested, many women have trouble articulating their reasons (Press & Browner, 1997). Markens et al. (1999) found that almost 85% of their sample of pregnant women said that they did not think a lot before deciding to accept MSS. When asked to describe why they had agreed, the majority of women referenced the routine nature of the test. Pregnant women typically report making a more active decision about amniocentesis, compared to MSS (Santalahti et al., 1998). The most common reason given for proceeding with amniocentesis was the uncertainty created by the unfavourable MSS results.

The perceived importance of gaining any information about the fetus also appears to play a role in pregnant women's MSS decisions (Gates, 1993). As one participant said, "the more information I have about my baby the better" (Press & Browner, 1997, p. 985). Many women believed that the information provided through MSS and amniocentesis would provide them with reassurance about the health of their fetus (Green et al., 1993; Moyer et al., 1999; Press & Browner, 1997). Although some women did acknowledge that they might find out that their fetus has a congenital disorder, they believed that the information could be used for emotional preparation.

Research has also examined the reasons women provide for rejecting MSS and amniocentesis. Women who decline MSS have been found to be concerned about the risks that

² The terms "prenatal screening" and "prenatal diagnostic testing" are often conflated. As such, the remainder of the document will use the terms MSS (the most common prenatal screening test) and amniocentesis (the most common prenatal diagnostic test) to distinguish between the non-invasive screening test and the invasive diagnostic tests.

can come from the information provided by the results: stress caused by the information, the risk of a false positive, and the risks of follow-up amniocentesis (Markens et al., 1999; Moyer et al., 1999). Perhaps more telling, Markens et al. found that the women who declined MSS did not view the screening as routine or necessary. Those who rejected the test were also more likely to spontaneously discuss MSS's connection to abortion (64%) compared to those who accepted the test (13%). When asked why they declined amniocentesis (14% of the sample), the women in Verjaal et al.'s (1982) study mentioned a number of reasons: unwillingness to abort an affected fetus, risk of fetal loss due to the procedure, limitations of the test, confidence in the pregnancy, and nervousness about the procedure. Taken together, the research on those who accept and those who reject MSS and amniocentesis indicates that these decisions are influenced by a number of different and interacting factors.

1.2.2 The importance of information presentation. Gates (1993) suggests that the way a physician counsels a pregnant woman will have an important impact on her decision. The way that information is conveyed, either explicitly or implicitly, can make women feel as though they have an obligation to have testing, or that it is the maternally responsible thing to do. Confirming these suggestions, Press and Browner (1998) found that the majority of women who are offered MSS accept it because it is “presented as the medically and maternally responsible course of action” (p. 362). Importantly, many women also report that because MSS is presented as routine, they do not feel comfortable declining the test (Press & Browner, 1993). Although research has shown that women tend to make more active decisions about invasive tests like amniocentesis as compared the MSS, which has no physical risks (Santalahti et al., 1998), Sjogren and Uddenberg (1988) found that pregnant women also find it difficult to decline amniocentesis when it is offered.

Press and Browner (1993) found that how women were informed about MSS and the information that they were provided had a greater influence on their decisions than did other factors like ethnic or social class background. The information provided to the women in this study revolved around the test procedure itself; the conditions screened for were only vaguely defined, and no information about the impact of these conditions or the potential decisions in the event of an unfavourable diagnosis was provided. Smith, Shaw, and Marteau (1994) found that MSS protocols often emphasize the laboratory aspects of the test at the expense of counselling components (e.g., the conditions the test might detect, the implications of negative and positive

results). A related finding is that this type of information presentation in prenatal diagnostic counselling increases pregnant women's factual knowledge about the tests with little impact on their actual decision-making (Verjaal et al., 1982). Press and Browner have asserted that this type of information presentation causes a blurring of lines between informing women and persuading them to participate in testing.

The accessibility of information and how risk information is presented also influence decisions about MSS and amniocentesis. Timmermans (2005) examined how risks were communicated and understood by prenatal patients. It was found that people preferred numerical presentations of risk, even if they had difficulty understanding them, over verbal terms for risk (e.g., "high risk" vs. "low risk", "small chance" vs. "likely") which can be interpreted differently by different people. Timmermans suggests that verbal terms are ambiguous, and as such, they allow for physicians to incorporate additional meaning that can influence women's testing decisions. In addition to the need for clear, numerical explanations of risk, information about MSS and amniocentesis must be accessible for pregnant women. O'Reilly (1982) found that the accessibility of information is the most important determining factor for information use.

1.2.3 Selective abortion decisions. Aside from MSS and amniocentesis decisions, women receiving an unfavourable fetal diagnosis must decide between continuing and terminating the pregnancy. It is important to note that an acceptance of MSS and amniocentesis is not equal to an acceptance of selective abortion for a fetal abnormality. Much research has found that favourable attitudes toward prenatal testing are not tantamount to favourable attitudes to selective abortion (Green et al., 1993; Hewison et al., 2007; Moyer et al, 1999; Press & Browner, 1997; Press & Browner, 1998). Many women state that they want the information about the health of their fetus even though they would not consider abortion. Despite these findings, and despite the fact that pregnant women are often unsure as to the decision they would make in the event of a unfavourable diagnosis, research has found that up to 95% of women choose to terminate the pregnancy when a serious abnormality is detected (Drugan et al., 1990; Edwards, Rothstein, & Young, 1989).

1.2.4 Psychological impact of selective reproduction decisions. Dick (1996) highlights the psychological effects of MSS and amniocentesis: fear of revealing a fetal abnormality, fear about having to make a decision about terminating a pregnancy, and fear of complications resulting from amniocentesis. MSS may also introduce new worry about fetal defects (Gates,

1993; Moyer et al., 1999; Press & Browner, 1997), cause anxiety in women receiving an unfavourable result, and provide false reassurance in women receiving a favourable result (Dick, 1996; Goel et al., 1996). Markens et al. have found that the worry introduced by MSS is enough that some women do not want to acknowledge or invest in the pregnancies until their results are returned to them. The information provided by the tests can be especially hard for women who do not intend to terminate their pregnancies, possibly resulting in a negative impact on the remainder of the pregnancy.

As already discussed, MSS is often portrayed as routine prenatal test, posing no physical risks to the pregnant woman or the fetus (Press & Browner, 1997; 1998). The majority of women appear to understand MSS in the same way. Along with the findings presented above, evidence suggests that MSS can indeed have serious consequences. For example, Lawson and Turniff-Jonasson (2006) found that women undergoing MSS report lower levels of bonding with their fetus compared to those with no MSS and those who had amniocentesis. This association between MSS and lowered bonding levels, found for those who did not receive amniocentesis, was consistent throughout the woman's pregnancy. This may have serious implications since fetal bonding has been found to correlate with positive prenatal health practices like receiving prenatal care (Lindgren, 2001). Prenatal bonding and attachment have also been found to be predictive of postnatal maternal behaviour and attitudes (Siddiqui, Haeggloef, & Eisemann, 2000). Lawson and Turniff-Jonasson concluded that the lowered levels of fetal bonding may be due to the ambiguity of MSS results, which provide probability ratios instead of definitive diagnoses. Other research has confirmed the fact that receiving MSS results is not reassuring to pregnant women (Kidd et al., 1993).

Women receiving unfavourable MSS results are given the option of proceeding with amniocentesis, which provides a definitive fetal diagnosis. Women who decide to accept amniocentesis may experience adverse reactions as well: depressed mood, feelings of guilt, and feelings of helplessness (Kowalcek, Muhlhoff, Bachman, & Gembruch, 2002). Sjogren and Uddenberg (1988) found that waiting for the tests and their results was a difficult time for women. During amniocentesis, fear of an abnormal result and fear of a miscarriage were present for the majority of women. The authors concluded that "the feelings of distress seemed to be fairly well compensated for by the idea of a happy pregnancy after having received a normal test

result” (p. 486). This statement does not acknowledge the fact that some women receive an unfavourable test result indicating a fetal abnormality.

The fact that amniocentesis currently takes place in the second trimester also has negative effects on pregnant women. The majority of women examined by Kornman et al. (Kornman, Wortelboer, Beekhuis, Morssink, & Mantingh, 1997) preferred the idea of first trimester testing, as they believed this would allow for an easier pregnancy termination, both emotionally and technically, if an unfavourable diagnosis was given. The decision to terminate a pregnancy in the second trimester is thought to be more difficult than in the first trimester as fetal movements have likely been felt, and the pregnancy is visible to others (Drugan et al., 1990). First trimester screening and termination, if chosen, would allow for more privacy in making these difficult decisions.

1.3 Informed Decision Making and Informed Consent

As decisions about MSS and amniocentesis have potentially serious consequences (e.g., loss of a fetus following amniocentesis, diagnosis and termination of an affected fetus), informed decision making may be particularly important for helping pregnant women cope with the potential implications of their decisions (Marteau, Plenicar, & Kidd, 1993). Informed consent is considered a basic principle of MSS and amniocentesis. The Canadian Guidelines for Prenatal Diagnosis (SOGC, 2001) state that prenatal counselling should be “given in a non-directive manner in order to allow an informed choice by the couple” (p. 6). In addition, they state that “couples should be made aware of the full range of options when confronted with an abnormal test result” (p. 6). There is evidence to suggest, though, that informed decision making is not currently being facilitated in prenatal counselling protocols.

For example, current MSS protocols tend to emphasize the laboratory aspects of the test over the implications of the tests and their results (Smith et al., 1994). In addition, although prenatal counselling has been primarily concerned with providing information without influencing decisions (Kolker & Burke, 1994), genetic counsellors and doctors make decisions about what to tell parents, when to tell them, and how to tell them, all of which are influenced by personal values (Sorenson, 1993). In their examination of how obstetricians present information about amniocentesis, Marteau et al. (1993) concluded that the misinformation that was occasionally presented (e.g., underestimates of the miscarriage risk), and the information that was not presented (e.g., information about the conditions being tested for), “appeared to reflect

both a lack of knowledge, and attempts to persuade women” to accept testing (p. 8).

In order to facilitate truly informed decisions, pregnant women need to understand the laboratory characteristics of the tests, the implications of the tests, the implications of the test results, and the conditions for which the testing is being offered (Goel et al., 1996; Marteau & Dormandy, 2001). Marteau et al. (1993) found that little information was provided about the conditions being tested for, and that no descriptions were provided about the nature of any of these conditions. Instead, the information provided during counselling focused on the tests themselves. Based on similar findings, Smith et al. (1994) concluded that women are not presented with the necessary information to make informed decisions about whether to accept testing or to prepare themselves for possible unfavourable test results. The fact that women are not routinely being made aware of the implications of abnormal test results, even though it is advised by the current Canadian guidelines, also suggests that the ability of pregnant women to make informed decisions is at risk.

1.3.1 Information presentation and informed consent. The information presented to pregnant women does not explain the experience and impact of raising a child with a disability, nor does it include information about the educational and medical supports that are available (Marteau & Dormandy, 2001). After completing an overview of the information presented to prenatal patients, Asch (1999) concluded that the information about prenatally diagnosable conditions was predominantly and unnecessarily negative. Raffle (2001) suggests that information has been presented in such a way as to encourage high rates of test acceptance over informed consent. This means that the negative impacts and implications of testing are downplayed or ignored, and the potential benefits of the test are the focus.

This may be especially true for MSS, which is often presented as a simple blood test (Press & Browner, 1997). By presenting MSS as routine, women are often not provided with sufficient information to make truly informed decisions (Kolker & Burke, 1994; Santalahti et al., 1998). It is important to understand how pregnant women make informed decisions about MSS, amniocentesis, and selective abortion in order to improve the information presented in prenatal counselling protocols. Providing pregnant women with relevant information on which to base their decisions will serve to improve prenatal care, and may result in decreased negative effects caused by the prenatal testing process.

1.3.2 Women’s knowledge following prenatal counselling. Chiang et al. (2005) point out

that reproductive decisions are not necessarily made by rationally weighing the risks and benefits and considering each of the alternatives. In fact, research has found that basic knowledge of MSS and amniocentesis is poor even after counselling. Press and Browner (1993), in their study of forty women undergoing MSS, found that not one of the women could describe or explain the conditions that could result in an unfavourable screening test result. Less than half of these women knew what their doctor would suggest if their MSS result was unfavourable. Other authors have also documented women's low levels of knowledge about the tests offered to them (Press & Browner, 1998; Santalahti et al., 1998).

Smith et al. (1994) found that although some women are knowledgeable about the practical aspects of the test, they are less knowledgeable about the likelihoods of specific results and the implications of these results. Verjaal et al. (1982) found that while women's knowledge of amniocentesis increased after counselling, information was still lost or misunderstood. The fact that many women are unable to accurately recall important information about MSS and amniocentesis again indicates that informed consent may be at risk. Marteau and Dormandy (2001) suggest that the conditions being tested for, the characteristics of the test, and the implications of testing need to be explained to pregnant women.

1.4 The Relationship between Attitudes, Intentions, and Behaviour

Michie et al. argue that informed decisions require more than knowledge about the tests and procedures being offered (Michie, Dormandy, French, & Marteau, 2004). These authors suggest that informed decisions also require that pregnant women behave in line with their attitudes. In other words, an informed choice would be one in which women both receive information about the tests and have a positive attitude toward undergoing the tests (Marteau & Dormandy, 2001). Cooke and French (2008) suggest that, in this context, a pregnant woman's attitudes reflect her positive or negative evaluation of accepting MSS. Michie et al. examined specific attitudes toward MSS, including "goodness," importance, and pleasantness of screening, along with the benefits and harms of screening.

There is evidence to suggest that these attitudes strongly predict intentions to accept MSS, and that these intentions are good predictors of actual screening uptake (Cooke & French, 2008; Michie et al., 2004). Cooke and French, in the meta-analytic review of 33 studies, found that the relationship between attitudes and intentions was higher for MSS than for other types of screening (e.g., cervical, colorectal, health check, mammography). Intentions were also found to

be better predictors of actual screening attendance compared to other screening tests. The authors suggested that the relationship may be stronger for MSS because “values other than personal health are at stake, i.e., those to do with unborn children and other family members” (p. 758). In other words, MSS may be seen as having a larger effect on people other than the woman being screened, as compared to another screening test like mammography.

Along with attitudes, subjective norms have been found to be strong predictors of intentions in prenatal screening (Michie et al., 2004; Cooke & French, 2008). Subjective norms refer to beliefs about what other people (e.g., medical professionals, partners, friends) think is the appropriate behaviour for the situation (Romano & Netland, 2007). The linkage between attitudes, intentions and behaviours related to MSS corresponds to that outlined by the theory of reasoned action (TRA; Fishbein & Ajzen, 1975). Specifically, TRA states that behaviour is a function of a person’s intentions to carry out that behaviour, and intentions are a function of their attitudes toward performing the behaviour and subjective norms about the behaviour. In other words, a causal chain exists where attitudes and norms form intentions, and intentions form behaviours.

Research examining this causal chain for MSS decisions has focused on attitudes toward pregnancy termination (van den Berg et al., 2008), test efficacy (van den Berg et al., 2008), subjective norms about screening (Cooke & French, 2008; Michie et al., 2004; van den Berg et al., 2008), and the test itself (Michie et al., 2004). While these foci provide some explanation for MSS decisions, they ignore the fact that MSS is not the end decision. Pregnant women predominantly use MSS to gain knowledge about the health status of the fetus (Green et al., 1993; Kolker & Burke, 1994; Moyer et al., 1999; Press & Browner, 1997). Using the information gained from MSS and amniocentesis, pregnant women must decide between parenting their child and aborting the fetus. In the case of an unfavourable result, women make a decision about their willingness to parent a child with a congenital disorder. This decision highlights the potential significance and explanatory power of examining women’s attitudes towards parenting a child with a disability. As will be explained further, Lawson (2001; 2006) has begun to explore the implications of these attitudes, particularly in relation to DS.

1.5 The Focus on Down Syndrome

Prenatal screening was originally designated for women considered to be high-risk due to an advanced maternal age (i.e., over the age of 35) or a family history of genetic disorders. More

recently, however, prenatal screening has been offered to pregnant women regardless of their risk status, with a particular focus on the detection of DS (Canick et al., 2003). This trend continues in Canada, where new medical guidelines suggest that all pregnant women should be offered MSS for DS as part of their prenatal care (SOGC, 2007). Cooke and French (2008) suggest that the effectiveness of a screening program depends on the level of uptake of those programs. High levels of attendance are necessary if screening programs are going to have a significant impact on the incidence of disease and disability (Cooke & French, 2008; Saxton, 1988). DS does not have a strong genetic inheritance pattern (Canick et al., 2003), and only 25% of infants with DS are born to women older than 35 (Ross & Elias, 1997). The previous reliance on screening pregnant women at an advanced maternal age left the majority of fetuses with DS undetected. The detection of disease and disability is viewed as a priority by the medical system, as it allows them to control the incidence of disability in society (Saxton, 1988). Therefore, the medical community, including the SOGC, believes that all women are candidates for prenatal screening for DS.

DS is the most common chromosomal abnormality detected prenatally (Kolker & Burke, 1994), and the most common non-inherited cause of mental retardation (Canick et al., 2003). One in 800 children born in Canada has DS (Canadian Down Syndrome Society, CDSS, 2008b). Some of the physical characteristics associated with DS are almond shaped eyes, light spots in the coloured portion of the eyes, a crease across the palm, small low set ears and nose, and low muscle tone. Children with DS also commonly have a variety of health concerns including heart problems (e.g., congenital heart disease), stomach and bowel problems, thyroid problems, and vision and hearing problems. Children with DS typically have moderate to severe learning disabilities, with an average IQ of around 40 (Canick et al., 2003). The CDSS (2008a) points out that the physical, medical, and mental differences in children with DS are highly variable and cannot be known simply through a diagnosis of DS. Put another way, although pregnant women can be given a certain diagnosis of fetal DS, the prognosis still remains uncertain.

1.5.1 The presentation of information about DS. Much of the existing literature on DS presents and discusses DS in a negative way (Alderson, 2001). For example, in their investigation of the national program for the prevention of DS, Zlotogora et al. state that “despite the program, the majority of Down syndrome infants are born alive” (p. 600; Zlotogora, Haklai, & Leventhal, 2007). The authors discuss this finding in terms of a failure of the program. In two

separate comparisons of the information provided before and after the birth of a child with DS, researchers found obvious contradictions (Bryant, Murray et al., 2001; Lippman & Wilfond, 1992). The information provided after a fetal diagnosis of DS focused on the medical complications and the ways in which the child would differ from non-disabled children. The information provided after the birth of a child with DS, however, focused on the ways in which the life of the child would resemble non-disabled children.

In many cases, prenatal counselling protocols provide little, if any, information about DS, and there is evidence to suggest that pregnant women are aware that important information about DS is not being provided. Women have indicated that they lack personal knowledge about raising a child with DS, and that this information was inadequate or non-existent in MSS protocols (Gekas et al., 1999; Moyer et al., 1999). Dick (1996) suggests that MSS information should include information about the implications of having a child with DS. By not including information about the lives of children with DS (e.g., the ways they can participate in family, school, and the community), prenatal counselling implies that DS is a predominantly negative event (Asch, 1999). Alderson (2001) states that “routine prenatal screening is based on the assumption that it is reasonable for prospective parents to choose to prevent a life with Down’s syndrome” (p. 2001). Supporting this assumption, Lawson (2001; 2006) found that perceptions of parenting a child with DS are salient when making decisions about selective abortion. Findings such as these highlight the importance of presenting information about parenting a child with DS to pregnant women facing decisions about selective reproduction.

1.5.2 The concerns of disability advocates. In order for women to provide informed consent for MSS for DS, they need to understand the purpose of the tests, the detection rate of DS, the likelihood of an unfavourable result, and the implications of such a result (Sadler, 1997). One implication of an unfavourable result is the possibility of raising a child with DS. Therefore, it seems imperative that women are given balanced information about what parents raising children with DS may be likely to encounter. The fact that women are not currently being given this information concerns many disability advocates. While the MSS guidelines that focus on the detection of DS are put forth as offering pregnant women more reproductive choice, these women are not provided with fair, accurate, and balanced information about DS with which to make an informed choice (Grant & Flint, 2007).

The CDSS believes that it is critical for pregnant women to receive accurate information

about the reality of raising a child with DS, instead of relying on common societal stereotypes (Grant & Flint, 2007). In other words, the CDSS, like other disability advocates, are calling for truly informed consent through the provision of balanced information about DS to pregnant women before decisions about MSS are made. The information presented, or not presented, in prenatal testing protocols seems to suggest that the health status of individuals determines their quality of life and their life chances. Parens and Asch (2003) contend that this view ignores the role of social perceptions and discrimination in the lives of people with disabilities. They suggest that living with a disability does not eliminate the chance of a worthwhile life.

As previously discussed, many women feel as though they are provided with inadequate or no information about DS on which to base their decisions about MSS (Gekas et al., 1999). Similarly, surveys of the general community indicate that up to one-half of individuals have had no personal experience with persons with DS (Lawson, 2001; 2006). Parens and Asch (2003) state that “widespread ignorance about the nature and experience of disability may contribute to ... poorly informed choices about prenatal testing and selective abortion” (p. 43). Confirming this suggestion, Lawson and Walls (in press) found that favourable contact with persons with DS resulted in less prejudicial attitudes and less reported willingness to use MSS and selective abortion.

The New England Medical Center has shown that when pregnant women are introduced to people living with DS and to families with a child with DS, the rates of selective abortion for DS are decreased (Parens & Asch, 2003). This finding provides support for the idea that when pregnant women receive more detailed information about DS, they are more able to see themselves raising a child with DS. Other research has found that people who have a personal relationship with a child with DS are less likely to consider MSS and amniocentesis (Julian-Reyner et al., 1993). Therefore, Parens and Asch (2003) conclude that MSS, amniocentesis, and selective abortion decisions are often driven by a lack of information and misinformation about what living with a disabled child is like.

Research by Bryant, Murray, et al. (2001) indicates that MSS information pamphlets are not attempting to reduce this misinformation. Specifically, after performing a content analysis of MSS information pamphlets in the United Kingdom, the authors found that 21% of the pamphlets gave no descriptive information about DS, and 13% simply described DS as a chromosomal abnormality. Further, 63% of the statements that were included about DS were

judged to be negative in content and/or tone, while only 12% were judged to be positive. These findings lend support to the assertions of disability advocates that balanced information about DS is not being provided for informed decision making. Like other authors, Bryant, Murray et al. conclude by saying that quality and balanced information about DS should be included in education pamphlets in order to facilitate informed decisions making.

The importance of this information is evidenced by the findings of Gekas et al. (1999). These authors found that despite the lack of provided information and personal knowledge about DS, 83.5% of MSS participants believed that DS is “incompatible with a normal life” (p. 3). Of these participants, 80.5% stated that they would consider terminating their pregnancy if their fetus was diagnosed with DS. According to disability advocates, findings such as these indicate that instead of making fully informed decisions, many women are basing their decisions on societal stereotypes. As such, Gekas et al. conclude by saying, “A decision on whether to undergo prenatal screening cannot be made without a minimum of information about Down syndrome itself given beforehand” (p. 6). Currently, evidence suggests that this ‘minimum of information’ is not being provided.

1.6 The Social Perceptions of DS

The findings from studies like Gekas et al. (1999) indicate that along with the potential physical and mental disabilities faced by children with DS, there are also stereotypes and prejudice to be faced in society. Moyer et al. (1999) found that although the majority of people do not have personal experience raising a child with DS, they believe that children with DS have fewer opportunities, are treated poorly by society, and are a burden and a strain to their families. Using hypothetical scenarios, Bell and Stoneman (2000) found that negative attitudes towards disabilities were associated with an increased likelihood of selectively aborting for disabilities. These authors also found that the primary reason for hypothetically terminating a pregnancy after a fetal diagnosis of DS was the perceived negative effect of the child on the rest of the family. Breslau (1987) suggests that the public’s view of people with disabilities is related to their views about the quality of life and the burden placed on the families of these children. Chiang et al. (2005) suggest that a fetus with DS is “considered undesirable by parents, health providers, and society in general” (p. 273).

Lawson (2001) has found that the perceptions of raising a child with DS are primarily negative, particularly in terms of time commitment, and financial and emotional costs. Using a

general community sample, Lawson (2006) found that people perceived parenting a child with DS as providing fewer rewards, less family continuity, and more social, financial, and emotional costs as compared to parenting a healthy child. The respondents also believed that they would receive less support from their family and friends. Surveys of the general community (Bell & Stoneman, 2000) and of pregnant women (Faden et al., 1987) have shown that reported willingness to abort is much higher in the case of a mental disability, like DS, than in the case of a serious physical disability. Actual selective abortion rates support these findings (Edwards et al., 1989) and show that the majority of women who receive a diagnosis of fetal DS decide to terminate the pregnancy (Green et al., 1993; Palomaki, Haddow, & Beauregard, 1996).

1.7 Experiences of Raising a Child with DS

Despite the negative views that exist about raising a child with DS, research findings suggest that the experience of parenting a child with DS may not be as negative as the general public believes. Hassal and Rose (2005) suggest that successful adaptation, rather than crisis, is the norm for parents caring for children with intellectual disabilities. Parents have reported the birth of a child with a disability as a positive experience for the family (Breslau, 1987). Parents have also indicated that their lives have been enriched by their disabled children (Yau & Li-Tsang, 1999). Van Riper, Ryff, and Pridham (1992) found that parents raising a child with DS did not differ in terms of individual, marital, and family functioning as compared to parents raising a non-disabled child. Kasari and Hodapp (1996) reported that parents of children with DS rate their children as more behaviourally and socially functional than do parents of children with other cognitive disabilities. These parents also reported more social support and less familial stress.

When siblings of children with DS were examined, the majority spoke positively of the experience, although some siblings did view the impact on themselves and their family as negative (Bryant, Hewison, & Green, 2005). The main determining factor for these siblings' attitudes appeared to be the quality of the sibling relationship, such that those experiencing a more positive relationship were less likely to want amniocentesis and selective abortion in a future pregnancy. Several other factors have been identified that influence family adjustment, such as personal resources, strength of marital relationships, characteristics of the disabled child, and availability of social support networks (Hassal & Rose, 2005; Yau & Li-Tsang, 1999). The presence or absence of these factors could be used to tailor prenatal counselling protocols to

meet the specific needs of pregnant women and their families.

1.8 Improving perceptions and information about DS

Given the possibility that reproductive decisions may be based, at least in part, on misinformation and societal stereotypes instead of personal experience, it is important to provide pregnant women with more detailed and value-neutral information about DS. In order for women to be able to make decisions about whether they are willing to raise a child with DS, they must be provided with accurate information about the reality of doing so (Asch, 1999). This means that pregnant women should be given sufficient information to understand both the potential difficulties and the potential joys of raising a child with DS. Chiang et al. (2005) suggest that pregnant women should be presented with information showing that it is possible to want to give birth to and value a child with DS, and information about real experiences of women raising children with DS. They suggest that this should be facilitated even before a pregnant woman is approached about MSS. While this information may be available to pregnant women elsewhere (i.e., outside of the MSS environment), research has found that the accessibility of information is a more important determinant of its usage than the quality of the information (O'Reilly, 1982). Therefore, in order to facilitate truly informed decision-making, the types of information outlined above should be made more accessible through inclusion in prenatal counselling protocols.

1.9 The Current Study

Because DS is not treatable either before or after birth, pregnant women have to decide between aborting a prenatally diagnosed fetus and preparing for life with a disabled child. The research discussed above suggests that although the majority of people do not have personal experience with DS, they are highly likely to abort a fetus diagnosed with DS. Disability advocates suggest that these decisions are based on misinformation and negative societal stereotypes. Because new Canadian medical guidelines suggest that all pregnant women should be offered MSS specifically for DS, it is especially important to examine ways to address misinformation about DS.

It is not currently known whether a presentation of more positive information about DS would influence MSS, amniocentesis, and selective abortion decisions. The current research is an attempt to examine this possibility. Previous research has shown that attitudes toward MSS are related to intentions to accept screening, which are then related to actual screening uptake (Cooke & French, 2008; Michie et al., 2004). Research has also shown that attitudes toward

parenting a child with DS are related to selective reproductive intentions (Lawson, 2001; 2006). These findings are in line with the TRA (Fishbein & Azjen, 1975), which states that attitudes influence behavioural intentions, which influence behaviours. Therefore, if pregnant women's attitudes about raising a child with DS are influenced by the presentation of information about DS, their intentions to participate in MSS, amniocentesis, and selective abortion should be similarly influenced.

Reflecting the importance of such information, Grant and Flint (2007) have suggested that parents facing MSS decisions should be provided with fair, accurate, and balanced information about DS. Instead of presenting pregnant women with such information, the MSS pamphlet currently provided to women in Saskatchewan focuses mainly on the laboratory aspects of the test, with only two short paragraphs dedicated to DS (MSSSC, 2001). The current study examined the possibility that the inclusion of information highlighting the more positive aspects of raising a child with DS would influence women's attitudes about and intentions toward raising a child with DS.

As a preliminary step in investigating the influence of information presentation on selective reproduction decisions, the current study examined the hypothetical decisions of female undergraduate students. Although this is admittedly different than "real-life" reproductive decision making, it is a valuable first step in determining whether different types of information impact reproductive decisions differently, and in determining the types of information that people deem to be important for making informed decisions. Participants were recruited and randomly assigned to one of three groups: those who received no information (the no information control group), those who received the standard MSS information pamphlet (the standard information group), and those who received the standard pamphlet along with a pamphlet from the CDSS presenting information about what parents of a child with DS may be likely to encounter (the expanded information group). Each group was asked about their personal experience with DS, their attitudes towards persons with DS, their perceptions of parenting a child with DS, and their willingness to consider MSS, amniocentesis, and selective abortion. Finally, participants were also asked to discuss the information they perceive to be important and necessary for making informed decisions.

Based on the previously discussed relationship between attitudes, intentions, and behaviours, a number of hypotheses were made. First, it was expected that people with negative

attitudes towards DS would report more negative perceptions of parenting a child with DS, and in turn, more willingness to consider MSS, amniocentesis, and selective abortion for DS. In other words, it was hypothesized that the relation between negative attitudes toward DS and selective reproduction may be mediated by negative perceptions of parenting a child with DS.

Second, because the current MSS information pamphlets do not contain detailed information about DS, differences between the control group and basic information group were not expected in terms of attitudes and behavioural intentions. Instead, differences were expected between these two groups and the expanded information group, such that people receiving more positive information about DS were expected to express more positive attitudes about DS, more positive perceptions of parenting a child with DS, and less willingness to consider MSS, amniocentesis, and selective abortion for DS.

By examining the impact of more positive information about DS on hypothetical selective reproductive decision making, the current study is a first step in providing empirical evidence to address the concerns of disability advocates. While disability advocates have been requesting the addition of more accurate and balanced information to MSS protocols (Grant & Flint, 2007), empirical evidence of effectiveness is necessary for these changes to be considered. Therefore, the aim of the current study was to determine the influence of more in-depth information about DS on attitudes, behavioural intentions, and hypothetical decision making, along with determining the types of information deemed relevant and necessary to make informed decisions about MSS, amniocentesis, and selective reproduction.

2. Method

2.1 Participants

The participants consisted of 163 women from the University of Saskatchewan. Participants were recruited both from introductory psychology courses at the University of Saskatchewan ($n = 122$) and through postings on the university's online Bulletin service ($n = 41$). The undergraduate psychology students received research credit within their introductory course for their participation. All other participants received \$5.00 for each half hour of participation. The participants signed up to take part in a group testing session. Each session was then randomly assigned to one of three experimental conditions: a control group ($n = 58$), a basic

information group ($n = 53$), and an expanded information group ($n = 52$).³ The average age of this sample was 19.6 years old (range = 17 to 30). Eighty-four percent of the participants were Caucasian, 6.1% were Asian-Canadian, 1.8% were Aboriginal, and the remaining participants classified themselves as “Other.”

Only women were recruited for the research for two main reasons. First, the language used in the current educational materials is directed at women. Second, MSS tests are performed on women’s bodies and require only the woman’s consent. Therefore, the intent of the present study was to focus on women’s reproductive decision-making. In order to ensure that the participants had no prior experience with the prenatal screening materials, women with previous pregnancies were not recruited for this study.

2.2 Materials

Participants in each of the three testing groups completed a questionnaire package. The questionnaire package examined the participants’ attitudes towards persons with DS (Scale of Attitudes toward Disabled Persons; Antonak & Livneh, 1988; revised to target Down syndrome), their personal experience with DS (familiarity questions), their perceptions of parenting a child with DS (Perceptions of Parenting Inventory; Lawson, 2004), and their willingness to consider MSS, amniocentesis, and selective abortion (selective reproduction questions). Finally, participants were also asked to discuss the information they perceived to be important and necessary for making informed decisions about selective reproduction. Although all of the participants received these questions, as outlined further below, the two information groups also received their respective information pamphlets and follow-up questions with their questionnaire packages.

2.2.1 Scale of Attitudes toward Disabled Persons. In order to first assess the participants’ prejudicial attitudes toward persons with DS, the Scale of Attitudes toward Disabled Persons (SADP; Antonak & Livneh, 1988) was used. The SADP is a 24-item self-administered scale that measures attitudes toward disabled persons as a group. Reliability analyses conducted by Antonak and Livneh suggest that the SADP is a psychometrically sound and reliable instrument (alpha coefficients ranging from .88 to .91). These authors also suggest that scores on the SADP correlate moderately with scores on the reduced version of the Attitudes toward Disabled

³ Numerous timeslots for the current study were posted simultaneously using an online sign-up system. While the researcher could set limits on the maximum number of participants in each timeslot, there was no set minimum. As a result, the number of participants in each group is not equal.

Persons Form-0 ($r = .54$; ATDP-Form O; Yuker, Block, & Young, 1970) indicating convergent validity. Further, Antonak and Livneh suggest that the SADP does not correlate with Crowne and Marlowe's (1960) Social Desirability Scale, indicating that the SADP is not overly influenced by socially desirable responding.

For the purpose of the current study, revised statements referring specifically to DS were used; these revised statements were constructed by Lawson and Walls (in press). The participants were asked to respond to each statement using a 6-point scale, ranging from -3 (I disagree very much) to +3 (I agree very much). An index of global attitude toward persons with DS is computed by first reverse scoring the negatively worded items. The sum of the responses is then calculated, and a constant of 72 is added to the total. The resulting scores can range from 0 to 144, with higher scores reflecting a more favourable attitude toward persons with DS. Lawson and Walls found that the revised statements were a reliable measure of attitudes toward persons with DS (coefficient alpha of .82 found in their study). The coefficient alphas found for the present study, which indicate an adequate level of reliability for the SADP-DS, are presented in the diagonal of the correlation matrix in Table 2. (See Appendix A for the revised SADP items.)

2.2.2 Familiarity with DS. The questionnaire then assessed the participants' personal experience with DS, using questions developed by Lawson and Walls (in press). Participants were first asked to indicate whether or not they had ever known someone with DS. They were also asked to indicate the quality of these relationships, if they existed, as previous research has found that the quality of relationship contact influences parenting attitudes which in turn influence reproductive decisions (Lawson & Walls). Specifically, participants were asked to rate the emotional closeness of the relationship and how personally comfortable they felt with this individual. These two items were rated on a 5-point scale, ranging from 1 to 5. The responses to these items were then summed together to create a relationship quality score, which ranged from 2 to 10, where higher scores represented a higher quality relationship. In case participants knew more than one person with DS, they were asked to respond while thinking about the person with DS who they felt they knew the best. (See Appendix B for the familiarity questions.)

The items used to create the relationship quality score do not have previously established psychometric reliability. The two items were correlated at .59 in the current study. This correlation indicates a high degree of convergence, while also indicating that the two items are tapping into different underlying dimensions of relationship quality. As the two items used for

this measure examine the construct of interest (i.e., relationship quality) they also appear to have face validity.

2.2.3 Perceptions of Parenting Inventory. The Perceptions of Parenting Inventory (POPI; Lawson, 2004) is a 28-item measure that examines perceptions of parenting, including both the costs and the rewards. The 6 subscales of the POPI measure: personal enrichment (measures happiness, pride, fun, personal rewards, enjoyment in watching child grow, rewards to family, growing closer to spouse, and becoming a better person through parenting), continuity of self and family (measures anticipation of becoming a grandparent, continuation of the family line, and adult relationship with the child), social isolation (examines how parenting may interfere with parent's important social relationships and leisure activities), commitment (measures the immediate and long-term care responsibilities of parenting), tangible instrumental costs (measures financial expense, emotional and physical toll), and perceived support (examines support from family, friends, and the community).

Following the methodology used by Lawson (2006), participants were instructed to think about what parenting a child with DS would be like when responding to each of the items on the scale. In other words, they were asked to rate the extent to which each of the 28 items would be experienced when parenting a child with DS. The participants were asked to respond to each item using a 7-point scale, ranging from 1 (strongly disagree) to 7 (strongly agree). Subscale scores are computed by summing the responses to the subscale items and dividing by the number of items within that subscale. Therefore, the subscale scores can range from 1 to 7, where higher scores reflect a stronger perception that the subscale items would be experienced when parenting a child with DS. Along with subscale scores, this measure provides a global perception of parenting score. The global score is obtained by reverse scoring the negatively worded items on the scale, and summing all of the items. The resulting scores can range from 28 to 196, with higher scores reflecting a more positive perception of a parenting a child with DS.

Using both young, childless university students and adults from the general community, Lawson (2004) examined the psychometric properties of the POPI. The POPI evidenced sound factor structure and construct validity for measuring the multidimensional nature of perceptions of parenting. In terms of criterion validity, the POPI was shown to relate both to a simple attitudinal measure (i.e., importance of parenting) and behavioural intentional measure (i.e., intention to have children). Specifically, this scale distinguished between individuals with

different attitudes and intentions toward parenting. The POPI has been shown to have sufficient reliability for measuring expectations of parenting, regardless of whether these perceptions are based on expectations (coefficient alpha = .85) or experience (coefficient alpha = .78; Lawson, 2004). The POPI-DS has also been found to have sufficient reliability for measuring perceptions of parenting a child with DS within the general community (coefficient alphas ranging from .90 to .65; Lawson, 2006). In the current study, the coefficient alphas for the global score and the subscales scores suggest adequate reliability (refer to Table 2). (See Appendix C for the POPI items.)

2.2.4 Selective reproduction questions. After completing the aforementioned items, the participants were asked to indicate their willingness to consider using MSS and amniocentesis in the event of an unfavourable result, and the likelihood that they would consider terminating a pregnancy subsequent to a fetal diagnosis of DS. Each of these items was measured using a 5-point scale, ranging from 1 (Definitely not) to 5 (Definitely yes). Although these questions are hypothetical, they were consistently presented in this order (i.e., MSS first, amniocentesis second, and selective abortion last) in order to mimic the order that these decisions are made in real life. Several open-ended questions were also included, which asked participants to identify the sources and types of information they believe would be important for them to make informed decisions (i.e., who they would want information from, what types of information they would like to have, etc.). The participants in the two information groups were also asked to indicate the quality and importance of the different forms of information they were provided. (See Appendix D for the selective reproduction questions.)

2.2.5 Demographic questions. Finally, the participants were asked to provide demographic information. Specifically, in order to provide information to describe the participant sample, participants were asked their age and ethnicity. In order to ensure that only women with no previous pregnancies participated, the participants were also asked to report their number of previous pregnancies. Finally, previous research has produced conflicting findings about the influence of religiosity on selective reproduction decisions. For example, Bell and Stoneman (2000) found that religious affiliation did not influence decisions about selective reproduction for DS, while Press and Browner (1998) found that religiosity was related to willingness to refuse MSS. In order to examine the potential influence of this variable in the present study, participants were asked whether they consider themselves religious, the strength of

their religious beliefs, and how often they participate in religious activities. These items were scored on a 1 to 5 scale, with higher scores reflecting stronger endorsement of the items. In order to compute a religiosity score, a mean was computed using the responses to the three items. The resulting scores ranged from 1 to 5, with higher scores reflecting greater religiosity. The coefficient alpha evident in the present study suggests an adequate level of reliability (refer to Table 2). (See Appendix E for the demographic questions.)

2.2.6 The basic information pamphlet. The basic information group received the MSS information pamphlet that is provided to all prenatal patients in Saskatchewan (see Appendix F). The pamphlet, *A Blood Test for Pregnant Women*, contains information about what MSS is, how it is conducted, and what the results can tell the patient. The pamphlet also contains information about further tests that can be done if the woman is found to have an increased probability for spinal or chromosomal defects. The final page contains basic information about open neural tube defects and chromosomal abnormalities, with two short paragraphs being dedicated to DS.

Following this pamphlet, participants were asked to complete a manipulation check (see Appendix G). The manipulation check consisted of 9 “true/false” questions meant to assess the participants’ understanding of the main points of the pamphlet (e.g., the procedure, the probability, the meaning of the results). Following this page, the correct answers were provided and explained. By asking participants to read the pamphlet, complete the manipulation check questions, and read the correct responses, the intent was that the participants would understand the basic points from the pamphlet. As the items from the manipulation check were not combined to create a scale (i.e., not used to measure a common underlying factor), a reliability index was not calculated for these items.

2.2.7 The expanded information pamphlet. The expanded information group received the same pamphlet as the basic information group, along with a pamphlet provided by the CDSS. The pamphlet, *Celebrate Being: About Down Syndrome* (see Appendix H), contains facts about what DS is, potential health issues, the effects on education and learning, and the future of persons with DS. While the probable difficulties of raising a child with DS are discussed (i.e., heart defects, different learning abilities, etc.), the pamphlet also presents positive information about the medical care and teaching methods available, and the impact of early intervention programs.

Along with the follow-up questions for the basic information pamphlet, the participants

in the expanded information group were asked to complete follow-up questions for the expanded information pamphlet (see Appendix I). Once again, these questions focused on the main points from the pamphlet (e.g., life expectancy and health complications of persons with DS). The correct responses were explained on the following page.

2.3 Procedure

The participants completed the questionnaire packages during small group testing sessions, ranging in size from 2 to 8 participants. Sessions were randomly assigned to one of the conditions (i.e., the control condition, the basic information condition, and the expanded information condition). The materials for each of the conditions were provided in booklet form. The participants in the control condition completed the items in the following order: the SADP-DS, the familiarity questions, the POPI-DS, the selective reproduction questions, and the demographic questions. The participants in the two information conditions completed the items in the same order, with the exception that they reviewed their information pamphlets, and completed the manipulation check questions, after completing the familiarity questions and before completing the POPI-DS.

The order of the questionnaire was chosen for a number of reasons. First, the SADP-DS was presented to all participants in order to make sure that the random assignment was successful (i.e., the groups did not differ in terms of initial attitudes toward persons with DS). Both the SADP-DS questions and the familiarity questions were provided before the information pamphlets to prevent the responses on these items from being influenced by this information. As the purpose of the study was to examine the influence of information on perceptions of parenting and hypothetical decision making, these questions were presented after the information pamphlets. Finally, previous research has shown that perceptions of parenting a child with DS are salient when making selective reproduction decisions (Lawson, 2001; 2006). Therefore, in an effort to get participants to think about DS in a personal way, the POPI-DS questions were presented before the selective reproduction questions.

After consenting to participate, the students were given their respective packages and were asked to work through the packages at their own pace. In order to prevent the participants from influencing the responses of others, they were instructed not to respond to or comment on any of the questions out loud. Instead, they were asked to raise their hand if they had questions, so that the researcher could answer them directly. After completing their questionnaire packages,

the researcher briefly went over the purpose of the study, and the expected results. The participants were then given the chance to ask any questions. Finally, the participants were given a written debriefing form, which contained the researchers' contact information in case questions arose at a later date.

3. Results

3.1 Initial Group Differences and Scale Properties

Table 1 contains the means and standard deviations of the study variables for each of the participant testing groups. In order to ensure that the three groups did not differ prior to the experimental manipulation, preliminary analyses examined group differences in SADP-DS scores (measure of attitudes towards persons with DS) and familiarity with persons with DS. No differences in the SADP-DS scores were evident between the groups, $F(2, 160) = 1.10, p = .335$. An examination of base rates of familiarity with persons with DS also revealed no group differences, $\chi^2(2) = 3.40, p = .18$. Overall, the majority of participants stated that they did personally know someone with DS (66.9%).

3.2 Descriptive Information for Attitudes and Intentions

Before examining the relation between attitudes and reproductive intentions, attitudes and intentions were examined in a descriptive way. Overall, both the participants' attitudes toward persons with DS ($M = 99.03$) and their perceptions of parenting a child with DS were positive ($M = 123.14$). In order to examine the participants' perceptions of the rewards versus the costs of raising a child with DS, the subscales of the POPI-DS were examined. The means showed that although participants anticipated a high level of rewards from parenting a child with DS ($M = 5.00$, mean of the Enrichment and Family Continuity subscales), the participants also anticipated a large number of costs from this relationship ($M = 4.75$, mean of the Isolation, Commitment, and Instrumental Costs subscales). A paired samples t -test revealed that the difference between perceived parental rewards and perceived parental costs was marginally significant, $t(162) = 1.85, p = .067$.

Figure 1 presents the participants' reported willingness to engage in MSS, amniocentesis, and selective abortion. In order to illustrate the differences in reported willingness more clearly, the 5 point rating scale was collapsed into a 3 point scale for each of the selective reproduction questions, resulting in the following response options: not willing to engage in selective reproduction, neutral, and willing to engage in selective reproduction. As can be seen in Figure

Table 1

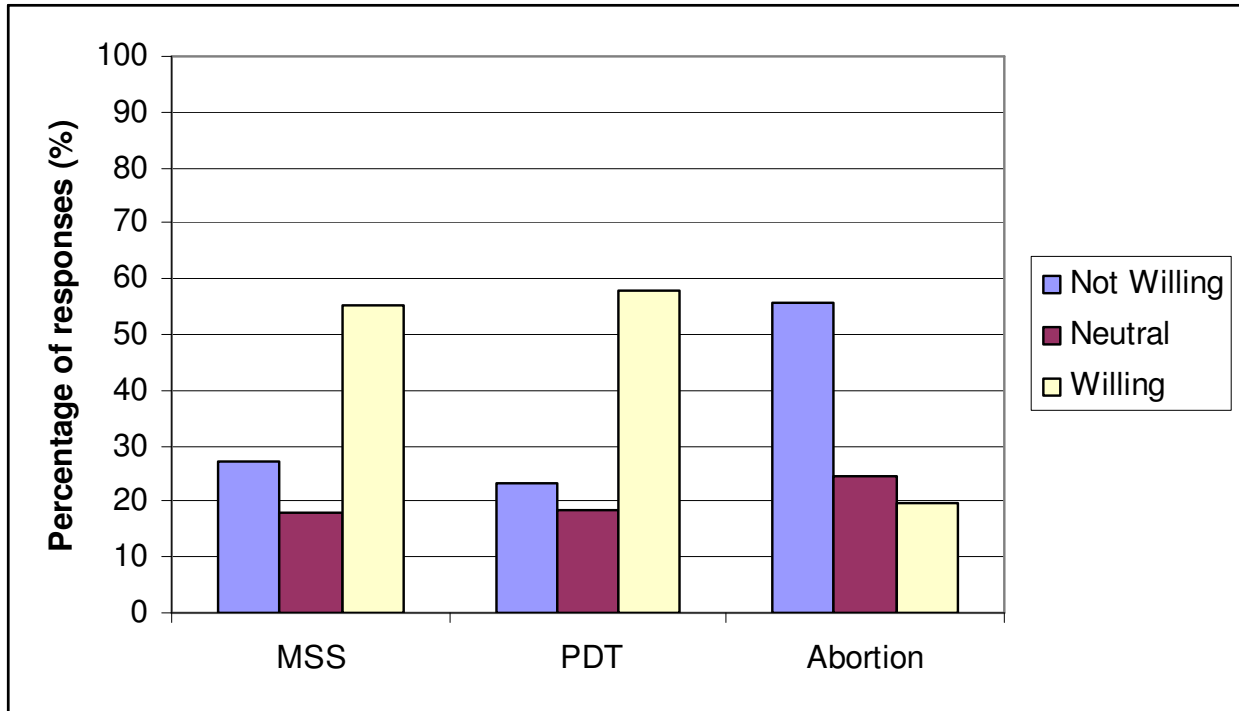
Scale/Item Means and Standard Deviations by Experimental Group.

Scale	Control <i>n</i> = 58 <i>M</i> (SD)	Basic information <i>n</i> = 53 <i>M</i> (SD)	Expanded information <i>n</i> = 52 <i>M</i> (SD)
SADP-DS ^a	100.91 (16.64)	96.39 (15.83)	99.63 (16.80)
Familiarity ^b			
Yes	44 (75.9%)	32 (60.4%)	33 (63.5%)
No	14 (24.1%)	21 (39.6%)	19 (36.5%)
POPI-DS ^c	119.98 (21.40)	123.02 (20.81)	126.31 (23.60)
Enrichment ^d	5.79 (0.90)	5.69 (0.87)	5.86 (0.90)
Isolation ^d	4.49 (1.36)	4.08 (1.21)	4.06 (1.40)
Commitment ^d	5.20 (1.19)	4.83 (1.33)	4.62 (1.33)
Costs ^d	5.31 (1.01)	5.08 (1.10)	5.01 (0.93)
Continuity ^d	4.17 (1.16)	4.07 (1.07)	4.43 (1.24)
Support ^d	6.09 (0.71)	5.95 (0.84)	5.83 (1.01)
Religiosity ^e	2.87 (1.21)	2.73 (1.09)	2.58 (1.13)
MSS ^f	3.22 (1.39)	3.70 (1.09)	3.44 (1.18)
Amniocentesis ^f	3.69 (1.17)	3.56 (1.08)	3.37 (1.25)
Abort ^f	2.24 (1.14)	2.45 (1.17)	2.33 (1.40)

Note: ^a Scores on the SADP-DS can range from 0 - 144, where higher scores reflect more positive attitudes toward persons with DS. ^b The frequency (and percentages) of yes and no responses is reported. ^c Scores on the POPI-DS can range from 28 to 196, where higher scores on reflect more positive perceptions of parenting a child with DS. ^d The subscale scores can range from 1 to 7, with higher scores indicating more endorsement of the subscale items. ^e The religiosity score is a mean score, which can range from 1 to 5, where higher scores indicate greater religiosity. ^f The selective reproduction questions were rated on 5 point scale, ranging from 1 to 5, where higher scores indicate a greater willingness to make use of selective reproduction.

Figure 1

The reported willingness of participants to make use of MSS, amniocentesis, and selective abortion.



1, the majority of participants reported that they would want to make use of MSS and amniocentesis. Following a hypothetical fetal diagnosis of DS, though, the majority of participants stated that they would not be willing to engage in selective abortion.

3.3 Relations between Attitudes and Intentions

In order to examine the relation between attitudes and reproductive intentions, correlational analyses were conducted. Specifically, in order to examine the possibility that perceptions of parenting a child with DS (as measured by POPI-DS scores) mediated the relationship between attitudes toward persons with DS (as measured by SADP-DS scores) and willingness to consider selective reproduction for DS (MSS, amniocentesis, and selective abortion), the zero-order correlations were first examined (see Table 2). SADP-DS scores were related to willingness to use MSS, amniocentesis, and selective abortion in the predicted manner. Specifically, more favourable attitudes toward persons with DS were related to less willingness to consider MSS, amniocentesis, and selective abortion for DS.

SADP-DS scores were also related to global POPI-DS scores. An examination of the POPI's subscales revealed that more favourable attitudes toward persons with DS were associated with the subscales related to the perceived rewards of parenting: Enrichment, Family Continuity, and Perceived Social Support. Finally, more favourable attitudes towards persons with DS were inversely correlated with the subscales related to the perceived costs of parenting: Social Isolation, Commitment, and Instrumental Costs.

After confirming the presence of zero-order correlations, the four step approach outlined by Baron and Kenny (1986) was followed to test for the hypothesized mediated relationship between SADP-DS scores and selective reproduction. Specifically, the SADP-DS scores served as the initial predictor variable, and selective reproduction intentions served as the outcome variable. Finally, the POPI-DS scores were the proposed mediator variable. Baron and Kenny's approach was used to investigate the hypothesised relationship between the predictor, mediator, and criterion (outcome) variables, as outlined below.

The first step of this approach involves conducting a simple regression analysis between the predictor (i.e., SADP-DS scores) and the criterion (i.e., personal endorsement of MSS, amniocentesis, and selective abortion). This initial step serves to verify that there is in fact a base relation between the predictor and the criterion variables that is subject to mediation by the intervening variable. On the second step, the hypothesized mediator (POPI-DS) is regressed on

Table 2

Intercorrelations and Scale Score Reliabilities.

Scale	1	2	3	4	5	6
1. SADP-DS	.80					
2. Familiarity ^a	.11					
3. POPI-DS	.60**	.04	.92			
4. Enrichment	.57**	.07	.77**	.88		
5. Isolation	-.49**	.01	-.83**	-.50**	.82	
6. Commitment	-.38**	-.09	-.65**	-.20*	.58**	.85
7. Instr. Costs	-.34**	.02	-.77**	-.39**	.67**	.58**
8. Continuity	.40**	-.09	.75**	.58**	-.51**	-.32*
9. Support	.31**	.10	.50**	.59**	-.28**	-.03
10. Religion	.05	.04	.26**	.22**	-.15*	-.18*
11. MSS	-.38**	-.15	-.31**	-.39**	.22**	-.15
12. Amniocentesis	-.33**	-.17*	-.33**	-.38**	.26**	.21**
13. Abort	-.44**	-.11	-.51**	-.61**	.39**	.19*

Note: Scale score reliabilities are reported on the diagonal. ^a Reliability index is not reported for single item measures. * Correlation is significant at the 0.05 level (2-tailed). ** Correlation is significant at the 0.01 level (2-tailed).

Table 2 continued

Intercorrelations and Scale Score Reliabilities.

Scale	1	2	3	4	5	6
1. SADP						
2. Familiarity						
3. POPI						
4. Enrichment						
5. Isolation						
6. Commitment						
7. Instr. Costs	.80					
8. Continuity	-.48**	.72				
9. Support	-.13	.37**	.67			
10. Religion	-.25*	.21**	.16*	.92		
11. MSS	-.14	-.25**	-.21**	-.17*		
12. Amniocentesis	.16*	-.21**	-.18**	-.14	.73**	
13. Abort	.29**	-.37	-.33**	-.28**	.56**	.56**

Note: Scale score reliabilities are reported on the diagonal. ^a Reliability index is not reported for single item measures. * Correlation is significant at the 0.05 level (2-tailed). ** Correlation is significant at the 0.01 level (2-tailed).

the initial predictor variable (SADP-DS) in order to confirm the necessary relation between the predictor and the proposed mediator. Steps 3 and 4 are both achieved within a final regression analysis which tests the relation between the proposed mediator (POPI-DS) and the criterion (reproductive intentions) while controlling for the initial predictor (SADP-DS). It is not sufficient to examine the correlation between the mediator and criterion variables, as their correlation may be due to the fact that they are both caused by the predictor variable (Kenny, 2008). Therefore, the initial predictor variable (SADP-DS) must be controlled in order to examine the effect of the hypothesised mediator (POPI-DS) on the criterion variable (reproductive intentions).

A significant regression equation in this final analysis verifies the existence of a relation between the mediator and the criterion, independent of any influence of the initial predictor (Step 3). The cumulative purpose of these first three steps is to establish that the necessary relationships exist among the variables in the hypothesised causal chain. If one or more of these relationships are non-significant, then the mediated relationship is not possible. If these relationships are substantiated, then the fourth and final step, which determines the extent of mediation, is carried out. Full mediation is indicated if the predictor variable (SADP-DS) is no longer a significant predictor of reproductive intentions when the mediator (POPI-DS) is controlled. In other words, if the path from the initial predictor to the criterion is reduced to zero in the final regression analysis, then it is concluded that the relation between these two variables is entirely mediated by the intervening variable. In contrast, partial mediation is indicated if the path from the initial predictor to the criterion is still significant when the mediator is controlled, but significantly reduced from that evidenced in Step 1.

If the final regression analysis supports a partially mediated relation, then the Sobel's test of significance (Baron & Kenny, 1986) is conducted to verify that the indirect relation between the initial predictor and the criterion, via the proposed mediator, is statistically significant. The Sobel test determines the significance of the indirect effect of the mediator by testing the hypothesis of no difference between the total effect and the direct effect. The test of the indirect effect is given by dividing the product of the regression coefficients from Steps 1 and 2 (i.e., the regression coefficients for the relationship between the predictor and proposed mediator and the relationship between the proposed mediator and the outcome variable) by the standard errors of these relationships. This ratio is treated as a Z test (i.e., values larger than 1.96 are significant at

the .05 level).

Baron and Kenny's (1986) four step approach was followed for each of the selective reproduction outcome variables (i.e., MSS, amniocentesis, and selective abortion).

3.3.1 MSS. First, the direct path between the predictor (SADP-DS) and the criterion (willingness to consider using MSS) was significant, $\beta = .38$, $t(161) = 5.19$, $p < .001$, which substantiated the basic relationship between attitudes toward DS and desire to use MSS. The path between attitudes toward persons with DS and perceptions of parenting a child with DS (POPI-DS), the proposed mediating variable, was also significant, $\beta = .60$, $t(159) = 9.45$, $p < .001$. The final path, between perceptions of parenting a child with DS and willingness to consider using MSS, controlling for SADP-DS, was not significant however, $\beta = -.13$, $t(158) = -1.47$, $p = .14$. This final result indicates that POPI-DS was not mediating the relationship between SADP-DS and likelihood of using MSS.

3.3.2 Amniocentesis. The direct path between SADP-DS scores and willingness to consider amniocentesis was significant, $\beta = -.33$, $t(161) = -4.50$, $p < .001$, as was the path from these scores toward POPI-DS, $\beta = .60$, $t(159) = 9.45$, $p < .001$. Finally, the path from the hypothesized mediator, POPI-DS, to the criterion variable of willingness to consider amniocentesis, controlling for SADP-DS, was also significant, $\beta = -.20$, $t(158) = -2.13$, $p = .04$. Although the path between SADP-DS and willingness to consider amniocentesis was reduced in this regression analysis, it was still significant, $\beta = -.22$, $t(158) = -2.34$, $p = .02$, thus suggesting that POPI-DS was only partially mediating this relationship. The Sobel test (Baron & Kenny, 1986) substantiated that the mediated model was marginally significant, $z = -1.96$, $p = .05$.

3.3.3 Selective abortion. Finally, the proposed mediated path between SADP-DS and reported likelihood of engaging in selective abortion was examined. The direct path between SADP-DS and selective abortion was significant, $\beta = -.44$, $t(158) = -6.19$, $p < .001$, as was the path from these scores toward POPI-DS, $\beta = .60$, $t(159) = 9.45$, $p < .001$. Lastly, the path from POPI-DS scores to likelihood of selectively aborting following a fetal diagnosis of DS, while controlling for SADP-DS, was also significant, $\beta = .39$, $t(158) = -4.70$, $p < .001$. As in the case of AMNIOCENTESIS, the relation between attitudes toward persons with DS and willingness to selectively abort for DS was reduced but still significant in this regression analysis, $\beta = -.20$, $t(158) = -2.36$, $p = .02$, thus indicating a partially mediated relationship. The Sobel test indicated that the mediated relationship was significant, $z = -3.99$, $p < .001$.

3.4 Influence of Information about DS

In order to examine the second hypothesis that receiving information about DS would influence perceptions of parenting and willingness to consider selective reproduction, group differences were examined on both the attitudinal measure (i.e., POPI-DS) and the intentional measures (i.e., reported willingness to consider MSS and amniocentesis, and reported willingness to selectively abort).⁴ No group differences were found in terms of the global POPI score, $F(2, 151) = 1.11, p = .33$. When the subscales were examined, the Commitment subscale evidenced a marginally significant difference, $F(2, 152) = 2.93, p = .06$. Follow-up t-tests revealed that the control group ($M = 5.20$) perceived raising a child with DS to involve more immediate and long-term care commitments than did the expanded information group ($M = 4.60$), $t(108) = 2.40, p = .02$. No other group differences were significant for this subscale.

In terms of the influence of information presentation on hypothetical selective reproduction decisions, group differences were found on the reported willingness to accept MSS, $F(2, 152) = 2.88, p = .06$. The basic information group ($M = 3.78$) reported slightly more likelihood to use MSS than the control group ($M = 3.22$), $t(108) = -1.99, p = .05$. There were no group differences in reported desire to use amniocentesis, $F(2, 152) = 1.44, p = .24$, nor were there group differences in reported willingness to selectively abort for DS, $F(2, 152) = .83, p = .44$.

3.5 Relationship Quality, Religiosity, and Selective Reproduction Decisions

As previously mentioned, when examining the relation between contact with persons with DS and selective reproduction decisions, it is important to examine the quality of the relationship (Lawson & Walls, in press). Therefore, as in Lawson and Walls, the two items measuring relationship quality (i.e., closeness of the relationship and comfort felt with person with DS) were summed to create a composite score. Correlations were then conducted between this score and reported willingness to consider MSS, amniocentesis, and selective abortion. As can be seen in Table 3, the composite relationship quality score was not related to decisions about MSS or amniocentesis. Participants who reported higher quality relationships were less likely to express desire to selectively abort following a hypothetical fetal diagnosis of DS. When

⁴ Prior to these analyses, however, the accuracy of the participants' responses to the manipulation check questions was examined. In particular, it was important to ensure that the participants understood that MSS is a blood test that poses no physical risk to the mother or fetus. Eight of the participants who received the MSS information pamphlet answered both of the related questions incorrectly. For this reason, these participants were excluded from the remaining between-group analyses.

Table 3

Correlations between Relationship Quality Measures and Selective Reproduction Intentions.

	Relationship Qual.	Closeness	Comfort
Relationship Qual.			
Closeness	.82***		
Comfort	.83***	.42***	
MSS	-.14	.04	-.30**
Amniocentesis	-.13	-.01	-.23*
Abortion	-.35***	-.20*	-.41***

* Correlation is significant at the 0.05 level (2-tailed).

** Correlation is significant at the 0.01 level (2-tailed).

*** Correlation is significant at the 0.001 level (2-tailed).

the closeness and comfort items were examined separately, it became clear that although perceived closeness was not related to decisions about MSS or amniocentesis, perceived comfort was associated with all three selective reproductive decisions. Specifically, participants who reported higher comfort with persons with DS were less likely to express willingness to consider MSS, amniocentesis, and selective abortion for DS.

Finally, the relationship between religiosity and selective reproduction decisions was analysed. As the three religiosity items were highly correlated ($r > .71$), the mean of these items was calculated to create a religiosity score. Correlational analyses revealed that participants who rated themselves as more religious were less likely to express desire to use MSS, $r(163) = -.17$, $p = .031$, and selective abortion, $r(163) = -.17$, $p < .001$. For decisions about amniocentesis, the relation to religiosity was marginal, $r(163) = -.14$, $p = .084$.

3.6 Information Needed to Make Informed Decisions

In addition to examining the aforementioned hypotheses, the current study also examined the information that participants perceived to be necessary for making informed decisions regarding MSS, amniocentesis, and selective abortion. Specifically, participants' responses to the two open-ended questions (i.e., what information would you need to make an informed decision? from whom would you like to receive this information?) were grouped into categories based on their content. (See Appendices J - L for summaries of the response categories by group for MSS, amniocentesis, and selective abortion respectively.) The information categories were then assigned to one of three themes: "Information about the Test", "Information about DS", and "Other Information". Table 4 contains the frequencies and percentages of participants providing a response that fell into each of these themes, separated by group.

Categories were assigned to the "Information about the Test" theme if they referred directly to the procedure (i.e., either MSS, amniocentesis, or selective abortion). For example, statements referring to the accuracy of the procedure, the risks and benefits of the procedure, and how the procedure was carried out were placed into this theme. Categories were assigned to the "Information about DS" theme if they discussed DS directly (e.g., posed specific questions about DS, spoke about the difficulties associated with DS, discussed the support available for children and families with DS, or discussed their chances of having a child with DS). All of the other information categories were placed into the "Other Information" theme. These categories included the opinions of others (e.g., doctor, family, friends), the post-result options, and the

overall health of the fetus.

3.6.1 Decisions about MSS. As can be seen in Table 4, the majority of participants stated that they would need more information about the MSS test in order to make an informed decision about whether to accept this test. Of these responses, participants most often focused on the risk of the test (42.6%), followed by the accuracy of the test (25.2%), other information about the test (21.9%), and the benefits of the test (10.3%). One participant summarised many of the statements about risk when she said, “I would want to know all the risks, and if they are worth the benefit of finding out.” Other participants also discussed emotional risks, including feeling “unsettled” by inconclusive results, regret, and other “emotional problems that may arise.” Information about the results also appeared in connection with responses concerned with the MSS procedure. As one participant said, “I would want to know what the steps are in this screening, and what the possible outcomes would be.”

The responses pertaining to “Information about DS” included general inquiries about DS (50.0%; e.g., life expectancy, severity of syndrome, health complications, etc.), chances of carrying a fetus with DS (43.3%), and the support available if a baby was born with DS (6.7%). One participant said, “I would need to know what to expect from a child with this condition. I would need to know if I had the baby, what kind of life the baby would have the opportunity for.” Other participants were concerned about the support available for children with DS, as illustrated by this statement: “whether the current educational and medical environment is adequate for the Down syndrome child to develop or grow up well.”

Of the responses falling under the “Other Information” theme, information about post-result options (15.4%) were most common. These participants wondered what their options would be if their fetus was diagnosed with a disability. One participant even wondered, “what the expectations are upon completion of the test.” Other common responses included the relation between the test and abortion (13.2%), and the doctor’s opinion (12.1%). Several participants also stated that the decision would need to be made with their spouse and/or family (9.9%).

3.6.2 Decisions about amniocentesis. Similar to the decisions about MSS, further information about amniocentesis was most commonly stated as necessary for making an informed decision about accepting amniocentesis. Participants once again focused primarily on the risk of the test (50.3%), followed by information about the test (26.6%), the accuracy of the test (17.3%), and the potential benefits of the test (5.8%). Similar to MSS, participants were

Table 4

Information reported as necessary for making informed decisions about MSS, amniocentesis, and selective abortion (frequency of participants making a response falling into each category).

Themes	MSS		
	Control <i>n</i> = 58 <i>f</i> (%)	Basic information <i>n</i> = 53 <i>f</i> (%)	Expanded information <i>n</i> = 52 <i>f</i> (%)
Information about test ^a	35 (60.3)	28 (52.8)	33 (63.5)
Information about DS ^b	22 (37.9)	12 (22.6)	17 (32.7)
Other information ^c	25 (43.1)	25 (47.2)	20 (38.5)
Amniocentesis			
Information about test ^a	34 (60.3)	35 (66.0)	36 (69.2)
Information about DS ^b	19 (32.8)	8 (15.1)	11 (21.2)
Other information ^c	21 (36.2)	23 (43.4)	11 (21.2)
Abortion			
Info about procedure ^a	15 (25.9)	12 (22.6)	9 (17.3)
Information about DS ^b	33 (56.9)	30 (56.6)	33 (63.5)
Other information ^c	30 (51.7)	22 (41.5)	25 (48.1)

Note: The percentages do not equal to 100 as participants were able to give more than one response. ^a Information about the procedure includes responses referring to risk, benefits, accuracy, and the test itself. ^b Information about DS includes responses referring to the chances of having a child with DS, the support available for families with children with DS, and other responses referring directly to DS. ^c Other information included responses referring to post-result options, relation to abortion, and the opinions of others.

concerned both about the physical risks (e.g., “the chance that I could lose my baby”) and the emotional risks (e.g., “the possible emotional effects it could have on me and my family”). Participants also stated that they would need more information on the actual amniocentesis procedure, as illustrated by this statement: “I would need to know the procedure of how its done, when the results come in, and any additional tests that may need to be done.”

Responses relating to the importance of information about DS focused on general inquiries about DS (56.8%; e.g., “I would want to find out what it is like to live with a Down syndrome child”), chances of carrying a fetus with DS (29.5%), and the support available for families raising a child with DS (13.6%). Participants expressed concerned with “how to properly care for a child with a disability,” the life expectancy of children with DS, and the pain that a child with DS may face. The most common response falling into the “Other Information” theme revolved around the health of the fetus (32.3%; e.g., “I would like to know if my baby was healthy, and if not, what was wrong.”), followed by post-result options (14.5%), and the doctor’s opinion (11.3%).

3.6.3 Decisions about selective abortion. Unlike for the two other decisions, participants most commonly stated that information about DS would be necessary in order to make an informed decision about whether to selectively abort following a fetal diagnosis of DS. These responses fell into two categories: general inquiries about DS (76.5%; e.g., how the syndrome affects every day life) and the support available for families with children with DS (23.5%). Incorporating the responses of many participants, one participant stated that she would need to know “what it is like to live with a child with Down syndrome, what care they need, financial needs, and any specific traits children with Down syndrome have.” Other participants expressed wanting to meet with parents of children with DS, and wanting to spend time with children with DS.

The risks related to the abortion procedure, including physical and emotional effects, were the most common category of responses relating to the “Information about Procedure” theme (65.1%), followed by the accuracy of previous test results (18.6%), and inquiries about the procedure itself (16.3%). Finally, the most common set of responses falling into the “Other Information” theme were those stating that more information was not necessary as abortion was not an option for them (42.2%). For example, one participant stated, “I think morally I couldn’t have an abortion so I probably wouldn’t look for information that would want me to have an

abortion.” This statement reflects the thoughts of another participant who expressed concern that further information may lead her to change her opinion about abortion. Some of the remaining responses under this theme related to gathering their family’s opinion (17.8%; e.g., “I would need to discuss it with my partner to decide if the responsibility would be too much”), personal circumstances (13.3%; e.g., “would depend on factors such as my income, marital status, how many children I have, what position I am in to care for a child with Down syndrome”), the age of the fetus (7.8%), and their doctor’s opinion (4.4%).

3.6.4 Group differences for decisions. Chi-square analyses were conducted to examine for possible group differences in the information reported as necessary for making decisions about MSS, amniocentesis, and selective abortion for DS. No group differences were found for decisions about MSS or selective abortion. Similarly, no group differences were found for “Information about the test” for amniocentesis, $\chi^2(2) = 1.44, p = .49$. A marginal difference was found, though, for the “Information about DS” theme, $\chi^2(2) = 5.03, p = .08$. An examination of the means suggested that the control group ($M = .33$) expressed more need for information about DS in order to make informed decisions about amniocentesis than did either the basic information group ($M = .15$) or the expanded information group ($M = .21$).

3.6.5 Important sources of information. Table 5 summarises the sources of information that the participants stated they would like to receive information from in order to make informed decisions. For each of the decisions (i.e., MSS, amniocentesis, and selective abortion), the majority of participants stated that they would like to receive the information from a medical professional. This was particularly true for decisions about MSS and amniocentesis. The participants referred primarily to physicians, but a small minority also mentioned nurses, specialists, and test technicians. As can be seen in Table 5, the remaining responses for MSS were distributed relatively evenly among others who had MSS, family and friends, families with children with DS, and carrying out their own research. For amniocentesis, after medical professionals, participants were most likely to respond that they would like to receive information from others who had previously gone through amniocentesis. Along with the other response options mentioned for MSS, participants stated that they would also like to receive information from support people and advisers (e.g., priests, counsellors) in order to make informed decisions about amniocentesis.

Although the majority of participants stated that they would like information from

Table 5

Reported sources of information for gaining information relevant for making informed decisions about MSS, amniocentesis, and selective abortion.

Received from	MSS		
	Control <i>n</i> = 58 <i>f</i> (%)	Basic information <i>n</i> = 53 <i>f</i> (%)	Expanded information <i>n</i> = 52 <i>f</i> (%)
Medical professionals	51 (87.9)	50 (94.3)	50 (96.2)
Others who had MSS	4 (6.9)	6 (11.3)	4 (7.7)
Own research	7 (12.1)	3 (5.7)	2 (3.8)
Family/Friends	5 (8.6)	4 (7.5)	2 (3.8)
Families with DS child	2 (3.4)	2 (3.8)	1 (1.9)
Other	5 (8.6)	4 (7.5)	2 (3.8)
Amniocentesis			
Medical professionals	54 (93.1)	47 (88.7)	51 (98.1)
Others who had amnio	2 (3.4)	7 (13.2)	5 (9.6)
Own research	4 (6.9)	3 (5.7)	1 (1.9)
Family/Friends	4 (6.9)	0	2 (3.8)
Families with DS child	0	1 (1.9)	3 (5.8)
Support people	1 (1.7)	0	4 (7.7)
Other	0	4 (7.5)	2 (3.8)
Abortion			
Medical professionals	42 (72.4)	39 (73.6)	36 (69.2)
Others who aborted	2 (3.4)	2 (3.8)	2 (3.8)
Own research	5 (8.6)	0	6 (11.5)
Family/Friends	10 (17.2)	5 (9.4)	7 (13.5)
Families with DS child	14 (24.1)	12 (20.7)	14 (26.9)
Support people	3 (5.2)	4 (7.5)	0
People familiar with DS	1 (1.7)	5 (9.4)	9 (17.3)
Other	0	3 (5.7)	3 (5.8)
N/A	6 (10.3)	4 (7.5)	3 (5.8)

medical professionals in order to make informed decisions about selective abortion following a fetal diagnosis of DS, participants were also likely to state that they would want information from families of children with DS. They were more likely to want information from families of children with DS when the decision was about abortion (23.9%) than when it was about amniocentesis (1.3%) or MSS (1.7%). Unlike for the other questions, participants also mentioned wanting information from other people familiar with DS in order to make decisions about selective abortion. This category included people like teachers working with children with DS, community support groups, and the Canadian Down Syndrome Society.

3.6.6 Usefulness of information pamphlets. In addition to the questions asking participants to list the sources of information necessary for making informed selective reproduction decisions, the participants were asked whether they believed that the information pamphlets they were provided helped them to make informed decisions about selective reproduction. As these questions only related to the two information groups, and as the expanded information group received an additional information pamphlet, independent *t*-tests were performed to look for group differences. No differences were found for the perception that the pamphlets were helpful in reaching decisions about MSS, $t(103) = -1.12, p = .265$. There were differences, however, for the perceived helpfulness of the pamphlets on decisions about amniocentesis, $t(103) = -1.90, p = .061$, and selective abortion, $t(103) = -3.14, p = .002$. Although the perceived helpfulness of the pamphlets was rather low for both groups, hovering around the midpoint, the expanded information group felt that the pamphlets helped them to make an informed decision about amniocentesis ($M = 3.6$) and selective abortion ($M = 2.9$) more than did the basic information group ($M = 3.2$ and $M = 2.2$, respectively). In other words, although there were no group differences in the reported willingness to use amniocentesis and selective abortion, the participants in the expanded information group were more likely to view the pamphlets as helpful for making an informed decision.

4. Discussion

The goal of the current study was to examine the influence of DS-related information on participants' attitudes about parenting a child with DS, and in turn, their hypothetical decisions about MSS, amniocentesis, and selective abortion. There were also two secondary goals: first, to investigate the relationship between attitudes toward persons with DS, perceptions of parenting a child with DS, and the desire to consider selective reproduction for DS, and second, to examine

the information deemed necessary for making informed selective reproduction decisions. Taken together, it was hoped that the current research would shed light on selective reproduction decision-making and would thus provide information relevant to the ongoing development of MSS and amniocentesis protocols.

4.1 Influence of DS Related Information

Although the three participant groups were given differing amounts of information about DS (i.e., no information, minimal information, expanded information from the CDSS), the groups did not differ in terms of their overall perceptions of parenting a child with DS, nor did they differ in their expressed desire to use amniocentesis or selective abortion following a fetal diagnosis of DS. The control group, who received no additional information about DS, did perceive parenting a child with DS as involving more immediate and long-term care commitment than did the expanded information group, who received more positive information about DS. This perception, though, did not result in more willingness to consider selective reproduction. The basic information group did report slightly more desire to use MSS than did the control group, but this difference was only marginally significant.

The presentation of expanded information about DS did appear to impact participants' perceptions of the extent to which their selective reproduction decisions were informed. Specifically, the participants in the expanded information group were more likely to report that the provided pamphlets helped them to make informed decisions about amniocentesis and selective abortion. Although the perceived helpfulness of the pamphlets for informed decision making hovered around the midpoint of the scale, the results indicate that their inclusion did increase participants' feelings of being informed. This difference was not found for decisions about MSS, which may reflect the fact that women treat MSS as routine, and do not make active decisions about accepting it (Chiang et al., 2005; Press & Browner, 1995). This point will be considered in further detail later.

The fact that the majority of participants, for each of the selective reproductive decisions, stated that they would like to receive any additional information from medical professionals points to the possible limitations of providing pamphlets in order to increase informed consent. As previously stated, many people have little person knowledge about DS (Gekas et al., 1999) and little knowledge about MSS and amniocentesis procedures (Verjaal et al., 1982). Because this knowledge is not commonplace, pregnant women may feel that medical professionals are the

best sources of this information. When the information needed is more widespread, like healthy behaviours during pregnancy, pregnant women have been found to rely on family members more than health care personnel (Lewallen, 2004). Regardless of whom pregnant women wanted information about prenatal testing from (i.e., family versus physicians), Jacques et al. (Jacques, Bell, Watson, & Halliday, 2004) found that the majority of women preferred face-to-face discussions. These discussions can provide women with the opportunity to ask questions and to play a more active role in decision making (Fraenkel & McGraw, 2007). Although face to face meetings are preferred, information pamphlets and books are often rated as important secondary sources of information (Aronson, Mural, Pfoutz, 1988; Jacques et al., 2004).

The lack of group differences on the perceptions of parenting measure may indicate that information pamphlets have a limited impact on people's perceptions and attitudes. Based on the previously found relationship between attitudes, intentions, and behaviour (Cooke & French, 2008; Michie et al., 2004), and the relationship between perceptions of parenting and selective reproduction intentions (Lawson, 2001; 2006), it is perhaps unsurprising that the participants' reproductive intentions were likewise unaffected by the provision of information pamphlets. Because the information pamphlets did not influence participants' attitudes, it is not surprising that the pamphlets did not influence reproductive intentions, which are themselves related to attitudes.

4.2 Relations between Attitudes, Perceptions, and Reproductive Intentions

It was hypothesised that the relation between attitudes toward persons with DS (as measured by the SADP-DS) and desire to engage in selective reproduction would be mediated by perceptions of parenting a child with DS (as measured by the POPI-DS). In other words, it was expected that negative attitudes towards persons with DS would be associated with negative perceptions of parenting, which would, in turn, increase the expressed willingness to consider selective reproduction. Attitudes toward persons with DS were found to be related to reproductive intentions and to perceptions of parenting a child with DS. More specifically negative attitudes toward persons with DS were associated with the perceived costs of parenting a child with DS (i.e., social isolation, commitment, and instrumental costs), while being inversely correlated with the perceived rewards of parenting (i.e., enrichment, family continuity, and perceived social support). The fact that the women's attitudes towards DS were related to their willingness to consider MSS, amniocentesis, and selective abortion supports the TRA

framework. In other words, the participants' attitudes were related to their reproductive intentions. The TRA (Fishbein & Ajzen, 1975) and previous research on MSS intentions (Michie et al., 2004) suggest that these behavioural intentions would then be related to actual selective reproduction behaviours.

The hypothesised mediated relationship was not found for decisions about MSS. It was found, however, for decisions about amniocentesis and selective abortion. These findings may be indicative of a hierarchy of decisions making, where certain selective reproduction decisions (i.e., MSS) are seen as less serious than others (i.e., amniocentesis and selective abortion). In support of this, Markens et al. (1999) found that the majority of pregnant women in their sample did not think a lot before accepting MSS. When asked to explain why they agreed to be tested, many women simply referenced the routine nature of the test (Browner & Press, 1995; Chiang et al., 2005; Press & Browner, 1997; Santalahti et al., 1998). Those women who rejected the test were much less likely to view MSS as routine, and were more likely to see a connection between MSS and selective abortion (Markens et al., 1999). Compared to MSS, women tend to report making more active decisions about amniocentesis and selective abortion (Santalahti et al., 1998).

The lack of a mediated relationship for decisions about MSS suggests that women may indeed be making less active decisions about MSS. It also suggests that while these decisions are related to attitudes toward persons with DS, they are not related to perceptions of parenting a child with DS. First, this finding provides support for disability advocates who have been calling for the inclusion of more detailed information about DS in MSS protocols (Asch, 1999; Grant & Flint, 2007). If pregnant women's attitudes and perceptions about persons with DS are inaccurate, their decisions about MSS may be based, at least in part, on this misinformation. Therefore, in order for pregnant women to make informed decisions about MSS, it seems important that they receive more detailed information about DS on which to base these decisions.

Second, this finding suggests that women are not imagining what it would be like to raise a child with DS when making decisions about MSS. Due to the perceived routine nature of the test, participants may not be personalizing their decision as much as for less routine decisions (i.e., amniocentesis and selective abortion). For decisions about MSS, then, women may be less likely to imagine their potential parenting futures (Huys, Evers-Kiebooms, & D'Ydewalle, 1992). For amniocentesis, though, there is a risk of miscarriage which leads many women to

contemplate their decision more closely (Santalahti et al., 1998; Verjaal et al., 1982). This further contemplation may lead women to personalise their decision, which may lead them to engage in this “imagined future” process and to think about their perceptions of parenting a child with DS.

Similarly for selective abortion, where pregnant women have to decide whether to terminate or continue a pregnancy, perceptions of parenting a child with DS may become very salient. If this personalisation through active decision making does cause pregnant women to imagine parenting a child with DS, this would explain why perceptions of parenting partially mediate the relationship between attitudes toward persons with DS and decisions about amniocentesis and selective abortion. Of course, other factors (e.g., direct pressure from others, perceptions of what others think they should do, general opposition to abortion) would also influence these decisions (Bell & Stoneman, 2000; Michie et al., 2002; 2004).

4.3 Relationship Quality, Religiosity, and Selective Reproduction Decisions

The current findings suggest that both the quality of relationships with persons with DS and religiosity play a role in selective reproduction decisions. Religiosity was related to all three selective reproduction decisions, in that participants who reported stronger religious beliefs were less likely to express a desire to engage in MSS, amniocentesis, and selective abortion. The relationship between selective reproduction and relationship quality was less straightforward. Specifically, relationship quality (i.e., both closeness and comfort with persons with DS) was not related to decisions about MSS or amniocentesis. It was related, though, to decisions about selective abortion, such that those reporting greater quality relationships with persons with DS were less likely to report a desire to selectively abort following a fetal diagnosis for DS.

This finding may lend support to the idea that decisions about selective abortion are more personalized, in that participants may have been more likely to think about their own relationships with persons with DS. This finding also supports previous research showing that the quality of contact with persons with DS is related to reproductive intentions (Lawson & Walls, in press). When relationship quality was examined closer, it became clear that the comfort participants felt with persons with DS was related to all three selective reproduction decisions, while perceived closeness was related solely to decisions about selective abortion. This may indicate that comfort is more general, and is related to overall attitudes towards persons with DS, while perceived closeness is more individual and related specifically to personal relationships.

4.4 Information Types and Sources for Informed Decision Making

The types of information that women stated they would need in order to make informed selective reproduction decisions also supports the idea of a hierarchy of decision-making. For decisions about MSS, the women studied predominantly wanted information about the MSS test, particularly reassurance that the test posed no risk. Little other information was deemed necessary for informed decisions about MSS. For amniocentesis, women were still primarily concerned with gaining more information about the test. This was particularly true for information about the risk of the test, particularly the risk of miscarriage. In contrast to decisions about MSS, though, women also focused on information about DS and the support available for families with a child with DS. For decisions about selective abortion, the majority of participants stated that they wanted more information about DS and parenting a child with DS. This provides support for the idea that women making decisions about amniocentesis and selective abortion are more likely to consider their perceptions of parenting a child with DS than when making decisions about MSS.

4.5 Implications of the Current Findings

First, it appears that the provision of additional information about DS does not have an impact on decisions about selective reproduction, at least not in the hypothetical. This may mean that providing people with additional information about DS does not influence their desire to practice selective abortion for DS (i.e., more information does not make people more willing to consider parenting a child with DS). It may also suggest, however, that an information pamphlet is not a sufficient means to convey information about the actual experience of raising a child with DS. Instead, it may be necessary for prospective parents to talk to parents raising children with DS, or to even spend time with children with DS. Reflecting this need, many of the participants in the current study stated that such meetings would be necessary in order to make informed decisions, particularly for selective abortion. In other words, in order for women to make truly informed decisions about whether to terminate or complete a pregnancy diagnosed with DS, they need to understand what raising a child with DS would be like. Underscoring the potential impact of such information, research has shown that when pregnant women are given the chance to spend time with families with a child with DS and people living with DS, the rates of selective abortion for DS are decreased (Parens & Asch, 2003).

Related to this is the finding that negative attitudes towards persons with DS and negative

perceptions of parenting a child with DS were associated with increased desire to make use of amniocentesis and selective abortion. Greater quality relationships with persons with DS, on the other hand, were related to less willingness to consider selective abortion. In addition, greater perceived comfort with persons with DS was related to less willingness to consider MSS and amniocentesis. Taken together, these findings provide empirical support for disability advocates' claims that decisions about selective abortion are based on stereotypes and misinformation (Parens & Asch, 2003). Particularly for decisions about MSS, where perceptions of parenting were not found to mediate the relationship between negative attitudes and MSS, addressing women's attitudes towards persons with DS in general may be important. These findings suggest that pregnant women facing these decisions should be provided with information not only about the tests themselves, but also about the implications of the results, and the conditions targeted by the test (Goel et al., 1996; Marteau & Dormandy, 2001).

When considering changes to prenatal counselling protocols, though, it may be important to consider the possible hierarchy of decision making. As already discussed, decisions about MSS are rarely active decisions, in that women may not be considering their potential futures with a child with DS. In support of this idea, the results show that these decisions are not related to perceptions of parenting a child with DS. If this is the case, it may not be necessary for women to receive information related to parenting at this decision point. Instead, it may be important to inform women about the test itself, and the implications of the test results. Because MSS can have negative effects on women, including the introduction of worries about fetal defects (Gates, 1993), anxiety (Dick, 1996), and lower levels of fetal bonding (Lawson & Turniff-Jonasson, 2006), it is important for women to be informed about these potential effects when making decisions about MSS.

The current study suggests that perceptions of parenting do mediate the relationship between attitudes and decisions about amniocentesis and selective abortion. For these decisions, then, it may be important to provide pregnant women with information pertinent to parenting a child with DS. For example, women could be told about the ways children with DS can participate in family, school, and the community (Asch, 1999). Chiang et al. (2005) suggest that pregnant women should be given sufficient information to understand the potential difficulties and the potential joys of raising a child with DS. In order to facilitate informed decisions about whether to terminate a pregnancy or raise a child with DS, it seems imperative that pregnant

women be provided with information about parenting a child with DS. This is highlighted by the fact that the women in the current study stated that they would need information about DS and raising a child with DS in order to make these decisions.

Since this information is not currently routinely being provided to pregnant women (Grant & Flint, 2007), it seems as though informed decision making may be at risk for these more active and personalised decisions. Therefore, pregnant women making these decisions should be provided with more detailed information about DS and about parenting a child with DS. In order to facilitate informed decision making, this information should present both the highs and the lows of parenting children with DS (Chiang et al., 2005).

4.6 Limitations of the Current Study

Although the hypothesised mediated relation was found between attitudes, perceptions of parenting, and selective reproduction (i.e., amniocentesis, and selective abortion), causal claims cannot be made because of the correlational and cross-sectional design of the present study. Similarly, while Baron and Kenny's (1986) approach for testing mediated relationships can be used to make causal claims, that cannot be done here. This approach can be used, though, to provide evidence of a relationship between variables. Previous research examining MSS also supports the existence of a relationship between attitudes, behavioural intentions, and screening behaviour (Michie et al., 2004). Future research could build upon this previous work. For example, instead of focusing on attitudes towards MSS, future research could focus on attitudes toward persons with DS and perceptions of parenting. The relationship between these attitudes, behavioural intentions, and actual selective reproduction behaviours could then be examined. Based on the current findings, and the findings by Michie et al., it is likely that these attitudes will be related to behavioural intentions, which may then be related to actual selective reproduction behaviours. Such research would also serve to highlight other factors that influence real-life reproductive decision making.

Another potential limitation of the current study is the characteristics of the sample recruited. The participants were all young, undergraduate university women. Although this sample may be unrepresentative of the general population, these participants constitute a group of well-educated prospective mothers of child-bearing age. Because the recent SOGC (2007) guidelines recommend MSS for all women, it is important to examine young women's attitudes toward screening and their attitudes toward the disabilities being screened for. Bryant, Green, et

al. (2001) suggest that examining young women's attitudes and experiences is particularly important as they may have less knowledge about DS and MSS, and may be more likely to accept MSS without considering the implications. Further research will be needed to examine the generalizability of these findings to a more diverse population of prospective mothers (e.g., individuals who have experienced a previous pregnancy, and those from varied age groups, socioeconomic statuses, educational and ethnic backgrounds).

A third potential limitation, involving both the sample and the method, is that the participants recruited for the current study had no experience with previous pregnancies. While this was necessary in order to examine the influence of the prenatal information materials, it also meant that women were asked to make hypothetical decisions about MSS, amniocentesis, and selective abortion. For many of these women, these types of decisions (and their perceptions of parenting a child with DS) were likely not very salient to them. The fact that the expected relationship between attitudes, perceptions of parenting, and selective reproduction decisions was still found, though, indicates the potential strength of this relationship. Also, the differences found between hypothetical decisions about MSS, amniocentesis, and selective abortion highlight the important distinction between these three decisions.

A final limitation surrounding the findings is that of social desirability (i.e., that participants were not responding honestly and were instead selected the responses that they thought would be most acceptable). If participants responded in this way, it would be impossible to know whether the findings reflect the participants' true attitudes. In an attempt to reduce socially desirable responding, the participants completed anonymous questionnaires in a group setting. The consent form was never attached to the questionnaire package, so the researchers could not identify specific participants. Additionally, the instructions informed participants that the researchers were interested in the many different opinions that people have, and that there were no right or wrong answers. The anonymous nature of the results was also emphasized.

4.7 Directions for Future Research

In addition to the research recommended in order to address the limitations of the current study, other directions for future research would be valuable. Previous research in the area of prenatal decision-making has predominantly used either hypothetical scenarios or retrospective accounts. Longitudinal studies that gather data at a number of intervals throughout the pregnancy (e.g., before making a decision about MSS, during MSS decision period, following MSS

decision, etc.) are needed in order to better understand the variety of factors that impact selective reproduction decisions. Such studies would also shed light on the information that is necessary for women to make informed decisions at each of the different decision points. The usefulness of different sources of information (e.g., medical professionals vs. parents of children with DS) throughout the prenatal period could be examined as well. Such information could provide further recommendations for the improvement of prenatal counselling protocols.

4.8 Conclusions

While the exact causal mechanism cannot be determined from these results, it appears that women's attitudes toward persons with DS are related to their decisions about selective reproduction, namely amniocentesis and selective abortion, partially through their perceptions of parenting a child with DS. Specifically, people with more negative attitudes toward persons with DS had more negative perceptions of parenting, and were more likely to express willingness to use amniocentesis and selective abortion for DS. It appears that women are more likely to personalise these decisions, perhaps by imagining their prospective parenting future. The lack of a mediated relationship for MSS suggests that the information given to women considering these decisions should focus more generally on DS, instead of focusing on the parenting aspects. More in-depth information should be provided, particularly information pertaining to parenting a child with DS, prior to decisions about amniocentesis and selective abortion. The current findings suggest that information pamphlets may not be sufficient to influence women's perceptions of parenting a child with DS. Supporting this fact, the majority of participants stated that they would like to receive information from medical professionals, which suggests that medical professionals may need to be educated on these topics as well.

While examining the influence of information on selective reproduction decisions and the relation between attitudes and reproductive intentions, the current study is also concerned with informed decision making: presenting women with the information needed to make informed decisions about MSS, amniocentesis, and selective abortion. Informed decision making is particularly important in this context, as these decisions can have serious consequences. Aside from the more well-known risks (e.g., miscarriage following amniocentesis), there are also lesser-known risks associated with MSS, including lower levels of maternal-fetal attachment (Lawson & Turniff-Jonasson, 2006), stress, uncertainty, and anxiety (Dick, 1996; Gates, 1993). These negative effects may be more pronounced for women who do not proceed to

amniocentesis (i.e., they do not receive a definitive diagnosis). Information about these risks should be included in MSS protocols, along with the inclusion of expanded information about DS in amniocentesis and selective abortion counselling protocols. Without the inclusion of such information, pregnant women may be unable to make informed selective reproduction decisions.

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Appendix A. The revised Scale of Attitudes toward Disabled Persons (SADP).

The statements presented below express opinions or ideas about people who have Down syndrome. There are many differences of opinion; many people agree and many people disagree with each statement. We would like to know your opinion about them. Please circle the appropriate number, from -3 to +3, which best corresponds with how you feel about the statement. There are no right or wrong answers. You should work as quickly as you can, but don't rush. There is no time limit. Please respond to every statement.

Key

-3: I disagree very much
-2: I disagree pretty much
-1: I disagree a little

+1: I agree a little
+2: I agree pretty much
+3: I agree very much

1. Children with Down syndrome should not be provided with a free public education.	-3	-2	-1	+1	+2	+3
2. People with Down syndrome are not more accident prone than other people.	-3	-2	-1	+1	+2	+3
3. A person with Down syndrome is not capable of making moral decisions.	-3	-2	-1	+1	+2	+3
4. People with Down syndrome should be prevented from having children.	-3	-2	-1	+1	+2	+3
5. People with Down syndrome should be allowed to live where and how they choose.	-3	-2	-1	+1	+2	+3
6. Adequate housing for people with Down syndrome is neither too expensive nor too difficult to build.	-3	-2	-1	+1	+2	+3
7. Rehabilitation programs for people with Down syndrome are too expensive to operate.	-3	-2	-1	+1	+2	+3
8. People with Down syndrome are in many ways like children.	-3	-2	-1	+1	+2	+3
9. People with Down syndrome need only the proper environment and opportunity to develop and express criminal tendencies.	-3	-2	-1	+1	+2	+3
10. Adults with Down syndrome should be involuntarily committed to an institution following arrest.	-3	-2	-1	+1	+2	+3
11. Most people with Down syndrome are willing to work.	-3	-2	-1	+1	+2	+3

12. Individuals with Down syndrome are able to adjust to a life outside an institutional setting.	-3	-2	-1	+1	+2	+3
13. People with Down syndrome should not be prohibited from obtaining a driver's license.	-3	-2	-1	+1	+2	+3
14. People with Down syndrome should live with others of similar disability.	-3	-2	-1	+1	+2	+3
15. Zoning ordinances should not discriminate against people with Down syndrome by prohibiting group homes in residential districts.	-3	-2	-1	+1	+2	+3
16. The opportunity for gainful employment should be provided to people with Down syndrome.	-3	-2	-1	+1	+2	+3
17. Children with Down syndrome in regular classrooms have an adverse effect on other children.	-3	-2	-1	+1	+2	+3
18. Simple repetitive work is appropriate for people with Down syndrome.	-3	-2	-1	+1	+2	+3
19. People with Down syndrome show a deviant personality profile.	-3	-2	-1	+1	+2	+3
20. Equal employment opportunities should be available to individuals with Down syndrome.	-3	-2	-1	+1	+2	+3
21. Laws to prevent employers from discriminating against people with Down syndrome should be passed.	-3	-2	-1	+1	+2	+3
22. People with Down syndrome engage in bizarre and deviant sexual activity.	-3	-2	-1	+1	+2	+3
23. Workers with Down syndrome should receive at least the minimum wage established for their jobs.	-3	-2	-1	+1	+2	+3
24. Individuals with Down syndrome can be expected to fit into competitive society.	-3	-2	-1	+1	+2	+3

Appendix B. The familiarity questions.

The following items ask you about your personal knowledge or experiences with persons with Down syndrome. Please read each question carefully and provide your answers using the scales or space provided.

	Not at all		Somewhat			Extremely	
1. I am knowledgeable about Down syndrome.	1	2	3	4	5	6	7
2. I am familiar with Down syndrome as a medical condition.	1	2	3	4	5	6	7
3. I am familiar with persons with Down syndrome.	1	2	3	4	5	6	7
4. I am familiar with persons with forms of mental retardation other than Down syndrome.	1	2	3	4	5	6	7
5. I am comfortable with persons with Down syndrome.	1	2	3	4	5	6	7
6. I am comfortable with persons with forms of mental retardation other than Down syndrome.	1	2	3	4	5	6	7
7. Have you ever known someone with Down syndrome?							
	<input type="checkbox"/> No						
	<input type="checkbox"/> Yes						

→ **if yes, please rate the closeness of your relationship with this person with Down syndrome** (if you have known more than one person with Down syndrome, please answer this question in relation to the person with whom you have had the closest relationship).

1	2	3	4	5
Not at all close	Not very close	Somewhat close	Quite close	Extremely close

Please note: This question continues on the next page.

→ **if yes, please rate how comfortable you felt with this person with Down syndrome** (if you have known more than one person with Down syndrome, please answer this question in relation to the person with whom you have had the closest relationship).

1	2	3	4	5
Not at all comfortable	Not very comfortable	Somewhat comfortable	Quite comfortable	Extremely comfortable

→ **if yes, how would you categorize your relationship with this person?**

- Immediate family member (brother, sister, etc.)
- Extended family member (aunt, uncle, cousin, etc.)
- Close friend
- Acquaintance (neighbour, school relationship, friend of family, etc.)
- Work related (teaching, care-giving, babysitting, volunteer experience, etc.)

→ **if yes, do you currently have a relationship with this person?**

- Yes
- No

Appendix C. The Perceptions of Parenting Inventory (POPI).

Please imagine that you have just become the parent of a child with Down syndrome. Please rate the extent to which you agree or disagree with the following statements based on your own opinions or perceptions, making reference to this child with Down syndrome for each response. Please indicate your level of agreement by circling the appropriate response on the scale provided.

	Strongly Disagree	Mostly Disagree	Slightly Disagree	No Opinion	Slightly Agree	Mostly Agree	Strongly Agree
1. Meeting my child's needs would be financially expensive.	1	2	3	4	5	6	7
2. Caring for my child would emotionally exhaust me.	1	2	3	4	5	6	7
3. My family and friends would provide social support to me.	1	2	3	4	5	6	7
4. My child would provide me with financial security in my old age.	1	2	3	4	5	6	7
5. I would worry about my child's future.	1	2	3	4	5	6	7
6. As a result of caring for my child, I would have less time to spend doing what I enjoy.	1	2	3	4	5	6	7
7. Caring for my child would bring me happiness.	1	2	3	4	5	6	7
8. Caring for my child would be a 24-hour per day responsibility.	1	2	3	4	5	6	7
9. My child would be a source of pride for me.	1	2	3	4	5	6	7
10. Parenting my child would put strain on my relationship with my spouse/partner.	1	2	3	4	5	6	7
11. If I had other children, they would benefit from the addition of the child to the family.	1	2	3	4	5	6	7
12. Providing for my child's needs would result in extra expenses for me.	1	2	3	4	5	6	7

	Strongly Disagree	Mostly Disagree	Slightly Disagree	No Opinion	Slightly Agree	Mostly Agree	Strongly Agree
13. Caring for my child would be fun.	1	2	3	4	5	6	7
14. Parenting my child would make me a better person.	1	2	3	4	5	6	7
15. My community would provide social support to me.	1	2	3	4	5	6	7
16. Caring for my child would be a never-ending responsibility.	1	2	3	4	5	6	7
17. I would need to provide care for my child for the rest of my life.	1	2	3	4	5	6	7
18. My spouse/partner and I would grow closer together through the experience.	1	2	3	4	5	6	7
19. I would enjoy watching my child grow up.	1	2	3	4	5	6	7
20. Caring for my child would interfere with me spending time with my friends.	1	2	3	4	5	6	7
21. My friends and family would help me to care for my child.	1	2	3	4	5	6	7
22. My child would carry on the family line and traditions.	1	2	3	4	5	6	7
23. Caring for my child would physically exhaust me.	1	2	3	4	5	6	7
24. Caring for my child would be rewarding.	1	2	3	4	5	6	7
25. Caring for my child would interfere with the time I wanted to spend with my partner/spouse.	1	2	3	4	5	6	7

	Strongly Disagree	Mostly Disagree	Slightly Disagree	No Opinion	Slightly Agree	Mostly Agree	Strongly Agree
26. My relationship with my child would change over the years from one of parent to one of friend.	1	2	3	4	5	6	7
27. I would look forward to being a grandparent in the future.	1	2	3	4	5	6	7
28. My child would be dependent on me for the rest of my life.	1	2	3	4	5	6	7

Appendix D. The selective reproduction questions.

Maternal serum screening, a prenatal screening test, can be used to determine if a woman is at an increased risk of having a baby with a chromosomal abnormality like Down syndrome. Maternal serum screening is a blood test that poses no risk to the mother or the unborn baby. If the test reveals that a woman is at an increased risk for a fetal abnormality, further diagnostic testing is needed to confirm the result.

1. **Would you want to make use of maternal serum screening in the future if you were to become pregnant?** (circle your response)

1 2 3 4 5
Definitely not Probably not Don't know Probably Definitely

2. **If you were offered maternal serum screening, what kind of information do you think you would need to make an informed decision?**⁵

3. **From whom would you like to receive this information?**

⁵ Participants in the two information groups will also be asked the following question:
Do you think that the information pamphlet you were provided would help you to make an informed decision about whether to make use of prenatal screening (prenatal tests, selective abortion)?

1 2 3 4 5
Definitely not Probably not Don't know Probably Definitely

Prenatal diagnostic tests, such as amniocentesis, can provide information about the health of a baby before it's born. Many women use these tests to reassure themselves that their baby is healthy, or if a diagnosis of disability is made, to either prepare for parenting a disabled child or to end the pregnancy by having an abortion.

1. Would you want to make use of prenatal tests in the future if you were to become pregnant? (circle your response)

1 2 3 4 5
Definitely not Probably not Don't know Probably Definitely

2. If you were offered prenatal testing, what kind of information do you think you would need to make an informed decision?

3. From whom would you like to receive this information?

4. **Suppose you had prenatal testing and learned that your unborn child has Down syndrome. Would you have an abortion?** (circle your response)

1 2 3 4 5
Definitely not Probably not Don't know Probably Definitely

5. **What kind of information do you think you would need to make an informed decision about having an abortion after finding out your unborn child has Down syndrome?**

6. **From whom would you like to receive this information?**

Appendix E. The demographic questions.

This section asks a few questions about you. These questions help us to determine if we have surveyed a wide variety of people. This ensures that our results will reflect the many differing views that different people may hold on these issues. Please take a few minutes to answer these questions.

1. **What is your age?** _____(years)

2. **Are you:** (check the correct response)
Single
In a committed relationship
Married
Divorced/Separated
Widowed

3. **Would you consider yourself a religious/spiritual person?**

1	2	3	4	5
Not At All		Moderately		Extremely

4. **Please rate the strength of your religious/spiritual beliefs.** (circle the correct response)

1	2	3	4	5
Not At All Strong		Moderately Strong		Extremely Strong

5. **How often do you participate in regular religious activities (attend church, synagogue etc.)**

1	2	3	4	5
Never		Sometimes		Frequently

6. **Are you:** (check the correct response)
Caucasian
Aboriginal
Asian-Canadian
African-Canadian
Other _____

7. **How many previous pregnancies have you had?** _____

8. **Do you plan to have children in the future?** (circle your response on the following scale)

1	2	3	4	5	6	7	8	9
Definitely Not				Maybe				Definitely

9. **How many children would you like to have?** _____

**Do You Have
Questions?**

Talk To Your Doctor

**A
BLOOD TEST
FOR
PREGNANT
WOMEN**

**Maternal
Serum
Screening**



Perinatal Education Program
Continuing Medical Education
& Professional Development
Continuing Nursing Education

December 2001

FL075

Maternal Serum Screening (MSS), a blood test for pregnant women, can provide some information about the health of your baby.

What is MSS?

- A blood test all pregnant women can have as part of their prenatal care.
- The results of the blood test can tell you about the chance of having a baby with spinal defects (open neural tube defects) and some chromosome abnormalities (Down syndrome, trisomy 18). These conditions are not common. They are described on the back of this pamphlet.
- It is your choice whether to have MSS. It will be done only if you want it.

How is MSS done?

- A small amount of blood is taken from your arm. This can be done between 15 and 18 weeks of pregnancy. The best time is 16 weeks.
- The amount of certain substances in your blood will be measured. These substances are made by the growing baby and the mother during pregnancy and are found in every pregnant woman's blood.
- The age of the baby must be known in order to interpret the blood test results. An ultrasound may be done at about the same time as the blood test, to help check the age of the baby.

What can the MSS result tell you?

- MSS is a screening test that can tell you about the chance of there being certain abnormalities of the unborn baby.
- If the results of the blood test show that the levels of the substances do NOT follow the common pattern, your baby may have a higher chance of having a spinal defect or a chromosome abnormality. This result is called a **risk above cut-off**.
- Most women with a **risk above cut-off** have babies who do not have these conditions. Further tests will be needed to show if the baby does have one of these conditions. Talk with your doctor about further tests. Make sure all your questions are answered.
- If the results of the blood test show that the levels of the substances follow the common pattern, the chance of your baby having one of these conditions is low. This result is called a **risk below cut-off**.
- 90% of women will have a **risk below cut-off**. However, even if the result is a risk below cut-off, MSS can miss Down syndrome, trisomy 18 or an open neural tube defect. There are also many conditions for which MSS does not screen.



What if the result is risk above cut-off?

- You can choose to have more tests to find out if the baby does have one of these conditions. You will be given choices about other tests.
- If there is an increased risk for Down syndrome or trisomy 18, you will be offered **amniocentesis**. During amniocentesis, a small amount of the fluid around the baby is taken and tested for Down syndrome or trisomy 18. Amniocentesis will cause a miscarriage in about one out of 200 women.
- If there is an increased risk for an open neural tube defect, you will be offered a detailed **ultrasound**. At the ultrasound, the head and back of the baby will be looked at. But, an ultrasound cannot see all cases of open neural tube defects. Amniocentesis might be offered when cases of open neural tube defects cannot be confirmed or ruled out with ultrasound.
- Most times the results of the ultrasound or amniocentesis will show that your baby does not have Down syndrome, trisomy 18 or an open neural tube defect.

What if the further tests show your baby has Down syndrome, trisomy 18 or an open neural tube defect?

- Your doctor will explain the test results and explain all your options to you. Knowing this information may help to plan your baby's delivery. Some women may choose not to continue the pregnancy. You will also have the chance to learn about the help that exists for children with Down syndrome, trisomy 18 and neural tube defects.

Open Neural Tube Defects

Open neural tube defects happen when the brain or spinal cord does not develop properly. Between 1 and 2 babies out of 1,000 are born with open neural tube defects. There are two kinds of open neural tube defects – spina bifida and anencephaly. The chance of having a baby with an open neural tube defect does not depend on the age of the mother.

Spina Bifida

In spina bifida, the bones of the spine are not fully joined. There may also be damage to the nervous system. Spina bifida causes physical and, sometimes, developmental disabilities. There is no way to predict how severe these effects will be. There is no cure, but treatment and support can help people with spina bifida.

Anencephaly

When a baby has anencephaly, the brain and skull do not grow completely. A baby with anencephaly will always die shortly after birth.

Chromosome Abnormalities

Chromosomes are carriers of genetic information. Down syndrome and trisomy 18 are chromosome abnormalities.

Down Syndrome

People with Down syndrome possess a wide range of abilities. All people with Down syndrome have a developmental disability. Some have added conditions that affect their health. There is no cure, but treatment and support can help people with Down syndrome.

Any woman at any age can have a baby with Down syndrome. About 1 in 800 babies is born with Down syndrome. The chance of having a baby with Down syndrome increases with a woman's age.

Trisomy 18

Trisomy 18 is associated with many physical abnormalities. Most infants with trisomy 18 die by one year of age.

About 1 in 8000 babies is born with trisomy 18. As with Down syndrome, the chance of trisomy 18 increases with a woman's age.

Appendix G. The manipulation check questions for the basic information pamphlet.

The following questions are based on the information presented in the pamphlet you have just read. Please circle your response to each of the questions presented below.

1. The maternal serum screening procedure is conducted by taking fluid from around the baby.
 - a. True
 - b. False
2. The maternal serum screening procedure poses a risk to the unborn baby.
 - a. True
 - b. False
3. The maternal serum screening procedure looks for spinal defects (open neural tube defects) and some chromosome abnormalities (Down syndrome, trisomy 18).
 - a. True
 - b. False
4. The results of the maternal serum screening procedure are 100% reliable.
 - a. True
 - b. False
5. A result indicating risk above cut-off means that the baby definitely has a spinal defect or chromosome abnormality.
 - a. True
 - b. False
6. If the results from a maternal serum screening test are risk above cut-off, further tests are needed to find out if the baby has an abnormality.
 - a. True
 - b. False
7. A result indicating risk below cut-off means that the baby definitely does not have a spinal defect or chromosome abnormality.
 - a. True
 - b. False
8. One in every 800 babies has Down syndrome.
 - a. True
 - b. False
9. People with Down syndrome have a wide range of abilities and personalities.
 - a. True
 - b. False

Please turn the page.

***Below are the correct answers to each of the questions you answered on the previous page.
Please take some time to review the correct answers.***

1. The maternal serum screening procedure is conducted by taking fluid from around the baby.
Correct answer: **False** The maternal serum screening procedure involves taking a small amount of blood from the pregnant woman's arm.

2. The maternal serum screening procedure poses a risk to the unborn baby.
Correct answer: **False** The maternal serum screening procedure does not pose a physical risk to the unborn baby. Follow-up prenatal diagnostic tests (i.e., amniocentesis) do pose a risk of miscarriage.

3. The maternal serum screening procedure looks for spinal defects (open neural tube defects) and some chromosome abnormalities (Down syndrome, trisomy 18).
Correct answer: **True**

4. The results of the maternal serum screening procedure are 100% reliable.
Correct answer: **False** The results of the maternal serum screening procedure are given as a statistical risk. As such, the results are not 100 % reliable. Most women with a result indicating risk above cut-off have babies who do not have these conditions.

5. A result indicating risk above cut-off means that the baby definitely has a spinal defect or chromosome abnormality.
Correct answer: **False** Most women with a result indicating risk above cut-off have babies who do not have these conditions.

6. If the results from a maternal serum screening test are risk above cut-off, further tests are needed to find out if the baby has an abnormality.
Correct answer: **True**

7. A result indicating risk below cut-off means that the baby definitely does not have a spinal defect or chromosome abnormality.
Correct answer: **False** 90% of women are given a result of risk below cut-off. However, even with this result, the maternal serum screening procedure can miss spinal defects and chromosome abnormalities. There are also many conditions for which maternal serum screening does not screen.

8. One in every 800 babies has Down syndrome.
Correct answer: **True** One in every 800 babies has Down syndrome. Although the chance of Down syndrome increases with maternal age, 80 percent of children with Down syndrome are born to women younger than 35 years old.

9. People with Down syndrome have a wide range of abilities and personalities.
Correct answer: **True** A popular generalization is associating people with Down syndrome as always loving, smiling, or happy. People with Down syndrome are not all alike – the diversity of personalities is similar to that of the general population.

What is Down syndrome?

Down syndrome is a naturally occurring chromosomal arrangement that has always existed and is universal across racial, gender and socio-economic lines.

One in every 800 babies has Down syndrome.

A person with Down syndrome has three copies of the 21st chromosome instead of two. The effects of this extra genetic material vary from person to person.

Down syndrome was named after John Langdon Down. Down syndrome is referred to as Down syndrome, not Down's syndrome. Unlike Lou Gehrig's disease (also known as ALS), John Langdon Down did not have Down syndrome – therefore it is not possessive, as in Down's.

People with Down syndrome often share some physical features, but this varies greatly between individuals. Individuals with Down syndrome will look like their family members and will have their own unique personality.

Although the chance of Down syndrome increases with maternal age, 80 per cent of children with Down syndrome are born to women younger than 35 years old. This is because younger women of childbearing age are more likely to have children than older women.

Down syndrome is not a disease, disorder or medical condition. It is wrong to refer to people with Down syndrome as "afflicted with" or "suffering from" it.

A popular generalization is associating people with Down syndrome as always loving, smiling, or happy. People with Down syndrome are not all alike - the diversity of personalities is similar to that of the general population.



Celebrate
About Down Syndrome






Canadian Down Syndrome Society

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Federally Incorporated January 1987
 Charitable Number 11883 0751 RR0001

*Canada's national voice for
individuals with Down syndrome*



Canadian Down Syndrome Society

Health Issues

Individuals with Down syndrome may have a greater incidence of certain health complications than the average person.

However, having Down syndrome does not guarantee the development of any particular health concern. Forty per cent of children with Down syndrome are born with a heart defect. Many of these heart defects repair on their own, while some do require surgery to correct the problem.

Babies with Down syndrome often have stomach and bowel problems. These usually appear right after birth and can be corrected surgically. Thyroid, vision and hearing problems are common in individuals with Down syndrome and are best treated if detected early. Appropriate medical care with proper detection and treatment for health concerns ensures the continued health for individuals with Down syndrome.

A little known fact is that having Down syndrome actually lessens a person's chances of developing certain illnesses or health complications, including many cancers. Ongoing research is investigating how this occurs. Again, there is no guarantee that these will not occur and preventative measures, early detection screenings and healthy lifestyles are still recommended.

Education and Learning

Down syndrome commonly results in an effect on learning style, although the differences are highly variable, just as physical characteristics or health concerns.

With assistance opportunities exist for effective methods of teaching each individual.

People with Down syndrome learn differently, but they do learn. As we find out more about how they learn and the best methods for teaching to their strengths, individuals with Down syndrome will likely learn more, faster and more efficiently.

The Canadian Down Syndrome Society believes quality inclusion is the best model for educating students with Down syndrome. Students with Down syndrome have the right to life-enhancing education experiences, which all children deserve. Diversity in the classroom enhances the learning, lives and citizenship of all students. Children with Down syndrome benefit from the experiences of learning with their peers in inclusive educational settings.

The Future

The Down syndrome community in Canada and the CDSS have made great strides since our founding in 1987.

We have seen advances in access to medical care, which enhance and save the lives of people with Down syndrome; life expectancy has more than doubled. Many people with Down syndrome live well into their 50s and 60s.

We have seen the benefits of early intervention programs, inclusion in school and work and the development of accessible resources for people with Down syndrome, families and the community.

Today, individuals with Down syndrome are going to post-secondary schools, working and getting married. People with Down syndrome are now given the opportunity to be fully contributing members of society.

Despite the great advances made, much more needs to be done. We need to ensure the inclusion of individuals with Down syndrome in their schools, communities and workplaces. Your support of the Canadian Down Syndrome Society will ensure this continues and allow us to speak for the 35,000 Canadians with Down syndrome.



Appendix I. The manipulation check questions for the expanded information pamphlet.

The following questions are based on the information presented in the pamphlet you have just read. Please circle your response to each of the questions presented below.

1. One in every 1500 babies has Down syndrome.
 - a. True
 - b. False

2. Down syndrome is a chromosomal abnormality which results in developmental disability.
 - a. True
 - b. False

3. People with Down syndrome have a wide range of abilities and personalities.
 - a. True
 - b. False

4. Integrating children with Down syndrome into schools can enhance the learning of all students.
 - a. True
 - b. False

5. Individuals with Down syndrome may have a greater incidence of health complications than the average person.
 - a. True
 - b. False

6. People with Down syndrome usually live to be around 30 years old.
 - a. True
 - b. False

7. It is impossible for people with Down syndrome to hold regular jobs.
 - a. True
 - b. False

Please turn the page.

***Below are the correct answers to each of the questions you answered on the previous page.
Please take some time to review the correct answers.***

1. One in every 1500 babies has Down syndrome.

Correct answer: **False** One in every 800 babies has Down syndrome. Although the chance of Down syndrome increases with maternal age, 80 percent of children with Down syndrome are born to women younger than 35 years old.

2. Down syndrome is a chromosomal abnormality which results in developmental disability.

Correct answer: **True**

3. People with Down syndrome have a wide range of abilities and personalities.

Correct answer: **True** A popular generalization is associating people with Down syndrome as always loving, smiling, or happy. People with Down syndrome are not all alike – the diversity of personalities is similar to that of the general population.

4. Integrating children with Down syndrome into schools can enhance the learning of all students.

Correct answer: **True** The Canadian Down Syndrome Society asserts that diversity in the classroom enhances the learning, lives, and citizenship of all students.

5. Individuals with Down syndrome may have a greater incidence of health complications than the average person.

Correct answer: **True** Heart defects, stomach and bowel problems, thyroid, vision, and hearing problems may all be more common in individuals with Down syndrome. Appropriate medical care with proper detection and treatment ensures the continued health for individuals with Down syndrome.

6. People with Down syndrome usually live to be around 30 years old.

Correct answer: **False** With advances in access to medical care, life expectancy of people with Down syndrome has more than doubled. Today, many people with Down syndrome live well into their 50s and 60s.

7. It is impossible for people with Down syndrome to hold regular jobs.

Correct answer: **False** Individuals with Down syndrome are going to post-secondary schools, working, and getting married. People with Down syndrome are now given the opportunity to be fully contributing members of society.

Please turn the page.

Appendix J. Frequencies of information reported as necessary for making informed decisions about MSS.

Category	MSS		
	Control <i>n</i> = 58 <i>f</i> (%)	Basic information <i>n</i> = 53 <i>f</i> (%)	Expanded information <i>n</i> = 52 <i>f</i> (%)
Risk	21 (36.2)	23 (43.4)	22 (42.3)
Accuracy	11 (19.0)	13 (24.5)	15 (28.8)
Info about test	15 (25.9)	8 (15.1)	11 (21.2)
Info about DS	14 (24.1)	5 (9.4)	11 (21.2)
Chance of DS	13 (22.4)	6 (11.3)	7 (13.5)
Benefits	3 (5.2)	9 (17.0)	4 (7.7)
Post-result options	6 (10.3)	6 (11.3)	2 (3.8)
Info from pamphlet	0	6 (11.3)	7 (13.5)
Relation to abortion	9 (15.5)	0	3 (5.8)
Doctor's opinion	1 (1.7)	7 (13.2)	3 (5.8)
Family's opinion	0	5 (9.4)	4 (7.7)
Support available	0	3 (5.7)	1 (1.9)
N/A, would accept	1 (1.7)	3 (5.7)	1 (1.9)
N/A, would not accept	4 (6.9)	0	0
Other	7 (12.1)	8 (15.1)	4 (7.7)

Appendix K. Frequencies of information reported as necessary for making informed decisions about amniocentesis.

Category	Control	Amniocentesis	
	<i>n</i> = 58 <i>f</i> (%)	Basic information <i>n</i> = 53 <i>f</i> (%)	Expanded information <i>n</i> = 52 <i>f</i> (%)
Risk	23 (39.7)	31 (58.5)	33 (63.5)
Accuracy	11 (19.0)	8 (15.1)	11 (21.2)
Info about test	19 (32.8)	14 (26.4)	13 (25)
Info about DS	15 (25.9)	3 (5.7)	7 (13.5)
Chance of DS	6 (10.3)	1 (1.9)	6 (11.5)
Benefits	0	6 (11.3)	4 (7.7)
Post-result options	3 (5.2)	4 (7.5)	2 (3.8)
Info from pamphlet	0	2 (3.8)	3 (5.8)
Relation to abortion	2 (3.4)	3 (5.7)	0
Doctor's opinion	0	4 (7.5)	3 (5.8)
Family's opinion	2 (3.4)	1 (1.9)	1 (1.9)
Support available	2 (3.4)	4 (7.5)	0
N/A, would accept	0	1 (1.9)	2 (3.8)
N/A, would not accept	1 (1.7)	1 (1.9)	0
Health of fetus	11 (19.0)	7 (13.2)	2 (3.8)
Other	3 (5.2)	1 (1.9)	3 (5.8)

Appendix L. Frequencies of information reported as necessary for making informed decisions about selective abortion.

Category	Control	Abortion	
	<i>n</i> = 58 <i>f</i> (%)	Basic information <i>n</i> = 53 <i>f</i> (%)	Expanded information <i>n</i> = 52 <i>f</i> (%)
Risk	12 (20.7)	6 (11.3)	10 (19.2)
Accuracy	0	6 (11.3)	2 (3.8)
Info about test	5 (8.6)	1 (1.9)	1 (1.9)
Info about DS	34 (58.6)	28 (52.8)	29 (55.8)
Doctor's opinion	1 (1.7)	2 (3.8)	1 (1.9)
Family's opinion	8 (13.8)	5 (9.4)	3 (5.8)
Support available	7 (12.1)	8 (15.1)	13 (25.0)
N/A, would abort	0	0	3 (5.8)
N/A, would not abort	16 (27.6)	10 (18.9)	12 (23.1)
Personal circumstances	5 (8.6)	4 (7.5)	3 (5.8)
Age of fetus	5 (8.6)	0	2 (3.8)
Other	5 (8.6)	2 (3.8)	3 (5.8)
