PRE AND POSTNATAL DOWN SYNDROME DETERMINATIONS: AN INVESTIGATION OF PAST EXPERIENCES AND POTENTIAL IMPROVEMENTS

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Abstract

The experience of receiving a Down syndrome (DS) determination in Canada has not been thoroughly explored. The purpose of this research project was to shed light on the experiences of Canadians receiving pre- or post- natal DS determinations in order to analyze the extent to which they align with best practice recommendations. Thirty-two narrative interviews were conducted with 42 participants (10 couples and 22 individuals). Participants relayed their story of receiving their child's or a prospective child's DS determination. Interviews were analyzed thematically with a focus on the explicit content of the participants' stories. Participants' stories often spanned from the time they were considering having children up to present day. Many parents and prospective parents relayed dissatisfaction with their determination experience. Experiences with prenatal screening suggested a lack of informed consent and subsequent difficulty interpreting the probabilities presented to them as a result of screening. Participants' stories illustrated that their care providers were often non-neutral, and applied implicit or explicit pressure about screening, testing, and termination decisions. When they received their determinations, participants tended to be dissatisfied with the duration of their consultations, dissatisfied with receiving the determination without their partner present, dissatisfied with the lack of up-to date information provided to them and dissatisfied with their care provider's communication skills for delivering the news. Participants reported being avoided by care providers when their baby was born and noted a lack of celebration upon the birth of their child. Parents also relayed stories about care providers whom they described as *"fantastic"*, *"great"* and *"lovely"*. Parents were satisfied with determinations that involved a neutral reassuring tone throughout which the baby was present and at the center of the discussion. Participants appreciated a thorough explanation of the indicators under consideration and their fallibility. They were satisfied with quiet, private, consultations wherein all of their questions were addressed, the next steps were explained, and the care provider stayed until it felt like there was a conclusion to their conversation and their questions. Most participants initially experienced negative emotional reactions to their child's determination. Many attributed their reaction to the lack of knowledge they had about DS and the lack of or superficial experience they had with people with DS. Several participants relayed that the most helpful information they received came from the provincial or national DS societies, but that this information often came late. A more formal relationship between support organizations and physicians who deliver the news could improve this flaw in the system. Since receiving their determinations, many participants looked back on their "journey" and framed it as simply "taking the scenic route". However, to frame all experiences in this way would be an oversimplification. The way that families are impacted by having a member with DS is likely influenced by child, family, and societal factors, all of which interact. Some families relayed significant challenges, which they believed the dominant narrative excludes. There is not one story of DS, and therefore the task of educating prospective parents about what life with DS will be like is challenging. The best way forward may be to present parents with a range of possibilities and help families evaluate these possibilities in the context of their own lives.

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Thank you to Tyson. I was told that grad school is the test of a relationship. We have since learned that trying to finish grad school during a pandemic with infant twins in the real test of a relationship. We're on the home stretch now.

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List of Abbreviations

DS	Down Syndrome
CDSS	Canadian Down Syndrome Society
CVS	Chorionic Villus Sampling
NIPT	Noninvasive Prenatal Testing
NSGC	National Society of Genetic Counselors
SDSS	Saskatchewan Down Syndrome Society
SOGC	Society of Obstetrics and Gynecology Canada
VATTA	Voices at the Table for Advocacy

Introduction

Estimates suggest that 67-92% of prospective parents who receive a fetal determination of DS choose to terminate their pregnancy (Mansfield, et al., 1999; Natoli, et al., 2012). This is a significantly higher prevalence than is typically found for several other prenatally determined fetal anomalies. Although there are a number of challenges associated with living with DS, the majority of individuals with DS report very positive evaluations of themselves and their lives (Skotko, et al., 2011a), parents of individuals with DS report high levels of pride and love for their child, (Skotko, et al., 2011b), and siblings of individuals with DS report that their life has been enhanced by their sibling with DS (Skotko, et al., 2011c). Parents of children with DS present levels of adjustment and wellbeing similar to parents of typically developing children and, frequently, higher wellbeing than parents of children with other intellectual or developmental disabilities (Corrice, & Glidden, 2009; Esbensen, & Seltzer, 2011; Glidden, et al., 2014; Hodapp, et al., 2001; Stoneman, 2007).

Even so, concerns about the quality of life for the unborn child (Korenromp, et al., 2007), perceived parental burden, and lack of perceived rewards in parenting a child with DS (Bryant et al., 2005; Korenromp, et al., 2007; Lawson, 2001; Lawson, 2006; Lawson & Walls Ingram, 2010) are cited as some of the most common reasons for ending a pregnancy with a prenatal DS determination. Therefore, there appears to be a discrepancy between the actual experience of parents of children with DS and what prospective parents envision. Perhaps prospective parents are making decisions to terminate their pregnancy based on stereotypes about DS and assumptions about parenting a child with DS, rather than on direct experience and knowledge. In line with this argument, previous contact with individuals with DS is associated with more favourable attitudes towards people with DS, more positive perceptions of parenting a child with DS, and a lower likelihood of intending to terminate a hypothetical pregnancy due to a DS determination (Lawson & Walls-Ingram, 2010).

Analyses of the information provided to individuals considering prenatal screening for DS or elective termination due to a DS determination find that it is typically medical and negative (Bryant, et al., 2001; Lawson, et al., 2012) and often focuses on a probabilistic description of the screening/testing process rather than a description of DS or life with DS (Williams, et al., 2002). The limited research available also puts forward that often, experiences of receiving a DS determination are negative (Buyukavci, et al., 2019; Guon et al., 2014; Hedov, et al., 2002; Nelson Goff, et al., 2013; Skotko, 2005a; Skotko 2005b; Wallace et al., 2018), with parents reporting dissatisfaction with both the lack of accurate information and the excess of negative information they received about DS (Buyukavci, et al., 2019; Guon et al., 2014; Hedov, et al, 2002; Nelson Goff, et al., 2013; Wallace et al., 2018). However, none of the available studies have been conducted in Canada[1], and therefore, the experiences of Canadians receiving determinations have not been thoroughly explored. The purpose of this dissertation was to gain an understanding of the experience of receiving a DS determination in Canada. This investigation can illuminate if experiences in Canada have been similar to those documented in other parts of the world, and the extent to which they align with best practice guidelines.

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[1] Seven percent of Wallace, et al.'s (2018) sample was Canadian. Otherwise, at the time of writing, no studies on this particular research question appear to have been conducted with a Canadian sample.

CHAPTER 1

AN INTRODUCTION TO DOWN SYNDROME, PRENATAL SCREENING, PRENATAL DETERMINATION, AND INFORMED DECISION MAKING

1.1 Genetic Etiology of Down Syndrome

DS is a genetic condition caused by the presence of extra chromosomal material associated with chromosome 21 (Canadian Down Syndrome Society, N.D.). DS is present in approximately 1 in 781 births in Canada (Canadian Down Syndrome Society, N.D.). Individuals with DS may experience the same medical issues as their typically developing peers but have an increased probability of experiencing certain medical conditions, including congenital heart disease, celiac disease, leukemia, hypothyroidism, diabetes, autism, visual and auditory impairments, seizures, and dementia in older age (Grieco, et al., 2015).

DS is characterized by a distinct phenotypic profile, which individuals with DS embody to varying degrees (Grieco, et al., 2015). Observational and social learning are typically strengths for children with DS and often manifest in strong social skills (Grieco, et al., 2015). Social development in individuals with DS usually advances in the same manner as in typically developing children (Grieco, et al., 2015). Their frequency of seeking out social interaction, frequency of positive facial expression, ability to imitate, and their frequent pro-social empathic behaviour supports the common descriptions of individuals with DS as charming, affectionate, funny, forgiving, and kind (Grieco, et al., 2015). Intellectual disability is one of the most prominent markers of DS (Constestabile, et al., 2010; Grieco, et al., 2015; Vicari, et al., 2005). Individuals with DS usually have Intelligence Quotient (IQ) scores ranging from 30-70 and averaging around 50, which indicates moderate to severe intellectual disability and represent the lowest 2.5% of the population (Vicari et al., 2005; Constestabile et al., 2010). Specific cognitive deficits may originate in attention, memory, and processing speed. Individuals with DS typically have difficulty with language skills, planning, organizing, inhibition, and self-monitoring (Grieco, et al., 2015). Regarding mental health, in younger populations they are less likely to experience psychopathology, but in older adulthood they are more likely to experience depression and comorbid social isolation, which are often considered markers of the prodromal phase of dementia (Burt, et al., 1995; Grieco, et al., 2015).

1.2 Experiences Living with Down Syndrome

Despite the clear challenges of living with DS, the vast majority of individuals with DS report that they are happy with their life (99%), they like who they are (97%), and they like how they look (96%) (Skotko, et al., 2011a). Parents of children with DS report that they are proud of their child (97%), that they love their child (99%), and that their other children get along well with their child with DS (95%) (Skotko, et al., 2011b). Siblings of children with DS report that they love their sibling (96%), they are proud of their sibling (94%), they are better people because of their sibling (88%), and they plan to remain involved in their sibling's life in adulthood (90%) (Skotko, et al., 2011c). Some qualitative studies suggest that problems people with DS face tend to stem more from negative attitudes and social barriers than from their genetic condition (Alderson, 2001).

The positive adjustment of parents of children with DS relative to parents of children with other intellectual/developmental disabilities has been so prevalent that it has been referred to as the "Down syndrome advantage" (Corrice, & Glidden, 2009; Esbensen, & Seltzer, 2011; Glidden, et al., 2014; Hodapp, et al., 2001; Stoneman, 2007). While some findings have suggested that the advantage can be attributed either solely or largely to confounds such as advanced maternal age or higher income, factors which are independently related to positive adjustment in parents (Blacher, & McIntyre, 2006; Corrice, & Glidden, 2009; Stoneman, 2007), others have suggested that although the DS advantage is small, it is consistent and can be attributed to higher functioning ability of individuals with DS, which contributes to higher wellbeing for caregivers (e.g. Corrice, & Glidden, 2009; Esbensen, & Seltzer, 2011). Although the debate about the nature of this advantage is ongoing (Corrice, & Glidden, 2009; Esbensen, & Seltzer, 2011; Flaherty, & Glidden, 2000; Glidden, et al., 2014), it is clear that the adjustment of parents of children with DS resembles the adjustment of parents of typically developing children more than it differs (Glidden, et al., 2010).

Although parents of children with DS do report certain difficulties more frequently than do parents of typically developing children, including that their children display more behavioral problems (Cuskelly and Dadds, 1992; Stores et al., 1998; Gau, et al., 2008), that they spend more time on caregiving activities (Erickson and Upshur, 1989; Pueschel, et al., 1991; Barnett & Boyce, 1995), and that a small proportion of them experience more stress, anxiety, and depression than parents with typically developing children (Noh et al., 1989; Sanders & Morgan, 1997; Padeliadu, 1998; Roach, Orsmond, & Barratt,1999; Gau et al., 2008), parents of children with DS also experience some relative self-reported benefits compared to parents of typically developing children. For instance, they are less likely to get divorced (Cunningham, 1996; Urbano & Hodapp, 2007) and they experience greater satisfaction with support from friends and community groups (Erickson & Upshur, 1989). They report similar levels of marital satisfaction (Noh, et al., 1989; Rodrigue, et al., 1992; Van Riper, et al., 1992); stress levels (Dumas, et al., 1991; Duis, et al., 1997; Stores, et al., 1998); family cohesiveness, adaptability, and communicativeness (Thomas & Olsen, 1993); and they have similar levels of confidence in their parenting skills (Rodrigue et al., 1992) as families with typically developing children.

1.3 Prenatal Screening and Testing for Down Syndrome

Although there are no statistics available on rates of elective termination for prenatal DS determinations in Canada, comparable statistics are available from other regions. In one systematic review of 20 studies from around world on the prevalence of selective termination for a number of fetal anomalies, approximately 92% of parents who received a fetal determination of DS chose to terminate their pregnancy (Mansfield, et al., 1999). This was a higher prevalence than was found for several other prenatally determined fetal anomalies encompassed in the same review including Spina bifida (termination rate of approximately 61%), Anencephaly (78%), Turner syndrome (71%), and Klinefelter syndrome (63%). Mansfield et al. found no difference between the rates of termination in the 1980s and 1990s suggesting that the prevalence of termination for these determinations was not decreasing. A more recent review of 24 American studies suggested that rate of termination for a DS determination in the U.S. was around 67% in the years 1995-2011 (Natoli, et al., 2012). However, these authors noted that there could be discrepant findings between their study and that of Mansfield et al., for a variety of reasons. First, it could have been that there truly are lower termination rates in the U.S.. Second, it could have been that termination rates are declining, as the Mansfield et al. study reviewed an earlier time period than did the Natolie et al., study. Third, younger women are being offered prenatal screening more than ever before, which could have increased the denominator of the prevalence equation, but not the numerator; more women (who may have no intention of terminating) are being offered the procedure, but no more are up-taking termination (because they never had an intention to). Taking these two large scale reviews together, the estimated rate of termination for DS ranges from 67-92%. As mentioned above, unfortunately no statistics exist for the Canadian context.

Although the exact methods and procedures for prenatal screening and testing for chromosomal anomalies vary by province and region, their fundamental features are consistent across Canada. First, although uptake is optional, offering prenatal screening to pregnant women is considered standard care across the country, as recommended by the Society of Obstetricians and Gynaecologists of Canada (SOGC; Chitayat, et al., 2011). The purpose of screening is to identify women in the general pregnancy population who have an increased probability of having a child with a chromosomal anomaly (Cartier et al., 2012). There are two broad categories of screening methods: maternal serum sampling, which is a measure of maternal biochemical markers in the pregnant woman's blood in the first and/or second trimester of pregnancy; and ultrasound screening, which measure first trimester nuchal translucency (thickness of tissue in the fetus's neck) and other markers in the first and/or second trimester of pregnancy (Cartier et al., 2012). The results become more accurate by using a combination of the methods.

The results of screening are presented to pregnant women as probabilities, such as a 1/100 or 1/400 chance of the baby being born with DS. Without considering screening markers, the incidence of DS is 1/800 births in the general pregnant population (Carson et al., 2010). The likelihood of DS increases with maternal age; for an average 35 year old pregnant woman, the probability of having a baby with DS is 1/385 (Carson et al., 2010). This is a population-based probability assessment method; a 1/385 probability means that for every 1 woman with particular marker levels carrying a fetus that would be born with DS, there are 384 women with the same marker levels carrying a fetus that would not be born with DS. Different regions in Canada have different screening probability thresholds for which they recommend considering further testing. In Saskatchewan for instance, if the markers suggest a probability higher than 1/385, consideration of further testing is recommended. A positive screening result (one that is at or above the regionally determined threshold) may provide an older woman with a probability assessment lower than the probability associated with her age alone. Likewise, the screening may assess a younger woman's chances as greater than that indicated by her age alone, although they still may not pass the regionally determined threshold to be considered a positive screen (Cartier, et al., 2012).

A corollary of screening being a population-based method is that for any individual pregnancy a screening result might not correspond with the fetus's DS status. That is, a positive screen does not mean the baby will be born with DS, and a negative screen does not mean the baby will not be born with DS (or any other health or social anomalies for that matter). The accuracy of the screening methods depends on the combination of methods used and the age of the pregnant woman. While detection rates (the rate at which the screen correctly identifies a fetus with DS) range from 87-100%, false positive rates (the rate at which the screen incorrectly suggests that baby will have DS when it actually will not) range from 4-44% (Perinatal Services BC, 2020).

Upon a positive screen, women are recommended to consider invasive deterministic testing. The two primary types of testing are amniocentesis (widely available) and chorionic villus sampling (CVS, available at certain specialized centers; Cartier et al., 2012; Carson et al., 2010). Amniocentesis involves the insertion of a needle through the pregnant woman's abdominal and uterine wall into the amniotic sac with the purpose of removing amniotic fluid, which is tested for DS indicators (Chodirker et al., 2001). CVS involves the insertion of either a transabdominal needle or a transcervical catheter with the purpose of obtaining a sample of chorionic villus tissue from the placenta, which is tested for DS indicators (Chodirker et al., 2001). As well as the increased probability of negative outcomes for the pregnant woman including bleeding, cramping, infection, and amniotic fluid leakage (Perinatal Services BC, 2016), amniocentesis involves a risk of miscarriage of between .6-1.0 in 100 (Cartier, 2012), and chorionic villus sampling of 1.0-2.0 in 100 (Perinatal Services BC, 2016).

Currently, a new type of procedure referred to as noninvasive prenatal testing (NIPT) is becoming more widely available across Canada and the world (Langlois et al., 2013; Ravitsky, 2015). This is a maternal blood test in which extracellular fetal DNA circulating freely in maternal plasma is analyzed (Ravitsky, 2015). Despite its name and the fact that it has a DS detection rate of 99.2% and a false positive rate of .09, in 2015 it was still considered a screening procedure in most parts of the world, and invasive tests were recommended following a positive result (Ravitsky, 2015). Although NIPT is available at personal cost across Canada, at the time of writing, provinces differed in whether their health care programs covered the cost of the test. Those that did required pregnant women meet certain criteria (e.g., have a positive screen by other methods; have had a previous child with DS) (Morrison, Armour, Allanson, & Carroll, 2016).

It is anticipated that NIPT will generate a number of benefits but also change or intensify some of the challenges and controversies surrounding prenatal testing and determination

(Ravitsky, 2015). Some of the anticipated benefits of NIPT include: increased reliability compared to other screening procedures; earlier results (first trimester versus second for some of the other screening procedures); increased access to testing (less expertise and cost of testing); increased ease, comfort, and safety for the pregnant woman; and less chance of miscarriage (Ravitsky, 2015). The most touted benefit is a reduced number of invasive procedures; it is expected that women who receive positive screens who previously would have continued on to invasive procedures will now or soon be able to opt for NIPT, the result of which may be negative, resulting in fewer women going forward with invasive procedures. In Canada, specifically, one estimate suggested that the introduction of NIPT could reduce the number of amniocenteses performed per year from 10, 000 to 300 and consequently reduce the number of amniocentesis-related miscarriages from 70 to 1 (PEGASUS, N.D.). Other potential benefits include reduced cost for the health care system as the number of invasive procedures decline and, eventually, elimination of invasive procedures altogether if the reliability rates of NIPT increase as they are projected to (Ravitsky, 2015).

The social and ethical implications of prenatal screening and testing have been passionately debated and the introduction of NIPT seems to only intensify the relevant arguments. Advocates argue that prenatal testing is a tool for informed decision making and enhances women's reproductive autonomy (Ravitsky, 2015). However, for women to make autonomous, informed decisions they need to have relevant information about the tests and the condition being tested for, which relies on competent, neutral counseling from health care practitioners, which to date, has been lacking (Skotko, 2005a; Nelson Goff, et al., 2013) (more discussion to follow). The anticipated routinization of NIPT also raises concerns about the erosion of informed consent for screening and testing procedures. Evidence suggests that physicians may consider counseling and consent procedures to be less important, and subsequently less rigorous for NIPT as it does not carry the procedure-related risks of invasive methods (Ravitsky, 2015; Silcock, et al., 2015; van den Heuvel et al., 2009). The routinization may also make women feel more pressure to undergo the tests which may make them feel or be perceived as more responsible for the birth of a child with a disability and less deserving of social, health, or financial supports (Ravitsky, 2015). Finally, prenatal testing has been criticized as fostering eugenic attitudes in society, contributing to stigmatization of and discrimination against individuals with disabilities (Benn & Chapman, 2010; Farrimond & Kelly, 2013;

Kellogg, et al., 2014; King 2011; Ravitsky, 2015; Vanstone, et al., 2014). Voices at the Table for Advocacy (VATTA), a group of Canadian individuals with DS, has made a short film (VATTA, 2014) about their concerns about prenatal testing, the impact it has on them, and the impact it has and might have on the DS community.

1.4 Factors Associated with Elective Termination

A number of demographic factors are associated with a preference for prenatal testing and elective termination. Higher religiosity is associated with less of a preference to pursue prenatal testing (Lawson, 2001) and less preference to terminate a pregnancy due to a DS determination (Bell & Stoneman, 2004; Bryant, et al., 2005; Lawson, 2001; Lawson 2006; Leung, et al., 2004). Evidence regarding the association of maternal age is mixed (Bryant et al., 2005; Quadrelli, et al., 2007). While some findings (Bryant et al., 2005), have suggested that mothers who would consider terminating a pregnancy due to DS were on average 6.8 years older than those who would not, others (Quadrelli et al., 2007) have suggested that women who terminate a pregnancy due to a DS determination are, on average, 4.3 years *younger* than those who continue their pregnancies. Others (Hawkins, et al., 2013) suggested that maternal age is unrelated to the decision.

Beyond demographic factors, concerns about the quality of life for the unborn child are cited as some of the most common reasons for ending a pregnancy because of a prenatal DS determinations (Korenromp, et al., 2007). These concerns include a doubt that the child would ever be able to function independently (92% of respondents), considering the "abnormality" too severe (90%), considering the burden for the child to be too heavy (83%), worrying about the care of the child after their and their partners' death (82%), considering the uncertainty of the disability too high (78%), and considering the level of respect for children with disabilities in our society to be too low (45%), which highlights perceived society-level prejudice towards disabilities. Inversely, continuing a pregnancy with DS is more likely when the decision maker believes they have social support in parenting a child with DS (Lawson, 2006) and when they have higher knowledge about available services for individuals with disabilities (Roberts, et al., 2002).

Other reasons for termination might include perceived parental burden and higher costs of parenting a child with DS (Bryant et al., 2005; Korenromp, et al., 2007; Lawson, 2001). Time commitment, financial expense, and emotional toll were the most salient perceived costs in a community sample (Lawson, 2001). In a sample of women who had terminated a pregnancy due to DS, 73% cited the anticipated burden on their other children, 64% named the burden on themselves, and 55% suggested that burden on their relationship with their partner were reasons they ended their pregnancy (Korenromp, et al., 2007). Only six percent of this sample mentioned financial burden as reason for termination. For women who had a sibling with DS, perceived difficulty of raising a child with DS was the main predictor of considering terminating a pregnancy due to a DS determination (Bryant et al., 2005). Other research has suggested that fewer perceived rewards, but not higher perceived costs are associated with terminating due to DS (Lawson, 2006; Lawson & Walls Ingram, 2010).

Attitudes towards people with DS are associated with both hypothetical and actual decisions to terminate a pregnancy with a DS determination (Bryant, et al., 2010; Bryant, et al., 2011; Lawson, 2006). For women who are pregnant, more positive attitudes towards people with DS earlier in a pregnancy predict a lower likelihood of both engaging in testing for DS later in the pregnancy and terminating based on a positive test result (Bryant, et al., 2010). In community samples, negative attitudes towards people with DS are also associated with a likelihood of terminating a hypothetical pregnancy (Lawson, 2006). Pregnant women who have ambivalent attitudes towards DS are more likely to uptake screening, but less likely to be sure about their termination intentions (Bryant, et al., 2011). Negative attitudes towards people with DS and people with disabilities in general, can also be observed in samples of women who terminated a pregnancy because of a DS determination, one in which 63% cited "simply not wanting a disabled child" as a reason for their pregnancy termination (Korenromp, et al., 2007).

The nature of previous experiences with individuals with disabilities is also predictive of termination decisions. Directly aligning with contact theory, which states that high quality contact counters stereotypes and prejudices, but low quality contact may actually foster them (Pettigrew & Tropp, 2006), higher quality or positive previous contact with individuals with DS is associated with more favourable attitudes towards people with DS, more positive perceptions of parenting a child with DS, and a lower likelihood of intending to terminate a hypothetical pregnancy due to a DS determination (Lawson & Walls-Ingram, 2010). Furthermore, individuals considering terminating an actual pregnancy due to a fetal anomaly draw on experiential knowledge about people with disabilities and parenting a child with disabilities when making these decisions (France, et al., 2012). These individuals draw on their own experiences with the specific disability and with other disabilities in general to make these decisions. That is, when considering a prenatal determination for DS, they may draw on their experiences with children or parents of children with spina bifida or autism, or both, for example. Presumably, they imagine that there are similarities in experiences of caring for a child with any disability and that these experiences can inform them about their potential future with a child with a specific disability. Women who have little personal experience with disability also report seeking out information from experiences of acquaintances to inform their decisions (France, et al., 2012).

1.5 Information about DS Currently Provided by Health Care Practitioners

Women and couples considering screening, testing and termination are supposed to be provided with information to help to fill gaps in their knowledge about DS and parenting a child with DS. Information presented to prospective parents about DS usually takes the form of an informational pamphlet (Williams, et al., 2002), is overwhelmingly medical in nature (89-91%), and either negative or neutral in valence (88-97%), but rarely positive (3-12%) (Bryant, et al., 2001; Lawson, et al., 2012). In a number of these types of pamphlets, no descriptive information about DS is provided (Bryant et al., 2001), and the focus is simply a description of the screening process (Williams et al., 2002). A minority of pamphlets (0-5%) include information on the psychosocial aspects of living with DS or parenting a child with DS (Bryant et al., 2001; Lawson et al., 2012). Further, health care practitioners have stated that they rely on these types of pamphlets to inform their patients due to their own lack of knowledge about or experiences with people with DS (Williams et al., 2002).

The limited research on parents receiving prenatal (and postnatal) DS determinations suggests that the experiences are often negative (Buyukavci, et al., 2019; Guon et al., 2014; Hedov, et al., 2002; Nelson Goff, et al., 2013; Skotko, 2005a; Skotko 2005b; Wallace et al., 2018). In a Swedish study (Hedov, et al, 2002), parents reported dissatisfaction with the duration of their determination consultations and suggested they would have liked longer uninterrupted meetings in which they could ask more questions. Seventy percent of parents reported that they did not feel satisfied with the amount or type of information about DS they received in their consultations. They reported that they received too much negative information about DS, a lack of written information about DS, and that their informant seemed to lack basic knowledge about DS and have poor communication skills for delivering the news. A study in Turkey found similar results, with most mothers reporting that DS was framed negatively, that they did not receive detailed information about the condition, and that care providers spent less than five minutes informing them about the determination (Buyukavci, et al., 2019).

Although no similar studies have been conducted in the Canadian context[2], researchers in the United States have found similar results. Women report that they are not counselled on quality of life issues for people with disabilities or the positive and negative aspects of having a child with a disability (Roberts, et al., 2002). Mothers report that physicians tend to emphasize the negative aspects of the condition, deemphasize the positive, and imply or explicitly state that the birth of a baby with DS is a regrettable happening (Skotko 2005b). Care providers often focus on "lethality of the condition, morbidity and burden," (Wallace et al., 2018, p. 660), themes which do not align with the lived experience of most parents of children with DS (Guon et al., 2014). Mothers are often dissatisfied with receiving the determination without their partner present, with the lack of up-to-date printed materials provided to them, and with not receiving contact information of other parents of children with DS with whom they could discuss their experiences (Skotko 2005b). They also report that the materials they were provided emphasized the negative aspects of DS (Skotko 2005b), that for prenatal determinations they felt rushed to make a decision about continuing the pregnancy (Skotko, 2005a), and that they were not provided with enough information to make an informed choice (Wallace et al., 2018). In one US study, researchers compared experiences of receiving a determination prenatally versus postnatally (Nelson Goff, et al., 2013). They found that parents receiving the results prenatally had slightly more negative experiences, but that both groups reported dissatisfaction with the lack of accurate information about DS they received as well as the lack of compassion and support they received from their health care providers. Those who received the determination prenatally reported feeling pressured by their health care provider to terminate the pregnancy, a finding which is common (e.g. Guon et al., 2014; Wallace et al., 2018).

One might question if perhaps the experience of receiving any unexpected determination, such as a pre- or post-natal DS determination, is inevitably somewhat dissatisfactory. Cunningham and colleagues (1984) examined this hypothesis, comparing a control group who received standard determination procedure to patients receiving a model determination delivered: 1) by a physician, 2) as soon as possible, 3) with the other parent present, 4) in a private place, 5)

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[2] Seven percent of Wallace, et al.'s (2018) sample was Canadian. Otherwise, at the time of writing, no studies on this particular research question appear to have been conducted with a Canadian sample.

with the infant present, 6) with as much time as needed for questions, 7) with the indication that a specialist would talk to the parents again as soon as they wanted, 8) with provision of a private place for the parents directly after the conversation, and 9) with the indication that a follow-up interview with the pediatrician would be arranged within a day. They found that 100% of mothers in the model determination condition but only 20% of mothers in the control group were satisfied with their determination experience.

Moreover, studies of parents or prospective parents receiving DS determinations demonstrate they are not invariably or totally dissatisfied with their determinations. Participants in previous studies have reported that certain care provider characteristics can make the experience more positive. For example, parents and/or prospective parents appreciate when care provides can read emotions accurately and respond with empathy (Lafarge et al., 2020). Participants in other studies have recounted experiences with special care providers who offered accurate and comprehensive information, did not pressure them to terminate the pregnancy, provided balanced and personalized counseling, and provided appropriate hope about the uncertainty of the child's birth and life span (Guon et al., 2014). Taken together, these results suggest that although many experiences receiving DS determination have been negative, they need not be.

Advocates and researchers have thus argued that more "balanced information" and better behavioural procedures are needed in advance of prenatal screening, and upon receiving the results of a prenatal determination in order to promote more informed decision making and more positive experiences with health care provision (France et al., 2012; Grant & Flint, 2007; Guan et al., 2014; Lawson & Walls-Ingram, 2010; Roberts, et al, 2002). Certain characteristics have been cited as important aspects of balanced information. The positive and negative aspects of parenting a child with a disability (Lawson & Walls-Ingram, 2010; Roberts et al., 2002), in particular detailing the rewards of parenting a child with DS (Lawson & Walls-Ingram, 2010), have been highlighted by some researchers, in addition to information about the services and supports available for people with disabilities and parents of people with disabilities (Roberts et al., 2012), potential medical issues, and quality of life issues (Williams, et al., 2002).

Some researchers have suggested that the balanced information should specifically highlight people's experiences with disability and parenting a child with disability (France et al., 2012; Williams et al., 2002), as this is the information that people seek when making termination decisions (France et al., 2012). Others suggest that the source of balance should come from an actual frequency equilibrium in valence (i.e., equal numbers of positive, negative and neutral statements) for both the content of the message and the tone (Bryant, et al., 2001). Disability advocates also suggest that the language used when presenting information needs to be chosen carefully, as terminology focussing on deficits such as *disorder*, *abnormality*, or *risk* may contribute to negative perceptions of the condition when alternatives such as *difference* or *probability* can convey the meaning without the negative connotation (Grant & Flint, 2007). They also argue that *determination* may be a more value neutral, and therefore appropriate, term than *diagnosis* when referring to the results of prenatal tests.

In the United States, the National Society of Genetic Counselors (NSGC; Sheets et al., 2011) has listed a number of essential components of the information that expectant parents should be provided upon receiving a pre or postnatal determination of DS (See Table 1.1). These pieces of information have been suggested to be the most vital based on input from parents of children with DS and genetic counsellors (Sheets, et al., 2011). Although parents and genetic counsellors had fairly high consensus on these descriptive information pieces, they did differ somewhat in the importance of some issues; parents valued information about the abilities and potential of people with DS more than clinical features.

Finally, some have argued that although the notion of balance in a description of DS or parenting a child with DS is theoretically desirable, it may be practically impossible, as the experiences of those with DS or their parents are extremely varied (Ahmed, et al., 2007; Hippman, et al., 2012). Hippman and colleagues (2012) argued that, instead, it would be more helpful to explore the range of possibilities regarding the family experience of raising a child with DS (i.e., discuss the experiences of a variety of individuals and families that have been entirely positive, entirely negative, and variety of mixed experiences) and help families evaluate these possibilities in the context of their own lives.

In addition to these informational pieces, best practices in behavioural protocol for delivering the determination have been outlined (Sheets, et al., 2011; Skotko, Capone, et al., 2009; Skotko, Kishnani, et al., 2009). The protocol involves a number of behavioural recommendations including use of neutral language (e.g., avoidance of negatively framed statements about DS such as “I’m sorry to inform you…”; referring to children or individuals

Table 1.1 Essential information for the initial discussion of a determination of Down syndrome

DS is caused by extra genetic material from chromosome 21. DS may be suspected based on physical findings, but the determination is confirmed by chromosome analysis.

Individuals with DS have a variable range of intellectual disability from mild to moderate.

Babies with DS have delays in achieving developmental milestones and benefit from early intervention including physical, occupational and speech therapy.

80% of babies with DS will have hypotonia.

50% of babies with DS have one or more congenital anomoly: 40—60% of babies with DS have a heart defect and 12% have a gastrointestinal defect that may require surgery. Assistance with referrals to specialists is appropriate for identified complications.

Children with DS are more like other children than they are different.

Raising a child with DS may involve more time commitment than typical children.

Individuals with DS can participate in community sports, activities, and leagues.

Individuals with DS can learn in a special education class or may be included in regular classes, and most can complete high school.

Individuals with DS can be employed competitively or in a workshop setting.

Individuals with DS can live independently or in a group home.

Individuals with DS have friends and intimate relationships.

Life expectancy extends into the 50s or 60s.

Information on local support groups, advocacy organizations, early intervention centers, printed material, fact sheets, books, specialist referral(s) as needed, and the option to contact a family raising a child with DS should be offered.

A personalized recurrence risk for future pregnancies should be offered.

Source: Sheets et al., 2011

with DS rather than “Down syndrome children”), provision of information including contact information for support groups, up-to-date printed material such as fact sheets and books, and the opportunity to meet with families who are raising a child with DS, those who have chosen to create an adoption plan, and/or those who have terminated a pregnancy (Sheets, et al., 2011).

In addition, protocol specifically for prenatal screening and determinations includes that: 1) the health care provider clearly describe the difference between screening and testing; 2) upon positive screening, health care providers should inform the patient that if DS is determined via testing their options include terminating the pregnancy, continuing the pregnancy and raising the baby, or placing the baby up for adoption after the birth; 3) when a definitive DS determination occurs, the news should be delivered by health care providers with the most knowledge about DS and who have received specific training on how to deliver sensitive determinations; 4) the news should be delivered in a personal visit or, if necessary, a phone call at a predetermined time; 5) health care providers must provide information about what DS is, medically and socially, including realistic expectations for children with DS today; 6) they should offer an up-to-date balanced bibliography of resources on DS; and 7) they should be offered follow-up meetings with themselves and other relevant health care providers (Skotko, Kishnani, et al., 2009).

For post-natal determinations all relevant recommendations from above apply, as well as: 1) the team should coordinate to ensure that the individual on the team who is most informed about DS be the one to deliver the results, 2) health care providers should inform patients as soon as they suspect DS, even if the definitive test has not been conducted, 3) the determination should be delivered in a private room, 4) parents should be informed together, 5) the infant should be present and referred to by name, 6) health care providers should begin the conversation with positive words such as “congratulations on the birth of …” and avoid language conveying pity or personal opinions, 7) for the first conversation, discussion of medical conditions should be limited to those that the infant is suspected of having, and 8) the care provider should provide contact information for local support groups and community services (Skotko, Capone, et al., 2009).

Regarding best practices, specifically in Canada, the SOGC has published counselling considerations for prenatal genetic screening (Cartier, et al., 2012). These considerations contain extensive direction in how to explain screening results in terms of probabilities and (e.g., what is positive predictive value, what is negative predictive value, what is the screen positive rate) and emphasize a number of times that the heath care provider relay the information that a positive screen does not mean the fetus has DS and that a negative screen does not necessarily guarantee the fetus does not have DS or is otherwise healthy. They also state that it is a myth that screening and testing are only offered for patients who would choose to terminate their pregnancy upon receiving a DS determination, and that counselling and referrals to the Canadian Down syndrome society as well as other support services will be provided if patients choose to continue the pregnancy. Although the authors stated:

> *It is important for women to understand that if a determination of Down syndrome or other anomaly is made, further consultation and support will be available to help her decide whether to continue or terminate the pregnancy. Women and families may require more information about what trisomy 21 is and about the possible health implications and long-term outcomes for people with this condition* (p. 493),

the counselling guidelines themselves provide no guidance for discussing what life is like for individuals with DS or parents of individuals with DS.

1.6 Informed Decision Making

Implicit in the calls for balanced information is the principle of informed choice or informed decision making. The general assumption about providing balanced information is that individuals are able to consider that information and make a rational decision between alternatives based on that information. A variety of definitions of informed choice have been proposed (see Table 1.2). Most of these definitions involve receiving information about the issues, deliberating the pros and cons of different outcomes, and making a decision that is consistent with one's own values. However, the definitions appear to vary in their specificity. Some suggest the decision should simply be "informed" (O'Connor, 1995), while others (e.g. Briss et al., 2004) specifically outline what an individual must understand in order for a decision to be deemed informed. For some, the level of knowledge an individual is expected to ascertain is formidable; to be deemed informed it is required the decision maker "understands the nature of the disease or condition being addressed; understands the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties" (Briss et al. 2004, p. 68). Others (e.g. van der Berg et al., 2004) are less specific, but nonetheless suggest that in order to be considered informed, the decision must be "based on sufficient knowledge about the relevant aspects of the alternatives" (p. 110).

Table 1.2. Definitions of informed decision making

Author	Definition
Summers (1994)	"Informed choice or decision making generally involves three components: information, comprehension, and voluntary choice." (p. 1689)
O'Connor (1995)	"…'effective' decisions, defined as informed, consistent with personal values, and acted upon" (p. 25)
Entwistle, et al., (1998)	"Evidence-informed patient choice involves providing people with research-based information about the effectiveness of health care options and promoting their involvement in decisions about their treatment. (p. 196)
Bekker, et al., (1999)	"An informed decision is one where a reasoned choice is made by a reasonable individual, using relevant information about the advantages and disadvantages of all the possible courses of action, in accord with the individual's beliefs." (p. 1)
Marteau, et al., (2001)	"An informed choice is one that is based on relevant knowledge, consistent with the decision-maker's values and behaviourally implemented." (p. 100)
Kohut, et al., (2002)	"Unlike the discrete event of an informed consent prior to a medical intervention, informed choice is considered *a process* of decision-making, which evolves through the evaluation of information and personal values…" (p. 266, emphasis added)
Green, et al., (2004)	"A decision is said to be informed when the relevant information about the advantages and disadvantages of all the possible courses of action is evaluated in accord with the decision-maker's beliefs, in order to reach a decision and take steps to make a choice." (p. 54)
Briss, et al., (2004)	"…defined informed decision making (IDM) as occurring when an individual understands the nature of the disease or condition being addressed; understands the clinical service and its likely consequences, including risks, limitations, benefits, alternatives, and uncertainties; has considered his or her preferences as appropriate; has participated in decision making at a personally desirable level; and either makes a decision consistent with his or her preferences and values or elects to defer a decision to a later time." (p. 68)

Rimer, et al., (2004)	"Informed decision making occurs when an individual understands the disease or condition being addressed and also comprehends what the clinical service involves, including its benefits, risks, limitations, alternatives, and uncertainties; has considered his or her own preferences, as appropriate; believes he or she has participated in decision making at a level that he or she desires; and makes a decision consistent with those preferences." (p. 1216)
van den Berg, et al., (2006)	"An informed choice is based on sufficient knowledge about the relevant aspects of the available alternatives... is consistent with the decision maker's values…[and involves] a process of deliberation about the alternatives" (p. 110)

Another point of departure between some of the definitions is that some (e.g. Bekker et al., 1999; van den Berg et al., 2006) suggest a choice must be deliberated or "reasoned" in terms of the pros and cons in order to be considered informed, while others (e.g., Marteau et al., 2001) do not explicitly mention the deliberation process as essential. Those that argue for its inclusion suggest that it is essentially implicit in other definitions as an informed choice necessarily refers to the outcome of a decision, and a decision necessarily involves deliberation (van den Berg et al., 2006). Finally, the variety of definitions differ by whether or not they consider behavioural implementation integral to the concept of informed choice. O'Connor (1995) explicitly stated that a decision must be "acted upon" (p. 25) in order to be considered a decision, and Marteau et al. (2001) outlined that a choice must be "behaviourally implemented" (p. 100). Although the reason behind including this component of the definition has not been explicitly stated, it may have been included because it could be argued that if one has not acted out the behaviour of choosing (either electing to do or not to do something) a choice has not yet been made.

There are strengths and weaknesses of each of these conceptual approaches to the definition of informed decision making. They have implications for measurement and outcomes in terms of numbers of individuals who would be considered informed. Some definitions may set a less demanding criterion for being considered informed. For example, Marteau et al.'s (2001) criteria in which the choice must be based on relevant knowledge, be consistent with the decision maker's values, and be behaviourally implemented is easier to satisfy than the criteria that involve an individual understanding *every relevant aspect* of the test and condition being tested for (e.g. Briss et al., 2004). It may be debateable whether under such exhaustive definitions very many individuals would ever be considered truly informed. However, simply because it is a difficult test to pass does not indicate it is an invalid definition of the construct.

One consistent aspect of all the definitions is the “value-consistent” criterion. That is, for a choice to be considered informed it must be consistent with the decision maker’s values. Value clarification is an oft-cited subcomponent of the informed choice process. Indeed, individuals who make a choice that they believe to be in line with their values experience higher levels of perceived decisional effectiveness (O’Connor, 1995). However, this definition precludes the possibility that there may be other factors beyond one’s personal values that influence their decisions, such as social norms and/or implicit or explicit pressure from significant others. As mentioned above, the definitions of informed choice are based on a rational choice model, in which the decision maker is assumed to be autonomous. They are expected to be able to weigh the pros and cons of a decision and make a choice that maximizes benefits and minimizes harms in line with their own personal values. However, “women do not make reproductive decisions in a vacuum” (Lawson & Pierson, 2007, p. 241). Women’s decisions are rarely fully autonomous, and are constrained by socio-political-cultural factors (Lawson & Pierson, 2007). This weakness in the rational choice model leads to two implications. First, although the notion of an informed choice including a value consistent decision may be desirable for women’s wellbeing, theoretically a choice can be made that is fully informed yet constrained by factors beyond personal values. Thus “value consistency” is theoretically a poor criterion for an “informed choice”, but is arguably a valid indicator of an autonomous choice and decisional satisfaction. Second, in order to fully understand women’s reproductive decision making, factors in women’s proximal and distal social contexts need to be examined in addition to individual level factors.

Actors in one’s proximal social context could include family, friends, peers, and health care providers. For example, variations in physicians’ characteristics are related to uptake of maternal serum screening (Carroll, et al., 1997; Chandra, et al., 2003; Woodward et al., 1997), suggesting that they have an influence on women’s decision making. Further, women considering prenatal testing identify physicians and their spouses as the most important individuals from whom they need support for their decisions and higher support from these sources predicts higher decisional wellbeing for the women (Wohlgemuth & Lawson, 2005). Higher perceived social support has also been found to be related to higher perceived personal autonomy in decision making.

Factors in the distal social context could include social norms, media framing, and governmental and medical policies. For instance, disability advocate groups argue that the prevalence of prenatal testing in and of itself indicates and perpetuates a social norm whereby having a child with a disability and being a person with a disability is viewed as undesirable by framing it as a disorder, a defect, or an abnormality rather than one of many variations on the human experience (e.g. Grant & Flint, 2007). Some have gone as far as to argue that prenatal testing perpetuates a norm in which children are constructed as "consumer objects subject to quality control" (Lippman, 1991, p. 23); as many conditions that are screened or tested for have no cures or treatments, the decision following prenatal testing is necessarily a "go or no-go" choice about if they will take this child, or if they would rather keep trying for a better "deal".

Empirical evidence lends support to the notion that more distal social forces such as social norms have an effect on women's decision making. As mentioned above there is evidence to suggest that prejudice and negative attitudes towards people with disabilities are related to decisions to terminate a pregnancy with a DS determination (Bryant, et al., 2010; Bryant, et al., 2011; Lawson, 2006). Negative societal attitudes towards people with DS and people with disabilities in general can also be observed in samples of women who terminated a pregnancy because of a DS determination, one in which 63% of participants cited "simply not wanting a disabled child" as a reason for their pregnancy termination (Korenromp, et al., 2007). This kind of explicit comment wherein individuals categorically state an aversion to parenting a "type of child" arguably conveys a social norm whereby that unconcealed aversion is socially acceptable.

Further evidence of the strength of influence from women's proximal and distal social contexts in which women make decisions about prenatal testing is suggested by one study in which 75% of participants reported that it would be too difficult to decline testing if a physician recommended it and 78% believed that they would not receive sympathy or social support if they gave birth to a child with a disability after not complying with a testing referral or choosing to continue a pregnancy despite positive test result (Gates, 1993). In these situations, an individual's ability to make choices based on their personal values and beliefs is constrained by their socio-political-cultural context. Accordingly, an addition to the rational choice models of informed decision making could include measures of an individual feeling supported as autonomous in their proximal and distal social context regardless of the choice they make in the face of a determination.

Primary factors in the decision maker's distal social context may include societal level ignorance and prejudice. The general public typically has a limited awareness of intellectual disability and limited understanding of what intellectual disability is (Scior, 2011). People with intellectual disabilities are frequently considered the least desirable group of people with whom to have contact (Gordon, et al., 2004; Nagata, 2007; Westbrook, et al., 1993). Social contact with them is viewed as less desirable than contact with individuals with physical disabilities (Brown, et al., 2011; Katz, et al., 2000), although still more desirable than contact with individuals with severe mental illness (Lau & Cheung, 1999; Saetermore, et al., 2001; Sigelman, 1991). Further, the more severe the intellectual disability, the more negative attitudes seem to be (Antonak, et al., 1995; Weller & Aminidav, 1992). Negative attitudes are also associated with false beliefs about the capabilities of people with intellectual disabilities, for instance the common misconception that most have severe disabilities (McCaughey & Strohmer, 2005). Members of the public who understand that most intellectual disabilities are mild show lower desired social distance (Ouellette-Kuntz et al., 2010), suggesting that more knowledge about intellectual disabilities may dispel stereotypes about people with disabilities.

In line with these findings, one variable that has been associated with more positive attitudes is prior positive contact with someone with intellectual disabilities. Although the evidence for the causal power of contact is relatively weak as most studies have been correlational in nature, it is a consistent finding (Antonak et al., 1995; Beckwith & Matthews, 1994; Beh-Pajooh, 1991; Choi & Lam, 2001; Horner-Johnson, et al. 2002; Lau & Cheung, 1999; Lawson & Walls-Ingram, 2010; Yazbeck et al., 2004). Although the cognitive/affective mechanism by which contact may affect attitudes (if contact, is indeed the causal factor) is relatively unknown, some researchers have posited that contact may reduce anxieties and fears people have about interacting with individuals with intellectual disabilities (Beh-Pajooh, 1991; Hudson-Allez & Barrett, 1996), or that contact can facilitate discovering the competence of individuals with intellectual disabilities (Roper, 1990). It is clear, however, that contact has to be positive or of good quality to be related to more positive attitudes (Lawson & Walls-Ingram, 2010; Pettigrew & Tropp, 2006; Scior, 2011).

1.7 Research Problem and Purpose

In sum, previous research suggests a clear discrepancy between the understanding the general public has about parenting a child with DS and the actual experience of parenting a child with DS. Given this discrepancy, perhaps individuals are making decisions to terminate their pregnancy based on stereotypes of DS rather than on direct experience and knowledge. In line with this argument, previous contact with individuals with DS is associated with more favourable attitudes towards people with DS, more positive perceptions of parenting a child with DS, and a lower likelihood of intending to terminate a hypothetical pregnancy due to a DS determination (Lawson & Walls-Ingram, 2010). Analyses of the information provided to individuals considering prenatal screening for DS or elective termination due to a DS determination find that it is typically medical and negative (Bryant, et al., 2001; Lawson, et al., 2012) and often focuses on a probabilistic description of the screening/testing process rather than a description of DS or life with DS (Williams, et al., 2002). The limited research available also puts forward that often, experiences of receiving a DS determination are negative (Buyukavci, et al., 2019; Guon et al., 2014; Hedov, et al., 2002; Nelson Goff, et al., 2013; Skotko, 2005a; Skotko 2005b; Wallace et al., 2018), with parents reporting dissatisfaction with both the lack of accurate information and the excess of negative information they received about DS (Buyukavci, et al., 2019; Guon et al., 2014; Hedov, et al, 2002; Nelson Goff, et al., 2013; Wallace et al., 2018).

However, none of the available studies have been conducted in Canada[3], and therefore, the experiences of Canadians receiving determinations have not been thoroughly explored. The experiences of Canadians should be investigated for two reasons. First, Canadians could have a unique experience with DS determinations because of our universal health care system. When the cost for DS screening and testing is covered by universal health care, they could be more likely to be routinized and informed consent could be eroded. Second, before it is justified to advocate for local change, it needs to be established if there is a local problem. That is, professional development seminars on how to deliver an empathetic DS determination do not need to occupy the time of Canada's obstetricians, midwives, pediatricians, and genetic counsellors if Canadians have been satisfied with their determination experiences. Therefore, the purpose of this dissertation was to obtain a preliminary understanding of the experience of receiving a DS determination in Canada. This investigation can illuminate if experiences in Canada have been similar to those documented in other parts of the world, and the extent to which they align with best practice guidelines. The primary research question for this dissertation

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[3] Seven percent of Wallace, et al.'s (2018) sample was Canadian. Otherwise no studies on this particular research question have been conducted with a Canadian sample.

was: *What have been the experiences of Canadians receiving pre and postnatal DS determinations? How do they understand and make meaning of these experiences?*

CHAPTER 2

METHODOLOGY

2.1 Theoretical and Epistemological Orientation

I chose narrative interviewing to be the method of data collection for this study for several reasons. First, storytelling is a widespread and everyday method of communication, which feels natural for many people (Riessman, 2008). Thus, I anticipated that telling their story of the determination might be easier and more intuitive for participants than responding to specific and perhaps irrelevant interview questions. Second, the storytelling approach allowed participants to take control of the conversation and prioritize aspects of the experience that were salient to them. This called my attention to important aspects of the determination experience that I might not have anticipated and would not have asked about in a standardized interview format. Third, narratives are communication tools that convey experiences meaningfully to outside audiences and thus are useful for political mobilization and activating change (Riessman, 2008). That is, narratives can be effective persuasive devices. The DS community can use the narratives collected and documented in this study to raise awareness and advocate for changes in current determination practice.

For the purposes of the project, narratives are considered communications in which the *"speaker connects events in a sequence that is consequential for later action and for the meanings that the speaker wants listeners to take away from the story"* (Riessman, 2008). That is, speakers make choices about which events to include, how to arrange and connect those events, and how to frame those events to convey a certain meaning to the audience. Therefore, the participants' narratives are considered reconstructions and not reflections of reality. This is consistent with a constructionist epistemology, the premise of which is that knowledge of the world is always a human and social construction: *"Truth, or meaning, comes into existence in and out of our engagement with the realities in our world. There is no meaning without mind. Meaning is not discovered, but constructed"* (Crotty, 1998, pp. 8-9). Although anti-essentialism is a tenet of constructionism, constructionists' stance on realism is debated. The position I take in this dissertation is anti-essentialist but not anti-realist (see Burr, 2015). That is, I do not deny the materiality of the world, or that there are "things" that are "real". However, I do not believe there are any conditions under which our understanding of the world could not be "carved up" differently (Burr, 2015). With reference to this project, what that means is that I firmly believe that these events occurred (with the proviso that memory is fallible, and that people may lie) but that there are innumerable ways they could be understood and made sense of.

As an analyst, I have made implicit and explicit choices about which aspects of the narratives to pay attention to, which patterns seem most salient, and how I should arrange and present my analysis to convey the meaning *I* have attributed to the narrative. In addition to the patterns and meaning that I might not have noticed, I have also made explicit choices about what to include in the narrative based on what seems most relevant given previous literature, what participants focused on, and what is simply the most interesting to me. For example, a significant amount of the dissertation is focused on participants' discussion of probability when it came to screening and testing. That is because my interpretation of participants' narratives was that they focused, to a great extent, on how the meaning of screening changed to them over time. Therefore, I interpreted this as an important aspect of their story. However, an alternative explanation for including this in the dissertation is that as a psychology student I might be more likely to notice and include dialogue that illustrated poor reasoning about uncertainty because it is a "hot topic" in my field.

Although my stance is more or less constructionist, in order to increase the readability of the dissertation and to respect that, *to participants*, they are telling their stories *as they experienced them*, I refrain from using constructionist jargon in my framing of their accounts. Instead I use realist language like "participants described", "participants reported", and "participants explained" to reflect that I trusted that participants were sincerely attempting to reconstruct events as authentically as possible. I also use realist language because I believe it is easier for a public audience to understand and my preference is for the dissertation to be accessible to the public, in particular, to the participants who told their stories, and to decision-makers.

That being said, several participants used language that implies that they also consider their accounts to be reconstructions rather than reflections of reality, even when they were relaying their own experience. For example, when one participant, Stephen, was beginning an explanation he prefaced, "*So ultimately what happens— or at least how we've described our experience— is that…*" indicating that he also takes a constructionist stance to his own knowledge. He qualified that that he could not actually tell me "what ultimately happens" or even what his experience was, but only how he and his partner *had described* their own experience. Therefore, he implied that his knowledge of experience is not direct, but mediated and moderated by language.

There are sections of the dissertation that will more obviously align with a constructionist approach. For example, in Chapter 9, the constructionist stance is most apparent as I compare the dominant narrative parents of children with DS tell about the experience of parenting a child with DS with a sub-narrative told by a small sub-set of the participants, who recognize and challenge the dominant narrative. This chapter exemplifies taking a critical stance towards taken-for-granted ways of understanding the world, which is a key principle of constructionism (Burr, 2015). In other parts of the dissertation, the constructionist approach is less apparent. Nonetheless, I present this research as an account of accounts, not as a reporting of "the facts".

2.2 Reflection on the Influence of my Personal Experience

As detailed above, I made innumerable decisions in conducting this research which have contributed to the form it has ultimately taken. I conducted the literature search, in which I made choices about what I considered relevant or not. I framed the research questions based on my assessment of the existing literature and political landscape. I chose where to advertise for participants and when the number of participants seemed to provide "theoretical saturation". I created the story prompt, picked details out of participants' stories that I deemed worthy of follow-up, and provided bodily feedback such as nods and empathetic facial expressions at moments of their narratives that I perceived to be poignant. I analyzed the data with a focus on what I perceived to be important and salient. I saw patterns in the data that have inevitably been influenced by my personal, professional, and academic history, because I am a person and not a machine. I can reflect on some aspects of my personhood that seem most obviously relevant to the construction of the dissertation.

Professionally and academically, I have been trained in the field of program evaluation. The purpose of evaluation is to assess the inputs, process, and outcomes of interventions. A primary goal of evaluation is to contribute to the improvement of interventions by providing evidence about areas of strength and weakness. Although this was not a commissioned evaluation project, it has become my tendency to view the world and my academic research through an evaluation lens. Therefore, as in an evaluation project, I tended to focus on areas of strength and weakness in the health care system in order to provide suggestions for improvement.

I have also studied social psychology for over ten years. I am steeped in social psychological theory. Therefore, I was more likely to relate the information conveyed in the narratives to social psychological theory. For example, at various times in the dissertation, I discuss stereotypes, attitudes, unrealistic optimism, and contact theory— concepts from social psychology— to explain the data. That does not mean that these concepts are constitutive of the data. It means that I make sense of the data with these concepts because they are part of my toolkit for understanding the world. A researcher with a background in gender studies or economics, for example, would come with a different toolkit of concepts for understanding. They would therefore see different patterns in the text as plainly as I have “seen” the patterns I present in my analysis.

Personally, I have a niece with DS who is a wonderful, multidimensional person. Being involved in her family means that I have had a personal relationship with someone with DS. I have watched her thrive in school, extracurricular activities, with friends and with her immediate and extended family. I have also been privy to some of the challenges of parenting a child with DS such as navigating the various systems that parents of typical children have limited interaction with. My niece’s story fits more or less within what I will call the “dominant narrative” in Chapter 9. Therefore, I may have entered into the research with positive expectations about what parenting a child with DS is like, which could have impacted the way I engaged with participants, and the patterns and meanings that I saw in the data. However, I have made an effort to point out examples in the data that do not align with the dominant themes and narrative in an effort to illustrate that there have been varied experiences and that, as much as I see patterns in the data, there is not only one story when it comes to receiving a DS determination or parenting a child with DS.

Historically and culturally, I wrote the final drafts of the dissertation during the first wave of the COVID-19 pandemic and during the Black Lives Matter (BLM) movement following the murder of George Floyd by a Minneapolis police officer. How exactly this cultural and historic position impacted how I wrote the dissertation is not clear to me, but given these are two of the most disruptive public health and human rights crises of my lifetime, it is difficult to argue that they would not have had an impact. The BLM movement has certainly made me aware of the weakness that I did not collect demographic information on race or ethnicity or make an adequate effort to recruit people of colour and other underrepresented groups to share their narratives. A few participants spontaneously self-identified as Indigenous, but the remainder of the sample appeared to be White. Therefore, this project has continued in the flawed tradition of psychological research before it which has centered privileged voices and overlooked or disregarded marginalized ones to the detriment of a full and nuanced understanding of the world (Henrich, et al., 2010), a mistake which I regret.

In summary, data do not "speak for themselves" and my own experiences have inevitably contributed greatly to the final form of the dissertation. However, it was my goal to center participants' accounts as much as possible. The purpose of this was three-fold. First, it was because I wanted to privilege their voice and the meaning of the experience to them. Second, it was because they often communicated so powerfully that my interpretation was redundant. Third, it was because grounding my analysis in the data provided a stronger argument for the claims I made throughout the dissertation.

2.3 Methods

2.3.1 Participants

The goal of the study was to provide information about the experience of receiving a DS determination in Canada, but because this was a preliminary study on the topic in the Canadian context, a geographically homogenous sample was utilized and the present research was situated in one Canadian province, Saskatchewan. Therefore, although the study was conducted in Canada and sheds light on the Canadian context, the results cannot be assumed to generalize to the entire Canadian population. Thirty-two interviews were conducted with 42 participants in Saskatchewan in 2016. Ten opposite gender couples participated; 21 mothers participated by themselves; and one father participated by himself. Participating in the interview as a couple or as an individual was not dictated by the researcher in any way. Participants either made a conscious choice about who they believed should be present, made an assumption about who should be present, were separated from their partner and therefore participated alone, or selected who would participate out of convenience for their family's schedule. It was anticipated that more mothers than fathers would volunteer to participate as women may have more of a stake in the issue given their unique and salient role in pregnancy, birth, and childrearing. The only requirement for participation was that volunteers had received a pre- or postnatal DS determination.

Participants were recruited via two methods. First, the Saskatchewan DS Society was approached in order to recruit their membership to participate in interviews. They were emailed a request to forward an invitation to their membership (Appendix A). The request/invitation focused on the purposes of the interview, an outline of the interview, and the value of these participants' contributions. At the end of the request e-mail, participants were asked to click on a link to provide their contact information if they were interested in participating. Second, invitations to participate were circulated via posters (Appendix B), Facebook™, and on the University's online message board (Appendix C). These invitations provided a link through which interested individuals could provide their contact information. In response to the advertisement on the University's message board, a student, and employee of AIM (Ability in Me), an organization that works with children with DS, approached me to suggest recruiting via AIM. Thus, the same request letter was sent to the AIM executive director.

Some volunteers provided their contact information via the survey link while others contacted me directly via phone or text, at which time I provided more information about the study and scheduled a time for the interview. I also provided the consent form in advance for those who contacted me via email. In addition to the final 42 participants, another 14 potential participants initially provided their contact information but did respond to follow-up contact methods.

The final sample included participants who received a pre- or postnatal DS determination between 1993 and 2015 (see Figure 2.1 and Table 2.1). On average, it had been seven years since the determination. While it is generally not advised to ask people years later how they felt about an event, longitudinal studies have substantiated that mothers are able to remember the event of a DS determination accurately many years later (see Carr, 1988), and the experience has been described as a legitimate "flashbulb memory" (May et al., 2020; Skotko, 2005) in which much detail remains clear over time. Mothers were between the ages of 22 and 44 (M = 32) when they received the determination (see Figure 2.2). Most of the participants were from the two largest urban centers in the province of Saskatchewan (see Figure 2.3).

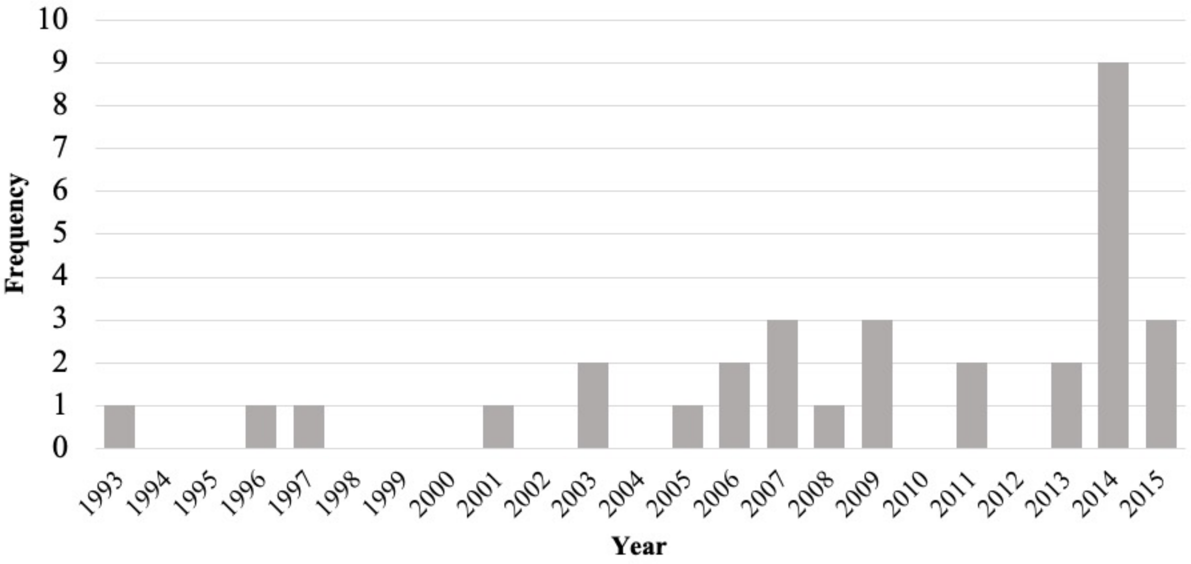

Figure 2.1 *Frequency of Determinations by Year*

Table 2.1 Participant determination by year

Year	Participant Pseudonym		
1993–1999	Iris		
	Jeanette		
	Sylvia		
2005–2009	Alma	Edith	Kate
	Arthur	Emily	Louisa
	Camille & Oscar	Joan	Margaret
	Charlotte		
2010–2015	Agatha	Judy	Ursula
	Alice & Charles	Mary	Virginia & Stephen
	Chloe	Maude & Leo	Zadie & Kurt
	Donna	Senga & William	Zora & Edgar
	Harper & George	Simone	
	Jane & Ernest	Shirley	

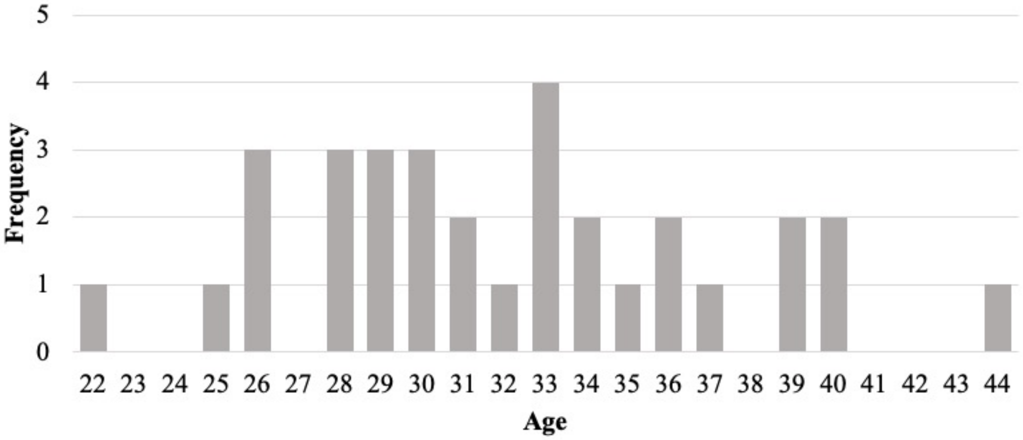

Figure 2.2 *Frequency of Determinations by Mother's Age*

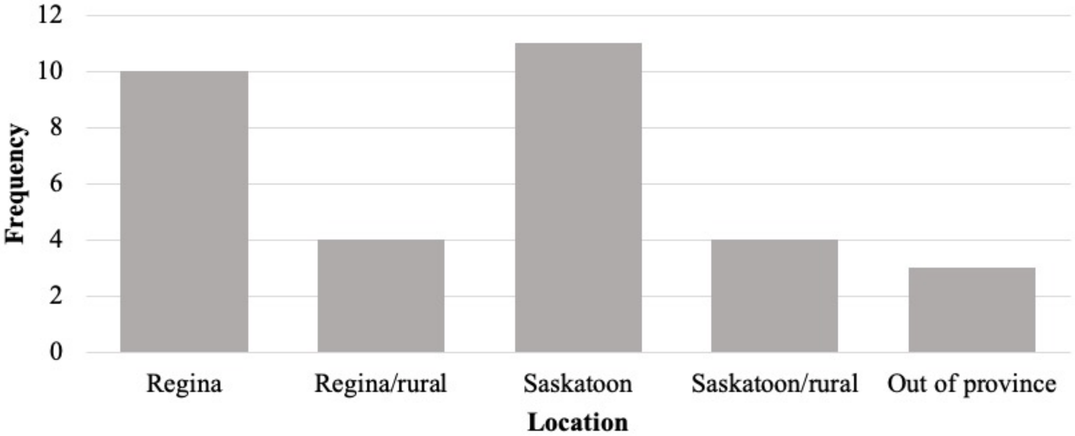

Figure 2.3 *Frequency of Determination by Location*

Nine of the determinations were confirmed prenatally. Twenty-three were confirmed postnatally. Of those 23, 12 had no suspicion of DS or other anomalies before birth and the remaining 11 had elevated screening results or other signs in pregnancy that DS or another anomaly could be possible. One participant, who received a prenatal determination, chose to terminate the pregnancy. One participant had a child who had passed away a few years after birth. The remainder of the sample currently had a child with DS.

2.3.2 Data Generation

Interviews occurred at a location identified as convenient by the participants. Three interviews took place in participants' offices, two at a University campus, one at a restaurant, three via online video conference, and the remainder took place in participants' homes. Upon arrival, I introduced myself and explained the purpose and process of the study and terms of privacy, confidentiality, and data ownership (See consent form, Appendix D). After receiving informed consent from the participants, the narrative interview followed an open-ended format with an initial story request:

> *I would like you to tell me the story of receiving the Down syndrome determination. Start at whatever point the story begins for you (maybe that's when you became pregnant, maybe sooner or later), and I'll listen until you feel like you've concluded. Please include all the detail you think I need to give me a picture of what you went through. This might include details about care providers, reactions from other people in your life, or details about how you felt or what you did in reaction to the news. But it also might not. Tell me your story.*

Many participants spoke for over 30 minutes unprompted after the initial narrative request, following which I probed to elicit more detail about salient events, clarify meanings, or if participants did not spontaneously provide information about an issue relevant to the study, I asked them follow-up questions to fill in those gaps (See Interview Guide, Appendix E). Common follow-up questions were related to the information that they received about DS, what beliefs they had about DS that prompted their initial reaction to the determination, and how their life has changed (or not) as a result of having a child with DS. This final question became a standard question after several participants spontaneously raised the issue and therefore piqued my interest in it.

The shortest interview was 19 minutes. The longest was an hour and forty-five minutes. Most interviews were about an hour long. The experience appeared to be an important one in the lives of most participants and the interviews are rich with detail. The idea of "telling me the story" of receiving the DS determination was understood by all participants in the way it was intended— participants chose their own starting and ending point and relayed external plot points (e.g. "he said…") as well as internal experiences (e.g. "I felt…") and interpretations (e.g. "it was clear that…"). I audio recorded the interviews and transcribed them as accurately as possible. I replaced participants' names with pseudonyms to protect their identity but preserve their humanity.

2.3.3 Analysis

During transcription I made short analytic notes when I noticed something interesting to me, relevant to previous research, and/or when I noticed what might become a pattern. Following transcription, I engaged in a thematic analysis of the narratives (see Riessman, 2008), with a focus on the explicit content of the participants' stories (see Braun & Clarke, 2006). I planned to engage in two levels of thematic analysis. First, the units of analysis were features of the narratives that corresponded with variable aspects of the determination scenario identified both by the best practices literature discussed previously, and inductively, through apparent salience to the participants conveyed through their storytelling. This first analysis also generally corresponded with the "categorical-content perspective", in which narratives are broken down into subcomponents by identifying regularities that convey meaning regarding the research purpose (see Hiles & Cermak, 2008). This helped to identify elements of participants' experiences that corresponded with or diverged from each other's, providing an idea of the extent to which aspects of the determination experiences vary across individuals, and how they do so.

I used NVivo as a tool for organizing the data. After familiarizing myself with the transcripts through several prereads, I generated initial or "open" codes (see Saldana, 2015). In this stage, features of the data that were meaningful in regard to participants experience of receiving the determination were noted through line-by-line coding. Then codes were organized into initial themes and subthemes and the relationships between themes were explored. The next stage involved reviewing themes and their associated codes to ensure that each theme told a cohesive story about the data in relation to the research question. Finally, themes were named, defined, and delimited. As per Braun and Clarke (2006), the process of coding, creating themes, reviewing them, and writing about them was recursive. That is, as I proceeded through the analysis, I often found I had to return to earlier steps to rethink and redevelop how I had categorized or conceptualized the data. In making decision rules as to what "counts" as a theme in this analysis, prevalence was considered in order to understand the most common experiences among the participants. As well as prevalence, inclusion of a theme was determined based on whether it captured something unique and salient in relation to determination experience.

There was also a goal to conduct a second analysis wherein the unit of analysis would be each case. This analysis would follow the "holistic-content perspective" (see Hiles & Cermak, 2008), the goal of which was to arrive upon a single theme that delineates the core narrative meaning of each story. Stories would then be compared to each other as wholes to potentially create a typology of narratives organized by theme with archetype cases as exemplars. Because the first analysis was so fruitful, the second analysis became beyond the scope of one dissertation and was not carried out for the present document. However, Chapter 9, discusses two types of narratives that were identified in the data— a dominant and sub-narrative, which is in the spirit of the second proposed analysis.

Although the structure of narratives was not analyzed per se, the narratives were broken down into narrative elements for their thematic analysis. Riesmann (2008) stated that any fully formed narrative includes six elements: an abstract, orientation, complicating action, evaluation, resolution and a coda. I found it useful to "lump" (see Saldana, 2015) data into these broad categories to conduct and present my analysis. Chapter 3 illustrates how participants viewed their life before the determination and how they set-up the story, and as such represents the orientation to the story. Chapters 4 and 5 focus on participants' approaches to screening and probability interpretations in screening results, which had the effect of complicating action. Chapters 6 and 7 are the climax of the story, focussing on when participants actually received confirmation of their child's DS. Chapter 8 represents the evaluation or "so what" of the story and deals with the emotional experience of receiving the determination and participants' attributions for those emotional reactions. Chapter 9 discusses participants' lives since the determination, which can be considered the result(s). And Chapter 10 is the "sign off" of the narrative wherein changes due to parenting a child with DS are discussed as well as where participants will go from here.

CHAPTER 3

"WHEN YOU GET PREGNANT, YOU'RE FULL OF IDEAS AND HOPES AND DREAMS": STORY ORIENTATION

This short chapter demonstrates how participants tended to "set up" their story by providing context about their lives before the determination. Participants described their active social lives, typical families, normal pregnancies, and dreams for their future children, which highlighted their optimism and perhaps naivety to the potential challenges they had in store. Some described difficulty becoming pregnant and previous miscarriages, which served to emphasize how wanted their child was and how vigilant they were to potential complications. Several also began by recalling seemingly insignificant occurrences that, with the vantage of hindsight, acted as foreshadowing for the coming events. They recalled the first (often dismissed) anomaly on an ultrasound, or the first time that health care providers raised the topic of DS.

3.1 *"Everything was normal"*: Homeostasis in the Time Before

Several participants began their story with a short description of homeostasis before the determination by describing their previous experience with pregnancy, children, and/or family life. For example, in this excerpt, Joan described the active social life that her family had before the birth of their child with DS:

> *My [other] daughter is nine, so we had a very typical pregnancy— a bit of a rocky delivery— with her. She had um, about a five to seven day stay in the NICU, otherwise, everything went swimmingly. A very typical two years with her. Didn't hamper our lives in any way. We camped, we still socialized with all of our friends. Um, you know all my girlfriends and I still got together as we did. We were very very social people, and we loved being out and just loving life.*

Through Joan's repeated use of the past tense, this description of previous homeostasis served to set up a sharp distinction between the time before and the time after the determination. In addition to establishing the temporal demarcation, participants' descriptions of homeostasis provided context regarding their lack of experience with non-typical children or birth. For example, Arthur emphasized the typicality he and his partner had experienced with the pregnancy and birth of his previous child and contrasted it with his experience with his child with DS:

> *Ok, I guess I'll start with maybe the framework of the family. So, there's me and my wife and we have two kids. So her older brother came along and had kind of a typical everything. Like a typical birth, no complications, no problems, he is a typical kid. Everything was normal… So that was the first experience with birth, right? And it was all like good. And with [child's] it was completely a different experience.*

Arthur's introduction established that his frame of reference for the birth of his child with DS was that of typical birth and of a typical child and that therefore the experience that he was about to describe was foreign to him. First-time parents also set up the experience as a foreign one by introducing the story with their expectations of pregnancy and parenting. For instance, Jane described her and her partner's idealistic mindset which highlights how unsuspecting they were of pregnancy complications and hints at naivety that might set them up for being 'blind-sided' by the determination:

> *We got pregnant quite quickly, and we were excited, obviously. He's our first, so— um, never thought that, you know, we would have any issues or whatever. You know, when you get pregnant, you're full of ideas and hopes and dreams.*

Participants also set up a prior homeostasis by describing the routineness of their pregnancy. This tended to serve as a "calm before the storm" foreshadowing of significant disruption to come with the determination. Margaret, for example, described how she had no "warning" in pregnancy:

> *Well I guess starting at the beginning was that the pregnancy— [child's] pregnancy— was a pretty normal pregnancy. There was no— nothing about it that put off any warnings. Um, all our ultrasounds were normal, there were no markers for anything, so everything was kind of going along just smoothly.*

In two narratives, the element of surprise was two-fold as participants described that the pregnancy itself was unexpected. For example, Camille explained that she was not expecting to become pregnant due to her age: *"When we met I figured I was too old to have kids. And so [child] was accidental. ((laughs))…"*.

In contrast to the participants who began their story with a short description of homeostasis, two participants began by describing their efforts to become pregnant. For these participants, the beginning of the story was not equilibrium, but fairly onerous fertility treatment. Beginning the narrative by describing the extensive process to become pregnant highlighted how wanted their child was and also that their DS narrative was only one chapter within a greater story. For example, even before any suspicion of DS, Chloe's experience with becoming pregnant extended over several years with multiple "false alarms" and accompanying emotional confusion and expectation management:

> *And we had a lot of difficulty conceiving. So we went through even fertility treatments…It would have been probably about that four year mark, almost and kind of decided, you know, it's not going to happen, and just kind of I guess pulled back and just didn't worry about it. I did end up conceiving and it was one of those like "wow! I can't believe it happened" and it was like a whole shocker kind of scenario. ...And at that ultrasound they had told me that they could not find an actual baby there. So um, of course, devastated, right? Tried for so long then nothing. So, you know, at that point it was kind of like "Ok well, everything happens for a reason. Obviously there must have been something wrong, you know, fine." So we just kind of continued on again. ...And then, I just, I felt different. And I was like, "I'm totally pregnant. I know it!" So I took a test— "nope negative". And I'm like "there's no way. Like I KNOW." I could just tell. So I waited a few more weeks. tested again— yeah, for sure I was pregnant. So, I was very leery at telling anybody. Because of what had happened previously. So I really held on to it a little bit…And uh, we waited for sure the, you know the 12 week mark till we went, knew for sure, "yep there's a baby there— all's good." Everything looks good, so it was good.*

Another four participants highlighted that they had had previous miscarriages. Participants who had previously experienced miscarriage, like Alice, tended to explain that they entered into the pregnancy vigilant of potential problems:

> *I guess I would say it probably started around the 12 week nuchal translucency scan. So leading into that I was pretty freaked out because we had had a miscarriage before, and at my prenatal check they couldn't find the heartbeat. And so when I went into— like I was already then anxious going into the 12 week scan— and so, you know, it was turned away from me and I kept like trying to see because, like is the baby alive or what's happening?*

Vigilance also appeared in the introductions of two participants who, like Senga, explained that at the outset of their pregnancy they were specifically concerned about the potential for DS, which led them to pursue prenatal screening[4]:

> *I guess for us it probably started in pregnancy, because, um, we were actually quite worried about Down syndrome for some reason, before we got pregnant. And I decided to do like the nuchal fold translucency and all the associated blood work to kind of screen for it.*

3.2 *"We'll just keep an eye on it"*: Foreshadowing (with the Vantage of Hindsight)

Other participants began their narrative with what was, with the vantage point of hindsight, the first hint that the future might differ from their expectations. In their story, these early hints tended to act as foreshadowing or to create a sense of dramatic irony. As a narrator they knew, and as a listener, I knew, that this was the first hint of what was to come, but at the time, the event felt insignificant to them. For example, Virginia described an anomaly picked up in a routine ultrasound that their physician was not concerned about:

> *I guess it started at our first ultrasound. We found—ah they found— the ultrasound tech found fluid around the baby's heart, and our family doctor said that, you know, sometimes ultrasounds pick up things that aren't a big deal. Um, fluid around the heart— she said it wasn't a large amount. She said it could go away. "It's so early in the pregnancy- we'll just keep an eye on it"— sort of thing. So we just went with it...*

Like for Virginia, the first sign of DS was often extremely vague in terms of what it might indicate. Participants were aware of an anomaly in screening, but beyond that were informed of very little. Here Maude explained that, to her knowledge, her care provider was also unsure of the meaning of the anomaly they detected:

> *Ok, well I guess we first— we had found that our triple mark, marker screening— those results were high. Um, so my doctor did mention that— she said it could be nothing but um it could be something. But she kind of didn't really say anything because she didn't really know.*

In other introductions, like Zadie's, participants indicated that while they were aware of an anomaly, their health care providers did not inform them as to what it might indicate:

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[4] Both of these participants subsequently received mixed indicators in screening (elevated triple screens, but no or few markers in ultrasounds), and physicians' interpretations that led them to assume their child did not have DS.

> *…at the twenty-week ultrasound with [child] there was indications of something— all they said was that you should think about getting a, um, more in depth ultrasound.*

Participants regularly drew on hindsight to indicate the significance of events that at the time were experienced as inconsequential. For instance, Louisa began her narrative by recounting a mundane conversation she had with a laboratory technician. What seemed like a routine event early in her pregnancy took on more meaning for her later when her first awareness of DS became a significant even in her life:

> *She was my third child. And so I went for the triple screen, which, it was the first time that I'd ever done that. So I didn't even know what I was going for. Um, I asked when I was at the lab why I was there and they said, "well this is your triple screen"— and my other daughter's only 16 months older than— so it was in a very short time frame and I didn't go for the triple screen with my other two kids— and so the lab tech just said "you're here for the triple screen", I said "I don't know what that's for", and she said "oh, well they're testing for Down syndrome."*

3.3 Discussion

The purpose of this chapter was to contextualize the participants' narratives. The excepts in this chapter illustrate how the narrative of the DS determination fit into the greater life story of the participants. Many participants began their narrative by making a clear demarcation between the "time before" and the "time since" the determination. The demarcation makes the point that their life has changed, that the event they are going to retell has had an impact on their life and changed who they are and how they view the world.

Additionally, one participant, Kate, set up her narrative by explaining that she has contemplated confronting the physician who delivered her child's determination ten years earlier:

> *I've been giving it some thought…something that I've actually wanted to do, and have not done and don't know if I ever will do, is I would like to approach the doctor, the family physician…*

Kate's introduction implies that her care provider's manner had a lasting impact on her and would be a focal aspect of her narrative. This was the case for many participants.

CHAPTER 4

"MY DOCTOR SAID TO ME, 'WOULD IT MAKE A DIFFERENCE?'": APPROACHES TO SCREENING

Chapter 4 focusses on how participants came to engage in prenatal screening or not. Some participants were screened without informed consent (one was *not* screened without informed consent). These participants described having appointments booked and undergoing procedures for which they did not know the purpose. Given the perceived routineness of the bookings and procedures, they were unaware at the time that there could be reasons to decline. Other participants explicitly pursued screening. Most of the participants who pursued screening cited a desire for reassurance, knowledge, and preparedness, although two indicated seeking information to inform a termination decision. Finally, participants who declined screening tended to equate screening with an openness to termination and viewed the rejection of screening and testing as a testament to the unconditional love they had for their future child.

4.1 "*Ok, you're pregnant, we're going to book this for you*": Routinized Screening

Participants who were screened without informed consent tended to be unaware of what the procedure was for and therefore did not provide informed consent for the procedure. For example, Louisa described how she was not informed as to why she was having blood drawn or what a "triple screen" tested:

> *And so I went for the triple screen, which, it was the first time that I'd ever done that. So I didn't even know what I was going for… and so the lab tech just said "you're here for the triple screen". I said "I don't know what that's for"*

While Louisa's comment highlighted her lack of knowledge of the purpose of her visit altogether, other participants described that the voluntary nature of screening was not explained to them. For example, Jane described that when her nuchal translucency scan came up, she was not offered it as a choice, but automatically scheduled for it:

> *I guess the first kind of testing that came up, was with the NT scan at 13 weeks I had it done. So um, that was something that when I went in to get my pregnancy confirmed with my family doctor was just automatically booked for me. I didn't even really realize that I had the choice of doing it or not. It was just "Ok, you're pregnant, we're going to book this for you"*

Several participants relayed that they had a lack of understanding of the nature and purpose of the procedure and/or that it was optional. Therefore, their participation in screening does not even meet the loosest criteria for an informed choice—"information, comprehension, and voluntary choice" (Summers, 1994, p. 1689). It could be argued that individuals, such as Jane and Louisa, have the ability to refuse care should they choose; however, when screening is presented as the single and obvious way to proceed, it is less likely that people will question its utility and purpose. Indeed, previous research has suggested that expectant parents accept screening because they perceive it to be a 'routine' aspect of prenatal care (Barr and Skirton 2013; Chiang et al. 2006; Markens et al. 1999; Pilnick et al. 2004; Thomas 2016; Williams et al. 2005), and may not even realize that there is a choice to be made, or that they have consented to anything (Green & Statham, 1996; Pilnick, 2004; Press & Browner, 1997). While health care providers may understand that all procedures are optional for patients, that might not be explicitly conveyed to patients, either because providers assume patients understand their rights, or because providers want to downplay the option to decline. Further, expectant parents might be dealing with an overload of information to process (Barr and Skirton 2013), view professionals' offer of screening as an endorsement of it (Heyman et al. 2006; McNeill et al. 2009; Remennick 2006), be swayed by institutional and provider support for testing (Pilnick, 2004; Press & Browner, 1997), or be swayed by implicit pressure to conform to social norms (Chiang et al. 2006). Finally, ultrasounds and NT scans are commonly framed as an opportunity to 'meet the baby' rather than as a detection tool for genetic conditions (Barr and Skirton 2013; Draper 2002; Heyman et al. 2006; Lupton 2013; Mitchell & Georges 1998; Thomas 2016; Williams et al. 2005). Therefore, the purpose of the procedure is obscured to prospective parents nullifying their informed consent.

In contrast to being routinely screened without informed consent, one participant, Alma, was seemingly automatically not screened (also, without informed consent):

> *I found out that my family doctor— um, you know you go for all your prenatal testing and stuff…my family doctor didn't send— like she didn't do the triple screen. Which was—I didn't— I don't know if I would have said "yeah that's ok" if she had brought it up to me… she just didn't order it. I don't know if because that's her own personal view on things …I didn't really pay attention to what the blood-work was that I was going for. I*

> *just assumed that she'd be doing it and that everything was fine. Because I never heard anything. So, that was upsetting to me, that I didn't have the screening.*

As Alma's passage indicates, her health care provider did not discuss the screen with her, or her motivation for not ordering the screen. It could have been an oversight, or it could have been the physician's personal opinion about screening that led to the omission. Alma explained that she is not sure if she would have opted for screening but that she never had the opportunity to make a choice about it because the option was never presented to her.

The routinization of screening as well as the withholding of screening contravene national guidelines and provincial health policy. The Saskatchewan Ministry of Health (Carson et al., 2010, p. 7) specifically dictates that

> *Women who present for prenatal care* ***must be offered*** *prenatal screening regardless of maternal age. Women* ***should be counselled*** *that screening for fetal Trisomy 21 and 18 and ONTDs [Open neural tube defect] is available and provided with a patient information pamphlet.* ***Discussion*** *about the methods of testing available, the performance of the test(s) as well as the implications of having screening will follow.* (emphasis added)

And the SOGC national guidelines (Cartier, et al., 2012, p. 490) state that:

> *Health care providers must be satisfied that* ***patients understand the screening available and that screening is entirely voluntary****, and* ***that they are making an informed decision*** *about whether to have testing. The decision should be documented.* (emphasis added)

What is supposed to be routine, according to the guidelines, is that woman are offered screening and counselled about its purpose, procedure, and implications. However, it is evident that, whether through oversight or choice on the part of the care provider, they do not always adequately convey the purpose or elective nature of prenatal screening or have discussions with expectant parents about why one would or would not engage in screening. Some prospective parents are screened or miss screening without their explicit choice in the matter.

4.2 *"For peace of mind"*: Pursuit of Screening

Of those who explicitly pursued screening, two were particularly concerned about DS. Shirley reported that she and her partner engaged in screening because her partner wanted to subsequently pursue testing so that they could terminate if they received a DS determination:

> *My doctor had asked if I wanted to do like the serum screen, like the triple screen. And it was something that me and my husband had talked about before— that we did want to do it…. when we were pregnant and wanting to start a family that was [husband's] biggest fear. Is that he said "I don't want a child with an intellectual disability." And he was adamant that we would get the testing and if there was an issue that we would choose to terminate.*

Judy also engaged in screening to inform a termination decision. Her sister had previously given birth to a stillborn baby with DS, which made her hyper-vigilant to the possibility of DS:

> *So, my sister had a baby who was born with Down syndrome. He was born dead…as soon as I got pregnant I was sort of obsessed with the idea that I needed to get Down syndrome screening.*

Like Shirley, her husband *"was very adamant that 'no', that was not the child he wanted*'. Shirley and Judy's experiences aligns with previous research findings that suggest fulfilling a partner's demands for testing (Helm et al. 1998; Jaques et al. 2004), perceiving a negative attitude towards DS and disability more generally (García et al. 2008; Gottfreðsdóttir, Sandall, et al. 2009), and obtaining information to dictate a termination decision (Etchegary et al. 2008; Williams et al. 2005) are all reasons expectant parents engage in screening.

However, most participants reported that they pursued screening for reassurance and information purposes. For example, Camille explained that when she and her partner engaged in screening it was to learn more about her pregnancy:

> *So we decided that a little bit for peace of mind, That we— AND in case there was any issues, we wanted to know about them. But our take going in um, after sort of discussing it, was that this is for information purposes only. We have no intentions of terminating if anything comes of it. And that is what we told our doctor when she referred us for the nuchal translucency test.*

Although Camille stated that she wanted to know if there were any complications with her pregnancy, she also described engaging in screening for "peace of mind". This reasoning aligns with previous literature that suggests some people engage in screening for reassurance that a fetus is unlikely to have DS (Bryant et al. 2010; Etchegary et al. 2008; García et al. 2008;

McNeill et al. 2009; Pilnick et al. 2004; Santalahti et al. 1998), and learning more about the pregnancy (Skirton and Barr 2007; van den Berg et al. 2005a).

In the current study, seeking reassurance was the most commonly cited reason (after the perceived routinization of screening) for engaging in screening. However, engaging in screening for this reason is illogical; screening is intended to *find* complications, and therefore has the potential to *create* rather than quell anxiety because it can bring to light complications that were previously unknown. Furthermore, the routinization of screening for reassurance or to meet the baby means that prospective parents are not always aware of, or prepared for, the complex information and choices associated with a result (Åhman et al., 2010; Baillie et al., 2000). Previous studies have found that parents presented with higher probabilities of DS after screening are often unprepared to hear that their child might have DS (Hunt, et al., 2005). Many have not considered the possible implications of an atypical result. Hunt et al., (2005) reason that there is a misalignment between clinicians' goals in screening and expectant parents' goals in screening; clinicians engage in screening to find problems, and expectant parents engage in screening to confirm there are no problems. Given that parents approach screening with different goals than do care providers, counselling parents prior to screening on a variety of potential results could serve to better prepare them for the possible outcomes.

4.3 "*It wouldn't have made a difference for us*": Declining Screening

Participants who described declining screening typically conceptualized screening as being comprised of the maternal serum screen and not the ultrasound screening. For example, Joan described that she waved "prenatal screens" and then went on to describe having ultrasounds:

> *I had waved with both my children, the prenatal screens…I figured that if it was something that was life altering, and the baby would be at risk, that would be picked up in the preceding um— the following— tests, like the ultrasound and all that kind of stuff.*

Only one participant described declining an ultrasound. Otherwise, those who thought of themselves as have declined screening actually only declined the serum screen. This misconceptualization of ultrasounds is not uncommon as previous studies have found that they tend to be framed as an opportunity to 'meet the baby' which downplays their purpose in the health care system of detecting anomalies (Barr and Skirton 2013; Draper 2002; Heyman et al. 2006; Lupton 2013; Mitchell & Georges 1998; Williams et al. 2005).

Some participants declined screening because of the lack of certainty from the results of screening and the potential for them to ruminate about a false positive screen: "*But I know that it's only, you know, it's only, it's— what is it, 70 per cent accurate or something? It's not necessarily [pause]— I didn't want to stress out with results that could be or couldn't be."* (Virginia). For these participants, if there was any doubt that the information could have been misleading, they would have rather not had access to it. For example, Harper explained that she did not want to worry about false positives: "*I chose not to do the screening because I'm a worry wart. So I didn't want to be worrying about potential false positives during my pregnancy and cause the stress and unwanted stuff for the baby".* These rationales align with previous research that has found that people decline screening due to the perceived inaccuracy and unreliability of the tests (Gottfreðsdóttir, Björnsdóttir, et al. 2009), and because of the complexity and inconclusiveness of the information the tests provide (Baillie et al. 2000; Heyman et al. 2006; Liamputtong et al. 2003; Markens et al. 1999; Remennick 2006).

The most common reason provided for declining serum was a rationale that "*it didn't matter*". What it was exactly, that did not matter was unclear in some responses. For example, Donna relayed that she did not pursue screening *"because it didn't matter in that sense."*. These kinds of responses initially seemed to indicate that the result of the screen was inconsequential, generally. However, through the interviews, it became apparent that some prospective parents assumed that the purpose of screening was to inform decisions about further testing, and subsequently, about terminating their pregnancy, which was not something they believed they would do. "It didn't matter" was shorthand for indicating that the results of screening would not have influenced their decision to continue the pregnancy. For example, Joan explained that she and her husband did not pursue screening because they had previously established that they would not terminate a pregnancy with a DS determination:

> *I had waived with both my children, the prenatal screens. Um, my husband and I at the time had talked and we decided that there would be no um— we would not choose termination or abortion, if it was something as simple as Downs or anything else that could be picked up on a prenatal screen.*

Likewise, Simone explained that, since she would not terminate a pregnancy for conditions that a screen could indicate, the screen was not important to her:

> *But I'm sure, like I probably told my OB with my first pregnancy that I'm not really— like I don't really care, regardless of like— I wouldn't terminate anyway. So I didn't feel like it was important for me to do it or whatever.*

These participants framed screening as a gateway procedure to amniocentesis (which came with an unwanted risk of miscarriage) and a termination decision (which many stated they would not consider), rather than a way to prepare for their potential child's needs:

> *…anyways it wouldn't have made a difference for us. I wouldn't have aborted. I didn't want to do the screening as well because if there were positives, I wasn't comfortable with going ahead with an amniocentesis. I didn't want to take the risk of having something happen to the baby and me miscarry so…* (Harper)

The reasons these participants cited for declining screening and testing align with previous research which has found that women decline screening and testing to avoid risks associated with deterministic testing such as miscarriage (Liamputtong et al. 2003; Markens et al. 1999; Pilnick et al. 2004; Browner & Preloran 1999; Browner and Press 1996; Lewando-Hundt et al. 2001) and termination not being an option they would consider (Etchegary et al. 2008; Heyman et al. 2006; Markens et al. 1999; McNeill et al. 2009; van den Berg et al. 2005a).

In addition to equating an openness to screening with an openness to terminate a pregnancy, participants also seemed to use "it didn't matter" statements as shorthand for explaining that they would unconditionally love their child. Maya made this point most explicitly:

> *We had opted to not get any testing done, other than, you know the ultrasound, because our feeling was after all that we had gone through to become pregnant, you know, we didn't want to risk a miscarriage because it certainly goes up when you start doing more invasive procedures. And um, there was sort of just that sense of "well we will love whomever we have" right?*

Some participant narratives demonstrated how health care providers' counselling fostered the "it doesn't matter" mindset about the consequences of screening. For example, Virginia's physician did not frame prenatal screening as an opportunity to learn more about her pregnancy and potential future child, but as a piece of information to inform a choice about termination:

> *…and then it came time for like the pre-screening in pregnancy. We opted not to do that…my doctor kind of said to me "would it make a difference?" and I didn't know I guess, what it would or wouldn't.*

The implicit meaning of the physician's question was, as understood by Virginia, if a DS determination would make a difference to her love for her child or decision to continue to the pregnancy. Although she stated that she did not know the answer, she did report that following this counselling she and her partner did not pursue screening.

The physician's counselling is not unlike suggestions provided by the Saskatchewan Ministry of Health (Carson et al., 2010) which state *"the purpose of aneuploidy screening is to help the pregnant woman, with her family, decide whether or not to have invasive diagnostic testing"* and that a woman might decide that she will not have invasive diagnostic testing because *"she would continue the pregnancy anyway no matter what the results of invasive testing and thus would not accept (and would have a good reason not to be exposed to) the risks of amniocentesis or CVS."* Although a woman' s choice to decline testing should be respected, these statements, like the physician's above, position screening and testing as unnecessary if a woman believes that she would not, under any circumstances, terminate her pregnancy. This precludes the possibility that women can engage in screening and testing to learn about their pregnancy and prepare for their child. These kinds of statements can contribute to the common misperception that screening is only for patients who would terminate a pregnancy if an anomaly were found (Cartier et al., 2012).

In hindsight, Maya explained that her original perspective on testing and potential fetal anomalies was perhaps uneducated and even somewhat naive:

> *And um, there was sort of just that sense of "well we will love whomever we have" right? I'm going to say that that was ah, kind of a nai—somewhat naïve— because we're generally optimists, right? And we didn't actually have, either of us, anyone with intellectual disabilities in our immediate family. Um, so it was kind of an uneducated um, worldview. Just that notion of "we're going to be positive about this". And so when the day finally came… we were not expecting any kind of problems...*

In hindsight, their dismissal of the value of testing for information gathering left them unprepared for the birth of their child who had complex needs.

Notably, participants tended to abandon the "it doesn't matter" perspective on potential anomalies when anomalies became more probable. For example, Donna, who earlier in her narrative explained she declined screening because *"it just didn't matter in that sense"* went on to explain that through ultrasounds they discovered the potential for DS, at which point they did decide to proceed with amniocentesis: *"And ah, we weren't going to do the amnio, but we decided at 32 weeks that we would just so we could be prepared and the NICU could be in there with her and everything when she was born".* When she and her partner became aware of the potential for health concerns, their perspective on testing changed from viewing it as a tool for informing termination decisions, to viewing it as a means to gather information to help them prepare for birth and their child. Virginia and her partner (whose physician asked *"would it make a difference?"*) also pursued amniocentesis when an ultrasound indicated fetal anomalies. Another participant, Zadie, likewise explained that she and her partner transitioned from declining screening for all three of their pregnancies, to becoming aware of potential health concerns through ultrasound, and finally, to pursuing NIPT:

> *So we didn't do any prenatal testing with any of our kids, but uh, at the twenty week ultrasound with [child] there was indications of something— all they said was that you should think about getting a more in depth ultrasound. And so we did four weeks later…and they said "there's five markers for Down syndrome and a heart defect"… They told us about the Harmony test— the blood test and it uh, wasn't covered, like it was $800, or the amnio which is free and can be done at any time... And um, after much discussion with family and each other we decided to do the blood test just to know and kind of prepare ourselves.*

Like Donna and Virginia, when Zadie and her partner became aware of potential fetal anomalies and associated health concerns, they valued testing as an information gathering and preparation tool. Thus, while many of these participants began their pregnancy with a view of screening as unnecessary, their rationale for dismissing it (i.e., that the results "didn't matter" to them) did not hold true. In fact, the condition and potential needs of their child turned out to be very important to them. When they declined screening, it was not because the results of screening would be inconsequential to their lives, but that the results of screening were inconsequential for their love for their child and inconsequential for their decision to continue their pregnancy. Therefore, when care providers frame the decision to engage in screening as a test of love for or acceptance of a child, they may restrict information gathering and preparedness for prospective parents. Instead of perpetuating the misperception that screening is only for people who would terminate a pregnancy, prospective parents should be informed that some people engage in screening for information gathering purposes and to be prepared for the needs of their future child, and that participating in screening does not mean they have to participate in testing or be open to termination.

4.4 Conclusions

The results of this chapter align with previous research which has suggested that expectant parents accept screening because they perceive it to be a ‘routine’ aspect of prenatal care (Barr & Skirton 2013; Chiang et al. 2006; Markens et al. 1999; Pilnick et al. 2004; Thomas 2016; Williams et al. 2005), and may not even realize that there is a choice to be made, or that they have consented to anything (Green & Statham, 1996; Pilnick, 2004; Press & Browner, 1997). These findings also support previous research findings which suggest that fulfilling a partner’s demands for testing (Helm et al. 1998; Jaques et al. 2004), perceiving a negative attitude towards DS and disability more generally (García et al. 2008; Gottfreðsdóttir, Sandall, et al. 2009), obtaining information to dictate a termination decision (Etchegary et al. 2008; Williams et al. 2005), seeking reassurance that a fetus is unlikely to have DS (Bryant et al. 2010; Etchegary et al. 2008; García et al. 2008; McNeill et al. 2009; Pilnick et al. 2004; Santalahti et al. 1998), and learning more about the pregnancy (Skirton & Barr 2007; van den Berg et al. 2005a) are all reasons expectant parents engage in screening. Importantly, these results contribute to the literature (Markens, Browner & Preloran, 2010) debunking the assumption that women who pursue screening are only doing so to make a decision about termination. Most of the participants who pursued screening did so to be reassured about their pregnancy and to learn about the condition of their fetus.

The reasons participants cited for declining screening and testing align with previous research that found that women decline screening and testing to avoid risks associated with diagnostic testing such as miscarriage (Liamputtong et al. 2003; Markens et al. 1999; Pilnick et al. 2004; Browner & Preloran 1999; Browner & Press 1996; Lewando-Hundt et al. 2001; Markens et al. 1999), because of the inaccuracies and unreliability of tests (Gottfreðsdóttir, Björnsdóttir, et al. 2009), because of the complexity and inconclusiveness of information provided (Baillie et al. 2000; Heyman et al. 2006; Liamputtong et al. 2003; Markens et al. 1999;

Remennick 2006), and termination not being an option they would consider (Etchegary et al. 2008; Heyman et al. 2006; Markens et al. 1999; McNeill et al. 2009; van den Berg et al. 2005a).

Regardless of participants' approach to screening, one thing is clear— no participants reported having balanced conversations with their care providers exploring the pros, cons, and potential outcomes of screening. Those who were automatically screened were not adequately informed about the purpose of the procedure and its voluntary nature, or adequately prepared for the possibility of fetal anomalies. Many of those who opted for screening were not sufficiently prepared for the possibility of anomalies or that the screen does not provide certainty or guarantee reassurance. For those who declined screening, the "it didn't matter" mindset seemed to be a powerful statement about unconditionally accepting their child. While the unconditional acceptance of a child is not logically contrary to learning about what their needs might be, when screening and testing are framed as a "test" of parents' unconditional love, it may block parents from using tests to learn about and prepare for their future child. Subsequently, like those who opted for screening, those who declined were not sufficiently prepared for the possibility of anomalies. Prompting parents with "would it make a difference?"—type questions puts them in a bind where saying *yes* seems to indicate they would love their child less, and saying *no* leaves them without information that could help them prepare for parenting. These types of prompts from health care providers may serve to close doors to those who simply seek information to be more prepared for the birth of a child who could have unique needs.

4.5 Chapter-Based Recommendations

Based on the findings from this chapter, the following recommendations are made to prenatal healthcare providers in order to improve informed decision making for prospective parents considering screening[5]. As per provincial (i.e. Saskatchewan) and national (i.e. Canada) guidelines, routinely offer prenatal screening to all pregnant women. As part of that offer:

a) Describe the procedure(s);
b) Explain the purpose of the screening;
c) Explain the voluntary nature of screening;
d) Describe the difference between screening and testing;
e) Describe the potential next steps (no testing, Amnioscentesis, CVS, NIPT);

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[5] Recommendations from every chapter are compiled in Appendix F

f) Explain that some people engage in screening to inform a termination decision, but that some people engage in screening to learn more about their pregnancy and prepare for conditions their child might have.

CHAPTER 5

"IT'S ALL KIND OF BULLSHIT TO BE HONEST": PROBABILITY INTERPRETATION IN SCREENING RESULTS

The focus of this chapter is how participants who underwent screening interpreted the probability estimates that they received as a result. Most participants described deferring to the authority of their health care providers to make sense of screening results. They also described, with hindsight, that when they received their screening results, they had a simplistic view of probability that was biased to expect positive outcomes. Several participants explained that the discussion their care providers offered about screening results did not align with their needs to understand the implications of the results.

5.1 *"He was pretty confident nothing was wrong"*: Deferring to Health Care Providers for Mixed Screening Results

Seven participants either had mixed signs in screening (n = 3) or what they considered a false negative screen (n = 4). For the three participants who had mixed indicators in screening, the serum screen indicated an elevated likelihood of DS but the ultrasound markers for DS were not present. While their care providers shared their screening results with them so that they could decide about further testing, all three describe deferring to the authority of their health care providers when making the decision. They described their care providers as suggesting further testing was unnecessary, which the participants interpreted as reassurance that their child would not have DS. For example, while Shirley described her physician as explicitly stating that Shirley and her partner could pursue testing if that was their preference, the physician also provided her own opinion, which the parents heeded:

> *… when the results came back it had shown that I was slightly high risk for Down syndrome. And I think it was 1 in 200 and— like it was high 200s, is what the risk factor was. So then from there we were sent to— um for a fetal assessment with Dr. [physician] over at [hospital] for a detailed ultrasound for soft markers and there was no soft markers detected and everything looked fine and she gave us the option of an amniocentesis if we wanted to further investigate or um the Harmony blood test as well…and at that time we kind of asked her what her opinions were. And we had the odds in our favour because after the ultrasound our risk went to 1 in 600 and something. So*

> *you know, she kind of just said "at this point I don't really think you'd need it but it's your decision" so we just chose not to… So we went through the rest of pregnancy and everything was ok.*

Senga and William had a similar experience, in which their serum screen results were elevated compared to Senga's age-related probability for DS, but their physician informed them that with all factors considered, the probability of DS was lower than their age-related likelihood:

> *So I think I was 15 or 16 weeks along when my um, quad screen or I think it was a triple screen back then, came back elevated risk for Down syndrome…Um, and then, our doctor got us into the high risk perinatologist within a few days… he did a high level ultrasound, and there was a marker, like her heart did have a bright spot, but he kind of crunched all the numbers, um, referred to our 13 week ultrasound scan, and then he was able to come up with a risk number and it was like 1 in 1200 or something like that… it was lower risk than my age at that time, so after we left that appointment, he offered to do an amnio, because he said "the gold standard is amniocentesis, because there is no way of actually knowing without that. BUT, these are your risk factors based on the numbers". So we just opted not to do the amnio because we kind of trusted that the numbers were in our favour.*

Senga described that although her care provider would not make any guarantees about DS without further testing, he seemed to imply that given the probability he calculated, testing was not necessary because DS was not likely. In hindsight William believed their care provider did not adequately prepare them for the possibility for DS. He believed the perinatologist did not thoroughly consider an ultrasound marker or convey its significance to them:

> William: *Yeah, looking back, I feel like he kind of brushed it off, the bright spot on the heart and stuff.*
>
> Senga: *Yeah.*
>
> William: *Like I think he kind of misrepresented the risks and stuff like…cause when the tech brought it up to him, he was just kind of like "oh, I'm not worried about it" and to me that was kind of— I don't know if it would have changed anything but it might have, you know— looking back I think that should have been a little more, you know, precise. For me, like I didn't know anything right?*

To William, the perinatologist did not fully explain the potential significance of the heart condition, especially considering William's lack of knowledge of what it could mean. From William's point of view, the perinatologist could weigh the meaning or significance of the heart condition in his considerations of the likelihood of DS, but without a thorough explanation, William and Senga could not consider its significance for themselves. Therefore, they deferred to the care provider's judgement and adopted his confidence:

> <u>Senga:</u> *...So I think that— I think he was pretty confident that nothing was wrong, like that she was not going to have Down syndrome. But then he did offer the amnio, like he did say the gold standard is amniocentesis, that's the only way you would absolutely know for sure. And we both just kind of said, "No, I think we're good. We don't want to do that. We both feel comfortable with everything."*

While their perinatologist technically reminded them that the choice to pursue amniocentesis was theirs, his confidence seems to have swayed them away from thoroughly considering the possibility that their child might have DS and what that might mean for their lives. Therefore, it may have led them to believe the amniocentesis was unnecessary.

Shirley's and Senga and William's experiences with their health care providers could be considered subtle 'nudges' away from testing for DS. Louisa, on the other hand, described how her obstetrician explicitly confirmed to her that her child would not have DS, without any definitive testing:

> *...A little while later, got a call from the doctor, doctor said "you have a higher chance of having a child with Down syndrome", um, but we will —um I can't remember exactly what happened from there. I think it was we went to the obstetrician at that point, and that I had a um, an ultrasound where they were testing for markers for Down syndrome, and all the markers did not show. So then the obstetrician said uh, "I hate these triple screens cause they're always—" um, not always, but— "they're 30% positive" so he said "go home, relax, you're not having a child with Down syndrome." And so that's— we walked away saying we're not having a child with Down syndrome.*

Louisa described her care provider as being completely confident that the result of their screening was a false positive despite no definitive testing. She and her partner adopted the obstetrician's confidence. When she reflected on her care provider's advice, she positioned him as having made a paternalistic decision for her:

> *I understand um, why he did it. And I think it would work great for most people. Like my husband was probably good, he probably needed to just put that out of his mind, whereas, I'm angry about it because I needed to do some more research. I needed to see what do I have in store? And I get why he would do it because he probably, I'm sure, you know some children would not be born, or given up or whatever and he didn't want that, so maybe that was his way of saying you know "it's ok, you guys can handle this", but I'm a like— I like to be prepared, so. But he doesn't know that, he doesn't know me from Adam.*

To Louisa, her opportunity to prepare for a child with DS was denied by her health care provider. She made sense of his simplistic dismissal of the probability for DS by framing his motivation as well-intentioned but mismatched to her desire to be informed.

Judy, who engaged in screening to inform a subsequent decision to terminate, did not actually have mixed screening. After expressing to her care provider that she was concerned about DS because she had a sister who had given birth to a stillborn baby with DS, she had a serum screening result which she described as very high:

> *I immediately tell him I have this sister. He says, 'oh don't worry about it. We'll get the blood test it will be fine' So I go for the blood tests and the first result was skyrocketingly high for the triple screen.*

She repeatedly expressed to her care provider that she was concerned about DS, but her care provider repeatedly dismissed her concerns:

> *…he tells me that I have these ridiculously high screening results. And he said normally …these results are so high, normally they wouldn't even report the first set of testing to people, but yours are very high. So I say, 'well what are we going to do about it', and he says 'nothing. We're going to wait for the second blood test' And I said, 'I want nuchal translucency screening, now.' Because I knew I could only get that in a narrow time frame— 'No no no. No need to worry. Just go home. No need to worry'.*

Unlike other participants, Judy did not defer to her health care provider's opinion that there was nothing to be concerned about. However, when she expressed her concern and requested additional screening, her obstetrician dismissed her concern and denied her request. Judy explained that this delay was a critical factor in why she subsequently had a later-term termination; she did not have the knowledge she needed to make an informed decision earlier in the pregnancy:

> *Because it was a termination at 22 weeks... I should never have actually had to give birth to that baby. That was horrible…Because the first step is to have the knowledge and the information to make a decision. And you can only do that nuchal translucency ultrasound at whatever it is, between 9 and 13 weeks. So there's sort of no room to screw around. You're screwing around with people's lives.*

5.2 *"All our testing was good…That's not supposed to happen"*: On False Negatives

Four participants had screening that they described as "wrong" or "false negatives". That is, all their screening results suggested a very low probability of DS, and yet their child had DS. For example, in this excerpt, Chloe described being shocked when she found out after birth that her child might have DS, given the low probability of DS that she received through screening:

> *Like so um, when I did do the blood work, and everything with the ultrasound came back good, you know, the risk that we got back was very low risk of odds of having a baby with Down syndrome. So I would say that I was relieved… All our testing was good. Ultrasounds always came back good. Like, baby was good. All of that kind of stuff…So once he was um, he must have been like in the nursery or somewhere… And so I was still in uh, the delivery area. And my husband came back and uh, crying ((tears up)) and that's when he said to me that "they're thinking that [child] had Down syndrome" and I was really surprised. I guess naive as well because I figured I had the prenatal testing. Everything was low risk. Like how could that be? That that's not supposed to happen.*

In our subsequent conversation, I asked Chloe to tell me more about the information she was given when she engaged in screening. She explained that at the time of screening she believed it would confirm for her if the baby had DS:

> *Basically, they didn't really say much. It was one of those that, you know, "they have this prenatal testing, um, basically it's blood work and your ultrasound, and it's just to see if the baby—", I guess, I don't know if it was actually said to me, or that that's what I perceived from it, but it was if the baby would have Down syndrome. Like I think I went into the testing, thinking that I would know then— yes or no.*

Chloe indicated that she did not remember exactly what her health care providers told her about screening, but that what she took away from the conversation was that she was engaging in testing (she refers to it as testing, not screening), that would confirm if her child would have DS. In her first passage, she mentioned "risks" and "odds" and thus knew to some extent that the screen was not completely confirmatory. However, she went on to demonstrate what seems to be a common cognitive error of understanding a low probability of DS to be a de facto determination of no DS.

Likewise, when Mary's screen suggested a probability of DS lower that that associated with her age, she understood it to indicate her child would not have DS:

> *And my age related risk was like 1/130 something odd. Um, and once I did the screening my risk dropped to 1 in over almost 400. So, I went forward with an understanding that nothing was wrong.*

Shirley and Senga (who had "mixed" screening results) indicated a similar understanding of a low probability screening result when they explained going forward in their pregnancies assuming their child did not have DS because they "trusted the numbers" or "trusted the odds" were "in their favour".

Both provincial and national guidelines emphasize that prospective parents need to be counselled on the fact that a negative screen (and therefore obviously an ambiguous screening result) does not guarantee that a fetus will be born without the anomalies the screen detects (or any other anomaly for that matter) (Carson, et al.., 2010; Cartier et al., 2012). However, these care providers seem to have ignored the possibility of DS rather than delve into a conversation on the inherent uncertainty of screening or the inherent uncertainty of the condition of any fetus, which the screening calls for. In fact, impressing upon prospective parents that DS and other anomalies are possible is likely warranted given that, as discussed in the following two sections, parents might have a predisposition to assume their fetus is typical.

5.3 *"We're talking pretty small chances here"*: Even with Elevated Screening Results

Some parents also tended to "trust the numbers" even when they received elevated screening results that indicated an increased chance (relative to their age-related probability) of having a child with DS. That is, even when their screening result was considered high, their focus tended to remain on the possibility their child might not have DS. For example, Camille and Oscar discussed the 1 in 80 probability they were presented with by emphasizing the 79 children who would not have DS in the 1/80 ratio:

> Camille: *So then we had the nuchal translucency test, and we were kind of, I wasn't worried about it. I honestly thought that, you know, the odds for my age, are what 1 in like, I don't know, what did they say, around 130 or?*
>
> Oscar: *Yeah, I thought it was 1 in 80*
>
> Camille: *Ok, maybe 1 in 80, but still that's 79. 79 on one side and 1 on the other. Right?...*
>
> Oscar: *We didn't know anyone with Down syn— with a child with Down syndrome, and we just didn't yeah, given the odds— we're both numbers people, so we were like "yeah there's no- we're talking pretty small chances here" even when you're talking 1 in 80.*

Alice and Charles had a similar perspective on a 1 in 54 probability. She acknowledged DS was possible, but still assumed their child would not have DS:

> *And then when I talked to Dr. [name] she had said that with the results, they were showing a 1 in 54 probability which was higher than just what I would, you know generally have. But, you know [dad] he was off in training at the time in BC, and so we were talking over the phone about this like "1 in 54 is, that's nothing to be freaked out about" and I think even at that time we had said "oh, even if it were, we would sort it out. We would you know, handle things" But at the time thinking not high likelihood.*

It could be considered rational to expect the more likely outcome. As Alice and Charles and Camille and Oscar described above, for a 1/80 or 1/54 screening result, the denominator of the ratio is larger, and therefore it is still more likely that the fetus will not have DS. However, the tendency for prospective parents to assume their child would be born without DS might be more of a bias to expect a positive outcome than an alignment with reason. Even as newly discovered indicators made a DS determination more probable, some participants continued to focus on the possibility that their child would not have DS. For example, Charles described that, even when there was a strong likelihood of DS, it still was not technically the most likely option when their 1/54 estimate creeped to 1/8:

> *Yeah, once we found out about the AVSD that's when I knew that there was a very strong likelihood. Because all the other numbers that we got— I mean even 1 in 8, you're talking 12%. It's a strong possibility, but it's not even close to the most likely one.*

5.4 *"I played the odds right till he was born"*: The Switch from Focus on the Probable to the Possible

Finally, even participants who received evidence to the contrary— probability estimates suggesting that DS was the *more likely* outcome— continued to focus on the chance that their child might not have DS. You can see in the following set of excerpts that parents slowly switch from a focus on the probable (with an exclusion to the possible) to a focus on the possible (with an exclusion to the probable) as the probability of DS goes from the least likely to the most likely outcome of their pregnancy. For example, Kurt and Zadie, who received NIPT (which they described as being 99% accurate) suggesting their child would have DS, described hoping until the last moment that the screening and testing would prove to be incorrect:

> <u>Zadie:</u> *So I do remember that, thinking like um, I think at one point there was like a 1 in 10 chance. Maybe that was— and even when we got the Harmony results in and it was 99% sure— I was still, like I accepted it and we got over it, but it was still like "oh but what if?" there's that 1.*
>
> <u>Kurt:</u> *oh yeah. I played the odds right till he was born. Right? Like without any— at the time I very honestly— I was hoping he wouldn't have Down syndrome, I think the majority of the time…I remember him being born and you know ((laughs)) looking at [child] being like "ahhhh I'm not sure if he has Down syndrome..." The NICU team is there like, you know, keeping him alive, and I'm like "ahhmmmm?"((makes questioning sound)) and I can't remember if I had asked the doctor there…he was like "he has Down syndrome" ((matter of fact voice)) and I'm like "mmmm?" ((laughing)) you know, but-*
>
> <u>Sarah:</u> *((laughs))*
>
> <u>Kurt:</u> *and it it's not like I was wishing so hard that I was like oblivious cause there was this 1 in 10 chance, and I was like "those are actually, you know, pretty good odds" right? But you know once we got— even at the Harmony test you know— 99% accurate— it was like 1 in 100— just thinking that, like you know…*

In the passages from Kurt and Charles, both acknowledged that, while they were aware of the possibility of DS (e.g. *"it's not like I was wishing so hard I was oblivious"* [Kurt]), they had not really accepted it the way they would when their child was born (e.g. "*so I knew it, but I KNEW IT when he came"* [Charles]). Another participant, Mary, also introspected about the difference between technically understanding and emotionally accepting the possibility of DS. She described her understanding of the possibility of DS as having both a cognitive and an emotional aspect. She cognitively understood that there were no guarantees, but emotionally she did not accept the chance of DS until after she received her child's definitive determination:

> *Ya, I don't think I had put much thought into it. I've certainly thought about it a lot more now…It's just all of a sudden the numbers are, I just think it's math. It's silly…So you know there are no guarantees I guess. And I sort of— I think intellectually, I thought that way before… And intellectually I understood all this stuff, but it wasn't until I'd gone through it that I think now I I've kind of integrated it emotionally as well.*

5.5 ***"Oh my gosh, like we're 1 in whatever"*: Coming to Terms with the Nature of Probability**

Several parents described having a moment of realization regarding the nature of probability (i.e., that someone has to be "the one"). For example, Alice described suddenly grasping that, although DS was not probable, it was possible, when she read a comment on an online message board to that effect:

> *…what I did was I would google the 1 in 57, you know like all of those— what those actually mean, and that's where, you know, you would get all the people saying like "oh yeah I was told this but it never was so they don't know what they're talking about" And I remember then on one of the threads one of the parents said that "look, you know, you're going— in this board we are all the 1s. You know—the— in in 57, the 1 in 2000. The 1 in whatever. And so you're going to have everybody in here with, you know, we had that experience…And I remember thinking like "Yeah, there always has to be one person where this is the reality."*

Mary also described reckoning with the nature of probability when her child was born with DS after she received a screening result that was lower than her age-related probability for DS. She explained that her initial perspective on probability was fostered by her health care providers, who seemed to assume her child would not have DS:

> *…but you know, I think what shocked me is these are just mathematical probabilities. And in the end, if you are the one, it doesn't really matter what the denominator is. And I hadn't really thought about it that way. Um, and actually, I can tell that the physicians don't really think about it that way. Because they don't really prepare you that there is the 1 in 400 or whatever it means that there is 1 in 400, so you might be that 1 in 400.*

> *They sort of look at it as the sort of risk decreasing and the fact that they don't encounter this very much. You know and if the risk decreases usually it's ok.*

She believed that, in care providers' experience, screening probabilities typically align with the outcome of the birth (it would because it is a population-based probability) and so they come to also "trust" the numbers. In her opinion, her health care providers did not prepare her and her partner for the possibility of DS. Mary's assessment is supported by previous research that suggested that, while physicians think in aggregate trends, parents are concerned about *their* pregnancy (Hunt, et al, 2005). Probability assessments are good at describing populations. They are not as useful for helping one parent or set of parents understand what is happening with their particular pregnancy.

5.7 ***"It's the numbers plus the discussion… and the bigger picture":*** **Discussion**

There is extensive evidence which suggests that most people are not good at interpreting probabilities and making judgements about the likelihood an event will occur (Kahneman & Tversky, 1984). Furthermore, individuals tend to believe they have unique invulnerability to negative life events (Perloff, 1983) and unrealistic optimism about their own insusceptibility to health challenges (Weinstein, 1987). Therefore, it is not surprising that participants in this study struggled with understanding what probability estimates meant for their particular pregnancy and continued to assume that their child would not DS. First, participants who were provided with a low probability of DS (or a negative screen) tended to overlook the possibility of DS. Next, participants who received elevated probabilities (positive screens) continued to disregard the possibility of DS even as the likelihood increased exponentially. Then, when participants had nearly confirmatory results (NIPT) suggesting their child would have DS, they switched focus to what was possible (no DS) rather than what was probable. Finally, when participants realized that their child did or would have DS, they were shocked.

That participants relayed being shocked that they could be "the 1", is not surprising considering that many felt inadequately counselled on the screening results they received. Participants relayed that their care providers did not discuss or explain probability estimates in a way that was helpful to them. For example, Shirley described how her care providers were unable to explain the meaning of the screening results to her and her partner:

> *…with this screening like there was no… they didn't even know what the results meant. Like when it comes back it was a ratio, like they didn't know how to explain it to us. They didn't know how to.... they just didn't know how to explain it to us.*

Charles explained that he believed health care providers used probability talk as a sort of shield to avoid talking about something they were uncomfortable with or unsure about:

> *Some of them would— you would tell they would feel a little bit uncomfortable and they weren't sure. And so they would use them [probabilities] to maybe give you an answer that would try to pacify you so that they wouldn't have to go into something that they weren't necessarily sure or comfortable with.*

He also described believing the health care providers he worked with withheld information because of a fear of being wrong:

> <u>Charles:</u> *What I got was a very strong fear from most people involved of anything remotely resembling a diagnosis. Um, and so to get anything out of anybody you usually had to talk to them a bit first and put them at ease. And make it clear that you weren't looking for a diagnosis…there was a very strong pressure to not have to take responsibility for anything. And that's where I think the amnio was a big one right. Because the amnio then gives you much stronger message. But even there—*
>
> <u>Alice:</u> *—well 99 point whatever percent—*
>
> <u>Charles:</u> *I was— I was— I'm 99 point whatever per cent sure that if we would have got the amnio they would have said "well this is 99 point 9 whatever" and still left— because nobody wants to be responsible for anything. And I get not wanting to be responsible but it, the lack of wanting to be responsible also blocks information from being shared".*

Charles also suggested that health care providers would discuss probabilities strategically depending on their own aims in any given conversation:

> *And the numbers got used in a few different ways over the course of it. In some cases you could tell that they were used to sort of ease back. So that you wouldn't react too strongly and in other cases, they used them to more impress upon you how big of a chance it is. Because 1 in 20 sounds far more significant than 5% right? And so they don't use percentages when they are trying to sear it into you. But when they're trying to make it seem like less of a, like something to be aware of, but not worry about, they came at you with, well, less specific numbers.*

At least some of Charles's assessment of the way physicians used statistics is supported by previous research which describes how clinicians rely on statistics as their means of non-directive communication in an attempt to be value neutral and only discuss "the facts" (Hunt, et al, 2005). Given their different goals, purposes, and values, patients and physicians can end up "talking past each other" in their consultations (Hunt, et al, 2005). Part of the problem is that physicians are concerned with presenting clinical information in a value neutral and accessible way, which tends to result in them following a script of anticipated questions and answers rather than responding directly to the issues and concerns actually raised by the parents. Hunt et al. (2005) argued that clinicians emphasize risk probabilities in their communications because they are supposedly neutral. However, patients' lack of understanding of how to interpret probabilities leaves them even more vulnerable to being influenced. A physician presents a probability and ultimately says "here's the information, do with it what you will", fulfilling their obligation to be neutral. However, as illustrated in Charles's narrative, in their attempt to be neutral, they can be interpreted as evasive, avoiding the questions and concerns that are really priorities for parents.

The experiences discussed in this chapter highlight the need for better patient counselling upon their receipt of screening results. Specifically, the difference between screening and testing and inherent uncertainty of screening results for any given pregnancy should be explained (SOGC guidelines already make this point. See Cartier et al, 2012). Then probability estimates could be used as anchors for more thorough conversations about the possibility of anomalies. As one participant, Mary, states, the screening results alone are meaningless, but they provide an opportunity for health care providers to discuss and prepare patients for the possibility of anomalies, which could bring real value to prospective parents:

> *I think it's all kind of bullshit to be honest. However, it's the numbers plus the discussion I think and the bigger picture that make a difference.*

Her perspective aligns with previous research which has found that patients are primarily oriented to the social domain where the meanings of health and illness are highly context-specific, situated within their particular life histories, and social and environmental situations (Hunt et al, 2005). Given the role social context plays in how patients make meaning of health information, a recitation of "the numbers", without a discussion of the context, leaves patients without the information they need to understand the implications of "the facts".

5.8 Chapter-Based Recommendations

Based on the findings from this chapter, the following recommendations are made to prenatal healthcare providers to improve informed decision making for prospective parents considering screening and interpreting screening results. As per provincial and national guidelines, routinely offer prenatal screening to all pregnant women. As part of that offer:

a) Describe the possible outcomes (“positive” screen, “negative” screen, and what might be an ambiguous screen);
b) Emphasize that a positive screen does not mean the fetus has DS and that a negative screen does not mean the fetus does not have DS (or any other anomaly);
c) Use the presentation of screening results as an opportunity to prepare parents for the possibility of anomalies.

CHAPTER 6

"YOUR SON HAS DOWN SYNDROME. WHEN CAN I SCHEDULE YOUR TERMINATION?": PRENATAL CONFIRMATION

Twelve participants had elevated screening (either serum or ultrasound markers) which aligned with their child's eventual DS determination. The focus of this chapter is on the often turbulent experience they had leading up to their prenatal determination and dealing with its initial aftermath. Several participants went through a period of receiving mounting but often confusing or contradictory evidence, which was challenging to navigate. Two of the most pivotal issues for these participants were decisions about whether to proceed with an amniocentesis and whether to continue their pregnancy when DS was confirmed. Participants relayed stories about care providers which illustrated their bias about DS, other fetal anomalies, prenatal testing, and termination. Combining the bias of care providers with the lack of up-to-date information provided about DS makes the prospect for informed decision making poor. Nonetheless, some participants relayed stories of demanding more information and adhering to their personal values.

6.1 Example case

A few participants who received a prenatal determination described their experience as being fairly straightforward with only minor challenges along the way. However, several participants described a convoluted process leading up to their determination. For example, Jane and Ernest narrated their determination story for 42 minutes without stopping or being prompted. They described their prenatal experience as *"an emotional rollercoaster"* with several highs and lows before reaching a conclusion.

First, their health care provider initially informed them that Turner syndrome, rather than DS, would be their child's likely determination, and that because of such a determination, a miscarriage was both likely and desirable:

Ernest: *…13 millimeters—*

Jane: *—13 millimeters—*

Ernest: *—for his nuchal fluid.*

Jane: *Yeah, the nuchal translucency. So, obviously that's very quite high and um, so in the radiologist's report, it indicated a chromosomal abnormality…But what they, what*

> *they had suspected was Turner syndrome. So at that point, Down syndrome wasn't mentioned or wasn't even on the radar. And um, so, during that meeting we tried to get as much information as we could, and um, just asked some more questions— "ok, Turner syndrome, what exactly does that mean?" and so she ah, let us know that it's um, only in girls, in female children, um, and wasn't very positive from that point on. Um, I guess, had indicated that it was very likely that I would have a miscarriage, and um, and said that it was be a blessing if I did. And um, yeah, cause I guess I asked the question "so at this point, it's likely that you know the baby won't make it?" And she said "yeah, it's likely you'll have a miscarriage" I said, "Ok, could it happen at any time?" And she said "Yep, any point it can happen and then yeah, that's when she said "and it would likely be a blessing if" you know," if you don't' have the baby" and uh, so we left that appointment pretty much destroyed and in tears.*

From that point, they described a need to know more about the pregnancy in order to make an informed decision about termination:

> Jane: *…I did a bunch of phone calls back and forth with them, to find out like what kind of testing can be done. So like I, obviously looked online or whatever, and found what different tests were available, so at that point I pushed for the amnio, that I want the amnio. I want to know for certain…*
>
> Ernest*: Because at this point termination was still a potential option right?*
>
> Jane: *Yeah. So like, our motivation, I guess, was that our child has a very unlikely chance of surviving. So we need to know for sure, before we make a choice. And at that point, I think, um, if it was Turner syndrome, we were probably leaning towards terminating the pregnancy. Um, but I don't know, I guess you can't really say that. We got beyond that point so we didn't have to make that decision in the moment, but— um, so ya, I had been in talks with them about what I wanted done at that appointment. So, I did want to have the amnio. I understood the risks, the 1%, um, of miscarriage at that point.*

In the meantime, they prepared for the future with the information that they had available. They believed that, because of the likely Turner syndrome determination, their child would be a girl and that their pregnancy would likely end in miscarriage. They were preparing for a funeral:

> Jane: *And at this point in our heads, um, we had thought it was a girl, because of the Turner syndrome. So we were preparing for a girl. Um, you know, in the three weeks*

> *between those two appointments when speaking with our families or whatever it was "it's girl" and you know, "we're likely going to lose the baby" and um, even planning like a funeral, like and all that kind of stuff.*
>
> <u>Ernest:</u> *Yeah, I phoned [funeral agency] just to talk about options of what do you do um, because it would have been late if that was what we were going to proceed with…*

However, at the amniocentesis appointment, Jane thought to ask about the sex of the baby, the result of which completely changed their perception of the pregnancy:

> <u>Jane:</u> *...so then at the end of the amnio, um, I asked the ultrasound tech, like "oh, well, when will we find out the gender of the baby?" ...and so the technician was like "Oh we can tell you right now" She's like "you've got a lot of blue in your future"...*
>
> <u>Ernest:</u> *And before we didn't want to know the gender but you're witty to ask the question because if it's a boy, then—*
>
> <u>Jane:</u> *—then it's not Turner syndrome. Which is a whole other kettle of fish right?*
>
> <u>Ernest:</u> *mmhmm.*
>
> <u>Jane:</u> *So you go from a 1% chance of survival to this is a whole other thing. Right? And um, yeah. So we kind of looked at each other and we were kind of in shock…So I confirmed, "so that means that our baby does not have Turner syndrome right?" And they said, "yep, absolutely right. The baby does not have Turner syndrome" So that was a crazy aha moment for us. And um, so we're like "Ok, then it's likely Down syndrome"*
>
> <u>Ernest:</u> *And this isn't super relevant to the story but the song that played on the radio was uh, Happy by Pharrell, and [smiles/tears up]*
>
> <u>Jane:</u> *So we left— like we went out of the room and we just kind of looked at each other and hugged and celebrated and at that point we knew our child likely wasn't going to die.*

Later, they received the results of the amniocentesis, which indicated their child would have DS:

> <u>Jane:</u> *at nineteen and a half weeks um, he called me at my office…so he called me at work at like 4 o'clock Monday and uh, at this point I'm expecting that you know, you're secretary would give me a call and say "please come in to our office, I'd like to talk to you and your husband. We have your results" But no. That did not happen. So doctor [physician] blurts out on the phone, "Um, your son"— or your child, or baby or whatever— "has Down Syndrome". So that's something that is shocking and you need to process and not really an appropriate way to deliver a diagnosis. And um, yeah. So, I*

> *guess, I— how do you process that? I don't know. I'm on the phone with him, my husband is not there, I'm in my office, I luckily had the door closed– in tears.*
>
> Ernest: *Well and he said more too, didn't he?*
>
> Jane: *Yeah. And then, um, like previously when we had the amnio, and we were con— um, like, we did think that the baby had Turner syndrome, and had discussed the options at that point, termination did come up as an option. Then after we found out that it wasn't Turners and whatever, it was likely Down syndrome and you know these are things you need to consider right? So, yeah, the next thing he said after "your son has Down syndrome" was "when can I schedule your termination? Would you like to come in on Friday and have the termination?" And I was like "...you know this isn't necessarily the course of action that we would like to take"... and he said "well, like I thought that was something that you had discussed when we were— when you were in my office" and I said, "well, you know that was a different circumstance"... And I guess having the experience that a large percentage of couples would make that choice at this point, that that's maybe where they go. It felt like, um, we were being pushed in that direction. And um, which is in my opinion, not appropriate…*

They also requested more information via an anatomy scan:

> Jane: *And we pushed for further testing and more information. And so we did— it was cutting it tight— but we did the anatomy scan, um, almost right at 20 weeks, like and um, so at that point we found out that [child] had a VSD, so heart defect that ventricular septal defect…And um, no bowel blockages, so he didn't have any issues there. His kidneys were fine. Um, basically every–*
>
> Ernest: *–Just the ASD tube—*
>
> Jane: *—Yeah, well at that point it was just VSD, we didn't know about the ASD…So that was all we knew and then, so when we met with him after that to go through um, that you know, he was he kind of looked at us and said, "you know like with this information, like this is something, this is a pretty common heart defect. A lot of kids have surgery and ah, basically, you guys can get through it. If this is what you want, you guys can get through it." And like, I think he even went as far as saying like "I don't think, like on this alone, this defect alone, in your child, I don't think you should consider termination, or*

> *something" or basically, like acknowledged our decision to not go ahead with termination at this point.*

Jane and Ernest's story more or less aligns with previous research on receiving DS determinations. Jane expressed she was dissatisfied with the duration of their determination consultations (see Hedov, et al, 2002); dissatisfied with receiving the determination without her partner present (see Skotko 2005b); suggested her care provider had poor communication skills for delivering the news (see Hedov, et al, 2002); reported that the care provider at least initially implied that the birth of a baby with DS is a regrettable happening (see Skotko 2005b); felt rushed to make a decision about continuing the pregnancy while on the phone (Skotko, 2005a); and reported feeling pressured by their health care provider to terminate the pregnancy (Nelson Goff, et al., 2013). This kind of experience was common in the narratives of those who received a DS determination prenatally. In particular, participants relayed increased tension around the time when they had to make decisions about engaging in amniocentesis or terminating their pregnancy. In addition to grappling with their own beliefs about these practices, they also had to contend with the opinions of their health care providers, friends, and family without being provided any or adequate information about DS.

6.2 *"Weigh your options"*: The Amnio

Amniocentesis was a salient and polarizing topic. Participants tended to discuss amniocentesis in one of two ways. Some participants, like Jane and Ernest, discussed it as a tool of informed decision-making and preparation:

> *So at that point I pushed for the amnio, that I want the amnio. I want to know for certain… I understood the risks, the 1%, um, of miscarriage at that point… I believe that people should be prepared, and they should have all the information. And I can't imagine going into that pregnancy, and going into that birth, not having that information.*

Likewise, Donna described that she and her partner opted for an amniocentesis to be prepared:

> *We weren't going to do the amnio, but we decided at 32 weeks that we would just so we could be prepared and the NICU could be in there with her and everything when she was born.*

Margot explained that she had a need to understand what was happening with her pregnancy:

> *…well they did ask me if I wanted it done and I was like 'well we have to know what the heck's going on here, right?*

And Virginia and Stephen narrated that they wanted to know what to expect:

> *…that's one of the reasons that we had uh that amnio done so late. Um, we knew it wouldn't change anything, but we just wanted to be prepared and to be able to process that news before we had the baby.*

The rationales of these participants provide support for the assertion that prospective parents engage not only in screening, but also in testing to gain knowledge about their fetus and prepare for birth and parenting. Amniocentesis is not only pursued for making termination decisions.

However, the other most common perspective on the amniocentesis was that it posed too much of a risk to the fetus and was unnecessary given that these participants would not consider termination. This perspective was illustrated by Alice:

> *And I said "I'm not having an amnio, I don't want to risk losing this baby to miscarriage" because the amnio wasn't going to change our minds about anything. We were continuing with the pregnancy. We had told them termination was not an option for us.*

Some prospective parents believed the benefit of information gathering outweighed the risk of miscarriage. For others, the risk outweighed the benefits. These are their personal choices. However, many of the participants who did not want the amniocentesis reported that they felt pressure from their health care providers to confirm their determination. Alice explained that, coupled with an already stressful pregnancy, this pressure was taxing:

> *But it was just the lead up that was, that was stressful. The rollercoaster of "things are good" "no, they're not" and then yeah, the pressure to do an amnio so that you can make a decision, you know, when our decision was very clear that we just wanted to continue on and wait it out and see what happens. But that being said, wouldn't change the fact that we did the serum screen or any of that because it made me that much more aware and always in the back of my head… we made it very clear that "yes, we understand but no, we're not doing an amnio to confirm, because we're continuing the pregnancy" — I think that should be a clear enough signal that they can stop pressuring us to do an amnio.*

Alice's story supports the claim that women can engage in screening without an intent to pursue testing. However, care providers might have a prejudice that screening is engaged in to make a decision about testing, and a positive screen should be followed up with confirmatory testing. Alice described her care provider as assuming that because she and Charles engaged in screening they would automatically pursue confirmatory testing:

> *He seemed much more judgemental and much— he was pushing for an amnio. And he had even said with the maternal serum screen– "why did you get that if you're not getting an amnio?". And I said "because we wanted to be prepared if there were any, you know things that showed up in the screen to prepare us for that." And he said that the purpose of the maternal serum screen is to tell if an amnio is required. And so there's a lot of back and forth with the amnio where he really wanted to push for that…. Um, I just remember him flat out even saying— like when I was saying no to the amnio— "AND IF THE CHILD HAS DOWN SYNDROME?", as if like that would somehow shock me into being like "oh, well I didn't think that was possible"*

According to Alice, her care provider seemed to believe that she must not fully appreciate the possibility of DS, given that she and Charles opted not to pursue amniocentesis. However, she felt comfortable living with the ambiguity until birth. Another participant, Ursula had a similar experience wherein the frequency with which she was offered amniocentesis felt like pressure to engage in testing as well as pressure to terminate a pregnancy with DS:

> *I noticed a lot it's always like, even how my doctor said, "weigh your options" so it's very talking about like, "do you want to have an abortion?" "do you want to have an abortion?" And by that time you're about 20 weeks pregnant when you find out. Even if you have your serum and they— because the only way to be 100% sure is that you have an amnio, um, and they can be very dangerous, and they ask— like I got asked if I wanted to have an amnio, I— like a lot.*

She felt like her health care providers needed certainty or assumed that she and her partner needed certainty via a determination; but she did not and was able to appreciate the likelihood of DS without confirmatory testing:

> *Um, but then you'd get asked again later. And it's always like the whole time going along like [child], in the ultrasound she didn't have a nose bone, she had a hole in her heart, her kidneys were different, um, my blood serums were really really high, so that's like a 97 or something. That like doctors still ask you if you want an amnio because that's the*

> *only 100%? Or they'll keep saying that your child MAY have Down syndrome. It's like "our child has Down syndrome" [matter of fact tone]*

However, Ursula was a unique case, because she was one of the few parents (perhaps the only parent, according to those who discussed it explicitly) who did not continue to hope that her child might not have DS until the last confirmatory sign, as discussed in Chapter 5.

The different perspectives on confirmatory testing underscore the importance of providing information, providing available options, and respecting prospective parents' choices, even if they are not the most common choices, or the choice that the care provider personally endorses. The findings underscore that an openness to screening does not necessarily indicate an openness to testing, and that testing does not necessarily indicate a plan to terminate.

6.3 The Husband, the Church, the Friends, the Parents, and the Physician: Proximal and Distal Social Actors in Considering Termination

While several participants indicated that termination was never under consideration for them, others reported having engaged in onerous and emotional deliberation about whether or not to end their pregnancy. Jane described the time she and Ernest spent making a final decision about continuing or terminating their pregnancy:

> *He gave us the results of the scan— the 20 week scan— and then was like "Ok, you need to make a decision by this date if we're doing the termination needs to be done, like before 20 weeks." So it was like days between all this happening. And we were at home, we were off work, we were a mess. We were crying on the couch for days on end, trying to talk it through. We basically were hermits in our own home, just him and I talking through everything… And going back and forth, like ya, to be honest like I think during the time we went one way or the other way and that switched probably hourly at that point.*

Camille also described that she and Oscar spent significant time grappling with their beliefs about termination. She explained that, for them, the determination might have changed their perspective on termination:

> *I mean we had gone into it saying this is only for information and we're not going to terminate. But when you find out that your child has a chromosomal abnormality that's all off the table. We had all those hard conversations…we did a lot of talking and soul searching around it.*

As Lawson and Pierson (2007) argued, women are influenced by their proximal and distal social context when they make reproductive decisions. This is clear in Camille and Oscar's and Jane and Ernest's recounting of their termination considerations. They had to contend with the views of family, friends, physicians, and their religious institutions while they grappled with their personal beliefs.

6.3.1 The Husband and the Church

Oscar explained that his religious beliefs played an important role in his considerations around termination. Oscar positioned himself as being supportive of Camille's choice in the matter, but explained that he anticipated negative outcomes for her, for their relationship, and for his religious identity if they chose termination:

> *Um, one of the things about the decision to terminate, I um, I kind of, ah— I'm Catholic. Um, but [mom] is not. I told [mom] that—and I don't know if this is entirely fair um— but I told [mom] that I would support whatever choice she wanted to make. However, knowing [mom] I felt that if she chose to terminate it would not be something that she would be able to live with. Um, I was very concerned that if we had terminated that um, not through anyone's fault or through anyone's wishing it to be so, but it would have been the end of our relationship. Um, I uh, cause I just don't think we would have been able to get over— you know, we'd look at each other and see the grief of the thing we had done. Um, I um, like I say, I don't know if it's entirely, if it was entirely fair for me to kind of put the whole decision on her, but at the same time I was kind of like "I can't force you into this and I can't force you out of it" you know, so I didn't know any better approach. I mean, my faith says, you know if you have an abortion you are ex-communicated. And I mean, I know a lot about the church, so I also know that that doesn't mean I'm going to Hell, ah, it means I'm— I'd be ex-communicated and I'd have to talk to a priest. And get it sorted out. Ah, but I also know that it's something that I would have worn for the rest of my days. Um, uh, so that's kind of where I was, and that's kind of what I pushed…I did kind of say to [mom], you know, "I will back you in whatever you do." And that, I would say I don't know that that was entirely fair, because that kind of, I didn't want to put it all on [mom] in some way. So, but I also didn't want to force her hand.*

In line with Lawson and Pierson's (2007) argument, Camille explained that she did not want to have her baby, and yet she proceeded with her pregnancy because of proximal social forces—Oscar's beliefs about abortion:

> *It's interesting because I didn't want to make a decision, right? I sort of a long time ago decided that I was going to keep any baby that I had. And yet when push came to shove I didn't want to. I really didn't want to. Um, I didn't want to make a decision. I wanted to have a miscarriage so that I didn't have to make a decision…I kind of abdicated my responsibility for making the decision to [dad]. He says he put it all on me, but I put it entirely on him and his faith. I said, "it will be really hard for [dad] if I choose to have an abortion. So I won't" And that's it. That's how I made my decision. It was not about- yeah, I made my decision for [dad].*

Although Camille and Oscar decided not to terminate their pregnancy, they did not decide to continue their pregnancy because they decided they wanted a child with DS. Their preference was to not have a child with DS; however, their beliefs about termination constrained their choice to continuing the pregnancy. Oscar described that they hoped for a miscarriage:

> *She had said there's a higher risk of miscarriage…And it was at that point that she said "50%" and so we did do a lot of hoping that it would— that the "PROBLEM" with air quotes, would go away on its own. Because we'd sort of come to the conclusion that we didn't— we weren't going to terminate. We were going to, I don't know, take the approach of what will be will be. You know, if we have a miscarriage then we have a miscarriage and if we don't, we'll have a child with Down syndrome.*

6.3.2 The Friends and the Parents

Other actors in their proximal social context were friends and parents. Some participants reported receiving relatively unbiased support from friends and family, but some family and friends explicitly tried to sway termination decisions which participants found stressful. Jane described receiving disparate recommendations from family members, which she frames as an additional stressor:

> *Praying, asking for answers…On the phone with our parents. And um, both our parents had different points of view. Mine were pushing for termination and um, said some things on the phone that you can't ever take back. And um, and I guess, with his parents, the options of termination never really came up. So, they were really just excited and wanted*

> *us to look forward no matter what I guess. So, we had yeah, definitely my family over here, and his family over here, and…So yeah, like dealing with family opinions on the subject as well.*

Oscar also had a conversation with a work colleague who strongly recommended Oscar and Camille terminate their pregnancy based on his experience with a child with a different condition:

> *So one significant conversation with a co-worker whose child had passed away previously from Tay-sachs, um, and I asked in the context of what his experience with the kids at the children centre had been like, but he— you know I explained my situation to him and he very flatly looked at me and said "abort" and I was like "I'm sorry?" and he's like 'You definitely want to abort this child. You do not want them to have a life of suffering. It is not fair. It's wrong. You have to abort this child". And so the conversation went on a little bit and I kind of explained, "look that's not what we're talking about"… it shook me up a bit.*

6.3.3 The Physician

Physicians are important actors in one's proximal social context. Women identify physicians as some of the most important individuals from whom they need support for their reproductive decisions (Wohlgemuth & Lawson, 2005). Jane and Ernest considered the counsel they received to be biased towards termination:

> *…so at this point we had a few days to make a decision. He was still somewhat pushing for termination…We were scared, inexperienced first-time parents going into a doctor's office and feeling like we're being led down one path… pressure from parents, from society, from medical professionals… it very well could have went that direction. You know if, being, not being the strong, you know, people that we are, we could have been led down a different path and have regretted it.*

They felt like their health care providers went beyond relaying information about the conditions under consideration (DS and Turner syndrome), and provided their personal opinion on the value of a life of someone with a disability, which they considered inappropriate:

> Jane: *…I just, yeah, will never forget the words— "It will be a blessing"*
>
> Ernest: *I remember my thought was that, and this is just from my perspective, it was not her job to tell us what would be— what we should feel. It's her job to give the*

> *information…You tell me the facts of the situation… the medical community… honestly, I don't know if they get a vote…we definitely felt the push for termination. And there should not be that.*

Another common way that physicians' beliefs about DS was apparent was their tone in delivering a prenatal determination. Contrary to guidelines (Skotko, Kishnani, et al., 2009), Oscar received their child's determination over the phone and their care provider framed the determination negatively by apologizing for the determination:

> *They called, with the results and they got me at home alone. And I didn't really– like I knew they were coming. And I was ready to hear that we, you know, we were having a child with Down syndrome, but I would have liked for those results to go to Dr. [physician], and then for her to have said "come into the office" or let's pick a time when you're both going to be home and have this conversation. Cause it was like… the doctor called and he said "I'm sorry to tell you, that your child has Down syndrome." And I distinctly remember the "I'm sorry".*

Participants also reported that they believed some of their care provider's personal opinions about terminating a pregnancy in general, or terminating a pregnancy because of a DS determination, influenced the options they provided to their patients. On one hand, Arthur and his partner were not informed about why they were being transferred from their regular care provider to a specialist, which he believed was strategic so that they would not consider termination:

> *He didn't tell us that we were having a special needs kid and what special needs we were getting, right? And we believe he withheld that information because he was so strongly pro-life that he decided to not tell us so that we would have no option to abort or anything. We believe that's what happened because just when you look— we didn't know at the time, but when you look back we got transferred …to a pediatrician. Why? What's the reason? He said because we're expecting complications. That's all he gave us right? But we actually, we don't have any proof but we really do believe that he knew exactly what was going on, and what was going to come out.*

Likewise Judy, who decided to terminate her pregnancy, reflected on why her health care provided repeatedly told her not to worry about what she described as very high screening results, and refused her request for a nuchal translucency scan. In her view, the care provider was restricting her choice because of his own personal beliefs:

> *It was either making a value judgement, which is what I believe, and I believe that he, for him, termination was not an option, so he didn't give that option to us– or he was completely ignorant of the facts.*

On the other hand, other care providers offered counselling that was skewed against termination. Oscar's care provider gave him her personal opinion that women who have abortions do not recover:

> *Anyway. I had a conversation with my family doctor, where I kind of faced my doubts and said "am I doing the right thing by going forward with this pregnancy? Are we, like are we doing the right thing? Or am I being selfish?" And she said… "I have worked with the women who have abortions and they don't get better afterwards" that's what she said. She was like "they, they don't get better after".*

6.4 Information Provided

Given the pressure prospective parents were experiencing from proximal and distal social forces, accurate up-to-date information could have helped them to understand their DS determination and make informed decisions. No participants who underwent screening for DS in pregnancy reported receiving any information about DS with which to make the decision to engage in screening or testing. Some participants, like Chloe, explained that from prenatal screening up to the birth of her child and beyond, learning about DS has been self-directed:

> <u>Sarah:</u> *When you were going through the prenatal testing, before you got the testing or during that time, did anybody tell you anything about Down syndrome then?*
>
> <u>Chloe:</u> *No.*
>
> <u>Sarah:</u> *…Um, when the pediatrician gave you the diagnosis finally, from the genetic testing, that was by phone?*
>
> <u>Chloe:</u> *Yes.*
>
> <u>Sarah:</u> *And at that point, or subsequent to that conversation, did you get any information about Down syndrome?*
>
> <u>Chloe:</u> *No. I honestly, I don't think we ever received any really about it. Like there was never a point where someone talked to us really about it. Or gave us any kind of reading material. It was "this is what it is. And you move forward."*

Jane and Ernest received information, but to them it was outdated, focused on the negative, and overly medical in nature:

> Sarah: *When he was telling you about Down syndrome, you said he sort of gave this spiel that seemed fairly outdated, can you tell me a little bit more about what that included?*
>
> Ernest: *It just seemed very 1980s textbook.. the information we got was 1980s textbook. Like the furthest it would go was "many lead productive lives"…*
>
> Jane: *…like it kind of ran down all the medical issues that an individual with Down syndrome could have, so you know, heart defects, and um, bowel disorders, kidney issues, um, short stature, I think even at one point he said, "oh, he may or may not ride a bike" stuff to that degree.*
>
> Ernest: *Maybe life expectancy, maybe. Like maybe incidence of Alzheimer's…*

Other participants, like Alice, explained that the lack of information provided is a barrier to informed decision making:

> *I would just say about that, you know, there is a lack of that information that's provided. You know, as soon as a person starts getting some indication that there's a greater probability, if there's some type of information that could be shared or even where they could go to for—you know, information that's evidence based. Not just Googling randomly and finding somebody's blog or you know the BabyCenter message boards because those things are all over the map…If that parent, at that time is feeling, you know pretty devastated already, you know, I don't know what stage it would be at, but at least then they would have some information that they could use then to help them make an informed choice.*

It was common for parents to explain that, with the lack of information they were provided, they engaged in haphazard internet searches which resulted in what turned out to be inaccurate or exaggerated information. As Alma said, *"you are just floundering in this big world of internet".*

Judy, who made a decision to terminate her pregnancy, also reported not being provided with adequate information in a timely manner. She explained that ideally, she would have received information and had a meeting with a genetics counsellor before she engaged in testing:

> *…even before the testing is when you need to have some preliminary information…you're left sort of asking your friend. That's not a good way to be educated. So, at that point, that's when the genetics counsellor should be involved.*

She described that, instead, a genetic counsellor came to speak to her and her husband immediately before her termination, timing which could not contribute to informed decision making, but did contribute to her stress:

> *A person from the genetics lab came, about five minutes before they inserted the medication to start the termination. And started talking to me about grains of rice… and how this is totally a random process… And I, that's all I remember of their whole spiel. And I remember, just remember, saying to the lady 'get out' I said 'what are you doing here five minutes before this procedure is about to happen? We've been sitting at home for 7 or 8 days or however long it was we were waiting for this amnio result. There was ample time for someone to contact us.' Like what good is this going to do now?*

Judy explained that in hindsight she believes that she would have still chosen to terminate her pregnancy, but that even those who are choosing to terminate should be provided with written information and an opportunity to ask follow-up questions:

> *Even if you are saying I wish to terminate, I think you should have been sent home with a pamphlet, at least. But the other thing that I think people need to realize is that a pamphlet doesn't really cut it. You need to be able to talk to someone and ask someone questions. You know like reading about it is one thing, but then that just creates more questions than answers.*

Likewise, Zadie and Kurt, who continued their pregnancy with a DS determination, also explained that when they finally received helpful information post-partum from the Saskatchewan Down Syndrome Society, it felt like it was too late because they had been dealing with the determination for months:

> Kurt: *…we should have had [this information] four months prior… I remember reading and like, "we already have a child with Down syndrome", like "huh" like, of all the research we did… you know, "I should have had this a while ago", right?*
>
> Zadie: *Yeah.*
>
> Kurt: *When you asked the question what sort of information we had, the first thing that came to mind was that right? Cause that was the one thing, through all the medical professionals we saw— NICU, the NICU doctor, [laughs] great doctor, bedside manner— I've never seen worse. Comical actually.*

6.5 Discussion

The trajectory from engaging in screening to receiving a DS determination tended to be nonlinear and complicated. As Jane and Ernest's story at the beginning of the chapter illustrated, there can be an extended period of knowing that something may be atypical with your pregnancy without knowing exactly what it is. Assumptions about the nature of the issue may change several times before it becomes clear. This period is unfamiliar and confusing to prospective parents who were expecting a typical pregnancy. Their expectation for how prenatal care would proceed is disrupted. In this unfamiliar future, parents are required to make decisions that they had not anticipated and therefore had not previously considered. They have to consider probabilities, which, as discussed in Chapter 5, they are not usually good at doing. They have to consider prenatal markers, which can be difficult to interpret for specialists; for parents to understand their implications is even more of a challenge. And they have to consider conditions, DS for one, with which they are usually unfamiliar. In sum, they are in a vulnerable decision-making position.

Findings in this chapter overwhelmingly align with previous research that has suggested that parents are not making decisions in a vacuum (Lawson & Pierson, 2007). Participants experienced pressure from family, friends, and their partners, as well as social institutions. Aligning with previous research, physicians tended to imply or explicitly state that the birth of a baby with DS is a regrettable happening (Skotko 2005b), parents felt rushed to make a decision about continuing the pregnancy (Skotko, 2005a), and parents felt pressured by their health care provider to terminate the pregnancy (Nelson Goff, et al., 2013). They tended to be dissatisfied with the duration of their determination consultations (see Hedov, et al, 2002), dissatisfied with receiving the determination without their partner present (see Skotko 2005b), dissatisfied with the lack of up-to date information provided to them (Hedov, et al, 2002; Skotko 2005b) and dissatisfied with their care provider's communication skills for delivering the news (see Hedov, et al, 2002). Most importantly, participants relayed that care providers were not neutral in their discussion of amniocentesis, termination, and DS itself. Without a neutral, information-driven approach by care providers the potential for informed decision making is undermined.

However, although parents are vulnerable to social influence, it was clear in several narratives how they continued to be agents. They did not simply accept the way their providers framed DS, amniocentesis, or termination; nor did they simply accept the incomplete counselling they received on these issues. For example, Jane explained how, when her care provider relayed her child's determination on the phone and asked her to make a decision about termination at the same time, she refused to do so and insisted on better decision-making conditions:

> *I was like "Whoa, kay whoa." Like "first of all I need to tell my husband this news…this is something— like we need to meet with you, we need to discuss this in person, like I can't just make this decision on my own obviously"… I said, "I need to talk to my husband, we need to discuss, this, we would like to meet you in person, so on Friday we will come in and meet you in your office and discuss all of our options."*

She also described how she and Ernest pressed for more information so that they could make the most informed choice possible:

> *And we pushed for further testing and more information…We were seeking information, right…Asking for the anatomy scan and wanting, you know an ultrasound of his heart, and wanting to know everything that we were dealing with up front. So we could make an educated decision…. It wasn't just Down syndrome, yes or no, it's like, kay, well what all is the story with this child and this birth? We need to know everything and then we need to analyze and then make a decision.*

Jane and Ernest highlighted that they used screening and testing as information gathering tools so that they could make a personal choice. Thus, although parents are in a vulnerable decision-making position, they are not incapable. For most participants, their vulnerability is because of their lack of knowledge about the procedures and conditions under consideration, not their inability to deliberate or come to their own conclusions. Their vulnerability highlights their need for accurate up-to-date balanced information, not their need for someone else to direct them towards one decision or another.

6.6 Chapter-Based Recommendations

The experiences and opinions relayed by participants in this chapter reinforce existing recommendations to health care providers regarding how to deliver determinations outlined by Skotko, Kishnani, and colleagues (2009) including:

a) care providers use neutral language;
b) the news should be delivered by health care providers with the most knowledge about DS and who have received specific training on how to deliver sensitive determinations;

c) the news should be delivered in a personal visit or, if necessary, a phone call at a predetermined time;
d) health care providers must provide information about what DS is, medically and socially, including realistic expectations for children with DS today;
e) they should offer an up-to-date balanced bibliography of resources on DS;
f) they should offer follow-up meetings with themselves and other relevant health care providers (Skotko, Kishnani, et al., 2009).

In addition, the findings underscore the guideline by Cartier et al., 2012 that, upon providing a determination, prospective parents should be counselled that (as with any pregnancy) they have the option to continue or terminate the pregnancy. Once a prospective parent has made a choice, that choice should be accepted and respected by care providers. Uptake of these recommendations could improve prospective parents' satisfaction with determination experiences, and improve informed decision making about continuing or terminating pregnancies with DS determinations.

CHAPTER 7

"I WAS LIKE 'WHEN CAN WE TALK ABOUT BEING DISCHARGED?' AND HE SAID 'I'LL GET BACK TO YOU'": POST-NATAL DETERMINATION

In addition to the seven participants (or couples) who had either mixed screening or "false negative" screening, another twelve participants (or couples) were not expecting their child to have DS before they were born. Four of these participants waived screening; another six did not explicitly mention having declined or undergone screening. Like Emily, — *"it was a normal pregnancy. Everything seemed ok"*— they detailed that, as far as they knew, there were no indicators of anomalies, and they were expecting a typical child at birth. Some parents became aware that their child could have DS soon after birth. Others described an onerous process in which several care providers offered them different and confusing opinions, the medical staff around them seemed to know something they did not, and/or while they were certain something was atypical, their care providers dismissed their concerns. Although the experience appeared to be inherently emotional (see Chapter 8), participants explained how the behaviour of their care providers could either exacerbate or alleviate their stress.

7.1 *"I knew that there was something. I don't know why…"*: Mothers' Intuition and Delayed Determinations

Some participants were informed about the presumed determination relatively quickly after birth. Their delivery team noticed indicators of DS and the presumed determination was delivered in the labour room. For example, Simone explained that her baby had trouble breathing immediately after birth, and that it was when her health care providers were dealing with this complication that they noticed and informed her of the potential for DS:

> *I didn't get the screening done, but I had a couple ultrasounds. And they didn't discover it then. And she also had a hole in her heart which they didn't discover in the prenatal ultrasounds. So yeah, I went to the hospital to have her and then everything was going fine. And then ah, once she was born, like they put her on me just like briefly, like for a split second, but she was um, like blue and couldn't breathe. So they had to— they took her off me right away and were working on her in the corner and I had no idea what was going on. So they— I think they had to, they had her five minutes or something, and I think as they were looking her over then they thought that she had some characteristics of*

> *Down syndrome. So once they had her stabilized, or as they were getting her stabilized, they came and told us that, that she has some characteristics of Down syndrome, but like we won't know for sure until we do the testing.*

Other parents had some time with their baby after birth before receiving the presumed determination. Several mothers (and one father) described knowing or sensing immediately that their child had DS. For example, Harper explained that even though she had little knowledge about DS or what might indicate DS, she felt like she knew her baby had DS from the moment she noticed something slightly unfamiliar with his toes:

> *I remember his— I noticed his toes, his feet. He had the space between his toes, so I was like "[dad], something looks funny with his feet" and he's like "I don't think so, I think they're fine" and yeah, then the resident doctor had asked if we noticed anything different and so then he had left and my family doctor came in later that evening and then she asked if we noticed anything about [child] and so I had said about, I thought his feet looked funny and then right away started crying because, [tears up] sorry I'll get emotional, I knew that there was something. I don't know why because I had no idea that that was a marker for Down syndrome. I didn't really notice in his face because they're kind of squishy when they come out anyways. But in the back of my mind I knew that it was Down syndrome.*

In some cases, health care providers addressed the issue within hours after birth and engaged in discussions about DS. For example, Senga described noticing her daughter's eye shape and having a discussion about DS with a physician shortly afterwards:

> <u>Senga:</u> *...they put her little hat on her and wrapped her up and handed her to me and that's when I looked at her eyes, and I SAW that she had the folds in her eyes and I just felt like my stomach dropped. And they still hadn't said anything yet. ...*
>
> <u>William:</u> *Well I remember the nurse came in first and she was like, did the doctor talk to you?... and as soon as she left, you turned to me and said "she has Down syndrome" ...because, you'd assume there's no other reason why the doctor would come in and talk to us...*
>
> <u>Senga</u>*: And then the doctor came to the door...and said "I was just looking through your chart and like looking at all of your prenatal tests", and then I think I stopped her and said "I know why you're here" and she's like "Ok", and then I said, "I see it too" and*

> *then she was like "Ok, there are a few markers that lead me to believe that she might have Down syndrome. Um, she doesn't have all of them, so I don't know for sure, but this is what I've seen." And then she offered to get the neonatal nurse practitioner over to talk to us, so then, [practitioner] came over and uh, she kind of went head to toe with [child] and pointed out— like the only thing she ended up having was she had a bulge of fat on the back of her neck, a fat pad back here, and then the eyes. Like she didn't have the normal simian crease that you would find with Down syndrome. She didn't have a lot of the other things, so we were still— but I just, I knew. Like as soon as I looked at her eyes I knew.*

Others care providers were dismissive of the mother's concerns even when the mother was persistent. For example, Zora (another maternity nurse) and Edgar described that Zora suspected since pregnancy that their child would have DS, and had her concerns and their child's health problems dismissed numerous times, to their frustration. First, in pregnancy Zora's suspicion of DS was dismissed:

> <u>Zora:</u> *when we went for the 20 week ultrasound, there was an echogenic focus on the right ventricle, and my first words out of my mouth were, "so he has Down syndrome" and then I said, the next words out of my mouth were "Can I have an amnio?" and my doctor said…no. Why did he say no, do you remember?...*
>
> <u>Edgar:</u> *Well, because it was only that one, it was just one marker and he was like "no no, it's common, lots of kids have it. It doesn't really mean anything. It can be connected Down syndrome— it could be connected to anything." [Mom] wanted an amnio, he sort of sluffed it off.*

After birth, Zora noticed indicators of DS, which she mentioned to a nurse, one of her coworkers, who again dismissed her intuition:

> *My very first, the first minute I saw him, the FIRST thought in my head was "what the FUCK, he had Down syndrome"…I was just in shock…Um, so that was my first thought and then I asked one of the nurses, like he was born at seven in the morning and then like and I had an epidural and I had to have morphine, and so I was like maybe he has low tone because of this, right? But I knew, in my heart and I didn't say anything because I wanted to talk to the pediatrician. So, then I asked one of the nurses if she thought [child] had low tone. 'Cause I had worked there so like I knew them, and I trusted her and I was*

> *like "do you think he has low tone?" and she was like, "I don't. I think he just has low tone because he was on morphine and the epidural and I'm thinking in my head like it's been like 30 hours since he had an epidural, or 20 hours at least. So I was like "I don't think—" but I didn't say anything.*

She presented her concerns to her pediatrician:

> *The first thing the pediatrician said when she walked in was "do you have any concerns?" and I went "yep". And I covered up his nose and his mouth. And then, um, and then she came over and actually checked him over… so then she kind of hummed and hawed and then she sent us straight for another… an ultrasound of his heart right?... So she sent us right away for that because of the echogenic focus on the ultrasound. So we went down there and I remember the nurse she said, "well do you have a soother for him?" And I was like "no"—"well he's not going to stay still for this." And that's when I started crying because he stayed perfectly still and I was like "oh god". Do you remember standing in the hallway going "why is he staying completely still?" Cause she was like "no kids stay still for this". And I was like "oh my god."… But um I remember thinking at that time, "Oh no, I'm really right."*

The pediatrician sent the child for tests for his heart, but also signed a discharge order when Zora specifically asked to stay in the hospital another night, given her concerns:

> Zora: *…we weren't able to establish breast feeding in the hospital, and um, I had asked if we could stay an extra night just to make sure that we had established breastfeeding. And ah, I'd asked the pediatrician that when she was there and she said yes you can stay… the nurse came and she said, "ok, you guys are discharged," and I was like "Uh, I asked to stay an extra night." And I was like "Look, do you need the bed?" like a nurse, again, "do you need the bed?" and they're like "no, but you guys have a discharge order. I called the pediatrician and got a discharge order" and I was like by this point I was pissed. I was like fine, we're going to fricken leave. So I was I was—just felt so mad. And so we left and we went home. We were home for like maybe seven minutes and you called 911*
>
> Edgar: *His lips were turning blue.*

When they were in the hospital, Zora also had a confrontation with a social worker, where she insisted that her hunch about DS was not baseless:

> *I was kind of standoffish with the social worker because I was pissed that she was there and I remember that I picked up his arm and I was like "if you want to tell me that this" —And I picked up his arm and I dropped it and I said "If you want to tell me that's normal, then you can. But I know it's not."*

Given her experience working on that ward, Zora believed that social work was called in by one of the nurses, not actually for support but because her suspicions and questioning was perceived by the staff to be unjustified:

> *The social worker said she was coming in because we were asking questions and getting more testing done for our child and she said she comes in to support families when their kids go for additional testing. And I was like "mmm... I used to work here and I never once saw a social worker". Like I know that the nurse has to ask for social work because I worked there. So someone requested it…That's the way it works. … "someone sicced social work on me. Like they think I'm an unfit mother. And I've only been a mother for like 24 hours." That's how I felt.*

A week later she saw her family physician who also denied the possibility of DS:

> *So we had our one week appointment with the doctor first, our family doctor who I had asked the amnio for, and he said "no I don't think [child] has Down syndrome. I think this is just a combination of you and your husband."*

During that time she also saw a few public health nurses who suggested that she was thinking about her child from the perspective of a nurse and not a mother:

> *The nurse there told me too "stop being a nurse and start being a mom". She said I was looking at him too clinically. And um, and then she was like "just stop looking for problems where there are none."*

Altogether, Zora and Edgar felt that their care providers were dismissive of Zora's concerns, and implied that Zora was not rational:

> <u>Edgar:</u> *I just think that I just think that everybody thought that [mom] was nuts.*
>
> <u>Zora:</u> *I definitely felt that*
>
> <u>Sarah:</u> *And what do you think about them thinking that?*
>
> <u>Edgar:</u> *That they are a bunch of idiots.*
>
> <u>Zora:</u> *You thought I was crazy.*

> Edgar: *I—I didn't really think you were cra- I NO! I didn't think you were crazy, like you're smart and you know your stuff, like I didn't think you were crazy no. I think you were, I thought you were, like, I wasn't disputing what you were saying. Of course you're going to say "oh maybe not, maybe not, maybe not" …but for them goofs to slough it all off and call social work and then send you home–*
>
> Zora: *Well yeah, and I felt like they sent us home because they were uncomfortable with me asking questions. That's exactly how I felt.*

Zora mentioned a few times in the interview that she felt dismissed by even Edgar, something that he denied was his intention; he believed he was simply considering other possibilities. Given the lack of support she experienced and lack of validation for her concerns, Zora questioned herself as well:

> *'Cause I was like going back and forth in my head "Am I crazy, am I not crazy?" and um, and I remember um, I was like "can you have post-partum psychosis 30 seconds after you deliver?" I was like "maybe I have post-partum psychosis. Maybe I am crazy."*

Finally, they came to the conclusion that, if it were not for Zora noticing indicators and continually pushing for testing, it could have been a significantly longer time before their child had a determination. They believed that the health care providers they dealt with throughout their care were disorganized and careless:

> Edgar: *I think like right right from that ultrasound where that thing was on his heart, up until, oh, right up until she called and said he had Down syndrome, probably even after that, I think the whole thing was—forgive my language— was just a clusterfuck. Nobody knew what they were doing, I think they were a bunch of idiots at the[hospital]. Like he should never have left the hospital. He should have been left in the hospital. They sent us home and calling 911. Like it was just like they were like, it was completely handled wrong by everybody at the hospital.*
>
> Zora: *I felt like they—*
>
> Edgar: *—Only for [mom] only for [mom] if [mom] had any other occupation other than a nurse*
>
> Zora: *—that had worked there—*
>
> Edgar: *—Nobody would have like, who knows when we would have found out!? Could be months, could be a year!*

7.2 "*..the neonatologist would say one thing and he would say another*": Inconsistent Opinions from Health Care Providers

In addition to being distressed by dismissive attitudes on the part of care providers, participants also described having to process varied and inconsistent opinions of health care providers as being a source a stress; while some health care providers were extremely confident nothing was "wrong," others would be extremely confident that the child had DS. These drastically different opinions were confusing to navigate and increased the turbulence of the "emotional rollercoaster" parents were already experiencing.

Shirley relayed an experience that began with her obstetrician using pejorative terminology followed by a listing of a multitude of complications associated with DS to present her child's presumed determination to her husband while she was still unconscious from a caesarean section. This determination occurred within the last five years, and yet still seemed to be one of the most insensitive and outdated:

> <u>Shirley:</u> *And then when he was born um, they brought my husband in afterwards to see him and the obstetrician at that point was the one that said "I think your son has something we like to call FLK syndrome" and so my husband [dad] was like "well what does that mean? what is FLK mean?" And he said "well it's something we call funny looking kid syndrome".*
>
> *<u>Sarah:</u> [gasp]*
>
> *<u>Shirley:</u> Yep. "And typically kids with that will have Down syndrome" and so then um [tearing up]*
>
> *<u>Sarah:</u> Just take your time*
>
> *<u>Shirley:</u> [crying] and then, um, then the obstetrician was just really kind of um, like he told [dad] like about all the problems that he could have 'cause they were— I was still unconscious and then they took him up to the (inaudible). He had issues just with breathing. He just had congestion and stuff and so they brought him up to the NICU for that. And then the obstetrician just told [dad] like "he'll probably have heart issues and he'll have these issues and these are the kind of things that medically will be wrong with him, and like intellectually this will be his like disability" and just kind of focusing more on the negative instead of on the positive.*

From that point, Shirley and her husband's care providers vacillated about their child's condition. Shirley, also a nurse, could tell that something was not typical about her child, but because of differing opinions of her care providers she continued to hope that she was wrong:

> *…my husband has a picture of me like looking at him for the first time and it's just like he— I could tell something was not right. Like he was just really flaccid and just kind of like laying there and having a hard time breathing and everything and then my obstetrician um, Dr. [Obstetrician] was actually on that weekend but she hadn't gotten on until a bit later. And so when she came on she went and had a look at the baby and she said "oh, there's nothing wrong with that baby. He's just a little shell-shocked from that traumatic entry. Like there's nothing wrong with him. Everything's fine." And so we took it as that and that maybe he just had like a traumatic delivery because he was in a really bad position…So she just said "those features will just pop back out and everything will be fine"…So we took it as like a positive thing like "Ok like he's fine, he's just a little shell-shocked right now". And then we went for rounds in the morning at the NICU and Dr. [neonatologist] who's the— one of the head neonatologists— he said "oh ya, this baby's fine. There's nothing we're concerned about. No, we don't need to do any genetic testing at this point" At that time I could see some of the residents like kind of had kind of a look of shock on their face like they knew something was not right. And that he—like, that there wasn't any further investigation. But as parents we were just like clung to that hope and like "ok like everything's fine" … The next day was a different doctor who did rounds and he was like "there is obviously something wrong. Look at this kid".*

She explained that like Zora and Senga, through her intuition and/or clinical experience, she felt she knew through the entire experience that her child would have DS. However, she deferred to the expertise of the health care providers who suggested that her child did not have DS:

> *I kind of knew that it was going to be Down syndrome, like that was going to be the diagnosis because like I'm a nurse and I um I'm just like— I just kind of knew. And then everyone else around us is saying "oh well THIS is normal, and THIS is normal" and I don't think it is and so all these like professionals are telling us like "Oh like it's— he's not going to have that diagnosis" and so you cling to that.*

Shirley described the experience overall as being the worst two weeks of her and her husband's lives, largely because of the focus on what was "normal" or "abnormal" about her child:

> *And so it was just like [pause] we [pause] we did not have luck with people. Um, we felt like people were extremely insensitive towards us and ... um... We didn't get an official diagnosis until he was about two weeks old. And that, like, leading up to that we kind of knew but every, everyone— it was just this flip flop thing because one doctor would say well, "ya like it could be Down syndrome." And then they thought maybe it was [inaudible]. They had all these other things they were throwing around and um.. like he— when one of the residents was like "but his hands are normal. His hands and feet are normal, and this is normal and this is normal" and like so there was just a lot of focus on... on what like his, what was wrong with him and it was [pause] like the worst two week of our lives.*

The back-and-forth focus on what was "normal" and "abnormal" about their child and the extreme confidence of care providers with opposite opinions were confusing and stressful to parents. However, it should be noted that the stress and confusion were not provoked by the children themselves. As Mary described, her son had a calming effect on her during an otherwise turbulent time:

> *…then we went down and it was kind of complicated in the NICU. …[Neonatologist] was saying— you know when you looked at my son he didn't have very strong, what they call soft markers. Um, they were pretty sketchy actually. So he was saying, he thought it might be 50/50. He wasn't even sure if he was going to bring it up with us until they sent for the chromosome test, because he didn't think it was worth bothering us…. The geneticist came up and was like "well, like, I'm almost positive this kid has Downs" And it was sort of confusing why the neonatologist would say one thing and he would say another, and who was right? He said he was 95% sure, I think. But he had to send for the blood tests, and we wouldn't know till Monday…So anyway, it felt like forever. And all throughout I just stared at him, and I tried to figure out what the answer was, what the truth was. And if I was on my own, in my room, I'm going to cry [laughs/cries]…Um, it was like a disaster. But as soon as I could see [child] there wasn't any worry. It was strange.*

7.3 ***"…they don't make eye contact with you":*** **Care Providers' Silence**

One of the most common themes in the narratives of those who received postnatal determinations was that they perceived an awkward and knowing silence to be resonating from the maternity ward and/or NICU staff. In particular, nursing staff seemed to avoid them and they had trouble finding people who had the authority to answer their questions. Those with the authority were sometimes aloof, avoidant, or combative. Maya described the convoluted process she and her partner went through when they were looking for answers:

> *So I went in and I took a look at her and I knew right away. And, you know, the exact order of things leaves me now, but the impressions I'm left with, my memory such as it is, would be perhaps then, saying to [dad] "do you think she's got Downs?" Um, and you know he of course, he wouldn't know for sure, and there were very few words, it was more looks to one another. You know, just like "well, ok, maybe" and this ah, place NICU is very busy, lots of nurses around— but um, looking at your baby and just knowing that, and then being in this environment where like the world is just spinning around you and you're getting the most— well at that time, very devastating news, just by the visual signs, but no one is there to speak to you as you see your baby. Like there was nothing in that way, that, you know, THEY knew. Of course THEY aren't going to say anything until they get tests done, right? So there is like no support there. When you arrive at the bassinet and you know that this is the case. It's just you and your husband and the baby and no one. No one. So, um, I just started asking people…. And I just started looking up at, you know, "who is our nurse?" like "what— like—can— I, we need to speak to somebody about our baby." I remember, you know, something along those lines. We didn't say, right out, like it was just more, "ah, we can we have some help here?" Um, and, you know, a nurse would look at you, and not be able to say anything, and say, well you know, um, "I can't answer your questions, but the nurse practitioner, uh, who's here, she— we'll find her and maybe she can speak to you about it." And because there was this sort of chain of command. So THEY know, like any nurse who had seen our baby KNEW, right? And um, and I guess it's not fair to say they knew, because I know that some babies can can look like, you know it can be a bit deceiving. Um, and that some look more like— and they also don't want to take responsibility for creating any kind of scare or you know asserting anything. But it's this— there's still got to be a better way than this, you know?*

She relayed that the atmosphere created by the silence was incredibly frustrating. When she and her husband were finally able to speak to a nurse practitioner, she described the practitioner's behavior as aloof and combative:

> *Um, but finally this nurse practitioner came over, and um, you know I used to have this little conversation so clear in my mind, cause it was sort of kind of bizarre, uh, and her, I, you know I said "we, we are concerned about our baby. Um, we think there might be, you know, something wrong here." And she she's the one who said "um, well we're waiting on tests so we can't say anything until we have the tests back, the results back" which were going to take, I forget if it was a few days or 2 days, whatever it was, it was a long time, um, and I said, "well I think it's pretty obvious that there's something wrong here." And, um, she said— it was kind of like we were speaking in code. That's how I felt, we were, right? And she said "well, what is it you, you think— what is it you need to know?" And I said something like "I don't know, what is it that I need to know?" it was like that kind of code— "Why don't you tell me what I need to know." Like it was just bizarre. And I said "well we think our daughter has Downs" and then she said "well, that's a possibility. And we're waiting on tests for that." Like WHY? Why would— you know, it might not have been word for word like that but it was definitely this convoluted guessing game of "you say this" and "I'll say that" and nothing was clear at that point. Plus, you're in shock. And you're trying to communicate while you're in shock and they're putting this puzzle in front of you that's just kind of blocking.*

Joan relayed a similar experience. Although she was informed of her child's suspected determination relatively quickly after birth, she still experienced a period of silence from her health care providers in which she knew that they were concerned about something but was not informed about what they suspected or what they were working on at any given time:

> *So the NICU team came in, it was very quite in the room. Nobody was telling me anything... one of the residents, I think he was a resident kind of came over, and you can kind of tell the ones that are green, right? Because they don't make eye contact with you, and uh he was charting right beside my head, and I kept looking over and I, it's, you know, looking to him and looking to what he was writing and it was like, "what are you writing?! Like what are yo—, what what's going on here?" And you know, nobody would really answer directly other than reassuring me.*

Like Maya, Joan eventually had an interaction with a nurse practitioner where they seemed to be implying something that was not clear to Joan, which left her trying to decode the intent of the conversation:

> *I kind of came to, and uh, was all settled in and finally, she had wrapped [child] in a blanket and brought him to the edge of my bed and sat him up like this [holds imaginary baby vertically], and the first question that came out of her mouth was "does he look like your daughter when she was born?" And I kind of looked at my husband and I looked and I said "I don't know. I haven't seen him. Hand me my baby" and I immediately got very defensive. Like, "what does this mean? What are you trying to get at? I don't understand what this means."*

Patricia and Jerome found out that their family physician suspected DS soon after the birth but did not inform them of her suspicion and tried to run tests without obtaining their consent. Jerome suspected DS when they were in the hospital and approached the nursing staff about his suspicions:

> Jerome: *As soon as she was born I suspected, just because of the way her face looked and like the way she moved her tongue around, ah, it just made me think that ah she might have Down syndrome. Ah, but I didn't say anything at the time. I just said– was a little taken aback. But no one else was saying anything. Like, the doctor, the nurse, like nobody was saying anything, so I wasn't going to bring it up. Ah, but it unsettled me, right off the bat. ...And they checked...checked muscle tone, and all that stuff. And so I was paying attention and I was thinking well, you know, she doesn't seem, she seems very floppy, and not quite like your regular baby. So I was expecting someone to say something. Ah, and I might even have mentioned something like "is everything ok?" or stuff like that and I was just reassured by the nurse or doctors or whatever....Ah, but I approached a nurse that we had been dealing with. And I said "you know if the baby had Down syndrome or something was up with the baby, you'd be letting us know right? You wouldn't, you wouldn't just be keeping it to yourself?" It's like "oh no, I'm sure everything's fine" and ah, she kind of brushed it off and tried to reassure me. But ah, not long after that, the doctor, our doctor, made a trip to the hospital to visit us, and then she basically said, "yeah, we think she might have Down syndrome. We're going to run tests and find out for sure" And ah, yeah, I was pretty upset.*

Patricia: *Well and I think—*

Jerome: *—I was upset, well, that she might have Down syndrome, but I was very upset at being left in the dark like that. Yeah. It was brutal.*

Patricia: *—And wasn't it, um, didn't she, she said "I wanted to do the test, with— I wanted to try to— I was trying to find a way to do the test"— ah, and the test should, should've taken two weeks I think. Right? Wasn't it two weeks?*

Jerome: *nine days*

Patricia: *—'Cause it was a long time to wait. I think. Anyway it doesn't matter, but she said "I was trying to find a way to do the test where I didn't have to worry you"– without our consent basically though…And I just thought, you know "but we are grown adults who yeah have a right to know and there's a reason why you need our consent."*

Some participants contrasted the silence they experienced from staff for this birth to the reactions to the birth of one of their other, typical, children. For example, Sylvia, who had her child in a smaller center 19 years ago, contrasted the experience with the excitement she felt from health care providers when her other child was born:

Sylvia: *She was born in [small town] so she was one of the last babies that was actually born at the hospital there. Um, so the local doctors, the local nurses um, so when she was born, nobody said anything to me about um, what they thought. But they got us um, sent off to [city] for tests…*

Sarah: *Um, so you said that initially, nobody said anything about what they thought, right? And so, I assume by 'nobody' you were referring to— was it a doctor who delivered—*

Sylvia: *—doctors, nurses—*

Sarah: *— doctors, nurses. Um, in hindsight do you think that they all knew and just weren't telling you? You're nodding, yeah?*

Sylvia: *I think so becau– yes. I think so because it was like with [other child] everything was all excited and happy. With [child] we didn't get that. It was like dark. It was shouldn't have bee— there was no excitement. She was still a baby. She was still a girl. She was still born. Um, but we didn't get the excitement that we did when I go to look back… Ya, it it— there should be no difference, between any birth. But there definitely was.*

She chalked their avoidance up to a lack of knowledge of DS and the lack of schema for knowing how they should react. She believed that things would be different in a more modern context:

> *I think they were sad for me. I I think maybe they didn't know. There's a whole lot of difference between 19 years ago and today's age I think… but, it was sad. And it made me sad. And emotions were, there was no emotion. Um, people didn't know what to say. People didn't know what to do. People avoided. Right? That's normal when you don't know right?*

However, another participant, Margaret, who had her child approximately 12 years later, had a similar experience. She described the behavior of the nursing staff as feeling as though they were withholding something, but that she could not quite articulate what about their manner felt unusual:

> *They kept coming in and they'd like kind of sit down at the foot of the bed and they'd hold her and be like "oh, she's really beautiful" and it was kind of like they weren't saying something but at the time, I'm also like— your adrenaline is still there so I didn't really know like what was going on. And so I was just like "yeah she's super cute. I think she's awesome" and she was a content baby so we were good and so that night like nobody said anything. I went to sleep with this little tiny baby in my room like normal…so it was kind of like there was really nothing going on aside from that somewhere in the back of my mind I was just like "that was weird".*

Margaret's family physician examined her baby and seemed to have seen some of the indicators of DS but did not inform her about them or about why she could not yet be discharged:

> *Um, and then our, the doctor who was supposed to deliver her, who never made it to the hospital on time— our family doctor— came in and he like looked at her, turned her over and did all the things that they do with the baby and measured her and was checking everything and he didn't really say anything. He was like "ok, alright like I'll we'll—" and I was like "when can we talk about being discharged?" and he said, "I'll get back to you."*

A pediatrician came to deliver the diagnosis the next day, but to Margaret, the fact that her family physician did not inform her of their suspicion violated what she previously considered a trusting relationship:

> *…it would have been almost better to come from somebody that I knew that night. Like I don't know what the purpose was of them withholding it to the next day and then having our family doctor come in, who I knew and trusted and not say anything and then call up the pediatrician who was a complete stranger at the time to deliver that right?*

After the determination, the nursing staff continued to avoid the topic of DS:

> *And not a single nurse in that entire time that I was there, that was on my, that was caring for me, even brought it up. They didn't— it wasn't even mentioned.*

Margaret relayed that she had since been informed by a friend on staff that the entire maternity ward staff knew about the determination. Like Sylvia, Margaret attributed their strange silent behavior to their lack of authority to discuss the suspected determination and to a lack of knowledge of how to approach a sensitive issue:

> *I would talk to some of like my friends who knew the people that were on staff that night and I'd say like "did [nurse] know? Like when she came in and sat with me?" My girlfriend was like "yeah, like they all knew. The entire staff knew" and I said now looking back my gut told me that something was up. Like I felt that it was off and at the time couldn't pinpoint it but in— like I said that it made the experience weird… And in truth it was just them not knowing how to do it and they were directed at that point not to say anything to me.*

Also like Sylvia, she compared the experience to her other births, when the maternity ward staff were congratulatory:

> *…like when [other child] was born it was, like everybody was like "oh!" like "baby! Baby! baby!" Like "congratulations! Happy! happy! Happy!" and [child's] was more like the silence and I didn't know why there was the silence until everything came around and I had some time to like digest that and put the pieces together.*

Although she understood that nursing staff do not have the authority to share their suspected determinations with patients, she explained that the fact that other people got access to information about her child and her life while she remained unknowing felt unjust:

> *…even now it's just funny, like an entire staff of people at the nursing station were told that and nothing had been passed down to the mom that was sitting there. That like— I don't know, it doesn't sit right even now and we're seven years out.*

Although Margaret's and Sylvia's children were born 12 years apart, their experiences with health care staff were strikingly similar, suggesting that the way maternity wards approach determinations has not significantly changed over time. In support of Margaret's and Sylvia's intuition that maternity ward staff discuss the presumed determination amongst themselves before parents are informed, some participants relayed stories wherein staff accidentally mentioned the suspected determination to them before it had been presented to them by a physician. For example, Mary explained how a nurse dropped by and let the presumed determination slip:

> *He came super-fast, within six hours of my water breaking he arrived, and he was born with something called imperforated anus. So that's the bowel doesn't quite complete. And so that immediately was wrong. I think when I looked at him, I could see that there might be something else. But actually, it didn't register wholly. Um, and honestly, how we got wind of the diagnosis beyond the imperforated anus was we were on the maternity ward. Our son had been moved to the NICU, it was very intense, and a nurse came in and said "are you the parents of the little guy with suspected Downs?" and I said "No. Um nope. He's got a bowel defect…"— and I think she could tell that she'd made a big mistake.*

7.4 "*They told me you wouldn't do this. You come up here and talk to me. I need my husband here*": Receiving Confirmation

After what was often described as an emotional rollercoaster of coming to terms with the possibility of DS, several participants described being dissatisfied with how they received confirmation of DS as well. In particular, participants were dissatisfied with receiving their determination over the phone or in a public space, without their partner present, with the short duration of the conversations, and with their care provider's nonchalant approach to the conversation. Alma explained that she received confirmation of her son's determination from a social worker, who whispered the results to her, whilst in a crowd of parents in the NICU:

> *Cause it was very nonchalant and like um, it was a social worker from [City]. We were on rounds. And there was like probably 10 people standing there. My husband and I were standing by the bedside, 'cause they keep the parents in on the rounds, so that you always have, you know you're always up to date with what's happening and you get to say "you know what about this? What about that?" "Can I hold him today?" and stuff like that. And she just kind of nonchalantly kind of walked up to me and whispered, "and by the*

> *way the chromosomes came back positive for trisomy 21" and I looked at her and I said "oh" and she said "yep, it's back" and that's it. That's how we were told that it was a for sure, that yes, [child] does have um, Down syndrome. So I was just absolutely shocked. And um, my husband didn't hear her too, I had to tell him. And he said, looked at me, and he just said "[mom] I already knew that. We knew that" and I don't think it upset him. But for me, it was um, um, it was horrible. Like I just thought "you could have probably sat me down and we could have talked about it" ...So, that was that. That's how we actually figured it all out. Nobody ever really said anything, or that was— that was about it.*

For her, even though she was aware of the likelihood of DS, the confirmation was still an event that warranted a private conversation. She considered the public determination to be insensitive; it left her unable to emotionally cope with the information:

> <u>Sarah:</u> *Um, the social worker diagnosis. Um, I think you pretty much already discussed how you felt about that. Um—*
>
> <u>Alma:</u> *—it was insensitive, I believe. I FEEL like it was very insensitive to my, my need of someone sitting down and showing me the piece of paper— like I just needed some concreteness of that. Um, I mean I think I knew the answer. I mean we always know usually the answer. You have an intuition of it… But—*
>
> <u>Sarah:</u> *mhmm. Um, it probably would have been better if you were in a private space, hey?*
>
> <u>Alma:</u> *—yeah—*
>
> <u>Sarah:</u> *—rather than—*
>
> <u>Alma:</u> *—at a bedside. And there was so many people around. And I felt like crying but I didn't— I couldn't cry, because there was too many people around. And I just shut down right, as soon— like I heard nothing else going on around, as soon as she said it. It was like, my world was spinning, that this was, this was my concrete reality for the rest of his life… But anyway. Yeah, it was— that was insensitive.*

It was also not uncommon for participants to receive confirmation of the determination by telephone, which several participants cited as being insensitive to their needs and inappropriate given the significance of the event. Edgar was exasperated when he recalled how Zora received the determination over the phone:

> *We went to [hospital] for genetic testing…I think [mom] knew anyway that he had Down syndrome, but nobody else would believe it. I was sort of sitting on the fence, I could see some of the features, and um, results of genetic testing came back through a telephone call, over the telephone, that's how that was dealt with, over a telephone call, "yeah your kid has Down syndrome."… "Oh well thanks for uh, providing the update over the telephone!" [Mom] completely lost her mind— very upset— emotional, obviously.*

Senga and William described how, although they believe their family physician is technically highly competent, when he delivered the determination to Senga over the phone, he was casual, brief and did not provide any counselling:

> Senga: *Then it was like the week after she was born that my family doctor called with the karyotype results and even though I knew it, that was like—*
>
> William: *—a punch in the stomach—*
>
> Senga: *[tearing up] a hard part. He called and he just said, "her results are back. And it's trisomy 21" And I was like "Ok" And he's like "How are you doing?" and I said, "uh, I'm ok" and then he's like "Ok! have a great day!"*
>
> William: *We have like it's funny, our GP, he's probably the most amazing GP in the city—*
>
> Senga: *He is. …*
>
> William: *He's an old BS doctor, but he's also like—*
>
> Senga: *I don't think he realized the impact of what he had told me on the phone. He's like "ok, have a great day, call if you need anything, kind of thing" And then he hung up.*

Finally, Mary described how she was upset when her geneticist tried to give her confirmation of her child's DS over the telephone, and, like some participants who received their determination prenatally, insisted on a more thorough, in-person conversation with her partner present:

> *But anyway, on the Monday waiting and waiting and waiting for the geneticist to come back and I said to the nurses in the NICU, like "he would never just call with this kind of information, like I want my husband here" and they said "no, no, he'll come up". Well, I was on my way to the breast pumping room, and um, I got a call and it was him and I totally freaked out on him. I said, "they told me you wouldn't do this. You come up here and talk to me. I need my husband here".*

7.5 “*He’s walking me through, he’s showing me what he’s looking for, his tone was so reassuring”:* Positive Experiences

As detailed above, several participants relayed that they were dissatisfied with aspects of their determinations. However, not all participants were dissatisfied, and even those who were, often still relayed positive aspects of their care. Participants appreciated care providers who were calm, kind, and thorough. In addition, participants who were satisfied with their discussions described how care providers centered the baby in the conversations, showed the parents the markers under consideration, and explained their thought process in a nonjudgmental tone. For example, Joan described the style of a geneticist who walked her through the indicators of DS (after the initial shocking experience with a nurse practitioner) which made her feel relieved and reassured:

> *…then, the geneticist —so her boss— came in and he took [child] and instead of taking him away from me, he assessed him on the bed while he was sitting with me. He unwrapped him, and he was assessing him on the bed, and they were taking notes, he was answering all my questions, he was showing me what he was doing. He was showing me all the markers that he could see, with the hand crease, lower set ears, um, a little bit of a notch on his neck, um, widespread toes, I think— oh and the pinkie, his pinkies are curved. So those little soft markers he was just kind of showing me, that’s what he was looking for. He wrapped him back up and he handed him to um, his dad and he said, I’m about, I’m about 99% certain that your son has Down syndrome. And it was.... kind of like [tears] a relief ‘cause it was it was, OK, this guy, has gone over him, with me, right here. He’s walking me through, he’s showing me what he’s looking for, his tone was so reassuring the whole time. There was nothing um, judgmental or hard, it’s just what it was.*

Participants appreciated when care providers spent time helping them process the news and answering their questions. They also appreciated care providers who explained the next steps and made them feel like they would be supported going forward. For example, Joan described how her geneticist and genetic counsellor explained the next steps, explained that they would continue to be available for support, answered all their questions, were realistic about challenges but optimistic about life for a person with DS in general, and stayed with them until they felt ready to move on:

> *And so, it was kind of like OK, what do we do from here? And then he involved us in the plan. We're going to go and do some blood work. You'll know within 7 to 10 days. I'll put a rush on it though. 'cause I know how much of an anxious time this is for families. I'll put the rush on it but don't expect it till such and such date. Um, we're going to follow up with you guys, we're going to make sure that everything is going ok. I'm going to go and call all the team that he's going to need. Is it going to be an easy first year? He said "no it probably won't be, but do people get through it? Absolutely. Is he going to have a super successful life and you guys are going to be as typical of a family? Yes, absolutely. He was just very reassuring. And his ah, genetic counsellor as well was very lovely and answered all of our questions. And stayed until we all kind of, it felt like a conclusion. [laughs] we kind of all came to a conclusion. And then they moved on.*

Margaret described a similar experience. While the knowledge that her daughter might have DS was shocking to her, she appreciated the calm and straightforward manner of her pediatrician. Like in the good care that Joan described, Margaret's pediatrician walked her through the signs and explained the next steps to her:

> *He said uh, as he's holding her, he says "some of the nurses have noticed markers on her that we think she has Down syndrome" and I think just like the entire room just like stopped moving. Like I don't— it was like the most surreal experience. Like he, he was very very soft about it and very matter of fact. [Child] is now seven years old and in seven years it's something that I've come to love about our pediatrician…it was just me and her and he was holding her and he gave her back to me and I looked at her and I said like "I don't know what you mean. Like I don't understand" I said "you have—" I said "I don't get it" and so um, Dr. [pediatrician] also being a fantastic human sat down on the bed and said "this is, these are the markers that we see. These are typical markers of children with Down syndrome" and he said um "[Child] has these ones" and he said "some can be explained away by genetics as well" so um he said things like she has tiny tiny ears, but I physically also have tiny tiny ears. So he said "that can be Down syndrome [or] that can be you." Um he said "what the nurse picked up right away were the almond shaped eyes, the kind of flat bridge" he said "but she also doesn't have the skin folds by her ears" so he said like "we want to do some more tests" he said "I want to order her an EKG because if she does have Down syndrome we need to make sure that*

> *her heart is healthy" ...So he had set it up as "Don't panic. We need to run a karyotype test. We need to do all these things. We need to make sure that she's healthy too, just in case."*

Likewise, Alice explained how the experience of discovering that your child has an unexpected condition that has associated medical complications can be inherently distressing, but care providers can alleviate some of the stress by providing calm, kind, thorough, non-judgmental counselling:

> *And then when it came to the actual— like I think I mentioned how Dr. [neonatologist] was just fantastic. She's amazing. She's the neonatologist at the— one of them— at the NICU and just I can't even begin to describe how she is because she's just such a calming— like in the midst of what could be a very stressful exp— and it is stressful because you know with every, you know seeing your baby going through all of that and being hooked up to everything— having someone there that's such a calming, kind presence and you know then when the official results were in and she just came over and was quietly explaining it all. And there wasn't any like "I'm sorry to tell you but" it wasn't anything like that. It was just very much "so we got the results back. This is what they say." And yeah, like that aspect of it was fantastic. So, she was great.*

7.6 Discussion

The findings of this chapter align with previous research which has suggested that parents are often dissatisfied with the short duration of their diagnosis consultations, with their informant's poor communication skills (Hedov, et al, 2002), with receiving the diagnosis without their partner present (Skotko 2005b), and with the lack of compassion and support they received from their health care providers (Nelson Goff, et al., 2013). Parents relayed stories in which care providers were dismissive of parents' concerns or expressed extreme confidence about determinations that ended up being wrong. Participants described being avoided and not understanding why. They noted a lack of celebration upon the birth of their child, and a lack of acknowledgement of DS even after the determination. They were dissatisfied with the staff on the ward knowing the presumptive determination before they did and with care providers who attempted to engage in testing without their consent. Parents were also dissatisfied with determinations delivered over the telephone, determinations delivered in public places, and insensitive delivery styles, especially those that included an abrupt rundown of potential medical issues (for which there was currently no indication) and/or pejorative or judgemental terminology.

However, parents were not uniformly dissatisfied with their determinations. They also relayed stories about care providers who they described as *“fantastic”*, *“great”, “amazing”* and *“lovely”*. Parents were satisfied with determinations that involved a neutral, reassuring tone (*“soft but matter of fact” “nothing judgmental or hard, just what it was”*), throughout which the baby was present and at the center of the discussion. Participants appreciated a thorough explanation of the indicators under consideration. They were satisfied with quiet, private, consultations wherein all of their questions were addressed, the next steps were explained, and the care provider stayed until it felt like there was a conclusion to their conversation. And, as Alice said *“there wasn’t any ‘I’m sorry to tell you, but…’”*.

These findings clearly align with the results of Cunningham and colleagues (1984) who found that 100% of participants were satisfied with their determination when it was delivered: 1) by a physician, 2) as soon as possible, 3) with the other parent present, 4) in a private place, 5) with the infant present, 6) with as much time as needed for questions, 7) with the indication that a specialist would talk to the parents again as soon as they wanted, 8) with provision of a private place for the parents directly after the conversation, and 9) with the indication that a follow-up interview with the pediatrician would be arranged within a day, compared to only 20% of participants who were satisfied with a typical determination. These findings also align with previous studies which have found that parents appreciate care providers who offered accurate and comprehensive information, did not pressure them to terminate the pregnancy, provided balanced and personalized counseling, and provided appropriate hope about the uncertainty of the child’s birth and life span (Guon et al., 2014).

Further, the findings reinforce Skotko, Capone, and colleagues’ (2009) recommendations (see below) for how to deliver a post-natal DS determination. That existing guidelines so perfectly illustrate the issues most important to parents in the present study raises the question of why, if those guidelines already exist, they are not followed. One possibility is that half of the determinations in this study occurred before such guidelines were published and when there were perhaps more negative conceptualizations of disabilities. However, half of the determinations in this study occurred in the last 10 years. Moreover, the most recent determinations do not differ markedly from older determinations, and some of the most recent determinations, Shirley’s for example, involved some of the most blatant violations of the guidelines. Other explanations for the lack of adherence to existing guidelines should be considered in future research. Are some health care providers uneducated about and/or unaware of best practices in delivering challenging determinations? Are some care providers experiencing time or resource constraints which inhibit their ability to spend enough time with parents who need it? Do some health care providers believe that behavioral protocols such as these are unimportant or outside their job descriptions? Or, are some health care providers simply unaware that they deliver determinations insensitively?

7.7 Chapter-Based Recommendations

The experiences and opinions relayed by participants in this chapter reinforce existing recommendations to health care providers made by Skotko, Capone, and colleagues (2009) for how to deliver a post-natal DS determination. Uptake of these recommendations could improve parents' satisfaction with post-natal determination experiences:

a) the team should coordinate to ensure that the individual on the team who is most informed about DS be the one to deliver the results;
b) health care providers should inform patients as soon as they suspect DS, even if the definitive test has not been conducted;
c) the determination should be delivered in a private room;
d) parents should be informed together (if relevant);
e) the infant should be present and referred to by name;
f) health care providers should begin the conversation with positive words such as "congratulations on the birth of …" and avoid language conveying pity or personal opinions; and
g) for the first conversation, discussion of medical conditions should be limited to those that the infant is suspected of having.

In addition, the findings suggest that

h) health care providers should point out and explain the markers that are under consideration;
i) health care providers should remain with the parents until the parents have exhausted their questions; and

j) health care providers should explain the next steps and confirm for parents when their next follow-up appointment(s) will occur.

CHAPTER 8

"IT WAS LIKE WALKING INTO A BLACK TUNNEL": THE EMOTIONAL EXPERIENCE

Chapter 8 is about participants' initial emotional reactions to the determination and factors that influenced those reactions. Emotional reactions included disbelief/shock/denial, anger, and devastation. Participants just-world beliefs were violated, and this perceived injustice made them angry. Some parents discussed wishing that the "problem" of their child would go away. They felt guilty over their negative feelings about their child and some felt a sense of responsibility or blamed themselves for the fact that their child had DS. The most common emotion was fear. When participants considered what beliefs about DS led to these emotional reactions, most suggested that the "unknown" was their greatest concern. They did not know what to expect and that made them fearful. Participants were also concerned about the discrimination their child might face, their ability to parent a child with a disability, and that parenting a child with DS would be never-ending. They felt a sense of loss over the future they had anticipated and were reluctant to embrace an alternative parenting experience. They also felt a sense of loss about the apparent way having DS could limit their child's potential. Many participants referred to the period around the determination as the most difficult time in their lives. However, there was a small subset of participants who did not experience the determination as *"earth-shattering"*. These participants either had life threatening complications in birth which made DS seems relatively insignificant, or previous positive experiences with people with DS.

Most participants, however, relayed that they had little pre-existing knowledge of DS and that what they believed was largely based on stereotypes. No one reported being provided with helpful information about DS when they initially received the determination. Most participants explained that they were dissatisfied with the information they were provided because it was often scant, antiquated, overly medical in nature, and negative. Several participants saw their appointments with genetic counsellors as opportunities to be informed, but that most of the counsellors seemed more interested in solving the puzzle of the origin of the anomaly than in helping them understand the implications of the determination.

8.1 "*All your thoughts of what life will be like just vanish and you have to reinvent them":* The Emotional Experience

8.1.1 *“I shattered like a glass vase”*: The Emotions

Disbelief, Shock, and Denial

Perhaps because of persistent illusions of invulnerability (Perloff, 1983) and unrealistic optimism (Weinstein, 1987), participants often first met the determination with some disbelief—the feeling that this could not be happening to them. Oscar explained that, although he had many emotional reactions to the potential determination, his first one was denial: *“my first thought, as I say, I was clinging to hope that this wasn’t happening and I was kind of in denial for quite a while”.* Margaret went into more detail to describe the utter confusion followed by denial she felt when she first found out about her daughter’s suspected determination:

> *…and I think just like the entire room just like stopped moving. Like I don’t— it was like the most surreal experience…I looked at her and I said like “I don’t know what you mean. Like, I don’t understand” I said “you have—” I said “I don’t get it”… Um, and I remember just like looking at this tiny baby saying like “I don’t, I don’t see it. Like I don’t see it at all” and like kind of convincing myself that it wasn’t there.*

The power of denial was so strong that, in an interaction with a health care provider, who also knew the presumptive determination, Margaret simply told her that her baby did not have DS:

> *…the lactation consultant came and said “well if she has Down syndrome we’re going to run into some problems with nursing” and so she was kind of trying to teach me how to nurse better, which at the time was kind of a bad conversation to have because I hadn’t really even accepted that this was the problem, right? That this was going to be the challenge. So I was like “no, she doesn’t have Down syndrome.”*

She went on to describe, like Kurt and Charles described in their prenatal experience (see Chapter 6), focusing on the chance that the presumptive determination could be incorrect, and that her child might not have DS. She focussed on the possibility that the health care providers could be wrong:

> *So um, we eventually got discharged that weekend and [older child] came home, ah my parents brought her home and I remember like yeah my sister came over and stuff and everybody just kept saying like “we don’t see it in her” and part of me was like “I don’t see it either.” You kind of had your fingers crossed for maybe like they’re wrong, like maybe they are entirely wrong.*

Detachment was also a common reaction, as described by Joan: "*Um, I hadn't really cried, for the entire time we were in the hospital. I just I felt like um, I was numb, and I kind of was away from it. I wasn't in it, I was away from it. I detached a little bit, um, when it came to that stuff.*"

Devastation

Several participants described having some sort of breakdown. For example, Joan described her husband's reaction to the determination with the metaphors of crumbling and falling. She explained that he was unable to carry on conversations and that he was so devastated that a family member assumed that their son had died:

> *…[child's dad] really had a rough time then. I— he was really, he really struggled the whole time um, he really struggled a lot. So that was a little bit tough to see… he crumbled, he fell, he couldn't carry on a conversation. My sister was at home with my daughter and she told me later on that when he walked through the door — 'cause she didn't know what was going on for 24 hours— but when he walked through the door the first time, she said the look on his face and the way he reacted, she thought the baby had died, was her exact— like she said "I thought he was dead, I had no idea what— and it took him 10 minutes to be able to get it together to tell me that he wasn't dead." Um, so he, he fell really hard really fast. Um, and did for a long time.*

Camille and Oscar explained that while Camille initially dissociated from the scenario, Oscar was perceptibly distraught:

> <u>Camille:</u> *So yeah, I think if I remember correctly, you were quite upset. And I was, I was more a little bit more— not pragmatic— I have attachment disorder and I tend to disassociate from my feelings and so [dad] was really really upset. I think you were crying. I think you broke down.*
>
> <u>Oscar:</u> *I was crying a little bit there. And then—*
>
> <u>Camille:</u> *And I just kind of held it together. In that, in that moment— not later.*
>
> <u>Oscar:</u> *In that moment. And then, yeah, you told me to go back to work.*
>
> <u>Camille:</u> *Yeah, I probably did. That would be my standard.*
>
> <u>Oscar:</u> *No, you insisted I go back to work, um, because the day wasn't over. And there was an hour left in the workday. And um,*
>
> <u>Camille:</u> *You went back, but you didn't last long.*
>
> <u>Oscar:</u> *No. I—*

> <u>Camille:</u> *—rightfully so—*
>
> <u>Oscar:</u> *—I pulled a colleague and my supervisor into a meeting room and proceeded to completely break down and explain what had happened. And said "I can't do my job today" uh, and then, you know, uh, drove home. Yelled a lot in the car. Told my boss, or got to my driveway, called my boss and told my boss I arrived safely in my driveway, cause I was really upset when I left work.*

Oscar went on to explain that the period following their child's prenatal determination was the most difficult time in his life:

> *…the pregnancy was an incredibly difficult time. You know I went through a three-and-a-half year custody battle and that was a walk in the park compared to the pregnancy with [child]. Um, you know, in terms of mental stress, and surrendering control and that kind of thing… the pregnancy was far and away the most difficult part of my life.*

Camille, initially detached, went on to explain that she felt more emotion stemming from their child's determination than she'd ever had to deal with:

> *Yeah, I don't know why— it felt desperate to me. So like it felt really desperate and I was devastated. Yeah. There was so much— like more emotion than I've ever dealt with. Like, just sobbing my eyes out. My heart felt like it was breaking. I have never cried so hard for so long, or so much.*

Arthur described a surreal experience he had after finding out his child's determination in which he spoke to animals, had a breakdown in his car, and went days without eating:

> *I walked to the side of the [city] hospital and it was raining and there was these geese, just walking around in the yard, a really nice area, right? And I just remember talking to the geese and I don't remember if people were around or not but they must have thought I was crazy that I had this conversation with the geese and I was telling them what I was going to do. I don't remember what I said, but I was completely, like not myself and I was just walking around, and I just remember I went to my car and I sat down and I closed the doors and I just cried like I never have cried before you know. It was an uncontrollable sobbing, and like heaving and like and I have never done anything like that. Actually since, either. But I just had this terrible like, I don't know what it was, like a breakdown. And then I think that was about day three after we had found out. And I remember my stomach was hurting. And I was feeling funny and I came back and I think I*

> *mentioned to the nurse, and she said "well you probably are hungry" you know, 'cause I wasn't eating or drinking 'cause I forgot to, you know, like I was in such shock…And I didn't even have a connection to my own hunger. It was weird.*

Violation of Just-World and Anger

Several participants described feeling angry because the determination felt like a personal injustice, something they did not deserve. Simone described wondering *"why us?"*, Kate described that *"I was just, you know, taken aback. I was shocked. I was— I was hurt."*, and William used the metaphor of being *punched in the stomach* to describe how the determination felt like a personal affront. Oscar explained that he was angry at a higher power for doling out this experience after he recently dealt with other personal challenges:

> Oscar: *Um, and I was kind of angry at God. You know, I had just come through this massive custody battle and it had been over for less than a year and then this happened. And I was like "this is not fair". There was a lot—*
>
> Camille: *—there was a lot of—*
>
> Oscar & Camille: *—of "this is not fair".*

Oscar went on to explain that he resented the situation and also resented others' rationalizations for his experience:

> *Um, a lot of anger and resentment. You know, people tell you that you know "he's a special kid who needs special parents and that's why God picked you". And I was kind of like "wow just stand there for a second so I can throw a shoe at you" you know? Um, 'cause I didn't want to be special parents. Um, ah, there was a lot of "I don't want this. This is not fair" you know "I would do anything to get out of this circumstance."*

He explained a sense of being so far away from the path he expected his life to take that he even resented organizations who were doing good work with children with disabilities:

> *I remember going into [location of services for children with DS] and seeing pictures of special needs kids on the walls and watching them, you know, walk kids with special needs through the facility and just thinking "I am not supposed to be here. My— I'm— this is not— my life is not supposed to bring me here." Um, and just really, for a while I was really resentful of that place. Like I could see that they were doing a good thing, but I was resentful that I had to be there. Um, that was a lot of reality.*

Alma described physically lashing out, throwing things in her room, angry with the world that this happened to her and her son, wondering what she had done to deserve it:

> *I remember losing my cool and got very angry at the world. And I started throwing stuff in my room. You know because you just think "why me? why does [child], why does MY son have to go through this?" And so, I remember, and then, even after, I mean you don't know that you're doing the stages of grief when you're in those situations, but after I was like "hey, you know what, I was, I was totally— why did I lose my cool? Like, really, it's nobody's fault." But I was just mad at the world. Like, that this had to happen to me. Like "what did I do to deserve this" is what you think, right?*

Wishing for a Do-Over

Like the parents who hoped for a miscarriage when they received a prenatal determination (see Chapter 6), some parents who received a post-natal determination explained that they had moments of wishing that their child would not survive complications, so that they could avoid their new circumstances. Sylvia explained wishing her child would pass away so that she could start over:

> *when [child] was born it was like "oh please", you know what, "just"—, and my thought and this is normal it's just "please [child]"— when we were told about her heart [condition], all of these other things it was just like "please, just, just die and we'll start all over again."*

Arthur explained he had a moment in which he saw a way out of his future with a child with DS, and that while he did not pursue it, even thinking it made him feel guilty:

> *Her blood was acidic so she was getting kind of blood transfusions, but only the platelets. So we had to sign permission slips for that, and I remember the doctor coming and saying you need to sign the platelets permission form, and I said "well what's the ...?" and he didn't have time right? I said "what if I don't sign this?" And he said, "well she will die", and I said, "so then why are you asking me to sign it?". He said "well you might not believe that you should get transfusions or whatever" and I thought, I remember thinking at the time I'm like "well, that's an easy way out of this" right? "I don't have to sign this form." And I don't know— it was a rollercoaster ride. I don't know if I was rooting for her or not in the beginning because of the effect on me, right? But for selfish reasons, to say well, "all I've got to do is not sign this form and my life's back to*

> *normal" right? "I'm not going to participate in this, like, special needs event" right? So I remember that, and then like having terrible guilty thoughts about that, right? Of course you sign the form and send it on its way, but yeah it was a rollercoaster, cause I wasn't sure if I was cheering for her or not cause it's a huge impact to me, from a selfish point of view right? As a parent, right?*

Guilt and Blame

Guilt and self-blame were common reactions to the determination and the other emotional reactions to the determination. Sylvia explained that she felt ashamed looking back at her wish for her child to pass away, but with the vantage of hindsight framed it as part of her coping process:

> *I've been told that's normal, that's part of my grieving. That's part of my process. Um, but it was just like— you know what, I just wanted something that was normal. But [child] is far better than normal…I'm ashamed, um, but you know what, I do realize that's part of my, that was part of my healing… and to move on.*

Margaret explained that she felt a mix of fear and guilt for being afraid, because it seemed to indicate a lack of unconditional love:

> *…At the time it's a very scary place to be, but then, any time as a parent— I carried this baby, I've bonded with this baby, I love this baby so the guilt kicks in that you shouldn't feel this way. You should just love her for who she is. And it took a little while to be able to work past that and just fully love her. So it um, I don't know. It's a hard, even now, like I feel guilty because those first days weren't the same as like [other child's] because I was in that place of fear and scared and that [child] didn't get that. And I have to let go of that at some point and know that like she was loved.*

Several mothers described blaming themselves or feeling blamed for the birth of their child, which was framed as a negative event. For example, Shirley explained that the way others talked about the birth made her feel like she should be sorry for having her child: *"…Just everyone, they, all they would say is "I'm sorry" and then it makes you feel like, like you should be sorry for having a child."*

Edith explained that it felt like a natural reaction to assume that her child's condition was due to something she had consumed or done in pregnancy:

> *So when I saw that I was kind of like, started wondering is there anything that I had done during my pregnancy— was it because I had smoked, was it because I had I didn't take my vitamins or um, I was actually on um, medication during my pregnancy 'cause after my son was born I had post-partum depression and I was on an SSRI and um, they thought I had bipolar too so I was actually on a low dose of a antipsychotic too. So I thought that the medications might have contributed to the DS, but I found out later that wasn't the case. But my brain was like, I was just racking my brain I was like "did I eat right?" you know I was like, I think it's the mom's first instinct to be like "oh there's something wrong with my baby it must be my fault. Or something I did"*

Harper felt the same way— that she, as the mother, was ultimately responsible for having a child with DS (which was framed as a negative event at the time), and described that she subsequently even feels guilty– about feeling guilty– for the birth of her son:

> *Um, and too, I feel guilty just when I think of the feelings that I had when we did find out because I was like "what did I give my family?" you know? "I'm supposed to have a healthy baby and now we have all these potential problems. What are we going to tell the rest of our family? What are they going to think?"*

Fear (of the Unknown)

The most commonly mentioned emotion was fear, and specifically, fear of the unknown. As Oscar described, he did not know what it would be like to have a child with DS, and he was afraid of the possibilities, *"I was really upset. I did a lot of crying in the first 48 hours. Uh, I mean, you know, I did not know what to expect. And I did not— and I was afraid of what would— what it would be like."* Likewise, Margaret explained that it was not DS per se that created her fear for the future, but the uncertainty about what a life with DS held for her child:

> *The future was so uncertain and I didn't know how or if we could like make it through ok. It, it's kind of like any parent's fear for their kid multiplied by like a million because there's a, an awful lot of extra questions that are added to it. Or that she had, that is was Down syndrome— it wasn't the Down syndrome itself that scared me or made me sad, it was that "I don't know" that made me really, really, scared.*

Arthur explained that neither he nor his wife had a schema for what was happening to them, and this lack of a framework for understanding, and therefore lack of a plan, made him feel extremely vulnerable and question his role as the "fixer" in his family:

> *Well, I remember, in my own family, my own projection of who I was in the family, I was the pillar of strength right? I remember right after that happened I felt like I shattered like a glass vase, right? Like I just completely fell apart, right? And I didn't think that was acceptable because I had to pull myself together because [mom] was recovering from a surgery and we've got this crisis we have to deal with and plan for and I had to have an answer, right? And that's never happened to me before. It wasn't a problem I could fix. I couldn't solve it, right? So that was really upsetting. And that really threw me off my game and I was not able to make a plan for what we were going to do, and I didn't have an answer so we tried to—and neither did she, right? We're sitting there talking and we're trying to say, like what are we going to do now? And looking at each other going "I don't know" Like "I don't have a plan. I don't know what to do." So that was really a new experience for me too, right?*

Mary articulately described the experience as an instantaneous loss and reimagining of expectations for the future:

> *It was devastating. I cried, I cried, I've never cried so much. And you sort of just have this like— all your thoughts of what life will be like just vanish and you have to reinvent them.*

As Mary stated in Chapter 7, (*"Um, it was like a disaster. But as soon as I could see [child] there wasn't any worry. It was strange."*), several participants explained that while the unknown was fear-inducing, their child was a grounding a force: *"Well and the unknown is scary right? Like once we met [child], kind of everything else melted away and it really wasn't as scary as we thought"* (Zadie). Even prenatally, Agatha explained that she had little knowledge of DS, and therefore feared the unknown and questioned her ability to cope with the possibilities of the unknown, but that she was grounded and reassured by her baby's heartbeat and movement. While she felt like the message she was receiving from medical professionals was that there was something deficient with her baby, her own bodily experience told her otherwise, and that the health care provider's perspective was based on a label rather than an actuality:

> *I didn't know anything, right? And it's the fear of the unknown…I'm not a person that shows a wide range of emotions really so my freak out is just me saying "Oh my god. I don't know if I can handle that. Like I don't personally know if I can handle that" But what am I handling? I didn't even know, right? …Listening to a baby's heart and feeling*

> *the baby move, you know there's nothing wrong with your child. It doesn't matter what's "wrong", with air-quotes, with your child.*

Grief

Many of the parents explicitly labelled their initial reaction to the determination as grief or encompassing the stages of grief. As Stephen explained, grief tended to be conceptualized as a sense of loss regarding the child and life one thought they were going to have before they received the determination:

> *...you go through grief... you grieve the loss of the child you thought you had. You don't necessarily— and we didn't necessarily grieve the child that we HAD— we grieved this schema of our family that we thought we were going to be having.*

Sylvia explained that the focus of her grief were the plans and expectations that she had for her daughter:

> *I'm grieving what I thought my daughter would be. You know the perfect little world of her being the— you know, doing this and doing that…Not her world where it's going to be different right? Where it's going to be changed. [Child] is still going to be [child]. But it is a change. But I think I'm grieving of what I'm planning for my girl?... It's grieving my plans.*

The conceptualization of grief as a framework for thinking about their emotional experience is popularized in the essay "Welcome to Holland" by Emily Perl Kingsley, which is shared among parents of children with disabilities. Margaret explained the essay, which is a metaphor for having a child with a disability, and how it aligned with her experience:

> *So it was kind of this grief of "this isn't the baby that I expected." It's like they tell the story— the Welcome to Holland is typically the story that they tell about Down syndrome— is that they were set up for this trip to France and like France is beautiful and France is all these things and you've got your bags packed and you're ready for this and you're excited for this. Then all of a sudden you get on your plane and you get off and you land and they're like "oh yeah by the way you're in Holland." And you're kind of mad because you're like "what the F is Holland?" like "I don't want to be in Holland, I don't know anything about Holland" ...and then so once you're in Holland, you take a moment to look around and to like breathe and to take it all in and you realize that*

> *Holland has a lot to offer that is actually very beautiful and there are really neat experiences to have in Holland. But it wasn't France.*

8.1.2 *"I jumped far into the future"*: Concerns about DS

Participants' emotions were tied to a variety of ideas they had about DS and how it would affect their lives and the lives of their children. Health problems were primary concerns. For example, for Judy and her husband, the assessment provided by a specialist that their child would likely not survive due to health complications, including a heart defect, was a primary factor in choosing to terminate their pregnancy. Several parents, like Kurt, wondered about a shortened life expectancy: *"…one of the first questions, things like, 'what's life expectancy?' What's— you know like, are we going to have a child that dies at a young age?"*. If the child was healthy at the time of birth, general concerns about the child's future were more common. Alma described her imagined future for her son as being stacked against him and wondering if he would be happy, because that was her priority:

> *Um, my concerns were to future [tears up] and like just how hard life can be without a bunch of things stacked against you…what is his life— is he going to be happy? Is he going to live? But you just want your kids to be happy. So that's what was going through my mind, was his future and what it looked like for him.*

Kate descried the realization that her daughter could have more struggles than a typical child and described concerns spanning 20 years or more into the future:

> *I just, I just knew that she would have potentially more struggles in life and I think I was kind of looking far into the future instead of focusing on today… I jumped far into the future and I worried about what kind of a life she would have and what, you know— who will take care of her someday when we pass away because we are older parents…Where will she be? Um, you know, will she drive? Will she have friends? Will she get a job? Will she finish high school? Things like that.*

Discrimination

Participants were worried about the bullying and discrimination their child might face, as Jeanette relayed, *"how's he— how's the world going to react to him? Like is he going to be shunned or bullied and that kind of stuff as he grows"*. Harper wondered about acceptance, *"Is he going to be accepted? Is he going to be loved? Will he have friends?"*. Mary explained that she was worried about her son being excluded and pitied *"…um, a life of ridicule and being on* *the outside. I still worry about that [very quietly] Um, so— and people feeling sorry for him".* Zadie, who had been personally exploring her worry about her son's future, also alluded to concern about pity or inauthentic inclusion, in which her son would be included as a "mascot" rather than individual:

> *… I've been trying to process those thoughts and feelings of why that's hard for me right now to, to think of him as a young adult and what his future might bring, but and I haven't figured it all out, but um, I don't want him to be like a mascot.*

Judy, who terminated her pregnancy with DS, relayed that a lack of friends and playmates was one of her husband's primary concerns, *"he made the comment, 'who would ever play with our child?' and I think he just, the idea of—and he said it would just be heartbreaking".*

Capacity to Parent

Several participants described having concerns about their personal capacity or competence to parent a child with DS. Margaret listed the questions she asked herself about her ability to parent her new daughter:

> *I think there's a lot of fear— for me as a parent it was fear of like can I give her everything that she needs? Like, am I equipped as a parent to do this? I know I can parent but I don't know what Down syndrome entails, so like am I ready to do this? Am I? Do I even have the skills to be able to raise this baby with Down syndrome?*

Jerome described being so concerned about his capacity to parent a child with DS that he considered giving up their child for adoption, an option that partner Patricia did not consider, but understood due to her concerns about parenting their child:

> Jerome: *I thought it would be very hard and difficult. Yeah. I just thought it would be something that I would not do well with. Ah so I was actually thinking that we would give her up for adoption. But [mom]—*
>
> Patricia: *—And I was not—*
>
> Jerome: *—no…I just didn't think I was going to be able to raise it a kid with those issues. I didn't think I would have the patience or—*
>
> Patricia: *—be able to do it. Right?...*
>
> Jerome: *...And I thought, yeah, there were parents that would jump at the chance and the baby would be better served with those parents probably…*

> Patricia: *... yeah I was I was scared for sure…The worry that you, you wouldn't do a good job and yeah. And it would, you'd be sort of stuck struggling trying to do well for the child and who knows… I didn't— I wasn't even able to think at.. I think I probably saw an extreme of someone really low functioning— the worst case scenario.*

Alice's reflections echoed similar concerns about her own ability to parent. She also described having expectations and stereotypes about parents of children with DS, and questioned if they matched her identity. She doubted she was this ideal parent:

> *Well and I think part of it too is, I didn't think I would be able to, you know, have what it takes to raise a child with Down syndrome. And because, I'm, I don't know if I was necessarily— you know like with the patience and the kindness and all of that, and so, you just, you worry about all of those personal limitations and you— and I think that's, you know, when they talk about, parents with kids with special needs, and how extraordinary they a—and it's kind of set up this bar, where like— I am not that person, and, you know, can be kind of lazy and so all of those different failures and thinking that you're not going to be everything that this child may need…really a lot of it was my own wondering "how am I going to handle this?"*

Tied in with personal capacity were concerns about support for children with unique needs and support for parents who are unfamiliar with DS. While Judy relayed that *"we were just fairly definite that we weren't prepared to deal with the level of need that this baby would have,"* she also explained that a factor in deciding to terminate their pregnancy was the lack of support they perceived in their rural community:

> *"one of the things that influenced our decision was we actually live on a farm. In a pretty small community. And one of the things was, when we were driving home from the appointment at the hospital there, my husband looked at me and said 'who the hell would help us out here?'*

Never-ending Parenting

Participants discussed being overwhelmed by the realization that the responsibility of caring for their child would likely extend past a typical timeframe. Margaret contrasted this with the assumption that responsibility for typical children tends to end after 18 years:

> *We have now somebody who is dependent on us for the next 50 years of their life right? Like is that what we had hoped and dreamed, right? Our hopes and dreams for kids is*

> *like 18 years, they're off on their own, they go to university, they become grown-ups and they do their own thing.*

Kurt reiterated that when planning a family, for the most part, people assume that the responsibility for parenting ends after approximately two decades. He feared being a lifetime caregiver:

> *But I'd probably— my fear initially was probably the thought or the fear of becoming like a lifetime caregiver, right? It's sort of strange as a parent. I think it's pretty natural to, you know you have a child— and, you know, not taking the joy away from that— but a lot of people including myself at that time would "well in 20 years from now they will be going to school, probably moved out". The one thought I had in my head was you know I assumed— and a lot of the fear I had was that I was going to be a lifetime caregiver.*

Oscar explained, that unlike typical pregnancies where concerns are more focused in the moment, when they received the DS determination, his mind rushed far into the future, and he suddenly had a lifetime of worries, including a vision of conducting caregiving activities into his elderly years:

> *…when you get this big diagnosis, you essentially start to worry about their whole life um, instead of just worrying about getting the pregnancy— worrying about "will my child ever leave home?". You know, "will I be changing diapers at 80?" You know like what's— you know all of these worries happen right away. You kind of get a lifetime of worries as a result of one conversation. Uh, when normally they spread out over 20 years of life. Um, so that was really difficult.*

Alternative Parenting Experience

It clear is that many parents had a preconceived notion of parenting that seemed to be centered around a typical child. When they received their determination, their expectation for what their child, and therefore what their parenting experience would be like, was disrupted. Mary explained that *"all your thoughts of what life will be like just vanish and you have to reinvent them."* William explained that he agrees with those who use the framework of grief to describe the experience. It felt like a loss to him, a loss of the life he expected, initiated by the loss of the child he expected:

> *It sounds messed up, a lot of people don't like the feeling of it, but it feels like the death of the child you thought you were going to have. They were like— because you realize you're not going to have the same life that you thought you were going to.*

Joan described her child's father's concerns. She believed that he had preconceived notions of a father-son relationship which would not be realized with a child with DS:

> *I think it was that picture of a boy, for him. Because it was you know— I assume, when you are a man and, you know, you're welcoming your boy into the world , it's like "this is going to be my fishing buddy, this is going to be my— I'm going to play ball with this kid, and finally" you know, "I'm not going to have to play dolls". It sounds so silly and stupid, but I think it's that stereotypical "got a buddy in life". He still has a buddy in life and we tried to tell him that you know "he's still going to be your fishing buddy. You can still play ball with him. You can do all that kind of stuff. It's going to look the same. It's going to feel the same. But I think he had to work through that. And STILL is working through that kind of stuff.*

Leo described wondering about missing out on typical milestones and moderating his expectations of the parenting experience:

> *I remember asking the geneticist um, like just wondering will I ever get to walk my daughter down the aisle and things like that. So yeah it was um, definitely going through a grieving process and a transition process and learning, learning about what to expect and what not to expect, and what will be different.*

Judy also reported that she believed a factor in her husband's resolution to terminate their pregnancy was that he had expectations for a particular parenting experience that DS would change, *"there was a fear of capacity, but also he had in his mind the idea that he would have a child that could play hockey, that could go hunting"*.

Stephen explained that, when they were planning for a family, he and his wife had particular expectations that the determination of DS seemed to preclude:

> *So ultimately what happens or at least how we've described our experience is that especially if it is your first child and you are a new parent, you are looking forward to all your firsts and you have this expectation of what your life could be like and you have these fantasies of what your life will be like. You look forward to your child, you look forward to everything and everything you look forward to um, you know, first teeth and*

> *first smiles and first day of school and graduating and having grandkids and all those kind of aspirations kind of all come with the potential of having kids. And so when you have a diagnosis of any sort of disability I guess that fantasy is no longer a fantasy because it has turned into a different reality.*

Arthur also explained that he and his wife had expectations about family life that were not realized and that part of his new reality was feeling pitied rather than envied by his peers, an unfamiliar sensation he still struggles with:

> *We had this total typical two kid family planned and I remember some emotions I felt were "I'm no longer going to be—" when I'm telling people my story, when it was still happening, like the 6 to 8 weeks of neonatal care, I'm running back and forth from the hospital and telling people our situation. Uh, I never experienced it before, but people were looking at me with pity, and were feeling sorry for me, and I really did not like that…I remember feeling that, like "I'm never going— I'm not going to be looked at from my peers with envy. I'm going to be looked at with pity", right? And I really wanted them to look at me with envy, right? Which is totally selfish and yeah. Um, so I remember those emotions happening too, you know? I was now going to be an object of pity and charity right? As a family right? And I didn't like that. So that was something new. And I still don't like that.*

Limits

For many, the apparent limits that DS put on their child was their main concern. As Chloe explained, a typical child came with endless possibilities for a successful future while a child with DS had limits:

> *And I think also the other side of that was that we had a boy, right? So we already had a girl and then we had this boy. And to imagine your life that "oh my god I have a boy!" in those first you know, few minutes of [child] being born it's like "wow" you know "he can be a fireman. He can be a policeman. He's going to play baseball. He's going to do all these great things." But then, that totally gets ripped out from you because it's like "no, he has Down syndrome". So then, because you don't know, and you're not educated, that crushes you.*

Senga and William also saw essential limits for their daughter, which they believed precluded her experiencing some stereotypical life milestones or careers. Senga described that DS was just one way that limits could be imposed on a child, but that any condition that limited her children from life possibilities would have saddened her:

> Senga: *…once you hear Trisomy 21 it puts, it automatically puts some limits on your kid whether you like it or not.*
>
> Sarah: *What are the limits?*
>
> Senga: *Like, you know, that she's probably not going to be a doctor, or a lawyer.*
>
> William: *She'll never backpack through Europe by herself. It's those type things, right?*
>
> Senga: *Right. Like there's going to be some limitations to what she can do independently, so as soon as I heard those words I saw those limits and I was sad for her. Like 'cause you want them to do whatever they want to do. That goes for any of them, like if something happened to her [motions to other child], like she got in a car accident and couldn't walk all of a sudden or something I would be heartbroken for her, that suddenly there's limitations on her…*

Ursula explained that it was a process to reconstruct her anticipated life story and the anticipated life story for her child, given the limits that DS seemed to impose:

> *…and it's not that you're not excited to have a baby, it's just that it's— I think of it as like when you get pregnant you think "oh, this kid is going to be", I don't know, everybody has an idea, it's like "oh it's going to be a boy and it's going to make the NHL" and "it's a girl and it's going to be this doctor that's going to..." and then when you find out then it's you have to go through the process of "oh the story is going to be different".*

Some parents described that they understood that there are no guarantees with any child, as to what their future might hold, but that with a typical child you do not know what the limits will be at the outset, so everything is possible, from a future in professional sports to a career in medicine. Jeanette described the moment when she "realized" that her son would not go to college, and even though she knew any typical child might not go to college, it was even less likely for him, and that this was another of the mounting limits she saw for him:

> *And I remember—that must have been what, six months old or something— and there was a commercial about college, and I broke down in tears because my kid would never go to college. No guarantee it would anyhow but [laughs], um, it was just another, there was going to be limits on him.*

Participants' concerns aligned with those suggested by previous research. Korenromp and colleagues (2007) found that parents had worries about independent functioning, never-ending parenting (especially past their own death), the uncertainty of the disability, the low levels of respect for children with disabilities in our society, and the burden on their family.

8.2 Influencing Factors

A small subgroup of participants described a less intense emotional reaction to the determination. A few of these participants had life threatening complications in birth (themselves or their baby), and explained that the determination of DS was unimportant in comparison. For example, Emily described how experiencing sudden hemorrhaging shortly after leaving the hospital affected her perspective on DS:

> *I almost didn't make it actually… So I ended up back, obviously in the hospital for another week, [child] was still in the hospital. And so I had just gone through that and then that's when we got our diagnosis. Um, for me, I think it was just like realizing how fragile life was, and so grateful that I was still alive. Um, Down syndrome didn't seem like a big thing.*

The remainder of participants who described less intense emotional reactions personally knew someone with DS before they received their child's determination. For example, Maude explained how she believes that experience tempered her reaction to her daughter's determination:

> *Um, well I think a little bit. Um, maybe not as strong because I do have a close friend who has a son with Down syndrome. And I loved him. He is so sweet…Um, so we had that. So then when I did get the news, yeah, I was a little bit shocked and I remember coming to tell [dad] and I just kind of thinking things through but it wasn't like the end of the world, I don't think because I knew, I had known a child with Down syndrome, um, yeah, I don't know. For us it wasn't— but yeah, I think we did have to shift "oh I wonder if she'd be able to do things the other kids can do?" Like you kind of worry for them. Like growing up. Their kind of life flashes before your eyes and you're wondering if, how functional they are going to be. What are they going to be able to do and so yeah, maybe worry, but I don't think it lasted too long. The more we read— we read tonnes of stuff— and realized you know, um, our baby could have a very fulfilling life and could do most*

> *things other kids could do, so maybe a little shock at first but it wasn't like earth-shattering I don't think.*

Ursula, who also reacted relatively positively to the determination, explained that she had previously had time to consider her reaction to a pregnancy with a disability determination, which prepared her for her child's determination:

> *...so for me, it wasn't that— I don't— I had a best friend in university when I was 18 that her sister-in-law um, they had a son that had Down syndrome. But I remember when they found out how like, it was like this big tragedy and like um, it was like "well I don't know what they're going to do" and I remember saying like "what do you mean 'what they're going to do', like what are you talking about?" and it was like 'cause they were talking about um, having an abortion or not. And I was like "that's even something that people do?" So it was kind of like then I was like "If I ever have something happen like that, I don't want to react like that". So it was like when I was younger I had this time to go through this.*

8.2.1 *"The only thing we knew were social stigmas"*: Pre-existing Knowledge of DS

In contrast to Ursula or Maude, most participants described having limited or superficial experience with people with DS or people with disabilities generally, and they often described this lack of knowledge as a contributing factor to their intense negative emotional reactions. Kurt explained how the only knowledge he and Zadie had about people with disabilities was the exposure they had through media:

> Sarah: *Explain to me what you were crying about then.*
>
> Kurt: *... if I thought about it, it's the unknown, right? The only think we knew— and it seems cliché to say "unknown"— but the only thing we knew were social stigmas right? And I think to really prove that is that night we actually— like you know, you Google Down syndrome right? Which, and you know, read what you can factually about it— but we literally watched—*
>
> Zadie: *—Standing outside the fire—*
>
> Kurt: *—Standing outside- the Garth Brooks song with the video you know [featuring a young person with Down syndrome], like that's really what we knew and we were trying to find a way to connect. So the only thing we knew was what— you know, outside of the 1/700 people have Down syndrome— that you don't really have a lot of social connection*

> *to— there's really what the media brings forward to you or what you might see through passing, right? And so there's, really the average person, at least in our generation doesn't really have any really good understanding of what it means to have Down syndrome. You now and even, I'm not old, and even the children and classmates I went to school with were quite removed from the classroom, right? ...It wasn't like, it's not like it is today where you know, our children are, they're much better integrated into the classroom, and that wasn't that long ago right? ... So there's this weird social stigma and we went home crying watching Standing Outside the Fire, [laughs] ...but it it's really the unknown, right? Like it was— we knew nothing, right? And the unknown was fearful, right? It was like walking into a black tunnel.*

Chloe, who described her emotional reaction to her child's DS determination as stressed, explained that her stress came from assumptions about people with disabilities that she made due to her own lack of knowledge of DS, and based on the limited representations of people with disabilities that she had been exposed to:

> <u>Sarah:</u> *What ideas did you have about Down syndrome or about being a parent of a child with Down syndrome that caused you stress?*
>
> <u>Chloe:</u> *I would say, um, honestly, because I've never been around it. I really knew nothing about it. It was that, my life was going to be awful. Like um, it, it was one of those things where it was like "I'm going to have this child who is never going to do anything. Never going to be anything. Going to depend on me for so much and going to struggle their whole life, and maybe potentially you know, um, like lack of better terms, like BURDEN our life. They, they're going to make it awful, you know, and it's going to be really hard because they're going to live with you forever. Or, you know, they're not going to do anything. I think that was probably my biggest thought. Because I didn't know. I've never been around it, I've never seen it, I guess, with my own eyes. And I would say anything that I have ever read or really been told from people who aren't in it, has been negative. Like it, there really isn't a lot of positives around it. So I would say that. That was probably my biggest stressor.*

Judy explained that her husband had a strong negative attitude towards parenting a child with DS, which she attributed largely to his lack of knowledge about DS:

> *My husband is not very tolerant of people who are different either, which is maybe a*

> *weakness of his. But he just did not want to be the parent of THAT kid. And I think it was a lot to do with the fact that he had— like I had been on the internet, googling away and trying to research and I don't think he did anything. Like in retrospect, I don't think he— so he's a person who would have, I think, benefitted from getting a pamphlet. Or having someone to ask questions. Because he basically just went to the thing and got told that the baby had hard markers for Down syndrome, but yet he had no idea, I don't think, what it was.*

Several participants referred back to their years in school to illustrate their lack of experience with people with disabilities. Camille explained that although she had some exposure to people with disabilities, it was not enough to make her comfortable with them:

> *I did not really know much of anything about Down syndrome. Um, you know I went to a high school that had a functional living skills program and our English class volunteered in there, so I had a little bit of exposure, you know just sort of in passing. And I was always sort of wildly uncomfortable. I was a nice kid, so I was not mean, but I was uncomfortable. I was like "I don't know— I can't understand"— you know some of the kids in there, not all of who had Down syndrome— you know they used communication devices or they attempted to talk and I could understand nothing. So yeah, it always just kind of made me a bit uncomfortable.*

William and Senga explained that their ideas about DS were informed by limited exposure to particular individuals with disabilities, whose characteristics they believe they likely generalized to the entire population of people with disabilities:

> William: *...I never had any experience with Down syndrome, So I didn't know like anything.*
>
> Senga: *Yeah, you didn't. Like he only knew the stereotypes that you see, like out in public. And when you're out in public, the ones that you notice are the probably the ones that maybe aren't as high functioning or have a helper with them, or things like that.*

Judy explained that her underlying concerns about DS were informed by a certain experience growing up where she witnessed the exclusion and stigmatization of someone with DS and their mother:

> *I grew up in a community that was about 500 people, and there was a boy— I mean, he was a man who had Down syndrome, so I knew— and he was fairly, um, fairly badly*

> *affected, I would say, um, I knew what it was to grow up and be shunned, and to not ever fit in and you know everyone was saying 'oh look, there's [name] and his mother.' And then, to me, um, his parents were older when they had him. We're not that young. And his parents died, and he ended up in a group home. And so there was all that sort of going on.*

A few participants also described how their work had exposed them to people with disabilities, but that this involved a limited sample of people who tended to have higher needs than the average person with DS and particular behavioral tendencies which made them uncomfortable. Mary described how she thought of these individuals when she worried about her son's future:

> *I have a lot of experience working with people with disabilities. And it, you know on one hand it's not the end of the world and on the other hand, that was actually harder, cause I mean the people, when I was working with at [workplace]… this was in an era, these were adults with Down syndrome who were institutionalized from a very young age. They were not given any support, any chance, really. And so yeah, there's a full spectrum of interesting and kind of challenging social behaviors and it was terrifying to have that knowledge in the background … my experience with some of the adults who came out to [workplace], was that they had some really really dysfunctional social behaviors like public masturbation and all sorts of things that made their lives very challenging to be socially accepted and functional. And I honestly think that, in retrospect, that has a lot to do with the environment in which they grew up and the expectations put on them, or not put on them. But at the time, yeah I had these visions of like some very like distinct— not all of them— but there was some very distinct [individuals] in my past where yeah, behaviors and stuff that were just completely at odds with social integration.*

Zora, a nurse, explained that, when she received her son's DS determination, she immediately thought of two previous clients who had challenging behaviors and assumed that her son would be similar to them. She had a friend who pointed out she was stereotyping people with disabilities:

> *I didn't have a lot of previous experience with Down syndrome. Like I remember being a nurse and we had a client with Down syndrome and he had dementia really bad. He would like scratch and spit and bite and I remember flashing to that when she told me Down syndrome … and I was like "oh my god". And we had another patient with Down*

> *syndrome and she was like the team mascot. We all loved her and we did everything for her. She didn't really, she wasn't like cognitively really well intact. So that was my only things that I thought of and I flashed to those two and like she used to always say "my buuuum" …That's instantly what I flashed to…I flashed to this guy biting and spitting and fighting and he didn't speak and he just like uttered— but that could have been the dementia— and I was like— that's what flashed against me— I was like "oh my god, this is what my future is going to look like". And I remember I told my girlfriend that worked [with me] that and I was like "that's all I have for experience-wise" and she was like, "[mom], education is much improved from what it was before and like," she was like "just because they were like that doesn't mean [child] is going to be like that."*

These findings support the contact theory of prejudice which states that *high quality* contact can reduce prejudice, but that impersonal or low quality contact does not, and can even act to engrain prejudice more and reinforce rather than dispel stereotypes (Pettigrew & Tropp, 2006). For example, Pace, Shin, and Rasmussen (2010) found that having a previous relationship with someone with DS was related to more positive attitudes towards people with DS and Lawson and Walls-Ingram (2010) found higher quality contact with individuals with DS was associated with more favourable attitudes towards people with DS, more positive perceptions of parenting a child with DS, and a lower likelihood of intending to terminate a hypothetical pregnancy due to a DS determination. The present findings particularly reinforce the condition that contact has to be high quality or positive contact in order to positively influence attitudes. Participants who had superficial contact with individuals with DS, who demonstrated socially unacceptable behaviors, relayed how that experience made them especially averse to parenting a child with DS.

In contrast, a few parents had the opportunity to meet parents of children with DS or even children with DS themselves when they received their determination. These parents reported that meeting people with DS revised their stereotypes and moderated their worries because they were able to see that children with DS were more similar to typical children than different and that the parenting experience was also comparable. Edith, for whom talking to a parent felt safer than to physicians, explained that talking to a mother of a child with DS was a huge relief, because it made her realize that a lot of her parenting experiences would be similar to those of a typical parent:

> *She was telling us stories about her little girl and you know funny things that she did or when she reached a milestone or her birthday or those kind of things and seeing the pictures too, was like really helpful. It was kind of like you could see her growing up and it was just like "Oh, ok, she's just like a normal kid. She's just a little bit, you know behind" She's not as quick to develop as other kids but she seems like pretty cool. So it was like a big sigh of relief, like I felt like I could breathe again and you know I felt like my little girl wasn't going to be just this Down syndrome diagnosis. She was going to be like our little girl.*

Like the majority of parents in the sample, Jane and Ernest had limited, if any, experience with people with DS or parents of children with DS. Through a personal connection they were able to meet a mother and her daughter with DS, an experience which they described as a *"lightbulb moment"*:

> Jane: *So a friend of mine at work. I had confided in her the day that I found out [child] had Down syndrome and she said that she had a friend that had a little girl with Down syndrome. Which, we didn't know anybody. Like we had nobody in our life, you know, had Down syndrome, and um, had gone through it. So, she gave me her number and I reached out to her and um, yeah. In the time period of when we were making the decision we went and met her and her daughter…so she told us everything, you know about her child and we met her little girl and yeah, it was a lightbulb moment I guess, and I guess now looking back on it, we kind of say to each other, "they don't really know—*
>
> Ernest: *—that they played a part in saving [child]'s life—*
>
> Jane: *yeah… It was very reassuring to speak with her and—*
>
> Ernest: *—and see her daughter—*
>
> Jane: *And see her daughter and the way they interacted and um, just even talking about all the supports in place, that was a huge thing. Just hearing about all the resources and supports in place for families and kids with Down syndrome. And like, basically, [that] it will be ok.*

8.2.2 *"It was a pamphlet…I was like 'that tells me nothing.'"*: Information Provided about DS

The majority of parents reported that they had limited experience with people with DS and that this lack of knowledge contributed to their negative reactions when they received their determination. Therefore, providing them with up-to-date information about the condition could help them learn about realistic expectations for their children and curtail worries based on stereotypes. However, several participants, like Zora, described that they never received any written information about DS:

> Sarah: *I'm wondering a little bit about um either in that phone call or in interactions after that, were you provided with some information about what Down syndrome is or…?*
>
> Zora: *Not once.*
>
> Sarah: *No information?*
>
> Zora: *Never once*
>
> Sarah: *Ok.*
>
> Zora: *Never ever once. Not at all….Not one piece of information, not one handout, nothing.*

Alma explained that, given her lack of knowledge and assumptions about parenting a child with DS, it would have been helpful to be directed to credible sources with accurate information, such as the CDSS:

> Alma: *I didn't know anything about it. I did a lot of internet searching. Um, at that point it would have been nice to have somebody say like, you know, "here's a great website" or, you know, because you go on there and you're just floundering in this big world of internet, right? But it would have been nice to have, like um, well now that I know, right, the Canadian Down Syndrome Society is awesome. And any time that they— you— I could have called them…They have a lot of information that's correct information. Um, so that. Those things, that would have been nice just to get a little package, saying you know… "if you do want some information, here's"— um, yeah.*
>
> Sarah: *So at that point when it was discussed, they didn't actually tell you anything about it at all?*
>
> Alma: *No. About Down syndrome?*
>
> Sarah: *Yeah, about what Down syndrome is, or what that would mean for your—*
>
> Alma: *No, at no point, no. Nobody really um— all we really knew was that— I don't think that he actually— anybody ever went through what that would mean for [child]. They did talk a lot about the medical conditions that could be associated. But never, you know what their personality would be. Or how our life would look after [child] was born.*

> *Cause, I mean, when you don't have a lot of experience with people with disabilities, you have no idea. You, you think it's all gloomy, and dark and you don't have a clue. You just like have all these ah, preconceived ideas that life will be over. Which is really sad because that's not at all what it's like. If anything it's open. It opens up your world, right? And makes it better.*

Other participants explained that they received written information about DS, but that what they received from their health care providers was inadequate. Patricia and Jerome explained that, after receiving a dearth of information from their health care provider, a better package came from the SDSS, but they wondered why it took so long, and why there were not better connections between the physician and the society:

> <u>Patricia:</u> *Did she even give us anything? A booklet or anything? I think it was some, it was really* pathetic. *I do remember looking at this going—*
>
> <u>Jerome:</u> *—possible a pamphlet—*
>
> <u>Patricia:</u> *—this is it? Like there was, it was pamphlet. Yeah, I think that's right. And it, and shortly thereafter someone from the Down syndrome society came and I don't know how long after but came with like a package of stuff where I'm like "THIS is what we needed. Like don't dump that [the determination] and then give us a little pamphlet that gives us nothing."*
>
> <u>Sarah:</u> *So she didn't really provide you any information about what Down syndrome is. Or what—*
>
> <u>Patricia:</u> *Very high level, it was like a, it was like a one sheet, pamphlet that was folded up, four ways or whatever. And it was really high—I seem to recall it was like a paragraph I focused in on and I was like "that tells me nothing." And there's like, how can it not be a better experience? To like— and this is three days later… you had three days to put something together and all you could do was muster up a pathetic pamphlet. So it didn't feel like there was a connection between the Down— either she wasn't connecting with the different organizations that— and not just focus in on Down syndrome but— does she not know the resources that she has at her fingertips?*

Harper explained that they received in-depth counselling, but only on the medical complications that are associated with DS, which contributed to their fear and worry for the future:

> George: *I think it was when Dr. [physician] come the next day? With aaaaalll the information. And it was ah, anything and everything that could go wrong. Not to say that it was going to go wrong with [child] but it was all that boom. Dropped in our laps.*
>
> Harper: *Yeah, that was a little bit scary. And disappointing it think.*
>
> George: *Well that was the "how are we going to deal with that? how are we going to deal with that? how are we going to deal with that?"...*
>
> Harper: *Yeah, yeah I think that part I think I wish would be different…. none of it was positive. It was alllll the negatives. Nobody said, you know, "you may have all these issues, BUT—*
>
> George: *"you might not either"*
>
> Harper: *…Well I just remember thinking after we were told all the things that could potentially happen I was like how are we going to have a life? Like how will we survive this? How are we going to both function and both still work? And raise our other daughter and try and give all the best options to help him reach his full potential with just the two of us. Like how, how are we going to do all that when he could have this this this this wrong, and, I don't know.*
>
> George: *But the biggest thing is it's not all going to happen, boom, at one time all in one crack. Like you're going to work through it, that's, I mean one of the biggest things is that it is manageable, right? There's all kinds of people to help you…that was information overload.*
>
> Harper: *… it's like you just wanted to, "I'll just pack a bag and move into the hospital where I have doctors and nurses that are here that know what they're doing that can help us and*
>
> *George: —And at that point we were still at what? at least five, six hours old right? He might have all those issues but we don't have that right now. He was talking about a thyroid problem. He was talking about a thyroid problem, like, when is that even going to start to affect him? When he's five? ten? three? It wasn't going to affect him right now.*

Edith also explained that her care providers bombarded her with potential complications of DS, in an impersonal, overly medical fashion which she believes caused her anxiety:

> *Well I think there— I felt a lot of anxiety because— from what I was reading and from what the health professionals were telling us about Down syndrome. It was in very*

> *clinical terms, you know like "the child might have imperforated anus. The child might have", you know "heart defects. The child might have cleft pallet." And like it wasn't in actual everyday layman's terms either. Which I don't mind, but when it's worded that way, when you're reading it, it kind of gives you like this kind of standoffish, arm's length view of what the child is like and it doesn't, it didn't make me feel like it was about my daughter, you know?*

Edith contrasted that experience with a visit she had with another mother of a child with DS. She felt safer and calmer with the mother, while with the health professionals she described feeling physical symptoms of anxiety:

> *Um, and having her point of view and her personal first-hand experience as a mother ah, with mom's words was a lot more comforting than having the health professionals' point of view. It kind of like gave it like a soft landing. Like I didn't feel like I was going to go "woomph" into the ground, you know, and like "splat", which is what it felt like when I was with the health professionals. Not always, but I felt like they were going too fast and like I felt like I was going to like "wham" into the ground with no parachute, you know? Um, and the way that they made it sound, they would always go to the worst— "well it could, this COULD happen" you know, and I'm just like "whooo, ok, ah" and I'd get a lot of anxiety, like I could feel my throat getting tight and my chest and things like that when they would be discussing my daughter and her health.*

And finally, several participants lamented the lack of positive information provided about DS and about raising a child with DS:

> *…but no one said all the joy that he was going to bring to your life. That it wasn't a death sentence. He still can learn. He's still going to so the same things that our other child does. You know, they'll still be able to form a bond with their sibling. It's not going to destroy your family. Yeah. And I wish that there could have been something in those pamphlets that we were handed out from a parent who's been there and said "you know what? It's overwhelming right now, it's shocking. When the shock wears off, come back and read this and it's going to be ok." I wish that's what we were given.*

Shirley explained that no one at the hospital informed her about the supports that were available for children with DS and that the way they ended up discovering these was through a personal connection. She also listed experiential aspects of living with DS that she would have been helpful to hear at the hospital:

> *And it wasn't until um like my husband's cousin is a pediatrician and so he is friends with his pediatrician. That's how we like, I asked her to be his pediatrician and it wasn't until I talked to Dr. [pediatrician] and everything like she said "well like there's programs like KCC, there's AIM, there's things like that, like the therapy" and no one had talked through that about us. Like or talked about that to us at all, like what's out there and no, there's no discussion about um, like what the range is and like no doctors said "there's people with, adults with Down syndrome and this is what they are capable of and their accomplishments and there's no focus on that… And it just kind of things like that would have been nice to have been told, like you know "there's people living with Down syndrome and people who have very meaningful and full lives" would have been nice to—at that time— to have been told.*

Oscar explained that what he needed to hear at the time of determination was to lose his preconceptions about DS because they were based on outdated experiences:

> *The one thing that was missing, um, and I guess this is sort of a reflection that comes later, you know because I've been thinking about this conversation and what sort of things could I have heard that would have made it better. Um, one of the things I feel that could have been better, was if somebody had stressed, essentially, you don't, you don't know Down syndrome from what you've seen in your life. Because it has changed so much over the course of my life…When I was born… children with Down syndrome were still being institutionalized. Um, I needed somebody to tell me, essentially to forget, or to drop my misconceptions at the door.*

Jane and Ernest described some content that the information should have included, pointing out the things that people with DS can do, rather than focusing only on potential problems. By the time they received some of the outdated information, they had already done some of their own research that allowed them to critically assess the validity of what they were hearing:

> <u>Jane:</u> *… I guess from what we know now, like, yeah including information that individuals will lead productive lives, and can go to university, can go to school. Can get married, can have relationships, can walk, can talk, Um, like yeah, at one point I think he said "your child may or may not walk" kind of thing. Like it was to that level, where it*

> *was like "Ok" and luckily at this point we had done our own research, so you know we had somewhat more knowledge, so I think we kind of took that with a grain of salt and were just were like "Ok, really?", you know, and depended on the SDSS information at that point, and then all the research we did from there.*
>
> Ernest: *Which he referred us to, so in his defense I think he was, he acknowledged without saying it, I think he acknowledged his own ignorance, by saying "you should really contact these people."*

Participants were less offended by the lack of up-to-date knowledge provided by their health care providers when the providers themselves acknowledged their deficiency and directed them to credible sources:

> Ernest: *I think the reference to the SDSS was really good …like presenting it in a more "here's a culture of people" not "this is a diagnosis and this is all the bad stuff"….Um, and the referral end was a very positive thing. Because the information he gave was dated but um, to his defense I think he knew it was dated and so he referred us to an organization that's much better.*

Many parents related that the best information they received was from the SDSS and/or CDSS (e.g. Patricia "*THIS is what we needed")*, but that this information almost always came too late (e.g. Kurt "*we should have had [this information] four months prior"*) or they had to seek it out themselves. Jane suggested that a more formalized relationship between health care providers and the CDSS and SDSS would be beneficial for new parents. Through this relationship, health care providers would systematically have accurate up-to-date information packages ready to go for potential or new parents. Jane also suggested that a more formalized system for setting new parents or potential parents up with existing parents of children with DS would be helpful:

> Jane: *I think there was one thing that could be really positive is like having a formal relationship with the SDSS that when you know, you have parents who are, um, being given this diagnosis, that there's possible a parent or couple or whoever, who is willing to speak with parents. You know, like, having that one-on-one conversation with that family was invaluable–*
>
> Ernest: *Which wasn't through the SDSS*
>
> Jane: *Yeah wasn't through the SDSS but like if that was relationship was somewhat formalized, I think that would be like huge. Or if there was like an information package*

> *that he could hand us, like at the office, with all the information, I think that could be really valuable. Like with everything that's up-to-date. And the, like the Canadian Down Syndrome Society as well, they have a really good like new parent package as well.*

Margaret, a volunteer with the SDSS, explained that the SDSS has new parent packages with informational resources that focus on both experiential and medical issues, as well as a committee of parents who are willing to go speak with new parents when they receive their determination:

> *So we partner with the CDSS. And so they have a book, it's called 21 Welcomes. And so it's a story, it's 21 stories of people with DS. Some of them are written by parents. Some of them are written by adults with DS, and so we have that in there. And it's kind of the real look at life being normal. That your life is going to be normal… We have our new parent committee, the direct contact information to a parent that you can talk to if you have questions, if you just want somebody's ear that isn't the doctor or isn't somebody, a specialist right? It's just a parent. We'll include— we have handwritten letters from other parents…we have books, we have like an array of books…You can get like a chicken soup for the soul type books. Or you can get like the medical books…Um, there's different ones called like Roadmap to Holland or Blue and they're books written by people about their experiences and in that comes a lot of knowledge right? About what Down syndrome is and what it looks like… So to be able to read about a family who has gone through this in recent years type of thing…So we have a pretty good network of people within our organization, who, parents and stuff that have said that if somebody is going for open heart surgery like I'm a mom who's gone through that. Link me up with them right? Or somebody else has said like "I'm happy to sit with a family and talk about it and have them meet like our baby" and that kind of thing.*

However, the SDSS relies on health care providers presenting the SDSS's contact information to the parents, which, as evidenced by the present findings does not occur systematically. Further, it puts the burden on the parents to reach out to the society for information. Alternatively, health care providers can ask the parents if they are interested in receiving a new parent package, and can reach out to the SDSS themselves to elicit a package. Since the system is convoluted and unsystematic, parents often go without the package, or sometimes nurses will contact the SDSS when they realize that specialists have not made the connection:

> *The only downfall is the way that our privacy laws are working in our province is that we don't get notification when somebody is diagnosed. So we rely entirely on nursing staff to basically give us the like an anonymous email or text saying there was a baby born in Saskatoon, in Regina, in wherever that was diagnosed, with Down syndrome and we like drop off a basket at the front desk.*

8.2.3 ***"She seemed more like a scientist"*: Genetic Counselling**

Several participants described receiving a visit from a "geneticist", "genetic counsellor", or "genealogist". Most of these participants explained that the role of this health care provider was not clear and that they did not help them to understand the determination or their feelings around it. For example, Zadie and Kurt were expecting counselling and information for them to adjust to parenting a child with DS but their genetic counsellor seemed to be focused on figuring out the etiology of DS in their circumstance:

> Kurt: *We saw a genetic counsellor.*
>
> Zadie: *Oh yeah. We did do that.*
>
> Kurt: *Yeah, that wasn't good. Well, I thought it was sort of a funny story in retrospect, but um, it was very informative actually, if I recalled, properly. I left, we were holding hands and um, like it I thought it went well, and I think I actually said "well that went well" and I looked over at her and [laughs] she was crying [laughs]*
>
> Zadie: *[laughs]*
>
> Kurt: *I was like "Oh, I guess, I guess not." right? and so, um, but—*
>
> Sarah: *[to mom] So how did it go from your perspective?*
>
> Zadie: *I don't remember it really. Like I, 'cause they had wanted us to look, or to give them information on our families, ah, health history, and um, and then that made me think "well, was this my fault?" I think. And so, I mean—*
>
> Kurt: *It did, yeah I guess in retrospect, it seems like more they were curious… [laughs] we went in thinking it was going to be more like a counselling session, uh, and although we did get some information on— which probably filled in some blanks for us, I don't recall— but it seemed like they were doing it more for their own curiosity and research than—*
>
> Zadie: *—Solving a puzzle as opposed to—*

> Kurt: *—Yeah, than, than actually provide us information and counsel us through that, right?*

Ursula's experience was very similar. She did not find the "genealogist" to be focused on her needs, and like Zadie's description, found her to be more of a scientist (solving a puzzle) than a counselor:

> Ursula: *So they asked us lots of questions like medical questions about our family and things like that. Um, so like your whole history, like your medical history and stuff like that. Um, and then like they'll like she'll meet with you again after if you want or like even again during um—*
>
> Sarah: *Did you find it helpful?*
>
> Ursula: *I wouldn't say I found it that helpful 'cause I found, she was more like very uh like a super nice girl but I would say she was more like ah— she seemed more like a scientist.*

The cause of the DS did not seem to be a relevant or primary concern for most parents at the time. They were concerned with what their future might hold and the intricacies of parenting their new child. Mothers were also concerned with feeling guilty about the birth of an apparently undesirable child and the meetings with the geneticist were an opportunity for that guilt to be dispelled. However, participants tended to describe the meetings as having the opposite effect. Zadie said the questions made her wonder if her child's DS was her fault. Likewise, Maya explained that the questions the geneticists asked seemed to be irrelevant, and ultimately made her feel blamed:

> *The interactions with um, the um, geneticists, was very interesting. So I remember going through a kind of a barrage of questions of a person with a chart, a clip board and a long form asking me a whole bunch of questions about Down syndrome in our family, which, there wasn't. Um, and kind of tried to assess what kind of Downs, like the reason for the Downs was. And um, I mean, that's all well and fine. They— I think— I'm a big believer in statistics and getting information and what have you, but then [dad] and I were in a small side room to NICU, with a geneticist and another person or two and essentially the questions were "was I offered a the amniocentesis tests?" and "why didn't I choose to"— they wanted to understand why— I guess that's a question you could ask, because our answer was we didn't want to risk a miscarriage. Um, and, but there was something,*

> *and maybe I read too much into it— I was certainly not in a very positive place, mentally— but what my take away was, my perception was regardless, whether they intended it or not, was that somehow I had a responsibility to be tested. And that then I would have had the option to terminate, but as we didn't make that choice, then I could, you know, I didn't have information, right? So that was the beginning of my, um, sense of society blaming. You know that there is sort of this underlying current that you know, you are responsible for this baby with disabilities coming into the world when you could have informed yourself— and I suppose we might still have said "yeah, we're still going to have the baby" right? So, um, I guess, like I carry that with me. I remember my feelings more than anything at that point in time. And what, what was the point of that interview? Was it more than just getting— like I had already given them information, um, beyond that, what, why did they need the answer to that question?*

One participant, Joan, did describe having a positive experience with a genetic counsellor, who she described as empathetic and comforting:

> *The genetic counsellor sat with us for hours, it felt like. I don't think it was hours, but it felt like hours. And we dug deep you know into our family trees. Um, into all of the genial pools… Um, and by the end of it, our, that genetic counsellor was in tears. She just, we just had a lovely connection, her and I and um, I just felt a lot of empathy coming from her. And it was finally refreshing to see somebody kind of recognize the situation and feel ok to show emotion. It was ok. That was ok. And it was ok to shed some tears. And just, embrace it, I guess, if that's what it was at that point.*

8.3 Summary

Most participants experienced negative emotional reactions to their child's determination. Many attributed their reaction to the lack of knowledge they had about DS and the lack of or superficial experience they had with people with DS; they feared the unknown. This suggests that healthcare providers could make the emotional experience less stressful by providing education about Down syndrome. However, like in previous research, participants were dissatisfied with the lack of information they were provided about DS and the overly medical and negative information provided (Hedov, et al, 2002, Nelson Goff, et al., 2013, Roberts, et al., 2002, & Skotko 2005b). They were also disappointed with the genetic counselling they received, which was overly focussed on the etiology of the condition rather than helping them process the news. Several participants relayed that the most helpful information they received came from the provincial or national DS societies, but that this information often came late. The few participants who were able to talk to parents of children with DS or meet children with DS when they were first processing their feelings about the determination explained that it was helpful. Seeing children with DS made them realize children with DS were more similar to typical children than different and that the parenting experience was also comparable.

Participants narratives indicated that better education about Down syndrome could improve the emotional experience when receiving a determination. However, educational materials could also include information about common emotional reactions, so that parents and prospective parents understand that they are not alone when they experience negative feelings. This could help to mitigate feelings of guilt that several participants relayed about their initial negative reactions.

8.4 Chapter-Based Recommendations

The experiences and opinions relayed by participants in this chapter reinforce existing recommendations regarding how health care providers should deliver determinations including:

a) health care providers should offer an up-to-date balanced bibliography of resources on DS (Skotko, Kishnani, et al., 2009);
b) they should limit the discussion of medical conditions to those that the infant is suspected of having (Skotko, Capone, et al., 2009); and
c) they should provide contact information for local support groups and community services (Skotko, Capone, et al., 2009).

In addition, the present findings suggest that

d) genetic counsellors or other health care providers involved in helping parents understand the determination should provide a basic sketch of the etiology of DS (i.e., that it did not result from actions of the mother during pregnancy) but refrain from focussing the conversation on family genealogy. The focus of the conversation should be on what the condition will mean for their child and their family life because these are the parents’ primary concerns.

Finally,

e) a more formalized relationship or system between health care providers and local support groups could be helpful, especially in the Saskatchewan context, where the current research took place. Specifically, it would be helpful for health care providers to have the existing SDSS/CDSS information packages (which parents cited as the most helpful information they received) ready to provide to prospective or new parents when they deliver presumed determinations. This would likely require coordination and shared costing between the support organizations and obstetricians' offices, midwives' offices, mother-baby units, and neonatal units. Although this collaboration would require time and resources, it would result in parents receiving the most helpful information in a timely manner and could alleviate some of the burden on health care providers to become extensively educated about DS.

Uptake of these recommendations could result in increasing knowledge about DS. According to participants, lack of knowledge about DS and fear of the unknown was a primary reason for the intense negative emotional reactions they initially experienced when they received the determinations. Uptake of these recommendations could also improve parents' satisfaction with post-natal determinations more generally, as lack of quality information about DS was a primary reason for dissatisfaction.

CHAPTER 9

"WE'RE IN THE SAME BOOK, BUT WE'RE IN DIFFERENT PARTS OF THE BOOK": DOMINANT AND SUB-GROUP NARRATIVES

This chapter examines how participants' stories have progressed since the determination. Most parents describe that their lives are significantly improved because of their child with DS and that parenting them has not turned out to be as challenging as they initially anticipated. Many participants compared parenting a child with DS to parenting a typical child, with a few more hurdles but also often more rewards. Participants' narratives often included a turning point wherein the devastation of the initial determination eased, their initial concerns were revised, and life became easier. They relayed that the change in trajectory was facilitated by getting used to the idea of DS through time, getting to know their child, and getting to know other parents and children with DS which normalized their experience and provided them with a sense of belonging. That is the story of the dominant narrative. There was also a small sub-group (n = 2) of participants who recognized the dominant narrative and challenged it. Their children with DS had significant challenges and parenting them was not at all like parenting a typical child. They felt marginalized and silenced in the DS community. In addition, there was one participant who represented the "third narrative", which is the story of deciding to terminate a pregnancy with a DS determination. Since only one individual who terminated their pregnancy volunteered to participate in the study, the story of people who make this decision remains largely untold here. However, the third narrative converges and diverges with the dominant and sub-narratives of those who had children with DS in interesting ways.

9.1 *"It's like taking the scenic route"*: The Dominant Narrative

9.1.1 *"When she was a few months old it hit me... we're so lucky"*: The Turning Point

Many participants explained that, while the time around the determination was one of the most difficult periods in their lives, they eventually experienced a turning point and things began to feel easier. Sometimes participants described a particular moment that was a catalyst for a changed perspective such as when Arthur recounted a night early on in parenting his new child, in which he had a break down, followed by making a decision to "suck it up":

> *I remember there was a defining moment for me. It was, I was staying home with the baby… and I just remember, I don't know who started crying, I think [other child] started*

> *crying or the baby started crying and I just couldn't handle it. They were crying and I just walked out of the house. And I was like "kay, I can't do this", right? And outside I just laid on the grass, and I laid there for five minutes and thought "I'm a terrible parent" because I'm putting myself ahead of my children" right? "I'm out here and I should be in there cuddling or whatever", figuring out why they are crying, right? And I remember just laying in the grass, I don't know, I think I was out there for five minutes. I was home with my kids alone, and I was laying in the grass and thinking, like I just can't do this, right? And I don't know, I was looking at the stars or something. And then I got up and went back in and just I said "Ok I've got to suck this up and figure this out" right? … I just remember that moment as something that was "Ok, I've got to figure this out because I've got to deal with my own emotions and be a parent at the same time" right? Because life doesn't stop and wait for you to catch up, right? So you've got to figure it out.*

Often, the change in perspective occurred over time. For example, Joan attributed the positive transition to becoming educated about DS, being guided by community (health/social/educational) supports and services, and connecting with other parents:

> *Then we came home and we did Christmas the best that we could. In amongst some of his appointments, and some follow ups— was trying to recover still from the delivery, dealing with a partner who was a puddle of water every time he'd walk through the door… That was, it was a tough, it was a tough few months, for sure, um, in that regard. So yeah, that's kind of— and then, it's just been— I don't know, it gets easier, like it's just gotten a lot easier. We connected with parents, we networked with parents, our team at [organization] really picked us up and we really just let them kind of take us under their wing and navigated that system. I immersed in the next year in research and finding, you know the best techniques, and we soon found where services were lacking here so we went to Calgary for a few of his services… Um, I felt so much better once I started networking with parents…It was amazing. Just amazing. It was the best therapy I've ever had, in life.*

A few participants explained that the way they perceived the situation changed when they became exposed to positive messaging from other parents of children with DS. For example, reading parent accounts online made Simone change her perspective on her child's DS. She went from pitying her family to believing they were lucky to have their new addition:

> *I remember kind of feeling sorry for myself and like our family for the first few months and then I— when she was a few months old it kind of like hit me like— or I don't know, maybe— and I probably had like a little bit of baby blues and whatever— and I was like "no, we're so lucky"… I feel it took me a few months to embrace it. And I don't know if it was necessarily the Down syndrome. She had so many health issues… But I guess like I remember reading a lot of stuff online just on various websites and I would follow these facebook pages…and just like everyone was— I realized when I was looking online, anyone who has a kid with Down syndrome— or 99.9%— like everyone was really positive and almost like love their kids more than they would otherwise. And I always loved her from the start, but I was just so stressed and anxious. And then it was when she was three or three and a half months old, all of a sudden it just like— and it was quite a sudden change…But yeah I think it was just, it probably was just time. And then just probably realizing that she's not going to be a burden, like she's going to[pause]— be a blessing. And from all this probably a lot of it was from stuff that I found online too. And personal like, everyone, it seemed like everyone who had a kid with Down syndrome felt like they were lucky. And that's when it kind of hit me, when she was a few months old that we're actually, like, really lucky.*

9.1.2 Acceptance Facilitators

Many participants framed their changed perspective as "accepting" the determination and accepting their new life circumstances. When probed for what facilitated this change, participants described simply taking time to adjust, getting to know their child, and connecting with other parents of children with DS as what made the difference for them.

Time. Some participants explained that time and *"go[ing] through your everyday process"*(Sylvia) was the biggest factor that helped them to accept the determination. Alma described time as a *"healer"*:

> *Time. I think time was the, it's the biggest healer…there was always awesome days, um, and then, you know it just became there was way more great days than there was bad days. But I would have bad days quite a bit when we first got home. But over time, those bad days just started going away.*

Arthur explained that it took a very long time for him to accept his new life. He felt like this change completely altered his life plans and consumed his family's life and that although he currently is content with an atypical family life, it took about seven years for him to gain that perspective:

> *There wasn't very much acceptance by my wife or myself when uh, baby was little. And that was a problem and the baby can feel that right?... And so we have this family dynamic going on where you know we got this baby that we don't really ask— we didn't ask for right? So, I think for me it took seven years before my acceptance came around and I could actually say like this is an event that I can actually integrate and deal with and be ok with. It took that long, you know… It was just this whole, like uh, I think the first two years was really rough because of all the medical appointments, it wasn't a normal thing, like we almost had to ah, give up our job to do all this right? … It consumed our life and it was— caused a lot of negative feelings of resentment right? Saying like this this has dominated our life and it's not something we've chosen and like we can't do what normal families do— we're not doing what normal families are doing because we're doing a different thing, right? So it takes a long time to think, like this is this is our normal, and this is fine, right? So what if they're going to hockey games or they're doing gymnastics or whatever, like I'm ok with doing what we do, right? So ah, now I am, right? At the time I wasn't. I was very resentful that I have to live this life now that I didn't choose... I think there was depression, you know, like about especially at first like we're hit with this, you've got to battle— you've got to survive as a parent and deal with your family, right?*

Arthur believes that personal growth over time is what has allowed him to accept his new reality:

> *Uh, time, mostly, you know. Getting to adjust to it… And it took a long time to come around… it was really tough to integrate, and it took a long time. And I don't know exactly what made the transition. It was probably I think growing as a person myself, you know, having seven years to mature and figure out this is what's going on, right?*

Getting to Know Their Child. Several participants explained their perspective on the situation changed when they got to know their new children and experienced the positive aspects of parenting them. Harper explained that bonding was the first step, and everything followed:

> *For me I think it was just spending time just being with him, bonding … and getting to know your baby and the rest pretty much follows because how can you not love them?*

Zadie explained that once she met her child and discovered their individuality and personality she changed her mind about what parenting a child with DS would be like:

> <u>Sarah:</u> *So what's the change? What's happened from then till now that sort of changed your mind frame?*
>
> <u>Zadie:</u> *I mean getting to know [child]…that unknown is gone and there's this happy kid who um, who's just like any other kid. I think that learning that part um, people could have told us over and over again, "he's going to be like every other kid" but I don't know that it would have sunk in until actually meeting him right? And like everything he does, every milestone is just that much more exciting than uh, the other kids. And um, ya, I think that and even like thinking about how I felt before I met him and the fear and the um— "I don't want that"— I just feel awful even thinking it right? Because he's just awesome. Like I mean he's a challenge, but so are our other kids. Like just parenting in general is a challenge and so he has different challenges at times, but no more difficult.*

Alma described how she and her husband fell in love with their new child and got to learn about him and see him as an individual, rather than as a child with DS:

> *Because, you know, we just fell in love with him. Everything that he did. We just snuggled— we just treated him like— and now, don't even— when I look at [child] I don't see anything but my little guy. Like I don't see Down syndrome first. I see [child]. Like it's just who he is. And Down syndrome doesn't define everything he does.*

Connecting with Other Parents. For the vast majority of parents, connecting with other parents of children with DS and seeing/meeting other children and adults with DS was cited as an extremely positive experience, fostering their acceptance of the determination, and helping them to feel positively about the future. Numerous parents explained that the benefit of talking with other parents was their ability to normalize the situation for them—to hear and see that their child would be, in essence, a child like any other:

> *…they got one of their nurses from neonatal, [nurse] who has a little boy with Down syndrome to come and talk to us… she pulled out a picture of [nurse's son] from her pocket and showed us this little boy. …and that's the one thing that stuck out to me, is her talking about [her son] and just like he's an ordinary kid, and showing me pictures and*

> *all that kind of stuff. So that was like, probably the highlight of that night for me, because somebody was normalizing it for us… [nurse] was like a glimmer of hope…I found [nurse's] email and I sent her an email and I said, "I probably didn't look like I was absorbing a lot of like what you were saying, but I want you to know that it did have a really positive impact on me, just seeing you as a mom, as mom to mom and talking about your [son] that you love so dearly and showing me his picture" …Um, yeah, so [nurse] was like the human side of it. She was speaking from her own personal experience and that's what I've found to be the most valuable thing is connecting with other people in your exact shoes. Nothing trumps that.* (Senga)

The normalization sometimes occurred through mundane events. For example, Margaret explained that seeing a six-year old with DS and her parent disagree about snack sizes made her see the typicality in children with DS:

> *[mother of child with DS] invited me over for coffee and that was it…I went over and I remember her daughter [name] at the time was like 6, and she walked out … and looks at her is and is like "I want a cheese slice" and goes to the fridge and gets out a cheese slice, but takes out like a stack of them. And [the mother] turns around and takes them away and stuff. And I was like "well that's normal. Like that's a pretty normal 6 or 7 year old thing to do" and it's just kind of was like "why wasn't I here sooner?"*

Edith explained that talking to a mother of a child with DS was a huge relief because it made her realize that so much of her parenting experience would be similar to that of a typical parent:

> *She was telling us stories about her little girl and you know funny things that she did or when she reached a milestone or her birthday or those kind of things and seeing the pictures too, was like really helpful. It was kind of like you could see her growing up and it was just like "Oh, ok, she's just like a normal kid. She's just a little bit, you know behind" She's not as quick to develop as other kids but she seems like pretty cool. So it was like a big sigh of relief, like I felt like I could breathe again and you know I felt like my little girl wasn't going to be just this Down syndrome diagnosis. She was going to be like our little girl.*

Joan explained that she first experienced the support of the DS community when she went to a Canadian Down Syndrome Society conference, where she met other parents of children with DS as well as individuals with DS. She described the strength that she got from interacting with the community as fuel for the days where parenting a child with DS is challenging:

> *…we went to the national Down syndrome conference. …and that was AMAZING...there were parents of babies, and there were parents of school-aged kids, there were parents of toddlers, parents of university students, and there were self-advocates there. So I could see people with Down Syndrome, presenting and walking around, living successful amazing lives… So when we came home from there I said "this is it. I can't stop this feeling now. To be a successful parent and advocate to this kid I have to tap into this. Like, every few months at least, because it was so empowering as a parent. And when you have those super shitty weeks where it's so heavy and all you get is bad news and you feel like you're getting curve balls thrown at you, that's what you have to— that's what pulls me out of it. For sure.*

Harper explained that she was not initially interested in the support of other parents, simply because of the time demands in their family, but that spending time with other families helped to normalize what her family was experiencing:

> *a social worker phoned and asked us to come in for one of the support group meetings. And I remember saying to [dad] "Oh my god, we've got all this stuff on our plate right now, who the hell has time for a support group? Whatever, let's just go in and then we don't have to ever go again." And now we go, since that first meeting, we've went to every meeting, since then. Which I'm glad that somebody did phone us because you're introduced to all these other families that are going through the same things as you and you get to see their children and hear their stories and their stories of how their child is driving them nuts just like their typical children, but then you're like, you know "Ok, we are having a normal life".*

For Ernest, who first connected with another parent prenatally, meeting them and their child with DS had several effects on him. It made him understand that people with DS are humans and individuals in their own right, and it provided him a changed perspective on what his child's slower development would mean for him:

> *For me it was seeing the joy and celebration of that mother with the milestones that her daughter was attaining and the practical reality of a HUMAN. Not me researching on Google, but seeing a human infant daughter that was all over the place, doing whatever,*

> *like, it isn't just something that I'm researching. It is an actual INFANT CHILD, TODDLER, that is living, that has Down syndrome…so that and just seeing and hearing the joy in her mother of like she was able to lift, hold a Cheerio. And it might seem like a minor thing, but she explained very well how you celebrate the milestones and like even though it takes longer, that you have your baby longer and it brings you more joy, was the way she kind of put it. Which is the truth of how we're living. Like our son, 19 months, he's not close to walking. I'm having an over/under with my parents if he's going to be walking at two. I don't think so, But I DON'T CARE, because you know I see the every little step…you know and it's a slower journey, but it's a more enriching journey and I feel like I got that from her. From the parent.*

Ernest and Jane went on to explain that meeting the mom and daughter with DS humanized individuals with DS and counteracted the stereotypes that they associated with DS. Instead of focusing on the disability associated with DS, they saw how much children with DS can do:

> <u>Jane:</u> *…how do you explain a lightbulb moment other than it was a lightbulb?* [laughs]
>
> <u>Ernest:</u> *It takes away the fear, the threat of a person with Down syndrome, right? Like you see the stereotype, like you know, the, almond shaped eyes, the other things… but when you see a human you value them as a human, as a baby living, then you can't hide from it…*
>
> <u>Jane:</u> *Yeah. Just like what society's perceptions are and how you grow up and how you know, your knowledge on individuals with Down syndrome, up till that point, 'cause yeah we hadn't had a lot of experience with individuals—*
>
> <u>Ernest:</u> *You do see the ability. That's something that I got from that experience. It's a slogan, but I LOVE it. Because like, otherwise, the perception I think where I was going with it, is you see the disability. And this was seeing the ability, when we interacted with the mom and the daughter.*

Senga discussed how she now acts as the model parent for new parents on her maternity ward, and she reflected on how new parents are often shocked at how "normal" her child with DS is:

> <u>William:</u> *I remember one time I was bringing [child] by the unit to visit you 'cause there was couple that just had a child*
>
> <u>Senga:</u> *Oh, yeah, you just happened to bring her to visit me. And after they were like "oh, she like—*

> William: — *'cause all she wanted to do was go to the park and go to the slide and she kept talking the whole time and they were looking…I was walking down the hallway kind of beside them, and they were like looking at [child] like "ok, she talks!"*
>
> Senga: *—and she stopped and talked to [child] and then after [dad] and [child] left, she was like "she talks?" and I'm like "yeah, she does" and then she's like, "and she had heart surgery?" I'm like "yeah" "she looks so healthy" I'm like "yep, she is healthy now. She had her heart fixed and she's doing really well" and so I was like "I know the instinct is to focus on all the limitations that are going to be there but I can tell you that it's not going to always be your focus, like you're not going to fixate on that."*

Alma also reflected on how meeting her son is frequently mentioned as a positive experience for parents of children with DS. In addition to her son being a fun, caring, charismatic person, she explained that new parents simply need to see people with DS so that they can learn that they are individuals like anyone else:

> *He's done very well. He's in um, a regular stream at school. He is so social. He talks a ton…and I mean he's just very social and I think that's why people like him. He's concerned about people…and I think that other parents need to see that, right? Especially the young ones, 'cause I, when [child] was born, I would be staring. If I saw anybody, like out in public, with a, like a person with Down syndrome, I would just watch them, their interaction with people and how is [child's] life going to look, and you know those kinds of things. So often it would just give me lots of hope for the future. Not anything but hope. But here's a person- he's a person….he makes every room better. Like whenever he's around, people will flock to him. 'Cause he is, he's a lot of fun.*

For several participants, connecting with other parents was a positive experience because it was validating to be around people who "got it". Connecting with other parents was also helpful for a more pragmatic reason— as Margaret described, parents share information with each other about the previously unfamiliar systems they had to be involved with now that they had their child with DS:

> *And so it was just somebody that got it— who understood. And so we hung out and eventually we hung out more and more. There was another family that had a baby that was within the same 10 months as [child] so she introduced us and so we ended up being friends and it kind of started that whole process of meeting up with other families that*

> *were local that had babies kind of the same age as [child] or that were a few years older and that could kind of offer some insight as to "well Ok, I had to go for this eye test. What do I expect?" Or PT, "when we're doing the full, like the work up, what does that mean?" And then [child]- they ended up finding that she did have a hole in her heart. And like "what does that mean?" and just somebody else's experience that wasn't a professional. That was just somebody that I could talk to the heart about it. It was nice to have that eventually.*

Earnest explained that it was refreshing to be around people with shared experience because it made them feel understood without having to explain themselves:

> *…it's so refreshing when you find people that are your tribe. Like people that get it. Like some people think they get it, but they only get it so far. There's other people that have lived it. So even how you express your feelings and the stress of all of the appointments you have to go to. Other people— many other people that were parents of typical children— they don't get that. They don't understand that stress of it…So now you seek out— you don't seek out all the time— but it's refreshing when you can talk to someone and they get it. Without, even if you don't really know how to put that into words. It's just nice.*

Jane relayed that she's made new life-long friendships with parents of children with DS. On the other hand she described being on what felt like a different path from mothers of typical children and that for that reason she struggled to form friendships with them:

> *Like in terms of the community, like the Down syndrome community, is absolutely amazing…. just you know, finding friendships there…These are the people in our life now. These are the people that get it. One thing that I have found is I have had trouble forming friendships with mothers of typical children. Like I tried going to a mother-baby group for a while after [child] was born and just found that it wasn't working for me. And we were on different paths and people didn't get it, and I didn't get their journey and they didn't get my journey, and that's fine. So then I have these friends over here in the Down syndrome community and that's where I'm happy—so you form new bonds, you form new friendships, you're a part of a new amazing community that we will have for life and that's amazing.*

Zadie and Kurt explained that connecting with other parents felt like therapy for them:

> <u>Zadie:</u> *And [program] is an amazing program that has started up right at the time that [child] was born…*
>
> <u>Kurt:</u> *Phenomenal program*
>
> <u>Zadie:</u> *It's helped.*
>
> <u>Kurt:</u> *… I couldn't imagine having a child with Down syndrome and not having that program… you know there's a therapy aspect of it.*
>
> <u>Zadie:</u> *It's connected us to other families… just connecting and comparing experiences I guess and you know, knowing you're not alone in it is good.*

9.1.3 *"I kind of forget that [they] have Down syndrome":* Life Now

The majority of parents relayed that eventually their life has improved because of their child with DS. As Harper stated, they face challenges and have bad days, but overall the value of their child outweighs the negative experiences:

> *It's not always easy. It's not always rainbows. There are days when you're ready to toss in the towel, but the good days FAR outweigh the bad and that's —not that they're bad but the difficult times I guess I should say— and that's something that I wish I would have been told at the time.*

Several parents, like Zadie, explained that the benefits of their child outweighed the challenges of parenting a child with DS:

> *…it's been a positive thing overall you know, when you look at everything. He's worth every stress and every little thing— he's just so awesome.*

Although most parents explained that the day-to-day challenges are not insignificant, their overall assessment of their experience parenting is positive:

> <u>Oscar:</u> *And there's so many things that we could tell you about him, but in the end it would be describing the whole life of a person. You know, but in terms of us, it's not that I'm happier, but that I have more joy. Because happy is sort of day to day whereas joy is a deeper abiding thing. Um, you know day to day, there are a lot of struggles—*
>
> <u>Camille:</u> *—it's a lot of work—*
>
> <u>Oscar:</u> *—and a lot of work. But you know, year over year, looking at him on the whole, there's an abiding joy there.*

Several parents explained that from their perspective, their child with DS is *"one of the best things that ever happened"* to them (Maude) and a *"blessing"* (Jane).

> <u>Camille:</u> *And [child] for all the challenges we have with parenting a child who has some special needs, he is the best thing that ever happened to me…You know, really he is a gift that I cannot imagine living without.*
>
> <u>Oscar:</u> *I have to echo [mom's] sentiments there.*

Sylvia explained that life with her child is not life as she expected it would be, but that it is better: *"you know, I just wanted something that was normal. But [child] is far better than normal."* Likewise, Chloe reflected that her life had changed more than she imagined it would, and that in contrast to what she was expecting when she received the determination, she considers her family to be lucky to have their child with DS:

> *It's definitely changed it all. But, more like for the better. More than I could have ever imagined it would ever be. And um, I often say that realistically we're the lucky ones because we have [child]. Um, everybody else are the ones missing out. Because they don't get to experience what we get to experience. Because it truly is amazing.*

Most parents relayed that parenting their child is similar to parenting any other child but with a few more challenges and more time commitment. Agatha compared the extra time raising her child takes to "taking the scenic route":

> *…it's not scary. It's just like raising any other kid, it just takes a little longer. It's like, I tell people that it's like taking the scenic route, and it's just as fun and just as beautiful.*

A few parents, like Ursula, described how, in contrast to the focus on DS when their child was first born, the fact that their child has DS is no longer central to their families' lives, or to their thoughts about their child:

> *…my mom said to me the other day, she goes "you know I kind of forget that [child] has Down syndrome". Like at the time when you're pregnant, that's the only thing you think about; you think that you're not going to forget or that you couldn't possibly imagine that you wouldn't be thinking about it. And you do slowly start to like— it's like that's just [child].*

Alma also explained how DS is not at the forefront of her mind when she thinks about her son because DS does not define him; it is just one aspect of who he is:

> *Because, you know, we just fell in love with him. Everything that he did. We just snuggled— we just treated him like— when I look at [child] I don't see anything but my*

> *little guy. Like I don't see Down syndrome first. I see [Child]. Like it's just who he is. And Down syndrome doesn't define everything he does.*

Kurt explained that he does not parent his child with DS differently than he does his children who do not have DS. He explained that while they anticipated negative change when they received their son's determination, their lives have changed positively, not because of DS, but simply because of having another individual in their family:

> *I don't parent any different. I don't believe [child] consumes any more or less time than the rest of our children. He probably gets the least amount of attention, quite realistically, right? The fact that he has Down syndrome, you know, hasn't changed our lives in the way that we thought it would at all. It's changed— he's changed our lives tremendously but not anything more or less than any other child without a Down syndrome diagnosis would. You know and it's impossible to think of what our family was even like before him. And that's again, not because he has Down syndrome, it's just because he's another person in our family, right? So you know, there's this fear that we had of tremendous change negatively. And it's been tremendous change positively. But again, I'm of the belief that it's not because he has Down syndrome it's just cause he's another child in our family.*

Alice and Charles relayed similar thoughts when they explained that parenting their new son with DS was remarkably like parenting their typical child, which refuted their initial expectations:

> <u>Charles:</u> *He's been, for me, what I didn't expect going in is I thought he'd be very different from her, and he hasn't been…The similarities are striking. Um, And I mean yeah, he's a little bit behind in terms of developmentally where she was at, but they do things the same way.*
>
> <u>Alice:</u> *Well and you'll hear in different things like you know slogans like "more alike than different" and before [child] I remember thinking like "c'mon" and then you realize no, it actually is surprising where it's slightly different but not substantially.*
>
> <u>Charles:</u> *…I assumed that it would be harder. I did. I mean babies are hard in general but that comes with the territory. I assumed that he would be more challenging.*

9.2 "*Not all children with Down syndrome are the same child*": The Sub-Group Narrative

As detailed thus far, most participants relayed that upon their child's determination they had negative beliefs about parenting a child with DS, but that for the most part, these beliefs did not come to fruition; their child had not changed their life in the way that they had assumed it would. However, there was a small but salient group of parents (n = 2) who described their child as having more needs than a typical child with DS. For this subgroup, their lives were affected substantially *more* than they imagined it would be upon their child's determination. They explained that, although parenting their child was rewarding, it was most often extremely challenging. This group felt that the information they received about DS presented a narrowly *positive* view of DS, which did not include their children or help them prepare for the complexities of their child's needs. Three main ways that the dominant narrative and the subgroup narrative differed are specified in Table 9.1.

While the dominant narrative described finding extensive support in other parents, as speaking with them normalized their experience and confirmed the near typicality of many children with DS, the small sub-group found it difficult to exchange stories with parents of "high-functioning" children. Just like how Joan relayed earlier that she had trouble relating to parents of typical children, Margot explained that she had trouble relating to parents of higher functioning children with DS:

> *I don't want to hear about other people's experiences. I'm like trying to swim in my own experience. I don't care about other people's experiences… When I talk to other parents of children with Downs, we're not even—we're in the same book, but we're in like different parts of the book. I don't even know how to explain that to you, because their kids are potentially walking…they are usually talking to some degree—it's just very different…Um, I did try the support group, but I just found… I didn't relate to them on any of the issues.*

In contrast to the parents who felt refreshed by being around other parents of children with DS, Margot described feeling silenced by the DS community. She felt like no one wants to acknowledge or discuss the difficult aspects of life for many people with DS, and since her son's life involves many challenges, that leaves her without a sounding board:

> *A lot of us that don't have high functioning kids get silenced when we mention you know, our experience in terms of—I'll give you a really simple example ok? I was totally silenced on, so do you remember when that [person in news] wanted to immigrate to*

Table 9.1 Dominant versus subgroup narrative

	Dominant narrative	Subgroup narrative
Impact of DS	*"The fact that he has Down syndrome hasn't changed our lives in the way that we thought it would at all. He's changed our lives tremendously, but not anything more or less than any other child would."*	*"There was nothing to prepare me for what I deal with… My son is not in the typical range of DS… And most of the literature and discussions around DS don't ever talk about the stuff that my son has. The extra stuff."*
Value of meeting other parents	*"Everyone understands and you know they're kind of in the same boat".* *"The Down syndrome community, is absolutely amazing…. These are the people that get it."*	*"When I talk to other parents of children with DS, we're not even—we're in the same book, but we're in different parts of the book."* *"I did try the support group, but … I didn't relate to them on any of the issues."*
DS organizations' presentation of DS	*"That was AMAZING… I could see people with Down Syndrome living successful amazing lives"*	*"The CDSS tends to put the most positive spin on the experience of having a child with DS. …A lot of times it is that positive. But… if you don't have that same happy experience, where do you fit in? …Are you kind of raining on the parade? … It's another marginalization…It's important that we include everyone. That we not just talk about the ones that are the center of attention for CDSS, but we talk about those that are not going to ever do some of the things that we like to brag about."*

> *Canada and he wanted to bring his disabled child…The boy has Downs, right? Immigration policies say "no you're not allowed to have a disabled child"…The Down syndrome community is outraged. I brought up the fact "yes, there is truth. We don't have enough resources for our children, we don't have enough this, we don't have enough that…And everyone was like … "you're being rude, our children can exceed at everything they want to do" and I'm like, "but not all children are savants."…Not all children are going to be high functioning…And no one wanted to hear that part of the discussion… there is no one to talk to when your child is not high functioning. There's no one. Because no one wants to talk about that.*

Margot explained that she was concerned that representations of people with DS tend to focus on high achieving people, when that does not represent the reality for most people with DS. She wondered about the repercussions of this public image for policy about DS:

> *And I—what scares me as a parent, and I see this more and more on social media is they are showing all these savants of Down syndrome people, you know like a lady who's been a preschool teacher, and dance instructor, and I have concern in terms of policy, and now maybe this is just me thinking too much…but I'm concerned in terms of policy that the government is going to say "well hey, if Down syndrome people can do this, why do they need one-on-one support in the education system? Why do they need all this help when they could be a teacher or a dancer, or? So I have concern about all the spotlight being put on the savants, in terms of the reality of it is, is that most of our kids are not going to do that stuff. Most of our kids are going to end up at Costco, maybe cleaning tables at Burger King, you know, so I think maybe because of who my child is, I'm a little bit more grounded in reality in terms of the potentials. In fact, I might even have a little bit of a negative, but [laughs] but yeah, no one wants to talk about the other stuff. … no one wants to talk about the problems of having these kids.*

While most parents found social support and inspiration in DS support organizations, the subgroup of parents felt marginalized by the narrowly positive view they presented. Although Maya believed that it was appropriate for the DS community to celebrate the accomplishments of individuals with DS, she also perceived the celebration to be disproportionately focused on "high-functioning" individuals with DS. She pondered what that meant for the inclusion of her and her child:

> *…not all children with Down syndrome are the same child. They are all different. Personalities, one thing, but the actual impact of their disabilities on their abilities— all different. And so I will never forget reading a letter that, I think it must have been in the Canadian Down Syndrome Society newsletter some years ago, from a father, who relayed the number of times he had been to the hospital with his child and the severity of the medical issues that this child with Downs was experiencing. And not that he loved the child any less, but that that is the reality of their experience with Down syndrome. But CDSS tends to put the most positive spin possible on the experience of having a child with Downs. Um, and rightly so because a lot of times it is that positive, right? But it is this tricky thing of speaking your truth. And so then if you don't have that same kind of happy experience, where do you fit in? With your issues and concerns? And are you kind of raining on the parade if you say, "just a second here, actually my child with Down syndrome is very low functioning" …But what are you going to do to build up the OKness of my child that is not achieving in the way that this other child might who's exceptional?*

She described that what resulted was a kind of marginalization of the sub-group of people with DS that do not fit the narrative of high achievers. She emphasized the importance of celebrating people with all ranges of abilities and that true inclusion means valuing people apart from their accomplishments and making space for and validating all experiences:

> Maya: *it's important that when research is done about people with Down syndrome, that we include everyone. Right? That we not just talk about the ones that are the centre of attention for CDSS, and so on, but we talk about those that are not going to ever do some of the things that we like to brag about…But it's also why I insist that people who are nonverbal, we find things for them, and you know that we try to make it as broad as possible. Because I, at the bottom of my heart I know [child] was supposed to be here, that she was just as valuable as anybody else and that people, again, when people decide whether they are going to terminate or not, they need to understand that, you know what, yeah, you might end up having a child that has MORE needs, and more severe disabilities, that is, that's life. You know, that's the chance you take… But you know we've got to, just, we can't just not include people again!*
>
> Sarah: *It's another level of marginalization?*

> Maya: *It's another marginalization, right? So we just, sort of "so now we're just going to talk about this group within this group" as being the ones that we're going to want to help strengthen our cause or whatever it is. So I'm babbling on now, but I just wanted to get that point out that my feeling about inclusion comes from that place of seeing— loving— a child that is not high functioning.*

9.3 *"Sometimes people have to make difficult choices for a number of reasons":* The Third Narrative

Only one individual (Judy) who chose to terminate their pregnancy volunteered to participate in the study, so the story of people who make this choice remains largely untold here. However, Judy's story illustrates some interesting convergences and divergences with the dominant and sub-narratives of those who had children with DS. Judy's story was not so different from the dominant narrative when she first found out about the possibility of DS. She and her partner had concerns about their capacity to parent a child with a disability, concerns about the lack of support available to them, and concerns about discrimination and isolation for a child with DS, which align with the concerns of other participants in this study and in previous research. Their screening showed indicators that their child would likely not survive, which made their decision to terminate more straightforward, but was not ultimately the deciding factor for termination. They did not want to parent a child with DS. In particular, her partner insisted that this was not the child he wanted. In a previous study, 63% of participants who terminated a pregnancy with DS determination cited "simply not wanting a disabled child" (Korenromp, et al., 2007).

It would be tempting to argue that Judy and her partner made their decision to terminate based on unfounded negative assumptions about DS, because the majority of parents, in this study and others, end up reporting more positive than negative outcomes of parenting their children with DS. However, it is impossible to know if Judy and her partner's concerns would have come to fruition or not. Although many parents of children with DS framed their experience as taking the scenic route, a small but salient group illustrated that the story is not that simple. In fact, some of Judy and her partner's concerns were starkly played out in the sub-group's narrative. For example, during their discussions about termination Judy relayed that her partner *"made the comment, 'who would ever play with our child?' and I think he just— the idea of— and he said it would just be heartbreaking"*. Although some parents' children had a different experience, like Alma who recounted that "*he makes every room better. Like whenever he's around, people will flock to him. 'Cause he is, he's a lot of fun"*, Margot explained that her child's lack of friends was indeed extremely challenging for her:

> *Probably the hardest— is the lack of friends for him. That's really hard. Now I shouldn't say, 'cause there is a little boy that lives across the street from us… and he does come over and hang out with [child] occasionally, but I can already see that he's, moving past, right? That he'd rather do other things, cause my son only likes to do like two or three things. And that, you know, that is hard to watch, because my son loves him, so much, he thinks he's great. And I get what's going on with this little boy. This little boy is growing up, right… So it does, I mean that's a layer of grief in terms of like, sometimes I get tired of being my son's friend, right?... I can never say to my son, like "go play with your friend down the street. I love you but get the hell out", like I can never say that to my son.*

Given the experiences relayed by the sub-group, it is not fair to say that Judy and her partner's concerns were baseless; there are some parents of children with DS who experience significantly more challenges than others. Like the sub-group, Judy illustrated that she was aware of the dominant narrative, and that although she did not disagree with it per se, she considers it simplistic in relation to the factors that contributed to her decision to terminate:

> *Because I think there's a lot of these 'rah rah!' you know, 'Down syndrome people are people too!' and I— yeah, they are, but sometimes people have to make difficult choices for a number of reasons.*

9.4 Discussion

Several participants relayed that in contrast to what they imagined when they received their child's determination, raising their child has not been that different from parenting a typical child. They relayed challenges and a slower pace, but an essence that is similar. This dominant narrative that likens parenting a child with DS to *"taking the scenic route"* aligns with previous research with parents of children with DS who have framed their experience as simply *"a change in plans"* (Van Riper, 2007), or *"not what you were expecting, but… still a beautiful journey"* (Pillay et al., 2012). The narrative also aligns with previous research which has suggested that the adjustment of parents of children with DS resembles the adjustment of parents of typically developing children more than it differs (Cunningham, 1996; Glidden, et al., 2010). In the present study, these parents tended to have a difficult time immediately after their child's determination but experienced a turning point wherein the devastation of the initial determination eased, their initial concerns were revised, and life became easier. Getting used to the idea of DS through time, getting to know their child, and getting to know other parents and children with DS which normalized their experience and provided them with a sense of belonging appear to be integral factors in changing their experience.

The sub-group narrative challenged the dominant narrative, or at least the universality of the *"scenic route"* experience. This minority of participants reported significant challenges in parenting their child with DS and unlike the majority who felt empowered by engaging with other parents and DS organizations, felt silenced. To them, the *"scenic route"* narrative applied to "high-functioning" children with DS and did not reflect their experience. The presence of the sub-narrative legitimates the concerns that motivated Judy's termination in the third narrative. As she imagined, parenting a child with DS can be very challenging. Other research has also reported that a small proportion of parents of children with DS experience more stress, anxiety, and depression than parents with typically developing children (Noh et al., 1989; Sanders & Morgan, 1997; Padeliadu, 1998; Roach, et al.,1999; Gau et al., 2008). There are various explanations for why some parents with DS "thrive" and others "have difficulty adapting" (Van Riper, 2007). Most studies indicate that the child's level of cognitive ability is not related to parental well-being (Manuel et al. 2003; Glidden & Schoolcraft 2007; Grein & Glidden, 2015). Rather, the child's behavioural phenotype tends to be one of the strongest predictors, with more behavioural challenges being indicative of lower parental well-being (Abbeduto et al., 2004; Esbensen & Seltzer, 2011; Pillay et al., 2012; Sloper et al., 1991; Cunningham, 1996; Stores et al., 1998; Hauser-Cram et al., 2001; Hodapp et al., 2003; Most et al., 2006; Bourke et al., 2008). The number and severity of health problems is also predictive of lower levels of parental adaptation (Pillay et al., 2012; Skotko et al, 2011b). Parents' emotional stability is also predictive of higher levels of well-being as is family accord (Grein & Glidden, 2015) and specifically an affirming style of problem solving (Van Riper et al, 2007).

Notably, Esbensen and Seltzer (2011) found that social support was not related to parental well-being, an outcome that even they questioned. In the present study the majority of participants extolled the positive impact of meeting other parents of children with DS. These were the parents who tended to describe their children's impact on their life as minor. But those who described their children as having higher needs that the average child with DS disagreed that interacting with other parents was helpful. Given these findings, it might be that general social support does not have an effect (or even has a negative impact), but that social support, specifically from those with a similar experience to one's own, does improve well-being.

The results of this chapter indicate challenges for counselling parents about screening, testing and termination decisions. What should a prospective parent, such as Judy, who had concerns about parenting a child with DS, have been told about DS? As evidenced in this study and others, parents have been dissatisfied with the overly negative and medical portrayal of DS when they received their determination (Hedov, et al., 2002; Skotko, 2005a; Skotko 2005b; Nelson Goff, et al., 2013). They call for more positive information to be provided, a request based in evidence given the overwhelming positive experience relayed by many parents of children with DS. However, as evidenced by some experiences represented in the current study, some parents experience significant challenges, and believe the dominant narrative paints an exaggeratedly positive picture. Although the majority of parents in this study are *"taking the scenic route,"* that is not applicable or relatable to all parents of children with DS. This is what presents the challenge of how to frame to DS when a determination is delivered or when termination is considered— there is not one story to tell.

Given that the way DS will impact a family is predicated on child variables, family variables, parent variables, and social variables, the most helpful approach for parents upon receiving a determination may be that suggested by Hippman et al (2012) which is to explore the range of possibilities regarding the experience of raising a child with DS and help families to evaluate these possibilities in the context of their own lives. This includes communicating the range of outcomes for individuals with DS, which could be conveyed with stories or videos, as well as helping families to imagine how a child with DS would interact with their lives. Parents could be encouraged to consider variables such as their own coping style, the strength of their relationship with their partner, and the support available to them (to name a few) and how these variables would interact with the various outcomes of DS.

The results of this chapter also present challenges for support organizations because it highlights a segment of their population who may be underserved. Many participants highlighted that they were inspired by the work of support organizations, particularly the way that support organizations would highlight the achievements and abilities of people with DS. However, there is a segment of parents who appear to need a different kind of support. It may be of value, for example, to create conversation circles for parents of children who experience a higher number of DS-related health complications, so that they have a venue to normalize their experience, information share, and feel a sense of belonging. It also may be of value to create informational resources that can be provided to parents of children with more DS-related complications. Finally, this group may need additional advocacy for educational, financial, and social supports given the higher demands of parenting their children.

9.5 Chapter-Based Recommendations

Based on the findings from this chapter, the following recommendations are made to prenatal healthcare providers in order to increase knowledge about DS and improve informed decision making:

a) health care providers should refrain from a monolithic presentation of DS and instead explore the range of possibilities regarding the experience of raising a child with DS; and
b) health care providers should help families to evaluate these possibilities in the context of their own lives.

Based on the findings from this chapter, the following recommendations are made to DS support organizations in order to support the diversity of individuals and families of people with DS:

c) DS informational resources should refrain from a monolithic presentation of DS and instead explore the range of possibilities regarding the experience of living with DS and raising a child with DS;
d) Organizations should consider how they could better support the marginalized members of their communities. This could take the form of informational resources, social support initiatives, as well as advocacy.

CHAPTER 10

"*ULTIMATELY, OUR STORY ISN'T FINISHED*": THE CODA

10.1 "*I have learned more from her than she's learned from me*": Changes Due to Parenting a Child with DS.

Several of the participants who were interviewed first spontaneously discussed experiencing personal development as a result of parenting a child with DS. For example, Arthur explained that his family has developed a stronger character through their experience:

> *I think it's had a dramatic effect on who I am today, right? Your experiences— you are the sum total of your experiences in life, right? So I have probably learned more from her than she's learned from me, you know. It's probably taught me a lot. And lot of good things, right? Mostly almost all good, right? It's shown me who I am, and you find out who your friends are, right? And you find out who truly are people that you can count on and who isn't. Like I think before we were kind of leading a superficial life, and it really changed, and you kind of get exposed to the other side of life and it has an effect on you and it really felt good, you know. The most painful things in life that happen to you are where you do your strongest growing and development of character I think. So I think it's made the entire family different. Like if it would have been with and without— like obviously you can't say what would have happened— but I'd say we're ten times better than we would have been.*

Given how salient the personal development seemed to be in the first few interviews, I began asking about any changes parents had experienced as a result of parenting their child with DS.

10.1.1 Empathy

Several participants explained that they have developed more awareness of the difficulties life can entail for people. For example, Emily described herself as previously being naïve to the challenges that children with diverse abilities and their families face until she herself experienced those challenges:

> *I think I was very naive. I kind of felt as a person that everyone was treated equally. Um, and I didn't really realize the challenges like when it came to school. Um, you know like I mean there's children with autism, there's children with all different diverse abilities and I just totally was clueless about those challenges. And even as a parent. Like even people*

> *that— you know, I knew families that had challenges but I didn't realize really what challenges they had until you're totally faced with it. Or the system— the school system, the challenges the teachers have until you're there and you're part of it.*

As Oscar described, for many participants, this increased awareness of life's challenges resulted in increased appreciation of or empathy for others' experiences:

> *…you know I go to the [DS support organization] now, and I realize that everybody's got a story, and everybody who has walked through those doors has worn some degree of what we've worn. And it's, you know, it's made me more appreciative of, sort of the whole "everybody is fighting a hard battle" kind of thing.*

Harper relayed that with more awareness of the various underlying conditions children experience, she is less likely to judge parents for their children's behavior and instead understand that what they are going through does not necessarily have an easy or obvious solution:

> *I know for myself I'm definitely less judgmental. Not that I think that I was before, but you know, you see the kids in the grocery store that are having the meltdown and you're thinking "why doesn't that mom do something to control her child?" well maybe that child has a learning disability or a sensory issue or something right?*

The increased empathy was often cited as manifesting in participants' professional practice, especially when they worked in health care or education. For example, Stephen explained that experiencing particular frustrations in the health care system himself made him better understand and appreciate what his patients would go through:

> *For me professionally, it's enabled me to be more empathetic than I was before for sure and being able to relate a different level and especial— when I was on paeds you know, connected with other parents. They were dealing with sick kids or chronically ill children or other diagnoses, and you develop a relationship with folks who you just know— who get it! And if you don't have a kid that goes through it and you've never been frustrated with an error or the wait time or anything that's completely outrageous…*

10.1.2 More Open-Minded and Decrease in Prejudice

One of the most common changes that parents cited was that they considered themselves more open-minded than they were prior to having their child. As Alma said, *"it opens up your world"*. Several participants describe overlooking and subsequently missing out on the value of an entire group of people (the disability community) before they had their child. For instance, Maude described how she was not really “seeing” people with disabilities before she had her child. Leo responded that he no longer makes assumptions about who people with disabilities are and what they can do:

> <u>Maude:</u> *I think it’s kind of made me notice more around me. Like, people who have disabilities and you know maybe I wasn’t— I wouldn’t stare— but maybe I wasn’t seeing them for who they were. I think I’ve been kind of more aware of that. Maybe that person does want to say hi and have a conversation and that’s maybe something I wouldn’t have done before. So I think it’s kind of challenged me to see everybody as— and it’s embarrassing to say that, but maybe I hadn't been doing that— you know, see people who might have some other disability or Down syndrome and I probably wouldn’t have gone up and talked to them or smiled or tried to interact. You know, those people are special too and they’ve got a story and they need people to interact with…*
>
> <u>Leo:</u> *And I guess just seeing past the labels and that people are people and um, yeah and can contribute and you can’t just stick a label on them and then write them off or put them in a little box and think that you’ve explained them or contained them.*

As Leo described, getting to know their child made them aware that everyone has value and contributes uniquely to family and society:

> *…that everyone is able to contribute and has value. They can contribute to life and bring joy to life I guess. And just kind of seeing, seeing people with, on the one hand it’s a challenge but on the other hand it is an opportunity. I guess to see value in others and to receive value and love from others in ways that um, well, like just how [child] expresses herself is different than how our boys express themselves. And how they give and receive love it’s— she’s different. And I guess it brings out different things in all, in every member of our family.*

Ernest described that his mind has been opened to people with DS, and that he seeks them out rather than avoids them. He also explained that this effect has generalized to other marginalized groups:

> *I mean just from a deeper thing from— after the diagnosis and him being here. It didn’t mean that we didn’t before care about people who were different, but you look, you LOOK at people with differentialities much different than you did before. You dive right in and then it’s just like now you seek people out with Down syndrome. But even beyond*

> *that, just seeing people that don't conventionally fit in to the world I view them differently. Not that I viewed them with a fear or an ignorance before, but now there's much more of a caring aspect.*

Charlotte explained that prior to having their child she and her partner were not aware of their bias. She previously felt pity for and avoided caregivers of children with disabilities. Now they seek out contact with these people:

> *…we didn't know that we were judgmental or not accepting of people. If I would see somebody in the store with a person with them who had a disability I would just like feel so sorry for them. I wouldn't make eye contact or like it was so awkward, and NOW we just go up to them at the store [laughs] and we introduce ourselves, right? Because you just— I don't know why. Yeah, we look at people a little bit differently.*

10.1.3 Experience Unconditional Loving

Participants discussed learning more about the act of love, specifically, about unconditional love: "*you're more accepting, more forgiving…I think [child]'s taught us what unconditional love is, really*" (Harper). Maya described learning about unconditional love when she discussed learning about loving a child for who they are, rather than for what they can achieve:

> *The biggest lesson for me was separating your love for the being, for the child as he or she is from your love for what they can achieve, right? Because I was an overachiever. I, you know I liked to see people doing their best and achieving what they can in life. I think that is important, but it isn't the be-all and end-all and that was the lesson for me. 'Cause my imagination before I had a baby— my imagination for who my child would be— of course it's the mini-me syndrome. And boy, I got smacked upside the head because "yeah guess what? You're going to have to figure this out because you're not going to get what you thought you were going to get." And I loved her so deeply anyway.*

Camille also explained that prior to having her son with DS, her life centered around achievement. Through having her son and realizing his inherent value her outlook on life has changed:

> *I have a type-A personality that was all about achievement. My whole life was about achieving and about intellectual achievement. You know, like either my grades or my salary were the driving sort of way that I evaluated my value as a person. And [child] is*

> *probably never going to get 90s in school. And he's maybe not going to have a $100 000 job and now I truly know that what gives someone value is not those measures. It– I, he is so, I mean he's so vibrant and social and engaging and he attracts people at– you know I just met with his preschool teachers to see how he's making out and they're like "we LOVE having him in our class. He is a fully participating member, and the other kids enjoy his company and they seek him out." And they don't know the difference between— I mean they know he's different. They know he doesn't talk as much and that he, you know— I don't know what preschoolers definitely necessarily notice— but they value him. And I value him. And that knowledge that his value doesn't come from how he makes out in school has changed how I look at the world. And everyone in it.*

10.1.4 Become Advocates

Parents had to become advocates and persist through difficult circumstances because their child had needs that were not automatically met by heath, social, or educational institutions. For example, Shirley described becoming more assertive and persistent after she felt she had misplaced her trust in health care providers:

> *It's forced me to be a lot more outgoing and to like fight for what I want and for what I know is right. I think like going into um, when I went into labour I just put so much faith into the professionals thinking they have it covered and they know what they're doing but there's so many parts where we were let down. Where the professionals lacked in professionalism and they lacked in knowledge. So it's definitely made me a lot um more aware of that and guarded I guess.*

Zora explained that she has had to struggle and persevere to obtain the supports that her son needs in the health care systems:

> *I had never thought I'd have to fight for somebody as hard as I've fought for everything for him. Everything that we've had to do for him has been a fight. That feeding tube assessment it took me two years of fighting for it…His splints took me 6 months to get.*

And Joan described how the particular challenges change as her son develops but that their family is constantly navigating some system to get him what he needs:

> *…then in his fifth sixth and seventh year now it's navigating the school system… I'm continually educating about him and his diagnosis. He's still nonverbal, so it's telling them "well, when he does this it means that, And he's cueing this it means that or um this*

> *sound means this…" So, it's continual. Like it's constant. It doesn't stop. [child]'s navigation of all the systems don't stop.*

10.1.5 Changed Perspective

The most common change participants discussed was a changed outlook on life wherein they developed a deepened understanding and acceptance that there are aspects of their life that are not within their control. This greater understanding stemmed from the principal realization that they do not have ultimate control over who their children grow to be, regardless of determinations:

> *…in retrospect, none of our children are the probably the kids I thought they would be today, right? And medical diagnosis has nothing to do with it…* (Kurt)

Mary explained a contributing factor in her initial devastation was the change in life plans and the life she imagined for her child. After having a conversation with a support worker, she realized that the future is unknown with any child:

> Mary: *And honestly, like both my husband and I say, "oh my god, did we ever overreact to that diagnosis". Like it was devastating. I cried, I cried, I never cried so much. And you sort of just have this like— all your thoughts of what life will be like just vanish and you have to reinvent them. But it's sort of— [child's] worker from the early childhood intervention program, she was— right from the get go, she's like "[mom], it's not just with a diagnosis like this, it's always like, maybe your kid ends of playing video games in the basement for the rest of his life and he has no ambition, and he has no diagnosis" [laughs]. But he isn't, you know, there isn't weddings and children and you know, all the things you had in mind. Like, having a kid is the ultimate kind of*
>
> Sarah: *—it's a gamble all the time?*
>
> Mary: *—gamble, that's right. You have no idea how they will turn out, or who they'll be.*

The lesson about releasing control expanded beyond their child and to life in general. Mary described how the birth of her child did not go as planned, and that the loss of control is the focus of her grief:

> *Like I had a doula, and I had a birth plan, and like not a SINGLE thing went according to plan... So that's the other kind of piece of shock and grief is like coming to terms with the fact that you can't plan this stuff [laughs] as much as you want to. Um, you can't anticipate every eventuality.*

Parents framed their preoccupation with an ideal future as a barrier to enjoying the positive aspects of parenting their child:

> Charles: *well as a parent, you want what's best for your kid. And you know that things are going to be more challenging, because they are. Um, it's not, you know— you know what they're going to face externally. You know what they're going to, you know, just— it's going to be different. It doesn't mean it's going to be bad. It's just going to be different. And so as part of wanting what's best for them— it's one of those things where as a parent you need to learn that you're not going to be able to control that, right? You're not going to be able to control that your child is going to become a doctor or isn't going to have addictions issues or there are just some things that you don't have control over and you have to be willing to accept it and there are actually really happy things, but—*
>
> Alice: *—you can't see that when—*
>
> Charles: *—when you're looking for an ideal that you don't even know exists— it doesn't exist.*

Several participants described that this realization resulted in more focus on the present, more effort towards aspects of life that they can control, and a reconsideration of their values. They truly value rather than worry about the future, what is out of their control and superficial aspects of life. For example, Louisa explained that her family no longer worries about what they now view as insignificant issues, and that they celebrate achievements that they would not have recognized as achievements previously:

> *We don't worry about little things, I think. …We celebrate the little things, I think is the biggest thing. We celebrate the little milestones that we took for granted with the other two when they, you know, when they learned to walk, it was just expected, where when [child] walked it was like a huge celebration. Everything is a big celebration. We're all about the celebration for sure.*

Louisa explained that this change of focus resulted in them living more presently— fewer expectations about the future and more focus on the victories in day-to-day life:

> *We live more presently …I think, 'cause the future is kind of unknown, like we don't know, we you know, with the other two girls you hope that they like I said, go to university and get married and have children and so you kind of expect that that's going*

> *to happen, and it may not, but you expect that that is going to happen, so you kind of plan for the future. Whereas with our youngest we don't know what the future holds for her. You know, maybe she will go to university, maybe she won't. I don't know. But we kind of live just in the moment, celebrating whatever's going on right now and we move forward from there and not have the expectation of anything that we don't know what's going to happen.*

Harper and George described slowing down and appreciating the beauty in the mundane aspects of life:

> <u>Harper:</u> *He's opened our eyes up to that. To slow down, smell the roses a little bit. I remember with [first child] you were always in some sort of silly competition with your friend's child right? Who got to this milestone first?*
>
> <u>George:</u> *—who talked first, who walked first—*
>
> <u>Harper:</u> "*oh MY kid is walking and MY KID says 15 words and she's only 15 months" or whatever*
>
> <u>George:</u> *—we celebrate the milestones as they come—*
>
> <u>Harper:</u> *Yeah. And with [child] that took me a while to let go of that timeline thing. I kept thinking "you should be doing this" —you know what? He gets there when he gets there.*
>
> <u>George:</u> *And it's ok.*

Sylvia described this change in focus as an acquisition of courage. While she previously felt pressure to complete certain activities or goals in life, as a result of parenting her daughter she now feels brave enough to approach her future without specific plans and to take chances:

> *It's changed my mindset. I was always kind of the perfectionist. Um, but [child] truly has changed that. She's given me— the last two years um, [child] has been involved in projects that I never would have ever have believed…Um, [child] has allowed me to take chances. [Child] has allowed me to go outside of my comfort zone. …. And we don't have to be the best. We don't have to have the best marks, we have to have the heart. And she has that heart and she's proven that and more…Um, my whole life is like "I need to do this, I need to do that" …[child] has given that to me to know it's all going to work out how it should be…So do I know what my life's going to hold? No. Am I worried? No. We're just going to go with the flow. And just keep being active, participating, involved, and sharing our story…Would I have taken chances before? No. 'cause I needed to know*

> *where it was all right. So in 19 years, that's all evolved and [child] has given that to me. Where before, never… so, just with [child] with who she is and growing up with her, she's given me the confidence now to say "you know what, I don't need to know what my future is going to be. I'm ok. It's going to happen the way it's going to happen"*

Emily explained that through her awareness that with any child, regardless of a determination, unplanned issues can arise, her outlook now is to simply appreciate what they have:

> *…now we totally— I mean of course, but we worry about that with our child— like [other child] as well, you know, what are they going to do when they are older and stuff. And she's had complications that we're dealing with that, I mean, we weren't expecting. So any, you know any child…you never know. So that's what my opinion is. You never know, and just enjoy.*

10.2 "*There's always…things that you have to keep accepting along the way":*

Although participants' stories more or less followed a typical narrative arc (exposition, rising action, climax, and resolution), participants implied or explained that, although they had 'brought me up to speed,' their story was not over. Several participants explained that their child's determination was not a one-time event, but that it is ongoing. For example, Margot explained that grief strikes intermittently as she experiences realizations of unanticipated losses associated with her son's determination:

> *…I think the diagnosis of Downs never feels like it ends. Like there's always layers of grief that you have to deal with— things that you have to keep accepting along the way. Probably our last major one was you know putting him into a functional life skills program. Moving him from streamlined to— and I know it's the right thing to do... I have accepted things like he's not going to university. He's not going to go to college. He's not goin— you know he's going to graduate. I'm hoping there will be some sort of job he can do but I'm guessing probably not under our current social structures. Um, you know that's all part of the diagnosis that, you know, the things that you have to always be thinking about…The diagnosis never ends. I guess, or the consequences of the diagnosis never ends. It's always part of your life whether you want it to be or not… Another layer of grief would be, my son lost his foot when he was [young]. You know with that went not being able to walk. Or I had to make the decision along the way, were we going to put*

> *him into an electric, into a chair, or were we going to keep trying to get him to walk…And so I had to make the decision for him to move to a wheelchair. And with that, you know, came accepting that he's probably never going to walk…there were two other children that were, that were, had disabilities but they could push their wheelchair. They could physically maneuver it. And it was like, when I when I watched them, you know it was just another layer of grief, it was like …he could do more sporting activities than my son will ever be able to do. So there, like right, there was a good layer…*

And Stephen and Virginia explained that the unique challenges they face as parents of a child with DS are ongoing aspects of coming to terms with their child's determination:

> Stephen: *Well and I mean ultimately our story isn't still finished right? I mean we didn't talk about finding childcare for [child]. And that process. I found childcare for [child], and you know I had to call a couple different people and as soon as they knew, you know, that [child] had Down syndrome it was like kind of hmming and hawing… and I would disclose and they're like "you know what— I just don't have space" And that's fine and that's fair and I'd rather people be upfront and being able to say "I don't have the skill sets" or "I'm uncomfortable" and ultimately why would we want to send our child to some—*
>
> Virginia*: —Someone like that. But it's an issue. Like all those kind of things are the things that are—*
>
> Stephen*: —Are, are a part of that, right? 'cause not only do you have to find appropriate childcare that fits with you family and your work life schedule, then you have to find the childcare provider that would be acceptable and appropriate…I drive to almost directly across the city for that. And so, you know, that should be in our—*
>
> Virginia*: —…like your story from diagnosis and even after it continues and, you know, it all comes from that diagnosis and everything you deal with afterwards.*

Indeed, Glidden et al. (2014) proposed that phenotypic trajectories of individuals with DS, and therefore the supports they might need, will change their slopes several times over a lifespan with multiple "periods of growth, of plateau, and of decline" (p. 400). Therefore, as Stephen said, their story is not finished, and they might gain more insight into what their child's DS determination means for them as events unfold throughout their lifespan.

10.3 Concluding Remarks

10.3.1 Screening

The present research sheds light on the experience of receiving a DS determination in Canada, and specifically, in Saskatchewan. Experiences with screening suggested a lack of informed consent, as no participants reported having balanced conversations with their care providers exploring the pros, cons, and potential outcomes of screening. Findings from previous research have been contradictory about this issue. Some studies suggest that there are high levels of informed decision-making (68% of participants) about screening (e.g. van den Berg et al., 2005b) while other suggest there are low levels (e.g. Green et al., 2004). One significant difference between the studies is that in the van den Berg et al. research, prospective parents were all provided with an informational resource about the procedure that targeted informed decision-making, and that in the country where the research took place, prenatal screening was not a routine part of care at the time. Under those conditions it might actually be surprising that *only* 68% of participants were deemed to have made an informed choice about engaging in screening. On the other hand, in Saskatchewan, where there is not a standard informational resource provided about screening, and where screening is considered a routine part of care, it seems reasonable that so many participants relayed stories marked by a lack of informed consent.

The present study adds to the literature about informed consent in screening by describing a tendency of some physicians that seemed to undermine informed decision-making. That tendency was framing the screening as a test of parents' unconditional love for their future child. Specifically, physicians reportedly asked questions like "would it make a difference" where saying *yes* seems to indicate parents would love their child less, and saying *no* leaves them without information that could help them prepare for parenting. These types of prompts from health care providers may serve to close doors to those who simply seek information to be more prepared for the birth of a child who could have unique needs. The present research also contributed to the growing body of work that debunks the assumption that women who pursue screening are only doing so to make a decision about termination (e.g Markens, Browner & Preloran, 2010). Most of the participants who pursued screening did so to be reassured about their pregnancy and to learn about the condition of their fetus.

In the present study, participants relayed that they struggled to accurately interpret the probabilities presented to them as a result of screening and reported that the discussion their care providers offered about screening results did not align with their needs to understand the implications of the results. These findings align with and extend the work of Hunt et al (2005), which described how clinicians rely on statistics in an attempt to be value neutral, but patients' lack of understanding of probability leaves them without a way to meaningfully interpret the information. The present findings also suggest that physicians' use of probability talk can be interpreted as evasive and avoiding responsibility. Thus, relying on probability talk without meaningful interpretation might not only result in talking past the patient but it might undermine the goal of appearing neutral by making the care provider seem like they are hiding something.

The present findings also extend previous findings that most people are not good at interpreting probabilities and making judgements about the likelihood an event will occur (Kahneman & Tversky, 1984), that individuals tend to believe they have unique invulnerability to negative life events (Perloff, 1983), and unrealistic optimism about their own insusceptibility to health challenges (Weinstein, 1987), but in the context of prenatal screening. This reinforces the point in the last paragraph that physicians can never present probabilities to patients and believe they have done the job of informing them without helping patients with interpretation. It also suggests avenues for future reasoning research in the area of prenatal screening. To what extent do prospective parents underestimate the likelihood their child will be born with an anomaly? Do their underestimations vary according to the actual proportion of the condition in the population or if they know someone who has had a child or pregnancy with an anomaly? Or do they vary according to the deficit in functioning associated with the condition? Or with the amount of media attention given to the condition?

10.3.2 Determinations

Participants' stories illustrated that their care providers were often non-neutral and applied implicit or explicit pressure to terminate pregnancies with DS determinations. This is not a new finding and does not uniquely contribute to the literature. However, it is worth noting that despite the calls from disability advocates and researchers, negative attitudes towards DS are still evident in the way reproductive health care providers talk about it and that narratives of those who experienced their determinations most recently are not markedly improved on this point. Therefore, any "common-sense" assumption that bias against DS could be a thing of the past is not substantiated according to the present data.

Many participants relayed dissatisfaction with their determination experience. They tended to be dissatisfied with the duration of their determination consultations, dissatisfied with receiving the determination without their partner present, dissatisfied with the lack of up-to date information provided to them, and dissatisfied with their care provider's communication skills for delivering the news. Participants reported being avoided by care providers when their baby was born and noted a lack of celebration upon the birth of their child. They were dissatisfied with the staff on the ward knowing the presumptive determination before they did and with care providers who attempted to engage in testing without their consent. Parents were also dissatisfied with determinations delivered over the telephone, determinations delivered in public places, and insensitive delivery styles, especially those that included an abrupt rundown of potential medical issues (for which there was currently no indication).

Parents also relayed stories about care providers who they described as *"fantastic"*, *"great"* and *"lovely"*. Parents were satisfied with determinations that involved a neutral reassuring tone throughout which the baby was present and at the center of the discussion. Participants appreciated a thorough explanation of the indicators under consideration and their fallibility. They were satisfied with quiet, private, consultations wherein all of their questions were addressed, the next steps were explained, and the care provider stayed until it felt like there was a conclusion to their conversation and their questions. These findings are not particularly new or unique (beyond the fact that the question had not been addressed in this geographic location before). They align with previous research (Buyukavci, et al., 2019; Guon et al., 2014; Hedov, et al., 2002; Nelson Goff, et al., 2013; Skotko, 2005a; Skotko 2005b; Wallace et al., 2018. They also align with the results of Cunningham and colleagues (1984) who found that 100% of participants can be satisfied with determination experiences when they are delivered in a respectful and sensitive manner[6] and they reinforce Skotko, Capone, and colleagues' (2009) recommendations for how to deliver a DS determinations. That existing guidelines so perfectly illustrate the issues most important to parents in the present study raises the question of why, if those guidelines already exist, they are not followed. This is an important question for future research. Are some health care providers uneducated about and/or unaware of best practices in delivering determinations? Are some care providers experiencing time or resource constraints which inhibit their ability to spend enough time with parents who need it? Do some health care providers believe that behavioral protocols such as these are unimportant or outside their job

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[6] See Chapter 7 for specific criteria

descriptions? Or, are some health care providers simply unaware that they deliver determinations insensitively?

Most participants experienced negative emotional reactions to their child's determination. Many attributed their reaction to the lack of knowledge they had about DS and the lack of or superficial experience they had with people with DS. Several participants relayed that the most helpful information they received came from the provincial or national DS societies, but that this information often came late. This suggests that a more formal relationship between support organizations and physicians who deliver the news could improve this flaw in the system. Although this collaboration would require time and resources, it would result in parents receiving the most helpful information in a timely manner and could alleviate some of the burden on health care providers to become extensively educated about DS. The appropriate partners and procedures for such a collaboration will likely vary by location, and could be specified by future local research and/or policy work.

Since receiving their determinations, many participants looked back on their "journey" and framed it as "taking the scenic route". However, to frame all experiences in this way would be an oversimplification. The way that families are impacted by having a member with DS is likely influenced by child, family, and societal factors, all of which interact. Some families relayed significant challenges, which they believed the dominant narrative excludes. There is not one story of DS, and therefore the task of educating prospective parents about what life with DS will be like is challenging. The present findings therefore support the suggestion of Hippman et al (2012), which is for patient education about DS to explore the range of possibilities regarding the experience of raising a child with DS and help families to evaluate these possibilities in the context of their own lives. In addition to providing support for Hippman et al., these results present challenges for support organizations because they highlight a segment of their population who may be underserved. While many participants emphasized that the messaging DS support organizations provide was integral to their acceptance of the determination, there is a segment of parents who appear to need a different kind of support. It may be of value, for example, to create conversation circles for parents of children who experience a higher number of DS-related health complications, so that they have a venue to normalize their experience, information share, and feel a sense of belonging. It also may be of value to create informational resources that can be provided to parents of children with more DS-related complications. Finally, this group may need additional advocacy for educational, financial, and social supports given the higher demands of parenting their children.

The subgroup narrative also raised theoretical questions about the meaning and function of social support. Esbensen and Seltzer (2011) found that social support was not related to parental well-being, an outcome that they questioned. In the present study, while the majority of participants extolled the positive impact of meeting other parents of children with DS, those who described their children as having higher needs that the average child with DS disagreed that interacting with other parents was helpful. Given these findings, it might be that general social support does not have an effect (or even has a negative impact), but that social support, specifically from those with a similar experience to one's own, does improve well-being. Future research could examine this potential distinction.

10.3.3 Limitations and Contextualization

Ultimately the findings suggest that improvements are warranted when it comes to counselling prospective parents about screening, testing, termination, and life with a child with DS. However, there are several limitations of the current work. First, it is unknown how representative the sample of parents is, given that they self-selected to participate. Therefore, it is an inherent weakness of the study that there are experiences that may not be represented in the data. Indeed, I perceived a dominant, subgroup, and third narrative in the data, but there could certainly be more stories. In particular, only one person who terminated their pregnancy volunteered to participate in this study. Therefore, the story of those who choose to terminate is largely untold here and should be a focus of future research.

A related contextualization is that the sample was almost exclusively composed of people who received their determination in Saskatchewan. The goal of the study was to provide information about the experience of receiving a DS determination in Canada, but because this was a preliminary study on the topic in the Canadian context, a geographically homogenous sample was utilized and the present research was situated in only one Canadian province, Saskatchewan. Therefore, the extent to which the results generalize to other locations depends on the extent to which their sociocultural context and health care systems resembles the context and systems in Saskatchewan. Some contextual factors as similar across Canada. For example, offering prenatal screening to pregnant women is considered standard care across the country, as recommended by the Society of Obstetricians and Gynaecologists of Canada (SOGC; Chitayat, et al., 2011). Other contextual factors may vary by Canadian province. For example, a recent national poll suggests that Saskatchewan residents do not hold the most nor the least endorsing opinions about abortion, but that opinions do vary across the country (DART & Maru/Blue Voice Canada Poll, 2020). Specifically, 87% of respondents from Saskatchewan/Manitoba believe that abortion should generally be legal in the first three months of pregnancy. This can be compared to 91% in Quebec, 89% in British Columbia, 84% in Ontario, 82% in Alberta, and 78% in Atlantic Canada. Similarly, 67% of respondents from Saskatchewan/Manitoba believe that a woman should be able to get an abortion if she decides she wants one no matter what the reason, compared to residents 75% in Québec, 75% in British Columbia, 69% in Ontario, 66% in Alberta and 65% in Atlantic Canada. These statistics suggest that there is variation in attitudes towards abortion across Canada. Because of the salience of abortion in the DS determination experience, these regional variations in attitudes mean that experiences receiving DS determinations could vary regionally. A diverse sample from across Canada would be able to corroborate if similar patterns are indeed found across the country. Nonetheless, patterns found in the current research markedly aligned with findings from other countries (i.e., Sweden and the United States), which suggests that there are aspects of the determination experience which are pervasive, and that the findings and recommendations may be transferable to other contexts.

A final limitation worth mentioning is our inability to accurately evaluate previous decisions. Post-decisional dissonance is an uncomfortable feeling after a decision which is caused by concern that we may have made “the wrong” choice. We tend to reduce this uncomfortable feeling by enhancing the attractiveness of the chosen alternative and devaluing the rejected alternative (Brehm,1956). That is, when asked afterward, we usually believe we have made the right choice. The implication is that most people will view their children as “worth the trouble” and most people will also evaluate their terminations as “the right choice”. This makes post-decision evaluations about whether continuing or terminating a pregnancy was the best choice, fraught with personal bias.

Despite these limitations, the findings provide preliminary evidence about the experience of receiving a DS determination in Canada by examining the experience in one Canadian province, Saskatchewan. The findings support existing recommendations and suggest unique recommendations for health care and for DS support organizations. The research can be used in health systems planning and medical education to inform best practices and ultimately improve patients’ experiences in the health care system.

10.4 Dissemination and Use

The plans for dissemination of the thesis include:

- Providing the thesis and summary documents to participants;
- Request to present to local Women’s Health Centres;
- Invitation to Women’s Health Centres to collaborate on local protocols;
- Request to present at OBGYN Grand Rounds, University of Saskatchewan Faculty of Medicine;
- Request to present at Pediatric Grand Rounds, University of Saskatchewan Faculty of Medicine;
- Request to present to University of Saskatchewan Nursing course (e.g. NURS 221.3 Patient and Family Centered Care in Clinical Practice);
- Summary of results to SDSS and CDSS and AIM programs;
- Submission of publication to Society of Obstetrics and Gynecology Canada; and
- Submission of publication to Paediatrics and Child Health (The journal of the Canadian Paediatric Society).

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Appendix A Participation Invitation Letter

Dear Saskatchewan Down Syndrome Society (board and executive director),

Hello, my name is Sarah Sangster. I am a PhD Student at the University of Saskatchewan. I am contacting you in order to locate and invite parents of individuals with Down syndrome to participate in a research study.

The purpose of this study is to explore experiences receiving pre and postnatal Down syndrome diagnoses. There is evidence in academic literature about these experiences for individuals in the United States and Sweden (to name a few), but little to no indication of what these experiences are like for Canadians. It is anticipated that the results of this study will be used to make recommendations to the medical community regarding how to deliver pre and postnatal diagnosis in a way that facilitates the most positive experiences possible for parents.

I'm reaching out to you in hopes that you will forward this email to your membership and encourage them to participate. Being involved would entail participating in a 60-90-minute interview about one's experiences receiving their child's Down syndrome diagnosis.
The main focus of the interview will be asking parents to tell the story of the diagnosis from their perspective.

Your membership is an invaluable source of knowledge in this area. They will be instrumental in this project. Anyone interested in participating can click the link below to provide their contact information: https://fluidsurveys.usask.ca/s/ExperciencesofDownSyndromeDiagnoses/

Thank you in advance! Your involvement will be greatly appreciated.

Sarah Sangster (MA, PhD Student)

Any questions about the purpose and use of the study can be forwarded to Sarah Sangster sarah.sangster@usask.ca.

Note: This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board on November 9th, 2016. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975. Fluid Survey is a USA owned company. Click on the following link for more information on: Fluid Surveys Data Privacy in Canada.

Appendix B Recruitment Poster

Department of *Psychology*
University of Saskatchewan

We are looking for volunteers to take part in a study investigating the ***experience of receiving a prenatal Down syndrome diagnosis***

If, in a past pregnancy, you (or your partner) used prenatal testing and received a fetal diagnosis of Down syndrome, please consider participating in this study. We are interested in what this experience was like for you. Both those who chose to terminate and those who chose to continue the pregnancy are invited to share their stories.

As a participant in this study, you would be asked to take part in a 60-90 minute interview about your experience of receiving the diagnosis.

This study has been reviewed by, and received approval through, the Research Ethics Office, University of Saskatchewan.

UNIVERSITY OF SASKATCHEWAN | usask.ca

For more information about, or to volunteer, for this study please contact:

Department of *Psychology*
University of Saskatchewan

We are looking for volunteers to take part in a study investigating the ***experience of parents receiving their child's Down syndrome diagnosis***

If your child was diagnosed with Down syndrome after birth, please consider participating in this study. We are interested in what this experience was like for you.

As a participant in this study, you would be asked to take part in a 60-90 minute interview about your experience of receiving the diagnosis.

This study has been reviewed by, and received approval through, the Research Ethics Office, University of Saskatchewan.

For more information about, or to volunteer, for this study please contact:

Appendix C. Recruitment Advertisement

We are looking for volunteers to take part in a study investigating the experience of receiving a prenatal Down syndrome diagnosis

If, in a past pregnancy, you (or your partner) used prenatal testing and received a fetal diagnosis of Down syndrome, please consider participating in this study. We are interested in what this experience was like for you. Both those who chose to terminate and those who chose to continue the pregnancy are invited to share their stories.

As a participant in this study, you would be asked to take part in a 60-90 minute interview about your experience of receiving the diagnosis.

This study has been reviewed by, and received approval through, the Research Ethics Office, University of Saskatchewan.

Please contact:
Sarah Sangster MA (PhD Student)
Department of Psychology, University of Saskatchewan
sarah.sangster@usask.ca (email)
https://fluidsurveys.usask.ca/s/ExperiencesofDownsyndromediagnoses/ (click link to provide contact info)

We are looking for volunteers to take part in a study investigating the experience of parents receiving their child's Down syndrome diagnosis

If your child was diagnosed with Down syndrome after birth, please consider participating in this study. We are interested in what this experience was like for you.

As a participant in this study, you would be asked to take part in a 60-90 minute interview about your experience of receiving the diagnosis.
This study has been reviewed by, and received approval through, the Research Ethics Office, University of Saskatchewan.

Please contact:
Sarah Sangster MA (PhD Student)
Department of Psychology, University of Saskatchewan
sarah.sangster@usask.ca (email)
https://fluidsurveys.usask.ca/s/ExperiencesofDownsyndromediagnoses/ (click link to provide contact info)

Appendix D. Consent Form

Interview Consent Form: Exploring Experiences Receiving Pre and Postnatal DS Diagnoses-Narratives

Researcher: Sarah Sangster, PhD Student, Department of Psychology, University of Saskatchewan Email: sarah.sangster@usask.ca or Phone: (306) 966-6159

Supervisor: Dr. Karen Lawson, Professor, Department of Psychology, University of Saskatchewan
Email: karen.lawson@usask.ca or Phone: (306) 966-2524

Purpose: You are invited to participate in a research study entitled "Exploring Experiences Receiving Pre and Postnatal DS Diagnoses- Narratives" Please read this form carefully, and feel free to ask any questions you might have about the study.

The purpose of this research project is to gain greater understanding about individuals' experiences receiving pre and postnatal Down syndrome diagnoses in Canada.

Procedure: If you are interested in participating, the study will consist of an audio-recorded interview lasting approximately 60 minutes. You will be asked to tell the story of receiving the Down syndrome diagnosis, and discuss different aspects of the experience. Only answer questions that you feel comfortable responding to. At any time you can request that the audio-recorder be turned off. At the end of the study you will be given a chance to ask any further questions that you might have.

Potential Risks: It is possible that if the experience receiving your child's Down syndrome diagnosis was particularly negative, you may feel a degree of psychological stress recounting the experience. Further, if you are someone who chose to terminate a pregnancy following a Down syndrome diagnosis, relaying your pregnancy termination story may be psychologically stressful. Only answer questions that you feel comfortable responding to. If you feel like any part of the study affects you negatively the researcher can provide you contact information for professional counselling services. You may contact the researchers by email should you have any questions or concerns. You may receive no personal benefits from participation in the study.

Potential Benefits: It is anticipated that this research will help to provide recommendations to the medical community in how to improve experiences receiving Down syndrome diagnoses.

Confidentiality: Your responses will be confidential. Although the researchers will use direct quotations from the interviews, quotes and data will be reported using a pseudonym and all personally identifying information will be removed. The data may be published in journal articles, conference presentations, and a summary for participants.

Storage of Data: All the data from the interviews will be securely stored for five years and then it will be destroyed beyond recovery. The data may be published in an academic journal and/or presented at a professional conference. When the data is no longer required, it will be destroyed beyond recovery. The data and consent forms will be stored separately and securely by the research supervisor at the University of Saskatchewan for a minimum of five years post-publication. After this point it will be destroyed beyond recovery.

Right to withdraw: You may withdraw from the research project for any reason, at any time without explanation or penalty of any sort, and any data that you have contributed will be destroyed beyond recovery. Your right to withdraw data from the study will apply until manuscripts have been submitted for publication. After this point, your results may have already been combined with those of other participants and it may not be possible to withdraw your data.

Questions or Concerns: This research project has been approved on ethical grounds by the University of Saskatchewan Research Ethics Board on **November 9th, 2016**. Any questions regarding your rights as a participant may be addressed to that committee through the Research Ethics Office ethics.office@usask.ca (306) 966-2975. Out of town participants may call toll free (888) 966-2975.To obtain results from the study, please feel free to contact us by phone (306 966-6159) or e-mail (sarah.sangster@usask.ca).

Follow up: To obtain results from the study, please email (sarah.sangster@usask.ca).

Consent to Participate:

I, ______________________________________ **(print your name),** have read and understood the description of the research study provided above. I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I agree to participate in the study, understanding that I may withdraw my consent to participate at any time without penalty.

______________________________	______________________________	______________
Name of Participant	*Signature*	*Date*

______________________________	________________________
Researcher's Signature	*Date*

Appendix E. Interview Guide

I would like you to tell me the story of receiving the Down syndrome diagnosis. Start at whatever point the story begins for you (maybe that's when you became pregnant, maybe sooner or later), and I'll listen until you feel like you've concluded. Please include all the detail you think I need to give me a picture of what it was like for you. This might include details about reactions from other people in your life, or details about how you felt or what you did in reaction to the news. But it also might not. Tell me your story.

Demographic Questions:

What year did you receive the diagnosis?
Where (rural/urban hospital/home) did you receive the diagnosis?
How old are you?
Where were you born?

Potential Prompts:

You mentioned_____. Tell me more about that.
Do you think your partner had a similar or different experience?
What was your partners reaction?
How did you respond when…
What did you feel when…
Why did you think it was important to…
What effect did that have on you?
Did that help you in any way?
Did that change anything for you?
What makes you say that?
What is it about ___ that made you___?
Could you explain what you meant by….?
You mentioned ____ . What's happened since then?
You mentioned ______ . What was the lead up to that?
How do you think it was for [insert health care provider]. How do you think they saw the situation?
Do you take away anything from this experience? If so what?

Appendix F. Recommendations

As per provincial (i.e. Saskatchewan) and national (i.e. Canada) guidelines, routinely offer prenatal screening to all pregnant women. As part of that offer:

a) Describe the procedure(s);
b) Explain the purpose of the screening;
c) Explain the voluntary nature of screening;
d) Describe the difference between screening and testing;
e) Describe the potential next steps (no testing, Amnioscentesis, CVS, NIPT);
f) Explain that some people engage in screening to inform a termination decision, but that some people engage in screening to learn more about their pregnancy and prepare for conditions their child might have.
g) Describe the possible outcomes (“positive” screen, “negative” screen, and what might be an ambiguous screen);
a) Emphasize that a positive screen does not mean the fetus has DS and that a negative screen does not mean the fetus does not have DS (or any other anomaly);
b) Use the presentation of screening results as an opportunity to prepare parents for the possibility of anomalies.

Recommendations to health care providers regarding how to deliver prenatal determinations:

a) care providers use neutral language;
b) the news should be delivered by health care providers with the most knowledge about DS and who have received specific training on how to deliver sensitive determinations;
c) the news should be delivered in a personal visit or, if necessary, a phone call at a predetermined time;
d) health care providers must provide information about what DS is, medically and socially, including realistic expectations for children with DS today;
e) they should offer an up-to-date balanced bibliography of resources on DS;
f) they should offer follow-up meetings with themselves and other relevant health care providers

g) prospective parents should be counselled that (as with any pregnancy) they have the option to continue or terminate the pregnancy. Once a prospective parent has made a choice, that choice should be accepted and respected by care providers.

Recommendations to health care providers for how to deliver a postnatal DS determination:

a) the team should coordinate to ensure that the individual on the team who is most informed about DS be the one to deliver the results;
b) health care providers should inform patients as soon as they suspect DS, even if the definitive test has not been conducted;
c) the determination should be delivered in a private room;
d) parents should be informed together (if relevant);
e) the infant should be present and referred to by name;
f) health care providers should begin the conversation with positive words such as "congratulations on the birth of …" and avoid language conveying pity or personal opinions; and
g) for the first conversation, discussion of medical conditions should be limited to those that the infant is suspected of having.
h) health care providers should point out and explain the markers that are under consideration;
i) health care providers should remain with the parents until the parents have exhausted their questions; and
j) health care providers should explain the next steps and confirm for parents when their next follow-up appointment(s) will occur.

Recommendations for health care providers for pre- and postnatal DS determinations:

a) health care providers should offer an up-to-date balanced bibliography of resources on DS;
b) they should limit the discussion of medical conditions to those that the infant is suspected of having; and
c) they should provide contact information for local support groups and community services.

d) genetic counsellors or other health care providers involved in helping parents understand the determination should provide a basic sketch of the etiology of DS (i.e., that it did not result from actions of the mother during pregnancy) but refrain from focussing the conversation on family genealogy. The focus of the conversation should be on what the condition will mean for their child and their family life because these are the parents' primary concerns.

e) health care providers should refrain from a monolithic presentation of DS and instead explore the range of possibilities regarding the experience of raising a child with DS; and

f) health care providers should help families to evaluate these possibilities in the context of their own lives.

g) a more formalized relationship or system between health care providers and local support groups could be helpful, especially in the Saskatchewan context, where the current research took place. Specifically, it would be helpful for health care providers to have the existing SDSS/CDSS information packages (which parents cited as the most helpful information they received) ready to provide to prospective or new parents when they deliver presumed determinations. This would likely require coordination and shared costing between the support organizations and obstetricians' offices, midwives' offices, mother-baby units, and neonatal units. Although this collaboration would require time and resources, it would result in parents receiving the most helpful information in a timely manner and could alleviate some of the burden on health care providers to become extensively educated about DS.

Recommendations for DS support organizations:

a) DS informational resources should refrain from a monolithic presentation of DS and instead explore the range of possibilities regarding the experience of living with DS and raising a child with DS;

b) Organizations should consider how they could better support the marginalized members of their communities. This could take the form of informational resources, social support initiatives, as well as advocacy.