

AOM Position Paper – Prenatal Genetic Screening

June 2013

The Association of Ontario Midwives (AOM) has undertaken to write this position paper on prenatal screening for fetal genetic conditions in response to members' concerns about the broader social and ethical implications of such screening and testing. The AOM is firmly committed to women's reproductive choice¹ and informed choice for all aspects of prenatal, intrapartum and postpartum care. The AOM thus supports midwives in providing informed choice to their clients with regard to prenatal genetic screening. The AOM also believes that prenatal genetic screening has considerable implications not only for the individual woman and her family but also for society as a whole. The AOM advocates for broader ethical and social discourse on the implications of prenatal genetic screening, especially as they relate to persons living with disabilities and their families.

As primary maternity care providers, midwives offer the current publicly funded prenatal screening options to all women through informed choice discussions. Midwives, as well as other obstetrical care providers, have expressed challenges in offering non-directive counselling on the topic of genetic screening.² The goal of informed choice is to exchange information about genetic screening while taking into account individual women's values and ultimately respecting and supporting their choices. Without appropriate counselling, the potential to promote women's autonomy and expand women's choices remains limited.³ It should also be noted that not all women may feel empowered by being offered prenatal screening. Some may feel that having to make complex choices interferes with their ability to experience and enjoy pregnancy.⁴ This also fundamentally challenges the midwife's role: promoting confidence in pregnancy and childbirth as normal human processes, while at the same time evaluating clients for the risk of pregnancy complications.

The way in which information is presented during an informed choice discussion and the choice of language used can ultimately affect decision-making. Definitions of "risk," "normal" and of "abled/disabled" are socially constructed and value-laden. When the language used to describe genetic screening is medicalized and disability is presented

¹ Association of Ontario Midwives, AOM Statement on Reproductive Choice, 2011.
http://www.aom.on.ca/Communications/Position_Statements/Reproductive_Choice_Position_Statement.aspx

² Vanstone M, Kinsella EA, Nisker J. Information-Sharing to Promote Informed Choice in Prenatal Screening in the Spirit of the SOGC Clinical Practice Guideline: A Proposal for an Alternative Model. *JOGC* March 2012. 269-275.

³ Seavilleklein, V. Challenging the Rhetoric of Choice in Prenatal Screening. *Bioethics* 23:1 2008: 68-77.

⁴ Samerski S. Genetic Counselling and the Fiction of Choice: Taught Self-Determination as a New Technique of Social Engineering. *Journal of Women in Culture and Society* 2009, 34(4): 735-761.

as a poor outcome, the social and ethical implications of screening may be minimized and the lives of people with disabilities may be inadvertently devalued.⁵

Across the province, 70% of women undergo prenatal genetic screening.⁶ As prenatal screening becomes the norm, women who elect to forgo screening may become marginalized and subsequently made to feel irresponsible, guilty or selfish about making a choice outside the societal custom. In the absence of a full informed choice discussion as part of genetic screening counselling, women may believe that all genetic testing is done to protect their baby's health. This is particularly important if screening is presented as routine with the potential to "opt out," rather than as an opt-in program. From the onset, women should be fully informed of the difference between screening for life-threatening anomalies, screening for treatable conditions for which early discovery could affect the plan of care, and screening for conditions such as Down syndrome, which do not preclude the possibility of a healthy, active and satisfying life. Women should be clearly informed of the goals of genetic screening and of potential further testing and treatment options, including an explanation of the conditions for which no treatment exists and under what circumstances a termination of pregnancy may be offered.

The AOM recognizes the potential tensions between an individual woman's choice and societal norms and pressures. Whereas midwives promote individual women's autonomy, midwives also recognize the relational nature of decision-making and believe it is important to consider the factors that may influence individual women's decisions.⁷ It is also important to examine the systemic barriers that impede women from exercising their autonomy. Women's decisions regarding prenatal testing cannot be considered in isolation from their historical context, current research agenda and political and economic climate.⁸ The AOM advocates for full reproductive choice and supports women's choices, including adequate support and resources for parents of children with special needs as well as sensitive care and support for women who chose to terminate a pregnancy or who chose to carry a nonviable fetus to term.

The AOM is concerned that women who have positive test results and elect not to terminate their pregnancy may be met by a lack of support for their choices. For example, as more and more pregnancies with Down syndrome are terminated and fewer babies are actually born with Down syndrome, these babies may be seen as even more "abnormal" and/or undesirable. The decision to carry an atypical pregnancy to term may become more uncommon and may therefore expose women to negative social judgments, inadequate community supports and adverse economic consequences.⁹

In addition, the AOM is concerned that the rapid development of non-invasive prenatal genetic tests, which are quickly being adopted into the provincial health care system, will

⁵ Lawson KL, Carlson K, Shynkaruk JM. The Portrayal of Down Syndrome in Prenatal Screening Information Pamphlets. *JOGC* August 2012: 760-768.

⁶ Better Outcomes Registry Network. Prenatal Screening Ontario. www.bornontario.ca.

⁷ Jacques AM, Bell RJ, Watson L, Halliday JL. People who influence women's decisions and preferred sources of information about prenatal testing for birth defects. *Australian and New Zealand Journal of Obstetrics and Gynaecology* June 2004: 233-238.

⁸ Seavilleklein.

⁹ Skotko B. With new prenatal testing, will babies with Down Syndrome slowly disappear? *Archives of Disease in Childhood* Nov 2009: 823-826.

normalize these screening procedures without full exploration of their impact on society and its values.

The AOM is committed to exploring ways to support midwives and other obstetrical care providers in engaging clients in values-based discussions about prenatal screening to support clients in effectively making an informed and autonomous choice . The AOM plans to create resources to that effect, as well as information on appropriate referrals and supports for women and their families, regardless of their choices. At the same time, as more sophisticated, accurate, non-invasive screening and diagnosis methods are being developed, the AOM recognizes a need for greater public discourse on the topic of prenatal genetic testing and its effects on society and on people living with disabilities.