

Opinions about prenatal screening invisible

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What pregnant women think about routine ultrasound tests for fetal abnormalities is largely ignored by the health profession says a Victoria University graduate who has completed some of New Zealand's only research into prenatal screening.

Ultrasound screens in the first trimester were once reserved for pregnant women deemed to be at risk of carrying a baby with Down Syndrome or Cystic Fibrosis but are now commonly offered to all women and much earlier in their pregnancy.

Sarah Donovan, who graduates this evening, says while prenatal screening in New Zealand is officially referred to as a choice, there has been little discussion about the pros and cons and the first trimester scan for fetal abnormalities test has effectively become an automatic part of pregnancy care.

"Women have been done something of a disservice in this area. Minimal information or support is provided and, in spite of the expectation that women give their informed consent, they are not encouraged to see ultrasound screening as something they need to deliberate over."

Dr. Donovan interviewed a group of women in the Wellington region with varying experiences of ultrasound screening. Some chose not to have a scan, several had false positive tests and one a false negative test during their pregnancies.

She says the accuracy of screening has recently been improved with the addition of a second check, requiring a blood test, but the results still need to be recognized as not completely reliable.

"Amniocentesis (a test done in the second trimester where amniotic fluid is taken from the uterus) is the only way to diagnose Down Syndrome with certainty and this carries the risk of miscarriage.

"Many women don't realize that screening is not a

precise science. Having a scan can be a negative experience because it can make women feel that pregnancy is a risky business. For those who had an abnormality detected it was a frightening and lonely experience. They felt they were left alone to make the decision about whether to opt for termination or proceed with the pregnancy."

Dr. Donovan believes the majority of women do back the availability of prenatal screening but want more information and support around deciding whether to have a scan and what to do if abnormalities are detected. She says a pamphlet on screening options has recently been developed, but this will only be beneficial for women if their GP or midwife takes the time to offer it and talk it through early enough in the pregnancy.

"There is an unrecognized tension between how screening is understood within the medical profession and how it is experienced by pregnant women themselves. The public health sector endorses screening which is seen as a health good and an economically useful approach.

"Medical literature often presents the reduction of Down Syndrome as a desirable public health goal. However, I found this is not necessarily in line with the views of 'ordinary people' on what is good use of health spending.

"This sort of tension around views of disability means it is a major and very complex decision for a woman to refuse a scan, or choose not to terminate a pregnancy. But, if <u>prenatal screening</u> is to be a genuine choice for women in New Zealand, these options should be recognized and supported to the same extent as any other options."

Dr. Donovan believes more public debate is needed on the wider issue of giving birth to children with disabilities.

"The medical profession might seek to decrease incidence of conditions such as Down Syndrome but we don't know what the general public thinks.



"There are actually a range of views out there including <u>women</u> who believe families should have the right to give birth to a disabled child and not be discriminated against for their choice."

Dr. Donovan, who works for the Mental Health Foundation, graduates tonight with a doctorate in Sociology. Her supervisors were Dr. Rhonda Shaw and Dr. Mike Lloyd who lecture in Sociology at Victoria University.

Provided by Victoria University

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