Pregnancy is usually a time of great joy and excitement for parents, a time of looking forward to welcoming a new little child into the world, into their family and into their hearts. It is a time of awe and wonderment at the new life growing within, a time of planning and preparing, a time of bonding and dreaming, thinking about the generations past and those yet to come and a time of looking forward with hope. However this hope can sometimes turn to fear when women are told after prenatal testing that 'there is something wrong with your baby.'

Many parents can feel shocked, bewildered and confused at receiving the news that their child has a genetic defect or health problem. Parents may be pressured to terminate and told that it is unfair to bring a disabled child into the world.

'Vivienne' describes her experience, 'They should give them the option to talk to somebody who has (a child with a genetic condition). You get pressured into getting rid of it instead of (a choice). They only ever tell you how bad it is going to be. You don't get the choice of talking to someone who's got a disabled child.' [1]

THE MYTH OF THE PERFECT CHILD

"Human life is always a good. It is a manifestation of God in the world, a sign of his presence, a trace of his glory."

POPE JOHN PAUL II

Parents may be presented with the worst case scenario and offered little support. Yet some, like Chris Nugent, do resist this pressure. 'The counsellor emphasised how horrible and fatal this condition was. We told her that termination was not an option for us. We got the response 'Are you doing this for religious reasons?' They did not know what to do with a couple who decided to continue a pregnancy like this in spite of the diagnosis. I asked her if she had any support for me. She said she would get back to me and give me the name of someone who had a child like this (Trisomy 18). I am still waiting...' [2]

Parents may be told, the pregnancy is not 'viable,' or the child will die anyway. Sometimes parents do not realise that 'early induction' or 'bringing on' the birth could be an abortion. Parents may begin to fear that if they go against such advice they will be 'on their own.' Medical staff may think that a termination will save the parents from much grief and suffering, and that they can have another healthy child. Parents are very vulnerable at this time.

BIG BROTHER IS WATCHING: GENETIC SURVEILLANCE

There is no doubt that the birth of a disabled child has come to be viewed by some as a 'disaster' or a 'tragedy.' We are told that such children place 'unacceptable social or psychological burdens' both on the mother and the family. In the view of some healthcare professionals a disabled child's quality of life is thought to be *so low that it is not worth living.* All too often as a result of prenatal testing, the child with the disability is eliminated rather than treated.

LINK TO LATE-TERM ABORTION

Often parents are not told until well into the pregnancy that there is something wrong with their baby. Some late term abortions are done for suspected foetal abnormality, where the unborn child is thought to have a condition such as Down's syndrome, Tay-Sachs disease, Spina bifida, dwarfism or even treatable conditions such as cleft palate. Most people think that no one would do abortions past viability; the point where the unborn babies can survive independently of their mother, now thought to be around 20-24 weeks gestation. Yet some doctors are willing to perform abortions almost up to birth.

Dr David Grundmann who performs late-term abortions[3] says 'If you want to have an abortion beyond 20 weeks, you're probably going to have to come to Victoria, to us.' He says 'the number of women coming for 'late second trimester' terminations increases each year, reflecting a greater unwillingness among doctors in other states to perform them.'[4] Dr Grundmann performs late-term abortion using a method he calls 'cranial decompression' which is more commonly known as 'partial-birth abortion.'[5] Many medical experts, including The American Medical Association (AMA) now say that it is never necessary to do a partial-birth abortion to save the life of a pregnant woman. The AMA says, that 'there is no place in a civilised society for this cruel and dangerous practice.'[6] Partial-birth Abortion has been banned in the USA.[7]

HOW MANY ABORTIONS ARE CARRIED OUT?

It is estimated that around one in three women will have an abortion at some stage in their lifetime.[8] In 2005 the rate of late-term abortion in Victoria almost doubled to 197, including 91 who came from interstate.[9]

THE EUGENIC IDEAS THAT LIE BEHIND PRENATAL SCREENING

The idea that a disabled child's quality of life could be so low that it would 'not be worth living' is not new in the medical world. It can be traced to Charles Darwin's theory of natural selection, and Sir Francis Galton's eugenic application of his ideas to human beings. Galton thought that through better breeding the human race could be improved.[10] Such ideas persist in the medical and scientific establishment today, especially among geneticists, bioethicists and population controllers.

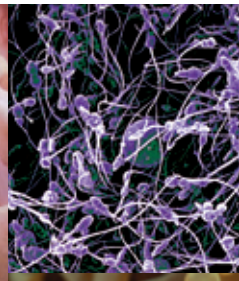
THE FUTILITY OF TRYING TO SCREEN OUT THE DISABLED AND THE SICK

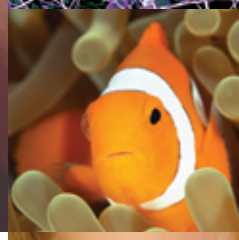
Yet for all this testing, we will still have disabled and sick people with us. Far more people acquire a disability after birth than are ever born with one.[11] People who acquire disabilities in later life such as in adolescence and adulthood vastly outnumber those who develop a condition as children. 'Disability is an inherent part of the human condition.'[12] Many people become sick or injured as a result of car accidents, work accidents, or through alcohol and drug abuse and other diseases. They are more likely to be discriminated against in a culture that only values perfection.

HOW PRENATAL TESTING AFFECTS OTHERS

Genetic screening is transforming the meaning of parenthood.[13] In the past, from the beginning of pregnancy parents formed an inseparable and unconditional protective bond with their children. Now that loving bond is conditional, tentative on the unborn child passing the screening tests. Parents may feel that they cannot allow themselves to become attached to their unborn child in case they decide to 'walk away.'

The availability of prenatal testing means that parents have to decide whether or not to give birth to a child with a 'disability.' Increasingly they will be seen as being responsible, or may even be blamed for the birth of children with a disability or disease. These parents, as well as those who reject prenatal testing in the first place may be considered less deserving of help both by the health profession and others.[14]





WOMEN'S EXPERIENCE OF LATE-TERM ABORTION

After nearly forty years of liberal abortion, considerable evidence is accumulating that abortion, for any reason, is *not* a simple procedure that allows women to get on with their lives.[15] Instead it leaves many women emotionally and psychologically scarred.

Despite the fact that some people believe that a woman pregnant with a 'disabled child' would be better to terminate, the evidence does not support this.[16] Women are left traumatised and grieving, afterwards. Studies have found that as many as 78% to 90% of women who abort in the second trimester for foetal abnormalities experience an acute grief reaction after the termination.[17] Selective termination has been described as a '…paradoxical form of suffering entailing the intentional loss of a desired pregnancy and killing to care.'[18] Psychologists now are questioning the assumption that selective termination reduces suffering.[19] Natalie, a woman who endured 'an induction' says she had 'massive reservations' about the abortion but was not given time or space to air them. 'A big part of the weight I carried was that we had to sign her life away. I would still have grieved at her dying (if we didn't abort and she died after birth), but I wouldn't be carrying the same weight. The burden you carry is too great.'[20]

CONCERN ABOUT SCREENING

Many people with a disability argue that prenatal testing and selective abortion makes them feel like they should not exist, that they should not be here. Are we saying that disabled people are really disposable? Is that the message we really want to send? 'Most disabled adults tell us that they would not have wanted to be aborted, so why do we assume that aborting them is justified on medical grounds?' [21]

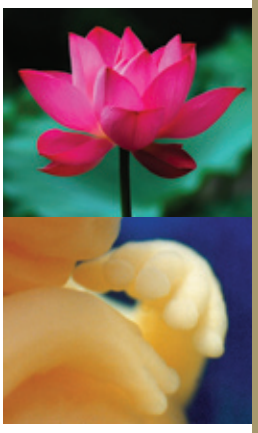
(from left): Zoe Mace with Domencia, who has Down's Syndrome, and her mother Rosa Monckton

UNCONDITIONAL LOVE: THE CALL TO CHANGE THE CULTURE

The ethics of prenatal screening and how we respond to its challenges is of great importance to the society we will become. Wesley Smith says that 'the morality of the 21st century will depend on how we respond to this simple but profound question: Does every human life have equal moral value simply and merely because it is human? Answer yes and we have a chance of achieving universal human rights. Answer no, and it means that we are merely another animal in the forest.' [22]

We know that 'We are not some casual and meaningless product of evolution. Each of us is the result of a thought of God. Each of us is willed, each of us is loved, each of us is necessary,'[23] as Pope Benedict reminds us. 'Human life is sacred and inviolable at every moment of existence, including the initial phase which precedes birth. All human beings, from their mother's womb, belong to God who searches them and knows them, who forms them and knits them together with his own hands, who gazes on them when they are tiny shapeless embryos and already sees in them the adults of tomorrow whose days are numbered and whose vocation is even now written in the 'book of life'. There too, when they are still in their mothers womb – as many passages of the Bible bear witness – they are the personal objects of God's loving and fatherly providence.' [24]

Pope John Paul II called us to become the people of life and love. We are called to show the world a new way of looking at every human life. We are called to welcome and support vulnerable parents and their children and to care for the sick and disabled. We are called to support and encourage all those faced with difficult pregnancies. Like Jerome Lejeune, the doctor who discovered the genetic cause of Down's syndrome, we are called to use our talents at the service of life. Do not be afraid to love, to welcome the vulnerable into your heart and your home, to make room for those who are different: for they teach us love and compassion. They teach us to be human. They too are a sign of God's love in the world, a trace of his glory, a sign of hope[25] and of the world yet to come.



Jerome Lejeune, Servant of God, you placed your talents in service of life. Awaken in us a new reverence for every human life, so that we might become witnesses of love and hope in the world. Amen.

DOMENICA'S STORY

'The other morning Rosa Monckton came downstairs to a scene of devastation in the kitchen. Her 12-year old daughter Domenica was covered in egg, cheese, milk, marmite and peanut butter which she'd tried to mix in a bowl to make a midnight snack. 'I have been like Auntie Nigella,' Domenica triumphantly told her mother, 'I couldn't sleep so I thought I should come downstairs and make myself something.'

They'd watched Auntie Nigella – celebrity chef Nigella Lawson…on television the night before. 'She was having the time of her life,' laughs Rosa, 54. Down's syndrome children learn by imitating other people and she'd seen Auntie Nigella in a scene from her programme getting up in the night to make something to eat. When something like that happens you can't get angry, you have to think 'this is great.'

Domenica is the child Rosa credits with opening her eyes to what really matters in life. Before her arrival, an event which Rosa admits initially left her poleaxed – Rosa's life had been enviably privileged. Rosa, the daughter of a viscount, a friend of the late Princess Diana, and successful businesswoman, was the managing director at Tiffany. At 38, she married journalist Dominic Lawson, son of the former chancellor Nigel and brother of Nigella and together they hosted glittering dinner parties at their London home. When their first daughter Savannah was born healthy, they counted their blessings. Then tragedy struck. A second daughter Natalia was stillborn at six months, and Dominica was born with Down's syndrome. While her husband, a non-believer, instantly accepted and adored Dominica, Rosa – a Catholic – was floored. 'After Domenica was born I have to confess I did indulge in the old 'why me?' syndrome,' says Rosa, whose friend Princess Diana was a huge comfort to her and offered to be Domenica's godmother.

Dominic Lawson says that when Domenica was born the news that she had Down's syndrome came as an enormous relief, since their second daughter, Natalia had died at 22 weeks. The consultant's 'We have a problem' he instantly interpreted as 'this one won't make it either.' His 'your daughter has Down's Syndrome' sounded more to me like 'but this one will live.' As the doctor gave him an idiot's guide to his daughter's 10 minute old body, and the stigmata of Down's syndrome two emotions coursed through him. The first was anger and he wanted to shout that 'This is my daughter you are prodding, not some random strip of flesh.' And the second emotion was love. While he had taken a while to bond with his first daughter Savannah, with Domenica he felt an intense, almost physically painful love for this third daughter, almost immediately. But he said the happiest of them all was Savannah who hated being the only child.

'Having a child with Down's syndrome is not without its challenges,' says Rosa. 'There is still a lot of prejudice and I've had to distance myself from my emotions when people stare. But Domenica has brought us so much joy, so much love. She has enriched our lives so much. She is my daughter and she is wonderful. She has the most amazing emotional intelligence and can tune into people's moods and feelings.' Rosa and Dominic plan to treat her the same way as her sister Savannah. Domenica now attends school, where she has two best friends, but Rosa admits that the future sometimes fills her with anxiety. Rosa plays a leading role in a number of charities, which support disabled children and their families, including *Kids, Downs Syndrome Education Centre* and *Downside Up*.

Rosa hopes that Domenica will go to college and one day live independently with appropriate care and support but realises there is very little support for adults with Down's syndrome. For now an enormous Leonberger dog named Aslan, after the lion from *The Lion, The Witch And The Wardrobe* – is trained to protect Domenica.

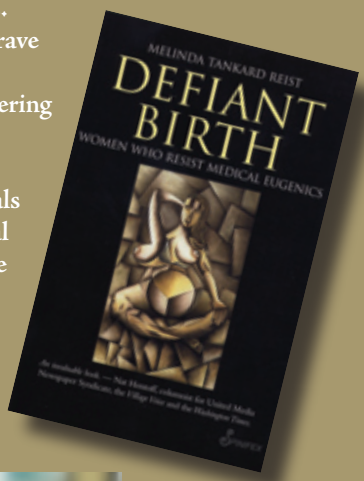
(Adapted from Helen Weathers 'My Down's daughter changed my life,' *The Daily Mail* 14/11/07 and Dominic Lawson 'Syndrome Stigmata' *Sydney Moring Herald*, 19/6/95 (first published in *The Spectator*)

RESOURCES

Gigi's Play House www.gigisplayhouse.com
Beautiful & moving 3 minute film 'I have a voice.'
The Catholic Downs Syndrome Society
http://catholicdownsyndrome.blogspot.com/
Prenatal Testing www.benotafraid.net
Prenatal Partners for Life www.prenatalpartnersforLife.org
Down Syndrome Association of Victoria www.dsav.asn.au
The Fondation Jérôme Lejeune
http://s221021824.onlinehome.fr/ws_prod/fondation_lejeune/
Shorty DVD, http://videoeta.com/movie/93282 and www.revearth.net/
Melinda Tankard Reist, *Defiant Birth: Women Who Resist Medical Eugenics*, 2006, (Spinifex: Melbourne)
Catherine Courtney, Jacqui Costigan, Erma Filder, *Ups & Downs: lives of love, challenge and commitment*, 2000 (PenFolk Publishing: Blackburn)
Clara Lejeune, *Life is a Blessing: A Biography of Jerome Lejeune*, (Ignatius Press: San Francisco)
Post-abortion healing – Open Doors 9870 7044 or 1800 647 995

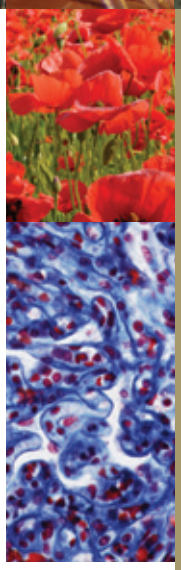
DEFIANT BIRTH

'Defiant Birth tells stories of women who continued their pregnancies despite intense pressure' from others. 'Some of the writers tell of grave misdiagnosis, others of life-changing experiences, discovering the joy and love in children considered unworthy of life.' Melinda Tankard Reist reveals the reality of modern medical eugenics but at the same time gives us reasons to hope and shows us how to stand in solidarity against this "choice."



FOOTNOTES

1. Melinda Reist, *Defiant Birth: Women Who Resist Medical Eugenics*, 2006 (Spinifex Press: Melbourne), p30
2. ibid, p31
3. Carol Nader and David Wroe, 'Late Abortion: The Doctor's Defense,' The Age 14/10/2005
4. 'The Fear Factor,' 03/11/06 www.abortionhelp.com.au/news/media_coverage/the_fear_factor (printed 11/4/08)
5. Partial birth abortion involves half delivering the baby, putting scissors through its head, and sucking the brain out under high pressure. An unborn baby at this stage of development would be born alive but Dr Grundmann ensures that, as he puts it, there is 'no chance of delivering a live foetus.' David Fagan, 'Doctor's boast fuels call for abortion reform,' *The Australian* 28/10/94, David Van Gend, 'On the Sanctity of Human Life,' *Quadrant* September 1995
6. The American Medical Association is writing to support 'The Partial-Birth Abortion Ban Act of 1997, Letter from P. John Seward, Executive Vice President AMA to The Hon Rick Santorum, United States Senate 19/5/1997. Also www.usccb.org/prolife/issues/abortion/fact198.html
7. www.wikipedia.org/wiki/Partial-Birth_Abortion_Ban_Act
8. 'Termination Of Pregnancy: A Resource For Health Professionals,' November 2005, *The Royal Australian and New Zealand College of Obstetricians and Gynaecologists* www.ranzcog.edu.au
9. Op cit Carol Nader and David Wroe
10. W. Malcolm Byrnes, 'Human genetic Technology: Eugenics and Social Justice,' *The National Catholic Bioethics Quarterly*, 1:4 Winter 2001 p565, and Bryan Appleyard, *Brave New Worlds: Staying Human in the Genetic Future* (London: Harper Collins, 1999)
11. Op cit Melinda Reist, *Defiant Birth*
12. ibid p7
13. Gilbert Meilaender, *Bioethics: A Primer For Christians*, 1996 (Eerdmans Publishing: Michigan) p51
14. Selena Ewing, *Women and Abortion: An evidence based review*, Women's Forum Australia www.womensforumaustralia.org p11
15. Melinda Reist, *Giving Sorrow Words: Women's stories of grief after abortion*, (Sydney, Duffy and Snellgrove, 2000)
16. Op cit Selena Ewing, *Women and Abortion*, p23
17. ibid
18. ibid p25
19. ibid p25
20. Op cit Melinda Reist, *Defiant Birth* p12
21. Margaret Somerville, *The Ethical Imagination: Journeys Of The Human Spirit*, 2006 (Melbourne University Press; Carlton) p189-190
22. ibid p124
23. Pope Benedict XVI, Homily *'Mass For The Inauguration Of The Pontificate Of His Holiness Benedict XVI,'* 24/4/2005 www.vatican.va/holy_father/benedict_xvi/homilies/2005/documents/hf_ben-xvi_hom_20050424_inizio-pontificato_en.html
24. Pope John Paul II, *The Gospel Of Life (Evangelium Vitae)*, 1995 (St Paul: Sydney) #61
25. ibid #34



PRENATAL SCREENING: CREATING A DUTY TO HAVE AN ABORTION?

Pregnant women are routinely offered prenatal tests to check that their unborn child is healthy. While prenatal testing cannot guarantee a healthy baby, it can give parents some information. Screening tests such as maternal serum testing and ultrasound give an indication of the risk of the unborn child having a medical condition. Often diagnostic tests are required to give further information. These include Amniocentesis and Chorionic Villus Sampling (CVS). There is around a 1% to 2% chance that these diagnostic tests may cause a miscarriage.

Prenatal testing can identify potential problems and allow parents and medical teams to prepare for the birth of the child with a certain condition. Sometimes emergency surgery, or blood transfusion are required soon after birth and doctors intervene before birth to save the life of the unborn child. Unfortunately all too often the real reason for offering prenatal testing is to screen for 'abnormal' foetuses and to offer selective abortion if anything unusual is detected. Sadly prenatal testing has become more of a 'search and destroy mission' rather than a genuine attempt to diagnose problems and to offer care to the unborn child. In agreeing to testing, parents may not realise that should any imperfection be detected that they will offered an abortion.

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Respect Life Office, Catholic Archdiocese of Melbourne. PO Box 146, East Melbourne VIC 8002. Phone: 03 9412 3373 Fax: 03 9417 2107
Email: RespectLife@jp2institute.org Website: www.respectlifeoffice.org

Designed by Ramesh Weeraratne. Catholic Archdiocese of Melbourne (Catholic Communications).