

Denying Disability: The Increase in Disability Directed Terminations – A Parent’s Perspective.

A sign I saw recently said there are two groups of people in the world – the diagnosed and the undiagnosed.

Martin Luther King Jr said that “the ultimate measure of a man is not where he stands in moments of comfort and convenience, but where he stands at times of challenge and controversy”. Antenatal screening for chromosomal and congenital abnormalities and chronic medical conditions for the express purpose of terminating young lives is challenging and controversial and for parents it is the field that we find ourselves playing on, not through choice but through circumstance. So I want to know where this attitude that children diagnosed with disability are ‘less human’ than the undiagnosed originated.

This attitude started, not at the end of World War 2 in 1945 when the true horror of the concentration camps as places of mass extermination by the Third Reich was exposed for the world to see or when the Holocaust began many years prior with the Nazi designation of “**life unworthy of life**”. In the year 258 St Lawrence was commanded by the Emperor Valerian to bring him the Church’s treasury. Some days later St Lawrence presented to Valerian the poor, crippled and maimed and stated ‘Behold the Jewels of the Church!’ St Lawrence efforts to reveal the truth may have been noble but he was martyred for his efforts. So this attitude has been enmeshed in the human condition since time immortal and mostly through ignorance.

Ernst Haeckel¹ an eminent German biologist, naturalist, philosopher, physician, professor and artist wrote in 1876 about the selective infanticide policy of the Greek city of ancient Sparta. Adolf Hitler read this material whilst incarcerated in Landsberg Prison for treason in 1924. He came to believe that Germany could become strong again if the state applied these same principles of racial hygiene and eugenics to German society. In 1928 Hitler wrote a book titled **Zweites Buch** in which he praised Haeckel’s work and endorsed what he perceived to be eugenic treatment of deformed children. He wrote:

The exposure of the sick, weak, deformed children, in short, their destruction, was more decent and in truth a thousand times more humane than the wretched insanity of our day which preserves the most pathological subject, at any price, and yet takes the life of a hundred thousand healthy children through birth control or abortion, in order subsequently to breed a race of degenerates burdened with illnesses.

¹ http://en.wikipedia.org/wiki/Ernst_Haeckel

According to the racial policy of the Third Reich² those that had no right to live were considered grossly inferior, had serious medical problems and were to be "euthanized". This policy targeted not only the Jews, Gypsies, homosexuals, Poles and Russians but started with the disabled.

In late 1938, Hitler received a family's petition for the "mercy killing" of their blind, physically and developmentally disabled infant boy. This little boy Gerhard Kretschmar was euthanized in July 1939 but just 3 weeks later, Hitler instructed his personal physician Karl Brandt to proceed in the same manner in similar cases. The *Reich Committee for the Scientific Registering of Hereditary and Congenital Illnesses* was founded to prepare and proceed with the massive secret killing of infants. Doctors and midwives were required to report all cases of newborns with severe disabilities. Those to be killed were "all children under three years of age 'suspected' of having 'serious hereditary diseases' such as idiocy and Down syndrome; microcephaly; hydrocephaly; malformations of all kinds, especially of limbs, head, and spinal column; and paralysis, including spastic conditions". Once war broke out, Action T4 as it was called was expanded to include older children and adolescents and expanded again to include disabled adults.

From the start of the T4 programme Hitler was aware that killing large numbers of Germans with disabilities would be unpopular with the public. After widespread protest from families and Churches, Hitler ordered its cancellation but it did not bring the killing of people with disabilities to an end. By the end of 1941 75,000 to 100,000 people with disabilities had been killed.

Today Grafeneck Castle stands as sentinel reminder of the at least 10,500 mentally and physically disabled people who in 1940 were systematically killed in huge numbers in the gas chamber at the Grafeneck Euthanasia Centre where the T4 programme was bought to life. Babies, children, young people and adults with Spina Bifida were amongst those killed - judged as "life unworthy of life".

At the close of the 2012 London Paralympic Games, James Parker from the Zenit News Agency³ challenged leaders and politicians to change the laws surrounding abortion in the United Kingdom which discriminate against any new life in the womb that might possibly be affected by a physical handicap, genetic problems or mental deficit. In the United Kingdom a baby with Spina Bifida can be terminated at any point through the pregnancy⁴. Many athletes didn't realize that had they or their teammates been conceived today that their lives would most likely have been terminated.

² http://en.wikipedia.org/wiki/Racial_policy_of_the_Third_Reich

³ <http://www.zenit.org/article-35463?l=english>

⁴ Cockayne R, Gibbon F, Leach P Neurosurgical input at pre-natal counselling for parents of babies with Spina Bifida, British Journal of Neurosurgery, 2012; Early Online :1-4

The gas chambers may not be operating today but antenatal screening has become a socially acceptable form of genetic cleansing (however polished the arguments may be). Society leads parents to believe that raising a child with disability is such a grave burden that it is both morally correct and medically appropriate to take expensive measures to ensure that such children are not born⁵. Prenatal testing reinforces unjustifiable fear of disability⁶. By screening for specific conditions prenatally, this fear is encouraged. The availability of antenatal screening and diagnostic testing has changed the experience of pregnancy, creating a need for reassurance from 'genetic anxiety' where parents are driven by fear of having defective, socially unacceptable children. Prior to the advent of screening, a baby was assumed to be healthy, unless there was evidence to the contrary. Now the balance has shifted towards having to 'prove' the health or normality of a baby. Dr Lisa Bridle notes that prenatal diagnosis raises profound questions about the value of children and the sort of communities we are creating. Robert Zachary, Paediatric Surgeon at Sheffield Children's Hospital in the UK recognized that the social environment shaped the experience of disability. Antenatal screening promotes and emphasises 'control' and 'choice', two words which go out the window when any new baby is born!

Prior to the Paralympics starting, in a segment called 'Eugenics, Helping or Eradicating Disability'⁷ the BBC NewsNight team asked whether it was a noble aim to rid the world of mental and physical disability. There is nothing noble about trying to eradicate the disabled before birth⁸. By doing that we hold to the same philosophy held by the Nazis that disabled people are inferior and that we should do all we can to eliminate them.

But the truth is that since 1975 we have been doing exactly that with Spina Bifida. MSAFP measurement through blood testing has been used as an antenatal screening test for open Neural Tube Defects since the 1970's⁹ when prenatal screening technologies were in their infancy. The *Lancet* reported that "the finding that AFP levels are often raised in maternal blood in association with neural tube defect of the foetus is an important advance in obstetric practice since it presents the possibility of a screening programme leading to early diagnosis and termination of these abnormal pregnancies"¹⁰. In fact the pioneers of AFP screening, Brock and Sutcliffe are recorded in the *Lancet* stating that their screening tool would allow for the termination of those diagnosed with anencephaly and spina bifida

⁵ <http://www.nathaniel.org.nz/component/content/article/14-bioethical-issues/bioethics-at-the-beginning-of-life/161-confronting-the-distortions-mothers-of-children-with-down-syndrome-and-prenatal-testing>

⁶ <http://www.nathaniel.org.nz/component/content/article/14-bioethical-issues/bioethics-at-the-beginning-of-life/161-confronting-the-distortions-mothers-of-children-with-down-syndrome-and-prenatal-testing>

⁷ http://www.disclose.tv/action/viewvideo/110961/Eugenics_helping_or_eradicating_disability_28Aug12_NewNight__BBC/

⁸ <http://theleadingedgeblog.com/exclusive-bbc%E2%80%99s-twisted-use-of-paralympics-to-push-eugenics-agenda/>

⁹ Wald NJ, Hackshaw AK, George LM : Assay precision of serum alpha fetoprotein in antenatal screening for neural tube defects and Down's syndrome.

¹⁰ Gagen WJ and Bishop JP : Ethics, justification and the prevention of Spina Bifida, *J Med Ethics* 2007 September; 33(9):501-507

A marker molecule, which indicates an affected foetus early enough to allow termination of pregnancy, has so far not been found. We suggest that AFP could act as such a marker molecule.

And so we have it; technology that was swiftly harnessed to uncover and prevent Spina Bifida and seen as a significant step forward in identifying abnormal babies and as a tool to facilitate pregnancy termination¹¹. The accepted coupling of “affected” pregnancies and “termination” enabled a clear distinction to be made between abnormal and normal babies in order to facilitate the termination of the abnormal. The idea that abnormality only leads to termination has become embedded in medical practice.

Increasing use of screening technologies for Spina Bifida came at a time when child mortality rates were falling. More than a quarter of all deaths in the first year of life were due to foetal abnormalities. So medical intervention shifted from preventing mortality after childbirth to uncovering abnormality prior to childbirth. Antenatal screening has become one of the most routine procedures in maternal healthcare, referred to as ‘recommended’, ‘essential’, ‘advised’, ‘important’, ‘sensible’ and ‘routine’. It sprang from the medicalisation of pregnancy and childbirth, technological advances and is based on the premise that being disabled is worse than being dead¹². Let’s be very clear about this, antenatal screening programmes are only considered ‘successful’ when they have identified babies with abnormalities. They do not follow the normal principles of medical screening which are defined in the Oxford Concise Medical Dictionary as

Tests carried out on a large number of apparently healthy people to separate those who probably have a specified disease, from those who do not.

The purpose of screening is for the detection of a condition requiring available treatment with the aim of curing, healing or mitigating the condition, or to reduce or prevent its impact and complications for the person after diagnosis.

Professor Fiona Stanley estimates that 5% of all babies are born with some form of disability. There is a 1 in 20 chance of having a baby with open Spina Bifida. The risk of having any NTD is approximately 1 in 10¹³. By 1977 an AFP screening programme for Neural Tube Defects was in place with an estimated increased detection rate of around 15%¹⁴. At

¹¹ Gagen WJ and Bishop JP : Ethics, justification and the prevention of Spina Bifida, J Med Ethics 2007 September; 33(9):501-507

¹² <http://neonatalresearch.org/2012/09/10/a-life-worth-living-myelomeningocele/>

¹³ Wald NJ et al Maternal serum-alpha-fetoprotein measurement in antenatal screening for anencephaly and spina bifida in early pregnancy. Report of U.K collaborative study on alpha-fetoprotein in relation to neural tube defects. Lancet 1977 Jun 25;1(8026):1323-32

¹⁴ Chan, A., Robertson, E.F., Haan, E.A., Ranieri, E and Keane, R.J. (1995), The sensitivity of ultrasound and serum alpha-fetoprotein in population-based antenatal screening for neural tube defects, South Australia

16-18¹⁵ weeks gestation, 88% of anencephaly, 79% of open Spina Bifida have AFP levels above the normal median. Ultrasound technology used in the second trimester has a 97% detection rate¹⁶.

The justification for introducing prenatal screening for Spina Bifida has been grounded historically on terms such as 'prevention', 'efficacy' and 'benefit'. An implicit link between diagnosis and prevention, abnormality and termination exists. There is no denying that screening can be a vital aid in monitoring pregnancies for therapeutic reasons with a view to safe delivery. However, most screening is performed in order to prevent the birth (or conception) of disabled children.

In a study on ethics, justification and the prevention of Spina Bifida¹⁷ it was noted that

'the failure of pregnant women to undergo antenatal screening and the subsequent failure to terminate on diagnosis was 'a hindrance to the efficacy of success in preventing the birth of babies with Spina Bifida'.

It reduced efficacy levels in practice from 95% to 65%. So for many years we have searched for anomalies and terminated pregnancies based on largely extremely prejudicial misinformation provided to parents, who are strongly influenced at a time of distress by the prejudice of the specialists whose care they are under. This prejudice is not shared by the rest of the population and in particular, by people with disabilities. It is impossible for society to have a truly positive, non-discriminatory attitude towards a group of people whose deliberate destruction it is simultaneously condoning. In fact, the Federation of International Gynaecology and Obstetrics (FIGO) have already recognised that with further advances in prenatal diagnosis that there is a potential danger of stigmatization or discrimination against adults or children affected by disorders¹⁸.

The prevalence of NTDs in New Zealand in the late 1970's and early 1980's was close to 2/1000 livebirths but as methods of prenatal screening and diagnosis have improved, this rate has fallen to 1/1000. Most pregnancies affected by NTDs are terminated¹⁹. The impact of antenatal screening on Spina Bifida can be clearly seen in the number of live-births for

1986-1991. BJOG : An International Journal of Obstetrics & Gynaecology, 102:370-376. Doi: 10.1111/j.1471-0528.1995.tb11287.x

¹⁵ Quest Diagnostics : Prenatal screening and Diagnosis of Neural Tube Defects, Down Syndrome, and Trisomy <http://www.questdiagnostics.com/testcenter/testguide.action>

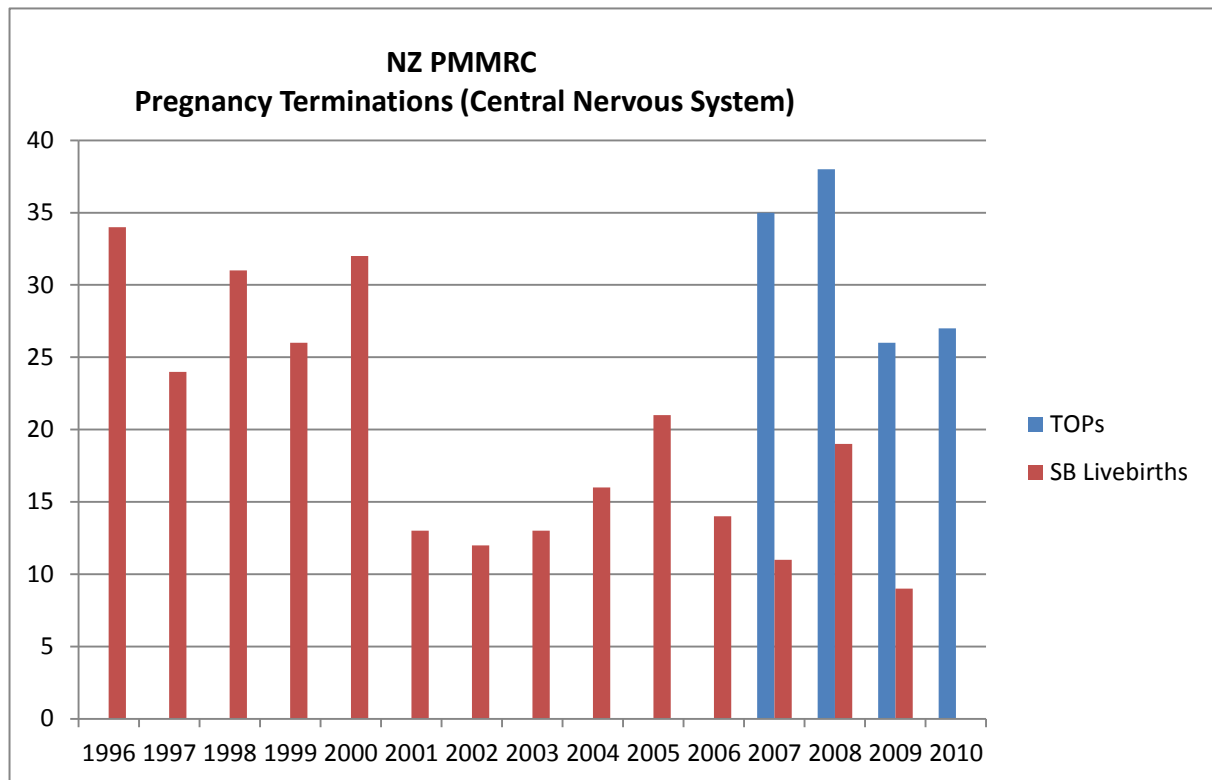
¹⁶ Wikipedia : Prenatal diagnosis http://en.wikipedia.org/wiki/Prenatal_diagnosis

¹⁷ Gagen WJ and Bishop JP : Ethics, justification and the prevention of Spina Bifida, J Med Ethics 2007 September; 33(9):501-507

¹⁸ http://www.ranzcog.edu.au/component/docman/doc_download/207-figo-s-recommendations-on-the-ethical-issues-in-obstetrics-and-gynaecology.html?Itemid=72

¹⁹ Carol Bower : Fortification of food with folic acid and the prevention of neural tube defects NZ Med J 2003; Vol 116 No 1168

recorded by the NZ Birth Defects Registry^{20,21}. From 34 in 1996 they have declined to just 9 in 2009.



I have collated similar data from Australia using statistics from the Australian Institute for Health and Wellbeing (AIHW) National Perinatal Statistics Unit^{22,23,24,25,26,27}.

²⁰ <http://www.hqsc.govt.nz/assets/PMMRC/Publications/PMMRC-6th-Report-2010-Lkd.pdf>

²¹ <http://www.nzbdmp.ac.nz/assets/FILES/Final%20published%20table%202000-2009.pdf>

²² AIHW National Perinatal Statistics Unit, Congenital Malformations Australia 1981-1992
[http://www.preru.unsw.edu.au/PRERUWeb.nsf/resources/CM/\\$file/bd1.pdf](http://www.preru.unsw.edu.au/PRERUWeb.nsf/resources/CM/$file/bd1.pdf)

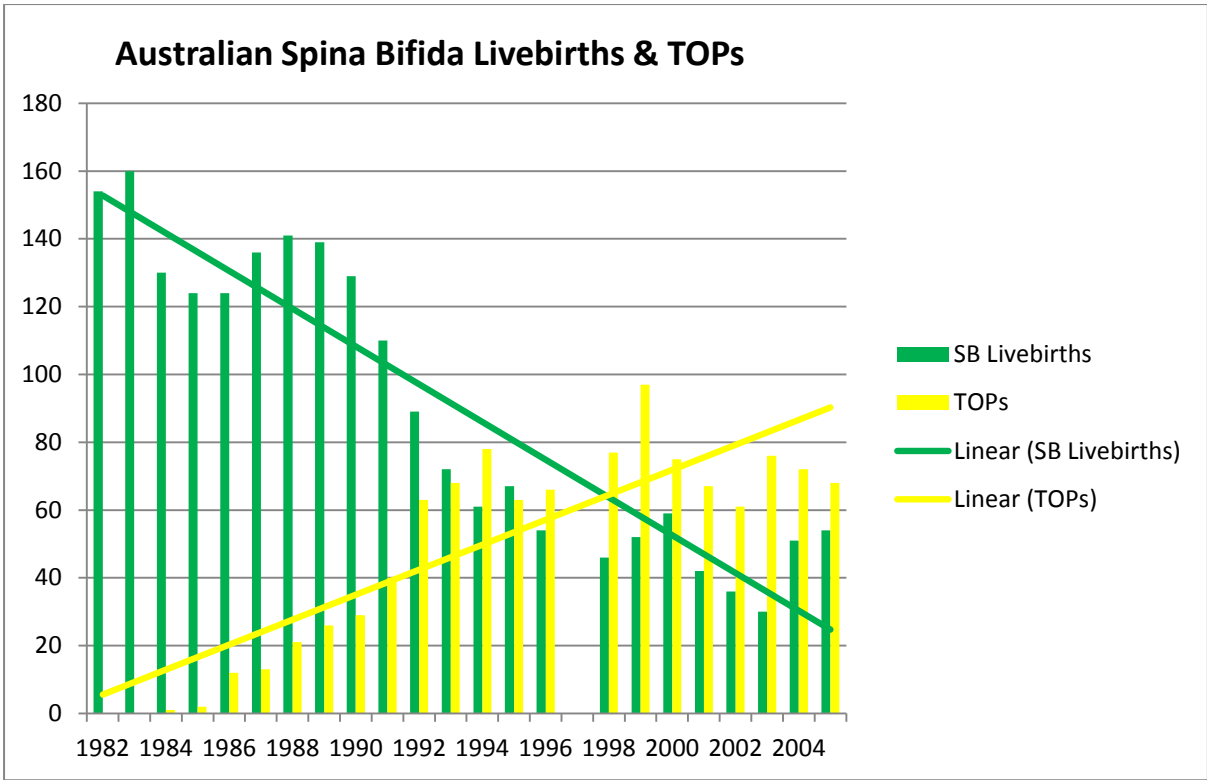
²³ AIHW National Perinatal Statistics Unit, Congenital Malformations Australia 1993 and 1994
[http://www.preru.unsw.edu.au/PRERUWeb.nsf/resources/CM/\\$file/bd2.pdf](http://www.preru.unsw.edu.au/PRERUWeb.nsf/resources/CM/$file/bd2.pdf)

²⁴ Congenital Anomalies in Australia 1998-2001
[http://www.preru.unsw.edu.au/PRERUWeb.nsf/resources/CA+2/\\$file/ca2.pdf](http://www.preru.unsw.edu.au/PRERUWeb.nsf/resources/CA+2/$file/ca2.pdf)

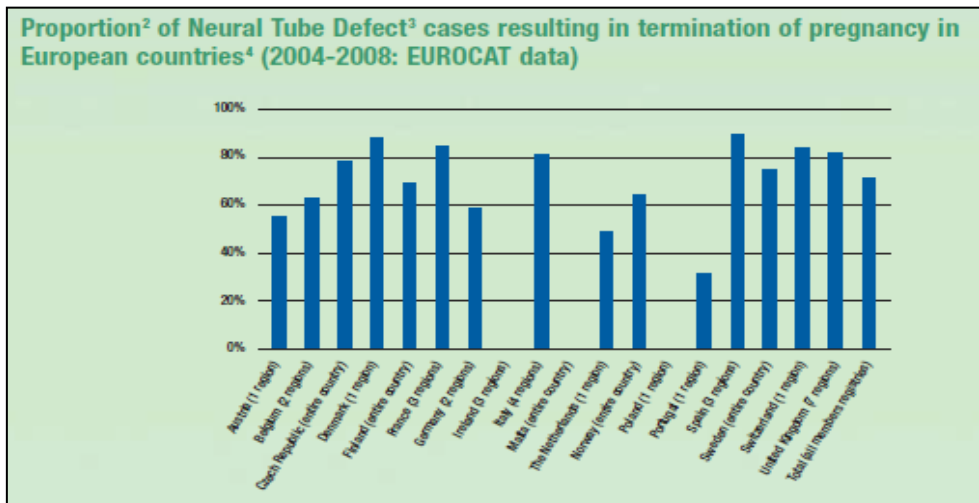
²⁵ Congenital Anomalies in Australia 2002-2003
[http://www.preru.unsw.edu.au/PRERUWeb.nsf/resources/CA+2/\\$file/ca3a.pdf](http://www.preru.unsw.edu.au/PRERUWeb.nsf/resources/CA+2/$file/ca3a.pdf)

²⁶ AIHW National Perinatal Statistics Unit, Neural Tube Defects, An epidemiological report November 2008
[http://www.preru.unsw.edu.au/PRERUWeb.nsf/resources/CA+2/\\$file/NTD+report.pdf](http://www.preru.unsw.edu.au/PRERUWeb.nsf/resources/CA+2/$file/NTD+report.pdf)

²⁷ Australian Institute of Health & Welfare
<http://www.aihw.gov.au/WorkArea/DownloadAsset.aspx?id=6442459053>



This pattern of live-birth reduction has been demonstrated in many other countries where antenatal screening programmes operate²⁸. There are high detection and termination rates for NTD affected pregnancies²⁹. These deaths are sometimes dismissed as being ‘only’ a small percentage of total terminations but in terms of statistics vastly greater discrimination is clear³⁰. In Europe 72% of pregnancies affected by a Neural Tube Defect between 2004-2008 were terminated³¹. That is 3,240 babies lost.



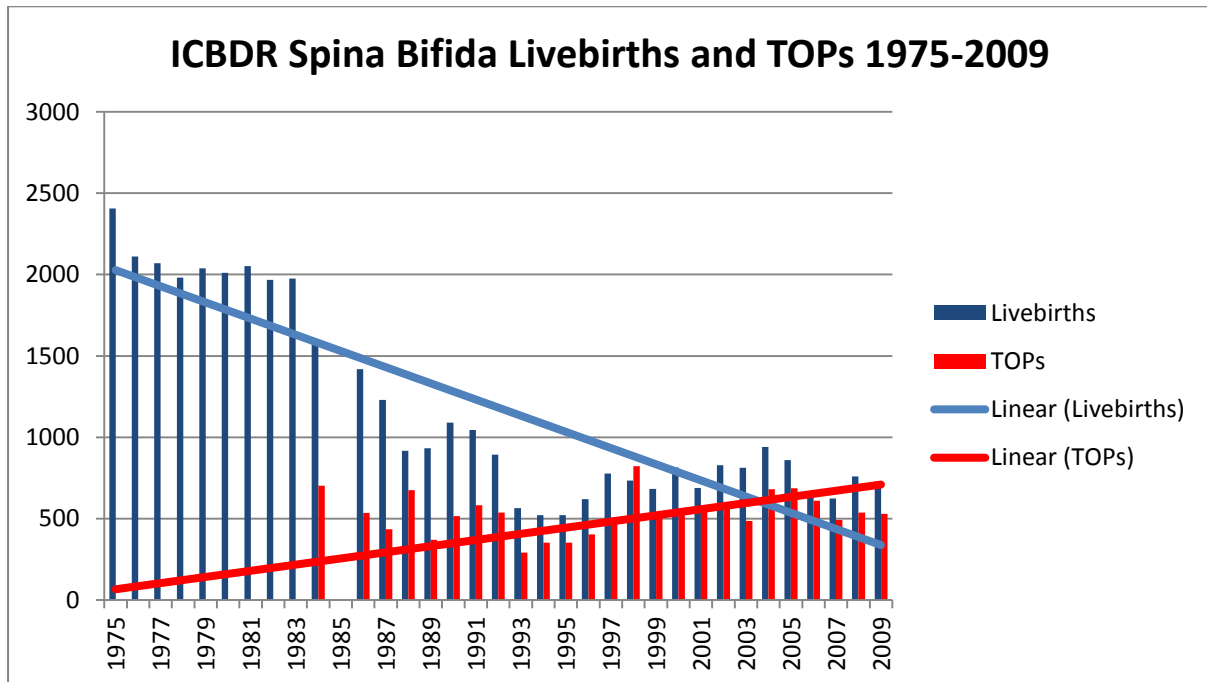
²⁸ Screening Brief : Antenatal screening for neural tube defects J Med Screen 1998; 5:167

²⁹ Cameron M, Moran P Prenatal screening and diagnosis of neural tube defects Prenat Diagn. 2009 Apr;29(4):402-11

³⁰ Alison Davis : A Disabled Person’s Perspective on Eugenic Abortion, SPUC, March 2003

³¹ http://issuu.com/if_sbh/docs/2nd_report_ntd_prevention_2011

Data collated from the International Clearing House for Birth Defects Registry shows the increasing trend for pregnancy terminations after prenatal diagnosis³².



The United Nations recognises that behind the statistics and the denial of rights to disabled children throughout the world is an attitude which views the life of a disabled child as of less worth, less importance and less potential than that of an able-bodied child. On 6 October 1997 a general discussion³³ was held where it was noted that the abortion of unborn babies known to be handicapped needed to be opposed with great force. The UN Convention on the Rights of the Child states that all children have the right to life. Failure to promote the survival and development of disabled children on an equal basis with their peers and discriminatory laws which deny their right to life represents a profound violation of the Convention. It is one thing to work to eliminate impairment but quite another to eliminate the person with the impairment. Any preventive strategy involving disability should not include the denial of life. Diagnosis and termination of pregnancies is not prevention. The UN Committee also noted that society should accommodate a wide spectrum of individual abilities rather than expect all to conform to one hypothetical and unachievable standard of 'normality'.

³² ICBDSR Annual Report 2010 <http://www.icbdsr.org/filebank/documents/ar2005/Report2010.pdf>

ICBDSR Annual Report 2009 <http://www.icbdsr.org/filebank/documents/ar2005/Report2009.pdf>

ICBDSR Annual Report 2007 <http://www.icbdsr.org/filebank/documents/ar2005/Report2007.pdf>

ICBDSR Annual Report 2006 <http://www.icbdsr.org/filebank/documents/Report2006.pdf>

ICBDSR Annual Report 2005 <http://www.icbdsr.org/filebank/documents/Report2005.pdf>

ICBDSR Annual Report 2004 <http://www.icbdsr.org/filebank/documents/Report2004.pdf>

ICBDSR Annual Report 2003 <http://www.icbdsr.org/filebank/documents/Report2003.pdf>

ICBDSR Annual Report 2011 <http://www.icbdsr.org/filebank/documents/ar2005/Report2011.pdf>

³³ <http://www.ohchr.org/EN/HRBodies/CRC/Documents/Recommandations/disabled.pdf>

In a blog 'To screen or not to screen?'³⁴, a father commenting about the antenatal scan process realised that he was "a wide eyed passenger" and "more interested in the geek-fest of technology" involved in the scan than what the scan was or wasn't showing. In another blog titled A Mother's Plea to the NHS³⁵, his wife and mother to their son Harry, born with Down Syndrome says that screening is deemed to be the beginning of the end for children with diagnosed disabilities and that this is far from a major medical advance. Like myself, she is against screening and termination being mentioned in the same breath of every piece literature parents to be can get their hands on. The word "screening" implies eradicating. In the 2003 World Atlas of Birth Defects³⁶ it was noted that the prevalence of neural tube defects at birth was expected to decrease through the combined impact of primary prevention, prenatal screening and termination. It seems that disability must be eradicated even at the highest levels. In contrast according to the International Centre for Birth Defects³⁷ the purpose of prenatal diagnosis is to increase the possibility of optimal management of the pregnancy and baby. They note that as birth outcomes improve, the practice of termination after diagnosis of congenital abnormalities may well change. Anthony Gallo, Paediatric Neurosurgeon says that technological change has been so rapid and so progressive that it is virtually impossible to give a completely accurate prognosis for a baby born with Spina Bifida. Over the past 20 years there have been radical improvements in medical care, management, and life expectancy for people born with Spina Bifida and prenatal surgery has been successfully trialled and introduced. Unfortunately the pace of change has also meant that doctors are simply unequipped to assist parents. A strong current of pessimism about life with Spina Bifida has persisted. We are still waiting for the disability discrimination to cease.

Any form of screening must be undertaken with the best interests of the baby at heart. Harry's mother asks why we can't change the whole approach and offer parents the chance to have a complete health scan of their unborn child to "better manage their pregnancy", instead of clinicians routinely discussing the option of termination after a positive diagnosis of any disability or medical condition. Why can't antenatal screening be about parents and clinicians being better prepared for the child coming into this world with or without disability? We know from experience that most parents who are prenatally diagnosed prior to 20 weeks are repeatedly offered termination.

³⁴ <http://harrysgame.wordpress.com/2012/09/26/to-screen-or-not-to-screen/>

³⁵ <http://livvi1205.blogspot.co.uk/2012/09/httpwww.html#comment-form>

³⁶ <http://www.prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf>

³⁷ <http://www.prenatal.tv/lecturas/world%20atlas%20of%20birth%20defects.pdf>

Obstetricians practicing today are the first generation whose knowledge, skills and experience have been requisitioned to effect the elimination of abnormal babies³⁸ despite the fact that The Royal Australian College of Obstetricians and Gynaecologists (RANZCOG) Code of Ethical Practice states that 'when a woman is pregnant there is a duty to consider the health of the woman AND the fetus'. From the same document 'doctors should not discriminate against any patient ... on the basis of disability' and 'the relationship shall be characterised by non-maleficence ... acting in a manner that minimises harm to the patient'. Doctors should 'act in the best interests of their patients'. If the mother and baby are both patients of an Obstetrician then I am unable to reconcile the Ethical Standards with the practices we all know are occurring.

The most recent and serious instance of disability discrimination is the Groningen Protocol, developed in the Netherlands to regulate and justify hastening the death of newborns with severe impairments. The Protocol states that people with severe disabilities have a poor quality of life – often so poor that others are entitled to decide that they should die. Doctors are directed to discriminate their counselling based on disability. Parents are counselled that their babies' impairments will result in a life not worth living and that they should die. Active life-ending measures are only recommended because of disability. Parents of a 'normal' baby that may need temporary help to breathe would be counselled to approve ventilation, but the parents of a baby with a severe disability would not.

The Protocol holds that it is medically and legally proper to withhold, withdraw treatment or medically terminate the life of a baby, when two out of the seven conditions indicated are met

- functional disability,
- pain, discomfort,
- poor prognosis, and hopelessness,
- lack of self-sufficiency,
- inability to communicate,
- hospital dependency and
- long life expectancy (with a disability)

The Protocol has been accepted as a standard of practice by the Dutch Paediatrics Association and through its application has caused the death of over 20 newborn babies with Spina Bifida.

³⁸ <http://www.obstetriciansforlife.com.au/patient-information/>

The Protocol is applied to premature babies, infants with Down Syndrome and other infants born with significant problems.

- babies with no chance of survival.
- babies that have a very poor prognosis and are dependent on intensive care.
- babies with a hopeless prognosis who experience what medical experts deem to be unbearable suffering. For example, a child with the most serious form of Spina Bifida. A baby like my son.

Health professionals have a duty to avoid discrimination and maximize the life possibilities of any child with a disability. It is not appropriate to give health professionals the power to decide that a disability is so severe that the 'best interests' of the child is to die.

Practices, like the Groningen Protocol, that counsel parents that it is best for babies to die because they have disabilities is in direct contravention of the standards required under the UN Convention on the Rights of Persons with Disabilities (UNCRPD)³⁹ and violates international human rights conventions that set the standards for legal and humane medical treatment. Applying such a protocol raises questions about the place of people with disabilities in society⁴⁰. The International Federation for Spina Bifida and Hydrocephalus (IF) fiercely opposes the Groningen Protocol⁴¹.

Through my online involvement in United by Spina Bifida⁴² I met a mother from the USA named Dawn who is a constant source of encouragement. Dawn was pregnant with twins but lost one of them at 10 weeks. At 16 weeks they did the AFP screening and her levels came back 4 times higher than the norm. An ultrasound quickly followed and so began the scariest day of her life. The radiologist left the room to get the doctor, that doctor then went to get another doctor who called in the genetics counsellor. These 4 professionals all sat there talking and looking at the screen as if Dawn wasn't even in the room. Finally they turned to Dawn and explained that her son, Eli, had a very severe form of Spina Bifida called rachischisis. They told Dawn that this diagnosis was incompatible with life and that she needed to terminate her pregnancy. She relates that her heart hit the floor but her faith did not. They sought 10 second opinions all of which corroborated the fatal diagnosis. Dawn and her husband decided to proceed but were reminded at every appointment not to have hope because Eli was not expected to survive - if by some miracle he was able to breathe, he would with absolute certainty be a vegetable quadriplegic with no quality of life. Doctors are notorious for giving negative judgements about the lives of disabled people⁴³, and Eli proved them wrong, he was born breathing on his own and had some movement in all of his limbs.

³⁹ <http://www.un.org/disabilities/convention/conventionfull.shtml>

⁴⁰ Pruitt Lisa J Living with Spina Bifida: A historical perspective, American Academy of Pediatrics DOI:10.1542/PEDS.2011-2935

⁴¹ <http://www.ifglobal.org/images/stories/groningen-d.pdf>

⁴² <http://www.facebook.com/groups/unitedbysb/>

⁴³ A Disabled Person's Perspective on Eugenic Abortion, SPUC, March 2003

Dawn says that her pregnancy was much more difficult than life with a child that has Spina Bifida.

This experience of pregnancy is one Dawn shares in common with all other mothers of babies born with Spina Bifida. When a diagnosis is made parents deserve accurate 'real life' information, support and help. We deserve to hear the positives, not just the negatives. It isn't any more draining or challenging than having any other child. It's just parenting, pure and simple, and it's driven by love.

Fred Rogers⁴⁴ is quoted as saying that what has been important in his understanding of himself and others is the fact that each one of us is so much more than any one thing.

A sick child is much more than his or her sickness.

A person with a disability is much, much more than a handicap.

A paediatrician is more than a medical doctor.

You're MUCH more than your job description or your age or your income or your output."

Spina Bifida is what our children have but it does not define who they are or will be. Spina Bifida is not something terrible and wrong, something that must be prevented, fixed, or cured because its impact can only be negative. It does not prevent people from achieving their full and unique potential. Spina Bifida has a tremendous impact on people, without it they would be completely different. People with Spina Bifida are proud of themselves, their accomplishments, and their success, all of which are not DESPITE Spina bifida, but BECAUSE of Spina Bifida.

Spina Bifida is a beautiful and unique part of who our children are. The scars on their backs show the love between a parent and a child and they show the absolute perfection of a little baby with unlimited potential. Spina bifida isn't anything of which to be ashamed.

Spina bifida is not the problem that can pose difficulty and challenge in our children's life but society where people with disabilities do not always have equal opportunity and are held back by prejudice and discrimination. What we need is an environment of awareness and acceptance.

When I received my baby's Spina Bifida diagnosis on January 12 2009 I had no idea that I would be speaking in Sydney at a medical conference 4 years later. I am Daniel's mother and I have become an advocate. Dr Lisa Bridle writing for the Nathaniel Centre in 2007⁴⁵ relates that losing potential members of society because of disability can be imagined as

⁴⁴ Fred Rogers, *The World According to Mister Rogers: Important Things to Remember*

⁴⁵ <http://www.nathaniel.org.nz/component/content/article/14-bioethical-issues/bioethics-at-the-beginning-of-life/161-confronting-the-distortions-mothers-of-children-with-down-syndrome-and-prenatal-testing>

doing without the colour yellow in a tapestry. We are not doing society a favour because people with disabilities have their own input, their own colour, they make a difference, they light up things ... like yellow does.

And yellow is the colour of Spina Bifida Awareness celebrated in October each year.

Diane Belcher
Executive Director
Spina Bifida New Zealand
www.spinabifida.org.nz
<http://www.facebook.com/groups/SpinabifidaNZ/>