

WORKSHOP

FOR THE

TASKFORCE

ON

PASTORAL RESPONSES

TO

ABORTION

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What is the reason behind women choosing to terminate their pregnancy after a positive pre natal test to disability and why does society sees this as an acceptable and in fact a normal course of action. The answer to this question lies in society's perception and attitude towards people with disability. In understanding the reason behind society's attitude towards disability there may an opportunity to open a door that liberates and free a people who have been locked away, literally, for many centuries.

After teaching his disciples to pray, Jesus said to them, 'And so I say to you: ask and you will receive; seek and you will find; knock, and the door will be opened to you.'¹

People with disability have had many doors closed on them. We need to look at how we can keep the door of inclusion open to people with disability. A doorstop is used to keep a door open or prevent it from banging shut. Once a door is open, many other doors can be accessed. The door most often slammed and locked in the face of people with disabilities is the door labelled life issues.

To define someone as disabled is laden with normative claims, legal considerations and functional measures. There is no single international definition of what constitutes a disability. In Australia the most common definition used is from the Disability Discrimination Act of 1992. The Act uses a broad, medically based definition of disability. It includes loss of physical and mental function, loss of part of the body, illnesses, bodily malfunction or malformation, conditions which cause learning difficulties, and psychiatric or emotional conditions.

This broad definition is helpful in that it addresses life activities in relation to limitations. This is often required in legislation and legal interpretation.²

Susan Wendell offers another definition in her article 'Towards a feminist theory of disability'. She says that disability is 'socially constructed from a biological reality'³. This definition acknowledges the power; dominant cultural norms have in shaping the perceptions we have of people with disability. Imagine the limitations of most middle aged people if glasses and contact lenses had not been invented or were not a cultural norm. We are also seeing this definition in practice in prenatal testing for disability. Testing for foetal defects can now detect over 450 conditions.

In his book, 'The Worth of a Child', Thomas Murray states, 'There is an implicit message within the goals of prenatal testing that society believes 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 born.'⁴

This unfortunately is a cultural norm in our Australian society. This was also backed up by the most recent study by the Southern Cross Bioethics Institute which stated;

Support for legal abortion is strongest in the cases of severe foetal disability (85%) or mild foetal disability (60%). But only 15% believe abortion is morally acceptable when the foetus is healthy and there is no abnormal risk to the mother.⁵

It is sometimes in the definition and perception of disability that stereotypes and oppression take root. Generally speaking, our society sees disability as a burden on humanity and a costly experience. There are some health insurers in America refusing to cover babies born with a disability who could have been identified by genetic testing. The insurers are calling this an elective disability and therefore uninsurable; suggesting or implying that having a baby with Down syndrome, spina bifida, dwarfism or cystic fibrosis is a lifestyle choice similar to taking up smoking!⁶ Genetic testing and awareness of ones genetic background is almost becoming a pre requisite for permission to start a family. The IVF providers market this as offering reproductive freedom and family balancing. Our almost obsession with producing the perfect child has given society an inherent right to the elimination and extermination of anyone deemed to be imperfect, unproductive or uninsurable.

This attitude, however, is not new. The extermination and oppression of people with disability have been happening for many centuries.

There is evidence that the Greeks abandoned their babies with disability on hillsides to die while early Chinese left their people with disability to drown in rivers (Anang, 1992). In Europe, Nero Commodus is said to have targeted bow and arrows on individuals with a physical disability and the Church in the 15th century sanctioned the extermination of people with disability (Durant, 1944; Onwuegbu, 1988). [History also alerts us to] the Spartans who killed people with disability as a matter of law; the endorsement by Martin Luther to kill babies with disability because they were 'incarnations of the devil'; the English eugenicists who eliminated people with disability under the Darwinian evolution theory of the 'survival of the fittest' and the Nazi Euthanasia Programme under Hitler to exterminate people with disability as they could not make any contribution to society. These persecutions recorded in western cultures are still evident today.⁷

Babies born with disability are often starved of nourishment and medical procedures are often denied. In our son's case we had to fight for the right for him to undergo open heart surgery. People with disability are denied access to organ transplants because they do not live productive lives. In its 1997 discussion paper, the National Health and Medical Research Council stated that for organ transplants, 'Exclusion criteria include age restrictions, abnormalities in other organ systems, previous history of malignant disease and other medical considerations.'⁸ Does the phrase other medical considerations include disability?

In our experience we would have to say yes. Our son needs a cornea transplant, but he has been refused this procedure because he has a disability. To add insult to injury, people with disability are often given priority in the assisted suicide movement that is currently unfolding in our society.

Throughout history people with disability have been stereotyped. Our perception of people with disability is often bent by our own culture. Just think of the stories from your own childhood and how many of the characters were people with disability. For example: Captain Hook; Tiny Tim; the Hunchback of Notre Dame; Mr Magoo; Snow White and the Seven Dwarfs; Dr Jeckly and Mr Hyde; Thumbelina; Giants; Dumbo; and Scar from 'Lion King'.

What are our images and perceptions of people with disability?

In magazines, the only images of people with disability we tend to see are those in charity advertisements, and their disability is the main focus of the representation. Often we are encouraged to pity the person represented, or give them support in another way. Likewise in the movies; disability is seen as a great storyline - one to inspire pity in audiences and Oscar nominations from your peers. For example Tom Cruise in Born on the Fourth of July, Russell Crowe in A Beautiful Mind and Audrey Hepburn in Wait until Dark. These actors are applauded for their fine performances, as though the representation of disability were an exceptionally dangerous and skilful thing. This is fundamentally wrong - we can only accept the beautiful people pretending to be incapacitated. Is this the equivalent of white actors 'blacking up' to play Othello?⁹

In her article 'We Don't Need a Fairytale World', Joanne Green writes,

From the cradle our children are taught about the value of physical beauty. Cinderella, for example, was the beautiful and morally good victim of her ugly stepsisters' brutality. In Grimm's account of sleeping beauty, (again, a child whose goodness was surpassed only by her beauty), the wicked fairy that caused all her trouble was, in fact, quite ugly and unacceptable even in the company of other fairies. Badness is described in fairytales by the presence of physical differences. Witches must be ugly, complete with warts and hooked noses. Trolls have to have hunched backs and sharp teeth. If a pirate is bad, he must be missing some part of his anatomy - a hook for a hand; a peg for a leg; a patch where an eye should be; virtually every bad character in children's classic literature is physically flawed in some visible way.¹⁰

From a young age we are exposed to attitudes and perceptions that distort our view of people who look, sound or speak differently from us. Society subtly teaches us that difference must be seen as a threat to the well being of the community and that this difference must be hidden or eliminated. Today the message is a little more subtle but perhaps more extensive with our widespread media exposure.

Fiona Strahan, a frequent consultant for disability advocacy in Australia told these stories.

About a year and a half ago, I was in a department store with my adult niece and was approached by a talent scout who asked if I was interested in acting. Within seconds my mind catapulted me into the leading role of a complex, passionate interesting person, perhaps Trudi from *Stones of the River* or Cady from *Maybe the Moon*. Both fantastic roles for dwarf women. I came crashing to earth as he asked excitedly if I had seen a particular advertisement on TV for a hardware shop which had short-statured people dressed as elves dancing around being cute and silly. He handed me his card and encouraged me to give their agency a call. I don't think at this stage I had uttered a word or inhaled a breath!

Not so long ago the Australian Motor Vehicle Accident Authority ran a series of advertisements using Paralympians who were speaking to the camera about how you too could end up like them as a result of your own drink driving/speeding or being hit by someone else in that state. Some felt the message implied that there is something far worse than death - and that is using a wheelchair...that disability is tragic, and even an elite athlete doesn't want to be disabled. The implication is also that if you use a wheelchair then you too would rather be either not disabled or dead.

In the winter of 2002, the Australian parliament conducted a conscience debate on a bill due to be passed approving the use of unused IVF embryos for stem cell research. In the media there seemed to be only two camps, one where politicians gave examples of suffering children, young people or adults whose lives would be turned around from a cure discovered by freeing up this testing. The alarming point here was the assumption of certainty that 'cure' will be found. The other camp took the higher moral ground, stating that the embryos are humans and should not be destroyed in experimentation. Some of those interviewed spoke with cynicism as desperate politicians rushed to the bedside of a child or adult with a disability to speak profoundly from their heart about how cures for people 'like these' will be prevented by the heartless, moralistic people who didn't want the bill to go ahead. The lobby for the bill was strong, emotions and compassionate righteousness flying high. One disability activist who was interviewed said, 'If that level of interest and righteousness was channelled by the same politicians to our independence, economic security and participation in the community, we'd be one helluva liberated group.'

But those in the 'against camp' were seen only to be those who represent the 'right to life' movement and they perceived the embryo as a life being destroyed. So where was the voice that says 'there might be something more powerful than a cure and that is the lives of people with a disability might be liberated by access to education and employment, security of income and tenure, accessible transport and so on'?¹¹

All these examples broaden the belief in our community that disability is something to be exploited and avoided, at all costs.

Another way in which our society perceives people with disability is through language. Language can be used to hurt, oppress and exclude people. Terms like retard, spaz, deaf and dumb, and deformed come with an explicit message. People with disability are oppressed by the use of disability terms to describe negative behaviour characteristics. For example; she can't see past her nose, limping along and the blind leading the blind.

It would be unacceptable to use racist words today and many steps have been taken to abolish and discourage the use of such words from our language. However, it's quite acceptable to call someone a moron or an idiot. Both these words were used as a medical definition of someone with an intellectually disability.

In spite of these destructive attitudes and perceptions, people with disability are starting to speak out; not as victims but as a people with purpose and value. They are claiming that there is nothing wrong or abnormal with having a disability. Their limitations come more from attitudes, stereotypes and external barriers created by society.

Some well meaning people express the view that we all have disability. Perhaps it would be better to say that we all have limitations as, to declare we all have disability of some form could shape attitudes that dismiss the real problems people with disability have and must face in their day to day living.

Jennie Weiss Block suggest that,

Perhaps, in the end, it is best for all people, disabled and non disabled alike, to acknowledge that our solidarity is found in the sharing of the human condition from which no one is excluded. Our unity can be found in our common, but different experiences of joy, pain, peace, loss, hope, limitation and suffering and in our shared dependency on God's love and mercy.¹²

In the past two decades the voices of people with disability and their families have started to be heard both in society and in the Church. Some changes have taken place in our Church but we still have a long way to go. Many of our churches are still inaccessible, very few Church documents are available in Braille, inclusion in our Catholic schools is still very low, many of our attitudes towards people with disability receiving the Sacraments is very poor and our own theology of disability is somewhat lacking. Our language within liturgical celebrations is often oppressive and the emphasis on some scriptural passages can lead to the misunderstanding of the gospel messages and a mixed message about people with disability.

As Church we need to be a place of compassion and relationship; a place where we all feel welcomed; a place where love abides and thrives.

This discussion has covered some of the reasons why society sees the need to terminate the life of a person with a disability. I believe that there is a deeper reason to why people with disability are so easily dismissed. I think that we, as a society, are afraid of everything that is disability. People with disability threaten our perceived view of what a life is.

Again, Jennie Weiss Block states,

We struggle to make sense of disability. The sufferings we see scare us. The fear of becoming disabled makes us uncomfortable. People with disabilities assault our cultural norms. We search for security in our values of attractiveness, independence, self sufficiency and productivity. We are startled by the fact that God might not care if we are attractive, independent and productive. And so we keep our distance. We look the other way ... We avoid coming face to face with two of our greatest fears; we are not perfect and we are not in control.¹³

This fear of not being perfect and not being in control is being fed over and over again by society in its quest for excellence, instant gratification and individualism. Our fear of difference is so great that even people from other countries threaten our very existence. Our race for riches blinds us to injustices and inequality in the workplace. Our inability to search for truth within our democracy has made us deaf to the pleas of those longing and searching for a fair and equal society. Our vanity in striving for perfection in our bodies, our children and our minds paralyzes us in any movement to provide the basic human needs of others.

With all this in mind I will now look at life issues facing people with disability and their families.

Starting a family in today's world is surrounded by science and secrecy. Many couples delay starting their family to acquire a certain level of financial security and job satisfaction. It is estimated that approximately seven per cent of couples of reproductive age are infertile.¹⁴ When couples face infertility issues they are usually referred to assisted reproductive services like IVF and GIFT. Last year over seventy million dollars of public funds were spent on assisting infertile couples become pregnant.¹⁵

IVF is a very demanding process and there is very little information about the number of women who miscarry or who are advised to terminate due to disability. The figures also do not indicate the number of embryos destroyed after preimplantation genetic diagnosis (PGD) of a disability. PGD is used to identify many disorders such as Cystic Fibrosis, Huntington's disease and Fragile X. Some parents refuse to terminate the pregnancy after a positive result from CVS or amniocentesis. We know of three families that have a child with disability directly linked to the IVF programme and who were strongly advised to terminate the pregnancy. None of the families regret their decision to continue the pregnancy. In fact, they said they would make the same decision again if they were faced with it.

It is interesting to note that the supporters of prenatal testing claim that disability is reduced by prenatal tests. This is false because the majority of disability is not genetically related and rather than increasing choices for women, such choices are actually reduced.¹⁶

As far as I know, we are unaware of the effects of eliminating, manipulating and destroying genes within our population. The question lies to whether our society is dictating to us what the definition of a human is and what attributes and abilities you must have to be fully human and to be acceptable to society.

Women with disability are often disadvantaged when it comes to reproductive rights. Most women with an intellectual disability are discouraged from relationships and marriage. Some women with disability are still sterilised after giving birth and often the child is put into foster care. There are very few support services for these women. Women with disability are, from the government record, one of the most marginalised and disadvantaged groups in Australia.

In 1998, eighteen per cent of all children aged less than eighteen years of age lived with a parent who had a disability.¹⁷ In some cases, children are responsible for the day to day care of these parents. Some of these parents are illiterate and have very few opportunities to mix with their peers. Often they struggle with parenting, hygiene and relationship issues. The biggest fear these parents face is losing their children to foster care if they make a mistake.

It takes a great deal of convincing and perseverance for women with a physical disability to be given permission to have a child. Yes, there are very few reproductive rights for women with any sort of a disability. We need to support all women and their families before, during and after pregnancy; all women, meaning and including women with disability. We need to understand, empower and be able to advise women and their families on the complexities of all the aspects of reproduction.

Regardless of whether a couple uses assisted reproductive technologies or conceive naturally, prenatal testing is almost a standard procedure for women who are pregnant. Besides not wanting to be burdened with a child with disability, another common reason is because doctors fear litigation if a baby is born with a 'preventable genetic disease'. The Wrongful Birth Suit has become an established part of tort law in Australia.¹⁸

Prenatal testing is frequently presented as a compassionate enterprise, assisting families to avoid the birth of a child with disability. Early testing is sought to avoid the difficulties of late terminations. However, earlier testing and multiple, periodic forms of testing also emphasize the importance of detecting all affected pregnancies and further entrench a consensus that the rational response to a positive prenatal diagnosis is termination. The language of 'choice', 'reassurance' and 'family well-being' obscures a reality that universal population screening is introduced because it is supported by cost-benefit analyses which assess the prevention of the birth of babies with disability as a core social benefit.¹⁹

After a child with disability is born many parents experience indifference and blame from many sectors of society. Some parents have actually received sympathy cards after the birth of a child with disability. In 1998, about 297,000 children or 7.6% of children aged less than fifteen years were estimated to have a disability.²⁰

Today, there is an increase in incidence of parents being blamed for not terminating pregnancies of identified genetic disability and they are strongly advised not to reproduce in the future without genetic counselling. These barriers especially exist for women with disability. Some women have said that this undervalues their role as a woman and their right to reproduce. It also suggests that society is taking away our reproductive freedom by enforcing negative and cost-based attitudes about disability. Society is declaring and proclaiming that the only life worth living is that which it deems as fully human, productive and capable.

The divorce rate among parents of children with disability is usually higher than the norm. It is estimated that there are 40,000 sole parent carers in Australia. Also, 30.6% of children with disability live in single-parent families, compared with an estimated 18.1% of children without disability.²¹

Long periods in hospital, ongoing illness, sleep deprivation, financial strain, behaviour problems and lack of support put marriages under a great deal of stress. I have known couples to separate because respite was so difficult to come by. After separating they could share the care of their child with disability. They didn't like the arrangement, but at least they had a break from a very demanding situation.

One parent of a child with disability told me,

If another person tells me that I have a place in heaven I will scream. Why don't they give me a hand now while I try and survive this hell on earth?

The 'hell on earth' she was referring to wasn't the child; it was the lack of understanding from her parish, the rejection from the parish school and the exhaustion in caring for her two other children, her husband and her child with disability that required ongoing medical care.

As the child with disability grows older many parents seek Catholic education and Sacramental preparation. Inclusion of children with disability is low within the Catholic system and most children with disability attend government schools. Parents express views of disappointment and disillusionment that they receive little support from the Catholic education system. They question the authenticity of a church that promotes life issues before birth, but seemingly forgets about the family after birth. What does it say to society that we do not, in the majority of cases, provide Catholic education for our children with disability? Often parents are faced with well meaning people telling them that their children don't need to receive the Sacraments because they are angels already. This takes away the humanness of the child and suggests that perhaps this soul does not need the nourishment, graces and blessings of the Sacraments. We need to support parents of children with disability. When we are supportive it is a clear message to society that we value and respect all life.

Often the forgotten member of the family living with disability is the sibling. The sibling of a person with disability is sometimes overlooked and they, at times, feel forgotten. Siblings need support from us as Church in many ways. We need to especially provide pastoral care for these children and young adults as the message they receive and perceive from the church community now may influence their decision on life issues at a later stage in their life.

As you can see a woman's decision to terminate her pregnancy when the child has a disability is acceptable and encouraged in our society, because people with disability are not valued, acknowledged or welcomed in our culture. People with disability are among the most oppressed people in our world. Our society values competition, perfectionism and individualism. If we hope to raise awareness of prenatal testing and the moral questions it raises and decrease the death rate of people with disability in our society, then we must value and support our brothers and sisters who live with disability. We must become a loving and inclusive Church where life is celebrated and limitations supported. The Church then can take the lead in forging a new value system in our society where everyone is valued, welcomed and precious, instead of reflecting the current culture of death so prevalent in today's world.

As the Body of Christ there is much we can do to promote the value of people with disability. I have a few suggestions that relate directly to the work of the taskforce.

- Celebrate life by celebrating International Day of People with Disability on a national Church level, which is held on the third day in December each year. Mass could be celebrated at a diocesan level, and school and parishes encouraged to celebrate the day. Invite people with disability to speak at these events.
- Invite a person with disability to speak at any of the Life Sunday celebrations. When we celebrate life we celebrate every life. It could have the theme 'Celebrate every body!'

- Initiate and develop a parish pastoral council (PPC) programme dealing with the pastoral care of women facing abortion. This programme would aim to:
 - 1) develop an understanding of the purpose of the PPC or equivalent and the pastoral care of women and families before, during and after pregnancy in the context of the local parish and its community
 - 2) inform the PPC on the pastoral needs of women and their families facing issues before, during and after pregnancy
 - 3) provide strategies to assist the PPC in supporting women and families facing issues around, during and after pregnancy
 - 4) provide examples of liturgies and prayer support for women and their families around, during and after pregnancy. This would be to address the need to recognise children who have died before, during and after birth and to offer closure to women who have experienced miscarriage, abortion, still birth, sudden infant death syndrome and the death of an infant through disability or illness
 - 5) build confidence and provide skills to enable and empower the PPC to educate, model and inspire the parish family to take steps to provide tangible and sustainable assistance for women and their families facing issues before, during and after pregnancy

I believe there is a need to re-educate our people in the parishes on life issues. We need to inform and empower parents, friends, priests and teachers, so that they can support or refer women facing difficult decisions to an appropriate service; but, most of all, form lasting and meaningful relationships with these women and their families so that they feel supported at every stage of the pregnancy.

I would also like to suggest that a prayer or prayers be written for women and their families facing difficult life decisions. We could encourage families, people in parishes, schools and Church agencies to use prayers on a regular basis or on the day life issues are celebrated in the dioceses for women and their families facing and experiencing difficult issues around pregnancy. The prayer could include women trying to conceive, those women facing difficult decisions around their pregnancy, women who are ill during pregnancy, women who experienced the death of a baby by miscarriage, abortion, still birth, illness, disability, SIDS and would also include a prayer or blessing for the safe delivery of the baby. This prayer or prayers could be distributed through parishes, schools and other agencies, as a prayer support, recognition and appreciation of the problems many women have to face with pregnancy.

Bill Williams, a theologian with cystic fibrosis, who died in 1998, wrote,

If we disappear from your sight, it may be because our courage failed. We decided not to burden you, and ourselves, with our presence. But, I've been with people who are not made anxious by my brokenness, and I've seen the difference. It is, in fact, the best definition of ministry I have ever heard; I nearly wept when I heard it, it so defined what I needed. Engrave this on your forehead, if you wish to do good:

Ministry is a non anxious presence.

You can tell such grace by its care, by its attentive ear, by its pace. When it reaches out to heal you, it is to give relief to you, not itself - and when it prays with you, it lets you declare your own burdens, rather than declaring what it finds burdensome about you.²²

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Footnotes

¹ Luke 11: 9-10

² Weiss Block, J. (2002). *Copious Hosting - a theology of access for people with disabilities*. The Continuum International Publishing Group Inc: New York. p. 33.

³ Wendell, S. (1996). *The Rejected Body: Feminist Philosophical Reflections on Disability*. Routledge: New York. p. 46.

⁴ Murray, T. (1996). *The Worth of a Child*. University of California Press: Berkeley and Los Angeles. p. 132.

⁵ *Give Women Choice: Australia Speaks On Abortion*. (2005). Southern Cross Bioethics Institute: Adelaide.

⁶ Tormey, S. (2005). *Conceiving Perfection*. Canberra's Child Vol 2 No 6. pp. 10-11.

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¹⁰ Green, J. (1993). *We Don't Need a Fairytale World*. WideSmiles Summer Issue.

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¹² Weiss Block, J. (2002). *Copious Hosting - a theology of access for people with disabilities*. The Continuum International Publishing Group Inc: New York. p. 36.

¹³ Weiss Block, J. (2002). *Copious Hosting - a theology of access for people with disabilities*. The Continuum International Publishing Group Inc: New York. pp. 36-37.

¹⁴ *Children with Disabilities in Australia*. (2004). Australian Institute of Health and Welfare: Canberra.

¹⁵ Tormey, S. (2005). *Conceiving Perfection*. Canberra's Child Vol 2 No 6. pp. 10-11.

¹⁶ Hume, J. (1996). *Disability, Feminism and Eugenics: Who has the right to decide who should or should not inhabit the world?*

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¹⁹ Bridle, L. (2000) *Confronting the Distortions: Mothers of Children with Down Syndrome and Prenatal Testing*. National Council on Intellectual Disability. Interaction, Vol 13, Issue 4, pp. 26-33.

²⁰ *Children with Disabilities in Australia*. (2004). Australian Institute of Health and Welfare: Canberra.

²¹ *Children with Disabilities in Australia*. (2004). Australian Institute of Health and Welfare: Canberra.

²² Williams, B. (1998). *Naked Before God*. Morehouse Publishing: Harrisburg. pp. 32-33.