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Abstract

This article raises issues around doctors' generally clinical approach to prenatal care which often does not include support, factual information or information on alternative options for prospective parents who know their child will be born with a disability. This article uses quotes from parents who question the assumption that a child with a disability is a negative experience, and notes that the old argument of the cost-benefit to society can no longer be used as a justification for abortion. **Keyword: Ethics**

LIMITS ON CARE - PRENATAL CARE

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Last month I sat on the end of a hospital bed while the mother of a child with a rare form of cancer cried out for some understanding from the specialists in charge of her child's medical condition. Through tears she explained to me that the specialists could not understand the love and joy that this child had given her family in her three short years. She said that, if they had any idea, they would not be making statements like:

"Well, we know so little of this cancer, as it is a very rare form and is only contracted by people with Down syndrome. In future, however, we will eradicate it because, with prenatal detection, we will be able to abort these babies so that other people won't have to go through the heartache that you are experiencing."

I mention this to illustrate the lack of tact that these comments display and the difficulty which people with a disability, and those closely associated with them, have in convincing even better-educated people that the worth of an individual can not be judged by a medical attribute. Where would such a practice start or stop? Such a policy could be a vehicle for euthanasia. After all, biologically speaking, people past a certain age or fitness level do not contribute much to the survival of the species. In fact, all parents who have their children now "off their hands" are of no further biological use to the gene pool.

While many of us may be of no use "genetically", you can see how absurd this argument is socially. I could not stand before you and say my mother is of no further use to the community and should therefore be disposed of. For exactly the same reason the biological argument is an absurdity when I am asked to accept that same statement in respect to my daughter, who happens to be deemed biologically imperfect.

This family, through the challenge of disability, turned what others saw as a tough situation into a rich experience.

Both my mother and my daughter are very dear to me, and they have brought meaning to my life. I do not judge them by their ailments. I do not count their chromosomes. Nor did the family of this young child, as they watched over her. In fact, they were grateful for every new day that they had with her, and the only time that they resented her handicap was when the cancer was diagnosed.

This family, through the challenge of disability, turned what others saw as a tough situation into a rich experience. In this they are not alone. There are many, many families which have met the challenge and found that their lives have been enriched beyond their expectations by the love and understanding they have developed. I also acknowledge that there are families who can not cope with that challenge, and I believe that they also need support in their choice.

I say this because I strongly advocate that, as the primary care-givers, family members have to live with the consequences of their choice and therefore should be pre-eminent in any decision to continue with a pregnancy. Unfortunately, in Australia, doctors have a very clinical approach to a diagnosis of a defective foetus and are more than prone to suggest abortion. To quote one parent:

"We really never know what we're getting when we elect to create another individual. And why assume that a child with a handicap will be a negative experience?"

Genetic counselling must not just look at genetics but should seriously look at the situation of the whole child within the family setting. Parents can not fully understand all the medical and long-term implications of such a diagnosis and are very vulnerable to external pressures during this traumatic period. Messages given by doctors, counsellors and others are not value-free, but in fairness to the family it is important that information should be factual and that alternative options should be presented simply and honestly.

In addition, parents should be supported so that they can cope and adjust to information which can be quite emotionally burdensome.

Our experience is that prospective mothers are often presented with no other option but termination, and our association does not accept that pressure groups or single-minded professionals should be forcing people into making decisions with which they do not feel comfortable.

Last year, a woman from Queensland was told she was carrying a child with Down syndrome, with the accompanying advice that she need not worry about it because the doctor could arrange an abortion for her "next week". When she said that her beliefs were strongly against abortion, she was told that she was "burying her head in the sand".

She persisted in her choice, saying that all she wanted from the doctor was the name of an organisation which could help her with information about the condition, only to be told that there was no such organisation. This indicates that the message being given by doctors in Australia is not always informed, enlightened or objective.

For this reason, our organisation produced a film called, "In Memory of Ella", based on the experiences of a group of families in northern Queensland.

It does not pretend to be objective, but the insights of the parents are enlightening, and therefore we aim to have the film introduced into medical training schools.

The film will be a useful tool to be used in genetic counselling and in the education of health professionals and the community, in that it causes viewers to question their preconceptions and think deeply about the heartfelt concerns of parents and carers.

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I do not want to resort to "doctor bashing" here, but I think it is important to point out that this experience affected the woman's health greatly, and her relationship with that doctor has never improved, even though he may have thought that he was offering her the best possible advice at the time.

On Thursday at the IASSMD conference, I discussed Australians' attitudes to abortion, which can be summed up as having more to do with religious beliefs than any other single factor. The other particularly salient fact is that only 30% of Australians are against a woman obtaining an abortion if the foetus is defective.

This creates a major dilemma for medical professionals. The dilemma results from the fact that doctors can terminate a defective foetus at 20 weeks because it has Down syndrome, but a baby with Down syndrome can be born at 24 weeks and have multiple complications from low birth weight. In that case, failure not to proceed with months of intensive care and multiple major operations to prolong life may be classed as "murder".

Our inconsistent approach needs to be addressed, and I look forward to hearing the solution to this dilemma in the next session.

The cost argument is presented by proponents of aborting foetus with disabilities. We no longer accept the arguments of past decades, such as the need to institutionalise people with intellectual disabilities because they are "better off with their own kind" in residential facilities. So it is now time that we tackled also the economic argument. In 1973, an article in *The Lancet* proposed that the "ideology of public health endorses total prevention as a desirable objective for a condition with rising prevalence like Down syndrome," and that Down syndrome is "such a severe affliction that what to do about it is relatively straightforward."

In 1985, Conley estimated the social cost of Down syndrome worldwide to be about \$3,621 billion, based on the excess medical, educational and residential services, whereas costs associated with prevention of Down syndrome amounted to only \$33 billion.

In fact, compulsory screening was advocated in 1973 on the grounds that:

"a foetus with a severe defect has a lesser moral claim on the mother than a 'normal' child because he or she is less likely to 'respond to the promise of becoming a person in the community of persons'."

This statement contains a strange view of motherhood! Surely a child requiring more maternal care and attention will elicit a strong parental response. Maternal attention is given in proportion to the needs of the child and not in proportion to some spurious assessment of moral worth.

In 1989, a balance sheet for an actual case of an adult with Down syndrome working in open employment demonstrated that the total cost benefit to the Australian taxpayer flowing from quality education services (to which every child in Australia should be entitled) is \$1.7 million per individual. This represents a saving in pension payments, fringe benefits, domestic support staff and tax payments made on his salary. In 1973, this option was just not available.

Obviously, the cost-benefit to society argument can no longer be used as a justification for abortion. In fact, if the proposals put forward in *The Lancet* in 1973 had been adopted, we would not know how much could be achieved by individuals with an intellectual disability.

The worth of a life saved is ultimately a value judgment involving ethical and social considerations. While conferences such as this can address these issues, there are too many variables and subjective judgments to make hard and fast rules. Therefore, a legal and ethical framework needs to be established in which people can make decisions that consider all the human factors of each individual case.

This framework should ideally contain guidelines relating to the extent of multiple disability which may deny any prospect of the child's ever living without constant medical support. A judgment on the fate of any individual must include the consent of both parents following extensive medical consultation and appropriate genetic counselling for the family.

The Netherlands is expected to prepare legislation to come into force in 1993 which will permit active euthanasia in:

"very rare cases where combined handicaps are so extreme that life is really too heavy a burden."

While these guidelines will be contentious, The Netherlands must be congratulated for at least having the courage to confront the issue.

In summary, we must now concede that times have changed. Many people with disabilities now face the prospect of living valuable and enjoyable lives, and many parents and carers can now share in that enjoyment.

At the same time, we must be prepared to confront the reality that some people with severe multiple disabilities can never share in that enjoyment, and that we now have technological expertise to identify these individuals early in pregnancy.

We must therefore have the courage to provide parents and professionals with the appropriate legal framework and the comprehensive genetic and social counselling to enable them to decide the fate of the foetus. And to those who choose, for whatever reason, to raise children with profound disability, we must extend the compassion and the financial and social support necessary to allow them and their children to confront their adversity with strength and dignity.

In a study released last Sunday in the latest Australian Medical Association Journal, a study on low-birth weight neonates carried out in the 1980s shows that the survival rate has jumped from 52% to 80%. The number of low-birth weight neonates with severe disabilities has dropped from 13% to 4% over that period. The researcher attributed these figures to better medical practice, and better educational and community support practices.

I mention this to illustrate how quickly progress has occurred in this area. For this reason, ethical guidelines must be able to adapt to advances in this area as well.

In conclusion, I would call for greater awareness and understanding from all professionals and interest groups towards people placed in such a stressful situation, and proper counselling and support offered to all families in whatever decision they make.