



A SELF HELP CENTRE

for People with Disabilities
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TO WHOM IT MAY CONCERN

INTRODUCTION

There are many issues related to Legislating Euthanasia. In this submission I focus on

- The area of disability because for many people to be “disabled” is to be “sick”. This makes people with disability especially open to being euthanized, a euphemism for “to be killed”.
- To use the word, “disability” is to bring to mind “inability” and that is applied to all situations. For example, many times, when accompanying someone with a vision issue, I am the one asked if the person would like tea or coffee, white with sugar. It is as though having a disability suggests that the person cannot make a decision, or that automatically their intellect is also impaired.
- In society, worth is judged by academic degrees, amount of income, kind of work that a person does, size of one’s house, boat or possessions etc. An alternative is to see the value of worth in the very gift of life of a person
- Vulnerable people including many people with disabilities want to please others.
- The scope of legislation “ending of life” will, if overseas experience is anything to go by, be expanded to the point that previous ‘safeguards’ are not sufficient to prevent abuse. In the proposals being discussed presently in Victoria there are already 68 risk safeguards to protect Victorians and health professional that have to this time being identified.
- Experiencing Community support contributes to understanding the meaning of life and the meaning of death.

My name is Mrs Barbara Harris. I am Co-ordinator of Emmanuel Centre, Self-Help centre with/for people with disabilities, their families and carers. I have been in this position for 36 years. I have shared the possibility of future Legislation in Western Australia around ideas raised in the proposed Victorian Bill with people associated with Emmanuel Centre. People with Disability and their families are really concerned about this proposal.

This submission addresses Term of Reference One by focussing on the capacity for authentic choice.

The Centre was established following Research for the International Year of Disabled Persons 1981 (IYDP)

DISABILITY, VUNERABILITY AND EUTHANASIA

We have grave concerns for people with disabilities and other vulnerable people in society.

We at Emmanuel Centre cannot understand that on the one hand society is beginning to accept that people with disability have worth and gifts to contribute to society, and on the other hand we are now thinking of Legislation that not only rejects the notion that all of life is worth living and that the community can assist people as they near death, but also says that people who are in pain, have no worth and should be assisted to die as quickly as possible. The proposed change in law suggests that society accepts that somehow pain is not a part of human condition and is to be avoided at all cost.

THE MOVEMENT TOWARD CHANGING THE PERCEPTION CAME WITH THE INTERNATIONAL YEAR OF DISABLED PERSONS 1981.

The overall focus of this Legislation was on the development of a person with disability as a worthwhile life.

The thrust of International Year of Disabled Persons 1981 was:

- Equalisation of opportunity
- Rehabilitation
- Prevention of disability.

This would result in a society of full participation and equality, defined as the right of persons with disability to take part fully in the life and development of their societies, enjoying life conditions like those of other citizens and have an equal share in improved conditions resulting from socio-economic development.

Other objectives of the year included

- Increasing public awareness
- Understanding and acceptance of people with disability
- Encouraging persons with disability to form organisations through which they can express their views, and promote actions to improve their situation.

IDENTIFYING OF SOCIAL ATTITUDES DURING IYDP

Social attitudes were identified as the major factor prohibiting full participation and equality. It is not unusual, even today, for a person to be given an identity through a label. Distinctions are made for funding programmes according to labels. This funding is for “people with mental health issues,” “for people who are Deaf,” “for people with autism,” etc.

My experience at Emmanuel is that people with disabilities have labels ingrained in their psyche about themselves. They also have generally learned that they need to be grateful so they want to please others by their decisions. A suggestion by a doctor, a support person, a “professional” to make a certain choice is accepted without question, and is seen as the right thing to do because it will please the “expert”. No amount of safeguards could be enshrined that would exclude all subtle influences over a vulnerable person apparently agreeable to their own euthanasia.

A MOVEMENT TOWARDS SEEING THAT DISABILITY IS NOT A FLAW

It is not my intention to address the overall positive impact of IYDP on the lives of people with disabilities, their families and carers. A direct result of IYDP 1981 is Legislation both at State level e.g. WA (1988) and Federal Legislation (1992) on the rights of people with disability.

These laws were directed at discrimination on the basis of physical, intellectual, psychiatric, sensory, neurological or learning disability, physical disfigurement, disorder, illness or disease that affects thought processes, perception of reality, emotions or judgement, or results in disturbed behaviour, and presence in body of organisms causing or capable of causing disease or illness (e.g., HIV virus). This Act also covers discrimination involving harassment in employment, education or the provision of goods and services.

I also refer you to the National Disability Insurance Scheme Act 2013 which highlights the shift in understanding the complexity of human beings and needs without categorising.

THE BIRTH OF EMMANUEL CENTRE

Emmanuel Centre came about as a result of Specific Research in WA. Response to a questionnaire and options for personal interviews highlighted that:

- Life is a gift
- Every person has gifts to be discovered by him/herself and by others and there is no hierarchy of the value of gifts
- Every person has gifts to share in an understanding of what it means to be fully human
- This discovery of gifts and sharing of gifts happens through contact of people to people.

The concept of Self Help in its purest form is an integral part of Emmanuel Centre. People come together :

- To get support
- To give support
- Learn skills,
- Interact with others
- Participate in community activities
- Make communal decisions
- Develop an understanding of humanity.

A MATTER OF CHOICE

The word “choice” is frequently referred to in debates of this nature. People say, “It is my life therefore it is my choice.” as though “my choice does not affect anyone else”. Every choice we make has repercussions for others. Just as our every breath affects the atmosphere so does our decision to die rather than live. Family, friends, the lady next door, the local shopkeeper is affected by decisions we make.

We did not have a choice to be born. That decision was made by someone else. Will the next legislation be that if I am not happy with my life I can sue my father for passing on his genetics to me? I have Factor V Leiden (Activated Protein C Resistance Genetic Disease in my lungs). As a result, seven years ago I made a choice I would live with this. This choice has impacted not only in the way I live but in my family and people around me. Prognosis by the doctors and professionals was that I would be dead within six months. I was then given the opportunity to be involved in experimental drugs and oxygen therapy requiring me to be connected to an oxygenator machine for nine hours per night. Seven years later, I am still working full time.

Our choices, because we are human, affect others. One must ask the question whether any of us can make an informed choice of euthanasia. I do not believe that any of us has enough knowledge to make an informed choice. There are too many things and circumstances that we cannot know now or in the future and our information is always going to be deficient and therefore unreliable.

MYTHS AND REALITIES

There are a number of myths about proposed Legislation on the freedom of an individual to End one’s life and ask for assistance to die.

- Myth: Assisted dying is an issue of personal liberty and personal choice

Reality: Over the lifespan of Emmanuel Centre, experiencing Community support has contributed to an understanding that we are not just individuals. Through people taking time out to live in community, life takes on a whole new dimension when lived with others. Living with others helps us understand the meaning of death as a part of the living process.

- Myth: Assisted dying is safe, easy and painless

Reality: Death and dying like birth cannot be scripted. No law or medication can achieve this including assisted suicide. Assisted suicide is not a simple procedure nor is it guaranteed to work instantly. Overseas data shows that there can be many complications, such as seizures. It may take several attempts and might need supportive medication to get rid of nausea etc.

- Myth: Euthanasia should be legalised because opinion polls support it

Reality: One cannot put faith in opinion polls even those that support a position overwhelmingly. For example, a developer put in an application for a liquor license for a commercial unit in a block of high rise flats. Residents in these units overwhelmingly supported the granting of a liquor licence based on convenience. The liquor and Gaming Board rejected the application noting that there were 213 liquor outlets in the vicinity and that convenience was not a criterion.

Finally, I share with you a true account of a “death with dignity”

Some years ago, a profoundly deaf woman from Ireland came to live in our Christian community housing. She used one handed Irish fingerspelling to communicate. She developed a friendship with an indigenous lady who had spent 45 years in a locked ward in a local psychiatric hospital before living in our community housing. The indigenous lady had fallen off a truck when her clan had gone walkabout. She had severe brain damage. They had an amazing friendship and were so happy to have each other and learnt their own ways of communicating. Both had severe and painful health conditions but were always beaming. The doctor wanted the deaf lady to go to a nursing home. She refused. We often wondered how we would be able to cope with her ever increasing needs. She always wore a hairnet to bed to keep her curls together. One morning she got up, took off her hair net, put on her best clothes and with a big smile on her face, died in the arms of her friend.

Gilbert Keith Chesterton once said that the Christian ideal has not been tried and found wanting. It has been found difficult and left untried.

The ideal that I am professing is in a similar category.

Life is a gift the beginning of which is beyond our capacity to choose. Every life and death is important and contributes to our understanding of the meaning of life and the meaning of death.

Barbara Harris

20th October 2017