Position Paper - “A Right to Life”
It was agreed at the 2006 Council Meeting that Self Advocates would develop material concerning some of the issues regarding their right to life and in particular their right to be born.

Robert Martin has spoken out on this issue many times and has drawn very strongly on the Convention on the Rights of Persons with Disabilities. He has been mindful of the use of language and has tried to set a middle ground without compromising the demand by people with an intellectual disability to have the right to be born on an equal basis to others.

At the 2007 Council meeting Robert presented the paper “A Right to Life” (see below) and it was agreed by the Council that it be adopted. It was also agreed to start operating the “Right to Life” as an official policy but in published format acknowledge that it is subject to the confirmation of the General Assembly in 2008. The Minutes of the 2007 Council meeting covering the discussion on this paper have been included for information at the end of the paper.

“A Right to Life”

1. The Convention on the Rights of Persons with Disabilities

   The preamble states:

   “Recognizing also that discrimination against any person on the basis of disability is a violation of the inherent dignity and worth of the human person”,

   “Recognizing further the diversity of persons with disabilities”,

   “Recognizing the need to promote and protect the human rights of all persons with disabilities, including those who require more intensive support”.

   The Convention on the Rights of Persons with Disabilities, Article 10 - Right to life says:

   “States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others”.

   The right to life assumes that a person with an intellectual disability has the right to be born on an equal basis to others. To deny this right denies the right to life itself.

2. Background

   Throughout history, persons with intellectual disability have faced discrimination, ridicule, denial of their human rights and rejection of their worth as human beings.

   They have been subjected to unlawful sterilisation and medical experimentation without their consent. Since the first eugenics laws were passed their right to procreation and all too often to life itself has been denied.
While there have been some recent temporary gains in their status, pre-natal testing has become the new threat to their existence. Reports show that when Down syndrome is found to be present during pregnancy, up to 90% of foetuses are terminated.

The argument is not about a woman’s right to control the number and spacing of the children they wish to have. There are national laws and ethical standards that guide these decisions. The concern is that there are few guidelines, based on ethical standards, to guide the decision as to who has the right to be born.

While the work to reduce those disabilities caused by inadequate health care, lack of immunisation, poor diet and lack of prenatal and postnatal care is clearly supported, this cannot be taken to mean that people with intellectual disabilities should be prevented from being born.

In many countries, people with an intellectual disability are being faced with a silent spring. Intellectual disability is being eliminated by the elimination of people with an intellectual disability from the human race through their termination during pregnancy.

3. **Recommendations / Inclusion International Action**

In solidarity with persons with an intellectual disability Inclusion International:

1. Affirms the value, dignity and worth of all people including those with an intellectual disability.
2. Advocates for the ethical and moral questions concerning prenatal testing and genetic engineering to be addressed both at the international and national level. Persons with intellectual disabilities and their families must be part of this debate and decision making.
3. Stresses the need for appropriate information, counselling and support services for parents when a disability is found to be present during pregnancy. This to include information on the value, dignity and worth of persons with disabilities.
4. Calls for greater education on disability awareness for parents and for those health professionals who are involved at either the prenatal or postnatal stages of child birth.
5. Advocates for improved early intervention services for disability so that parents will be aware of the assistance that can be made available if their child is born with a disability.
6. Demands that the presence of a disability during pregnancy must never become automatic justification for termination.

International Conventions and National laws must respect the right for a person to be born with a disability - on an equal basis to others.

Robert Martin
Chairperson of the Taskforce for Self Advocacy
Paper on “A Right to Life”

Robert introduced the paper “A Right to Life” that was scheduled for discussion at the meeting the following day and moved (seconded Quincy) that in solidarity with persons with an intellectual disability II:

1. Affirms the value, dignity and worth of all people including those with an intellectual disability.

2. Advocates for the ethical and moral questions concerning prenatal testing and genetic engineering to be addressed both at the international and national level. Persons with intellectual disabilities and their families must be part of this debate and decision making.

3. Stresses the need for appropriate information, counselling and support services for parents when a disability is found to be present during pregnancy. This to include information on the value, dignity and worth of persons with disabilities.

4. Calls for greater education on disability awareness for parents and for those health professionals who are involved at either the prenatal or postnatal stages of child birth.

5. Advocates for improved early intervention services for disability so that parents will be aware of the assistance that can be made available if their child is born with a disability.

6. Demands that the presence of a disability during pregnancy must never become automatic justification for termination.

Diane proposed the following questions relating to the paper “A Right to Life”:

1. Whether we want to accept the recommendation to adopt the paper?

2. Whether the paper becomes an official position of II and whether it should go to the General Assembly?

3. If it is accepted as a position paper, how do we move forward and implement it?

There was a great deal of discussion on the paper including the following:

- JP Gadkari outlined a different position saying that when a right to life is given you have the right to live and you must have the circumstances around you to sustain that life. Governments (States) must ensure that conditions do not apply that prevent a right to live – especially poverty and its consequences. The right to life is linked to the right to live.

- Ingrid thanked Robert for the paper and suggested that what we want is a strong paper that sticks to one topic, in this instance the right to life.

- Connie reminded the meeting that this was not a paper about the UN Convention and as such should not draw on the Convention.
Fred said there were two separate issues here, the right to life and prenatal testing. We need to be clear about the focus and define the right to life and need simplicity of presentation. Ingrid added that the second point “advocates for the ethical and moral questions….” suggests that we are not saying prenatal testing can not be done but that we will discuss it.

Haydee said that the medical person decides who should be and who should not be but all people are normal people. Mia read out a statement about giving people a chance.

It was agreed that the paper “A Right to Life” be adopted.

Moved: Robert Martin
Seconded: Quincy Mwiya

Diane asked the meeting to discuss the next steps now that the policy had been adopted and suggested that it was important to go back to members on the critical issues.

The following actions were agreed:

1. To start operating the “Right to Life” as an official policy but in published format acknowledge that it is subject to the confirmation of the General Assembly in 2008.

2. To write a letter to members explaining that the position was adopted by Council as a matter of urgency and to ask the regions to discuss the policy in preparation of the General Assembly.

3. To send the policy to official agencies such as the WHO.

4. To obtain (Desmond and Robert) further background information to the paper to use in a covering letter.

Ingrid suggested that Point 2 of the recommendations was rather broad and that we had to progress the ethical and moral question about genetic screening. Desmond agreed to undertake an historical search of material to assist in developing separate discussion papers. Diane requested the following:

1. For the Regional Representatives to nominate someone from their regions for a reference group to review the historical information and come up with a policy.

2. For Raquel to follow up with a memo reminding the Regional Representatives to nominate someone.

3. For Councillors to pass back to II the reactions of members to the policy.