**SUMMARY OF THE PROCEEDINGS OF THE IASSIDD ACADEMY WORKSHOP & ROUNDTABLES WHICH EXAMINED ASPECTS OF THE PAPER**

**“The New Eugenics”**

**IASSIDD: Academy Pre-Conference Workshop**

**The New Eugenics – Concerns, Arguments and Questions**

**Chair**: Trevor Parmenter

**Background**

* There is increasing concern in parts of the disability community that there is a quiet rise of the “New Eugenics”
* To date there has been limited debate or discussion of this issue within the academic or professional community concerned with IDD.
* This Workshop seeks to begin a dialogue on this issue.

**Aims**

* Provide an overview of the factual developments in ending the lives of human beings affected by IDD (Tim Stainton).
* Provide insight into different approaches to Quality of Life (Trevor Parmenter).
* Discuss arguments related to the key themes: neonatal euthanasia; genetic screening and selective termination; physician assisted suicide (Hans Reinders).
* Do these trends represent a “New Eugenics”? (Hans, Tim & Trevor).

**Inputs by participants (Group 1):**

* Is withdrawing life support a form of Euthanasia?
* Question of equality: that people with disabilities are able to ask for Euthanasia, how about people with disabilities? What are their rights in this case?
* How do you define the “end of life”?
* Legalised Euthanasia – that people with disabilities to be excluded?
* (In Singapore, we are looking at the assessment of mental capacity of the people with severe intellectual disabilities but can the tools for assessment provide an accurate measurement of the mental capacity in terms of the PWD ability to understand and express their choice? Will the proxy be able to express the intention of the person with intellectual disability?
* QOL looks at the achievements, does it apply only to people with mild intellectual disabilities.
* Self-determination & Life that is not worth living?
* Euthanasia -ending of life administered by the doctor by the patient’s request.
* Trends towards intervention for social ends than medical reasons.
* Economic argument – how much money we want to spend on the people with disabilities?
* Lack of disability support is causing the “suffering”.
* Doctors made decision for example, tube feeding for the PWD but did it improve the QOL of the PWD?
* Complex issues with regards to having a proxy to represent the PWD especially for those PWD with high support needs, how do we understand their choice? For children below a certain age, parents act as their proxys with regards to, for example, medical care
* Do we advocate for “no screening”, as conditions such as the prevalence of thyroxine levels can be a serious problem to the baby if it goes un-checked.
* Standards and principles led by genetics
* Families would like to have more help on how to help their children learn.
* More nuance around genetics
* Consider thoughtful contribution
* Introducing the new Eugenics will capture people’s attention
* Scientists devote their time to discover a whole range of injections to prevent and take away some diseases (through immunisation)
* How the views and attitudes of the community change over time?
* Abortion laws does not protect the foetus. Abortion is carried out below 24 weeks and is allowed beyond 24 weeks if the foetus has an abnormality. A moral concern that the child with disability is not valued.
* <https://sg.theasianparent.com/abortion-in-singapore> there is no defined age limit for an abortion. No legal requirement for minors under 21 for parental consent. anyone may request for an abortion, as long as they are of sound mind and body and understand the risks and details of the procedure.  Do not need consent from anyone.
* An awareness what is acceptable.
* Instead of curing them, we are letting them die sooner.
* The EAS – more clarity in the proposition (especially in assisted dying and laws supporting it)
* Different themes and values are emerging which are not peculiar to end of life discussion and issues.
* It is valuable to discuss issues on discrimination.
* Legal and ethical issues.
* Problems of terminating a life?
* Danger that people with intellectual disability are led to end their lives, are we getting rid of them?

**Inputs by participants (Group 2)**

* -Strategically wise to go into the discussion on the New Eugenics.
* Slippery slope – correct and is always true because of changing times
* Who do you want to convince?
* Nuances are missing in the paper
* Cultural dimension
* Is it a lifestyle choice?
* Technological advances made possible lives that would not exist some decades ago.
* In the beginning, parents have more choices about the child’s life than later on.
* Social answers to suffering, including physical suffering are not always enough. Some suffering will endure even when care is improved.
* Good Genetics instead of new Eugenics
* Who is the audience of the messages of the paper?

**Roundtable: PIMD & Ethics SIRGS**

**The new Eugenics - Can persons with intellectual and multiple disabilities be happy?**

**Chair:** Bea Maes

**Purpose:** Discussing the scope of the argument against the new eugenics. While moral concern about ending human life affected by IDD may be widely shared, a different position can be taken regarding the lives of PIMD. Must we consider their lives in a different way?

**Rationale:** The new eugenics is criticized for its assumptions regarding the QOL of persons with IDD, the assessment of which is said to be too heavily dependent on medical prognostics. Does this position hold for the group of persons with PIMD?

**Summary:** Ending the lives of newborn children whose lives will be affected by IDD in neonatology is a growing concern. Moral justifications for these acts advanced thus far focus on the prognosis of severely disabling conditions of premature born infants, claiming that they will have a life full of suffering from their severe conditions. The implications of this position for persons with PIMD will be discussed.

**Introduction by the speakers**

The speakers were asked to formulate an answer on the question: Can persons with intellectual and multiple disabilities be happy?

Harald Goll

Harald stated that the worst case of having an intellectual disability is anencephaly. These children have no brain and have a very short life. For both children and parents this leads to suffering, so elimination of the child would be best for both. Although, not all parents do agree because the child has a positive impact on the lives of these families. There experiences are not different from other parents having a child with a disability and the child gets a name and place in the family. Especially mothers develop a strong relationship with the baby.

Conclusion: Bad medical condition does not necessary need to a bad life.

Tim Stainton

Tim indicated that this is a stupid question, because it assumes that the group of persons with PIMD has no unique experiences. The real question we need to ask is: how do we come to this question? There are underlying assumptions that people with a disability have no prospect and suffer, so they cannot be happy. Moreover, we must eliminate the suffering as much as possible. So it is our moral duty to eliminate persons with PIMD because it is our moral duty to eliminate the suffering …

Conclusion: The focus must not be on the question ‘can they be happy?’ but must be on the underlying assumptions which lead to this question.

Roy Brown

Roy stated that the nature of humanity and the nature of disability is not understood by everyone. When thinking about the central question the interplay between environment and disability is critical. The principles of quality of life [(1) Dignity of disability, (2) Ethically base policy and practice, (3) Personal and professional values, (4) Duty of care, (5) Normalization, (6) Exclusion/inclusion, (7) Resilience, (8) Perception (need for information about disabilities in the community, (9) Self-image, (10) Empowerment, (11) Personal control, (12) Inter and intra personal variability, (13) Life domains, (14) Holism, (15) Imagining the future, (16) Lifespan, (17) Opportunities and choices] are issues we need to think about with the person with a disability, but also with their families because how can they function if they don’t have the resources.

Conclusion: It is our responsibility to make the community more aware about disability, only in this way major changes are possible. In this the feelings of the person and parents are relevant. We need to provide them with information so they can make up their own minds

Marga Niewenhuijse

Marga stated very clearly: yes they can be happy. Although, she raises other questions: Can we predict in just born children what quality of life they will have? Some parents do have serious concerns about the quality of life of their child. Can we decide about end of life in a different way than based on the quality of life?

Conclusion: We need to dare to ask those questions.

**Discussion**

*Can people with PIMD be happy? Do persons with PIMD have a valuable life?*

The four speakers all gave a very clear answer: yes; or they even stated it is a stupid question.

* A parent indicated that people with PIMD indeed have a life that is valuable and worth living.
* Someone states that the term ‘new eugenics’ is confusing because it seems to devaluate the ‘new genetics paradigm’. The new era of genetics brings new possibilities and makes proactive and positive interventions possible. We can now identify reversible conditions. He indicates this may become a game changer in the ethical debate. New genetics gives raise to new developments, new ethical challenges, new possibilities of prevention. This enables parents and frontline carers. Eugenics and genetics are not related. Eugenics are unrelated to science.
* One of the panel members reacts that there will still be changes and stress for the parents at home. We need to enable them in order to function at home and find ways to train professionals. There is a need for multidisciplinary work in providing better circumstances to raise children with an intellectual disability.
* Another panel member agrees on the importance of the questions and dilemma regarding the potentially reversible syndromes, but indicates it is just one thing. Not everything is or will be reversible and the responsible genes or causes for every disability will not be found.
* A professional pointed to the importance of focusing particularly on the group of persons with PIMD. Their questions and concerns are not comparable to those of other groups with an intellectual disability. She raises the question: would we choose not to prevent or reverse a syndrome or disability, if we could? She can’t see why. Why are we frightened to discuss prevention? She does not doubt that persons with PIMD can be happy, but asks would we not want them having even a better quality of life?
* Someone indicates we need to value people for who and what they are (e.g. deaf people see themselves as minority). She states they can be happy and we need to look at conditions that even maximize their happiness. At the same time, she states that she personally would go for any treatment she could. This does not mean that you don’t respect people for who they are and what they are.

In summary: They can be happy and can have a valuable life and we must look for conditions that maximize their life quality as much as possible. Prevention does not implicate that we are saying that their life is not valuable. All human beings deserve respect.

*Although we say they can have a good quality of life, parents may have concerns about the quality of life of their children.*

* A professional stated that it is difficult for parents to express that they doubt the quality of life of their child. We have to be open to the emotions and suffering of parents, and give space for their concerns. Quality of life is a value. Parents indicate that they trust people who know their child very good in evaluating if the life of their child is of good quality.
* A professional indicates that when you do not look at these emotions of parents, you cannot have a good relationship with them. Also, if people with PIMD have valuable lives, we need to make space to talk about these concerns of parents.
* Someone indicates that we as professionals have our normative views, although we need to talk to people without our presumptions. People with PIMD can be happy, but are also suffering or in pain, which may be horrible to watch for parents, so they may have doubts. If we could lose our normative views and values, and listen to the experiences of parents, this would be helpful in the discussion.
* Some parents feel guilty for not having done prenatal testing. Medical doctors sometimes say unhelpful things to parents. Many people in the community don’t see that persons with PIMD can have a life of good quality and put extra pressure on parents.

In summary: We should be open for concerns of parents about their child’s quality of life and raise community awareness.

*What about the public awareness about the quality of life of people with PIMD?*

* A panel member indicates that there still are a lot of negative attitudes about what persons with an intellectual disability are able to. We must enable families to make their own decisions, not doctors social workers,…. because they are not there on a day to day basis.
* Quality of life is not always the only argument in ending life. Parents may also indicate they are not capable to take care. We cannot decide for people with PIMD, because they have never had a voice in this discussion. Euthanasia is often no option for persons with PIMD, because they cannot consent.
* Using photo/video to show what the life of persons with PIMD is about, can be powerful.
* We need to broaden this to a societal issue. Not every family can cope with the support needs of the child with PIMD. It is a political reality that there is a battle for the resources allocated to provide care for the children. It is not us you need to convince that they can be happy and not only public awareness, also policy and politics.

*Recommendations?*

* We should be very careful in terminology: new eugenics, eugenics, new genetics … using words that put people or arguments in a negative or emotional perspective, does not help the debate. Attacks using words as ‘eugenics’ do not advance the debate.
* We need to respect the integrity of anyone who takes a position in this debate. We do not need new normative positions.
* There should be support for parents to provide evidence that people do have valuable lives, but we should also be open for their concerns. Give them space without the feeling of being judged. Some aspects of ethics may be at risk of denying personhood.
* The importance of raising public awareness is stressed.
* Parents should be part of the debate. Consulting parents about this issue should be done with the utmost sensitivity.

**Roundtable: Quality of Life, Health & Ethics SIRGs**

**Chair: Trevor Parmenter**

**Title:** The new Eugenics - What QoL do we want for Persons with IDD? Health-related, Service-related, Holistic?

**Track:** QoL SIRG in cooperation with Health and Ethics SIRGs

**Purpose:** The key argument in justifying ending human life affected by IDD depends on assessments of prospective QoL. The purpose of the discussion is to consider how diverging conceptions of QoL impacts the key argument of the new eugenics.

**Rationale:** The history of QoL research shows that diverse and contrasting approaches to the concept of QoL have pursued different interests. Medical prognostics for living a life with (severe) IDD as indicating Health related-QoL have been advanced to justify ending human life affected by such conditions. The question is whether the QoL of persons with IDD in the context of human services warrant the rejection of this justification.

**Summary:** The moral evaluation of ending human life affected by IDD hinges on how considerations of (future) QoL for the persons involved and their families. The discussion considers whether diverging approaches to QoL may lead to other conclusions.

**Introduction by the speakers**
Alice Schippers spoke about the mountain of normalcy and able-ism.

Ivan Brown spoke about the fact that professionals and caregivers make judgements for persons and that is not good as there is poor correlation between subjective and self-ratings of QOL. He mentioned that the gap is that the scales are made up by academics who do not experience it as persons with IDD do- persons might have very different criteria of QOL  so we need to understand what is it that is important to them.

Hans Reinders spoke about need to look at how we research QOL in people with ID.

Laurence Taggart spoke about how health professionals determine QOL of persons. Hence, there is a need to train professionals to support parents. He also mentioned that recognising contributions persons with IDD can make is important.

**Open discussion-**

- are we going to condemn what doctors are doing as medical might be suign different idea of QOL than disability world?

- Should not assume that if you have ID you will have poor QOL.

- Important to consider women's rights to do what they want.

- It is more about not telling people what to do but giving people a structure to make a decision.

- There is a need to define what is intelligence.

- Early intervention reinforces the notion that we need to make them 'more normal'.

- It is important to ask what dissatisfaction is, instead of what you are satisfied with.

- There is a need to include people with ID in discussion about such issues.

**Roundtable: Down Syndrome and Ethics SIRGs**

**Title**: **The New Eugenics – Is Down Syndrome a Disappearing Condition?**

**Chair:** Rhonda Faragher

**Track:** Down Syndrome SIRG in cooperation with Ethics SIRG

**Purpose**: New technologies in genetic screening and testing have brought standardized routinization of testing for Down syndrome much closer. The discussion will assess the prediction that this means the condition will disappear.

**Rationale**: the issue is addressed as part of the eugenics project initiated by the Ethics SIRG, part of which is to engage medical assessments of living a life with Down syndrome.

**Summary:** Emerging routinization of ‘non-invasive prenatal testing’ on Down syndrome is resulted in extreme low incidence in a few countries. Based on recent data the question will be discussed whether these examples are foreboding a future trend or whether they are exceptions to a much more diverse picture.

**Introductions by speakers**

Hans Reinders highlighted the impact of advances in technology and Public Health Policy

Rhonda Faragher presented an Educator’s perspective, highlighting the achievements of people with Down syndrome in education, employment and community living.

Tonni Coppus spoke from a medical approach and emphasized it is parents’ choice. Doctors’ role is very small. Emphasized the concept of “Lives worth Living” for people with Down syndrome. The discussion requires the provision of information in order for informed choice.

Roy Brown suggested the journey from the “Old Eugenics” to the “New Eugenics” is a continuous process. He presented the concept of ancient views in modern times, pointing out examples of religious views such as a Canadian Anglican Synod report (later withdrawn) that “people with Down syndrome could not be considered fully human”. He also drew attention to the need to compare objective and subjective measures of Quality of Life (with an emphasis also on Family Quality of Life) and the importance of observation and assessment in a familiar environment.

Sue Buckley questioned whether the prevalence/incidence of Down syndrome is going down. The ageing process has increased prevalence. Despite improved services some families really do struggle (Cunningham reported 25% in a 1988 study). Are doctors too negative and the community too positive? She drew attention to the Nuffield Ethics Report. Sue advised we should not exaggerate the positives of a life with Down syndrome- it helps no one.

**Discussion comments**

Sue’s presentation was challenging. Should Learning Disability Nurses be involved in screening? Development of a leaflet on foetal anomaly screening. Issues of false positives and false negatives e.g case of breast cancer screening. Doctors have a responsibility to convey messages parents can understand. Down Syndrome Scotland has produced materials to inform all practices. Women are able to make choices. Questions were raised whether the White Paper challenges women’s rights. Why is the issue on the table? It’s not about disability rights. Are people being given accurate information? Response: We are trying to give the best information possible. But accuracy of information is paramount. The decision is not only for mothers- fathers and other stakeholders do have a role in the decision making, But it is the mother’s body.

**Roundtable: The New Eugenics - What Do Families Say About Ethics and Quality of Life?**

**Chair:** Tim Stainton

**Track:** Family SIRG in cooperation with QoL and Ethics SIRGs

**Purpose:** The prevention of disability through genetic screening and selective termination is justified on grounds of expectations of QoL for the disabled child and the family. The focus is on assessing such expectations.

**Rationale:** the issue is addressed as part of the eugenics project initiated by the Ethics SIRG and seeks to engage expectations about future QoL of persons with IDD and their families from other disciplines than medical prognostics.

**Summary**: Family experience frequently has challenged medical prognoses of ‘poor quality’ in that the person with IDD achieved a level of performance clearly exceeding what medicine predicted to be possible. The discussion will assess that challenge.

**Introduction by speakers**

Tim Stainton:

Tim outlined the main arguments contained in the lead article in the Journal special issue, as well as presenting his perspectives as a parent of a child with a disability.

Alice Schippers

Alice presented the topic 'Quality of Life: changing the lens', trying to bring forward that there is a 'social tyranny of normalcy' and that people with disabilities and their families feel confronted by these norms, imposed on them and not being able to live a 'normal' life.

Alice showed the short video trailer of Andrea van Beek, a soprano and mother of two children with profound disabilities. She recorded sounds made by her second son Jim and performed a 'moving duet'. One of the striking texts in this performance says: 'If I could've prevented it, then I would've prevented it', illustrating the above.

Sandy Magana

Sandy’s comments drew upon a paper recently published in the “Stateman” written by a mother with a son with Down syndrome who stated:

*...noninvasive prenatal tests have become a contentious flashpoint in the abortion debate. Lawmakers in Texas and other states have filed bills, such as House Bill 2434 and Senate Bill 1033, to stop fetal termination as a result of a Down syndrome diagnosis. In response, more individuals are coming out publicly to state their belief that a majority of Americans would terminate if they received a prenatal diagnosis. While articles discussing the validity of a child’s existence are offensive, termination of fetuses with Down syndrome is widespread. In fact, in the United States, research suggests prenatal screening leads to a third fewer individuals with Down syndrome.*

*I am an ardent believer that there is an ethical case for having a child with Down syndrome, but those bills in Texas and other states will not eradicate the bias held against Down syndrome. Instead, public and medical profession education is needed to demonstrate that individuals with Down syndrome are as worthy of life as everyone else.*

*There are numerous explanations for reluctance in bringing a child with Down syndrome into the world. The most reported explanation is a sense of loss of the child who will not meet the conventional expectations of a good life. This hesitancy is not surprising. Nonetheless, that pressure for perfection can be a strong motivation for parents to choose termination. I understand the emotional turmoil of discovering your child may be different from how you imagined, but the reality is life is not much different from how it would have been.*

Trevor Parmenter

Trevor outlined problems associated with assessing quality of life with traditional instruments, especially that of people with high support needs. On what basis do people predict that a person’s quality of life is not going to be satisfactory. How do people giving advice to families know that their life will be one of continual hardship? Do these people rely upon anecdotal impressions or upon factual research?

Ivan Brown

The new eugenics assumed people with ID, and presumably their families as well, have poor quality of life, however, the data we have to date does not support that view at all.

Based on Bob Cummins extensive research, the "average" person rates life satisfaction, which is arguably a very similar concept to quality of life, consistently 74-76 on a scale of 0-100. We do not know if families rate their life satisfaction in a similar way, but assuming they might do so, we can at least get a strong suggestion from looking at their Family quality of life ratings. When these are transposed to a 0-100 scale, the results for various countries, ranged from 68 to 78. This suggests the families may not rate their own quality of life much differently from the way people in the general population rate their life satisfaction.

Cummins' "golden triangle of happiness" which is his three factors that contribute most to life satisfaction: relationships, financial security, and meaningfulness. Looking at similar domain scores in family quality of life, we see that families rate Family Relationships very high, Values and Careers (which might be indicators of meaningfulness) as about Cummins' average, and Finances as lower. These three things dig down a bit into the overall FQOL ratings, to suggest that families seem more satisfied with their family relationships and less satisfied with their family finances than the average (person) from Cummins' work, but on the whole it is very difficult to even suggest that they are viewing their lives as more negative that non-disabled people.

**Discussion comments**

Differential approach re the murder of a child- more sympathy for a family if the child has a disability. Undervalued life of a person with an intellectual disability, Role of Unitarianism and the moral framing of the question- disability is just different as disability = suffering. The issue of normalcy- families have to work to show their quality of life is better. Would I want my child to be different? – a higher level of normalcy must be shown. My daughter gets privileges owing to her disability. The debate is not pro or anti-abortion. We should have more information for young couples re possibilities of the future life of a person born with a disability.

The role of the media in a continuation of stigma. Why do people with an intellectual disability die earlier? Neonatal Departments have shown little change in attitudes over the years. It’s not just syndromic. People are impacted by the birth of a child with an intellectual disability- is it a myth? The debate is unbalanced- most abortions are of foetus without a disability condition. There is a need for freedom of choice- families do take the situation seriously. Will we restrict families from seeking a cure? It’s not an either /or question. Families have to prove hardship in order to get support.