



**World Intellectual Property Organization and Life Sciences Symposium on
Intellectual Property and Bioethics
A civil society perspective
September 4th 2007**

Introduction

The world's newest nation, Timor Leste is a place I know quite well as I used to work in Timor for Caritas Australia, the Catholic overseas aid and development agency. In more recent years, while working for the Franciscan Friars, I initiated several small agricultural programs in the southern part of the island where Franciscans have been engaged with local people since the early 1980s. The larger international community to which we all belong knows that because of the extreme violence - before but especially after the referendum of August 30th 1999 – many, many people were driven from their land. Perhaps what is lesser known is that in the years prior to the violence, Timor Leste experienced a severe and prolonged drought. For successive years, seeds were not planted due to social dislocation, or planted in poor soil with little rain, or gardens were toiled sporadically. When things finally started to settle down, often people who had been displaced by the conflict returned to their land to find that it had been taken over by others.

Our time today is short and while many, many descriptions and explanations could be given about this situation, let it suffice for the purposes of this discussion to use this brief story to indicate two very different approaches to food security in Timor Leste. One approach saw farmers buying Genetically Modified rice seed from large international companies. The modified rice, they were assured, would produce bigger yields; particularly if used in conjunction with such and such brand of fertilizer that had been made especially for *this* rice seed.

The other approach to food production and food security might be called the organic approach that uses more traditional and indigenous farming techniques. Techniques which, by the way, we are not proposing to leave as static realities as they often produce insufficient food for many families. Hence there has always been a time every year in Timor known simply as the 'hunger season'.

The story line of the two different approaches is familiar enough to all of you and at this stage does not need further elaboration.

As time is of the essence, I do not want to exhaustively compare the two approaches. Rather, I see them as an appropriate starting point for civil society agencies such as Franciscans International. Why? Civil society agencies ought always to base our activities, and our development of conceptual frameworks for public policy, on the *experience* of local people and local ecosystems.

Our task– to develop a conceptual and ethical framework in which to address questions of intellectual property and bioethics policy development – must begin and end in the *experience* of 'ordinary' people. Their experience - our experience – not only becomes a lens through which we discuss or evaluate inventions, interventions,

patents, licensing regulations, or even the Universal Declaration on Bioethics and Human Rights. Their experience becomes our *goal* or our end. We hope that whatever we do at the ‘pointy end’ of policy development in Geneva makes a qualitative difference to the current and the future life experiences of ordinary people. Thus, we propose to look at intellectual property and bioethics issues through a broad conceptual framework that *connects* and then *articulates* the connections between human rights, peace building and environmental integrity.

As will become clear today, the perspectives of Franciscans International are grounded in the reality of ‘ordinary’ people as well as in the local ecosystems in which vulnerable communities live. Our particular emphasis on peace building provides us with the tools not only to think about how conflicts that erupt over inequitable resource management might be transformed, but how they might be prevented from happening in the first place. Therefore the perspective offered by Franciscans International is, I hope, a conceptual framework rooted not only in philosophical and scientific theory, but also in an inclusive and connected spirituality, and an engaged praxis which springs from the field.

Within our broad framework, there are three guiding questions that inform and motivate our participation in, and our evaluation of intellectual property and bioethics practices, procedures and policies:

- Does this action, invention, practice, protection of intellectual property help us to not only *consider* the dignity of the most vulnerable in society but to *privilege* them?
- Does this action, invention, practice, protection of intellectual property help us bridge the knowledge, technology and resource accumulation gap that separates the ‘north’ and ‘south’? Or more simply, does it lessen the potential for conflict?
- Does this action, invention, practice, protection of intellectual property help us to live sustainably on the planet in this generation - and the next?

With such questions providing an ethical imperative for our involvement in the conversation, we then propose a cyclic methodology to guide our work. The methodology proposed has four modalities, modalities which are similar to those used in the sciences: *observing; thinking; judging; and then acting with responsibility*. Civil society agencies such as ours will, however, engage these modalities from a different platform than that of our scientific and law colleagues and we will therefore generate questions and insights that are reflective of our distinctive role in the international conversation.

Observing

This modality suggests that civil society agencies must have a strong research orientation. Our research must be empirically based on the *experience* of local people. In keeping with our 800-year-old tradition, the members of Franciscans International live and work among ‘ordinary’ people in communities that are the most vulnerable and most at risk of exploitation. But civil society agencies such as ours want not only to observe ordinary people but also observe local ecosystems. In the case of Timor Leste, our *modus operandi* means that we observe *all* experiences of local farmers - that is, farmers who use the GM products AND the farmers using the organic

methods, AND also the farmers engaged in other traditional practices. Our comprehensive research thus prompts us to inquire about the impact of various practices on local ecosystems. Having gathered data, we invite grassroots Franciscans from the field to feed that data to their NGO headquarters- in Geneva, New York or Bangkok.

The observation modality also suggests, as is clear from our participation in this conversation, that our research must be cognizant of what's happening in other arenas. We must be skilled and authentic observers and data gatherers in related fields such as biotechnology, or inter-governmental debate on intellectual property. Also, as much as NGOs can, we should acquaint ourselves with what's happening or going to happen in Trade Related Intellectual Property discussions.

Within a conceptual framework that has an ethical imperative such as ours, observation will mean that we may eventually have to be the voice of these communities in public policy debate – therefore our observations better be good! Clearly this implies an obligation that our research is sound and professional, and that we build the capacity and skills of our members in the best practices of observation, data gathering, and forensic evidence collection. In 2008, a key focus of our environmental work will be on the provision of training and technical assistance to Franciscans so that they might engage more effectively in people-centred ecosystem analysis and management. We will begin this program in the Asia Pacific region through our new Bangkok office but we hope to broaden such technical assistance to Franciscans in Latin America and Africa in subsequent years.

Which moves us to the next modality in the cycle.

Thinking

We know that raw data collection is necessary but it must be analyzed carefully in order for us to make evaluative assessments about what's useful and what's extraneous. In other words, the capacity to *think* and to think carefully about the facts before us is essential if civil society agencies are to enter the debate in meaningful ways. But the capacity to think, for us, must be enlarged to include not only scientific thought but also social, economic, cultural and political thinking.

The capacity to *think*, to really think and not just act, is what the great German Jewish political philosopher Hannah Arendt called the most crucial dimension of 20th century politics.¹ And in her estimation, the lack of this dimension in the lives of ordinary people and political policy making was what caused even 'good' people to abuse science and technology to throw fellow human beings into ovens or to throw an atomic bomb onto civilians. The examples, in this context, can appear extreme. Yet Arendt's argument is that such tragic collisions between technology and politics are not unique but are, unfortunately, repeatable, especially if thinking is left to technocrats and policy makers who are disengaged from the lives of ordinary people. The situation is compounded of course when ordinary people take little responsibility to engage in thinking or when they feel so disempowered and disconnected from their governments that thinking is left to specialists.

¹ Cf., Young-Bruehl, Elizabeth. *Why Arendt Matters* London: Yale University Press, 2006

This is an enormous challenge for policy makers and civil society agencies alike.

The practical consideration or lesson that we take from political philosophy then is that the sort of thinking that is required in the conversation between intellectual property and bioethics is qualitatively different from the *calculations* that are in the tool kit of scientists, lawyers, and technocrats. Calculation of risk, financial management, and cost benefit ratio in which biotechnology companies and others rightly engage is necessary. But calculation such as this is inadequate to the conceptual task facing civil society agencies as we attempt to analyze the data or evidence collected from the experience of ordinary people in local ecosystems. Beyond analysis, our task has to be to find ways of disseminating information so that ordinary people in local ecosystems will *think* about the consequences of what's happening around them.

In this second modality, civil society agencies attempt to *think* through the data gathered and then ask, whose voice is not being heard? Who has been neglected? Whose experience has not been examined? Who exactly conducted the research in the Papua New Guinea highlands? Was a price paid to the entire community for access to their knowledge or was the Chief the only one who received 20 pigs? Was prior and informed consent *confirmed*? By whom? What monitoring and evaluation of benefit-sharing has occurred to substantiate arguments? *Where* are HIV drug therapies being tested and why? What can 'informed' mean to people who are terminally ill with HIV and AIDS related illnesses and yet who long for a cure for themselves and their children? In the patents that have been granted recently, is a pattern forming in ownership and degrees of restriction? Who is resisting – and why? In medical research, what's the impact on the availability of new therapies to the 'developing' world? When debt is compared between the farmers in Timor who bought the GM seeds with the farmers who engaged in organic techniques, which farmers ended up in greater debt? Who is debt free? Who has better food security in the long term?

Good quality thinking by *trained thinkers*, rather than the undisciplined or exclusive thinking of those isolated from the reality of people's lives, has the capacity to see connections and inter-connections, and therefore it starts to become reflective – and patterns emerge that will help us make decisions.

Judging

The third modality in our cyclic methodology is that of judging. Judging can be a mysterious process, one that philosophers and psychologists acknowledge resists easy definition as modes of coming to judgment vary so much. But what we do know, even intuitively, is that judging always precedes decision, even if by a split second of insight, or by a long process of consultation and argument. So, much of what we hope to achieve in this modality is about the movement towards a practical decision. A further point of clarification may be helpful at this point, and that is that the judging in which civil society engages, is not of itself pejorative, meaning it's not necessarily *judgmental*.

When civil society agencies engage in a process of judging the facts that have been observed and analyzed, we engage in a *reflective* process that is geared towards the inclusion of different experiences and different perspectives.

In this modality, philosophical and ethical principles help us to further decipher the experiences *within* the global community of the neglected, while discerning the alarming patterns that separate the neglected from the over-resourced. For example, for Franciscans International, our judging will be motivated and shaped by the principle of solidarity that is, the principle which evokes in us an intellectual commitment to and empathy for those who are most dispossessed and disadvantaged. Solidarity for us will determine a practical preference or choice for the most marginalized communities - not because we feel sorry for them but because we genuinely acknowledge, at the intellectual as well as emotional level, the profound and multiple interconnections of humanity. The ancient Stoics referred to this sense of connectedness as *oikeosis*. Today, the principle of solidarity challenges us to think in an ever-expanding way about our connectedness, not only to human life, but also to all life forms and to the planet itself.

Civil society agencies such as ours will look to the UDBHR, specifically to Article 3.2, and will note with alarm that the principle states an unhelpful dualism by stating that “the interests and the welfare of the individual should have priority over the sole interest of science or society”.² We are alarmed at such dualistic thinking for, in our opinion, the principle of the common good is a sophisticated and nuanced principle allowing us to fully acknowledge the dignity of each and every human person within “society” *and* within humankind. How might this concern play out for us in a practical way? For us, human dignity and the common good are not an either or choice; when it comes to making prudent decisions in the life sciences and intellectual property, civil society agencies such as ours will attempt to promote that which we believe enhances rather than detracts from the integrity and authenticity of created entities. We may not want, for example, to blindly accept a novel application of a therapy derived from a new discovery in genome sequences but will rather be interested in seeing whether or not the proposed application advances both human dignity and the common good.

Our judgment will also be shaped by the principle of subsidiarity – a principle which tells us that decisions in bioethics and intellectual property ought not only to be made at an appropriate level of industry but at the lowest level possible so that the public can share in the process as much as possible. Common sense suggests to us that the higher the level of the decision-making, the more likely it is to be removed from the ‘ordinary’ people. Subsidiarity is a principle and a practice which also gives teeth to the notion of transparency.

Traces of the principle of subsidiarity can be found, I think, in the principle that guides much of the public policy debate in the life sciences that is, *ordre public*. There are echoes too of Kant who urges us to move from decisions made in *sensus privatus* to those made in *sensus communis*. Or in other words, from individual decision-making to the decision-making that occurs within the community. When

² Extract from the Universal Declaration on Bioethics and Human Rights in ‘Bioethics for the World,’ European Molecular Biology Organization, Volume 7, Number 4, 2006.

thinking about scientific discovery and invention in the field of the life sciences – we must be aware of the importance of moving judgment and decision from the laboratory of the individual scientist in the closed circles of a company, to the open and transparent dialogue between technology companies, law firms, the civil society agencies and governments that help constitute the international community.

To conclude our thoughts on the modality of judging and deciding, we must turn, even briefly, to the thorny area of the conflict between competing rights-holders. For civil society agencies within the Catholic social justice tradition to which Franciscans International belongs, the thinking about competing rights has reached a point of development where we can offer the international conversation three fundamental principles:

- The needs of the poor take priority over the wants of the rich;
- The freedom of the dominated takes priority over the liberty of the powerful;
- The participation of marginalized groups takes priority over the preservation of an order which excludes them.³

It is our role and responsibility to bring these principles into play in all decisions about bioethics and the intellectual property system.

Critiques which begin in experience and which are sharpened by logic must be influenced by principles if they are to be responsible. And so this takes us to the fourth modality in our methodology.

Acting Responsibly

It can be tempting to think that many actions in a laboratory is value-neutral but when the methodology reaches the point where policies have been formulated - based on good observation, exhaustive thinking, and sound judging - then the action that follows must be *responsible*.

Responsibility in this sense carries with it the strong belief that the ‘do no harm principle’ applicable to medicine and humanitarian aid delivery is not sufficient for today’s bioethics and intellectual property issues. Rather, it is the pursuit of a concrete good that must define the objectives of our programs. The copyright which has been granted, the clinical trials that have been concluded, the patents that have been taken out, or the licenses that have been restricted ought to have a real life application that can be translated into therapies and vaccines, or seeds and fertilizers that have a positive impact on the poor in local ecosystems. Responsible action will imply a timeframe beyond the immediate moment and immediate generation. Sustainability is a principle, yes, but it must be monitored and evaluated over time and space and hence it’s an essential dimension of the civil society that wants to act justly and responsibly.

³ cf., Hollenbach, David SJ, *Claims in Conflict: Retrieving and Renewing the Catholic Human Rights Tradition*. Mahwah, New Jersey: Paulist Press, 1979

Responsible action, intelligently conceived but with a compassionate impulse, can be perceived and judged by the senses and will be known by its fruit: poverty reduction, human rights, peace, and ecological integrity.

Conclusion

Within the intellectual property and bioethics policy conversation and deliberation, which usually occurs between the science laboratory and the philosophers, between headquarters and the field, civil society argues that it is necessary to open space for the concerns and the participation of the people, so that an enlarged circle or expanded world view can begin. This space will have as its core the dignity of the human person and the common good, with an orientation to radical responsibility for those who are most vulnerable. It will not see the poor as a consideration nor as an interruption, but rather, as the ones for whom this research is undertaken. For civil society advocates, the conclusion is clear: the experience of vulnerable communities will be privileged in policy formulations.

Civil society agencies' contribution to the conversation between intellectual property and bioethics will be concerned with enhancing human rights principles and standards and environmental justice principles in the international arena. For us to do this is necessary because the State parties which should usually construct national bioethics infrastructures are often, but not always, those with dubious to appalling human rights records and at whose hands poor management or exploitation of the ecosystems and biodiversity are the rule rather than the exception. A strong and dynamic intellectual property system which deliberately draws upon the internationally agreed human rights standards, the bioethics systems and the Millennium Development Goals would be a positive contribution to bringing coherence and consistency to the dialogue table. Such a contribution, which pushes for and expects compliance to *laws* rather than principles would be an invaluable tool in genuinely advancing the multiply endangered rights of the poor.

We look forward to participating in future conversations where those with an all-embracing world-view sit together at the table to talk about the next great steps in human ingenuity. We look forward to that space where all of us can be mutually provocative – pushing one another's assumptions in order to refine frameworks and language, and to serve a bigger world in building a better future.

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