

## **Working Session: Politics and Strategy**

**Moderator: Francine Coeytaux**

**Notetaker: Sam Anderson**

### **Introduction by Francine Coeytaux:**

Conversation to be divided into three parts:

1. Issues
2. Initiatives
3. Policies

Discussion proceedings:

1. Introductions
2. Participants write desired topics on notes, post notes on the board
3. Groups narrows down topics, determines best initiatives and policies to meet a common goal

### **I. Issues**

Issue groups, taken from anonymously posted suggestions:

- Human cloning
- Reproductive technologies
  - Selection (especially sex selection)
  - Commodification
  - Access to reproductive technologies
- Education and 'Meanings of genetics'
- Standards and evaluations
- General social justice and equity concerns

Speaker 1:

The issues fall into a continuum – what people want done versus what they *don't* want done.

Speaker 2:

"Should and shouldn't" are important, but we're also interested in *how* these technologies are approached.

Speaker 1:

Suggests the group should pick a 'future' issue—anticipating a situation which has not yet come to pass—and look at how to deal with it in a proactive, perhaps 'preventative' manner.

Moderator:

Seconds that suggestion: The group should discuss one 'future' topic with a *proactive* solution, and one 'damage control' topic with a *reactive* solution.

Speaker 3:

Suggests reproductive technology is the most central issue on the board right now, along with germline engineering.

Speaker 4:

Would like to discuss education of the public as a general topic.

Speaker 5:

Personalized medicine: an issue we can be involved in on the 'ground floor.' Should there be limits to the market? What role can activists and academics play in suggesting limits to the market?

Four issues chosen by the group:

1. Reproductive technologies
2. Germline engineering
3. Education, or 'enlightening' 'the public'
4. Market forces, especially behind personalized medicine

## II. Next Steps: Initiatives and Policies

Group:

Potential actions fall along two particular continuums:

1. Banning vs. encouraging
2. Concrete vs. philosophical

### A. Reproductive Technologies

#### Initiatives

1. Coalition building

Speaker 6:

Who is *not* sitting at this table, and how are they part of this conversation?

Speaker 1:

Some of the old forms of coalition building are being supplanted by online communities – less formal, more accessible, "network-based" communication. We ought to be encouraging these dynamic, grassroots efforts.

Several others:

Those efforts are valuable, but lack a certain rigor; also, many people do not have access to a computer

2. More empiricism

Speaker 4:

We need more empirical data in order to make informed decisions.

Speaker 7:

Gathering long-term quantitative data would be a useful initiative.

3. "Listening projects"

Speaker 6:

We need to be gathering input from the full range of stakeholders – not just tell people what to do or how to think. We often don't know how these technologies really impact peoples' lives.

Speaker 8:

We need to be cognizant of the narratives we're creating, especially in terms of the *language* we use.

Speaker 9:

Qualitative data—the stories—are as important as the quantitative.

#### Concrete policies

1. Restrict number of times one can be a donor.

Speaker 5:

Regulation limiting of embryos is something already done in some places, so it may not be infeasible politically.

2. Increased attention to outcomes and informed consent for sperm donors

Speaker 2:

Egg donation centers heavily emphasize that the egg will become a person; sperm donation centers do the exact opposite “for fear of freaking out the sperm donors.”

Group:

Sperm donors need counseling and informed consent: donors need to understand the gravity of what they are doing, that they will become fathers.

3. Establish registries for donors and offspring

Speaker 7:

Start/expand donor registries; for offspring and donors’ sakes (see #4) but also helping to collect long-term data.

4. Right-to-know for children of donors

Speakers 3, 6 & 7:

Apply open adoption policies to donation.

5. International agreements on improving research and regulation of these technologies

Speaker 3:

We need a broad understanding/agreement that reproductive technologies at large need to be better researched and regulated.

Speaker 5:

There’s a risk that restrictive national-level policy would push people to find technology (e.g. surrogacy) abroad ... hence the need for an international agreement.

Speaker 7:

On the other hand, we can’t even pass an international ban on human cloning or make real progress on global warming agreements; there are parallel difficulties involved in enacting (and enforcing) international regulation of reproductive technologies.

Speaker 3:

There are also parallel semi-successes, such as financial agreements preventing the flight of assets from one country to another to escape national-level regulation.

Speaker 4:

There needs to be a governmental entity responsible for regulating the industry and the treatment of offspring and donors.

(Aside: Surrogacy)

Speaker 1:

What do we think about surrogacy? There's a case to be made for banning it, as contrasted to organ donation, where benefits are more tangible.

Speaker 6:

Can we really succeed in banning surrogacy?

Speaker 4:

Agreed; point of comparison: The war on drugs has certainly failed to effectively ban drugs, and added negative consequences.

Speaker 6:

Banning surrogacy on a national/state level pushes the effect onto new groups, probably those less equipped and protected, e.g. India and Ukraine.

## **B. Germline Engineering**

### Initiatives

#### 1. Legislative framework

Speaker 4:

We need to go into the policy discussion with some conceptual backing, such as an IOS report.

Speaker 10:

This process is often neglected or not taken into account when it comes time to legislate ... but first: What do we want? What do we want the regulation to do?

Speaker 4:

We want to take the decisions out of the hands of corporations, including the skewed way they communicate these topics. "These issues are way too important to be left to the experts" — the public deserves a voice in it.

Speaker 9:

We also have to think pragmatically about state vs. federal levels — where do we have 'captured' interest?

## Concrete policies

### 1. International ban

Speaker 3:

Techno-utilitarianism is engrained in the U.S. (and elsewhere) – therefore, it is important to draw a line and say “we as a species will not cross this line.” Germline engineering is where we have the best opportunity to do so.

Speaker 1:

The reason this failed before was that the Vatican (and others) wanted a full ban on human cloning, not just germline engineering – but there’s no “strict line” between different times of cloning.

Speaker 7:

This would be a huge first – but if there’s anywhere we can do it (topic-wise), it’s here. The timing could also be in our favor with a new administration.

Speaker 3:

Germline engineering is also an issue that cuts across right and left, and “forms very strange bedfellows.”

Speaker 4:

One parallel outcome: the patent office saying it will never issue a patent on a human being.

## **C. Education**

### Initiatives

#### 1. Start our own “council”

Speaker 9:

What’s needed: to create our own voice, stepping up against other groups, e.g. the President’s Council on Bioethics.

Speaker 1:

Setting up a council raises questions about credentials and trust; in other situations (e.g. the Sierra Club), a ‘council’ can be a single voice, maybe not adequately representative of the stakeholders. Skeptical that a ‘council’ would achieve much—might it not just face louder opposition?

Speakers 4 & 9:

Less skeptical: “You have to start somewhere.” “What harm can it do?”

Speaker 3:

It's worth creating something people have to pay lip service to, even if it doesn't work as effectively as we might like it to, just because it does *something*. A movement has to be ready to jump in and take advantage when an issue becomes hot and attention is drawn to the issue, e.g. Dolly the sheep and animal cloning. A future example could be when the first human is cloned.

Speaker 4:

Public awareness is already up on some issues, e.g. Myriad and BRCA (gene patenting); octomom (reproductive technology). "There's always going to be an issue we can be capitalizing on."

### Policies

1. Require public access to all publically funded research

Speaker 5:

While we're at it, private sector transparency would go a long way ...

Speaker 11:

Seconded; we need to get more stakeholders involved.

Speaker 12:

Bringing about big regulatory changes is quite a daunting task; how do we make claims for why it should happen at a federal level?

Speaker 9:

It may be possible to gather state-level support by bringing together governors.

Speaker 4:

Pragmatically speaking, it still feels like more of a federal issue.