

## **POLICY AND STRATEGY BREAKOUT SESSION 4**

Moderator: Gina Maranto

Rapporteur: Colin O'Neil

Introduction by Gina Maranto:

- I would like us to think about key issues that concern us individually, then what are the key points collectively and how can we affect change on a range of scales.
- Then if we can I would like us to identify the different modes of action to accomplish goals.
- Take 5 minutes to write out individual key concerns, then aggregate them, pick out collective 3 or 4, then strategize goals and outcomes.

Concerns

Speaker 1

- Consumers are getting uninformative information, and then are making genetic and repro-tech medical choices and decisions based on this mixed uninformative information.
- We must ask, who are their consultants? Are they medical professionals, the biotech industry, scientists, etc? How can we be more proactive in providing accurate information?

Speaker 2

- I think our long-term goal is to prevent the dystopic future we fear and in the short term we discuss the policy omissions relating to lack of oversight.
- We must be conscious of the disconnect between communication and policy. The short-term policy goals seem to be extremely relevant but there is a gap between short-term and long term goals.

Speaker 3

- I think we need to address the exploitation issues relating to surrogacy, and
- We need to address the rights of the persons that are the production of surrogacy, and
- We need to address the research gaps relating to health risks of repro-tech and surrogacy.

Speaker 4

- I think we need to address the hazy vision of eugenics in society, the lack of understanding or knowledge about eugenics.
- How can we address democratic control of science so it is available, usable and beneficial?
- It's important that we start addressing the underlying issues with capitalism and begin putting it into the discussion. There's an elephant in the room — capitalism is the room.
- We have to stop using and find a different word for "enhancement" — this is a deep messaging problem because it sounds too positive. Its going to be hard to reframe the issue to convey the true (negative) problems with enhancement.

Speaker 5

- Need to elevate the level of public discourse and engagement relating to the lack of public awareness and the subsequent ability to be swayed by misinformation.
- Need to reframe and discuss what we're offering people and not discuss what we're taking away — offering a positive agenda.
- Currently we're trying to insert ethics into policy. Rather, we need to find other avenues to address these ethical issues; what is the appropriate arena for discourse?

- There is no place in the policy arena for discussing the animal welfare issues relating to these issues.
- I also want to call attention to the fact that these technologies affect animals and animal welfare *and* then expand the conversation to include animal justice and rights.

#### Speaker 6

- Recognize that there is a cycle here between human technologies and animals; the line gets blurred real quickly.
- We should be aware about the inclusion of historically excluded groups in discussions about society and technology.
- Need to take note of the issue of sex selection both in the pro-choice and the anti-choice context.
- Also, we should address the expansion of DNA databases in criminal and civil context.

#### Speaker 7

- We need to diversify oversight to include groups who have historically been excluded with the goal of having more democratic control of science.
- Need oversight of ARTs as well as more research regarding risks, screening practices, and reproductive tourism.
- I think the area of biobanks and human tissue is a tricky topic — people should have some control over their use and donation, which brings up ideas of informed consent and property rights.
- Personal genomics should also be addressed in the context of genetic privacy and discrimination.

#### Speaker 8

- I feel we need to address the tensions between individual and public access to genetic information, touching on patents and the ownership of information.
- We also need to address the expansion of genetic testing — both consumer testing and also expanding oversight of newborn screenings.
- We need to address the rise of the DIYBio group that is emerging — this presents new problems.

#### Speaker 9

- I am critical of knee-jerk prescription for regulation without working through the process and devising thoughtful content but on the other hand don't disagree with the call for a discussion surrounding the need for regulation.
- Rather than focusing on the technologies themselves, we should focus on regulations relating to truth in advertising; i.e., informed consent rather than regulating who can get these technologies.
- We must understand the context in which we need a healthy critique of science and its role in policy but don't simply demonize science. This way of thought could be socially dangerous, leading to creationism and climate deniers.

#### Speaker 10

- We should think about the regulatory infrastructure that could be beneficial.
- Initial frameworks can be helpful and there are opportunities in existing regulations. Now we need to locate points of leverage in existing frameworks.
- A lot more productive work can be done in the clinical community. There is a distinction between a professional society's Principles and the practices of its members. We need to help in strengthening professional societies' ethical principles (specifically, about ART) to be more binding.
- Eliminating social inequities should be a foundation for our work, but may not be an opportunity for regulation and may be more of a social element.

#### Speaker 11

- We should address how to complicate the narrative, by bringing in histories of eugenics, etc., and get the public involved, especially getting those affected involved.
- We'd like to see mandating these histories in classrooms.
- Note that the public fails to see connections between historical lessons and current issues.

#### Speaker 10

- We need to take a step back with the education work and address how completely unequipped we are as a society to deal with these technologies.

#### Discussion

#### Maranto

- Where are the common threads?

#### Speaker 7

- There's a vast spectrum pertaining to regulation, education, information, funding, enforcing guidelines.
- Can we draw lines?

#### Speaker 9

- Information can be one of the more positive forms of regulation, tapping into consumer awareness.

#### Maranto

- Should there be a call for a deeper discussion of what is governance or regulation?

#### Speaker 6

- I think we need to identify the places and spaces where such conversations go on relating to the regulatory spectrum.

#### Maranto

- Can we identify individual leverage points of where we can join the conversation?

#### Speaker 11

- In thinking about eugenics, this relates to how we can decentralize the decision power by addressing the historical gaps.

#### Speaker 6

- In the repro-tech discussion, eugenics is taken out of the "state mandate" and when individuals make choices they don't see the connections to eugenics.

#### Speaker 2

- We might be able to tie eugenics with direct-to-consumer genetic testing, as well as with popular misconceptions about the role of the gene in the media and among politicians, then tie it to an improved understanding among various publics about real and problematic aspects of genes.

- Changing the understandings of what genes are and are not, would I hope include the history of state and market-based eugenics.

Speaker 12

- Humans have an unfortunate but true history of selectivity in children (eugenics, selective infanticide, etc.) but maybe can we see how new genetic technologies fit into this larger history.

Speaker 7

- There are two objectives to be accomplished: We need informative information and good empirical evidence as the first step, but that doesn't necessary allow people to make the proper choices still.
- We need some democratic control of science in the area of ARTs, biobanks, etc.

Speaker 5

- I think short-term deliverables versus long-term goals still needs to be flushed out.

Maranto

- We are at a place right now where we're trying to conceptualize the theoretical and pragmatic approaches to these problems and also nail down tangible and long-term goals. However, I think for now we have addressed our individual concerns and identified many collective concerns and strategies. Thanks for a lively discussion!