

## **Policy and Strategy**

**Moderator: Patricia Williams**

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### **Guiding Questions**

- What policies will be needed at both local and national levels?
- What particular issues will be strategically useful to focus on in near and middle terms?
- What needs to be broken down in a more-easily facilitated way?
- What initiatives need to be taken now? Educational, Legal, Regulatory...

### **Introduction - Pat Williams**

- Priorities as proposed by participants: SynBio, Funding for research, reallocation to public health laws, coalition building, genomic databases, use of race as a biological category, social justice in biopolitics to progressive forums, epistemology of life and health, conceptualizing health in a global perspective, distribution and sharing of human cells and tissues, therapy vs enhancement, how do we translate current policies to public, how to promote funding and support of research that measures ACTUAL harms, equal access to increasingly personalized medicine
- Secondary priorities: Nanotech, drugs and gene transfer, grass roots funding, education of researchers, variation of property rights with gene cells and tissues, gene patents (ownership and knowledge commons), transnational policies, focus on genetics for solutions to health inequities, extreme longevity being normalized, how to deal with regulation gaps across transnational reproductive market, meaningful forms of self satisfaction destroyed by genetic enhancement
- Distilling the categories:
  - Social Justice Questions
  - Medical Implications
  - Framing/Translation/Research Questions
  - Funding Concerns

### **Speaker 1**

- The categories proposed assume that we (others) know what we are talking about
- Interpretation of reality is not yet coherent in terms of creating new concepts to deal with new reality
- Epistemological problems: There are serious issues of interpretation

### **Speaker 2**

- Synbio is becoming the frame that geneticists are using to prove that nature does what we want it to do. It's about hype and technology, and the "technology of the Day."
- What do we want to have happen, and what are the pathways to these outcomes?

### **Speaker 3**

- There is no unifying sense of a normative framework that we are pushing toward: For example, looking to protect who is vulnerable (we can work toward this as a group)

### **Patricia**

- We've heard a lot about specific factual situations the past couple days; for example, forensic databases and the serial killer in California; international trafficking of eggs and an IVF clinic raffling eggs. Let us talk in more specific terms

#### **Speaker 4**

- Vulnerability may not be the best way to frame the issues. For example, false consciousness in ART receivers (a population not vulnerable in the typical way, but a serious problem that must be addressed).

#### **Speaker 1**

- Most examples provided have been very American – i.e., taking a specific human body and enhancing it, commodifying it.
- The other side is the MASS PRODUCTION of these examples, largely in other countries.
- The West is a lab for usage of single items, to prepare it for a wider market.
- Mass production leads to mass waste. In this case, Human bodies.
- We do not know enough about mass production happening in third world countries
- The relationship between human bodies and production is important.

#### **Speaker 5**

- I agree with Speaker 1, US in relation to the rest of the world, BUT within the US there are people who are used in the production end as well.

#### **Speaker 1**

- YES! It is happening both in lab and mass forms here and elsewhere

#### **Patricia**

- The global economic issues should not be separated from the domestic class issues.
- We are more linked to global markets than we recognize

#### **Speaker 5**

- Also by race! People with dark skin are universally treated disparately, seen in the context of the US alone and transnationally.

#### **Speaker 6**

- Idea of mass production, bodies coming into the system. Conceptualizations of vulnerability have to change!
- There is a key difference between individuals' reproduction devalued versus *bodies* being devalued because they are part of a particular market context.
- The facts regarding who is vulnerable and how are quite complex

#### **Speaker 7**

- If the actual concern is broader than vulnerable populations, then the focus in passing laws will be how to make sure that this tech is available to ALL.
- But what if we don't want the technology at all? Then the use of vulnerable populations as a proxy is dangerous. Once there is the will to do it at all, everyone is harmed. Maybe we shouldn't use vulnerable populations

#### **Speaker 8**

- One line of thought from proponents: We may have to tolerate genetic castes for the 'beautiful future'

- Another line: We have to make sure that poor folks will have access to the technologies. “Bring them up!” We need a genetic lottery. To allow this beautiful future, we have to allow anybody and everybody to move up to the higher genetic class

**Speaker 7**

- We have a genetic lottery! It’s called life!
- Attempting to legitimize enhancement for everybody does serious damage.

**Speaker 5**

- Technologies are used to reinforce the inequitable categories of race and class.
- Access to the technology is clearly not the only issue at hand.

**Speaker 7**

- If the issue is framed as equity makes it seem like an issue that CAN be fixed.

**Speaker 1**

- Accessibility issues are actually issues of whether voices can be in the debate to begin with. Bringing more voices to the table is essential.

**Speaker 8**

- Technology changes. Finding a single problem that spans across ALL the genetic techs may be the best approach.

**Speaker 7**

- But it's easier to get something in that is narrow. And then you can say “look, this is the same thing” about other less-related problems later.
- This is a tactical choice you can make

**Speaker 8**

- We approach different issues with a broader point of view
- Forensic database issue: This problem exists already: there is already unequal representation in the database. Do we put EVERYBODY in? What policies do we propose and support? How do we talk about it?

**Speaker 7**

- If you frame it as privacy, then it is ignoring that the technology is something we don’t want to legitimize at all in the first place!

**Speaker 1**

- This discussion is still inner-American!

**Patricia**

- This is actually a framing conversation. Speaker 1, can you give an example from another, less American context? The current discussion is about language

**Speaker 1**

How do we practice what we are suggesting without staying just in Western Discourse?

**Patricia**

The meta-language with which this is all discussed will supersede national borders. We have to find it!

**Speaker 10**

- It is most important to look at rules. Internationally, we are talking about rules.
- What do we recommend? We need to talk about strategies and action.

**Patricia**

- There is a difference between *framing* and *underlying principles*. Underlying principles change with different populations. FRAMING does not change (we don't want it to).

**Speaker 10**

- Is the right policy the same across all societies?

**Speaker 3**

- Is it more about privacy, dignity and property? These more socially defined ideas can vary in different countries.
- Taking about the future, redefining the human, it is ABOUT THE HUMAN.

**Speaker 8**

- Framing vs. specific issues and solutions must reflect and reinforce each other.

**Speaker 5**

- When we talk about privacy in the US, it cannot be separated from RACE.
- The reason Americans *should* be concerned about privacy is because the vulnerable people are people of color.
- If it was a universal database, there would already be more concern about it!
- Privileged people are willing to give up privacy because it is not their own privacy that is being given up!
- The way we perceive whether there is a violation of privacy is RELATED To these social hierarchies.

**Speaker 4**

- Privacy means different things to different cultures.
- The American concept of privacy does not exist in some parts of the world.
- It is ALSO about gov't surveillance, which means different things in different places.
- Part of the issue is about the government, police knowing who you are.
- It is about WHO HAS THE POWER OVER INFORMATION - the power over those who are disadvantaged.
- Pieces of human information that we are using technology to capture.

**Speaker 1**

- If this a global issue, global organizations are a good place to address the issues.

**Speaker 8**

- A good way to start may be to ask: what was the problem that the technology was invented to solve? Infertility, health, disease

- Discussing the unintended consequences overlooks that we might want to reframe about the problem and NOT The technology. How do we BETTER solve the issue than using these technologies?
- Let us propose alternative solutions.

#### **Speaker 7**

- Sometimes intended consequences ARE the problem.
- AND vulnerable populations are often the way to frame the issues.

#### **Speaker 4**

- We are ALL vulnerable people in some ways.
- 'Unintended consequences': We should not focus discussion on this idea because many of the techs were invented for violence and control.
- Follow the money: it comes from power and military. That people want over humans and populations and geopolitical boundaries.
- Remember that the goal of the tech is not just saving the world but to assert dominance.
- Who is controlling information, gathering it, and how it's being used
- 'And lets stay away from the idea that 'science is neutral.'

#### **Speaker 10**

- Genetics is a huge issue, but how do we get people interested in it?
- Look at the applications: e.g., criminal justice.
- What are the techs about? What needs to be the safeguards?

#### **Speaker 1**

- Power relations: whoever the stronger side is, there is always a negotiation. Things don't happen without two sides.
- A good strategy would be a feminist way of working. Get lots of local groups talking about the issues of health and reproduction. Gather the information that is being shared in these groups and fight in a way that the issues are nonnegotiable.
- Grassroots! Publish until it is in the global eye!

#### **Speaker 4**

- YES! Use databases like this! Evidence-based advocacy.

#### **Speaker 6**

- Even if we are trying in our local context to define who is vulnerable and how, we always have to be cognizant of how are impact is felt in other places.
- Follow the impact. The unevenness, regardless of the issue needs to be dealt with.

#### **Speaker 11**

- There is a divide between not wanting government to intervene, but also the NEED for government to intervene in certain issues.
- Public distrust in government is at all time high.
- Educating the public, mobilize in figuring out WHAT WE DON'T WANT GOVERNMENT TO BE DOING and what they should be doing.

**Speaker 7**

- Public attitudes are not quite this clear cut.
- Sometimes publics change their minds! They trust the market, but not necessarily the players in the market (this is clearly US context).

**Speaker 1**

- Use the United Nations! The population council!
- This might provide a broader framework of thinking.
- Use them to make large working discussion groups across the globe.
- Use the leverage around the world to make an impact.