

POLICY AND STRATEGY BREAKOUT SESSION 3

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Introduction by Ben Hurlbut

The core question for us is: What is to be done? What is the right kind of change? We should think in this session about four policy categories:

- 1) What are the **issues**?
- 2) What kinds of **values and norms**? A focus on human rights is a good starting point.
- 3) What are the **institutions**? Courts, etc.
- 4) Who are the right kind of **people** to reach out to?

I would like to solicit from people their opinions on these four topics, and give rationales.

Speaker 1

One of the values that I hear over and over is our mutuality and that we have to move forward in this human race together. There is a sort of interdependence. Our strategies may perhaps be influenced by that.

Speaker 2

The issues most important to each of us tend to be the ones we are working on at this particular time. For me, then, they are:

- The inclusion in databases of DNA from those who are arrested, and not convicted. This usually targets people of color and immigrants. This raises the question of how we can achieve a balance of public security and privacy/autonomy. There is the issue of storing the biological sample in a database as well.
- What is being done about it right now? Well, the ACLU has some lawsuits going on. The European Court of Human Rights issued a warning for the UK on DNA collection. As you can see, there are *some* efforts to prevent a genetics surveillance society. But more has to be done.

Ben Hurlbut

Can you further articulate what the problem is? What is it that should unify us? What are the relevant sites of action? What should be changed, and who are the right people to do it?

Speaker 2

The problem is that traditionally people were not under surveillance. There is a movement to get everyone's DNA into a national surveillance program. This is a great difference, having those people in a database who have not been convicted, but just arrested. The *fear of crime*, the number of crime shows is incredible; *this is a problem*. Sometimes the public then moves in a direction of accepting surveillance. The most extreme would be each of us wearing a band of DNA and a GPS system on our arm, to allow the police to find out what we are doing if they wanted to watch us.

Speaker 3

So it is a privacy concern, right?

Speaker 2

- Privacy and justice. If it was required of everyone it would be just privacy. But in terms of justice, minorities and the poor would be most at risk.
- Oddly, the medical field is going in the direction of privacy, while forensics is not. Forensics lacks the privacy component.

Ben Hurlbut

Let's talk about privacy issues, and state vis-a-vis the individual citizen.

Speaker 3

In regards to forensics, privacy trends are different than in medicine. In medicine, there is a new idea of privacy. There are two potential outcomes with this: 1) everyone will have access to your genetic information, or 2) it will be kept private, it is highly sensitive. Those are the issues, and the question is whether genetics something special?

Speaker 1

One of the things I want to speak to is how you work with people who have such different views of privacy, security, etc. How do we have a conversation that only the privileged are concerned with? Minorities aren't really even thinking of some of these issues.

Speaker 2

Well, things could get worse.

Speaker 1

We have to strategize about what to do if we have different calculations about how we even got to this point. We sometimes imagine a past that never was, and a reality that can never be – almost like a “city on the hill” notion. How do we get on the same page? Those at the margins have the best view of what is going on. We need to bring them into our conversation so we have a better idea of what is going on.

Speaker 4

In my experience as a medical anthropologist, some of these discourses don't even have relevance, doesn't resonate, for people on the ground. For example, I work with some who are being recruited for genetic studies. They are trying to help their loved ones. But the work we do is to talk with those people who just signed the forms and to see what they really understand. Someone mentioned a deficit model, and we need to understand what the public understands or what they do not. We should apply this to the discussion then of policy and strategy.

Speaker 5

I want to share something about the European experience, and how people united around a concept of human rights and dignity to create a treaty. Maybe we can focus on these values as universal. We need to focus on informed consent, not misinformed consent, which is an affront to human dignity. And here comes the more universal value of social justice. Patients and researchers are interdependent on that. But there is the question of who is in power to call the shots. But the treaty is working. People are beginning to try to make decisions for themselves. We should look at that. Here are a few examples:

- People in Russia have a different experience with government and being told what to do by the government, and a different understanding of human dignity. In Russia they established biomedical committees to protect dignity – these are institutions that have proportional

representation. This might not work everywhere. But many people are going to the bioethics committees, to do good things in the structure.

- Africa is doing this as well. Here is an example of an institution where there could be nongovernmental representations, since governments might want to implement their own policies, and not what is best for the people).
- I don't know how appropriate it is to focus so much on the US. There are some values that we could use, some institutions in other parts of the world that we could learn from, and that could be adjusted to fit the US framework and to be democratic and inclusive.
- Lastly, bioethics is about only the ethical concerns. Biopolitics is about participation and transparency. Transparency has not been provided for in the bioethics realm.

Speaker 6

One of the problematic value norms issues is that biotech enthusiasts see things like human frailty – and want to see how you can avoid that. The transhumanists and singularity people do this. Those around this table however, reflect more of the mutuality values voiced by Speaker 1. Here are some of the issues we should look at:

- Resource allocation: How can we get decent healthcare to everyone? We have a tension between lots of money to technologies and getting health care to the most people.
- How can we look to share what we have now vs. how can I improve as an individual (we very much focused on the individual).
- How do these concerns translate to strategy and policy?
- We could talk about resource allocation at NIH.
- What are other ways of thinking of sharing resources, more focused on sharing for the common good?
- Our basic resources are so stretched. But then you hear people at the singularity meeting speaking about new technologies. The unfairness of this makes me very angry.

Speaker 7

There has been too much consensus in this conversation. It is important to divorce the personalities of the transhumanists and their main representatives' beliefs from the point that sometimes we can use technology to answer broad sweeping questions rather than trying to solve issues incrementally. Historically, technology did sometimes provide solutions – and sometimes low tech provided solutions. I think that transhumanist beliefs should be taken more seriously.

Speaker 8

Some believe that ensuring privacy in this genomics era would solve all the problems. But I don't think that is the case. I would be careful with privacy. Even though we have GINA, it does nothing for handicapped communities. Sometimes ideas of privacy can do harm to marginalized people. They reify the notions of autonomy and that can harm some marginalized groups, and it can keep some of the system of oppression intact.

Ben Hurlbut

- To summarize at this point: An idea like privacy is something that we use in the US, but this may only be a band-aid solution. Information might be another issue like this. For example, is informed consent really doing what it is supposed to do?

- Can we use the deficit vs asset model as we continue this discussion: What are our assets? It seems that agreement that privacy matters is one of our assets. It seems that knowing more is also one of our assets. It seems that autonomy of the patient matters.
- However, if we move to Russia, we get a different model. The norm that was the foundation for European bioethics – human dignity – is nearly absent in the US.
- Let's articulate some of the assets; they seem to be the right places for intervention. Then maybe we want to ask something about the levels at which we want to make use of these assets. For instance, should it be at a cosmopolitan or local level, or somewhere in between? We have to look at what kind of world we want our technologies to create, but we have to be sensitive to the norms entrenched in the cultures we live in. We need to look at this when considering new models of institutions. We need to stay attuned to the kinds of questions we ask. Again, what are the right levels of intervention? How should technologists be involved – is technology the place to think about the kind of world we want to create? These are important questions we need to address: Is it technology? Making use of well-established norms? Should we look to national / cultural differences to consider a diverse view of considerations? So let's play around with this a little bit. Let's articulate some assets. What are the sorts of things that are cross-cutting between narrower issues and problems?

Speaker 9

One asset is an agreement on our opposition to human modification and particularly germ line enhancement. That has been difficult to approach on a policy or strategy level. I don't think that we want to leave sight of that.

Speaker 10

I would like to add the whole stewardship on the natural world; the parallel between concern for nature and the concern for human genes. For example, the commoditization of children – is it a human right for one human not to be designed by another human? What about a generation in general? Do they have a right to not have built into it aspirations, etc? Is that the kind of world we want to leave for human generations?

Speaker 1

I can think of two assets that are movement based:

- The human rights movement. We can tap into that. We are at the dawn of a new social movement that brings people together instead of separating them into different identity silos.
- The women's movement to problematize patriarchal social norms and assumptions. There are assumptions that don't always get addressed, and we can challenge those assumptions. For example, who gives us the human right to assign dignity, to decide for future generations? We undervalue the women's movement as a source for challenging the current model.

Speaker 6

An asset of our group is that we are willing to talk about dignity. Dignity is a concept that can bring in a lot of our concerns. But the challenge is to be specific, rigorous, acknowledging the vagueness in finding consensus definitions of dignity. Maybe just more discussion about dignity, why it is important, and how it can be translated into policy would be useful.

Speaker 5

It brings people together who have different values to talk about policy.

Speaker 2

Did anyone talk about germ line modifications in the President's Council for Bioethics?

Speaker 6

We didn't make any clear recommendations, except to have a four-year moratorium. But we were negative towards it.

Speaker 2

I am guessing that there is more public antagonism to human cloning versus modification of human germ line. Was your Committee strong about that?

Speaker 6

Yes, we were pretty strong about that.

Speaker 2

Are there any institutions or norms to prevent people in the fertility field from attempting these sorts of manipulations?

Speaker 3

Medical malpractice, that's about it.

Speaker 6

There's the RAC. And I think one would have to go to an IRB.

Speaker 11

We did a survey of all the countries in the world, and the policies on these issues. Several dozen have banned IGM and reproductive cloning. The U.S. is really the rogue nation on that score. And many countries ground their policies here in a framework of human rights and human dignity. How can we leverage this near universal belief on these issues to have effect in the US? What is a strategy, what is the campaign? These questions should be asked. For example, the women's community in Germany supported banning the most serious genetic manipulations. How can we put these women from Germany in discussion with women's groups in the US? I think there is a low-hanging fruit for an international campaign that would both have an international focus, and make a difference in the US. Maybe some people would be willing to do that work.

Speaker 7

I think any sort of categorical ban on modifications is a bad idea. The efforts to modify the human genome are going to be driven by naiveté and greed. But categorical opposition isn't going to work. The lines drawn between therapy and enhancement are too fuzzy. If some of the distrust in some institutions could be channeled towards those who are greedy and trying to advocate for modifications, then this could be an asset.

Speaker 10

It is not only the human genome, but actual human children. The question should be: how do we get from Point A to Point B without harming children?

Speaker 7

The kind of modification that would be done by recklessly ambitious parents ought to be banned. But I am not confident enough that with the development of science a categorical ban based upon harmful effects is going to maintain its traction in 50 years. And that's different than saying that we should do a categorical ban based on other concerns (essentialist ones).

Speaker 2

I can't help thinking of the general reaction that when we do something to children, we are experimenting. Think of vaccinations. Think of IVF. The real question is when we put a barrier saying "No, we can't do such experiments" or "Well, if we want to get to a certain point, how do we accept such risks?"

Ben Hurlbut

- The question then is how does one create a barrier? Is this a risk we can accept if there is informed consent? Or is the risk not acceptable?
- The ways in which the state can tell us which is good or bad are limited. One of the pathways is through consumer protection, not a communitarian notion of the state and human dignity. In looking at institutions, – it is about the *how* to effect change not the *whether*.

Speaker 5

Don't leave out the rights of future generations.

Speaker 12

I was thinking about how we have spent a lot of time thinking about markets. One possible site of intervention could be collaboration between the government and the market.

Speaker 4

I think an asset is a history and legacy of grassroots activism. How can we learn from the models of having grassroots voices? Institutions in the US could be an asset because they exist, but how can we have grassroots movements influence the institutions to benefit us? How can these voices help us guide such anticipation? These are some more of the questions that we should be asking.