

POLICY AND STRATEGY BREAKOUT SESSION 4

Moderator: Rayna Rapp

Rapporteur: Doug Pet

Introductions

Rayna Rapp:

- Anthropology is great at talking about these issues in a very negative way; I look to all of you to bring a positive light.

Poses the prepared questions; asks for responses and for people to lay out issues for discussion

Participant 2:

- We should limit patent term to 10 years for biotech and pharmaceutical patents. Have an explicit research exemption for patents. Repeal the Bayh-Dole and Stevenson Wadler acts – although this is not likely. These rules have allowed for the commercialization of institutional research institution discoveries in a way that has commercialized the academy and commodified biotech.

Participant 3:

- I'm disturbed by blurred line between *observation* and *discovery* in terms of patents. There are intergenerational accountability issues. What are facts of nature? What is not discoverable? Are the processes of women's bodies facts of nature? Or are they just observed, replicated and then patented? Are these observations not discoveries? Facts of nature: do they fall into this category?

Participant 4:

- Arguments by European patent office: was this discovery inevitable? We are eroding the conceptual frameworks of what it means to let people patent life; in green AND red biotechnologies

Participant 5:

- Certain biological discourse comes to predominate public discussion. These are the discourses that take isolate parts of genes or what have you, and talk about them in such a way that lets them be privatized and traded, etc. The political economy's structure will favor certain understandings. Even Venter knows his enterprise *as he's outlining it* is bound to fail; public ignorance of biology is so immense that it is overlooked that his project's task really has to many dimensions to conceive. Certain biological facts are favored because of political structures and understandings. This is where we need to attack

Participant 6:

- If our pattern of law is driven by political economy and trading, etc., how does one respond to or try to alter that framework, which is perpetuated by patent offices and legislative bodies? What I am hearing is that there are no realities or facts of nature to which we can appeal; they are too complex, we don't know them. We *need* to appeal to a different set of values of how life should be dealt with; one that's different from the

political economy. The strategies that we forge for working in these areas of policymaking depends on the nature of the argument that we're trying to make. Look at recent examples of how conservative analyses has been appealed over the years; appealing to rhetoric of "natural" human traits; they get away with it. Should we try to get away with an appeal to "facts of nature" and hope no one calls us on it? OR should we be more honest and theoretical and say that we are appealing to values of social justice rather than those of profit and growth?

Participant 3:

- Chakrabarty v. USPO: at first patent offices (197980) said this was not a new form of life. The supreme court defeated the US patent office; this opened the door to where we are now. USPO was berated; since then, they kick back and say basically: bring us what you think is a new form of life. There must be a distinction between engineered organisms and the processes that are the same in all healthy human bodies. Chakrabarty did NOT destroy any distinction between the existing processes within my body and those of organisms engineered and created in Petri dishes. The public would understand this

Participant 6:

- The science of biology does NOT allow us to draw a line between what is natural fact and what is discovery. Drawing a line like this is social act not a biological one

Participant 5:

- Even the *choice* to study and pursue and privative and patent certain things is not driven by underlying biology. Ideology of breaking things down and parsing them up—this favors some kinds of explanations. Many biological points are excluded from public discourse because they cannot enter into the market place. Here's a strategy: We look to the antiglobalization movements as a model; has to do with mobilizing democratic potential. We ask: do we have a say? OR are we just on the receiving end of some tyrannical structure that tells us what will be developed and marketed?

Participant 7:

- Regarding policy: This morning there was a discussion of a more democratic system and how we are being prohibited from participation. BUT I DON'T BUY THIS. You are not entitled to say that unless you have tried to participate and been denied access. But I think that access is THERE. Last week, at the FDA hearing, anyone could sign up and testify. I was the only public interest org there! Following GINA, I've been given plenty of access; I don't see a lot of other people there. Frankly, I don't think we are in position to say we're being kept off the table when we're not trying to be at the table in the first place. The government agencies have bent over backwards to accommodate people to come to the table. The accessibility has increased under Obama, but it also applies in general. We passed GINA under Bush; staffs don't change with every administration. I find it too easy to throw stones; the fact is that we are not showing up in sufficient numbers. When we *are* prohibited, we can use that to move towards a point of access. Too often we want to choose the issues we want to work on in the perfect world. But we need to look for moving targets, be opportunistic; look for points of entry (at least in the short term).

Participant 2:

- What are the specific points of entry?

Participant 7:

- DTC, gene patents, DNA forensics, gene patents. There's stuff happening! This is our point of entry right now. We use these as platforms to talk about other issues. You cannot bring issues to the table when they are not active and when there is not political/legislative point of entry. We are losing! We are saying lots of interesting things that have no effect on what's happening. We need to get in the game; right now we are not in the game.

Participant 8:

- The Brownback legislation was important in testing realm in terms of giving pregnant women info on diagnosed conditions of embryos. Funding for implementation hasn't happened—it could reform the way info is passed after diagnostic results. It was intended to change the nature and quality and kind of info provided. It would change how education and licensing is done for people who provide that information

Rayna Rapp:

- Who is the we here, who should be at the table? Coalition building?

Participant 7:

- What happens when you're not at table; those at the table get to set the terms. The Genetic Alliance (GA) is at the table with regard to legislation around the Brownback bill; not necessarily who you want at the table. GA has done as good a job as any other organization in the greater genetics community at understanding this concept about the importance of being at the table. So GA is a model to follow in terms of this action.

Participant 8:

- We can't do these things at the policy level if there is no grassroots movement to back it up; that's what GA has: people who are affected by these issues. We're trying to do this at AHB, by working with victims of these new policies. For example, egg donors without informed consent; we are collecting their stories of suffering. When we talk to students about this nothing happens; but when we have a legislative agenda (eg, warning labels), we can get hundreds of signatures, and energy builds. We've educated thousands of young people about dangers of hormones and harms, etc. None of what we're doing would be worth anything if we weren't connecting it with people's lives. The value is not abstract...it's in health! The victims have families who can be part of these movements. 10 years? Why not ban it all together; there will still be a gold rush for those 10 years.

Participant 10:

- I'm looking for the "problem statement"! We don't agree on an agreed problem statement. Jeremy and I could probably work something like this up in 10 minutes. But here we are stuck in an abstract academic discussion. The wider relevant discussion has to do with this whole idea that companies are trying to patent the building blocks: nanotechnology, synthetic biology, genome patenting→that is where the whole argument is headed. It's a whole privatization of the building blocks of life and matter—

it's connected to other areas as well. So in order to tie them together, we need a problem statement that we're all working to solve.

Participant 7:

- Maybe a bumper sticker: "No patents on life, no payment for life!" I have not heard a damn word in this conference about changing language from donors to sellers. No one is talking about men selling sperm. Why can men sell and women not: it's degrading to men and to children. I know there are differences but men are silenced in this argument.

Participant 5:

- Look at other movements. The issue comes back to democracy; point of convergence; need to bring this issue forward. People on the receiving end need to have a say in what is developed and applied. It's Great that the FDA opens this up to public but there are no structures to incorporate the democratic input. They will put on a "charade" of a public hearing; but they go and do what they want anyway.

Participant 2:

- Concerned about Jeremy's assertion because it reinforces the old idea of the ivory tower egghead that never gets out and engages. People aren't saying that they were shut out, it's more about: how do we get engaged? Which table do we go to? We don't want to replicate this divide, the misconception that people in policy are shallow and not on the ground; it perpetuates a bad divide. It comes back to getting a problem statement. What struck me about Jeremy's statements: how could we think about the Tarrytown group? As something that would be built into something like the Genetic Alliance? How do we conceptualize this group? We currently rely on GRG and CGS to be engaged and we appreciate it. But how can we find a way to focus our energies as a consortium in a sustainable way? How do we focus our "diverse energies"

Participant 7:

- Something Diane said is pertinent: we at Tarrytown can do only part of that. GA is successful is because of who is the face of their issue. Tarrytown doesn't have a face of the issue→we need one to be successful. What I live by as an advocate: the media wants to know who are the victims? VICTIMS ARE THE FACE OF AN ISSUE. We need to go beyond what is conformable, and make alliances with types of groups that can more actively bring those individuals into our community and the conversation making them the face of the issue.

Participant 4:

- We criticize researchers and condemn them as evil. BUT we forget that a number of funding organizations mandate as a condition for funding: industry partnership! We attack the research but NOT the agencies that are really responsible for these outcomes. I like the comment about no patenting life. We look at egg selling and obsess about it. However, this came in a context where we allow the selling of other human biological materials. We still tolerate organ trafficking. We need to look not just at victims but beneficiaries. If we condemn egg donation for research, then it's on 2 grounds: either

commodification or lack of voluntary choices. We allow people to be professional research subjects, w/o proper informed consent.

Participant 8:

- When we talk about what's wrong with egg harvesting, we mean that we want meaningful informed consent. It's scandalous that no long term followup studies have been taken. The only studies around are wrought with conflict of interests. There is a need for a national registry to track egg donors, to enable meaningful informed consent. Women are concerned about what they have done to their bodies and their children. We say egg donations so we don't talk to them as mercenaries and we want to see and respect their perspectives and not accuse them

Participant 4:

- Many people donate eggs for family and friends. We need to compare this to those who are doing it for money, and need to consider motivations

Participant 8:

- Most women wouldn't sell their eggs if they were not socialized into the rhetoric that you're really helping someone.

Participant 5:

- This is how modern capitalism works. You go to Starbucks because it gives you meaning when you have this kind of transaction: buying coffee = helping children.

Participant 10:

- That's right, the "Are you a dreammaker" campaign

Participant 5:

- This obscures the idea that women are selling eggs because they don't have good income. This all really interconnects with broader politics of social justice, but it ignores basic economic issues

Rayna Rapp:

- Does anyone else want to speak and or change the subject?

Participant 6:

- We need to recognize a kind of a dilemma: The policy process as it is imposes certain kinds of limits in terms of: what kinds of changes can be entertained. It's a dilemma: there are some aspects of biotech issue where change and reconceptualization beyond policy limits would be desirable or are needed. Short term strategy of consumer protection, etc. that would strengthen but not fundamentally change the commercial aspect of this. It was said that we need to put on a face, vividly portray in individual human terms the victims or the beneficiaries of our issues. YET, Erik made a remark: in the policy arena there is a convergence of concern around many technologies, not just genetic, about directly owning and manipulating the "building blocks of life." In *my* opinion, this is an idea of a broader concept policy problem, not a victim problem. There is a broader moral concern there about what we are doing; this concern doesn't

necessarily lend itself to a victims, assaults on the body, vivid images, etc. How do you work within the constraints of the policy process (which requires “victims”) when you are dealing with wider issues like: should we really be doing these things to the building blocks of life? With that problem statement, could one ever get a hearing and be taken seriously? How can we get some traction on this?

Rayna Rapp:

- Do we think we can come to a place where we have a few things to focus our discussion on now? There is a huge global aspect to this; we can’t go there in the next 20 minutes, but it must stay in the back of our minds. What are the global connections? What could our intervention strategies be? I’m hearing egg donation (global); surrogacy project (global); and gene patenting (AA’s bumper sticker).

Participant 4:

- Policy and strategy need to be global. In Canada egg donation is not compensated; however (loophole) you can import sperm that was paid for in other countries. All policies must have international components if we want them to be effective.

Participant 10:

- We need to be international on some level. Look at WHO and bilateral trade agreements: what’s really being negotiated is intellectual national property rights and services. These broad agreements which enable big companies to hang onto these intellectual property rights make it ultimately difficult for groups like the ACLU to challenge things like gene patents on a legal basis. The treaties require country compensation. as we talk about what is the problem statement, the US trade representative and WTO need to be looked at. Trade deals are being negotiated that are locking up the last 50 years or more of patent laws—this is happening kind of below everyone’s current radar screen. We need to go to those tables

Participant 12:

- I’m going to go broad just to through things out there. In a way, there are similarities between our want for a biotech fix and our want for a legislative fix. The desire for a legislative fix is perhaps short term thinking. It doesn’t change the balance between how technology is developed and used in the marketplace; doesn’t change the development and distribution issues. Broad thinking: one way this has come to be is that neoliberals have taken over economic departments in universities, and they take important influential roles in government.

Participant 7:

- We need to look at the ethical training of research scientists. Regardless of legal framework, how can we move to more ethically sound advances in biotech if researchers at the front line of have no grounding in ethics? In the top 25 universities in the country, you can go through a whole degree in science without required ethics exposure/training. Even those who *want* ethics training can’t get it because they are taught in other departments or there are credit issues. UCB is a great example; the biologist don’t get it. Schlissel had no idea there would be an uproar over his gene

testing kits, to the degree that they didn't bring in any ethicists to design the program. They really didn't think there would be any conflict.

Participant 5:

- We need to ink up with broader social movements; this is a global justice issue. A lot of the education takes place in the context of the social movements that are concerned with achieving specific ends (global justice movement, antiglobalization movement, etc.) When I lived in the US, we created coffee shop series where people would speak and ask questions about issues (Iraq, oil, etc). This is why the antiglobalization movement was very successful: it involved many constituencies

Rayna Rapp:

- Is there a WE that emerges from this Tarrytown group? Is there a possibility for a consortium, where can start to connect with these wider groups? How about working groups from within this group, made up of groups that already link up somehow?

Participant 10:

- We need to ask how this massive frame is to be used on a practical basis, and in a way that doesn't get lost in the media. We will be applying a new social justice framework to national and global law. We can't ignore the attacks that will emerge, following things like the issue at Berkeley and the ACLU decisions. We need to figure out how to be very sophisticated, and how to build civil society/grassroots activism into this after the frameworks have been developed. I don't know if we yet agree on what the problem is.

Participant 4:

- What are the priorities? There could be significant differences among us.

Participant 8:

- For me the frame is healthy people and healthy environment. Look at these things in terms of health and we can get really broad support. We should critically look at every technology and see how does it affect health.

Participant 10:

- It is hard to fight the money powers that be. We need strength in numbers. Regarding GMO food, some people don't care. We need to find a hook that people understand: people now buy organic "because it tastes better!" We got at them by actually skirting the issue, but getting to the same end. Not even getting at the real issue, but making it cool and appealing (vegetarianism, etc.).

Rayna Rapp:

- This ignores the people who aren't buying organic

Participant 10:

- But there are A LOT of them

Rayna Rapp:

- We need to keep our eye on that larger problem statement. It could be health, patenting of life, or something else. At the same time we need to think about short term or middle term: registry for egg donors, gene patenting, ACLU case. We need a balance. What about bioethics education for scientists? Not only is it not in the program, but they think it's a bunch of garbage. Where can we get them where they are young? My premed and medical anthropology students are avid supporters of bioethics.

Participant 3:

- Erich, could you give us some idea of what steps are needed to get toward a problem statement? With a mind for moving towards advocacy? Lengthy or pithy? Embracing multiple problems and complex or simple and accessible?

Participant 10:

- They can be any or all of the above depending on whom you are trying to ignite. I support short and concise, brevity of words. Perhaps something that could appeal to those at this conference and then be touched up with media appeal and delivered to broad outside groups. It depends completely on the audience. It can be reworked for different publics.

Participant 7:

- It can't be limited to just words, *you need stories*. People don't relate to abstractions, but rather to things they can identify with. If they can see it happening to them, their sister, brother, or family, etc. You have to personalize it! Otherwise it is very difficult to get something done. Legislators want you to show them the problem; if you can't tell them who it affects and how, then they won't want to talk to you; legislators don't deal in abstractions, you need to bring it down to more the more practical.

Participant 2:

- Here's an example, using forensic DNA. We can use it to stir up/cause some trouble: let's make a condition of owning a gun that you must supply a sample of DNA. See what kind of response you get from people who might not ordinarily be concerned with genetic issues and privacy then!

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