

CONCEIVING THE FUTURE

Reproductive-justice activists on technology and policy



Emerging reproductive and genetic technologies have raised critical issues for social-justice movements. For the past few years, the organization Generations Ahead has been meeting with advocates from reproductive rights and justice organizations to help these groups address the ramifications that new technologies pose. *Bitch* convened a roundtable discussion with some of the women who've been engaged in these national conversations so they could share their views on the intersections of reproductive rights, reproductive justice, and reproductive technology. —Andi Zeisler and Emily Galpern

All of you are reproductive justice advocates in one form or another, so can you each talk about your interest in issues relating to new reproductive and genetic technologies?

→EMILY GALPERN, project director on Reproductive Health Rights and Justice at Generations Ahead:

Most of the conversations that have happened in both the public arena and the policymaking realm have been among scientists, bioethicists, and the industry. There hasn't

been much space for or response from social justice organizations. Generations Ahead is interested in organizing those who are usually ignored or silenced, yet who will be impacted by the use and development of these technologies. We work with groups focused on reproductive rights and justice, racial justice, disability rights, and LGBTQI rights, to raise awareness about the issues, engage them in conversation with each other, and ensure that they will be central players in policymaking.

We use a reproductive-justice frame-

work, which allows us to take everyone into account and ensure that one community does not benefit at the expense of another. RJ [reproductive justice] allows us to look at a history of oppression and racism around reproductive issues. It allows us to acknowledge that these issues are not clear-cut; it's not as simple as being either for or against use of these technologies. They're not just about abortion and the moral status of the embryo. It's important to really look at both the benefits of these technologies and the potential dangers that they pose, on physical and ethical levels.

→KIERRA JOHNSON, executive director of Choice USA, a national youth-focused and -led leadership development organization:

Choice USA's mission is to train the next generation of reproductive-justice organizers and advocates. We primarily work with people under the age of 30 to educate on the issues—but more important, to link issues

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education with skills building so we can build the next generation of communicators and organizers to move the reproductive-justice agenda.

The women we work with, mostly on college campuses, are the ones who are being aggressively recruited for their eggs. Increasingly, these technologies are being marketed to young women, and yet it's difficult to find those young women actually being engaged in some of the larger, broader national policy conversations. So our interest is in getting these women to actually be involved in the policymaking and the conversations around it.

→ **MIRIAM YEUNG**, executive director of the National Asian Pacific American Women's Forum, an organization focused on advancing human rights and social justice for Asian Pacific American women and girls:

Reproductive justice is a more useful frame when discussing this issue than the choice frame. We're not just talking about autonomy of choices and privacy of choice. As we talk about assisted reproductive technologies, there are bigger and broader community ramifications. I think both the queer communities and the women of color communities I've worked in experience these ramifications disproportionately. Reproductive justice allows us to focus on something that we haven't, which is the connection to supporting women to have kids, not just to choose *not* to have kids. Within the queer context, this has been really important because ARTS are critical to the formation of queer families.

→ **MIA MINGUS**, co-executive director of SPARK Reproductive Justice Now (Formerly Georgians for Choice), a grassroots reproductive-justice organization based in Atlanta:

One of the most interesting things for me about these technologies is the opportunity that we have to address disability in our movements in general, whether it's the reproductive rights, health, or justice movements, but es-

pecially reproductive justice. We need to talk about the larger medical-industrial complex and the underlying ableism that surrounds people when they are making these decisions [about using genetic technologies]. I feel like reproductive and genetic technologies are another opportunity to allow us to be able to either consciously build a bridge with the disability community or to step away from it. I'm interested to see how that plays out.

→ **JACKIE PAYNE**, director of Government Relations for Planned Parenthood Federation of America:

We entered this discussion about reprognetics a couple of years ago at the Reproductive Justice for All conference Planned Parenthood put on with Smith College's Women's Studies department. We examined four main issues and looked at laws and policies through a reproductive-justice lens. That was our entry into this world, and we've definitely been continuing to explore it both at the national level and at some of our affiliate levels.

Does the mainstream media address reproductive-justice concerns in its narrative about the larger subject of reproductive technology? If not, what are some crucial issues it should be covering?

→ **MY**: One of the things that I've watched in mainstream media which has been really interesting—and in my opinion, maybe slightly dangerous—is this kind of full-scale acceptance of genetic technology as good. We've got *New York Times* articles that just assume that every woman would want to screen her fetus for Down's syndrome. Suddenly we're paying more attention to our genes than anything else. Has reproductive justice as a framework been brought into the mainstream media? I don't think so. It's such a complicated message that it's better suited for progressive magazines than for the mainstream.

→ **KJ**: I wholeheartedly agree, and I think it's something

that we're going to have to deal with. Talking about these issues and their complexities—it's difficult to fit that into a sound bite. We have to work in a collaborative way with progressive media to get more coverage and hit on these pieces in a way that people can take with them in a two-page article or a 15-minute thing on public radio.

Does the ongoing abortion debate impact the public discussion surrounding reproductive technology?

→MM: The reproductive-rights debate is so abortion-centric that it does make it hard to provide an intersectional approach with a lot of our messaging, whether it's through media or through word of mouth. Abortion is really the only touchstone a lot of people have in terms of a conversation about anything to do with reproduction.

→JP: It's interesting how the same technologies and medical treatments are treated really differently with respect to reprogenetics. People only understand ART in the context of people they know and love trying to have children. So it's very positive: These are the folks who want to have babies. And then you have abortion, which is put in a very negative context, without any understanding that there are women who, for example, very much want to have children but now is not the right time for them. The same exact activity in one context is a negative—is an abortion—and in another context is selective reduction [the process by which a woman pregnant with multiples aborts one or more of the fetuses because she wants to have fewer children, or due to fetal congenital disabilities or health risks to the woman or fetuses].

Another example in that same line of thinking is the concept of "gender balancing"—choosing to abort because of the fetus's sex. You've got parents with two boys, and they would be willing to have another child if the third child was a girl, but if it's a boy, they're not going to continue that pregnancy. That activity is an abortion, but on *Oprah* it's called gender balancing. It's setting new judgments about what are acceptable reasons for having an abortion and what are not. So that really does take us into a whole new world, potentially, of how we think about abortion.

We are all exploring these emerging technologies and how and whether to regulate them, and what we're seeing is that the very first forms of regulation in the United

States are clearly designed by folks with an anti-choice agenda, trying to use these issues to further that agenda. An example of that is a prohibition on aborting a pregnancy based on a test showing that the fetus has a "gay gene," which is purely theoretical at this point but has been proposed in state legislation. It's supposedly an anti-discrimination law to protect future "gay babies" from homophobic parents. This is the context in which we're starting to see the regulation of these technologies.

→EG: In the U.S., anything having to do with reproduction inevitably gets pulled into the abortion debate. In countries where the legality of abortion isn't debated, regulation has progressed in a very different way. In Canada, for example, women's rights activists were involved in the development of a comprehensive national regulatory framework for assisted reproduction and related technologies. They didn't have to be as concerned about the impact that regulating the use of these technologies would have on the legality and safety of abortion for women.

→KJ: I think the dialogue around abortion rights and these new emerging technologies also presents an exciting opportunity to move away from a defensive strategy that responds to punitive policies. It presents an opportunity for the reproductive-justice community to create a road map for the government about what they should do to meet the needs of everyday people living in this country, and about what government responsibility and accountability looks like.

In general, what are some of the guiding principles that you all would like to see used to develop policy that relates to these new technologies?

→JP: I think a lot of us are still in the exploration phase in trying to figure out what good policymaking in this area looks like. What I might understand as good policy from a reproductive-rights background may be insufficient unless I have conversations with folks from racial justice and disability rights and other movements to come up with a good solid social-justice answer. I think we're still trying to get to that.

→EG: Some of the principles that have emerged from the convenings we've held so far are equity and justice, valuing all families, affirming (Continued on page 63)

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(Continued from page 60) the rights of women, young people, people of color, and economically vulnerable people, and affirming the value of the lives of people with disabilities. One example that's come up is that you can imagine a future where women are not covered by insurance if they decide not to do genetic testing when they're pregnant. Say a pregnant woman has genetic testing and finds out she's carrying a fetus that's going to be born with a disability, and she decides to continue the pregnancy: An insurance company could claim that's a pre-existing condition, and refuse to cover the delivery or the child's healthcare after birth. So applying these broader principles would make sure that women aren't criminalized for *not* using technologies.

What are some of the challenges facing each of your communities as your organizations grapple with these issues?

→MY: The biggest challenge with these issues is that they are so complex. Organizations try to have clear mission statements and clear goals and clear objectives. But in reality, we all have stakeholders who have lives that are way more complicated than what we sometimes see. The challenge for us is to acknowledge the real lives that people have, and to make these stories live and breathe so that they can inform the policies we eventually need to see.

→KJ: One challenge is a lack of access to information. Choice USA is working on an egg-donation campaign with Generations Ahead, really trying to address the subject of college students being recruited as egg donors. Answering the questions about health impacts is a challenge, and so far there hasn't been a space to have those conversations beyond, "This is merely a service you can choose to do or

not to do and potentially get paid for it." We're trying to create that space, to complicate the conversation.

We've got a whole generation of young people who, since they were 10 years old, have had a political administration where science is discredited and treated like theory and not fact—and yet where, simultaneously, technological and medical solutions are common, the everyday answer to every problem. So how, then, can we get through to the social and political implications of the conversation when this is the norm?

→MM: One of the most challenging parts is the ableism that is so inherent in these reproductive technologies. Most people have some awareness, some starting point, around race and gender and sexuality, but for most people there is no starting point on disability. Even the mainstream disability movement is not really taking a radical stance around what ability means. People can understand how white bodies are more desirable and how black and brown babies are devalued, but don't recognize who gets valued and who doesn't around disability, especially when you're bringing justice to the center of the conversation and pushing out the surface notion of just "choice."

→JP: ART is an emerging area that has virtually no regulation in the United States, and everyone's learning curve is incredibly steep. And since so many of us, no matter what area of work we're in, see ourselves implicated in or connected to this subject—whether it's our own way of hoping to get pregnant or things that our friends are going through—it's very personal. And in light of that, we have a huge opportunity to just practice our policy-making differently, to bring together different strains of the progressive movement and hopefully approach policy-making with less fear and fewer knee-jerk reactions, and with more courage that together we'll be able to move forward. ●