

## **Reproductive Technology and Ableism**

Based on the belief that disability is a defect rather than a dimension of human diversity, **ableism** affects those with disabilities by inhibiting their access to and power within institutional structures that fulfill needs, like health care, employment, housing, government, education, religion, the media, and the legal system.  
(definition from Equal Access)

Equal Access is a group that promotes equality and access for Unitarian Universalists with disabilities. Find out more on their website (<http://www.equalaccess.org/>) or at the UUA's webpage on Disability and Accessibility (<http://www.uua.org/accessibility/>).

*Read these two articles and consider your own opinions about the intersections of reproductive choice, reproductive technology, and ableism.*

### **Disability, Prenatal Testing and the Case for a Moral, Compassionate Abortion (Excerpts)**

*By Sierra, RH Reality Check 8/16/2012*

Hermeneutics, the “for women” arm of *Christianity Today*, recently ran an article by Sarah Eekhoff Zylstra on prenatal testing: “What You Need to Know About the Hidden Benefits (and Costs) of New Prenatal Tests” (<http://blog.christianitytoday.com/women/2012/07/what-you-need-to-know-about-new-prenatal-tests.html>).

Apparently, science can do something awesome: tell you the genome of your fetus within the second trimester:

Using a blood sample from the mother and saliva from the father, scientists at the University of Washington mapped out the entire genome of a child while he was in the womb. The discovery, which was published June 6 in *Science Translational Medicine*, makes it possible to spot disorders from sickle cell disease to cystic fibrosis to Down syndrome in the second trimester of pregnancy.

Best of all, at least for those of us who shiver at the thought of an amniocentesis, is that it's noninvasive.

About 10 percent of the free-floating in a mother's blood belongs to her baby, and by comparing her blood with her own and the father's DNA, scientists can pinpoint which DNA belongs to the baby. From there, they can sequence the child's entire DNA code. Or at least, they can get pretty close. Their accuracy rate was about 98 percent in the infant boy they tested.

Zylstra says that, “at first blush,” this information looks “incredible.” Yes, it does. Because *it is*. This kind of technology gives us more control over our own reproduction, which means that we're better able to make ethical decisions about our parenting. As Zylstra points out, parents who are expecting a special needs child can prepare in advance for what that means. But there's a catch:

You can be emotionally prepared for his birth. You could choose a C-section if that was warranted, or line up services for him, or join a support group. **Or abort him.** That's the rub, said Gene Rudd, president of the Christian Medical and Dental Associations.

It's hard to imagine this test wouldn't be the instigation of selective abortions, since many women with prenatal diagnoses of Down syndrome currently abort, he said. **Prenatal testing in a country with legal abortion lets parents decide if that child is "good enough" to live.**

**Having an abortion to prevent a child from being born with Down syndrome or another disability can be a positive moral choice.** The disability rights movement is hugely important and I support it. It's especially vital for individuals with mental illnesses, who are often judged as "not really disabled" because there's nothing visibly wrong with them. Disabled people have a long history of being medically abused, used as test subjects without consent, being abandoned or forced to live in squalor, and being generally reviled, disrespected and treated like freaks. We *need* a movement to rectify that and prevent it from ever happening again. I'm glad we have one. Now. Here's where I depart.

**Respecting the rights of disabled people does *not* mean honoring or celebrating disability itself.** Apart from the perspective and political activism that many disabled people have found via their experiences as a discriminated-against class, I'd wager most people who are disabled would rather not be. Just like poor people value their wisdom but would really rather not be poor. I've been a poor kid. I'm still pretty poor. I've learned a hell of a lot about empathy from being poor. But would I *choose* to be poor? No. Would I want others to be poor kids? No. Would I jump at the chance to end poverty once and for all? Yes! I want people to listen to what I've learned, but I don't want them all to have to learn it the hard way, like I did. I would wager that at least some disabled people feel the same. When you argue that children with Down syndrome are "special gifts" or that raising them is a "rewarding experience" for parents, you are **appropriating their difficulties and fetishizing their difference. That is the opposite of respecting a disabled person.**

Amy Julia Becker of "Thin Places" (<http://www.patheos.com/blogs/thinplaces/2011/06/90-of-babies-with-down-syndrome-aborted-really/>) writes:

**I hate the thought that there will be fewer people with Down syndrome in the world** as a result of advances in prenatal testing. As I've written before, it impoverishes us all when we selectively abort babies based upon particular characteristics (gender, for instance, in China and India... disabilities here in America).

I understand this argument. I do. I get how parents of Downs children learn from their experiences and love their children fiercely and imagine how empty and cold the world would be without children like theirs. But this line of reasoning makes me profoundly uncomfortable. By all means, love your child! By all means, share your hard-earned wisdom! But to wish for Down syndrome to *never go away?* to never be cured? *Why would you wish that?*

I can't help but think that it's not about the children's quality of life (wouldn't you choose a life for your child that *didn't* include Downs, if you could?) but about the parents' inability to distinguish between their love for their kids and the condition from which their kids suffer. By all means, celebrate your child and his or her wonderful uniqueness! (I say this without irony.) But don't

reduce your child to the mere fact of having Downs, as though having Downs makes them a kind of endangered species and that Down syndrome *must continue forever* because kids like yours would never exist again without it. Your child would be special, you would have that bond, with or without Downs.

**Wanting to eradicate a condition that causes suffering or dependence in a population is *not the same as wanting that population to die*.** Imagine for a moment that we're not talking about abortion. If it were possible to "cure" Down syndrome prenatally, preserving the same fetus, would you deny your child the treatment because you'd hate to see fewer Down syndrome children in the world?

**Special needs children aren't high-maintenance pets that exist to teach you lessons about fortitude and compassion. *They are people*.** And it's *because* a special needs fetus will become a person at birth that abortion should be on the table. Responsible, *moral* reproductive choices involve doing the hard math and yes, making decisions to either give your child the best possible long, independent life or to terminate the pregnancy early if you know you can't. Clinging to a sound byte belief system that makes your decisions for you ("Abortion is murder!") or abdicating responsibility ("God will provide as long as I don't get an abortion!") means shirking your fundamental duty as a parent: to make decisions with your child's best interests at heart until your child can do so herself. That responsibility may lead you to give birth to and raise a disabled child – and more power to you! – as long as you're doing it with your eyes open and taking every possible precaution to make sure you can deliver on the promise of care you are making your newborn child. But it may also mean having an abortion.

**Focusing on the "rewards" to parents of raising a special needs child means privileging parents' personal growth over the best interests of their potential child.** If parents choose to bring into this world a child that cannot be reasonably expected to care for himself as an adult, they are gambling with their child's future. Who will care for him or her when the parents are gone? Do they have the resources to provide for their child's medical needs? Do they have other children who would be neglected because of their parents' intense focus on caring for the special needs child?

Now, I understand that many, many Downs people are able to function in the world without immediate care, but others can't. I think it's awfully brazen and selfish not to consider one's potential child's quality of life *for the entire duration* of that child's life before deciding what to do. I think it's necessary to ask tough questions of yourself, to honestly answer the question of whether or not you can provide that child with everything he or she will need *for life*.

Not every family can afford the medical care of a special needs child. Not every family can afford the *time* spent caring for a special needs child, especially if they already have multiple children. To demand that families that *know* they lack these resources nonetheless give up everything to bring a child into a world where it will be neglected, inadequately treated by doctors, and in all likelihood end up in foster care or, as an adult, homeless, is cruelly insane. To focus on mere "life" to the exclusion of the quality thereof is not just stupid, it's evil. It is deliberately inflicting suffering on others to soothe your own conscience.

**And: parents and caregivers are people, too.** They do not forfeit their own needs when they have children; indeed, doing so is actually *harmful* to children. Recall the many times I've said that having a stay-at-home mother made me feel hopeless and guilty about becoming a woman. I was put in the impossible position of either following in her footsteps, thereby ensuring that every female in our line would do nothing but sacrifice for her children and never get to have her own dreams, or *not* following in her footsteps and feeling guilty that I was (a) rejecting her by rejecting her lifestyle and (b) doing my own potential children some kind of injustice, even though I didn't want my children facing the quandary I was! I wished my mother had more of a life outside of raising me, because then I would be freer to have a life, too.

**If parents choose to welcome a special needs child into their family, they *must* consider how it will affect not only that child, but also themselves and their other children.** They must make room for breaks and self-care to preserve their own health, mental and physical. In my own church, there was a woman with two children who got pregnant and found out her child had a fatal defect. She decided against having an abortion, believing that God would honor her and heal her child (or at least provide for it). The child lived 13 years in unspeakable pain, without cognition, undergoing surgery after surgery until she died – and by this time the family had exhausted its resources, the other two children had been practically abandoned. The mother had worked herself to the bone, endured a failed promise from God, and had to mourn the child all over again at the end of it all. That child was not a “blessing.” It was not a “rewarding” experience – though the mother might tell you so out of sheer love and the need to justify her situation. The child's birth *destroyed her family*, and she was never even aware enough of her own existence to realize she was loved.

**It is possible to choose abortion based on a positive screening for genetic disorders *because you are morally opposed to inflicting suffering on others.*** It is possible that women who abort fetuses with Down syndrome or more serious disorders do it *not* because they hate Downs people or like genocide or are selfish, but because they honestly believe it's what's best for their families.

## **Disability, Abortion, and Ethics: A Response to Sierra (Excerpts)**

*By S. E. Smith, RH Reality Check 8/30/2012*

I'm still seething over [her] post at RH Reality Check, in which I am essentially informed that my life has so little value, is so not worth living, that I was such a burden on my father to raise, that I should have been aborted. Things like this are why I have problems interacting with the mainstream reproductive rights movement (<http://tigerbeatdown.com/2011/05/10/getting-some-nuance-up-in-your-reproductive-rights/>), which seems bent on using us as a tool just as much as the right is. In this piece, in which not a single actual living disabled person appears, the author proceeds to lay out an argument for abortion for disability that has, rightly, gotten the disability community up in arms.

It starts with a very dismissive, snide, flip introduction in which the author effectively says 'read this or not, I don't really care, but don't hate me!' The key sentence of the introduction tells you a lot about what is to follow: 'I believe that abortion of a disabled fetus can be a compassionate choice made for morally sound reasons, and does not at all conflict with the respect due to disabled people.'

I...disagree.

But let's take Sierra's points one by one, because it seems that whenever disabled people react with anger to rhetoric like this, we're penalized for it. So, Sierra, here we go. Prepare for logic.

Sierra points to an article about prenatal testing (<http://blog.christianitytoday.com/women/2012/07/what-you-need-to-know-about-new-prenatal-tests.html>), which I happen to agree is great science. We can find out more about a fetus than ever before with the benefit of tests which allow us to make informed choices about the pregnancy. Those choices can include abortion, preparing for birth, taking special precautions, and other measures that are private medical decisions. Inevitably, the fact that it's possible to test for many common disabilities means that abortion for disability is going to come up as a topic.

This is a fraught ethical subject, and it's fraught in no small part because of the social devaluation of disability. On the right, people with disabilities are fetishised as tools and instruments to a larger end; conservatives make sweeping statements about 'respecting life' when it comes to fetuses who might be born with disabilities, though of course they do nothing to support those fetuses once they're born. This rhetoric does not allow room for the fundamental humanity of people with disabilities. Meanwhile, the left treats us like we don't exist and aren't a part of society, and don't *belong* in society, frequently advancing arguments like Sierra's: that abortion for disability is, quote, '**a positive moral choice.**'

She says the article fetishises disability. Again, I agree on this point. Like a lot of media, it talks about disability as a 'gift' and the author, like Sierra, apparently didn't feel the need to include the

voices of *factual disabled people* in her piece. Sierra proceeds to give lip service to the disability rights movement, but here's the moment where she goes off the rails:

**'Respecting the rights of disabled people does *not* mean honoring or celebrating disability itself.'**

An actual recordskip occurred in my house at this moment. Excuse me, but some aspects of the disability rights movement absolutely *are* about honouring and celebrating disability itself. I'm disabled and *proud*. I *love* who I am and I'm not settling for this body and mind, dealing with it because it's there, overcoming anything, or making the best of a bad deal. I am who I am because of my disabilities, I love who I am, I love my disabilities as part of myself. You're better damn well bet I'm going to honour and celebrate that, and raise my fists in solidarity with disabled people all over the world who feel the same way.

At the same time, that doesn't mean all disabled people share that sentiment and experience. And that's okay, because there's room in disability rights for everyone. What I am pushing for is disability as a value-neutral status that *individual disabled people, not the people around them*, get to make of what they will. Maybe that means celebrating your amazing body. Maybe that means corrective surgery. Maybe that means something else entirely.

**'I'd wager most people who are disabled would rather not be.'**

Wrong. Maybe instead of speculating about the experience of disability, you should have consulted actual people with disabilities, explored the vibrant and lively disability rights movement, and interacted with the people you're writing about. I'm assuming you didn't think to do that because you apparently believe we live lives of unrelenting suffering, and/or we can't communicate with nondisabled people; or was every potential interview subject too busy to fit you into their schedules between morning misery and afternoon moping?

Sierra says:

I get that who we are is shaped by experience and that many disabled people consider disability to be integral to their personalities – just as I see poverty as a formative experience for me – but I doubt they would have chosen to be disabled in the first place. Would they have voluntarily given up able bodies for the wisdom earned from being disabled? Would they refuse treatment, if it were available? Would they choose to suffer disabilities just so that their parents could have the “reward” and “special gift” of raising them?

Let's deconstruct this a bit. Again, Sierra is speculating on an experience that is not hers, and she's making assumptions based on her own view of the world. She 'doubts' that we would choose to be disabled. She doesn't know that. As she herself acknowledges in her own snikey introduction, fetuses aren't capable of making choices (we're focusing, for the purpose of this piece, on congenital

and genetic disability rather than acquired disability). I can say, *from my own experience*, that I wouldn't choose to be any different even if, yes, sometimes my disabilities are frustrating and pose obstacles for me. I can also say, *from my own experience*, that I have refused some treatments for my disabilities, and so do some other people with disabilities.

In fact, some people forcibly labeled as disabled, like some autistic people and some Deaf/hard of hearing folks, *don't identify as disabled*. And they refuse treatment for what they (rightly) see as a natural human variation.

Speaking of fetishising disability, Sierra, I'm not 'wise' because I'm disabled. I'm a human being. Disability hasn't conferred any more or less wisdom. Disability is not 'suffering,' and the fact that you use this word clues me in to the fact that you have a very ableist view on the world, for all that you attempt to use language from the disability rights movement to convey your understanding of what it's like to live with disability. And you're centring parents here in a rather striking way.

**'Wanting to eradicate a condition that causes suffering or dependence in a population is *not the same as wanting that population to die.*'**

Statements like 'I want a cure for autism' or 'I want a cure for Down Syndrome' are eliminationist in nature. These statements indicate that you want an entire population to disappear. And, newsflash, attitudes like these are why parents who torture, abuse, and kill their disabled children are often not held accountable. Because raising a disabled child is *such hard work* and the *extenuating circumstances* should surely be considered when evaluating the case.

Sierra and I actually agree on point two; acting like disabled children are some kind of special lesson and growth object is indeed dehumanising and gross. That said, *disability doesn't create inherent suffering*. It's notable that she focuses on only two disabilities, Down syndrome and cystic fibrosis, in this piece. I'd be curious to know which other disabilities she believes fall under the rubric of 'suffering.' Individual parents need to make individual choices based on available information about the pregnancy and their lives, something I think Sierra and I can also agree upon, but she's pushing very hard on the argument that abortion for disability is almost *necessary* if you want to make the correct ethical choice for a pregnancy.

Simply put, it's not. It's not like the idea of aborting for disability is anything new, or that parents don't get a *lot* of pressure to jump to abortion rather than more information as soon as a prenatal diagnosis is delivered. Choosing abortion because you don't have the capacity to care for a child is a reasonable ethical choice, and it's not the only option, though I'd note that people are not exactly lining up to adopt disabled children, nor are social services rushing to provide support to disabled children and their families. Choosing abortion because you feel *no one* could offer the child a good quality of life is a value judgment on someone else's life, but it's also a personal choice because you're the one carrying that fetus, which makes it yours to make and no one else's. Ultimately, the option people feel most comfortable with is a personal decision, and that decision is the most ethical one for a given pregnancy.

Next, she brings up the issue of class, a key component in this discussion, as I've actually talked about here in the past (<http://tigerbeatdown.com/2011/05/12/wrongful-birth-not-just-the-stuff-of-jody-picoult-novels/>). However, Sierra's approach to it is utterly backward. Rather than saying we need to talk about the lack of social support for people with disabilities, including both the lack of financial resources and the ableism rife in this society, she apparently thinks the solution is to abort disabled children. Because their lives aren't worth living (see 'suffering' above) and their parents can't afford to give them the quality of life they deserve, the natural solution is not agitation on a larger scale for social change to tear apart the system that forces people to make the decision to abort for economic reasons, but to simply promote abortion as the right moral choice. No one should have to abort a children for economic reasons or for lack of social and community resources, and *that* is what we should be working towards.

Her next point rehashes some very old, tired, and boring arguments about how caregiving is so *hard* and won't someone think of the family. Here's the thing: Providing care for *any* child is difficult, and disabled children do present some extra challenges. The problem here, though, is not that children with disabilities are inherently difficult to care for, but that caregivers enjoy absolutely no social support.

Accessing respite care, funding for aides, daycare, and other forms of assistance is virtually impossible, unless you are, yes, very wealthy. We need to be talking about this. We need to be asking why discussions about abortion for disability focus on how awful disability is and how painful it is to have a disabled child, instead of how terrible it is that society can't be bothered to promote the welfare of disabled people. We need to be asking why arguments like Sierra's are advanced over and over again, and why people like Sierra don't examine the deeper social issues going on here.

I've often said that choosing abortion for disability doesn't mean that you hate disabled people. But when ableist society is contributing to the pressures on you to abort, you need to acknowledge that. I want all children to be born into homes where they are eagerly anticipated and will receive love and support throughout their lives, no matter what their disability status might be. And I want all parents to have all the information they need about their pregnancies to make the best choices for them, and for their children. And I want all parents to have social support so they aren't forced to make choices on the basis of external pressures like lack of money, lack of access to care, and other issues that can come up when making decisions about a pregnancy.

But I'm not going to sit still for someone telling me that my life is suffering, that my life is not worth living, and that ergo I should have been aborted and people like me should be aborted. I'm on the autism spectrum. There are a lot of people in the world who want to eliminate people like me. I'm not interested in playing the gross anti-choice game of 'just think who might have been aborted!' but I would like to point out that because there's a widespread belief that autism is bad and should be eliminated, *living autistic people*, as in *actual human beings who are around right now*, face increased prejudice. That includes hate crimes committed against us, it includes discrimination, it includes abuse by parents and 'caregivers.'



And that is a problem that articles like this contribute to. I don't want to be used as a pawn by the right *or* the left to advance its own agendas about reproductive rights and parenting. Ultimately, parents need to decide what they are equipped for, and I want to provide a world where their choices are supported.

In a world where people, yes, celebrate and honour disability, our lives would be valuable and we would be considered on equal footing as nondisabled people. And in that world, people wouldn't talk about disability in terms like 'suffering' and say that parents have a moral obligation to abort to 'avoid inflicting suffering.' They'd say that *all parents* have the right to make decisions about what happens inside their own bodies, on the basis of as much information as possible, and those decisions are *private* and not subject to public discussion and judgment.