

Faithful Choices
A sermon delivered by Rev. Rebecca F. Benner
At the Accotink Unitarian Universalist Church
Sunday, February 18, 2007

READINGS

from *Newsweek*, January 29, 2007, by George Will

What did Jon Will and the more than 350,000 American citizens like him do to tick off the American College of Obstetricians and Gynecologists? It seems to want to help eliminate from America almost all of a category of citizens, a category that includes Jon.

Born in 1972, Jon has Down syndrome. That is a congenital condition resulting from a chromosomal defect that causes varying degrees of mental retardation and some physical abnormalities... There also is increased risk of congenital heart defects, childhood leukemia and Alzheimer's disease...

As women age, their risk of having a Down syndrome baby increases. It has become standard practice for women older than 35 years old to be offered genetic counseling and diagnostic testing.... new ACOG guidelines recommend that all pregnant women, regardless of age, be offered such counseling and testing.

The ACOG guidelines are formally neutral concerning what decisions parents should make on the basis of the information offered. But what is antiseptically called "screening" for Down syndrome is, much more often than not, a search-and-destroy mission: At least 85 percent of pregnancies in which Down syndrome is diagnosed are ended by abortions.

Medicine now has astonishing and multiplying abilities to treat problems of unborn children in utero, but it has not ability to do anything about Down syndrome...So diagnosing Down syndrome can only have the purpose of enabling—and, in a clinically neutral way, of encouraging—parents to choose to reject people like Jon as unworthy of life.

from *Newsweek*, February 12, 2007, Letter in response to George Will
by Leah Guggenheimer

Early screening may lead some parents to abort, but it probably leads just as many to research their child's disability and prepare themselves, their medical team and their home environment to lovingly raise a child with special needs. *Special* is exactly the right word—special rewards, but also special challenges that are better met with education, preparation, and acceptance. What is gained by forcing ill-prepared parents to badly raise a child who needs even more love and support than a typical child? How can one rationally oppose "Forewarned is forearmed"?

from *The Washington Post*, January 14, 2007, by Patricia E. Bauer

She was a fresh-faced young woman with a couple of adorable kids, whiling away an hour in the sandbox at the park near my home. So was I, or so I thought. New in town, I had come to the park in hopes of finding some friends for myself and my little ones.

Her eyes flicked over to where my daughter sat, shovel gripped in a tiny fist, and then traveled quickly away. The remark that followed was directed to the woman next to her, but her voice carried clearly across the playground. “Isn’t it a shame,” she said, an eyebrow cocked in Margaret’s direction, “that everyone doesn’t get amnio?”

It’s been more than 20 years, but I saw the face of that woman again when I read about the recommendation from the American College of Obstetricians and Gynecologists (ACOG) this month that all pregnant women get prenatal screening for Down syndrome. I worry that universal screening brings us all closer to being like that woman at the sandbox—uninformed, judgmental, and unable to entertain the possibility that people with disabilities have something to offer.

...What’s gone undiscussed in the news coverage of the guidelines seems to be a general assumption that reasonable people would want to screen for Down syndrome. And since nothing can be done to mitigate the effects of an extra 21st chromosome...the further assumption is that people would be reasonable to terminate pregnancies that are so diagnosed...

I understand that some people very much want this [early screening], but I have to ask: Why? Among the reasons, I believe, is a fundamental societal misperception that the lives of people with intellectual disabilities have no value—that less able somehow equates to less worthy. Like the woman in the park, we’re assigning one trait more importance than all the others and making critical decisions based on that judgment.

In so doing, we’re causing a broad social effect. We’re embarking on the elimination of an entire class of people who have a history of oppression, discrimination, and exclusion.

from *The Washington Post*, January 20, Letter to the Editor
by Bennett Rushkoff and Karen Whitesell

We wholeheartedly agree with Patricia E. Bauer’s statement that her daughter and all other people with Down syndrome—indeed all people—“have value and dignity and are worthy of celebration.”...

But screening for Down syndrome is not necessarily inconsistent with valuing people who have Down syndrome. A pregnancy involving a Down syndrome fetus has a much higher risk of ending in miscarriage or stillbirth. By identifying these high-risk pregnancies, prenatal testing can help physicians increase the odds of a woman successfully delivering her Down syndrome baby.

Eleven years ago, our first daughter died during birth after weeks of undiagnosed fetal distress. Only after the autopsy did we learn that she had Down syndrome. Had this diagnosis been made early in the pregnancy, increased fetal monitoring might have saved our daughter’s life.

SERMON

The world of prenatal testing, diagnosis, decision-making, and treatment has become increasingly complex in recent years. With advances in knowledge and technology, potential parents are faced with opportunities and choices that no generation has had before. This is true, of course, not only in the area of prenatal medicine, but in almost all areas of health—genetic screening and treatment for adults, the possibilities and complications of stem cell research and treatment, options for hanging onto life for much longer than has ever been possible before. The changes and advancements in what is possible, in what we must consider and decide between, have come dizzyingly fast, leaving us little or no time to allow our hearts and minds to catch up. Much

more is possible, but we have not yet had the chance to explore enough the moral and ethical issues at stake, or the philosophical and theological questions involved.

Though this is true across the spectrum of medicine, I do believe there are particular issues and questions involved in advances in prenatal medicine. Issues that go to the heart of how we understand and value people, what our place is in the history of humanity, how much of nature we can and should control. Having recently entered the world of these questions, these choices, I want to explore with you what I believe some of the big questions are and what I believe is at stake for all of us in these conversations.

As I have moved through my pregnancy, my mother and I have, of course, had conversations comparing and contrasting our experiences of being pregnant. The biggest difference is clearly in this area—the approach of the medical establishment and the knowledge and choices available to parents-to-be.

My mother, when she was pregnant with me, thirty-five or so years ago, went to the doctor regularly, as do I. About halfway through her pregnancy, they were able to hear my heartbeat using a stethoscope, which they then listened to at every subsequent visit. She was given general advice on nutrition and how to take care of herself, but both my parents and the doctor assumed everything would be fine and moved forward with confidence.

My experience has been somewhat different. Partly this comes from the fact that I am older than my mother was when she was pregnant with me. I have moved into what they call “advanced maternal age” (an official diagnosis), which makes me and the baby more vulnerable to a whole host of complications. But much of the difference in our experience comes from advances in medicine and technology. Derek and I were able to see a sonogram picture of our baby very early on, and have seen him or her a number of times since. We could hear the heartbeat much earlier than my mother and father did, and we know much more about how the baby is growing and changing.

We also know much more about what can go wrong. Some of this comes from the doctor, some from the reading we have done, and some from my time spent as a chaplain on a high-risk labor and delivery unit and neonatal intensive care unit of a Chicago hospital. We have been offered a variety of tests, many of which we have chosen to do. The advice given about food and exercise and general pregnancy behavior may include much knowledge not present a generation ago, but it also includes a good deal of anxiety and sometimes the underlying message that, with a wrong step here or there, we can easily ruin this baby’s life.

The advances that appear to be just around the corner are even more striking. These days, doctors can test for a good number of genetic and congenital problems including, as the editorials and letters make clear, Down syndrome. That list is only going to get longer. We already are able to determine the sex of the baby long before it is born. Soon, perhaps, we’ll know a fetus’s future likelihood of getting breast or prostate cancer, of being overweight, or not very tall. And it is not farfetched to think that maybe someday doctors will be able to test for character strengths and weaknesses, for emotional stability, for attractiveness, for particular talents or interests, for sexual orientation or gender identity.

Not all of these things are determined solely by genetics of course, and our environment and upbringing have a great deal to do with the people we eventually become, but it is increasingly clear that some elements of who we are and who we can be are present from before our birth.

Knowledge about the condition and likely future path of a particular fetus is one thing, but the larger issues come when we have to decide what to do with that knowledge. As the two editorials I read from earlier make clear, prenatal testing for Down syndrome has, intentionally or not, led to a high number of abortions of Down syndrome fetuses. We know that in China, with its at times very strict one-child policy, knowing the sex of the baby has allowed families to abort a girl child in hopes of having a boy. Families that carry genetic diseases like cystic fibrosis or Tay-Sachs or Huntington's disease are these days faced with decisions about what to do if they discover their baby will be born with the disease as well.

As the response letters I read from earlier illustrate, the question of whether to terminate or continue a pregnancy is not the only one at play. Families can use an early diagnosis to prepare, to educate themselves, to line up a medical team prepared to deal with the problem, to choose a hospital with the resources necessary. Children can be saved with such advance knowledge. I would imagine that the decisions process in almost all of these situations is heartwrenching, whatever choice is made, and it is hard for us to sit in judgement of this.

But all of this speaks only to the practical, logistical elements of this issue. What I believe is most important is the deeper questions of the kind of world we hope to have, the way we value people, our understanding of our place in the universe.

One of the most powerful pieces of writing on parenthood I have ever read was something I saw a long time ago. Though I searched for it to share with you this morning, I didn't remember enough about the author or the context in order to find it, so you will have to settle for my recollection of what it said.

The piece talked about becoming a parent being the deepest lesson in learning how to offer unconditional love. We choose many of the loves in our lives—our partners and spouses, our friends and communities. But our children come to us chosen only in the abstract. Whatever hopes we have for our children, they are who they are, something which is ultimately out of our control. If we fulfill our task as parents, we love them whoever they are, to whatever degree they live up to our hopes and expectations, whatever the surprises they bring. We love them—gay or straight, able or disabled, fat or thin, smart or not, athletic or not, musical or not, quiet or loud, difficult or easy. As a parent, we are called on to find a source of love that goes beyond achievement or expectation. The writer did not claim that this was easy, or automatic, but rather that becoming a parent gives us the opportunity to learn this kind of love and to offer it to another.

This idea is put in a slightly different way by Leon Kass, in his book *Life, Liberty, and the Defense of Dignity: The Challenge for Bioethics*. In a chapter on the dangers of human cloning, Kass writes:

When a couple normally chooses to procreate, the partners are saying yes to the emergence of new life in its novelty—yes not only to having a child, but also to having whatever child this one turns out to be. In accepting our finitude, in opening ourselves to our replacement, we tacitly confess the limits of our control.

...our children are not our children: they are not our property, not our possessions. Neither are they supposed to live our lives for us, or to live anyone's life but their own. Their genetic distinctiveness and independence are the natural foreshadowing of the deep truth that they have their own, never-before-enacted life to live. Though sprung from a past, they take an uncharted course into the future. (p. 161)

In both of these ideas we can hear echoes of our Unitarian Universalist principle of respecting the inherent worth and dignity of every person. At the ultimate level, we are not more or less

worthy because of our intellect, our attractiveness, our musical or athletic ability, or even our kindness. We are of value simply because we are.

So how does both the current reality and future possibility of prenatal testing affect these ideas? What impact do the choices and possibilities that exist now and which might come in the future have on our belief in the ultimate value of all people, on the challenge of offering genuine unconditional love, on the humility that comes only with realizing that we are not in control? What does it mean that the vast majority of fetuses diagnosed with Down syndrome are aborted? What will it mean if and when we are able to modify a fetus's genetics to make a child who is more beautiful, more intelligent, more ambitious? What kind of world will it be when we start choosing who our children are rather than receiving them as a gift from the miracle and mystery that is life?

In some ways, it feels that these questions border on fantasy. Who knows if the technology will ever exist to make such choices. And yet, as we know, version of these choices are already being made and we are not talking about it nearly enough.

When Derek and I were going through the various tests earlier in my pregnancy, I was struck by how alone with the decisions we were. In one way, I relished this. Of course they should be our decisions. Who else could possibly tell us whether or not we should raise a Down syndrome or other kind of disabled child? Only we could know what is right for us and it was really nobody else's business. In many ways, I can only honor and respect the thoughtful, probably often agonizing decision that many people have to make.

At the same time, all these individual choices shape our society as a whole. If indeed, a generation from now, there are no more Down syndrome children, will the world be a better place? What if the time comes when we, or at least those of us with money and access to high level medical care, are able to choose our child's level of attractiveness or intellect, or choose his or her sexual orientation? Will we then see this as more than the choices of individual parents? Will we then start having the conversations we should be having now?

When I think about our child who will be born a few months from now, of course I want a happy, healthy child. Of course I want a child with the best possible chance of having a good, relatively easy, productive life. What parent-to-be doesn't? But my values about what makes a good and productive life may very well influence too much what I think it takes to *be* happy and healthy. I want a child who is joyful and curious and confident. If I am honest, I want a child who does not inherit my ever-present struggle with weight or my tendency toward anxiety. I want a child who *does* inherit my talent for music and a laugh like mine (and my mother's), which is loud and distinctive enough to embarrass his or her own children when they come along. I want a child interested in learning and perhaps more adventurous than I have been. I could go on and on about my hopes and dreams. But I have to ask myself—would either this child or I be better off if I could make these things be true?

Among the greatest gifts that children bring to us are mystery, possibility, and a combination of characteristics, strengths, weaknesses, struggles, and triumphs that is far better, far richer than anything we could cook up ourselves. We know how much trouble parents and children get into when parents have a particular life planned out for their child. Pushing our children to fulfill our dreams almost never works. Will the world really be a better place if we are able to program them to do so? How will they ever become their own people? How will we ever learn our proper and limited place in the universe?

Imagine the choices that people would have made some generations ago. Imagine the qualities that would have been chosen, or eliminated. Imagine the children we would have been if our parents had chosen for us, or our grandparents had chosen for them. Do we really believe we are so much wiser?

There are no easy answers here. The line between decisions being made today for health and to avoid suffering and decisions that might be made tomorrow for happiness or vanity or convenience is fuzzy at best, and we may not know when we cross it. Perhaps we already have.

All I know is that we need to be talking about this. We cannot pretend that the recent medical, genetic, and technological advances affect individuals alone. We need to speak up, to remind ourselves what is at stake here. We need to remember that we do not always know what is best and that mystery can bring us greater gifts than anything we might create on our own.

We will not be able to stop the march of technology, to lessen the choices we face. But perhaps we can slow things down enough to allow our hearts and minds to catch up. To remind ourselves that just because we *can* doesn't mean that we *should*. To make sure that our choices reflect not only the practicalities of a situation, but also what we hold most dear.

As we think about the generations to come, and the world we want to leave them, I want to close with these words from Kahlil Gibran:

Your children are not your children.

They are the sons and daughters of Life's longing for itself.

They come through you but not from you,

And though they are with you yet they belong not to you.

You may give them your love but not your thoughts,

For they have their own thoughts.

You may house their bodies but not their souls

For their souls dwell in the house of tomorrow,

which you cannot visit, not even in your dreams.

You may strive to be like them, but seek not to make them like you.

For life goes not backward nor tarries with yesterday.

You are bows from which your children as living arrows are sent forth.

*The archer sees the mark upon the path of the infinite, and He bends you with His might that His arrows
may go swift and far.*

Let your bending in the archer's hand be for gladness;

For even as He loves the arrow that flies so he loves the bow that is stable.

May we remember that it is so. Amen.