

## Communications

Many people are alarmed at the prospect of cloning human beings and altering human genes. Even if these things could be done safely and without unintended consequences there is certainly no consensus about what human traits are 'normal', about whether any sort of genetic 'enhancements' might be desirable, or even what such 'enhancements' might be.

Why do people want children and how does DNA testing fit into that? What is a 'normal' human being? If genetic engineering can create happier, healthier humans, why not prevent people with 'defects' from having children or clone those with the 'best' DNA? Should we enhance the DNA of some to create superhumans who are mentally or physically gifted? Will the future see a genetic underclass whose parents did not 'improve' their genetic inheritance? Does this mean we are playing God?

To help bring these issues into public discourse, we are producing *Making Perfect People*, a one hour television documentary about the use of DNA testing by several differently able families when they are having children. These stories are grounded in everyday life while they are framed by observations from several scholars who offer historical background plus ethical and social perspectives.

Some of the families in the film:

Matt and Amy, a dwarf couple (who some think should not have been born let alone plan to have children), challenge the assumption that life as a dwarf is not worth living. We see the family at the Little People of America convention, at home, and at work. As Amy puts it, "What's perfect? Who is to decide what's perfect?" They are equally delighted with all their children, both average size and little.

Rachel and Barry, Ashkenazic Jews whose families were nearly wiped out by the genetic policies of the Nazis. In reestablishing their families after the Holocaust many felt threatened by the prevalence of certain genetic diseases in the inbred Ashkenazic Jewish population. The community developed D'or Yeshorim, a voluntary pre-marital genetic testing program which helps carriers for certain genetic diseases avoid marrying so as to reduce the incidence first of Tay-Sachs disease and now Canavan's, Gauche's, and cystic fibrosis. While the program is purely voluntary and has always maintained strict confidentiality to avoid stigmatization of carriers, it is now raising concerns as it tests for more and more conditions. "Everyone has something," says Rabbi Tendler, a bio-ethicist at Yeshiva University, "pretty soon we won't be able to marry anyone."

Felix and Jacinta, a couple who are thriving in the Deaf community in Seattle and are planning their first child. They disagree about whether they might prefer to have a deaf child who could fully join them in the Deaf community or a hearing child who will be able to participate more fully in the

broader society.

Note: The preview video gives a sense of our filmic approach and some of the ground we will cover, but only the section on the dwarf family is complete. We hope to acquire completion funding in order to finish *Making Perfect People* by the middle of 2002.

Consultants: Troy Duster - Director, Institute for the Study of Social Change, UC Berkeley and past Chair of the Working Group on Ethical, Legal, and Social Implications of the National Institute for Human Genome Research; Robert Resta - editor of the *Journal of Genetic Counseling* and Director of Genetic Counseling Services for Swedish Medical Center in Seattle; Marsha Saxton - lecturer in disability studies at UC Berkeley, research associate at the World Institute on Disability, member of the ELSI Working Group; Rabbi Moishe Tendler - biologist and professor of Talmudic Studies at Yeshiva University.

For more information: Melissa Young/Mark Dworkin, 360-341-1269, <info@movingimages.org>, or <www.movingimages.org> and click "In Production."

Melissa Young and Mark Dworkin

To be published by Modern Language Association in August 2002: *Disability Studies: Enabling the Humanities* edited by Sharon L. Snyder, Brenda Jo Brueggemann, and Rosemarie Garland-Thomson; \$40.00 cloth; \$22.00 paper (suggested retail).

Images of disability pervade language and literature, yet disability remains an unspoken topic in today's culture. The twenty-five essays in *Disability Studies* provide perspectives on disabled people and on disability in the humanities, art, the media, medicine, psychology, the academy, and society. Introduced by Sharon L. Snyder, Brenda Jo Brueggemann, and Rosemarie Garland-Thomson and containing an afterword by Michael Berube (author of *Life As We Know It*), the volume is rich in its cast of characters (including Oliver Sacks, Dr. Kevorkian, Samuel Johnson, Mark Twain, Walt Whitman, Nero Wolfe); in its powerful, authentic accounts of disabled conditions (deafness, blindness, MS, cancer, the absence of limbs); in its different settings (ancient Greece, medieval Spain, Nazi Germany, modern America); and in its mix of the intellectual and the emotional, of subtle theory and plain spoken autobiography.

This title will be available through <www.mla.org> and also through booksellers.

You are invited to subscribe to a new electronic discussion list on the pedagogy of disability. DS-Teaching

invites conversation among people who have any degree of involvement in teaching disability studies - teachers or prospective teachers, students or prospective students, authors or artists whose works are used in the classroom, activist-scholars or activists who are not involved in scholarship, and anyone else with a pedagogical interest in the field.

This list is a discussion forum for the learning community of teachers and students of disability studies. Because disability studies is an interdisciplinary field, it seeks to include membership and representation of as wide a variety of disciplines and approaches as possible. Because the field is strengthened by cross-cultural perspectives, it seeks to include as international a membership and representation as possible. We also hope to serve as a bridge academia and activism, as both communities can benefit one another, and both are crucial components of disability studies as a whole.

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