

AMNIOCENTESIS FOR PRENATAL CHROMOSOMAL DIAGNOSIS

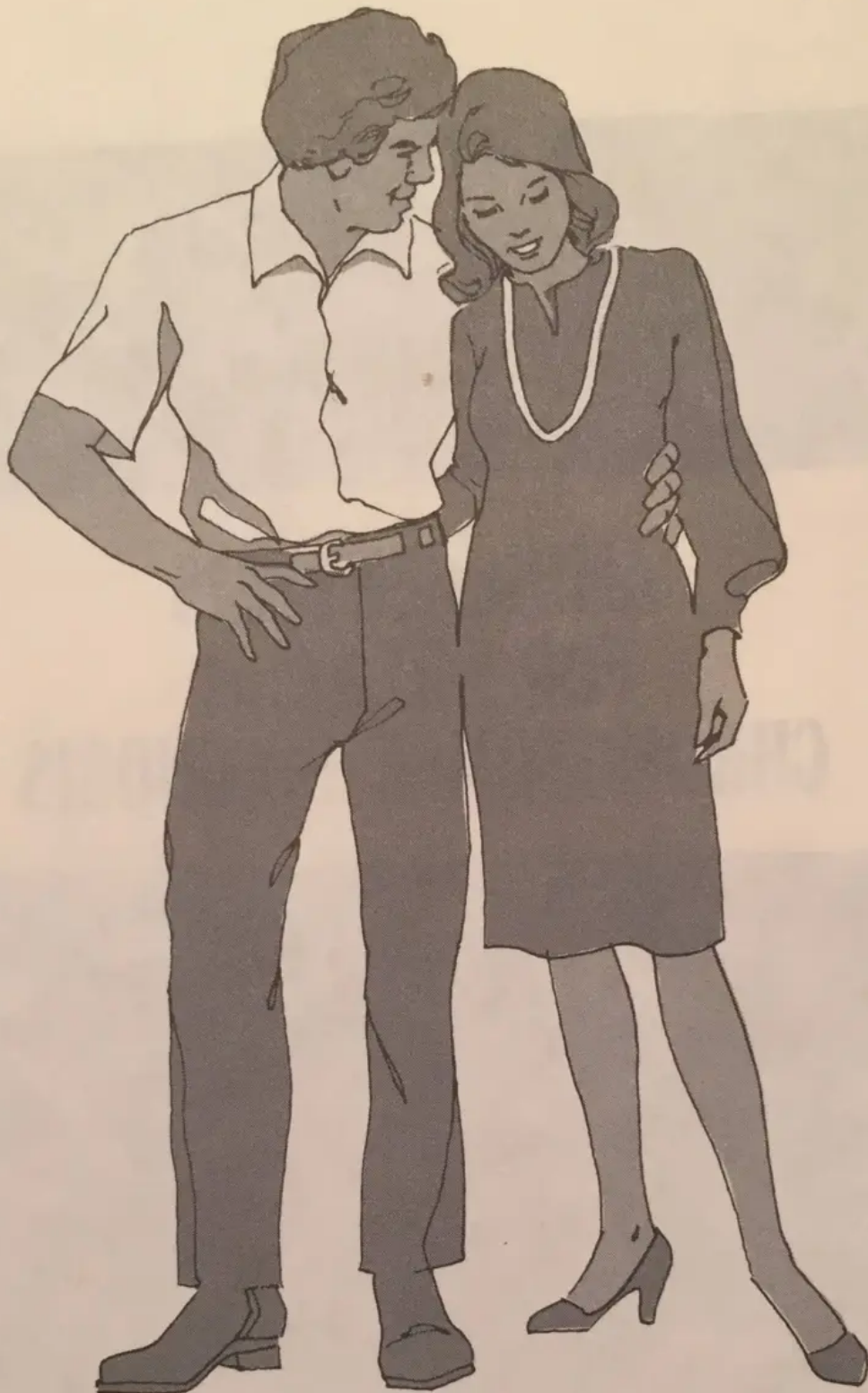
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U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
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“2. Pregnancy is usually a happy time. Most newborn infants are normal and healthy. Even so, parents often wonder if their unborn child will be normal.”[1]

By the late 1970s, reproductive decisions and the sense of normality were challenged and redefined by the women's liberation and disability rights movement, among others. However, as the U.S. Department of Health, Education, and Welfare pamphlet "Amniocentesis for Prenatal Chromosomal Diagnosis" conveys to readers, the desire for a "normal" pregnancy complicated the choice over abortion and the desirability of a "normal"—coded as nondisabled—infant. Considering the historical context in which scientific knowledge about amniocentesis, genetic testing, and disability was produced can help us interrogate the uses of new technologies and the ethical implications of their uses.



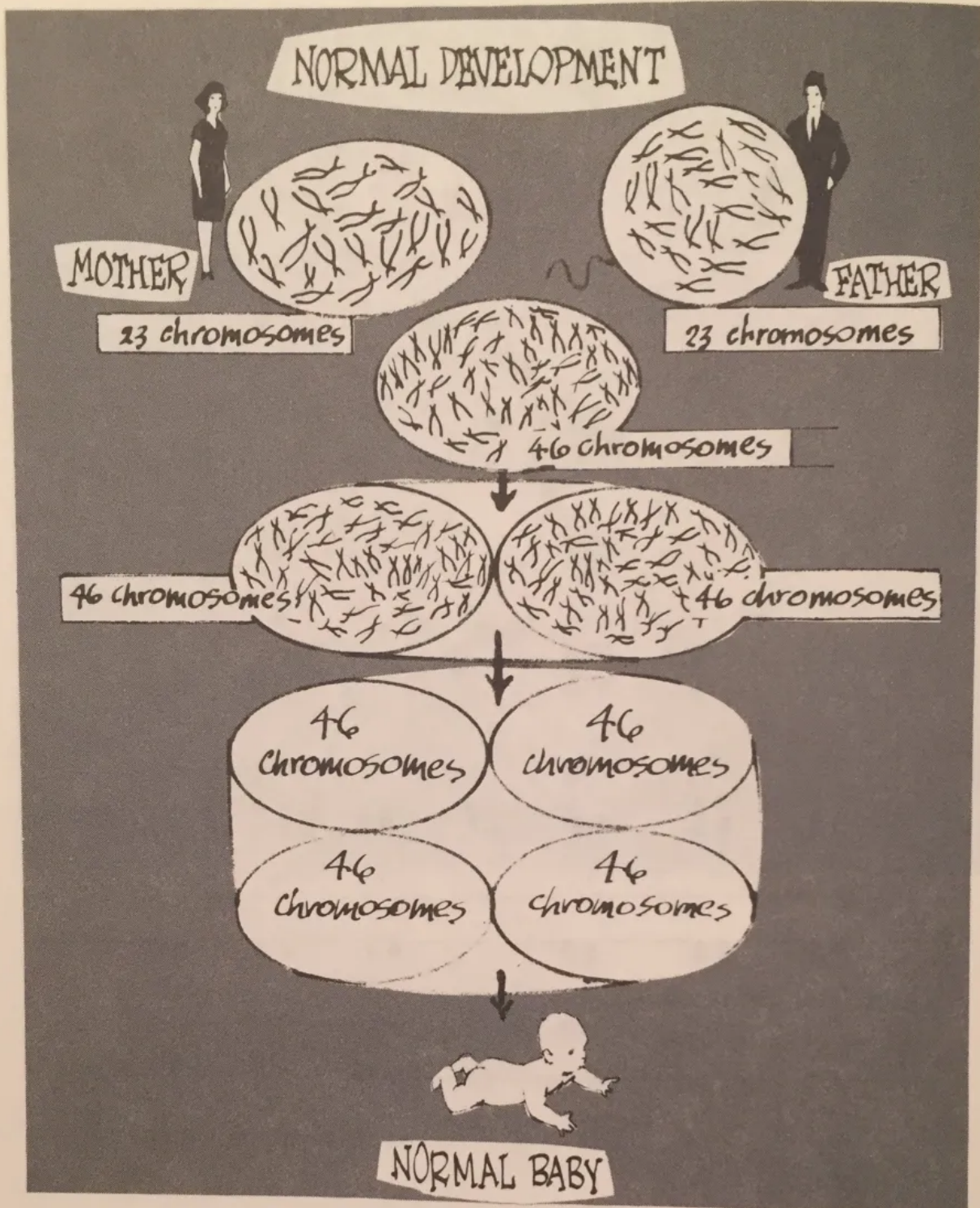
2. Pregnancy is usually a happy time. Most newborn infants are normal and healthy. Even so, parents often wonder if their unborn child will be normal.

The second page of *Amniocentesis for Prenatal Chromosomal Diagnosis*. The pamphlet was meant to give families the opportunity to make informed decisions about amniocentesis and the outcome of the test.

Amniocentesis was first utilized in the United States in the 1960s as a procedure to detect fetal abnormalities. The procedure requires that fluid be extracted from the amniotic sac surrounding the fetus. The amniotic fluid contains cells from the fetus that are sloughed off and could be cultured and tested for “abnormal babies.” The procedure’s safety was improved upon into the 1970s, and it became one of the leading methods used for counseling pregnant women with certain risk factors: being over the age of 35, having a family history of genetic diseases, and having already given birth to infants with disabilities. This technology and the medical community’s expanding comprehension of genetics allowed for physicians and genetic counselors to more accurately predict disability. Envisioning disability through amniocentesis was a more conclusive break from the past where counseling was provided based on family history of birth defects alone. For many American women, their families, and healthcare professionals, one of the main benefits of amniocentesis was catching a “defective” baby before it was born. Determining the sex of the fetus was one of the secondary conveniences of the test. Frequently, “abnormal” and “defective” were part of medical parlance used in opposition to “normal” when describing a fetus.[2]

American families would have welcomed amniocentesis as appropriate prenatal care since many likely witnessed or were aware of previous public health crises. Between 1957 and 1962, thalidomide (a drug used to treat pregnant women’s morning sickness) produced birth defects in Canada and Great Britain. In the United States, from 1962-1965, the German measles (rubella) epidemic caused many women to give birth to children with disabilities. For many families, the portrayal of disability as a tragedy and something to be avoided at all costs led many to turn to scientific and medical intervention.[3]

Predicting disability such as Down syndrome, known as mongolism in the 1970s, gave mothers and their spouses the opportunity to assess their emotional and financial capabilities to care for their baby. For families who received a positive test result for Down syndrome, abortion became a viable alternative to carrying the fetus to term. Before *Roe v. Wade*, genetic tests like amniocentesis were believed to be crucial to widespread legalization of abortion, since eliminating disability in society was preferable. Conservatives opposed abortion on moral grounds, but the medical community viewed it as a viable method to helping patients. In 1966, at the International Congress of Genetics, Dr. Cecil Jacobson of the George Washington University Hospital said, “A parent should not be handicapped by the theological or legal problems when high risk of malformation is diagnosed and therapeutic abortion is counseled.” This belief carried into the 1970s by the American College of Obstetricians and Gynecologists and other medical organizations that approved of abortion in the likelihood of a child being “deformed or retarded.”[4]



6. In the normal reproductive cycle the mother's egg—containing 23 chromosomes—is fertilized by the father's sperm—also containing 23 chromosomes. This union results in the development and growth of a fetus (unborn baby) whose cells have the normal number of chromosomes—46.

Page six of *Amniocentesis* describes the development of the fetus while outlining the significance of having a “normal” number of chromosomes. Informing families of the science behind reproduction was thought to provide for more informed decisions.

By 1973, when *Roe v. Wade* became law and gave feminist health activists a victory, the disability rights movement was already demanding inclusion in society. One of the first major moments of the movement was in 1962 when Ed Roberts sued for and won admission to the University of California, Berkeley. He then went on to establish the Center for Independent Living, which pushed for deinstitutionalization and demanded community inclusion. The same year that *Roe* was decided in the Supreme Court, Section 504 of the Rehabilitation Act of 1973 granted some federal

rights to people with disabilities. Despite some of these initial gains, disability was still stigmatized and viewed as a medical problem to be fixed.[5]

Amniocentesis represented an intersection between medical authority, a woman's right to choose, and disability rights. The use of such testing was part of what disability activists and scholars today refer to as the medical and social models of disability. Where the medical model is preoccupied with curing or fixing, in the case of amniocentesis by suggesting abortion, society ignores how it limits the lives of people with disabilities. The social model maintains that society is the disabling factor in a person with an impairment's life by limiting inclusion, constructing barriers in built environments, funding for needed medical equipment, refusing employment to people with disabilities, and so on. Furthermore, what physicians and families had not considered was that genes could only say what disability the fetus might have, and as Ruth Hubbard has said about genetic tests, "they contain very little information about what kind of a person that fetus will become and what significance the condition in question will have in her or his life or in the lives of the people among whom she or he will live." [6]

Newspaper and medical journal articles of the time occasionally commented on the rarity of abortions after using amniocentesis to test the fetus. The reality was that most of the test results seldomly revealed a birth defect. Regardless, amniocentesis gained widespread approval in the medical community as a safe genetic test by the 1980s, despite some experts expressing disbelief that amniocentesis was not used to its full capabilities.[7]

Societal acceptance of science and medicine and the construction of disability as tragedy is one of many ways that amniocentesis can be read. In applying a disability history perspective to amniocentesis, we see not only how disability was shaped as a tragedy and the worst fate to befall a family in the past, but we also consider how newer reproductive technologies shape our lives and assumptions about the future. Finally, by using disability as a framework of analysis we can examine how society constructed "normality" to the exclusion of people with disabilities.

[1]U.S. Department of Health, Education, and Welfare: Public Health Service, *Amniocentesis for Prenatal Chromosomal Diagnosis* (Atlanta: Center for Disease Control, ca. 1980), 2.

[2]Otto McClarrin, "Happiness Through Health," Column in the *Racine Courier*, December 25, 1976; Tabitha M. Powledge, "Amniocentesis: Checking on Babies Not Yet Born," *New York Times*, April 4, 1976, E16.

[3]Joseph R. Hixson, "Forecasts from the Womb: A Report on a New Science that Can Save the Lives of Unborn Babies," *New York Times*, January 19, 1967, 56.

[4]U.S. Department of H.E.W.: Public Health Service, *Amniocentesis for Prenatal Chromosomal Diagnosis*, 5-9.

[5]Jacqueline Vaughn Switzer, *Disabled Rights: American Disability Policy and the Fight for Equality*

(Washington, D.C.: Georgetown University Press, 2003), 58-59, 63.

[6]Ruth Hubbard, *Profitable Promises: Essays on Women, Science and Health* (Monroe: Common Courage Press, 1995), 41.

[7]Rita E. Watson, "Prenatal Testing is Called Underused," *New York Times*, January 27, 1980, WC13.

Further reading:

Kline, Wendy. *Bodies of Knowledge: Sexuality, Reproduction, and Women's Health in the Second Wave*. Chicago: The University of Chicago Press, 2010.

Rapp, Rayna. *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. New York: Routledge, 2000.