PRENATAL SCREENING: QUALITY CONTROL AND THE GENETICS GATEWAY

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Preface

This thesis critically evaluates the progress of prenatal genetic testing, and how it, along with concurrent social pressures (such as the goal of having the ideal child) may have altered parental decision-making, autonomy, and attitudes toward children. Literature in this area is not particularly robust, however the scholarship contributed by Barbara Katz Rothman, Rayna Rapp, Adrienne Asch, Abby Lippman, Leon Kass, and others provide critical insights for this topic. Distinctive to this thesis is the analysis of prenatal genetic testing with a view of the eugenic history of genetics and public health initiatives in maternal health. This thesis will describe what current genetic screening pursuits may indicate with this historical understanding. I will discuss the dynamics of these subjects, and how they correspond with current social demands for perfection and the growing commodification of children. With this analysis I will attempt to shed greater light upon how our current prenatal screening technologies can modify the parent/child relationship, and what this may mean as medical science and technology advance. This thesis will be organized in a three-chapter format, providing a historical viewpoint and analysis of salient ethical issues.

Chapter 1: The Historical Perspective

To provide a historical framework for the modern development of prenatal genetic screening, I will introduce eugenics and its influence on medicine and public health initiatives. This will present a context for the establishment of the Division of Infant and Child Hygiene within the Indiana State Board of Health, and the Indiana Better Baby Contests. An in depth examination of Dr. Ada Schweitzer, director of the Division of Infant and Child Hygiene during the Baby Contests, will attempt to elucidate her impact on the health of Hoosier infants. Her eugenic views and approach to infant health, in addition to the overall results of her work will be clarified in this approach.

The historical perspective of Dr. Schweitzer's public health initiative will provide a relevant structure for understanding the emergence of contemporary prenatal genetic screening. As demonstrated by other scholars, the ideals of eugenics were not dramatically discarded with the modern development of genetics. Authors Wendy Kline, Diane Paul, and Daniel Kevles will be particularly important in assisting to articulate this aspect of eugenics. Dr. Schweitzer's initiative will further illustrate this understanding of eugenics.

Chapter 2: Transition to Modern Genetics

With this historical introduction, I will highlight the ways in which current screening methods differ from past initiatives, and describe the current status of prenatal genetic testing. I will compare the parental response to Ada Schweitzer's initiatives (such as the letters they wrote to her worrying about their children's contest scores) and today's parents' anxieties regarding health, intelligence, and capacity for success and how genetic testing influences this. Aubrey Milunsky's *Genetic Disorders and the Fetus* will assist in presenting the scientific community's view of prenatal testing, and how to counsel parents to make "rational" decisions. I will disagree with Milunsky's view of this decision-making, which will be supported by important literature by Barbara Katz Rothman and Rayna Rapp. Among other points, Katz Rothman argues that the experience of motherhood has been fundamentally changed with the introduction of amniocentesis and other technologies. With this insight I will distinguish what may be considered "eugenic" about current prenatal screening measures.

Chapter 3: Autonomy, Commodification, and Additional Ethical Issues

To critically evaluate the use of prenatal screening, I will focus upon parental decision-making. This will include an evaluation of the significance of choice and autonomy provided with screening, especially within the context of being referred for testing by a physician, given particular social prejudices, pressures, or negative experiences. As a fundamental ethical issue of this subject, it will be significant to question to what degree parental autonomy is secured in the prenatal screening process and referral. Although prenatal genetic counseling is performed in a "non-directive" manner, the process of referral and screening may not be as value-neutral or unproblematic as this approach may suggest.

In conjunction with the issue of autonomy, I will additionally consider what is viewed as parental decision-making rights with regard to children, and what this may indicate with respect to the commodification of infants and children. It may be argued that children are already commodified to the extent that parents pressure children toward specific achievements; and commodification may be viewed centrally within the social pressures of prenatal testing. Authors Adrienne Asch, Abby Lippman, Leon Kass, and Barbara Katz Rothman will especially be important in framing the discussion of autonomy and commodification. In particular, I will examine and evaluate attitudes parents may form toward their selected children in general, and especially toward those children who do not turn out as expected. Although children may disappoint their parents no matter their biological origin, I will consider the weight of the parental "investment" in technology to obtain a certain kind of child. I will consider the ways in which genetic screening can further the notion that children can (or should) be an object to be chosen like an ordinary product. As it is a compelling social value to have "normal" children, it is likely that there will be continued parental demand for the cultivation of technology to assist in achieving this standard. With regard to the paramount value of autonomy, it may be questioned if there can be an ethical argument to preclude parents from choosing what kind of child they want.

Coupled with the overall central question of autonomy, I will analyze the prevalent argument of genetic counselors and others that the unique element of personal choice involved with prenatal genetic screening indicates that the practice is not eugenic. A further issue in parental autonomy relates to the value or quality of life determinations that parents make in these situations, and how these appraisals may further involve commodification with this choice.

Chapter 1: The Historical Perspective

Introduction

The introduction of Darwin's *Origin of Species* and the height of the industrial revolution prepared the stage for the eugenics movement. The desire to have the best offspring was by no means a new idea, yet the tenor of eugenics emphasized more than what was typically presented by this pursuit. What made the eugenics movement distinctive was the infusion of science along with the new optimism of economic and social progress. The events of the late nineteenth and early twentieth century offered humanity a sense of mastery of their world that had not been experienced before. Eugenics was remarkable in that although it was a movement initiated by the academic elite, it extended to have broad social and political appeal.

Eugenics had an undeniable influence on medicine and public health initiatives in the early twentieth century. This chapter will present the context for the establishment of the Division of Infant and Child Hygiene within the Indiana State Department of Health, and the Indiana Better Baby Contests. An in depth examination of Dr. Ada Schweitzer, director of the Division of Infant and Child Hygiene during the Better Baby Contests, will attempt to illuminate her unique motives, vision, and impact on the health of Hoosier infants and mothers. Her eugenic perspective and approach to infant health, in addition to the overall results of her work will be presented in this approach. The historical perspective Dr. Schweitzer's public health initiative will provide a focused example of the influence of eugenics in maternal and infant care. In addition, it will provide a relevant contribution to understanding the complexities of the eugenics movement.

Biographical Information

Dr. Ada Schweitzer, a native Hoosier, was born in LaGrange County, Indiana in 1872. She attended Michigan State Normal School, and pursued her medical degree from Indiana Medical College in 1902 after teaching for a few years. Schweitzer conducted bacteriological research and held health conferences for mothers and girls while in medical school, which in part focused on childhood illnesses such as measles, diphtheria, and typhoid. Once she obtained her degree, she became a bacteriologist in the State Laboratory continuing the work she initiated during school. Schweitzer presented in several forums, including an exhibit on typhoid in 1915 for the American Medical Association in San Francisco.[1, 2, 3, 4] Schweitzer was motivated by the ideas of progressive maternalism, and eugenic ideals. Progressive maternalists embraced the infusion of science into motherhood, the understanding of mothers as professionals, and

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[1] See 1880 US Census Records, http://www.ancestry.com/

[2] "Indiana's Work in Child Hygiene," *Indiana Business Women* 4, no. 2 (1921): 15, Better Babies Program Files, Indiana State Archives (ISA)

[3] Alexandra Stern, "Making Better Babies: Public Health and Race Betterment in Indiana, 1920-1935," *American Journal of Public Health* 92, no. 5 (2002): 742

[4] Logan Esarey, *History of Indiana From Its Exploration to 1922 With an Account of Indianapolis and Marion County Vol. IV* Dayton Historical Publishing Co, 1924 (accessed via website: http://members.tripod.com/~debmurray/marion/marbioref-50.htm#aschweitzer) See also Obituary: Dr. Ada Estelle Schweitzer, Annals of Internal Medicine, 1952 Jan; 36 (1): 221

being the vital bearers of the future. Her ambitions in this area lead to her involvement in a number of child welfare projects, and in 1918 she was given an appointment in the US Children's Bureau, and in October of that year, she was assigned to take charge of a survey to determine the physical and mental normalcy of children.[5]

Schweitzer's association with Dr. John Hurty began in 1906, when she was hired through the Board of Health as an assistant bacteriologist for the state laboratory that was established in 1905. Hurty, the director of the Indiana State Board of Health from 1896 until his retirement in 1922, was a passionate eugenist.[6] While the germ theory was gaining acceptance, the theories of human heredity had caught the attention of physicians (such as Hurty) who were enthusiastic about developing a superior citizenry. He was committed to purging the unfit from Indiana, and was instrumental in the passage of the 1905 marriage law, in addition to Indiana's momentous sterilization law of 1907.[7] He not only sponsored legislation, but was an active eugenics lecturer as well, and he repeatedly warned his audiences that Indiana was suffering from "race suicide," indicating the impact he believed defectives would have on the entire population.[8]

Hurty's proposed response to the crisis included the control of the environment, limiting breeding to eugenic parents, and "molding future generations through scientific child-saving programs."[9] He saw to it that this critical component of child saving and laying the groundwork for the future materialized with the formation of the Division of

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[5] Esarey, *History of Indiana*

[6] Grace L. Meigs, director of the Child Hygiene Division, Children's Bureau, to Sherbon, March 22, 1916, 4-11-1-5, CF 1914-20, RG 102, USCB, NACP

[7] Alexandra Stern and Howard Markel, *Formative Years: Children's Health in the United States, 1880-2000*. (Ann Arbor: University of Michigan Press, 2002), 127

[8] Stern and Markel, *Formative Years*, 124

[9] Stern and Markel, *Formative Years*, 128

Infant and Child Hygiene in 1919.[10] Ada Schweitzer's unique experience, support of eugenics, and acquaintance with Hurty placed her in prime position to be tapped for leadership in this agenda.

Creation of the Division of Infant and Child Hygiene

Indiana was ahead of other states when it came to a number of public health initiatives. By 1907 Indiana lead the nation with a pure food statute which was passed in 1899, a vital statistics act, and the first eugenic sterilization law. As a further distinction, the Indiana State Board of Health was ranked sixth nationwide in terms of effectiveness according to the American Medical Association in 1915.[11] In response to the substantial infant and maternal mortality rate, and certainly as a result of his keen interest in child hygiene, Hurty submitted the proposal to the legislature for an additional division. In 1919, Indiana created the Division of Infant and Child Hygiene. That same year, he appointed Ada Schweitzer as director of the division as she was completing her previous assignment.

Hurty boasted to colleagues about Schweitzer's ability to carry the innovative science of eugenics and infant hygiene to the far reaches of rural Indiana, beyond what had been attempted by previous health officials.[12] Hurty felt that he had the optimal

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[10] Ibid

[11] James H. Madison, *Indiana Through Tradition and Change: A History of the Hoosier State and its People, 1920-1945* (Indianapolis: Indiana Historical Society, 1982), 309

[12] Hurty to Children's Bureau, June 18, 1920. 4-15-2-16, CF 1914-20, RG 102, CB, NACP

candidate to reach the Indiana population, and indoctrinate the people with eugenic ideals and scientifically based approaches to motherhood. By the time of her appointment to the division, Schweitzer had already extensive experience organizing an assortment of child hygiene projects and maternal education classes. She was also an active participant in notable eugenic forums such as the Indiana Mental Hygiene Association. Schweitzer evidently possessed the characteristics that Hurty desired of an individual to fill the position.

Schweitzer was giving direction to division personnel even before it was provided appropriations by the legislature, as they were adamant that they could not let babies "die while waiting for the Department to be organized."[13] She instructed them to continue to gather general health information about the children, such as their defects, height, and weight, in addition to obtaining birth registrations.[14] Women from various club and civic groups were directed to carry out these instructions before Schweitzer's arrival to the division.[15] These groups were instrumental in laying the groundwork, and continued to be active participants in various initiatives after the division was fully operational. Clubwomen sponsored mother's classes, assistance for expectant mothers, and placed information on maternal and infant health in public libraries, among other activities, all of which ensured that Schweitzer's endeavors would be maintained and cultivated at the local level.[16]

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[13] Indiana Child Welfare Committee to County Chairman, July 16, 1919, Report of the Child Welfare Committee, Division of Infant and Child Hygiene (DICH), ISA

[14] Ibid

[15] Albion Fellows Bacon to Tri Kappa Secretary, Aug 11, 1919, Report of the Child Welfare Committee, DICH, ISA "A few days ago we sent you a letter explaining a plan of cooperation between the State Board of Health, the Indiana Child Welfare Committee, the Extension Division of Indiana University, and the Tri Kappa." See also Albion Bacon to Tri Kappa Secretary Aug 6, 1919

[16] Schweitzer, "Some of the Ways in which Club Women have Cooperated with the Child Hygiene Division," 1924, DICH, ISA

Before the division was formally created, numerous local groups had already taken the initiative to begin their own "child saving" programs. Each was independently pursuing their work, and did not have any formal coordination. Schweitzer needed to not only provide guidance for the state's official division, but devise a way to recruit these independent groups to be under her direction as well.[17] Fortunately, Schweitzer had already built a rapport with a number of groups as a result of the child hygiene lectures she had previously organized and presented (while in medical school and immediately after), and they were eager to work with her: "Five years ago, Dr. Schweitzer conducted a Health day at Winona Lake Chautauqua. This year as soon as the Child Hygiene Staff program was announced, a request came from the Directors of the Winona Lake Chautauqua for a Health Week, under the Supervision of the Director of The Child Hygiene Division."[18] When Schweitzer initiated her work at the division, she quickly began to receive requests from a variety of civic clubs, towns, and counties to hold additional health conferences and lectures. Many were excited to coordinate with Schweitzer; evident with the volumes correspondence she received. The success of her early exhibitions encouraged Schweitzer to continue to develop infant and maternal health education in this format, and to support the fairs to be initiated on a larger scale.[19]

The crisis of the infant and maternal mortality rates across the nation did not go unnoticed by the federal government, and the reduction of infant mortality became the

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[17] Schweitzer to H. C. Carpenter, May 5, 1919, DICH, Correspondence, ISA "As our appropriation is not available until October, I am working under numerous handicaps, one being the number of organizations that are attempting child hygiene work independently of each other. As they seem willing to cooperate with us, we are trying to formulate a program that will bring about better coordination of effort."

[18] Report for the Quarter Ending September 30 1920, DICH, Department of Labor Children's Bureau Correspondence, ISA

[19] Schweitzer to Anna Rude (Director Division of Hygiene, U.S. Children's Bureau), July 27, 1920, DICH, Department of Labor Children's Bureau Correspondence, ISA

primary objective of the US Children's Bureau in 1921.[20] That same year, the Sheppard-Towner Act was passed. Administered by the US Children's Bureau, the act granted matching funds to states that established infant and maternal welfare agencies and approved legislation for such public health objectives. The resources provided by this act *tripled* the budget that Schweitzer had to work with, significantly enabling the proliferation and reach of the fledgling division.[21] Schweitzer took full advantage of her funds to extend the depth of her team, and the scope of her programs. The Sheppard-Towner Act would prove to be the boost necessary for drastically increasing the division's functional capacity and effectiveness.

Ada Schweitzer and the Division

Schweitzer's energy and dedication as shown in her previous child hygiene projects, was given an enhanced platform with her appointment to the Division of Infant and Child Hygiene. She was eager to educate women on the proper science of motherhood, teach them who could be considered "fit" to reproduce, and monitor their children with her guidance. This education was essential to ensure quality infants; motherhood was not just a personal choice, it was a political act which required proof of

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[20] Stern and Markel, *Formative Years*, 130

[21] See Richard A. Meckel, *Save the Babies: American Public Health Reform and the Prevention of Infant Mortality 1850-1929* (Ann Arbor: University of Michigan Press, 1998)

merit.[22] Eugenics elevated the responsibility and achievement of motherhood by emphasizing the unique position of women to promote the superiority of the population. As a physician and a woman, Schweitzer was a vital instrument for this message. She intended to provide families with information identifying the fitness of their offspring, and guidance as to what would be appropriate regarding future children. Schweitzer was confident that with the appropriate instruction, she could improve maternal care and the quality of children. As such, the overarching goal of the Division was indeed "baby saving;" accomplished by monitoring infant and child health, in addition to advising and educating mothers regarding their children.

When Schweitzer and her team were on location, they invited mothers to bring their children for examination, and provided medical and nutritional advice and circulars. Schweitzer's 1920 annual report identified that the Division had already conducted conferences in 27 of Indiana's 92 counties, examined 8,000 children, and presented in 290 towns.[23] It was not long before letters poured into the Division addressed to Schweitzer from mothers inquiring about the conferences and asking for further advice regarding their children. Schweitzer had a significant audience that needed little convincing of her authority, and they were anxious to implement her directions. Eugenic ideology was a pervasive force by the 1920s, and was promoted everywhere from universities to home town organizations. It influenced decision making regarding marriage and family, in addition to perceptions and standards of "normal". The pressure to produce children that could be considered good enough to compete in what would

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[22] See Wendy Kline. *Building a Better Race: Gender, Sexuality, and Eugenics from the Turn of the Century to the Baby Boom* (Berkley: University of California Press, 2001)

[23] "Annual Report of the Division of Infant and Child Hygiene, Indiana State Board of Health for the Year Ending September 30, 1921," 4-11-1-3, CF 1921-24, RG 102, CB, NACP

become the Better Baby contests, or receive high marks during medical evaluations, is evident in the letters that Schweitzer received and generated enough anxiety to make some consider not becoming parents at all.[24]

Schweitzer sent numerous letters to local physicians, parents, civic leaders to promote the maternal health classes, describing and reiterating the "hazards" of motherhood: "much remains to be done before the average loss of mother's life per thousand has been lowered…Last year 436 Indiana mothers lost their lives when their babies were born, 1 to every 166 births."[25] In addition to these letters Schweitzer also sent the schedules of classes and lectures, which included other statistics and information: "In 1921 in Indiana 68,247 babies were born. Of these 2,358 died before reaching the age of one week… Many mothers do not realize the value of being under a doctor's care throughout their pregnancy… Some men still think that the best obstetrical care is too expensive, yet a funeral costs more."[26] Schweitzer was concerned that parents did not have the knowledge or training to adequately meet their responsibility to produce satisfactory children, and as such the educational thrust of the division was her primary focus: "Because so many women do not understand the scientific basis of mother care, a course of instructions in the essentials of such care has been prepared… It is hoped to impress prospective parents with the importance of safeguarding in every possible way our Indiana mothers and babies."[27] Schweitzer was confident that with the proper training and knowledge of eugenics, in conjunction with Indiana's existing marriage and sterilization laws, superior children would fill Indiana's population.

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[24] Kline, *Building a Better Race,* 91

[25] Schweitzer, "The Hazards of Motherhood" 1921, DICH, ISA

[26] Schweitzer, "Facts Concerning Maternity and Infancy" 1922, See also "Outline of Classes for Mothers," DICH, ISA

[27] Schweitzer, "The Job of Being a Parent" 1924, DICH, ISA

Better Babies and Eugenics

The theory of evolution displaced man from his vaulted position over the rest of creation, yet it also ushered in the critical notion that the trajectory of human development could be manipulated like any other stock animal. The concurrent industrial progress and urbanization produced a new America. The rapid change of this period encouraged the belief that society could be molded to a particular ideal. With this foundation eugenics was presented as a natural extension and application of scientific knowledge, and its vision seemed to support values (such as intelligence and physical prowess) that many believed to be important for prosperity. Advocates of eugenics argued that the movement was concerned with not only the "imbeciles and epileptics but with the average middle-class family and with the genius as well."[28] In depicting the movement as for the well being of society and the benefit of traditional families, proponents of eugenics offered convincing evidence for participation. The appeal extended beyond the academic and elite, as it came to be viewed as a progressive social plan that would bring about a utopian-like civilization filled with those that had the most gifted physical and mental qualities.

The benefits of a eugenic program appeared to be so self-evident that leaders within the movement were confident that eventually romance and "eugenic principles" would go "hand in hand for happier homes, healthier children, and the minimization of

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[28] "Social Problems Have Proven Basis of Heredity: What the Work Done in the Eugenics Record Office at Cold Spring Harbor Has Proved in Scientific Race Investigation". New York Times. New York, N.Y.: Jan 12, 1913

imbecility, hereditary disease, pauperism, and crime."[29] This perspective was not unlike that of Schweitzer. Once women were properly trained in infant hygiene, she was confident they would become progressive mothers who would produce a superior crop of babies. Schweitzer conceded that the "gates of heredity" were closed once a baby was born, and therefore was adamant regarding the need to restrict birth to only fit parents and then provide these parents with sound training in scientific child rearing.[30] Only in this manner could better children be produced. Schweitzer regarded this strategy as plainly obvious even to the common farmers whom she informed: "You can not make a silk purse out of a sow's ear, neither can we make a citizen out of an idiot or any person who is not well born."[31] This common-sense presentation, rather than mysterious new-fangled science, was an essential component to Schweitzer's message.

Schweitzer's ideas about the inferior part of the population were like those of many adherents to eugenics who came to the realization that the problem of the unfit was an epidemic. One of the primary problems was considered to be individuals that possessed substandard mental capacity, or were "feebleminded." With the assumption that mental deficiency was heritable, the rampant growth of an unfit population was a leading fear. The Indiana Society for Mental Hygiene, established in 1916 in response to the "menace of the feebleminded," was an assortment of Indiana's prominent reformers and public officials.[32] Dr. Schweitzer was a vocal member from the very beginning, and presented a paper at the 1917 conference. Her lecture at the conference, "The Menace of the Mental Defective," illustrates her observation of the problem:

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[29] Ibid

[30] Stern, "Making Better Babies," 749

[31] Schweitzer to Mr. George B. Lockwood, March 20, 1916, DICH, ISA

[32] "Mental Defectives in Indiana Second Report of the Indiana Committee on Mental Defectives: A Survey of Eight Counties," December 27, 1918, Board of State Charities, ISA

> In many localities, the morasses of mental defectiveness which Have existed there for decades afford no foundation for this structure (of public health). Into these sinkholes of civilization have been poured sympathy and money… and (yet) they have continued to become wider and deeper…Studies of groups of these people living in more or less isolated communities show them to be antisocial with a tendency to intermarry and to produce numerous offspring having the defects of the parents somewhat accentuated in each succeeding generation…They live in a shiftless way under unsanitary conditions and resent any interference with their habits. …The utter irresponsibility of these defectives may be considered both the cause and the result of the high percentage of alcoholics among them… (they)mate with mental defectives possibly of some other type and proceed in their usual prolific manner to perpetuate both types of defectiveness…[33]

Schweitzer viewed the prevention of marriage of the feebleminded as only a partial solution, and considered the sterilization and segregation of "recognized idiots and imbeciles" as essential to lower their reproduction and prevent venereal disease.

The problem of feebleminded was intertwined with Schweitzer's initiative to improve the fitness of Indiana's children. She regarded the prevention of feeblemindedness as one of the keys to improving the vitality and efficiency of the individual. [34] Schweitzer believed that the condition of the population was the "province of every thinking person," and that the overwhelming understanding was that only those that were deemed fit could produce a "race of individuals sound in body and mind." [35] With the introduction of the marriage and sterilization laws, Schweitzer viewed her role as primarily with the education of the public as a means to supplement the legislation. This included informing individuals as to what were considered to be desirable

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[33] Schweitzer, "The Menace of the Mental Defective" 1917 Indiana Conference on Mental Hygiene, DICH, ISA

[34] Ibid

[35] Ibid

characteristics of physical and mental disposition, the “undesirability of mating high grade defectives having similar traits,” in addition to advocating frequent medical examination “especially proceeding marriage, (the) proper provision for prenatal and infant care, medical supervision of children in the avoidance of physical and mental habits…(and) cultivation of an altruistic spirit which will readily sacrifice personal ease to racial welfare.”[36] Schweitzer was confident that implementing a multifaceted approach of citizen cooperation with eugenic legislation would ensure the stability and health of the population.

The lectures, conferences, and health fairs were not only Schweitzer’s venue for health education, but also the opportunity for her to expound on the “virtues of Indiana’s eugenic marriage and sterilization laws, which she believed ensured the robustness of Hoosier babies.”[37] Beyond her involvement with the Mental Hygiene Society, Schweitzer wrote several essays, articles, and poems to deliver her views. In 1923, Schweitzer presented the “Physical Inequalities of Children” which identified that: “Parents cannot give to children that which they themselves lack. If both parents are mentally defective, the child will be mentally defective. Children of this type are hopeless…”[38]

The baby contests began in 1920, and were the most popular event that the division supported. Schweitzer presented the baby contests as a “School of Education in Eugenics,” in which the benefit would be better Indiana babies.[39] In her essay, “The

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[36] Schweitzer, “The Menace of the Mental Defective” 1917 Indiana Conference on Mental Hygiene, DICH, ISA

[37] “Abstract of Lectures for Mothers’ Classes,” 11-16-1, CF 1925-28, RG 102, CB, NACP, See also Stern, “Making Better Babies,” 747

[38] Schweitzer, “Physical Inequalities of Children” 1923, DICH, ISA

[39] Schweitzer, “The Benefits of a Better Baby Contest” 1920, Better Babies Program Files, ISA

Benefits of a Better Baby Contest," Schweitzer outlined the sources of inferior infants: "We have scientific proof that the baby whose life began when either both parents were poisoned by fatigue, alcohol, or disease, does not have a fair chance."[40] She utilized the language of crops and breeding to appeal to her audience, who typically had been raised on farms and understood this rationale. In the mother's classes that she initiated, Schweitzer encouraged the women to investigate before their marriage what "undesirable heritable traits or constitutional disease lurked in either side of the family line that might lower the vitality of possible offspring."[41] These classes became widely popular, and in 1925, "16,649 women - more than 50 percent of all attendees nationwide - took mothers' classes in Indiana under the aegis of the Division of Infant and Child Hygiene."[42]

She was perhaps not as overt a eugenist as other colleagues, but was consistent in her views of what was unfit and what was healthy. In this way, Schweitzer promoted eugenic policies and perspectives as she attempted to improve children's health and modernize rural mothers. Schweitzer seemed to be principally interested in the role of parents in carrying out the proper scientific applications that she was promoting. As a eugenist she supported sterilization and marriage legislation to ensure that only fit parents reproduced. However, in her capacity at the division she seemed focused on children's health as a means to ensure eugenic products. Most of Schweitzer's eugenic rhetoric was directed at parents: "A vast majority of parents voluntarily brought their own children because they wished advice concerning them. A few came at the request of committees or of their physicians, or of the county nurse. There were some who were feebleminded

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[40] Ibid
[41] Stern and Markel, *Formative Years*, 135
[42] Ibid

and some who were too shiftless to carry out instructions…"[43] By focusing on children's health and parental education, she was confident in the division's endeavor to improve the future.

The height of the baby contests came in the mid-1920s, and Schweitzer endeavored to establish them as valuable in that they "set the best standards of health before the parents that they may compare these with the actual condition of their child."[44] In 1923 the *Indianapolis News* established a sponsorship of the contests, and provided more space for articles in addition to full-length pages with photos of contestant babies.[45] This gave the division and the contests a tremendous boost in publicity, and enthusiasm for the continued to gain in popularity. The state fairs were known to pull in one-fifth of the population, and this was a captive audience that Schweitzer could not ignore as an opportunity to deliver her message.[46]

Schweitzer was given the authority to oversee all of the components of the contests, especially the scoring and award of prizes, to ensure they were as fair and objective as possible. To maintain the level of professionalism that she expected, Schweitzer used scorecards "based directly on the template formulated by the American Medical Association and the Children's Bureau."[47] As a result, she consistently distinguished the contests supported by the division at the state level, and those that were taking place without their involvement on the county level. It was no secret that the

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[43] Schweitzer, "Report by State Board of Health Child Hygiene Division on Examination of Preschool Children," August 1, 1932, DICH, ISA

[44] Schweitzer, "Why Have a Baby Contest?" *Monthly Bulletin of the Indiana State Board of Health* 31, (1928): 125. Division of Infant and Child Hygiene, ISA

[45] "Indiana State Fair Better Baby Activities," *Monthly Bulletin of the Indiana State Board of Health* 30, (1927): 136-140. Division of Infant and Child Hygiene, ISA

[46] Stern and Markel, *Formative Years*, 124

[47] Schweitzer to A.F. Bentley, June 18 and June 20, 1923, DICH, ISA

criteria for a baby contest to be legitimate, in Schweitzer's eyes, it needed to be authenticated directly by the involvement of her division.

The Schweitzer Impact

During her term from 1919 to 1933, Ada Schweitzer lectured to hundreds of civic associations, authored an abundance of articles and poems, and assessed the physical condition of babies in all of Indiana's 92 counties. After one decade, the division had examined 77, 584 children, lectured to 55, 171 mothers, and reached almost half of the population with the distribution of pamphlets. In her final five-year assessment, Schweitzer reported that the division was averaging 80 counties per year, audiences for mother's classes had increased in the previous two years by 83,443, and film presentations had more than doubled since the time of her last report.[48] Over 14 years she built an authoritative, effective, and respected public health agency. Schweitzer unquestionably modified Hoosier attitudes about health, maternity, and childhood with her direct recommendations and broad appeal. Parents were indeed attentive to her eugenic message, and eager to utilize her advice.

In 1932 the last baby contest was held, as a result of the change in the state's political profile with the 1933 elections. Republicans were blamed for Indiana's continued economic crisis, which had persisted since the 1929 stock market crash. The 1933 election was a significant victory, as Democrats took control of the Indiana House

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[48] Ada Schweitzer, "Statement of Five-Year Trend for Health Council," January 17, 1933, DICH, ISA

of Representatives for the first time since 1914.[49] The new governor, Democrat Paul V. McNutt, promised the public that the government would be reorganized to eliminate bureaucratic redundancy. Consequently, he dismissed the entire division and established the Department of Child Health and Maternal Welfare under the Indiana University School of Medicine. A new administrative bill had gone under effect, which placed the State Board of Health and other departments under the direct supervision of the governor, "giving him absolute power of both appointments and salaries."[50] Schweitzer insisted upon conducting her work as usual up to the very end, although she was long aware that the division would likely be dissolved.[51] No female physicians or reformers were included in McNutt's reorganization, which was to emphasize pediatric teaching and training through the medical school instead of Schweitzer's "hands-on infant and maternal hygiene projects."[52]

The dissolution of the division seemed to largely be the result of a new governor seeking to establish himself. However, Schweitzer had apparently also generated significant jealousy among other medical professionals. As with similar agencies in the country, Schweitzer's staff at the Division was predominantly women and not physicians, all of which provoked the indignation of the (almost entirely) male medical establishment.[53] The efforts of the division and Schweitzer to professionalize infant and maternal welfare and urge mothers to consult their physicians ultimately "enhanced the authority of doctors and bolstered the notion that private primary care was the most

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[49] Madison, *Indiana Through Tradition and Change*, 78
[50] Schweitzer to Oppenheimer (US Children's Bureau), February 13, 1933, DICH, ISA
[51] See Schweitzer to Helma Fernstrom, August 5, 1932, DICH, ISA
[52] Stern and Markel, *Formative Years*, 143
[53] Stern, "Making Better Babies," 747

credible mode of child health."[54] The infusion of science into motherhood was indeed one of her goals, and making sure that they regularly consulted their physicians was an important element of this. Nevertheless, Schweitzer's success in this area did not seem to appreciably endear her to other physicians.

Eugenics certainly informed Schweitzer's outlook on health, and how to achieve better babies. It served as a framework for her support of strict enforcement of marriage and sterilization laws, in addition to her understanding of health and disease. Schweitzer's eugenic views may be considered classic in many respects; to identify superior babies as an example and motivation for other parents was a natural extension of the eugenic ideal to have the best offspring. For Schweitzer, eugenic ideals were best achieved in the realm of eugenic education, adult fit marriages, sterilization, and segregation of defectives. Perhaps owing in part to her recognition that the "gates of heredity" was closed after birth, Schweitzer consistently desired infants and children to be dutifully cared for by progressive mothers that were well informed of eugenic expectations for their offspring. Schweitzer's unique approach was evident in her work, and helped to define the lasting impact she had on Indiana mothers and children.

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[54] Stern and Markel, *Formative Years*, 130

Chapter 2: Transition to Modern Genetics

Beyond a handful of attentive academics, few appreciate the range and depth of individuals and viewpoints involved in eugenics. It was a movement in which various scholars and regular citizens turned to science to provide an authoritative and rational explanation for the world and means to correct its ills; an endeavor that has not significantly changed in the last hundred years. Although eugenics took on different forms in various countries, the concept of social responsibility and "scientific activism" to provide personal and social fitness was indeed shared.[55] The movement is frequently castigated as "pseudoscience," like astrology or alchemy, and therefore to have little bearing on today's *real* science of genetics. Under this view, legitimate geneticists of the 1920s recognized the fallacy of eugenics and eliminated it from their work. The sharp divide that many attempt to draw between genetics and eugenics generates historical accounts of genetics devoid of its roots, and "underlies the mocking tone that often creeps into descriptions of the eugenics movement."[56] By retracing the steps from Schweitzer's Better Baby Contests to today's prenatal screening, we will observe how eugenics has been intertwined in the development of genetic testing.

During the Depression, budgets shrank and Schweitzer's division was a casualty of this reality. However, the stresses of this period also seemed to encourage eugenic principles. For instance, in a 1937 *Fortune* magazine survey of its readers found that 66

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[55] See Mark Adams. *The Wellborn Science: Eugenics in Germany, France, Brazil, and Russia. New York*: (Oxford University Press, 1990) 120
[56] Ibid

percent favored compulsory sterilization of mental defectives, 63 percent for criminals.[57] Support for such initiatives did not fade when the Nazi abuses were exposed after World War II, as eugenics was not disposed of but repackaged and renamed in a variety of ways.[58] The postwar period brought a shift to individual choice and private decision making under the new terms of "medical genetics".

Some eugenicists, such as Charles Davenport, had always given "marriage advice" to those that inquired. However, genetic and pre-marriage counseling did not formally emerge until the 1940s with heredity clinics and university genetics departments.[59] During this period the American Eugenics Society and others directed their attention to this medical type of approach, and paved the way for facilities devoted explicitly to genetic advisory services.[60] Similar to Schweitzer's initiatives, the focus was to educate individuals on eugenic values (and selecting a fit mate) to create the right family. One of the first genetic clinics, founded in 1941, was the Dight Institute for Human Genetics at the University of Minnesota. Its creation was the result of the estate that Charles Fremont Dight left to the University to promote eugenics. His will stipulated that a site be maintained for "consultation and advice on heredity and eugenics and for rating of people, first, as to the efficiency of their bodily structure; second, as to their mentality; third as to their fitness to marry and reproduce".[61]

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[57] Philip R. Reilly. *The Surgical Solution*: *A History of Involuntary Sterilization in the United States.* (Baltimore: Johns Hopkins University Press 1991) 125

[58] See Daniel Kevles, *In the Name of Eugenics: Genetics and the Uses of Human Heredity,* rev. ed. (Cambridge: Harvard University Press, 1995)

[59] Molly Ladd-Taylor, "'A Kind of Genetic Social Work': Sheldon Reed and the Origins of Genetic Counseling," In: *Women, Health, and Nation: Canada and the United States since 1945*, Ed. Georgia Felberg et al. (Montreal: McGill-Queen's University Press, 2003) 67-83. See also, Kline. *Building a Better Race*

[60] Paul, Diane. *Controlling Human Heredity: 1865 to the Present.* (Atlantic Highlands: Humanities Press International, 1995) 122-23

[61] Sheldon Reed. "A Short History of Genetic Counseling." *Dight Institute Bulletin* no. 14, (1974): 1-10

Clarence Oliver, the first director of the Institute, asserted that “a geneticist should prevail upon some persons to have at least their share of children as well as show a black picture to those with the potentiality of producing children with undesirable traits”.[62] Clinicians were optimistic that once clients were taught of their hereditary, they would “nearly always follow their doctor’s advice”.[63] Sheldon Reed, director of the Dight Institute from 1947 to 1977, disliked the term “genetic hygiene” that was often used to describe the clinic’s service, and presented “genetic counseling” as an alternative when he became director in 1947.[64] He advocated neutrality with respect to the reproductive decisions of clients, but like others he expected that once counseled clients would do the right thing: “It could be stated as a principle that the mentally sound will voluntarily carry out a eugenics program which is acceptable to society if counseling in genetics is available to them”.[65] Even without the formal laboratory diagnostics for prenatal testing (which was soon to come), genetic counseling was already an active component of the modern eugenic message.

The ability to test the fetus for particular characteristics was realized in 1955, when Serr et al. (and a year later Fuchs and Riis) reported that antenatal determination of sex could be made by examining the X-chromatin body in human amniotic fluid cells.[66] Then in 1959 Jerome Lejeune, a French physician, developed the first karyotypes of Down’s syndrome. However, he was opposed to the development of prenatal testing and

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[62] Clarence P. Oliver, “Human Genetics Program at the University of Texas.” *Eugenical News* 37, (1952): 31

[63] Tage Kemp, “Genetic Hygiene and Genetic Counseling.” *Acta Genetica et Statistica Medica* 4, (1953): 241

[64] Kevles, *In the Name of Eugenics*, 253

[65] Sheldon Reed. “Heredity Counseling and Research.” *Eugenical News* 37, (1952): 43

[66] D. M. Serr, L. Sachs, M. Danon. “Diagnosis of sex before birth using cells from the amniotic fluid.” *Bulletin of the Research Council of Israel* 5B, no. 2 (1955): 137 and F. Fuchs, R, Riis “Antenatal sex determination.” *Nature* 177, no. 4503 (1956): 330

intended to find cure for Down's syndrome.[67] Nevertheless, even without formal testing, it was common practice to allow damaged or defective babies die in the back of hospital nurseries or automatically send them to institutions. Families were instructed to forget these babies and have other children; the birth of a disabled baby was "understood to be an unqualified tragedy from which women should be spared".[68]

Despite Lejeune's intentions for his research, the development of karyotyping quickly left the bench to be applied the bedside. The diagnosis of fetal chromosomal disorders by karyotypes was reported in 1967, and in 1968 the *Lancet* published the first report of an abortion performed to prevent the birth of a fetus diagnosed with Down's syndrome.[69] Soon after, in 1969, the first master's level program for professional genetic counselors in the U.S. was established.[70] These professionals would take on the task of genetic advising that physicians themselves had previously handled. Academics assumed that once the principle of parental choice for a normal child was established, the desire for normal children could be relied on to result in the "voluntary elimination of affected fetuses".[71]

During the 1960s and 70s, paternalism in medicine was being challenged and personal autonomy was becoming an established standard in healthcare practice. Concurrent with this event, prenatal screening increased dramatically with legalized abortion and official endorsement. In 1960 there were between thirty and forty counseling centers in the U.S.; by 1974 the number had inflated to about four hundred.

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[67] J. P. Gaudilliere, *Inventer la biomedicine.* (Paris: La Decouverte, 2002), 2044

[68] Barbara Katz Rothman, *The Book of Life: A Personal and Ethical Guide to Race, Normality, and the Implications of the Human Genome Project.* (Boston: Beacon Press, 2001) 178

[69] Carlo Valenti, Edward J. Schutta, Tehila Kehaty, "Prenatal Diagnosis of Down's Syndrome," *Lancet* 2, no. 7561 (1968): 220

[70] Diane Paul, *Controlling Human Heredity: 1865 to the Present.* (Atlantic Highlands: Humanities Press International, 1995) 130

[71] James V. Neel, "Lessons from a Primitive People." *Science* 170, no. 960 (1970): 821

Almost a quarter of these centers were created and maintained with assistance from the National Foundation of the March of Dimes.[72] At a meeting of the American Academy of Pediatrics in 1975, the results were presented of an NIH collaborative study indicating that amniocentesis for prenatal diagnosis was not only "reasonably safe for mother and fetus but also very accurate".[73] Another analysis estimated in 1974 that $5 billion spent over 20 years to reduce the incidence of Down's syndrome with voluntary screening and abortion, would save the U.S. more than 18 billion.[74] With these and other formal approvals, prenatal screening started to become a permanent fixture.

Most prominent and pioneering scientists in genetics at this time were active eugenicists, and did not shy from being vocal about their perspective. Like many others, they equated medical genetics with "good eugenics," and believed that eliminating the unfit could be just as easily (or even better) accomplished by individuals.[75] Even Francis Galton believed that coercion was not necessary to make the right reproductive choices.[76] Much like Ada Schweitzer believed, geneticists surmised that one only needed to be educated of this rational approach to complete their responsibility. For instance, Nobel Prize-winning geneticist Hermann J. Muller proposed the establishment of sperm banks stocked with superior "germinal material," and artificial insemination to generate superior human specimens. Donations to the bank would be voluntary, and from "persons of unusual moral courage, progressive spirit, and eagerness to serve mankind"; so Muller was confident that the plan was compatible with democratic values for

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[72] Kevles, *In the Name of Eugenics*, 257

[73] B. J. Culliton, "Amniocentesis: Hew Backs Test for Prenatal Diagnosis of Disease," *Science* 190, no 4214 (1975): 537-540

[74] Kevles, *In the Name of Eugenics*, See also: Allen Buchanan et al. *From Chance to Choice: Genetics and Justice*. (New York: Cambridge University Press, 2000) 55

[75] Paul, *Controlling Human Heredity*, 124

[76] Sir Frances Galton, *Essays in Eugenics*, (London: The Eugenics Education Society, 1909)

society.[77] He believed that the establishment of reproductive control was the right way to accomplish eugenic ideals. Although he conceded that the earlier version of eugenics was mistaken, he considered that to be “no more argument against eugenics as a general proposition than… the failure of democracy in ancient Greece (as) a valid argument against democracy in general”. Francis Crick, who identified the structure of DNA with James Watson, stated that he agreed with Muller and wondered himself “why people should have the right to have children”. [78, 79]

The attitudes of these scientists are not surprising; eugenic explanations of human behavior and biology were endorsed in classrooms around the country well into the 1960s.[80] In addition, prominent eugenic journals and societies still existed (or changed their names to something innocuous) for academic discussion. The American Eugenics Society for example did not find it necessary to change its name to the Society for the Study of Social Biology until 1973. This change did not signify any change in ideology; as the society’s directors clarified, it did “not coincide with any change of its interests and policies”.[81] It is evident that long after the last Better Baby Contest, eugenics was embraced by leading biologists and geneticists, and was “integral to the research programs of prominent, powerful institutions devoted to the study of human heredity”.[82]

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[77] Hermann J. Muller, “Better Genes for Tomorrow,” In: *The Population Crisis: Implications and Plans for Action*, Eds. Larry K.Y. Ng and Stuart Mudd, (Bloomington: Indiana University Press, 1965), 246

[78] Kevles, *In the Name of Eugenics*, 261

[79] Kevles, *In the Name of Eugenics*, 263

[80] See Paul, *Controlling Human Heredity*

[81] “A New Name – Society for the Study of Social Biology (formerly the American Eugenics Society),” *Social Biology* 20, no.1 (1973): 1

[82] Daniel Kevles and Leroy Hood. *The Code of Codes: Scientific and Social Issues in the Human Genome Project*. (Cambridge: Harvard University Press, 1993): 317

Amniocentesis was the first method of prenatal screening, but by the 1980s, ultrasound screening, chorionic villus sampling, and maternal serum alpha-fetoprotein screening were utilized as well. The original use of prenatal ultrasound screening was to correct gestational age, locate the placenta, and identify twin pregnancies. With the improvement of imaging technology, the capacity to disclose structural abnormalities was quickly seized upon.[83] Media coverage worldwide of the advances in genetic biotechnology throughout the 1980s assisted in transforming "prospective parents' hopes into real expectations for having a healthy baby". The introduction of maternal serum testing in particular provided the ability to screen all women with a simple blood test, and dramatically widened the scope of detection.[84, 85] However, widespread use of the test was somewhat resisted until professional organizations such as the AMA warned of the medical malpractice risk that could be incurred if doctors neglected to offer screening.[86]

These "recommendations" provided a heavy push to include screening as standard prenatal care. This standardization became obligatory in California when in 1986 it became the first state to mandate that all prenatal care providers offer the maternal serum screen test to every pregnant client. The scope of this mandate was immense; as a result, by 1990 over 60 percent of eligible Californians were tested with the maternal serum

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[83] See L. Bricker, et al. "Ultrasound screening in pregnancy: A systematic review of the clinical effectiveness, cost-effectiveness and women's views." *Health Technology Assessments* 4, no. 16 (2000). P. A. Dubbins, "Screening for chromosomal abnormality." *Seminars in Ultrasound, CT and MRI* 19, no. 4 (1998): 310-317 and R. A. Filly, "Obstetrical sonography: the best way to terrify a pregnant woman." *Journal of Ultrasound Medicine* 19, (2000): 1-5

[84] A. Milunsky, *How to have the healthiest baby you can*. (New York: Simon and Schuster, 1987) A. Milunsky, *Choices, not chances: An essential guide to your heredity and health*. (Boston: Little, Brown, 1989) and A. Milunsky, *Heredity and your family's health*. (Baltimore: Johns Hopkins University Press, 1992)

[85] A. Milunsky, "Genetic Counseling: Preconception and as a Prelude to Prenatal Diagnosis." In: *Genetic Disorders and the Fetus: Diagnosis, Prevention, and Treatment.* Ed. A. Milunsky, (Baltimore: The Johns Hopkins University Press, 1992)

[86] American College of Obstetricians and Gynecologists, "Professional Liability Implications of AFP Tests," DPL Alert, May 1985

screen.[87] As part of its keen interest in this endeavor, the state put a great deal of effort in the design of informed consent and patient education. Success of the program was measured by the number of decisions to terminate after diagnosis, since the public health "benefits" of screening entirely depended on the avoidance of those detected with anomalies.[88]

Genetic screening and counseling sessions are most often initiated by the obstetrical services, and typically the only indication being "advanced maternal age".[89] Women's conventional exposure to this notion of age-related risk produces what Abby Lippmann has termed "iatrogenic anxiety". This refers to the generic pregnancy anxieties that women identify with their respective age, and "the statistical category to which they have respectfully been assigned". Lippman further asserts: "It is no coincidence that the prenatal procedures the medicalized approach to pregnancy promotes, are offered to pregnant women as the means by which to assess and alleviate the problem of risk that fostered this iatrogenic anxiety in the first place". This effectively "enlists women to become self-regulating and self-disciplining".[90] Sociologist Rayna Rapp reiterates this observation: "The current generation of pregnant women is the first to be given an epidemiology of trepidation, and taught to live by the numbers".[91]

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[87] Carole H. Browner and Nancy Ann Press, "The normalization of prenatal diagnostic screening," In: *Conceiving the new world order: The global politics of reproduction*. Eds. Ruth Ginsberg and Rayna Rapp. (Berkeley and Los Angeles: University of California Press, 1995) 310-14

[88] Nancy Press and Carole H. Browner, "Why women say yes to prenatal diagnosis," *Social Science and Medicine* 45, no. 7 (1997): 986

[89] Barbara Katz Rothman, *The Tentative Pregnancy: How Amniocentesis Changes the Experience of Motherhood*. (New York: WW Norton & Co., 1993): 36

[90] Abby Lippmann, "Prenatal testing and screening: constructing needs and reinforcing inequalities." *American Journal of Law and Medicine* 17, no. 1-2 (1991): 15-50

[91] Rayna Rapp, *Testing Women, Testing the Fetus: The Social Impact of Amniocentesis in America*. (New York: Routledge, 2000): 106

This medically generated anxiety has increasingly been produced by obstetrics in general, and prenatal testing in particular.

Like other scientists, scholars, and experts, Watson concurred with the screening and elimination approach, stating that by "terminating such pregnancies, the threat of horrific disease genes contributing to blight many families' prospects for future success can be erased". In addition, Watson asserted that attempting to "see the bright side of being handicapped is like praising the virtues of extreme poverty… there are many individuals who rise out of its inherently degrading states, but we perhaps most realistically should see it as the major origin of asocial behavior".[92] The sentiments of cost and burden are echoed in a variety of bioethics and medical professionals' justifications of prenatal diagnosis and abortion, the cost to the family, the child, and society were simply too immense to allow such lives to continue. In a world of limited resources, selective abortion was presented as an appropriate response.

Other prominent bioethicists went further with this concept of cost and harm, asserting that to knowingly bring a child with impairment into the world (whether cystic fibrosis, Down syndrome, or deafness), is unfair to the child because it robs him or her of the "right to an open future". Joel Feinberg identifies the conflict of parental autonomy and a child's future autonomy with cases such as that of a Jehovah's Witness parent objecting to a needed blood transfusion for their child.[93] Feinberg introduces the "open future" argument as a means to appropriately balance parental autonomy in such

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[92] J. D. Watson. "President's essay: genes and politics." *Annual Report Cold Springs Harbor.* (1996): 19

[93] J. Feinberg "The child's right to an open future." In: *Whose Child? Children's Rights, Parental Authority, and State Power.* Eds. W. Aiken, H. LaFollette. (Totowa, NJ: Rowman & Littlefield; 1980): 124-153

instances. Dena Davis extends Feinberg's concept to that of prenatal testing; with an analysis of the desire to have a child with a particular disability (such as deafness), and taking advantage of prenatal information to ensure such a child. Davis contends that disabilities limit the range of life options or "open future" available to the child.[94] As a result, parents have a responsibility to provide their children with nurturance and opportunities that will enable them to lead satisfying lives. Due to the disadvantages of disability, Davis's use of the "right to an open future" argument asserts that parents should not subject a child to these limitations, and as a moral imperative ought to avoid deliberately bringing such children into the world.[95] On the basis of "significantly reduced life options," other arguments presented by ethicists advanced that it was not only unfair but morally wrong to bring a disabled child into the world.[96] Such positions reiterate the call for social responsibility in reproduction that was accepted as biological fact in the eugenics movement.

Throughout the 1980s and 1990s, various researchers and physicians advocated following California's lead in universal screening. Studies emphasized the cost savings that would be obtained with expanded screening, and asserted that all women would want to avoid disabled children, not just those over 35. For instance, analyses eagerly affirmed that prenatal screening was "cost effective" at any age by evaluating the costs of offering amniocentesis to be easily offset by the savings associated with preventing the birth of an

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[94] D. S. Davis. "Genetic dilemmas and the child's right to an open future." *Hastings Center Report* 27, no. 2 (1997): 7-15
[95] Ibid
[96] R. M. Green, "Parental Autonomy and the Obligation Not to Harm One's Child Genetically," *Journal of Law, Medicine and Ethics* 25, (1997): 5-15, See also L. Purdy "Genetics and Reproductive Risk: Can Having Children be Immoral?" In: *Reproducing Persons: Issues in Feminist Bioethics* (Cornell University Press, 1996)

infant affected by Down's syndrome.[97] In addition, of women given a positive diagnosis of Down's syndrome, reports cited figures as high as 93% would then terminate their pregnancy.[98] Under the canopy of personal choice, the general assumption was made that reasonable, rational people would want to screen for disabilities and terminate pregnancies that are diagnosed as positive. That the expected decision is termination is evident in reports identifying the "major obstacles" interfering with "rational decision making" as "religious beliefs, denial, lack of a grasp of probabilities, and lack of knowledge about genetics and biology".[99] As a result of these cost-benefit analyses and recommendations from researchers, new guidelines from the American College of Obstetricians and Gynecologists were announced in January 2007 stating that all pregnant women should be offered screening for Down syndrome regardless of age.[100]

Genetic counselors are uniquely placed in the delivery of information to expectant parents. In addition, they consider themselves as being nondirective in this position as they are simply providing amniocentesis as a means to acquire information; something believed to be value neutral. Instructional textbooks intended for counselors recognize the position of the counselor, and note that current technologies allow them to report about birth defects that may have little or no genetic basis, and common diseases of adulthood that have heterogeneous causes. In addition, it is acknowledged that they may

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[97] Thomas Elkins, and Douglas Brown, "The Cost of Choice: A Price Too High in the Triple Screen for Down Syndrome." *Clinical Obstetrics & Gynecology* 36, no. 3 (1993): 532-40, See also R. Conley, A. Milunsky. "The economics of prenatal genetic diagnosis." In: *A Prevention of Genetic Disease and Mental Retardation*. Ed. A. Milunsky, (Philadephia: Saunders, 1975): 8 and S. Hagard and F. A. Carter. "Preventing the births of infants with Down's syndrome: a cost-benefit analysis." *BMJ* 1, (1976): 753-56

[98] Ryan Harris, et al. "Cost Utility of Prenatal Diagnosis and the Risk-Based Threshold," *Lancet* 363, (2004): 276-282

[99] C. O. Leonard, G. A. Chase, B. Childs, "Genetic Counseling: A consumer's view." *New England Journal of Medicine* 287, no. 9 (1972): 433-9

[100] ACOG Committee on Practice Bulletins. ACOG Practice Bulletin No. 77: screening for fetal chromosomal abnormalities. [Journal Article. Practice Guideline] *Obstetrics & Gynecology* 109, no.1 (2007): 217-27

soon be capable of providing information regarding "normal" behavioral and physical traits.[101] However, although these capabilities and the position of the counselor implicate an array of ethical issues, these developments are not identified in any way as problematic territory. Beyond the issues created by the use of these measures, the complexity of genetic information, as well as the counselor's client volume creates an impractical situation for achieving comprehensive client education even with ample time and a sophisticated listener.

Acknowledging these subjects, genetic counselors are nevertheless advised to simply present information "in ways that the client can interpret and act on". In addition they are to entice clients to anticipate how a course of action could affect them, such as "consequences for the interrelationships of the couple, the effects on their other children, the suffering of the affected child, the possible social stigma," among other personal costs. Reflecting on the "economic burden of a defective offspring on society" is considered by some a reasonable point to make in addition.[102] As one author states, remaining "impartial is difficult and takes conscious effort but is largely attainable. The difficulty lies mainly in trying to remain impartial while aiming to prevent the occurrence of genetic disease".[103] The "efficacy" of genetic counseling is often identified in terms of comprehension. Essentially, the client should be provided with the information that will enable them to make the most "rational" decision.[104]

As can be observed with modern counseling, the concept of properly educating individuals regarding genetics so that they may make appropriate choices was an

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[101] Ann Platt Walker. "The Practice of Genetic Counseling," In: *A Guide to Genetic Counseling.* Ed. Diane Baker, Jane Schuette, and Wendy Uhlmann, (New York: Wiley-Liss, 1998): 6-8
[102] Milunsky, "Genetic Counseling," 8
[103] Ibid
[104] Milunsky, "Genetic Counseling," 28

important component of Ada Schweitzer's initiative. Schweitzer's common sense presentation in avoiding offspring that are "feebleminded" or inferior was part of the broad appeal of her work and that of others within eugenics. Galton in particular believed that eugenics ought to be "introduced like a new religion". Once society understood the value of eugenics, the public would naturally integrate the practice into daily life and general decision making. He considered it to be essential that we "cooperate" with nature by securing humanity with the fittest individuals. Galton mused that what nature routinely carries out "blindly, slowly, and ruthlessly, man may do providently, quickly, and kindly. As it lies within his power, so it becomes his duty to work in that direction".[105] He understood the importance of bringing eugenics to the common person. Once these persons bought into the value of eugenic practice, it would be perpetuated by these same individuals as they attended to their societal duty. Reflecting on this, Galton acknowledged that the "power of social opinion is apt to be underrated rather than overrated. Like the atmosphere in which we breathe and in which we move, social opinion operates powerfully without our being conscious of its weight".[106] Drawing attention to the progression of eugenics and genetics with that of professional and public opinion, we may observe the important points of continuity that result in action and policy.

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[105] Galton, *Essays in Eugenics*, 42
[106] Galton, *Essays in Eugenics*, 107

Chapter 3: Autonomy, Commodification, and Additional Ethical Issues

The 2007 guidelines from the American College of Obstetricians and Gynecologists, state that all pregnant women should be offered prenatal screening. These guidelines are the new phase in the aggressive movement for quality control in reproduction. Such guidelines ought to induce reconsideration of the intentions, goals, and implications of prenatal testing and the medical management of pregnancy. Disappointingly, the announcement of the recommendations did not immediately generate serious debate or discussion by bioethicists, physicians, or the public. The guideline introduction was without fanfare as a minor news side note, as though the extension of prenatal screening to all was simply a logical continuation of what has already been implemented. Is society's penchant for medical testing so ingrained that individuals no longer flinch when more is introduced, or are we simply unaware of the effects it could have on potential parents, children, and our attitudes toward each other?

Modern medicine has provided the opportunity for more people to enjoy life. At this point in history the outlook for a disabled individual's health has never been better; yet at this same moment our ability to seek out and eliminate particular individuals in utero has never been greater. This unique juxtaposition calls into question the assumption that eugenics is not relevant to modern medicine. In spite of this, attempting to discuss the issues related to prenatal testing and eugenics with a genetic counselor or physician does not likely generate much engagement on their part. Such professionals, and indeed many other scientists, ethicists, and academics, are likely to wave off suggestions that these two subjects have much to do with each other. After all, patient autonomy is the prevailing ethic in medicine, sterilization laws have been repealed, and the Nazi atrocities are a thing of the past. Yet, we should not take much reassurance with such a response. Genetic determinism is as prevalent with the public today as it was in the past, and most of our social stereotypes and prejudices are still powerfully active. The pressures for conformity and aesthetic appearance or function are as strong as ever and assuredly have an impact on values for reproduction.

Leon Kass provides an important counter to those disinterested professionals: "We physicians and scientists especially should refuse to finesse the moral question of genetic abortion and its implications and to take refuge behind the issue, 'Who decides?' For it is we who are responsible for choosing to develop the technology of prenatal diagnosis, for informing and promoting this technology among the public, and for the actual counseling of patients".[107] Biomedical researchers and clinicians not only develop the technologies of medical care, but are also frequently given a central role in designing health policies. As Kass suggests, they are in a unique position to decide the direction of scientific investigation, and influence institutional and public acceptance of what they create. Yet when a technology or procedure arrives to the bedside, patients assume it has been given a full and nonbiased assessment by competent authorities and given the moral rubber stamp by the appropriate experts.

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[107] Leon Kass. "Implications of Prenatal Diagnosis for the Human Right to Life," In: *Intervention and Reflection: Basic Issues in Medical Ethics*, Ed. Ronald Munson (Belmont: Wadsworth Thomson Learning, 2000) 618

A primary argument made by promoters of prenatal testing is the existence of strong social demand for this screening. However, statistics demonstrating the persistent increase in the usage of diagnostic screening tests by medical professionals were essential in persuading public authorities and others that the public was widely in favor of testing. The argument provided by scientific experts then became a self-fulfilling prophecy: by stressing how many tests have already been performed, more tests are regarded as necessary.[108] This tactic operated in a similar manner with the implementation of eugenic policy; scientific professionals presented their reasonable data showing the menace of the unfit, and politicians and the public eagerly adopted the proposed solutions.

Autonomy, the Illusion of Choice, and the Routinization of Prenatal Testing

The emphasis on patient autonomy and self-determination became a cornerstone ethic in medicine during the 1960s with the period's expanding technical abilities and changing social tide. Modern medicine no longer could paternalistically inform the patient of a treatment plan, but needed to engage them in ways that would allow decision-making among the options available. However, autonomy can be fully exercised only by those properly informed or comfortable enough to use it. This becomes difficult to

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[108] Carine Vassy. "From a Genetic Innovation to Mass Health Programmes: The Diffusion of Down's Syndrome Prenatal Screening and Diagnostic Techniques in France," *Social Science and Medicine* 63, no. 8 (2006): 2047-48

achieve with over half of the U.S. population considered to have low health literacy.[109] A lack of basic health knowledge creates considerable difficulty for patients attempting to communicate with their physicians and understand many other aspects of their care. Medical professionals can easily miss this type of inadequacy since those that do not know what to ask are likely to ask nothing at all. When patients are deficient of the knowledge to make an informed decision, they cannot fully participate in the management of their health. Although doctors control when and how they deliver information to patients in order to facilitate understanding, the nation-wide rates of low health literacy demonstrate that many patients do not fully comprehend or engage in their care.

As a concept of self-governance, autonomy is especially difficult to ensure for patients in the complex and arcane territory of genetics and prenatal testing. Informing the patient sufficiently to make typical health care decisions is a task in of itself, to attempt to accomplish such a feat with a situation involving genetic information creates another challenging layer. Yet it would be a mistake to designate autonomy as the unitary consideration in testing; multiple interests are at stake that are not revealed under simplified terms of personal “choice”. Any one-dimensional notions of genetic counseling belie the numerous subjects that influence decisions regarding prenatal screening and children. Such factors include physicians’ and counselors’ attitudes toward testing, patients’ experience with the medical system, opinions of family members, an

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[109] National Public Health Week - April 5-11, 2004 - Eliminating Health Disparities: Communities Moving from Statistics to Solutions Tool Kit. “Health Disparities: A General Overview. http://www.apha.org/NPHW/facts/HealthDisparities.pdf

array of social pressures, and attitudes that patients' may have developed toward disability and medical testing.[110]

Although genetics has become a mainstream topic in popular media, this does not translate into substantial knowledge or understanding of genetics or its application in prenatal screening. As with rates of overall health literacy, overall knowledge of prenatal diagnostics and the meaning of the results that are presented is low according to several studies, indicating that patients are not well-prepared to make decisions regarding screening. For instance, although most women are referred for genetic testing through their physician, a recent study identified that fifty-five percent of those surveyed "stated they received no information from their care provider," and only a third considered them as a "very helpful" source of information. The purpose of the testing was also not well understood, as nearly half of the same respondents did not consider ultrasound as a screen for anomalies, and nearly sixty percent stated that they were not informed it was their option to proceed with testing.[111]

Research that further probed prenatal care clinic visits reported similarly disappointing results. Obstetricians' discussions regarding genetic testing with patients "averaged 2.5 minutes for women younger than 35 years of age and 6.9 minutes for older women," and were seldom comprehensive; topics discussed most often were limited to the practical details of testing and only twenty-two percent of providers indicated that

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[110] Leslie Biesecker, "Clinical Commentary: The Law of Unintended Ethics," *Journal of Law, Medicine and Ethics* 25, (1997): 17

[111] Ruth Kohut, Deborah Dewey, and Edgar J. Love. "Women's Knowledge of Prenatal Ultrasound and Informed Choice," *Journal of Genetic Counseling* 11, no. 4 (2002): 265-76

ultrasound screening is voluntary.[112] With this information, it is not surprising that couples often are not aware of what information a prenatal diagnostic test may reveal or specifically what the testing has to do with the health of their fetus.[113] Coupled with this lack of awareness of what testing entails, individuals generally have difficulties comprehending abstract possibilities, and what such information can or cannot indicate.[114] When presented with a set of "odds" that their child may have some sort of impairment, it is challenging for couples to comprehend what such information means. Some may overestimate the relevance of a small probability, or underestimate certain others. In her observation of women going through prenatal testing, Rayna Rapp noticed many patients politely insist that they understood what was being presented, and (as in other medical interactions) when they did not grasp a concept they would blame themselves rather than the unclear explanation.[115] This and other research suggests that women, and parents in general, have limited knowledge of the purpose, limitations, and potential consequences of prenatal testing, and as a result, lack sufficient information to support informed autonomous decision-making.[116]

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[112] Barbara Bernhardt, et al. "Prenatal Genetic Testing: Content of Discussions Between Obstetric Providers and Pregnant Women," *Obstetrics and Gynecology* 91, (1998): 648-55

[113] K. Eurenius, et al. "Perception of information, expectations and experiences among women and their partners attending a second-trimester routine ultrasound scan," *Ultrasound, Obstetrics and Gynecology* 9, (1997): 86-90; and T. M. Marteau, M. Plenicar, and J. Kidd. "Obstetricians presenting amniocentesis to pregnant women: practice observed. *Journal of Reproductive and Infant Psychology* 11, (1993): 3-10

[114] G. A. Chase et al. "Assessment of risk by pregnant women: Implications for genetic counseling and education." *Social Biology* 33, no. 2 (1986): 57-64

[115] Rapp, *Testing Women, Testing the Fetus,* 113

[116] See Heather Skirton, "A Report of Two Linked Studies of Knowledge and Attitudes to Prenatal Screening and Testing in Adults of Reproductive Age in Japan and the UK," *Midwifery*, Jan 30 2007, (e-pub ahead of print); V. Goel et al. "Evaluating patient's knowledge of maternal serum screening." *Prenatal Diagnosis* 16, no. 5 (1996): 425-430; J. M. Green, M. P. M. Richards "Women's Knowledge of Prenatal Screening Tests. The Relationship with Hospital Policy and Demographic Factors." *Journal of Reproductive and Infant Psychology* 11, (1993):11-20; Kohut, "Women's Knowledge" 265-76; and T. M. Marteau "Towards Informed Decisions about Prenatal Testing: A review." *Prenatal Diagnosis* 15, no. 13 (1995): 1215-1226

The autonomy ethic in medicine requires informed decision-making, but also calls for the respect for patients' choice *not* to have particular information imposed upon them. Presenting unwanted detail regarding prenatal testing may force patients into an involuntary situation. Several researchers have debated the value of reporting abnormal ultrasonic markers to patients since they frequently are of no clinical significance, but often result in considerable patient anxiety.[117] However, most women enter prenatal exams without knowledge of such possibilities and consider an ultrasound examination (for instance) to be a positive experience, and as a result few are likely to have the foresight to opt out of receiving particular information regarding abnormalities unless they are explicitly given the opportunity to do so. Indeed, it is quite unusual for a patient to be aware that an ultrasound may identify fetal anomalies, to have reflected on the implications of such a finding, *and* to be forceful enough to present her views prior to the examination.[118]

The offer of testing usually has an accompanying indication of its benefits, making it difficult for patients to consider the screening as something they may not want. A survey of women going through with amniocentesis or chorionic villus sampling indicated that seventy-five percent of them found it difficult not to accept a prenatal diagnostic test once it was offered. Many of the women stated that they felt "free from

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[117] See J. C. Hobbins, R. O. Bahado-Singh, and D. C. Lezotte, "The genetic sonogram in screening for Down syndrome: response to the JAMA study," *Journal of Ultrasound Medicine* 20, (2001): 269-272. and R. A. Filly, "Obstetrical sonography: the best way to terrify a pregnant woman." *Journal of Ultrasound Medicine* 19, (2000): 1-5

[118] Robert Boyle, Lachlan de Crespigny, and Julian Savulescu. "An Ethical Approach to Giving Couples Information About Their Fetus," *Human Reproduction* 18, no. 11 (2003): 2253-2256

external pressure," but nonetheless felt an "obligation" to have the testing.[119] An obstetrician, reiterating this issue, noted that a growing number of women in his practice appeared to become emotionally "trapped" by a testing procedure to which most consented to with the expectation of a pleasant experience and expert reassurance.[120]

Several have argued that screening provides reassurance for the expectant mother, and they are choosing to make sure everything is going well. However, many authors have noted women's efforts to establish an emotional distance from the fetus were "often accompanied by feelings of confusion, alienation and ambivalence… (and) the experience of uncertainty regularly predisposed for long-lasting distress, even after the ruling out of a chromosomal aberration by invasive testing".[121] Several studies have also identified that parental distress after screening can then negatively affect their attitude and relationship with the child after birth, or force them into making other difficult choices.[122] A "vulnerable child syndrome" has been recognized that develops in the wake of disease risk labeling or other similar events during pregnancy, birth, or infancy, in that the parents may perceive their child to be particularly susceptible to illness or injury.[123] Such a posture toward children alters the dynamic of the parent-child relationship in ways that may not have occurred otherwise. It has further been noted that

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[119] B. Sjogren and N. Uddenberg, "Decision making during the prenatal diagnostic procedure. A questionnaire and interview study of 211 women participating in prenatal diagnosis," *Prenatal Diagnosis* 8, no. 4 (1988): 263-273

[120] Filly "Obstetrical sonography" 1-5

[121] M. J. N. Weinans, et al. "How women deal with the results of serum screening for Down syndrome in the second trimester of pregnancy." *Prenatal Diagnosis* 20, no. 9 (2000): 705-708

[122] T. M. Marteau, "Towards informed decisions" 1215-1226; T. Thelin, et al. "Psychological consequences of neonatal screening for alpha-antitrypsin deficiency. *Acta Paediatrica Scandinavica* 74, (1985): 787-793; and H. Markel, "The stigma of disease: implications for genetic screening," *American Journal of Medicine* 93, (1992): 209-215

[123] J. A. Burger, et al. (1993) "Psychological sequelae of medical complications during pregnancy. Pediatrics 91, no. 3 (1993): 566-571 and M. Thomasgard and W. P. Mertz "The vulnerable child syndrome revisited." *Journal of Developmental and Behavioral Pediatrics* 16, no. 1 (1995): 47-53

prenatal screening results can induce a clinically significant level of anxiety, and there are several documented mechanisms by which such intense stress can negatively affect the fetus.[124]

Prenatal screening has largely been subsumed under the normal procedures of obstetric care during pregnancy. In no small part this has been due to the possibility of malpractice jeopardy for a physician, which is more likely to occur when a woman is not tested. Tests such as ultrasound, maternal serum screens, and amniocentesis are blandly presented as standard care, an arrangement which significantly contributes to patients' acceptance rates. For instance, in an evaluation of the procedures for offering maternal serum screening in California, the test was often described as "just a simple blood test". And although women were sometimes informed that screening was not mandatory, it was found that this statement was often paired with the emphasis that screening was a California state program or that it was recommended.[125] The researchers, Nancy Press and C. H. Browner, found that although their interviews with the women revealed both to them and to the women that the informed consent process was not successful in conveying "information about test procedures and the conditions being screened for, or to get women to consider ethical issues involved in screening," their subjects "overwhelmingly professed satisfaction" with the amount of information they had been given.

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[124] T. M. Marteau, et al. "The psychological effects of false-positive results in prenatal screening for fetal abnormality: A perspective study." *Prenatal Diagnosis* 12, no. 3 (1992): 205-214; J. S. Seng, et al. (2001). "Posttraumatic stress disorder and pregnancy complications." *Obstetrics and Gynecology* 97, no. 1 (2001): 17-22.; and J. Teixeira, N. M. Fisk, and V. Glover, "Association between maternal anxiety in pregnancy and increased uterine artery resistance index: Cohort based study." *BMJ* 318, (1999): 153-157

[125] Nancy Press, and C. H. Browner, "Risk, autonomy, and responsibility: Informed consent for prenatal testing," *Hastings Center Report* 25, no. 3 (1995): S11

Intriguingly, Press and Browner additionally report that their subjects' responses were "notably brief and stereotypical to all interview questions which concerned the moral aspects of prenatal diagnostic testing, their reasons for accepting the test, or what they might do following a hypothetical positive result".[126] The results of their study overall revealed that women tended to consent to maternal serum screening without an encouragement to give it much thought. When the women were inquired further to think more about the test, they continued to frame the screening "in exactly the terms it had been presented to them - as having to do with reassurance, as simply another part of responsible prenatal care. Some even suggested that they had taken the test because they wanted to 'do everything (they) could to help (themselves) and the baby'".[127] Certainly there are situations which prenatal testing results could provide an opportunity to treat and therefore help the fetus, but more often than not the conditions tested for are not treatable, and the primary option with screening is termination not treatment. The interview responses that Press and Browner obtained reveal a general lack of this understanding, and what the overall purpose of screening truly is.

The results of Press and Browner's interviews, among other studies, suggest that strong institutional or provider support is the best predictor of prenatal testing acceptance.[128] The way that screening is presented not only affects patients' decisions, but also shapes their understanding of the meaning and purpose of these procedures. The discussion of screening with that of other typical blood tests and prenatal care routine makes it difficult for the patient to distinguish one test as unique from all others, and also

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[126] Press and Browner, "Risk, autonomy, and responsibility" S12
[127] Ibid
[128] Press and Browner, "Why women say yes," 979-989

establishes a clear assumption that the test is going to be done. This not only encourages women to be tested, but simultaneously discourages them from reflecting about their decision. Indeed when any medical tests appears to be standard, or supported and recommended by the medical community, patients do not have a reason to be suspicious and will likely accept such an offer without question. Routine prenatal care is viewed as a responsible action, and an obligation which directly influences the health of the infant, and with screening subsumed under this rubric questions are not likely to be aroused. These points reveal the powerful "social, moral, and economic forces" which direct women to prenatal screening and accepting the testing as "routine".[129]

Existing in the world of standard medical practice, there is no debate of the ethical concerns that exist. For instance, those few women that did exhibit misgivings about screening did not seem to "regard their fear as a reasonable response to the inherent tensions in a test which can find, but not correct, problems".[130] Of subjects interviewed, nearly eighty-five percent of those who agreed to testing not only stated that they did not deliberate much in their decision, but they also had trouble articulating "precisely *why* they had accepted testing".[131] Those interviewed by Barbara Katz Rothman described the utilization of screening and subsequent decision-making as their "only choice;" although they were not being *forced* per se, the women did feel "the experience of no-choice in a choice situation".[132] With California as a prime example of the rapid establishment and acceptance of screening procedures, it is clear how the American College of Obstetricians and Gynecologists' latest universal testing guidelines came without a hiccup of debate.

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[129] Lippman, "Prenatal genetic testing," 15
[130] Press and Browner, "Why women say yes" 986
[131] Press and Browner, "Why women say yes" 984
[132] Rothman, *The Tentative Pregnancy,* 180

Attitudes of Health Care Professionals and Nondirectiveness

Scientists, physicians, and other health professionals are “unused to thinking that their work is anything but self-justifying, (and) may balk at suggestions that their work may not be unqualifiedly good in results”.[133] Those that endorse prenatal screening typically offer nondirective genetic counseling, patient autonomy, and personal choice as distinguishing features from that of eugenics. While claiming value neutrality may be an attractive position, it disregards what is at stake with these procedures, and obscures typical underlying assumptions that “rational” people will make the “right” choices when they are informed. Indeed, Francis Galton, Ada Schweitzer, and those that established the first genetic counseling centers *counted* on individuals to voluntarily follow eugenic logic once properly taught. Nondirectiveness is attractive to genetic professionals in that it absolves them of any responsibility of arriving at a recommendation, and places the burden fully on the patient. The insistence of neutrality creates a lack of open discussion of what the over-arching goals of aggressive screening are and the relevant meaning of eugenics.[134]

There are key elements of typical genetic counseling sessions that create problems for the claim of nondirectiveness. It is difficult to claim neutrality as a guiding ethic for a technology explicitly cultivated to identify and accordingly eliminate those with genetic flaws. The very existence and routinization of prenatal screening implies anything but

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[133] Leon Kass, *Life, Liberty and the Defense of Dignity*. (San Francisco: Encounter Books, 2002): 25
[134] M. Stacey, “The new genetics: A feminist view.” In: The troubled helix, Eds. T. Marteau, and M. Richards (Cambridge: Cambridge University Press. 1996) 331-349

neutrality. Developing and offering this testing presumes that scientific and medical resources ought to be utilized to diagnose and eliminate the identified fetuses. Despite this, genetic counselors and medical professionals are trained to believe they are neutral and nondirective while offering this "value-charged technology".[135]

The shaping of the legitimacy of prenatal testing is derived from "wider cultural assumptions about the positive value of any kind of screening. From the moment screening techniques are developed, they benefit from a favorable preconception".[136] In addition, as in a traditional medical setting, the patient enters the counseling situation with a distinct knowledge disadvantage and is dependent on the information that is chosen to be presented. Although the patient may be "free" to refuse any testing or medical procedure offered, they must assert this refusal to a *professional* providing a recommendation for such screening. The offering of a procedure immediately implies that it is something that the individual ought to take advantage of, and is for their best interest. It is assumed that information and knowledge is a positive pursuit that enables educated decision-making. However, the structure of the offering encounter does not initiate a thoughtful discussion or raise particular ethical flags for expectant parents to consider; rather, screening is suggested with the expectation that it will be accepted.

The offering of testing implies that the conditions that may be detected ought to be avoided, and in this manner "entails a tacit recommendation to terminate a pregnancy if the fetus is abnormal… the offer and acceptance of genetic counseling has already set

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[135] Rapp, *Testing Women, Testing the Fetus*, 59

[136] Jerome Burne. "More than you need to know?" *The Guardian*, November 15, 2003. http://www.guardian.co.uk/medicine/story/0,,1084393,00.html

up a likely chain of events in everyone's mind".[137] Such information is not empowering, it is incapacitating.[138] The role of the parent is no longer simply that of a caretaker, but as a quality control officer as well. Information is never neutral, and the expected response is evident with high acceptance and termination rates, as most couples that receive positive results for defects choose to terminate. This response weakens parental ability to accept children as they are, and encourages them to judge the quality of the particular fetus. The weakening of parental acceptance of their children provides a basis for inflated notions of what parenting can bring in terms of fulfilled expectations. Children inevitably differ from what parents envision, and reinforcing particular expectations with genetic testing creates an opposing standard from the unqualified acceptance parents ought to have for their children. If prospective parents cannot accept and nurture a child that departs from their desire, they may not be truly prepared for the experience of parenthood. Prenatal screening generates a criterion to be met to warrant parental nurturance: we will love you unconditionally, *if* you pass this test.

Although many argue that termination of those with lethal or "serious" defects can be justified, and believe that we can ensure a non-arbitrary distinction between "serious" and cosmetic or treatable conditions, such boundaries do not hold in actual practice. For instance, during the 1980s and early 1990s (when prenatal screening became more fully developed and more frequently offered), the number of babies born with cleft lip fell by forty-three percent and those born with club foot fell by sixty-four

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[137] A. Clarke, "Non-directive genetic counseling." *Lancet* 338, (1991): 1524

[138] Barbara Katz Rothman, *The Book of Life: A Personal and Ethical Guide to Race, Normality, and the Implications of the Human Genome Project*. (Boston: Beacon Press, 2001): 190

percent, even though both are rectifiable surgically.[139] Medical and genetic professionals nevertheless refer to boundaries such as sex selection to demonstrate that prenatal testing can be limited to legitimate "medical conditions," and therefore testing is morally acceptable and not eugenic. However, the sex of an individual is identifiable *genetically*, and is "associated with variations in phenotype, health, longevity, life chances".[140] Although these are the descriptive terms offered in the diagnosis of disability, we have accepted that gender ought not to be a basis for distinction or valuation, even though it makes a difference physically.

Gender selection is considered incompatible with the unconditional acceptance that parents ought to have for their children, and that developmental psychologists have affirmed is essential to successful parenting.[141] Social efforts need to continue to emphasize the value of each, rather than reinforce negative attitudes. This situation seems to be precisely what those with disabilities assert; that there is more to someone than simply a particular diagnosis. Regardless, as the "normalizing gatekeeper," parents are asked to decide on the value of life amidst their perceived fears of raising a disabled child.[142] Medical genetics and society sets the standards for what are acceptable and unacceptable children, and parents are placed in the role of confirming those values.

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[139] P. Alderson, "Some unanswered questions," In: *Considered choices? The new genetics, prenatal testing and people with learning disabilities,* Ed. L. Ward, (Kidderminster: British Institute of Learning Disabilities Publications, 2001): 54

[140] Rothman, *The Tentative Pregnancy*, 200

[141] President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "Screening and Counseling for Genetic Conditions: A Report on the Ethical, Social, and Legal Implications of Genetic Screening, Counseling and Educational Programs." (Washington, D.C.: U.S. Government Printing Office, 1983)

[142] Rapp, *Testing Women, Testing the Fetus,* 131

Although women going through prenatal screening are in a medical setting, where they are accustomed to receiving a practitioner's recommendations, they are instead being asked to come up with an answer. The woman must take the full responsibility and blame for whatever decision is made. Prenatal testing individualizes the problem, and allows the rest of society to neglect taking collective responsibility for the needs of its members. Katz Rothman accurately describes this circumstance of choice: "We make it the woman's own. She 'chooses,' and so we owe her nothing. Whatever the cost, she has chosen, and now it is her problem, not ours".[143] This is not to suggest that counselors are not providing guidance, rather, they must select what information the woman is given and thereby "decide what is to count as a fact, which facts to present, and how to present them". These decisions impose a "professional frame" within which patients are confronted with a restricted range of options from which they are expected to choose.[144]

This professional frame does not automatically indicate an intentional deceit or hidden agenda on the part of the counselor; however one can "channel" patients through the decision-making process by couching replies to women in terms that are liable to generate action in the track believed to be correct.[145] Although this may seem directive, counselors do not actually suggest any particular option; although they may emphasize the negative aspects of a condition. For conditions deemed "serious," nearly thirty percent of U.S. genetic professionals acknowledged that they would provide negatively slanted counseling, and those polled said they personally would terminate a pregnancy

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[143] Rothman, *The Tentative Pregnancy*, 189

[144] A. Clarke, "The process of genetic counseling," In: Genetics, Society, and Clinical Practice. Eds. P. Harper and A. Clarke (Oxford: BIOS Scientific Publishers.) 179-200

[145] Williams, Clare, Priscilla Alderson, and Bobbie Farsides. "Is nondirectiveness possible within the context of antenatal screening and testing?" Social Science and Medicine 54, no. 3 (2002): 344

involving Down's syndrome, and many would abort for any abnormality.[146] The problematic attitude of providers regarding disability is further revealed in a study of mothers who wanted to continue their pregnancy, despite a positive diagnosis. The study found that some professionals continued to emphasize a negative outlook throughout their conversation with these prospective mothers, asking questions such as: "What are you going to say to people when they ask you how you could bring a child like this into the world?"[147] Even while aiming to be nondirective, counselors by necessity shape the session by focusing attention toward some topics and away from others, and as such lead the overall decision-making.

Families with a disabled child are often thought to be dysfunctional or exceptionally burdened financially and emotionally, and it is presumed that many marriages end in divorce as a result of this stress. Genetic and medical professionals (and several academics) also suggest that a poor quality of life is inevitable for those with disabilities, and terminating such fetuses is therefore a kind of altruism. Despite the literature indicating the rewards of raising children with disabilities; those in bioethics, public health, and genetics "remain woefully – scandalously – oblivious, ignorant, or dismissive of any information that challenges the conviction that disability dooms families".[148] Such assumptions are relentlessly exemplified in medical research that

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[146] D. C. Wertz, "Society and the not-so-new genetics: what are we afraid of? Some predictions from a social scientist." *Journal of Contemporary Health Law and Policy* 13, no. 2 (1997): 177; and Rothman, *The Tentative Pregnancy***,** 46

[147] D. T. Helm, S. Miranda, N. A. Chedd, "Prenatal diagnosis of down syndrome: mothers' reflections on supports needed from diagnosis to birth," *Mental Retardation* 36, (1998): 55-61; See also C. Dunne and C. Warren, "Lethal autonomy: the malfunction of the informed consent mechanism within the context of prenatal testing." *Issues in Law and Medicine* 14, no. 2 (1998): 165-202

[148] Adrienne Asch, "Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy," *American Journal of Public Health* 89, no. 11 (1999): 1654

correlates quality of life with particular levels of disability.[149] Such research typically emphasizes that the most negative aspects a disabled person suffers are as a direct result of their disability. Adrienne Asch identifies this stance as one of the false assumptions underlying the negative view of disabled persons' quality of life. The other assumption that Asch describes which contributes to this view is that because there may never be a complete physical recovery, there is not an opportunity to have a rewarding life. Asch argues that social factors are the primary source of the difficulties that disabled persons face, and that disability does not preclude having a meaningful life.[150] The impossibility of neutrality is visible in the inherently unequal professional-patient relationship that exists in the clinical environment. The negative pressures in society and medicine result in an overwhelming abortion rate and significant psychological costs for women.[151]

Although counselors may emphasize an assortment of issues such as cost, time, dependency, and the child's future when parents receive a positive diagnosis, these are in fact general concerns that every parent faces, and are not unique to those with disabled children.[152] Often parents do not understand the limits of prenatal diagnosis, and believe they can decide depending on the severity of a particular disability. Yet the diagnosis of a condition such as Down's syndrome cannot predict the degree of mental retardation, or other health concerns, nor can it predict the experience of having any child. Any

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[149] R. Baily, "Prenatal testing and the prevention of impairment: a woman's right to choose? In: Encounters with strangers, feminism and disability. Ed. J. Morris, (London, The Women's Press, 1996): 156, D. Kaplan, "Prenatal screening and diagnosis: the impact on persons with disabilities," In: *Women and prenatal testing (facing the challenges of genetic technology)*. Eds. K. Rothenberg, E. Thomson (Columbus: Ohio State University Press, 1994):50, and D. C. Wertz, and J. C. Fletcher "Ethical and social issues in prenatal sex selection: a survey of geneticists in 37 countries," *Social Science and Medicine* 46, no. 2 (1998): 255-73

[150] Asch, "Prenatal Diagnosis," 1650

[151] T. Shakespeare, "Choices and rights: Eugenics, genetics and disability equality. Disability and Society 13, no. 5 (1998): 665-681, and C. Mansfield, S. Hopfer, and T. Marteau. "Termination rates after prenatal diagnosis of Down's Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A systematic literature review." Prenatal Diagnosis 19, no. 9 (1999): 808-812

[152] Rothman, *The Tentative Pregnancy*, 162

assurances of a "normal" child still cannot guarantee one that a parent envisions or hopes for. Barbara Katz Rothman points out that even ordinary children can be distressing and demanding, "talk to themselves, have imaginary friends, stare into space, and won't respond. Ordinary, bright kids sometimes do not learn to talk for a long time, have trouble with their letters, fail math". Prenatal screening cannot ensure "normal" children, but it does reinforce social biases and changes the parent-child relationship by encouraging children to be the viewed as the embodiment of a diagnosis.[153]

The ideal model presented by genetic professionals combining individual rights, self-determination, and truly informed consent does not readily take into account the practical circumstances of interactions between health professionals and patients or the power and information imbalance that exists.[154] Such issues, coupled with most patients' low health literacy and the poor comprehension of probabilistic results, present a much different model of prenatal screening. Abby Lippman observes that "some features of prenatal diagnosis do increase control, but allocate it to someone other than a pregnant woman herself".[155] Our acceptance of the notion that parents ought to produce the "right children" has created the sentiment that a woman is irresponsible if the screening offered is not taken advantage of. Disabled children born to women that do not consent to screening and abortion may be viewed as less deserving of support, since this pregnancy outcome was deliberately *chosen*. Such considerations invariably limit autonomy, and

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[153] Rothman, *The Tentative Pregnancy*, 173

[154] D. Chambliss. "Is bioethics irrelevant?" *Contemporary Sociology* 22, no. 5 (1993): 649-652 and R. DeVries and P. Conrad. "Why bioethics needs sociology." In: *Bioethics and society: Constructing the ethical enterprise.* Eds. R. DeVries, and J. Subedi (Englewood Cliffs, NJ: Prentice-Hall 1998)

[155] Lippman, "Prenatal genetic testing" 15

frustrate individual efforts to accept a particular child into the world.[156] However, as families raising disabled children and those with disabilities reveal, impairment does not prevent a positive parenting experience or fulfilling life for the individual.

Aggressive screening technology reduces a potential human being to one part (genes) rather than considering the whole person that could be.[157] The offering of testing for particular traits and disabilities designates that *these* are the factors on which parents ought to base their decision-making. It establishes a particular class of human beings as having a life that is not worth living, and therefore justifiably eliminated from the population. Genetic testing promises so much, yet delivers little on its claims of improving autonomy and parental "choice". Although screening is presented as enhancing reproductive decision-making it is a "calculated mode of influence that increasingly limits the field of possible conduct in response to pregnancy," and with the acceptance of testing "pregnant women are enlisted to facilitate the normalization of the fetal body".[158] In this manner, the birth of a disabled child will be increasingly viewed as an act of negligence. Marsha Saxton asserts: "the message at the heart of widespread selective abortion on the basis of prenatal diagnosis is the greatest insult: some of us are too flawed in our very DNA to exist; we are unworthy of being born…"[159] As the expectations and standards of production increase, individuals will be expected to comply.

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[156] Gates, Elena. "Ethical Considerations in Prenatal Diagnosis," Fetal Medicine [Special Issue] The *Western Journal of Medicine* 159, no. 3 (1993): 391-395

[157] For the purposes of this thesis, I am putting aside the question of when a developing embryo or fetus becomes a person. The basis of my argument is focused on the future an embryo or fetus is denied through selective abortion.

[158] Shelly Tremain, "Reproductive freedom, self-regulation, and the government of impairment in utero," *Hypatia* 21, no. 1 (2006): 36

[159] M. Saxton, "Disability rights and selective abortion," In: *Abortion wars, a half century of struggle, 1950-2000*, Ed. Rickie Solinger (Berkeley. University of California Press, 1997): 391

Others argue that prenatal testing allows parents to prepare for a disabled child when they do not terminate, the perceived "win-win" of being able to terminate or being able to "get ready". The aspect of preparation seems reasonable, but the benefit of such information is assumed, and does not truly ease the experience or assist parents with their disabled children. When parents with disabled children were interviewed by Press and Browner, the unhelpfulness of "advance notice" was made fully apparent.[160] The notion of preparation gives an implicit but misleading guarantee of what is to come; obscuring that the possibility of caring for an ill or disabled child cannot be eliminated by even the most aggressive prenatal screening. Some parents may desire testing because they could "never raise a retarded child," or "couldn't bear" a disabled individual, "as if these things could be predetermined… (and) written in code ahead of time".[161] The elimination of those with congenital impairment does not prevent the occurrence of any other trauma that may occur during pregnancy or delivery that can be disabling, nor does it safeguard children from any number of potentially disabling accidents. Prenatal testing does provide a false sense of "security" and reinforces the notion that caring for an individual with impairment shackles the caretaker to a miserable existence.

For those that consider the goal of pregnancy to be the production of a healthy baby, screening and abortion simply allows the woman to move on and try again to meet this goal. If a normal child is not to be expected, why bother continuing? Katz Rothman describes this "product-oriented" logic toward pregnancy, and identifies how this concept leaves out any consideration for the woman's experience of pregnancy.[162] Dutch

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[160] Press and Browner, "Why women say yes," 986
[161] Rothman, *The Book of Life***,** 212
[162] Rothman, *The Book of Life*, 181

midwives that Katz Rothman interviewed reiterated the importance of a “good pregnancy” in which the woman enjoys the expectation of a baby. The midwives differentiated the status of the fetus from the woman’s personal experience: if the fetus’s impairments cannot be treated, “Why spoil the pregnancy?”[163] These midwives identified the value of pregnancy, and how prenatal screening and termination ruined a potentially positive overall experience. As a result of this value, many of the midwives interviewed found a good pregnancy to be very important, whatever the outcome.[164] Even in instances in which it is certain that the baby will not survive infancy, Katz Rothman emphasizes that screening and abortion results in the death of the woman’s expected baby, “without the saving grace of a good birth and a good death”.[165]

The Problem of Genetic Determinism

Prenatal screening, like traditional eugenics, furthers the notion that we are primarily the products of our genes. Although we may give a nod to environmental contributors, “genetic determinism” emphasizes genes as the most important basis for what we are or can become. The language used in regard to genetic disease “leads us to the easy but wrong conclusion that the afflicted fetus or person is rather than has” a

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[163] Rothman, *The Book of Life*, 183
[164] Ibid
[165] Rothman, *The Book of Life*, 185

particular disease.[166] In the context of genetic screening, determinism supports the assumption that "genetic diagnostics of any kind have more predictive power than other kinds of health risk assessments, and that all genetic health problems inevitably unfold in the lock-step fashion of our traditional models".[167]

How disability is viewed in relation to the individual is fundamental to how the practice of screening may be considered. Some scholars assert that the human essence remains unchanged despite such intervening afflictions; others maintain that what it is to be human (and therefore have value) is lost with the absence of particular capacities. Whether identity consuming or related to an identity, how disability is considered with regard to the person reveals what is truly indicated by the label of disability. If those with impairment are indistinguishable from their disability, in that it is essential to what the individual is, then it may be claimed that one could eliminate disability with prenatal screening and termination. For instance, if one *is* a Down's syndrome baby, rather than having the condition of Down's syndrome, then this disability may be considered to be an identity consuming property. Viewing an individual as having the condition of Down's syndrome presents the perspective of this trait as an accidental feature of the person's existence, which does not change who they are as human beings. An individual with bipolar disorder may however view themselves as inseparable from their condition, in that they cannot think of themselves as being who they are without this particular trait. Nonetheless, such an individual is more than the itemized list of clinical symptoms of bipolar disorder, however integral that property may seem to be to the person's concept

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[166] Kass, "Implications of Prenatal Diagnosis," 619

[167] Eric Juengst, "Concepts of Disease after the Human Genome Project" In: *Health Disease and Illness: Concepts in Medicine*. Eds. Arthur Caplan, James McCartney, and Dominic Sisti, (Washington D.C.: Georgetown University Press, 2004) 248

of self. The reductive view of *being* one's disability or disorder fails to consider the person beyond the impairment. Individuals are more than a particular condition, and have value regardless of the afflictions they may have.

When we can identify particular genes, we can exert control and predict them. Yet, even our classic examples of straightforward "single gene" disorders such as Huntington's disease do not necessarily produce the symptoms typically believed to be certain. Research has discovered that carrying one of Huntington's multiple genotypes that cause symptoms does not ensure that a problematic clinical syndrome will develop.[168] Despite such exceptions, determinism persists throughout public and academic sectors and forms the strong social obligation for disease carriers to not "spread" their affliction. Science and media hype project genetics to be the secret to our health and well-being.

Deterministic thinking does extend hope for a better world: we just have to create better people. Genetic makeup will become the new (and scientifically legitimate) basis for discrimination. The original eugenics involved clumsy attempts of control, our sophisticated modern approach offers a more antiseptic and clinical version, "but both are hopelessly mired in the reductionist thinking that fails to imagine the whole as something more".[169] Yet with all of the anxiety over our genetic resultants of reproduction, a mother's zip code still remains the best predictor of an infant's mortality and life

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[168] C. M. Benjamin, et al. "Proceed with care: Direct predictive testing for Huntington Disease," *American Journal of Human Genetics* 55, (1994): 606-617; and R. C. Strohman "Ancient genomes, wise bodies, unhealthy people: Limits of a genetic paradigm in biology and medicine," *Perspectives in Biology and Medicine* 37, (1993): 112-145

[169] Rothman, *The Book of Life*, 225

chances.[170] Our modern amazement and preoccupation with our genes further distracts us from the larger social and moral considerations of our most central problems. As Asch emphasizes, it is these social considerations which are the primary source of the difficulties that disabled persons face. Genetic determinism leads us to consider genes as the basis of all our troubles, and therefore genetic technology as the supreme solution. As such, genetic counseling providers are attentive to guiding their clients to make the "correct" reproductive decision.

The Goals of Testing

Some authors suggest that it is possible to logically separate the disabilities that we want to prevent, and the persons that currently have such impairments. In this way, one can consider the prevention of a disabled infant from being born as simply preventing that pathological impairment and not an actual person, and therefore no moral or eugenic implications are incurred regarding those living with disability.[171] This argument does not consider the conditions identified to be identity constituting in any morally significant way, "because there is no person or other morally significant subject upon which an

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[170] Rothman, *The Book of Life*, 228

[171] Buchanan et al., *From Chance to Choice*, 184; See also J. Harris. *Clones, Genes, and Immortality: Ethics and the Genetic Revolution*. (Oxford University Press, Oxford 1998)

identity might be constituted".[172] These authors contend that parents could be encouraged to avoid the birth of those that are disabled, while still supporting antidiscriminatory policies, without inconsistency.

The question of moral status for a fetus or embryo or its moral identity in relation to the person who may be born with a disability, is a significant and ongoing debate. If aborting a fetus involves eliminating the moral equivalent of a *person*, then such an action is morally problematic; if, however, it is the elimination of something that may *potentially become* a person, then the action is considered morally permissible. Regardless of the level of moral status that may be assigned to the fetus, prenatal screening itself is problematic. Even with a concession that a fetus has no moral status, eliminating on the basis of impairment devalues those persons with disability. The prevention those with impairments from being born indicates the disdain society has toward disability in general and disabled persons specifically.

It is often claimed that prenatal screening does not reinforce unjust prejudices as, for instance, sex selection could.[173] Yet the motivations to go to such lengths to prevent those persons that would have disabilities (or be a particular gender) cannot indicate that one equally values the life of such individuals. Society's negative view of life with disability is communicated with the development prenatal screening and efforts to urge it on every pregnant woman. Eliminating fetuses on a singular feature indicates that such a condition "invalidates the whole of the person the fetus would potentially become, and

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[172] T. Stainton, "Identity, difference and the ethical politics of prenatal testing," *Journal of Intellectual Disability Research* 27, no. 7 (2003): 534

[173] Buchanan et al., *From Chance to Choice*, 184

that this cannot but have implications for those currently living with such conditions".[174] Once a particular life is considered to not be of value, it becomes expendable and ceases to have meaning as an entity deserving rights, protection, and care. It is not avoiding just *any* fetus, but one deliberately tested, marked with a particular characteristic, and subsequently devalued as a result of that feature.

Prenatally screening and avoiding a disability is accomplished by avoiding the entire individual, and society views such lives as burdens that are expendable, or ought not to exist. There are many assumptions about raising a child with disabilities, and genetic screening seeks to allow the avoidance of these presumed experiences. Reflecting on the "blandly underinformed and underinforming routinization of mainstream aspects of prenatal diagnosis," we can observe the duty and personal responsibility concepts at work as they had with Ada Schweitzer's eugenic education projects and other similar initiatives of that period. Eugenic propaganda reinforced that society's ills could be resolved by preventing certain types of individuals, and a collective responsibility to achieve a community improved by science. Schweitzer's maternal and child hygiene efforts presented this logic to mothers, and their duty toward future generations. The interests we actually have in mind with prenatal testing differ significantly from those of curing certain illnesses.

What is perceived to be important in having a child factors importantly into how various authors view the ultimate goal of reproduction and the assistance of science in achieving that goal. If we view children as products that ought to fit a particular design, then an efficient and precise quality control seems to make sense. Customers are not

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[174] Stainton, "Identity, difference" 534

satisfied if the product invested in is defective and does not function properly. For instance, Daniel Kevles considers the purpose of reproduction as the creation of "independent, autonomous individuals… who will no longer need nurturance". In the prenatal screening process, Kevles suggests that parents ought to base their decision-making on the likelihood that the individual will develop that purpose of independence.[175] However, this view assumes that genetic screening and clearance of normality guarantees an end product person that will fit this or any ideal. Nevertheless, Kevels contends that individuals can morally make such decisions, and medical professionals are obligated to comply, even if the decision has been made with "a eugenic calculus, with which the provider did not agree".[176] However, this suggests that children are like property, existing purely for the parents.[177] This view additionally does not recognize the involvement of the medical community in the development and promotion of screening, the prejudices of society that enable this response, or any further consideration other than what is presumed to be personal choice.

Ronald Green considers the goal of prenatal screening as the prevention of harms to society and children, by not allowing disabled individuals to be born. Green not only asserts that preventing such persons averts harm, but *failing* to do so is morally wrong. Whether "knowingly, deliberately, or negligently," he believes that a child is "morally wronged" when brought into the world "with a health status likely to result in significantly reduced life options relative to other children".[178] In response to notions that the particular child that may result ought to be reflected upon, Green finds that a

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[175] Kevles and Hood, *The Code of Codes***,** 258
[176] Ibid
[177] Kass, "Implications of Prenatal Diagnosis," 622
[178] Green, "Parental Autonomy," 10

child "should not be compared with that child's own nonexistence. Rather it should be compared with *the reasonably expected health status of others in the child's birth cohort*".[179] These considerations identify fetuses and children as "fungible" or generic and interchangeable, and Green finds no moral quandary in eliminating such units identified as disabled or unacceptable. However, the concept of fungible entities does not accurately portray the woman's prenatal experience with a child. Pregnancies are not generic, and those that are lost are not replaced but uniquely regarded and contemplated.[180]

A major focus of Green's perspective is the assumed suffering incurred by the parents and children with impairment. Yet actual and potential suffering should not be confused, as this muddies the issues to be analyzed. The harms believed to be experienced by disabled children and parents are often inaccurate or incomplete, and Green's assessment does not provide an adequate presentation of such relevant concerns. The obligation to avoid the birth of a child affected by genetic disorder is a eugenic justification that fails to consider or value those outside of an arbitrarily constructed norm. The concept of such a standard and what it means to deviate from that criteria presents as a meaningful question with regard to prenatal screening.

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[179] Green, "Parental Autonomy" 8

[180] Biesecker, "Clinical Commentary" 16, See also Rothman, *The Tentative Pregnancy*

Issues regarding Quality of Life and Prejudice

At the basis of many quality of life assertions for prenatal screening is the notion of "species-type functioning," which has been imported into the bioethics discourse from the work of Christopher Boorse. The distinctions of normal and abnormal function are, according to Boorse, empirically grounded in objective scientific findings of the natural world.[181] This definition is utilized to support normative consequences in the writings of Norman Daniels, Dan Brock, and others. These determinations suggest that those that are disabled have a lower quality of life as a result of impairments placing them outside the norm, and that such lives ought to be prevented.

Although several academics and medical professionals claim that we can simultaneously value impaired individuals, and non-eugenically eliminate those with these same characteristics, such a convenient logic does not seem to be convincing. It is difficult to reason that a society "which had overcome its fears of disability and truly considered disabled people as equal members" would still have such an intense interest in prenatal testing.[182] In addition, the overwhelming negative bias of health care workers generates difficulties for the counsel they provide and avow to be impartial. Our pervasive discrimination of those with disabilities extends to bioethics and medical literatures; exhibiting assumptions and stereotypes that strip value from those with

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[181] See Christopher Boorse, "Concepts of health." In: *Health Care Ethics.* Eds. D. Van de Veer and T. Regan, (Philadelphia, Pa: Temple University Press; 1987): 359-393

[182] David S. King, "Preimplantation genetic diagnosis and the 'new' eugenics." *Journal of Medical Ethics*. 25, no. 2 (1999): 181

impairments. The presumed lack of quality of life has been challenged in a number of studies, yet this reasoning persists as a factor offered to parents.

To most observers, those with disabilities seem to live an undesirable daily existence at the expense of their caretakers. However, studies that interview disabled persons reveal a majority that considers their quality of life as good or excellent.[183] The anxiety that the disabled have unsatisfying lives is reinforced by prenatal screening, and assists to generate the notion that parents will be permanently disappointed by having such a child. Although those with disabilities report that they have “serious limitations in activities of daily living,” they nevertheless frequently report they have a good or excellent quality of life.[184] They understand their condition, set meaningful goals, and remain connected in their social networks. These tactics seem not much different than what other individuals do to maintain a positive outlook in life, yet many still insist that those with disabilities must be worse off than “normal” persons or are an undue burden for parents.[185] As a result of such perceived certainties, academics and genetic counselors alike promote prenatal screening. This, in accordance with the assumptions that Asch describes, generates the belief that the suffering incurred with disability can only be avoided by preventing those affected individuals.

Given our differing positions in life, we each must contend with a variety of opportunities that are not open to us. In the pursuit of an opportunity our experiences open particular doors while closing off certain others, and those with disabilities consider

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[183] Albrecht, Gary, Patrick Devlieger. “The disability paradox: high quality of life against all odds,” *Social Science and Medicin*e, 48 (1999): 977-988

[184] Ibid

[185] See J. Botkin, “Fetal privacy and confidentiality,” *Hastings Center Report* 25, no. 3 (1995): 32-39; and D. C. Wertz, and J. C. Fletcher. “A critique of some feminist challenges to prenatal diagnosis,” *Journal of Women’s Health*. 2, no. 2 (1993): 173-188

themselves as no different in this regard. Some persons with disability may have a negative view of their life, just as a “normal” individual can. One cannot predict that an individual will have such a view, or what particular life experience will be had in either instance, as a result we ought to “err” on the side of life. It may be contended that some impairments are so inherently distressing, that we ought to err on the side of not inflicting a life of pain on the individual. Such an argument may further assert that the point of life can be outweighed by the burden of life. However, life has intrinsic value, and is of ultimate value to the person even if subjectively. Although the presence or absence of a disability does not predict quality of life, nor inherently makes such persons worse off, this unexamined assumption stubbornly persists. It is considered unreasonable to base preferences on race, gender, or orientation, but such reasoning is not applied to those with impairments.

Intending to choose persons based on assumptions of quality of life or normality incorporates the eugenic ideals professed to be distilled from modern prenatal screening. In addition, clinicians, counselors, bioethicists, and others regularly dismiss data indicating that those with disabilities and their families do not necessarily view their lives negatively.[186] Such experts may contend that such accounts reflect a “denial of reality” or “an exceptional ability to cope with problems”.[187] Despite professional skepticism, parents arguably ought to know that studies confirm that “there is a level of agreement

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[186] National Organization on Disability. 1998. National Organization on Disability/Louis Harris Survey of Americans with Disabilities. New York: Louis Harris and Associates

[187] J. E. Tyson, and R. S. Broyles, “Progress in assessing the long-term outcome of extremely low birth weight infants,” *JAMA* 276, (1996): 492-493

approaching consensus that the overall adaptation profile for families who have children with disabilities basically resembles the overall profile for families in general".[188]

Although individuals with a close relationship with someone that has a disability find it "more difficult to evaluate the meaning or worth of that person's existence solely in terms of their genetic disease," genetic testing encourages the consideration of individuals in precisely narrow terms; that there is no need to discover anything beyond the identified impairment.[189] Prenatal screening reinforces the notion that certain persons are too flawed or unacceptable, and a conscious decision therefore needs to be made regarding their life. This practice indicates "an intolerance of diversity not merely in the society but in the family," potentially harming parental attitudes toward children in general.[190] The notion that "defectives should not be born" is a standard without boundaries. It will be the "soft-hearted rather than the hard-hearted judges who will establish the doctrine of second-class human beings, out of compassion for the mutants who escaped the traps set out for them".[191] The routine acceptance of screening prevents thoughtful consideration of what is at stake in our aggressive testing practices.

Prenatal genetic screening requires deciding what is "normal" and "abnormal," which presumes that we know what these mean. The concept of defining and enforcing a particular "normalcy" is at the core of what screening attempts to accomplish, and was

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[188] P. Ferguson, A. Gartner, and D. Lipsky, "The experience of disability in families: A synthesis of research and parent narratives," In: *Prenatal Testing and Disability Rights*. Eds. E Parens and A. Asch, (Washington, D.C.: Georgetown University Press; 2000): 72-94

[189] T. Duster and D. Beeson. "Pathways and Barriers to Genetic Testing and Screening: Molecular Genetics Meets the 'High Risk' Family. Final report" (Washington, DC: US Department of Energy; October 1997) See also Rosamund Scott. "Prenatal Testing, Reproductive Autonomy, and Disability Interests," *Cambridge Quarterly of Healthcare Ethics* 14, (2005): 65-82

[190] Erik Parens and Adrienne Asch. "Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations," *Mental Retardation and Developmental Disabilities Research Reviews* 9, no. 1 (2003): 42

[191] Kass, "Implications of Prenatal Diagnosis," 619-20

what eugenicists of the past fervently advocated.[192] Screening is presented as the means of ensuring a normal child, yet it misleads parents in this perceived control. Testing cannot guarantee a life without disability, numerous childhood disabilities occur by accident and illness, yet this practice encourages us to think of children as products that can be rubber stamped by a quality control method. Society treats “a small set of identities it endorses as if they were intrinsically true,” creating enormous pressure to consider anything that differs to be “fundamental threats, deviations or failures in need of correction, reform, punishment, silencing or liquidation”.[193] The physically and mentally able control the discourse, and identify which features are unacceptable, and this dogmatization feeds into the discrimination of others and shapes the further development and usage of genetic screening.

Deviations from “normal species functioning” are considered diminishing to the range of opportunity open to the individual;[194] as a result, disability may be believed to be incompatible with a satisfactory existence. A particular level of health is considered intrinsically desirable, and a “prerequisite for an acceptable life”.[195] The functional deficit of a disability is assumed to deprive the individual of the “right to an open future”.[196] Although those that will have a disability may have fewer options for the “open future” that philosophers and parents envision, this does not preclude many people with disabilities to find their lives satisfying.[197] Prenatal screening is not offered as a means to prevent a health inequality, but to prevent the birth of a person that has an

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[192] Rapp, *Testing Women, Testing the Fetus*, 38

[193] Stainton, “Identity, difference,” 536

[194] See N. L. Daniels, *Just Health Care: Studies in Philosophy and Health Policy.* (Cambridge, England: Cambridge University Press:1985)

[195] Asch. “Prenatal Diagnosis,” 1651

[196] Feinberg, “The child’s right,” 124-153

[197] Asch, “Prenatal Diagnosis,” 1652

undesirable characteristic. It places qualifications on who ought to receive the nurturance of a family and society, and does not consider the variety of ways that individuals may contribute to the community.

Choice and Commodification

Parents are unconstrained in choosing whether to reproduce, and many have asserted that they should also have the liberty to decide to avoid an undesirable product of reproduction. Yet this kind of posture toward children and reproduction seems to treat human life as commodity. It ought to be considered what it means to increasingly regard a child "not as a mysterious stranger given to be cherished as someone to take our place, but rather as a product of our will, to be perfected by our design and to satisfy our wants".[198]

The history of eugenics demonstrates the pitfalls in viewing individuals as chattel to be controlled. Notions of what is to be socially valued are overwhelmingly subjective, and encourage the view that persons are not of value unless they meet a certain criterion or contribute in a specific way. Individual choice does not eliminate the problem of eugenics, but is another means of pursuing such ideals. As more characteristics are being characterized as genetic, and possibilities expand, the options to be chosen regarding one's offspring will become a veritable "eugenic boutique".

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[198] Kass, *Life, Liberty,* 11

It may be argued that parents are the best to know what type of child they could handle raising, and they should not be burdened with what they do not want to take on. However, individual preference is difficult to argue without an uncontentious basis to appeal to when preventing a particular life for the sake of it seeming to be inferior. The idea that children ought to be chosen by personal preference denies that the value to be "found in different kinds of human life may be incommensurable".[199] These factors make it difficult to justify eliminating a developing human being simply for features that parents disvalue. Being able to choose always seems like a benefit to have, especially from the point of view of a consumer presented with a variety of products. Yet this does not seem to be the interaction we ought to have with our children, who inevitably vary from what parents envision. Prenatal screening can provide an illusion of choice, but children are still "hostages to fortune".[200] The social issues involved with our attitudes toward those that do not fit the norm and our response to them cannot be solved by making impairments and individual problem.[201]

The modern focus on aesthetics and beauty has an inevitable impact on how those with disabilities are viewed and judged. An array of interventions may be obtained to eliminate imperfections. The availability of these products and services has become the acceptable response to flaws; something is expected to be obtained to eradicate it.[202] The social concept of what is physically acceptable unsurprisingly affects "medical practice in general and policies on prenatal diagnosis in particular".[203] Prenatal screening requires

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[199] G. Gillett, "The unwitting sacrifice problem," *Journal of Medical Ethics* 31, no. 6 (2005): 329

[200] Rothman, *The Tentative Pregnancy*, 7

[201] Rothamn, *The Tentative Pregnancy*, 9

[202] D. Morris, *Illness and society in the post-modern age.* (Berkley: University of California Press, 2000): 29

[203] D. I. Bromage, "Prenatal diagnosis and selective abortion: a result of the cultural turn?" *Medical Humanities* 32, no. 1 (2006): 42

the judgment of whether a unique individual should be discarded because of a perceived amount of suffering believed to be attached with that life.[204] However, each individual is slated to experience a combination of harms and goods throughout life, but consider it to be worthwhile nonetheless. This perspective makes it difficult to regard “a search and destroy policy towards genetic abnormalities” to be a justifiable response.[205]

When a great deal of time and energy is invested to ensure a particular reproductive outcome, it becomes more difficult to accept anything less than what was expected. This mentality creates selective acceptance, a morally problematic stance toward children.[206] The increased use of testing has furthered inflated the belief that screening is necessary to produce a healthy child, and that the medical management of pregnancy can assure a particular outcome. With the extended offering and acceptance of testing, those that are disabled will increasingly be viewed as reproductive errors or oversights. These attitudes and expectations modify the experience of pregnancy and parenthood, as they did a century ago.

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[204] Rothman, *The Tentative Pregnancy*, 9

[205] Gillett, “The unwitting sacrifice problem,” 331

[206] Parens and Asch, “Disability Rights Critique,” 43; See also Rothman, *The Tentative Pregnancy*, 243

Modern Eugenics

Prenatal screening reveals our consummate trust in what medical science provides to ensure acceptable offspring, and neglect of conversations that question whether we ought to aggressively pursue such testing. Genetic interventions have been ingrained in the public conscious as an unquestionable good, with only a few technical obstacles, and bioethicists have been recruited to quell the fears of those that are resistant. Eugenics is a method of coping with human differences. The goals of eugenics have not changed, but are now couched in sanitary terms of choice and quality of life arguments. Even without formal government enforcement, coercive forces persist in directing individuals toward perceived ideals and norms. That persons have little value unless they meet a certain criterion reflects a eugenic rational, insistent of a particular standard.

Prenatal screening is eugenic as it “necessarily involves the systematic selection of fetuses”. Although the term “eugenics” is “scrupulously avoided” in most scientific and medical discussion regarding prenatal diagnosis, except when it is disclaimed as a motive, this testing “presupposes that certain fetal conditions are intrinsically not bearable”.[207] Prenatal testing is presented as a means of ensuring a healthy child, as a reasonable and routine aspect of prenatal care, and regards those that do not take advantage of it as denying themselves of important information. The perceived good in obtaining all available information, and taking control, is emphasized in this manner.

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[207] Lippman, “Prenatal genetic testing and screening,” 24-25

Prenatal testing does not guarantee perfect health, yet it is extended in a way that leads recipients to believe that screening will provide such validation. Eugenics deems certain individuals as unfit to warrant their inclusion in the human community, or to provide them with social goods. It supports the view that a particular standard is necessary for life to have value, and science will assist in achieving that goal. However, advances in scientific knowledge are not likely to help us resolve moral issues, or with determining what the goals of medicine should be.

References

ACOG Committee on Practice Bulletins. ACOG Practice Bulletin No. 77: screening for fetal chromosomal abnormalities. [Journal Article. Practice Guideline] *Obstetrics & Gynecology* 109, no. 1 (2007): 217-27

American College of Obstetricians and Gynecologists, “Professional Liability Implications of AFP Tests,” DPL Alert, May 1985

Alderson, P. “Some unanswered questions,” In: *Considered choices? The genetics, prenatal testing and people with learning disabilities,* edited by L. Ward, Kidderminster: British Institute of Learning Disabilities Publications, 2001

“A New Name - Society for the Study of Social Biology (formerly the American Eugenics Society),” *Social Biology* 20, no. 1 (1973): 1

Asch, Adrienne. “Prenatal Diagnosis and Selective Abortion: A Challenge to Practice and Policy,” *American Journal of Public Health* 89, no. 11 (1999): 1649-1657

Baily, R. “Prenatal testing and the prevention of impairment: a woman’s right to choose? In: *Encounters with strangers, feminism and disability.* edited by J. Morris, London, The Women’s Press, 1996

Benjamin, C. M. et al. “Proceed with care: Direct predictive testing for Huntington Disease,” *American Journal of Human Genetics* 55, (1994): 606-617

Bernhardt, Barbara et al. “Prenatal Genetic Testing: Content of Discussions Between Obstetric Providers and Pregnant Women,” *Obstetrics and Gynecology* 91, (1998): 648-55

Biesecker, Leslie G. “Clinical Commentary: The Law of Unintended Ethics,” *Journal of Law, Medicine and Ethics* 25, (1997): 16-18

Botkin, J. “Fetal privacy and confidentiality,” *Hastings Center Report* 25, no. 3 (1995): 32-39

Boyle, Robert, Lachlan de Crespigny, and Julian Savulescu. “An Ethical Approach to Giving Couples Information About Their Fetus,” *Human Reproduction* 18, no. 11 (2003): 2253-2256

Bricker, L. et al. “Ultrasound screening in pregnancy: A systematic review of the clinical effectiveness, cost-effectiveness and women’s views.” *Health Technology Assessments* 4, no. 16 (2000)

Browner, Carole H. and Nancy Ann Press. “The normalization of prenatal diagnostic screening,” In: *Conceiving the new world order: The global politics of reproduction* edited by Ruth Ginsberg and Rayna Rapp. Berkeley and Los Angeles: University of California Press, 1995

Burger, J. A. et al. “Psychological sequelae of medical complications during pregnancy. *Pediatrics* 91, no. 3 (1993): 566-571

Burne, Jerome. “More than you need to know?” *The Guardian*, November 15, 2003. Accessed January 11, 2007 http://www.guardian.co.uk/medicine/story/0,,1084393,00.html

Bromage, D. I. “Prenatal diagnosis and selective abortion: a result of the cultural turn?” *Medical Humanities* 32, no. 1 (2006): 38-42

Chase, G. A. et al. “Assessment of risk by pregnant women: Implications for genetic counseling and education.” *Social Biology* 33, no. 2 (1986): 57-64

Clarke, A. “Non-directive genetic counseling.” *Lancet* 338, (1991): 1524

Clarke, A. “The process of genetic counseling,” In: *Genetics, Society, and Clinical Practice.* edited by P. Harper and A. Clarke Oxford: BIOS Scientific Publishers. 1997

Conley, R. and A. Milunsky. “The economics of prenatal genetic diagnosis.” In: *A Prevention of Genetic Disease and Mental Retardation* edited by Milunsky A., Philadephia: Saunders, 1975

Daniels, N. L. *Just Health Care: Studies in Philosophy and Health Policy.* Cambridge, England: Cambridge University Press: 1985

Davis, D. S. “Genetic dilemmas and the child’s right to an open future.” *Hastings Center Report* 27, no. 2 (1997): 7-15

Dubbins, P. A. “Screening for chromosomal abnormality.” *Seminars in Ultrasound, CT and MRI* 19, no. 4 (1998): 310-317

Dunne, C. and C. Warren. “Lethal autonomy: the malfunction of the informed consent mechanism within the context of prenatal testing.” *Issues in Law and Medicine* 14, no. 2 (1998): 165-202

Duster, T. and D. Beeson. “Pathways and Barriers to Genetic Testing and Screening: Molecular Genetics Meets the ‘High Risk’ Family. Final report” Washington, DC: US Department of Energy; October 1997

Esarey, Logan. *History of Indiana From Its Exploration to 1922 With an Account of Indianapolis and Marion County Vol IV* Dayton Historical Publishing Co. 1924 Accessed October 10, 2006 http://members.tripod.com/~debmurray/marion/marbioref50.htm#aschweitzer

Elkins, Thomas and Douglas Brown, "The Cost of Choice: A Price Too High in the Triple Screen for Down syndrome." *Clinical Obstetrics & Gynecology* 36, no. 3 (1993): 532-40

Eurenius, K. et al. "Perception of information, expectations and experiences among women and their partners attending a second-trimester routine ultrasound scan," *Ultrasound, Obstetrics and Gynecology* 9, (1997): 86-90

Feinberg, J. "The child's right to an open future." In: *Whose Child? Children's Rights, Parental Authority, and State Power* edited by W. Aiken and H. LaFollette. Totowa, NJ: Rowman & Littlefield. 1980: 124-153

Ferguson, P., A. Gartner, and D. Lipsky, "The experience of disability in families: A synthesis of research and parent narratives," In: *Prenatal Testing and Disability Rights* edited by E. Parens and A. Asch, Washington, D.C.: Georgetown University Press. 2000: 72-94

Filly, R. A. "Obstetrical sonography: the best way to terrify a pregnant woman." *Journal Ultrasound Medicine* 19, (2000): 1-5

Fuchs, F. and R. Riis. "Antenatal sex determination." *Nature* 177, no. 4503 (1956): 330

Galton, Sir Frances. *Essays in Eugenics*, London: The Eugenics Education Society, 1909

Gates, Elena. "Ethical Considerations in Prenatal Diagnosis," Fetal Medicine [Special Issue] *The Western Journal of Medicine* 159, no. 3 (1993): 391-395

Gaudilliere, J. P. *Inventer la biomedicine.* Paris: La Decouverte, 2002

Goel, V. et al. "Evaluating patient's knowledge of maternal serum screening." *Prenatal Diagnosis* 16, no. 5 (1996): 425-430

Green, J. M. and M. P. M. Richards. "Women's Knowledge of Prenatal Screening Tests. The Relationship with Hospital Policy and Demographic Factors." *Journal of Reproductive and Infant Psychology* 11, (1993): 11-20

Green, R. M. "Parental Autonomy and the Obligation Not to Harm One's Child Genetically," *Journal of Law, Medicine and Ethics* 25, no. 1 (1997): 5-15

Hagard, S. and F. A. Carter. “Preventing the births of infants with Down’s syndrome: a cost-benefit analysis.” *BMJ* 1, (1976): 753-56

Harris, Ryan et al. “Cost Utility of Prenatal Diagnosis and the Risk-Based Threshold,” *Lancet* 363, no. 9405 (2004): 276-282

Hobbins, J. C., R. O. Bahado-Singh, and D. C. Lezotte, “The genetic sonogram in screening for Down syndrome: response to the JAMA study,” *Journal of Ultrasound Medicine* 20, (2001): 269-272

Juengst, Eric “Concepts of Disease after the Human Genome Project” In: *Health Disease and Illness: Concepts in Medicine* edited by Arthur Caplan, James McCartney, and Dominic Sisti, Washington D.C.: Georgetown University Press, 2004

Kaplan, D. “Prenatal screening and diagnosis: the impact on persons with disabilities,” In: *Women and prenatal testing (facing the challenges of genetic technology),* edited by K. Rothenberg and E. Thomson, Columbus: Ohio State University Press, 1994

Kass, Leon. “Implications of Prenatal Diagnosis for the Human Right to Life,” In: *Intervention and Reflection: Basic Issues in Medical Ethics,* edited by Ronald Munson, Belmont: Wadsworth Thomson Learning, 2000

Kass, Leon. *Life, Liberty and the Defense of Dignity*. San Francisco: Encounter Books, 2002

Kemp, Tage. “Genetic Hygiene and Genetic Counseling.” *Acta Genetica et Statistica Medica* 4, (1953): 240-47

Kevles, Daniel and Leroy Hood. *The Code of Codes: Scientific and Social Issues in the Human Genome Project*. Cambridge: Harvard University Press, 1993

King, David S. “Preimplantation genetic diagnosis and the ‘new’ eugenics.” *Journal of Medical Ethics* 25, no. 2 (1999): 176-183

Leonard, C. O., G. A. Chase, and B. Childs, “Genetic Counseling: A consumer’s view.” *New England Journal of Medicine* 287, no. 9 (1972): 433-9

Lippman, Abby. “Prenatal genetic testing and screening: Constructing needs and reinforcing inequality.” *American Journal of Law and Medicine* 17, no. 1-2 (1991): 15-50

Madison, James H. *Indiana Through Tradition and Change: A History of the Hoosier State and its People, 1920-1945.* Indianapolis: Indiana Historical Society, 1982

Mansfield, C., S. Hopfer, and T. Marteau. "Termination rates after prenatal diagnosis of Down's Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A systematic literature review." *Prenatal Diagnosis* 19, no. 9 (1999): 808-812

Markel, H. "The stigma of disease: implications for genetic screening," *American Journal of Medicine* 93, (1992): 209-215

Marteau, T. M. et al. "The psychological effects of false-positive results in prenatal screening for fetal abnormality: A perspective study." *Prenatal Diagnosis* 12, no. 3 (1992): 205-214

Marteau, T. M., M. Plenicar, and J. Kidd. "Obstetricians presenting amniocentesis to pregnant women: practice observed. *Journal of Reproductive and Infant Psychology* 11, (1993): 3-10

Marteau, T. M. "Towards Informed Decisions about Prenatal Testing: A review." *Prenatal Diagnosis* 15, no. 13 (1995): 1215-1226

McBryde Johnson, Harriet. "Unspeakable Conversations or How I Spent One Day as a Token Cripple at Princeton University." *The New York Times Magazine,* February 2003, 50-55, 74-76

Meckel, Richard A. *Save the Babies: American Public Health Reform and the Prevention of Infant Mortality 1850-1929*. Ann Arbor: University of Michigan Press, 1998

Milunsky, A. *How to have the healthiest baby you can*. New York: Simon and Schuster, 1987

Milunsky, A. *Choices, not chances: An essential guide to your heredity and health*. Boston: Little Brown, 1989

Milunsky, A. *Heredity and your family's health*. Baltimore: Johns Hopkins University Press, 1992

Milunsky, A. "Genetic Counseling: Preconception and as a Prelude to Prenatal Diagnosis." In: *Genetic Disorders and the Fetus: Diagnosis, Prevention, and Treatment* edited by A. Milunsky, Baltimore: The Johns Hopkins University Press, 1992

Miner, Paul. *Indiana's Best! An Illustrated Celebration of the Indiana State Fairgrounds, 1852-1992*. Indianapolis: Indiana State Fair Commission, 1992

Monk, C. et al. "Maternal stress responses and anxiety during pregnancy: Effects on fetal heart rate." *Developmental Psychobiology* 36, no. 1 (2000): 67-77

Morris, D. *Illness and society in the post-modern age.* Berkeley: University of California Press, 2000

Muller, Hermann J. "Better Genes for Tomorrow," In: *The Population Crisis: Implications and Plans for Action*, edited by Larry K.Y. Ng and Stuart Mudd, Bloomington: Indiana University Press, 1965

National Organization on Disability. National Organization on Disability/Louis Harris Survey of Americans with Disabilities. New York: Louis Harris and Associates, 1998

Neel, James V. "Lessons from a Primitive People." *Science* 170, no. 960 (1970): 815-21

Oliver, Clarence P. "Human Genetics Program at the University of Texas." *Eugenical News* 37, (1952): 25-31

Press, Nancy and Carole H. Browner. "Risk, autonomy, and responsibility: Informed consent for prenatal testing," *Hastings Center Report* 25, no. 3 (1995): S9-12

Press, Nancy and Carole H. Browner. "Why Women Say Yes to Prenatal Diagnosis," *Social Science and Medicine* 45, no. 7 (1997): 979-989

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

Reed, Sheldon. "Heredity Counseling and Research." *Eugenical News* 37, (1952): 41-46

Rothman, Barbara Katz. *The Tentative Pregnancy: How Amniocentesis Changes the Experience of Motherhood.* New York: WW Norton & Co., 1993

Rothman, Barbara Katz. *The Book of Life: A Personal and Ethical Guide to Race, Normality, and the Implications of the Human Genome Project.* Boston: Beacon Press, 2001

Saxton, M. "Disability rights and selective abortion," In: *Abortion wars, a half century of struggle, 1950-2000*, edited by Rickie Solinger, Berkeley: University of California Press, 1997: 374-95

Scott, Rosamund. "Prenatal Testing, Reproductive Autonomy, and Disability Interests," *Cambridge Quarterly of Healthcare Ethics* 14, (2005): 65-82

Seng, J. S. et al. "Posttraumatic stress disorder and pregnancy complications." *Obstetrics and Gynecology* 97, no. 1 (2001): 17-22

Serr, D. M., L. Sachs, and M. Danon. “Diagnosis of sex before birth using cells from the amniotic fluid.” *Bulletin of the Research Council of Israel* 5B, no. 2 (1955): 137-8

Shakespeare, T. “Choices and rights: Eugenics, genetics and disability equality. *Disability and Society* 13, no. 5 (1998): 665-681

Sjogren, B. and N. Uddenberg, “Decision making during the prenatal diagnostic procedure. A questionnaire and interview study of 211 women participating in prenatal diagnosis,” *Prenatal Diagnosis* 8, no. 4 (1988): 263-273

Skirton, Heather. “A Report of Two Linked Studies of Knowledge and Attitudes to Prenatal Screening and Testing in Adults of Reproductive Age in Japan and the UK,” *Midwifery* 2007 Jan 30, (epub ahead of print)

Stacey, M. “The new genetics: A feminist view.” In: *The troubled helix*, edited by T. Marteau and M. Richards, Cambridge: Cambridge University Press. 1996. 331-349

Stainton, T. “Identity, difference and the ethical politics of prenatal testing,” *Journal of Intellectual Disability Research* 27, no. 7 (2003): 533-39

Stern, Alexandra and Howard Markel. *Formative Years: Children’s Health in the United States, 1880-2000*. Ann Arbor: University of Michigan Press, 2002

Stern, Alexandra. “Making Better Babies: Public Health and Race Betterment in Indiana, 1920-1935,” *American Journal of Public Health* 92, no. 5 (2002): 742-752

“Social Problems Have Proven Basis of Heredity: What the Work Done in the Eugenics Record Office at Cold Spring Harbor Has Proved in Scientific Race Investigation,” New York Times. New York, N.Y.: Jan 12, 1913

Strohman, R. C. “Ancient genomes, wise bodies, unhealthy people: Limits of a genetic paradigm in biology and medicine.” *Perspectives in Biology and Medicine* 37, (1993): 112-145

Teixeira, J., N. M. Fisk, and V. Glover, “Association between maternal anxiety in pregnancy and increased uterine artery resistance index: Cohort based study.” *BMJ* 318, (1999): 153-157

Thelin, T. et al. “Psychological consequences of neonatal screening for alpha-antitrypsin deficiency.” *Acta Paediatrica Scandinavica* 74, (1985): 787-793

Thomasgard, M. and W. P. Mertz. “The vulnerable child syndrome revisited.” *Journal of Developmental and Behavioral Pediatrics* 16, no. 1 (1995): 47-53

Tremain, Shelley. “Reproductive freedom, self-regulation, and the government of impairment in utero,” *Hypatia* 21, no. 1 (2006): 35-59

Tyson, J. E. and R. S. Broyles, “Progress in assessing the long-term outcome of extremely low birth weight infants,” *JAMA* 276, (1996): 492-493

Valenti, Carlo, Edward J. Schutta, and Tehila Kehaty, “Prenatal Diagnosis of Down’s Syndrome,” *Lancet* 2, no. 7561 (1968): 220

Walker, Ann Platt. “The Practice of Genetic Counseling,” In: *A Guide to Genetic Counseling* edited by Diane Baker, Jane Schuette, and Wendy Uhlmann, New York: Wiley-Liss, 1998: 1-18

Watson, J. D. “President’s essay: genes and politics.” *Annual Report Cold Springs Harbor* (1996): 19-20

Weinans, M. J. N. et al. “How women deal with the results of serum screening for Down syndrome in the second trimester of pregnancy.” *Prenatal Diagnosis* 20, no. 9 (2000): 705-708

Wertz, D. C. “Society and the not-so-new genetics: what are we afraid of? Some predictions from a social scientist.” *Journal of Contemporary Health Law and Policy* 13, no. 2 (1997): 299-346

Wertz, D. C. and J. C. Fletcher “Ethical and social issues in prenatal sex selection: a survey of geneticists in 37 countries,” *Social Science and Medicine* 46, no. 2 (1998): 255-73

Wertz, D. C. and J. C. Fletcher. “A critique of some feminist challenges to prenatal diagnosis.” *Journal of Women’s Health*. 2, no. 2 (1993): 173-188

Williams, Clare, Priscilla Alderson, and Bobbie Farsides. “Is nondirectiveness possible within the context of antenatal screening and testing?” *Social Science and Medicine* 54, no. 3 (2002): 339-347

Material from the Indiana State Archives

Schweitzer, Ada. “Division of Infant and Child Hygiene,” *Monthly Bulletin of the Indiana State Board of Health*, December (1924), Division of Infant and Child Hygiene

Schweitzer, Ada. “Why Have a Baby Contest?” *Monthly Bulletin of the Indiana State Board of Health* 31(1928), 125, Division of Infant and Child Hygiene

“Indiana State Fair Better Baby Activities,” *Monthly Bulletin of the Indiana State Board of Health* 30, (1927): 136-140, Division of Infant and Child Hygiene

Schweitzer, Ada. “Physical Inequalities of Children” 1923, Division of Infant and Child Hygiene

Schweitzer, Ada. “The Benefits of a Better Baby Contest” 1920, Better Babies Program Files

Schweitzer, Ada. “The Job of Being a Parent” 1924 Indiana State Board of Health, Division of Infant and Child Hygiene

Schweitzer, Ada. “The Hazards of Motherhood” Indiana State Board of Health, Division of Infant and Child Hygiene

Schweitzer, Ada. “The Menace of the Mental Defective to Public Health” 1917 Indiana Conference on Mental Hygiene, Division of Infant and Child Hygiene

Schweitzer, Ada. “Some of the Ways in which Club Women have Cooperated with the Child Hygiene Division” 1924, Division of Infant and Child Hygiene

Schweitzer, Ada. “Report by State Board of Health Child Hygiene Division on Examination of Preschool Children,” August 1, 1932, Division of Infant and Child Hygiene

Schweitzer, Ada. “Statement of Five-Year Trend for Health Council,” January 17, 1933, Division of Infant and Child Hygiene

Abbott, Grace to Ada Schweitzer. May 24, 1924, Division of Infant and Child Hygiene

Schweitzer, Ada to Mr. George B. Lockwood. March 20, 1916, Division of Infant and Child Hygiene

Schweitzer, Ada to Grace Abbott. May 22, 1924, Division of Infant and Child Hygiene

Schweitzer, Ada to A. F. Bentley. June 18, 1923, Division of Infant and Child Hygiene

Schweitzer, Ada to A. F. Bentley. June 20, 1923, Division of Infant and Child Hygiene

Schweitzer, Ada to E. Melville. July 5, 1923, Division of Infant and Child Hygiene

Schweitzer, Ada to R. Gregg. July 10, 1923, Division of Infant and Child Hygiene

Schweitzer, Ada to S. Grossman. October 23, 1924, Division of Infant and Child Hygiene

Schweitzer, Ada to H. C. Carpenter. May 5, 1919, Correspondence, Division of Infant and Child Hygiene

Schweitzer, Ada to Anna Rude. July 27, 1920, Division of Infant and Child Hygiene, Department of Labor Children's Bureau Correspondence

Schweitzer, Ada to B. Havens. July 2, 1919, Division of Infant and Child Hygiene Correspondence

Schweitzer Ada to S. Davis. June 27, 1923, Correspondence, Division of Infant and Child Hygiene

Schweitzer, Ada to W. Rosen. September 19, 1923, Division of Infant and Child Hygiene

Schweitzer, Ada to E. Henry. January 4, 1933, Division of Infant and Child Hygiene

Schweitzer, Ada to Oppenheimer. February 13, 1933, Division of Infant and Child Hygiene

"Outline of Classes for Mothers." 1924, Division of Infant and Child Hygiene

"Facts Concerning Maternity and Infancy." 1924, Division of Infant and Child Hygiene

"Indiana's Work in Child Hygiene." *Indiana Business Women* 4, no. 2 (1921): 15, Better Babies Program Files

Indiana Child Welfare Committee to County Chairman, July 16, 1919, Report of the Child Welfare Committee, Division of Infant and Child Hygiene

Report for the Quarter Ending September 30 1920, Division of Infant and Child Hygiene, Department of Labor Children's Bureau Correspondence

“Mental Defectives in Indiana Second Report of the Indiana Committee on Mental Defectives: A Survey of Eight Counties.” December 27, 1918, Board of State Charities

Material from the National Archives at College Park

“Abstract of Lectures for Mothers’ Classes.” 11-16-1, Central File 1925-28, Record Group 102, United States Children’s Bureau

“Annual Report of the Division of Infant and Child Hygiene, Indiana State Board of Health for the Year Ending September 30, 1921.” 4-11-1-3, Central File 1921 24, Record Group 102, United States Children’s Bureau

“State Fair Better Babies Demonstrations.” 11-16-1, Central File 1925-28, Record Group 102, United States Children’s Bureau

Schweitzer to Lathrop, September 5, 1918, 9-1-2-3, Central File 1914-20, Record Group 102, United States Children’s Bureau

Schweitzer to Haines, September 28, 1926, 11-16-1, Central File 1925-28, Record Group 102, United States Children’s Bureau

Hurty, John to Children’s Bureau, June 18, 1920. 4-15-2-16, Central File 1914-20, Record Group 102, United States Children’s Bureau

Curriculum Vitae

Mary Elise Huerter

Education

Loyola University Chicago - Cum Laude May 2005
Bachelor of Science
Biology Major
Chemistry and Bioethics Minors

Indiana University August 2007
Master of Arts
Focus: Bioethics

Work History

Medical and Administrative Assistant September 2001 - August 2007
Chicago Consulting Physicians
Dr. James A. Runke - Medical Director

Duties and Responsibilities: general medical history, blood pressure, SNELLEN visual acuity. Administer X-rays, pulmonary function tests, lower extremity Doppler testing, Cardiovascular stress testing, EKGs, blood draws, Visual Field testing, and DENVER assessments with regard to evaluations for Social Security Disability, in addition to direct communication/correspondence with adjudicators and supervisors in the Bureau of Disability**,** evaluation scheduling/ report generation and other administrative duties. Involvement with training/overseeing new staff as a senior Medical Assistant. *Illinois Department of Nuclear Safety Accreditation in Medical Radiation Technology*

Research Experience

Graduate Research Assistant August 2006 - May 2007
Indiana University Center for Bioethics
Dr. Eric Meslin - Director

Worked directly with academic scholars pursuing the identification, study, and dissemination of research findings regarding current bioethics issues such as: biopharmaceuticals, genetic testing, and biological specimen repositories; with the goal of assisting policymakers and informing the general public with lectures and seminars. Projects included, but were not limited to, researching and organizing information for the Director's presentations given at local and international lectures, organizing and planning meetings, collaborating to organize and construct an innovative repository of relevant bioethics works as a resource for research scientists and Center faculty, collaborating to produce ethical policy recommendations to the Indiana State Department of Health regarding pandemic influenza preparedness.

Research Assistant January 2003 - June 2003
Biology Department, Microbiology focus
Loyola University Chicago
Dr. Domenic Castignetti
Isolation and identification of iron chelating
siderophore membrane proteins to enable
discovery of overall mechanistic function.

College Activities/Leadership Responsibilities

Human Osteology Teaching Assistant August 2004 - January 2005
Anthropology Department
Loyola University Chicago
Dr. Anne Grauer
Assisted students in developing proficiency
in identifying human bone fragments,
organization of class labs, quizzes, and tests

Evoke-Big Questions in Biology October 2003 - May 2004
Loyola University
Dr. Domenic Castignetti
Student/Faculty group analysis of
current Bioethical issues

Loyola Women's Club Rugby September 2001 - May 2005

Loyola Student Ambassador September 2001 - May 2005
Undergraduate Admissions
campus tours, over-night stays, shadowing
to classes for prospective students.
Panel speaker for Loyola Open Houses

Eucharistic Minister, Lector, Choir Member September 2001 - May 2005
Loyola University Ministry

Volunteer Experience

Ambulance Volunteer Rider June 1999 - May 2005
St. Catherine's Hospital
East Chicago, Indiana
Assist patient transport, stabilization,
vitals, IV set-up, on-scene back up

Emergency Room Volunteer June 1998 - May 2005

St. Catherine’s Hospital
Piloted the emergency room volunteer assistance program
Responsibilities included, but not limited to, wound irrigation/dressing, assisting suturing/suture removal, splints, casting, EKG testing, triage, patient transport

Awards and Honors

Loyola Women’s Rugby January 2004
Outstanding Athletic Leadership Award
Loyola University Chicago

Loyola Women’s Rugby Commitment Award January 2004
Loyola University Chicago

Dean’s List- seven semesters August 2001 - May 2005
Loyola University Chicago

Loyola Student Ambassador Distinguished Speaker August 2003
Loyola University Chicago Undergraduate Admissions

Undergraduate Admissions Service Award August 2003
Loyola University Chicago Undergraduate Admissions

Dr. John Waddas Memorial Award - Best Female Leadership May 2001
Bishop Noll Institute (Hammond, Indiana) Award granted to one female graduating senior

Steven Rader Memorial Award May 2001
Superior Athletic Leadership and Service
Bishop Noll Institute (Hammond, Indiana)
Award granted to one graduating senior

St. Catherine’s Hospital Outstanding Volunteer Award April 2001
St. Catherine’s Hospital (East Chicago, Indiana)