

## Down syndrome: Coercion and eugenics

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**Abstract:** Experts agree that coercion by insurance companies or governmental authorities to limit reproductive choice constitutes a eugenic practice. We discuss discrimination against families of children with Down syndrome who chose not to have prenatal testing or chose to continue a pregnancy after a prenatal diagnosis. We argue that this discrimination represents economic and social coercion to limit reproductive choice, and we present examples of governmental rhetoric and policies condoning eugenics and commercial policies meeting criteria established by experts for eugenics. Our purpose is to sensitize the clinical genetics community to these issues as we attempt to provide the most neutral nondirective prenatal genetic counseling we can, and as we provide postnatal care and counseling to children with Down syndrome and their families. We are concerned that if eugenic policies and practices targeting individuals with Down syndrome and their families are tolerated by clinical geneticists and the broader citizenry, then we increase the probability of eugenics directed toward other individuals and communities. *Genet Med* 2011;13(8):708–710.

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Experts agree that coercion to limit reproductive choice by insurance companies or governmental authorities constitutes a eugenic practice.<sup>1–6</sup> This coercion can be influenced by economic considerations, such as an insurance company refusing to pay for the care of a child with a disorder identified in utero if the mother/couple decides to continue the pregnancy.

Eugenics is recognized to be one form of genetic discrimination, and genetic determinism can be a driver for both genetic discrimination and eugenics.<sup>5–7</sup> The existence of genetic discrimination is recognized by federal legislation, in the form of the Genetic Information Nondiscrimination Act (GINA) of 2008.<sup>8</sup> GINA provides stronger barriers against genetic discrimination than existed before its passage. However, just as the Civil Rights Act of 1964 has not eliminated discrimination, more than 45 years after its passage,<sup>9</sup> GINA will not completely eliminate genetic discrimination or protect us from a resurgence of eugenics.<sup>6</sup>

We will discuss that discrimination against individuals with Down syndrome and their families exists, and we will argue that this genetic discrimination represents social and economic coercion to limit reproductive choice. A consequence of these influences for genetic professionals may be an erosion of nondirective counseling.

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### DISCRIMINATION AGAINST CHILDREN AND FAMILIES OF CHILDREN WITH DOWN SYNDROME

Before we discuss contemporary examples of discrimination against families of children with Down syndrome who chose not to have prenatal testing or chose to continue a pregnancy after a prenatal diagnosis, we will describe the historic existence of genetic discrimination against individuals with intellectual and developmental disabilities, including those with Down syndrome. One notorious example is the case of *Buck v. Bell*, in which Supreme Court Justice Oliver Wendell Holmes, Jr, arguing in favor of forced sterilization of those with intellectual disabilities, is quoted, “Three generations of imbeciles are enough.”<sup>10</sup> The Nazis, who developed their concepts and practices from the American Eugenics Movement, followed their “principle” of “life unworthy of life,” moving from forced sterilization to the killing of children “suspected” of having “serious hereditary diseases,” which included children with Down syndrome, as the initial stages in their progression toward mass exterminations in the death camps.<sup>11</sup> Therefore, there is historic precedence for discrimination against those with intellectual and developmental disabilities, including individuals with Down syndrome, leading to eugenic practices.

Prejudice and discrimination against individuals with Down syndrome continue today.<sup>12–16</sup> Families of children with Down syndrome also experience discrimination. For example, when a physician had a newborn with this disorder, she and her husband recalled “that the hospital staff was abuzz: ‘How can a doctor have a child with Down syndrome?’”<sup>17</sup>

Contrary to the principle of nondirective counseling that we have always considered a core value in medical genetics, parents tell us that the prenatal counseling they received was aggressively directive. The concern regarding prenatal coercion and discrimination has come up in every extended discussion we have had with families of children with Down syndrome, since our arrival in the Linda Crnic Institute for Down syndrome on August 1, 2010, and is a serious concern for these families. As one mother told us (personal communication), “I happen to be pro-choice, and that means I get to choose (to continue or not to continue the pregnancy), not my doctors!” This mother was given blatantly erroneous information in the early part of this decade, for example, that the life expectancy of a child with Down syndrome born then was 3 years, when the data indicate it was approximately 50 years or more.<sup>18</sup> It is difficult to infer intent, but this mother felt this archaic information was intended to have a direct and coercive influence on her choice, and many other families agree with her.

This mother’s experience is not an isolated incident. It has been documented that women in Spain, who had a prenatal screen indicative of a fetus with Down syndrome and chose not to have a confirmatory test and to continue the pregnancy, felt pressured by their physicians to confirm the screening result.<sup>19</sup> Mothers in Spain delivering an infant with Down syndrome received little or no information regarding this condition from their physicians. The mothers were upset that physicians did not connect them with parents of children with Down syndrome. These mothers suggested the following strategies for health care professionals: inform parents immediately when you suspect that their infant has Down syndrome; be sensitive and compassionate; provide a great deal of

information immediately that is up-to-date; do not ask why the mother had her child; and provide contact information for parents of children with Down syndrome and support groups for parents of children with Down syndrome.<sup>19</sup>

Women in the Netherlands who elected to terminate a pregnancy after a prenatal diagnosis of Down syndrome were concerned that “the child would never be able to function independently” (92%), “the abnormality (was) too severe” (90%), the “burden” “was too heavy” for “the child itself” (83%), “my other child(ren)” (73%), or “myself” (64%).<sup>20</sup> These Dutch mothers thought that the medical staff had significant influence, although most did not feel pressured.

Because of concerns that women were given out of date information or no information at the time of a prenatal diagnosis of Down syndrome, and physicians were not aware of recent advances, in general education for children with Down syndrome including postsecondary education, Kleinert et al.<sup>21</sup> developed an interactive tutorial program that improved knowledge about Down syndrome for residents in Obstetrics and Gynecology, and Pediatrics, so that they could provide information that was accurate and balanced. Both groups of residents improved in their knowledge of Down syndrome and in their perceived comfort levels for delivering a prenatal diagnosis (Obstetrics and Gynecology residents) or a postnatal diagnosis (Pediatric residents). This or similar training programs could improve the quality of information regarding Down syndrome presented to parents by Obstetrics and Gynecology and Pediatric residents.

Skotko et al. provided evidence-based guidelines for informing parents at the time of a prenatal<sup>22</sup> or postnatal<sup>23</sup> diagnosis of Down syndrome. In a study examining what and how Pediatric residents in Massachusetts were taught about children and youth with special health care needs, Pediatric residents and faculty members indicated that the residents would benefit from more formal training opportunities to learn from families about caring for children and youth with special health care needs such as Down syndrome.<sup>24</sup> Faculty recommended that residents need to see the child outside of the hospital to appreciate his or her quality of life. Faculty emphasized the advocacy role for the parents of children and youths with special health care needs.

The need for balanced and accurate information is even more compelling with the January 2007 practice bulletin from the American Congress of Obstetricians and Gynecologists, which recommended that all pregnant women, of any age, should be told that screening for Down syndrome was available.<sup>25</sup> A survey of American Congress of Obstetricians and Gynecologists Fellows and Junior Fellows, conducted between October 2007 and April 2008, indicated that 95% of respondents offered screening for Down syndrome to all pregnant women in their practices.<sup>26</sup> This same study found that 40% of respondents felt their residency training about the screening for, and diagnosis of, Down syndrome “was less than adequate.” These data show the need for additional sources of accurate, balanced, and up-to-date information (e.g., on the life expectancy of individuals with Down syndrome<sup>18</sup>) for physicians to prevent misinformation from influencing decision making.

Pressure is exerted by governmental entities to terminate pregnancies when prenatal testing indicates a fetus with Down syndrome. The California prenatal screening program described such pregnancies that are continued as “missed opportunities.”<sup>27</sup> The March 2009 brochure for women with a positive screen for Down syndrome from the California Prenatal Screening Program states: “This birth defect causes mental retardation and some serious health problems.”<sup>28</sup> Further descriptions of Down syndrome include: “Infants with this birth defect are moderately retarded, a few are mildly or severely retarded. Heart defects are

common. These heart defects can usually be treated with surgery and medication. Other serious health problems often exist with Down syndrome. Medical treatment can help some of these problems.”<sup>28</sup> Describing the majority of children with Down syndrome as moderately retarded, while only a few are mildly retarded is not correct. Janet Carr in her 1995 book<sup>29</sup> reports that 53% of young adult females (aged 21 years) with Down syndrome had IQs >50 and 18% of young adult males with Down syndrome had IQs >50, putting them in the mild range. Overall, 34% of individuals with Down syndrome were in the mild range. These results were confirmed by Jamie Edgin (Personal Communication), who found 39.4% of individuals with Down syndrome had mild intellectual disability and 1% had borderline intellectual functioning. We are concerned that the inaccurate and overly negative information provided by California may be intended to coerce a woman into a decision to terminate her pregnancy if the fetus is diagnosed with Down syndrome.

The policy of the National Health Service (NHS) in the United Kingdom is described as “geared to ensuring” the termination of such a pregnancy, and “is still based on the idea that the birth of a baby with Down’s is an unmitigated disaster.”<sup>30</sup> The California program’s rhetoric and brochure, and the NHS’s policies threaten personal autonomy and reproductive freedom.<sup>6</sup>

## DISCRIMINATION LEADS TO ECONOMIC AND SOCIAL COERCION THAT LIMIT REPRODUCTIVE CHOICE

We argue that this discrimination represents economic and social coercion to limit reproductive choice. The rhetoric from the California prenatal testing program, while perhaps not eugenic per se, since it does not represent a formal policy of the state, is considered to facilitate eugenics.<sup>6</sup> The March 2009 brochure from this program<sup>28</sup> does not present current information regarding individuals with Down syndrome and could be considered coercive and leaning toward eugenics. A policy of a governmental entity, like that of the NHS, or a practice, like the professional and educational publications from California, to limit reproductive choice is considered by many to be eugenic.<sup>6</sup>

The California program’s position is most definitely based on economic considerations—in terms of cost and effectiveness.<sup>27</sup> We assume that the policy of the NHS is similarly economic in nature. Private insurers are also motivated by economics. A health insurance company informed a mother that they would only cover her baby if she underwent prenatal testing and terminated the pregnancy if the fetus was affected.<sup>2</sup> If the mother continued a pregnancy with an affected fetus, then she would be economically responsible for the care of that child. The insurer’s message was clearly one of economic coercion to limit this woman’s reproductive freedom. Allen<sup>3</sup> considers this scenario to be moving toward eugenics, and Holtzman<sup>2</sup> considers it to be eugenic.

In addition to these blatant policies of economic coercion to limit reproductive choice, there are also more subtle social cues. The mother who felt her obstetrician was pressuring her to terminate her pregnancy by providing erroneous and highly negative information. Or the physician, who happens to be the mother of a baby with Down syndrome and whose colleagues wonder how this could happen. These would be examples of social stigmatization associated with being a parent of a child with Down syndrome that may be a coercive influence as parents learn that their fetus has this disorder.

## PURPOSES IN BRINGING THESE ISSUES OF DISCRIMINATION, COERCION, AND EUGENICS TO THE ATTENTION OF MEDICAL GENETICS PROFESSIONALS

One of our purposes is to sensitize the clinical genetics community to these issues as we attempt to provide the most neutral, nondirective, prenatal genetic counseling we can, and as we provide postnatal care to children with Down syndrome and their families. As medical genetics professionals, each of us must ask whether we have been influenced by the social perspective that devalues the life of the individual with Down syndrome. If we wish to be supportive of families in their choice and provide optimal care to their children, then we must recognize the risk of discrimination and coercion. We also need to work with agencies and health care providers to ensure the information about the potential and the quality of life for individuals with Down syndrome is included in information given to couples at the time of prenatal or postnatal diagnoses.

Another purpose is to recognize the risk of broadening these coercive, discriminatory, and, frankly, eugenic policies and practices. The economic and social environment in the early 21st century is similar to that which gave rise to the American Eugenics Movement in the early 20th century.<sup>1,3,5-7</sup> We are concerned that eugenic policies and practices targeting individuals with Down syndrome and their families may be tolerated and even facilitated by medical professionals. The citizenry sees us as the experts in this area, and, if they see us as condoning these policies and practices, then we increase the probability that eugenics, under a different name, will be directed toward other individuals and communities.

There are some excellent examples of efforts to improve the quality of information available to the public regarding Down syndrome. One of these is the March of Dimes website, which provides information that is current and evidence based.<sup>31</sup> Edwards and Ferrante<sup>32</sup> should be commended for assembling representatives from the National Down syndrome Society, the National Down syndrome Congress, the American College of Obstetrics and Gynecology, the American College of Medical Genetics, and the National Society of Genetic Counselors to discuss prenatal screening and diagnosis of Down syndrome. Their effort points to the need to involve advocates for individuals with Down syndrome, both parents and self-advocates. A couple whose fetus or newborn has Down syndrome needs to have the most up-to-date and accurate information regarding the potential and the quality of life for individuals with Down syndrome.

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