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At Home with Down Syndrome and Gender^{*}

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ABSTRACT: I argue that there is an important analogy between sex selection and selective abortion of fetuses diagnosed with Down syndrome. There are surprising parallels between the social construction of Down syndrome as a disability and the deeply entrenched institutionalization of sexual difference in many societies. Prevailing concepts of gender and mental retardation exert a powerful influence in constructing the sexual identities and life plans of people with Down syndrome, and also affect their families' lives.¹

Home is where an individual can most be herself. Home is where one does what one wants, wears what one wants and eats what one wants. At home, the walls are painted in a favorite color and the pictures on the walls reflect one's personal interests. Home is where we share our lives with the people we have chosen. Some of us choose to live alone. We decide who comes in and out of our homes and for what purpose. Home is where we may entertain family, lovers, and friends if we like (Lakin, Bruininks, and Larson 1992, 236).

My brother Leo is thirty years old. He lives in my parents' home, a two-story house in Edmonton, Alberta, Canada. His room upstairs is across the hall from my parents' bedroom. The window faces out to the street, overlooking the driveway. At 9:00 o'clock every evening, my parents ask Leo to go to his room. He closes the door and turns out the light. He often listens to music through headphones or lies awake waiting to

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¹ I am aware that the use of the term "mental retardation" is contested, and contestable. Many disability theorists in the United States and Canada use the term "cognitive" or "intellectual" impairment (or disability), and in the UK, the preferred term is "(person with) learning difficulties." I continue to refer to mental retardation, because it is the term and concept familiar to most philosophers. My aim here is precisely to throw into question the meanings associated with this term. Thanks to Shelley Tremain for bringing this point to my attention.

hear his digital watch beep at the beginning of every hour. He likes to wait until midnight before going to sleep.

Sometimes my parents invite their friends over to their home. Leo enjoys chatting with the guests, eating and drinking, sometimes listening to the music they make, sometimes performing for them or with them. He has been taking voice lessons for seven years and loves to sing songs with piano accompaniment. When my parents tell him to go to bed, he protests that he would rather stay up until the guests leave. Eventually, if my parents insist, Leo reluctantly goes up to his room. Often when the guests finally leave the house, they hear Leo calling to them from his window overlooking the driveway. He says “Good night!” and invites them to come again soon.

If anybody asks me about my brother, I usually explain that he lives at home with our parents. In recent years, however, Leo has been saying that he does not feel “at home” there. He says he wants to find his own apartment in New York City, and support himself by working at the university, like his sister (Wong 2000). Sometimes he says he wants to go to law school, or that he wants to get married and have children. These are the kind of long-term plans that most parents look forward to discussing with their adolescent and adult children. When Leo talks about these dreams and plans, however, my parents shake their heads and laugh gently. Based on what they have observed so far, my parents believe that Leo is not capable of living on his own. They plan for him to stay in their home as long as they live. If he outlives them, he will not make the major decisions about what place he eventually calls home; I will do so, as his legal guardian. Leo does not know of these plans, and we do not share them with him. Instead, we joke that no apartment in New York City could have a vegetable garden like the one where Leo tends the potatoes with father, nor would Leo find free concerts featuring the music that mother plays every day. We know that Leo will never go to law school, because he cannot do the conceptual thinking necessary to study law. He does not know this, and we do not tell him this. Instead, we warn him that law school is very hard work and ask where he would find the money to pay the tuition. When Leo speaks of wanting children, we can’t even wrap our minds around the image of Leo finding a lover let alone becoming a parent, so we fall silent. Father, mother, and sister--each of us does the utmost to prevent my brother from realizing what strikes most people when they first meet him: that he has Down syndrome (DS).²

How did Leo come to share our family home? Were my parents planning and preparing for a child with Down syndrome? Did they make an explicit commitment to taking care of their son for the rest of their lives? Not at all. Unlike most prospective parents today, in 1971 they had never heard of “Mongoloid babies,” as they were then commonly called. They did not have access to prenatal genetic testing. They did not even know whether they were expecting a girl or a boy. Hours after Leo’s birth, the doctors diagnosed him with Down syndrome and advised my parents to institutionalize him immediately, predicting that he would be very difficult to raise at home. My parents did

² Down syndrome, the most frequently occurring chromosomal abnormality, causes mental retardation and increased risk for certain health problems. In the United States it occurs once in approximately every 800 to 1000 live births. Over 350,000 Americans have Down syndrome (NDSS 2002).

not want to give up their baby son so soon. They decided to take him home and to raise him with me. They reasoned that they could always decide to put Leo in an institution later on if caring for him became too troublesome. Thirty years later, they are still looking after Leo at home.

In 2001, as I think about my own plans to start a family, I realize that my situation is very different from my mother's. If I become pregnant after age thirty-four, medical professionals will ask me as a matter of routine whether I choose to undergo prenatal testing. I will have a choice of technologies for testing the fetal genetic material, each with a different degree of accuracy and associated risk factors. If I undergo testing, the goal will be to detect the presence or absence of whatever genetic conditions doctors currently consider severely disabling, including anencephaly, spina bifida, Tay-Sachs disease, and Lesch-Nyhan syndrome.³

If my fetus is diagnosed with any of these conditions, I will be asked to decide whether I want an abortion. The information provided by genetic testing for a certain fee, (depending on my insurance coverage), can reduce but never eliminate the possibility that I will give birth to a child with a disability unexpectedly, like my mother did.⁴ I can, of course, refuse to undergo any testing at all, and take my chances. If I do have a child with a disability, however, I think it would be helpful for me to know in advance so that I can learn as much as possible about that disability before the birth. For this reason I will undergo testing. The difficult question is what to do with the results of the prenatal diagnosis. What if the fetus is diagnosed with a disability? Will I choose to carry it to term, or to have an abortion? I know that it will be a struggle to think through these momentous decisions while pregnant, while transforming physically and emotionally on the way to motherhood.

Knowing what I know now, should I continue to carry a fetus diagnosed with Down's? Would it be wrong for me to abort a fetus with Down's, or would it be wrong for me *not* to abort? This is the central question I wish to raise. My perspective is necessarily conditioned by my subject position, having grown up at home with Leo. Acquiring a sibling with DS by chance is very different from making the decision to nurture a fetus with DS in my own body and to welcome a child with DS into my home. Unlike my parents, I can't remember life before Leo. Unlike my parents, while growing up I was never primarily responsible for Leo's care, although I was often his helper, his babysitter, and his teacher. Since I left home ten years ago, Leo has visited me periodically, and for the duration of his visits I am his primary caregiver. My perspective is thus based on twenty years' experience of living with a child/teenager with Down's, and a much more limited experience of taking care of a young adult with Down's.

³ Note that the following diagnoses were once (and for some people still are) considered undisputed grounds for abortion: sickle cell anemia, Down syndrome, adult-onset Huntington's, cystic fibrosis, and even hemophilia (Bernard 1974, 253).

⁴ There can be damage to the fetus during various stages of pregnancy, including the last stages and during the birth itself. Some congenital impairments (perhaps as many as 50 percent) have no etiology. And since testing still involves a risk to the fetus, it is unlikely that women not in a "high risk" category would test for genetic disorders.

Realizing that my perspective is far too limited and personal, I turn to advice from others to help me in my decision. Michael Bérubé, the father of a boy with Down's, writes: "Obviously, I can't and don't advocate abortion of fetuses with Down syndrome; indeed, the only argument I have is that such decisions should not be automatic" (1996, 79). Before starting my own family, I want to clarify what I think philosophically and personally about life with Down syndrome by exploring the following four questions: First, what makes life worth living for an individual with Down syndrome, and for her parents? Second, is life with Down syndrome so bad that it's not worth living at all? Third, how is sex selection different from selective abortion of fetuses with Down syndrome? Fourth, how do gender roles and mental retardation interact to construct the sexual identities and life plans of people with Down syndrome?

It is important to note that every woman's answers to these questions will be determined in different ways according to her class position, ethnic, cultural, and religious community background, and personal experience with disabilities. Rayna Rapp (1999) argues that very few cases fit the liberal feminist ideal of one woman making a personal choice. Her anthropological fieldwork amply documents the fact that pregnant women deciding about prenatal testing are not only influenced by their interactions with genetic counselors, nurses, and doctors. They may also take into account (more or less voluntarily) the views and interests of their spouses or partners, children, parents, grandparents, extended family, and friends (1999, 5).

Although I cannot address each of these influences separately, I acknowledge that my thinking is rooted in my life experience as a middle-class, agnostic, Chinese and Japanese Canadian sister of a young man with Down syndrome. I have also been influenced by the views of friends who have become parents in their late twenties and early thirties, who are mostly professionals, graduate students, or junior academics living in Canada, the United States, and Western Europe. In thinking about prenatal testing, I have no direct access to the experiences of mothers and fathers, of people with disabilities, of people who have religious faith, of atheists. I do not know what it would be like to grow up in cultures other than Chinese, Japanese and Canadian, or with a working-class or owning-class background. This is a deeply personal piece of philosophy, not a sociological survey; others have spoken and will speak for themselves elsewhere.

I. What Makes Life Worth Living for an Individual with Down Syndrome, and for Her Parents?

Here I consider not only the life of the potential individual who may develop from the fetus, but also the lives of the prospective parents, their family, and the community surrounding them. It is clear that my answer to this question will shape my reflections on the next three questions. Many philosophers have developed moral theories to define the concept of flourishing. What most moral theories have in common is that each one aims to define what is good for a specified group of beings. Not every theory specifies the same group: for Aristotle only noble men can truly flourish, while other philosophers broaden their scope to include ordinary men, women, children, non-human animals, or even the environment in the range of relevant beings. There are several competing

definitions of the good life. The proper means of achieving the good life is also an open question: whether it is to be attained by acting rightly, refraining from acting wrongly, acquiring virtues, having a good will, or maximizing happiness.

Although thinkers differ widely on their thickly detailed conceptions of the good, it is possible that most of us could agree upon a very thin version of the good that would suffice as a baseline below which lives would be considered to be worthless. Consider the minimalist view that establishes two jointly necessary conditions. A life isn't worth living unless a person 1) takes pleasure at least occasionally in being alive, and 2) can share her experiences with other people by using body language, or could look forward to doing so.

The first requirement summarizes the medical profession's utilitarian credo that a life filled with excruciating pain is not worth living, while the second embodies the common intuition that people are social animals who cannot thrive in complete, permanent isolation from others. As Hannah Arendt argues, the life of a human being proceeds only on condition that there is interaction with other human beings: "For human beings, to live means . . . 'to be among men' . . . , and to die, 'to cease to be among men'" (1960, 5). People might differ dramatically in their descriptions of the life that is maximally worth living, or add further baseline requirements, while agreeing that any life lacking these two requirements is not worth living.

The provisional definition above may suffice when thinking about the individual who may eventually develop from the fetus being tested. Thinking from the perspective of potential parents, however, demands a different description of the good life, one that acknowledges the rewards and challenges of parenting. Only a very selfless, perhaps martyr-minded woman would agree to continue a pregnancy that would reduce the quality of her own life to the minimal level described above. What makes life as a parent worth living--or, in other words, what rewards do parents expect in return for the sacrifices they make in raising children? Let us consider three conditions that most people see as centrally important to becoming a parent. Suppose that a person has the view that she does not want to become a parent unless she is confident that 1) her child will survive long enough to become a member of her cultural or religious community, and 2) she will be able to develop a close and loving relationship with her child, and 3) she will be able to pursue her other significant life plans while parenting.

I propose the first condition because in many religions and cultures, an infant must survive a certain period before being recognized as a nominal member of the community. Various rituals such as Christian baptism (a few days after birth), Jewish circumcision or Hebrew naming ceremony (eight days), and the Chinese one-month party mark the moment when the infant is officially welcomed into the community. If a pregnant woman learns that the fetus she is carrying will not survive until the relevant milestone, she may not consider the project of parenting worthwhile. Depending on their spiritual/cultural beliefs, some parents may consider it essential to see their child become a Bar or Bat Mitzvah at thirteen, take confirmation in early adolescence, or even reach the threshold of adulthood at eighteen (twenty in Japan). Thus, the life expectancy of the fetus in question becomes relevant when these parents consider whether it is worth

continuing any given pregnancy.⁵ In contrast, other parents may choose to take on the project of nurturing any human life, no matter how abbreviated, if they find intrinsic value in the parenting process regardless of its outcome.

The second condition--whether parents develop a close and loving relationship with their child--may indeed be affected by the particular characteristics of the child. Autistic people have difficulty establishing relationships with others. However, the parents' attitudes toward the child are equally if not more influential. For example, it may be difficult for a mother to bond with her child if she is someone who considers parenting to be a project of holding out very high expectations for her child. Peter Singer writes: "To have a child with Down syndrome is to have a very different experience from having a normal child. It can still be a warm and loving experience, but we must have lowered expectations of our child's abilities. We cannot expect a child with Down syndrome to play the guitar, to develop an appreciation of science fiction, to learn a foreign language, to chat with us about the latest Woody Allen movie, or to be a respectable athlete, basketballer or tennis player" (1993, 256). Singer argues that parents who do not want to lower their expectations should not continue pregnancies diagnosed with Down's.

The third condition--being able to pursue other life plans while parenting--is similarly complex. The parents' life plans may include raising other children, which may be difficult depending on their socioeconomic status. A wealthy couple might be able to hire enough caregivers for a severely disabled child to enable both parents to lead full and rich lives throughout their child's lifetime. Raising an only child with severe disabilities may exhaust the resources of some families, while other families have enough to support and nurture three or four other siblings in addition. A working poor mother might find herself giving up all her other life projects in order to sustain just one "normal" child for sixteen years, or until he can work to support himself. Finally, some life plans are incompatible with the project of having children, such as specializing in frontline war zone reporting or devoting one's life to meditation and prayer.

I have suggested baseline conditions for a worthwhile life for the individual with the disability and for her close family--parents and siblings. What about the broader perspective of society? Although people with disabilities and their families pay taxes to support the services they require, nondisabled people are also asked to contribute to the cost of health care and education for all. Despite liberal political rhetoric in this country, many nondisabled people hold a conception of the good life that excludes adequate services for people with disabilities. Some choose to assess the value of human life in terms of cost to society. If people with disabilities increase the cost of health care, require "special" education, and are unable to participate fully in the labor force, then their existence makes life less worth living for those who judge the quality of life by economic measures. Some point out that allocating public funds to services for people with Down syndrome may compromise other important expenditures such as poverty relief, basic education, and foreign aid. It is certainly true that some policy makers encourage

⁵ In the 1940s, only 40 percent of all children with DS survived until age five (Little and Leshtz 1995, 345). Now, with recent advancements in clinical treatment and better care at home rather than institutionalization, 80 percent of white people with DS reach age 55, and many live even longer (NDSS 2002).

different worthy causes to compete against each other, framing the debate in terms of a tiny slice of the economic pie. According to this zero-sum view, whatever is allocated to people with Down syndrome diminishes the resources otherwise allocated to the homeless, the poor, and the internationally needy, and vice versa. However, people who take this narrow perspective often lose sight of the overall basic structure of society, which currently allocates plenty of money for the military industry, agricultural subsidies, and tax breaks to wealthy corporations and well-off individuals. If a majority of American citizens decided to revise their political priorities, there would be more than enough in national and state budgets to provide housing, health care, and education for everyone, with and without disabilities.

I will not pursue the larger project of providing an argument for my view that some human lives also have value beyond their aggregate cost or benefit to the economy. I will simply mention that many people value justice more than wealth in their conception of the good life. For them, the denial of opportunities and resources is an issue of distributive injustice that can be corrected by public policy (Bickenbach 2000, 353). For a social condition to be just, it must enable all people to meet their needs and exercise their freedom (Young 1990, 34).

II. Is Life with Down Syndrome So Bad That It's Not Worth Living at All?

This question can be addressed with the help of genetic counselors and doctors, who play a crucial role in interpreting the meaning of prenatal diagnoses to prospective parents (see Rapp 1999). If someone finds the minimalist view too meager, instead believing that being completely able in mind and body is a necessary requirement for a worthwhile life, then she will decide to abort a fetus diagnosed with any disability whatsoever, including DS. Rapp's research has shown that people place differing values on mind and body. Some prize physical integrity and outward appearance, rejecting any fetus that will develop visible marks of being different, while others set a minimum standard of cognitive ability as what makes life meaningful and worthwhile regardless of physical condition. Adrienne Asch cites research studies showing that "whites and middle-class people in general showed more discomfort with Down syndrome and retardation, whereas people of color and those of lower socioeconomic status expressed more fear of physical vulnerability" (1989, 87). For example, during genetic counseling sessions Rapp recorded that one Puerto Rican working-class woman was willing to carry any fetus that would be retarded as long as it would walk and see, and "look normal." Some academic couples stipulated that they wanted any child of theirs to be able to pursue post-secondary education. Some people set even higher standards for a worthwhile parenting experience: one couple said, "If he can't grow up to have a shot at becoming the president, we don't want him" (Rapp 1999, 92). While such remarks may not be based on a fully thought-out moral theory, they nevertheless reveal a diversity of views about what makes life worthwhile.

Many people have struggled to draw a line dividing genetic conditions into two kinds: those that inevitably make everyone's lives go unbearably badly, and the others. Some attempt to distinguish between "serious" and "minor" genetic conditions using various criteria. For example, Jeffrey Botkin recommends offering prenatal diagnosis for

cystic fibrosis, Fragile X Syndrome, and Down syndrome--but not for fetal PKU, Huntington's disease, and Tourette syndrome (Botkin 1995, 32–39). In the state of Iowa, Medicaid covers abortions for anencephaly or severe, open spina bifida, but not for Down syndrome, which officials do not consider sufficiently serious (Wertz 2000, 285).

I am in no position to attempt a similar classification, because I lack the relevant medical knowledge of the myriad genetic conditions, and equally importantly, I have not met people and their families living with these conditions. Rather, I want to focus on the concrete complexities of my family's life with Down syndrome in order to develop theoretical points that might (or might not) apply to other kinds of disabilities. Just as I have drawn insight from other women's experiences, I hope that a careful account of my deliberations might be helpful to other women making their own decisions about prenatal testing and selective abortion.

III. How Is Sex Selection Different from Selective Abortion of Fetuses with Down Syndrome?

I will start by considering what seems to be a prevalent distinction between selective abortion of female fetuses and selective abortion of fetuses with Down syndrome. Many feminists hold the following position: *It is a woman's reproductive right to abort or to carry to term any fetus she conceives. It is not wrong to abort a fetus because it is diagnosed with Down syndrome. However, it is wrong to abort a fetus because it is diagnosed female.* In other words, selective abortion of fetuses with Down syndrome is morally permissible, or discretionary, while sex selection of fetuses is morally impermissible. What are the reasons grounding this distinction? In the following discussion, I shall compare the trait of sex to the trait of DS in order to ground my claim that the moral status of sex selection is the very same as that of selective abortion. In my view, the reasons to oppose sex selection are also reasons to oppose selective abortion against DS. On the other hand, proponents of selective abortion who see nothing wrong with it should also see nothing wrong with sex selection.

What are the reasons to oppose sex selection? There are two aspects of being female: biological sex, and its social correlate, gender, which is "the deeply entrenched institutionalization of sexual difference" (Okin 1989, 6). Being born with XX chromosomes has certain biological consequences, including the potential for certain (sometimes more painful than pleasurable) experiences that people with XY chromosomes never encounter, such as menstruation, pregnancy, labor, breastfeeding, and menopause. However, those who would claim that life for women is worse than life for men do not usually appeal to the biological differences. Rather, as feminist theorists have explored in great detail, the social realities of gender are much more influential than biological sex in shaping the possibilities for one's life. In some societies, a fetus prenatally diagnosed as female is considered a potential candidate for abortion. Although Western liberal feminists may recoil at the implication that women's lives are less worthwhile than men's, let us consider a hypothetical society in which the decision to abort a female fetus might make sense to a woman. Let us suppose that in this society, women are expected to marry in order to establish their social significance, and that birth order establishes a hierarchy of priority for the use of family resources. Imagine a

particular family in which the mother has already had several daughters and has not yet borne a son for her family. Imagine also that this family has limited financial resources, and that the basic structure of society does not provide adequate support for unmarried women or widows. In this imaginary scenario, being the youngest of several daughters would offer much more limited possibilities than being the first, much-wanted son. Because of the way that gender is socially constructed and economically structured--*not* because of the biological limitations imposed by sex--the average woman in such a society undeniably faces considerably bleaker life prospects than the average man. In this society, if a woman endures so much excruciating pain and suffering that she finds her life intolerable, it may be traceable to her female hormones--but it is much more likely to be the result of cultural attitudes about gender, combined with the effects of economic oppression and class divisions.

Feminists have spent ample time clarifying the distinction between biological sex (having chromosomes XX or XY) and its social correlate, gender.⁶ Might there be an analogous distinction between trisomy 21 (having three twenty-first chromosomes instead of two) and the social construction of people with Down syndrome as disabled?

Many people “correct” me when I compare having Down syndrome to being female. They object strenuously to my view that both are genetic conditions that have been socially constructed as disabilities in the majority of human civilizations. Perhaps they resist this analogy because they do not recognize that the medical model of gender is surprisingly similar to the medical model of disability. As recently as the eighteenth century, the men in white coats of medical science declared unequivocally that people born with XX chromosomes were physically weak, delicate creatures of inferior intellectual and moral capacity who would never complete more than a grade school education. Because this model was widely accepted, people believed that it was part of women’s nature to bear and raise children, to do tasks of manual labor in the home or on the farm, and to live severely restricted lives under the benevolent rule of father, husband, and head of state. Women were not considered capable of choosing their husbands or heads of state any more than they chose their fathers. The average woman had scant opportunities to shape her living conditions or to define her own sexuality, let alone to assert her reproductive rights. Of course, a handful of exceptional individuals seemed to be capable of taking charge of their lives. Some women created works of art and science, some lived with mates of their own choosing, some fraternized with citizens, statesmen, and intellectuals, and a very few even ruled great empires. However, these women were not considered to be representative of the burdensome masses of common women. After all, they were highly privileged and well-educated women, often with very supportive men in their families, with plenty of resources at their disposal.

John Stuart Mill objected to this medical model of gender, writing in 1869; “I consider it a presumption in any one to pretend to decide what women are or are not, can or cannot be, by natural constitution. They have always hitherto been kept, as far as regards spontaneous development, in so unnatural a state, that their nature cannot but

⁶ The sex-gender distinction has been questioned by Judith Butler (1990) and others.

have been greatly distorted and disguised” (1973, 219).⁷ Attempting to assess the potential of women judging from their state in nineteenth-century England is like measuring the stunted growth of plants kept in restrictive containers, deprived of light and space. As long as the epistemic enabling conditions (allowing spontaneous development) do not obtain, we cannot make any knowledge claims “concerning the peculiar tendencies and aptitudes characteristic of women” (Mill 1973, 219).

Mill’s objection has the same force when applied to the medical model of DS as a disability. As recently as the 1970s, the official medical diagnosis for a person born with an extra twenty-first chromosome was “Mongoloid idiocy” (Bérubé 1996, 27). According to the best-trained medical practitioners when my brother was born, children born with Down’s would never be able to walk, talk, dress themselves, or recognize their parents, much less complete high school. Today, often generalizing from their acquaintance with one or two individuals with DS, many people still believe that people with DS are best off institutionalized, that they are capable, at best, of doing manual labor in the home, on farms, or in sheltered workshops, and that they necessarily lead severely restricted lives under the benevolent rule of parents, social workers, and politicians for whom they did not vote. People with DS are not considered capable of choosing their caregivers, their teachers, or their advocates any more than they chose their own parents. The average person with DS has scant opportunities to shape her living conditions or to define her own sexuality, let alone to assert her reproductive rights. Are these not unnatural conditions that would impede the spontaneous development of any human being?

As further evidence that the medical model does not adequately describe life with DS, consider the racial and socioeconomic disparities in the longevity of people with DS. In the 1940s, only 40 percent of children with DS survived until age five (Little and Leshtz 1995, 345). In an article entitled “Down Syndrome Longevity Seen Linked To Race,” published in *The Atlanta Journal and Constitution* on 8 June 2001, M.A.J. McKenna cited a recent study conducted at the Centers for Disease Control and Prevention. According to this study, white individuals with Down syndrome now live twice as long as blacks and four times as long as Asians, Hispanics, and Native Americans with DS. Whites with Down syndrome live until the age of 50, but the life expectancy for Blacks is 25 and “others” 11. When comparing the life expectancy of whites and Blacks in the same socioeconomic class the disparities are not nearly so great, indicating that class and social standing, not the genetic features of racial difference, are at play. These statistical variations suggest that a person’s longevity, far from being strictly determined by the genetic condition of DS, is linked to social and economic factors that can be influenced by policy changes.

Over the past twenty years, a handful of exceptional individuals with DS have proven themselves capable of taking charge of their lives. Chris Burke is a well-known TV actor who has published his autobiography (1991); Jason Kingsley and Mitchell Levitz have written a book together (1994); Sujeet Desai has a black belt in Tae Kwon Do, plays the clarinet, the piano, and the violin, and is now studying at a music school in Massachusetts (Desai, 2002). All of these young men have finished high school and are

⁷ Gurpreet Rattan convinced me that this passage from Mill is relevant to my argument.

pursuing further education. Today, self-advocates with Down syndrome give speeches, attend conferences, and travel the world. Undeniably, these are for the most part highly privileged and well-educated people with plenty of resources at their disposal, often with very supportive “normal” family members, and therefore they are not considered to be representative of people with Down syndrome in general. In the public imagination, if Albert Einstein represents Jewish male scientists, and Michelangelo represents Italian male artists, why should Indira Gandhi be considered an exceptional woman politician? Why shouldn't Chris Burke represent people with Down syndrome?

Those who advocate the social model of disability hold that a condition such as Down syndrome cannot be reduced to the underlying physical or mental state of the person--in other words, the medical model is incomplete and inaccurate. Rather, the fact that people with Down syndrome are considered “disabled” in many societies is actually a complex phenomenon that results from interactions between intrinsic features of human minds and bodies and features of the physical and social environment in which people live and act. Down syndrome, like other disabilities, is not a dichotomous state that people either have to the maximum extent or do not have at all. The medical diagnosis of Down syndrome is defined by the presence of third chromosome on the twenty-first allele; either we have two chromosomes there or we have three. For the social model, on the contrary, disability is fluid and continuous, existing in various forms and degrees. Finally, no disability can be understood independently of the complete context--that is, features of the physical and social environment--of the person's life (Bickenbach 2000, 344). Can the social model of disability successfully describe the realities of having Down syndrome *and* of being a woman?

Let me consider three objections to my claim that gender is analogous to a disability. The first, most immediate objection is that *sex is not a disease, but Down syndrome is*. The rationale given is that “sex is biological, distributed fifty-fifty among the human population, and carries no biological deficits. Its social correlate, gender, causes social disabilities for women in some societies, but prenatal diagnosis identifies sex, not gender”(Wertz 2000, 263). Dorothy Wertz argues that out of all prenatally diagnosable genetic conditions, selecting for sex is the only case “where there is clear potential for harm to the wider society, by unbalancing the sex ratio or perpetuating gender stereotyping” (2000, 263).

Maintaining a balanced sex ratio is currently considered important because interaction between men and women is the currently favored mechanism for reproduction and population growth. To be completely accurate, demographers concerned with encouraging heterosexual reproduction should measure the ratio of heterosexual men to heterosexual women falling within the age range of reproductive fitness. Lesbian, gay, and infertile adults should be excluded from these ratios, as should adults who are not sexually active. Since men can reproduce for many more years than women, the preferred sex ratio would have women outnumbering men by some proportion, and prospective parents should be encouraged to abort all male fetuses until this ratio is reached. Clearly, sexual reproduction and population growth is not the main concern of most people who oppose sex selection.

Why is it wrong to abort a fetus because of its sex? Buchanan et al. enumerate the detrimental social consequences following widespread use of sex selection in India. In a society where males are valued for the economic advantages they bring, reducing the number of females intensifies competition among males who need to marry and reproduce (Buchanan et al. 2000, 183). They argue that this increased competition defeats the very reason for a family's having more male offspring, which is to gain an advantage over other families. They conclude that the imbalance in sex ratios makes the situation worse for more families. It is therefore socially desirable to maintain a sex ratio around 50-50 in the general population.

How is the trait of Down syndrome different from the trait of sex, in this view? To be sure, DS is not distributed 50-50 among the human population; the ratio is more like one in 850 live births, and is currently decreasing due to selective abortion. Why is it that the male-female ratio is so important, while very few worry about maintaining the ratio of Down's to non-Down's people in our society? This question strikes some readers as quite bizarre. Why, they ask, should anyone strive to maintain a certain number of people with Down's in our society? What kind of person would seriously consider such a proposition? Wouldn't it be better for everyone concerned if we could eliminate people with DS entirely from the population, either by prenatal genetic intervention or selective abortion?

Consider that it may be equally possible one day to eliminate all biological females from the population. As we develop new reproductive technologies and as world population approaches the limit of sustainability, woman may become obsolete. It is now theoretically possible that the entire earth might one day be populated solely by men. If you do not embrace this sci-fi scenario with gleeful anticipation, reflect on the reasons why you think women are valuable to the human race. If not solely because of our reproductive abilities, then what is it that we contribute to a society that men cannot provide? I suggest to you that your answer will be informed by the many experiences you have had over your lifetime, having grown up with women in your family, having gone to school with girls, having had women friends and colleagues, and having learned of the accomplishments of women all over the world. To anyone who claimed that a world without women would be just as good as this one, we would have volumes to speak about how women have enriched our lives and made us who we are today. We would not be convinced by the arguments of men who had lived exclusively in sex-segregated environments; rather, we would encourage them to interact with more women before making up their minds about this question.

For me and 350,000 families at home with Down syndrome in the United States alone, the scenario of a world without people like Leo is just as horrifying and unimaginable as a world without women. This man with an extra chromosome is different from other men, just as women with our XX-chromosomes are different from men with XY-chromosomes. I perceive that Leo is different but no less valuable than I am, because I have grown up at home with Down syndrome and have had the experience of a completely integrated family. What proportion of the general population lives in segregated environments that exclude people with Down syndrome from participation? How many people have attended school with students with Down syndrome, have friends

and colleagues with Down syndrome, and are aware of the accomplishments of people with Down syndrome all over the world? Until we live in a society where people with Down syndrome are fully integrated into our lives, I do not think that we can know the extent and quality of their contributions. This is why I oppose the use of selective abortion to reduce the number of people born with Down syndrome, just as I oppose the use of sex selection to reduce the number of women in this world.

Many will object, “Having DS clearly entails having biological deficits, while being female carries none. It can’t be morally permissible to carry to term a fetus knowing that it will suffer from severe limitations.” As any medical textbook more than one hundred years old will confirm, women were also once considered to have many biological deficits. Unless women’s bodies have changed dramatically over the past hundred years, the only explanation is that the definition of “biological deficit” has changed. After all, not all humans have the same biology: men have certain capacities, and women have other unique capacities. Today, we choose not to see these differences as deficits, partly because feminist theorizing has exposed the masculinist bias of the medical establishment, and partly because our social norms declare the interaction between men and women “essential” to the flourishing of our species. Analogously, people with DS have some unique capacities, and “normal” people have others. For example, many people with DS have an enhanced ability to imagine what other people might like, what other people might need, what other people feel. Watching the Special Olympics, it is striking that people with DS will stop to comfort an injured competitor, willingly forfeiting the medal. This aptitude to act out of empathy rather than self-interest may not be a strictly biological trait, but it is mysteriously associated with having an extra twenty-first chromosome. As it happens, because our society considers keen competitiveness more valuable than empathetic helpfulness, people with DS are considered “deficient” because of their “inability” to keep their eyes on the prize.

What would it mean for all of us to be at home in another possible world? Imagine, if you can, that half of the people in the world had DS. In such a different world, I wonder what the definition of “biological deficit” might be. Perhaps we would consider 50 percent of the population to be “diseased.” Perhaps people would segregate themselves into two classes, just as many existing societies treat women and people of color as second-class citizens. On the other hand, perhaps there would be integrated households, educational resources, public facilities, and political structures. Perhaps the interaction between people with DS and those without it would even be seen as essential to the flourishing of the human species. Some may consider this a fanciful and perverse thought experiment. It is a simple extension of what I have lived: in my family, which consists of one person with DS and three others, the most meaningful family activities involve all four of us.

For example, my parents have always made it a point to include the whole family in every card game, unlike some other families that might choose to split into smaller groups according to the different abilities and interests of each member. This meant that we chose to play games that Leo could learn and remember. Other families may play complex games like bridge or poker; in our family, we play simpler ones like whist, Joker, and Crazy Eights. Buchanan et al. describe the simpler game as a “less demanding

infrastructure for social interaction,” because the rules of the game require fewer literacy and numeracy skills (Buchanan et al. 2000, 288). However, they overlook the fact that playing a simpler game may be actually *more* demanding for some people.

How so? Our game-playing experience may be limited in terms of cognitive complexity for Leo’s sake, but it requires that the rest of us perform emotional feats just as difficult as any encountered in bridge or poker. Instead of perfecting our poker faces, we’ve learned to simulate shocked disbelief whenever we get the Joker, just as Leo makes it unmistakably, hilariously evident when he manages to pass it on. Our conception of a good game with family friends isn’t one in which subtle and brilliant strategies are successfully deployed and glorious battles are won. Instead of learning to react quickly to rapid play, we cultivate good-humored patience as we wait endless minutes for Leo to sort his cards carefully by suit and number. We develop the ability to speak clearly and concisely as we struggle to explain the rules of the game in terms he can understand easily. In playing with one less cognitively skilled, we restrain our reflex to take advantage of him thoughtlessly. Adults who have wrestled with children know the challenges of avoiding the use of overpowering force (not winning at the cost of humiliating the opponent) while still providing enough of a challenge to engage the weaker one (not disappointing him by losing too easily). Playing chess with Leo is a strangely meditative experience, for he assesses the board anew at each move, heedless of long-term strategy. One discovers ways to respond afresh to each of his unpredictable moves, often abandoning one’s own overall plan to focus on the details of the moment.

These abilities are primarily emotional, but also require cognitive skill. Notice that the set of abilities required to play Joker with Leo is not simply a subset of the abilities required to play poker; it’s not just a “simpler version.” The emotional requirements of the infrastructure are not written anywhere in the rules of the games, but without them the game dissolves. The infrastructure that includes retarded people (like Leo) excludes certain nonretarded people. For example, a professor friend of ours enjoys playing contract bridge with his peers but cannot play “Go Fish” without getting frustrated, bored, and irritable. At our table, it is the ruthlessly competitive, impatient players who lose. It is no simple matter to play well with grace, thoughtfulness, empathy, compassion, patience, and presence of mind--all characteristically Chinese and Japanese cultural values. A future society without Down syndrome may be one in which more complicated games are played by all, but its members may perform well on a limited set of cognitive skills while losing other valuable abilities. What would happen if such a society lost sight of the unavoidable fact that all humans are vulnerable in different ways, and that we flourish through mutual interdependence?

It is paradoxical that while my parents speak with me and others freely about how living with Leo’s Down syndrome has affected our lives, Leo himself is not (self-awarely) at home with Down syndrome. The mental retardation caused by DS, unlike the physical symptoms, influences his very ability to perceive and understand the nature of DS itself (Weinberg 1988, 274). My parents’ decision to protect Leo’s ignorance of his own condition may be simply an extreme case of denial. As friends have pointed out to me, we have no way of knowing whether Leo may be simply “playing along” with the family narrative, pretending not to notice all the ways in which he is treated differently.

Still, the decision not to speak of DS with Leo reflects my parents' judgment that his interests are best served by encouraging him to identify as a normal person. In their view, encouraging Leo to identify himself as "a person with Down syndrome" would wrongly imply that there are certain properties attached to Leo as an individual. According to Martha Minow's (1990) relational analysis of difference, having Down syndrome isn't inherently a difference in Leo, any more than being "normal" is inherent in me. Instead, the difference is in the relation that Leo and I bear to one another. This approach asks each individual to "question the assignment of difference that the community had treated as obvious" (Minow 1990, 213). Thus, I attended a French immersion school because I was interested in learning French, while Leo attended a vocational school because he was interested in learning to look after animals. Or so the story goes.

Denying the difference can only displace it, of course, not eradicate it. The family rather than the individual becomes the locus of difference. Here is the narrative that has become second-nature to me as Leo's sister: if my experience is different from that of my friends, or people I read about or see on TV, it is not because Leo has Down syndrome. Instead, it is our entire family that is different from other families. We just happen to enjoy the plays of William Shakespeare, which offer entertainment at a range of cognitive and emotional levels, more than foreign films which require the ability to read small print quickly. Sometimes the difference gets shifted to specific family members, so that father and mother are seen as making quirky personal choices, rather than saying that our family has adjusted to Leo's special needs. For example, my mother claims that she refrained from speaking to us in Japanese because she didn't want to alienate her Chinese mother-in-law, not because Leo was having enough trouble learning his first language. Growing up, I always thought my father disliked travelling, because he never took business trips like his colleagues--only later did I realize that he had purposely limited his professional activities in order not to leave my mother overnight taking care of Leo and me alone. These are the ways in which we distribute the differences throughout the family, in order to "normalize" our lives with Down syndrome.

Denial of difference has also helped many people defy gender stereotypes. As a child, reading countless fairy tales in which the princess waited passively for the prince to rescue her, I decided to model myself on the active, powerful, resourceful prince. My peers repeated the incantations to me: "Remember, you're a girl. Girls don't rescue boys." To this a precocious feminist might have responded, "Actually, girls can do whatever they want." But the best I could do was to say, "Well then, I'm not a girl." Similarly, we deny that Leo has Down's because we don't want him to feel limited by this society's negative, stigmatized perceptions and misinformed notions about people with Down syndrome and mental retardation in general. When he returns home upset because someone has called him a "stupid retard," we tell him to ignore the taunts of unkind people and that he is a smart and good person, just like the rest of us. For us to acknowledge that he is "a retard," we believe, would be making the mistake of accepting

the identity that others impose on him.⁸ Perhaps our view can be compared to that of some sympathetic obstetricians, who advise new parents not to waste energy perusing the outdated and pessimistic medical literature about Down syndrome. Rather, my family has decided to focus on making Leo's life as rich as we can, strategically denying that he belongs to a socially stigmatized minority group. Is that so different from my strategy of choosing powerful princes as role models for myself in order to reject the role of distressed princess?

The second objection to my analogy is this: *Unlike gender, mental retardation is not socially constructed.* For all the elaborate dancing around difference, nothing can hide the brute fact that there are some things that Leo just cannot do. No matter how much I talk about social construction, my brother Leo will never be able to read this essay and respond to it in writing. No matter how many hours he spends in classrooms and labs, he will not understand theoretical physics, nor will he discover a cure for AIDS, nor does he have the remotest chance of becoming Prime Minister of Canada. Even the most devoted family member or activist cannot deny that every person with DS is mentally retarded to some extent, and that there is an upper limit to what she can achieve because of this retardation. The same cannot be said of women in general. I concede this point. The extra twenty-first chromosome always entails cognitive limitations to some degree, and there is nothing analogous in the case of the XX-chromosomes.

Although Down syndrome often includes physical health problems, usually the mental retardation most acutely limits a person's range of activities. Most people with DS read at around grade-school level, and most have difficulty with math. Almost all require some degree of supervision and assistance in the daily activities of living: budgeting, shopping, and cooking. In contrast, many women have matched men in all areas of intellectual achievement, and a few have surpassed their fellows.

What I do want to question is why the abilities of extraordinarily talented and fortunate individuals are so often compared with the abilities of the most severely retarded people with DS. The most high-functioning people with DS may have a quality of life comparable to or better than that of underprivileged, low-functioning people without DS. Frederick Douglass asks that "[i]f the very best type of the European is always presented, I insist that *justice*, in all such works, demands that the very best type of the Negro should also be taken" (1982, 257).

Furthermore, why is it so terribly important to scale the peaks of intellectual greatness? I do not understand theoretical physics, nor do most people I know, and yet we enjoy our nongenius lives. Perhaps a better standard for quality of life is the extent to which an individual fulfils his or her potential. If I compare my own life as a graduate student to my brother's life at home, I am not sure which of us is doing a better job of achieving his/her potential. Although Leo is dissatisfied with his current situation, he does lead a pretty full life. He enjoys playing basketball with friends, although I'm not sure whether he counts as a "respectable" basketballer by Singer's standards. (I certainly

⁸ Another possibility that our family has not considered is to "reclaim" the term "retard," along the model of other derogatory terms such as "queer," which has been reclaimed with pride by some gay men, lesbians, bisexuals, and transgendered people.

do not.) He does not play the guitar, but he can sing songs ranging from Broadway musicals to Italian opera arias and express the emotions appropriate to the lyrics. Having recently started violin lessons, his long-term goal is to perform the Sibelius Violin Concerto, Sarasate's *Zigeunerweisen*, and other devilishly difficult pieces that he loves to hear. He may never reach that goal, but then again, neither did I in my violin-playing days. Leo may not have seen the latest Woody Allen movie, but he has developed an appreciation of opera and drama and can chat with me quite knowledgeably about the plots, productions, and music. Play him any 30-second excerpt from *Don Giovanni* and he will identify the act, scene, characters singing, and the basic action at that moment. Once while we were discussing the difference between envy and jealousy, he spontaneously alluded to *Othello* to make sure that he had understood the distinction correctly ("So Othello is *jealous* of Desdemona, while Iago is *envious* of Cassio, is that right?"). Although he will never experience the pleasures of writing elegant logical proofs, Leo can share joys and sorrows with friends and family, communicate his dreams and desires, and take action to shape his own life. Isn't this enough to make his life worthwhile?

The third objection to my analogy between sex selection and selective abortion against DS is this: "*Normal*" women can be fully in charge of their sexuality and reproductive rights, but people with DS simply cannot. Many people agree that Leo's life may not be completely worthless, but point out that it is less worthwhile because it is limited to activities enjoyed by a child or preadolescent. Faced with the question of Leo's sexual desires, my parents offer a characteristically Japanese and Chinese response: silence. Nobody quite knows how to deal with the idea of an individual with Down syndrome being sexually active, let alone having her own family. I know that this unease is not unique to my family. When we were growing up, I don't recall anybody ever encouraging Leo to plan on becoming a father someday, just as nobody suggested that he think of pursuing a postsecondary education. Such goals, which are an important part of many human lives, are simply unthinkable for someone who "suffers from" mental retardation, as the expression goes. Here is a plausible refutation of my sex-DS analogy: XX-chromosomes do not affect a person's ability to express her own sexuality and to decide whether, how, and when she will reproduce. The extra twenty-first chromosome does eliminate this very important dimension of life, no matter how disability is constructed.

Consider the many indisputable hurdles that people with Down's encounter when they endeavor to express their sexuality. Not all of these obstacles can be compared to the difficulties that women and men have faced because of the deeply entrenched institutionalization of sexual difference. Some of them, I would argue, are due to the deep-rooted institutionalization of a hierarchy based on intellectual achievement. For this reason I will limit the following remarks to the mental retardation that always accompanies Down syndrome, keeping in mind that different degrees of mental retardation might lead to different conclusions. I shall set aside for the moment the other (physical) symptoms. Hence, this discussion of mental retardation may apply to those who are mentally retarded due to poor nutrition, head injuries, fetal alcohol syndrome, or

other non-genetic causes. I shall consider several commonly-held beliefs about the sexuality of retarded people.

Common belief: Retarded people are not “real” men and women; they are asexual or desexualized. A personal anecdote may illustrate the point. I sometimes train at a women’s karate club that does not allow men to participate. When I asked whether my younger brother could visit a class to watch me practice, the other women first inquired how old he was. When I told them he was twenty-nine, they refused. When I added that he had Down syndrome, they said, “Oh, that’s different then, he’s welcome to watch us practice.” What made them change their minds? Why is it that Leo’s presence didn’t disturb these women, some of whom are sexual assault survivors, the way that a “normal” twenty-nine-year-old man’s presence would have done? I believe that because Leo is retarded, they assigned him the status of a small (presexual) child, like the two-year-old boys who are allowed to accompany their female caregivers into women’s bathrooms and locker rooms. (One of the women confirmed my hypothesis when she attended Leo’s birthday party and song recital a few days later. Although she had spoken with Leo previously about his interests in opera and basketball, her well-intentioned gift to him was a colorful toy fire truck suitable for a small toddler.) This group of women disregarded the fact that Leo is a sexually mature man, considering him so desexualized that he did not count in their eyes as a man at all. As a retarded man, he was the exception to the rule intended to exclude “normal” men from the facility.

One alternative explanation is that the karate club members perceived me as having a special obligation to take care of my brother because I could not leave him alone at home. Perhaps they invoked an exception to make it possible for me to practice karate without neglecting a relative who needed care. On that model, however, I wonder whether they would have permitted me to bring a non-retarded male relative with me. Imagine that I suggested bringing my visiting non-retarded cousin to karate practice, perhaps because I had to help him administer some complicated medical treatment every thirty minutes. I suspect that despite my obligation to care for this physically ill man, he would have been considered a “real” man and therefore asked to wait outside. On the other hand, imagine how my cousin might have reacted if the women had said to him, “This space is for women only, but since you’re sick, it’s all right. Come on in.”

In our society, not everyone enjoys freedom of sexual expression. There are certain groups of people whose expressions of sexuality are routinely ignored, marginalized, or actively discouraged: young children before puberty, adults “past their prime” (women after menopause and very old men), bisexual, transgendered, lesbian, and gay people, people with physical disabilities, and retarded people (Silvers 1998). Disability activists have shown that people with physical disabilities can express their sexuality although their bodies may not perform the functions usually associated with normative heterosexuality (Shakespeare, Gillespie-Sells, and Davies 1996, 99–107). Infertility is not inherently an impediment to living a sexual life, nor is a heart condition, nor blindness, nor cerebral palsy. Similarly, I argue that mentally retarded people have the potential to express their sexuality even though they may lack certain cognitive capacities normatively linked to sexual activity. A person need not use language in order to indicate her desires and aversions. However, in this society mentally retarded adults

are caught in a double bind. They are pervasively treated like perpetual children misplaced into sexually mature bodies who should be carefully monitored and prevented from expressing themselves. Institutional structures as well as social norms restrain their sexual impulses. If a retarded person acts on her impulses, for example hugging a person she finds attractive, she's punished by her parents or social worker for "inappropriately showing affection" and further restrained. If she learns to suppress her impulses and doesn't show them, she's considered asexual and therefore isn't provided with opportunities to develop romantic companionship.

Common belief: Retarded people do not have sex lives, therefore they do not need privacy. In 1889 Alexander Johnson was secretary of the Indiana Board of State Charities, and was soon to become superintendent of the Indiana School for the Feeble Minded. He wrote of his charges that "they have weak wills and feeble minds. They would be unsafe in the outer world. They must be kept quietly, safely, away from the world, living like the angels in heaven, neither marrying nor given in marriage" (Trent 1994, 84). In the past century, not much has changed. In most institutions for retarded people, there are still no locks on the doors or any other personal space. Many people have experienced the difficulties of trying to lead an active social life while living with one's parents or in an institution like a sex-segregated boarding school where bedrooms can be searched at any time. Historically, women have been denied the privilege of privacy even beyond adolescence, passing directly from their father's dominion to their husband's, their every social interaction strictly monitored by watchful eyes. Unmarried men enjoyed the privileges of adulthood in the classic "bachelor" apartment: a room of one's own in private, the right to choose one's own friends and to invite them to stay overnight on occasion. These living arrangements are now available to young people moving out of their parents' homes, both men and women. And yet most retarded people rarely have the chance to invite friends to stay overnight, for they are too seldom respected as having their own sex lives to discover (Kingsley and Levitz 1994, 92). In fact, the sexuality of retarded people is often viewed as an issue of public concern, rather than a private matter. As Superintendent Walter Fernald wrote in 1907, "the community is not the place for an adult imbecile. A defective boy or a defective girl may be tolerated, but an adult human being, with the mind of a child and the body and passions of an adult, is a foreign body in any community... when adult life is reached some provision must be made to protect not only these people themselves, but the community from the consequences of their incapacity" (Trent 1994, 84).

Common belief: Retarded people cannot control their sexuality and therefore should not express it. The public perception of retardation affects men and women differentially: with men the fear is that they will molest others, especially children, while with women the fear is that they will be raped if they express sexual desires. In both cases nonretarded people are afraid not only of the abuse itself, but also of the retarded children that might result. It is striking that in slave-owning times, white Americans harbored similar fears about Black men's sexuality running out of control and engendering children of mixed racial heritage. There is also a suggestive parallel to the way in which our social norms once dictated that women should dress modestly, moderate their expressions of sexuality, and stay indoors after dark in order to protect themselves from

rape. The feminist response is that the threat of rape is an unacceptable reason for keeping women's sexuality in check. Instead, we need to build a society in which women can express their sexuality freely because they are legally protected from rape. Critical race theorists attribute widespread fears (and fantasies) about Black male sexuality to the racist ideology that supported the social practice of slavery. Restricting the sexuality of Black men is not an acceptable response to racial stereotyping. Instead, we need to build a society in which all people can express their sexuality openly because they are freed from racist assumptions and legally protected from discrimination. Why then do so many group homes, schools, parents, social workers, police officers, and well-meaning strangers in the street continue to prevent mentally retarded people from expressing their sexuality?

Common belief: Retarded people are likely to have retarded children and therefore should be sterilized. This belief dates to the nineteenth century, when mental retardation professionals became involved in the eugenics movement. James Trent argues that "they promoted sterilization, especially vasectomies and tubal ligations, as part of their response to the menace of the feebleminded, a menace they created and sustained" (1994, 272). The fear that retarded people will have children is only partly justified, because many conditions that cause retardation are not hereditary, and some (such as Down syndrome) result in male infertility. However, many people concur with Judge Oliver Wendell Holmes, who in 1927 authorized the forcible sterilization of a young girl whose mother was retarded, writing, "Three generations of imbeciles are enough" (Trent 1994, 199). To be entirely consistent, people interested in preventing the birth of retarded children might therefore consider supporting sterilization of other at-risk parents, including women over the age of 35, heavy cigarette smokers, alcoholics and drug addicts, and people living in poverty who have insufficient access to prenatal nutrition and care. These mothers and fathers tend to have more premature and low birth-weight babies, with an increased risk of neurological damage, causing mental retardation (Streissguth et al. 1989, 3-11; Rapp 1999, 72). Compared to retarded men and women, these men and women may be equally likely to father or deliver babies with mental retardation.

Common belief: Retarded people are incapable of being good parents. A single lesbian who wants to have children may have to face moral indignation and contempt from her family and community, but with enough support she can create a family of her own choosing, and even raise children without a partner. In this case the obstacles to her life plans can be alleviated by public policies that recognize women as mothers without imposing a traditional heterosexual family structure, and provide financial support so they can either hire help or afford to care for their children themselves. In this case, gender is not a disability that prevents women from attaining their goals. By contrast, imagine a man in a very privileged position: He is heterosexual, of European heritage, independently wealthy, living in a mansion where a cook, a maid, a personal trainer, and a driver are employed. He has been in a loving relationship with a wonderful woman for a few years, and has decided that he wants to live with her and raise children with her, hiring a nanny to help with childcare. His parents are longing for their first grandchildren

and live nearby, so they will be able to help take care of the children whenever the nanny is sick. So far this scenario is quite idyllic.

Now imagine that this man also happens to have Down syndrome. Feel the new frown lines on your forehead. How dare he think of bringing children into this world, when he can't even take care of himself? He can't cook, clean, or drive a car. He claims to be in love with this wonderful woman, but how could their relationship be legitimately consensual? If she also has DS or some other disability, then she must be staying in the relationship because she doesn't know any better. If she is a "cognitively normal" woman, why then she must be with him out of pity, low self-esteem, or a well-intentioned, Florence Nightingale sense of duty, unless she is craftily taking advantage of his wealth and ignorance. It would be absurd for this couple to have children because the brunt of the childcare work would fall to the mother, and the grandparents and other relatives would certainly have to help raise the children. If this wealthy man decides to hire a nanny to help him take care of his children, then he won't be a "true" father, for he won't be the one providing the daily childcare. And what can a retarded man teach children, anyway? If he hires tutors for them, again he is failing to be a good father. Fathers are expected to provide for their children, to develop a close relationship with the children, and most importantly provide strong role models of splendid manhood.

What does it mean to be at home with parenthood? It is true that the average adult with DS cannot take care of children without help from other people. It is also true that the average "cognitively normal" adult cannot take care of children without help from other people. For some reason, it is considered perfectly routine for a "cognitively normal" person to have meals delivered to her home, to pay someone to clean her apartment and do the laundry, to take a taxi across town, or to leave her children with a nanny. However, a person with DS is considered "incapable of independent living" if she hires the very same employees to do the very same tasks. As far as I can tell, the relevant difference is that usually the person with DS does not choose the employees. Instead, social workers or family members select the employees and negotiate with them, even if the money to pay them belongs to the individual with DS. A very thin veneer of autonomy preserves the illusion that the "normal" customer has purchased freedom from dependency by the mere fact of choosing her own caregivers.

Common belief: Retarded people are best off having relationships "with their own kind." There is a taboo on sexual or even simply romantic relationships between retarded and nonretarded people. One day, Leo asked my friend Sarah to be his girlfriend. She declined politely, but later told me in private that she had thought about the possibility seriously for a moment. Why are we so quick to dismiss the thought of a retarded man with a non-retarded girlfriend? Silvers has pointed out that in many nontechnological countries, there are no general taboos against romantic relations between retarded and non-retarded people (Silvers, personal correspondence, June 26, 2001). The majority of these are relationships between cognitively typical males and cognitively limited females, not the other way round. Is this perhaps because traditionally, patriarchal society associates high capacity with male roles and lower capacity with female roles? Consider a male colleague of mine, who claims that he could never be romantically involved with any woman capable of engaging him in intellectual

dialogue. Although his position may be extreme, he reminds us of the many men who prefer mates of lesser educational achievement, if not lesser cognitive capacity. However, it is highly unusual for a woman to choose a mate who can't keep up with her intellectually.

Common belief: Retarded people are exclusively heterosexual. What does it mean to be at home in drag? The historical and social imagination lacks people who are both retarded *and* gay/lesbian/ bisexual/transgendered (as far as I know). Why is it hard to imagine retarded people choosing to defy social norms? My brother is not shy whenever he has a crush on one of my friends: at various times, he has focused his attentions on Sarah, Laura, Petr, John, and Ken. He has a particular fondness for large men with beards, which my parents discourage him from expressing. He also enjoys dressing in women's clothes and wearing perfume. (I remember going out to concerts as a child, accompanied by the scent of Chanel No. 5 emanating from my mother and my brother.) My parents have done their best to minimize Leo's cross-gender behaviors, discouraging him from "inappropriately" hugging men and wearing perfume. Although I encourage him to try on my dresses in my apartment and among friends, I too ask him to change back into jeans before going out in public.

Many caregivers/parents manage the appearances of their retarded loved ones in order to present a normal version of the person's self to outsiders and to themselves. This includes wearing clean, good-quality, stylish clothes that reinforce their gender identity, especially whenever they go out in public. This enforcement of heterosexual appearance and behavior is especially striking because most people now believe gay and cross-gender behavior is not a matter of choice--so we should expect to find it across the population, regardless of people's cognitive levels. Why do I support, even encourage cross-gender behavior for normal people, but not for people like Leo? Because of the stigma surrounding homosexuality and cross-dressing, I fear having people think he's even more bizarre than usual. It is usually taken for granted that retarded people will conform to their gender roles if they have been properly socialized by their caregivers, so a retarded man in drag implies a negligent caregiver.

IV. How Do Gender Roles and Mental Retardation Interact To Construct the Sexual Identities and Life Plans of People with Down Syndrome?

Most readers probably remain highly skeptical of the analogy between living with Down syndrome and being female. I shall make one last attempt to defend this analogy by exploring the influence of socially constructed gender roles upon the roles assigned to people with retardation. This discussion is relevant to the paper because socially enforced roles often overlap such that it is difficult for us to distinguish them. For example, when someone directs his anger at me, it is hard for me to know whether he is just having a bad day, or whether he is also upset by my actions or my quirky personality. There is the additional possibility that something beyond individual idiosyncrasy is at work. It might be relevant to consider my gender, my race, my class background, my position of authority as a teacher, or my junior position as a graduate student. It would be a mistake for me to claim that any one of these factors was solely responsible, should I experience a decreased quality of life compared to other people. At the extreme, if I suffered so much

that I decided my life was no longer worth living, it would be too simplistic for others to conclude that life as a woman is worth living, but not life as a graduate student. Rather, it is the intersection of several factors that creates the nexus where I live my life. In exploring the complexity of life with Down syndrome and gender, therefore, I want to start interrogating how these two social disabilities are interconnected.

How are gendered roles linked to cognitive capacity? Femininity has historically been constructed as evoking home, domesticity, and lower intellectual capacity. As it happens, managing a household requires quite an array of cognitive capacities. When I was growing up, my mother did most of the household managing, allocating tasks to herself, husband, daughter, and son according to each person's aptitude, abilities and preferences, and other contributions to the household. My mother thought it more important for me to do well in school and to practice music, so Leo was given more household chores than I was. Leo happens to help out a lot inside the house: cooking and cleaning in the kitchen, doing laundry, vacuuming--what used to be called "women's work." When I lived at home, my father would call me to help him with carpentry projects, fixing the car, or mowing the lawn. He wanted me, the nonretarded daughter, to help him because these were "more dangerous tasks" requiring more skill and coordination. But isn't stirring a boiling pot over a hot stove potentially just as dangerous as hammering nails? In fact, Leo also shovels snow, takes out the garbage, weeds the vegetable garden, and dumps out the grass clippings, which are all stereotypically "masculine" tasks. In a bizarre way our gender roles have been exchanged because of Leo's retardation. In most cultures, the traditional expectations of a son are that he should leave home, pursue a career, make a new home, and start his own family. Because I have higher cognitive capacities than my brother, this masculine, autonomous role has fallen to me. In Japanese tradition, the youngest daughter is traditionally expected to stay at home with the parents and help look after them, keeping them company as they age. This is the caregiving role that Leo has inherited because he has been feminized by his retardation.

For a retarded man like Leo, the gendered roles established by social consensus catch him in a double bind. Because his cognitive limitations prevent him from doing "men's work", meaning highly paid, well respected work, he fails by the standards of the bread-winning, independent, autonomous "public" masculine role. Leo works twenty hours a week packaging headphones for an airline company, but because his workplace is a "sheltered workshop" he is paid only \$1.25/hour. Repetitive jobs involving light manual labor carry no social cachet, nor could he possibly support himself on such a low wage. Many of the jobs currently available to the retarded resemble low-paid jobs often held by people of color: assembly work, cleaning and maintenance, deliveries, animal care, and the like. What are the alternatives? Leo can perform some aspects of care-labor quite well: looking after young children and elderly family members, doing household chores such as laundry and dishes, cooking simple meals for others. Although some of these tasks require the ability to empathize with others and to imagine their needs, they are not considered to be tasks demonstrating or requiring "high cognitive capacity." Instead, the caring, staying at home "private" role is associated with femininity, so in taking up this role he compromises his masculinity.

Because we were born eleven months apart, Leo and I share the same age for one month every year. As I write this, we are both thirty years old. We have always considered ourselves “twins,” and we celebrate each other’s achievements and share our sorrows in tandem. Despite many arguments to the contrary, I continue to believe that the struggles he faces at home with Down syndrome are not so terribly different from my frustrations as a cognitively “normal” woman starting to make my own home. It is a difference in degree, perhaps, but not of kind.

I have made a start at exploring the controversial analogy between sex selection and selective abortion of fetuses diagnosed with Down syndrome. It should be clear that my conception of what makes life worth living has been deeply influenced by my life both as a woman and as the sister of a man with Down syndrome. I see no sharp line between the difficulties of being a woman in a patriarchal society and those engendered by having Down syndrome in a society focused on cognitive capacity. My intuition is that the possibilities for people with Down syndrome will increase as our society dismantles the deeply entrenched institutionalization of sexual difference. If we can move toward overcoming the Enlightenment fetishization of cognitive ability and dislodge the institutional barriers enforcing cognitive difference, perhaps we can build a society in which everyone is at home with gender *and* with Down syndrome.

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