

Zooming Out: Solidarity in the Moral Imagination of Genetic Counseling

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Introduction

Prenatal genetic testing allows potential parents to screen for and diagnose an ever-increasing number of conditions. However, because there is no treatment for the majority of currently detectable conditions, the information opens the door to selective termination, which some in the disability community consider morally problematic. Genetic counselors, and the other genetics professionals who offer these tests, have a professional obligation to help each client¹ navigate the implications of genetic information and to make a decision, which, while legally considered a personal and private decision, inevitably spills over into the political realm.

In this paper, I begin by giving an overview of the nature of the tension between the disability community and the genetic counseling profession. However, my goal is not to side with one group or the other. Instead, I would like to take a step back and consider the lens through which the tension between the two communities has been viewed, namely, in terms of the principle of autonomy. While I do not intend to question the importance of reproductive freedom, I would like to ask whether the language of choice and freedom fully captures what is going on here. In brief, I argue that the principle of autonomy as the primary framework for understanding both the problem and potential responses to the problem, is insufficient, and that looking to the relational underpinnings of autonomy may shed greater light on

¹Historically, genetic counselors have used the term “client” rather than “patient” because the psychosocial aspects of the profession derive from Rogerian client-centered therapy and because many founding figures in the profession were Ph.D.s rather than M.D.s, and wanted to make clear that they did not claim to be treating sick patients. Today, genetic counselors tend to use the terms interchangeably. I use the term “client” out of respect for the original intention.

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previous responses and future possibilities. Shifting the theoretical lens will not resolve the tension between the two communities; but perhaps looking at the problem from different angles will broaden our ability to imagine currently unforeseen alternatives.

In particular, and following the 2015 article by Bruce Jennings and Angus Dawson entitled “Solidarity and the Moral Imagination of Bioethics,” my aim is to consider if or how the concept of solidarity² might enrich thinking about the tension between the genetic counseling profession and the disability community. I consider the role of the concept of solidarity in terms of what the authors refer to as the “calculus of consent” and the “moral imagination,” which I will interpret broadly as tools for understanding the past and imagining the future.

Why solidarity? Jennings and Dawson note that “[i]n contemporary neoliberal societies ... ideological currents are promoting a calculus of consent based on interests that separate rather than interests that join” (2015: 32). In controversies where consensus is elusive, where both sides have a legitimate concern, perhaps it is worthwhile to zoom out, rather than remain mired in a yes or no tug of war, and to shift from an exclusive focus on interests that separate to a broader view that contextualizes individual interests and makes apparent the conditions for their possibility.

Certainly state programs in recent history could dissuade anyone from using the language of solidarity; however, promoting the interests of groups over the rights of individuals is not my intention. The aspects of the concept of solidarity that interest me here are the following: Solidarity as the structural context of individual freedom and solidarity as rooted in historical memory. Both aspects situate individuals within a complex network of relationships to other human beings, including those who lived long ago and those who will live in the future. Jennings and Dawson refer to solidarity as a “shaping sensibility” that “informs other normative principles and ideals rather than supplementing or competing with them, a perspective that gives a relational³ interpretation to regulative ethical principles such as justice, liberty, and beneficence” (2015: 32). Because reproductive freedom is at the heart of debates about the limits of prenatal genetic testing, it is particularly important to view the concept of solidarity as shaping the analysis rather than replacing the principle of autonomy.

² See Prainsack and Buyx 2012 for an in depth analysis of the uses of the term solidarity in bioethics literature.

³ There is an enormous body of literature on ethical theories that critique excessive individualism and prioritize relationships. See, for instance, the ethics of care developed by Carol Gilligan (1982) and Nel Noddings (1984). Many contemporary analyses by phenomenologists, feminists, post-modernists, social-justice theorists, cultural theorists, etc., start from the notion that individual relationships constitute or are prior to the individual. See, for instance, Mackenzie and Stolijar (2000), “Relational Autonomy: Feminist Perspectives of Autonomy, Agency, and the Social Self.” See also Kenny et al. (2010) for a summary of the inadequacies of the dominant individualistic approach and a discussion of relational autonomy, relational social justice, and relational solidarity in the context of public health.

The Disability Critique of Prenatal Genetic Testing

The disability⁴ critique of prenatal testing centers around two primary claims: “that prenatal genetic testing following by selective abortion is morally problematic, and that it is driven by misinformation” (Parens and Asch 2000: 13). Screening for Down syndrome has been around the longest and exemplifies some of the thornier aspects of the critique. When a pregnant woman is offered diagnostic testing (amniocentesis or chorionic villus sampling), she may use this information to prepare for a child with Down syndrome, but she may also use the information to decide whether or not to pursue termination. Although genetic counselors would like to view themselves as offering the neutral facts, many people feel that the implication in offering the test is that it may be preferable to avoid having a child with this condition (Saxton 2000; Patterson and Satz 2002). Some families who have children with Down syndrome, and some individuals with Down syndrome, feel that testing communicates⁵ a fundamental disrespect for the lives of individuals with Down syndrome (Bauer 2005).

Adrienne Asch has characterized the moral wrong of selective abortion as reducing a whole person to a single trait: As in other forms of discrimination when a person is reduced to her sex, color, or sexual orientation, selective abortion communicates that one quality is sufficient to render one person’s life less valuable than other lives (Asch 2000). As Martha Saxton (1998) puts it, the message is that “some of us are ‘too flawed’ in our very DNA to exist” (391). The objection here, called the *expressivist objection*, is that prenatal genetic testing sends a message that it is better not to exist at all than to exist with a disability. Asch argues that the moral wrong lies not in the

⁴I follow Adrienne Asch in using the term to include “all health-related departures from species-typical functioning” (Asch 2003: 319, Note 10). See also the definition of disability in the Americans with Disability Act of 1990. While I will use broad terms such as disability community and disability movement, I am aware that groups “are not unified monoliths,” as Joseph Stramondo puts it prior to clarifying his intention to use the term “disability movement.” He writes, “This term is deliberately broad and meant to encompass the substantial range of sometimes divergent tactics and ideologies deployed by disabled people, but it is not assumed that all disabled people engage in such action, have the same political beliefs, or use identical advocacy approaches. In addition, while the lived reality of disability is an important feature of my argument, the ‘disability movement’ is not simple shorthand for people who experience life with an anomalous embodiment or medical impairment but instead refers to a particular subset of disabled people who are conscious of their own subordinate social position and engage in political action accordingly” (Stramondo 2016).

⁵The claim that there is a “message” communicated in the offering of or existence of prenatal genetic tests is best understood in the context of the contrast between the medical and social models of disability. If much of the reason why people with disabilities are un-able is rooted in the lack of societal accommodation, then offering prenatal testing conveys a message that society would rather address the challenges associated with disabilities by preventing people with disabilities from being born rather than taking measures to improve institutions and practices that could enhance the lives of people with disabilities. See Asch 2003, “Disability Equality” in *Prenatal Testing*. See also Susan Wendell (1996) who says selective abortion sends the message that “we do not want any more like you” (in *The Rejected Body*).

choice of termination itself, but in the choice to abort *this* particular fetus in cases where the pregnancy is otherwise desired. She calls this the *any/particular* distinction: To terminate because it is not the right time is to say ‘I don’t want *any* baby right now,’ whereas to terminate following prenatal testing, whether because of sex or genetic condition, is to say ‘I don’t want *this* particular baby’ (Asch 2000; Saxton 2000).

Some take the argument a step further and say that the mere existence and availability of prenatal testing constitutes a judgment of people currently living with the conditions for which there is testing (Madeo et al. 2011; Patterson and Satz 2002). In offering the test, the medical professional communicates that this is a condition whose impact is sufficiently devastating as to warrant prevention altogether. True, clients are not forced to get these tests, or terminate on the basis of results if they do pursue testing, but often the social impact of the existence of the tests is to pressure parents to do both (Munger et al. 2007; Press 2000). For instance, parents who have carried pregnancies with fetuses affected by trisomy 21 or spina bifida report being asked whether they got “the test” (Bauer 2005). Awareness that they will face this question, and that the determination of sympathy or judgment hinges on the answer, inevitably constrains the “choice” facing parents (Jennings 2000; Lippman 2003).

A further dimension to the disability critique of prenatal testing is that by reducing the number of people with genetic conditions, like Down syndrome, we may decrease the social urgency of improving disability accommodations and reducing discrimination (Wasserman and Asch 2006). This perpetuates the medical model of disability, which assumes that the problem is with the particular trait rather than with society’s unwillingness to increase accommodations for people with that trait (Saxton 2000; Kaplan 2000).

Messages Sent and Received

The disability critique of prenatal genetic testing has been challenging for the genetic counseling profession to digest because the accusation is at odds with how the profession views itself: Genetic counselors view themselves as “*helping people* understand and adapt to the medical, psychological and familial implications of genetic contributions to disease” (Resta et al. 2006, my italics). The demographic attracted to this profession, typically white, middle-upper class women,⁶ frequently believe themselves to be good, tolerant individuals, who respect all choices and celebrate human diversity. The goal, as many genetic counselors see it, is to promote informed choices, not to send messages about the lesser value of certain people. What could be wrong with providing more information? And, as genetic counselor Robert Resta puts it, gently encouraging genetic counselors to laugh at themselves, “Some of our best friends are people with disabilities, right?” (Resta 2011: 1786).

⁶Early genetic counselors were men, but by the 1970s most counselors were white, middle-upper class women; and, according to a 2010 survey by National Society of Genetic Counselors (NSGC) women still make up 95% of the field, with 92% identifying as white or Caucasian (Stern 2012: 25–26). See also p. 74 for a discussion of Nancy Steinberg Warren’s 2004 organized retreats on challenges to diversifying the profession.

Does prenatal genetic testing or selective abortion following testing send a “message” that disabled lives are not inherently valuable? A number of authors have raised objections to the *expressivist argument*. Buchanan (1996) argues that there can be no message if the person supposedly sending the message does not actually hold the belief that is the content of the message received. Lindemann Nelson (2000) disagrees, to a certain extent, and offers the example of the confederate flag: The flag may send a message in support of slavery even if the person flying the flag insists that he merely intends to honor his heritage and ancestry. But, says Lindemann Nelson, “abortions are not flags” (2000: 197). An abortion, unlike a flag, is not a symbol or a socially agreed upon way of communicating in the broader context of a language.

Regardless of the ontological status of abortion, one could argue that a message has been received. Bellamo (2009) found that 80% of study participants (377 members of advocacy organizations for Down syndrome) agreed with the statement “Prenatal diagnosis is used to decrease the population of individuals with disabilities,” and 90% agreed with the statement “Genetic counselors influence patient decisions.” Furthermore, even if counselors do not believe or intend the purpose of prenatal testing to be decreasing the population of individuals with Down syndrome, the fact remains that this is a consequence of prenatal testing. Even though the chance of conceiving a baby with Down syndrome increases with the age of the mother, the number of babies born with Down syndrome has not increased in countries or populations where delayed childbearing has increased (Resta 2011; Cocchi et al. 2010; Caplan 2015; Stern 2012). However, there has been a “relative increase and re-distribution of babies with Down syndrome and other disabilities among certain ethnic and lower socio-economic status groups” (Resta 2011: 1787). Since the chance to conceive a baby with Down syndrome is equal in all populations, the breakdown of births of babies with Down syndrome according to socioeconomic and cultural lines suggests that attitudes towards and/or access to prenatal testing are responsible for this difference (Resta 2011; Cocchi et al. 2010).

Even if genetic counselors do not intend to send a message about the value of life with a disability, empirical studies about information given during genetic counseling sessions support claims by disability advocates that genetic counselors harbor a negative bias toward people with disabilities. Farrelly et al. (2012) found that genetic counselors were more likely to mention termination than pregnancy continuation and adoption. Studies also show that genetic counselors focus primarily on the biomedical aspects of genetic conditions rather than on quality of life issues for a child with a disability (Roter et al. 2006; Farrelly et al. 2012). Counselors did not, for the most part, offer information about what capabilities and skills might be present alongside limitations. In other words, genetic counselors were neither perceived to be offering, nor claiming by self-report to offer, a balance of both positive and negative dimensions of various conditions (Madedo et al. 2011). It should be acknowledged, however, that in response to these findings many genetic counseling programs and genetic counselors have made an explicit attempts to address biases and improve relations with the disability community. Interestingly, responses to the disability critique are generally couched in terms of enhancing client autonomy. It is to these responses that I now turn.

Responding to the Disability Critique

The ideal of non-directiveness⁷ has long dominated the genetic counseling ethos, floating intact above the ebb and flow of scholarly critiques about its possibility and desirability (Kessler 1997; Biesecker 1998; Caplan 1993; Gervais 1993; Sorenson 1993; Patterson and Satz 2002; Weil 2003; Arribas-Ayllon and Sarangi 2014; Suter 1998). For the purposes of this paper, the term can be understood in its most simplistic sense: The role of a genetic counselor is to offer her client relevant information about genetic disease and risk, and allow the woman to make her own decision without influencing, i.e. *directing*, her in one way or another. The assumption is that the client can make an autonomous decision only when the counselor behaves in a non-directive manner, and the counselor achieves her goal of non-directiveness if she offers neutral, scientific facts and omits opinions about what the patient ought to do. A neat distinction between facts and values sits unexamined in the background. Genetic information is assumed to be value-neutral, and so if the genetic counselor presents information and does not tell the client how to act on it, she is assumed to be leaving her values out of the discussion, including any value-judgments about the value of life with disability.

The professional motivation for adopting non-directiveness as a foundational principle for genetic counseling is usually described as a means to distance or differentiate genetic counseling from eugenics (Weil 2003; Biesecker 1998; Sorenson 1993). Resta (1997) questions this narrative by pointing out that early practitioners in “human genetics” seemed to have no qualms affirming non-directiveness in one breath and eugenic goals in the next.⁸ Still, it does not follow from this that the *intent* was not to give an appearance of a distinction between eugenics and human genetics clinics.

Alexandra Stern (2012) points out that Sheldon Reed, the man who coined the term “genetic counseling” as a “kind of genetic social work without the eugenic connotations” (Reed 1974), was well aware of the importance of distancing the new field of human genetics from eugenics. At the same time, he acknowledged that the two terms were synonyms: “As late as 1979, Reed explained in a lecture that ‘our present day use of the term ‘human genetics’ instead of ‘eugenics’ may be financially and politically expedient but there is no great philosophical distinction between them’” (Stern 2012: 20). Stern suggests that the field of genetic counseling could be considered “neo-eugenic”:

⁷For a history of how non-directiveness became central to the profession of genetic counseling see Stern, *Telling Genes*, 2012, especially Chap. 6, where she outlines the convergence of several distinct aspects: The development of client-centered counseling by Carl Rogers; Sheldon Reed’s choice of the term client rather than patient as the subject of genetic counseling; the birth of bioethics as a discipline, along with its particular focus on client autonomy as response to past abuses (human experimentation, paternalism, etc. Interesting, the noun “non-directiveness” did not enter the literature until the 1980s, when it became part of a “form of professional identity construction” (144); See also James Sorenson, “Genetic Counseling: Values That Have Mattered,” for a discussion of the different values that structured the field as it transitioned from eugenics, to medical genetics, to genetic counseling performed by masters-trained professionals.

⁸See Resta (1997) “Eugenics and Nondirectiveness in Genetic Counseling,” p. 256.

Even if dissimilar to the state-sanctioned eugenics of the past, which entailed forced sterilization and marriage laws, the omnipresent pressure on American women to produce the ‘best’ or healthiest children possible using available genetic and reproductive technologies resonates with the quest for superior biological fitness and could be considered neo-eugenic (2012: 12).

Even though non-directiveness cannot be, historically speaking, a response to the contemporary disability critique of prenatal genetic testing, it can be useful to think of it this way. Disability scholars and activists tend to structure their critiques of prenatal testing in terms that suggest that the field of genetic counseling has not yet attained its ideal of non-directiveness. This critique ranges from pointing out specific lapses to raising more abstract or systemic concerns. First, there are the straightforward and easy to address lapses of the profession’s own moral code (for instance, if someone were to actively urge a woman to consider termination). More abstract or systematic concerns can be difficult or impossible to address: For instance, if “the process of prenatal counseling itself presupposes an implicit bias to abort any fetus deemed ‘defective’” (Patterson and Satz 2002: 119), it is hard to see what can be done besides abolishing prenatal genetic testing, which is clearly not on the table. Problems related to prenatal testing can be remedied only if there is something specific about the process, other than its existence, that can be altered.

The following is an example of an argument about the existence or nature of genetic testing. Jennings argues that the ground and discourse of the profession is shaped by technology, so the “counseling may be neutral as regards the personal beliefs of the counselor, but it cannot be neutral as regards the very context of genetic technology itself” (2000: 136). Like Patterson and Satz’s argument, Jennings’ argument highlights the existence of technology as a system of power that structures reality and thus implicitly *directs* the conversation between counselor and client: “Prenatal genetic testing technology shapes choice by in effect making everything into a choice,” Jennings writes (2000: 135). Prior to what Abby Lippman has referred to as the “geneticization” of pregnancy, pregnancy could proceed without requiring a decision at every turn; women did not find themselves in the office of a genetic counselor, unclear about why, only to learn that because they are older than 35-years-old, they have the option of learning about conditions, which raise the option, if diagnosed, of raising the option of considering a termination.

Balanced Information and Unconscious Negative Bias

There are also critiques in-between the two extremes above, and it is these to which the genetic counseling community has responded. These related critiques, which I will refer to as the *unconscious negative bias* critique and the *balanced information* critique, proceed roughly as follows:

- (a) *Unconscious negative bias critique*: Counselors unconsciously replicate the negative biases of society toward people with disabilities because they have had few interactions with people with disabilities and therefore lack the ability to imagine how good life can be with disability (Parens and Asch 2003).

- (b) *Balanced information critique*: Counselors offer a biased picture of life with a disability because they discuss negatives such as medical risk but exclude positives such as unique abilities and quality of life (Stern 2012).

With respect to the second critique, the *balanced information* critique, changes began in the 1960s and 1970s. In the 1970s, groups mobilized to reject negative labels such as mongoloid, retarded, handicapped, dumb, etc. (Stern 2012). The work continues today. In 2006, Brian Skotko, medical geneticist and advocate for people with Down syndrome, wrote a Letter to the Editor to the *American Journal of Obstetrics and Gynecology* to point out that a study published in the journal used words such as “handicap,” “risk,” and “normal,” rather than non-directive options, such as “disability,” “chance,” and “without disabilities.” “In previous studies,” he writes, “mothers of children with Down syndrome asked their health care providers to use sensitive language during counseling. We must all be reminded that our words make a difference” (2006: 625–626).

The movement to include positive information has, for better or worse, recently culminated in state legislation, such as Pennsylvania’s *Down Syndrome Prenatal and Postnatal Information Act*, also known as *Chloe’s Law*. This legislation, named after a little girl with Down syndrome, mandates that positive information be included in counseling sessions about Down syndrome and requires the Department of Health to make available “up-to-date, evidence-based information about Down syndrome that has been reviewed by medical experts and national Down syndrome organizations” (Pub. L. 2450, No. 130, Cl. 35, 2014). In addition to information about the medical facts, parents are to be given resources for support such as phone numbers for national and local Down syndrome organizations.

Setting aside the question of whether laws are the best way to encourage the provision of positive information, the general shift towards balanced information is considered by many to be an improvement. Previously, studies (Skotko 2006; Skotko 2009) have shown that mothers who chose to continue pregnancies after a diagnosis of Down syndrome were not happy with quality of the information given during diagnosis. Skotko found that physicians⁹ delivering prenatal diagnoses did not claim by self-report to offer unbiased information: 13% said that they “‘emphasize’ the negative aspects of DS [Down syndrome] so that parents would favor a termination [and] 10% actively ‘urge’ parents to terminate” (Skotko 2006: 2362). This is clearly an area where providers could improve.

Dixon (2008) argues that medical professionals do not give sufficient information to women following a prenatal diagnosis of Down syndrome for their decisions to be considered truly informed. He refers to the “failure of non-directive pre-abortion counseling” and suggests a link between this failure, as well as biased information during screening and testing, and the “very high abortion rate for fetuses

⁹It should be noted that these studies include physicians, not genetic counselors, and non-directiveness is not generally considered a cornerstone of physician practice. Some studies show that women were less likely to terminate if they received information about aneuploidy from a geneticist or genetic counselor rather than an obstetrician. See Munger et al. 2007.

diagnosed with Down syndrome” (2008: 3). Thus the concept of non-directiveness is flipped on its head. Whereas in the past “non-directiveness” meant listing medical facts and letting the client decide, today, *only* including medical facts is considered directive (because medical facts are not neutral but negatively biased). Some argue that the positive information movement threatens the ideal of non-directiveness (Caplan 2015), but regardless, it is clear that the movement has had real impact on the way genetic counseling is approached.

In addition to improving the quality and balance of information, the genetic counseling community has worked to increase student and counselor interaction with families raising children with disabilities in order to decrease the unconscious negative bias of genetic counselors. Writing in 2007 about her own experiences counseling clients about Down syndrome, Brasington, a genetic counselor, describes her transition from thinking in terms of the medical model to thinking in terms of the social model of disability. Her transformation was in large part due to interacting with families parenting children with Down syndrome. The expectation that this type of experience might transform genetic counselor attitudes, and accordingly counseling methods, is what informed the curriculum design of the genetic counseling program established by Judith Tsipis in 1992 at Brandeis University. Other programs have followed suit, with some programs including disability studies in their curricula and many offering structured opportunities for students to interact with individuals with disabilities in a non-clinical setting (Madeo et al. 2011; Saxton 2000; Sanborn and Patterson 2014).

Further responses to the *unconscious bias critique* have included professional workshops and meetings that encourage communication between the disability community and the genetic counseling profession. What has come out of these conversations is an intention to increase education about disabilities and “exposure of healthcare providers to individuals with disabilities ... to foster awareness” (Madeo et al. 2011: 1782). To facilitate interactions that improve communication between the two communities, the American Board of Genetic Counselors offers continuing education credit for counselors who participate in specific volunteer activities (Madeo et al. 2011).

Decreasing Unconscious Bias in Order to Enhance Reproductive Freedom

The changes discussed above are said to be done in the service of altering the bias of genetic counselors so that they will provide genuinely non-directive counseling that allows clients to make informed choices. This justification is regularly given even when there are numerous other important reasons for the changes. For instance, Asch (2003) devotes the introduction of her “Disability Equality and Prenatal Testing: Contradictory or Compatible?” to a discussion of how prenatal testing followed by selective abortion affects “social institutions beyond the family,”

“express[es] views that worsen the situation for people who live with disabilities now and in the future,” and is at odds with “reforming such institutions as schools [and] workplaces” (2003: 316–317). But she then concludes her introduction by stating her intention in the article as follows: “My concern is to facilitate true reproductive choice for women by urging changes in the way prenatal testing occurs and the rhetoric that surrounds it” (2003: 17).

Changing attitudes and language very well may enhance reproductive choice. But Asch’s vacillation between the social and the private may reveal the poverty of a framework that justifies only in terms of freedom of choice. To claim that the goal is primarily to facilitate the reproductive choices of women and couples seems a myopic explanation given some of more systemic concerns raised in the literature, including by Asch herself. Attention to some of the specific issues raised by disability activists and scholars suggests that more reproductive freedom is not precisely what is sought. Notice how Asch’s writing displays an ambivalence between the social and the private:

Despite the symbolic and tangible changes attributable to laws like the Americans with Disabilities Act, the nation’s disabled population is still less educated, less employed, less involved in civic life, less represented in the political process, and less influential on the design of products than their numbers warrant (Asch 2003: 331).

And then, ten pages later, the reversion to information and reproductive choice:

Yet I persist in believing that as part of the *goal of creating such a welcoming society*, we must persuade professionals to *change what they tell prospective parents* about life with disability; convince those parents to learn about how children and adults in today’s world survive and thrive; and then *endorse the choices* people make about their reproductive and family lives (Asch 2003: 341, my italics).

She is willing to “endorse the choices of parents,” but only after they have been convinced of the value of life with disability. When she writes of the “the goal of creating such a welcoming society,” I believe she reveals that while reproductive freedom may be valuable, both in itself and as a means, it is not the end. Framing the issue primarily in terms of enhancing autonomy may be too narrow to capture what is needed.

Zooming Out: Solidarity as Shaping Sensibility

A core feature of a prenatal genetic counseling session is to emphasize the personal nature of decisions related to prenatal genetic testing. When clients ask a counselor which tests she would have or what she would do if she had an abnormal result, the counselor’s response tends to center around reminding the client how personal the decision is and how much these decisions vary from woman to woman. These decisions certainly are personal, but, as anthropologist Rayna Rapp notes, “private choices always have public consequences” (1988). Similarly, Patterson and Satz

raise the question of how genetic counselors should respond to the claim that “the very enterprise of genetic counseling is political” (2003: 120). Further, Jennings reminds us of the “enormous political apparatus of scientific research and testing facilities, to say nothing of the enormous public (whether governmental or corporate) investment and expense that genetic testing technology represents” (2000: 131); and Saxton points out that “[a] woman’s individual decision, when resulting from social pressure, or colluding with ‘a trend,’ has repercussions for all others in the society” (2002: 157).

While I would not go as far as Jennings in concluding that “[i]t is breathtakingly implausible ... to characterize the use of genetic testing in obstetric practice in our society as a ‘private’ act in any sense” (2000: 131), I do think that the focus on enhancing reproductive choice frames the discussion in terms of the private realm. Reproductive decisions certainly are a private matter, but genetic testing, broadly speaking, has social dimensions as well. In this section, I explore how the concept of solidarity might contribute to what Jennings and Dawson refer to as the calculus of consent, or, in this context, the reasons for responding to the call of the disability community. I conclude by considering the contribution of the concept of solidarity for imagining future responses to the disability critique of prenatal testing. I begin with some clarification of the terms calculus of consent, moral imagination, and solidarity.

Jennings and Dawson use the term “calculus of consent” to encompass justifications for obeying laws, rules, and norms that benefit others as well as “stories that a society tells about itself and that individuals tell about their place in it” (Jennings and Dawson 2015: 31). As adapted to my topic, the calculus of consent will refer to justifications of the guidelines and suggestions discussed above, such as “to enhance reproductive freedom” or “to achieve genuine non-directiveness.” By moral imagination, Jennings and Dawson mean “the capacity to take a critical distance from the given, to think reality otherwise” (Jennings and Dawson 2015: 31). In the same way, I use moral imagination in the context of this paper to refer to taking a step back from the controversy and contemplating new possibilities for the future. Taken together, I use the concepts of moral imagination and calculus of consent to reflect on the past and imagine the future.

I use the concept of solidarity to refer to a pre-reflective bond between individuals and between grouped individuals that moves us to act on one another’s behalf “just because.” Or, put more philosophically, it is the condition for the possibility of recognizing one another as ends, but not as abstract ends: As embodied, vulnerable, mutually-dependent beings who stand in a dialectical relation of “needful freedom” with the world (Jonas 2001; Kittay 2011). In other words, our individuality and freedom are premised upon dependence. We cannot go out into the world and pursue our diverse projects as individuals without first attending to the material needs of our bodies. The response to an *other*, in the recognition of this shared dependence, is rooted in a feeling of solidarity.

The Calculus of Consent and the Response to the Disability Critique: Enhancing Autonomy?

Jennings and Dawson suggest that one of the crucial contributions of the concept of solidarity to bioethical discourse is to add a relational dimension to other ethical principles. Without the concept of solidarity, they say, the interests of individuals are viewed as separate and distinct, constituted prior to relationship, not in and through relationship with others. The picture is one of isolated atomic individuals whose interests are sometimes at odds with one another and sometimes compatible, but only incidentally or instrumentally so: “a vision of the individual agent unencumbered, as it were, by solidarity is a vision that stresses the uniqueness of each person and emphasizes difference and separation rather than sameness and commonality. Instrumental ties are the limit of relationally” (2015: 33).

Viewed within an individualistic framework, what is the justification for the genetic counseling profession to work with the disability community? Perhaps it does so out of a kind of “enlightened self-interest”: The profession may improve its public image when it demonstrates attention to the accusation of negative bias towards individuals with disabilities. It also improves its “self-image” by proving it can live up to its own ideal of non-directiveness and serve its clients in the way it claims to: Providing information so that clients can make autonomous decisions. This explanation does not seem to capture the reasons why the genetic counseling profession has worked with the disability community or why it should continue to do so.

In a society without solidarity, Jennings and Dawson write, “individuals must obey common rules ... not for the sake of others or their rights or interests—those things are incidental—but for the sake of their own protection ... There is no encumbrance here, no normative push of commitment or obligation, no motivational pull of mutual recognition and resemblance” (2015: 33). To apply this thinking to the genetic counseling profession’s response to the disability community is not to say that genetic counselors are bad people or that they do not want to show respect for individuals with disabilities; I think they do, and this is precisely why framing the “why” of responding to the critiques of above in terms reproductive freedom does a disservice to both communities.

When one considers what the disability community gains from working with the genetic counseling profession, the limits of an individualistic framework, i.e. the reproductive freedom framework, become clearer. As discussed above, some in the disability community say that their aim is to improve reproductive freedom. Arthur Caplan wonders if this is whole motivation of some of the recent positive information laws: “They see the legislation as pro-information and, thus, pro-client autonomy, although, if abortion rates did not change in states with such laws, it is fairly certain the legislation would be seen by many pro-life and disability proponents as a failure” (2015: 3). If this is true, then providing balanced information to enhance the reproductive freedom of women is a means to an end: To decrease abortion rates of individuals with disabilities, or at least to create a welcoming society where individuals with disabilities are respected and able to participate in society to the fullest

extent possible. The goal, then, is not merely or even primarily “choice,” but, to use the language of Jennings and Dawson, “right recognition” and “right relationship.” And the genetic counseling community responds or should respond to this call for recognition out of an obligation, because of the “motivational pull of mutual recognition and resemblance,” not simply to enhance the autonomy of clients or improve its perception among the public and in the disability community.

Again, this is not to dismiss the importance of reproductive autonomy, but to zoom out and consider the conditions that make individual freedom possible. Jennings and Dawson describe how solidarity grounds the structural context of freedom:

The normativity of social political life is grounded on what might be called ‘right recognition’ and ‘right relationship.’ We define solidarity as a moral practice that is fundamental to a social and cultural structure of right relationship. Right recognition is a condition of moral and political membership, rights, and equality—the recognition of the moral standing and respect of each person. Right relationship is a condition of mutuality—the mutuality of interdependence, care, and concern for others and their relational human flourishing (2015: 32).

Applying these ideas, we would justify the actions of the genetic counseling profession not by saying it is good for the profession or even that it is good for the reproductive freedom of clients; instead, we would look to the background and context of a right like reproductive freedom and say it is good to recognize the moral standing of people with disabilities because, well, they have moral standing and deserve recognition, just as we all do. While people can and have offered instrumental reasons for giving rights to people who lack them (black people, women, LGBTQ individuals, and so on), ultimately, the reason to, for instance, grant black people or women the right to vote, is not that it benefits the country but that they are persons who deserve recognition and the rights that follow from this recognition. Likewise, we stop using offensive language to describe black people, women, gay people, trans people, people with three chromosomes, etc. not to enhance freedom, although this may occur incidentally, but to respect the humanity of the other.

The argument applies as well to the justification for increasing the “exposure” of genetic counseling students and practicing genetic counselors to individuals with disabilities. Why should genetic counseling students interact with people with disabilities? Why should genetic counselors advocate for people with disabilities or otherwise interact with them in non-clinical settings? The argument is that this “exposure” decreases unconscious bias against people with disabilities by enlarging the imagination of counselors to include living well with a disability. This in turn makes non-directive counseling possible because the counselor has supposedly freed herself from bias. So in this view, the justification for meeting people with disabilities is to enhance the autonomy of pregnant women via non-directive counseling.

Some or all of this may be true, but I would argue that the broader reason for interacting with people is less instrumental: It is not “so that” or “in order to,” but because this recognition is owed and is long overdue. The demand to recognize the other as fully human is rooted in a relationship that already existed but was un- or under-acknowledged. Recognition is not about interests, desires, or results; it can be inconvenient and uncomfortable to give up a position of power that was premised upon others not being recognized, as is clear from the history of other groups that

have struggled for political recognition and social respect. But we have an obligation to do it anyway: “just because” or “because it is owed”:

[I]t is moral commitment, not strategic advantage, that lies at the motivational core of solidarity ... At least in an elementary way, the act of standing up for establishes mutuality and reciprocity among individuals and groups involved in the struggle against injustice (Jennings and Dawson 2015: 36).

When the genetic counseling community stands beside the disability community, when it responds to concerns as best it can, when it works for the equal participation of citizens in our shared society, our shared humanity is affirmed. Individual rights, such as reproductive choice, are possible only in the context of this mutual recognition.

Historical Memory and the Moral Imagination

I have up until now concentrated on what has occurred and how it tends to be explained. I would like to conclude by considering how the concept of solidarity might enrich imaginings for the future, particularly with respect to the education of prenatal genetic counselors. For a topic so intimately and perilously related to individual and social identity as genetics, a sense of temporal context is essential. Jennings and Dawson describe the context-giving dimension offered by a focus on the concept of solidarity:

Solidarity grows out of a sense of historical memory and tradition, and it feeds on the gratitude that others have made to one’s way of life ... [S]olidarity is a concept that inherently leads us to view our actions and the rights, well-being, health, and dignity of others as placed spatially and temporally, as bound together in a here and a now (2015: 32).

Insofar as the role of the genetic counselor is to help a client make sense of genetic information, she must be sufficiently steeped in the history of genetics and its abuses to anticipate the social reverberations of her explanations and respond with nuance and sophistication. Stern refers to the “considerable historical amnesia” of the profession with respect to its “racialized past” (2012: 73). Many communities of color associate the field of human genetics with the forced sterilization of the very recent past.

The pedigree, the mainstay of the genetic counseling session, was developed by early twentieth century eugenicists: “From 1910–1939, the ERO [Eugenics Records Office] as America’s premier eugenics research organization, train[ed] the hundreds of eugenic field workers who traveled from state to state to produce pedigrees of supposedly ‘defective’ families” (Stern 2012: 34). The pedigree then “migrated intact” to medical genetics in the 1940s (Stern 2012: 34) and continues to be used today. Students taking pedigrees should have the opportunity to learn that each line sketched across the page recalls a potent history; they should not be caught unawares by clients who feel the echo of past traumas in the casual line, circle, and square of the pedigree. To add a sense of historical memory to the genetic counseling curricu-

lum would mean a greater emphasis on the origins of human genetics, no matter how shameful—or rather, precisely because of the shameful aspects of this history. As Stern writes, “The field of genetic counseling carries burdensome historical baggage that imposes limitations and can unwittingly hinder the field and its practitioners” (2012: 3). Perhaps the profession should spend less energy distancing itself from eugenics and more energy understanding the eugenic impulse and its temptations. To include greater attention to the history of eugenics and the evolution of the field of human genetics is to acknowledge what Hannah Arendt called “the banality of evil,” and to admit that the frailty of good intentions will never be a thing of the past. Nathaniel Comfort refers to the relief of suffering and human improvement as the twin impulses of eugenics and all of medical genetics. Eugenics coupled with state control is only one manifestation of eugenics; the impulse, he says, is “timeless” and manifests differently in different ages: “It is the urge toward selection of the best offspring possible, toward the elimination of hereditary disease, and toward human engineering—‘the self direction of human evolution,’ as one Progressive-era poster put it” (Comfort 2012: xi). To recognize the way that the eugenic impulse continues to structure our motivations today, and cultivate a deeper appreciation of this continuity, may help genetic counselors better understand how the public perceives the field (Stern 2012). To study history is to recall that the present will some day be the past and to remain curious about what people in the future will conclude looking back.

To add a sense of historical memory to the genetic counseling curriculum might also mean a greater attention to the history of ideas, such as autonomy, non-directiveness, and value-neutrality. “If any one of us ever did, no one in our group can imagine having a view from nowhere,” write Parens and Asch following the completion of the Hasting Center’s two-year project exploring the disability critique of prenatal testing (2000: ix). What would it mean to have a “view from nowhere” and what theoretical insights led many philosophers to reject this possibility? While I would not recommend that genetic counseling students delve deeply into debates about scientific realism, I cannot help but find it disappointing that fifty-four years after Thomas Kuhn wrote about scientific observations being theory-laden, and twenty-five years after Dan Brock explained the difficulties with assuming a fact/value distinction in the health care provider/client relationship, genetic counseling is taught as though there were not mounds of literature, some written by genetic counselors, complicating this neat division of labor.

For genetic counselors to be equipped to facilitate constructive conversations with clients who are grappling with complex moral questions, they need to have a sense of the history of debates about moral questions relevant to the field. The uninterrogated acceptance of the fact/value distinction, in which genetic counselors bring the facts and the clients brings the values, leads genetic counselors to a naïve kind of ethical relativism in which client beliefs are true because they are believed by clients. While affirming client values is important, oftentimes clients are struggling to uncover their values or to distinguish their own values from the values of their culture, or their parents, or their partners. In situations like these, mere affirma-

tion, while clearly non-directive, is not particularly affirming of the client's genuine needs.

I want to emphasize that genetic counselors and those who work closely with them have generated a significant amount of literature about the history of the field, including the relevance of applying alternative theoretical frameworks to problems faced by the field. For instance, Satz and Patterson apply feminist standpoint epistemology to the tension between the genetic counseling profession and the disability community. They quote feminist philosopher Sandra Harding putting to work Patricia Hill Collins's African American feminist philosophy on the project of "mak[ing] dominant groups 'fit' to engage in collaborative ... enterprises with marginal peoples" (Harding 1993: 68). With respect to improving relations with the disability community, some of the work of becoming 'fit' is accomplished by increasing interactions with individuals with disabilities. Nothing compares to the experience of knowing 'this' person. However, these 'particular' interactions could be even more powerful if students had the opportunity to explore various frameworks within which they could situate their insights. While many genetic counseling students and genetic counselors aim to be accepting of everyone and affirming of all difference, the suggestion here is that being fit to interact with certain people requires going beyond mere intention to accept others:

Such a project requires learning to listen attentively to marginalized people; it requires educating oneself about their histories, achievements, preferred social relations, and hopes for the future ... it requires critical examination of the dominant institutional beliefs and practices that systematically disadvantage them; it requires critical self-examination to discover how one unwittingly participates in generating disadvantage to them and more (Harding 1993: 68).

Rigorous self-examination cannot occur simply by turning inward; genetic counseling students must also have some opportunity, however limited due to the inevitable time constraints of training, to soak up some of the lessons from the decades of discourse on the moral issues related to genetic counseling. To further disability awareness and student self-awareness, we need content that links past and present, that baffles and inspires, that concretizes differences while recalling our shared vulnerabilities as embodied beings.

The actions that the genetic counseling profession has taken thus far in addressing balanced language in genetic counseling sessions and increasing interactions between people with disabilities and genetic counselors may be viewed as the first indication that the framework of solidarity informs, albeit unacknowledged, the decision-making of the genetic counseling community. These changes may indeed enhance reproductive autonomy, but to recognize solidarity as a tacit value (Jennings and Dawson 2015) is to enlarge the framework that structures the moral imagination of the genetic counseling profession in a way that points to the relational underpinnings of autonomy.

To see what was previously hidden opens the possibility of envisioning alternative forms of moral learning. For instance, Jennings and Dawson refer to 'standing up beside' as the fundamental posture of solidarity, and they name three additional aspects that trace the evolution of possible growth: *Standing up for*; *standing up*

with, and *standing up as*. While the distance to the kind of identification indicated by the preposition ‘as’ is a long way off and perhaps not desirable as a goal, the genetic counseling profession has been working on taking a public stand in response to calls from the disability community. The genetic counseling community has already begun the work of ‘standing beside’ the disability community: Recruiting individuals to genetic counseling programs and genetic counseling training program advisory boards who have disabilities or have cared for someone with a disability (Shakespeare et al. 2009; Madeo et al. 2011), working with advocacy groups, and getting to know individuals with disabilities outside clinical contexts, are all instances of moving closer, of positioning ourselves in a shared space. To stand beside each other in the future, to become fit for collaboration, is to also to recall the temporal relations that shape present positions. Perhaps we can further the lateral movement already begun by also stepping back, zooming out, and recalling the past as we reflect on what implicit habits of thought structure decision-making and constrain visions for the future.

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