

Public Choices:

An Examination of Policy Statements about Prenatal Testing

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Abstract

Disability rights activists have been trailblazers in the public debate about prenatal genetic testing. They provide meaningful critique about whether such testing should be offered and, more importantly, guidance about adequately and appropriately informing decision-makers. This paper illuminates the rhetorical devices that the disability and medical communities use in policy statements to frame the issues surrounding prenatal genetic screening and testing. The qualitative analysis focuses on how these stakeholder groups imitate and engage the abortion conversation in both form and content, particularly in their use of the language of choice. As medical communities begin to create practice guidelines surrounding emerging genetic technologies and their implementation into prenatal care, disability rights organizations have a timely opportunity to re-engage these conversations. Policy statements may help to rally allies and to make Disability Studies and disability rights perspectives active in the public sphere.

Keywords: prenatal diagnosis; Down syndrome; health policy; personal autonomy; choice behaviour

Les militantes en droits des personnes ayant un handicap ont fait preuves de pionnières dans les débats publics à propos des tests génétiques prénataux. Ils ont formé une critique utile quant à savoir si de tels tests devraient être offerts ou non; ce qui est plus important encore, ils ont offert des directives pour informer de manière adéquate et appropriée ceux et celles qui doivent prendre cette décision. Cet article clarifie les procédés de rhétoriques utilisée dans leurs énoncés de politiques, d'une part par les communautés de personnes handicapées, et d'autre part par la communauté médicale, afin de structurer la discussion à propos du dépistage et des tests génétiques prénataux. L'analyse qualitative qui est employée ici permet de concentrer notre

attention sur la façon qu'on ces parties prenantes d'imiter et d'interagir avec les débats sur l'avortement, tout particulièrement lorsqu'ils utilisent le langage du choix. Maintenant que la communauté médicale développe de nouvelles directives de pratique et de mise en œuvre pour les technologies génétiques émergentes dans les soins prénataux, les organisations pour la défense des droits des personnes handicapées se trouvent idéalement placées pour relancer ces conversations. Les énoncés de politiques peuvent aider à rallier les alliés à cette cause, et à rendre plus actifs dans la sphère publique les études critiques sur le handicap ainsi que les perspectives des organisations pour les droits des personnes handicapées.

Mots-clés: dépistage prénatal; Trisomie 21; politique de santé; autonomie individuelle; modélisation du choix

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Introduction

In the public sphere, the abortion debate has co-evolved with that of prenatal testing; at about the same time as North America began questioning the legality of abortion, genetic testing for Down syndrome entered clinical practice (*Morgentaler v. The Queen*, 1976; Nadler, 1968; *Roe v. Wade*, 1973). Historically, amniocentesis – the “gold” standard for prenatal diagnosis – was only offered to women over the age of 35 because the risk of having a child with Down syndrome increases with age. The procedure has some risk of digit, limb, or even pregnancy loss (Eddleman et al., 2006). Since the 1970s, technological advances have reduced these associated risks, and new medical procedures allow for similar diagnostic capacity using a maternal blood sample (Lo et al., 1998). For some, the results of such testing may shape decisions about pregnancy management.

Arguments in favor and in opposition of the availability of prenatal genetic testing have focused on women’s reproductive choice and ultimately fallen into the discursive strategies used in the ongoing public conversation about abortion. Many pro-life groups object to abortion on moral and philosophical grounds, affording rights to a fetus that the state should protect; conversely, pro-choice advocates argue that a pregnant woman’s rights trump any that might be afforded to a fetus. This polarized debate raises questions about whether abortion should be legally allowed and whether public funds ought to support such services.

The moral and political issues related to abortion can become distractions from the alternative, yet pressing questions of whether prenatal genetic screening and testing should be offered and, if so, how and what procedures should be offered. They also raise related questions

about who ought to be offered such testing, when, for what purpose, and for whose benefit. At the intersections of clinical practice and public health, such questions bring to the foreground broader issues about access to healthcare services, as well as social expectations about family and parenting.

Building upon previous scholarly works that have looked at the bioethical and rhetorical dimensions of prenatal genetic testing (Lippman & Wilfond, 1992; Potter et al., 2008; Press & Browner, 1994; Seavilleklein, 2009; Wilkinson, 2008), this paper extends this conversation by taking into consideration key stakeholders. As Varvasovszky and Brugha (2000) describe in relationship to health policy and planning, stakeholders are actors who have an interest, are affected, or can influence a particular issue. Due to their differing characteristics, I have selected the disability and medical communities. Both share interest in this issue and policy will impact both; however, disability communities have less power in decision-making than their medical counterparts. Clinical practice guidelines inform practice and policies. In contrast, the disability communities' position statements most notably impact practice via prospective parents (i.e., prospective parents receive such messages through the media, critically assess the issues at stake, and may be compelled to take personal action). The disability and medical communities hold seemingly oppositional positions: the medical communities support current practice, while the disability communities oppose it. I utilize the plural term "communities" to describe both disability communities and medical communities in order to acknowledge the diversity within each broad category. For example, the disability communities include people with disabilities (both with and without prenatally identifiable conditions), their families, disability rights activists, and their allies. On the other side, the medical communities include physicians (both those with specialized genetic training and those without), allied health professionals, healthcare

policymakers, and healthcare insurers and payers. Thus, these communities' policy statements reflect a variety of positions related to prenatal testing. This embedded diversity of attitudes and opinions, particularly as projected to a public audience, is central to my analysis.

The purpose of this paper is to explore how these key stakeholders use the language of choice. This analysis shows that both disability and medical communities trade on this language to subtly persuade their readers, particularly those who may hold differing political and/or ethical positions. By evoking multiple meanings of choice in their statements, they promote their ideological perspectives. The disability communities frame the issues through a lens of "informed choice," while the medical communities use a lens of healthcare consumerism, suggesting that patients have a range of options to choose as they wish. These deliberate word selections build upon the ever-present yet tacit conversation about abortion. The analysis identifies strategies that these stakeholders should implement in policy statements, given that both emerging technologies and current practice warrant new guidance.

Methods

Text Selection

I examine the debate between the disability and medical communities using a purposive sample of policy statements. Both the disability and medical communities represent stakeholders in the matter of prenatal genetic screening and testing. Disability communities are diverse with regards to political and religious viewpoints and are not explicitly asking whether or not abortion should be legal, but rather whether individuals ought to be able to choose the traits of a particular fetus, or more precisely – given current technologies – to choose *against* certain traits. I have selected the medical communities because they remain the gatekeeper of pregnancy termination services and a valued profession with disciplinary power.

By design, policy statements represent a collective of opinions for their respective groups. I make no assertion that such texts provide a representative account of all people with disabilities or all medical professionals. Nonetheless, these documents convey a specific point-of-view. These texts are not direct responses to each other; in fact, the disability communities' statements likely do not intend to counter that of the medical communities' or vice versa (e.g., the disability communities may have never read clinical practice guidelines about prenatal testing, or alternatively, the authors of the clinical practice guidelines may have never heard the messages of the disability communities). While these statements are displayed publicly and intended for a general audience, I suspect that the messages they convey are insulated rather than truly shared and exchanged. For the most part, the public gains access to these policy statements not directly, but rather filtered through the media or in how they inform clinical practices that impact patient care.

Disability Rights Organization's Policy Statement

To explore the disability communities' perspective on genetic testing, I use the Disabled People's International (DPI) policy statement entitled *Disabled People Speak on the New Genetics* (2000). DPI is a network of disabled persons' organizations that aims to promote the human rights of disabled persons by encouraging economic and social integration, representing constituents from 130 countries (Disabled People's International [DPI], 2012). I selected this organization because of its cross-disability support, as opposed to a disability-specific organization, such as the Global Down Syndrome Foundation. While the topic of "new genetics" addresses issues related to genetic research and genetic technologies generally, the text provides specific language regarding prenatal screening and testing. This text provides little explanation about these perspectives so I supplement this primary text with work from disability rights

advocates and Disability Studies scholarship. Feminist Disability Studies scholar Asch (1999) highlights a critical evaluation of the offer of prenatal testing is necessary to promote reproductive autonomy, including legal abortion; in doing so, she crafts a critique of prenatal testing that is distinct from a pro-life stance. Broadly, Disability Studies scholarship advocates for reproductive autonomy (Klein, 2011; Ormond, Gill, Semik, & Kirschner, 2003; Piepmeier, 2013; Saxton, 2006), including critical discussion about the implications for the meanings of family (Ginsburg & Rapp, 2013; Kent, 2000; Kittay & Kittay, 2000).

Clinical Practice Guidelines

In order to see how the medical communities have responded to the demands of disability communities, I use the Clinical Practice Guidelines of the Canadian College of Medical Geneticists (CCMG) and the Society of Obstetricians and Gynaecologists of Canada (SOSG) entitled *Canadian Guidelines for Prenatal Diagnosis* (Canadian College of Medical Geneticists and Society of Obstetricians and Gynaecologists of Canada [SOSG], 2001). The Society of Obstetricians and Gynaecologists of Canada is a foundation that supports education, research, and women's healthcare.

I also use the American Congress of Obstetricians and Gynecologists (ACOG) news releases related to this topic entitled *ACOG's Screening Guidelines on Chromosomal Abnormalities What They Mean to Patients and Physicians* (American College of Obstetricians and Gynecologists Office of Communications [ACOG], 2007, May) and *New Recommendations for Down Syndrome: Screening Should Be Offered to All Pregnant Women* (ACOG, 2007, January). ACOG is a non-profit advocacy organization comprised of women's healthcare physicians. I chose to examine this web-based communication as a primary text because of its

accessibility to the public, supplementing these texts with the practice guideline only available to members and those with subscriptions to the organization's journal, *Obstetrics & Gynecology*.

It is worth noting that medical professionals with specialized genetic training contributed to developing both sets of clinical practice guidelines. As Davis (2010) notes, genetic specialists – perhaps even more than other health professionals – hold autonomy with high regard. Davis suggests that this focus is at least in part due to the fact that the medical genetics community understands its historical connection to eugenics. Within the field, the focus on patient autonomy has led to the development of two central tenets: value-neutrality and nondirective counseling. Taken together, the value of a decision is solely based upon what is right for that particular patient, and providers should not try to influence a decision (Davis, 2010). While these fundamental tenets underpin these practice guidelines, they may have little significance to the majority of providers who do not have specialized genetic training but are involved with the delivery of information about prenatal tests.

Data Analysis

With the intent to provide both grounded and practical insights, this research addresses issues of language, power, and context. Discourse analysis is a qualitative research method that illuminates the ways in which language encapsulates values that reveals how language enacts particular perspectives and creates situated meanings (Gee, 2010). By examining texts with a set of guiding questions to interrogate the use of language, the analysis employed a form of directed content analysis (Hsieh & Shannon, 2005). Using ATLAS.ti 7™, the analysis explored the work of disability and medical communities' statements differentiate their interests and claims from the abortion debate.

Discussion & Interpretation

Extending Choice

Within North America between 1960 and 1985, the public discourse articulated both motherhood and abortion as a “choice” (Condit, 1990). The language of choice surfaces in these texts about prenatal genetic screening and testing; however, the stakeholders extend the meaning of choice, embedding it within larger conversations about autonomy and consumerism.

By appealing to an expanded conceptualization of choice, DPI may have been attempting to re-direct the public discourse away from abortion debates. DPI (2000) describes prenatal testing as lacking “informed choice” and suggesting “no free choice” can occur within the current medical context (p. 6). This understanding of choice is implicitly connected to bioethical understandings about autonomy, which outline that voluntariness, understanding, recommendation, and authorization are some of the key elements of informed consent (Beauchamp & Childress, 1994). Consistent with other Disability Studies scholarship (e.g., Asch & Wasserman, 2005; Bérubé, 1998), DPI suggests that medical practice fails to provide complete and accurate information about disability (understanding) and that society offers inadequate social supports for many families to raise a child with a disability (voluntariness). While bioethics specifically uses the term informed consent, DPI (2000) substitutes consent with choice:

With respect to the impact of genetics on reproduction, we support women’s right to choose with respect to their pregnancies. However, we deplore the context in which these choices are made. There is no *informed choice* [emphasis added] as long as genetic counseling is directive and misinforms parents about the experience of disability. There can be no free choice as long as myths, fears, stereotypes of and discrimination against disabled people continues. There is no free choice if women are under social pressure to accept routine tests. There can be no real choice until women feel able to continue with a pregnancy knowing that they will be bringing their child into a welcoming society that provides comprehensive systems of support (p. 6).

DPI's rhetorical construction centers prenatal testing as a conversation about autonomy more than about reproductive choices. They frame their argument to question prospective parents' freedom to choose to accept or reject genetic testing independently of any decisions about pregnancy management. DPI indirectly acknowledges the evidence suggesting that knowledge about a particular trait itself *does* change prospective parents' desire for their future baby, with 92% and 58% of prospective parents terminating a pregnancy following a definitive diagnosis of Down syndrome and Klinefelter syndrome, respectively (Mansfield, Hopfer, & Marteau, 1999). The implicit question DPI raises is whether such information *should* have such an impact and why.

DPI (2000) critiques multiple elements of informed consent throughout their policy statement. They argue that: most clinicians have a limited understanding about living with disability; stereotypes about disability further limit prospective parents' understanding about whether or not to accept prenatal testing; social pressure to accept routine prenatal testing is coercive; and disability discrimination may make prospective parents feel unable to knowingly continue pregnancy and feel ill-equipped to raise a disabled child. This rhetorical shift to informed choice is a useful strategy to create discursive space for pro-choice allies.

The SOGC practice guidelines and ACOG news releases do not explicitly use the word "choice." SOGC (2001) does describe program-level choices, "Different programs may choose different cut-offs [age-related risk calculations by which to determine whether amniocentesis would be offered] depending on local resources" (p. 3). This suggests a community-centered approach, implying flexibility between providers. While ACOG removes the language of choice, they nonetheless address the substantive issues of informed consent that DPI poses. They are explicit that such screening is not required or even a recommendation. To illustrate this, ACOG

(2007, May) quotes Dr. Driscoll, the primary author of the Practice Bulletin and an obstetrician-gynecologist (who also has certifications in medical genetics):

We are not recommending that all pregnant women be screened but rather we are recommending that all pregnant women be *offered* screening. Physicians are ethically obligated to fully inform our patients of their healthcare options, including prenatal testing. It is entirely up to the patient whether or not she wishes to be screened for fetal chromosomal abnormalities without judgment from their physician (para. 5; emphasis in original).

ACOG asserts that prenatal testing involves decision-making on the part of each individual patient. Both SOGC and ACOG explicitly recognize an extension of choice beyond that of the abortion debate. SOGC suggests a consumer-driven choice, and ACOG stipulates that their change in the practice guidelines affords women with a greater range of options. In this manner, these medical communities draw upon values about healthcare consumerism, where choice implies the consumer's ability to choose whichever tests from a range of healthcare services.

DPI may have reservations about the *offer* of prenatal testing that ACOG proposes, especially given the pressures that may accompany it. While DPI actively engages the language of choice, both SOGC and ACOG successfully evade its use. ACOG discusses informed consent at least minimally by acknowledging some of the bioethical issues at stake, but SOGC does not specifically address these.

Murky Metaphors

DPI uses explicit metaphors connecting genetics to eugenics and to mass destruction. The repetitive use of genetics in conjunction with strategically placed references to elimination, manipulation, and human rights violations blurs any preconceived notion of genetics as distinct from eugenics. While they make no attempt to define eugenics, they capture the underpinning values of eugenics. In particular, they try to take the negative association with eugenics and import it into the conversation about such testing. DPI (2000) only uses the word "eugenics"

twice (on pages 3 and 5) – but these more subtle rhetorical connections are perhaps more effective:

Human genetics poses a threat to us because while cures and palliatives are promised, what is actually being offered are genetic tests for characteristics perceived as undesirable. This is not about treating illness or impairment but about eliminating or manipulating foetuses which may not be acceptable for a variety of reasons. These threaten our human rights (p. 3).

DPI suggests that if the purpose of prenatal screening is to eliminate particular fetuses, then the practice of such screening sends the message that the lives of people with disabilities are not worth living; they imply that our human rights are threatened when diversity is neither valued nor tolerated. They highlight that genetic testing provides a mechanism to identify differences in order to be eliminated: “What we do oppose is genetic cleansing, driven by profit motive and social efficiency, informed by prejudice against disabled people and carried out in the name of cure or treatment” (DPI, 2000, p. 5). DPI conveys a variant of ethnic cleansing, where disability is analogous to ethnicity. Of particular significance is the notion that a powerful social group tries to eliminate another less powerful group; however, they strategically avoid explicit reference to the actors.

Consistent use of first-person, plural pronouns may help the audience identify with the victim, and then the audience can substitute a social player of any kind (i.e., biomedicine, economics, politics, etc.) as the agent with power. This rhetorical move is different from traditional metaphors of pro-life advocates who liken individual doctors to Nazi war criminals (Smith, 1995). The ambiguous actors leave interpretation to the audience, which may be a useful strategy. From within this rich discursive space, most people can identify a powerful actor and an oppressed one. In this manner, DPI focuses on genetic testing and its implications rather than the implications of pregnancy termination. Specifically, they highlight how genetic testing identifies

traits perceived as undesirable with the intent to eliminate or to manipulate, as opposed to abortion rhetoric that often frames women or doctors in a negative light.

DPI (2000) also makes a direct association to nuclear power, stating

Nuclear energy is a source of life and a cause of death. If given an opportunity to express their opinion surely the victims of Nagasaki or Chernobyl would have fought for stricter regulation of the practical use of that new scientific knowledge. The same is true of the revolutionary developments in human genetics (p. 3).

While DPI makes explicit connections to the atomic bombings of Hiroshima and Nagasaki during World War II, DPI leaves some ambiguity and does not define either the victims or the agents with control of the genetics. As such, DPI creates a recurrent theme for the need of social responsibility in science that again situates their concern on the social dimensions that may make genetics problematic, rather than individual actors or individual choices.

The medical communities use implicit or unintended metaphors. Neither ACOG nor SOGC adopt any of DPI's metaphors. They also do not take the opportunity to acknowledge any social factors that may make genetic testing or the offer of such testing problematic. Likely trying to differentiate between tests that identify *risk* for a particular condition (i.e., screening) from tests that identify *specific* genetic traits, ACOG (2007, January) avoids using the term "genetic testing" and instead, they consistently use "screening":

According to the new guidelines, the goal is to *offer screening tests* with high detection rates and low false positive rates that also provide patients with diagnostic testing options if the *screening test* indicates that the patient is at an increased risk for having a child with Down syndrome (para. 5; emphasis added).

In contrast, SOGC (2001) attempts to avoid using metaphorical language by defining terms at the outset: "These guidelines apply to non-invasive screening techniques (including maternal serum screening and ultrasound) and to invasive techniques (including amniocentesis and chorionic

villus sampling)” (p. 2). Perhaps unintentionally, the medical communities fail to recognize the metaphors at play when using the term screening.

At its core, screening is about identifying and examining particular characteristics, but in definition, the purposes have evolved. Historically, the purpose of screening was to separate out and remove the unwanted (like with gold or coal). The idea of separating out and removing the unwanted is exactly the message DPI suggests is morally questionable in relationship to prenatal tests.

According to Morabia and Zhang (2004), the United States Army implemented one of the earliest screening programs in 1917, using paper-based tests to identify potential recruits with psychiatric conditions as unfit for service. Nowadays, screening has become ubiquitous with healthcare; such that most people understand the purpose is to identify health conditions in people without signs or symptoms with the hopes of early treatment and management.

The medical communities draw upon what have become familiar discourses related to cervical cancer (e.g., a Pap smear) and/or sexually-transmitted infection screenings (e.g., HIV testing), and their words reflect this dominant understanding: “ACOG revised its guidelines that now recommend offering *fetal chromosomal screening to all pregnant women, regardless of age*, because of improvements in low-risk, *noninvasive screening methods*” (2007, May, para. 1; emphasis added). Similarly, SOGC (2001) states, “maternal age alone is a relatively *poor predictor of fetal chromosomal abnormalities*. Where facilities exist for additional *screening methods*, such as *maternal serum screening*, estimation of risk based on maternal age in isolation may not be appropriate” (pg. 2; emphasis added).

ACOG’s use of “screening to all pregnant women” might be viewed as an appeal to justice. This may be a useful rhetorical strategy, as the appeal to this distinct moral principle

relates to different issues (i.e., autonomy relates to the decision to have a genetic test, whereas justice relates to access to the test). More central to this issue, however, is the public's understanding of screening; in particular, what is the benefit of screening? With cancer screening, the purpose is to identify cancer early, so that intervention (e.g., chemotherapy or tumor removal) is possible; alternatively, with sexually-transmitted infection screening, the purpose is to identify the condition to begin treatment. Even in the absence of available cures, preventing transmission (e.g., mother-to-child, partner-to-partner) is an understood benefit. Particularly in a public sphere, the medical communities' use of the term screening in relationship to prenatal genetic testing may be problematic, because screening and prevention in this arena implies eliminating undesirable traits and preventing the lives of those with such traits.

Missing Action

At present, there is no cure or treatment for a prenatal genetic diagnosis. The most recognizable benefit gained from testing is knowledge. Knowledge gained can reassure prospective parents about a "healthy" future child, give time to prepare for a child with a disability, or provide the opportunity to interrupt the pregnancy. The medical communities likely do not want to convey the message that pregnancy termination is even a potential benefit. As a profession, obstetricians and gynecologists are intimately involved with family planning and pregnancy management, including pregnancy termination. Given the contentious political-legal environment, practice guidelines may be reluctant to address abortion. Some may fear that such attention might ultimately constrain access to abortion services.

SOGC makes no reference to abortion as a potential action following these prenatal genetic tests. Similarly, ACOG circumvents any discussion about pregnancy termination and

makes no reference to abortion in these news releases. Thus, these medical communities present screening for fetal chromosomal abnormalities as quite separate from pregnancy termination.

The news releases are intended for a broad public audience with a diversity of beliefs and values held about both prenatal testing and abortion, so ACOG's representation is likely appropriate. However, if the potential relationship between prenatal testing and abortion is not conveyed, then the public is largely dependent upon patient-clinician interactions to make this connection. Unfortunately, this approach may not promote education about the practice of prenatal testing. As Rapp (1996) discusses in relationship to "positive" genetic diagnoses using amniocentesis, some prospective parents may misinterpret or misunderstand this tacit connection between screening and pregnancy termination.

Not only is the word "abortion" unsaid, ACOG substitutes "20th week of pregnancy" to address legal implications associated with the offer. Given the time needed to obtain results from invasive testing, the 20th week of pregnancy encroaches on the beginning of many states' restrictions of pregnancy termination. For example, the original news release highlights:

The new ACOG guidelines recommend that all pregnant women consider less invasive screening options for assessing their risk for Down syndrome, a common disorder that is caused by an extra chromosome and can result in congenital heart defects and mental retardation. Screening for Down syndrome should occur before the *20th week of pregnancy*" (ACOG, 2007, January, para. 2; emphasis added).

They use this tactic in the subsequent news release, as well. While this may help to distance their guidelines from some audience members, they also seemingly decontextualize relevant facts about prenatal genetic testing. Specifically, they do not acknowledge that such testing can lead prospective parents towards a series of pregnancy decisions that may result in pregnancy termination. Press and Browner (1997) discuss how many pregnant women understand routine prenatal care, including prenatal genetic screening, as beneficial. In fact, many believe that such

care helps to ensure a healthy baby. Additionally, Press and Browner (1994) suggest that the topic of abortion is absent from patient education materials. Rather than obscuring the potential connection between such testing and pregnancy management decisions, I argue that ACOG should make greater efforts to develop and to promote health education related to prenatal testing and to further respond to DPI's critiques about physicians failing to fully inform patients.

Not surprisingly, DPI references abortion. The repeated and strategic use of the word "choice" may implicitly bring to mind abortion rhetoric, and their use of the word "abortion" may further substantiate the connection. Most of this usage specifically refers to the current legal status of such services. For example, "We are threatened by abortion laws which discriminate against the birth of disabled children" (DPI, 2000, p. 4). This explicit connection between abortion and law may be particularly problematic for those concerned about preserving the availability of legal abortions. If DPI aims to promote further public discussion about whether or not the practice of prenatal testing should continue as is, then perhaps using the word "abortion" in conjunction with "law" should be limited. This language use may surface underlying fears about altering the legal status of abortion laws, which may alienate audience members who are sympathetic to their interests. Furthermore, those reluctant to draw attention to politically susceptible abortion laws may not engage in dialogue about prenatal testing.

Conclusions

Given the ever-growing availability of genetic testing, including the application of cell-free fetal DNA analysis (Hahn & Holzgreve, 2002), this realm of public policy will become increasingly important to healthcare and public health. Committee opinions about non-invasive methods of prenatal genetic diagnosis have been recently published (Devers et al., 2012; Langlois, Brock, & Genetics Committee, 2013; Schaefer & Mendelsohn, 2013), so it is

foreseeable that medical communities craft new practice guidelines within a short timeline. This creates an opportunity for disability rights organizations to draft policy statements addressing these new technologies. Even if such statements are completely disregarded by existing medical establishments, connecting with the general public may create opportunities to educate others about disability, to identify new allies wary of mass implementation and widespread adoption of prenatal genetic testing, or to develop critical consumers aware of the potential erosion of informed healthcare choices. In so doing, disability communities ensure their representation as a stakeholder in this ongoing public issue.

By directing the conversation to address specific issues at stake with prenatal genetic testing, disability communities can help to continue providing more balanced coverage of disability representations to the public and to guide clinical practice. However, much of the critiques of prenatal testing have come from disability-specific organizations. Given that emerging technological advances allow prenatal tests to identify a wider range of genetic conditions, I think that future recommendations should increasingly reflect cross-disability alliances. Coordinated, unified efforts – across disability communities and with allies – are needed to influence this public conversation. This analysis suggests that disability communities must delve into precisely how clinicians are misinforming or not providing informed consent in order to highlight mechanisms to improve upon current practice. Additionally, disability communities have to make efforts to engage directly with prospective parents who may need and want the information that only disability communities can provide. Publishing position statements on the Internet alone is insufficient; efforts must be made to enter mass media, including newspapers, health education materials, radio, etc. In order to make a public case for diversity, disability communities need to engage with local healthcare systems, media outlets,

and beyond. By utilizing multiple mechanisms, disability communities can help to transform a private, patient-provider encounter into a public conversation. I contend that this is the best way to enhance reproductive autonomy and to further promote disability as valued diversity.

Through examining policy statements, this analysis reveals how the deliberate word choices may also re-shape conversations about abortion. The disability and medical communities actively extend the notion of choice beyond that of abortion rhetoric. Disability communities transform informed consent into informed choice, while medical communities focus the conversation on healthcare consumerism. By drawing upon this notion of healthcare consumerism, future policy statements from disability communities may want to make space to address other related, but equally relevant issues, like home- and community-based services, disability representations in health education materials, and education and employment opportunities. These issues can constrain prospective parents' understandings about the capability of a child with a disability, and they also build upon the notion that individuals should have a range of available options (e.g., not only the option to choose a child with a disability, but also the option to raise such a child in their own home and community; disability representations that show people with disabilities flourishing in their lives, rather than predominantly focused on cures and treatments; people with disabilities who have equal access to a diverse set of education and employment opportunities as their peers without disabilities).

While the medical communities did not adopt this language of choice, some address the issue of informed consent. However, they do not readily address the relationship between prenatal genetic testing and pregnancy management. In this rhetorical move, they neglect the disability communities' critique that a woman's choice to have or not have prenatal genetic testing should reflect what parents think is the purpose of testing. Disability communities use

mixed-metaphors, which creates multiple opportunities to engage their audience, and given that the audience likely comes from diverse political and moral backgrounds, this technique may be a useful strategy. On the other side, medical communities, perhaps unintentionally, use the word “screening,” which taps into multiple meanings – given their equally diverse audience, this may prove to be problematic. The notion of screening with the purpose to eliminate elevates the existing concerns of disability communities. I would not say that the word “screening” is itself the problem, but rather I contend that medical communities should be more transparent about the potential connection between such prenatal tests and pregnancy management choices. While I recognize that medical communities may be reluctant to address abortion head-on in a practice guideline, its absence suggests that the information available during decision-making is vague; excluding abortion from the practice guideline fuels existing concerns about public misunderstandings and constrained reproductive choices. Medicine is a model for other health professionals and possesses the power to influence policy, practice, and patient education. Therefore, I would argue that medical communities have a responsibility to the public to be open about abortion. While this may initiate unwanted public conversations about reproductive autonomy, I think it also presents an opportunity to ensure that practice guidelines reflect the need for providers to discuss with their patients that pregnancy termination is a potential outcome of such testing.

By looking at the rhetoric of both the disability and medical communities together, we see that public conversations about prenatal genetic testing are notably complex. Both groups are similarly entangled in multiple discourses and perhaps unintentionally engaged in issues unrelated to the task of their policy statements. Those trying to convey messages about prenatal genetic testing to the public need to be mindful not just of the science, but also of the rhetorical

elements at play – particularly how the rhetoric provides a connection to values and assumptions that likely influence the way in which the audience interprets what is being said. Careful use of language can help to navigate the competing discourses and to realize shared values in order to answer fundamental questions: should prenatal genetic testing be offered, for which conditions, and if so, how?

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References

American College of Obstetricians and Gynecologists Office of Communications. (2007, May

7). ACOG's screening guidelines on chromosomal abnormalities what they mean to patients and physicians [Press release]. Retrieved from <http://www.acog.org/About-ACOG/News-Room/News-Releases/2007/ACOGs-Screening-Guidelines-on-Chromosomal-Abnormalities>

American College of Obstetricians and Gynecologists Office of Communications. (2007, January

2). New recommendations for Down syndrome: Screening should be offered to all pregnant women [Press release]. Retrieved from <http://www.acog.org/About-ACOG/News-Room/News-Releases/2006/New-Recommendations-for-Down-Syndrome>

Asch, A. (1999). Prenatal diagnosis and selective abortion: A challenge to practice and policy.

American Journal of Public Health, 89(11), 1649-1657. doi:10.2105/AJPH.89.11.1649

Asch, A., & Wasserman, D. (2005). Where is the sin in synecdoche? Prenatal testing and the

parent-child relationship. In D. T. Wasserman, R. S. Wachbroit, & J. E. Bickenbach (Eds.), *Quality of life and human difference: Genetic testing, health care, and disability* (pp. 172-216). New York, NY: Cambridge University Press.

Beauchamp, T. L., & Childress, J. F. (1994). *Principles of biomedical ethics*. New York, NY:

Oxford University Press.

Bérubé, M. (1998). *Life as we know it: A father, a family, and an exceptional child*. New York,

NY: Vintage Books.

Canadian College of Medical Geneticists and Society of Obstetricians and Gynaecologists of

Canada. (2001). Canadian guidelines for prenatal diagnosis: Genetic indications for prenatal diagnosis. *Journal of Obstetrics and Gynaecology Canada, 105*, 1-7.

Condit, C. M. (1990). *Decoding abortion rhetoric: Communicating social change*. Chicago, IL: University of Illinois Press.

Davis, D. S. (2010). *Genetic dilemmas: Reproductive technology, parental choices, and children's futures*. New York, NY: Oxford University Press.

Devers, P. L., Cronister, A., Ormond, K. E., Facio, F., Brasington, C. K., & Flodman, P. (2012). Noninvasive prenatal testing/noninvasive prenatal diagnosis: The position of the national society of genetic counselors. *Journal of Genetic Counseling*, 22(3), 1-5.
doi:10.1007/s10897-012-9564-0

Disabled People's International. (2000). *Disabled persons speak on the new genetics* (Report). Retrieved from http://www.dpi-europe.org/bioethics_issues/bioethics_issues/bioethics-english.pdf

Disabled People's International. (2012). *Welcome to Disabled People's International: Nothing about us without us* [Webpage]. Retrieved from <http://www.dpi.org>

Eddleman, K. A., Malone, F. D., Sullivan, L., Dukes, K., Berkowitz, R. L., Kharbutli, Y., ... D'Alton, M. E. (2006). Pregnancy loss rates after midtrimester amniocentesis. *Obstetrics and Gynecology*, 108(5), 1067-1072. doi:10.1097/01.AOG.0000240135.13594.07

Gee, J. P. (2010). *An introduction to discourse analysis: Theory and method*. New York, NY: Routledge.

Ginsburg, F., & Rapp, R. (2013). Enabling disability: Rewriting kinship, reimagining citizenship. In L. J. Davis (Ed.), *The disability studies reader* (4th ed., pp. 185-201). New York, NY: Routledge.

Hahn, S., & Holzgreve, W. (2002). Prenatal diagnosis using fetal cells and cell-free fetal DNA in

- maternal blood: What is currently feasible? *Clinical Obstetrics and Gynecology*, 45(3), 649-656. doi:10.1097/01.GRF.0000024301.19473.DE
- Hsieh, H., & Shannon, S. (2005). Three approaches to qualitative content analysis. *Qualitative Health Research*, 15(9), 1277-1288. doi:10.1177/1049732305276687
- Kent, D. (2000). Somewhere a mockingbird. In E. Parens & A. Asch (Eds.), *Prenatal testing and disability rights* (pp. 57-63). Washington, DC: Georgetown University Press.
- Kittay, E. F., & Kittay, L. (2000). On the expressivity and ethics of selective abortion for disability: Conversations with my son. In E. Parens & A. Asch (Eds.), *Prenatal testing and disability rights* (pp. 165-195). Washington, DC: Georgetown University Press.
- Klein, D. A. (2011). Medical disparagement of the disability experience: Empirical evidence for the “expressivist objection.” *American Journal of Bioethics Primary Research*, 2(2), 8-20. doi:10.1080/21507716.2011.594484
- Langlois, S., Brock, J.-A., & Genetics Committee. (2013). Current status in non-invasive prenatal detection of Down syndrome, trisomy 18, and trisomy 13 using cell-free DNA in maternal plasma. *Journal of Obstetrics and Gynaecology Canada*, 35(2), 177-181.
Retrieved from <http://sogc.org/wp-content/uploads/2013/04/gui287CPG1302E.pdf>
- Lippman, A., & Wilfond, B. S. (1992). Twice-told tales: Stories about genetic disorders. *The American Journal of Human Genetics*, 51(4), 936-937.
- Lo, Y., Tein, M., Lau, T., Haines, C., Leung, T., Poon, P., . . . Hjelm, N. (1998). Quantitative analysis of fetal DNA in maternal plasma and serum: Implications for noninvasive prenatal diagnosis. *The American Journal of Human Genetics*, 62(4), 768-775.
doi:10.1086/301800
- Mansfield, C., Hopfer, S., & Marteau, T. M. (1999). Termination rates after prenatal diagnosis of

- Down syndrome, spina bifida, anencephaly, and Turner and Klinefelter syndromes: A systematic literature review. *Prenatal Diagnosis*, 19(9), 808-812. doi:10.1002/(sici)1097-0223(199909)19:9<808::aid-pd637>3.0.co;2-b
- Morabia, A., & Zhang, F. (2004). History of medical screening: From concepts to action. *Postgraduate Medical Journal*, 80(946), 463-469. doi:10.1136/pgmj.2003.018226
- Morgentaler v. The Queen, 1 S.C.R. 616 (1976). Retrieved from <https://scc-csc.lexum.com/scc-csc/scc-csc/en/item/2684/index.do>
- Nadler, H. L. (1968). Antenatal detection of hereditary disorders. *Pediatrics*, 42(6), 912-918.
- Ormond, K. E., Gill, C. J., Semik, P., & Kirschner, K. L. (2003). Attitudes of health care trainees about genetics and disability: Issues of access, health care communication, and decision making. *Journal of Genetic Counseling*, 12(4), 333-349. doi:10.1023/A:1023953022290
- Piepmeyer, A. (2013). The inadequacy of “choice”: Disability and what’s wrong with feminist framings of reproduction. *Feminist Studies*, 39(1), 159-186. Retrieved from <http://hdl.handle.net/2027/spo.0499697.0039.109>
- Potter, B. K., O'Reilly, N., Etchegary, H., Howley, H., Graham, I. D., Walker, M., . . . Wilson, B. J. (2008). Exploring informed choice in the context of prenatal testing: Findings from a qualitative study. *Health Expectations*, 11(4), 355-365. doi:10.1111/j.1369-7625.2008.00493.x
- Press, N., & Browner, C. (1994). Collective silences, collective fictions: How prenatal diagnostic testing became part of routine prenatal care. In K. H. Rothenberg & E. J. Thomson (Eds.), *Women and prenatal testing: Facing the challenges of genetic technology* (pp. 201-218). Columbus, OH: Ohio State University Press.
- Press, N., & Browner, C. H. (1997). Why women say yes to prenatal diagnosis. *Social Science &*

- Medicine*, 45(7), 979-989. doi:10.1016/S0277-9536(97)00011-7
- Rapp, R. (1996). The power of “positive” diagnosis: Medical and maternal discourses on amniocentesis. In D. Bassin, M. Honey, & M. M. Kaplan (Eds.), *Representations of motherhood* (pp. 204-219). New Haven, CT: Yale University Press.
- Roe v. Wade, 410 U.S. 113 (1973). Retrieved from <http://www.law.cornell.edu/supremecourt/text/410/113>
- Saxton, M. (2006). Disability rights and selective abortion. In L. J. Davis (Ed.), *The disability studies reader* (2nd ed., pp. 105-116). New York, NY: Routledge.
- Seavilleklein, V. (2009). Challenging the rhetoric of choice in prenatal screening. *Bioethics*, 23(1), 68-77. doi:10.1111/j.1467-8519.2008.00674.x
- Smith, L. (1995, May 3). Antiabortion group's leaflets liken doctors to war criminals. *The Washington Post*, p. 3. Retrieved from <http://www.lexisnexis.com>
- Schaefer, G. B., & Mendelsohn, N. J. (2013). ACMG statement on noninvasive prenatal screening for fetal aneuploidy. *Genetics in Medicine*, 15(5), 395-398. doi:10.1038/gim.2013.29
- Varvasovszky, Z., & Brugha, R. (2000). How to do (or not to do) . . . A stakeholder analysis. *Health Policy and Planning*, 15(3), 338-345. doi:10.1093/heapol/15.3.338
- Wilkinson, S. (2008). “Eugenics talk” and the language of bioethics. *Journal of Medical Ethics*, 34(6), 467-471. doi:10.1136/jme.2007.021592