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LETTER FROM THE EDITOR

Disability, Medicine, and Ethics

If we are to understand the current relationship between the disability community and the medical community, we must turn to history. People with disabilities have long faced discrimination, some of it at the hands of medical professionals.

In the United States, as part of the eugenics movement, forced sterilization of those with disabilities was ruled constitutional by the US Supreme Court in 1927 in *Buck vs. Bell* and remained legal in some states until 2003 [1]. Eugenic efforts in the United States would eventually be used as models for the radical application of eugenic ideas in Nazi Germany [2], which sterilized and euthanized persons with disabilities.

Another well-known major act of discrimination against people with disabilities was their widespread institutionalization. From the mid-nineteenth century until the 1960s, it was normal practice to isolate and segregate individuals with disabilities in institutions [3], which became infamous for mistreating those in their care [4].

At the same time, medicine has also made essential advances in the treatment of individuals with disabilities. In some cases, medicine has even greatly extended the lifespan of people with disabilities. For example, the average lifespan of individuals with Down syndrome has risen from around 25 years in the 1980s to 60 today, due to multiple medical advances, including advances in open-heart surgery for congenital heart defects [5].

Despite medical advances in the care of individuals with disabilities, tensions between the disability community and the medical community remain. Ultimately, one could argue that it is the medical community—by distinguishing “normal” from “abnormal”—that sets the foundation for broader social and cultural expressions of discrimination against people with disabilities. For this reason, the medical community has been accused of assigning lesser value to the lives of those with disabilities [6, 7].

Tensions between the disability and medical communities can be better understood by examining differences between the medical and social models of disability. The medical model of disability, which is still largely accepted in the medical community, views disability as a pathology and thus as something to be treated or cured. Rather than viewing disability as a problem to be solved, the social model views disability as diversity to be valued. The social model of disability suggests that disability is largely socially

situated or constructed, rather than caused by the individual's attributes [8]. This model separates impairment from disability; the term "impairment" is used to describe the body, such as the lack of a limb or the dysfunction of a particular organ or system, and the term "disability" to refer to the disadvantage caused by social structures rather than the impairment itself [9].

As both a medical student and family member of a person with Down syndrome, I have personal experience with the tensions between the two communities. As a medical student, I have spent hours studying and memorizing the "pathologies" affiliated with disability—attributes that are supposed to be problems in need of cure. As a sibling and self-described disability advocate, I value disability as diversity and can easily describe ways in which it is in fact society, not impairment, that is disabling to many people with disabilities. I am fascinated by medical advances such as cell-free fetal DNA testing but terrified by the ways in which they could be used to promote further discrimination against people with disabilities.

However, I would like to put forth the idea that the medical and disability communities actually have the potential to be exceptional allies. Medicine is poised to support people with disabilities to live the lives they desire based on their personal goals. In order for this to occur, patients with disabilities must feel as though they can discuss any physiologic challenges they face as a result of an impairment without fear of discrimination. Similarly, physicians must be able to appropriately discuss and support patients in addressing socially constructed challenges they face.

In this issue of the *AMA Journal of Ethics*, I have worked with many exceptional authors to address the roles of physicians in balancing the social and medical models of disability. We consider both the role medicine plays in *disabling* and even the smallest ways it could begin to combat this history. The history of institutionalization and eugenics are addressed in this issue. Turning to the modern era, Gareth M. Thomas and Barbara Katz Rothman [examine](#) the use of noninvasive prenatal testing and whether it promotes new eugenic practices.

Undoubtedly, unconscious bias plays a big role in discrimination against any group of people, including those with disabilities. The issue of bias when discussing reproductive health care for women with disabilities is the focus of three articles. In their [case commentaries](#), Stephen Corey and Peter Bulova weigh the risks and benefits of performing a pap smear when the patient does not fully understand the need for the procedure, while Sonya Charles specifically examines the need to obtain assent or consent in such a case. In another [case commentary](#), Kruti Acharya and John Lantos discuss a mother's request for a hysterectomy for her daughter, who struggles to manage her menstrual cycles. Anita Silvers, Leslie Francis, and Brittany Badesch [examine](#) whether women with disabilities should have equal access to reproductive health

services. The issue of bias in reproductive health care also arises when delivering prenatal diagnoses of disabilities. Eva Schwartz and Kishore Vellody address such issues in their [case commentary](#), which examines how to ethically deliver a diagnosis of Down syndrome following prenatal testing and appropriate counseling if the patient requests an abortion.

Medical education may provide an avenue to address unconscious biases toward people with disabilities more broadly. Kerry Boyd [describes](#) McMaster University's Curriculum of Caring, which educates medical students about providing compassionate, person-centered care by incorporating the views and experiences of persons with disabilities.

Not only do many people hold unconscious bias toward individuals with disabilities, but individuals with disabilities, particularly intellectual disabilities, face numerous health care disparities; they often have difficulty finding and accessing appropriate medical care despite their high medical needs [10]. Lyubov Slashcheva, Rick Rader, and Steve Sulkes [make a case](#) for classifying people with disabilities as a medically underserved population.

People with disabilities also frequently face discrimination in the workplace. Yvonne Kellar-Guenther [responds](#) to an article by Carrie Griffin Basas, which argues that workplace wellness programs institutionalize disability bias, by sketching the ideal workplace wellness program.

The legal world also has much to offer in guiding interactions and avoiding discrimination when working with people with disabilities, the most relevant legislation being the Americans with Disabilities Act (ADA) of 1990. Another ethical question that overlaps with the legal realm is about decision-making capacity and types of decision making. Both historically and presently, persons with disabilities tend to be seen as limited in their abilities to make informed health care decisions. However, they simultaneously have the right to be involved in their care. In [the podcast](#), Susan Mizner discusses how we can preserve their autonomy in making health care decisions. Richard Weinmeyer [considers](#) the roles health care organizations must play in preventing injuries that can lead to disability for health care professionals.

Finally, the value of disability is discussed in multiple pieces. George Estreich [discusses](#) the divides that exist between patients with disabilities and their physicians as strategies for bridging them. Janet DesGeroges [provides](#) a parent's perspective on the conflicting pressures parents face when a child is discovered to have hearing loss. Jasmine Zahid [reviews](#) Rosemarie Garland-Thomson's article that argues for disability as a narrative, epistemic, and ethical resource.

This issue of the *AMA Journal of Ethics* only begins to introduce the tensions between the disability community and the medical community. In doing so, it seeks to bring to light some of the concerns of the disability rights movement about the care of individuals with disabilities. I encourage you to continue to explore and discuss how viewing disability as either pathology or as diversity may affect the ways in which we care for our patients with disabilities and how it can influence their health.

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ETHICS CASE

Prenatal Risk Assessment and Diagnosis of Down Syndrome: Strategies for Communicating Well with Patients

Commentary by Eva Schwartz, MD, and Kishore Vellody, MD

Amelia, a third-year medical student who is doing her obstetrics and gynecology rotation, is spending a day in a university abortion clinic. After she has seen several patients and observed a couple of procedures, the attending physician, Dr. K, hands Amelia a chart filled with background information and a handout listing the information she will need to gather and instructs her, "Amelia, please go learn this patient's story and see what kinds of question she has about the procedure."

The first thing Amelia notices when she opens the chart are the words "trisomy 21." She knows well what this means—in addition to her medical training, she has an adult brother with Down syndrome. As she continues to read, she learns that the woman, Victoria, is 33 years old and is 12 weeks pregnant. Victoria has had a long battle with infertility because she has mosaic Turner's syndrome. She has had seven miscarriages but has a one-year-old son at home.

At eight weeks gestation, Victoria had an abdominal ultrasound that showed thickening of the nuchal fold. She subsequently had cell-free fetal DNA testing which indicated she had a high chance of having a child with Down syndrome. Amelia wonders what kind of counseling Victoria received prior to arriving in the abortion clinic, particularly since she has not had a true diagnostic test for Down syndrome, such as a chorionic villus sample, and there were no notes in her health record from any genetic counseling sessions.

Amelia takes a deep breath and knocks on the patient's door. Inside the room, she finds a teary-eyed woman, sitting and holding hands with her husband. When Amelia asks Victoria about her story, she explains, "We were so happy to be pregnant again after having so many miscarriages. It was devastating to learn about the Down syndrome. We just...can't imagine putting that kind of burden on our family."

Amelia responds, "I'm sorry to hear that you've been through so much. I hope that we can provide the support you need." She goes on, "Do you feel as though you have received adequate information about Down syndrome?" Victoria nods, tears streaming down her cheeks; her husband stares at the floor.

Victoria seems to regard the cell-free DNA test as diagnostic of Down syndrome; this worries Amelia, particularly since it seems that she has not received any counseling. She's also concerned that Victoria's and her husband's decision to abort might not be an informed one. Amelia feels some obligation to speak up on behalf of the often-underestimated and undervalued population of people with Down syndrome. She wonders whether to speak to Dr. K and to Victoria and her husband about her concerns, and she wonders what to say.

Commentary

In 2007, the American College of Obstetricians and Gynecologists (ACOG) recommended that all pregnant women, regardless of age, be offered prenatal screening and diagnostic testing for Down syndrome [1]. While Down syndrome can be suspected prenatally based on serologic screening, the diagnosis can only be definitively made using chorionic villus sampling (CVS) or amniocentesis. This distinction between screening and diagnosis applies to the newer cell-free fetal DNA screening, which, while more accurate, is still considered a screening test [2]. Screening tests can yield information about the probability of a potential condition but do not make clear whether the condition is present or determine the condition's severity. So, for pediatricians and family practitioners—and eventually, with the advent of newer screening tests, obstetricians—to communicate effectively with prospective parents, it is essential to both communicate these points and clarify that the identification of trisomy 21 is not in any way a prognosis for the newborn with Down syndrome or for any family members' future quality of life.

As with any major medical decisions involving risk assessment and probabilities, choices about how to proceed with a pregnancy following an unexpected diagnosis require that a patient be offered accurate, objective information about the condition of the fetus and about potential challenges. Such information should be free of value judgments so that patients can make decisions based, as much as possible, on their own values and desires. Most importantly, clinicians must set aside their own personal opinions and respect a patient's autonomy.

The Problem of Bias

In this vignette, we find Victoria and her husband in apparent distress over recent test results indicating a high chance of having a child with Down syndrome and their decision about whether to terminate the pregnancy. To ensure that Victoria can make an informed decision that expresses her values, her clinicians are obligated to provide her with accurate, up-to-date information on Down syndrome that is as unbiased as possible. This means presenting all the potential options, including continuing the pregnancy, beginning arrangements for their child's adoption, and terminating the pregnancy. While Victoria's autonomy allows her to choose among several outcomes for her pregnancy, she cannot make an informed decision, and her autonomy would be undermined, if she received biased information from her clinicians.

How clinicians handle bias is an important consideration in this and similar cases. Clinicians' behavior can sometimes be at odds with the ethical standard for clinicians to express respect for a patient's autonomy. One anonymous survey of nearly 500 physicians who deliver a variety of prenatal diagnoses found that 23 percent of them urged termination and 14 percent urged continuation of the pregnancy [3]. These statistics suggest that many physicians draw prominently upon their own values when discussing patients' medical options in this kind of situation.

Indeed, if a clinician in this case were to use the word "burden," for example, to prognosticate about a parent's quality of life with a child with Down syndrome, this would be an example of a kind of "urging" communication that would be inappropriate, unethical, and undermining of the patient's autonomy. In the case, it appears that Victoria has not received information about what one might expect in the life of a person with Down syndrome. It also seems that she has not received information about adoption agencies that specialize in responding to newborns with special needs.

Additionally, we do not know what information, if any, Victoria received about the termination procedure itself, which is not without risk, or what to expect while recovering from an abortion. It is crucial for her physician to convey that abortion is not the only acceptable option for Victoria. Regardless of the physician's personal opinion, Victoria's decision should not be directed by the clinician in any way. Appropriate counseling, for example, should not include any expression of value judgments about Down syndrome as a diagnosis or suggest that one pregnancy outcome is ethically better than another.

Strategies for Communicating the Probability of Down Syndrome

One meta-study examined methods of delivering unexpected news of a prenatal diagnosis of Down syndrome that were preferred by expectant mothers [4]. Ethical guidance to be culled from that study is listed here:

1. The preferred person to communicate the news is a health care professional who is knowledgeable about Down syndrome. This might not always be the obstetrician, so collaboration with other experts might be necessary.
2. Respondents indicated a preference that the diagnosis be given as soon as possible, in the company of the expectant father or partner. This allows the potential diagnosis to be discussed with the expectant parents and any other support that they may wish to have with them in a thoughtful, confidential way. If necessary, this communication can be done over the telephone at a prearranged time.
3. Respondents indicated they preferred up-to-date information about what Down syndrome is, its causes, and expectations for people with Down syndrome today. They also wanted to be offered opportunities to establish social connections with

parents who have children with Down syndrome. These connections would provide social, cultural, emotional, and practical support and education for expectant parents in a way that a clinician likely could not.

4. Respondents preferred that information be delivered in a nonjudgmental fashion, with respect for the parents' feelings and personal decisions. Particularly, they preferred that sensitive and respectful language be used, rather than value-laden language (e.g., "I have bad news to share") or offensive language (e.g., "mongolism," "retarded").
5. Respondents indicated that they wanted to receive an up-to-date bibliography of resources about Down syndrome.
6. Respondents indicated a preference that follow-up appointments be offered not only with an obstetrician but also with specialists who might help respond to their future questions (e.g., a genetic counselor, Down syndrome specialist, or cardiologist).

Roles of Good Counseling

In the case, it is not clear what, if any, counseling Victoria had prior to the current clinical encounter. Victoria has seemingly arrived at an abortion clinic without understanding her available options or even receiving a clear diagnosis. Amelia's suspicion that Victoria did not receive adequate counseling might indeed be correct; far too many women who have had children with Down syndrome report dissatisfaction with the information and support provided after receiving the diagnosis [5].

Amelia's attempt to discover whether Victoria has received any information on Down syndrome yields little. She's right to ponder several questions. *Was the information accurate and up-to-date? Has Victoria been offered connection with a local Down syndrome support group or Down syndrome center for more information? If indeed she has received that information, which questions about Down syndrome does she have at this point? Has she been given an opportunity to meet in person with a professional knowledgeable about Down syndrome so that she may ask those questions?*

There are multiple points at which Victoria could have received prenatal counseling—perhaps at the time of the first ultrasound or, certainly, at the time of the cell-free fetal DNA testing, even though this test is not diagnostic. Long before she was sitting in the abortion clinic, she should have met with a genetic counselor, a Down syndrome specialist, or possibly even the parent of a child with Down syndrome. However, she is now at a point when the time for good counseling might have passed. But it's still not too late for Amelia to introduce the importance of those opportunities.

What, If Anything, Should Amelia Say?

Amelia, too, must not engage in attempts to convince the patient to make a decision she views as best. Amelia's wishes to be an advocate for those with Down syndrome is

commendable and important. Both authors of this commentary can empathize with Amelia's situation. We both have siblings with Down syndrome who have influenced many lives in remarkable ways. However, Amelia's inclination to "speak up on behalf" of this population must be tempered by recalling that counseling discussions should always focus on the patient's and family's goals and not the clinician's values. For Amelia to push Victoria toward one outcome would be unethical.

Amelia has an opportunity as a medical student to discuss her concerns with the attending physician. Although this might be difficult, it is important. It is reasonable for Amelia to share her concerns with the attending physician, not only because Dr. K is her faculty mentor, but also because Dr. K might not realize that Victoria has not received appropriate counseling. Dr. K could then demonstrate to Amelia how to counsel a patient, even at this late stage in Victoria's decision-making process.

It should be noted that even if Amelia or Dr. K offers it, Victoria does have the option to decline further counseling and discussion regarding risk assessment or diagnosis. However, if Victoria wishes to discuss these things further, she should be provided with information that allows her to make an informed decision. Although it might be appropriate for Amelia to ask if Victoria has further questions or wishes to speak to anyone else regarding the chances of a diagnosis of Down syndrome, Victoria has the right to choose which information she would like to hear. At no time during her pregnancy should Victoria be forced to discuss the potential diagnosis or her pregnancy options against her will.

Even if she has refused counseling, Victoria retains a right to choose outcomes of her pregnancy that best align with her own family's goals and values. Our role as clinicians is simply to provide patients and families with information to use in making their own decisions, without influencing them intentionally or unintentionally.

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Further Reading

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National Down Syndrome Society website. <http://www.ndss.org>. Accessed January 20, 2016.

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Kishore Vellody, MD, is an associate professor of pediatrics at the University of Pittsburgh School of Medicine in Pennsylvania. He is also medical director of the Down Syndrome Center of Western Pennsylvania and on the executive committee for the Board of the National Down Syndrome Congress, whose Professional Advisory Committee he directs. In addition, he hosts the Down Syndrome Center of Western Pennsylvania Podcast and moderates the Dear Self About Down Syndrome blog. Finally, and most importantly, he has a family member with Down syndrome.

Related in the *AMA Journal of Ethics*

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[Informed Consent and Prenatal Testing: The Kennedy-Brownback Act](#), September 2009

[The Virtue of Drawing Lines in Genetic Testing](#), May 2003

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ETHICS CASE

Considering Decision Making and Sexuality in Menstrual Suppression of Teens and Young Adults with Intellectual Disabilities

Commentary by Kruti Acharya, MD, and John D. Lantos, MD

Dr. Jones is a gynecologist who has been seeing Amy for the past few years to help with menstrual suppression. Amy was diagnosed with cerebral palsy at birth; she experienced some global developmental delay as a child and was in special education in school. Now 25, Amy works part-time at a local grocery store. Amy's mother currently holds her medical power of attorney, but she makes a concerted effort to include Amy in her medical care decisions, as she can express many of her wants and needs.

Dr. Jones remembers that Amy is a healthy young woman overall but has struggled with heavy and painful periods since her first menses at 13. Hygiene has also been difficult for Amy; she often forgets to change her pads, which results in staining of her clothes. Continuous-use oral contraceptive pills were successful at suppressing her periods for several years; then she switched to the medroxyprogesterone shot so she would not need to take any daily medications. Last year, however, bothersome breakthrough bleeding prompted Dr. Jones to order a pelvic ultrasound, which revealed that Amy had several small uterine fibroids. Subsequently, he recommended a hormonal IUD for menstrual suppression, which was placed under anesthesia. Amy and her mother arrive for a follow-up visit six months after its placement, and Dr. Jones is eager to hear how things have been going.

Dr. Jones quickly learns that Amy has been doing very well at work and has recently started dating. Her new boyfriend, David, also has cerebral palsy. Amy proudly explains that she and David have been dating for three months.

Dr. Jones asks, "What do you and David like to do together?"

Amy grins and says, "We like to go to the movies. Our parents go with us, but we make them sit a few rows back."

Dr. Jones goes on to ask, "Amy, I wanted to see how your periods have been. Has the IUD helped?" Amy replies, "I don't have cramps anymore but I still am bleeding a small amount almost every day. I try to wear a pad but I sometimes forget and bleed on my clothes."

Amy's mom confirms, "Unfortunately, she is still struggling with the bleeding and it's really hard for her to stay clean, especially at work."

Later, speaking privately with Dr. Jones, she asks, "I have wondered about the possibility of having Amy's uterus taken out. Her bleeding has still not stopped and we know that she has fibroids. I am happy that Amy has been able to find such a nice boyfriend, but I really don't anticipate that she will ever have children. She has gone through sex education classes, but I don't think she really understands 'the birds and the bees.'"

Dr. Jones nods and replies, "I know Amy is pretty capable of expressing her wants and needs. What do you think she would say?"

Amy's mom sighs and says, "I haven't brought up the idea with her yet. I'm concerned about how she might respond. She probably would not be happy to hear that she would never be able to have children. However, she doesn't understand what having a child is really like. At least as things are now, I do not anticipate her being able to care for a child independently. She still lives with us and requires a lot of support herself."

Dr. Jones then says, "I understand your concerns and certainly empathize with your difficult situation. I would like to take time to consider this more."

Commentary

This case raises ethical issues about the treatment of young adult patients with intellectual disabilities: distinguishing caregiver convenience from patient benefit, respecting the desires of patients who might not have decision-making capacity, and appropriate counseling and teaching regarding sexuality for adults with intellectual disabilities.

According to the 2010 US Census, 1.7 million children and adolescents aged 6 to 15 years have developmental disabilities [1]. For most teenagers with disabilities, puberty occurs at the same age as in peers without disabilities, although some neurodevelopmental disabilities are associated with early puberty [2]. Teens with autism spectrum disorders might experience slight delays in the onset of menarche [3].

Hygiene

Menstrual flow, whether normal or increased, can be difficult to manage for patients with disabilities, and some teens with disabilities might require assistance from a caregiver (e.g., to properly place a menstrual pad or remember to wear or to regularly replace it). Other teens with disabilities might remove pads or not dispose of them properly [4].

The American College of Obstetrics and Gynecology recommends pharmacological menstrual suppression for teens (or adults) with disabilities who need significant help with menstrual hygiene [5]. There are a variety of treatments that can reduce menstrual flow, but complete amenorrhea is difficult to achieve with any hormonal treatment. In this case, despite trying increasingly invasive pharmacological and physical interventions to suppress her menses, Amy still has continued bleeding, and her problems with hygiene persist. An ethical and clinical question confronting her parents and Dr. Jones is how to respond to these facts.

Ethical considerations. All treatments have side effects, including some that are quite severe. Ethical issues in hormonal or surgical suppression of menstruation have to do with balancing potential risks and benefits. In order to assess the benefits of a given treatment course, two things are necessary: the first is an accurate characterization of the problem. Objective data about the number of days of bleeding and the number of days of adequate and inadequate menstrual hygiene would be helpful to quantify the magnitude of the problem. The second is an understanding of the reasons offered by [the person who is requesting the treatment](#) to suppress menstruation (i.e., the person with the disability and the caregiver might have different reasons). If the caregiver is making the request, it is important to tease out whether the primary motivation is to decrease caregiver burden (i.e., convenience) or whether it is to improve quality of life for the person with the disability. If the primary motivation is to decrease burdens to the caregiver, then it would be appropriate to consider solutions other than medication for the patient. If the focus is on the teen's quality of life, then medication might be a more ethically appropriate choice.

Menstrual suppression. Although the benefits of hormonal therapy are mainly psychosocial and hygienic, the risks are physical, including potentially life-threatening complications such as thromboembolism [6]. Medroxyprogesterone can also decrease bone density [7]; limited ability to bear weight is of particular concern for patients with cerebral palsy because they are already at increased risk of osteopenia and osteoporosis [8]. Hormonal treatments can also affect the metabolism of drugs, particularly antiepileptic drugs [9] and antiretroviral medications [10], so physicians will need to carefully monitor doses of other medications the patient might be taking. Generally, a satisfactory treatment regimen can be developed and maintained [11]. Behavioral interventions can be important therapeutic adjuncts to hormonal treatments for menstrual hygiene. Visual or audio alarms on mobile apps or programmable watches, for example, can help remind a patient to place or replace a pad. Procedures under general anesthesia, as was the case with the IUD insertion, also carry their own risk. The risks of general anesthesia have been well described in the anesthesia literature [12].

Sterilization. The request for a hysterectomy is an ethically complex option because it would mean permanent and irreversible sterilization. Of note, the fibroids in this case are

a classic red herring. Fibroids, alone, are not an indication for hysterectomy [13]. Thus, there does not appear to be a bona fide medical indication for hysterectomy in this case at this time. If there were a bona fide medical indication for hysterectomy and all other medical and behavioral options had been exhausted, then the need to get Amy's consent for surgery would decrease; instead, considerations of her best interest would become more important than respecting her autonomy.

Even in that case, however, involuntary sterilization would not be ethically acceptable. Involuntary sterilization has a long and sordid history in both the United States and other countries. In the early twentieth century, involuntary surgical sterilization was part of a nationwide eugenics program designed to prevent persons with intellectual and other disabilities from having babies. In 1927, these eugenic practices were upheld by the Supreme Court decision in *Buck v. Bell*. That ruling upheld a Virginia law that allowed states to forcibly sterilize residents in order to prevent "feeble-minded and socially inadequate people from having children" [14]. After the ruling, more than 60,000 involuntary sterilizations were performed in the United States [15]. After World War II, forced sterilization of individuals with disabilities gradually lost favor. In 1942, the Supreme Court declared procreation to be a fundamental human right [16], and the United Nations Convention of the Human Rights of People with Disabilities recognizes fertility as an inherent human right [17].

Today, it is illegal to use federal money to pay for involuntary sterilization [18]. Many states have statutes that ban involuntary sterilization or require judicial approval. However, as the American Academy of Pediatrics notes, "The complexities of federal rules, state laws, and judicial rulings have created a confusing and contradictory array of restrictions on surgical sterilization of persons with developmental disabilities" [19].

As the possessor of medical power of attorney, Amy's mother has been legally designated as Amy's [proxy decision maker](#), but it is not ethically justifiable for her to make decisions based solely on her own values and judgment. As discussed above, it is benefit to the patient, not to the caregiver, that must balance or outweigh the risks to the patient. Furthermore, these decisions should be made following the practice of shared decision making, that is, by considering and prioritizing Amy's personal values and preferences and ensuring she has an active, strong voice in her future planning. Perhaps a next step would be for Dr. Jones to facilitate a discussion that includes Amy. Her mother's concerns about Amy's decisional capacity and future independence are appropriate, but even if Amy might not be able to fully assess the consequences of her options to make an informed choice, her desires can help guide her mother's decision-making process.

There is no way to assess Amy's understanding of a hysterectomy and its implications without having a discussion with her. In evaluating her ability to make such a decision, it

is important to distinguish two key concepts: decisional capacity and competence. Decisional capacity is determined by a physician after a clinical assessment of a patient's ability to make an informed decision [20], whereas the presence or absence of competence is determined by judges after reviewing medical information and testimony. Decisional capacity varies with the specific task or decision under discussion, whereas competence is a global assessment. To have decision-making capacity, one must be able, among other things, to understand the implications of a particular decision.

Many women with intellectual disabilities can give informed consent [21]. People with intellectual disabilities should be assumed to have capacity to make decisions unless there is good evidence to question their capacity. In this case, a decision about sterilization requires some understanding of contraception, pregnancy, childbirth, fertility and infertility, and parenting [22]. Amy might, as her mother fears, not be happy with a plan that curtails the possibility of having children. On the other hand, she might accept that she would never be capable of caring for children herself. In either case, hysterectomy should not proceed unless she agrees to it with some understanding of the implications of her decision and of the risks of the surgery.

Amy's Sexuality

In this case, both Dr. Jones and Amy's parents seemed to welcome and accept her relationship with her boyfriend, but there is no indication that they have talked to her about sexuality. For example, it is unclear whether Amy is aware that the medications she has been taking for menstrual suppression are also contraceptive agents. In the case as presented, it is unclear whether Amy understands the implications and possible consequences of sexual activity. According to her mother, she did receive some sex education, but we do not know the content of that education or whether it was adequate. Parents might avoid bringing up sexuality with their children with disabilities—as Amy's mother seems to have done—because they are uncomfortable with the topic (and perhaps fearful that the child has experienced sexual abuse), have little knowledge themselves about sexuality and disability, or are concerned that such a conversation might encourage sexual intercourse [23].

Amy's parents and caregivers should know that people with intellectual disabilities can have intimate social relationships, including friendships and romantic and sexual relationships. For example, Chamberlain et al. found that 51 percent of a sample of 41 11-to 23-year-old women with mild intellectual disabilities had engaged in intercourse, and 32 percent continued to be sexually active [24].

Typically, developing teens learn about social boundaries and limits of touch through repeated everyday peer interactions. Their peers with disabilities can experience more social isolation, which might limit their exposure to natural learning environments in which physical interactions occur.

Therefore, formal education about sexuality and sexual health is critical for people with disabilities. Many people can be taught what is or is not appropriate and healthy sexual behavior and how to engage in sexual behavior within socially appropriate limits. However, people with disabilities tend to be viewed as either incapable of understanding these issues or as asexual [25]. As a result, they might not receive appropriate sex education. To ensure understanding, curricula need to be explicit and adapted to an individual's level of health literacy. Plain but accurate terms should be used to describe body parts, for example. Visual material and models can be helpful, particularly for participants with limited verbal skills.

Sexual education should not be confined to school settings, however; it must be reinforced at home by parents and professional caregivers. By discussing sexuality and sexual health with their teens and young adults with disabilities, parents can equip their children with necessary tools to navigate emerging intimate relationships.

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ETHICS CASE

Is Proxy Consent for an Invasive Procedure on a Patient with Intellectual Disabilities Ethically Sufficient?

Commentaries by Stephen Corey, MD, Peter Bulova, MD, and Sonya Charles, PhD

Dr. Smith, a family medicine physician, is preparing for a full day of patient appointments. She is looking over the chart of Stephanie, a new patient, who is here for an annual physical. Stephanie is 30 years old and has autism. Dr. Smith notices that Stephanie has had regular uneventful periods but has never had a pap smear. Dr. Smith knows that pap smears are recommended for all women starting at the age of 21, so she makes a mental note to ask specifically about any previous pap smears and enters the room to meet Stephanie, who is sitting quietly in the corner, looking intently at one of the pictures hanging on the wall. Dr. Smith first introduces herself by saying, "Hi Stephanie, my name is Dr. Smith, but you can call me Julie. Nice to meet you." Stephanie looks up and nods but does not say anything. Dr. Smith introduces herself to Stephanie's caseworker, Hannah, then turns back to Stephanie and asks, "Tell me how you have been doing over the past year, Stephanie."

Stephanie waves her hand, expressing "so-so," and Hannah explains, "She's nonverbal, but you can ask me any questions you need to know. I have her whole file and know her well." As the conversation progresses, Dr. Smith learns that Stephanie has lived in a group home for about 15 years. She struggles with some behavioral problems at the home and has difficulty communicating her needs to the staff.

Dr. Smith remarks, "I notice that Stephanie has never had a pap smear before, at least according to our records. I wanted to check and make sure that information is accurate, since we would typically recommend this important screening for a patient of her age."

Hannah responds, "Yes, that is correct. It has been discussed in the past, but we have always been concerned that a pap smear would be too distressing for her. Stephanie is very sensitive to sensory stimuli, especially anything painful. She's required to get a flu shot every year to live in the group home, and it's always so awful for her. I am not sure that a pap would be worth her distress, especially because she is not sexually active."

Dr. Smith wonders if this is true. She asks, "Have there ever been any concerns about sexual abuse with Stephanie?"

Hannah answers, "Certainly not since she has been in the group home. She is very well supervised, and we have never had any problems with abuse among our staff. But we have very little information about her life prior to coming to the group home. She does not have any family involved in her care at this time."

Dr. Smith replies, "Screening recommendations are indeed recommendations and not requirements, so I am open to discussion about the pap smear for Stephanie. However, given her unclear history I am inclined to err on the side of doing one. There is a high rate of sexual abuse in patients with intellectual disabilities. Since we do not know much about her previous history, I would rather be safe than sorry."

Hannah sighs and says, "Well, Stephanie has dental work done under sedation every year, so perhaps she could just have her pap smear done at the same time. She wouldn't even have to know it was done. We have done it before with some of the other residents, and it was a great solution."

Dr. Smith considers Hannah's suggestion, but she feels uncomfortable performing such an invasive procedure if it can only be done by deceiving the patient and by using a sedative as a chemical restraint. Dr. Smith feels that doing a vaginal exam and cervical test without Stephanie's knowledge or consent to be more ethically problematic than doing a routine dental exam. She worries that performing the pap without permission of a sedated patient borders morally on rape. Even though Hannah is Stephanie's official decision maker, Dr. Smith wonders whether it is ethical to leave Stephanie out of the decision entirely.

Commentary 1

by Stephen Corey, MD, and Peter Bulova, MD

Informed consent is a cornerstone of medicine and ethics and is generally regarded as a foundational expression of a clinician's respect for a patient's autonomy. No procedure can legally or ethically be performed without consent. However, consent decisions for patients with intellectual disabilities are typically legally assigned to a surrogate, usually a relative or caregiver. In Stephanie's situation, the case suggests that her autism is so disabling that she does not have decision-making capacity and so cannot give informed consent. It is assumed, therefore, that she also does not have the capacity to give an informed refusal. From a legal perspective, she can neither consent nor refuse. But what about from an ethics perspective?

The case suggests that Stephanie gets dental care under sedation, and that consent for this is given by Hannah. Should it be any different for a pelvic exam and pap test? What are ethically relevant considerations when deliberating about how we ought to regard

consent, assent, or refusals for patients with intellectual disabilities? The rest of this article considers these questions.

Justifiability of Restraint

Even though patients with severe developmental disabilities can require restraining for activities of daily living such as meals, medications, shots, and bedtime, and even when consent has been legally obtained from a surrogate decision maker who endorses these reasons for physical restraint of a patient, we suggest that there are good reasons to question whether physical restraint is appropriate to facilitate a pelvic exam for Stephanie. We argue in what follows that the use of physical restraint is inappropriate in this case. Additionally, we argue that there should be no exceptions to respecting the refusal of a person with intellectual disabilities to undergo an invasive exam if physical restraint is required to carry out the exam, even if the patient's surrogate authorizes the use of physical restraint.

The use of anesthesia, is, however, ethically acceptable in our view. It is acceptable to do a pelvic exam at the same time as Stephanie's dental work. Stephanie might resist having an intravenous needle for anesthesia and consequently may need to be physically restrained by the arm for this procedure, but, in our experience, most caregivers would feel that the surrogate's legal consent to physically restrain a patient for insertion of an intravenous needle for the purpose of anesthesia administration is appropriate, if it is absolutely necessary to facilitate an important procedure or treatment.

Distinguishing a Pelvic Exam from Dental Work

Restraining Stephanie for a pelvic exam is different from restraining her to facilitate the dental work. Dr. Smith has concerns that performing a pap without Stephanie's permission might constitute rape. But, if a clinician has legal consent and either anesthetizes or gains the cooperation of the patient, it certainly would not be rape. The pap test not only detects cancer of the cervix, but can also detect precancerous conditions that are 100 percent curable if treated early. When appropriately performed, a pelvic exam and pap test do not incur physical trauma. With an anesthetized patient there's no reason to expect that a patient would be physically or mentally traumatized. Additionally, there are significant benefits, including screening for sexual abuse that would not be discovered any other way. However, if, as a clinician, you still feel the procedure performed under anesthesia would in any way cause a degree of trauma similar to that caused by rape, then you ought absolutely not to do the procedure.

Dr. Smith considers not even doing a pap test. This brings up the question of what kind of reproductive health care should be given to a woman with an intellectual disability. Some suggest that the answer is *the same care that would be given to a person without a disability*. So, if women with a disability should have the same reproductive health care as women without a disability, this means that, like care for other patients, a decision to do

something should be based on whether the patient needs it and after deliberating collectively on the balance of risks and benefits involved.

There are cases in which one should consider the patient's refusal of an indicated procedure, even though the patient does not have capacity to refuse appropriate care. This again requires evaluating the risks and benefits of the procedure in context [1].

Assumptions about the Sexual Lives of People with Intellectual Disabilities

So does Stephanie need a pap test? Clinicians might assume that patients with disabilities have low rates of sexual activity, and therefore that a pap smear is not indicated [2]. This is a myth; there is a significant rate of sexual activity, as well as sexually transmitted infections, among women with disabilities. Although it does not specify whether sexual contact is consensual, the National Study of Women with Physical Disabilities found that 94 percent of respondents were sexually active, with sexually transmitted infection rates the same as in women with no disabilities [3]. Although women who have never been sexually active are at low risk of cervical cancer and abnormalities on a pap test, to assume a particular woman with a disability is in that category does not take into account the high rate of sexual abuse, which is more commonly experienced by women with disabilities than women in the general population. One literature review found that people with developmental disabilities were 4 to 10 times more likely to be victims of violence and/or sexual assault [4].

Sexual abuse can also be difficult to detect. Women with intellectual disabilities might lack the verbal skills to report abuse [5] and are more likely than women without disabilities to experience abuse at the hands of someone we assume can be trusted, such as attendants, caregivers, and even health care professionals (M.A. Nosek, PhD, unpublished data, 2003). While Stephanie's caregiver does not suspect that Stephanie has ever suffered sexual abuse, it is still a possibility, and therefore it is the responsibility of the physician to consider and screen for it.

And how ought we to determine whether the benefits of the pap smear balance or outweigh the risks? Guidelines recommend pap tests on all women ages 21 to 65 who have a cervix [6]. At age 21, Stephanie would not be due for another pap for three years. Should Stephanie be given anesthesia for an annual pelvic exam when she is not due for a pap? The American College of Obstetricians and Gynecologists (ACOG) recommends annual gynecologic exams whether or not a pap test is due [7]. ACOG does not specifically address this issue in women with disabilities or those without decision-making capacity. The organization does not clarify whether and when these recommendations would change for a patient who is assessed as needing anesthesia to undergo the exam. However, given the additional risks of anesthesia, we would not recommend doing yearly pelvic exams for an asymptomatic woman who needs anesthesia for her exams. Instead, we would recommend only doing a pelvic exam when

the patient is due for a pap test, since the potential benefits might not outweigh the risks in these cases. We recommend reviewing the benefit/risk ratio on a case-by-case basis.

However, it is important to make sure that this recommendation does not lead to underscreening of cervical cancer for women with intellectual disabilities. In the past, physicians have underscreened: overall, women with intellectual disabilities receive poorer-quality general health care and have significantly lower rates of screening for cervical cancer than women without intellectual disabilities [2]. Yet, screening has become more important than ever, and there is a national movement to improve screening practices in this population [8]. People with intellectual and physical disabilities are now living longer lives than they once did [9], and intellectual disability might have only a minor impact on a person's longevity [9, 10].

Instead of forgoing screening, clinicians need to find ways to make care more accessible and acceptable for those with disabilities. For example, in this case, one possible alternative, particularly for patients whose disability does not substantially compromise their manual dexterity, is a "self-collected" cervical sample performed by the patient or a trusted caregiver [11]. Given her sensitivity to physical stimuli, it's not clear whether self-collection would be an option for Stephanie, but we offer it as an option that might be suitable for some patients.

We would like to clarify here that anesthesia can describe relieving pain, discomfort, and anxiety, and does not necessitate unconsciousness that might be inferred from the term *sedation*. Regardless of whether Dr. Smith decides to give Stephanie a pap smear under anesthesia or obtain a sample some other way, maintaining a respectful environment for the patient—through strategies such as explaining the procedure beforehand with words or pictures in a manner appropriate to the patient's health literacy level, having the patient tell the clinician when she is ready for him to begin, and honoring her requests to stop or pause—is paramount [12], as is preventing Stephanie's experience from being negative or frightening. Additional strategies for doing so include having a trusted caregiver present and reducing the anxiety-provoking effect of stimuli by introducing equipment and people during a preprocedure visit. Implementing these strategies would require the physician explicitly to clarify that his conduct is therapeutic and neither intentionally sexual nor abusive. Clinical language used by the physician should explain the examination processes thoroughly. Counseling done by people experienced in working with patients with intellectual disabilities might also help Stephanie through an examination.

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Commentary 2

by Sonya Charles, PhD

At the end of the case scenario, Dr. Smith “worries that performing the pap without permission of a sedated patient borders morally on rape.” Some might find this attitude perplexing, but this commentary will show this is a valid concern. While it might be *legal* to perform a pelvic exam and pap test action with proxy consent, we can still ask whether and when it is *ethical*. Chemical constraint—sedation, in this case—can count as a form of coercion. If chemical restraint is required to subdue a patient or quell her verbal or nonverbal expressions of resistance or opposition to a pelvic exam, then it does begin to look a lot like rape. According to the Department of Justice, the definition of rape is this: “The penetration, no matter how slight, of the vagina or anus with any body part or object, or oral penetration by a sex organ of another person, *without the consent of the victim*” (emphasis added) [1]. As we can see, consent is the crucial element in determining whether and when penetration is defined as rape. Thus, the main issues in this case are information disclosure and the patient’s capacity to respond to that information. I will argue that Dr. Smith and Hannah owe Stephanie a developmentally appropriate conversation at her level of health literacy about their concerns and suggested course of treatment. If possible, they should obtain Stephanie’s assent to continue. To illustrate why this is ethically required, I consider two relevant practices: nondisclosed pelvic exams in teaching hospitals and assent for children unable to legally consent to treatment.

Controversy Regarding Nondisclosed Pelvic Exams: The Example of Teaching Hospitals

To begin, let us consider the similar issue of nondisclosure of [pelvic exams on sedated women](#) at teaching hospitals. If a woman has routine gynecological surgery at a teaching hospital, she (like everyone else) will likely sign a consent form that includes a blanket consent to allow students to examine and do procedures on her. Historically, teaching hospitals have used this as an opportunity for medical students to practice vaginal exams and have not required any explicit consent for them [2]. After some controversy in 2003, many hospitals revised their practices to require explicit consent for pelvic exams [2, 3] and some states instituted legal requirements [4]. However, blanket consent is still perfectly legal in most places, and some hospitals continue to perform pelvic exams on unconscious women without explicit consent [5]. Those who argue against the practice claim that women would be “upset” [3] and some anecdotal evidence suggests that many women would feel “violated” [6] to find out that this could be happening without their explicit consent.

I believe the uneasiness that many medical students and women feel about this practice is because of the parallels to rape [7]—especially since research shows that many women are willing to give consent for a pelvic exam in a teaching context when they are explicitly asked [2]. When fully autonomous women—despite having voluntarily signed

blanket consent forms—are being penetrated (sometimes by multiple people) without their knowledge or explicit consent [5, 6] and are not comforted by the legality of blanket consent [4], it suggests that consent for a particular examination at a particular point in time for a particular purpose (presumably, a clinical or teaching purpose) is important.

Since ethical questions have been raised about vaginal exams on unconscious women who are (presumably) fully competent [2, 4, 5], it is certainly worth taking a closer look at the ethics of a pelvic exam for Stephanie in this case, particularly if her unconsciousness is required to carry it through. Given patients' alarm at penetration without specific disclosure, I argue that, if any physician plans to perform an invasive procedure or examination on an unconscious woman, he or she is ethically required to disclose this information to the patient—in a way appropriate to that patient's health literacy level.

Disclosure to Patients Not Legally Able to Give Consent: The Example of Children

Next we more fully consider health literacy and the role of the patient's decision-making capacity—specifically at what level she is able to participate in this decision. In Stephanie's case, some readers may feel that disclosure of an intended pelvic exam might be irrelevant or counterproductive because they assume that Stephanie will not understand it. I argue that it is health professionals' responsibility to disclose in a way the patient can understand.

When it comes to informed consent, autism creates a special challenge. While some individuals on the autism spectrum are highly intelligent and have a good understanding of what people are saying to them, some may have problems with expressive communication. For this reason it seems impractical to make a general response to the question of whether proxy consent is appropriate for all patients with autism or other kinds of intellectual disabilities—even those with court-appointed guardians. I will, therefore, consider this question only for Stephanie as an individual in this particular case. We are told Stephanie is nonverbal, lives in a group home, and has a legal guardian [8]. However, it is also clear from her brief exchange with Dr. Smith that she has some ability to communicate; Stephanie appears to understand Dr. Smith's general question and to appropriately respond. With this in mind, would it be possible for her to participate in some kind of patient education or consent process? We have a clear example of such processes in pediatric ethics.

Most children are not legally allowed to give consent for health care treatment. Yet, the Committee on Bioethics for the American Academy of Pediatrics (AAP) strongly encourages developmentally appropriate disclosure and an attempt to obtain assent [9]. So, there seems to be a relevant consensus in the pediatric community that

Patients should participate in decision-making commensurate with their development; they should provide assent to care whenever reasonable.

Parents and physicians should not exclude children and adolescents from decision-making without persuasive reasons [10].

Let me clarify that, in referring to the AAP statement, I am not trying to infantilize those with disabilities. Rather, I am using this statement to establish precedent for involving patients in the decision-making process even when they are not legally able to give informed consent. Children have legally recognized proxy decision makers—their parents—but the AAP recognizes the inadequacy of proxy consent (especially as children get older) and promotes a policy of transparency and empowerment [9]. To better assess our current case, it is worth reviewing this summary of specific AAP recommendations for obtaining assent, which should include at least the following elements:

1. Helping the patient achieve a developmentally appropriate awareness of the nature of his or her condition.
2. Telling the patient what he or she can expect with tests and treatment(s).
3. Making a clinical assessment of the patient's understanding of the situation and the factors influencing how he or she is responding (including whether there is inappropriate pressure to accept testing or therapy).
4. Soliciting an expression of the patient's willingness to accept the proposed care. Regarding this final point, we note that no one should solicit a patient's views without intending to weigh them seriously. *In situations in which the patient will have to receive medical care despite his or her objection, the patient should be told that fact and should not be deceived* [11] (emphasis added).

If children (even young children) deserve this level of disclosure and consideration, it is very difficult to argue that Stephanie does not.

Recommendation

Dr. Smith and Hannah should explain their concerns and what they plan to do in a way that meets Stephanie's level of understanding. Explaining that they would like to sedate her so that she can avoid the unpleasant sensory experiences that cause her distress can and should be part of this discussion. Stephanie clearly knows that she is sensitive to stimuli and might welcome the sedation. Indeed, sedation as a chemical constraint is not coercive or an unjustifiable use of force *if one has consent or assent* from the patient.

Furthermore, as we see from the AAP recommendations, even if Stephanie does not assent and Dr. Smith and Hannah decide there are good reasons to proceed with this procedure anyway, they still have an ethical responsibility to *disclose* as fully as possible

to Stephanie what they are planning to do. To sedate her and penetrate her without disclosure does indeed put their (technically legal) actions dangerously close to the definition of rape.

Finally, we must consider that current practices set precedents for future practices—which makes disclosure and assent even more necessary for establishing an ethical track record of patient care over time. So, what might this mean for Stephanie? If the pap is performed and there are precancerous or cancerous cells, what then? Presumably, Stephanie would need a series of medical procedures in order to determine the severity of her health issue and to treat it. Would this mean that Dr. Smith is now faced with the need to repeatedly sedate Stephanie and perform invasive treatments? Even if no problems are found during the initial exam, it is likely Dr. Smith and Hannah would consider other preventative exams in the future. Therefore, how Dr. Smith approaches this exam will set a precedent for his future treatment of Stephanie and with other patients.

In sum, I argue that disclosure and assent are crucial in this case. Controversy noted above over practicing pelvic exams on unconscious women without their explicit knowledge and consent suggests that legal consent does not always coincide with ethical practice. Fortunately, the AAP guidelines for obtaining assent from pediatric patients provide an example of how we might meet ethical standards in our current case. Even though Stephanie has a legal guardian, it is clear that she also has some ability to understand and communicate. For this reason, Dr. Smith and Hannah owe Stephanie an explicit discussion about their proposed plan of treatment.

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MEDICAL EDUCATION

The Curriculum of Caring: Fostering Compassionate, Person-Centered Health Care

Kerry Boyd, MD



This drawing was provided by a patient for whom the legendary phoenix bird has great significance. This drawing was provided by a patient for whom the legendary phoenix bird has great significance. Drawing by Mario Monteil Lechuga. Permission for use granted by artist.

A Call for Compassionate, Person-Centered Health Care

Clinicians' compassion and empathy have been found to be associated with improved clinical outcomes [1, 2]. The Associated Medical Services (AMS) Phoenix Project issued a Call to Caring in 2012 to reemphasize the importance of [compassionate, person-centered care](#) in medical practice. AMS Phoenix Project defines person-centered care as "high quality health care that respects an individual's preferences, needs and values and is provided in an empathic and compassionate way" [3]. This emphasis stands to benefit health care recipients as well as clinicians at each point of care and to contribute to

broader health care reform. The Royal College of Physicians and Surgeons of Canada's CanMEDS Physician Competency Framework identifies person-centered care as an important emphasis of the competencies [4]. Despite agreement that compassion and person-centeredness are important, it appears that these characteristics wane as health professionals [move through their training](#) [1, 5, 6].

Educational interventions including personal encounters with patients, modeling by mentors, and reflective activities (especially early in training) can foster caring qualities such as compassion and [empathy](#) [6-9]. Additionally, longitudinal experiences for health care learners with marginalized patient groups have promoted positive attitudes toward those underserved populations [9-11]. Experiential learning in clinic- or community-based settings also fosters communication and interpersonal skills that are essential to engage patients from diverse populations in shared decision making [12-15].

Effective two-way communication is foundational to person-centered care [12, 13], particularly when patients have complex needs that may make communication more difficult. There has been a paucity of curricula and standardized guidelines [16] to help trainees make communication adaptations in situations where significant communication barriers exist. Such barriers commonly affect patients with developmental disabilities (DD), who can present with cognitive and communication challenges in addition to complex medical and mental health needs. Health professionals report [inadequate training](#) in the care of patients with DD [17, 18].

Person-Centered Care for Patients with Developmental Disabilities

The literature consistently describes the population of people with DD as having more than average medical and mental health comorbidities coupled with more barriers to the kind of individualized care that meets their needs [17, 19]. Although physical barriers to access for persons with disabilities are being addressed in many countries, system-related barriers remain significant with DD being considered beyond the scope of practice for many generic services [19, 20]. More challenging are clinicians' attitudinal barriers and unconscious biases toward people with disabilities, which are beginning to be addressed in health care training [21, 22]. Common ethical challenges in the care of persons with DD tend to center upon concepts such as human rights, recognition of personhood, dignity, intrinsic worth, and respect for agency in decision making [23]. Furthermore, health care clinicians express feeling inadequately equipped to assess and treat people who present with significant cognitive or communication deficits, identifying a need for more experience and training [17, 18]. Therefore, it is important for health care curricula not only to equip students with relevant knowledge and skills, but also to influence attitudes [21], address unconscious biases [22], and instill respectful, caring competencies. Fortunately, training that incorporates patients with disabilities has been found to improve knowledge, attitudes, comfort, and willingness to provide care [24-27].

Curriculum of Caring: Addressing Barriers to Care

Beginning in 2008, the Niagara Regional Campus of McMaster University's Michael G. DeGroote School of Medicine provided trainees with experiences to increase their capacity to provide competent and compassionate care to people with DD. A three-phase program, the Curriculum of Caring, has been developed in which people with DD and their caregivers contribute to the education of medical students throughout their three years of medical training. In 2011, the program was extended to include students at Brock University's Center for Applied Disability Studies and Nursing with the further benefit of interprofessional learning [28]. Video and web-based resources [29] have been also been created in order to expand the reach and application of the Curriculum of Caring [30].

Program Premise: Experience is the Best Teacher

Active inclusion of people with disabilities in medical decision making is recognized as a human right and ethical standard [31]. No longer is medical paternalism accepted in the care for people with DD. Self-advocates are urging health care professionals to gain an appreciation of each person as an individual rather than fixating on disability [32]. Focus groups of adults with DD emphasize the importance of attitudes (genuine respect), skills (especially appropriately adapted communication), and competencies (treating relevant problems) [33]. And health care recipients living with DD are increasingly appreciated as best suited to teach about the care they need and how to deliver it [31-33].

McMaster University's program development has been shaped by the educational literature, student evaluations, and multiyear contributions of people who have lived experience with DD. The result has been a three-phase progression of experiential learning that incorporates early exposure to people with DD, clinical skills training, and opportunities to practice in interdisciplinary team settings.

Phase one: early exposure. Students participate in an interprofessional half-day at Bethesda, a regional provider of community-based services for children and adults with DD. They interact with "Bethesda Day" hosts from an adult day program and hear from a parent of a child with special needs. These direct interactions are augmented by an overview, led by the author, of DD, resources for further reading [34, 35], and local services, with an interprofessional emphasis. Learners consistently note that hearing personal narratives had the most impact in sensitizing them to the needs of those who live with disabilities and motivating them to acquire more skills and experience.

Phase two: clinical skills training. This phase teaches pre-clerkship students to "Communicate CARE" by communicating "clearly, attentively, responsively, engaging the person first and others as appropriate" in interviews with patients with DD. Communicate CARE emphasizes environmental and interpersonal adaptations that

contribute to the comfort and success of interviews. Students are given opportunities to interview volunteer patients with varying cognitive or communication profiles and mental health needs. These interactions are followed by group discussion about the interviewers' experiences, what they learned from the people they encountered, and how they can apply it to their practice.

Phase three: application. Application of Communicate CARE and clinical competencies takes place in interprofessional team settings for two to eight days of the trainees' psychiatric clerkship rotations. Learners participate in clinic interviews, team discussions, and collaborative treatment planning in order to increase their capacity to deliver relevant person- and family-centered care to people with DD. In other clinical settings, students encounter children and adults with DD who have health and mental health needs, anecdotally reporting benefits from the Curriculum of Caring experiences.

Feedback and Impact: Mutual Benefits

The Curriculum of Caring has been informed by personal experience with DD and health care. The involvement of patient educators, research participants, and family advisors has been central in devising and refining a curriculum aimed at shaping health care professionals' attitudes and practices. Students report increased comfort, confidence, and competence working with patients with DD incrementally after each phase. They also provided comments about their Curriculum of Caring experiences.

"The more experience the better! Every encounter makes me feel more confident and determined to learn more in order to best serve this population as a future family doc."

"This experience definitely improved my confidence in working with this population."

"I would love the future experience of working with this population."

"Great learning experience and I would now love to look into nursing jobs that work with people with disabilities."

Students' questionnaires indicated that meeting adults with DD and hearing parent narratives had the greatest impact on their appreciation of person-centered care. The postintervention comments strongly suggest that encountering people with DD provokes thought, promotes compassion, and fosters caring among future clinicians. A nursing student involved in Curriculum of Caring focus group research and video development communicated the influence of the experiences on her future practice.

These individuals have truly inspired me to continually integrate the concept of caring into everything I do as a future health care professional, and to ensure that the voices of our patients are heard to meet their unique needs.

Curriculum of Caring has also garnered positive feedback as students have used their skills in various clinical settings. A medical student who experienced the three phases of Curriculum of Caring for people with DD wrote:

I wanted to share with you an example of our time at Bethesda having significant/ripple impact: yesterday [two classmates] and I were rounding on surgical patients with our resident; one of our patients was a non-verbal middle-aged woman with cerebral palsy. The three of us were way more comfortable communicating with her and examining her than the resident—I like to think we modeled a bit to him!

In addition to the benefits for trainees, patient educators have described personal benefits. Mother and daughter participants reported:

“The role-playing to make the videos has given her [my daughter] a lot of self-confidence, especially when she has to visit a doctor in real life (even her doctor noticed this). She used to be very quiet, hang her head and avoided eye contact, but now she is more confident and talkative and even asks questions.”

“It helped me figure out that I can talk for myself instead of people talking for me.”

The Curriculum of Caring has created a ripple effect, expanding the network of people who share the vision of improved care for people with DD. Health care recipients, learners, and clinicians all stand to benefit from this necessary and transformative movement of compassionate, person-centered care.

Expanding the Curriculum of Caring’s Application and Influence

Curriculum of Caring has expanded into a web-based forum for health care learners to hear from people affected by DD. More specifically, the Curriculum of Caring website [30] gives people with DD experience opportunities to be health care educators via video.

Phase one. “Voices of Experience” features a cross-section of willing and capable spokespeople providing unscripted personal narratives and advice. Personality, vitality, and valuable insight are expressed in videos featuring people whose lives are touched by disability.

Phase two. The clinical communication skills module includes an “Interview with CARE” primer complemented by video interviews that model “Communicate CARE” in practice. The videos depicting medical and nursing encounters were co-created with the McMaster/Brock Simulated Patient Program, students, and actors from the Niagara community (featuring Bethesda’s SpotLight Drama troupe).

Phase three. This online community of practice features clinical, research, educational, and self-advocate experts from around the province of Ontario, sharing their wisdom and advice while broadening the network of shared resources.

These experiential learning opportunities and video-based resources have been designed to instill caring competencies, including attitudes, communication skills, and person-centered practices for treating people with DD. Web-based materials expand the educational impact. The Curriculum of Caring model has potential to broaden the application further to benefit more clinicians and other disadvantaged populations.

Conclusion

The AMS Phoenix Project calls for transformation of professional training, practices, and systems that will bring about renewal of compassionate, person-centered health care. The Phoenix Project: Call to Caring comes at a time when there is a need for transformation in the way services are delivered, with an emphasis on person- and family-centered care. With the legendary phoenix bird in mind, the people with DD involved in the Curriculum of Caring have risen from their difficult experiences to the challenge of fostering a renewal of compassionate, person-centered care. Their inclusion in the experiential learning of health care students is a vital force in addressing the exclusionary barriers they experience as health care recipients. They challenge and inspire us, as professionals and educators, to rise up and partner with them in the ethical cause of compassion.

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IN THE LITERATURE

Workplace Wellness Programs and Accessibility for All

Yvonne Kellar-Guenther, PhD

Griffin Basas C. What is bad about wellness? What the disability rights perspective offers about the limitations of wellness. *J Health Polit Policy Law*. 2014;39(5):1035-1066.

In recent decades, employee wellness programs have become widespread among large companies. A study by Rand showed that, in 2009, 92 percent of US employers with 200 or more employees offered [wellness programs](#) [1]. While on the surface, the goal of improving employee health seems benign at best, some worksite wellness programs are focused less on population health improvement and more on reducing corporate costs. This emphasis on corporate costs, combined with the fact that employers wield a lot of power over employees, can lead to a potentially coercive approach to wellness that feels obligatory and tied to job performance. In “What Is Bad about Wellness? What the Disability Rights Perspective Offers about the Limitations of Wellness” [2], Carrie Griffin Basas walks the reader through the wellness program philosophy of health as attainable through self-responsibility and modern workplace wellness programs, using court cases and the history of wellness and disability rights movements to suggest that these programs may be discriminatory and set up unrealistic expectations about health for all persons. Griffin Basas argues that the way these programs affect persons with disabilities provides “a mirror for a critique of wellness as neoliberalism by exposing the flaws in its arguments about behavioral control, personal responsibility, and bodily optimization” [3]. A brief working definition of neoliberalism can be helpful here. Briefly, neoliberalism characterizes a range of views that privilege self-reliance-based (rather than interdependence-based) and autonomy-oriented (rather than communitarian) ways of being in the world. Neoliberalism has been widely critiqued for rewarding traditionally privileged traits, such as male, white, able-bodied, and heterosexual [4].

Throughout her article, Griffin Basas argues that employee wellness programs and the wellness philosophy create a power divide that continues to grow between healthy workers and those with disabilities (as well as other minority groups with limited access to resources for health and safety); those who are healthy (and have access to resources) are rewarded for getting healthier, while other groups are unable to benefit and therefore drop further behind. She begins by discussing the 2012 court case *Seff vs. Broward County*, which highlights the opposing forces surrounding workplace wellness programs. In this case, employees who did not complete a health questionnaire and

biometric screening were [charged](#) \$20 every two weeks. Griffin Basas argues that this case simultaneously illustrates wellness programs' positive emphasis on supporting health and their negative aspects—depersonalizing employees and punishing employees who do not or cannot take part in “healthy behaviors” like exercise or achieve health-related goals like weight loss.

The structure of a wellness program, she explains, may make it difficult for persons with disabilities to take part. The author reviews Mello and Rosenthal's work on two types of wellness programs—one in which rewards are based on participation regardless of outcomes, and one in which rewards are based on attainment of goals such as a certain BMI or smoking cessation. For example, while some workplace wellness programs are focused on activities like joining a gym or filling out an annual survey on health behavior, others may focus on cholesterol targets or a specific body mass index (BMI) [5]. Both approaches can present barriers: it may be difficult for a person who needs to rely on public transportation to get to a gym that can accommodate a particular physical disability, and it may be unrealistic for a wheelchair user with fragile bones to take part in a weight loss program. Programs that fail to acknowledge these barriers are unethical if there are rewards tied to program participation or meeting targets, such as the reduction in insurance premiums L.L. Bean offered to its employees who took part in its Health Lifestyles Program [2].

The discussion then shifts to the origins of the workplace wellness movement. For employers, improving employee wellness contains costs—“encouraging employees to get involved in their own healthcare leads to a more healthy population that costs less to insure” [6]—and promotes occupational safety as well as an emphasis on work-life balance, job satisfaction, and emotional well-being. When these programs were introduced, persons with disabilities saw this emphasis on elimination of injury as positive, but, Griffin Basas argues, adoption of the wellness movement philosophy by corporations has led to some unintended consequences such as reinforcing a negative bias towards hiring persons with disabilities. With the passage of the Americans with Disabilities Act (ADA) came a backlash, the view that people with disabilities were putting a burden on businesses and employers to spend money by making accommodations that spurred reluctance to hire persons with disabilities. Griffin Basas argues that workplace wellness programs cast persons with disabilities as a liability on an organization's balance sheet.

It was not only people with disabilities who were viewed as burdensome to employers. Griffin Basas argues that the wellness movement has taken on a neoliberal bent, representing wellness as controllable through personal responsibility and choice. Health—an absence of illness or impairment—became defined as the result of choices, leading to an emphasis on prevention. This emphasis in turn has led to societal discrimination against those who supposedly “don't take responsibility for their health,”

including elders, or portrayal of them as villains. It is here that Griffin Basas points out that, one day even people without classical “disabilities” will also be part of a marginalized group viewed as a burden to employers.

Towards the end of the article, Griffin Basas provides a call to action to health and disability advocates:

Resources are limited, and rather than appropriate them to further benefit the already healthy, they should be shifted toward the inclusion of outliers, such as people with disabilities. Instead of mainstreaming people with disabilities toward a homogenized definition of health, advocates should dismantle current definitions and replace them with ones that are nuanced and inclusive, less hierarchical, and free from paternalistic assumptions [7].

Griffin Basas asks us to consider “why barriers to health equity exist” [7] before inadvertently creating any programs that divide healthy and sick people. The social model of disability argues that disability exists because of the way society is organized [8], challenging people to think through ways to remove barriers that restrict life choices for persons with disabilities. Worksite wellness programs that reward participants based on a decrease in weight or gym memberships are creating societal barriers and thus undermining equity.

Consistent with her larger argument that wellness programs provide a critique of the neoliberal emphasis on self-responsibility for health, Griffin Basas ends the article by showing that workplace wellness programs may not be the answer to improving population health, the impetus behind the wellness movement. In particular, she relies on Mattkey, Schnyer, and Van Busum’s 2012 literature review [1], which found that the returns on investment for these programs is unclear, most likely because so few eligible employees participate.

Response

If workplace health programs can perpetuate injustice, should we dispense with them altogether? As a public health practitioner, I say no. I fully support the wellness movement to reduce or eliminate diseases that are lifestyle-driven through education efforts and programs or techniques designed to increase readiness to adopt healthy behaviors. Workplace wellness programs can play a key role in the wellness movement because they employ two key strategies in public health: enlisting nontraditional health partners and influencing the social determinants of health.

Enlisting nontraditional partners in promoting public health. Healthy People 2020, a federal health promotion initiative, recognizes the importance of working with nontraditional

health partners to meet health goals [9]. Employers are a nontraditional health partner, and their involvement could increase the reach of health messages.

Increasing protective social determinants of health. The term “social determinants of health” is often used to refer to [nonmedical factors](#) influencing health [10], and the Centers for Disease Control and Prevention recognize that the work environment can be such a determinant, a risk factor that can lead to poor health or a protective factor that can lead to maintaining good health [11]. One could argue that employers who offer workplace wellness programs are creating a protective factor by providing external motivation for engaging in healthy behaviors as well as, depending on the program, resources such as to teach healthy eating, track movement, and provide nicotine patches to help reduce smoking. However, it is important that these programs be delivered with an emphasis on improving an individual employee’s health rather than on just decreasing employer health care costs.

Accommodations: Reconciling Wellness with Respect for the Person

To reap the positive benefits of wellness programs without the discriminatory aspects Griffin Basas draws attention to, it is important that workplace wellness programs be accessible in a way that is useful to everyone. One way workplace wellness programs are encouraged to overcome this bias against those who cannot easily take part is to allow alternate paths to success—personalized health goals rather than standardized or required outcomes [5]. (This approach, too, though, can be ethically problematic if there are barriers to requesting permission for a more personalized approach. For example, some programs just require employees to let the employer know they need to set a different goal. Allowing requests is not the same, however, as ensuring that employees do not feel singled out for having to make them. Other programs require a physician recommendation for an accommodation, an additional hurdle for the employee.)

In my opinion, one way to achieve personalization is through accommodations, a requirement in Title I of the ADA [12]. The ADA states that employers must provide a reasonable accommodation to persons with disabilities who are employees unless to do so causes undue hardship. There are many examples of an accommodation for a person or a group of people benefitting many, even those without disabilities. Griffin Basas points to examples outside of the workplace, including accommodations made by cities and businesses to increase mobility such as power-operated doors and curb cuts; these accommodations are also helpful for large deliveries and parents pushing strollers [2]. Schur et al. found that making accommodations for all employees led to higher employee satisfaction. Finally, accessibility need not entail accommodations [13]; Griffin Basas notes examples of workplace wellness programs that offer programs that are individualized to fit the need of the employee.

I believe the key to decreasing the discrimination of workplace wellness programs is to allow alternate paths to success—personalized health goals rather than set health outcomes [5].

Ultimately, wellness, like disability, can take many forms. As Griffin Basas notes, “to accept disability as difference means to give up the idea that people can and should always control their bodies and, therefore, to dispense with the notion that they are responsible for their lack of compliance” with able-bodied norms of health [14]. Workplace wellness programs can look to other individualized health care approaches such as motivational interviewing and patient navigation for examples of systematic approaches to working with people in an individualized way that is responsive to their situation and their needs. Recognition of the person who is taking part in the program can help increase access (justice) and minimize maleficence (do no harm).

I feel it is important to create ways for everyone—regardless of race, socioeconomic status, and ability—to adopt healthy behaviors that minimize their risk of, or decrease the burden of, lifestyle-influenced diseases. One approach is to include nontraditional partners—including places of worship, community agencies like libraries or social service programs, and community health workers who go out into the community they serve—to help reach people and deliver health information or health programming [9]. Workplace wellness programs can play a vital role in wellness promotion and act as a protective factor as long as they can remain accessible and responsive to individual needs and goals. To achieve these aims, those who design workplace wellness programs need to work with all stakeholder groups, including persons with disabilities, to understand their needs as well as question reductionist thinking that assumes that disability is the product of poor choices and attitudes and health is a demonstration of positive ones. As Griffin Basas reminds us, ultimately, we will all be sick and disabled at some point. That does not degrade our worth as humans and does not take away from our desire to be as healthy as possible. We should not forget that the key to wellness is meeting persons where they are and allowing them to be part of the conversation about what wellness looks like for them.

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IN THE LITERATURE

A Defense of “The Case for Conserving Disability”

Jasmine Zahid

Garland-Thomson R. The case for conserving disability. *J Bioeth Inquiry*. 2012;9(3):339-355.

Garland-Thomson’s Case for Conserving Disability

Rosemarie Garland-Thomson makes a moving case for conserving the existence of disability [1], which she describes as “preserving intact, keeping alive, and even encouraging to flourish” disability in society and humanity [2]. She begins her paper by making the point that disability affects everyone who lives long enough, making her readers feel the conversation is relevant to them. She then poses the question of how it can be possible for disability—something that all humans will have eventually, if we are lucky to live long enough—to “disqualify us from full membership in the human community” [3]. To answer this question, she next turns to David Mitchell and Sharon Snyder, who explain that we associate disability with, in Garland-Thomson’s words, “pain, disease, suffering, functional limitation, abnormality, dependence, social stigma, and economic disadvantage” [4]. With this understanding of disability and what Garland-Thomson refers to as “[eugenic logic](#),” we are left to conclude that “the world would be a better place if disability could be eliminated” [4].

In her paper, Garland-Thomson defines eugenic logic as “a utopian effort to improve the social order, a practical health program, or a social justice initiative that is simply common sense to most people” [4]. Eugenic logic is a controversial phrase, which Garland-Thomson acknowledges in a footnote. John Banja [deems](#) the fear of eugenic logic to be “unreasonable” based on his assessment that disability rights advocates misunderstand the medical model and are perhaps using “motivated reasoning”—choosing a conclusion before gathering all the facts [5]. Michelle Bayefsky [6] asserts that the term eugenic is “vastly overused” [7]. By using a term that critics deem to be unreasonably fear inspiring or unnecessary, Garland-Thomson makes a point: if eugenic logic as she defines it is “common sense to most people” [4], our commonsense understanding of disability is part of the problem, indicating the need for Garland-Thomson’s case for conserving disability.

The bioethical question being considered is why we should conserve disability—as opposed to trying to eliminate it. Garland-Thomson explains that her choice to use the term “conserve” is intentional, as it does the semantic work of suggesting that

disabilities can be understood as resources or benefits to be kept [2]. Furthermore, although she is answering a bioethical question, she does not reference the bioethical debates about genetic enhancement and philosophical questions about personhood. This implies that her argument is geared not toward a particular debate but to our cultural or commonsense understanding of disability in general. Although Robert Sparrow and others refer to Garland-Thomson's argument for disability conservation as a critique of preimplantation genetic diagnosis and prenatal testing [6, 8], I maintain that the most moving aspect of her piece is its push for a broader reshaping of cultural perceptions of disability.

It is important first to understand how Garland-Thomson defines disability. Garland-Thomson provides both a political and cultural definition of the term. She refers to the Americans with Disabilities Act of 1990 and the United Nations Convention of Rights of People with Disabilities of 2009 to make the point that, though these frame disability in social and political terms, they remain dependent on the medical understanding of disability as "impairment, restriction, dysfunctionality, abnormality" [2]. For a cultural definition of disability, Garland-Thomson turns to constructivism and phenomenology, which share the idea of "disability as a way of being in an environment" produced by the "discrepancy between body and world, between that which is expected and that which is" [9]. Combining this idea with her earlier point that everyone who survives long enough will age into disability, she concludes that "disability is thus inherent in our being: What we call disability is perhaps the essential characteristic of being human" [9].

Garland-Thomson's case for conserving disability depends on the idea that disability is a preservation-worthy resource in three unique but interconnected ways: narratively, epistemically, and ethically. For understanding of disability as a narrative resource, she turns to the work of Leslie Fiedler and Arthur Frank. Fiedler argues that disability is a narrative resource for people without disabilities; Frank posits that disability is a narrative resource for people with disabilities themselves. Fiedler advocates "disability-as-freakdom"; freaks, in Garland-Thomson's words, "inspire...wonder through their extravagant differences from ordinary folks and their simultaneous eerie, distant sameness to their unexceptional brethren" [10]. Frank focuses instead on how illness contributes to understanding the self and one's identity.

Epistemically, Garland-Thomson argues, disability offers new ways of experiencing the world around us. Garland-Thomson cites Hellen Keller's experiences as an example of how some senses are heightened in the absence of others. She introduces the idea of embodied cognition from psychology to explain "that people draw on their bodily experiences not only to think and know but also to construct our social reality" [11].

Finally, she frames disability as an ethical resource that contributes to our sense of community; in philosopher Eva Kittay's words, conserving disability "will build solidarity with others, cultivate human sympathies, and create an open human community" [12].

Raising Three Concerns

Although Garland-Thomson makes a compelling argument for disability as a sociocultural resource, there are a few concerns that I would like to discuss. The first concerns willingness to embrace conservation of disability on an individual and institutional level, and the second concerns whether disability is the sole source of the benefits that Garland-Thomson presents in her argument; and the third concerns the choice of the word "inherent" to describe disability.

Willingness to conserve disability. Although it seems that disability enables the human community to benefit from interdependence, the practical worry is that perhaps not all people want—or maybe are even capable of—enduring the downsides of disability in order to participate in that interdependence. In his article, "Imposing Genetic Diversity," Sparrow asserts that "different experiences produced by being disabled are ones that one might reasonably desire to seek out or avoid" [13], as becomes clearer when considering whether one would want one's child to have a disability.

On an institutional level, the concern is similar—whether institutions want to conserve disability. Some have argued that, currently, institutions such as workplaces operate according to the "eugenic logic" Garland-Thomson describes. The idea is that, if institutions are currently constructing a workplace environment that is not accommodating to disabilities, we might infer that they are either unable or unwilling to conserve disability in the workplace for the future. In a recent *New York Times* article, Tara Siegel Bernard points out that the critics of wellness programs worry that these programs are a form of discrimination against "less healthy workers" [14]. Indeed, Carrie Griffin Basas [argues](#) that companies are using wellness programs as a way to discriminate against those with disabilities and that our society's philosophy of neoliberalism, which prioritizes independence or autonomy in the workplace, manifests in these programs [15]. Griffin Basas explains that "state intervention is kept to a bare minimum unless it supports these goals" and that "ethical problems become economic ones" [16]; wellness programs promote discrimination by inadvertently punishing those with disabilities who cannot participate. Griffin Basas makes a compelling argument that wellness programs institutionalize disability bias not only in the workplace, but also in today's society.

Consider the American Medical Association's wellness program, for example. For those who cannot participate in the suggested exercise activities (which exclude exercises that individuals with disabilities can participate in), there is an option to attend "lunch and lecture" sessions. A closer look at these lunch lectures, posted as videos on the

organization's internal website, reveals that 27 percent (7 of 26) focus on exercise (American Medical Association internal communications)—undermining the lecture program's potential to include those with disabilities who cannot exercise in the suggested ways. A problem here is that the definition of *exercise* that wellness programs tend to promote presumes able-bodiedness and is, therefore, exclusionary. As I discuss in the following section, Garland-Thomson addresses these concerns about wellness programs in her work.

The uniqueness of disability as a source of benefit. The second question I have is whether we need disability to attain these benefits. Garland-Thomson cites Arthur Frank when making her case for disability as a narrative resource, but Frank writes about those with illness more generally, not disability, the permanent state Garland-Thomson defines as a "discrepancy between body and world" [9]. This characterization does not seem to clarify whether the phenomenological benefits attributed to permanent disability could not also be garnered from temporary illness. The worry, then, is that illnesses, which can be temporary, can also be a narrative resource for understanding oneself or others—making it unclear whether disability is unique in providing such a resource.

It is also not clear that disability is unique as an ethical resource. Garland-Thomson states that disability as an ethical resource "will build solidarity with others, cultivate human sympathies, and create an open human community" [12]. It seems reasonable to believe that there are other phenomena and circumstances that promote solidarity, sympathy, and community. She does make a case that disability contributes to the development of these things, but it is not clear whether that would be enough for some to be persuaded of her overarching case to conserve disability.

The claim that disability is inherently human. The last concern is an issue of semantics. Garland-Thomson asserts that disability is "inherent in the human condition" [17]. The Oxford Dictionary defines inherent as "existing in something as a permanent, essential, or characteristic attribute" [18]. In a later article, Garland-Thomson uses the term "inevitable" to describe disability [19]. If the claim of permanence or inevitability were based solely on her idea that all who live long enough experience disability, then it would be questionable, since many such people have lived a life prior to developing disability and some people die without ever having personally had disabilities. Consider Bob, who has lived a life without disability, and has passed away from a cardiac event prior to developing a disability in old age. To say that Bob is not human, because he has at no point experienced disability, would not make sense. But Garland-Thomson's use of the term "inherent" is intended, however, to describe humanity, as I conclude in the next section.

Defense: Answering these Concerns

Individual willingness to conserve disability. With regard to the problem of whether “experiences produced by being disabled are ones that one might reasonably desire to seek out or avoid” that Sparrow poses [13], Garland-Thomson’s story of the mother who has a child with Tay-Sachs, a fatal disease, can provide some insight into approaching that problem. The mother admits that had she known her son would have Tay-Sachs, she would have had an abortion. What is moving about this specific story is that a mother who stands by the claim that she would have aborted her child if she had known about his disability also describes the love she has for her son as “blissful” [20]. Garland-Thomson uses this story to make a few different compelling points about suffering. One is that “suffering expands our imagination about what we can endure” [20]. A second is that the dependency that people with disability have on their loved ones provides the “opportunity to profoundly love another human being” [21]. A third point is about the effect that disability has on our control of the future—the problem being that the existence of disability “present[s] the difficult challenge for modern subjects not only to live in the moment but also to engage in a relationship not based on the promise of the future” [22].

It’s worthwhile to take a moment to emphasize the implications of Garland-Thomson’s third observation about suffering. Consider how often and how carefully you have made a plan for the future, whether it is simply for what you will do with your time tomorrow or years from now. Imagine not being able to do that—not being able to have an idea of what your tomorrow or future might look like (or what Garland-Thomson calls not having “predictable narratives”). If the thought makes you uneasy—feel vulnerable even—then Garland-Thomson has accurately described your relationship with the future and how disability challenges it. She eloquently concludes that “disability’s contribution, its work, is to sever the present from the future” [23]. This is not to say that disabilities make it impossible to plan for tomorrows. Rather, Garland-Thomson explains, the existence of disability is not only “an antidote to modernity’s overreaching” focus on curing and fixing, but also the source of “a narrative of a genuinely open future...not controlled by the objectives, expectations, and understandings of the present” [23].

In her commentary on Sparrow’s article critiquing Garland-Thomson, Bayefsky concludes of Garland-Thomson’s definition of disability, “we are left not far from where we began—with vaguely positive intuitions regarding the value of human genetic diversity” [24]. Bayefsky’s conclusion seems unwarranted. Garland-Thomson’s conclusion is not vague but specific: she has identified three ways in which disability, some of it attributable to human genetic variation, contributes to our world—as a narrative, epistemically, and ethically. Additionally, she has given us a new perspective on disability, describing it in phenomenological terms. Ultimately, Garland-Thomson is redefining disability. The act of redefinition changes our understanding or perceptions of what is being redefined. Rather than leaving us “not far from where we began,” Garland-

Thomson's argument increases our understanding of disability and gives us an opportunity to shift our perspectives on what it means to have a disability. Garland-Thomson digs deeply into human fears about the future and provides novel insight into why people might have an aversion to conserving disability.

Institutional willingness to conserve disability. Garland-Thomson's work addresses issues in today's working world, confronting disability issues on an institutional level. In a later paper, Garland-Thomson specifically discusses the idea of "world-building" [25]. She makes the point that, while it is not the kind of world we are currently building, it is possible to build a world of inclusion. She specifically mentions the workplace as a space that can be made more inclusive [9]. One might imagine that an inclusive workplace means making wellness programs accessible to those with disabilities and de-emphasizing the value of autonomy in the workplace for the sake of building an inclusive world. Although her vision does not solve practical problems, it does raise awareness about the world that we are building.

The uniqueness of disability as a source of benefit. What remains unclear is whether disability is necessary in attaining the three benefits that Garland-Thomson argues to be reasons for conserving disability. The worry is that, for example, temporary illness might provide similar narrative resources; other diverse experiences might provide similar epistemological resources; and community-based cultural practices could provide similar ethical resources. In other words, it is not clear why disability ought to be conserved in order to attain resources that might be available elsewhere. If the argument is that X ought to be conserved because it provides Y resources, then it must be the case that Y is only attainable from X.

The claim that disability is inherently human. The use of the term "inherent" ultimately does not pose a threat to Garland-Thomson's overall argument of how disabilities are benefits because her claim is not that disability is inevitable or permanent for all individual people, but that it is inevitable for some and inherent in the human community overall.

Conclusion

Garland-Thomson's paper inspires readers to reconsider their commonsense or cultural understanding of disability and goes much further, answering the question of how disabilities are benefits. In doing so, Garland-Thomson ultimately gives her readers a novel insight into what it means to experience disability in today's world.

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STATE OF THE ART AND SCIENCE

Keeping the Backdoor to Eugenics Ajar?: Disability and the Future of Prenatal Screening

Gareth M. Thomas, PhD, and Barbara Katz Rothman, PhD

Introduction

In this short commentary, we reflect on how ideas about disability intersect with prenatal technologies and what this likely means for the future landscape of reproductive medicine. In what follows, we assess the argument that prenatal technologies represent a form of “eugenics,” defined here as practices and policies designed to promote the reproduction of people with desired attributes—and, thus, avert the reproduction of people with undesired attributes (e.g., people with disabilities). The idea that the world and the people in it would be better off if everyone were born “healthy,” that is, without “defect,” is the essential principle of eugenics (translated literally as *well-born*). At the beginning of the twentieth century, eugenics emerged as an important ideology and social movement in the US and beyond [1], reflected most profoundly not only in the institutionalization of certain people with disability (and other social groups) but also in policies of segregation and enforced sterilization programs. Whilst the word has dropped out of favor in the US, the actual practice of eugenics remained fairly consistent in US medical services over the decades both before and after Nazi Germany’s appropriation of eugenics for its own horrifying purposes [2].

We consider the idea of eugenics in the context of prenatal screening, that is, a nondiagnostic test providing information about the chance of a fetus having a condition or disease. (In contrast, a diagnostic test, such as amniocentesis or chorionic villus sampling, can establish the presence or absence of a condition in a child, although it should be noted that diagnostic tests are not 100 percent accurate and are susceptible to human error.) Increasingly sophisticated prenatal screening techniques have been embraced in scientific circles, yet disability rights groups have condemned them as devaluing certain lives and, thus, as being ethically problematic and even eugenic [3, 4]. We turn our focus to noninvasive prenatal testing (NIPT), the latest version of prenatal screening for Down syndrome to be offered in the US. NIPT is used to analyze cell-free fetal DNA (cffDNA) in a pregnant woman’s blood at around ten weeks’ gestation. It can predict the chance of a fetus having a genetic condition such as Down, Edward, or Patau syndrome; the detection rate for each syndrome is reported as being around 99 percent; for example, at least 99 percent of all pregnancies in which a fetus has Down syndrome can be detected using NIPT [5]. Screening for sex chromosome disorders (for example, Turner syndrome) is also possible via NIPT. Although most pregnant women will receive

a lower-chance (or “lower-risk”) result, some will have a higher-chance (or “higher-risk”) result, meaning it is very likely that a fetus has a genetic condition. In such instances, diagnostic testing can validate this.

Because NIPT, in particular, has the potential to detect many different conditions and genetic variations, some argue that concerns about its “eugenic potential” may be particularly acute [6-8]. That said, we focus this commentary on screening for Down syndrome (the reasons for which we offer later). In the context of Down syndrome screening, we suggest that this practice—whilst facilitating pregnant women’s decision making and helping them, in certain situations, to prevent difficult circumstances or to prepare for certain outcomes—becomes a method by which certain lives are marked as either valued or devalued—and could be, thus, considered as a matter of what Shakespeare calls “contemporary eugenics,” in that it devalues certain ways of *being* in the world [9]. Further, we argue that the continuing development of prenatal screening technologies plays a key role in the problematic framing of people with disabilities.

The Future Landscape of Prenatal Screening: Social and Ethical Issues

NIPT intensifies long-debated issues in prenatal screening, including assessing whether “nondirective care” and “informed choice” are achieved and if screening heightens anxiety [10-18]. Other [social and ethical questions](#) may also be asked of this new technology. Since NIPT is reported as having a 99 percent detection rate for some genetic conditions, how is this knowledge managed by pregnant women? Will this create added social and medical pressure to take tests—and does this affect a woman’s ability to “choose not to choose” [19]? What effects does the “seeping” of NIPT into medical systems have for pregnant women? What happens to “choice” when screening is performed at earlier gestation and “risk” is diminished [5]? How do pregnant women understand and handle inconclusive results as well as “variants of uncertain significance” (variation in the normal sequence of a gene, the significance of which is unknown) and “incidental findings” (undiagnosed medical conditions found unintentionally)? Will NIPT fuel further anxiety among pregnant women, as reported, in relation to earlier forms of prenatal screening/testing [15, 16, 17-18, 20-22]? Finally, how is NIPT implicated in already inequitable medical systems in the US and beyond?

An array of other scholars have reflected on the social and ethical issues associated with NIPT in more detail and nuance than is possible here [5-8, 23-33]. We direct the reader to these excellent resources for further information. At this point, we focus on whether this form of prenatal screening constitutes a form of eugenics, defined here as techniques and policies that allow for the reproduction of people with “desired” attributes and reduce the reproduction of those with “undesired” attributes. This is hugely important in the context of NIPT since the technology has the potential to provide a diagnosis of fetal sex for clinical indications (for example, Duchenne muscular dystrophy) and single-gene disorders (for example, achondroplasia, thanatophoric

dysplasia) as well as trisomies (Down, Edward, or Patau syndrome). Further, NIPT may be expanded to include next-generation sequencing or microarray testing that would make it feasible to screen for subchromosomal deletions and duplications in the fetal genome, including chromosomal imbalances too small to be detected via standard karyotyping. If this happens, who decides what will be screened for? Will all identified genetic variants be shared with pregnant women, and how will they contend with the potential production of what Bernhardt et al. call “toxic knowledge” [34]? Will pregnant women receive support in the form of expert counseling to digest the results of testing for a large range of genetic diseases and disorders [35]? Such questions can only be answered in due course, but, for the time being, we ask whether the future landscape of prenatal screening can be considered a matter of eugenics.

A New-Genics? The Example of Down Syndrome

In order to illustrate our argument, let us consider Down syndrome, both to narrow our focus and because the condition has been connected with prenatal screening programs for many years—including NIPT. Down syndrome is a variable condition, and, although some symptoms are common, the prognosis of people with the condition remains unclear. This means that if a pregnant woman receives a prenatal diagnosis of Down syndrome, she is [unlikely to receive information about](#) the level of physical and cognitive impairment a child would have. Diagnostic tests (even at their most accurate) for conditions like Down syndrome only tell pregnant women if the fetus does or does not have the specific chromosomal marker. They do not tell women about the severity or the breadth of impairments that may follow; one fetus with a diagnosis of Down syndrome could not survive pregnancy whilst one child born with the condition could graduate from college. It is this complexity and variability, interestingly, which means that some people—including health care professionals—can hold ambiguous views and express various anxieties about prenatal screening and testing for Down syndrome, with some citing this uncertainty when claiming that screening could perhaps be considered a eugenic practice [36].

This troubled relationship between prenatal testing for Down syndrome and how the condition is interpreted is complicated further when reading the accounts of parents who have children with the condition. In both empirical studies [37–39] and autobiographies [40–46], mothers and fathers identify numerous difficulties—be they medical, social, familial, educational, vocational, political, or economic—associated with parenting a disabled child, but they also recount their positive experiences, recognizing their situation as one which should not always be viewed as unwanted, pitiful, or disastrous [47]. Research has shown how the positive experiences of parents of a child who has Down syndrome, or some positive reflections on the condition more broadly, are not always communicated during prenatal screening consultations [36]. This view has led some disability rights groups to organize campaigns against prenatal screening. For example, the “Don’t Screen Us Out” campaign was organized by an advocacy group for people with

Down syndrome in light of the development of NIPT and argues that screening would have a “long-term effect on the population of the Down syndrome community and enable a kind of informal eugenics in which certain kinds of disabled people are effectively ‘screened out’ of the population before they are even born” [48].

Reflections on the way that Down syndrome is represented connect with the notion of “choice,” i.e., that pregnant women are able to choose whether to have prenatal screening or testing and, if a diagnosis is established, whether to terminate or continue a pregnancy. However, this notion of choice has been problematized for years and for several reasons [12-16, 49]. The first reason is that this choice is based on what would, in other circumstances, be [considered insufficient](#) information; screening only indicates the *chance* of having a child with a genetic condition, and the prognosis, as touched upon above, can be uncertain. It is in this context that we should consider NIPT. Attempts at finding fetal markers in maternal blood have been made over the last 30 or more years, each heralded as about to “change everything” in prenatal testing and each ultimately not providing sufficient diagnostic accuracy to be anything other than a screening test. The screens—from nuchal fold tests for chromosomal conditions during “routine” ultrasounds through to current testing procedures—bring women into a situation in which they may have to decide whether to knowingly continue a pregnancy with a diagnosed fetus or terminate a hitherto wanted pregnancy.

Secondly, the decision to have a screen or not may be framed as a “choice,” but the pressures surrounding the choice—e.g., the services available, expectations, cultural attitudes toward disability, familial and other support—interfere with this choice being freely made. This process of starting with routine care and facing ultimate questions about the meaning and value of human life, the life of one’s potential child, is what Samerski calls “the decision trap,” that is, how engaging with genetic technologies can cause choices to become “traps” that people enter both willingly and eagerly [50]. For Lippman, the rhetoric of choice is meaningless; to knowingly carry to term a baby with Down syndrome “cannot be a real option when society does not truly accept children with disabilities or provide assistance for their nurturance” [51]. Indeed, the women that Rothman interviewed in her own research were often quite clear that, whilst they would not choose to end a wanted pregnancy for mild or some developmental delays, they did wish to spare their potential children the difficulties of extreme disabilities, especially in a world not providing the necessary services, assistance, and accommodations [12].

Related to this point, Skotko warns that promoting “choice” as medical progress in the context of prenatal screening may lead to the “disappearance” of people with Down syndrome [52]. Skotko’s argument is important to consider in light of termination statistics from around the world. A report from the National Down Syndrome Cytogenetic Register claims that in 2012 in England and Wales, 90 percent of 1,259 fetuses diagnosed prenatally with Down syndrome were terminated [53]. Moreover, in

England and Wales, the annual rates for termination after a Down syndrome diagnosis between 1989 and 2012 have ranged from 88 percent to 94 percent [5]. In addition, 10 out of 18 European countries are reported to have an average termination rate of 88 percent after a diagnosis of Down syndrome [54]. Finally, termination rates of 95 percent in certain areas of Australia [55] and 74 percent in select US states are reported [5, 56].

Within this context, and drawing on our claims as outlined above, one may argue that prenatal screening represents a form of eugenics and that the “choice” promised by such techniques is [not necessarily a \(free\) choice at all](#). Force is not involved in prenatal screening decision making (except in presumably rare but understudied familial circumstances) but, arguably, eugenics does not require force. One can claim that even making screening available for Down syndrome and other genetic conditions is already, by definition, suggesting that they are not valued reproductive outcomes [57–59].

But we do urge caution here. Some parents may undertake screening to “prepare” for what they may perceive to be an unexpected and challenging situation, meaning that the outcome is not *always* viewed as “unvalued” (at least by them). In addition, we argue that it is [unhelpful](#) and offensive to pregnant women and medical services or systems that they use to equate *all* prenatal screening and testing to eugenics as popularly understood—usually relating to Nazi Germany. Since NIPT can potentially detect a range of genetic conditions and gene deletions and duplications, it would be wrong to indulge in exaggerated hype about how NIPT and all current screening procedures translate to this kind of eugenics—and that there is some sort of “plot” to deliberately eliminate all fetuses with Down syndrome or other genetic conditions.

This is not to say, however, that a discussion about the future of prenatal screening through a lens of eugenics is unproductive. Screening and testing are unlikely ever to be separated from their eugenic roots. As such, it is fairer to use Shakespeare’s helpful distinction between “historical eugenics” (operating at the population level) and “contemporary eugenics” (operating at the level of individuals and families) [9]. Shakespeare’s argument is that, whilst prenatal screening and testing do not translate to the old eugenics, the practices of reproductive medicine and the context under which reproductive decisions are made, particularly with respect to problematic cultural attitudes towards disability, can undermine the capacity for free choice and can promote “eugenic outcomes” [60].

Arguably, thus, screening for Down syndrome amounts to what we could call a *contemporary eugenics*. The race for a diagnosis for Down syndrome and other genetic conditions—often in the absence of a cure—can be seen as a commentary on which lives are valued or not. Further, the development of new and more accurate technologies contributes to the continuing negative portrayal of disability. Indeed, what frequently

becomes lost in conversations about prenatal diagnostics is how disability is shaped by cultural ideas of “the normal” and a complex interplay of social, cultural, material, biological, economic, and political factors. Research also shows that there has been limited, or nonexistent, discussions of disability—and what it means to have a disability (such as Down syndrome)—to accompany the rapid growth of prenatal technology, particularly in the medical context [7, 61, 57]. This will likely present problems with new technologies like NIPT, which are likely to cause the category of “normal” to diminish and the category of “abnormal” to grow.

Conclusion

We argue that prenatal screening (and specifically NIPT) for Down syndrome can be considered a form of contemporary eugenics, in that it effaces, devalues, and possibly prevents the births of people with the condition. The routinization of Down syndrome screening in many countries across the world, the US included, has ensured that the complex and controversial nature of NIPT, and technologies like it, has been muffled. We must emphasize that we do not lay the blame for the current situation at the feet of pregnant women, the medical profession, or any other social group. We are in this position due to historical and contemporary developments including—among other things—the historic institutionalization of people with disabilities, the growth of genetics, the introduction of prenatal testing for terminating conditions other than Down syndrome, the passing of certain abortion laws, the acceptability of screening as an appropriate medical practice, the medicalization of pregnancy, and the public exclusion of and discrimination against people with disabilities. It is in this context that we should critically reflect on the social and ethical issues of new forms of prenatal screening.

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HEALTH LAW

Safe Patient Handling Laws and Programs for Health Care Workers

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Introduction

Being a health care professional is a tough job. Anyone who has spent time in health care knows firsthand the multitude of responsibilities and pressures these professionals field every workday. Whether it is overseeing a patient's intake, coordinating care with other staff, facilitating a patient's rehabilitation, or cleaning patients and administering medications, the work of health care is physically and mentally demanding.

In recent years, the strains of one particular job duty—patient handling, which typically involves manually lifting, moving, or repositioning patients—have become dangers, increasingly severe and all too common. Changes in working conditions have led to a greater likelihood of a musculoskeletal injury for health care professionals than for workers in all industries [1]. These injuries—often to health care workers' backs, necks, legs, and arms—are frequently devastating, severely hampering the ability of a nurse, for example, to carry out routine duties or ending her career entirely [2, 3].

Since researchers began adducing evidence of just how widespread these injuries were in nursing personnel and other staff in the 1990s [4], several states have sought to address the problem of nursing-specific musculoskeletal injuries through laws and programs. Laws enacted to better protect nurses, nursing assistants, and orderlies, however, have met with mixed success.

Working Conditions that Lead to Injuries

The rise in workplace injuries among nurses and staff stems from a combination of three trends. First, demands on the bodies of nurses and hospital staff have been intensified by an ongoing shortage of nurses around the country that began in 1998 and worsened due to national economic instability beginning in the early 2000s [5]. Although the number of positions in the health care sector has grown since 2001 and the number of nurses entering the labor market has increased, it is estimated that there could be as many as 260,000 unfilled nursing posts in the US by the year 2025 [5]. With fewer staff members, nurses and other personnel must care for more patients and execute more duties.

Second, rising rates of obesity in the US mean that health care professionals are caring for patients who are heavier and sicker [2]. Nurses and staff must regularly maneuver

patients who weigh 300 pounds or more and whose limbs alone can weigh 60-70 pounds [2].

Third, because hospitals are treating patients with comparatively minor procedures and health issues in outpatient clinics and reserving hospital beds for those with serious conditions requiring around-the-clock care [2], staff members are encouraged to help patients get out of bed and move as often as possible, even though these patients might have limited ability to move under their own power [2]. In assisting patients with moving around their rooms, repositioning them in their beds, and other tasks that require physical support of patients, people who do hour-to-hour care face many possibilities for injury.

The Injuries that Result from Patient Handling

The stories of nurses, nursing assistants, and orderlies who have experienced an injury while handling a patient often follow a common pattern: one moment, the staff member is lifting or turning over a patient and, the next, hears a pop and feels a sharp pain running down his or her back and legs—the signs of a collapsed disc [6]. As one nurse put it, “It felt like hot tar was just going down my spine, into my butt” [3]. Hours later, the pain is so consuming that walking feels impossible, and what lies ahead could be months, if not years, of physical rehabilitation, surgeries, and medications that might or might not alleviate the suffering.

Researchers have found that patient handling injuries are not in fact abrupt, freak instances but the result of compounded damage from weeks, months, or years of using lifting techniques hospital staff have been trained to execute [6]. While supposedly protective, in actuality these maneuvers do little if anything to protect staff when they must bend over patients repeatedly, lift patients while reaching, or shift patients’ unevenly distributed weight [7].

Safe Patient Handling Laws

Political and legal attention to nursing and staff injuries began in the 1990s, when federal researchers at the National Institute for Occupational Safety and Health (NIOSH) investigated back injuries in nursing home staff [4]. What NIOSH found, and what the Bureau of Labor Statistics continues to report [2], is that nursing assistants and orderlies suffer back and other musculoskeletal injuries at three times the rates of construction workers and that personal care aides, nursing assistants, and orderlies have more injuries than people in any other occupation. In 2003, the American Nurses Association launched the national Handle With Care campaign to “build a health care industrywide effort to prevent back and other musculoskeletal injuries” [8].

Spurred by these advocacy efforts [9], 11 states have enacted safe patient handling laws or promulgated rules and regulations to address and prevent workplace injuries to

nursing staff: Ohio, Texas, Washington, Rhode Island, Maryland, New Jersey, Minnesota, Illinois, New York, Missouri, and California [9, 10]. Except for Ohio, all of these states' legislation has required health care facilities to establish comprehensive safe patient handling programs [9].

These programs include the development of policies for handling patients, the creation of guidelines for appropriate training, and the acquisition of necessary equipment [9] designed to help health care professionals safely lift and move patients. In addition, these programs call for the collection and evaluation of data in each health care facility to better understand and address the policy and equipment needs of specific patient care environments [9]. All decisional authority for these actions is to come from a safe patient handling committee composed of health care workers who provide direct patient care at a designated facility and specialists with expertise in implementing and overseeing safe patient handling programs [9].

Some of these state laws also include additional features. For example, in Washington State, the safe patient handling law mandates that hospitals obtain needed lifting equipment, for which they will receive a tax credit [11]. In New Jersey, the state law sets out a nonretaliation provision stipulating that a facility cannot take legal action against a health care worker for refusing to lift or move a patient due to either a reasonable concern about patient or worker safety or a lack of appropriate training or access to safe lifting equipment [12]. Ohio's legislation is different from that of the other ten states; it created a long-term, interest-free loan program for nursing homes to use to purchase and install equipment and fund staff education and training that discourages staff from manually lifting patients [13].

When safe patient handling laws are passed and the programs are actually implemented in health care settings, the results are impressive. When 31 rural community hospitals in Washington State implemented a "zero lift program," replacing manual patient lifting with lifting equipment and devices, patient handling injury claims decreased by 43 percent [14]. Two years after instituting a safe patient handling program, a medical center in New Jersey saw a 57 percent reduction in workplace injuries and an 80 percent reduction in lost workdays [15].

These significant drops in both the number and the severity of injuries yield significant financial savings, too. Although the Occupational Safety and Health Administration (OSHA) acknowledges that the costs of instituting safe patient handling programs can be significant (e.g., equipment, training), it cites numerous studies demonstrating that the capital investments in these programs can be recovered in less than five years [16]. At Stanford University Medical Center, an \$800,000 safe lifting program resulted in a five-year \$2.2 million net savings, approximately half of which came from a decrease in worker compensation claims and a reduction of pressure ulcers in patients [17]. And, in

New York, the largest health care provider in the western part of the state made a full return on its \$2 million investment in three years and saved \$6 million in patient handling injury costs over seven years [18].

Obstacles to Establishing Safe Patient Handling Laws and Programs

Unfortunately, resistance to establishing safe patient handling laws and programs and the lax oversight of existing programs continue to stifle their development and implementation.

A 2015 investigative series by National Public Radio (NPR) posited several reasons why safe handling programs are being undermined or loosely monitored. For one thing, the series argued, nurses, nurse assistants, and orderlies are too often considered secondary within the highly hierarchical medical world; although industry groups and associations recognize that nurses and others are susceptible to disabling on-the-job injuries, they do not make responding to this problem an organizational priority [2, 3]. Nurses at some hospitals have reported that their claims have been ignored by administrators and hospital leadership and that they suspect the reason could be financial—specifically, that money paid to an injured worker or used to implement a safe patient handling program is money not spent on infection control measures or other patient care matters [3].

In the case of enacting safe patient handling laws, the NPR series found that opposition to enacting protective legislation has been framed by politicians and hospital lobbying groups in terms of keeping unnecessary, burdensome regulations and “costly mandates” out of the hospital setting [3].

Regarding enforcement of extant laws, officials admitted to NPR that these laws typically have little enforcement power because conducting inspections and assessing adherence to the law requires money, personnel, and resources that many state labor safety departments simply do not have [3]. Even the assistant secretary of OSHA acknowledged the slow uptake and enforcement of these laws, stating that Congress is perhaps best equipped for moving these standards forward by creating a national law on safe patient handling [3].

Congress did act on this matter in December 2015, introducing in both the House [19] and the Senate [20] the Nurse and Health Care Worker Protection Act of 2015, which “requires the Department of Labor to establish a standard on safe patient handling, mobility, and injury prevention to prevent musculoskeletal disorders for health care workers” [21]. Future action on this bill remains to be seen.

Conclusion

Work-related dangers faced by nurses, nursing assistants, orderlies, and other health care workers are real and frequent. With changing patient populations and working conditions, health care workers face unnecessary risks of disabling pain and suffering. Safe patient handling laws and the programs they support offer considerable benefits: reducing the injury rates of the hospital labor force, curtailing injury-related costs, enhancing patient care and safety, and acknowledging the physically demanding nature and overall value of nursing and other health care work.

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POLICY FORUM

Would People with Intellectual and Developmental Disabilities Benefit from Being Designated “Underserved”?

Lyubov Slashcheva, Rick Rader, MD, and Stephen B. Sulkes, MD

Despite social movements in favor of equality in health care, fiscal and political realities often lead to inequality: that is, those with the resources and skills to navigate the health care system and to access care remain well, while the “have-nots” retain an increased disease burden [1]. As Cynthia Jones proposes, such health disparities “are morally problematic because they exemplify and aid in perpetuating a centuries-old system of injustices” [2]. One response to this moral problem is [prioritarianism](#), which, Leslie Scheunemann et al. explain, “attempts to help those who are considered worst off by giving them priority in situations in which all cannot receive a particular resource.... The goal is to give all individuals equal opportunity to live a normal life span” [3]. In the United States, the federal government indicates regions or groups in need of priority access to certain health care resources by designating them *medically underserved areas or populations* (MUAs or MUPs, respectively). Medically underserved areas are designated on the basis of a physical or numerical shortage of primary care clinicians for a given geographic region. Although certain regions may have sufficient clinicians per square mile, people in various demographic groups (e.g., based on income level or other factors) may still not be able to access necessary services; recognizing such demographic groups as medically underserved populations could help acknowledge this problem.

The Example of American Indians as Medically Underserved

Although designating residents of [rural areas](#) as medically underserved has expanded opportunities to profoundly and positively affect the health of these populations [4], the prioritarian response to the health disparities facing American Indians has not succeeded in alleviating those disparities.

Prioritarian programs. In 1956, the [Indian Health Service](#) (IHS) was established to provide for the health care of members of Indian tribes [5]. The Indian Health Care Improvement Act, passed in 1976 [6] and permanently reauthorized in 2010 [5],

contained a vast array of provisions designed to increase the quantity and quality of Indian health services...[including] consolidation and authorization of funding for existing IHS programs, funding authorization for facilities construction, and authorization for health and medical

services for urban Indians... IHCIA authorized Medicare and Medicaid reimbursement for services performed in Indian health facilities [7].

In 1980, the federal government's Health Professional Shortage Area (HPSA) designation was introduced [8]; members of Indian tribes and health care facilities that receive funds allocated by the 1976 act are designated HPSAs [9].

Persistent disparities. These efforts, however, have not eliminated disparities or the persistent disease burden faced by American Indians. Compared to the overall population, the life expectancy for American Indians is 4.2 years less than that for the population overall [10], and they "are more likely than the overall population to report being in fair or poor health, being overweight or obese, having diabetes and cardiovascular disease, and experiencing frequent mental distress" [11].

When they are compared to Caucasians, the disparities are even more striking:

American Indians and Alaska Natives have an infant death rate 60 percent higher than the rate for Caucasians. AI/ANs are twice as likely to have diabetes as Caucasians.... AI/ANs also have disproportionately high death rates from unintentional injuries and suicide. In 2012, the tuberculosis rate for AI/ANs was 6.3, as compared to 0.8 for the White population [12].

The literature mentions two main causes for the persistence of these disparities: chronic lack of funding for Indian health programs [13-15] and "issues that prevent them from receiving quality medical care...cultural barriers, geographic isolation, inadequate sewage disposal, and low income" [12]. Efforts to address these factors have been introduced over time, but have not yet succeeded in overcoming them. All this suggests that challenges that individuals and communities face in accessing care and maintaining health are multifactorial and may not be adequately addressed by the groups' mere designation as underserved.

The Argument for Designating Persons with Disabilities as a Medically Underserved Population

People with disabilities certainly face health disparities. In a recent review boasting the provocative title "Persons with Disabilities as an Unrecognized Health Disparity," Gloria Krahn et al. [16] note that "adults with disabilities are 4 times more likely to report their health to be [only] fair or poor than people with no disabilities" [17]. Seeking reasons for this finding, the authors point to lack of access to care. They report that "adults with disabilities are 2.5 times more likely to report skipping or delaying health care because of cost" [18] and that, "although they have higher rates of chronic diseases than the general population, adults with disabilities are significantly [less likely](#) to receive

preventive care” [18]. Others have detailed that “children with SHCHNs [special health care needs] and their families represent an important underserved population.... Substantial disparities are present in access, satisfaction, and family impact” [19].

Beyond literature references, the co-authors of this article can attest from careers of caring for patients with intellectual and developmental disabilities (IDD), in which they interface with thousands of patients and their families each year, that families’ reports overwhelmingly echo the documented findings: that (across the life span) patients with disabilities experience a patchwork form of uncoordinated health care that leaves them without adequate access to essential health care services. Additionally, a 2002 report from the US surgeon general noted that, “compared with other populations, adults, adolescents, and children with MR [mental retardation (*sic*)] experience poorer health and more difficulty in finding, getting to, and paying for appropriate health care” [20].

There are many examples of “cultivated care”—the term one of us (RR) has used elsewhere to describe health care delivered in a comprehensive, coordinated, caring, culturally competent, and continuous fashion—for people with IDD. This intentional practice model may be instrumental in reducing health care disparities affecting persons with IDD when coupled with innovations such as the medical home, appropriate case management, targeted physician and dentist training, preventive measures, expanded knowledge about secondary conditions, and medical advocacy. But alone it is still not enough to address the disparities documented in the surgeon general’s report; one potential (and probably critical) impediment to addressing these disparities is the nondesignation of this population as medically underserved. Underserved population designation could bring about several benefits [21] for the IDD population: scholarship or loan repayment incentives for clinicians to serve this population, the expansion of physician and dentist training in the care of persons with IDD, funding for expanded prevention and screening of people with IDD, community health center grants to provide care specifically to the IDD population, prioritization in research of issues affecting people with IDD, and the inclusion of people with IDD in clinical trials—particularly in later-stage therapeutic research.

In response to documented disparities, the American Academy of Developmental Medicine and Dentistry (AADMD) appointed a Task Force on Health Disparities, which affirms that persons can be at risk of being medically underserved regardless of their zip code, ethnic roots, or primary language, and, where appropriate, this should be recognized (unpublished data). Based on our data, it seems clear that the phrase “where appropriate” applies to persons with IDD. The AADMD leadership used the definition employed by the Health Resources and Services Administration (HRSA) to ascertain the appropriateness of recognizing persons with IDD as an MUP: according to HRSA, a population can be considered medically underserved if its Index of Medical Underservice (IMU) score is less than 62.0. This score accounts for multiple features of a population,

including poverty, mortality rate, age, and clinician density—meaning how many clinicians in a given specialty, such as mental health, primary care, or dentistry, exist in a given area or patient population [22]. The resultant IMU score for persons with IDD is 54.1, which is well below the determination threshold of 62.0.

Would Designation Make the Right Difference?

Even if designation did occur, merely improving marginalized persons' access to the health care system cannot change the experience of health care for a person, family, community, or population. Designating people with IDD as an MUP will not necessarily promote or ensure high-quality "cultivated care" for them.

There are numerous impediments to high-quality care for people with IDD. Given that people of color and people with disabilities both face social and cultural marginalization, it is reasonable to infer that the disparities faced by people of color may be similar to those confronted by people with IDD. The Institute of Medicine's [23] focus groups on addressing racial disparities in health care cited impediments to high-quality care, including the negative effects of some health care professionals' attitudes (e.g., stereotyping, lack of respect for patients, improper diagnosis and treatment), communication barriers, and financial barriers.

A few of these hurdles to high-quality care for people with IDD include the following:

1. Health care professionals are not adequately exposed to this population during training [24].
2. Medical professionals lack knowledge of logistics (motivation, competence, liability avoidance, and confidence) involved in providing care to persons with IDD [25].
3. Treatment of patients with IDD is poorly reimbursed, which discourages some from treating the complex needs of persons with IDD [25].
4. Informed consent for patients with IDD may be complicated by guardianship (i.e., the legal designation of another person as the patient's decision maker), which requires extra effort and increases clinician concern about effectively communicating with patients, managing complex conditions, and the risk of litigation and malpractice [25].
5. The medical model's focus on cure is still prevalent, which may be irrelevant or harmful to the experience of health and well-being that persons with IDD experience.
6. Clinicians are often inadequately equipped to collaborate with colleagues in other specialties or care management organizations to coordinate the care of their patients with IDD, which hinders their ability to attend to all their clients' needs and contributes to a sense of futility and self-insufficiency (all of which might hinder satisfaction in caring for persons with IDD) [25].

7. At times, the expectations for a “normal” life that families have for their members with IDD may be unrealistic, introducing tension into the patient-clinician relationship that discourages the development of creative, individualized long-term treatment plans and calls into question whether the patient’s self-determination is guiding the planning [25].
8. Ongoing invisibility, marginalization, and devaluation of people with IDD can negatively influence clinical encounters by convincing both patients and clinicians that it is acceptable for persons with IDD to receive second-tier health care [26].

These complex obstacles to optimal care for persons with IDD all need to be addressed. Although important, an MUP designation cannot fully respond to the barriers described because they are more complex than a simple lack of access to care.

Conclusion

Despite these remainders, however, the official recognition of people with IDD as an MUP would be a welcome complement to ongoing efforts to address obstacles to care. Prominent organizations, including the American Medical Association [27] and the American Dental Association [28], have passed resolutions affirming the need for this crucial step and now join the efforts of the AADMD in advocating for ensuring that those whose society has not offered sufficient supports can experience well-being as fully as possible.

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Additionally, professional organizations such as the American Society for Reproductive Medicine (ASRM) and the American Congress of Obstetricians and Gynecologists (ACOG) urge that access to medical care be available without discrimination [6-8]. As for sterilization, ACOG urges that disability is not a reason in itself for or against it and that any such decision must be made on a basis that preserves, as much as possible, the patient's autonomy [7]. This guidance is not always followed. In this paper, we explore how reproductive medicine for women with disabilities may be unfairly obstructed by this kind of laxity in guarding against discrimination and by mistaken assumptions about disabled people. We also recommend how such discrimination may be avoided.

Mistaken Assumptions about People with Disabilities

Several general assumptions commonly are made—mistakenly—about people with disabilities.

Assumptions about decision-making ability. One common mistake is to assume that a patient's having a disability necessarily affects the person's competence. Clinicians may dismiss the possibility of achieving informed consent when patients have intellectual or developmental disabilities, wrongly [equating](#) certain diagnoses with an inability to understand or communicate at the requisite level. Clinicians may be inexperienced in helping patients with disabilities understand complicated medical questions or unwilling to take the time to explain when patients have difficulties in communication. For example, they may neither realize that anyone's decision-making ability is affected by both individual capacity and social context, nor be aware that, for patients with intellectual disabilities, assessment of abilities may be improved by acknowledging positive support from family or community relationships and social services [9-12].

As a result, people with disabilities may be inappropriately subjected to paternalistic judgment, including judgments about their very ability to consent to sex or reproduction [13]. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) Article 12 requires equal legal recognition of persons with disabilities. The CRPD guidance also recommends appropriate supports for persons with disabilities in exercising their legal capacities. In line with CRPD recommendations, many jurisdictions have been exploring methods for supported decision-making—that is, methods of deciding in which persons with intellectual or psychiatric disabilities work with others to determine and pursue their goals [14, 15]. ACOG goes further, stating that it is "essential" to obtain the assistance of professionals trained in communicating with people with intellectual disabilities when ascertaining capacity to provide informed consent for any surgical procedure [7].

Assumptions about sexual and reproductive interests. Disabled people too often are stereotyped as needing special protection, including measures that curtail their ambitions for intimate relationships and family life. It is inaccurate to [assume](#) that being

disabled means having no sexual or reproductive interests or being sexually inactive, celibate, or asexual. For example, the sexual interests of people with physical disabilities such as spina bifida or cerebral palsy may be underestimated based on false assumptions about their sexual capabilities [16, 17]. People with sensory disabilities such as blindness may be burdened by others' false assumptions about their parenting abilities [18, 19]. And people with intellectual disabilities may be looked at merely as potential victims of sexual predation or exploitation, rather than as people with sexual interests or capabilities who need not only protection but also sex education and recognition of their agency [20].

Assumptions like these may be the reason that people with disabilities unjustly receive less access to medically indicated reproductive care than other people of similar age and sex. Too frequently, ordinary preventative services such as noninvasive birth control, pap smears for women who are sexually active, or mammography are not offered or are denied to women with various kinds of disabilities because they are wrongly supposed not to need them [21–23]. Mistaken assumptions about patients' abilities to use these services also reduce access to care [24]. So may concerns that these patients may require lengthier visits—for example, to navigate narrow examination rooms crowded with furniture or access equipment designed with the assumption that all patients can stand—or lack of familiarity with how the disability may affect a physical, cognitive, or communicative component of the appointment [24].

Misjudging Women with Disabilities in the Context of Reproductive Health Care

We now turn to assumptions that lead to misjudgments in reproductive care for women with disabilities.

Assumptions about risks of pregnancy. First are exaggerated or misdirected concerns about the riskiness of pregnancy when a person with a disability is involved. It is not unusual for women whose disabilities do not affect their gynecological functions to have their pregnancies labeled high-risk and to be referred for unnecessary consultations or tests by an overanxious clinician [25, 26]. Caesarean sections and induction of labor may occur more frequently in women with disabilities, even in the absence of standard medical indications [25, 26]. An illustrative example is that of a pregnant triple amputee referred to genetic counseling although her impairment was not inherited. A perinatologist to whom she also was referred denied that her pregnancy was high-risk and warned her against being talked into a caesarean section just because her absence of limbs made other physicians nervous [27]. Clinicians should take care that assumptions about risks are not prompted or exaggerated by unwarranted generalizations or stereotypes. If risk is considered per patient, and it is determined that a pregnancy would be of significant physical risk to a particular woman because of her disability, she may also achieve lower-risk parenthood by being offered access to surrogacy [12].

Assumptions about probability of treatment success. Clinicians should avoid conflating judgments that an intervention would be futile—for example, a determination that pregnancy is physiologically impossible because a patient lacks a uterus—with judgments that prognosis is poor (in which cases pregnancy would be physiologically possible, but unlikely). In cases deemed to have a low probability of pregnancy, some patients with disabilities, just like some patients without, may still wish to try to achieve pregnancy. According to the ASRM, treatment may be ethically provided in such cases if patients are fully informed about their prospects and clinics develop patient-centered, evidence-based policies about when they are willing to provide fertility services [28].

Beliefs about parenting ability. Much less clear, but not less frequent, are judgments about fitness to parent that motivate reluctance to provide fertility services. Mistaken assumptions about parenting ability may discourage referrals for fertility therapy [29, 30]. People with disabilities who reproduce are sometimes condemned as posing risks to or imposing burdens on society. Women with disabilities who have experienced pregnancy frequently report being targeted by complaints about their selfishness, based on the assumption that their relatives will have to raise their children or that their children will become burdens to taxpayers [12, 27].

Despite increased understanding of heritability, disabled women may also be discouraged from pregnancy out of misplaced fear that their children will in turn have disabilities [27]. As legal history underlines, people with disabilities have been subject to forced sterilization for precisely these reasons [31, 32]. The US Supreme Court's 1927 decision in *Buck v. Bell* upheld involuntary sterilization on the grounds that it was necessary "to prevent our being swamped with incompetence. It is better for all the world if...society can prevent those who are manifestly unfit from continuing their kind" [33]. This reasoning is both misleading, as many disabilities are not heritable, and profoundly biased, as it expresses the idea that the existence of disabled people impedes or otherwise harms everyone else.

Whether withholding reproductive services from patients is discriminatory depends on the beliefs that prompt it: are all prospective parents vetted to discover whether they are likely to raise children safely and well—or has stereotyping made disability a trigger for withholding services? The ASRM opines that fertility programs may withhold services to prospective parents—but only on the basis of "well-substantiated judgments that those patients will be unable to provide minimally adequate or safe care for offspring" [34]. The ASRM cautions clinicians to "pay special attention to treating equally persons with disabilities who request fertility services" [35] and notes that children thrive within a wide range of "parenting approaches or homes" [35]. Especially noteworthy is the ASRM stricture that scrutiny of potential parenting ability should not be applied to persons with disabilities unless applied to persons generally [6]. The ASRM is explicit that this

antidiscrimination provision applies to both potential parents with intellectual disabilities and mental illness and those with physical disabilities.

This advice—to respond to patients with disabilities with respect—requires attention to individual differences, language and culture, counseling settings, stressors, and medications [7]. It may be generalized to all areas of medicine and to all disabilities as good guidance for acting ethically by avoiding discrimination.

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MEDICAL NARRATIVE

An Open Letter to Medical Students: Down Syndrome, Paradox, and Medicine

George Estreich

If you're reading this, you could be anyone—a bioethicist, a Facebook friend, an adult with Down syndrome—but the “you” I have in mind is a future clinician. As a writer and parent of someone with Down syndrome, my aim is to share questions and insights that may be useful to you. Clinical encounters involving people with intellectual disabilities can be both charged and complex; understanding the complexities may help improve the encounters, by helping clinicians [see the patient more clearly](#). I will focus on Down syndrome, because it's what I know best, but ultimately I wish to emphasize similarities between people with Down syndrome, people with other disabilities, and those of us who, because we lack named conditions, are presumed to be “normal.”

At this point, you may be expecting to be scolded or inspired. In the first case, I would recount an anecdote involving an insensitive physician and warn you against analogous behavior, perhaps cautioning you against language offensive to people with disabilities. In the second, I would offer an appealing, positive story about my daughter, thus inspiring you to recognize her essential humanity, to see her as a person and not as a diagnosis.

These are common scripts, and they have their uses. Still, I try to avoid them. Practically speaking, no one was ever scolded into enlightenment, and what we call “inspiration” is often weaponized sentiment, a battering ram with a Positive Message printed on the end. Although I've written a book [1] about my daughter, the humanity and value of people with Down syndrome—and of people with other disabilities, however defined—is a starting point for me, not a persuasive destination. One should not need an inspiring story to be valued.

I wrote the book about my daughter for many reasons, but one was that since the attention she drew was inevitable, I might as well work with it. If people were going to stare, I might as well lend some depth to the picture; because, as I found, they were often staring at a projection. This projection—call it a huggable ghost—was a vague shape, a diagnosis with a personality, a mix of sweetness and tragedy, of angels and heart defects and maternal age. It was a way of imagining Down syndrome, but it hid the individual. The projection, the ghost, obscured the child.

In that book, my project was to restore the child to view. In this letter, my project is to help banish the ghost from the exam room. To that end, I want to discuss some of the obstacles to seeing people with Down syndrome clearly and on their terms, and to suggest a paradox: since one of the greatest of those obstacles is the medical description of the condition, a thoughtful physician will need to both absorb that descriptive knowledge and be able to set it aside.

No one says that people with lung cancer have a particular personality, but the idea that there is a "Down syndrome personality" (sweet, affectionate, cheerful) is, in my experience, common among clinicians. It's less common among parents, but even when asserted, it's usually to support an individual story, and not an idea of diagnostic sameness. Parents are intensely aware of a child's distinct personality and situated life, her story in time.

The tendency to equate diagnosis with personality has roots in medical history, and ultimately in the history of Western thinking about race. The condition now known as Down syndrome was first described in Western medicine in 1866, by the young physician John Langdon Down, then medical superintendent of the Royal Earlswood Asylum for Idiots [2]. When Down christened the condition "Mongolian idiocy," believing the "idiots" in his care to have descended a hierarchy of races *in utero*, he grafted ideas of race onto ideas of disability. It was a brilliant error, a stroke of blurry insight: the list form could incorporate both observable features and presumed ethnic characteristics. Down was no simple racist, and in his treatment of asylum residents, he was ahead of his time [3]. But he saw the individuals under his care through the lens of group attributes.

For this reason, the claim that people with Down syndrome are "sweet," however well intentioned, makes me uneasy. It feeds the perception that Down syndrome is the "good" special need, the appealing one, which seems unfair to kids with behavioral difficulties. It can also misfire in any number of ways: children with Down syndrome who are expected to be sweet but aren't can be seen as disappointments; children with Down syndrome are often expected to give hugs to strangers, a real problem given the high rates of sexual abuse committed against women with intellectual disabilities [4]; children with Down syndrome can be seen mainly in terms of static behavioral qualities and not in terms of what they might learn.

But most of all, "sweet" is something you say of a child. People with Down syndrome now have a life expectancy of around 60 [5]. If we think of them as permanent children, we will be less able to imagine a place for them in the world as adults.

There are few certainties with Down syndrome. Because we know where it begins (with a nondisjunction, or a failure of a chromosome pair to separate during cell division) and what results (an infant with a suite of typical features), we can believe, too easily, that it

is known. But the condition is incredibly variable, and those variations, entering a changing world, result in many different outcomes.

Ironically, among all the [probabilities](#), [possibilities](#), and distant chances associated with Down syndrome, the primary certainty—what used to be called “retardation”—is not clearly within the domain of medicine. To have an atrioventricular canal defect, or leukemia, is one thing. But to be less able than most to manipulate information, to reason abstractly, is another. It’s not only that people with Down syndrome have a range of abilities, which overlaps with the range considered “normal.” It’s that ability itself cannot be measured or considered outside of social context.

Even setting aside the long history of underestimating what people with Down syndrome can do, it’s worth noting that people with intellectual disabilities, besides being among the most despised minorities in our culture, are cast in a harsh light by a society that prizes intellectual ability and accomplishment. Negotiating our text-heavy, Information Age democracy requires an unprecedented degree of literacy and technological ability. In work, in education, those abilities are heavily incentivized. Indeed, our educational system encourages us to equate intellectual performance with self-worth, to motivate ourselves by seeing ourselves as our grades and accomplishments. Teaching English at the university level, I’ve seen this in many of my students—and in myself, too, a lesson I’ve learned too deeply to forget.

Which brings me back to you, reader. You don’t get into medical school without taking ability itself—and particularly intellectual ability—seriously. The entire project assumes capabilities that tend to be diminished in people with Down syndrome: skill with language and numbers, ease with abstraction, the ability to process, retain, and manipulate large quantities of information.

A question, then, is how to imagine the value of people who don’t have those abilities: how to value your own achievement without devaluing those for whom those achievements are difficult or impossible. Much in our culture, from ubiquitous insults based on intelligence to the medical definitions of normalcy to the relative invisibility of people with disabilities, teaches us separation. Clinical encounters tend to take place across a gulf, a chasm both narrow and deep. The question is how to step across it.

The divide between doctor and intellectually disabled patient can be framed as a divide between able and disabled. But I think it is best seen in terms of interpretive power.

To be intellectually disabled is to have your life be synonymous with an opinion not worth listening to: on Facebook, in every comment section, in conversation, that’s what the words *idiot*, *moron*, and *retard* imply. Conversely, being a clinician confers authority: your words matter, weighted not only by study, experience, and your resulting expertise,

or by the prestige accorded the profession, but also by the white coat, the stethoscope, the successive human barriers (e.g., receptionist, nurse) that frame an appointment, the ritual of gates dividing you from the patient.

You have, in other words, power to declare meaning. Paradoxically enough, your best course may be to refrain from using it. That is, apart from treating a given patient with Down syndrome like any other, the power to declare meaning entails *not* pronouncing what a patient is or what her life means, but instead learning to listen.

From the moment a child is diagnosed with a disability, her parents are swamped with interpretations, advice, and predicted futures. But predictions and interpretations, even comforting ones, may be less useful than an honest uncertainty. For any child, the agents of nurture—parents, clinicians, therapists, educators—are there to help keep her future as open as possible. That way, the child, when she is ready (when she is no longer a patient, no longer a child) can begin to find her own way, and to choose the meanings for herself.

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SECOND THOUGHTS

Avoiding Assumptions: Communication Decisions Made by Hearing Parents of Deaf Children

Janet DesGeorges

Lizzy, age 7 months, had just been identified as deaf, and her parents were preparing to make decisions regarding communication choices for her, such as whether to pursue cochlear implants or teach her sign language. Lizzy's parents were encouraged to attend a workshop on decision making in deafness by her early intervention clinician. When they sat down at the first session and looked around, they saw many deaf and hard of hearing (D/HH) people in the audience signing to one another. Lizzy's mother couldn't help herself—privately, her first feeling was grief. She thought, "This has nothing to do with our daughter, with our family." How could her daughter be part of something that felt so foreign to her?

As she looked up on the stage, there was one person speaking and an individual next to the speaker signing. "Ah, they must have an interpreter up on stage," the mom surmised. As she focused her attention on the speaking person, however, she gradually became aware that the presenter was in fact the person who was signing, and the interpreter was voicing for that person. She had just assumed that the presenter was the hearing, speaking individual.

The description of the school was also a surprise to Lizzy's parents. For the all-deaf student body, accessibility was provided through visual communication (paging systems, captioning, and sign language). For the first time, Lizzy's parents could visualize a world in which deaf people could thrive, not defined by the "deficit" of living in the world without the sense of hearing.

When those around them learned they were undertaking this process, everyone seemed to have opinions they weren't shy about sharing:

"If you sign to your child, she will never speak."

"If you don't sign to your child, she will grow up to hate you and turn from your family to Deaf culture and community."

"Your daughter has a right to her natural language: ASL."

"It's a hearing world, and you need to be hearing to make it through."

All this only made the decision seem weightier and more daunting. What was the right decision? Was there a "right" choice? Whose choice was it to make?

Responsibilities Facing Parents of Children with Deafness or Hearing Loss

The implementation of universal newborn hearing screening, with the result that more than 97 percent of infants are now screened for hearing loss in the US [1], as reported in 2013 by the Center for Disease Control (CDC), and has created a new generation of deaf and hard of hearing (D/HH) children whose hearing loss is identified earlier than ever before. Because research shows that infants who receive early intervention by six months of age show better language outcomes than children who do not [2], there is pressure to begin intervention quickly. With the advent of cochlear implants (devices surgically implanted behind the ear with an electrode thread into the cochlea), there has been an increase in implantation of younger children and of infants as young as 12 months. But families need time to develop well-informed choices regarding language, communication, methodology (e.g., cued speech, listening and spoken language [LSL] therapies, different signing systems), and technology use—including the use of cochlear implants—and, if they have not had much exposure to deafness, time for their perceptions to evolve. Indeed, the great majority—90 to 95 percent—of deaf and hard of hearing children are born to hearing parents [3]. Generally speaking, these parents have no prior experience with deafness or hearing loss [3], and they are asked to make definitive, often life-altering choices for their D/HH children.

Pressure on Parents

Decision making regarding communication and language choices for children often weighs heavily on parents. This is true for both medical decisions—in the case of cochlear implantation—and/or nonmedical decisions, such as incorporating the use of sign language. This decision making usually takes place within the first few months postdiagnosis, a time of intense vulnerability for parents, as “experts” in the field (e.g., medical practitioners, linguists, early intervention providers, deaf/hard of hearing individuals) hold strong opinions about what the “best” path for D/HH children might be in terms of language and communication acquisition. The “[war on communication choices](#)” for deaf people has been carried on for generations in political, moral, educational, and clinical contexts. In my experience, parents are often at the center of this vortex of debate, and many people feel they have a right or an obligation to tell parents what is best for their D/HH children.

Historically, there seem to me to have been two primary viewpoints on deafness. In one, deafness is viewed as pathological, a medical condition or disability, and in the other deafness is embraced as a cultural difference, something to be celebrated [4]. (Deaf culture is often defined as the set of social beliefs, behaviors, art, literary traditions, history, values, and shared institutions of communities that are influenced by deafness and that use sign languages as the main means of communication.) These viewpoints have traditionally been very binary (implants *or* signing, etc.). The fact is, however, many families may choose to seek medical intervention for their children while at the same time beginning to explore the social, educational, and cultural implications of those

choices. The quality and quantity of information a family needs to form their own sense of what this experience means for them and their child comes from a variety of sources. The cultural identity and belief system of a family influences and gives meaning to this process.

In recent years, experts' views have evolved to include the idea that parents don't need to make a "choice" between spoken or signed language but can incorporate both—some form of bilingualism—into a child's development [5]. Signing, speaking, and a combination of the two are all viable options that can lead to success for D/HH children, depending on the individual child. According to an analysis of 181 research studies on language development in children who are deaf, researchers "have not yet found *the* approach that supports development across the domains of social functioning, educational achievement, and literacy. A single such approach is unlikely" [6].

The journey a family goes through upon discovering that a child has hearing loss is a distinctly personal one, leading to choices that others probably should not judge. Parents have moral and legal authority and responsibility to make decisions on behalf of their children and the right to exclude others from such decision making. It should not be assumed, just because parents of a deaf child are hearing, that their decisions will be based on wanting their children to also be hearing. Families who do choose spoken language for their children are not denying who their deaf children are, but are seeking good communication and language skill development options for their particular child and have a right and an obligation to do so. One Deaf woman recently suggested this important distinction between her *hearing* and her *self*: "I wish that I had understood from the beginning that the Cochlear Implant changed the way I heard, but did not change who I am."

For Parents and Clinicians

Hearing parents of children who are D/HH must evolve in their understandings of hearing loss to make good decisions on behalf of their children, as well as monitoring the needs of their own children, their own beliefs and desires, and ways of assessing and interpreting their child's progress in language and communication.

Families may begin to understand, embrace, and delight in their deaf children who are different from them, including adopting a new language (American Sign Language and/or other visual signing systems) outside the context of their culture and family.

Parents' decision making is an evolving dynamic that requires time, as well as knowledge and understanding of—and support for—their own child's makeup and propensities. There is a vast amount of information and knowledge, both personal and expert, a family needs in order to make effective choices for their child who is D/HH. These sources of information often come from other families of children who are D/HH [7], members of

the Deaf and hard of hearing communities, educational institutions, and medical professionals with specific expertise in the field of deafness. Input from multiple sources allows the family to obtain a diversity of needed perspectives, expertise, and values to create a balanced, viable system of support for attaining successful outcomes for children.

Ultimately, while parents have rights and obligations to make choices for their young children, the journey is not entirely within the realm of parental control and evolves as the child grows. Parental rights and obligations seem naturally to lessen in strength and scope as children gain decision-making ability [8]. As the author of *The Parenting Journey: Raising Deaf and Hard of Hearing Children*, Karen Putz, notes, "Sometimes on the course of the journey...the path changes in ways we can't imagine. As our kids get older, they begin to weigh in on our decisions and make decisions of their own. Sometimes their decisions go against everything we've known" [9].

Families value professionals who know how to explain medical and technological options while also honoring the realization that parents are the ultimate decision makers for their child. This delicate balance can be a challenge for professionals who are trained in the "craft" of service provision but usually not given explicit training in the more esoteric art of "family support." Professionals who have the ability to incorporate dynamic family support into direct service provision congruently create a structure for a meaningful partnership with the families they are serving.

An important point for families is that they need to quickly become knowledgeable in an arena that is new and sometimes overwhelming. Families must know and understand the unique needs of children who are deaf or hard of hearing and apply that general knowledge to their own children, families, and community. In the end, when parents are given good support and make decisions for their own child, that child has a wonderful chance of fulfilling her or his own—and his or her family's—hopes and dreams for a meaningful life.

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Suggested Readings and Resources

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