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Disability Ethics in Neonatology:
A New Script for Neonatologists Informing Parents About Their Infant with Down Syndrome

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Disability Ethics in Neonatology:
A New Script for Neonatologists Informing Parents About Their Infant with Down Syndrome

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Abstract

Disability Ethics in Neonatology: A New Script for Neonatologists Informing Parents About their Infant with Down Syndrome
By April R. Dworetz, M.D., M.P.H.

This thesis establishes a new script to help neonatologists and parents of neonates who are newly diagnosed with Down syndrome (DS) to better imagine the potential future life experience for the infant. It incorporates disability ethics and ethical avenues for communication about children with DS. And it provides a nonableist way for healthcare professionals (HCPs) to help parents facing an unexpected situation.

The introductory chapter examines the script's importance, the medical and social models of disability, and reviews of neonatal and disability ethics, and includes a brief overview of Down syndrome. In the subsequent four chapters, I discuss the contextual factors leading to this conversation: neonatal ethics, disability ethics, giving "bad news," and the language of disability. Together these chapters address both the need for and the concepts essential to this alternative dialogue.

The core chapter (chapter 6) of this thesis comprises two scripts—the old script and the new script—and an analysis of the old. The old script, a hypothetical conversation between a neonatologist and the parents of a newborn with DS, illustrates the ableism (discrimination against disabled people) typically present in these discussions. I analyze the old script for ableist attitudes and associated ethical issues. Then I present the new script, an imagined dialogue between a different neonatologist and the same parents. This script exemplifies a nonableist and ethically superior way to convey to parents that their baby has DS. This script accomplishes four goals: (1) it emphasizes the importance of nonableist communication, (2) it speaks the language of HCPs, (3) it guides the HCP to use different content for such conversations in the future, and (4) it offers a template for HCPs upon which to base their discussions.

As a result of adopting this innovative conversation, neonatologists and other HCPs may re-envision disability. In addition they may provide better support for their inexperienced parents, better care for their patients, better bonding between parents and infants, and a better lived experience for the parents and their disabled children. My goal is to disseminate this script to neonatologists and pediatricians to encourage a different image of babies with DS—and all disabilities.

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Abbreviations

AAP: American Academy of Pediatrics

AHA: American Heart Association

BIS: Best Interests Standard

DS: Down syndrome

ELBW: Extremely low birth weight

HCP: healthcare professional

LST: life-sustaining treatment

NICU: Neonatal Intensive Care Unit

T13: Trisomy 13

T18: Trisomy 18

WHO: World Health Organization

WWLST: withhold(ing) or withdraw(ing) life-sustaining treatment

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Chapter 1

Introduction: Neonatology, Disability, and Decision Making for Disabled Infants[1]

My Thesis: Goals and Significance

The goal of my thesis is to generate an alternative, preferable script for neonatologists talking with parents about their infant with Down syndrome (DS) (for detailed explanation, see below). This improved dialogue both retains necessary facts about the diagnosis and incorporates concepts that disability advocates and scholars contend are missing from the medical model of disability (see below)—including nonableist language that changes the tone of the communication and a nonableist view of disabled people.[2] By expanding the discussion about disability, I am inserting a moral element into a medical conversation.

The drawbacks of the traditional conversations have stimulated and guided the development of the scripts. In order to support the new script, I have written chapters that comprehensively introduce subjects that affect this conversation. These topics include neonatal ethics, disability ethics, giving "bad

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[1] Some disability scholars prefer the term, *disabled infants* (or people), others prefer the phrase infants (or people) *with disabilities*. I use both forms interchangeably and hope I do not disparage anyone.

[2] *Ableism* is discrimination toward disabled people. Although some disability scholars use *disableism* in place of *ableism*, I prefer the latter term. *Ableism* suggests that the discrimination pertains to the lack of recognition of an individual's ability rather than his disability. See chapters 3 and 5 for a more detailed discussion.

news," and the effects of language on disability.[3] They provide the background needed for both analysis of the old script and development of the new.

Along with providing fodder for development of the new scripts, the disadvantages and subsequent analysis of the old scripts form the arguments needed to convince neonatologists that changing their conversations creates a scenario consistent with the best interest of their patients. My arguments and suggestions for action and language arise from a neonatologist's bioethical and disability perspective. This view leads me to the following assumption: Disabled infants matter morally.[4]

Improved health and wellbeing of these morally significant disabled infants necessitates a model of care that bridges the gap between the perspectives of healthcare professionals (HCPs), parents, and disability advocates. HCPs, mostly unaware of models of disability, perceive themselves as healers. They take care of patients and keep up with current research so that they can restore health or function to their patients. Their goals include diagnosing and treating medical illnesses or disorders with hope for a cure; social agendas seem to me to retain little place in the medical care agenda. Yet the provision of this medical care implies agreement with a set of values with which HCPs may not agree—or with which their patients and family members may not agree. This unrecognized

[3] I place quotation marks around "bad news" because physicians traditionally use the term to describe information about a parent's disabled child. However, this information is not necessarily bad news to the parents. See chapter 3 for a more comprehensive discussion.

[4] Peter Singer has challenged the idea that disabled infants matter morally (Singer 2011, 160–67). I disagree. For a more thorough argument, see chapter 3.

complicity demands clarification of the role HCPs may play in harming their patients and suggestions for alternative narratives.

Like most of the medical world, neonatologists know little about disabled persons' perspectives of life. Most of the colleagues with whom I have discussed this topic think—and I myself thought, before I learned about disability—that children with "profound" neurodevelopmental disability, or other "severe" congenital anomalies have lives not worth living.[5] The extensive scholarship about disability has not reached most HCPs, as evidenced by the attitudes and actions of many of my colleagues in neonatology and ethics consultations that I have attended at a large public hospital. Yet, HCPs greatly impact the lives of disabled persons, sometimes to the extent of recommending whether to continue or end life based on the prospect of disability.

At the same time, many disability advocates, activists, and scholars do not recognize the goals and obligations of HCPs (Barnes and Mercer 2010, 59–60; Kittay 2011, 615) when demanding a change in medical care for disabled people. Instead they want physicians to embrace the idea that disability stems from the lack of environmental and social accommodations and reject the concept that disabled people necessarily need treatment. Many disability scholars have told

[5] *Profound*, *severe*, *moderate*, and *mild* are terms that are frequently used by the medical profession to describe degree of disability. The labels are subjective; they involve categorization used both by physicians for prognostication and by researchers for data compilation. Unbeknownst to many in the medical profession, these descriptives create classes of disability that may not reflect the disabled person's self-described degree of disability. In medical writing, *profound neurodevelopmental disability* encompasses multiple possible disabilities associated with cerebral palsy, intellectual disability, blindness, and hearing loss. The definition and severity vary depending on the reporter; different authors of studies of neonatal outcome as well as diverse HCPs define this outcome differently. For a longer discussion of these issues, see chapters 2 and 3.

me harrowing tales of insult and injury at the hands of HCPs. In most of these stories I have recognized the other side of the story: the physician doing his job, though imperfectly.[6]

Despite the preference of disability advocates that physicians embrace their perspective, physicians have a duty to diagnose and treat. The predicament occurs due to the lack of understanding by and communication between the two parties. This thesis begins this conversation between disability scholars and healthcare professionals.

With this new script, I hope to help HCPs understand the advantages of changing scripts. When they try the new script (or even a part of it), I expect them to experience its benefits in terms of the responses of the parents of their disabled children. At the beginning of this journey of learning about disability ethics, I started to recognize the positive aspects of disability. In turn, I attempted a more positive exchange with parents of a disabled patient. Their encouraging response inspired me to continue to change my conversations with other parents. Little by little these experiences have convinced me that a different attitude about disabled people is priceless for helping the parents of disabled children who are newly diagnosed as well as the children themselves. My aim is for other HCPs to read my work, make some changes in their own discussions with parents, and eventually change, at least to some degree, the way they care for disabled patients.

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[6] I have thought hard about the most suitable words to use for gender nonspecific pronouns. I find that *she or he*, *him or her*, and *s/he* interrupt the flow of the sentence. Rather than use gender nonspecific pronouns that others have invented (or make up my own), I choose to use different gender-specific pronouns with gender-neutral meaning in alternate chapters. That is, for odd chapters I use male pronouns to represent gender-neutral pronouns; in even chapters I use female pronouns to represent gender-neutral pronouns.

Therefore, the new script—a product of my thesis—may help HCPs do their job better by increasing beneficence and decreasing harm for disabled families and their patients. The script may assist parents in perceiving the potential for a good life for their disabled children; this may improve bonding with and acceptance of their children. Additionally, it has the potential to give the parents a head start in educating themselves about how to provide their children with some of what they require to live the best life possible. The disabled newborns cared for by these HCPs likely may have the advantage of loving, caring parents who have become the best parents they can be. And these newborns, along with the rest of us, may benefit from a little less ableism in this world.

In my thesis I argue that HCPs should accomplish three objectives to benefit the lives of disabled patients and their families. First, they should learn about the lived experiences of disabled people. Second, they should incorporate their newfound understanding of disability into their dialogues with patients. Finally, they should treat their patients as complete people instead of regarding them as their disabilities.

This thesis will matter for bioethics and neonatology. As far as I know, this is the first practical reference addressing and resolving some of these bioethical dilemmas faced by physicians and disabled people. This writing arises from the viewpoints of both HCPs and disabled people: in a sense conflict resolution *in absentia*. The thesis delves into the bioethical quandaries of neonatologists when providing care for infants newly diagnosed with DS. And one can generalize these specific arguments into general arguments for the medical care of disabled people. The changed script does not compromise the physician's duty, but it does provide

some of the cooperation that disabled advocates demand. My thesis provides important information about the needs of disabled neonates and their parents that hopefully will initiate a new understanding of disabled patients by neonatologists.

Creating a script that incorporates goals from the social model of disability (see below) into the medical model (see below) engages neonatologists in ethical actions that align with their professional goals. In this way the new scripts can effect change in the neonatal and disability communities. I have already begun to try variations of the script in practice and intend to implement this new script in regular neonatal care,

In the remainder of this chapter, I describe the methods of this thesis including a sketch of how my interests, thoughts, and experiences led me to this thesis and a brief overview of the resources I used. Next, I present brief introductions to neonatal care ethics, disability ethics, and the two major conceptions of disability. The subsequent part of this introduction succinctly outlines each of the chapters of my thesis. For chapter 6, the core of my thesis, I describe the process I used to create and develop the two scripts, including the analysis of the old script. Finally I discuss how I plan to implement this new script.

Methods

Situating the Researcher

My clinical and academic interests and focus within neonatology have converged toward the creation of this thesis. My curiosity about and attentiveness

to discussions with parents of my newborn patients has grown over the years. I have spent significant time pondering the best way to tell a parent what he does not want to hear including that he must help me choose between providing comfort care and aggressive, painful medical care that likely will result in his child being disabled. Though I routinely give parents such information, I constantly fine-tune my approach and search for a better way.

Regarding disabled children, the first "aha moment" happened when I heard a talk by Anita Silvers about people with disability at an ethics conference commemorating the 25th anniversary of the Baby Doe rules.[7] I suddenly realized that disabled people have worthy lives too. Of course, I knew that some disabled people have attained some of the goals that our society holds dear. But I suddenly saw people with disabilities in a new light: I recognized that all people with disabilities also have abilities. And disabled people sometimes have abilities that I wish I had.

It took me awhile to mesh this insight with my work with neonates. After all, neonatologists use advanced technologies to save babies who otherwise would have died. And since I highly prize autonomy in the hierarchy of ethical principles, I did not question the fact that I often presented *possible* "profound" disability as a judicious and practical reason for providing comfort care. Not until I started to think about disability ethics, in part thanks to Rosemarie Garland-Thomson's introduction of it in an ethics class, did I have any doubts about my moral

[7] Anita Silvers is a leading philosopher, disability scholar, feminist scholar, and bioethicist.

reasoning for basing treatment decisions on questionable prognoses of disability.[8]

As my knowledge of disability studies advanced, my misgivings about the way HCPs identify and value disabled people increased. I started to observe the cruel (though private) comments that other HCPs made about disabled infants. And comments about the inabilities and lives of disabled parents made me more and more uncomfortable. I remember remarks made about a cognitively (or intellectually) disabled mother who loved her son and spent every day learning to care for him. When he was ready to go home, one of the nurse practitioners insisted that the mother could not take care of him due to her intellectual disability. For another mother, I heard concern that she could not take care of her infant at home because she was physically disabled. This was despite these parents living with the infant's grandparents to guarantee continuous help.

To be sure, I have not lost all of my discriminatory attitudes toward disabled people, partly due to my inability to completely comprehend their situations. However, I know that some aspects of the care most neonatologists provide to disabled infants should change. And my situation makes me the best person (with much support from others) to lead the transformation.

I initially planned to write new scripts for discussions between neonatologists and the parents of three types of disabled neonates: infants with Down syndrome, deaf infants, and infants with "profound" neurodevelopmental disability. So far, I have only addressed the infant with DS. However, I plan to

[8] Rosemarie Garland-Thomson is an internationally acclaimed cultural disability scholar, literary scholar, feminist scholar, and bioethicist.

write the other two scripts for future publications. Meanwhile, my particular interest in how we speak to parents of newborns with DS arose from many conversations I have had with such parents. Once I started to think about this topic for my thesis, two memorable experiences helped to shape the new script.[9]

The first involved me congratulating the mother of a child with DS who I had just met. I followed the congratulatory comment with a mention of her baby having DS. I said something like "Congratulations. Your baby has such beautiful skin. And Dr. X told me that your baby has Down syndrome." The nurses and nurse practitioners thought the juxtaposition of my remarks bizarre. The mother also looked at me with surprise. But the mother soon opened up to me about her mixed feelings, an important step to her subsequent bonding with her baby. This encouraged me.

A month or two later, I took over the care of a newborn with Down syndrome on his second day of life. I will call him Jonny Calm. During sign-out, the neonatologist informed me that Jonny's parents were "in denial" and waiting for the confirmatory tests.[10] When meeting the parents I introduced myself and congratulated them. They smiled and immediately warmed to me. I told them that I understood that Jonny may have Down syndrome and that his test results were pending. They agreed and did not have an obvious emotional response. I asked how they felt about the possibility that Jonny had Down syndrome. Ms.

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[9] I have changed details and names in all stories relating to my patients in this thesis in order to hide their identity.

[10] Sign-out is the process of transferring information about a patient from the off-going HCP to the on-coming HCP: the transfer takes place at change of shift (for example, in the afternoon from the daytime physician to the on-call physician) or change of service (when the daytime physician in charge changes from one physician to another).

Calm said she would love Jonny either way. She had an uncle with Down syndrome and he was an integral part of her family. Mr. Calm stated that he preferred that Jonny not have Down syndrome, but he too would love him regardless of his chromosomal results. Both parents wanted to wait for the test results. The Calms were not refuting the facts, and denial played no role here; the Calms were accepting Jonny, Down syndrome or not.

These two incidents and many other conversations with parents of disabled infants helped me shape the new script. I also used thirty years worth of conversations with parents and neonatal colleagues to build a conversation that balanced the needs of the patients, the families, the neonatologists, and the healthcare system.

Resources

In addition to my personal experience with colleagues, patients, and their families, my resources consist of medical and bioethical journal articles and books, legal cases, medical organization policies, educational websites, and a few magazine articles. I have spent much time over the last few years in personal conversations with neonatal and bioethical colleagues, disability scholars, and disabled people; I have read journal articles and books about the lives and quality of life (QOL) of disabled people. Importantly I have also read about, observed, and pondered the language used by society—physicians, scientific authors, bioethicists, ordinary people, family, and caregivers—to describe disabled people.

My most helpful references are listed here. Of the neonatal outcome literature, Adams-Chapman et al. (2008) Allen (2002; 2008), Hintz et al. (2011),

and Stephens and Vohr (2009) stand out as my major references. I primarily refer to American Academy of Pediatrics (AAP) guidelines (1994; 1996; 2007), Kopelman (1997; 2005), Kopelman and Kopelman (2007), Lam et al. (2009), Saigal, Rosenbaum et al. (2000), and Saigal, Stoskopf, Feeny et al. (2000) for my neonatal "end-of-life" resources.[11] Some of these neonatal "end-of-life" care references address bioethical concerns as well. The major "end-of-life" bioethical contributors include AAP recommendations (1996), Asch (2000), Cuttini, Casotto et al. (2009), Cuttini, Nadai et al. (2000), Rebagliato et al. (2000), Lam et al. (2009), LaRochelle et al. (2009), Wocial (2000). Books (or chapters in edited books) and journal articles comprise the majority of my sources for disability theory and advocacy. These include Barnes and Mercer (2010), Clark and Marsh (2002), Davis (1995; 2010a) and his many contributors, Sandel (2007) and Solomon (2012). I relied on the following authors for disability bioethics information: Albrecht and Devlieger (1999); Bellieni and Buonocore (2009); Garland-Thomson (1997; 2012); Janvier, Farlow, and Wilfond (2012); Janvier, Barrington, and Farlow (2014); Linton (2010); Scully (2008a; 2009); Silvers and Francis (2009); Shakespeare (2008; 2010); and Shakespeare, Iezzoni, and Grace (2009). For my Down syndrome references I mostly use AAP (2001); Soper (2007); Skallerup (2008); Pace (2011); Sheets et al. (2011); Skotko, Capone, Kishnani (2009); Skotko, Levine, and Kaplan (2011); Sandel (2007) Van Riper (2007). Menikoff (2001) is my key legal reference (along with specific court

[11] I do not like the term "*end-of-life*" *decision making* which usually refers to choosing between comfort care (end of life) and continuation of treatment (continuation of life). I use the term here because it reflects the way many journal articles refer to this decision. For the remainder of this thesis, I will use the term *life-or-death decision making*.

cases). Giving "bad news" references include Brewin (1991), Fallowfield (1993), Fallowfield and Jenkins (2004), Ptacek and Eberhardt (1996). Language and slur information came largely from Anderson and Lepore (2013b), Croom (2013), Deutscher (2010), Harpur (2012), Jule (2008), and Kailes (2010). Finally, regarding policy, I draw on the US Child Abuse Prevention and Treatment Act (CAPTA) (42 U.S.C. § 5106a(b)(2)(C) 2012), AAP guidelines (1994; 1996; 2001; 2007), and American Heart Association (2006; 2013) and AAP standards.

I cite sources by page number (when applicable) in the text of my thesis and list the complete reference in the bibliography. A paragraph that lacks a reference contains either general knowledge or my thoughts and ideas grounded in my many years of experience in the neonatal intensive care unit (NICU).

Major Concepts in This Thesis

Ethical Issues of Neonatal Care

With technological progress enabling neonatologists to save the youngest lives comes the responsibility for neonatologists to discuss treatment options with the families of the babies (AAP 1994, 532; AAP 2007, 402; Mercurio 2009b, 358–60). Neonatologists often discuss the option for comfort care after withholding or withdrawing life-sustaining (WWLST) treatment for extremely low birth weight infants, severely disabled newborns with congenital anomalies (that is, newborns with structural deviations from the norm that cause death or severe disability), and severely asphyxiated term neonates (AHA and AAP 2006,

e1035).[12] Policies from the AAP and AHA permit "severe" or "profound" morbidity and mortality to guide decisions by physicians and parents to WWLST from neonates (AAP 2007, 401–3).

In order to better clarify some of the terms I use to discuss the neonatal aspects of disability, this paragraph briefly reviews the basics of pregnancy duration and prematurity. A pregnant woman's due date is calculated to be 280 days or 40 weeks after conception. A preterm delivery occurs before 37-weeks gestation, and after this point, a delivery is considered to be at term. Though full term infants can have life-threatening conditions, most of the sick babies in our unit are preterm. The younger (in terms of gestational age) and smaller newborns have a higher risk of illness and future disability than older and larger newborns. By 34- or 35-weeks some infants eat well, keep their temperatures within normal range, and go home with their mothers. Below 30-weeks we worry about bleeding in the brain. But we see the highest risk of disability below 28-weeks. A few babies have survived at 22-weeks gestation.

The primary ethical aspect of neonatal care for the tiniest preterm and sickest term infants is deciding whether to initiate—or continue—aggressive therapy or initiate comfort care. I base this determination on thirty years of neonatal experience and countless articles about neonatal "end-of-life" care in bioethics and pediatric journals. Such decisions require clear and accurate communication of diagnosis, prognosis, and treatment options between the

[12] Asphyxiated neonates experience inadequate blood flow and/or oxygen to the brain *in utero* (or during delivery); this often causes long-term "severe" disability.

neonatologist and the infant's parents. Usually the decision rests on the infant's likely quality of life, particularly the potential for disability.

Typically, in my unit at Emory University Hospital Midtown and according to accepted medical-ethical practice (AHA and AMA 2011, 287–88), parents of babies born from 23 0/7-weeks to 24 6/7-weeks gestation may opt for resuscitation or comfort care in the delivery room.[13] Comfort care consists of warmth, swaddling, pain medication if needed, and parental love. The parents can also opt to withhold or withdraw life-sustaining treatment and provide comfort care after stabilization in the NICU because withholding life-sustaining treatment (LST) is considered ethically equivalent to withdrawing LST (Mercurio 2009b, 360; The International Liaison Committee on Resuscitation 2006, e984).[14] In addition, if the neonate develops extensive bleeding in both sides of the brain, a severe intestinal infection, or severe respiratory disease, the parents may choose to provide comfort care instead of continuing LST.

Full term infants also may develop severe problems that make WWLST and comfort care an option. Primarily this occurs with asphyxiated babies or babies who have "severe" congenital anomalies, physical variations that occur during fetal development. Depending on the extent of the asphyxia or involvement of the congenital anomalies, the baby may develop a range of brain

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[13] In the delivery room, resuscitation consists of initiating life-sustaining treatment including artificial breaths, intubation for attachment to a ventilator (a machine that helps an infant breathe), chest compressions, epinephrine (to restart the heart if it has stopped) and/or fluid provision. If parents of infants at 22 0/7- to 22 6/7-weeks gestation request resuscitation, many neonatologists will provide it.

[14] In addition to the resuscitation procedures in the delivery room, decision makers may choose to withhold or withdraw life-sustaining treatment in the NICU. These include medications to sustain blood pressure, antibiotics, other medications, intravenous fluids and nutrition, and enteral fluids and nutrition.

damage from "minimal" to "profound" with long-term outcomes including death, intellectual disability, or cerebral palsy.[15] Some congenital anomalies also severely limit the child's life expectancy. We do not resuscitate infants with anencephaly or other congenital anomalies considered incompatible with life at my unit at Emory University Hospital Midtown.[16]

Children with a diagnosis labeled *incompatible with life* either are not expected to breathe off the ventilator or have syndromes for which medical training and studies indicate early death. Some of these situations depend on circular reasoning (babies who need but do not receive resuscitation die). Still, AAP policy (1994; 1996; 2007) supports the option of WWLST for many of these infants. The designation *incompatible with life*, although supported by AAP policy for some congenital syndromes and asphyxiated babies, remains somewhat subjective as I further discuss in chapter 2. Regardless, depending on their parents' preferences, term infants who were resuscitated and have a high likelihood of severe disability may have intensive care withdrawn.

Thus, this decision to end the life of a tiny baby often rests on the possibility for disability, not on a terminal condition (AAP 2007, 402–3).[17] Many neonatologists have said to me (and I would also have stated, before I started thinking from a disability viewpoint) that physicians and parents make the decision based on the likelihood of death or a "life not worth living." The

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[15] Cerebral palsy is a disorder of movement, muscle tone, and balance.
[16] *Incompatible with life* is a term used to describe infants who will die, usually within the first few years, without LST. However, the designation varies according to the physician.
[17] Some neonatologists might consider the condition "terminal" if they believe that the infant will die. However, neonatologists have no adequate algorithm that effectively prognosticates death for the sickest of babies (Koogler, Wilfond, and Ross 2003, 38–40).

surrogate decision maker (the parents for most infants) may decide what constitutes a "life not worth living." This approach reveals the lofty position that autonomy holds in the current ethics of healthcare. However, from my experience of the WWLST conversations between my colleagues and parents, our discussions emphasize the infant's potential disability more than the family's values.

In helping the parents to make such a decision, neonatologists tend to provide the different options of care, including continued "aggressive" care, continued "aggressive" care but no intensification, continued "aggressive" care but no chest compressions, continued "aggressive" care but no intubation, and comfort care.[18] In order for the parents to provide fully informed consent, most physicians talk with the parents about the infant's prognosis. This prognosis, though often including possible death, usually focuses on the likelihood of "severe or profound" disability. The physician may take the decision-making process down one of three typical paths: (1) highlight the probability of a poor quality of life for a "severely" or "profoundly" disabled child with disability, (2) focus on the parents' values, or (3) ask about their "goal" for their child.

Here I relate one example of each of these routes toward a decision. The first was a patient of mine, whom I will call George Profound. George was a 6-week-old, ex-23-week preterm neonate (at the limit of viability) who had severe immature lung disease and large hemorrhages in both sides of his brain. As a result of the hemorrhages, the ventricles in his brain enlarged and he developed

[18] Comfort care is the provision of comfort for the baby in terms of warmth, holding, sometimes feeding, and pain medication concomitant with withdrawal or withholding of LST. Though death does not necessarily follow the initiation of comfort care, almost all neonates who receive comfort care die.

hydrocephalus.[19] Before I started caring for him, three neonatologists had discussed whether to continue LST or provide comfort care on the basis of his prognosis for probable "profound" disability. At least some of the neonatologists had told the Profounds that the "worst case" scenario was that he might never speak, possibly never communicate, "be confined to a wheelchair or bed," and need diapers for the rest of his life.[20] I was told the parents were in denial. As a result, I tried again, marking the fourth time one of the neonatologists tried to help them make a "reasonable" decision. I call this "battering the parents." A few neonatologists have criticized my objections to repetitive WWLST conversations after the parents have made a decision to continue life support; they assert that insisting parents learn to cherish and love their disabled children is just as bad as pushing them toward comfort care. I agree. Adoptions are viable options. HCPs should include alternative choices if the parents clearly do not want to care for their disabled infant.

The second patient, let us call him Baby Joshua Sanctity, was an extremely preterm baby who required high settings on the ventilator and had large hemorrhages in both sides of his brain. If he survived until discharge, he had a

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[19] Ventricles are spaces in the brain that contain spinal fluid. When they function normally, the choroid plexus (an area of the brain that involutes at about 34-weeks gestational age) produces spinal fluid that flows toward the spinal canal. The arachnoid villi (projections in the venous areas of the brain and spinal cord) absorb the spinal fluid into capillaries and veins along the path. A blockage of spinal fluid occurs. In preterm infants with bleeding in the brain, this obstruction results from an increase in the viscosity of the spinal fluid (due to the blood), a decrease in absorption in the arachnoid villi or venous pools. In response brain cells may die and the ventricles may enlarge, a condition called hydrocephalus (Behrman, Kliegman, and Nelson1992, 1488–89).

[20] Disability scholars and activists prefer active descriptions of environmental accommodations and avoid phrases that describe disabled people as victims. Therefore, this child would "use a wheelchair" rather than be confined to it. See chapter 5 for more details.

high likelihood of developing significant disability and the potential for multiple surgeries and hospitalizations throughout his life. I knew that the family, conservative Baptists, believed strongly in the sanctity of life. Still, my responsibility required that I raise the option of WWLST. They believed in G-d's power to heal. And what if G-d did not create a miracle for Joshua? Then they would love, cherish, and care for him. For the Sanctitys, their clear values and beliefs informed their choice about care for their infant. They wanted Joshua to live his sacred life for as long as possible. Their values and beliefs led them directly to their decision.

In each of these situations, the neonatologists (including me) used the words *severe* or *profound* to describe the infant's disabilities. These two categories of disability produce images created by the imaginer (see chapter 3 for a detailed discussion of using such descriptors). That is, *severe* or *profound* disability may mean different things to different people. Specific definitions also vary according to different journal articles, studies, experts, and practicing neonatologists (see chapter 2 for more on these categories). In addition, disabled people object to these categories: what is profoundly disabling to one individual may be mildly disabling to the next. Disability is only skin deep.

Recently a maternal-fetal medicine physician asked me to consult with a patient who was pregnant with a fetus with short arms and legs.[21] They were concerned because she refused to abort after multiple recommendations; for these doctors continuing the pregnancy seemingly had no value. Yet, the day

[21] A maternal-fetal medicine specialist is an obstetrician with training in high-risk obstetrics.

before this consultation, I had attended a Society for Disability Studies conference at which I spoke on a panel with a brilliant disabilities scholar with short arms and legs, a man who clearly leads a worthwhile life.

When relying on categories without precise definitions, parents need more information in order to provide true informed consent for withholding or withdrawing life-sustaining therapy.[22] Even without categorizing disabled people, many parents have not thought much about what specifically it is that makes an infant's life worth or not worth living. A life that one person does not value may equal the life another person values, both from the disabled person's and surrogate's viewpoint. The obstetricians recommended abortion because they did not envision good life for the fetus of their patient.

The same lack of imagination pervades decision making for treatment of sick neonates. At times the parents choose a treatment option for their infant based on their individual phantasmagorias of their child's future life. But, when I have asked my disability studies colleagues about the quality of life of an institutionalized child who has minimal communicative ability and painful contractures and requires a caregiver to dress, bathe, and feed him (by a tube that tunnels into his stomach via a hole in his abdomen) (an outcome that concerns most neonatologists), they question my assumptions about the quality of that individual's life. They remind me that with or without physical or psychic suffering, the child is a person.[23] This part of the disability advocacy argument

[22] What constitutes "informed consent" could provide the subject for another thesis. I will not address it in this thesis.

[23] The issue of personhood is complex and controversial. I briefly address this issue in relation to the right of a disabled infant to live or die (see chapter 3).

creates a dilemma for me, one I still ponder: can someone have a good quality of life if he cannot communicate and lives in an institution? And what if he has the pleasures of touch, sound, smell, and imagination, but also has the displeasures of pain, abuse, and suffering? The quality of life of a noncommunicative person is an important, but difficult to answer question.

But for many other disabilities, and even for the noncommunicative, institutionalized person, I suggest that the reason neonatologists give the option to parents to WWLST from their potentially disabled child is the bias our society has against disabled people (in addition to the reality that standard of care dictates such conversations). Many people—but not all—do not want to have a disabled baby. The high percentage of abortions for babies with congenital anomalies confirms this statement. And yet, not all parents opt for WWLST when given the chance.

I have gathered numerous reasons why parents opt to keep their children alive based on conversations with my colleagues. Some neonatologists think that many parents conceive of giving consent for WWLST as "killing" their child. Several think that parents cannot bear to part with their babies, who often look like any other baby. Others assert that parents are "in denial" about the potential realities. A number note that some parents play the "miracle card."[24] And, some parents truly value a disabled child's life.

Only two reasons that parents opt for comfort care and death come to mind. First, parents do not want their child to suffer and expect suffering with

[24] Parents "play the miracle card" when they express the *certainty* that G-d will create a miracle and save their baby.

continued treatment. Second, the parents do not value the life of a child with significant disability.

Down Syndrome and Neonatal Care

My thesis, though, concentrates on parents who have children with Down syndrome (DS) that is recognized at birth. These parents do not have a life-or-death decision to make. Rather, they usually have a learning curve to manage. They often, though not always, have adjustments to make from their negative attitude toward disabled people and from their initial expectations of a nondisabled child. They may have this hypothetical nondisabled child to mourn. And they have much to discover about their child's future. They usually know little about their child's abilities and disabilities, but they frequently have many misconceptions about what lies ahead.

I propose that the difficulty some parents have adjusting to the idea that they have a baby with disabilities reflects the bias that they (and so much of society) have against disabled people. Just like with parents who are deciding between continuing life support and switching to comfort care, their initial responses and, in some cases, their long-held values reflect a bias against disability. At the same time, the physician informing them of their child's disability often has the same bias. The physician's expertise in the child's medical care creates a conversation about the medical implications of the disability rather than the potential and ability of the infant. Although parents may want to learn about the medical issues, especially early-onset and life-threatening conditions, they also need to learn about their child's future capabilities.

To illustrate the imperative for a different construction and conversation, I present a baby who I will call Rashawn Ball. He was born with an abnormal heart rhythm. Eventually I realized he would probably die within his first year of life. Before I knew the extent of his medical illness, Mr. Ball asked me if Rashawn would ever play ball. I did not know. Mr. Ball appeared devastated. I told him that I used to do my math workbooks during recess, because I didn't like sports. In response, I saw contempt on his face. For Mr. Ball, physical prowess trumped cognitive ability. I asked if it would be so bad if Rashawn became a doctor. He smiled; I had reframed the situation. What one person enjoys, another scorns. This may hold true for parent and child, whether or not they are disabled.

Additionally, Mr. Ball wanted to understand Rashawn's potential abilities. I did not have the answer at that point, just like I do not know the potential abilities of any infant born in the unit. Once we had a diagnosis we could better inform him. But for some children, including children with DS, we have a host of possible—or probable—abilities to communicate. Physicians do not always have the knowledge to discuss such nonmedical matters. However, just like acquiring medical information about their patients, physicians have the responsibility to acquire life skill information or, at least, suitable references. In this way parents may get what they need to start to accept, love, and bond with their new infant.

In order to make the transition to caring, affectionate, and attaching parent, I suggest that the parent should learn about his child's disability from a disability perspective. That is, he should gain knowledge about how his child will have the ability to do some things and not have the ability to do other things, just like every child.

This requirement usually pertains to new parents of babies with DS. In my experience, the feelings of new parents whose child is born with previously undiagnosed DS vary. Most seem upset, shocked, sad, overwhelmed, or angry. However, such grief usually dissipates with time. Sometimes the shift occurs in minutes or hours, while other times the process takes longer: months or even years. But I have found that by the time most infants with DS leave the NICU, their parents have bonded with and started to accept them. This process continues until, as discussed in chapters 2 and 6, their parents see them as "gifts" who have taught them much about life.

But I find that neonatologists do not typically recognize that disabled babies can have a good quality of life (not to mention that nondisabled babies often have a poor quality of life). Additionally, nondisabled babies sometimes grow into disabled children or adults. Neonatologists do not inform parents of apparently nondisabled neonates about their infant's potential for disability later in life: mental illness, cerebral palsy, learning disabilities, attention deficit disorders, and so on. However, they often tell parents of infants with DS about conditions that will likely not occur.

I suggest that the reason for this behavior on the part of pediatricians and neonatologists reflects the medical understanding of disability: that a disabled neonate *is* his syndrome. These doctors often expect the parents of a child newly diagnosed with DS to express shock, disbelief, and existential angst.

Introduction to Disability Ethics

Though many ethical issues arise from neonatal decision making and informing parents about their disabled newborn, for this thesis I focus upon both ethics of disability and disability ethics. I use these two terms in accordance with Jackie Leach Scully's (2008a, 9–17) definitions. She defines the *ethics of disability* as the morally appropriate way of interacting with disabled people in many contexts, only one of which is healthcare. Scully emphasizes *disability ethics* by defining a new type of ethics:

> a form of ethical analysis consciously and conscientiously attentive to the experience of being/having a 'different' embodiment (Scully 2008a, 11)."

That is, part of the ethical analysis should include the viewpoints, knowledge, and life events of people with disabilities.

Disability ethics matters in these NICU situations because neonatologists often talk with parents of disabled newborns. Physicians, at least the physicians I have worked (and spoken) with, generally are not aware of the concept of disability ethics; yet without such awareness, physicians may unknowingly discriminate against their disabled patients.

Major Models of Disability: The Medical and Social Models

Attempts to define disability prompt passionate disagreements amongst disability scholars and activists (Koch 2008, 18–20; Oliver and Barnes 2012, 11–24). These disagreements center on the two core models of disability, the medical model and the social model. Although other models have been developed

(including alternative social models), the social and medical models still predominate (Scully 2008a, 22–30).

According to the medical model, an impairment such as an illness, injury, disorder, or congenital anomaly—causes the disability (9 2010, 29; Barnes and Mercer 2010, 18–24; Linton 2010, 224; Oliver and Barnes 2012, 19–20). As a result, the impaired individual embodies the disability. Linton claims that

> the medicalization of disability casts human variation as deviance from the norm, as pathological condition, as deficit, and significantly, as an individual burden and personal tragedy. (Linton 2010, 224)

The impairment refers to a statistical deviation from the norm of physical or mental function due to genetics, illness, or injury (Shakespeare 2010, 268). In this model, disability is the limitation of function caused by "the biology of the person" (Scully 2008a, 23). The (presumably undesirable) impairment is the target of treatment; ameliorating or eliminating the impairment to allow maximal functioning is the goal of treatment (Davidson 2010, 136; Oliver and Barnes 2012, 19–22; Smith 2009, 15, 18). Within this medical archetype, disabled persons are "abnormal."

On the other hand, the strong social model of disability does not situate the cause of disability with the disabled individual.[25] Rather, this model blames the social, economic, and political responses to disabled people for the disability (Davidson 2010, 136; Edwards 2008, 26–27; Koch 2008, 18–20; Oliver and Barnes 2012, 19–20, 22–23; Scully 2008a, 25–27; Shakespeare 2008, 11–14; Shakespeare 2010, 267–69; Smith 2009, 18–21). The physical or cognitive

[25] The social model I describe here is the extreme model, which has prompted challenges by several counter-models (Scully 2008a, 25–27). Scully identifies this more extreme model as the *strong social model*.

variation of the individual does not disable (Andreou 2010, 464; Edwards 2008, 26–27; Koch 2008, 18–20; Shakespeare 2008, 11–14). Instead, society's failure to provide an economic and social environment that translates for individual phenotypic variation creates the disability and engenders society's discriminatory attitudes toward people with disabilities.[26] These discriminatory stances trigger exclusion from social and economic activities. Such marginalization and society's intolerant attitudes promote disability. Thus, from the perspective of the strong social model, social change, social and political understanding, and political engagement with disability issues alleviate disability.

The disability activists and advocates, who champion the strong social model, reject the medical model because it perpetuates disability (Barnes 2010, 29–31; Edwards 2008, 26–27; Kittay 2011, 627; Oliver and Barnes 2012, 19–24; Scully 2008a, 27; Shakespeare, Iezzoni, and Grace 2009, 1815–16; Shakespeare 2010, 266–72; Smith 2009, 16).[27] They use their social, economic, and political arguments to criticize the medical model. Depending on their philosophical, experiential, medical, social, and cultural viewpoints, however, disability scholars often disagree about the defining characteristics and details of the preferred social model of disability (Koch 2008, 18–20; Scully 2008a, 27–30; Shakespeare 2010, 266–72). Even so, they agree that both positioning disability solely in the

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[26] I borrow this meaning of *translates* from Douglas Scott, the founder and Artistic/Executive Director of Full Radius Dance, a dance company that takes choreographed works and *translates* them for dancers with disabilities.

[27] More recently some disability activists and scholars (such as Tom Shakespeare and Eva Kittay) have rejected the strong social model of disability, claiming that it does not capture the entire intricacy of the lives of disabled people (Kittay 1999, 171–72; Scully 2008a, 27–30; Shakespeare 2008, 11–13). Though Shakespeare still maintains that social and environmental barriers create exclusion, he also allows for the need for some medical treatment and rehabilitation.

medical realm often harms disabled people and social, economic, and political conditions should change to accommodate disabled people.

Nevertheless, other social models, such as the social-relational models, incorporate aspects of the medical model and also conserve the socio-economic, environmental, and social disabling arguments of the strong social model (Scully 2008a, 27–30). For example, Scully states that she and other feminist disability scholars, using an ethic of care theory (Kittay 1999, 53–54; 2011, 615), agree that socio-economic, environmental, and social factors cause disability, but they also recognize that "social-relational" (Scully 2008a, 25–29) influences play a part. Scully asserts that "subjective experience of the impaired body," "its psych emotional aspects," and "the processes through which disability is constructed by cultural representations and language" (Scully 2008a, 27, 172–73)—in addition to social, economic, and environmental barriers—contribute to disability. Kittay clarifies these ideas:

> The prototypes of the environmental fix that the social model of disability urges are alterations in the physical environment. As important as these are, still more important is the environment of inclusion: of welcoming many sorts of bodies and minds, seeing the world as enriched by this diversity, and embracing the possibilities as well as the challenges presented by those who diverge from the norm. (Kittay 2011, 627)

In this way feminist scholars insist on the interwoven contributions of "private experience and public oppression"(Scully 2008a, 29) to disability.

In addition to the feminist theorists, poststructuralist disability scholars reject the strong social model. The poststructuralists' concerns involve the ableist attitude of society toward disabled people and the continued potential for social discrimination even if the socioeconomic and environmental barriers are

removed (Scully 2008a, 28). From this perspective, cultural "representation" and language perform primary functions in "understanding the ontological and moral meaning of disability" (Scully 2008a, 28). Taking this theory a step further, Carol Thomas suggests that

> in any "real" social setting, impairments, impairment effects and disableism are thoroughly intermeshed with the social conditions that bring them into being and give them meaning. (Thomas 2007, 137)

Here Thomas indicates that social and economic discrimination of disabled people involves the impairments, their effects, and the ableism on a social-relational basis.

This engagement between the social and medical models makes the most sense to me. The disregard of impairment effects on disability has raised the greatest difficulty for me in understanding the social model of disability.[28] I personally have witnessed the impairment effect in my patient's parents, in patients I cared for many years ago, and in disabled family and friends. Physicians see this effect regularly.

For physicians to outright reject the medical model and wholly embrace the strong social model would require an unlikely transformation. Yet some movement has occurred. In 2001, in response to objections to the medical model view by the social and political disability community, the World Health Organization (WHO) (WHO 2012) updated its definition of disability to include the *impact* of impairment rather than solely the *cause* of impairment. This redefinition incorporates aspects of the social model (see below for a detailed

[28] Impairment effects, as described by Thomas, are the direct consequences of physical impairment on physical, psychological, or cognitive function (Thomas 2007, 137).

explanation) along with the notion of "medical or biological dysfunction" (Chan et al. 2009, 334–35) that originates in the older medical model. These newly included viewpoints from the social model consist of (1) the abilities of persons with impairment and (2) the social and environmental elements that play a role in inclusion and functioning of disabled individuals.

However, the WHO's redefinition, though it has possibly affected global health organizations and HCPs in the United Kingdom, does not seem to have influenced the practice of many HCPs in the United States. Most HCPs, having trained within the medical model system, perceive disability according to the older medical model definition. Occasional medical specialists (psychiatrists, for example) and sub-specialists (physiatrists, for example) incorporate social and environmental accommodations into their healing duties. I would speculate that most HCPs think about disability as a primarily physical or intellectual impairment. This medical construction of disability affects attitudes that HCPs—and society in general—have toward disabled people.

Over the past thirty years, psychologists, bioethicists, rehabilitation professionals, and psychometricians have studied attitudes of nondisabled persons toward people with disability (Livneh 1988, 46). These studies demonstrate that even personal caregivers and HCPs, those who regularly interact with disabled persons, maintain negative attitudes toward them.

In this vein Oliver and Barnes, disability activists and scholars, describe how medical professionals perceive disabled persons: "disabled people become objects to be treated, changed, improved and made 'normal'" (Oliver and Barnes 2012, 19). The authors imply that HCPs intend to fix the less-than-whole patient.

By doing so the HCPs devalue disabled people and perpetuate the dependency of the disabled on the nondisabled.

However, healthcare specialists I know do not choose or attempt to harm their disabled patients. Medical education has instilled in physicians the duty to help patients (beneficence) and not harm patients (nonmaleficence). However, they hold a mandate to treat, rehabilitate, transform, or cure their patients. Their goal is to minimize disability (which they perceive as impairment) and suffering, and maximize function. Because HCPs emphasize health, they justify their stress on healing, ability, transfiguration, and restoration. Treatment or rehabilitation as harm is a foreign concept to HCPs. Physicians may recommend treatment, even when it is mostly ineffective, in hopes of an improvement or cure. They usually do not recognize the harm of stigmatization, ableist language, or always trying to "fix," "treat" or "cure" their disabled patients. Yet, for the benefit of these patients, HCPs should familiarize themselves with some of the nonmedical facets of disability.

Although leading health organizations have made changes to the medical model regarding social attitudes and medical care of disabled persons, my concern is that these shifts have not filtered down to healthcare professionals. HCPs know little of the changed model. Still they perceive a moral difference between disabled and nondisabled persons; their practice therefore reflects this discrimination. The medical model persistently attributes suboptimal functioning of disabled persons to their specific physical, mental, or emotional damage. Though impairment may cause impairment effects, negative attitudes worsen the

experience of impairment by influencing the degree of disability, function, and health.

Adrienne Asch, a disability bioethicist, agrees that HCPs should learn about disability:

> It is time for people in medicine and bioethics to listen to people with disabilities and their families who consistently report that their lives are not tragedies, that often their lives are as satisfying as those of nondisabled people, to the extent that scores on self-report standardized psychological measures can be trusted. (Asch 2000, 249)

A large part of the harm done by the medical model consists of the discrimination, intolerance, and unfairness that are perpetrated against persons with disability by individuals, workplaces, communities, and policies (Shakespeare, Iezzoni, and Grace 2009, 1815–16). Despite major differences in perspectives about disability, supporters of both the medical and various social models agree that the lives of many people with disabilities are less than ideal, whether due to innate impairment or barriers to inclusion. My experience suggests that advocates of both models think that they are working for improvement in the lives of disabled people. Still, HCPs delivering medical care to disabled persons may not know of the different models or the specific concerns of their disabled patients. Eva Kittay develops this argument by stating that

> all the carers, parents, physicians, and hospital review boards must be informed by the lived experience of disability. (Kittay 2011, 615)

Kittay, expanding her point about the role of HCPs, adds that

> an ethic of care would demand that the medical personnel recognize their asymmetrical power. In their role as carers, they have to listen to parents' views and concerns. But because the new parent, if not herself disabled or already the parent of a disabled child, is likely to bring her own ableist biases to the situation, and as the physician is professionally liable to see disability as a medical condition only, a fully adequate

> response will require information from those better situated to provide a perspective from a life lived with disability. (Kittay 2011, 615)

If unaware of the issues, HCPs can neither alter their view nor improve their care.

The Outline of My Thesis

The intersection between the ethical option to forgo neonatal intensive care for babies with potentially "severe" disability and the ethical responsibility toward those potentially disabled babies forms the essence of my thesis. For an outline of my thesis please see the table of contents. In the following four chapters (chapters two through five), I discuss neonatal ethics, disability ethics, giving unexpected news to parents of disabled neonates, and the effect of language on ableism.[29] These chapters consist of reviews of each topic. They provide background for contributing arguments to the penultimate and principal chapter of my thesis. This chapter, the Down syndrome chapter, comprises four sections: a brief introduction to DS, the old script, an analysis of the old script, and the new script (see next paragraph for details).

I compare two different dialogues between a neonatologist and two hypothetical parents, Mr. and Ms. Langley. In each conversation, the physician informs the Langleys that their newborn has (previously undiagnosed) DS. The old script represents how physicians typically inform parents that their infant will be disabled; I base this dialogue on my personal experiences, conversations with

[29] The neonatal ethics chapter includes an examination of the standards of care and ethics of WWLST for newborns. Though this does not directly impact my major task of creating a new way for neonatologists to speak with families of neonates with DS (presented in chapter 6), it previews important information that I originally planned for this thesis and will write at a later date. The future article will address an innovative conversation for neonatologists to have with parents of children with significant disability.

and observations of my colleagues, journal article recommendations of how to give “bad news,” and personal writings by parents of children with Down syndrome. This script reflects a “best practice” approach to giving “bad news” (as suggested in journal articles). I then analyze the script according to the ethical issues discussed in the previous chapters. Finally, I offer a “new script” for neonatologists to use when discussing, in a nonableist format, with new parents that their newborn has DS. This “new script” incorporates published references; information in chapters two through five of this thesis; and many discussions I have had with colleagues, patients with DS, disabled people, and disability advocates.

In my last chapter I summarize my arguments and conclude with a discussion of the significance and future directions of my work.

Chapter 2

The Ethics of Life-or-Death Neonatal Decision Making

A Brief History: The Ethics of Life-or-Death Neonatal Decision Making

As technology advanced in the late 1960s and early 1970s, smaller, younger, and sicker babies were resuscitated and survived. Neonatal intensive care units (NICUs) arose. And neonatologists started to see babies that survived with severe disability (Hintz et al. 2011, 63, 67; Stephens and Vohr 2009, 631–33).

The ethical dilemma of choosing between saving a disabled baby and allowing her to die was introduced publically in 1971. Two babies with Trisomy 21—also known as Down syndrome (DS) —and duodenal atresia (a complete obstruction of the intestines) were allowed to die at Johns Hopkins University because their parents refused consent for life-sustaining surgery; the parents' preference for death resulted from concerns regarding the effect of the infant's survival on the family (Mercurio 2009a, 838–39). Only two years later, Duff and Campbell (1973, 892–94) sanctioned withholding life support for infants following discussions and consensus between parents and physicians. Their rationale depended upon beneficence for disabled infants, families, and society (Duff 1982, 43–44).

In 1982, the case of Baby Doe in Bloomington, Indiana, brought this controversy to the legal arena. Baby Doe was born with DS and tracheoesophageal atresia, another potentially fatal disease that can be remedied

by surgery.[30] Baby Doe's parents refused surgery. The hospital and administrators took the case to court. The court and two subsequent appeals upheld the right of the parents to withhold medical treatment. Baby Doe died before the United States Supreme Court was able to hear the case (Mercurio 2009a, 842).

This case stimulated the development and codification of the Baby Doe rules. The Baby Doe rules, controversial from the outset, stem from the Reagan government's anti-abortion stance. These rules, also known as the 1984 amendments to CAPTA, the Child Abuse Prevention and Treatment Act, require that a state receiving federal funds for child protective services programs have a system for responding to reports of "withholding of medically indicated treatment from infants with disabilities who have life-threatening conditions" (CAPTA 42 U.S.C. § 5106a(b)(2)(C) 2012).

These rules mandate medical treatment, including nutrition and hydration, to sustain life for all infants except if:

> (i) The infant is chronically and irreversibly comatose; (ii) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or (iii) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under such circumstances would be inhumane. (45 CFR. 1340.15(b) (2)(i)–(iii) 1990; Scott 2009, 804)

Interpretative guidelines from the Department of Health and Human

[30] A trachea-esophageal fistula is a connection between the esophagus and one of a few parts of the trachea. This fistula allows contents to flow between the esophagus and trachea. The most common type of fistula causes milk in the esophagus to enter the trachea, causing coughing and respiratory distress. This condition is life threatening and requires surgery for correction (Behrman, Kliegman, and Nelson 1992, 941–42).

Services clearly state that (1) withholding or withdrawing treatment may not be based upon opinions regarding the future quality of life (QOL) of a disabled neonate; and (2) even for the case of an exception in which the medical provider may forgo medical treatment, the rule requires the provision of hydration and nutrition (45 CFR Part 1340 Appendix). For the medical profession, the Baby Doe rules represent intrusion of the government and the anti-abortion propagandists into medical decision making, an action that belongs between the physician and the parents of the infant.

For the disability community, as Silvers and Francis (2009, 1062) so eloquently argue, the Baby Doe rules are actually "protection against the denial of services to disabled people." Further, they argue, the Baby Doe rules mandate

> prohibitions against disadvantageously differential treatment. Read in this way, the words of the Baby Doe regulations state that infants with disabilities must not lack access to medically indicated treatment that would be offered to infants who have similar medical needs but are free of the shadow of disability. (Silvers and Francis 2009, 1062)

Reinterpreting the Baby Doe rules as symbolic of protection against disability discrimination changes the conversation.

With this new exchange we are no longer talking about the right to die. Rather we are talking about the right for a disabled child to live and get medical treatment. In this dialogue, the disabled person via the surrogates, usually the parents, becomes a conversant.

Ethics of Neonatal Life-or-Death Discussions

Despite the Baby Doe rules, neonatologists continue to regularly discuss withholding and withdrawal of life-sustaining medical treatment with parents of their patients. However, babies with Trisomy 21 are no longer considered too intellectually impaired to have a good quality of life and neonatologists and surgeons consistently treat the medical problems of these infants. With the conversation of treatment of infants with DS off the table, the controversy has moved to newborns with extremely low gestational age or severe asphyxia who can now be saved due to the massive expansion of life-sustaining technologies. These infants develop variable and sometimes physical, intellectual, and behavioral outcomes considered devastating. Neonatologists have conversations with pregnant women and their families concerning withholding resuscitation in the delivery room when the babies are less than 25 weeks and with new parents of tiny preterm babies with what are thought to be ”bad outcomes.”

The ethical considerations that neonatologists use to guide practice in decision making regarding forgoing life-sustaining treatment include four bioethical principles: beneficence, nonmaleficence, respect for the patient, and autonomy (American Academy of Pediatrics 1994, 533). In 2007, The American Academy of Pediatrics' (AAPs') Committee on Fetus and Newborn published guidelines for forgoing intensive care for infants (AAP 2007, 401–3). The parents of the infant, acting as surrogates, have the right to make healthcare decisions, including refusing treatment for the infant in some circumstances.[31] Because the

[31] Parents cannot always choose to refuse treatment for their infants, even when they consider this option to be in the best interests of their child. For example, parents who

infant cannot express her values and preferences, the parents, with guidance from the medical team, choose treatment options consistent with the "best interests" of the neonate (AAP 2007, 401). Thus the surrogates decide with the medical team by weighing benefits and burdens of treatment choices; ideally, beneficence outweighs harm. The Committee on Fetus and Newborn recommends that the neonatal team and family make the decision whether to forgo life-sustaining treatment (LST) depending on "the probabilities of death and 'severe' disability based on the best available data" (AAP 2007, 402).[32]

How do parents make such a difficult decision? The components of the decision-making process may include: (1) comprehending the medical diagnosis, prognosis, and treatment options; (2) understanding their role as surrogates for their baby; (3) distinguishing the physician's opinion or recommendation (if offered) from their own choices; (4) identifying their own values and beliefs; and (5) detecting their own biases regarding life, death, and disability. After discussing these issues, the parents make a decision for their infant. Essentially these parents, with the medical team's input, balance benefits and burdens via a complex calculus that involves factual information and moral

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refuse a life-saving blood transfusion for their child will have their right to refuse treatment overridden by a judge. Physicians and hospitals accept refusals of treatment that concur with their idea of an ethical and legal option.

[32] I place *severe* in quotation marks because the degree of disability attributed to an individual by others may differ greatly from the disabled person's self-report and identity. Additionally, the rating of disability does not necessarily have to do with the physical, psychological, or mental factors, but the quality of accommodations. That is, social model supporters perceive the identity of disability to be positive. The medical model advocates, who see the impairment as the disability, consider the identity of disability to be negative, and, thus, will rank the disability according to the severity of the impairment (Siebers 2011, 9–11).

values (Kon 2011, 35; Kopelman 2009, 373–74; Lorenz 2003, 476–78) to make a treatment choice in the best interest of the infant.

The Committee on Fetus and Newborn specifically recommends forgoing intensive care when death is likely and the risk of severe morbidity is high (AAP 2007, 402). Preferences of the parents, the usual surrogates, should decide treatment when the prognosis is unclear, but survival would likely result in "diminished quality of life for the child" (AAP 2007, 402). However, physicians may override a parent's preferences in the cases of certain death, harmful treatment, futility, or when the parent's decision conflicts with the "best interests" of the child (AAP 2007, 402–3).

The Best Interests Standard (BIS)

The Best Interests Standard is a practical method used to determine the best possible option for treating an infant or adult who does not have the capacity to make decisions (Kopelman 1997, 277; Kopelman and Kopelman 2007, 187). Allen Buchanan and Dan Brock (1990, 88, 94, 123, 235–37) first developed the concept in terms of "acting so as to promote maximally the good (i.e. well being) of the incompetent person" (Buchanan and Brock 1990, 94). Beauchamp and Childress stipulate four requirements for decision making by surrogates:

1. Ability to make reasoned judgments (competence)
2. Adequate knowledge and information [authors note: informed consent]
3. Emotional stability
4. A commitment to the incompetent patient's interests, free of conflicts of interest and free of controlling influence by those who might not act in the patient's best interests (Beauchamp and Childress 2009, 187)

Thus, their method of determining the option that is in the best interest of the infant (or incompetent person) involves a competent, knowledgeable surrogate who determines the treatment that provides the greatest benefit for the patient.

The criteria for what constitutes the best interests of an infant vary according to the bioethical or neonatal scholar (Salter 2012, 184–89). For example, some authors insist that the best interests of the child should include only the child's objective interests, but exclude family considerations and subjective concerns (Beauchamp 2009, 138–40; Buchanan and Brock 1990, 132–33; Cornfield and Kahn 2012, 334–35; Jonsen, Siegler, and Winslade 2006, 90); Marcello et al. 2011, e935–38; Mercurio 2009b, 360; Truog and Sayeed 2011, 44–45). Others stress the subjective nature of any life-or-death decision for parents and physicians (Campbell and Fleischman 2001, 123–25; Isaacs 2011, 43; Kopelman 2009, 374). They allow the social, economic, and psychological interests of the family (including siblings) to weigh in the decision regarding treatment of the infant.

And some neonatologists consider the surrogate's characteristics or the family's ability to care for the child to be a reason to override the surrogate's decision (Larcher 2013, 106–7; Marcello et al. 2011, e937). One example involves neonatologists going to court when a Jehovah Witness parent refuses a blood transfusion. On the other hand, physicians who disregard a surrogate's choice because of the family's socioeconomic status, age, marital status, or education–and (I suggest) race—creates a more ethically problematic situation (Marcello et al. 2011, e938). Such neonatologists claim that the infants of young, poor, single mothers have worse outcomes than those of older, middle class, married parents.

Regardless of the reason for which treatment choices involve other factors beside the best interests of the infants, non patient-related issues influence such decisions.

Loretta Kopelman (1997, 277) expands upon this concept of the BIS. She claims that the BIS guides the parents to make the most practical (rather than ideal) decision, a resolution that is in the supposed best interests of their child (Kopelman 1997, 278). According to Loretta Kopelman and Arthur Kopelman (2007, 377), the BIS requires the implementation of three elements for ethical decision making in specific cases:

1. After completely understanding the medical diagnosis, treatment options, and prognosis for the infant, the surrogate weighs the benefits and burdens both of the treatment options and of life after each of the treatment options (including comfort care). The surrogate then chooses, based on her values and resources, a *prima facie* treatment path that increases the benefits and lessens the burdens for the infant.
2. The surrogate selects among a number of options as long as the choice meets a minimally-acceptable standard, one usually determined by healthcare professionals (HCPs) and the courts.
3. The surrogate makes decisions about a treatment plan that adheres to the surrogate's ethical and legal responsibilities to the patient (Kopelman 2005, 346; 2007, 188; Kopelman and Kopelman, 2007, 373).

These three ethical constituents comprise the basis for Kopelman's BIS.

Autonomy, beneficence, nonmaleficence, and respect for the patient should guide each of these three components of the BIS. In healthcare, autonomy

of an individual relates to her right to choice her own treatment (Beauchamp 2009, 99). However autonomy requires three conditions: (1) the provision of information that affords understanding of the possibilities, (2) the capacity to comprehend the options and make a decision, and (3) the absence of outside, unjustified pressure or control. For the person who does not have capacity to make autonomous decisions, a surrogate selects the best option. It seems that in this way, autonomy calls for the surrogate to base decisions about the infant's care on values and factual information. Beneficence and nonmaleficence establish the need both to assess the benefits and burdens of treatments and to choose the treatment that maximizes the benefits and minimizes the burdens (Beauchamp 2009, 149–52). Nonmaleficence also informs the last two elements of the BIS, the use of the minimally acceptable standard and compliance with the surrogate's responsibilities by protecting the patient from harm. Respect for the patient enlightens all of the guidelines since the decision reflects what seems best for the patient.

Loretta Kopelman (2005, 345) provides a strong argument for the Best Interests Standard. She understands the BIS as diametrically opposed to the Baby Doe rules. She construes the Baby Doe rules as prohibiting alleviation of suffering, compassionate care, and personalized treatment options for some infants (Kopelman 2005, 332). Additionally, she interprets the rules as limiting the right to refuse medical treatment for infants, a right that adults hold. Instead she proclaims the right of infants to die, if their parents judge their disability to be too great to allow a quality life. And yet, she does not argue for this right to die

for older children with the same risk of disability. Nor does she address the rights of disabled infants to live.

In the United States, case law grants parents the right to refuse medical treatments for infants (Miller v. HCA 2003). For a physician to veto a parent's decision for her infant, a court must intervene. The BIS provides a best possible choice based on the values, beliefs, and life-situation of the parents (Kopelman 2005, 346; 2007, 188; Kopelman and Kopelman, 2007, 373). In our society the parents' values most likely manifest what is best for their child. Loretta Kopelman (2009, 373) argues that the strength of the BIS lies with the duty of the parents to create the aforementioned *prima facie* treatment plan maximizing benefits and minimizing burdens, identifying minimally acceptable treatment options, and focusing on their legal and ethical obligations to the infant.

Although Kopelman's arguments for the BIS have strengths, criticisms abound (AAP 1996, 149–50; Frader 2005, 1601–2; Murray 1985, 8–9; Salter 189, 191, 193–96; Truog and Sayeed 2011, 44–45). In this thesis I propose four aspects of this decision making scheme that emphasize the inadequacy of the BIS: uncertain prognoses, physician variability (or bias), parent bias, and parents' self-knowledge about their values and beliefs. These essential elements have not been addressed as a cohesive group regarding their effect on the BIS, though bioethicists have expressed concern about the consequences of each of these essential elements. These issues may cause parents to make decisions that do not fit the BIS, creating a dilemma for using the BIS to guide decision making.

Uncertain Prognoses

Kopelman's Best Interests Standard requires that the neonatologist divulge the infant's medical diagnosis, prognosis, and treatment options to the parents so they can make informed decisions about treatment options. However, determining valid and reliable prognoses is challenging at best, and not all parents understand the information or know how to make the decisions (Ambalavanan 2012, e116–22; Christakis and Iwashyna 1998, 2391–92; Dupont-Thibodeau et al. 2014, 31–32; Janvier, Barrington, and Farlow 2014, 39; Mack and Joffe 2014, S25, S28; Ridley and Fisher 2013, 642–44).

The "minimum threshold of acceptable care" or "good enough" option (Kopelman and Kopelman 2007, 379), an integral part of the Kopelmans' BIS, fails to attain their goals due to the inability of neonatologists to accurately prognosticate. In fact, either it creates confusion about what choice to make or potentiates harm depending on where one sets the threshold. With a high threshold for "good enough," the unavailability of treatments may exclude any acceptable treatment. With a low threshold, acceptable treatment options may cause harm to the infant. Kopelman (2005, 348) suggests that neonatologists set the thresholds since they have the most knowledge about these very sick infants' situations.

Regarding prognostication, Kopelman and Kopelman (Kopelman 2009, 375: Kopelman and Kopelman 2007, 376) also claim that the determination of benefits and burdens entails both objective and subjective features.[33] Objectively,

[33] Prognostication is the action by a physician of predicting the expected outcome and health status for a patient with a specific disease or condition.

they maintain, one can predict whether a treatment will completely cure or even help an infant. Kopelman submits that the objective features, including prognosis, may help determine treatment when the subjective features are uncertain, that is, when the parents lack insight into their own values. I argue here that neonatologists cannot sufficiently prognosticate.

My claim is that the importance of prognosis resides with the decisions about life-sustaining treatment that infants' parents make. Although situations do occur in which neonatologists accurately predict treatment outcomes, in complex life-or-death decisions, this objectivity is difficult to realize (Bellieni et al. 2012, 73–74; Tyson and Stoll 2003, 367–69, 381–82; Tyson et al. 2008, 1673, 1676–77, 1680). Neonatologists struggle to foresee morbidity and mortality of their patients.

When talking with parents about withdrawing or withholding life-sustaining treatment for their infant, neonatologists use statistics and general possibilities and probabilities to explain prognoses (Kuschel and Kent 2011, 586–87). Statistical data have limits in the decision-making process. These facts are uncertain. Yet parents often base life-or-death decisions on them. This uncertainty is attributable to both the shortage of accurate survival and outcome data and the difficulty in predicting outcomes for individual babies in individual neonatal intensive care units (Stephens and Vohr 2009, 631–32; Tyson and Stoll 2003, 367–69, 381–82; Tyson et al. 2008, 1673, 1676–77, 1680). For example, neonatologists usually have available statistics from a few large-scale studies that are based on out-of-date data (Adams-Chapman et al. 2008, e1173; Janvier, Barrington, and Farlow 2014, 42; Visschers et al. 2009, 284–85). They, like their

patients, often do not understand the difference between population statistics and individual outcome. Most important, statistics, of course, are probabilities, not predictors.

In addition to the ambiguity in the application of statistics to individuals, the general failure to understand statistics creates problems for prognostication. Some parents may not understand statistics. Consequently, depending on personality, a parent may expect either survival or death with a fifty percent mortality rate. Some parents see the cup half full; others see it half empty.

These statistics of outcomes for sick infants are calculated either from single-center or multi-center trials or from annual data derived from the individual NICU. Because practice varies somewhat with each neonatologist and with each NICU, practices and outcomes from a specific unit differ from the practices and outcomes of other units. For example, a unit that generally does not resuscitate 23-week infants has a much higher rate of mortality and long-term morbidity (for 23-week infants) than the unit that resuscitates all 23-week infants. The data from the patient's own unit may reflect the practices of that unit. But a single unit has only a small number of patients (relative to a multi-center trial). With small numbers, the likelihood that the statistics represents true rates decreases. So, the small number of 23-week infants seen in a NICU over a year provides data that does not reflect an accurate mortality or morbidity rate.

On the other hand, the large population studies base their data on a much larger number of patients, even if the practices differ among different units. These larger studies provide the most useful outcome data. Methodological differences partly explain the different study results. Overall, different

investigators report different morbidities and mortalities, making the prognosis for an individual baby dependent on the study the neonatologist chooses to quote (Allen 2002, 223; Lorenz 2003, 478; Stephens and Vohr 2009, 632–38).

Sometimes physicians do not have enough information to provide valid prognoses. In a review of neonatal outcomes, neonatologist and neonatal development specialist Marilee Allen (2008, 125) notes that neonatologists can use indicators such as cranial ultrasounds to prognosticate, but not diagnose future neurodevelopmental impairment. The varying definitions of *outcome*—along with other major differences in the diverse studies—make the data difficult to understand, even for physicians (Allen 2002, 223; Lorenz 2003, 478).

This complexity arises from the propensity for the outcome studies to lump multiple neurodevelopmental effects into general categories such as *mild*, *moderate*, *severe*, and *profound* disability. Often a severity category covers multiple types of neurodevelopmental impairment such as unilateral blindness, hearing loss, severe cerebral palsy, varying degrees of intellectual impairment, physical developmental delay, and behavioral impairment (Adams-Chapman et al. 2008, e1171; Allen 2002, 223–25; Hack 2008, 787; Stephens and Vohr 2009, 633). And various studies define each category differently, so that *severe disability* pertains to different degrees of disability depending on the particular study. These dissimilar definitions create both obstacles to comparing studies and confusion when the neonatologist attempts to remember which data goes with which outcome group. Additionally, classifying children into labeled groups, determined by the researcher, appends values to the disabilities the children experience (as *profound*, *severe*, etc.) rather than allowing the parents to

determine their values concerning the disabilities their child may have. Many neonatologists think of profound disabilities as limiting enough to consider whether the neonate's potential quality of life is worth living (Dupont-Thibodeau et al. 2014, 32–33; Janvier, Barrington, and Farlow 2014, 43).

Moreover, the reporting of most neurodevelopmental outcomes is based on mental and physical development tests at eighteen to twenty-two months of age (Stephens and Vohr 2009, 633–37).[34] These results can also be difficult to interpret. After thirty years of reviewing follow-up data of preterm infants, I do not understand how developmental test scores correlate with functional abilities. That is, for infants assigned to categories of *severe disability* or *moderate disability*, neither their test scores nor their classification elucidates what kind of life, or quality of life, they will have. If a child has a mental development index (MDI) two standard deviations below the mean, will the child read? Write? Have a conversation? Studies of children with cognitive impairment describe different functional abilities with the same MDI score. Additionally, some studies describe improved outcome, while others describe worse outcome as children reach school age and adolescence (Ment et al. 2003, 710; Stephens and Vohr 2009, 634). The insufficiency of outcome data makes prognostication difficult and confusing.

As I have suggested above, neonatologists rely on obsolete, confusing, deficient, and unreliable outcome data to inform their discussions with parents about the future of their infant's life. And parents then make decisions about whether or not to keep their neonates alive based on uncertain outcome statistics

[34] Neurodevelopmental outcomes also depend on auditory and visual testing, as well as clinical or electroencephalogram (EEG) evidence of seizures.

that they often do not understand. If the Best Interests Standard is based in part on prognosis, and if prognosis for extremely sick infants is uncertain, then the BIS does not provide adequate guidance for parents of disabled infants**.**

Physician Variability

As well as misinterpreting and misunderstanding mortality and morbidity data, physicians unintentionally—or intentionally—may direct parents and skew the treatment decisions toward their own values, preferences, and views of the world (Dupont-Thibodeau et al. 2014, 33; Janvier, Barrington, and Farlow 2014, 39). This occurs while neonatologists try to make sense of the existing knowledge for actual, living extremely ill infants.

Even though the BIS precludes a role for the neonatologist's values and beliefs, the medical team guides the infant's family by providing information about prognosis and direction regarding ethically and legally appropriate medical treatment—all susceptible to physician bias. If the physician pushes his values on the parents without regard to the parents' values, then the result, though possibly an ethical choice, does not represent the best interests of the child from the parents' perspective. The surrogacy principle requires that the parents choose what they consider the best interests of the infant. In fact, though, physicians' values and beliefs often affect their patient's parents' decisions (Kuschel and Kent 2011, 586).

In today's healthcare system, physicians often recommend treatments meant to influence parents' decisions. However, when their own morals and principles inform their counsel, the parents may choose an option in conflict with

their own preferences. When the physician's values, beliefs, and culture match those of the parents, then harm may not occur. But when the physician and parents see life, death, and disability differently, the treatment plan may not reflect the parents' preferences.

Despite BIS recommendations about physician neutrality, studies demonstrate that physicians' life-or-death care practice reflects their attitudes and beliefs (Cohen et al. 2008, 248–52; Cuttini, Nadai et al. 2000, 2113–16; Hinkka et al. 2002, 110–13; Larochelle et al. 2009, 464–68; Miccinesi et al. 2005, 1966–68, 1970–71; Sprung et al. 2007, 1735–38). In a study evaluating life-or-death treatment decisions by physicians using semi-structured interviews of hospital staff, Larochelle et al. (2009, 462–63) demonstrates that variations of care for adult patients depend to a large part on the physician. The discrepancies in treatment they attribute to physicians include: (1) aggressiveness of initiation of treatment, (2) communication skills regarding initiation, substance, and style of discussions, (3) collaboration with other medical staff, and (4) the relationship between the physician and the patient or surrogate. Larochelle et al. (2009, 464–65) demonstrates that religious beliefs, cultural values, the perception of when a patient is dying, quality-of-life viewpoints, and fear of failing trigger variations in care, or physician bias.

Other multi-center and multi-national trials in Europe also indicate the role of the beliefs and values of physicians in determining the path of treatment for seriously ill neonates (Cohen et al. 2008, 248–52; Cuttini, Nadai et al. 2000, 2113–16; Hinkka 2002, 110–13; Miccinesi et al. 2005, 1966–68, 1970–71; Sprung et al. 2007, 1735–38). Religious affiliation, religiosity, culture, views about

quality of life, and country of practice influence life-or-death decisions such as withholding or withdrawing life-sustaining treatment (WWLST) and whether to initiate cardio-pulmonary resuscitation (Rebagliato et al. 2000, 2454–59). A Finnish study by Hinkka reports that the degree of training and experience affects the approach of physicians to forgoing life-sustaining treatment (LST), with the younger, less experienced doctors more likely to provide more intensive care.

The EURONIC (European Project on Parents' Information and Ethical Decision Making in Neonatal Intensive Care) studies are multi-center and multi-national trials that were done in Europe. One of them reveals that discrepancy of physicians' beliefs and life-or-death practices in the NICU depend on country of practice (due to both legal regulations and associated cultural influences), duration of neonatal intensive care practice, age, ethics committee involvement, and prominence of religion, but not gender (Cuttini, Nadai et al. 2000, 2113–15). In a review of the literature, Carlo Bellieni and Giussepe Buonocore (2009, 614) describe psychological factors such as "fear of death" and "personal prejudice" against preterm infants, along with cultural and demographic factors that influence physicians' life-or-death preferences.[35] Overall, significant evidence associates physicians' life-or-death care routines in neonatal, pediatric, and adult contexts with the physicians' beliefs and attitudes.

Healthcare professionals' bias against disability is an example of such beliefs and attitudes (Bellieni and Buonocore 2009, 614; Bellieni et al. 2012, 74).

[35] Although Bellieni and Buonocore's paper addressed influences on life-or-death practices for preterm infants, I expect that the same issues affect those for disabled full term infants in the neonatal intensive care unit.

HCPs, like the rest of society, regard disabled people poorly or with ambivalence (Albrecht and Devlieger 1999, 978, 982; Brillhart 1990, 80–82; Katz, Hass, and Bailey 1988, 48; Wright 1988, 5–6). In a EURONIC study, Marisa Rebagliato et al. (2000, 2454) states that most physicians deem severe intellectual disability to be equal to or worse than death. Concerning severe physical disability, more variability exists, but many physicians also consider it worse than death.

Physicians of neonates and children have biases against disability that influence life-or-death decision making for their patients (Lam et al. 2009, 1506; Saigal, Stoskopf, Feeny et al. 1999, 1995–96; Streiner et al. 2001, 154–56). Saroj Saigal and colleagues describe a study in which subjects described preferences for five hypothetical health states of disabled children (Saigal, Stoskopf, Feeny et al. 1999, 1992). Subjects included neonatologists; neonatal nurses; adolescents born at extremely low birth weight (ELBW); adolescents (controls) born at term; parents of adolescents born at ELBW; and parents of adolescents born at term. The study results demonstrate that HCPs (nurses and physicians) rated the two most severe outcomes markedly lower (as less preferable) than parents (of either term or ELBW infants) (Saigal Stoskopf, Feeny et al. 1999, 1994–96). HCPs also ranked the two most severe outcomes lower than both groups of adolescents. Similarly, Lam et al. (2009, 1506–8) interviewed neonatologists, parents of preterm infants, and parents of term infants. The subjects evaluated hypothetical health states. The investigators report that

> parents of preterm infants as a group were most likely to save the infant at all costs and prepared to tolerate more severe disability health states. (Lam et al. 2009, 1501)

Thus, parents are more likely than physicians to prefer LST, even with a prognosis of significant disability.

The above findings, that parents' and physicians' values differ regarding disability, have a profound impact on decision making for life-or-death care of neonates (Silvers and Francis 2011, 38). The typically negative portrayal of the conceivable disabilities for extremely low gestational age and asphyxiated infants (Bellieni et al. 2012, 74; Parens and Asch 2003, 40) may further alienate—or influence—parents. These negative attitudes may partially reflect the neonatologists' desire to ensure that parents understand the seriousness of the impact of their child's potential disability on the life of their child, themselves, and their family. In addition, because healthcare workers aim to save lives or at least improve them, they think in terms of improving health, not creating poor health. Carlo Bellieni and colleagues support this contention when they state:

> Neonatologists can be overwhelmed by the burden to continue the cures with the risk of a future disability. The vision of disabled babies, most of which are former prematures, induces a sense of impotence, sorrow, and in some cases of guilty [sic] in the caregivers, especially taking into account the burden to the family and the difficulties that the disable [sic] baby will found [sic] in an unresponsive society. (Bellieni et al. 2012, 74)

This type of interference of the HCP's values and beliefs may disrupt the informed consent process for such a major decision as WWLST from an infant.

One example of physicians' marked influence on parents' decisions during the past decades and currently is the care for infants with Trisomy 13 or 18.[36] At least since I was an intern in pediatrics many pediatricians have been convinced

[36] Trisomy 13 and 18 are congenital syndromes associated with multiple anomalies, heart disease, early death, and, for those who survive, substantial cognitive disability. Trisomy 13 is caused by three chromosome 13s. Trisomy 18 is caused by three chromosome 18s.

that these diagnoses are "lethal" (American Heart Association 2006, e1035; Behrman, Kliegman, and Nelson 1992, 284–85; Hurley 2014, 1–2, 4; Janvier, Farlow, and Wilfond 2012, 294; Koogler, Wilfond, and Ross 2003, 38–39; McGraw and Perlman 2008, 1106; Nelson, Hexem, and Feudtner 2012, 870). Though this understanding is beginning to change (McGraw and Perlman 2008, 1108), my experience and some of the studies cited here indicate that many neonatologists continue to approach infants with Trisomy 13 (T13) or Trisomy 18 (T18) as if they are going to die within the days or weeks after birth.[37] Such "common knowledge" is often passed from generation to generation of pediatricians. These physicians tell parents that the condition is lethal: most babies die within the first month of life and more than ninety percent die within the first year. A few live three or four years. And many neonatologists will not resuscitate or use advanced technologies for infants with "lethal" conditions—or will only do so if the parents insist on resuscitation.

Yet, it appears, many neonatologists fail to understand the circular nature of this reasoning. The mortality rate increases when infants are not resuscitated. Neonatologists are not giving these babies a chance to survive. But, these neonatologists insist, those who survive have *profound* neurodevelopmental delay including *profound* cognitive delay. And these neonatologists, including me before two years ago, typically describe survivors as unable to walk, sit, or communicate.

[37] Recently a colleague of mine had an infant patient with T18 whose mother expressed a desire for her daughter to survive as long as possible. Still, my associate did not provide adequate nutritional and caloric supplements for the baby to gain weight and refused to keep the baby in the hospital long enough to ensure growth. Other colleagues have asked me if I really a value the life of a child with T18.

They are wrong. Annie Janvier, a bioethicist and neonatologist, and her colleagues report on 332 parents of 272 infants with Trisomy 13 or 18 who survived after birth (Janvier, Farlow, and Wilfond 2012, 294). The parents were contacted through social media sites dedicated to children with Trisomy 13 or 18. Eighty-seven percent of parents were told that "their child was incompatible with life," fifty-seven percent that their child "would live a life of suffering," and fifty percent that their child "would be a vegetable" (Janvier, Farlow, and Wilfond 2012, 295). Of those with non-mosaic Trisomy 13 or 18, twenty-five percent received aggressive care after birth and fifty percent received comfort care.[38] Slightly more than one-third of those who received comfort care died in the hospital, but approximately one-third lived for greater than one year. Most parents of children who died described their child's life experience as positive. Of twenty-five children who had heart surgery, twenty-one survived for more than one year after surgery and almost half were still living five years after surgery (Janvier, Farlow, and Wilfond 2012, 296).

For the 112 children with non-mosaic Trisomy 13 or 18 who lived and received some or full intervention, about one-half survived for more than one year and about one-quarter survived for greater than five years (Janvier, Farlow, and Wilfond 2012, 295–96).[39] Of the children still alive at the time of the study, approximately half required oxygen or some gastrostomy feedings (feeding through a tube placed through the skin into the stomach). All had "significant

[38] Non-mosaic indicates that all of the cells of an individual have the same number and type of chromosomes. In people with mosaicism, different cells have diverse genetic compositions.

[39] Intervention for children with Trisomy 13 or 18 could include resuscitation, respiratory support, tube feedings, cardiac surgery, and other surgery.

developmental delays," but none were noncommunicative. They all smiled. About thirty-five percent said words. Half of the three to ten year olds walked with a walker. And more than seventy-five percent ate by mouth. Ninety-five percent of parents responded that they recognized what their children needed. They all advanced developmentally. All parents reported a positive quality of life for their children,

My experience suggests that neonatologists still resist resuscitating infants with Trisomy 13 or 18 and argue strongly against surgery for these infants. When I discuss evidence about outcomes of children with T13 or 18, with my colleagues, many do not understand why I would think that such outcomes render an infant with T13 or 18 worthy of medical intervention. Their thought processes involve assumptions and biases about a life not worth living. The ensuing judgment, that treating the infant is futile, outweighs parental preferences to keep the child alive despite profound disability. Such ideas represent physician bias intruding on the rights of parents.

For example, Carlo Bellieni et al. (2012, 74) note a marked difference in the criteria for forgoing LST between neonatal and adult patients. They report that neonatologists fear leaving the infant with the burden of a life of severe disability. Annie Janvier and Mark Mercurio (2013, 333–34) describe the greater willingness of HCPs to allow infants to die than to allow older children to die. They suggest that this difference may reflect the neonatal teams' "fear of 'creating' a disabled child" (Janvier and Mercurio 2013, 335). They conclude that either policy should equalize the indications for forgoing LST for infants, children, and adults or moral reasoning should be developed to justify the different treatment

of infants. Regardless, this finding reflects common attitudes of HCPs toward persons with disability.

Parent Bias

Another impediment to reaching a decision in the best interests of the neonate is parent bias. I propose three types of bias to which parents are susceptible: disability bias, miracle bias, and emotional bias. All three generate dilemmas for decision making in the NICU.

As with society in general, parents often possess biases against individuals with disabilities (Gilbride 1993, 139–50). Parents' specific characteristics may help determine such biases. For example, religious preferences, race, and physician recommendations motivate decisions for parents of severely disabled children (Arad, Braunstein, and Netzer 2008, 364–66; Bellieni and Buonocore 2009, 614; Moseley et al. 2004, 935–36). Although parents accept disability more than physicians (Lam et al. 2009, 1506; Saigal, Stoskopf, Feeny et al. 1999, 1994–96), I have cared for many babies whose parents choose to forgo LST due to the potential for disability.

Most parents do not hope for disabled children, although some deaf parents have genetically selected deaf children (Bauman 2005, 311; Mand et al. 2014, 722). My experience and evidence suggests that parents often feel devastated when they realize they have a disabled child. Yet some parents who have disabled children fight for them to survive.

Parents expect the perfect child. That is, they expect a "normal" child with an open future that parents can fill in according to their own values and desires.

Few get the perfect child, but usually years pass before the parents recognize their child's foibles and disabilities. By then, the parents usually love their child and work hard to accept her for whom she is rather than whom they wanted her to be.

But when the disability appears right after birth, a crisis often ensues. The parents mourn the loss of their perfect child and make a decision about this new one. But rather than reflecting the best interests of their child, a decision to forgo LST may reveal their own disability bias. So much of a new parent's view of disability has to do with their personal hopes for their child and not with the child's best interests.

For example, parents of children with Down syndrome routinely feel devastated on hearing the news, so much so that seventy to ninety-six percent of women with fetuses diagnosed with Down syndrome have abortions in some parts of the United States (Choi, Van Riper, and Thoyre 2012, 160; Mansfield, Hopfer, and Mareau 1999, 809–11). However, many parents, including parents of infants diagnosed after delivery, change their attitudes after living with their children. They talk about the "gift" of having a child with Down syndrome, how much the child has taught them about life, and how much the child has contributed to the entire family.

Thus, parents really do not know what having a disabled child will mean to them ahead of time. They can tell themselves stories from the interactions they have had with disabled children, but they usually do not know how they feel or what they will do. Some parents advocate for their disabled children and create a beautiful family. Others fall apart experiencing divorce, poverty, depression.

Although this struggle and uncertainty about making value-laden judgments and choices is similar to that of making any difficult value-laden decision in life, the repercussions are much greater when one's infant's life is in the balance. Parents ignorant of what it means to parent a child with a disability and unaware of what it means to be disabled may choose to end the life of a child that could live a functioning, happy, and productive life. Disability bias by parents may cause a child to die due to ignorance and naivety.

The second bias that often shapes parents' decisions about WWLST is what I call the "miracle bias." These parents believe that G-d will create a miracle for their child. They do not think about what treatment option would reflect the child's best interests. Instead, they concentrate on a miracle healing the child completely. This "miracle bias" differs from parents' preference to follow G-d's direction. Such parents accept what G-d gives them. Whether G-d keeps their infant alive or allows her to die, they believe that G-d has a purpose. In these situations, parents accept having a severely disabled child because G-d made the choice. This attitude contrasts with that of the parents with the "miracle" bias. When parents expect G-d to miraculously heal their child, they do not always accept having a severely disabled child.

I would never want to take hope away from a parent. But, relying on G-d to heal while refusing to believe that G-d would save the child to have a life of profound disability is a form of denial. Knowing that G-d will create a miracle and save the infant at the same time that the doctors continue to keep the child alive with aggressive intensive care creates a conflict of interest. I have seen too many

babies whose parents really do not value a profoundly disabled child's life get passed over for a miracle and end up "profoundly" disabled for life.

Finally, parents also experience emotional bias. Parents hold on to their child, not wanting to say good-bye, even though they do not value a profoundly disabled life. Their values may point toward allowing the infant to die, but their hearts do not let go.

Sometimes parents' biases, whether against disabilities, in favor of miracles, or emotional, has nothing to do with what is in the best interests for them or their infant. Instead parents choose based on fear, attachment, or ignorance of their own values.

Parents' Knowledge of their Values

In response to criticism about personal variation regarding defining benefits and burdens, Loretta Kopelman and Arthur Kopelman (Kopelman 2009, 375: Kopelman and Kopelman 2007, 376) suggest that the determination of these factors involves both objective and subjective features. As previously mentioned, they maintain that objectively one can predict whether a treatment will completely cure or even help an infant. They also state that parents should subjectively calculate whether the encumbrances of continuing life-sustaining treatment outweighs the satisfactions the child would know from living. However, they claim that this prediction varies with the parents' values, beliefs, and worldviews. The Kopelmans submit that the objective features may help determine treatment when the subjective features are uncertain. Situations do occur in which accurate prognostication of treatment outcome is possible.

However, in complex life-or-death decisions, this objectivity is difficult to realize due to neonatologists' inability to accurately prognosticate (Bellieni et al. 2012, 73–74; Tyson and Stoll 2003, 367–69, 381–82; Tyson et al. 2008, 1673, 1676–77, 1680).

Despite sometimes inaccurate prognoses, parents often use their values to make tough decisions about their infant's future (Kon 2011, 35, Ladd 2003, 488). Based on my experience I propose that parents who know their own values and beliefs have a much easier time making such decisions. Those parents who care deeply about their child's quality of life choose to permit her to die comfortably when she has a poor prognosis. On the other hand, parents who believe intensely in the sanctity of life and will love, cherish, and care for a profoundly disabled child choose to continue LST despite their child's poor prognosis. For such parents, their values and beliefs lead them directly to their decisions.

But what of people who have never thought about the meaning of life, death, or disability? Emotional anguish, the complexity of the facts, the psychological reactions to the information, and their decision-making skills complicate their deliberations. They either have a much harder time making a decision or they make emotional, not value-laden, decisions. Of course, emotional responses sometimes reflect values and beliefs, but not always.

In such cases, the parents may choose a treatment they do not really prefer. For example, a parent who follows the doctor's recommendation may later regret that she did not give her child a chance to survive, regardless of the outcome. On the other hand, a mother that just cannot "kill her baby," or who knows "G-d will create a miracle" may in fact not value the life of a profoundly disabled child. In

such cases, the parents may make the decision, but the parents' values do not enlighten the decision.

The problem lies with the decision-making process. Autonomy for the parents to decide about treatment means deciding—based on their own values and beliefs—for the best interests of the child (and family, according to some bioethicists), not what they feel is best at the moment. Thus, the parents, with the physician and with other friends or family, must traverse difficult terrain: soul searching; understanding their values and beliefs about life, death, and disability; and resolving their differences into a decision for their newborn.

I propose that these difficult discussions should begin before the crisis situation: during the prenatal obstetric visits, during the prenatal neonatal consult, and during dinners with family, friends, and colleagues either before or during pregnancy (Dworetz 2013). These discussions can then act as prelude to the discussion between the parents and the neonatologist when the crisis strikes.

The choice by the parents of a treatment that fits into a legal and ethical, medically acceptable range, does not mean the choice is in the child's best interests. Nor does it mean that the treatment option was decided ethically. The parents' values should inform an ethical decision that fits the best interests of their infant.

Summary: Best Interests Standard and Uncertain Prognoses,

Physician Variability, Parent Bias, and Parents' Knowledge of their Values

As discussed above, Loretta Kopelman and Arthur Kopelman (Kopelman 2005, 348–50; Kopelman and Kopelman 2007, 376, 378–79) the BIS requires that the surrogate decision maker—the parents in our discussion—understand the medical information including prognosis and treatment options; and choose from a number of ethically and legally satisfactory medical treatment options that are in keeping with the physician's medico-legal responsibilities. The subjective features of the decision should reflect the surrogate's values, beliefs, and preferences. The objective features reflect a "good enough" (Kopelman and Kopelman 2007, 379) standard, one that is ethically and legally allowable, but not necessarily the absolutely best option for the infant.

I have shown how uncertain prognoses, physicians' variability, parents' biases, and parents' knowledge of their values and beliefs present circumstances that affect whether the decision made by parents actually concurs with the Best Interests Standard. Thus, the BIS can fail to provide the best option available, because the best option available depends to such a large degree on these unreliable factors. And more importantly, critical life decisions made by parents and physicians for neonates may not be in the infants' best interests.

CHAPTER 3

DISABILITY ETHICS

Normalcy

To understand disability, one must understand the concept of normalcy because medicine defines disability as a deviation from the norm. While this subject could comprise an entire thesis, I limit this section to a brief introduction of normalcy.

Normal has different meanings depending on whether a variable is measured by statistical means and falls within a standard distribution or is measured by a binary system in which it symbolizes the opposite of *abnormal* (Linton 2010, 231). Both definitions of *normal* and *abnormal* generate problems for disabled people in many ways; the history of *normalcy* elucidates this process.

The modern definitions of *normal*, *normalcy*, and *normality* appeared in English in the mid-1800s after Belgian scientist Adolphe Quetelet introduced the notion of *l'homme moyen*, the average man, who was quantified using "physical and moral qualities" (Hacking 2002, 107). Quetelet determined these measurements by applying Johann Carl Friedrich Gauss' concept of *normal distribution* (or Gaussian distribution) to populations rather than individuals (Davis 2010a, 4–6; Hacking 2002, 108–9). Quetelet's ideas developed the associations both between *abnormality* and *disability* and between *disability* and *eugenics* (Davis 1995, 23–28, 33–34).

To understand Quetelet's role in positioning disability as a target of eugenics, we should start with Gaussian distributions (Hacking 2002, 121). Statistically, all assessments of a single characteristic fall into a normal

distribution around the mean. Where each measurement falls along this curve determines how close it is to the mean (Davis 2010a, 6–7). Quetelet extended this concept to measurements of traits of individual people and then, further, to the distribution of traits of people of a specific race (or other group of people) (Hacking 2002, 108–9) in which each point along the curve represented a trait of a person rather than a measurement. Therefore, he created subsets of people whose traits fell below and above the mean.

The distribution's center delineates the *norm*; the extremes demarcate the *abnormal*. Most people's features lie within the curve (Davis 2010a, 6–7). Those who do not fit within the "normal distribution" are "abnormal." Scientists and society describe those who fall above the curve in superlative terms (for example, *genius* or *athletic*); they value those above the curve. However, physically, mentally, and intellectually disabled people fall below the curve; they are labeled "abnormal" or "deviant" (Davis 2010a, 6–7). A series of historical, political, scientific and social circumstances has constructed and perpetuated these characterizations.

This system of measurement, categorization, and evaluation underpinned the eugenics movement that arose in response to both Quetelet's application of the Gaussian distribution to populations and Darwin's popularization of natural selection and statistical knowledge of normal distribution (Hacking 2002, 108–14). At the same time, statistics' advancement in the nineteenth century in part stemmed in part from the eugenics movement (Davis 2010a, 7).

Sir Francis Galton, a leader of the eugenics movement, developed statistical systems to measure heritability and phenotypic variation in response to

his cousin Darwin's work; he also investigated human phenotypic variation (Davis 2010a, 7). Galton's studies that defined people with deviations below the norm as "abnormal" contributed to his initiation and leadership of the eugenics crusade. He promoted "selective breeding" (Stanford Encyclopedia of Philosophy, Race) to supposedly improve the human race (Galton 1904, 3–6). For Galton, eugenics meant "the improvement of our stock" (Galton 1904, 6) by increasing the proportion of the "best specimens" (Galton 1904, 3) in each succeeding generation. Though Galton did not list morality among the attributes of such specimens, he did include "health, energy, ability, manliness, and courteous disposition" (Galton 1904, 3). Eugenicists desired—and still desire—to eliminate the "defectives" (Davis 2010a, 7). According to Ian Hacking, a philosopher,

> "Galton" stands for improving averages, by whatever standards of value can be taken for granted. When it is a matter of living beings, that translates into eugenics. (Hacking 2002, lxxi)

Eugenicists favored—and still favor—the elimination of the so-called "defectives" (Davis 2010a, 7).

According to Davis (2010a, 7–8), the interweaving of eugenics and statistics created the concepts of disability and the disabled person; it then redefined disabled people as "abnormal." Once disabled people fell outside of the Gaussian distribution, they became abnormal. As soon as the eugenics movement designated people outside of the curve as undesirable, disabled people became objectionable, defective, deviant. Through his work on fingerprinting, Galton used this idea of disabled people's deviance to assert that physical characteristics identify the person. This encouraged the rationale that physical variation, the disabled body, determines an individual's identity.

Galton, pursuing his eugenics objectives, altered his statistical methods to a ranked system using quartiles rather than a Gaussian distribution (Davis 2010a, 9). In this ranked approach, the extreme above the normal distribution became the ideal. Prior to the notion of normal distribution, only G-d or gods were ideal; people had ideal features, but no person was ideal (Davis 2010a, 4). Physically and mentally disabled people were marked less than perfect, just like all other people. Galton's ranked statistical approach changed the way society perceived disability by transforming the human ideal from unattainable to attainable. Davis expounds on Galton's effect: this achievable "ideal" of the body (including the mind) emphasizes both the "norm" and the glorification of the "ideal." In this way, people learn to desire the "ideal" body and reject the "imperfect" body. Society seeks social advancement by chasing perfection in body and mind (Davis 2010a, 4–9).

These visions of eugenics, popular in the late nineteenth and early twentieth centuries in the United Kingdom and the United States, promoted discrimination against disabled people (Davis 2010a, 10). Eugenicists not only desired a putatively higher-functioning populace, they aimed for the eradication of disabled people. They lumped all people identified by traits that fell below the mean into an undesirable cohort. Physically, mentally, cognitively, and socioeconomically disabled people joined criminals to form the "devalued" group. Eugenicists' asserted that the association of disabled people with immorality and degeneracy generated fear, distaste, and discrimination against disabled people (Davis 2010a, 11).

Rosemarie Garland-Thomson claims that the eugenicists plan to purge the

world of disabled people. She writes that

> both the modern eugenics movement, which arose from the mid-nineteenth-century scientific community, and its current counterpart, reproductive technology designed to predict and eliminate "defective" fetuses, reveal a determination to eradicate disabled people. While the rhetoric claims that such procedures are aimed at ending disability, the reality is often that people with disabilities are eliminated. (1997, 34–35)

Regarding the eugenicists' desire to get rid of disabled people, Ian Hacking addresses the "ethical" theory that propels the moral thinking of what, seen from a disability vantage, appears immoral. He maintains that the abolition of disabled people by the eugenics movement

> was motivated by very much the same philanthropic utilitarian considerations that underlie all "liberal" attempts to modify a population." (Hacking 2002, 121)

Similar utilitarian views also underlie the current selective abortion approach to prenatal genetic testing, though I suspect that many whom promote or engage in selective abortion due to disability diagnosed by prenatal genetic testing are unaware, at least consciously, of its association with eugenics.

Meanwhile, in the eugenics movement of the late nineteenth and early twentieth centuries, eminent leaders promoted the eugenics movement, fostering discrimination against disabled people (Davis 2010a, 11; Garland-Thomson, 2012, 340). These principals included Karl Pearson, Charles Davenport, Alexander Graham Bell, Charles Davenport, John D. Rockefeller, Prime Minister Neville Chamberlain, Prime Minister Winston Churchill, President Theodore Roosevelt, H.G. Wells, John Maynard Keynes, and more. Such eugenicist politicians and intellectuals from the United States and the United Kingdom (along with leaders

from other European countries) paved the way for legislation mandating the sterilization and institutionalization of disabled people. This legislation laid the path for society to perpetuate bias against disabled people, a practice that persists today.

Scientists and healthcare professionals (HCPs) also continue to regard disabled people as abnormal (Lewis 2010, 161). This viewpoint arises from both definitions of *normality*: first, the medical concept that pathology proscribes normality and that normality excludes pathology; and second, the normal distribution, which medical providers frequently reference. The dualistic view reinforces the medical goal of treating the pathology—or "abnormality." The medical habit of measuring physical characteristics and plotting them on a normal distribution curve invokes normality's second meaning, fitting within the normal distribution. These calculations include weight, height, head circumference, mental development, physical development, sight, and hearing levels, for example. As mentioned before, the norm, derived from statistical distribution, by definition integrates the concept of extremes (Davis 2010a, 6). Measurements, or people with specific traits, that fall within the normal Gaussian distribution (or bell curve) are labeled *normal*. Those that fall outside of the normal distribution are described as "devastating from the norm" and are labeled *abnormal* or *deviant*.

In this way, HCPs classify disabled people as *abnormal* and as in need of medical care (if available). The repair work occurs in the form of surgery, casting, psychotherapy, bedside conversations, and medication. Advances in medicine have rendered treatment and hope of functional improvement – if not cure –

possible for some disabled people. The more extensive reconstruction of people with disability takes the form of more complicated surgeries, new medications, innovative technologies, and genetic manipulation, all of which rely on the recent and on-going developments in medicine. Genetic knowledge and technology now allow parents to prevent the birth of some disabled infants by employing prenatal diagnosis and either prenatal treatment or abortion. The potential for genome therapy also promises to treat or prevent many genetic diseases. Such expansion in medical science appears beneficial from the medical model perspective.

As discussed in chapter 1, there are two major models of disability, the social and medical models. The medical model does not easily explain how prevention, treatment, or cure of impairments harms disabled people (Linton 2010, 224–25; Longmore 1995, 82–85). Many disabled people experience restrictions or pain in life that they would prefer to live without. But the answer does not always reside with medical management. The social model's remedy entails a change in society's attitude toward disabled people.

The medical model harms disabled people through aggressive therapy, even in the absence of evidence-based benefit. This harm results from the medical model practice that attempts to relieve impairment regardless of the physical, emotional, financial, or economic costs. Technological growth and scientific progress create a cultural expectation to "fix" disabled people (Garland-Thomson 2001, 355–56; Longmore 1995, 82–84). Disability advocates allege that such treatment indicates society's (and the medical profession's) cultural obsession with nondisabled, "ideal" bodies and their preference to eliminate disabled people (Garland-Thomson 2001, 355). This seems a logical allegation

when considering the recommendation of many obstetricians and the decision of many parents to choose abortion rather than birth a disabled child.

Additionally, the medical system's persistent effort to repair or eliminate disabled people implies a society that devalues disabled people (Linton 2010, 230; Longmore 1995, 84). The lack of affordable social, technological, and economic support for permanently disabled people provides further evidence of this devaluation. The label *abnormal* and its many synonyms (*handicapped*, *visually-impaired*, *special*, etc.) cause alienation of disabled people from nondisabled people (Davis 2010a, 9; Linton 2010, 231). However, preventing, treating, or curing disabled people—notwithstanding the preferences of the individual— ignores the social construction of disability (Barnes 2010, 30; Lewis 2010, 161; Linton 2010, 224–25; Shakespeare 2010, 272). Therefore, this emphasis on medical processes for people with disabilities precipitates their cultural, economic, and political marginalization.

Such discrimination against disabled people invokes disability advocates' assertion that the medical model of disability ignores the social, physical, and economic impediments that play a huge role in how well disabled people function in society. For example, William Peace (2014, 20–22) remembers his first hospital stay after becoming paralyzed as a teenager. The physicians talked to him about rehab and wheelchair use; they never talked about the most important question most teenage boys would want to have answered: Will I be able to have sex? As Simi Linton (1998, 37–39, 45, 57) and other disability advocates argue, if society aspires to better functioning for disabled people, then more effort and financial backing should focus on removing barriers to physical, social, and

economic access rather than on prevention and cure (Scotch 2001, 383–90; Shakespeare 2010, 268–69). The elimination of discrimination against disabled people also requires the resolution of society's negative attitude toward disability (Linton 2010, 223–26).

Cultural Disability and Normalcy

Cultural perspectives of disability rely on society's narrative about disability and disabled persons, the ensuing persistence of exclusion, and the responses to this disaffection. In this way, the meaning of disability arises from the culturally specified otherness of bodies and minds (Garland-Thomson 1997, 5). One way to look at this characterization is through the cultural understanding of normalcy, a theory of disability discussed by Lennard Davis (1995, 23–24), some of which I have reviewed above. However, other concepts of normalcy have surfaced in disability scholarship over the past few decades.

Rosemarie Garland-Thomson's (1997, 6) book, *Extraordinary Bodies*, introduces the arguments for a cultural definition of disability. Her main objectives in writing the book were threefold: (1) to revise the way people—including disability scholars—comprehend and describe "the cultural construction of bodies and identity" (Garland-Thomson 1997, 5); (2) to readjust the "entrenched assumptions" about persons with and without physical disability as extreme polarities based on physical differences (Garland-Thomson 1997, 6); and (3) to change the basic concept of physical disability to that of a culturally interpreted definition that recognizes how discrimination based on physical

variation is analogous to “race, gender, class, ethnicity, and sexuality” bias (Garland-Thomson 1997, 6).

Garland-Thomson focuses on how disability is represented in culture (Garland-Thomson 1997, 6). She examines in what manner disability’s cultural appearance and interpretation arise from “bodily variation” which results in “otherness.” This “otherness’ of people with disabilities is analogous to the otherness of people with alternative genders. The parallels hold true for racism and race, classism and class, bias against specific ethnic groups and ethnicity, and LGBT homophobia and LGBT identity.

Furthermore, “by scrutinizing the disabled figure as the paradigm of what culture calls deviant” (Garland-Thomson 1997, 6), Garland-Thomson explicates the ways in which cultural “assumptions support seemingly neutral norms” (Garland-Thomson 1997, 6). In this way she addresses how

> all forms of corporeal diversity acquire the cultural meanings undergirding a hierarchy of bodily traits that determines the distribution of privilege, status, and power. (Garland-Thomson 1997, 6)

She further argues that “legal, medical, political, cultural, and literary narratives” (Garland-Thomson 1997, 6) that promote ableism establish the reality of people with physical disabilities. These narratives create images of physically disabled people that represent aberration, deficiency, and inadequacy. In this way, Garland-Thomson “moves disability from the realm of medicine into that of political minorities, to recast it from a form of pathology to a form of ethnicity” (Garland-Thomson 1997, 6). She renounces the common understanding that physical disability is an unquestionably fixed state that, by its essence, attributes

low status, dependency, weakness, and adversity to the afflicted. Instead she creates the portrayal of physical disability as

> a representation, a cultural interpretation of physical transformation or configuration, and a comparison of bodies that structures social relations and institutions. Disability, then, is the attribution of corporeal deviance—not so much a property of bodies as a product of cultural rules about what bodies should be or do. (Garland-Thomson 1997, 6)

Thus, cultural disability is the framework for this new definition of disability: disability is the consequence of the cultural depiction (in all its forms) of phenotypic variation that creates social, political, and economic inequality between those with and without physical difference.

Rosemarie Garland-Thomson (1997, 8–9) furthers this concept of cultural disability by coining the word *normate*. The normate represents the "ideal" individual in terms of physical traits, intellectual abilities, and emotional control; the normate also exemplifies the "ideal" in terms of gender, sexual preference, religion, race, character, and social position. According to Garland-Thomson, only the rare person can qualify as normate—and only briefly. Normates wield power and control by force of their traits (Garland-Thomson 1997, 32). This term therefore allows most people to understand the issue of marginalization based on character traits. Garland-Thomson elucidates:

> The problems we confront are not disability, ethnicity, race, class, homosexuality, or gender; they are instead the inequalities, negative attitudes, misrepresentations, and institutional practices that result from the process of stigmatization. (Garland-Thomson 1997, 32)

The concept *normate* therefore both portrays the absurdity of ranking physical or mental characteristics and refocuses ableism into the realm of the environment.

More recently, Garland-Thomson (2012, 339) proffers an alternative

perspective of disability and normalcy. She claims that disability is a norm experienced by most individuals at some point during their lifetime; that is, disability is a universal experience. Garland-Thomson (2012, 341) develops this concept of disability from what she calls "counter-eugenic logic." Eugenics uses genetic engineering to attempt to improve the genetic traits of the human population. In this way eugenics intends to improve society by eliminating disabled persons. Counter-eugenic logic emphasizes conserving disability—purposely taking action to maintain non-normate traits—for the benefit of society. Both ethical and epistemic claims support counter-eugenic logic (Garland-Thomson 2012, 341–49).[40]

The ethical claim employs a cultural perspective that reframes human talents and limitations as gifts rather than accomplishments (Garland-Thomson 2012, 347–8; Sandel 2007, 96–7). This perspective acknowledges that all human beings are worthy for their being, not for their traits. This ethical recognition of all humans and acceptance of who they are reframes disabilities as gifts. Sandel suggests that nondisabled people can learn about life and humility from disabled people. In this way, conserving disability rather than enhancing the disabled body or brain represents an ethical concept that augments moral action.

"Disability as epistemic resource" (Garland-Thomson 2012, 345) gives rise to the concept of disability as norm. Garland-Thomson (2012, 345–47) suggests that the experience of disability itself produces knowledge of a type that can only be gained by living in a disabled body. This type of wisdom may include other

[40] Garland-Thomson (2012, 344–345) also discusses "disability as a narrative resource." However, this topic is not relevant for this thesis.

sensory information not heard, seen, touched, smelled, or tasted by nondisabled people; or it may comprise what Jackie Leach Scully (2008a, 91) describes as "experiential gestalts," knowledge arising from living in a disabled body.

Using both ethical and epistemic arguments for conserving disability, Garland-Thomson applies the notion of conserving disability through the lens of cultural normalcy.

Quality of Life

To evaluate how one's abilities and disabilities affect people, researchers have assessed QOL. In 1995, The World Health Organization (WHO) defined QOL as

> individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. (WHO Division of Mental Health 1995)

In other words, QOL represents an individual's assessment of multiple areas of life. These areas may include health (both physical and mental), social interactions, economic status, and a self-reported sense of welfare that may comprise more subjective experiences like contentment, happiness, security, freedom, satisfaction, enjoyment, whether needs are met, and "the life consequences of such essential requirements" (Constanza et al. 2007, 268–69).[41]

Despite the WHO's definition of QOL, researchers disagree about how to measure QOL (Felce and Perry 1995, 51–54; Moons, Budts, and De Geest 2006, 895). Some prefer both subjective and objective measures; others prefer only

[41] "The life consequences of such essential requirements" means how having such necessities and whether they are accommodated affects life.

subjective measures. Meanwhile, many medical investigators study health-associated QOL that reflects only the objective aspects of disability (Felce and Perry 1995 54–60; Moons, Budts, and De Geest 2006, 892).

David Felce and Jonathan Perry (1995, 60–63) report on the multidimensional nature of quality-of-life assessments. They review the literature and conclude with a list of three elements: "objective life conditions" (1995, 58), "subjective feelings" (1995, 58), and "personal values, aspirations, and expectations" (1995, 54). These three domains are influenced by external factors, and they interact with each other. This process results in one's overall quality of life. Each of the three spheres consists of the same five factors:

1. *Physical wellbeing* involving health, fitness, and physical safety
2. *Material wellbeing* comprising "finance or income, quality of the living environment, and privacy, possessions, meals or food, transport, neighborhood, security, and stability or tenure" (Felce and Perry 1995, 60–61)
3. *Social wellbeing* including "the quality and breadth of interpersonal relationships" and "community activities and the level of community acceptance and support" (Felce and Perry 1995, 60–61)
4. *Development and activity* encompassing "the possession and use of skills in relation to both self determination—competence or independence and choice or control—and the pursuit of functional activities—work, leisure, housework, education, and productivity or contribution" (Felce and Perry 1995, 60–61)
5. *Emotional wellbeing* concerning "affect or mood, satisfaction, or [sic] fulfillment," "self-esteem, status/respect, and religious faith" (Felce and Perry 1995, 60–61).

These five aspects of objective experience, subjective experience, and aspirations combine to thoroughly define QOL.

Further delineating quality-of-life models, Moons, Budts, and De Geest (2006, 893) critique the conceptualization of QOL used for studies in the disabled population. They review the different approaches to QOL in the biomedical and nursing literature: "normal life" (the ability to take care of needs and stay healthy), social utility, happiness, satisfaction with life, achievement of personal goals, and "natural capacities" ("normally inborn physical and mental capabilities") (Moons, Budts, and De Geest 2006, 894). They propose that satisfaction with life, a subjective assessment, is the most appropriate method for determining QOL (Moons, Budts, and De Geest 2006, 899). In this model, QOL extends beyond health evaluations for people with disabilities, because their disability alone does not define them (Albrecht and Devlieger 1999, 979).

Using a broad quality-of-life assessment, multiple studies describe a good QOL, including health-related QOL, for people with even moderate to severe disabilities (Albrecht and Devlieger 1999, 982; Asch 2000, 248–50; Shikako-Thomas et al. 2009, 827–31; Vuillerot et al. 2010, 72–75). Albrecht and Devlieger (1999, 984–85) report that the people with disabilities who report a fair or poor QOL experience pain, fatigue, loss of control over their body or mind, and communication difficulties. In a study by Vuillerot and co-authors (2010, 72–75), adolescents with neuromuscular disease and adolescents without disability have similar QOL in most categories. The adolescents with neuromuscular disease have *higher* self-perception scores in terms of school performance and their relationships with teachers, and lower scores in terms of leisure activities.

Surprisingly, children who use ventilators do not report significantly worse QOL than children who do not use ventilators. White-Koning and colleagues (2008, 621–23) demonstrate that professionals predict a lower QOL in the psychological well-being domain than parents of children with severe cerebral palsy and cognitive impairment. However, neonatologists' predictions of low QOL due to disability are not supported by existing research in which people with disability evaluate the quality of their own lives.

QOL depends to a large degree on the evaluator of that quality of life. A few studies compare the responses of different evaluators (the disabled individuals, the parents of the children with disability, and the HCPs) about the quality of life of extremely low birth weight (ELBW) infants at different ages.[42] The results of these investigations provide insight into assumptions about the QOL of disabled people (Lam et al. 2009, 1503–6; Saigal, Feeny et al. 1996, 453; Saigal, Stoskopf, Feeny et al. 1999, 1994–95; 2000, 571–73; 2006, 1146).

These studies suggest that, as expected, adolescents who were ELBW infants report greater impairment, in terms of intellect, vision, pain, and self-care (Saigal, Feeny et al. 1996, 453; Saigal, Rosenbaum et al. 2000, 572–73), than teens who were born at term. However, this additional morbidity does not translate into perceptions of worse quality of life (Saigal, Stoskopf, Pinelli et al. 2006, 1146). Parents and their disabled teens (or adult children) agree on the teens' (or adults') functional disabilities, but the disabled children perceive themselves to have a better QOL than either their parents or HCPs recognize (Lam et al. 2009, 1503–6; Saigal, Feeny et al. 1996, 453; Saigal, Stoskopf, Feeny

[42] Extremely low birth weight infants are those born weighing less than 1000 grams.

et al. 1999, 1994–95; 2000, 571–73; Zwicker and Harris 2008, e368, e372–73). Nonetheless, teens and adults of different birth status mark their own health-related QOL similarly despite different functioning scores. This research also suggests that health-related QOL improves with increasing chronologic age for ex-preterm infants. Most notably for this thesis, HCPs (neonatologists and nurses) consider these ex-ELBW infants with disabilities to have a lower QOL than any of the other respondents. Thus, HCPs, even more than parents, consider QOL of disabled people lower than the disabled people perceive their own QOL; this intimates that bias against disability (at least in terms of QOL) may exist among HCPs and parents.

In addition to the lower rating of QOL for persons with all types and ranges of disability (as expected in a cohort of ex-ELBW teens and young adults), HCPs understand "profound" disability more negatively than young adults or their parents (Saigal, Stoskopf, Feeny et al. 1999, 1994–95). For their study, Saigal and colleagues interviewed HCPs (neonatologists and nurses), two cohorts of adolescents (one group that consisted of those who were ELBW infants and the other group made up of those who were term infants), and the parents of both parties of adolescents. The investigators provided preference ratings for four or five different hypothetical scenarios of children with disability. HCPs considered "profound" disability scenarios as "life worse than death" significantly more frequently than the parents or either group of adolescents did.[43] No difference

[43] The two "profound" disability scenarios that Saigal describes are:

1. Sandy who is hard of hearing and uses a hearing aid and is nearly blind even with glasses; "uses equipment, but not the help of another person, to walk" (Saigal, Stoskopf, Feeny et al. 1999, 1993); emotionally expresses anger, worry, or

was noted between HCPs and parents in the "mild" or "moderate" categories.[44] Again HCPs are shown to perceive disability in distinctly negative terms.

To summarize: first, self-reported QOL of disabled adolescents and young adults is similar to that of nondisabled adolescents and young adults, despite recognition of their impairments; second, HCPs have a more negative view of the quality of life of disabled children compared with both disabled and nondisabled adolescents and their parents; and, finally, some disabilities may not affect QOL from the disabled adult perspective.

Not all agree that the QOL of a significantly disabled person is good. Peter Singer, a philosopher who writes on the morality of infanticide, perceives the life of a severely disabled person as one not worth living (Singer, personal communication; 2011, 162). Though this topic could extend for pages or chapters, I limit myself to the basic aspects of Singer's arguments. First, he claims that

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sadness; learns at his own rate; employs resource aids for learning in school; uses physical aids "to eat, bathe, dress, or toilet" (Saigal, Stoskopf, Feeny et al. 1999, 1993); has intermittent pain that responds to acetaminophen and does not interfere with daily activities; and

2. Pat who is deaf, blind, or unable to speak; "uses equipment, but not the help of another person, to walk" (Saigal, Stoskopf, Feeny et al. 1999, 1993) emotionally expresses happiness and rarely worries; learns at his own rate; employs resource aids for learning in school; gets help with at least one activity of daily living from an assistant; and has intermittent pain that responds to acetaminophen and does not interfere with daily activities.

[44] The following are the "mild" and "moderate" categories:

1. The "mild" disability category that Saigal describes is Jamie's situation. Jamie sees, hears, and talks; walks, bends, lifts, jumps, and runs on his own; emotionally seems happy and unworried; learns "more slowly than the rest of the class" (Saigal, Stoskopf, Feeny et al.1999, 1993); does activities of daily living independently; and does not experience pain.
2. Chris represents the "moderate" group. He sees, hears, and talks; uses "the help of another person, as well as equipment, to walk (Saigal, Stoskopf, Feeny et al. 1999, 1993); emotionally expresses anger, worry, or sadness; learns without aid; does activities of daily living independently; and does not experience pain.

> the fact that a being is a human being, in the sense of a member of the species *Homo sapiens*, is not relevant to the wrongness of killing it; instead, characteristics like rationality, autonomy and self-awareness make a difference. Infants lack these characteristics. Killing them, therefore, cannot be equated with killing normal human beings or any other self-aware beings. The principles that govern the wrongness of killing nonhuman animals that are sentient but not rational or self-aware must apply here too.
> . . . the most plausible arguments for attributing a right to life to a being apply only if there is some awareness of oneself as a being existing over time or as a continuing mental self.
> . . . No infant—disabled or not—has as strong an intrinsic claim to life as beings capable of seeing themselves as distinct entities existing over time. (Singer 2011, 160)

Besides (1) equating nonrational or non-self-aware animals with human infants and (2) maintaining that all infants have less of a right to life than rational and self-aware adults, Singer also argues that he does not justify killing all disabled infants. Instead, the parents should decide whether the infant should die. He defends killing disabled infants by stating that

> the quality of life that the infant can be expected to have is important.
> . . . The difference between killing disabled and normal infants lies, not in any supposed right to life that the latter has and the former lacks, but in other considerations about killing.
> . . . One important reason why it is normally a terrible thing to kill an infant is the effect the killing will have on its parents. It is different when the infant is born with a "serious" disability. Parents may, with good reason, regret that a disabled child was ever born. In those circumstances, the effect that the death of the child will have on its parents can be a reason for, rather than against, killing it." (Singer 2011, 160–63)

Thus, Singer asserts that killing a "seriously" disabled infant may constitute a moral action. To attempt to clarify which infants are "seriously" disabled, he addresses degree of disability. He suggests that certain disabilities are more severe than others; he submits that a child with a spectrum of (severe) disorders

has a life "that can reasonably be judged not to be worth living" (Singer 2011, 162).[45]

Singer bases his ethical arguments for the moral defense of killing disabled infants on utilitarian principles, specifically the preference for greater happiness and less misery. He evaluates both the "'prior existence' version" and the "'total' version" (Singer 2011, 162–63) of utilitarianism to validate his assertions. Singer, speaking of an infant with hemophilia, describes his contention using the "prior existence" adaptation:

> The infant exists. His life can be expected to contain a positive balance of happiness over misery. To kill him would deprive him of this positive balance of happiness. Therefore, it would be wrong. (Singer 2011, 162)

to kill him. On the other hand, Singer uses the "total" view of utilitarianism to interpret the right to life of an infant with hemophilia differently. The focus is not on the individual measure of happiness or misery, but on the overall amount. Singer's example considers whether the parents of the infant with hemophilia would have another child with a (presumably) "better life than the one killed" (Singer 2011, 163). He explains that

> the total amount of happiness will be greater if the disabled infant is killed. The loss of happy life for the first infant is outweighed by the gain of a happier life for the second. Therefore, if killing the haemophiliac infant has no adverse effect on others, it would, according to the total view, be right to kill him. (Singer 2011, 163)

However, Singer does not consider the possibility that the parents will not have

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[45] Singer gives the example of a child with Tay Sachs disease, a nervous system disease that usually causes death by four to five years of age. Most children with this disease experience a progressive decrease in muscle mass and tone; loss of developmental milestones; eventual minimal movement and interaction with the environment; blurry vision or blindness; difficulty hearing; and seizures (Behrman, Kliegman, and Nelson 1992, 346–47; Singer 2011, 161).

another child. Nor does he mention the possibility that killing their child may have emotional consequences for the parents that they do not foresee when they are first faced with their disabled newborn. These points are in addition to the many ethical rebuttals to Singer's utilitarian argument (that I have no time to address here).

Many disability advocates, bioethicists, philosophers, disability scholars, and other academics have disputed Singer's contentions (Asch 2000; Baroff 2000; Colosi 2003; Jeffreys 2001; Johnson 2003; Koch 2004; Pauer-Studer 1993; Somerville 2002; Sundström 1995; Szasz 2001; Tillman 2013). They have refuted his ethical arguments and accused him of ableism. Still, Singer claims to respect disabled people who "are now living their own lives" (Singer 2011, 165) despite his assertions that killing disabled children may be morally justified. He insists that such disabled people differ morally from infants with disabilities whose lives are not worth living.

Although this thesis is not the place to respond to Singer's controversial assertions, the subjects of this chapter indirectly address many of the non-philosophical elements of his line of reasoning. I include the comments of one disability scholar, Adrienne Asch. Responding to Singer's claim of the moral correctness of killing infants with certain disabilities for the purpose of preventing poor QOL (and suffering), Asch emphasizes:

> It is time for people in medicine and bioethics to listen to people with disabilities and their families who consistently report that their lives are not tragedies, that often their lives are as satisfying

> as those of nondisabled people, to the extent that scores on self-reports standardized psychological measures can be trusted. (Asch 2000)

She continues,

> People with disabilities, like anyone else, can find one facet of their lives problematic, disappointing, frustrating, and not decry the whole of their lives. There are other moral values than happiness: loyalty, integrity, striving for self and world improvement to name a few. Singer would probably not dispute the claim that other values exist, but by trying to reduce them all to "happiness" and to measure the value of a life by calculating happiness and pain, he misses the richness and complexity that exists in all life. (Asch 2000)

The QOL studies mentioned earlier in this chapter start to fill a void of personal knowledge about disabled people gained via the experiences of disabled people. Further research using QOL studies more encompassing of the whole person than health-related QOL would provide more information about life satisfaction and quality. The QOL of disabled persons both reflects and has implications for their lived experience.

The Lived Experience of Persons With Disability

This thesis addresses the limitations of current conversations about disability in the neonatal intensive care unit (NICU). In my experience, conferences between HCPs and parents about neonatal care for their sick, disabled infant omit the lived representations of disability. There is typically some discussion of disability and related concepts: “severe” disability, inability to communicate, “severe” cerebral palsy, “wheelchair bound,” “mental retardation,” (some replace “mental retardation” with intellectual or cognitive disability),

"vegetative state," diapers, feeding tube, and so on.[46] However, positive aspects of disability for the infant or family—the disabled persons' perspectives of disability and the good situations and feelings a disabled person can experience—rarely reach the family's ears. HCPs seldom depict encouraging portraits of disabled people such as good QOL, happiness, love of family and friends, abilities of the disabled individual, potential achievement of life milestones, and so on. In part this is because physicians are often ignorant of these embodied realities, in part because they have worse attitudes about disability compared with parents and disabled people themselves (as previously referenced). These biases persist in parents as well. Eva Kittay, writing about her daughter who has "severe" cognitive and motor disabilities, suggests that parents find dispensing with bias difficult. From the perspective of parents of "profoundly" disabled children she states that

> we must acknowledge our limited grasp of life lived with a disability. As much as we love our children, we are unlikely to see the world from their perspective, and we are likely to continue to harbor biases we retain from an "horizon of ability." (Kittay 2011, 627)

The intersection of the medical and social models can address this limitation (see chapter 1 for a more thorough discussion of the different models). Medical training guides HCPs to think of prognosis as health outcomes in terms of diagnostic categories: cerebral palsy, intellectual disability, inability to eat by mouth, speech impediments, behavioral problems, etc. On the other hand, most disability advocates and scholars, who approach disability from an experiential viewpoint, recognize that disability is more than just impairment (Andreou 2010, 464; Barnes 2010, 29; Barnes and Mercer 2010, 18–24; Davidson 2010, 136;

[46] The preceding terms denote negative depictions and ableist descriptions of disability.

Edwards 2008, 26–27; Koch 2008, 18–20; Linton 2010, 224; Oliver and Barnes 2012, 19–20, 22–23; Scully 2008a, 25–27; Shakespeare 2008, 11–14; 2010, 267–69; Smith 2009, 18–21; Thomson 1997, 49–51). In fact, they assert that the disability lies primarily in the societal response to the impairment.

Some of these disability advocates argue that the medical model is harmful to disabled persons (Andreou 2010, 464; Barnes 2010, 29; 2012, Barnes and Mercer 2010, 18–24; Davidson 2010, 136; Edwards 2008, 26–27; Koch 2008, 18–20; Linton 2010, 224; Oliver and Barnes 2012, 19–20, 22–23; Scully 2008a, 25–27; Shakespeare 2008, 11–14; 2010, 267–69; Smith 2009, 18–21; Thomson 1997, 49–51). They claim that the medical model's assessment of the individual as impaired and the response society has to that impairment cause the harm. Additionally, disability advocates suggest that the social model can prevent such harm and achieve benefits for disabled people.

For example, if a society considers a person with Down syndrome (DS) to be uneducable and undesirable due to his cognitive disability and facial anomalies and, therefore, institutionalizes all children with DS, then the society will produce uneducated adults with DS who do not work and who are isolated from social situations. On the other hand, a society that values and educates children with DS will produce educated adults with DS who can belong and contribute.

To me, this concept of the environment as the disabler can be challenging for physicians to grasp because it requires a complete revision of their worldview achieved via their extensive training and medical culture. In response, I add a medical perspective to the disability advocates' viewpoint. HCPs may better relate

to a social model alternative that incorporates their perceived obligations as HCPs. If they can better relate, they are more likely to assume some of the ideas in their practice.

Barnes' Arguments and Negative Thinking About Persons with Disabilities

To elucidate the ethical problems with the medical model, Colin Barnes (2010a, 29–31) highlights six ways in which the medical model creates a negative attitude toward disabled people (Asch 2000, 248–50; Oliver and Barnes 2012, 19; Smith 2009, 16–17). Barnes (2010a, 29–31) proposes six drawbacks of the medical model. Each drawback portrays ethical dilemmas created by the medical model of disability and, in part, remedied by the social model (Asch 2000, 248–50; Oliver and Barnes 2012, 19; Smith 2009, 16–17).

Barnes' (2010a, 29) first argument against the medical model involves the difficulty in defining psychological, cognitive, and physical normality (see the beginning of this chapter for a discussion of normalcy). Functional impairment also dodges precise definition. Barnes suggests that the complexity of delineating mental and physical norms (and, in turn, mental and physical impairment) relates to various "temporal, cultural, and situational factors" (2010a, 29). Therefore, what was normal in 1930 (such as developing tertiary syphilis years after developing primary syphilis) is no longer normal in 2014. What is normal for an unwed, pregnant American woman is not normal for an unwed, pregnant Iranian woman. And what is normal for an 18 year old may not be normal for a

90 year old. Time, mores and ethos, and circumstances define normal; defining normal is complex.

Medical training represents normal in terms of a Gaussian distribution of traits and deviation from the norm. An impairment or deviation from the norm usually exists when a patient (or his parent) seeks healthcare—or when a neonatologist admits a newborn to the NICU. The healthcare system usually aims to treat the patient with a goal of better functionality, regardless of the definition of the norm. In my experience, HCPs rarely understand the harmful impact that their attitudes about deviation from the norm have on people with disabilities. This lack of understanding can cause increased harm to disabled patients.

The medical definitions of "normal" and "functional impairment" cause harm in three main ways. First, in my view, the HCP rarely recognizes the harm he produces—and therefore he cannot correct it. For example, a deaf patient who makes an appointment with a physician for a strained muscle expects the physician to concentrate on the strain. If after addressing the strain, the HCP informs his patient that a cochlear implant would "cure" the patient's deafness, then the physician has announced to the patient that deafness is the patient's chief problem, his "abnormality." The physician may not know that this patient does not want a cochlear implant; the patient may have a huge support network in the Deaf community.[47]

[47] "Deaf" with a capital "D" refers to an individual who is part of the social and cultural Deaf Community. In this thesis I will discriminate between deaf, the physical description of someone who does not hear and who experiences his deafness as an impairment, and Deaf, the person who does not hear, but who experiences his deafness as a cultural linguistic minority.

Second, the HCP may mistakenly label a patient "abnormal." For example, a physician may consider a patient who measures more than two standard deviations below the mean "abnormal" when the individual actually falls within the normal distribution for their situation. For instance, I have seen witnessed medical assessments costing thousands of dollars for small-for-gestational-age infants.[48] Some evaluations are necessary. But if the mother measures five feet and weighs ninety-five pounds, and the father measures five feet six inches and weighs 145 pounds, the medical evaluation is wasteful because the infant's small size is genetically determined. Too many HCPs just look at the numbers and the medical definitions of *normal* and *abnormal*, perceive abnormality, and initiate the testing. The damage to the parents, and eventually to the child, has social relevance. It lies in the label of "short" or "abnormal," and not just in the squandering of healthcare dollars.

Finally, the HCP may label a patient "abnormal" because he has traits that fall outside the normal distribution for those traits. For example, a child with Down syndrome who has ears set lower than the normal distribution of ear positions and has intellectual abilities that fall out of the normal distribution for all children are labeled "abnormal." Despite their label, these children have many abilities and feelings (Brasington 2007, 733–34; Sheets et al. 2011, 433–34; Skallerup 2008, 171–88). The child with DS may have a life he considers happy, loving, and satisfying. But this medical (and bioethical) categorization of normal

[48] Small for gestational age infants measure less than the tenth percentile for weight, length, and/or head circumference for their gestational age.

or abnormal may not be meaningful for the lived life of that individual child and may in fact have a negative impact separate from any physical markers.

These three aspects in which HCPs bring about nonmedical injury substantiate Barnes' first objection.[49] The concept of difference from the norm creates harm to disabled persons; medical professionals should be trained to recognize this harm. By seeing the disabled person as other than abnormal—as having a life experience that may differ from that assumed by the HCP—the HCP can do good.

Barnes' (2010a, 29–30) second critique of the medical model is its emphasis on changing the impairment rather than the physical and social environment. Though I agree with Barnes that the emphasis on changing the impairment frequently creates problems for the patient, I do not agree that the medical model should focus only on modifying the physical and social setting. From a medical perspective, the purpose of healthcare is to cure or treat the impairment, not to alter the environment for disabled people. In fact, this falls into the hands of disability specialists—occupational therapists, child life specialists, technology specialists, architects, legislators, policymakers, and others (including others whose fields have not yet been conceived). Although HCPs may assist with this goal by referring their disabled patients to the experts, these professionals should prioritize the practice of their specialty.

However, the HCP should communicate in ways that incorporate the social model: less use of ableist language that reveals underlying negative attitudes,

[49] HCPs (and others) can create injury that extends beyond medical injury. This injury can involve the abnormal classification of the patient.

more discussion about the positive aspects of having a disabled child, and more knowledge and dialogue regarding potential abilities of their disabled patient. HCPs could also work in collaboration with disability specialists, advocates, and organizations. For example, a physician may prescribe medication or surgery to treat hypertonia of a patient with cerebral palsy.[50] Meanwhile, he should also refer the patient to physical, speech, and occupational therapy for better environmental accommodation, and, he should refer to specialists who advise about household, learning, social, and career adaptations. Organizations that provide facts about the specific disability and support groups may help the patient and parents. Parent advocates who have children with a similar disability may reach out to the parents of these patients who are newly diagnosed; such parents may provide much needed emotional assistance along with advice and advocacy strategies. In today's healthcare system the parents need guidance from others besides their HCP.

Although I do not contend that the healthcare professional must exclusively address environmental accommodations for the disabled person, I do agree that the HCP should identify the need to change the environment rather than focusing solely on repairing the "abnormality." Many disabled people relate situations in which physicians offer treatments for their chronic impairments that are unhelpful or harmful (Anita Silvers, personal communication). Sometimes, the HCP's treatment plan fulfills the HCP's need to treat the

[50] Hypertonia is an increase in muscle tone (muscle stiffness) associated with cerebral palsy.

abnormality rather than benefit the patient. In this way, the HCP may concentrate too much on treating the disability.

In addition, this emphasis on treating the physical or cognitive impairment affects the way in which an HCP describes and approaches a disability. The HCP who recognizes the positive aspects of being disabled and discusses them with patients incorporates the social model into his practice. Learning about the lived experience of disability (Parens and Asch 2003, 45), refocusing on the positive aspects of being disabled, and providing guidance (or referrals for guidance) to promote optimal environmental support minimizes disability and benefit patients. Though I agree that HCPs focus too much on the treatment of disability, I disagree with Barnes that they should concentrate instead on the social model goals of accommodation. Rather they should incorporate the social model into their scope of practice.

I also partly agree with Barnes' third difficulty (2010a, 30) with the medical model: the understanding that disability arises from impairments—physical, cognitive, or psychological—rather than from the environment. Barnes claims that disability evolves from the barriers of the social and physical environment to persons with phenotypic variation. HCPs tend to direct treatment of the impairment in hopes of improvement or cure. But this is not the whole story.

At first I found this aspect of the strong social model peculiar. Do disability advocates really think that HCPs should not attempt to treat a treatable

impairment?[51] Emphasis on the unfriendly environment's impact on disability is understandable, but why disparage therapy or cure? In fact, Barnes (2010a, 30; 2010b, 30) recognizes the suitability of treatment in some situations. As I discussed in chapter 1, Kittay (2011, 167) and Scully (2008, 29), who amend the social model, take this a step further and emphasize that impairment also causes disability. But, Barnes recommends emphasizing a patient's QOL rather than simply treating the impairment, the whole person rather than the impaired part.[52] Furthermore, according to Barnes and to some degree in my opinion as well, emphasis on the need for change in the social and physical surroundings may provide more assistance and improvement in health than emphasis on improving the impairment. It seems to me while, sometimes, repairing the impairment improves QOL, other times, repairing the impairment does no good. In either situation, for the HCP to stress environmental accommodations (though not solely) will diminish the disability.

In my experience, HCPs can overlook this understanding of disability. They usually perceive physical, cognitive, or psychological impairment as entirely detrimental to life. Patients who want to alleviate disease, pain, fatigue, injury, and phenotypic variation pursue medical treatment to relieve their symptoms and improve their QOL. The natural corollary to this experience is the perception

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[51] For a discussion of the distinction between impairment and disability, see the "Major Models of Disability: The Medical and Social Models" subsection of chapter 1.

[52] In trying to find a synonym for "impaired" in order to avoid using the word twice in one sentence, I found the following words in a thesaurus: damaged, reduced, lessened, decreased, weakened, diminished, compromised, harmed, spoiled, blighted, prejudiced, ruined, marred, and worsened; no synonyms were acceptable.

that disability is undesirable and negative. The viewpoint of the social model can add insight to a physician's understanding of disability.

How can disability be positive? People with a disability have many qualities. They almost always have cognitive aptitudes, physical abilities, a personality, and relational competences; they sometimes can work, play, be happy, have friendships, love, be loved, and get married. The disability does not define the person.

People learn to live with many so-called silent disabilities. These disabilities fall outside the normative distribution of the specific characteristic for the population, but do not disturb the lives of those affected, are not apparent to others, or do not greatly matter to most of society. For example, people who have tone deafness are not considered disabled by most. People who read slowly (like me) are not considered disabled as long as they have other cognitive abilities to cover up for their reading speed. Most of the time people with color blindness have a hidden disability. And mathematicians with poor writing skills are not thought of as disabled. Neither are people who lack athletic ability or who have an average IQ. These purportedly invisible disabilities are mostly unseen.

But people with these alleged hidden disabilities have abilities. Mentally healthy people may be tone deaf. And opera singers may experience depression. People who read slowly may excel at medicine. And people who excel at medicine may have Asperger's syndrome. Individuals with color blindness may not face discrimination until they apply for a job as a pilot or FBI agent. Mathematics students with poor writing skills may fail their introductory English course. People with a low IQ may have great athletic ability. And people with poor

athletic ability may have a high IQ. When disabilities are "silent" they are easier to overlook and we only see the abilities; when disabilities are discernible, they are harder to overlook and we often fail to recognize the person's abilities.

Whether people with phenotypic variation and disability have impairments that are amenable to treatment or not, their lives would benefit from an environment that minimizes their disabilities rather than creates barriers to adequate functioning. For example, the availability of Braille numbering and sound signals on elevators and in crosswalks and the provision of sight dogs decrease the disability of a blind person; he may not see, but he can walk where he wants to go, cross streets, and make his way around buildings beneficial for socialization, economic gain, and possibly happiness.

Many proponents of the strong social model (see chapter 1 for a more detailed discussion of the strong and social-relational models) aver that disability is primarily due to the social, economic, political, and/or cultural environment (Barnes 2010b, 30–2; Davis 2010a, 2–3, 10, 158; Edwards 2008, 26; Koch 2008, 18–20; Scully 2008a, 25–28; Shakespeare 2010, 268–70; Silvers 1998, 87). They assert that technical aids, personal aids, physical environmental transformations, work modification, anti-discrimination laws, and social acceptance of phenotypic differences will eradicate disability (Davis 2010b, 301–3; Shakespeare 2010, 268–69). Nonetheless, advocates of the various social-relational models claim that many phenotypic variations would result in functional disability even if society eradicated social and physical barriers (Scully 2008a, 25–30). For example, functional impairment for people with chronic pain or significant multi-sensory neurodevelopmental impairment would persist without barriers.

However, the fact of impairment does not negate the important contribution of the social, physical, and cultural barriers to disability (Shakespeare 2008, 11–12; Thomas 1997, 264; 2008, 16–17; Vehmas 2008, 23). Alterations of the physical environment and of social attitudes toward people with phenotypic variations will certainly minimize disabilities, stigma, and exclusion, but will not totally eradicate them, as suggested by some social model scholars such as Jackie Leach Scully, Carol Thomas, and Tom Shakespeare.

On the basis of Kantian ethics, feminist moral theory, care ethics, utilitarianism, pragmatism, and principlism, not offering treatment for impairment on the basis of blaming the environment for the disability is unethical, unless the patient refuses the treatment. On the other hand, for HCPs not to recognize and incorporate into their practice (to some degree) the extent to which physical, social, economic, and political obstacles contribute to the disability of their impaired patients creates a healthcare system that partially benefits and partially harms.

Barnes' fourth argument against the medical model is the damaging psychological effect of the emotional pressure applied to disabled persons to adjust to a life of discrimination (Barnes 2010, 30). I presume Barnes means that the medical model's emphasis on treating impairment implies that HCPs encourage disabled people to adapt to discrimination. Certainly the medical model establishes disability as negative and being within the normal distribution as positive (Davis 1995, 7; Shakespeare 2010, 268–70). And HCPs prefer their patients to adjust (over time) to changes in abilities as a result of any illness, disease, or injury. Acceptance of new situations helps people adapt

psychologically. Adjustment to a life of disability does not necessarily imply tolerance of a life of discrimination.

On the other hand, HCPs would benefit their disabled patients if they educated them about the potential for discrimination, the need for advocacy, and existing useful organizations and websites. Ignorance of the subjective experience of disability does not excuse HCPs from their responsibility to better inform their disabled patients about how to live high quality lives and exercise their rights. Education for these HCPs would go far in helping them to better understand disability and improve the care they provide for their patients. With this knowledge HCPs would have a better chance of helping their patients resist a life of discrimination.

Barnes' (2010a, 30) fifth argument against the medical model is that the definitions of *impairment*, *disability*, and "*handicap*" suggest a fixed condition.[53] This perception of a fixed condition results in the creation of barriers between disabled and nondisabled persons and enables bias and discrimination against disabled persons (Barnes 2010a, 30). From the perspective of the medical model, when the phenotypic variation is permanent, the impairment is fixed. However, function is relative to expectation and performance (Oettingen and Mayer 2002, 1198–200). The medical view of a fixed impairment creates barriers between disabled and nondisabled people. The barriers occur both when others perceive the phenotypic variation as the primary characteristic of the individual and

[53] *Handicap* is no longer an acceptable word for disabled people due to its negative association.

through society's perpetuation of discrimination and bias against disabled persons.

In some ways this argument of Barnes' is a semantic one. To me a medically-fixed condition refers to the physical, cognitive, or mental phenotype. I do not include the patient's adjustment or abilities in the definition. Yet in thinking of the meaning of *condition*, I recognize that other aspects of life are essential. Thus, as Barnes implies, if HCPs insinuate that a disabled person's condition —phenotype, attitude, abilities, function—will never improve (is fixed), then they enable bias and discrimination.

Though the medical model may exaggerate the distinction between disabled and nondisabled people in other ways, the perception of a fixed impairment does not necessarily cause the discrepancy. If the patient seeks care for treatment of an impairment stemming from the phenotypic variation, then treatment is appropriate. However, if the HCP encourages unnecessary or unwanted treatment for a phenotypic variation to better fit the expectations of nondisabled persons rather than aid the patient, then the concerns raised by the fifth argument are legitimate.

The sixth and final argument against the medical model of disability pertains to the language commonly used in our society (and by medical professionals) to describe disability (Barnes 2010a, 30). This language refers to the functional problems in daily living rather than the limitations of environmental and attitudinal access created by society. Such words and phrases create the impression to all that the disabled person is inferior due to his functional limitations. Disability activists, advocates, and scholars prefer

language that places the blame on failure of the environment to adapt to disability (and, thus, remove barriers) so that the disabled person can function without limitation. An example that Barnes uses is the difference between asking the questions, “Does your health problem/disability affect your work in any way at present?” (Barnes 2010a, 30–31) and “Do you have problems at work because of the physical environment or the attitudes of others” (Barnes 2010a, 30–31)? The first question suggests that the impairment causes problems; the second implies that the physical and social environment triggers difficulties.

Sometimes, though, the recounting of patients’ functional abilities provides information important for the HCP. If pain were limiting someone’s work, then the answer to “Do you have problems at work because of the physical environment or the attitudes of others?” would not help the HCP treat his patient’s pain. However, “Does your health problem affect your work in any way at present?” would provide important information. Scully’s assertion that certain aspects of the impairment itself (for example, emotional pain, uncontrollable physical pain, or cultural representation) may cause disability for an individual come into play (Scully 2008a, 27, 172–73). An HCP’s exploration of the patient’s lived experience—via the patient’s report or, in the case of a patient without the capacity to communicate, the surrogate’s report—can provide data that are invaluable and prevent the use of unnecessary ableist language.

I agree that HCPs should transform their use of language; they should not perpetuate discriminatory attitudes toward their disabled patients. By changing the words and the implications of their sentences, HCPs both reduce the discrimination experienced by their disabled patients and help their patients to

view their disability, at least in part, as a function of lack of environmental accommodation. Hopefully nondiscriminatory language will encourage disabled patients to become more proactive in changing the environment to aid in their functioning (see chapter 5 for a more detailed exposition on ableist language). In this way HCPs can assist their patients to live healthier and happier lives.

From Barnes' (2010a, 29–31) six arguments against the medical model arises the overall claim that the medical model promotes negative thinking about persons with disabilities. Such negative attitudes support discrimination against persons with disabilities (Asch 2000, 248–50). A disability bioethicist, Jackie Leach Scully (2008a, 2–5, 16, 171–73), describes the common thinking about disabled people: they are lumped together and perceived as unhappy and abnormal incompetents who possess a poor QOL.[54] She submits that "unusual embodiment" produces unusual moral understanding, suggesting that disabled and nondisabled people may have different moralities (Scully 2008a, 9, 11–13, 154). Partly rooted in feminist ethics, she advocates for discussion of relationships, community, environment, personal narratives, and social history as part of the moral conversation. Scully (2008a, 154–55) further claims, and I agree, that disability must be studied, described, and experienced in order to replace theoretical constructs of the lives of disabled people with the experiential breadth of life as a disabled person.

[54] HCPs often think like the rest of society about people with disability. Their judgment may be altered by their medical experiences to some degree, but their nonmedical life experiences and society's attitude has a huge impact on their attitudes toward disabled people.

I personally experience unfavorable attitudes toward disability by many healthcare professionals. They find phenotypic variation and disability to be undesirable, unworthy, and unsatisfactory. Examples abound: the maternal-fetal medical specialist who wanted me to convince the pregnant woman to abort her fetus with short arms and legs (as described in the chapter 1); the neonatologist who was distressed when he thought he was harming his patient because the newborn had a high likelihood of neurodevelopmental disability and the parents refused to withdraw life-sustaining treatment; the nurse practitioner who insisted that she would never raise a "mentally retarded" or physically disabled child if she had one. In part this negative view of disability originates with general society; in part it derives from HCPs' experience: from patients or parents who want a cure or treatment for their disability and from parents who want children without disabilities. Another etiology for this standpoint resides with the HCP's job description: to treat and cure when possible. Significant disability can represent failure for many HCPs.

A negative attitude about disability by HCPs represents a failure of both the medical model and the healthcare system. Healthcare workers should realize that positive attitudes can help heal, as can words. More education about life with disability—for HCPs at all levels of training and experience would expose them to more of the ideas that disability advocates deem so important for good medical care. Recognition of this situation could encourage HCPs to discuss disability with patients in a more positive and knowledgeable way. Once they witness the

positive reaction of a patient to their encouraging interpretation of disability, they will understand how optimistic attitudes can help heal, as can their words.[55]

Typically, when HCPs discuss a phenotypic variation with a patient, they discuss the expected or potential medical difficulties. Physicians and other HCPs are trained to diagnose, prognosticate, treat, and communicate to the patient or parent these issues. They should discuss potential problems to inform and educate their patients about the diagnosis, treatments, complications, and probable outcome. They also should apprise patients of the services, interventions, and aids available to them. HCPs should review resultant functional problems with patients because that is their duty. However, they may fail to think about the whole person. Although some may argue that environmental accommodations reach beyond their purview, I propose that discussions regarding physical and social adaptations as well as about disability advocacy have the potential to change the lives of their patients and their patients' families. And so, environmental accommodations fit into their purview.

To summarize, I argue that medical training and the medical traditions create and reproduce many of the obstacles that Barnes identifies in his six difficulties with the medical model—and that contribute to discrimination against disabled people by creating negative interpretations. To overcome these impediments and to help improve the lives of disabled people, HCPs should accomplish three goals: (1) to learn more about the lives of people with

[55] The first time I told the parents of an infant with DS about the marvelous qualities of children with DS and the benefits to the parents and families, I observed a beneficial attitude transformation for the parents that I never expected (see chapter 1 for the details of this anecdote). I did not expect this response, but it encourages me to continue the approach with other families of potentially disabled children.

disabilities, both the positive aspects and the psychological effects of disability; (2) to include their new understanding of disability in their communication with and treatment plans for disabled people; and (3) to treat patients as whole individuals rather than diagnoses.

A Goal for Bioethicists

The ethical conflicts regarding the medical model and treating people with disabilities indicate a need for bioethicists to get involved in the discussion. As Scully suggests, bioethicists should study the empirical and experiential bioethical contexts of disability (Scully 2008a, 153–55).

Bioethicists and other researchers should explore both the advantages and disadvantages of disability in cultural, environmental, and moral contexts. They should explore the role of "impaired embodiment" (Scully 2008a, 9, 154) from a cultural perspective as well as in light of the physical lived experiences of people with disability. They should explore the perceptions of disabled people and their families in terms of QOL. They should explore what levels of disability are incompatible or rarely compatible with a good QOL, if any. They should explore the limits of acceptable phenotypic variation, after which point the consideration of withdrawal or withholding of life-sustaining support is no longer discriminatory but ethical. They should explore whether such limits exist. They should explore how to prevent some of the morally problematic situations in which HCPs currently engage due to ignorance of disabled peoples' experiences. They should explore disabilities as described by disabled people in order to better understand what is ethically acceptable or unacceptable in terms of QOL and

permissible interventions (Scully 2008a, 153–60). And they should make sure that physicians access this new knowledge so that they can better understand the lives of their patients with disabilities; better inform their patients of the abilities of, as well as the challenges for, disabled people; and better treat their patients as whole people, disabled or not.

With this knowledge of disability, the HCP can still treat impairments that impede function when desired by the patient or family. The changed attitudes from this new learning can allow for less judgmental and more well-informed descriptions of disabilities. The medical conversation about impairment will change from centering on a necessarily devastating condition limiting QOL to focusing on a problem that affects a part of the person, but does not change the whole person. The language of disability should not disparage disabled people. Environmental aids and advice should be a larger part of medical care. In this way, the framework in which the patient or family learns about the disability can become more balanced and knowledge-based.

More specifically, this information should transform the discussions between neonatologists and families of disabled babies. Along the way, HCPs and bioethicists will hopefully develop a new discourse about disability. By forging new appreciations about disability, HCPs can continue to treat impairments that create problems in functioning for the disabled person and, at the same time, provide an understanding of the world of the disabled person and his or her family. This world should include not only negative views of disability, but positive portrayals that reveal every individual as a complete person with abilities and disabilities.

The balanced interpretation of disability that neonatologists and other HCPs should convey to families requires a basic knowledge of communicating what is called “bad news” in the medical literature. In the next chapter, I discuss the aspects of conversations between neonatologists and families necessary to elicit values and thoughts from families and, also, inform parents of unforeseen (or prenatally identified) information about their infant.

CHAPTER 4

GIVING "BAD NEWS"

Introduction

In this chapter I discuss how healthcare professionals (HCPs) should ideally "give bad news" to patients.[56] The use of the term "bad news" refers to the assumption that most parents do not want to hear that their infant deviates from the health norm; parents find that receiving "bad news" is painful (Fallowfield and Jenkins 2004, 312; Fox et al. 2005, 157). In my experience, parents, who have not had a warning (such as preterm labor or a prenatal diagnosis of a congenital anomaly or syndrome) expect a "perfect" child with no anomalies, no disorders, and no diseases. They do not expect any variations—physical, developmental, psychological, or intellectual. Thus, when a neonatologist informs parents that their baby has or will have disabilities, she delivers "bad news," not necessarily because the information is bad, but because a change in expectations from the norm may create surprise, disappointment, and the need for adjustment.

Bor and colleagues define "bad news:"

> Situations where there is either a feeling of no hope, a threat to a person's mental or physical wellbeing, a risk of upsetting an established life-style, or where a message is given which conveys to an individual fewer choices in his or her life. (Bor et al. 1993, 70)

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[56] In this chapter I place quotation marks around "bad news," because parents may perceive the news to be bad, unwelcome, or neutral depending on their views about disability. In neonatology, while the infant is the patient, the parents receive the "bad news" from the medical team. Therefore, in this chapter, I will refer to *parents* as the recipients of "bad news." This differentiates them from the infant patient. I will use *patient* to refer to either the infant or adult patient, depending on the subjects in the study.

Two review articles, one in JAMA (Ptacek and Eberhardt 1996, 496) and the other in The Lancet (Fallowfield and Jenkins 2004, 312–13) describe "bad news" in view of its dichotomous nature: its objectivity and subjectivity. Objectively, as I mentioned above, "bad news" refers to a change in expectations. Still, the information may include the potential for pain or suffering, either temporary or long-term. It may involve the need for surgery and hospital stays. Most people would not want to learn that their child must go through these processes.

Subjectively, the recipient of the "bad news" determines how "bad" the news is. For example, a diagnosis of congenital deafness would be considered bad news by most hearing parents. However, Deaf parents who want their child to be a part of their Deaf cultural world might welcome the news. Some parents might consider polydactyly, an extra digit of the hand that can be easily removed (or not removed), "bad news," while another set of parents might not care. Thus, HCPs should take into account the subjectivity of "bad news" when communicating with parents.

The way that HCPs talk with parents about their infant's medical condition has ethical implications. Over the past few decades the healthcare system has engaged in ethical shifts from paternalism to autonomy and from nondisclosure to disclosure (Beauchamp and Childress 2009, 288–93). Specifically, the communication pattern may affect the four bioethical principles delineated by Beauchamp and Childress (2009, 257–83): autonomy, beneficence, nonmaleficence, and justice. The styles and methods of HCPs have influence how these principles are used, and how important decisions are made.

More paternalistic HCPs are less likely to allow parents to choose between options of care for their child, instead strongly suggesting what they consider best for the child. Though some parents may appreciate this approach, others may feel bullied or impotent. HCPs can do harm by insisting on choices not in keeping with a family's values. Additionally, HCPs can prevent the patient from living her best life possible by unknowingly expressing their bias against the disabled child.

I have observed a neonatologist trying to convince parents of a child with a congenital anomaly who would likely have— as we understand it—minimal interaction her environment to accept comfort care. The parents, both lower socioeconomic inner city people with mental illness diagnoses, understood the likely outcome and wanted her to live. The neonatologist, Dr. A., stated that she was not trying to convince the parents to forgo the life-sustaining ventilation and opt for comfort care (see chapter 2). But hearing her words and tone—and the responses of the family—I disagreed with her assessment of her communication. Her boss, Dr. B., a rather paternalistic neonatologist, told her that she should withdraw the ventilator regardless of the family's wishes. Dr. A. refused; autonomy was too important to her. Eventually, Dr. A., making no headway with the parents, transferred the baby to another hospital for surgery. At the other hospital, the surgeons refused to perform surgery. The parents protested. I heard that the parents would not take the baby home anyway because of their neglect of other children. And the baby was taken off the ventilator while being provided with comfort care—and she died.

The above scenario shows how damaging a poor method of communication can be. Developing an oppositional relationship with one's

patient's parents due to a difference in values is harmful. In such a situation, neither HCP nor parent can make a decision that is clearly best for the infant. The fact that the parents' mental illness played a role in a decision for the infant calls into question the application of the principle of justice in the care. The permanent harm done to the parents and the infant seems obvious. Only the physicians' values were prioritized. But in the case of a disabled child that lives, such as a child with Down syndrome, the conversation has other ethical effects. An HCP speaking disparagingly about a disabled neonate can influence the parents in ways that can interfere with bonding. Additionally, parents' lack of complete knowledge about the future abilities of their child and an ableist outlook transmitted by the HCP has the potential to create a negative experience in the lives of the entire family. For more on these issues, see chapter 6.

How to Give "Bad News"

HCPs should give "bad news" in the way that parents can best comprehend in both physical and emotional contexts. For the parents, not understanding the "bad news" may result in bad decisions: those not consistent with their beliefs, values, and desires. Hearing "bad news" in a way that causes more emotional distress than necessary may create a psychological state that hinders comprehension, acceptance of the information, and decision making, in addition to causing excess suffering. Hearing "bad news" in ways that alienate the parents from the HCPs may prevent the optimal bonding with and care for their infant.

Thus, the way a physician communicates the diagnosis, prognosis, and treatment options to parents affects the parents' understanding of and attitude

toward the medical issue (Fallowfield and Jenkins 2004, 312). Clarifying the parents' values rather than assuming how they will react will facilitate the communication of such information and improve the parents' adaptation.

But studies reveal that physicians often give "bad news" poorly (Fallowfield 1993, 476; Fox et al. 2005, 159; Mast, Kindlimann, and Langewitz 2005, 244, 247–49). Physician training concerning the delivery of "bad news" is inadequate (Fallowfield and Jenkins 2004, 312; Harrison and Walling 2010, 619). Physicians tend to learn from experience. This reliance on on-the job training means that proficiency in imparting "bad news" primarily depends on the physician's innate ability and talent for figuring out how to give "bad news."

According to Brewin (1991, 1207–8), physicians use one of three modes of imparting "bad news" to patients: the "blunt and unfeeling" method that provides clear and transparent information without empathy, the "kind and sad" approach that provides empathy but lacks support or hope, and the "understanding and positive" manner that involves clear and transparent information, responsiveness, empathy, support, and hope.[57] Exercising the third option, the "understanding and positive" style along with responsiveness to verbal and body language feedback, is the preferred mode of delivery.

In a study reported by Parker et al. (2001, 2055) of 356 cancer patients who answered a questionnaire about preferences in regards to communicating "bad news," patients' preferences varied with demographics—particularly sex, age, and level of education. They found that women cared more about learning about their disease and getting support from the physician compared with men (Parker

[57] I will describe how physicians can relate these approaches later in the chapter.

et al. 2001, 2054). Patients with a higher level of education wanted more information about their disease and cared more about how the news was delivered compared with patients with a lower level of education. Despite the differences in preferences among different demographic groups, the content of the conversation, support by the physician, and the physical situation were of primary importance to patients.

Fallowfield and Jenkins (2004, 314) reviewed research done on communicating "bad news" in obstetrics, pediatrics, acute trauma, and cancer settings. They report that the quality of the relationship between physician and patient or parent may shape the reaction to "bad news," and the reaction to "bad news" may in turn alter the physician-patient relationship. According to Sharp and colleagues, in a study of children with developmental delay, parents prefer experienced physicians who "ideally" communicate "bad news" (Sharp, Strauss, and Lorch 1992, 541–45). In another study, Stanley Klein (1993, 185) discusses the importance of perceiving the parents as partners, and thereby maximizing the abilities of the parents. This partnership may include diagnostic methods, treatment options, care for the child during procedures, and expertise in the child's symptoms and degree of illness. However, because parents may not be used to partnering with healthcare providers, they may need explicit guidance regarding the importance of their involvement in their infant's care (Klein 1993, 186). The approach by which the physician communicates "bad news" potentially influences the parents' response, their comprehension of the information, and their ability to make decisions for their child.

To better organize important facets of the physician's communication strategy for delivering "bad news," I have clustered the crucial aspects into eight categories, building from others' characterizations of these notions (Ptacek and Eberhardt 1996, 497–99; Quill and Townsend 1991, 464–68). These eight categories are: (1) pre-conversation preparation; (2) physical space; (3) timing; (4) people; (5) conversations: content and format; (6) conversations: parents' response and response to parents; (7) conversations: values; and (8) conversations: summary and follow-up.

(1) Pre-conversation preparation

The pre-conversation preparation for the physician consists of organizing the meeting and learning about the family's coping style, if possible (Emanuel, von Gunten, and Ferris 1999, M2–2; Fallowfield 1993, 477). The physician also should know the details of the case (Fox et al. 2005, 160). The healthcare professional should give thought to the structure and content of the meeting, and how the communication will take place (Klein 1993, 186).

(2) Physical Space

The physical space contributes to the conversation by providing privacy, quiet, comfort, and enough room for all participants (Fallowfield 1993, 477; Klein 1993, 185; Ptacek and Eberhardt 1996, 497). A room should afford enough space for a face-to-face conversation with the physician close to the parents and allows for good eye contact and touch, if appropriate (Quill and Townsend 1991, 477). Enough seating for everyone means the physician can sit too. A standing

physician implies a hurried, short conversation, whereas sitting creates the impression of available time and decreases the power differential between the physician and the patient. The availability of tissues allows the health care team to offer a modicum of support. The room's characteristics set the stage for a partnership between parents and physician that leads to sounder decision making.

(3) Timing

The initial conversation should occur soon after the instigating event or test result. I know from clinical experience that parents respond negatively to knowing that a test result was reported a week earlier, but the physician is just getting around to informing them. The timing should consider the convenience of the parents and family, but also the comfort level of the physician in giving the news (Ptacek and Eberhardt 1996, 497).

In addition to timeliness, the physician should allot adequate time for an uninterrupted conversation. The meeting should include sufficient time for the reporting of the "bad news," the parents to comprehend the information, the family to respond, and the HCPs and parents to interact (Fallowfield 1993, 477; Fallowfield and Jenkins 2004, 316; Ptacek and Eberhardt 1996, 497).

(4) People

The HCP should encourage the parents to include other family members, friends, clergy, staff, or anyone else who may offer support during the conversation (Emanuel, von Gunten, and Ferris 1999, M2–2; Fallowfield 1993,

316). If the parent is single, the HCP should ask if she wants other support persons to attend the meeting (Klein 1993, 186). The parents may want other staff members for support as well: a nurse, a chaplain, a social worker, or another physician. However, sometimes having too many participants in the room feels overwhelming to parents. Inviting other support persons both give the parents the expectation that a difficult discussion is planned and provide an opportunity for them to surround themselves with the support—or privacy—they desire.

Some investigators have suggested that multiple members of the healthcare team deliver "bad news," ensuring transmission of information from the various professionals' viewpoints (Fallowfield 1993, 477; Ptacek and Eberhardt 1996, 498). This format helps with exchanging different effective communication methods between team members (Klein 1993, 186). For the patients, the presence of diverse professionals helps to improve transmission of bad, neutral or good news. The presence of multiple team members also benefits future patients by improving physician communication: it results in better methods of conveying medical information and participating in shared decision making over time. However, too many HCPs may overwhelm the parents. If a team approach creates anxiety for the physician or parents, an individual approach is preferable.

(5) Conversations: Format and content

Although the previously discussed preparation offers hints of a serious conversation to come, the physician can let parents know about the "bad news" more directly by simply stating that she has "bad news" or that some of the

information may be upsetting. This provides the necessary warning of "bad news" for the parents. Sometimes, the physician's body language, including a concerned expression, forewarns the parents.

However, some situations do not allow for such groundwork. For example, when a baby is born with an unexpected life-threatening anomaly (or even an anomaly compatible with life), the neonatologist should impart at least some "bad news" immediately, because the parent will notice the infant's anomaly. Even then, the conversation should begin with a hint of the difficult conversation to come (Fox et al. 2005, 160). The physician can introduce herself, inform the parents that she would like to speak to them about their baby, and ask if they want to include any family members for support. This, along with the physician's body language, provides the necessary foreshadowing, even if only for a brief moment.

For the initial conversation, and, actually, for all of the conversations, the parents should dictate the content to a large degree (Fox et al. 2005, 160–62). Certainly, the physician must provide at least some minimal amount of information, but how, when, and how much depends on the parents. Asking the parents questions about their learning styles, how they want to communicate, and how much they want to know allows them to lead. And listening to their answers and their body language helps in figuring out what they want (Quill and Townsend 1991, 466).

To give parents a sense of control, the HCP may ask the parents what they know (or understand) about what's going on with the baby (Emanuel, von Gunten, and Ferris 1999, M2–3; Fallowfield 1993, 478; Fox et al. 2005, 160;

Ptacek and Eberhardt 1996, 498). Once the parents have stated what they comprehend and have no questions, the physician should ask how much they want to hear (Quill and Townsend 1991, 466). Ideally, the physician and parents have a bidirectional conversation. Thus, the HCP learns what the parents need and the parents have some say over the depth and length of the conversation (Quill and Townsend 1991, 465). If the physician must tell parents information they do not want to hear, she must negotiate the details (Emanuel, von Gunten, and Ferris 1999, M2–4). First she must learn why they do not want to know about the details of their baby's condition. Then, depending on the reason for the refusal, the physician has options: (1) give the parents more time, (2) bring in support figures, (3) talk to their preferred surrogate, or (4) consult the ethics committee.

Many parents choose to know the details of the problem, prognosis, and options of treatment (Fallowfield 1993, 316); others only want to be told what is wrong and when their baby will come home. If the parents lead with their inquiries, the physician can provide what the parents need, not more or less (Quill and Townsend 1991, 466). At the same time, the physician should ask questions of the parents throughout the meeting (Fallowfield and Jenkins 2004, 316; Fox et al. 2005, 161–62). These questions might include: How are you feeling? What are you most afraid of? What is the worst thing you are worried will happen? What do you understand about your baby's situation? The physician can repeat the same question many times during the discussion if necessary. In this way she molds the discussion to the parents' needs and allows a dialogue rather than a monologue.

In addition to eliciting feelings and understanding from the parents, the neonatologist must provide medical information to the parents. The HCP should use commonplace, clear-cut, concise, and simple language to relay truthful and accurate content (Emanuel, von Gunten, and Ferris 1999, M2–5; Fallowfield 1993, 478; 2004, 316; Fox et al. 2005, 160; Quill and Townsend 1991, 465). Parents from other countries and cultures may have other preferences different from those to which HCPs are accustomed. Physicians should investigate these choices by asking questions. By conveying information in ways that parents can grasp, they prevent misunderstanding and misperceptions that can complicate decision making and the parents' emotional journey in the neonatal intensive care unit.

At the same time that the physician delivers this medical information, she must offer emotional support (Fallowfield and Jenkins 2004, 313, 316). While the content must be truthful and accurate, the sensitivity and care expressed by the physician can influence the response of the parents. Families want the physician to portray empathy rather than a distant professionalism (Fallowfield and Jenkins 2004, 315; Finlay and Dallimore 1991, 1524–25; Ptacek and Eberhardt 1996, 498). Finlay and Dallimore (1991, 1524) report that even when parents perceive news as devastating, they appreciate the empathy, sensitivity, and support of the physician delivering the news. They do not mind if the physician shows emotion (Fallowfield 1993, 477); for many parents a physician's emotion evokes her caring. They want her to show concern for the patient's suffering and maximize comfort. Fallowfield and Jenkins (2004, 314) suggest: "The way in

which bad news is conveyed can substantially influence their emotions, beliefs, and attitudes toward the medical staff and how they view their future."

The physician can express empathy by sharing her feelings about the situation (Emanuel, von Gunten, and Ferris 1999, M2–5; Fox et al. 2005, 165–66). Fox and colleagues (2005, 163–64) recommend that the physician use the following structure: listen, name, summarize, request corrections, confirm. These steps involve the physician listening to what the parents understand, "naming the idea, value or feeling that the parents expressed" (Fox et al. 2005, 163), summarizing what the parents say, requesting corrections from the parents, and confirming that the physician understands what the parents mean. Repeating the parents' words both expresses empathy and allows for clarification of their thoughts and feelings.

In addition, nonverbal messages of kindness and consideration can re-emphasize the verbal message of empathy by the physician. The physician's cognizance of her own body language prevents her body from sending a different message from her words (Ptacek and Eberhardt 1996, 497). I know this from my personal experience. When I am extremely tired and busy, I have alarmed a family or two when approaching them just to update them. My expression of exhaustion and overwork must make it appear as if I am worried. I have since learned to start with "Everything's okay" when I do not trust that my body language corresponds with my intentions. In addition to matching the message, body language can facilitate the seriousness of the conversation and signal empathy.

Once the physician has informed the parents of the "bad news," she must allocate time for the parents to absorb the report. Offering the family extra time may allow them to respond emotionally (Emanuel, von Gunten, and Ferris 1999, M2–5; Fallowfield 1993, 478). Multiple authors who have written about delivering "bad news" describe the need for "pauses" (Fox et al. 2005, 161). Silence affords the parents time to think and feel. These hiatuses allow the parents time to react emotionally, to comprehend the information, and to comment or ask a question. The parents who want to know the details will ask questions and show both understanding and interest. Others will react emotionally and not hear anything more after the simple communication of "bad news." Asking how much the parents want to know can save the physician from providing untimely information and allow the parents to hear the news at the rate they can best tolerate (Fox et al. 2005, 162). Usually these discussions require multiple meetings.

(6) Conversations: Parents' Emotional Response and Physicians' Response to Parents

Parents respond to "bad news" in many ways, depending on their coping style, personality, and comprehension of the news. Typically they employ one of five coping mechanisms: "denial, blame, intellectualization, disbelief, and acceptance" (Quill and Townsend 1991, 466). Parents may respond with silence, incredulity, anguish, anxiety, anger, guilt, fear, feelings of hopelessness and helplessness, extreme sadness, acceptance, or even relief (Emanuel, von Gunten, and Ferris 1999, M2–5; Fallowfield and Jenkins 2004, 316; Quill and Townsend

1991, 466). Having their emotional concerns addressed may enable parents to hear more of what the physician says.

In a study of 189 parents of children with cognitive or developmental delays, cerebral palsy, genetic syndromes, or other disabilities, Sharp, Strauss, and Lorch (1992, 539–46) confirm that parents want time to express emotions and ask questions. In this study the parents reported on their experiences and preferences regarding the communication of their child's diagnosis. Although parents tend to accept that the physician controls the conversation, almost half of the parents (47%) reported that the physician allowed them time to express their feelings. Most parents wanted the physician to show empathy. Parents responded that they would have liked a referral to other parents of children with similar disabilities. However, only 19% of the respondents reported receiving a referral to other parents, and only 8% of parents who learned of the diagnosis at birth received a referral. Overall, they preferred that the physician allow them time to speak and to express their feelings.

As I have suggested, the physician can develop a better relationship with the parents and get more information across if she listens to and empathizes with their emotional responses (Emanuel, von Gunten, and Ferris 1999, M2–6). This process should occur throughout the meeting (Brewin 1991, 1208). If the parents do not express their emotions verbally, sometimes their facial expressions and body language furnish a clue. The physician can facilitate the process by asking—sometimes repeatedly—how they are feeling or what they are worried about. Or the physician can affirm the parents' concerns, thereby validating the parents'

emotions. The conversation may go better if the parents feel comfortable expressing their emotions to the physician (Klein 1993, 188–89).

If the parents are upset about their child's disability or condition, expressing their emotions can begin the healing process; they may start to mourn the child they expected and accept the child they have. This transformation to acceptance may take months or years in full, but without it the parents may not parent their infant optimally. This concept of accepting disability is the cornerstone of my thesis. Expressing emotion is only the first step of the process. The entire family may benefit when the transformation occurs earlier. The physician can have invaluable input. She has many tools at her disposal: empathy, reframing, eliciting the parents' feelings, allowing parents to express their emotions, and remembering that disabled children are children with many qualities beside their disabilities.

For this reason, the neonatologist should not concentrate solely on the infant's deviation from the norm. Instead, she may empower the parents by describing the positive characteristics of their disabled baby. Sometimes, I suggest, the physician can also reframe the situation. She can affirm the parents' emotions and show them another way of seeing their child. Rashawn Ball, the infant who I described in chapter 1, is an example. His father almost cried when he realized Rashawn would not play ball, but had not considered that instead he might practice medicine. Still, in retrospect, I realize that an additional comment confirming his distress that his son would never play sports would also have been helpful and kind.

Regardless of the recurring need for validation of emotions (Fallowfield and Jenkins 2004, 316), each parent's reaction necessitates a different response from the physician. For example, for an irate parent a physician should acknowledge that feeling angry is common (Emanuel, von Gunten, and Ferris 1999, M2–6). Once, a father whose previous baby had died in our neonatal intensive care unit exploded with anger after I told him (and his partner) about their new baby's "severe" brain damage. I initially thought to call security; I thought that he might harm me. When his partner tried to calm him down, I changed my mind. I told them that it was normal to feel so angry, and that I would feel extremely angry in his shoes. He spent a bit more time expressing his anger, and then started to cry.

Denial is another common reaction of parents receiving "bad news." According to Klein et al (1993, 189), "denial is a reaction to anxiety." For such parents, trying to batter them with the facts will only create more anxiety and greater denial. Instead, they need time to express their feelings. Encouraging them to verbalize their emotions can help them to accept their new situation and also prevent depression, since unexpressed anger or anxiety has been shown to lead to depression.

On the other hand, some silent parents feel too emotionally overwhelmed to think or talk (Klein 1993, 188–89). They may stare off in the distance (Brewin 1991, 1208) as they try to prevent themselves from breaking down. Others understand the information, but do not have any questions. Still others do not understand what the physician has said. In this situation, the neonatologist could

either investigate the silence or end the meeting with plans to meet again soon. The physician has the responsibility to decipher the meaning of the silence.

Determining what the patients' emotional response signifies in cases of uncertainty may help the conversation flow more smoothly (Klein 1993, 188–89). Sometimes listening and empathizing is enough. Other times "the physician must listen, acknowledge, legitimize, explore, and empathize" (Quill and Townsend 1991, 466). If the meaning remains uncertain or the emotional response is too overwhelming, then further inquiry can occur at subsequent meetings.

(7) Conversations: Values

An important part of the "bad news" discussion is the ascertainment of the parents' values. This feature is often left out of the discussion because of time limitations and the intensity of the medical and emotional conversations (Fox et al. 2005, 162). In our current ethical climate, autonomy (or for infants, autonomy by surrogate) usually gives the parents the right to make shared decisions (with the physician) for their infant, within a generally-acceptable ethical standard.

When parents and neonatologist are deciding between continuing life-sustaining treatment and comfort care for an infant, the parents' values usually override the physicians' values.[58] So, if parents choose not to resuscitate a 23-week infant, ethically the physician should not resuscitate the child. Conversely, if parents want something that is generally deemed ethically acceptable, but the physician is morally opposed, the physician should withdraw from the patient's

[58] Comfort care involves providing comfort—using swaddling, skin-to-skin holding by a parent, and pain medication— while withholding or withdrawing life-sustaining treatment.

care and refer the family to another physician who will agree to the desired treatment.

Physicians can help parents by exploring their values about life, suffering, and death. Asking parents about their values, beliefs, attitudes, principles, religious beliefs, and the stories they know will help them discern their values so that they can then apply them to the decision at hand (Fox et al. 2005, 162). Some parents know their values; others have to discover them. Regardless, if the parent does not take this step, the decision may not reflect what the parents really want.

Chris Feudtner (2014, 2306–7), a pediatrician and bioethicist, suggests that HCPs can use hope to explore parents' values. He claims that hope is an important component of giving "bad news." He depicts hope as a broad multi-level concept that changes with time and situation and aids with discerning the values and beliefs that help guide decision making. From Feudtner's experience with terminally ill patients, he describes the different types of hope.

Parents of infants may hope the neonatologist can cure their infant's disease, but if that is not possible, they may hope for, if not a miracle, a few weeks with their child at home. The levels of hope reflect different aspects of the parents' goals and aspirations for their child—from little hopes to grand hopes. Hope also spreads out when the infant's situation changes. Parents of a newborn with previously undiagnosed DS may hope the baby will eat well enough to go home when her mother leaves the hospital. But when they find out that their baby has congenital heart disease, they may hope that the baby will get through the surgery without complications. The initial hope does not harm them by setting up

unrealistic expectations. Rather it reflects their emotions of love and caring toward their child. Feudtner (2009, 2306–7) claims that asking families about hope at all levels helps him to understand their values and principles that guides their decisions.

(8) Conversations: Summary and follow-up

Often parents do not comprehend much of what is said after the initial sentence or two that transmits the "bad news" (Brewin 1991, 1208; Quill and Townsend 1991, 466). Even parents who understand often require more than one conversation to truly absorb and comprehend the facts. The physician should not assume that the parents heard all of the information during the initial discussion. Instead, she should summarize the conversation and inquire once more what the parents understand and what more they want explained (Fox et al. 2005, 161). The physician should advise the parents to talk to each other about their feelings and values (Klein 1993, 189). The physician should inform the parents that mourning their "perfect" child does not occur quickly. In this way, the parents may also be reminded that the physician is available for further conversation. Finally, the physician should recommend forms of support to the parents. This assistance may include other staff members, online and in-person support groups, family, friends, and clergy (Emanuel, von Gunten, and Ferris 1999, M2–6).

After summarizing, a specific follow-up meeting for further information processing and checking emotional valence may provide comfort for the parents (Fox et al. 2005, 161). The parents may feel supported and know that a set forum

exists for answering questions that may arise. Letting them know how to get in touch with the physician adds an additional security net.

Thus, giving “bad news” requires careful thought and effort on the part of the physician and other HCPs. One key component of the conversation that has been left out of this discussion, the language we use to describe disability, is the subject of the next chapter.

Chapter 5

Language and Disability

Introduction

As I prepared for this thesis, the language I was using began to muddy my thoughts. Reading the work of disability scholars has introduced me to a new vocabulary, new semantics, and new syntax, but the scholars do not always agree on the preferred language. From my perspective as a healthcare professional (HCP) (including a 30-year history of working within the medical model of disability), this concept of nonableist disability language raised more questions than it answered. But more importantly, this new vernacular stimulated my curiosity about how language affects thought as well as how thought affects language. I discovered that the reasoning behind language preference often provides insight into the challenges vital to a group.

For example, scholars have investigated language's relationship with gender and race (Anderson and Lepore 2013a; 2013b; Croom 2013; Jeshion 2013; Riemer 2014; Vervecken and Hannover 2012), including the role of slurs in creating and perpetuating sexism and racism. Less has been studied about language and disability (Hadley and Brodwin 1988, 147–49; Harpur 2012, 325–37; Snow 2013). Even so, the issues of language and gender or race provide insight into the relationship between language and disability (Croom 2011, 343–44; Kailes 2010, 4–5; Linton 2010, 226). The research about linguistic methods that successfully transform sexist or racist attitudes can potentially inform approaches for altering attitudes toward disability.

This section describes how slurs develop and considers the connection between language and disability.

Slurs

Racial, ethnic, sexist, classist, and ableist slurs populate our language. Their meanings and effects harm the individuals and communities they disparage. According to the Oxford English Dictionary, the verb *slur* means "smear, stain, smirch, sully" (Oxford English Dictionary). The Merriam-Webster Dictionary defines the noun *slur* as "an insulting or disparaging remark or innuendo" and "a shaming or degrading effect" (Merriam-Webster Dictionary). Slurs are aimed at sets of people who share a characteristic such as race, ethnicity, religion, gender, sexual preference, class, or disability (Anderson and Lepore 2013a, 25; 2013b, 351–54; Croom 2013, 178). Though the published literature regarding ableist slur words is sparse, philosophers and linguists study the meaning of racial, gender, ethnic, and religious slurs. They agree that slurs are offensive, demeaning, and taboo (Croom 2013, 177–78).

The use of slur words enlightens the listener (or reader) about the prejudices of the speaker, but also pejoratively categorizes groups of people (Croom 2013, 182–83). In general (and not regarding slurs in particular), classifying groups elicits expectations for both conduct toward and treatment of their members, according to Adam Croom, a linguist who refers to Erving Goffman's work (Croom 2013, 183–84; Goffman 1967).[59] Thus, the way one labels particular groups affects the way one behaves with respect to them. In this way, society defines how individuals within

[59] A taboo is defined as a ban due to social custom or aversion.

these cohorts act and outlines their social identity—though the way they actually behave and their selfness may differ greatly from the way the general population characterizes them.

More specifically, by using slurs, a speaker can degrade the social identity and thus the "social capital" of the target group or individual (Croom 2013, 184–86). His use of slurs does this by creating difference between himself and the recipient(s) of the slurs, thus creating a superior or more powerful position for himself and an inferior or less powerful position for the recipient(s). Such speakers create offensive and damaging situations for both the members of the attacked group and other individuals influenced by the words. Croom describes this destructive power in terms of racial slurs:

> Thus, the use of derogatory language, including the use of racial slurs, is thought to have played an instrumental role in the perpetuation of race-based discrimination because slurring terms offered racist speakers a linguistic resource with which to dehumanize their targets and identify them in 'sub-human,' rather than fully human terms. (Croom 2013, 190)

Similarly, people may categorize persons with disabilities as different and, therefore, inferior (Croom 2013, 189; Nash et al. 2012, 71–74; Wehmeyer 2013, 122–24). For example, hearing persons may classify deaf from birth persons as belonging to a substandard group; those with hearing may then label those without hearing as "deaf and dumb" because they do not speak (even if they sign). Or people with an IQ of one hundred may perceive those with an IQ of eighty as atypical and second-rate, and call them "retarded."[60] These terms foster and perpetuate discrimination against disabled people in general, and deaf and intellectually disabled people in particular.

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[60] I still hear *mentally retarded* used in medical conversations by HCPs and families. This is despite publicity about its implication of disrespect and lack of dignity towards people

The history of this disparaging language provides insight into the societal bias against people with disability. Clark and Marsh (2002, 3–3.12) list many such words and describe the "historical implications" of each. I review a few to give an example of the ableism embedded in such terms. *Idiotus*, the Greek source for *idiot*, means "a person who does not take part in public life" (Clark and Marsh 2002, 3.3). *Cripple* has two possible etiologies: (1) from the Middle German *kripple* meaning lacking power, and (2) from the Old English *crypel* meaning a person who creeps (Clark and Marsh 2002, 3.6). *Crazy* derives from the late sixteenth century, when it meant either "diseased, sickly" or "full of cracks or flaws" (Online Entymology Dictionary). "Why *idiot* and *cripple* now represent belittling terms for disabled people does not take much imagination. They developed their meanings on the basis of scornful attitudes toward disabled people, and sustain such viewpoints.

The exception to the rule for slurs occurs with "non-derogatory in-group use." People within an "in-group," the group targeted by the slurs, often use *appropriated* slurs in a positive, or non-derogatory, way (Anderson and Lepore 2013b, 350, 358–59; Croom 2013, 177–78, 190–194).[61] Using a slur in this way requires a repositioning of the slur word from negative to positive implication. The appropriated slur then promotes greater solidarity within the group and a redefinition of the positive aspects of the group. Examples include disability groups "taking back" *crip* and feminist groups "taking back" *girl*. Regardless, the slur remains taboo and offensive when used by outsiders.

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with intellectual disability. Additionally, the federal and most state governments have removed *retarded* from government statutes and laws (Downes 2013; Social Security Agency 2013).

[61] *Appropriated* slurs are slurs (those typically used in a paradigmatic way) used by the "in-group" to represent a positive attitude.

However, slurs are not the only type of language that can disparage and exclude, as I explain in the next section.

Language and Disability

The interaction between language and thought first entered my cognizance in relation to sexism. In the 1970s, feminist scholars began to critique language for its androcentricity and sexism. Allyson Jule describes the impetus for this area of scholarship:

> Questions and criticisms of sexist language have emerged because of a concern that language is a powerful medium through which the world is both reflected and constructed. (Jule, 2008, 13–16)

Research supports the idea that the form and use of language reflects cultural attitudes about gender (Eckert and McConnell-Ginet 2013, 39–40; Ehrlich and King 1998, 59). At the same time, studies demonstrate that the form and use of language can also alter cultural attitudes (Clark and Marsh 2002, section 1; Deutscher 2010a, 7; Flanigan 2008, 28–29; Harpur 2012, 325–28). Researchers find that correcting people changes linguistic practices. These examples depict some of the interactions between language and gender; they also inform the newer research examining linguistics and disability.

According to Guy Deutscher a linguistic scholar, “cultural differences are reflected in language in profound ways” and “a growing body of reliable scientific research provides solid evidence that our mother tongue can affect how we think and

how we perceive the world" (Deutscher 2010a, 7).[62] The way we use language arises from our cultural history, our native language, and what we think. Additionally, it influences what others understand and, at times, what others think.

This bidirectional influence between language and thought implies the strong effect words have on attitudes toward groups that experience discrimination, including disabled people. June Isaacson Kailes, a disability policy consultant, states:

> Language is powerful. It structures our reality and influences our attitudes and behavior. Words can empower, encourage, confuse, discriminate, patronize, denigrate, inflame, start wars and bring about peace. Words can elicit love and manifest hate, and words can paint vivid and long lasting pictures. (Kailes 2010, 4)

Kailes uses potent words to portray that words are potent. Her expressions suggest the capability declarations and insults have to persuade listeners.

Disability scholars agree that the language we use impacts the thought of speakers and the listeners (Clark and Marsh 2002, section 1; Charlton 2010, 157; Hadley and Brodwin 1988, 147; Harpur 2012, 327–34, Kailes 2010, 4–9; Scully 2009, 64–65). Similar to the linguistic issues with sexism, ableism is revealed and fabricated by its semantic, pragmatic, and prohibited expression (Anderson and Lepore 2013a, 25, 43; Swoyer 2011, 34–35, 38). Is a woman wheelchair-bound or does she use a wheelchair? Is she handicapped, crippled, or disabled? Or does she have a disability? Is she abnormal? Or is she normal in more ways than not? Is she unable or is she capable? Is one person disabled and the other able-bodied, or is one person disabled and the other person nondisabled?

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[62] This is in contrast to Chomsky's theory of the innateness of language (Birjandi and Sabah 2012, 52–53; Cowie 2010, 1, 2.1, 2.2). Deutscher's work, based on linguistic studies, has created contention in an already controversial field.

Analogous to engendered language amplifying sexism, the language of disability magnifies disability discrimination (Charlton 2010, 157; Linton 224–36). Paul Harpur (2012, 325–33), a lawyer and disability scholar, provides a clear argument for the power of language to both perpetuate—and potentially alleviate—society's interpretation of disability. His work concerns both language's influence on thought and thought's influence on language. Harpur states that "politics, domination and control" (Harpur 2012, 327) affect language and that prejudice is projected through language. Tom Shakespeare agrees: "This prejudice is not just interpersonal, it is also implicit in cultural representation, in language and in socialization" (Shakespeare 1997, 17). Thus, language about disability shapes society's perceptions and cultural attitudes about disabled people. Importantly, Harpur (2012, 328–30) argues that society recognizes disability as absence of ability, not difference of ability.

According to Simi Linton in "Reassigning Meaning," a chapter in *The Disability Studies Reader*, two rationales for the importance of language regarding disability are:

> the linguistic conventions that structure the meanings assigned to disability and the patterns of response to disability that emanate from, or are attendant upon, those meanings. (Linton 2010, 223)

She argues that ableist words, used to describe disability, actually cause an unfavorable understanding of disability. In turn they prompt reactions that cause further discrimination against disabled people.

Thus, the many ableist words that purportedly represent disabled people instead insult and victimize them. June Isaacson Kailes addresses how the ableist voice causes harm:

Avoiding negative attitudes and stereotypes means neutralizing disability-

> related terms. Disability-related language should be precise, objective, and neutral in order to avoid reinforcing negative values, biases and stereotypes. Unfortunately disability-related terms often are subjective and covertly, through innuendos and tone, carry excess baggage in the form of feelings, biases and attitudes. When used, these terms are often offensive to people with disabilities. They often cringe, lose attention or sometimes strongly react when confronted with such ablist and handicapist language which is subjective and biased language reflecting discriminatory attitudes and practices. Such use of language promotes distance, sets up we versus them and superior versus inferior relationships, and carries connotations regarding values, expectations, skills, and abilities (good versus bad, strong versus weak, fast versus slow, high versus low expectations, and well versus sick). (Kailes 2010, 5)

Although Kailes writes about the discrimination that disabled adults experience as a result of ableist language, I propose that the harm done by the users of such language extends to the situation in which physicians speak to families about disabled children (or to disabled children themselves).

Furthermore, Linton (2010, 223) asserts that the language used to describe disability stems from medical language describing signs, symptoms, and diagnoses of impairment. She concedes the advantages of using medical definitions in terms of the benefits of treatment, health, comfort, and prevention. On the other hand, using medical terminology leads to the concept of "normal" (intelligence, physiognomy, behavior, or function) and its "human variation" (Linton 2010, 230–31) counterpart. This normal/abnormal dichotomy negatively affects the understanding and status of disabled people

According to Linton (2010, 230–31), *normal* has two meanings: (1) the fit within a normative distribution and (2) a value assessed in comparison with abnormal.[63] *Normal* implies value; *abnormal* implies less value than "normal." (See chapter 3 for a more complete definition of normal). Society values being normal:

[63] See "Normalcy" section in chapter 2 of this thesis for more information on normal and normalcy.

being normal engages people, while being abnormal repels people (Davis 1995, 29–30; Linton 2010, 231). By defining who is "abnormal," society excludes disabled people and shapes social rank.

In general, "abnormal" people (by both definitions) are excluded socially, politically, and economically (Davis 1995, 29–30; Linton 2010, 231). In this way, the labeling of disabled people as abnormal designates inferior social status for them and preserves the preference to exclude disabled people from the mainstream of society—and its social, political, and economic culture.

As a result, society rationalizes the continued discrimination against people with disabilities because of their separation into a discrete, devalued, abnormal category (Linton 2010, 231). Garland-Thomson (1997, 5–6) claims that disability is a cultural formulation of the body's deviance from the expected form or function. She coins the word *normate* to describe "the constructed identity" of people who embody what society and culture see as normal (Garland-Thomson 1997, 8). However, it is the language used to characterize normal and abnormal that provides the basis for this social formulation.

The medical model attributes an individual's illness to her being. Since "human variation" resides outside the range of "normal," the medical community has labeled *disability* as defective, inadequate, onerous, tragic, challenging, and in need of treatment. In this way, society's use of the language initially created by the medical community promotes a damaging paradigm of disability (Linton 2010, 223–25). Such language implies that disabled people have lives not worth living or, at best, miserable, insignificant lives. Though this construct arises from the medical model, not only HCPs have such a pejorative understanding of disabled people.

In addition to normal/abnormal, the passivity/control dichotomy results in language that further marginalizes disabled people (Linton 2010, 232). This too arises from the medical model concept of disability. Language that attributes passivity endorses an image of subservience, powerlessness, incompetence, vulnerability, and misery. Terms such as *afflicted*, *victim*, *suffering*, *unfortunate*, *wheelchair bound*, and *deaf and dumb* produce an image of disabled people as helpless, weak, needy, dependent, wretched, and not intelligent (even when the disability is not intellectual) (Linton 2010, 232–33; Clark and Marsh 2002, 4.1, 4.2, 4.5). This language (often unknowingly) causes continued discrimination against and increases the perceived inequity of persons with disability.

By using words describing impairment, the medical model generates another lexicological problem for disabled people. Such words also are associated with discrimination, and they include terms that describe disabled people as deviating from the norm: slurs like *spastic*, *invalid*, *dumb*, *retarded*, and *crazy* (Linton 2010, 227–28; Clark and Marsh 2002, 8–8.3). These words, though theoretically applying to an individual part of the patient, frequently are directed at the whole person. Whether speakers apply these expressions metaphorically (she is a "vegetable") or descriptively (she is "spastic"), these (and other) slurs harm people with disabilities. Some of these words are spoken by HCPs either with patients (for example, spastic, invalid, vegetable, and retarded), while others tend to be said in conversation between HCPs but not directly to the patient (for example, crazy or dumb). Such language and portrayals reflect the medical model of disability: unwanted impairment that creates a disabled life. But disability activists and scholars endeavor to take disability out of the medical purview and place it in the realm of society, economics, and politics.

Another linguistic concept, *passing*, is embodied in negative psychological and cultural attitudes toward disability that engender obstacles for disability advocates.[64] As with any group who attempts to pass, rejecting a trait implies it is unwanted, shameful, harmful, or unpleasant. For people with disabilities passing may take multiple forms: photos without the wheelchair, choosing to keep a diagnosis of mental illness hidden, or denying a learning disability. But passing may cause harm to the individual by leading to, for example, lack of identity, lack of a community, self-hatred, and unease (Linton 2010, 229–30).

Similar to passing, the disability community has rejected the concept of "overcoming" disability (Linton 2010, 228–30). Linton claims that a disabled person who passes creates emotional upheaval for himself. The social model of disability stipulates that society and the environment must accommodate persons with disability. But the term *overcoming* suggests an inadequate state requiring the individual's ability to rectify the "problem." Moreover, according to many disabled people with whom I have spoken, they are unable or do not want to overcome their disability. Once again words have been responsible for furthering a misunderstanding of disability and disabled people.

Using words that create negative perceptions about disability nourishes and preserves discrimination against persons with disability, and also perpetuates the medical model of disability (Linton 2010, 224–25). This perception of disability places the "abnormality" with the disabled individual rather than with society's failure to provide the accommodations for people with disabilities needed for them to

[64] Passing occurs when a person acts in a way to try to hide a characteristic. For example, a light-skinned black person might "pass" as a white person. This would involve implying or asserting that he is white (Linton 2010, 229).

flourish. A change to the social model remakes disabled people into a socially-disregarded cohort who experience injustice in social, economic, and political terms. In other words, disabled people require accommodation and social inclusion so that they can function without disability. The disability reflects the social and political viewpoint of the public (at least in part) rather than only the impairment of the disabled person (Linton 2010, 225; Scully 2008, 25–29, 172–73). If the nondisabled community alters their language regarding disability, they have a chance to re-examine their understanding of and attitudes toward people with disability.

In addition, Harpur (2012, 325–33) argues that for language about disability to change, the public—and thus HCPs—must perceive disability via the social model. A new language, reflecting the social model of disability, would produce a more positive view of disability as physical or mental capacities that require accommodations. This different language may do two things. It may provide new ways of perceiving disability and promote self-determined and positive identity for disabled people. Harpur (2012, 325–33) claims language can compellingly transform society's view of disabled people. New words allow disabled people to recognize that they are part of a group that together can advocate for social, political, and economic change (Linton 2010, 225). In this way, language can shape public opinion about disability and transform cultural attitudes.

Medical and legislative spokespersons have devised language in attempts to remove some of the discriminatory words used previously (Kailes 2010, 9; Snow 2013, 2). The disability community has challenged some of this language. For example, disability advocacy groups reject words that appear respectful, like *challenged*, *handicapped*, and *special*, but, in fact, represent exclusion for disabled people

(Linton 2010, 226–27). *Challenged* suggests that the individual has something to "overcome" in order to get what he wants. *Handicapped* implies a disadvantage. *Special* alludes to a variation from the normate. All three words actually represent euphemisms for lacking ability.

Thus, language is important in reframing disability from a medical model representation of impairment to a social model representation of discrimination. The debates about using *able-bodied* versus *nondisabled*, and *disableism* versus *ableism*, corroborate this point (Harpur 2012, 328–30). The word *able-bodied* characterizes the disabled person as not able-bodied—though she may be (Linton 2010, 223, 226). *Nondisabled* places the emphasis on the person with disability instead of the person without ability.

The story of *ableism* epitomizes the process of change in language for discriminated groups. Disability activists and scholars have previously used *ableism* and *disableism* interchangeably to represent the prejudice and discrimination occurring against people with disabilities. Both terms apply to the social tendency to identify the "perfect" body as the normal, and the "impaired" body as the abnormal.

However, by looking deeper one finds that *ableism* and *disableism* evoke different attitudes. *Ableism* suggests that the discrimination aims at the abilities of the individual. *Disableism* implies that the discrimination targets the embodiment of the individual (Harpur 2012, 328–31).[65] Harpur argues that *ableism* is a more positive and powerful word for describing the negative treatment of, disregard for,

[65] Embodiment refers to "someone or something that is a perfect representative or example of a quality, idea," and so on (Merriam-Webster Dictionary).

and prejudice against people with disability. For him, the *dis* in *disableism* perpetuates the myth of the nonability of disabled persons.

The disability community has proscribed many other words that were once preferred by their community, for example, *impairment* and *handicap*. United Kingdom disability scholars prefer the use of *disabled person* rather than *person with disability*. The former implies that people are disabled by society and the latter suggests that the disabled person holds responsibility for the disability (Clark and Marsh 2002, 2.1–2.2). The United Kingdom disability advocates hope that avoiding the word *disability* will diminish the public habit of interchanging impairment and disability. However, the converse exists in the United States and Australia, where disability advocates prefer *person with disability* rather than *disabled person*. For them, *disabled person* evokes the notion that the entire identity of the person is disabled (Harpur 2012, 327–28).

Based on the idea that society perceives disabled people as people without ability rather than as people with different abilities, Harpur (2012, 330–33) argues that *disabled person* and *person with disability*, although terms chosen by the disability community, perpetuate the political oppression of that very community. He claims that *disability* and *disabled* hold negative connotations. Yet, he stops short of arguing for a new term (Harpur 2012, 329–30).

I suspect that the needed change in language about disability will occur as a process. The preferred words will change with time and space. Now we use ableism, person with disability, disabled person, and nondisabled person. Tomorrow we may use other language and it is the public's responsibility to keep up with the disability community's preferences about which language they prefer.

Conclusion

This chapter reviews how language has a profound effect on disabled people. Much of what is known about language and disability is grounded in what is known about language and race and gender. Words describing disability arise from the medical model and, thus, often reflect negative and biased attitudes about disabled people. The language then spreads these negative connotations throughout the world, propagating ableism. Changing the understanding of disability from the medical to the social model will require an adjustment in the language used to portray and appreciate disability.

Chapter 6

A New Script for Pediatricians: Communicating with the Parents of a Neonate with Down Syndrome (DS)

Introduction

In this chapter, after a brief introduction of DS, I present a case study of Baby Sophia Langley, an infant with Down syndrome. Although Sophia is a fictitious patient inspired by my experience with an actual patient, I base this dialogue primarily on two sources: (1) conversations I have had with parents of children with DS and (2) books and journal articles I have read about parents' experiences with their child with DS (Skallerup 2008; Solomon 2012, 169–219; Soper 2007). Mr. and Ms. Langley's remarks and reactions are also inspired by both the responses of parents I have known and whose babies I have cared for and the books I have read. I label this case study *Old Script* because it represents the way neonatologists typically approach new parents of infants with Down syndrome. Though the old version describes a discourse performed in a way that follows published recommendations for physicians giving "bad news" (see chapter 4), it does not address disability in the way I propose physicians introduce the subject to parents of newly diagnosed, disabled newborns.

Using the work of previous chapters, I then analyze the old script. I examine the dated scenario for attitudes about normalcy and manifestations of ableism, scrutinize the transcript for ableist language and physician and parent bias, and explore the dialogue for exchanges about the parents' familiarity with

their values. Finally, I evaluate the script in terms of the medical and social models. Drawing upon ideas from the analysis, I then shape a *new script*, which I consider a preferable script, for the case study of Baby Sophia Langley. This new version portrays ideas necessary for physicians to use when speaking with new parents of children with Down syndrome. It introduces moral considerations into these medical conversations. If I attain my goal, it will stimulate thought among neonatologists about how to talk to parents of disabled patients. And it will start to change the way neonatologists carry out such discussions. Before I present these scripts and the analysis, I introduce Down syndrome both from a medical viewpoint and as a social construct.

Introduction to Down Syndrome

Down syndrome, or Trisomy 21, is a condition with which some infants are born as a result of having three twenty-first chromosomes. According to the most recent statistics available (for years 2004–06) from the Centers for Disease Control (Centers for Disease Control), approximately 6,037 infants with Down syndrome are born in the United States annually (Parker et al. 2001, 1012). These 6,037 infants represent one infant per 691 live births (or 14.4 infants per 1000 live births). Many fetuses with DS die due to either miscarriage or medical abortion. In England and Wales, an average of twenty-five to thirty-two percent of women pregnant with a fetus with Down syndrome had a miscarriage after approximately fourteen or ten weeks respectively (Savva et al. 2006, 501). I assume that the rate is similar in the United States. This rate of miscarriage is much higher than that for women pregnant with infants without DS. In some

areas of the United States, ninety-two percent of women pregnant with a fetus with Down syndrome abort the fetus.

Medical Aspects of Down Syndrome

Babies with DS have a range of phenotypes, abilities, and medical disorders. The families of these infants have varying feelings and responses, both immediately and in the long term, about their children. The following description of the medical aspects of DS use typical medical language.

The phenotype of infants with Down syndrome consists of multiple features that may include hypotonia, or low muscle tone; pale, sensitive, and mottled skin; a short, flat back of the head; large fontanelles, the soft spots on top of the head; thin, straight, soft hair; a short neck with extra folds of skin at the back; almond-shaped, up-slanting eyes; epicanthal folds, extra skin at the inner corners of the eyes; white spots on the iris of the eye called Brushfield spots; small, low-set, and unusually shaped ears; a wide nose and flat nasal bridge; small nasal passages; a small mouth; a large tongue (that sticks out of the small mouth); hyperflexible joints; small hands and feet; short fingers including a small fifth finger that curves inward; a single palmar crease; and a space between the first two toes (Skallerup 2008, 2–7) Only some of these physical traits occur in any individual with Down syndrome. Some of these features also occur in people without Down syndrome. Additionally, except for hypotonia, none of these qualities causes medical problems or requires treatment.

On the other hand, many medical conditions associated with Down syndrome do require therapy or treatment, sometimes involving surgery, for both

well being and, in some cases, continued life (Leshin 2002, 187–98). Some of these problems occur in infancy, others later in childhood or adulthood. Hypotonia is one symptom that presents in the newborn. It causes poor feeding in infancy and slows the pace of motor development (such as sitting, walking, and speaking). Other medical issues that often occur in newborns with DS include multiple gastrointestinal, cardiac, hematologic, oncologic, orthopedic and endocrinologic system problems. Congenital physical variations cause most of these problems. The gastrointestinal disorders include duodenal atresia,[66] tracheoesophageal fistula (see Chapter 2), gastroesophageal reflux,[67] Hirschsprung's Disease (<1%),[68] and constipation (AAP 2001, 442). Cardiac congenital disorders affect approximately fifty percent of infants with DS (AAP 2001, 442). These heart diseases range from small holes that close on their own to anatomical configurations that require open-heart surgery. Hematologic associations in infancy can involve either low or high platelet counts at birth; a leukemoid reaction which is associated with an increased risk of leukemia in

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[66] Duodenal atresia is a congenital condition caused by narrowing of the first part of the small intestine. The narrowed lumen causes blockage of flow of stomach contents and regurgitation (Behrman, Kliegman, and Nelson 1992, 951).

[67] Gastroesophageal reflux (GER) is a condition in which the contents of the stomach flow backwards into the esophagus and sometimes into the mouth or nose. Depending on its severity, GER can cause vomiting, pain due to irritation of the esophagus, and/or aspiration of milk into the lungs. The only medical treatment is an antacid. When GER causes aspiration, a surgical procedure involving tightening of the sphincter between the esophagus and stomach, and placing a feeding tube through the skin into the stomach is required (Leshin 2002, 189).

[68] Hirschsprung disease is the congenital absence of nerve cells lining a part of the colon. Most of the time this area is just above the anus, but sometimes the lack of nerve cells can involve the entire colon. This absence of nerve cells means the colon does not move its contents through the colon and out of the rectum. As a result, the infant has constipation and may develop a life-threatening infection of the gut. Treatment for Hirschsprung disease is surgical removal of the affected colon (Leshin 2002, 190).

early childhood; and, rarely, leukemia in infancy.[69] Congenital hip dysplasia also occurs frequently. Hypothyroidism (15%) is the primary type of endocrine disease seen in infants with DS.[70] Ophthalmologic disorders include congenital cataracts (15%), blocked tear ducts, and strabismus.[71]

As an infant with DS gets older, another category of disability emerges: developmental and cognitive disabilities (Skallerup 2008, 169–93). Though these disabilities are not apparent at birth, they do affect all infants with Down syndrome. The degree of cognitive disability ranges from "mild to profound" (AAP 2001, 442; Lott and Dierssen 2010, 623). However, it is clear from personal experience and from the variety of descriptions in books and journal articles (Skallerup 2008) that what mild and profound mean in this context is neither easily understood nor well defined. Intellectual disabilities involve learning, memory, and language acquisition (Lott and Dierssen 2010, 623–24). The developmental disabilities also affect multiple areas of development and vary in intensity.

Children with DS develop, but at a slower pace than is typical (Skallerup 2008, 169–77). The rate depends on multiple factors: genetics; the attitude of the family toward their child with DS; the degree of stimulation and education in the familial environment; early educational intervention; interactions with other

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[69] A leukemoid reaction is a marked increase in mature and immature polymorphonuclear cells, a type of white blood cell that fights infection (Leshin 2002, 193–4).

[70] Hypothyroidism is a low level of thyroid hormone that can cause intellectual disability if not treated with thyroid hormone medication (Behrman, Kliegman, and Nelson 1992, 1418–19). In this paragraph, percentages in parentheses indicate the percentage of infants with DS who have the disease mentioned immediately before the parentheses.

[71] Cataracts cause cloudiness of the lens, resulting in poor vision (Leshin 2002, 196). Strabismus is the misalignment of the eyes, causing them to suppress vision in one of the eyes, which leads to poor vision (Leshin 2002, 196).

children; other medical conditions and hospitalizations; hearing and visual disabilities; the presence of autism; occupational and physical therapy; and the family's ability to successfully advocate for their child.

A few other medical problems occur in childhood or adulthood rather than infancy (Leshin 2002, 187–97). These include autism; hearing (75%) and visual (60%) disabilities; leukemia (<1%); short stature; stroke; immune system dysfunction resulting in more frequent respiratory and ear infections (50–70%), some of which require hospital treatment; atlantoaxial instability; seizures; sleep apnea (50–75%); decreased pain sensitivity; celiac disease (due to gluten causing injury to the intestinal wall); and heart valve disease (AAP 2001, 442).[72] Adults with DS have a high risk of early-onset Alzheimer's disease. Clearly, healthcare professionals (HCPs) have many medical concerns when they diagnose a newborn with DS.

The above lists, though extensive, do not include all of the associated conditions. But they might allow one to understand the concern that HCPs and parents have when a baby with DS is born. From my experience, though, the greatest initial concern for both physicians and most families regarding their child with DS concerns her cognitive disability. In part this occurs due to our society's greater disdain for people with this disability (Rose, Kent, and Rose 2012, 859–62).

[72] Atlantoaxial instability occurs in approximately fifteen percent of children with DS. The first two vertebrae of the neck move excessively and may cause pain and difficulty walking due to nerve entrapment. The treatment may include surgery to release the spinal cord and stabilize the neck (Leshin 2002, 191–92).

Social Aspects of Down Syndrome

A plethora of memoirs assert the benefits and blessings of having a child with DS. This attitude suggests that for many people, parenting a child with DS is not as devastating as some new parents—and physicians—may think. Parents often remember the words used by the physician in first informing them of their infant's diagnosis. They report painful memories because of the physician's disparaging attitude toward their infant. (Skotko, Capone, Kishnani 2009, e754–55).

Parents do not want to hear woeful, erroneous, or obsolete information; they do not want to hear pessimistic or offensive language. Skotko reviewed what parents dislike about the initial exchange regarding their infant with DS:

> Parents resented when the information was delivered in a manner perceived to be insensitive, unkind, or unconcerned with the welfare of the mother. They further thought the delivery was unprofessional when news was provided to 1 parent before the other. The use of language conveying pity (e.g., "I am sorry to have to tell you this, but . . ."), personal tragedy (e.g., "Unfortunately, I have some bad news to share . . ."), or extreme sorrow (e.g., "I know this might seem like a devastating loss . . .") was considered unnecessary and not always reflective of mothers' emotional states. The percentage of mothers who felt that their physicians used respectful, nonjudgmental language varied over time, with no particular trends. 30% (n=95) in 1969, 24% (n=79) in 1980, 74% (n=59) in 1984, 65% (n=139) in 1985, 44% (n=62) in 1986, and 44% (n=65) in 2002.[73] (Skotko, Capone, Kishnani 2009, e754–55)

These data suggest a need for physicians to learn about better communicate with parents of neonates with DS.

What would families prefer from their infants' physicians? According to

[73] Skotko assembled these data from many journal articles. For the specific references see Skotko, Capone, Kishnani (2009, e754–55).

Skotko,

> parents want to have access to complete and accurate information for the following questions: What is DS? What is its cause? And, what does it mean for a family to have a member with DS, in practical terms? (Skotko, Capone, Kishnani 2009, e754)

This "complete and accurate information" involves medical facts as well as details about the child's life: her abilities, her social interactions, the realities of family life, and the help she will need. This usually requires having parents of a child with DS available to speak with new parents, because most HCPs do not learn about their patients' lives at home and school. And most neonatologists do not care for older children with DS.

Children and adults with DS require services and accommodations in order to live the best life possible. Physical, speech, and occupational therapies, especially for children, increase some of their developmental abilities. Inclusive and exclusive forms of education lessen cognitive disability of children with DS. As children reach the teenage and young adult years, social gatherings improve the quality of their social lives. And services such as group homes and job placement programs provide accommodations that help people with DS achieve independence. The availability of services, though, varies according to location, state policy, school policy, and parental advocacy. Advocacy education is not in the scope of the HCPs' duties. But organizations aimed at supporting people with DS, such as the National Association for Down Syndrome (NADS), can teach parents advocacy skills.

This Chapter

The remainder of this chapter, the focal point of my thesis, consists of (1) an old script of Dr. Crass communicating with the Langleys about their newborn in the way I consider typical of physicians today; (2) an analysis of the conversations from the old script in terms of the concerns regarding disability I have expressed in previous chapters; and (3) my proposal of a new Script in which Dr. Class has a conversation that is less ableist with the Langleys. Both scripts comprise two conversations, the initial session in which Dr. Crass or Class informs the Langleys of Sophia's diagnosis and the second session in which Dr. Crass or Class provide the test results. The innovative new script meshes the medical perspectives with the social perspectives of disability. However, this new scenario, though improved, does not represent an end-point. Rather, with more feedback from parents—and from HCPs that change their communication patterns—I hope the "New Script" will consistently change to reflect the needs of babies and their families.

The Old Script for Baby Sophia Langley

Baby Sophia Langley was born at 37-weeks gestation to a 27-year-old married woman with an uncomplicated pregnancy, labor, and delivery. When Sophia needed an isolette because she was hypothermic in the regular nursery,

she was admitted to the neonatal intensive care unit (NICU).[74] The neonatal nurse practitioner (NNP), Rhonda, had noted that Sophia had low muscle tone and physical stigmata of Down syndrome including low-set ears, simian creases, and up-slanting eyes with epicanthal folds.[75] The prenatal evaluation displayed no indications of chromosomal anomalies. Therefore the NNP asked the neonatologist, Dr. Crass, to confirm her suspicions that Sophia had Down syndrome. Dr. Crass agreed with Rhonda. Next, Dr. Crass had to meet with Sophia's parents and give them the "bad news."

She found Sophia's parents in Ms. Langley's post-partum room. Dr. Crass introduced herself to Ms. Langley, a constitutional law professor, and Mr. Langley, a professor of microbiology. Then she sat down across from the Langleys, her face communicating caring and sadness, she said, "I just examined Sophia. What do you think of your little girl? Did you notice anything different about the way she looks?"

The Langleys looked at Dr. Crass. Her body language and facial expression told them that something was wrong with Sophia. But they could not imagine what. Mr. Langley, worried now, replied, "We think she's great. She's so beautiful. Why, what's wrong?"

Dr. Crass responded, "I'm so sorry. I'm afraid I have bad news for you. Your baby has Down syndrome. I'm really so sorry."

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[74] Hypothermia occurs when an individual's body temperature drops below the normal range. Preterm and sick infants may have low body temperature; they then require a radiant warmer or isolette to increase their temperature.

[75] A simian crease—preferably called a single transverse palmar crease, as simian refers to apes—is a crease or marking on the palm that continues from one side of the palm to the other. More typically, two creases start at either side of the palm and do not meet in the middle. A single transverse palmar crease commonly occurs in children with DS.

Shock, grief, and tears replaced the Langleys' excitement. They had not noticed anything unusual about Sophia. They had expected a "perfect" child. Visions of a broken life supplanted their dreams of a flourishing family. But, maybe the doctor was wrong. Ms. Langley said, "But Sophia looks fine."

Dr. Crass handed Ms. Langley a tissue and stated, "Actually, Sophia has many stigmata of Down syndrome. She has a flat head, up-slanting eyes, small, low-set ears, and a bunch of other abnormalities. I realize this isn't what you want to hear from me. But she really looks like she has Down syndrome." She then told them that she sympathized with their anguish. She put her hand on Ms. Langley's shoulder and said that she wished this had not happened.

With a look of disbelief, Ms. Langley asked Dr. Crass about Sophia's other "abnormalities."

Dr. Crass explained, "Sophia has low muscle tone. That means her arms and legs are floppy. She's not as strong as a normal baby. Her head flops even more than is usual for babies. She has a small mouth that makes her tongue look big, and has a big space between her big toe and her second toe. These features suggest Down syndrome. I'm sorry for this news. I recognize that this isn't what you wanted. We will make the definitive diagnosis by chromosomal analysis. The results will be back in a day or two."

At this point tears were running down Ms. Langley's face, and Mr. Langley appeared angry. Ms. Langley questioned whether Sophia really had Down syndrome: "I'm young. I'm only 27. Maybe that's just the way she looks."

Dr. Crass responded, “I’m almost positive Sophia is a Down’s baby. Even though the risk is greater for an older mother, most Down’s kids are born to young mothers. “

Mr. Langley, with an angry facial expression and tense body language, interrupted. He demanded to know why they had not found out when his wife was pregnant so “they” could have aborted.

Dr. Crass informed them that the screening tests do not pick up one hundred percent of Down’s fetuses.

She said, “Only women with specific indications—indications that do not apply to Ms. Langley—require amniocentesis. Sometimes ultrasound fails to discover signs of Down syndrome. We sent chromosomal tests to confirm what we see.” The Langleys would have to wait for the test results.

The Langleys had nothing to say. Ms. Langley was sobbing; Mr. Langley was holding Ms. Langley. Dr. Crass handed Mr. Langley a tissue. Dr. Crass leaned forward and gently placed one hand on Ms. Langley’s shoulder and the other on Mr. Langley’s shoulder.

Dr. Crass allowed the Langleys time to experience the pain. She thought of all of her patients in the NICU that she had to examine before she left, but she needed to help the Langleys through this crisis.

The Langleys finally looked up. Dr. Crass followed their cue and initiated her discourse about DS. “Babies with Down syndrome have too many, that is three, twenty-first chromosomes; normal babies have two. This extra chromosome causes Down syndrome, sometimes called Trisomy 21. Testing for the extra chromosome will provide a definitive diagnosis for Sophia. Also, a

number of medical problems are associated with Trisomy 21. I prefer to wait for the results of the chromosome testing before reviewing all of the potential medical problems. But I'll tell you about the ones you may have to worry about in the next few days. Before we get started, though, I'd like to understand what you know about Down syndrome."

Mr. Langley looked up with a surprised expression on his face. He responded, "That they're mentally retarded." That most people abort if they get the chance."

Dr. Crass looked caringly at Mr. Langley and replied, "Well, yes. Down's kids are mentally retarded. And in some areas ninety percent of women with fetuses who have Down syndrome choose abortion." She paused. Then she added, "You sound angry."

Mr. Langley replied, "Yes, I'm angry. If we had known, we could have aborted."

Ms. Langley spoke up, "Well, yes. But now Sophia is here. Dr. Crass, what else do we have to worry about?"

Dr. Crass, recognizing that she had to get back to Mr. Langley's feelings, responded to Ms. Langley, "If Sophia has Down syndrome, her heart and her intestines are the main concerns right now. She doesn't have a heart murmur, but if she develops signs of a heart problem, then we'll get an ECHO, an ultrasound of her heart. Additionally, if her chromosomes come back positive, we will do an ECHO just to make sure she doesn't have heart disease. Regarding her intestines, we'll see if she has any problems with eating or having bowel movements. And if she does have problems with eating or passing stool, we'll have to do special

radiology procedures to see if she has a blockage in her intestines. She may not latch on well while breastfeeding; we may have to feed her by bottle or a tube going into her stomach. And, of course, she'll be developmentally delayed, mentally retarded, and have a speech impediment. She'll need physical therapy, occupational therapy, and speech therapy, not to mention special classes in school."

As Dr. Crass paused, Mr. Langley interjected, "So, maybe Sophia doesn't have Down syndrome. You said, 'If Sophia has Down syndrome.'"

Dr. Crass gave Mr. Langley an understanding look. "I realize how hard it is to believe that Sophia is a Down's. I said 'if' because we do not have the genetic confirmation. But the nurses and I have seen lots of babies with Down syndrome. We can say with near certainty that Sophia has it. Parents often have a hard time believing that their newborn baby has a problem when they've been dreaming of the perfect, normal child. It will take time to really absorb all that I'm telling you. But I'm pretty sure that Sophia has Down syndrome. "

Mr. Langley repeated, "Well, I don't believe it. Let's see what the tests show. Doctors can be wrong too."

Dr. Crass agreed, "You're right. Doctors can be wrong. And I hope I am."

Ms. Langley asked Dr. Crass what they should do.

Dr. Crass again looked at the Langleys with a sympathetic expression. She suggested that they spend as much time as possible with Sophia. She encouraged Ms. Langley to continue to try to nurse Sophia. If Sophia could not nurse, then Dr. Crass recommended Ms. Langley pump her breasts every two to three hours and

try a bottle. If Sophia would not take a bottle, at least she could get the breast milk through a feeding tube.

Dr. Crass also advised the Langleys to talk about their values, about the important things in life. She said, “I grasp this is hard for you. But Sophia needs you to be the good, loving parents you’ve been planning to be. Let’s wait for the test results. It’ll only be two or three days. I’ll see you again tomorrow and we can talk again. If there’s a burning question before then, ask the unit clerk to contact me.”

After Dr. Crass left the room, Sophia’s parents were terrified. The responsibility of a normal new baby and the many tasks to learn were frightening enough. The thought that their baby would be “mentally retarded” was crushing. Ms. Langley felt overwhelmed. And what if Sophia had heart problems? Would she live? Maybe the doctor was wrong. Mr. Langley, though, wanted to explode; he had not agreed to parent a child with Down syndrome. The doctor was certainly wrong.

Their next thoughts were about what to tell their friends and family. They expected many visitors over the next few days. They did not want to see them. They did not want to talk to anyone. They wanted to go to sleep and wake up in a few days to find out that this was all a bad dream. Anyway, how many times had they heard stories of doctors giving the wrong diagnosis? They had not noticed any problems with Sophia. She was beautiful. Her nursing was not great, but many babies did not latch at first. Dr. Crass was probably mistaken.

During the two days between meetings, the Langleys spent a lot of time in Ms. Langley’s room. They visited Sophia at feeding time. Sophia nursed poorly

due to her hypotonia but the Langleys thought she was just a little sleepy. They were sure she was "normal." Sophia's nurses reported to Dr. Crass that the Langleys were in deep denial. Dr. Crass prepared for a long, difficult conversation.

That morning, only forty-eight hours after their first conversation, Dr. Crass received the call from the lab confirming that Sophia had Down syndrome. She saw the Langleys at Sophia's bedside. With a solemn face and empathetic body language, she informed them that she had received Sophia's chromosomal test results.

Dr. Crass suggested a meeting. Although she offered to include their family members, friends, medical staff, or clergy, the Langleys preferred to speak with Dr. Crass alone. Sophia's nurse, the NICU social worker, and the Langleys followed Dr. Crass to a private conference room. On the way, Dr. Crass requested that the unit clerk hold her phone calls to ensure undisturbed privacy.

In the conference room the Langleys sat together on a couch; Dr. Crass and Sophia's nurse sat across from them. The social worker sat on a chair next to Ms. Langley. Dr. Crass began, "I am quite pleased with the way Sophia eats. The nurses tell me that she takes some of her bottle at each feeding and that you're pumping plenty of breast milk, Ms. Langley." Then Dr. Crass hesitated. She leaned in and with physical gestures emanating pity, gave the Langleys the results of the testing, adding, "Regarding the test results: I'm so sorry, Sophia's test results confirm that she is a Down syndrome. I regret having to break this news to you."

The Langleys were shocked. They had been so sure that Dr. Crass was mistaken. Looking downward, Mr. Langley folded his hands around his head. Ms.

Langley started to cry. Dr. Crass handed a tissue to Ms. Langley and gave them some time to absorb her words.

Ms. Langley broke the silence, "Are you sure? Maybe the test is wrong."

Dr. Crass replied, "I wish it was. Unfortunately, the FISH test is rarely wrong. I'm sorry. I wish I could tell you otherwise."[76]

Mr. and Ms. Langley felt devastated. They had no idea what having Down syndrome meant. Dr. Crass had alluded to associated problems, but they could not remember much about them. They were certain they did not want a baby with Down syndrome. Mr. Langley had no idea what they would do. Ms. Langley wondered how she could live with a Down syndrome child, a "retarded" child. That was not what she had planned.

After a long pause, Dr. Crass again expressed sorrow about their terrible situation. She told them that she recognized the difficulty of their circumstances. She asked them what they were feeling.

Ms. Langley answered first, "I'm so sad. We never wanted a baby with Down syndrome. John is right; we would have aborted. This is so horrible. We had so many plans. But I'm also worried about Sophia. I'm afraid she will die from a heart problem. And if she lives, her life will be so hard. She'll be teased and bullied. Her life will be awful and so will ours."

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[76] FISH refers to fluorescent *in situ* hybridization, a method for detecting specific chromosomes in a patient's cells. The cells do not have to grow for the test to be performed, allowing for results in only one or two days. The technique involves adding a fluorescent probe (single-stranded DNA) to the chromosomes from the patient's cells. The probe binds with and fluoresces the corresponding chromosomes. The number of fluorescent markers per cell indicates the number of the targeted chromosome per cell (Bui, Bleenow, and Nordenskjöld 2002, 632–33).

Leaning toward her, Dr. Crass looked caringly at Ms. Langley. “I realize that you’re scared. It’s a big job being a parent and it’s harder to parent a Down’s child than a normal child. It will be hard for you, but take it a day at a time.” Then Dr. Crass looked at Mr. Langley.

Mr. Langley stood up and shouted, “I don’t understand how this happened. This just can’t be. I never wanted a baby with Down syndrome and I still don’t. I wanted a daughter with whom I could ride bicycles and go on nature hikes to teach her about the ecosystem. And I just knew she would discover something important some day, making her mark on this miserable world. And now look what I have.”

In a quiet voice, Dr. Crass spoke compassionately. “It must hurt a lot. You had this dream of who your daughter would be. Now you have someone else. You have to take time to mourn that other baby. And you have to take the time to form a relationship with Sophia.”

Mr. Langley sat down and began to cry. After a few moments of silence, Dr. Crass changed the direction of the conversation. She asked the Langleys what they knew about DS.

Mr. Langley answered, “Sophia is mentally retarded and her face looks funny.”

Ms. Langley interrupted, “I think she’s beautiful. I don’t see what you’re talking about.”

Dr. Crass replied, “She is beautiful. As she grows you will recognize more of the typical facial features of Down’s. She will be ‘mentally retarded.’ What else do you know about?”

Ms. Langley said, “You mentioned something about heart problems. Is she going to die?” She could not decide if she was secretly hoping Sophia would die.

Dr. Crass responded that she did not expect her to die from heart disease. She answered, “Down’s kids used to die in their teens or twenties, but medical advances have extended their life expectancy. They still have a lower life span than normal people, but many live into their sixties.”

Dr. Crass added, “I heard a heart murmur this morning and the cardiologist will see her today. She’ll do an ECHO, an ultrasound of her heart, to determine if Sophia has a heart problem. About half of Down’s kids have heart disease from birth.”

Ms. Langley asked, “What will happen if she has heart disease? What is heart disease?”

Dr. Crass replied, “Heart disease in babies is abnormal structure of the heart. Sometimes the abnormal structure causes problems for the baby, sometimes not. I can’t say for sure what type, if any, Sophia may have. First, let’s get the results of the ECHO, and then we can talk more about Sophia’s prognosis. I can tell you that some heart problems require medical treatment; others require surgical treatment. We’ll have to wait and see.”

Dr. Crass paused again to allow the Langleys to think about all she had just said. Then Dr. Crass inquired if the Langleys wanted to hear about other problems that kids with Down syndrome often have.

Mr. Langley looked uncertain, but Ms. Langley responded, “Yes.”

Dr. Crass checked with Mr. Langley that he was okay with hearing more. Then she advised the Langleys that many medical problems can affect babies with

Down syndrome, but not all would afflict Sophia. Once more she warned them that Sophia would be developmentally delayed and "mentally retarded."

"Of course," Dr. Crass told them, "how slow she will be is hard to say at this age. Her physical disorders will hinder her abilities and add to her developmental delay; her low tone, her floppiness, will make it difficult for her to eat, speak, and attain her milestones on time. Sophia's speech impairments will make her difficult to understand. She will roll over late, sit late, crawl late, walk late, and talk late. She will be behind in school due to learning problems."

Dr. Crass reminded them about possible intestinal deformities. She said, "Sophia still tolerates feeding. Most likely she does not have intestinal deformities or blockages. We will observe her for any intestinal problems she may develop. Right now Sophia has a low platelet count. Platelets aid the clotting process. I don't expect any problems with clotting and the low platelets will probably increase with time. We'll just check them every week."

Dr. Crass could see that the Langleys were overloaded with information. She decided to leave the potential for hearing difficulties, vision problems, frequent upper respiratory and ear infections, thyroid disease, spine abnormalities, leukemia, and early Alzheimer's disease for a later discussion. The Langleys had plenty of time to acquaint themselves with all of the associated impairments of Down syndrome.

Dr. Crass requested that the Langleys recap what she had told them. Together, they repeated most of what she had described. They appeared sad and overwhelmed. She asked how they were feeling.

Mr. Langley retorted, "How do you think we're feeling?"

Dr. Crass said, “You tell me. Some parents feel numb, others feel angry, others feel sad, others feel like they are falling apart, and others feel like they’ll deal with whatever comes their way. So, I’d like to hear from both of you. What are your greatest fears?”

Mr. Langley responded, “My life is over. This is the worst thing that ever happened to me.”

Dr. Crass replied, “So you feel that this is the worst thing that has ever happened to you. That is normal. Nobody wants to find out that his daughter has Down syndrome. So feeling sad and overwhelmed, and a little bit angry, is natural.”

Mr. Langley said, “Yes. I am sad and overwhelmed and a little bit angry.”

Dr. Crass responded, “Adjusting will take time. Just take it one day at a time.” Then she turned to Ms. Langley, “How about you? What are you afraid of?”

Ms. Langley answered, “I’m not sure. I don’t want Sophia to have Down syndrome, of course. But she’s still my baby. I’m just not sure I’m the right one to take care of her. I had such high hopes and dreams for my baby. And now this.”

Dr. Crass gave Ms. Langley time to think about what she had said. Then she told her that many mothers consider the situation to be frightening and devastating. “Sophia is your baby, though. You’ll be taught how to take care of her. The silver lining of having your first baby in the NICU is having nurses teach you how to take care of your baby. I’m not worried about your ability to tend to Sophia. Just take things one day at a time.”

Ms. Langley asked what they needed to do for Sophia for now.

Dr. Crass told the Langleys they should spend time with Sophia when she is awake. They could kangaroo with her and learn the basics of baby care.[77] "Having a baby in the unit is stressful. You must take care of yourselves: sleep enough, eat nutritiously, and persevere with your exercise. Those are all stress busters. You can even go out to a movie once in a while."

She told Ms. Langley to keep working on breastfeeding once or twice a day. Both parents could start acquiring tricks from the nurses to help Sophia bottle feed more easily. Eventually, Sophia's muscle tone would improve and she might nurse. Until then they would work on bottle-feeding. And they would tube feed her when she would not finish her bottle.

The Langleys appeared exhausted. Dr. Crass knew that they could not take in any more. With a gentle and caring smile, Dr. Crass told the Langleys that she would give them time to absorb what she had said and talk between themselves, unless they had other questions.

Ms. Langley asked Dr. Crass if she knew of any parents of children with Down syndrome with whom they could speak.

Prompted by Dr. Crass' questioning glance, the social worker replied, "Unfortunately, we don't. Talking to other parents can confuse matters. After all, every child is different."

Dr. Crass reminded the Langleys that they could get in touch with her or the social worker if they had questions or concerns. Otherwise, she would see them again the next day.

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[77] Kangarooing is the process by which a parent holds her naked baby against her bare chest. Studies suggest that kangarooing is beneficial to the baby in many respects.

The Langleys walked down the hall slowly; they were trying to hang on.

Analysis of conversation between Dr. Crass and the Langleys

Introduction of analysis

How a physician approaches, apprises, advises, and emotionally assists the parents of a neonate with a potential disability may have long-term implications for the child's well being (Fallowfied 2004, 315, 317; Sharp, Strauss, and Lorch 1992, 545). This effect plays out through the attitude the parents develop toward the child's disability, a perspective that is initially informed by the words, body language, knowledge, and approach of the HCPs transmitting the news. For this reason, I analyze Dr. Crass' conversations with the Langleys to detect opportunities for improvement in the way she discusses disability. In so doing, I introduce (or reintroduce) five topics I use in the analysis: (1) giving "bad news," (2) normalcy and ableism, (3) physicians' negative attitudes toward disability and the language they use, (4) parents' bias and grasp of their values, and (5) Barnes' arguments against the medical model. After introducing each topic, I analyze the scenario described above to illustrate it, identify bioethical dilemmas, and then present suggestions for improvement. My recommendations are based on an original approach using a social-relational model of disability framework within a medical model system.

Giving "Bad News"

Dr. Crass gives "bad news" expertly. She prepares before each family meeting; she remembers the details of Sophia's history, clinical status, and

diagnosis; and she prepares the rooms for comfortable conversations in which she can easily communicate. Dr. Crass times the second meeting for just after she receives the FISH analysis and arranges for a confidential, interruption-free discussion. Furthermore, she arranges for the presence of the staff members she wants in attendance and invites the Langleys to summon support persons to join them.

Moreover, Dr. Crass ensures that the content and format of both discussions focus on the Langleys' concerns. In the first interchange, she starts by giving them a warning with her facial expression, her body language, and the mention of "bad news." During the second meeting, she alerts them to the "bad news" to come by asking whether they want support persons present. In both conferences, Dr. Crass begins by asking what they comprehend and permits them to lead the dialogue. She asks the Langleys how much they wish to know. She inquires about how they experience the information. She uses simple words and sentences and checks frequently to make sure they understand. She keeps quiet during pauses so that the Langleys have time to feel, think, and emote. She proffers the truth, but provides hope. She gives some "good news" (that Sophia is eating fairly well) along with "bad news." Her face, body, and words emphasize empathy. She offers emotional support throughout the two difficult exchanges. She validates the Langleys' emotional responses. And finally, Dr. Crass encourages them to talk to each other about their values.

The mode and method of communication that Dr. Crass demonstrates exemplifies the epitome of physician-parent interaction as described in the review of giving "bad news" in chapter 4. However, it also typifies problems with

the way neonatologists conventionally talk about DS with new parents. Although Dr. Crass clearly and kindly communicates "bad news," much of her message reflects views about disability typically held by physicians. By illustrating how Dr. Crass expertly gives "bad news," I take her ability to relate information out of the equation. That is, I do not confuse poor communication skills with disability bias. Rather, I focus on the aspects of ableism and ableist expression that she unwittingly demonstrates.[78] From a disability viewpoint, her language and palpable underlying attitude about disability express bias. The following sections highlight the problems with Dr. Crass' interactions with the Langleys and submit viable alternative strategies.

Normalcy and Ableism

The concept of normalcy and the inequity of ableism are prominent in the discussions between Dr. Crass and the Langleys. As I discussed in chapter 3, the definition of normalcy relates to abnormality. Though a child with DS has traits and abilities outside the standard deviation, she also has many attributes within the standard deviation. A neonatologist promotes ableism by labeling an infant with DS as *different*.

Calling attention to the concept of normalcy creates problems for the parents of a newborn with Down syndrome. For parents who value their child, whether or not she has DS, broaching the concept of abnormality may raise barriers between parents and physician. This does not mean that the parents do not want to learn about medical complications associated with DS or about the

[78] As mentioned in chapters 1 and 3, ableism is the preferred label for disability bias.

potential for intellectual disability. Rather, it indicates a preference to avoid labeling their child as abnormal. Furthermore, regardless of the parents' understanding of disability and abnormality, defining an infant as abnormal emphasizes what is wrong with the baby rather than what is right.

Many physicians argue that infants with DS do have "abnormal" traits, that is, characteristics that do not fall within the normative curve. Additionally HCPs have asked me why we should avoid the word *abnormal*. They express the view that children with DS are abnormal and will never attain intellectual milestones their parents would hope for. I sometimes engage in the same arguments with myself. However, my story of my patient with heart disease who I called Rashawn (in chapter 1), whose father wanted him to play ball, reminds me that we do not necessarily get what we hope for in our children. Only sometimes we learn that our dreams were only dreams right after our child's birth.

Additionally, one difficulty of determining the best language to use for healthcare discussions arises from the fact that the medical model largely developed medical words that exclude people with disabilities. Disability bioethicists and HCPs have this challenge to overcome in order to provide the best care for their disabled children.

This script ignores socially valued and medically neutral traits. Instead it selects for physical features that are socially devalued and require medical intervention. For parents who consider their infant with DS to be abnormal, confirmation by the HCP may prolong the family's difficulty in accepting their infant. Thus, the neonatologist can harm the infant and the family by asserting the abnormality of the infant with DS.

Dr. Crass identifies neonates with DS as abnormal in multiple ways. First, when she describes Sophia's "stigmata," she uses the phrase "a bunch of other abnormalities." In fact, Dr. Crass persistently expresses her view that children with Down syndrome are anomalous by the way she talks about DS. When reviewing the genetics of DS, she says, "too many, that is three, twenty-first chromosomes, normal babies have two. That extra chromosome causes Down syndrome." But Sophia's third twenty-first chromosome is not extra for her. From a medical viewpoint Sophia is aberrant; but from a social viewpoint, Sophia has a specific genotype that results in a specific phenotype (Scully 2008a, 23–25, 30–32; Scully 2008b, 800–1).

When depicting Sophia's phenotype Dr. Crass disparages her by classifying her as atypical. She refers to Sophia's "abnormalities," rather than describing "variations." Dr. Crass describes Sophia's physical characteristics that differ from most other infants, including low muscle tone, small mouth, big tongue, flat head, low-set ears, and up-slanting eyes. These descriptions compare Sophia's traits with a statistical amalgam. Although each of the features Dr. Crass illustrates appear in babies with and without Down syndrome, they all fall outside the normal distribution for the given characteristic. From the medical model viewpoint, calling her features abnormal makes sense. However—and as I stated in chapter 3—calling a disabled person different or deviant is degrading and devaluing. In addition, according to disability advocates, emphasizing her physical differences causes harm; the emphasis belongs on accommodations for the disability. Besides, the Langleys do not have the pleasure of hearing about the

ways Sophia looks, behaves, and will develop like other babies, qualities that are socially cherished.

And Sophia has many traits that fall within the normal distribution. A medical professional's duty requires assessing, diagnosing, and possibly treating medical problems that could interfere with an individual's functioning (or life). In other words, physicians look for anomalies, illnesses, disorders, and impairments and disregard other characteristics. Nevertheless, the HCP should remind the parents that many of the patient's features are those they expected or wished for. I do not mean that Dr. Crass should distinguish attributes by where they fit in the standard distribution. Rather, by pointing out qualities that fall both within and outside of the normal distribution, Dr. Crass would provide a balanced view of Sophia's characteristics.

Yet the Langleys and, I suspect, most parents want to understand why the physician thinks their infant has Down syndrome. It seems that describing attributes using nonableist explanations (for example, describing Sophia's features associated with DS by their appearance rather than comparing them to "normal" traits) would help the parents to perceive their baby as an individual rather than as abnormal.

Though Dr. Crass repeatedly both articulates and indirectly indicates her attitude that Down syndrome constitutes deviance, she would insist that she cares about children with disabilities. Her approach, dependent on her experience with new parents of neonates with Down syndrome, specifies the need

for empathetic care. She should support parents hearing unexpected news about the "perfect" baby they anticipated.[79]

By providing this care and concern, Dr. Crass conforms to professional medical standards. However, she (like many HCPs) falls short of demonstrating respect for people with disabilities. Dr. Crass' unintentional ableism emerges in multiple ways:

1. Her apology upon initiating the conversation
2. Her perception that Sophia *is* her disability
3. Her view that disability ruins lives
4. Her omission of the many benefits of having and being a child with DS
5. Her failure to communicate that the lack of accommodation, at least in part, causes disability
6. Her choice of words

I describe these six forms of ableism in the following examples from the old script.

Multiple examples of ableism permeate the exchanges between Dr. Crass and the Langleys. Reporting to the Langleys that Sophia "is a Down syndrome" and talking about "Down's kids" exemplifies Dr. Crass' negative inclination regarding disability. Calling Sophia her disability implies that Sophia is her disability: that every aspect of Sophia embodies her disability. Such an implication creates harm for disabled people; the disability encompasses the disabled person. In fact, disabled people are "people first" (Clark and Marsh 2002, 4.2, 6.1; People First; Snow 2013, 1).

[79] The concept of the "perfect" child relates to the nonmedical expectations of parents for the "normal" or "gifted" child. For a further discussion of the concept see chapter 2.

In fact, the HCP is obligated to educate the parents about the infant's potential abilities in an effort to curb discrimination. She should instruct them that ableism may harm their child and, therefore, the family; she should coach them about overcoming disability bias and fighting for accommodation for the good of all parties. But HCPs should acquaint themselves with bigotry regarding disability before they can teach it; then they can help themselves and their future patients.

Physicians' Negative Attitudes Toward Disability

In this section, I look at physicians' variation (or bias) and language regarding disability in the scenario of Dr. Crass and the Langleys. Dr. Crass, an expert in reporting "bad news," must acquire new ways to speak about disabled newborns by becoming aware of society's negative attitudes and ableist terminology. In chapters 2 and 5, I reviewed the ethics of physician variability and the language of disability. Chapter 2 described the negative effect of physician bias on developing a plan of treatment and shaping family decision making for the disabled neonate's wellbeing. Chapter 5 furnished evidence about the importance of language in perpetuating or reducing ableism. Both issues create bioethical violations when not addressed.

Physician preference, the physician's choice of treatment based on her own values and worldviews, creates an ethical dilemma when the physician imparts both her position and incomplete, inaccurate information about disabled people to parents of children with disability. Such actions emanate from an embedded conviction that disability is devastating, or at least disturbing, for both child and

family. Dr. Crass makes assumptions about disabled people; she unintentionally articulates both her prejudice about those with disabilities and her ignorance of life with Down syndrome. But Dr. Crass has been acculturated in a society that devalues disability and trained in a system that views disability negatively. Her stances reflect those of her culture; they do not emanate from her alone. Regardless, her partiality seeps through her interactions with the Langleys.

How does Dr. Crass let her predisposition influence her work? From the beginning, Dr. Crass communicates her distress and sorrow that Sophia has DS. She reinforces the idea that having specific features of DS—and disability in general—is a life crisis; she does not expect parents to cherish a child with DS. Dr. Crass' words transmit her opinions and reveal her ableism: "Nobody wants to find out that his daughter has Down syndrome."

Dr. Crass utters her injurious remarks with compassion. Nevertheless, she should empathize without intimating that the diagnosis is a catastrophe. Dr. Crass presupposes that when the Langleys discover that Sophia may have Down syndrome, they will be shattered. A neonate newly suspected of having DS often elicits parental distress: shock, disappointment, sadness, and fear (Crouse 2007, 91–93; de Groot-Van der Mooren 2014, 2; Ptacek and Eberhardt 1996, 496; Sheets et al. 2011, 1246; Skotko, Capone, Kishnani 2009, e752). But for some families (including families whose babies I have cared for) the news occasions delight, warmth, and acceptance. Dr. Crass' attitude about Sophia having DS may have impacted the Langleys' reaction.

Given that parents more frequently respond negatively, Dr. Crass' conjecture makes sense, but the neonatologist's values have no place in the

conversation. Checking out the parents' feelings before sympathizing generates invaluable data. Dr. Crass could, and should, convey understanding and caring based on the Langleys' reaction, not on her own speculation. Although one expects parents to feel anxiety or dismay about their child having heart or intestinal disease requiring surgery, Dr. Crass makes assumptions about how the Langleys will perceive Sophia's diagnosis of DS. She disregards the possibility that the Langleys may not be upset.

Each parent responds differently. Recognizing whether a parent is devastated or excited, in shock or taking the news in stride, sad or happy, establishes a starting point. In the introduction I related the story of Jonny Calm whose parents did not care much whether he had DS. The neonatologist and her team, though, assumed his parents were "in denial" because they did not express disappointment or distress. It was not until I asked how they felt that Mr. and Ms. Calm revealed how they felt. I am uncertain where the communication failed. But sometimes a physician's assumptions can result in her misreading a parent's thoughts and mindset.

Explicit—if subconscious—physician bias against infants with disability seems to suggest to parents that children with DS are children not worth having. Many obstetricians and genetic counselors disseminate this prejudice even when the fetus is *in utero:* they commonly recommend abortion for disabled fetuses, including those with DS. Besides substantiating the concept that a child with disability is bereft of a valuable life, these stances endorse the notion that disabled children disrupt families' lives, a common stereotype (Choi, Van Riper, and Thoyre 2012, 161–63; Pace, Shin, and Rasmussen 2011, 1258–59; Parens and

Asch 2003, 43). Hearing such comments from anyone—friends, family, society, or physician—may introduce uncertainty, confusion, and ableism into the conversation.[80] But when the obstetrician or genetic counselor expresses such notions, the asymmetrical relationship between the HCP and new parents creates the potential for an enormous impact on the parents' decision. Additionally, a discussion about an important, delicate family choice that takes place in a healthcare setting establishes it as a medical rather than personal decision. What must parents feel, whether they are joyful or saddened that their fetus—or baby—has DS, when their physician expresses pity or sympathy for their misfortune?

A neonatologist sets up a conflict with parents when she erroneously assumes that parents will be crushed upon hearing that their newborn has Down syndrome. This discord generates an ethical dilemma: the physician inadvertently causes hardship for the family. The family may experience emotional pain and disharmony due to the physician's negative stance apropos their disabled neonate; in turn, the tension may cause bitterness and distrust within the family or between family and physician. And the physician's destructive attitudes about disability add force to any bias against disability that the parents may already hold.

I have observed that bias on the part of the physician may create a number of other ethical predicaments. If the physician distracts the parents with her

[80] An example of society introducing ableism into the discussion is Richard Dawkins' recent Twitter comment. In response to a woman who tweeted "I honestly don't know what I would do if I were pregnant with a kid with Down syndrome. Real ethical dilemma" (McCourt 2014/8/20), Dawkins responded: "Abort it and try again. It would be immoral to bring it into the world if you have the choice" (Dawkins 2014/8/20) Such adamantly narrow-minded thinking about having a child with DS can only make such decisions tougher and more complicated for parents (Guardian 2014).

prejudice (as Dr. Crass does), she may consign the parents to a morally uncomfortable position in terms of their duty toward their infant. Because the parents have the ability, and obligation, to maximize their child's welfare, not recognizing the encouraging characteristics and promise of their disabled infant may cause them to harm her rather than help. The interference with bonding, amplified when the physician reinforces the parents' preconceived notion against disability, undermines the parents' responsibilities. Instead of assessing and acting in the best interests of their baby, the parents may limit her potential. For example, when Dr. Crass tells the Langleys about Sophia's developmental delay and the difficulties she would have with sitting, walking, talking, and other developmental, she fails to inform them of Sophia's capacities. Rather, the Langleys continue to perceive Sophia as "less than." They are not informed that certain interactions and therapies can help Sophia optimize her abilities.

How can a physician avoid misconstruing or misinterpreting the Langleys' parents' responses—and, therefore, what the parents need? She should explore how the Langleys feel. She cannot behave empathetically if she does not know to which emotion she should react. Should she act sad and sorry, or happy and congratulatory? Or do the parents just need facts because they do not realize what DS means? Parents may appear surprised, stunned, anxious, distressed, confused, doubtful, happy, or calm.

If the parents display shock, devastation, anger, or sadness, then the neonatologist should empathetically talk about the loss of the infant they dreamed about and the pleasures of this new, real baby. Ignoring these parents' feelings and providing only the beautiful aspects of having a child with DS would

be callous, unkind, and harmful. However, if the parents do not articulate their reactions, the physician should not assume they are in denial or too overwhelmed to speak. Asking directly may inform the physician. And finally, for parents who convey happiness, pleasure, acceptance, and love, ignoring their feelings and providing only the negative aspects of having a child with DS would be similarly callous, unkind, and harmful.

I suppose that many physicians think that presenting DS to parents as good or neutral news contravenes the recommendation to prepare the parents for "bad news." Body language and even words can prepare the parents for potentially concerning news. But establishing an accepting and encouraging tone—along with empathy and compassion—may initiate a more inspiring, empowering journey for the parents.

The physician may not realize, though, that what she says and how she says it make a difference (Fallowfied 2004, 315, 317; Sharp, Strauss, and Lorch 1992, 545). And even if the realization that Sophia has Down syndrome devastates her parents, a more balanced explanation of her diagnosis and prognosis—along with an empathetic delivery—may facilitate the Langleys' adjustment and benefit Sophia in the long run. In fact, in a review of Down syndrome publications between 1960 and 2008, Skotko and colleagues conclude that:

> Physicians should begin their conversations with positive words, such as congratulating the parents on the birth of their child. They should avoid language conveying pity, personal tragedy, or extreme sorrow; moreover, they should avoid offering unsolicited personal opinions. The first few words that doctors use have been shown to set the tone for the remainder of the conversation. Moreover, mothers remember the first words 20 years after the initial discussion. (Skotko, Capone, and Kishnani 2009, e755)

The words Dr. Crass speaks convey disability intolerance; they transmit her discriminatory attitude toward disabled children. Some of Dr. Crass' comments—for example, "her arms and legs are floppy" and "she's not as strong as a normal baby"—not only depict her phenotype, but attribute abnormality. Dr. Crass talks about programs for learning-disabled people as "special classes," a euphemism distasteful to disability advocates because of the contrast between "special" and "gifted" classes. During her second interchange with the Langleys, Dr. Crass repeats Mr. Langley's assertion that Sophia will be "mentally retarded." Mental retardation is a slur and a comparison with an unstated norm; it offends disabled people because of its demeaning tone (Crouse 2007, 92; Kailes 2010, 20; Nash et al. 2012, 71–74; Skallerup 2008, 8). I suspect Dr. Crass is either unaware of the offensive nature of the term or simply repeating what Mr. Langley said.

But even I have difficulty trying to communicate the concept of cognitive disability in words that a layperson recognizes. My two solutions allow for clear explanation without using slurs:

1. To use either *cognitive* or *intellectual disability* and elucidate it: difficulty with some abilities such as understanding, learning, or communicating
2. To explain that the new phrases, *cognitive* and *intellectual disability*, have superseded the old *mental retardation,* because disabled people consider *mental retardation* to be insulting

The second method teaches parents that *mental retardation* is now considered demeaning; it helps them comprehend new, nonableist replacements for slurs (such as intellectual disability) without feeling offended.

Language also plays a role in parental appreciation of a newborn with newly discovered disability. I propose that a parent who hears nonableist descriptions of her infant's disability may start to think about her child in more positive ways; a parent who hears ableist slurs may see her more negatively. Furthermore, physicians who use ableist slurs may lose the trust and respect of the family, leading to ethical dilemmas. Although a physician (and parents) may not recognize all of the currently identified slurs, for the sake of her disabled patient she should avoid discriminatory language while imparting facts free of bias. I have found that social education for HCPs filters through cultural networks. That is, HCPs learn about what is appropriate to say or how to act through people they know: friends, family, children, colleagues, continuing education lecturers. Some physicians do a better job than others learning cultural mores. However, I advocate for continuing education regarding disability for HCPs so that they do not unintentionally insult their patients or their patients' families or trigger damaging perceptions about disability.

Dr. Crass' use of ableist words and expressions of disdain causes ethical harm for the Langleys and Sophia. Yet the Langleys are unaware of the harm Dr. Crass causes. Dr. Crass communicates distressing descriptions of Sophia. In this way the neonatologist perpetuates her partiality against disabled people and neglects to help the Langleys overcome their prejudice. We cannot conclude that Dr. Crass has negatively affected the Langleys. All three adults appear to have similar values regarding disability. They all perceive having a child with DS as undesirable.

Dr. Crass expresses her feelings about children with DS when she relates the many impairments associated with DS, but leaves out the many abilities. Mr. and Ms. Langley are devastated that Sophia has DS, do not want a "mentally retarded" child, and would have aborted had they had the chance. But Dr. Crass could furnish realistic promise for the Langleys by managing her preconceived notions about disabled people generally, and people with DS specifically. Hearing about Sophia's qualities and abilities may transform the way they would think about Sophia as she grows up. I postulate that hearing about the qualities and abilities of children with DS might transform the way pregnant women and their partners think about choosing abortion.

In the first two meetings, the Langleys do not have the opportunity to learn about Sophia's attributes and capacities. Dr. Crass fails to communicate many encouraging facets of Sophia personally and of Down syndrome in general. If Dr. Crass had congratulated the Langleys on the birth of their little girl, she would have affirmed what was an exciting event for them. She mentions Sophia's beautiful hair to lessen the impact of the "bad news." This comment suitably acknowledges a favorable characteristic of Sophia. With greater appreciation for children with DS, Dr. Crass may emphasize more of Sophia's many positive qualities and communicated the idea that disability does not define Sophia.

Parents who have children with DS complain about how HCPs talk about the children's delays, but not about their abilities (Hodson 2007, 35; Huffman 2007, 39; Roach 2007, 27–29; Skotko 2005, 675; Skotko, Capone, Kishnani 2009,

e754; Solomon 2012, 202).[81] During both conversations with the Langleys, Dr. Crass overlooks the parts of Sophia's life that will bring Sophia and her parents delight, love, contentment, and fulfillment. Rather, she focuses on medical problems associated with DS. But the Langleys know little about DS. Along with learning about intestinal deformities, heart defects, and "mental retardation," they have a duty to find out about endearing, inspiring, and reassuring qualities of people with DS. They have an obligation to appreciate Sophia's future ability to hope, laugh, cry, and be affectionate; they must gain knowledge that Sophia will achieve developmental milestones (sit, crawl, walk, talk), grow, learn, look at the world in awe and wonder, go to school, play sports, have friends, get a job, and possibly get married (Brasington 2007, 733–34; Sheets et al. 2011, 433–34; Skallerup 2008, 171–88).[82] Reinforcing Sophia's many positive traits would start to place her third twenty-first chromosome into perspective.

Besides the many abilities of children with DS, they have special value because they are children. The child with disability is a child, regardless of disability. The social construction of disability theory raises this notion by

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[81] *Delays*, *slow*, *retarded*, *late*, and *behind* exemplify how physicians (and educators and society in general) judge child development in relation to the norm or normate. This comparative pace of so-called development is ableist.

[82] I have consolidated this list of traits that parents want to hear and need to know both from journal articles describing studies of parents' preferences concerning genetic counseling for their child with DS and from numerous published stories of families with children with DS. These stories usually come from the parents of children with DS, although one comes from two boys with DS. They include "The Shape of the Eye" by George Estreich, "Raising Henry" by Rachel Adams, "Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives" edited by Kathryn Lynard Soper, "Bloom: Finding Beauty in the Unexpected—A Memoir" by Kelle Hampton, "Expecting Adam: A True Story of Birth, Rebirth, and Everyday Magic" by Martha N. Beck, "Count Us In" by Jason Kingsley and Mitchell Levitz, "Life As We Know It" by Michael Bérubé, "The Year My Son and I Were Born: A Story of Down Syndrome, Motherhood, and Self-Discovery" by Kathryn Lynard Soper, and others. See reference list.

identifying the lack of accommodation rather than the physical or medical factors as the primary etiology of the disability (Scully 2008a, 25–27; Siebers 2011, 4; Vehmas and Makela 2009, 47–49). Many disabled adults have developed their own identities involving "representations" of their own disability that differ from society's assessment of their disability (Couser 2010, 533; Davis 2010c, 301–2; Garland-Thompson 1997, 135–7; Siebers 2011, 4–6). Examples include the aforementioned memoirs about Down syndrome. These identities help express the significance of these disabled individuals, an important concept for physicians to understand. The neonatologist (or other physician) places the disabled patient at a distinct disadvantage when the physician does not grasp the worth of the disabled being.

Taking the concept of identity of the disabled person to the more specific level of a distinct patient, the neonatologist must discuss the infant, who has DS, rather than the "Down syndrome infant." Sophia, like most other babies, is dependent, needy, lovable, and soothing, and she will become her own person, with her own personality, her own abilities, and her own talents. What is more, she, like most children, will tax her parents' patience, create chaos in the family, throw tantrums, and make her parents wonder why they ever had children. For a physician to describe an infant with DS as a typical newborn to her parents will ease much of their angst; in addition it will make this world a better place for disabled children by teaching one more family about the ordinariness of disability.

Though evidence points to a major change in families' lives when their baby has DS, the transformation may present unexpected pleasures (Crouse 2007, 91–92; Saxton 2010, 123; Skotko, Levine and Goldstein 2011, 2338–41; Solomon

2012, 190–93, 218; Van Riper 2007, 118; Yunke 2007, 114–16). For example, in *The Memory Keeper's Daughter* (Edwards 2005), a novel, a woman (not the mother) raises a child with DS instead of taking her to an institution as planned. This woman, uninformed about Down syndrome, finds value and devotion in her life through raising this child, in ways that she would otherwise not have experienced. In authentic life, too, many families report that their children with DS add meaning, strength, perspective, joy, and love to their lives. Learning about this potential could provide hope and perspective for parents of those unexpected and perhaps initially unwanted neonates.

Moreover, the physician should advise the parents that things will be okay, that they are starting "an amazing journey" (Vesper 2007, 66). Many parents of children with DS report that being told they would be okay helped them to cope. In this manner, the family receives hope. Courage and hope, by way of positive words, will likely assist new parents with their transition (Skotko, Capone, Kishnani 2009, e755).

Using encouraging words to relate these positive qualities of children with DS is an important aspect of the HCPs' conversation with parents. Still, the HCPs also have the responsibility to inform the parents of the medical conditions correlated with DS. This change in discussion does not eradicate the medical part of the conversation. Along with the attributes of a child with DS, the HCP should include in the discourse the medical conditions that often coexist with DS. A discussion considering these medical disorders as well as future abilities fully informs the parents of what they may expect in their child's future.

And new parents should be informed that parents who initially are distraught tend to show resilience, eventually changing how they feel (Van Riper 2007, 122–24). In one survey the great majority of parents appreciated having a child with DS: they were proud; they perceived their viewpoint on life to be more positive due to their child with DS; and they observed more sensitivity and empathy from siblings (Skotko, Levine, and Goldstein 2011, 2340–41). Moreover, parents reported learning important life lessons: patience, acceptance, love, happiness, appreciation, kindness, perseverance, tolerance, and advocacy skills. At the same time they reported challenges with their children. These parents recommended putting new parents in touch with experienced parents of children with DS, offering the number or website for a local DS organization, and furnishing a list of appropriate books.

In our scenario, Dr. Crass and the social worker fail to supply referrals for the Langleys. In their second conversation, even though the Langleys request to speak with other parents of children with DS, Dr. Crass and the social worker do not arrange for them to do so. A parent who volunteers to speak with new mothers and fathers can answer questions with which the healthcare team may be unfamiliar (National Down Syndrome Society). Someone who has raised a disabled child may possess the expertise to emotionally support and factually enlighten inexperienced parents of a disabled newborn. Though every person with DS has differing abilities, a veteran parent can relate stories about their child and may facilitate adjustment and hopefulness for new parents. They might likewise advise inexperienced parents about advocacy, valuable information for the family and their newborn.

I think a change to a disability mindset will present a challenge for many healthcare professionals. As I mentioned in chapter 1, the first time I tried a positive, appreciative, and educational approach like that I have outlined in this section, the mother, who was quite upset about having a baby with DS, looked at me with a quizzical expression (as did the neonatal nurses and nurse practitioners in the room). But upon hearing positive qualities of her baby, the mother began to appreciate her baby and became more interactive. New methods of introducing disability to new parents may not come naturally. More educational activities about disability, both at conferences and during bedside teaching in the healthcare environment, may partially remedy this situation.

Parents' Bias and Knowledge of Their Own Values

In our scenario, the Langleys would prefer a child without Down syndrome. They represent a typical example of parents' preferences. They know little about DS, but they abhor the thought of raising such a child. The Langleys had dreamed about a daughter who would follow in their footsteps and pursue intellectual interests. Of course, without DS Sophia may have had no desire to pursue an academic career, but the Langleys would have figured that out over time. And by then, they would love her and, hopefully, accept her choices. In other words, any child may not fulfill parental expectations, but disabled children fail to realize the role of the imagined child soon after birth.

With Sophia's diagnosis of DS soon after birth and Mr. Langley's damaged story of expectation, he thinks about the missed opportunity to abort this stranger. He does not want a daughter with "mental retardation" and multiple

medical disorders. His preference does not have to do with Sophia's physical pain due to medical disorders nor her emotional suffering due to social isolation. Rather, "stupid" people repulse him. He could never love someone with the "dumb-appearing" face of a child with DS. Mr. Langley made it clear when he responded to Dr. Crass' queries: "That they're mentally retarded. That most people abort if they get the chance" and "I don't understand how this happened. This just can't be. I never wanted a baby with Down syndrome and I still don't." Mr. Langley cannot imagine raising such a child. His prejudice against disability, especially cognitive disability, blocks any feelings of love he might have for Sophia.

Ms. Langley says she would have aborted Sophia if she knew about the diagnosis prenatally. She never wanted an intellectually disabled daughter. But she loves Sophia despite her DS. She worries that she will not be able to protect Sophia from society's mistreatment of "the mentally retarded": teasing, social disregard, and condescension. She actually thinks that Sophia has a beautiful face. She fell in love with Sophia's almond-shaped eyes the moment she saw her. Ms. Langley is not sure she will surmount her great disappointment. Though she started out with a bias against disabled people, Sophia will change her (though she does not know that yet). And she worries that her husband will not adjust and will leave her and their daughter.

At the end of the first exchange, Dr. Crass advises the Langleys to examine their values and outlooks on life. The Langleys are not making a life-or-death decision for Sophia. Most likely their values will change as they get acquainted with her. On the other hand, Mr. Langley focuses on the missed opportunity for

abortion. Further exploring his beliefs and attitudes might help him understand his underlying principles, or could prompt dialogue about putting Sophia up for adoption. Though Ms. Langley would argue against adoption, the interchange would improve communication. Mr. Langley would express his emotions. And Ms. Langley might escort him down another path. Or, at a minimum, Mr. Langley's thoughts and sentiments about disability would become transparent to both him and Ms. Langley. Though we should commend Dr. Crass' allusion to values, she might have gone further by mediating such an important discussion.

As mentioned in the previous subsection, Dr. Crass also could have assisted the Langleys by talking about the pleasures of having a child with Down syndrome. They might not accept the optimistic outlook for Sophia at first. In fact, they might not emotionally respond to encouraging details. But they would have in the back of their minds the concept that she will be able to gratify, amuse, care, have fun, love, and flourish. Once they grieved for the loss of the Sophia they had awaited, they hopefully would move on to accepting the one they had. Then they could remember the physician's words about her abilities and gifts.

The Medical Model, Social Model, and Barnes' Arguments

In this final subsection, I scrutinize Dr. Crass' conversations with the Langleys through the lens of Colin Barnes' arguments against the medical model of disability (see chapter 3) (Barnes 2010a, 29–31). As presented in the introductory chapter, the differences between the medical and social models create discrepancies between preferences of HCPs and disability advocates. The

distinctions between the different models inform the difficulty neonatologists have discussing an infant's disability with her parents.

While reviewing obstacles facing children with DS, Dr. Crass uses the medical model of disability in which she was trained. Thus she conveys her attitude that disability stems from genotypic and phenotypic traits, from impairment. For example, she describes the associated medical problems and the ways children with DS deviate from the norm, typical depictions by HCPs. The trouble with her discourse provides multiple examples of the drawbacks of the medical model. Dr. Crass does not recognize that barriers facing children with DS, at least in part, are due to deficiencies of social, environmental, and economic accommodations. Elements of essential dialogue are missing. She fails to appreciate and exercise the social-relational model's concepts. Furthermore, she inadvertently supports some of Barnes' arguments against the medical model.

Dr. Crass' portrayal of Sophia demonstrates Barnes' first argument against the medical model: the complexity in defining normality and the fact that the norm changes across time, culture, and space (Barnes 2010a, 29). Dr. Crass may be using a definition of the norm that fits with the current time, medical culture, and hospital space. However, conceptions of normality change when adding the social-relational model's concept of space and culture. Even "norms" of medical attitude have markedly transformed over time.

The history of medical care for neonates with DS supports Barnes' contention regarding the complexity of normality. Fewer than 30 years ago, our society allowed infants with DS to die from treatable life-threatening anomalies; today we would be appalled at the idea (Ginsburg and Rapp 2010, 246; Haslam

and Milner 1992, 304; Saxton 2010, 123). Newborns who did not have life-threatening conditions were often sent to institutions where, for the most part, they suffered without love, stimulation, or education (National Association for Down Syndrome; Solomon 2012, 181, 211).

Today, children with DS primarily live at home surrounded by their loving parents and siblings, at least either until they reach their early twenties or their parents die. Ideally during their younger years their parents provide care, schooling, life lessons, and advocacy. The quality of care and the love children with DS receive is still progressing. But infants with DS, though not left to die, do not procure enough accommodations to make their disabilities disappear. The reasons parents must put their young adults into institutions once they are grown include a dearth of group homes, social services, and job opportunities. Dr. Crass illustrates the state of the art today; hopefully, it is just a transitional status.

As I mentioned earlier in this chapter, HCPs, including me, have a hard time grasping the rejection of the term *abnormal* from the medical lexicon. My reasons for the difficulty in understanding why *abnormal* is disdained include:

1. Children with DS (and others with disability) fit the definition of *abnormal* according to the interpretation of many HCPs.
2. HCPs undergo training that labels people without "important" traits—that is, traits that HCPs, and society, consider important for social inclusion, happiness, and economic prosperity—as *abnormal*.
3. For most people, and certainly for HCPs, intelligence possesses maximum worth (I would surmise that more discrimination exists against intellectually

disabled people than physically disabled people, depending on the extent of the disability).

4. Truly comprehending the concept that the environment causes many of disabled people's disabilities is difficult.

These issues negatively affect the conversation between Dr. Crass and the Langleys.

Dr. Crass does not understand why (or even that) disability advocates find the word *abnormal* objectionable. She does not understand that by communicating Sophia's "abnormalities" to the Langleys she decreases their likelihood of imagining her life as fulfilling and worthwhile. And she does not understand that by using her own portrayal of Sophia's life—rather than that of the lived experience of a person with DS—she misconstrues Sophia as abnormal. She does not understand that *abnormal* means different things to different people. These four factors demonstrate Dr. Crass' ignorance about the harms of the term and concept *abnormal*. They cause harm to Sophia. If Dr. Crass understood more of the effect the environment has on disability, she might have helped Sophia and the Langleys. The complexity of abnormal certainly played a disadvantageous role in this situation, confirming Barnes' first argument.

The discussions between Dr. Crass and the Langleys also exemplify Barnes' second point: discrimination against disabled people results from the medical model's vision of mutable beings and inflexible environs. This interpretation creates healthcare's reliance on treatment, rehabilitation, and cure (Barnes 2010a, 29–30). Dr. Crass creates a picture of DS for the Langleys that involves multiple areas of impairment requiring rehabilitative therapy. This label of impairment is

part of her job as she sees it, fixing the medical deficiencies that render Sophia different. But such singular focus on repair kindles discrimination.

And Dr. Crass ignores the issues of disability inequity. She does not discuss modifications that could help Sophia: patience with Sophia's timeline to attain milestones, sign language to communicate before she can talk clearly enough for others to understand, learning programs, social programs, and advocating for Sophia regarding her needs throughout her childhood, adolescence, and young adulthood. Many of these matters should be addressed in subsequent discussions. Still, Dr. Crass does not impart the fundamentals required to support and promote Sophia's gifts, talents, and optimal functioning in today's world.

Barnes' third contention highlights the medical model's tendency to treat the physical (or psychological) impairments with the goal of normalizing or enhancing the disabled person (Barnes 2010a, 30). Dr. Crass only talks about possibly treating Sophia's medical abnormalities (for example, heart disease). She does not talk about "normalizing" Sophia's speech or hearing loss, but she certainly would if given the opportunity.

Still, some of these recommendations may be desired. If Sophia had heart disease, we would want Dr. Crass to bring up the possibility of surgery so that she could survive or live a more energetic life. If others find Sophia's speech difficult to understand, then speech therapy to "normalize" her speech for better communication would be desirable. Disability advocates may claim that other environmental accommodations may work as well as speech therapy. If so, then these other options would work too.

Thus, I agree that Dr. Crass' lack of knowledge about the concept of environmental accommodations creates harm because she does not provide the family with enough information to optimize Sophia's inclusion. She fails to treat Sophia as anything but her disability. However, an important part of her job involves diagnosing and remedying associated medical conditions.

Dr. Crass' negative stance in regards to disability relates to Barnes' fourth claim that the medical model causes harm by expecting disabled people to adjust to a life of discrimination (Barnes 2010a, 30). This discriminatory posture transpires throughout Dr. Crass' conversations—in the form of language and an unfavorable construction of disability—due to both her worldview and her lack of knowledge. From the very beginning of Sophia's life, Dr. Crass' ableist, though well-intentioned, mindset leads the way; the doctor indirectly teaches the Langleys that they must start adjusting to a lifetime of bigotry.

Nonetheless, I disagree with this fourth argument in part. Dr. Crass does not actually expect or pressure the Langleys to adjust to discrimination. She would prefer that the Langleys (and Sophia) adapt to Sophia's disabilities. She would not want Sophia to experience any discrimination. In fact, she does not recognize that she herself discriminates against disabled people. Though the medical model may create the problem in one sense, the lack of knowledge of the social model by HCPs creates the problem in the other sense.

Barnes' fifth dispute with the medical model is portrayed in our scenario as well. This claim, that the medical model of disability signifies an unchanging state of impairment, is elicited when Dr. Crass fails to educate the Langleys about Sophia's potential for growth, development, and social interaction (Barnes 2010a,

30). As reviewed at length in the subsection, "Physicians' Negative Attitudes Toward Disability" of this chapter, Dr. Crass repeatedly depicts incompetency, but rarely elucidates competencies associated with DS. For her, and for the Langleys, DS is the condition that Sophia will always have; Sophia is her DS. Dr. Crass' image of Sophia as a "mentally retarded" child with typical "stigmata" of DS does diminish her (and the Langleys) expectations of her future abilities. Such a portrayal and attitude may limit Sophia's functioning.

Finally, Dr. Crass illustrates Colin Barnes' sixth statement against the medical model: the individual takes the blame for her disability, and the healthcare system impugns the disabled person. The medical model creates language that defines disability in relation to the impairment rather than the scarcity of environmental, social, political, and economic adaptation (Barnes 2010a, 31–31; Oliver and Barnes 2012, 11, 20–24; Scully 2008a, 22–23, 30–32; Siebers 211, 3–4, 25). Dr. Crass uses such phrasing. She compares Sophia to the normate phantom and holds Sophia responsible for her disability when she says,[83] "How *slow* she will be is hard to say at this age. Her physical troubles will *hinder* her abilities and add to her developmental *delay*: her *low* tone, her *floppiness*, will make it *difficult* for her to eat, speak, and *attain* her milestones on time. Sophia's speech impairments will make her *difficult* to understand. She will roll over *late*, sit *late*, crawl *late*, walk *late*, and talk *late*. She will be *behind* in school due to learning *problems*."

[83] The normate represents the "ideal" individual in terms of physical traits, cognitive abilities, and emotional control; normates wield power and control by force of their traits (see chapter 3) (Garland-Thomson 1997, 32).

Instead, Dr. Crass might have said, “Sophia will develop on her own timetable. You and Sophia’s teachers will be able to provide many advantages for her. You can learn sign language so that you can communicate with her and she can communicate with you and others before she learns to speak. You should investigate how to best prepare her for school. She will require teachers who understand how to teach her. In this way she will receive the best education possible. She can socialize and learn if you provide the appropriate environment for her. As she gets older she’ll need other types of accommodations.” These simple modifications take the blame away from Sophia and place it on the dearth of physical and social adaptations.

In the ideal situation Dr. Crass would have used words and expressions that would heal rather than harm. She would have professed ways to decrease disability, not by changing Sophia or treating DS, but by removing barriers to education, socialization, and eventual independence. However, this failing of HCPs comes from more than just the medical model; it arises from the attitudes of society in general against people with disabilities. Still, though good medical practice obliges Dr. Crass to inform the Langleys of potential medical disorders associated with DS and their treatments, transforming the discussion by interposing the social model attitudes would go a long way toward helping the Langleys and Sophia.

If the physician’s goals are to optimize potential and kindle the best family situation in which the child can grow, then she must recognize society’s oppression of disabled people. This apperception and a kinder, gentler, more

honest communication pattern with parents will not only enhance the world for children with Down syndrome, but for all disabled people—and all people.

The New Script for Baby Sophia Langley

This thesis presents a new script, a preferred method for HCPs to speak with parents about their infant with DS. It incorporates the concepts presented in the analysis of Dr. Crass' conversation with the Langleys. This new doctor, Dr. Class, would terminate if her fetus had a diagnosis of Down syndrome. But she keeps her values out of this preferred dialogue. And aware of both the blessing of disabled children and their struggles (due to the society within which they live), she takes a distinct approach. She, like Dr. Crass, is an expert in giving unexpected news; but she does not assume that the unexpected is bad. The Langleys remain the same. The following is the new script:

Baby Sophia Langley was born at 37-weeks gestation to a 27-year-old married woman with an uncomplicated pregnancy, labor, and delivery. When Sophia needed an isolette because she was hypothermic in the regular nursery, she was admitted to the NICU. The neonatal nurse practitioner, Rhonda, had noted that Sophia had low muscle tone and physical stigmata of Down syndrome including low-set ears, simian creases, and up-slanting eyes with epicanthal folds. The prenatal evaluation displayed no indications of chromosomal anomalies. Therefore, Rhonda asked the neonatologist, Dr. Class, to confirm her suspicions that Sophia had Down syndrome. Dr. Class agreed with Rhonda. Next, Dr. Class wanted to meet with Sophia's parents and give them the unanticipated news. She

called Ms. Langley's obstetrician, Dr. Black, and requested that he join her for the meeting.

They found Sophia's parents in Ms. Langley's post-partum room. Dr. Class introduced herself to Ms. Langley, a constitutional law professor, and Mr. Langley, a professor of microbiology (Dr. Black already knew the Langleys). Then they sat across from the Langleys. With a caring and kind expression, Dr. Class said in a pleasant voice, "I just examined Sophia. Congratulations! She has the most beautiful almond-shaped eyes. How is everything going?"

The Langleys looked at Dr. Class and Dr. Black. The two of them together, their visit to the room, and their body language and facial expressions told them that they had some kind of news for them and it was not good. But they could not imagine what was wrong; their pulses raced.

Mr. Langley replied, "Everything is fine. We think Sophia's great. Why? What's wrong?"

Dr. Class, in a thoughtful voice, said, "Sophia *is* great, and beautiful. You are so lucky to have her. I wanted to let you know that she seems to have some physical features associated with Down syndrome. But we cannot be sure until we get some blood tests back."

Shock, grief, and tears replaced the Langleys' excitement. They had not noticed anything unusual about Sophia. They had expected a "perfect" child. Visions of a broken life supplanted their dreams of a flourishing family. But, maybe the doctor was wrong. Ms. Langley said, "But Sophia looks fine."

Dr. Class handed Ms. Langley a tissue and stated, "Yes, Sophia does look fine. And she is fine."

"But I thought you said she may have Down syndrome," replied Ms. Langley.

"Well, yes, I think she does. But that doesn't mean that she isn't fine. She's the same Sophia that you gave birth to a few hours ago. I realize you were not expecting Sophia to have Down syndrome. You seem quite upset."

"What did you expect? That we would rejoice because she has Down syndrome?" retorted Mr. Langley.

With concerned body language and an empathetic tone, Dr. Class told Mr. Langley that she did not expect anything: Each parent responds in his or her own way. Would you like to tell me about your thoughts?"

Ms. Langley was crying. Mr. Langley retorted angrily, "Are you kidding me? This is the worst thing that could ever happen to us. This will ruin our lives."

Dr. Class responded, "I understand. This was not what you expected and you feel like your life is coming apart."

Ms. Langley dried her tears and looked at Dr. Class. "I'm confused. Why are you saying she's fine if you think she has Down syndrome? That's a horrible thing to have. What makes you think she has it?"

Dr. Class replied, "Children with Down syndrome have certain facial features associated with Down syndrome. People without Down syndrome sometimes have those features too, but not usually many of them together. So, for example, Sophia has those beautiful almond-shaped eyes. They are a beautiful shade of hazel. I can see she gets those from you, Mr. Langley. Her facial features are not typical for most babies of European heritage, but similar to the characteristics of many Asian babies. She needs a little extra help supporting her

body and maybe with feeding due to the tone of her muscles. But her muscle tone will increase as she develops. Sophia also has a wide space between her first and second toes. Her hands and fingers are wider and shorter than usual. And her ears and mouth are smaller than typical. But her mouth is large enough so that she will be able to eat. She has a line on her palm that goes all the way across, something one of my colleagues had. None of these signs will cause any physical difficulties for her."

At this point tears were running down Ms. Langley's face, and Mr. Langley appeared angry. Ms. Langley questioned whether Sophia really had Down syndrome: "I'm young. I'm only 27. Maybe that's just the way she looks."

This time Dr. Black responded. He explained that even though the risk is greater for an older mother, most infants with Down syndrome are born to young mothers.

Mr. Langley, with an angry facial expression and tense body language, interrupted. He demanded to know why they had not found out when his wife was pregnant so "they" could have aborted.

Dr. Black informed them that the screening tests do not pick up all babies with DS.

He said, "Only women with specific indications—indications that do not apply to Ms. Langley—require amniocentesis. Sometimes ultrasound does not discover signs of Down syndrome. We sent chromosomal tests for confirmation." The Langleys would have to wait for the test results.

The Langleys had nothing to say. Ms. Langley was sobbing; Mr. Langley was holding Ms. Langley. Dr. Class handed Mr. Langley a tissue. Dr. Class

reached over and gently placed one hand on Ms. Langley's shoulder and the other on Mr. Langley's shoulder.

Dr. Class allowed the Langleys time to experience the pain. She thought of all of her patients in the NICU that she had to examine before she left, but she needed to help the Langleys grasp the circumstances and talk about their anguish.

The Langleys finally looked up. Dr. Class followed their cue and said to Mr. Langley, "When you said that you would have aborted, you sounded very angry."

"I sounded angry?" retorted Mr. Langley. "What did you expect? You just told us our baby is going to be mentally retarded and we weren't able to abort her." Ms. Langley was silently agreeing with Mr. Langley.

Dr. Class let Mr. Langley's comments sink in. Then she said in a calm, caring tone, "I can see that you are both very upset that Sophia probably has Down syndrome."

"Yes, we're upset. Who wouldn't be? We have a child we never wanted."

Ms. Langley spoke up, "Well, yes. But now Sophia is here."

Dr. Class answered, "It's very natural to be upset, angry, or shocked. Lots of parents feel this way when they find out that their baby has a medical condition.[84] And often parents feel confused about the mixture of happiness and anger and sadness all at once. This isn't what you expected, and it will take some time to get used to. What do you know about Down syndrome?"

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[84] Frequently new parents expect the "ideal" child; this imaginary child possesses all the traits the parents prefer. But the real child has her own distinctive characteristics, not those of the illusory image. For parents of children with DS, the realization of their actual child as different from their fantasies occurs sooner than for the parents who adjust to their child's attributes as she grows.

Mr. Langley looked up with a surprised expression on his face. He responded, “That they’re mentally retarded. That most people abort if they get the chance.”

Dr. Black answered, “You are correct, Mr. Langley. In some areas ninety percent of women with fetuses who have Down syndrome choose abortion. And I recognize that you would have preferred to terminate if given the chance. I wish our tests were perfect. All of the prenatal tests that screen for Down syndrome came back normal for your wife. The ultrasounds gave no indication that Sophia had Down syndrome. I just reviewed your chart to make sure.”

Mr. Langley retorted, “Well, maybe the tests were right. Maybe Dr. Class is wrong.”

Ms. Langley added, “Is that possible?”

Dr. Class replied, “It is possible; we all make mistakes. I’m pretty sure Sophia has Down syndrome, but we do need to wait for the test results. The FISH analysis determines the number and types of chromosomes in her cells. People with Down syndrome have three twenty-first chromosomes. The FISH will provide a definitive diagnosis for Sophia. The results should be back in two or three days.”

Dr. Black interrupted, “Dr. Class has excellent clinical judgment. But we do need to see what the chromosome results show.”

Mr. Langley said, “If we had known we could have aborted, like most people do. Now our lives are ruined.”

Dr. Class responded, “This feels like the worst thing that could ever happen to you. You didn’t expect Sophia to face any adversities and now this. It’s quite a shock, isn’t it? “

“Yes it’s a shock. With all the technology, you’d think someone would have discovered it earlier,” Mr. Langley barked.

Ms. Langley quietly said, “John, Dr. Black said sometimes the tests are wrong. It’s not his fault.”

Mr. Langley answered angrily, “I don’t care if it’s his fault or not. Now it’s too late. We have no choice.”

Dr. Class paused, letting Mr. Langley reflect on what he was feeling. Then she responded, “Mr. Langley, it is okay to be angry. I hear that you feel boxed in, that you have no choice. I understand that it seems like your life is ruined. That is how many parents react. But many parents change their minds once they get to know their child. I hope that you will have a similar experience.

“Although many women terminate their pregnancies if they find out their fetus has Down syndrome, parents who unexpectedly deliver a baby with Down syndrome often ultimately consider him or her a blessing. Many parents of children with Down syndrome have reported that they and their families have benefited greatly from having the child.”

Mr. Langley countered gruffly, “That can’t be. How can they benefit?”

Dr. Class answered, “Parents find that their children with Down syndrome teach them a lot about their values and what’s important in life. They learn patience, tolerance, appreciation, kindness, and perseverance. And many parents have misimpressions about raising a child with Down syndrome. They describe

how their children bring pleasure and love into the home. Sophia will love you, appreciate you, dance with you, sing with you, and make you laugh. If you would like to read more about raising children with Down syndrome, you can find loads of books written by parents of children with DS who appreciate, admire, and love their children with Down syndrome (Van Riper 2007, 117). I will also lend you one or two of the better books."

Dr. Class turned to Ms. Langley, "What about you, Ms. Langley? How are you feeling?"

Ms. Langley spoke up. "I too think it's awful that Sophia might have Down syndrome. We definitely would have aborted if we had been aware. But shocked or not, Sophia is our daughter. I don't want her to have Down syndrome, but she's here. We can't give her back now. And I don't think I'd want to. I never wanted a child with Down syndrome, but it looks like we may have one. Our life is about to change drastically."

Dr. Class responded, "It's hard to accept that things are unlike what you planned. And it's normal to be angry, upset and in shock. But, Ms. Langley, your attitude will help you. Just remember that everyone copes differently with stress. Have you two lived through a stressor like this before?"[85]

"No."

"Well, everyone deals with stress in their own way. It's important to recognize that and to appreciate that in each other. There is no right or wrong. It's important for the two of you to talk to each other about your feelings, how

[85] The wording of this question implies that the stressor of having a child with DS is similar to other life stressors rather than a distinctive catastrophe unlike any other.

you're doing, and what you're thinking. You'll each cope in your own way. It's best if you listen to and support each other, even if you think your way of managing is better. It's important for the two of you to be on the same team. Sophia needs you both."

Dr. Class allowed a minute for them to think about what she had counseled. Then she asked if they would like to speak with the chaplain or social worker. They might want to bring their religious leader to the hospital. Dr. Class would be glad to speak with her. And Dr. Class offered them a referral in case they wanted to speak with a counselor.

Then she asked them, "Have you had enough for today or do you want more information about Down syndrome?"

"Definitely more information," responded Ms. Langley.

Dr. Class was not sure Mr. Langley could take much more, but when she looked at him, he nodded his head in agreement. Therefore she asked Ms. Langley, "What more do you know about Down syndrome?"

Ms. Langley responded, "They are mentally retarded. And they have a lot of medical problems, don't they?"

Dr. Class said, "People with Down syndrome do have cognitive disability, meaning that they have some learning and comprehending difficulties. I use the term *cognitive disability* because disability specialists tell me that the term *mental retardation* is now considered inaccurate. The thought is that Sophia is not slow (or retarded), but she learns another way. However, Sophia will learn and will develop. She'll just do so on her own timeline. The degree of cognitive disability varies among children with Down syndrome. Two boys with Down

syndrome even wrote a book about their experiences. Many adults with Down syndrome have jobs and get married. There are a number of medical disorders that occur more frequently with Down syndrome. But before I get to those, I'd like to tell you about some of the things children with Down syndrome can do. Is that okay?"

Ms. Langley answered, "Of course."

"Well as I told you, children with Down syndrome learn and develop. That means you will see developmental progress with Sophia every step of the way. She will smile.[86] She will roll over. She will sit up. She'll crawl, walk, and talk. She'll say her ABCs. But she'll do each when she's ready and in her own way," Dr. Class continued, watching the first signs of a smile on Ms. Langley's face since the beginning of the conversation. "And we can't predict when that may be, just like with all other children.

"Sophia is dependent, needy, lovable, and cuddly. She will become her own person, with her own personality, her own abilities, and her own talents. She, like most children, will also tax your patience, create chaos in your family, throw tantrums, and make you wonder why you ever had children." Dr. Class ended with a wry smile.

Dr. Class and Dr. Black allowed the silence that followed. They could see the Langleys digesting her comments.

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[86] Informing the Langleys of what Sophia *will* do—instead of what she *will not* do—is vital to this script. With such specificity of positive and expected developmental steps these new parents can imagine Sophia in familiar ways. It is the lack of an imaginable life script about people with disabilities that so unhinges people.

Mr. Langley would not look up. Ms. Langley asked about the medical conditions Sophia might have.

"A bunch of health situations can be associated with Down syndrome. That doesn't mean she will have these ailments; it means she has a higher chance of experiencing them than a child without Down syndrome. I'll only mention the ones that we have to worry about right now.

"About half of babies with Down syndrome have heart disease. I don't hear a murmur, but we'll watch her closely. If the tests confirm that she has Down syndrome, we'll get an ECHO, an ultrasound of her heart, to evaluate her for heart conditions. The other major health issues we worry about in the newborn period are intestinal disorders, obstructions of the gut. So far, Sophia seems to tolerate her feedings and has frequent bowel movements; that makes me hopeful she doesn't have any intestinal blockages. We'll have to wait a few more days to know for sure.

"Sophia does have a high white blood cell count and low platelet count, which is often seen in babies who have Down syndrome. White blood cells fight infection; platelets help with clotting. I will follow her cell counts every day for now and make sure they stay within acceptable boundaries. I do not expect a problem, though."

Ms. Langley, with a worried look, posed the question, "What if they go out of the boundaries?"

Dr. Class said, "We can give her platelets if her platelet count gets too low. I doubt that her white blood cell count will get too high. We will address that if we have to."

At the end of this discourse, Ms. Langley was crying. Dr. Class offered her another tissue and placed her hand on her shoulder. Mr. Langley looked at his feet.

Dr. Class waited a minute or two, and then asked, “Ms. Langley, are you breastfeeding Sophia?”

“I tried after she was born, but she didn’t latch on.”

“Many babies don’t latch on right away. Sophia has not gained all of her muscle strength yet. So, she may have a hard time. Don’t worry. She can bottle feed or feed through a tube, if necessary, until she gets stronger. She won’t starve. Still, your breast milk provides the best nutrition for her. If you pump every two to three hours, you can feed her your breast milk.”

“I already started pumping.”

“That’s great. It really does make a difference for Sophia. Before we go, I have some information for you.” She handed Ms. Langley a sheet of paper and said, “These are the names, web addresses, and numbers of some organizations that assist families of children with Down syndrome. You can meet other parents, if you’d like. You can discover a lot about the lives of both children with Down syndrome and their families from some of these parents. Of course, you must keep in mind that Sophia is an individual and will not have the same story as any other child with Down syndrome. However, you may find the connection and other stories helpful. Is there anything more you’d like to hear from me or Dr. Black right now?”

Ms. Langley asked Dr. Class what they should do.

Dr. Class again looked at the Langleys with a compassionate expression. She suggested that they spend as much time as possible with Sophia. She encouraged Ms. Langley to continue to try to nurse Sophia. Regardless, she should pump her breasts every two to three hours. She said, "I know this is hard for you. But Sophia needs you to be the good, loving parents you've been planning to be.[87] Let's wait for the test results. It'll only be two or three days. I'll see you again tomorrow and we can talk again. If there's a burning question before then, ask the unit clerk to contact me. Is there anything else I can do for you now?"

"No," answered Ms. Langley. Mr. Langley looked away.

"Fine," responded Dr. Class. "Everything is going to be okay. Dr. Black and I are available to you. You can contact Dr. Black at his office. To reach me, call the NICU desk and they'll put you through. I'll see you briefly tomorrow, but let's have a conference again in two days, before you're discharged. I should have Sophia's test results by then. If you would like to bring along family members, friends, medical staff, or a clergy person, please do."

Mr. Langley spoke up, "We will speak to you alone. Anyway, I'm sure the tests will show Sophia doesn't have Down syndrome. I just don't believe she does. Let's see what the tests show. Doctors can be wrong too."

Dr. Class agreed, "You are right. Doctors can be wrong. Let's see what the test results show."

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[87] This comment shifts the focus from Sophia as an alien object by placing her in a familial relational context. It encourages bonding with Sophia, who is a particular distinctive recognizable individual living in this world, rather than an abstract ("normal") ex-fetus.

After Dr. Class and Dr. Black left the room, Sophia's parents were terrified. The responsibility of a new baby and the many tasks to learn were frightening enough. The thought that their baby would have cognitive disabilities was crushing. Ms. Langley felt overwhelmed. And what if Sophia had heart problems? Would she live? Maybe the doctor was wrong. But if Dr. Class was right, she knew she would cope. Mr. Langley, though, was angry; but somehow he did not feel as angry as he had earlier. Still, he had not agreed to parent a child with DS. The doctors just had to be wrong.

Their next thoughts were about what to tell their friends and family. They expected many visitors over the next few days. They did not want to see them. They did not want to talk to anyone. They just wanted to go to sleep and wake up in a few days to find out that this had all been a bad dream. Anyway, how many times had they heard stories of doctors giving the wrong diagnosis? They had not noticed the traits in Sophia that Dr. Class had talked about. She was beautiful. Sophia did not nurse strongly or long enough. But many babies do not latch on at first. Still, Mr. Langley was sure she was "normal." Dr. Class was probably mistaken, he thought.

During the two days between meetings, Ms. Langley spent a lot of time at Sophia's bedside. Mr. Langley was at the bedside for about half of her feedings. Sophia's nurses reported to Dr. Class that Mr. Langley was in deep denial; Ms. Langley waffled between denial and acceptance. Dr. Class prepared for a long, difficult conversation.

Forty-eight hours after their first conversation, Dr. Class received the call from the lab that Sophia had Down syndrome. She saw the Langleys at Sophia's

bedside. With a caring facial expression and empathetic body language, she informed them that she had received Sophia's chromosomal test results.

She suggested they move to a private conference room. Sophia's nurse, the NICU social worker, and the Langleys followed Dr. Class to a private conference room. On the way, Dr. Class requested that the unit clerk hold her phone calls to ensure undisturbed privacy.

In the conference room the Langleys sat together on a couch. Dr. Class and Sophia's nurse sat across from them. The social worker sat on a chair next to Ms. Langley. Dr. Class began, "I am quite pleased with the way Sophia eats. The nurses tell me that she takes some of her bottle each feeding and that you're pumping plenty of breast milk, Ms. Langley. And Mr. Langley, I understand you fed her half of her bottle. I'm so glad things are going so well. But before we get into that, I think you want Sophia's test results."

The Langleys both looked up at Dr. Class apprehensively. Dr. Class saw the tension in their faces and shoulders.

Dr. Class continued, "Sophia's test results confirm my observations. She does have Down syndrome. You are a very lucky family to have her."

The Langleys were shocked. They had hoped Dr. Class was mistaken; Mr. Langley had been so sure that she was wrong. Looking downward, he folded his hands around his head. Ms. Langley started to cry. Dr. Class handed a tissue to Ms. Langley and gave them some time to absorb her words.

Mr. Langley broke the silence. "Are you sure? Maybe the test is wrong."

"The test is rarely wrong," Dr. Class responded gently. "Sophia has Down syndrome."

Mr. Langley felt devastated. He felt his anger boiling up again. He did not know what to do. He wanted to run out of the room and never come back. How could he live with a Down syndrome child? But Sophia was sweet; he had sort of started to love her. But he was going to have to protect himself and cut off those feelings now that he knew.

Ms. Langley was surprised that she did not feel as bad as she had expected. She was upset and scared, but more for Sophia than herself. After all, Sophia was her baby. She already loved Sophia. And she would do what she needed to make Sophia's life the best possible.

After a long pause, Dr. Class asked the Langleys how they were feeling.

Ms. Langley answered first, "I'm sad. I never wanted a baby with Down syndrome. We had so many plans. But mostly I'm worried about Sophia. I'm afraid she will die from a heart problem. And if she lives, I'm afraid her life will be so hard. She'll be teased and excluded from activities. I'm not sure I'm up to this."

Leaning toward her, Dr. Class looked caringly at Ms. Langley. "I realize that you're scared. It's a big job being a parent. And frequently parents find it more challenging to parent a child with Down syndrome. But, I have no doubt you are both up to the job. She's a lucky little girl to have the two of you."[88]

Mr. Langley appeared surprised. "Maybe Janet is up to the task, but I am not. This is awful. I never wanted a child with Down syndrome and I still don't. I wanted a daughter with whom I could ride bicycles and go on nature hikes to

[88] This is a continuation of how the script shifts focus from the individual infant with a medical diagnosis to a baby in a relationship with her parents. No child turns out the way a parent imagines because our imaginations are limited. Every person surpasses the narrow picture others have of her. Often it is the parents that best know about the strengths and abilities of their children as they grow.

teach her about the ecosystem. And I dreamed of her discovering something important, making her mark on this world."

Dr. Class spoke compassionately. "It must be disappointing. You had this dream of who your daughter would be. Now you have someone else. You have to take time to mourn that other baby. And you have to take time to form a relationship with Sophia. But, you never know. She just might ride a bike someday. And she might like to take a walk in the woods with her daddy, discovering diverse animals and plants; and some other baby you thought you wanted might not. And she will contribute to this world—and to the lives of everyone she meets—in ways you cannot even imagine."

Mr. Langley looked surprised. He asked, "What do you mean? Contribute?"

Dr. Class said, "Well first of all, lots of people with Down syndrome have jobs. She may not have the talents to get a PhD in microbiology or become a constitutional lawyer, but neither do I. What I was referring to is the way people with Down syndrome help people to understand that we all have abilities, but they are diverse and unpredictable. She will take you on an amazing journey. One you never would have gone on without her."

Quiet ensued.

Mr. Langley broke the silence and probed: "Really? An amazing journey? Where? To the land of mental retardation?"

"Mr. Langley, my first patient with Down syndrome made an indelible mark on me. Though I took care of him 30 years ago, I remember him and the conversations we had. I recall how much I liked him; I value his appreciation of me, even to this day; I remember how he made me laugh; and most of all, I

treasure the transformation in my attitude about people with cognitive disabilities. He changed the way I practice; how many people have that type of effect on others in their lifetime?"

Mr. Langley pondered Dr. Class' words.

Ms. Langley broke the silence. "What I'm really worried about are the medical problems associated with Down syndrome. Does she have heart disease? Or all those intestinal problems? Or leukemia?" asked Ms. Langley, appearing more fearful now.

Dr. Class responded, "I see you've been reading. Sophia does not have leukemia. We confirmed that by checking her white blood cell count. She doesn't seem to have any intestinal blockages: she keeps your breast milk down, and she has bowel movements. As for her heart, I heard a heart murmur this morning and the cardiologist will see her today. She'll do an ECHO, an ultrasound of her heart, to determine if Sophia has heart problems. About half of children with Down syndrome have heart disease from birth."

Ms. Langley asked if Sophia could die from heart problems.

Dr. Class replied, "I can't say for sure what type, if any, Sophia may have. First, let's get the results of the ECHO, and then we can talk more about Sophia's prognosis. I can tell you that some heart problems require medical treatment; others require surgical treatment. We'll have to wait and see."

Ms. Langley said quietly, "I hate for her to have to go through heart surgery. She's so tiny."

Dr. Class responded, “She is tiny. But we do heart surgery on even tinier babies than Sophia. First, let’s get the ECHO before we talk about heart surgery. What else are you worried about?”

Ms. Langley answered, “I read that she might have hearing problems and not be able to communicate.”

Dr. Class nodded. “A little more than half of babies with Down syndrome have some hearing limitation. That can certainly impact their speech. Again, that doesn’t necessarily mean Sophia will not hear. We’ll do a hearing test to check her hearing now, but she’ll need one again at six months and then every year. Some children with Down syndrome have speech and communication difficulties, especially when they are young. Using sign language with Sophia when she’s little will help. I actually think we all should know sign language. Then we could all communicate with deaf people, including older people (which most of us will be) with deafness acquired late in life. Anyway, with patience and hard work she will talk, even if she has some hearing loss.

“And remember, she’s developing on her own timetable. Just like every parent, you will get to see her attain milestones and rejoice with her: when she smiles, sits up, stands, and says her first word. You’ll feel pain when she gets frustrated or skins her knee. And you’ll get scared when she tries to run across a busy street. That’s all part of parenthood.”

Dr. Class could see that the Langleys were overloaded. She would leave the potential vision difficulties, frequent upper respiratory and ear infections, thyroid disease, cervical spine complications, obesity, and early Alzheimer’s disease to a

later discussion. They had plenty of time to adjust to all of the disabilities associated with Down syndrome.

Then Dr. Class inquired about what the Langleys understood of what she had told them. Together, they repeated most of what they had discussed. They appeared exhausted. She asked how they were feeling.

Mr. Langley retorted, “You keep asking. What is wrong with you? How do you think we feel?”

Dr. Class nodded to show her understanding and said, “You tell me. We’ve been talking about numerous issues, and feelings change. Some parents feel numb, others feel angry, others feel calm, others feel fearful, and others feel fearless; some feel sad, others feel happy, and yet others feel like they’ll deal with whatever comes their way. So, I’d like to hear from both of you. What are your greatest fears?”

Mr. Langley responded, “I’m upset. I’m overwhelmed. I’m angry. We could have avoided this. You keep trying to tell us the good things, but how am I supposed to believe you?”

Dr. Class replied, “Feeling upset, overwhelmed, and angry is not unusual. Your world changed two days ago.”

Mr. Langley said more quietly, “I just don’t think I can live with this. How can I face anyone?”

Dr. Class asked Mr. Langley, “For some families adoption is a choice. Is that something you are thinking about?”

Ms. Langley broke in, “No, John. We can’t put Sophia up for adoption. She’s our baby.”

Mr. Langley shook his head. “No. I suppose that would not be an option for us. She is our baby,” he said wearily.

“Mr. Langley, I’d like you to speak with a father of a four-year-old with Down syndrome. He felt exactly like you do when his son was born. He can answer a lot of questions that I can’t answer for you. It might give you a different perspective.”

Mr. Langley nodded his agreement.

Dr. Class went on, “Adjusting will take time. Just take one day at a time.” Then she turned to Ms. Langley, “How about you, Ms. Langley? What is your greatest fear?”

Ms. Langley replied, “I’m not sure. I don’t want Sophia to have Down syndrome, of course. But I feel like she’s my baby. I love her. I guess I am afraid I won’t be a good enough mother.”

Dr. Class told her that many mothers fear they cannot live up to the task of raising their baby. “You’ll learn how to take care of her. Just like you’ve learned to hold her and feed her. Just like every mother learns to care for her baby. I remember when I took my first child home. I was a neonatologist, but I had never nursed or bathed or tended my own baby. A new baby and the related changes to the family challenge every parent; most parents are unsure about the new experience and their ability to live up to the task. The silver lining of having your first baby in the NICU is having experienced nurses teach you how to take care of your baby. I’m not worried about your ability to care for Sophia. Just take things one day at a time.

"Sophia is sweet and cute, and she has many more qualities you haven't yet discovered. She will teach you much, just like every child teaches her parents. People with disabilities express satisfaction with their lives. It's often the people looking at them from the outside that claim that disabled people have a poor quality of life. She will have difficulties. All children can and will have difficulties; all people will and do. If you love her and care for her and work hard to fight for what she needs, Sophia will have a good life."

Ms. Langley asked what they needed to do for Sophia now.

"Well, how do you think Sophia is doing?"

Ms. Langley answered, "Sophia drinks some of her bottle very slowly. The nurses are teaching us a few tricks to make it easier for her. She has a harder time with breastfeeding. But I don't mind pumping. Then John can feed her."

"Oh! Mr. Langley, you've been feeding her?"

"We take turns. We both want to feed her."

Dr. Class said, "I'm so glad! She eats better than I expected, and you both get to feed her. Don't worry about the breastfeeding; she will get there." She also told Ms. Langley to keep pumping. Eventually, Sophia's muscle tone would get stronger and she might nurse. Until then they would work on bottle-feeding. And they would tube feed her when she could not finish her bottle.

"Keep up the good work," Dr. Class told them. "Spend time with Sophia while she is awake. You should kangaroo with Sophia and learn the basics of baby care. Having a baby in the unit is stressful for parents. You must take care of yourselves too: sleep enough, eat nutritiously, and persevere with your exercise. Those are all stress busters. You can even go out to a movie once in a while."

Dr. Class added, “We’ll get the ECHO and hearing test today. That will give you some more information. But your job right now is to get to know Sophia, and to love her.”

Dr. Class could see that the Langleys needed time alone. She would leave further discussion about Sophia and her advocacy talk for another day. With a gentle and caring smile, Dr. Class told the Langleys that she would give them time to absorb what she had said and talk between themselves, unless they had other questions.

Ms. Langley asked Dr. Class if she knew of any mothers of children with Down syndrome with whom she could speak.

Dr. Class smiled and invited the social worker to give the Langleys the phone numbers of a volunteer couple who could help. Then she reminded the Langleys that they could get in touch with her or the social worker if they had questions or concerns. Otherwise, she would see them again the next day.

The Langleys walked down the hall trying to hold on.

Chapter 7

Conclusion

My thesis presents a new, improved way for healthcare professionals (HCPs) to communicate with families of neonates recently diagnosed with Down syndrome (DS). This novel conversation arises from interweaving a disability perspective with the typical medical model of disability. Disabled people, disability advocates, and disability scholars have contributed to the disability viewpoint. I have selected the parts of their positions that seem necessary and appropriate to improve the care that HCPs provide for their disabled patients and patients' families.

The first five chapters of my thesis provide background information for the heart of my thesis, a new, ableist-free conversation for HCPs to have with parents when informing them that their newborn has Down syndrome. Throughout this thesis, I have outlined multiple arguments for a change in language, attitude, and content in discussions with families of infants with DS (and with families and patients of disabled people in general). In this chapter I review the previous chapters and summarize my arguments, detail some of the implications of this work, and finally lay out the future directions I foresee.

Summary and Arguments of Thesis

Chapter 1 introduces a number of concepts that underlie the thesis, including the methods I used, a discussion of ethical issues in neonatal care, a brief overview of Down syndrome, and a review of both the medical model and multiple variants of the social model of disability.

In chapter 2, I present a practical and ethical review of decision making about withholding or withdrawing life-sustaining treatment (WWLST) for extremely low birth weight neonates. I explain the ethical concept of the Best Interests Standard and its advantages. Then I argue against it. Next, I show how uncertain prognoses, physicians' variability, parents' biases, and parents' variable knowledge of their values and beliefs create circumstances that affect whether the decision made by parents actually aligns with the best interests of the disabled infant. Thus, critical life decisions made by parents and physicians for neonates may actually harm rather than benefit the infant.

Next, in the "Disability Ethics" chapter, I investigate different aspects of disability studies to furnish the reader with a general understanding of this field. Those with medical, but not disability, backgrounds may find the viewpoints of disability advocates and scholars difficult to fathom at first. These ideas form the underpinnings of the disability perspective. Without at least a superficial comprehension of these concepts, HCPs may find the changes I am recommending to their conversation with the families of disabled patients enigmatic.

Thus, chapter 3 addresses the following topics regarding disability:

1. The devaluation of disabled people by calling them abnormal
2. The eugenics history that has victimized and still victimizes disabled people
3. The cultural disability notion—that the meaning of disability arises from the culturally-specified otherness of bodies and minds
4. The social-relational model of disability that attributes some of the effects of impairment as well as the social, physical, and economic environment to disability

5. The medical model of disability's effect on disabled people
6. The good quality of life that many people with disabilities have, but which HCPs may not recognize
7. The lived experience of people with disabilities

Together, these elements comprise the basis for understanding why and what HCPs must learn about the arguments of disability advocates.

I argue that calling others, including patients, "abnormal" extends the embodied differences to their entire life. Envisioning the disabled person as his disability does not allow for his abilities. When HCPs start comprehending some of these disability concepts, they may be motivated to take on the challenges about which some disabled patients complain:

1. The tendency for HCPs to try to treat or cure with procedures that may do more harm than good
2. The fear that HCPs participate in eugenics by recommending abortion for disabled fetuses
3. The psychological damage done when the medical system just expects disabled people to accept a life of discrimination
4. The fact that language matters
5. The concept that the medical model creates negative attitudes among HCPs toward persons with disabilities.

In chapter 4, I describe the standards of best practice of giving bad news. This chapter provides the background for the ways I develop the two scripts about how physicians should talk to parents of children recently diagnosed with DS. This allowed the two neonatologists in my two scripts to engage in current best practices

for giving "bad news" to parents. In this way, the comparison between the two scripts relates to ableism and disability awareness, the focus of this thesis.

Chapter 5 expounds upon language as a conveyer of ableism. I relate much of the discussion of language's implications to scholarly work on language in sexism and racism. This chapter emphasizes that slurs, language usually used for the purpose of devaluing and demeaning an "other" group, do real harm. Victimized groups define language preferences and slurs. Many derogatory words that describe disability arise from the medical model and are one more reason that HCPs must lead the way in changing the words we use, as well as their approach to treatment for and their attitudes about their disabled patients, in making a better world in which disabled people live.

The central part of my thesis, chapter 6, consists of three parts: (1) an "old" script showing how HCPs typically talk to parents of children newly diagnosed with DS, (2) an analysis of the *old script* using the topics covered in the previous chapters, and (3) the *new script* incorporating disability awareness into the conversation. This script represents the benefit to patients when the social model infiltrates the medical model.

Implications

This thesis describes a new way to inform and converse with parents about their infant who has Down syndrome. This new discussion offers potential benefits for the children, the parents, and the HCPs. It creates a new manner of thinking for HCPs, a method that should spread to parents and their disabled children, as well as to society at large. Also, this difference in attitude will ideally expand and begin to

apply to children with other disabilities beside DS. I discuss three key implications of my thesis in this section.

First, this thesis has identified problems with current conversations that resemble the old script. Through learning a new way of having the conversation, HCPs will hopefully realize that they should do the following:

1. Rid their dialogue of slurs and other language not preferred by disabled people
2. Discuss the positive aspects of a specific disability, not only the negative
3. Leave their attitudes toward disabled people (whether positive or negative) out of the conversation
4. Recognize that a disabled child is not his disability
5. Rid the conversation of ableism
6. Inform the parents of the advantages (as well as the disadvantages) that families with disabled children recount
7. In sum, HCPs must educate the parents about their child's diagnosis—the good, the bad, the ugly, and the beautiful.

Using this new discussion, HCPs may learn more about their disabled patients (as well as their nondisabled patients). They may recognize that disability does not necessarily entail an unhappy, unable, or incapable life. They may realize that disabled children are not necessarily "abnormal." And they may begin to appreciate that good things can come from both having a disabled child and being a disabled child. These new attitudes of HCPs may, in turn, make future conversations easier and more helpful.

In addition to allowing HCPs to learn more about their patients, this new way of communicating may benefit parents, which may indirectly benefit patients. By paying attention to parents' reactions to the information that their child has DS, the physician may be able to address the positive and/or negative feelings the parents express. This may promote increased trust and a better relationship between the HCP and the parents. The physician may help the parents obtain a more balanced grasp of their disabled child by

1. using nonableist language;
2. exhibiting a positive, or at least neutral, attitude toward disability;
3. discussing potential abilities as well as disabilities; and
4. imparting a possible vision of the child as he grows (learning, laughing, walking, talking, working, marrying).

This information may increase understanding and accelerate bonding, both important processes for parents in accepting their child with DS. If HCPs use an accepting, encouraging tone to help parents see their child as an individual, they may lessen confusion and hardship, augment understanding, and help families cope better. When parents start with a less agitated, more educated introduction to the world of disability, their child has the chance for a superior start in life. In this way HCPs may facilitate the parents' parenting skills, optimize the infant's potential, and kindle the best family situation in which the child can develop.

Finally, this thesis guides HCPs in a more ethical practice for their disabled infants. The new script increases beneficence by supporting parental bonding with their child, encouraging acceptance and understanding of their child with DS, and potentially enhancing the infant's life. In addition, this preferred script fosters

nonmaleficence by introducing the child into a less ableist environment and educating his parents in the best ways to care for him. The new script also promotes justice by helping to establish a less discriminatory atmosphere. And finally, HCPs cultivate respect for autonomy for the neonate through the parents by viewing the best interests of the child from a different vantage point.

Thus, this new script, by increasing the healthcare professional's understanding of the lived experiences of neonates with DS, advancing the benefits of a transformation in the conversation, and improving the ethical practice of neonatologists, will not only enrich the world for children with Down syndrome, but for all disabled people—and all people.

Future Directions

This thesis has raised many questions for me. These uncertainties take two forms: what I do not know but want to learn and what I thought I knew but have found I do not. The first has me reading and writing more about disability studies: I have spent a career learning about ethical issues in neonatology, but only a short time learning about disability perspectives. I have more to discover. But more than that I have more to ponder: my understanding of the normalcy argument; my thoughts about using *severe* and *profound* and the expected quality of life associated with such labels; and the role of racial and socioeconomic factors in raising disabled children.

Aside from my own educational needs, this thesis has provided me with enough future work to fill the rest of my days. First, I plan to publish papers in both bioethical and pediatric journals. They will incorporate the old and new scripts as

well as disability ethics and medical/social model analyses, as appropriate for each intended journal. Next I plan to write and publish the two additional chapters I had originally planned for this thesis: HCPs speaking with parents of deaf children who were recently diagnosed and "profoundly" disabled infants. And then I hope to publish a book of the combined writings.

I also have plans to start a community project with Jennifer Sarrett who recently received her Ph.D. in disability studies at Emory University and currently works at the Emory Center for the Study of Human Health. We propose to develop referrals for families of people with multiple types of disabilities so that HCPs, including social workers, will have the capability to provide resources for information not as readily provided by medical staff. We plan to create a listing of organizations and online and local support groups as well as establish a network of parents of children with disabilities willing to speak with parents of children with similar disabilities.

My third goal is to develop a discourse between HCPs, bioethicists, and disability studies scholars. I expect I will accomplish this by means of

1. journal articles
2. presentations and workshops at national (and international) pediatric, bioethics, and disability studies conferences
3. the classroom for teaching bioethics to medical students, residents, fellows, and bioethics and disability studies graduate students at Emory University and
4. and bedside teaching for medical trainees and professionals.

To aid interdisciplinary discourse, I would like to apply the concepts and techniques of conflict resolution to the conversation. Having taken a four-day

workshop at the University of Pennsylvania School of Medicine with Autumn Fiester and Edward Bergman, I recognize the advantage of using such a technique to encourage people who do not understand each other and have very different values, beliefs, and goals to come to some type of compromise.

Writing, speaking, and presenting workshops will start the conversation about disability. Bioethicists, who frequently train in the medical model, often think from the medical model perspective of disability. Of course exceptions exist: Adrienne Asch and Erik Parens immediately come to mind. But bioethicists can do more to look at the advantages and disadvantages of disability in cultural, environmental, and moral contexts. This could include exploring the role of "impaired embodiment" (Scully 2008a, 9, 154) and considering the physical realities of a disabled life. Bioethicists should investigate the views about quality of life among disabled people and their families. Bioethicists should study whether any levels of disability are incompatible with a good quality of life; at what point, if any, does disability make limitation of life-sustaining treatment preferable to continuation for all patients?

In these ways bioethicists can delve into some of the currently acceptable practices of HCPs that in actuality create morally problematic situations for themselves or their patients. This potential stems from medical professionals' and bioethicists' ignorance regarding the lives of disabled people. By learning about these experiences, bioethicists will discover what is ethically acceptable or unacceptable in terms of quality of life and determine permissible interventions for disabled newborns or disabled patients of any age.

Finally, while doing this thesis, I have thought of multiple possible research studies to carry out in the next few years. One such study would follow the children

and families of parents who did not opt for forgoing life-sustaining treatment and comfort care when given the choice. I would investigate the child's outcome and the parents' preferences and attitudes at different stages after the decision-making conversations. Other areas of possible investigation include a study of attitudes toward disability among parents of fetuses and neonates. The assessment would occur prenatally and at multiple times postnatally. Finally, I would like to study disabled adults who have a deep-seated anger toward the medical care system because of years of suffering at the hands of HCPs. The study would evaluate their attributable causes for the anger (for example, pain, suffering, unnecessary procedures, necessary procedures, benefit and harm, no benefit but harm, etc.) and their preferred experiences. Clearly, many more studies are needed to figure out how to best care for disabled babies.

This thesis has generated more questions than answers.

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