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Surgically Shaping Children

Technology, Ethics, and the Pursuit of Normality

Edited by

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To my parents,
Rachel and Henri Parens,
who balanced shaping and letting be
as well as any child could wish
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This volume explores the ethical questions that arise when surgery is used to make children look more normal. It grows out of The Hastings Center’s Surgically Shaping Children project, which is, as it were, the child of two other Hastings Center projects I have had the privilege to direct.

The first of those projects, on prenatal testing and disability rights, took up the ethical questions that emerge when we selectively abort fetuses shown by prenatal genetic tests to carry disabling traits (Parens and Asch 2000). More specifically, that project (funded by the Ethical, Legal, and Social Implications of the Human Genome Project [ELSI] program at the National Institutes of Health) investigated the disability community’s critique of such testing. While the project gave me a deep appreciation of that critique, it also gave me an appreciation of just how heterogeneous are the disabling conditions we can test for (from Tay Sachs to extra fingers)—and of just how difficult it can be to make useful generalizations about “disabling conditions.” In addition to making me want to continue to engage the disability community’s arguments, that project made me think it would help to narrow the focus and begin to investigate particular cases.

Thus, our Surgically Shaping Children project (funded by the National Endowment for the Humanities) took up three cases, which are themselves heterogeneous. The first case involves surgeries to make children’s ambiguous or atypical genitalia look more normal; many adults with such atypical anatomies refer to themselves as intersexed. The second involves surgeries to lengthen the legs of children who have achondroplasia; adults with achondroplasia refer to themselves as dwarfs or Little People. Originally, I thought that our third case would consider surgeries to make the features of children with Down syndrome look more normal. Because it turns out that fewer and fewer of those surgeries are being done, however, we decided to concentrate on another set of craniofacial surgeries: those done on cleft lips and palates. Though I didn’t know it at the time, as I explain below, going from a controversial to a non-
controversial class of surgeries would turn out to complicate—and thereby deepen—our reflections. For that change in course, I am deeply indebted to Dr. Wendy Mouradian, a member of our project’s working group.

The other “parent” of the Surgically Shaping Children project was our Enhancing Human Traits project (also funded by the National Endowment for the Humanities), which explored the ethical debates that surround efforts to use medical technologies to improve human traits and capacities (Parens 1998). Surgical breast enlargement was one of the classic examples circulating in the background of the project. Another was the use of Prozac to improve normal moods—or, in Peter Kramer’s famous phrase, to make some people feel “better than well” (Kramer 1993). Indeed, we often spoke in that project as if the central question was, What are the ethical costs of various efforts to make us better than normal? But that formulation of the project’s central question, with images of shallow and greedy social climbers in the background, failed to identify what I now see as that project’s primary concern.

That concern was not about persons pursuing frivolous ends or unfair social advantages, as real and important as those concerns may be. It was about pressures on persons to transform the bodies—and thereby the selves—they were thrown into the world with. From that angle, giving tall girls hormones to slow their growth was and is every bit as worrisome as giving short boys hormones to enhance theirs. In one formulation, the worry was about individuals becoming different from who they really were—or, as some would put it, “inauthentic.”¹ As Carl Elliott saw before I did (Elliott 2003), my fundamental concern was about how we are using these technologies to transform human identities.

The Surgically Shaping Children project brings that concern about using technology to transform identities front and center. We weren’t talking about advantage-seeking social climbers. Instead, we were talking about parents and children, who hoped that more normal appearance would improve psychosocial functioning. They hoped that transforming children’s bodies could transform how those children are experienced by, and thus experience, others and the world.

Moreover, insofar as this project was about children, it forced me and the working group to face one of the deep tensions at the root of many if not all of the debates regarding what we might call “self-shaping technologies.” Parents have two fundamental obligations. One is to let their children be, to let them unfold according to their own desires and capacities. The other parental obligation is to shape children, to promote their flourishing or psychosocial functioning.

 Whereas during our Enhancement project I could forget or ignore the obligation to transform ourselves in some circumstances to achieve some ends, I could no longer forget or ignore it in our Surgically Shaping Children project. No matter how firmly
we believe in the obligation to allow our children to unfold in their own way, we cannot ignore our obligation also to shape them.

This book explores that tension between the obligations to let children be and to shape them. Given the depth of that tension, and given the heterogeneity of the facts of the different cases, at the end of the day, our Surgically Shaping Children working group could agree on only one unsurprising but nonetheless important conclusion: based on respect for persons, individuals (whether children alone, parents alone, or children and parents together) must be helped to make truly and fully informed decisions. But at the beginning of the day, all those involved in making such decisions, especially parents, need to be helped to reflect on what life with atypical anatomies is—and is not—like. And they need to be helped to explore that fundamental tension between their obligation to shape their children and their obligation to let their children unfold in their own way. This book aims to promote such “beginning-of-the-day” reflection. The ideal of truly informed decision making is as easy to invoke as it is difficult to achieve.

The Structure of the Volume

Our project pursued three intertwined strands of inquiry, each of which can be glimpsed in the phrase surgically shaping children. Most generally, we were interested in the large conceptual, ethical, and social issues that arise when we use technology to shape ourselves, to make ourselves look more normal. To help us from straying too far from the world of flesh-and-blood persons making life-altering decisions, we limited our conversation to one mode of technological shaping: surgery (as opposed to, say, pharmacology or genetics). In another effort to keep us from straying too far, we limited ourselves to talking about surgeries that arise when the potential patient is a child. Thus our attention to the surgical shaping of children.

All three of those strands are visible in each of the four major parts of the book. Part I offers narratives from people whose views about appearance-normalizing surgery grow out of their experience as a person with (or parent of a person with) an atypical anatomy. Going from the particular to the general, Part II offers broader theoretical reflections on the meaning of using technology to fulfill our desire to look more normal. Part III provides reflections about the surgical context from medical professionals involved in the delivery and improvement of surgical care. The final part offers reflections and ultimately practical advice about how parents, children, and medical professionals can improve decision making about appearance-normalizing surgeries.

In the spirit of affirming a wide variety of ways of being, this volume includes es-
says in a variety of formats: from personal narratives and scholarly essays to those about the need for new data and about how to promote truly informed decisions. The contributions are not only written by people with a variety of lay and academic backgrounds, but by people with different perspectives: from those who are highly skeptical about the value of appearance-normalizing surgeries to those whose livelihoods depend on delivering such surgeries. For all of their differences, all of the authors are ultimately grappling with the same basic question regarding the ethical and social implications of surgically shaping children.

Part I. Personal Narratives about Appearance-Normalizing Surgery

When we began our project, I asked surgeons who try to normalize the appearance of children with atypical genitalia to put me in touch with persons who were glad to have had the surgeries. I was told that such people had moved on with their lives and had no desire to draw attention to an anatomical difference that no longer existed. Although that account is surely plausible, surgeons themselves are increasingly aware of the need to collect data to support it (Sytsma 2004).

As Alice Dreger, Cheryl Chase, and the Intersex Society of North America have amply and painfully shown, however, myriad children born with atypical genitalia who have had such surgeries are outraged and do want to talk. Many of these now-grown children have already written eloquently not only about how those appearance-normalizing surgeries deprived them of sexual sensation, but about the agonizing psychological pain caused by the secrecy and shame that have attended their surgeries (Dreger 1999).

Indeed, children with intersex conditions can suffer the excruciating consequences of secrecy and shame even when they are not subjected to surgeries aimed at making their genitalia look more normal. Sherri G. Morris, author of the first essay in this collection, was born with an intersex condition called androgen insensitivity syndrome. She was raised and always experienced herself as a woman, but didn’t find out until she was in law school that she had been born with a male karyotype (XY) and male gonads (testes). Even though Morris was not subjected to the sorts of appearance-normalizing surgery that have deprived many intersexed people of sexual sensation, she did have surgery as an infant to remove her testes. When she entered puberty, she was told that surgeons had removed her “twisted ovaries.” As Morris observes, it was not the physiological effects of androgen insensitivity syndrome that caused her suffering. Rather, it was “the realization that I had been told lies by those from whom I had a right to expect the truth—my parents.” Secrecy, silence, lies, and shame produced suffering so great that she considered suicide.
To her great good fortune and the reader’s, Morris found out the truth about her condition and, as we’re often told it can, it set her free. Her message resonates throughout this volume: if children with atypical bodies are assured of their caretakers’ unconditional love, if those children are helped to understand the facts about their bodies, and if, whenever possible, they are included in decisions about the treatment of their own bodies, they will be fine.

Unfortunately, even when families intend to express unconditional love, they don’t always succeed. In her essay, Cassandra Aspinall writes as a person affected with cleft lip and palate, as the parent of an affected child, and as a social worker who helps families manage the care of children with craniofacial differences. Aspinall describes what it was like to learn from her own grandmother that she was “different”—and that that wasn’t okay. When she was four, Aspinall sat on her grandmother’s lap and tried to interpret her palpable sadness:

[My grandmother] wanted to tell me it was okay that I was different. She traced her finger over the upper line of my lip and began to talk about the fact that my lip was not like most people’s, but that that was okay. She told me that because my upper lip already had what was called a Cupid’s Bow, I would not have to “paint on” that sort of look the way she did with lipstick. I remember I had trouble understanding what she was talking about. She seemed upset, but I didn’t know why. I wanted to make her feel better, but I didn’t share her sadness about my face or myself.

In hindsight, Aspinall sees that her grandmother was sad at the thought of her granddaughter being rejected by others. Perhaps her grandmother worried about her prospects for finding love. Though her grandmother was worried about the harmful and wrongful reactions of others, Aspinall got the impression that something was wrong with her. As she writes, “It is strange that [my grandmother’s] desire to protect me from harm had the unintentional consequence of making me feel bad, of actually causing me harm.”

Thus Aspinall approaches one of the project’s core questions: What are the costs to the child when the surgery’s primary purpose is not to make the child feel better, but to make others feel better about the child? Should an affected person who feels fine about her body change her body to make others feel better? To her credit, Aspinall does not ignore the respect in which how others feel about us affects how we ultimately feel about ourselves. But she makes vivid the respect in which the surgeries we were talking about were done more for others than for the children whose bodies were being altered. She never shies away from the complexity of these questions. She does not argue against parents deciding for their children in all cases. Indeed, she says explicitly that she has never regretted that she received primary cleft lip surgery, even
though that surgery was not about repairing physiological function, but was about improving her appearance (and thereby her psychosocial functioning). And she wants to invite us to think about whether anatomically typical persons should change their views rather than requiring anatomically atypical persons to change their bodies.

If there is increasing agreement that parents should not decide for children about surgeries to normalize atypical genitalia and widespread agreement that in our imperfect world parents should decide for children about primary surgeries to repair cleft lips and palates, the nature of the agreement about surgeries to normalize short limbs falls somewhere in between. In most cases, there are medical reasons to wait until the child is almost in her teens before doing these surgeries. Even if there were not, however, given the trade-offs, reasonable parents would wait for their child to be old enough to share in the conversation about the surgery.

Or so Emily Sullivan Sanford suggests in her essay. When she wrote the story of her life before, during, and after surgeries to lengthen her short arms and legs, Sanford was still a college student. With honesty and insight, she gives an account of how, in spite of the pain and long-term undesirable side effects associated with the surgeries, she is glad to have endured them.

As Sanford’s essay makes clear, she comes from a family who loved her deeply and sought to support her in whatever decisions she made. As the essay also makes eminently clear, a huge part of why she can look back and be glad about the surgery she underwent is that she was allowed to decide for herself. That is, she decided for herself to the extent that any of us ever does. She does not imagine that we make decisions alone, and is perfectly frank about the fact that her parents invited her to consider the surgeries. But she draws a stark contrast between her own situation and that of children whose parents presume to choose for their children. She writes:

During one clinical check-up, I felt chills down my back and anger in my cheeks as I heard a mother confer with the surgeon about limb-lengthening for her 7-year-old daughter. “Children can’t make the decision of course,” she smiled, “they’re too young.” I pitied her daughter immediately because, although I was sitting in a wheelchair similar to the one to which she would also soon be confined, I had brought myself there.

Again, to her great credit, Sanford does not ignore any of the inconvenience, pain, or long-term physiological costs that attended her decision to have the surgeries. Nor does she seem to have any need or desire to deny that she was born with achondroplasia. As the title to her essay emphasizes, the surgeries did not change her shoe size.

From a young woman who decided with her parents for limb-lengthening surgeries, we turn in the next essay to a parent who, with her husband, has struggled with decisions about possible surgeries for their daughter. With marvelous frankness and
clarity, lawyer and documentary filmmaker Lisa Abelow Hedley writes about the depth of her desire that her daughter LilyClaire, who is a dwarf, appear more normal—and about the depth of her commitment to protect her daughter against “those marauding, seductive, and unattainable notions of normalcy.”

When LilyClaire is 7 years old, surgeons face Hedley and her husband with a difficult choice. Because they believe that LilyClaire is not old enough to decide for herself, Hedley and her husband engage in a sometimes excruciating process of deciding what is in her best interests. Specifically, they have to decide whether, in addition to subjecting LilyClaire to a surgery that will straighten the bowing in her legs (and thereby prevent cartilage degeneration), they will also subject her to an additional six months of treatment to lengthen her legs by 2 to 4 inches.

The goal of preventing cartilage degeneration is straightforwardly medical; it aims to promote what we might call normal physiological functioning. The goal of adding height, on the other hand, is primarily psychosocial. Of course, for anyone who rejects dualist conceptions of the relationship between the physical and the psychical (the body and the mind), the distinction between physiological and psychosocial aims is fuzzy. Improved physiological functioning usually has positive psychosocial effects, and improved psychosocial functioning can have positive physiological effects. It’s a continuous loop.

But in practice, in thinking about and choosing among interventions, parents and children make distinctions. Using fuzzy and unstable distinctions seems to beat the alternative of abandoning the effort to think critically about the options. In the end, Hedley and her husband decide for their daughter the question about the intervention to achieve the physiological aim. And they decide to let their daughter decide for herself the question about the intervention to achieve the psychosocial goal. As powerful as is “the seduction of the surgical fix,” she and her husband elect to wait to let LilyClaire decide for herself about the extra 2 to 4 inches.

Part II. Technology and the Pursuit of Normality

Philosopher James C. Edwards invites us in his essay to step far back and to reflect on the meaning of using technology to shape ourselves and our children. On one well-known view, technology is a morally neutral tool that we can put to whatever ends we desire. On the alternative, Heideggerian view that Edwards explicates, however, technology is anything but neutral. It is “a particular way of revealing things.” It “lets things be seen—in a particular way; it reveals them as having a particular character, a particular Being.” According to Heidegger, what is characteristic of the technological way of revealing things is that things are “set upon” and “challenged forth.” The result is