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“Love, too, has to be learned”: Reflecting on Love in Counseling Parents

In 2004, the Archives of Pediatrics published a Hastings Center proposal for new guidelines for treatment of intersex conditions that recommended delaying cosmetic procedures until a child could consent. In an invited critique, pediatric endocrinologist Erica Eugster wrote that a delay in cosmetic surgery would be inadvisable, not for any medical reason, but because it would impede a “family’s ability to accept and unconditionally love their child.” Eugster’s position—one that appears to be a prevalent, if largely unspoken motivation for corrective genital surgery—raises a central issue in the management of DSDs, which is the imperative to facilitate the attachment between child and parents. This paper examines this issue of fostering attachment in the “extraordinary” case of DSDs, figured historically as “a disorder like no other,” and asks how the treatment of DSD’s as “disorders like many others,” could provide a basis for fostering the parent-child relationship.

Many of you will be familiar with the study conducted by psychologist Suzanne Kessler a few years ago where college students were asked to imagine that they had been born with “clitoromegaly,” a condition defined as having a clitoris larger than one centimeter at birth. In response to the question as to whether they would have wanted their parents to sanction clitoral surgery if the condition were not life-threatening, an overwhelming ninety-three percent of the students reported that they would not have wanted their parents to agree to surgery. Kessler reports that,

[w]omen predicted that having a large clitoris would not have had much of an impact on their peer relations and almost no impact on their relations with their parents...they were more likely to want surgery to reduce a large nose, large ears, or large breasts than surgery to reduce a large clitoris (Kessler 1998, 101).¹

¹ This prediction is borne out by the fact that there is no published evidence suggesting any “hazards, biological or otherwise, of having a large clitoris.” While men with small penises have suffered some indignity, published studies have found that, “[c]ontrary to conventional wisdom, it is not inevitable that such [men] must ‘recognize that [they] are incomplete, physically defective and...must live apart.’” (Kipnis and Diamond 1999, 181).

These findings, Kessler reflects, are not surprising given that the respondents characterized genital sensation and the capacity for orgasm as “very important to the average woman, and the size of the clitoris as being not even ‘somewhat important’” (Kessler 1998, 101-2).

Men in the study were faced with a different dilemma, the one facing parents of boys with “micropenis,” a penis smaller than the putative standard of 2.5 centimeters at birth. Their question was whether to stay as male with a small penis, or to be assigned female. More than half rejected the prospect of gender reassignment. But, according to Kessler,

That percentage increases to almost all men if the surgery was described as reducing pleasurable sensitivity or orgasmic capability. Contrary to beliefs about male sexuality, the college men in this study did not think that having a micropenis would have had a major impact on their sexual relations, peer or parental relations, or self-esteem (Kessler 1998, 103).

In a separate study, Kessler and her team asked students to imagine that their child was born with ambiguous genitalia. Students in this study indicated they would make what Kessler describes as “more traditional choices” to consent to “corrective” or cosmetic surgery. Their rationales mirrored those of parents which can now be found on internet bulletin boards devoted to parenting children with intersex conditions: Students reported that they did not want their child to feel “different,” and believed that early surgery would be less traumatizing than later surgery (Kessler 1998, 103). Like parents over the last forty years who have been faced with these difficult decisions, students did not reflect on the somatic experience of the child, and with it, the possibility of lost sensation that so concerned the students in the first study.

Kessler’s paired studies confirm a kind of common sense that individuals, as individuals, are disinclined to compromise their erotic response for the sake of cosmetic enhancement. At the same time, parents, as parents, want “what is best for their child,” and

the promise of a “normal life” figures prominently in that conception. The juxtaposition of the two studies raises the obvious, if nonetheless vexing, question: Why would parents consent to procedures on behalf of their children that they would refuse for themselves?

This question goes to heart of what I want to address today. The stark differences between hypothetical choices individuals would make for themselves and those they would make for their children, raises some important questions about what motivates corrective genital surgeries. I think that this study suggests that we need to consider with the utmost care the assumptions—centered mostly on the value of “normalcy” promised by surgeries—that lead well-intentioned physicians and parents to see surgery as the answer to challenges children may face as a result of having anatomies that differ from the norm. More than anything else, it appears that doctors are motivated to recommend and perform surgery because they believe sincerely that surgery is the best way to help families deal with atypical genitals.²

In 2004, the *Archives of Pediatrics* published a proposal written by a Hastings Center working group for new guidelines for treatment of intersex conditions that recommended delaying any cosmetic procedure until a child is old enough to consent (Frader, et al. 2004). In an invited critique, pediatric endocrinologist Erica Eugster responded that a delay in cosmetic surgery would be inadvisable, not for any medical reason, but because it would impede, as she put it, a “family’s ability to accept and unconditionally love their child” (Eugster 2004, 428).

Apart from the significant fact that Dr. Eugster has such a grim view of parents’ capacity to love their children—one that I think would be readily challenged by any number

² In making this claim, I should add a caveat, however. The work of Katrina Karkazis, who was unable to attend these meetings, points to how our understanding of the “good intentions” of doctors may be, if not suspect, then a good deal more complicated than we generally like to believe (see e.g. Karkazis 2005).

of physicians who work with children and families faced with other congenital disorders—it does raise a central issue in the management of DSDs, which is the imperative to facilitate the attachment between child and parents.

Against the perspective offered by Dr. Eugster I think we should consider the reflections offered by bioethicist Adrienne Asch. Asch affirms that “the most compelling argument for early surgery is that by altering the child’s appearance, the parent will more easily, naturally, and wholeheartedly invest in the child who looks more like what he envisioned” (Asch 2006, 240). But, Asch cautions:

what seems like a ‘fix’ to the parents and professionals may not feel like a ‘fix’ to the child whose body has been changed. By undertaking surgery before children can voice feelings about their bodies and their lives, the most loving parent can unwittingly undermine the child’s confidence that she is lovable and loved. It is confidence in that love and loveableness that provides the foundation for dealing with what life brings (Asch 2006, 229).

Asch’s point here gets to yet another conflict in the motivations of parents with respect to the decisions to consent to cosmetic surgery. As Alice Dreger writes in “What to Expect When You Have the Child You Weren’t Expecting,” the imperative to “do what’s best” for a child introduces another kind of conflict in parents’ own motivations. While, Dreger writes, “‘doing what’s best’ clearly speaks to the idea of doing everything you can for your child [,] it also seems to negate the idea of accepting your child just as she is...it seems like opting for surgery might be rejecting your child” (Dreger 2006, 254), or at least, this is the message that may be unintentionally expressed.

Dreger offers to parents the following advice:

You have to keep in mind the decision you make about your child will affect how she thinks, not only about herself, but about your relationship with her, and how she thinks about the meaning of appearance. As you think about who you want your child to become, think about whether you’re modeling that outcome in your methods (Dreger 2006, 262).

Asch echoes this sentiment, affirming that the alternative to surgery is (and indeed cannot be) to “do nothing” (as one urologist put it during a meeting I attended). Asch writes that during

their child’s early life, the adults need not be passive and feel that their options during this time are limited to railing at societal cruelty. Whether or not the children ever choose surgery, how their parents and doctors behave toward them can give children tools for dealing with decisions about surgery and life (Asch 2006, 229).

I think that these two views—on the one hand, the idea that a parent must “do everything [she] can to improve” a child’s prospects, on the other, “accepting and loving the child you have,” capture, in another way, precisely that conflict demonstrated in Kessler’s study of college students’ responses. It may very well be that the birth of a child with an abnormality of any sort can present problems for parents with respect to forming attachments to that child. But there are a variety of ways—nonsurgical ways—to address that challenge which can also be responsive to the kind of warning implicit in Asch’s counsel regarding how parents’ behavior can provide—or fail to provide—tools for living.

In making this claim, I should emphasize that I by no means intend to minimize the distress parents may feel on the birth of a child with atypical genitalia. We know that parents often experience shame and confusion. It is no doubt for this reason that in the “Consensus Statement” issued by the Lawson Wilkins Pediatric Endocrine Society and the European Society for Paediatric Endocrinology, the authors state: “It is generally felt that surgery that is carried out for cosmetic reasons in the first year of life relieves parental distress and improves attachment between the child and parents.” “But” the authors immediately note, “The systematic evidence for this belief is lacking” (Hughes, et al. 2006, 4).

On the one hand, a surgeon’s efforts to normalize a child’s body to alleviate the shame that can result from the birth of a child with atypical genitalia may seem reasonable,

but it is also in the surgeon's power to normalize the child's condition for the parents, that is, to explain that:

“These are things that happen, that there are in fact many children like this, and importantly, if you'd like to speak to some parents of children like yours—those who opted for early surgery and those who did not, I can help facilitate these connections for you.”

It is absolutely imperative that parents be provided with information, resources, and behavioral support. Without such support, parents may feel not only isolation but shame, which they could project onto their child.

As one social worker who helps families with craniofacial deformities puts it:

In my experience, if time is not dedicated to talking about the almost automatic development of shame, and how to reframe this experience, then it continues to flourish. This then leaves everyone at risk for creating a plan that is directed by shame-based decisions even when we least expect it. It's important to avoid the impression that all negative reactions can somehow be stopped with surgery or other medical care. Shame can best be dealt with when we talk about it. The idea is to talk about it out loud or directly. Shame can be an isolating and terrifying thing, especially when it is either all we talk about or something we never talk about. (Consortium 2006, 27).

Surgery, in other words, cannot prevent feelings of inadequacy, of being “damaged goods,” but can send the powerful message that the body isn't normal, that it is in need of a “fixing.”

Psychologist Silvan Tomkins, whose work on affect has recently been so influential, describes how shame is “felt as an inner torment, a sickness of the soul” (Sedgwick and Frank 1995, 133). “There is no feeling more painful” (Biddle 1997, 227), Jennifer Biddle writes in a landmark feminist article on “Shame.” Shame is damaging, certainly, to one's sense of self, and to one's relationships, particularly with parents and extended family, but I

think we do not consider some of the unexpected ways that shame can also be debilitating to adults.

I want to suggest here that a good part of the motivation for corrective surgeries for children with atypical genitalia, and for the secrecy and silence that has surrounded them is owing to the historical treatment of intersex as a “disorder like no other.” I think that understanding DSD’s as “disorders like *many* others,” could provide some basis for fostering the parent-child relationship. I can say that I came to this proposal, in part, through my recent discussions with one family whose story—or by now, many stories—provide important lessons with respect to the damage that the conventional treatment of atypical genitalia can bring to a parent-child bond, and also how, in this case, the family’s coping with treatment of the underlying disorder, which requires the same skills and assistance as so many diseases or chronic conditions, can provide models for the assistance of families.

I first became acquainted with the woman I call “Ruby” when I was working on a project on feminist ethics and intersex several years ago (see Feder 2002). She has two grown daughters, both diagnosed with salt-losing CAH after being announced as boys and going into adrenal crisis soon after their birth. I have maintained contact with Ruby in the interim, and met her daughters a few years ago. I contacted them again, knowing that if there were experts in adult care, they would be the ones to ask. Not only did their ambiguous genitalia signal a serious life-threatening condition, their CAH—much like diabetes—would require lifetime management.

Theirs is a long and complicated story, so I certainly won’t attempt to recount it here. Rather, what I want to relate very briefly today is how talking to Ruby and her two daughters about the challenges they face today made me understand, in a different way, why it is so important that parents think carefully about the messages they send to their children

through the medical decisions they make on their behalf when they are young. Ruby's decisions to consent to corrective genital surgeries have had lasting effects for her daughters who have had to understand that her decisions were guided above all by doctors' understanding of "the right decision," that is, to make the external genitalia of the girls conform to their sex of assignment. But if Ruby did not have the resources or information to make different decisions about cosmetic surgeries at that time and in that place, her fierce attentiveness to her daughters' health, her willingness to challenge doctors' conclusions when her experience indicated she must, and most importantly, her instruction of her children in the ways of providing information and interacting with doctors over the long years of their treatment, expressed unambiguously her commitment to their health and well-being.

What she did, over and over again, was to support and guide them in describing their symptoms clearly to doctors, and from an early age, she insisted that doctors address their questions to, and seek information from, her daughters themselves. That is to say, she instructed her children in the ordinary business of seeking medical care—for a disease or disorder like any other. What makes her story so heartbreaking, as I have detailed elsewhere, is the incredible lack of support she received throughout these years, the secrecy she maintained—and maintains still, and the isolation she continues to experience.

Let me turn to the young women she still affectionately calls "my girls." Growing up with the assistance of specialists who were keenly interested in developing their expertise in an area of medicine that was only beginning to be understood, her daughters learned not only to recognize their own symptoms—and to trust their mother who had herself learned to anticipate crises—it came as a surprise when, as adults, they were unable to find doctors with any expertise in, much less genuine knowledge about, managing adult CAH. This is a state of affairs that has at least once threatened the life of the younger daughter, who, having

taken herself to an emergency room with a syringe of solu-cortef she was unable to administer at home, found herself alone on a gurney in the hallway of an ER. The attending physician ignored the instructions on her medic-alert bracelet and refused to contact the endocrinologist on call. Just when he was preparing to release her, visibly ill and incoherent, her sister arrived—having received an emergency call from her mother—to explain in plain terms that if the physician did release her, she would not be alive the next day, and that she was calling their endocrinologist who would explain to him her need for immediate care.

This is but one of the many stories that this family has shared. It's such a complicated tale—of medical incompetence, in this case, but also of a family's banding together to take care of one another. But it's a challenging story because it emblemizes what Ruby's daughters, with the stalwart support of their mother, have had to do to in order to secure the medical attention most of us—and most people with chronic conditions that receive more attention and are more common, are privileged to take for granted.

I have tried in this short time to do too many things. I think that one of the important lessons I have learned in talking to parents, and in my own experience as a parent, is that almost nothing comes “naturally.” Everything has to be learned. This was a point that the doctors at that Children's hospital embraced when it came to learning about this disorder that was taking the lives of children shortly after birth, and was perhaps why Ruby was “permitted” to participate with the doctors as a partner in her children's care, and in the gathering of information necessary to understand this frightening disorder. And if Ruby understood early on that learning was essential to the well-being of her daughters, she embraces the ways that she must continue to learn as her daughters struggle, into adulthood, to negotiate the difficulties of finding medical care and with the challenges—both medical and social—of having unusual anatomies and gay identities. What Ruby understands so well,

and what Dr. Eugster seems not to have grasped, is, as Nietzsche puts it in the *Gay Science* (§ 334), “One must learn to love” (Nietzsche may seem like a surprising source of insight on love, but I find this passage quite remarkable, and I wanted especially to share it with this group today.)

One must learn to love.—This is what happens to us in music: First one has to *learn to hear* a figure and melody at all, to detect and distinguish it, to isolate it and delimit it as a separate life. Then it requires some exertion and good will to *tolerate* it in spite of its strangeness, to be patient with its appearance and expression, and kindhearted about its oddity. Finally there comes a moment when we are used to it, when we wait for it, when we sense that we should miss it if it were missing; and now it continues to compel and enchant us relentlessly until we have become its humble and enraptured lovers who desire nothing better from the world than it and only it.

But that is what happens to us not only in music. That is how we have *learned to love* all things that we now love. In the end we are always rewarded for our good will, our patience, fairmindedness, and gentleness with what is strange; gradually, it sheds its veil and turns out to be a new and indescribable beauty. That is its thanks for our hospitality. Even those who love themselves have learned it in this way; for there is no other way. Love, too, has to be learned.

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