

Intertwined Identities: Challenges to Bodily Autonomy*

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Abstract

Over the last decade, the international media has devoted increasing attention to operations that separate conjoined twins. Despite the fairly low odds that a child or adult will survive the operation with all of their vital organs intact, most people fail to question the urgency of being physically separated from one's identical twin. The drive to surgically tear asunder that which was originally joined, I suggest, is motivated in part by a refusal to acknowledge intercorporeality as a basic condition of human existence that doesn't undermine identity but makes it possible in the first place.

Keywords: Conjoined twins, Identity, Intercorporeality, Autonomy, Surgery

Marking Autonomous Bodies

The physical boundaries of the human body have historically served as both a theoretical and practical means of distinguishing one person from another, as well as one group of people from another. "One body, one identity" is a basic legal, ethical, political and social presupposition that we both implicitly and explicitly rely upon in our everyday dealings with others. Conjoined twins and, to a lesser extent, parasitic twins, challenge, or at the very least disturb, this seemingly self-evident truth about human existence. Margrit Shildrick observes that conjoined twins are not only, as Foucault asserts, the "privileged signifier of the monstrous" but also the "limit case of the disabled body." (Shildrick 2005: 30-31) While the rarity of conjoined twins seems to guarantee their exceptional corporeal status, I maintain that the intercorporeal connections that all human beings sustain with one another are dramatically revealed through the complex ties that bind together conjoined twins. By looking at the various "paradoxes" that conjoined twins have embodied for their social peers across time and space,

we can arrive at a better understanding of the challenges intercorporeality poses to traditional, rationalist conceptions of identity.¹

The very distinction between conjoined twins and parasitic twins and the extraordinary ethical, legal, social, and political dilemmas these people have faced (all centered around the crucial question, “One person or two?”), collectively provide insight into prevalent cultural concepts of personal identity that are so taken for granted, so much a part of the Husserlian “natural attitude,” that they rarely get interrogated as such. Both experiences of exteriority as well as interiority are complicated by a conjoined twin’s intimate connection to her sibling’s body. A productive means of addressing precisely how and why conjoined twins trouble the dominant understanding of autonomy that underlies popular conceptions of personal identity is through the discussion of marking presented by French feminist theorist Collette Guillaumin’s in “Race and Nature: the System of Marks.”

In her essay, Guillaumin discusses the multiple ways in which bodies are marked as well as the ways in which the race of white bodies and the sex of male bodies are usually unmarked precisely so that the racial and sexual markings of other bodies can be revealed. Marking the bodies of others, she argues, has historically been intended to designate bodily inferiority, which in turn has been used to justify the social subordination of those whose bodies are marked as other to those whose bodies are unmarked and hence, deemed natural, thereby serving as the standard that all bodies should emulate. Guillaumin distinguishes between voluntary and involuntary markings, that is, those markings that people choose for themselves, such as hair styles, clothing styles, piercings, tattoos, etc. and markings made on individuals’ bodies without their consent such as the brandings performed by slave-owners on the foreheads of slaves, and the tattooed numbers on prisoners’ arms that Nazis used to identify concentration camp inmates. Guillaumin clearly identifies bodily marking as a strategy used to create social and political hierarchies according to which some bodies are experienced as more powerful than others because of their markings (e.g. royal dress, uniforms, etc.) or the alleged absence of markings (e.g. their white skin, or maleness). However, she does not dwell in detail on the significance of her basic distinction between voluntary and involuntary markings themselves and the corresponding body modifications that they entail.

While cases of involuntary markings appear to be fairly clear-cut to the extent that they are performed without the knowledge and/or consent of the person in question, it is less evident whether any markings can truly

be called voluntary if this latter signifies a decision made by an individual agent alone. For, as Guillaumin herself acknowledges, there are always cultural forces at work that help to create the context for specific marking practices; accordingly, individuals' decisions to mark themselves can never be understood outside of the larger habitus (to use Pierre Bourdieu's language) to which they belong and within which their bodily modifications will invariably be interpreted.

All too often, however, contemporary rhetoric concerning "voluntary" body modifications (e.g. cosmetic surgery, surgical implants, prostheses, etc.), justifies the latter via an uncritical appeal to a Kantian framework that emphasizes the rational autonomy of the person making the decision about what she wants to do with her body. Echoing the classic abortion rights perspective of "it's my body so I can do what I want with it," the emphasis then gets placed on making sure that others don't interfere with my right to mark my body as I see fit and/or on creating a safe cultural space in which an individual can express her difference from other bodies without being denigrated or harmed in any way.

Such a model, I would argue, laudable though its goals may be, also buys into a problematic logic of identity in which my individuality can only be achieved by separating my interests, needs, and desires from those of others. Although the focus of this discussion will be on an example of involuntary marking, namely, separation surgeries performed on unconsenting conjoined twin infants, precisely because it is here that the damage done by an uncritical allegiance to an anti-relational conception of identity is most readily apparent, one of my goals is to turn our collective attention to the ways in which unexamined commitments to enlightenment ontologies are actively setting the stage for our understanding of both voluntary as well as involuntary body modifications.

Through a critical examination of the case of the Bijani sisters, adult conjoined twins who requested separation surgery and who died in the process in 2003, I will also question whether any choice to undergo body modification is purely voluntary. Denying that body modification decisions are solely made as a result of individual choice is not intended to undermine a strong sense of bodily agency, but rather, to challenge whether this experience of agency requires that one's own body be viewed as autonomous from the bodies of others. For my bodily choices never take place in a vacuum; they are always responsive to the situation in which I find myself and, more specifically, they both reflect and affect the ongoing intercorporeal connections that constitute what Heidegger called the *Mitsein*, or my being-with-others in the shared world of our concern.

I will now consider a few specific cases of separation surgeries performed on conjoined twins, in order to reveal how these surgeries indelibly mark not only the bodies of the patients, but also mark a refusal to confront the limits of traditional presuppositions about identity, more specifically, a “one body, one identity” logic that the very existence of two individuals in a single body calls into question. Since most separation surgeries are performed on conjoined infants (with the notable exception of the Bijani sisters whom I will be discussing later), most of these surgeries appear to be clear cases of involuntary marking, at least for the patients themselves who are too young to be consulted.² However, unlike the involuntary markings described by Guillaumin, markings which are intended to visibly signify the inferiority of one body in relation to others, separation surgeries are intended to *normalize* bodies, that is, to take bodies that are deemed to be naturally inferior to other bodies and to transform them so that they can be unmarked in their conformity to the non-conjoined bodies of other members of society. The success of this process, of course, depends on the ability of the surgeons and the families to make the massive scars and disabilities produced by the surgeries invisible to others. Even though this often turns out not to be possible (indeed, virtually all twins who survive these surgeries need years of follow-up surgeries and rehabilitative therapy), the idea of both twins, or at least one twin, achieving a “normal” existence as an *autonomous* individual remains the ideal that motivates surgical and familial decisions.

While there are many conjoined twins who have survived to adulthood and even quite a few alive across the world today, their testimonies about their experiences have not typically been sought by surgeons and the families of conjoined infants contemplating separation surgery. This refusal to gain valuable information directly from those whose lived situation is similar to the patients is not surprising, however, because, as Simone de Beauvoir argued in *The Second Sex* over half a century ago, when societal myths conflict with reality, it is reality that tends to be rejected and the myth that is retained.³ Feminist philosopher Nancy Tuana has more recently identified this strategy as a part of what Eve Sedgwick originally called an “epistemology of ignorance,” an epistemological framework founded on a refusal of knowledge. Indeed, as Cheryl Chase, Alice Dreger, Ellen Feder and other intersex theorists and activists have poignantly revealed, the same strategy has been at work in the case of “normalization” surgeries performed on intersex infants: parents are routinely denied access to the testimony of other parents who have had intersex infants and who have refused surgery as well as the testimonies of adult intersex individuals

themselves.⁴

My own interest in the recent media attention given to separation surgeries performed on conjoined twins in the U.S. and abroad, arises out of a broader, feminist concern with issues of autonomy, identity, embodiment, and relationality that are invoked and troubled by the existence of conjoined twins. Sandra Harding's exhortation to look to specific examples of how "epistemologies of ignorance" operate in order to come to terms with their systemic influence in our lives is precisely the strategy that I pursue here. (Harding 2004) However, working with the specific sensationalized example of conjoined twins carries with it substantial risks, namely, that of further subjecting these extraordinary bodies to an exoticizing, othering gaze. While I was doing research for this project, poring through books and articles on conjoined twins, I was struck by how often these works unwittingly participate in what Rosemarie Garland Thomson, following David Hevey, terms the "enfreakment" of these individuals by relying so heavily on freak show handbills and disturbing photographs of various types of conjoined twins to elucidate the contexts in which they have been understood and interpreted. (Thomson 17) Even though the aim of these works is primarily to debunk popular understandings of conjoined twins as freaks and to foreground their basic humanity, the photographs themselves serve to re-inscribe the oppressive practices of objectification under which most conjoined twins are condemned to live out their lives. By discussing this danger openly, I am hoping to disrupt what feminist film theorist Gertrud Koch has identified as the "suturing" of the viewer's gaze to the objectifying, exoticizing gaze of the camera. (Koch 1985) Rather than avoid these images altogether (a strategy doomed to failure since they pervade the media on a regular basis), I am arguing that mediating our perception of them through critical analysis allows for new ways of seeing and moving beyond entrenched epistemologies of ignorance.

The Dominant Logic of Identity

The "dominant logic" of "one body, one identity" creates the context in which separation surgeries are presented as miraculous, altruistic attempts to provide conjoined twins with a particular form of bodily integrity (paradoxically achieved through cutting open and irremediably altering these bodies) that is predicated on the physical separation of one body from another. If one ascribes to this taken-for-granted logic of identity, the refusal of conjoined twins (and more frequently of their parents since most of these surgeries are performed on infants) to opt for separation surgery might seem

irrational and perhaps even immoral. It should not be surprising, then, that parents' and doctors' enthusiasm for separation surgery, even when neurological damage and/or damage (or even removal) of other vital organs is an inevitable result for each twin, is typically portrayed in glowing terms. On October 13, 2003, for instance, the Houston News posted the following story on its website, significantly entitled: "Twin Boys Begin New Lives After *Successful* Separation." (my emphasis) The report describes the father's and doctors' reactions to the surgery as follows:

The boys' father, Ibrahim Mohammed Ibrahim, fainted when he heard the operation was over. "At one point when someone came up and said, 'you have two boys,' the father jumped to my neck and he hugged me and he fainted and I cared for him," said Dr. Nasser Abdel Al, who was with the family for the marathon operation... "He told me that he never dreamt of such a moment," said Abdel Al. He added that Ibrahim's wife, Sabah Abu ed-Wafa, "was crying like everybody else."

A bit later we are told:

Dr. Kenneth Salyer...said his feelings had ranged "from moments of ecstasy to moments of concern and anxiety." Swift [who we are informed was one of five pediatric neurosurgeons involved in the operation] described an unexpectedly difficult moment separating the left hemisphere of Mohamed's brain from part of Ahmed's. "It was very, very stuck together." He said it was too early to tell what kind of neurological damage the boys might have.

Despite this rather chilling reminder that the ultimate outcome of the surgery cannot yet be ascertained, the report, as its very title bears out, "Twin Boys Begin New Lives After Successful Separation," presents itself as a success story. And yet, the report itself contains the possibility of a counter-reading that enables us to see the surgery as a vehicle to achieve normalization at any price, even if the boys' lives and/or well-being are sacrificed in the process. For instance, at the end of the report we are told that:

As conjoined twins, Mohamed and Ahmed smiled and giggled, babbled in English and Arabic and tried to move

around any way they could. But experts had said they were getting behind in their development, compared with other children their age, because they were unable to explore the world. When doctors concluded that a separation surgery was possible, the risks were explained to the parents. The boys' father told the doctors to go ahead. "If they're left this way, they're not going to be normal," Ibrahim said through a translator earlier this year."

In a separate example from NBC Channel 4 posted on its website on September 11, 2003 regarding two 9 month old identical twin girls who had undergone separation surgery, we see the dominant logic of "one body, one identity" (and the "pounds of flesh" it quite literally exacts) again at play:

For the girls, it's the beginning of life with two separate bodies able now to participate in society as two individuals," Stein [one of the surgeons] told a press conference afterward. The large intestine could not be divided and went to one twin. Surgeons also performed a liver separation and did reconstruction on the girls' urinary and reproductive tracts. Stein said there were still many challenges ahead for the girls. "Once you separate the kids, the hardest part is how to get them back together. How do you get them in one piece when you are short of tissue?" The next 24-48 hours are critical, but in the coming months and years the girls will see specialists to be fitted for prosthetics to help them lead normal and independent lives.

Perhaps the most well-known early twenty-first century case highlighting the dilemmas of separation surgeries was that of twenty-nine year old Iranian conjoined twins, Ladan and Laleh Bijani, who died in the summer of 2003 in an operation in Singapore to separate them (they were joined at the head). The two women were warned that they might not survive the surgery, and that they might suffer serious brain-damage as a result of the operation. Both sisters were insistent that they wanted to proceed with the operation despite the serious risks involved. Their physical separation, they argued, was worth the possibility that they would not survive the operation. In the end they died, separate in body but as inextricably conjoined in death as they were throughout their lives.

Based on her own substantial research on conjoined twins, historian of anatomy, Alice Dreger, believes that the Bijani sisters are the only adult

conjoined twins ever to seek surgical separation.⁵ Although some adult twins have, in times of anger, expressed a wish to be separated once and for all from the other twin (for instance, such a wish has been documented on the part of the most famous conjoined twins, Cheng and Eng, and is depicted as the primary desire of Eng in a recent novel about them), no other adult conjoined twins who might be candidates for it, aside from the Bijani twins, have so actively and publicly pursued separation surgery. The majority of these overwhelmingly unsuccessful operations are undergone by infants and small children. In these latter cases, it is the parents and doctors who seek separation surgery, unless, as often happens, the parents abandon the conjoined twins or give them up for adoption (the Bijani sisters were themselves adopted as babies by the doctor who initially advocated for their eventual separation surgery).

If the Bijani sisters are the only, or even one of the only, sets of consenting conjoined adult twins to seek this radically experimental surgery, given the fatal consequences of their surgery, we must confront the question of why parents, doctors, and society as a whole deems such surgery to be so urgent and so desirable even when the overwhelming majority of conjoined twins do not express the extreme dissatisfaction with their situation reported by Ladan and Laleh Bijani. Given that the standard for a successful surgery, as Dreger documents, is merely for the separated twins to survive the operation, and that only a small percentage of separated conjoined twins are able to leave the hospital after the separation procedure, we must wonder what has raised the level of cultural anxiety so high that the surgery nonetheless seems like the only viable alternative to an unlivable existence, an existence that many individuals nonetheless live, finding love and happiness along the way.⁶ According to Dreger,

The persistent claim behind much of this separation work is that separations must be attempted for the good of the patients- that a life joined is no life worth living (no mind what conjoined twins themselves say). However, I conclude here instead that attempts to separate twins are driven largely by a deep-seated concern for cultural norms of individuality. Bodies whose congenital conformations defy those norms- the bodies of conjoined twins- are treated with surgeries designed to bring the bodies into conformation with cultural norms. (4)

Many conjoined twins, it should be noted, are not candidates for separation surgery at all. Dicephalic twins, conjoined twins who have

separate heads but a single lower body, cannot be separated without killing one of the two twins and it should be no surprise that these twins, in particular, have seemed to pose the greatest challenge to the dominant logic of “one body, one identity.” Even in these cases, however, surgery is sometimes recommended with the ostensible aim of improving the quality of life for the surviving twin by giving her sole use of shared vital organs. These cases of “twin sacrifice” as Dreger refers to them, involve surgically asphyxiating the twin the doctors determine to be medically less viable and harvesting her organs for her sibling. She notes that “in all of the cases the intentionally sacrificed twin died, but notably, *in not a single case* has the twin chosen to survive ever actually survived to go home or even to live free of a ventilator. Angela Lakeberg [the famous conjoined twin who underwent this procedure in 1993], who was dead by her first birthday, seems to have survived the longest by far.” (17) Though there is currently a twin who has survived a sacrifice surgery performed in the UK in 1996, Dreger’s observation that these surgeries have routinely failed should nonetheless lead us to wonder why bringing about the death of one twin when the chances of securing the life of the other is so uncertain is still perceived as a desirable option.

Despite the fact that 1) it is ordinarily illegal to harvest organs from an unconsenting living donor, 2) that most people find such a concept to be morally reprehensible, and 3) that in many cases where the intentional killing of one twin has been carried out, both twins could have lived an indeterminate amount of time without the surgery, it is astounding that doctors are still so eager to perform this type of surgery. The example of twin sacrifice, a procedure that is totally unacceptable to perform on a singleton in order to save the life of another singleton, succeeds in bringing home Dreger’s point that corporeal autonomy is so prized as the very hallmark of identity that medical professionals and many laypeople are willing to accept death itself as the price for even one twin to achieve bodily autonomy from the other. And, it must be noted, the surviving twin’s total dependency on machines to live even a short time, belies the idea that autonomy is even being achieved through the operation. In Dreger’s words,

In spite of documented cases of reasonably successful joined lives, many singletons, especially surgeons, find it inconceivable that life is worth living as a conjoined twin, inconceivable that one would not be willing to risk all-mobility, reproductive ability, the life of one or both twins-to try for separation. Why, then, is this? (11)

Bodies on Display

In *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature*, Rosemarie Garland Thomson takes up this question, not only with reference to conjoined twins but more generally with regard to all disabled individuals who are typically deemed by the able-bodied majority to be leading lives of terrible misfortune. Rather than take the obvious strategy of demonstrating that the lives of conjoined twins and other individuals with “extraordinary bodies” are not so bad as they may seem (the project of Daniel P. Mannix’s first hand account of living as a freak on the carnival circuit in the second half of the twentieth century, entitled *Freaks: We Who are Not as Others*), Thomson deftly turns our attention away from these “freaks” themselves and onto the practices of “enfreakment” that serve to consolidate the position of what she terms the “normate.” The “normate,” Thomson declares, “is the constructed identity of those who, by way of the bodily configurations and cultural capital they assume, can step into a position of authority and wield the power it grants them.” (8) By projecting onto the freak those undesirable qualities that the normate finds intolerable in himself such as feelings of bodily insecurity and vulnerability, and by declaring the unnaturalness and unlivability of this abject subject position, the stage is set for submitting these “deficient individuals” to a stringent disciplinary regime that is self-justifying (both literally and figuratively) for the normate even as it delegitimizes the actual bodily experiences of those whose bodies transgress society’s corporeal norms.

While in the past many individuals judged to be corporeally deficient have escaped life-threatening attempts to normalize them because they could not afford the costly surgeries deemed necessary to “correct” them, the rising popularity of separation surgeries of conjoined twins in order to “showcase” the brilliance of the doctors and the cutting-edge technologies of a given medical center and even nation, has meant that more and more often these procedures are being performed *pro bono*, so that the patients’, their families’ or their guardians’ economic class need not be an obstacle. However, even the most naïve layperson cannot fail to note through all the media attention paid to the surgeons both before and after the separation procedures, that the surgeries offer incredible career-defining opportunities for the doctors to learn more about the interiority of the body, allowing them to separate that which was indissolubly connected in order to technologically create (like a veritable demi-god) two independently functioning human beings.⁷ Thus, unlike most elective and non-elective procedures in the U.S.

today (and the U.S. has performed more separation surgeries than any other nation), the hospital, rather than the patients, usually foot the bills. They thereby enjoy not only the worldwide reputation of being able to perform the most complicated, collaborative surgery possible (there are typically over 25 doctors in the operating room alone and the surgeries commonly run longer than 24 hours), but also they receive extra “brownie points” for providing these life-altering procedures for free to individuals who never could have afforded them on their own.

The material benefits of performing these surgeries then, extend far beyond the interests of the patients themselves, and this cannot be overlooked if we are to understand why they are so frequently performed even when those in the best position to judge if a life conjoined is worth living, are not even consulted to gain their perspective on the issue. As Dreger notes, not only do most adult conjoined twins with the exception of the Bijani sisters view this surgery with horror, but there are also many historically documented cases where, upon the death of one twin, the remaining conjoined twin still refused to be surgically separated from her deceased sibling, even when this procedure had a fairly high likelihood of success and the failure to undergo the procedure signified certain and imminent death. The most famous example of this willingness to die together rather than to live on without one’s conjoined twin, is the so-called Biddenden Maids who were born in 1100 and lived for 34 years. “When one died” Dreger tells us, “the survivor refused offers of separation, declaring, ‘As we came together we will go together.’ This sister then died six hours later.” (The Wall Street Journal, 7/9/03)

If we are to take seriously the presence of epistemologies of ignorance hidden in our everyday theories and practices, then it is clear that the unique intercorporeal connections that distinguish the lives of conjoined twins have much to teach us. For not only conjoined twins but, as Merleau-Ponty observes, each of us experiences our interiority through (and not despite) our connections with the bodies of others. If an autonomous body remains the *sine qua non* without which an individual identity is impossible, then this is only because we fail to listen to those people whose bodies defy conventional understandings of autonomy. “The paradoxical fact,” Dreger asserts,

is that *being conjoined is part of conjoined twins’ individuality*. If we singletons cannot understand that- if we cannot comprehend a life of two consciousnesses in one continuum of skin- that says something more about us than

about them. For we need only to look to history to see that they, too, manage to be human, that they, too, manage to eke out an individualized existence in a very connected world. (26)

The possibility of separating conjoined twins provides a respectable medical medium for resolving concerns about identity and individuation, concerns that are undoubtedly aggravated by the fact that many people in many parts of the world today have a good chance of dying in hospitals hooked up to machines that regulate the very functioning of their internal organs. Political, ethical, and social commitments to bodily autonomy as a mark of identity help to guarantee a view of conjoined twins' existence as irremediably and tragically impoverished. And, if bodily autonomy becomes the very mark of the human, it is surely no surprise that separation surgery appears to be worth any price.

Conjoined twins offer us an opportunity to reassess our own corporeal commitments to specific identity politics. Indeed, they have the potential to reveal especially poignantly a key point of feminist care ethicists, namely, that autonomy is itself a problematic ideal insofar as it forces us to deny the value of the primordial experience we share with conjoined twins, that is, being born connected to another. Adopting a relational approach to individuality, one that emphasizes that this latter can only be achieved through others rather than despite them, is, I would argue, a productive way to combat reductionistic conceptions of "one body, one identity." To do this, as Lorraine Code suggests, we need a revision and expansion of the epistemological imaginary, in this case, regarding our traditional understanding of identity as grounded in bodily autonomy. (Code 2007)

The medical and societal emphasis on the urgency of separation surgeries for conjoined twins to realize their individual identities, presumably for the first time, or in more than *name* only since each conjoined twin is given their own name at birth, may indeed turn out to be a primary case of epistemological ignorance, or what Marilyn Frye identifies as "not knowing what we're doing." (Frye 2004) The risk of this type of ignorance is that it reinforces and legitimizes an impoverished conception of our own relational identities as well as the relational identities of the twins themselves. More specifically, conjoined twins incarnate and generate fears of our intercorporeality, the intimate connections between our own identities and the identities of others as they are embodied (that is lived) from moment to moment in our daily lives.

In performing the “miraculous” technological feat of separating what is depicted as never intended to be joined to begin with, these surgeries enable us to maintain what Kaja Silverman calls a “dominant fiction,” in this case the dominant fiction that we can only be individuated by (forcibly) separating our bodies from the bodies of others. (Silverman 1992) By transforming our epistemological imaginary concerning the possibilities and limits of identity, we can combat the deleterious effects of clinging to the dominant logic of “one body, one identity.” As we have seen, this is a logic that conflates autonomy with bodily separation from the other, a form of epistemological ignorance that, in the case of conjoined twins, leads to a willingness to sacrifice, or, at the very least, to compromise severely, one or both bodies in the name of normalization and progress.

The active embodied agency consistently expressed both by infant and adult conjoined twins reveals how important it is to disentangle the “webs of belief” that support the epistemological imaginary associated with the logic of “one body, one identity.” (Code 2007) Disentangling the dominant logic of “one body, one identity,” paradoxically, may lead us to think more carefully about exactly whose interests are being served in the surgical disentangling of the complex intercorporeal connections between the bodies of conjoined twins. Indeed, Merleau-Ponty’s famous words that appear toward the end of the *Phenomenology of Perception* take on even more force when applied to the distinctive intercorporeality of conjoined twins for, if we read these words with conjoined twins in mind, we can see even more clearly how the body within can never be separated from the body without:

True reflection presents me to myself not as idle and inaccessible subjectivity, but as identical with my presence in the world and to others, as I am now realizing it: I am all that I see, I am an intersubjective field, not despite my body and my historical situation, but, on the contrary, by being this body and this situation, and through them, all the rest. (1962: 452)

Although Merleau-Ponty has been criticized by feminist theorists such as Irigaray, Butler, Young, and others for universalizing his own masculinist perspective, presenting us, as in this passage, with an omnivorous vision that incorporates all that it perceives, his recognition that the individual is not “an idle and inaccessible subjectivity” but rather “an intersubjective field” offers a crucial corrective to the image of a discrete autonomous body as the norm or even an ideal that human beings should be striving to

achieve. To take our bodies and our situation seriously, as Merleau-Ponty exhorts us to do, requires that we acknowledge the multiple ways in which our bodies are interconnected with, and dependent upon other bodies, both animate and inanimate in all aspects of our existence. Thus, rather than view the intimate connections between our own bodies and those of others are something that needs to be eliminated or at least minimized in order to “secure” our individuality, we must rethink the very concept of identity in order to see that it only has meaning in and through, and not despite our relations with others. This is a lesson conjoined twins are uniquely suited to teach us since they explicitly materialize the ties that bind us indissolubly to our fellow human beings. Challenging the uncritical assumption that a conjoined existence is not a life worth living, may therefore provide an unexpected means of acknowledging the depth of the intercorporeal relationships that define what it means to be a human being.

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(Endnotes)

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- 1 This essay is inspired by my interest in bringing Merleau-Ponty's rich notion of intercorporeality to bear on contemporary discussions about identity and marginalization in feminist theory as well as in the rapidly growing field of disability studies.
 - 2 I will leave aside the role of the twins' families for the moment though it undoubtedly complicates the issue.
 - 3 Beauvoir, of course, was referring to what she calls, "the myth of woman" but I am suggesting that her analysis can be applied to other social myths as well. Here, I am thinking particularly of the myth that identity cannot be achieved without bodily autonomy from others.
 - 4 Thanks to the work of the former Intersex Society of North America (ISNA) in particular, information is increasingly being made available to doctors and to families about the deleterious physical and psychological effects of these surgeries. In fact, some doctors have stopped recommending genital surgery on intersex infants as a result of this information. The ISNA website is an invaluable resource and should be consulted for further details on the surgeries as well as on living life without them: www.isna.org. There are many striking parallels between the case of conjoined twins and the case of intersex infants that must necessarily be taken up in another study. However, many of the claims I am making about the involuntary surgical marking of conjoined infants in the name of a normalization that is never practically achievable for the patient in order to assuage cultural anxieties about identity can also be applied to intersex infants.
 - 5 Indeed, in a 1998 article Dreger claims: "I have yet to find an instance in which conjoined twins have sought out separation." (10) Although there may well be other cases of adult conjoined twins who have desired surgical separation, the fact remains that the overwhelming majority of adult conjoined twins have not sought out this surgery.
 - 6 In her 2004 book, *One of Us: Conjoined Twins and the Future of Normal*, Dreger claimed that only 5% of conjoined twins are able to leave the hospital, that is survive outside of a hospital setting, after separation surgery. Given how many more separation surgeries have been performed since she published *One of Us*, this percentage has undoubtedly risen but even if it has doubled, tripled or even quadrupled, the odds are still against either twin being able to lead a "normal" life since, even in the most successful cases, numerous follow-up surgeries are necessary for organ repair (and occasionally organ donation) and cosmetic reconstruction, as well as intensive physical and occupational therapy, medications, and continuous medical supervision.
 - 7 Although, as Dreger amply illustrates, this is merely the goal, not the reality.

“Bodily autonomy,” as an abstract philosophical principle, dates back at least to the ancient Greek philosophers. Over the centuries, legal scholars and political philosophers have thought hard about the relationship between rights and laws, the individual and the group, and the sovereign state and the autonomous individual. In American activist circles, bodily autonomy is most often invoked around the fight for reproductive rights. But what I haven’t seen is an effort to harness this principle in a way that binds our seemingly separate movements together. In each case, these issues require a government that refrains from coercing disabled bodies and protects disabled bodies from private coercion. Bodily autonomy extends over these seemingly quite disparate issues. Related Article.