

## **Doctor’s Orders: Parents and Intersexed Children**

**By Ellen K. Feder**

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Between May of 2000 and August of 2001, I spoke with parents of “intersexed” children, children born with genitals that are neither clearly male nor clearly female. Routine protocols for “managing” these children include corrective genital surgery and gender reassignment. Since 1995, when intersexed adults first spoke publicly about the debilitating physical and emotional effects of these protocols, a growing body of work testifies to the pain and suffering wrought not only by the incisions and scars left by genital surgeries in infancy and early childhood, but by the secrets and silence maintained by doctors and families.<sup>1</sup>

I sought out these parents – through Internet bulletin boards and personal contacts – because I could find no information that addressed the experience of *parents* of intersexed children. This was striking, I thought: Parents are charged with making the difficult decisions associated with genital surgery and changing gender assignment, and yet there was next to no research available on their experience. Moreover, there are effectively no resources or support available for parents of intersexed infants. The absence of support is even more remarkable when one considers the abundance of resources now available for parents with children born with other congenital problems. Parents and family members are urged to seek help, to join or form support groups. Their children have access to other children like themselves. By contrast, parents of intersexed children are not given the opportunity to meet other parents who have faced similar dilemmas; they are not offered the opportunity to consult mental health professionals with expertise in intersex or even gender development. When they are not urged to keep the “truth” about their children to themselves, they are led to believe that the intersex condition has been “corrected,” and that their children will grow up to be “normal” girls or boys.

In reviewing the literature on intersex, it becomes clear that parents’ isolation and the striking failure to take account of their experience are not unfortunate effects of the treatment protocol; they are, rather, *essential components of that treatment*. The appearance of ambiguous genitalia in a newborn differs markedly from the host of other conditions – from congenital heart defects to cleft palate – that traditionally warrant surgical intervention. Ambiguous genitalia simply do not constitute a “medical emergency.” Doctors agree that in most cases of intersex, early surgical intervention is not necessary for the child’s functioning. They also concede that early surgical intervention can result – like any surgery – in harm. With few

exceptions, however, doctors continue to perform these surgeries, and defend their practices – which include the failure to secure informed consent from parents – as sound, and even as necessary.

Parents’ treatment in cases such as these is striking for the instrumental fashion in which they are regarded by doctors. One doctor with whom I spoke related what he understood as his job when it came to talking to parents of intersexed infants: “I need to lead them to the right decision.”<sup>2</sup> Certain details of a child’s condition, and particularly details that might, in the doctors’ judgment, interfere with the successful rearing of the child in his or her assigned sex, should, he claimed, be withheld as part of the treatment protocol. The doctor’s revelation might be jarring; common sense and fundamental bioethical principles alike dictate that parents must be fully apprised of their child’s condition, provided with the understanding that can make truly informed consent to treatment possible. The routine withholding of information in the case of parents of intersexed infants highlights the acute vulnerability of parents – the vulnerability that makes their treatment as what Kant would characterize as “mere means” possible.

In her book *Love’s Labor*, Eva Kittay calls attention to the disadvantageous situation of those she calls “dependency workers,” those who care for the “inevitably dependent.” Parents of young children are dependency workers, as are those whose professional lives are dedicated to the care of the elderly or those with profound disabilities. Dependency workers who care for the vulnerable, are, as Kittay explains, themselves vulnerable by virtue of a “secondary,” or “derivative dependency.”<sup>3</sup> The secondary dependency of parents is not always apparent in an individualist culture in which parents’ sovereignty over themselves and their children is presumed and valued. I would argue that the situation of parents of intersexed children is not different from that of any parent as far as the issue of dependency is concerned; there is an extreme variant of the vulnerability all parents face.

In the first part of this chapter, I explore Kittay’s analysis of dependency and dependency work as it relates to parents of intersexed children. In attending to the stories of parents, we must attend also to the story of the medical conceptualization of intersex itself. Part II reviews the cursory treatment of parents in the medical literature, and specifically the work that was guided by the dominating influence of psychologist John Money. Despite the fact that Money’s reputation has been irrevocably damaged by the revelation of the deception he engineered in the now infamous “case of John/Joan,” the protocols of intersex management that everywhere bear his mark retain a powerful and enduring authority. To explain this authority, and its function in parents’ relationship to their intersexed children, I turn in the third part to the work of Pierre Bourdieu. It might seem odd to pair the work of Kittay, a liberal feminist who works in the tradition of analytic philosophy, with the work of Bourdieu, a theorist firmly grounded in the Continental tradition. I argue, however, that Bourdieu’s conception of *habitus*, and in particular, the preservative and conservative nature of *habitus*, provides a powerful descriptive account that makes sense of the treatment of parents of intersexed children as dependency workers.

Bourdieu’s account, I conclude, complements Kittay’s normative analysis and furthermore demonstrates the radical implications of her work for change.

What follows is taken from a transcript of the first interview I conducted for this project.

### I. “RUBY”: A MOTHER’S STORY<sup>4</sup>

*The first was born in 1961. Doctors thought she was a boy. Her clitoris was enlarged, her labia fused. She was given a male name. But she became sick almost immediately. She couldn’t breastfeed, she lost weight, and on New Year’s Eve we took her to the ER. The doctors thought she was going to die, but one doctor knew about pediatric endocrinology, and transferred her to the children’s hospital in the city. They diagnosed her with CAH<sup>5</sup> and explained that she was female. She had no testicles, but a uterus and ovaries.*

*At three months, she hemorrhaged; her urethra was connected to her vagina. She had surgery, and they performed a clitorectomy at the same time. She had another surgery when she was two.*

*The same thing happened with my second daughter. Everyone thought, “This one’s the boy,” but I knew. I just knew it was a girl, but we gave her a boy’s name. When we brought her home, she became very sick. So I insisted that I be sent to the children’s hospital again. She was kept in the hospital for a long time, because the doctors thought that any talk about a son would upset my older daughter. At three months she had the clitorectomy. This was a female, and she needed to look like a female. They did leave tissue, but she had series of infections and she had more surgeries – five by the time she was five years old. She has almost no clitoris left, and massive scarring.*

*My daughters received medical care throughout their childhood. Once a month, sometimes more, we drove a whole day to get to the hospital. Fifteen hours there and fifteen hours back, with two active children in the backseat. And at the hospital I would have to fight the doctors. They would conduct a study on the salt levels, and make my children sick, and I had to yell at them to stop. The doctors almost gave up on my younger daughter, and I took over a lot of her care. I had to dilate her urethra, and it was so hard. I did cultures for the doctors, too. I grew the bacteria, and the doctors would tell me what antibiotics to give her. I was the one who had to coordinate her care, and I was determined that my daughter not die because her mom didn’t fight for her.*

*We were lucky to be part of these studies, though. As my daughters got older, they started to complain about the examinations. But somebody before my first child was born allowed these doctors – many doctors – to examine their child, to figure out what all this was about. My younger daughter is angry with me as an adult. She felt that she was raped, medically raped. And she’s right. And I know how she feels. When you have a baby, you lose your right to modesty, and everyone is looking everywhere. But it was necessary, in my mind, just like when I gave birth. I told my daughters I wish we didn’t have to do this. How would you feel having seventeen doctors look at you all at once? But it wasn’t just that I felt a responsibility. This was a teaching hospital, and their treatment was being subsidized.*

*No one wanted to talk about the gender issues, how my daughters wouldn’t play with their dolls. Both girls are gay. No one wanted to talk about that. Their father didn’t want to deal with the gender issues at all, and his family thought that we had turned two little boys into girls. We divorced in 1976.*

*I had pastors who told me that they didn’t know how to pray for me. And I told them I know how you can pray for me. You imagine a God who is bigger than all of these problems and you ask Him to help me.*

As infants and young children, humans are dependent. We need others – most often our parents – to commit themselves to the work of providing what we cannot secure for ourselves. Children who are ill or medically fragile are not exceptions in this respect; their needs magnify the needs – for preservative love, fostering growth, and training for social acceptance<sup>6</sup> – that are common to all children. As the needs of these children are magnified, so, too, are the corresponding demands upon parents with ill or medically fragile children. Those engaged in the practices of mothering will recognize the love that motivates Ruby’s determination that her “daughter not die because her mom didn’t fight for her.” While Ruby’s efforts can be seen as heroic, it is difficult to imagine mothers and fathers who would not want to do everything in their power to save the lives of their children. Ruby’s explanation to her daughters of the need to consent to invasive examinations reveals both an attempt to foster moral growth and to teach a difficult lesson in training for social acceptance. Other parents sacrificed their children’s comfort so that doctors could help you, she tells them, and now we are obliged to do the same. And in life there are times that you must “go along to get along.” Sometimes there’s no choice.

In providing care to a dependent other, dependency workers are themselves dependent on others to provide the resources they need to do their work as caregivers. All parents require assistance from a host of individuals and institutions to secure what their children need in the ways of education, health care, and social security. Parents’ own needs, too, must be met in order to enable them to attend properly to their charges. Precisely because Ruby’s situation will not permit her to take such support for granted, what Kittay calls the “secondary” or “derivative dependency” – as aspect of the situation of all dependency workers – is especially visible in her case.

The early withdrawal of familial support, first by her in-laws who believed she had robbed them of a grandson two times over, and then by her husband, who failed in so many ways to stand by his wife, meant that the help upon which most mothers in some form rely was largely withheld. The constraints on Ruby’s access to the medical care necessary to maintain her children’s health demonstrate her dependency on the individual physicians who managed the clinical studies in which her children were enrolled. So long as Ruby’s daughters remained subjects of the studies conducted by the hospital, their care would be generously subsidized. Refusal to consent to experimental treatments or yet another examination of her children’s genitals would have put Ruby and her family at considerable financial, and thereby medical, risk. Caught in a bind of financial and medical exigency, Ruby could not really be understood to have a choice in the matter. To refuse a medical intervention would have been, in effect, to risk her children’s lives. This was a risk she would assume only at those times when she clearly perceived that an intervention itself posed the worse threat. That a mother would be faced with such a dilemma starkly underscores the special vulnerability that accompanies secondary dependency.

### **Dependency Work and the “Transparent Self”**

As a parent, Ruby made decisions on behalf of her young children. Such is the responsibility of the dependency worker who, as in the case of parents of young children, must act to meet the needs of one who cannot meet them for herself. Kittay proposes the conception of a “transparent self” to describe the distinctive connection a dependency worker must maintain in order to engage meaningfully in the work of caring for a dependent other. A “transparent self” is a “self through whom the needs of another are discerned, a self that, when it looks to gauge its own needs, sees first the needs of another.”<sup>7</sup> While the achievement of a perfect “transparency” is not possible, Kittay advances the concept as a regulatory ideal to describe the attunement to the needs of another that is necessary for the successful performance of dependency work.

In thinking about the standard cases of mothering, attunement to the needs of a child appears to take two primary forms. In the first, a mother can attend to the dependent child in ways that are sensitive to expressions of need a child can express only imperfectly. For example, a mother can use attentive interpretive skills to discern whether an infant is crying because she is wet, hungry, or wants to be held. In the second, she can use what could be termed the “everyday social knowledge” she has as an adult to anticipate the needs a child cannot. Such needs would include skills required in social interaction with peers and adults, or toilet training. In addition, however, there is an array of needs to which a child may be subject, and for the satisfaction of which the mother will herself require extensive assistance. While a mother might be able to discern a child’s discomfort in the common case of an earache, for example, she may not be able to discern the specific cause of the pain. Though the child may be able to express pain or discomfort, she cannot

communicate what she needs to treat her medical condition; “everyday social knowledge” does not usually provide such professional and technical information. Where, as in the case of an earache or other medical problem, the two primary forms of attunement are not finally effective in meeting the needs of her charge, the mother must depend on doctors’ “expert knowledge” both to understand and to respond to the needs of her child. Cases such as Ruby’s are complicated, I want to argue, by the fact that the “expert knowledge” she is offered as definitive of what her children “need” may not itself be attuned or sensitive to the genuine needs of her children.

In the paradigm case of a dependency relationship as Kittay sees it, three aspects define the labor of the dependency worker:

It is the work of tending to others in their state of vulnerability – care. The labor either sustains ties among intimates or itself creates intimacy and trust – connection. And affectional ties – concern – generally sustain the connection, even when the work involves an economic exchange. For the dependency worker, the well-being and thriving of the charge is the primary focus of the work. In short, the well-being of the charge is the responsibility of the dependency worker.<sup>8</sup>

To all appearances, Ruby both understands and assumes her responsibilities in just the way Kittay here describes. There can be no question that Ruby cares deeply about her daughters, or that her concern for their well-being could be described as anything less than fierce. In the paradigm case of a dependency relationship, connection cannot but be understood as a necessary corollary of care and concern. And yet, the connection between Ruby and her daughters, and particularly her younger daughter, is attenuated. If it is not for lack of care or concern that the connection between mother and daughters is strained, it seems that the effects of the repeated experience of violation her daughters suffered nevertheless eroded the trust essential to a relationship between a dependency worker and her charge. It was not Ruby who performed surgery or conducted the exams. But it was Ruby who, willing or not, sanctioned these actions. The tragic paradox of Ruby’s situation is precisely this: Her caring and concerned attempts to fulfill her responsibility for what Kittay calls the “well-being of her charge” led her to consent to actions that resulted in harm to her charge, and eventually, to an erosion of her connection to her charge.

Ruby fulfilled her responsibility to her daughters the best way she knew how. Her “knowing how,” however, was tainted by the flawed “expert knowledge” on which she had to depend. The possibility of effecting harm in an effort to do right by one’s charge is a risk, certainly, for any dependency worker. In this sense, Ruby’s situation exemplifies the sometimes perilous nature of dependency work. Ruby’s marked dependency on, and vulnerability to, her children’s doctors magnifies and essential relationship not immediately apparent in examinations of dependency relationships, namely, the relationship of the dependency worker to the third party Kittay calls a “provider.”<sup>9</sup> A provider is a person or persons responsible for the supply or regulation of some significant external resources. A provider may be the head of a household, who supplies financial support necessary to the maintenance of a child or other dependent. In Ruby’s case, the provider who figures most

prominently in her life and that of her children is the hospital medical team managing her daughters’ care. Even as a provider enables a dependency worker to do her work by supplying necessary resources, a provider may also limit the autonomy of a dependency worker by exploiting her dependency to carry out some other agenda. The relationship between a provider and a dependency worker, like that between a dependency worker and her charge, then, is characterized fundamentally by inequality.<sup>10</sup> Ruby’s daughters received life-saving care as a result of the benevolent intervention of the doctors. But at the same time, doctors’ management of “the gender issues,” that is, their insistence on cosmetic genital surgeries and their failure to address issues related to the nonconforming behavior of her children, wreaked havoc in their lives.

### “The Gender Issues”

The prominence of “the gender issues” in the life of Ruby and her children both do and do not distinguish their experience. Even for parents of children with no genital ambiguity, maternal work can involve complications around questions concerning gender. Training for social acceptance may require a mother to direct her daughter to behave at times more “like a girl” or teach her son to behave more “like a boy.” At the same time, a parent may come to believe that a social script dictating a particular gender behavior is not appropriate for her child. Parents with convictions concerning the problematic nature of gender scripts may resist the imperative that encourages them to direct their children to behave according to the norms associated with a certain gender. For the most part, however, mothers generally harbor no doubts or questions, mothers may experience less anxiety when their children fail to conform to particular line of behavior. Unencumbered with doubts about her child’s sex, a mother may shrug off her daughter’s aversion to dolls. She needn’t question whether such an aversion is a sign that her daughter isn’t “really a girl” or wonder whether she “did the right thing in treating her as a girl.” Anxiety that parents may feel if a daughter prefers trucks or a son prefers dolls is not concerned so much with their children’s “sex” but with the possibility that their child will experience homosexual desire. The difference between the kind of “gender panic” manifested by parents afraid that their “apparently normal” girl or boy might be homosexual and that experienced by parents of children with ambiguous genitalia is the apparent tangibility of the diagnosis of Intersexuality.<sup>11</sup>

Ruby’s situation is complicated by such doubts concerning what she calls “the gender issues.” Her husband’s family responded with shame and criticism; her husband coped with the situation by withdrawing, first emotionally, then physically. More upsetting to her than even her family’s shortcomings, however, was the alternating silence and denial she faced when she started asking doctors questions. “Why,” she asked again and again, “do my girls behave this way? And what can I do to help them be more like girls?” In response to her questions, most of the doctors at the hospital had no answer. One impatiently cut her short: “They’re girls.

What’s the problem?” The doctor’s refusals to respond meaningfully to Ruby’s questions may be symptomatic of doctors’ own anxiety over whether they had made the right decisions in the management of Ruby’s daughters. Whatever their motivation, the doctors here compound Ruby’s vulnerability. Making every effort to fulfill her responsibilities to her daughters, she has had to rely on the recommendations of medical authorities who are themselves subjects of prevailing conceptions of sex and gender. When she seeks advice to address the consequences of the earlier recommendations, she is given to understand that her questions – questions that have arisen from her attentive connection to her children – are improper.

Ruby understood that her job as a mother was to help her girls grow up to get along in this world. Being a female and acting like a man wasn’t going to get them far. When the girls had health problems associated with CAH, she could make sure that her questions were answered, and she could *do something* – she could monitor their cortisol levels or make sure they stayed hydrated. But when it came to the fact that her girls wouldn’t play with “girls’ toys” or really act “like girls,” she was on her own. It is here, where Ruby deals with the gender roles and identities of her daughters, that support is conspicuously withheld, and her own ability to provide support is undermined.

It is only in retrospect that the “gender issues” began with the clitoridectomies performed when the girls were only a few months old. In Ruby’s memory, there was no question that they would be performed. She and her husband were informed of the necessity for genital surgery in the same way a parent would be informed that a child’s congenital heart defect would have to be corrected: The procedure was imperative for the healthy development of the child. The consent to corrective genital surgery was not a question, but a form that she and her husband signed along with all the others, consenting to the different procedures or administration of medicine their children required. It would be many years before her daughters would be able to articulate the effects of the surgeries, and thus many years before Ruby could understand the meaning for the consent she had offered.

Ruby credits the close relationship she now enjoys with her older daughter to hard work and the help of a therapist Ruby sought out after her divorce. Ruby’s involvement in her daughter’s life has meant that she can also be a resource to her daughter’s close friend, another woman with CAH, whose mother never spoke to her about her condition. Things have not worked out so well with her younger daughter, who has found the maintenance of intimate relationships almost impossible. Despite Ruby’s efforts, her relationship with her younger daughter has been strained for many years. Ruby is sympathetic. She understands her daughter’s physical pain and emotional isolation are constant reminders of the violation she experienced in infancy and throughout childhood. But her daughter’s anger – undimmed by the years – is difficult for Ruby, too; her daughter’s pain and distress are constant reminders of her role in inflicting that injury.

### Trust and Domination

Trust is one of the factors crucial to the success of the relationship between a dependency worker and her charge. Kittay writes that the “charge must trust the dependency worker will be responsible to and respectful of her vulnerability and will not abuse whatever authority and power has been vested in her to carry out these responsibilities.”<sup>12</sup> The fraying of trust between Ruby and her daughters is not owing to any questionable intentions on Ruby’s part. Rather, it is Ruby’s own vulnerability to her children’s doctors that renders fragile, in turn, Ruby’s relationship with her daughters. Her complicity in making decisions and maintaining secrets that effected so much harm in the lives of her daughters drove a wedge between her and the daughters for whom, and about whom, she cares so deeply. Ruby’s children experienced pain, both momentary and enduring, physical and emotional, as a result of decisions in which she participated. And yet, isolated by the doctors, and herself subject to the secrecy of her children’s treatment in which she was forced to collude, Ruby’s vulnerability as a dependency worker was exploited, and so exacerbated.

It is precisely because inequality characterizes the relationship between the dependency worker and her charge that trust is essential to the success of a dependency relationship. If trust that an abuse of power will not occur is essential to the dependency relationship, the illegitimate exercise of power – domination – is anathema to it.<sup>13</sup> Domination manifests itself in the physical scars on her daughters’ bodies; it reveals itself in her younger daughter’s difficulty in forming intimate relationships, and it is evident in the emotional rift between Ruby and her younger daughter. At the same time, however, it is difficult to apply the term *domination* to a situation such as Ruby’s. *Domination*, as Kittay uses it, is associated with a willful agent of power, and while the illegitimate exercise of power has left its mark, it is nonetheless difficult to locate the agent who left those marks. Ruby, who went to such lengths to ensure her children’s well-being, is an unlikely “agent of domination.” As Ruby tells it, the doctors, too, make for poor culprits: Those recommending and performing genital surgeries do not intend harm; on the contrary, it is their firm belief that genital surgeries are essential to the healthy psychosexual development of a child born with ambiguous genitalia. Doctors who ask that patients make themselves available to colleagues and medical residents for repeated examination by medical personnel do not mean for patients to experience violation; rather, they understand themselves to be engaged in important educational work that advances medical progress. And yet, the injury suffered by Ruby’s daughters, and the many others who have recently spoken out against cosmetic genital surgeries, points to the exercise of power absent “moral legitimacy.”<sup>14</sup>

### *Mary’s Story*

Twenty-five years after Ruby’s first child was born, a young mother named Mary brought her twelve-year-old daughter, Jessica, to the pediatrician. The day before, Jessica had just come out of the shower after a ballet lesson when Mary noticed, out of the corner of her eye, a “growth” emerging from her daughter’s labia. Mary had called the doctor, who agreed that Mary should bring Jessica in the following morning. Her daughter did not question why they would be going to the doctor. “Jessica was the type of child who never questioned me. She never spoke back. Never. Because she wanted to make me – us, her parents – happy, and not displease us.”

That same day, Jessica’s pediatrician sent her to a pediatric endocrinologist. A sonogram revealed that Jessica did not have a uterus, but undescended testes.<sup>15</sup>

*The pediatric endocrinologist asked to speak with me alone. Jessica was in a different room. The doctor and I then sat and she explained to me that Jessica had XY chromosomes and Jessica would not be able to bear children. She also explained to me that this was something I should never, ever bring up with Jessica. I should never talk about it with Jessica. We should just take care of it as quickly as possible so that Jessica could live a normal life. I agreed to this because it was what she asked me to do. I was very young at the time. I was just in my late twenties.*

*Naturally I was shocked; I was stunned, I was saddened. I went home and told my husband, who had just come back from work. I told him all about it, what the pediatric endocrinologist said. I had never seen him cry before but he just broke down and sobbed in my arms. That’s when it impacted me the most... There were a lot of tears, a lot of feeling bad for Jessica, knowing that she couldn’t have children naturally.*

Mary was instructed to tell Jessica that “her ovaries hadn’t developed properly and they would have to come out.” Jessica was not told that her testes would be removed because doctors feared they would become cancerous. Nor was she informed of the clitorrectomy<sup>16</sup> that would be performed at the same time.

Only a month later, Jessica was in the recovery room of the children’s hospital. Mary remembers finding her daughter moaning in bed as she recovered from the anesthesia. She thought it was only from the pain, but Jessica has since told her that, having reached down, she realized that “a piece of her was gone.” In the week that Jessica spent in the hospital, nothing was said about the clitorrectomy. Doctors did inform her, however, that she would have to return to the hospital in a week to evaluate the effects of what they called “the plastic surgery.”

Mary remembers that before the surgery, immediately after, and in the follow-up evaluation, “scores of male residents would come in to examine” her daughter. Mary had consented to the examinations because she knew that her daughter was being treated in a teaching hospital. It was not until years later, when Jessica had obtained her medical records and confronted her parents with what she had learned, that Mary would hear from her daughter’s mouth, the terrible effects, not only of the surgery and the deception, but of the repeated examinations.

Looking back, it seems obvious to Mary that her daughter, who regarded her enlarged clitoris as perfectly normal, would have experienced the surgery and the examinations as painful violations. But if at the time she entertained such thoughts, she put them out of her mind. She remembers asking whether she should seek counseling for Jessica and in response was told the story of another girl with AIS who, as a teenager, had stolen a look at her records when the doctor was called out of the office. That girl, the doctors informed Mary, had had to be placed in a psychiatric institution as a result of learning “the truth.” The surgery had taken care of the problem, Mary was told, and further discussion would only raise potentially damaging questions for Jessica. What was important was that Jessica look normal. If she looked normal, she would be able “to live her life as a normal girl.”

When Mary speaks for the importance of the “normal appearance” of her daughter’s genitals, it is difficult to discern whether her remarks reflect her own concerns or those of the doctors. Appearance, as opposed to sensation, is the governing criterion that determines whether genital surgery (and in some cases, a change in gender assignment) is indicated.<sup>17</sup> Perhaps it should not be surprising that parents of children with ambiguous genitalia follow the lead of doctors when it comes to making sense of a condition they have most likely encountered for the first time. Mary’s response, as well as Ruby’s, reflects the experiences of many other parents.<sup>18</sup> In focusing on genital appearance, rather than on the experience of the child, the mother fails to identify with her child, and in so doing, she puts both her child and her relationship to her child at risk.

Mary’s story underscores one of the recurrent themes implicit in Ruby’s narrative, namely, what might be described as a clouding of the dependency worker’s “transparent self” as a result of a *failure of identification* with her charge. Kittay’s discussion of the transparent self emphasizes the priority of the charge’s needs over those of the dependency worker. The dependency worker as a dependency worker must defer her own needs in order to accommodate those of her charge.<sup>19</sup> The image of the “transparent self” also implies a capacity to recognize the other’s needs through identification with the other. A mother of an infant can appreciate that hunger or a wet diaper would make one cross. Even if she does not directly know the particular discomfort, she can draw on her own experience to appreciate what her charge may experience. But in the case of children with genital ambiguity, it appears that a parent is forced to forsake this knowledge.

In a study conducted by psychologist Suzanne Kessler, 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 conditions were not life threatening, *93 percent* of the students reported that *they* would not have wanted their parents to agree to surgery:

Women 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... [T]hey were more likely to want surgery to reduce a large nose, large ears, or large breasts than surgery to reduce a large clitoris.<sup>20</sup>

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.’”<sup>21</sup> Men in the study were faced with a different dilemma, the one facing parents of boys with a “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 reassigned as 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.<sup>22</sup>

This study confirms a kind of common sense that individuals are generally disinclined to compromise their erotic response for the sake of cosmetic enhancement. If asked if they themselves would be willing to subject themselves to cosmetic surgery, it is quite likely that parents would refuse. But when acting on behalf of their children, the majority of parents do opt for surgery.

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.” Students’ rationales mirrored those of parents, which can now be found on new Internet bulletin boards devoted to parenting intersexed children: Students reported that they did not want their child to feel “different” and believed that early surgery would be less traumatizing than later surgery.<sup>23</sup> Like parents faced with these difficult decisions, students did not reflect on the possibility of lost sensations. It may be uncomfortable for parents (and even for those who are only imagining themselves as parents) to focus on the feeling in a child’s genitals – it may sexualize the child in a way that causes discomfort to the parents. However, the case of children with ambiguous genitalia demands that parents take account of just those feelings in order to fulfill their obligations as dependency workers. To do that, parents require the assistance of the experts on whom they have come to rely when their own knowledge proves insufficient. Unfortunately, Kessler’s team did not ask students participating in the first study what they would have done if faced with the decision of whether to consent to surgery for their children. If such questions had been included, it is possible that students in the first group would have been more disposed to identify with the children and to be more cautious about making cosmetic surgical decisions.

The juxtaposition of Kessler’s studies suggests a conflict in the case of Intersex between the needs of the individual child and the norms and expectations that govern

society. A parent’s obligation to her charge is complicated by the fact that socialization is also constitutive of her charge’s needs. But socialization is not generally understood to be the dependency worker’s primary obligation. In *Love’s Labor*, Kittay writes that a “mother, acting in a manner compatible with the norms of maternal practice, does not force her child to sacrifice the child’s own well-being for another’s benefit. Such coercion is not commensurate with a maternal practice that remains true to the well-being of the child.”<sup>24</sup> When parents such as Mary are presented with situations for which they can provide no context, and so are unable to make judgments concerning what is right for their children, they must rely on doctors to provide direction and advice. In place of the parent who has shared such a close relationship to her child, Mary becomes an agent of her daughter’s violation. But parents like Mary who become agents of violation become, at the same time, objects of domination. Their relationship with their child is compromised, and the dependency worker is, as dependency worker, compromised, by virtue of her inability to identify with her charge. As is evident in her story, as well as that of Ruby, she was “led” by doctors to consent to actions that her child experienced as – and that now she has since acknowledged to be – coercive.

How are we to understand the doctor’s attitudes? Why, for instance, do they justify and endorse practices that privilege cosmetic appearance of genitals over the capacity for sensation? Why do they see their own practices as justified and beneficial? In the next section, I provide an overview of the ways in which the medical establishment has theorized and handled the condition of intersexed children.

## II. MONEY’S THEORY

In Mary Cassatt’s painting *Mother and Child*, a young girl, perhaps three or four years old, sits naked on the lap of her mother. One of the mother’s hands rests lightly on her daughter’s shoulder in a steadying gesture. The other hand holds a mirror to her daughter’s face, which the girl’s hands clasp awkwardly at the handle’s lowest portion. Both faces turn toward the mirror as mother and daughter regard the effect of the mother’s work. The mirror reflects the face of the child; her eyes look directly at the viewer.

One might read the portrait as an eloquent statement of an important dimension of maternal practice, namely, the role of the parent in the development of the child’s identity. In holding the mirror to the child’s face, supporting her as she reaches both hands to position it just so, the mother instructs her daughter in the ways of self-consciousness, that is, to see herself the way others see her.

Cassatt’s painting is reproduced on the cover page of a 1970 article dealing with parents of children with ambiguous genitalia. It is an arresting image to introduce this, the first essay and, to date, the only research project dedicated to consideration of parents of intersexed children. “Divergent Ways of Coping with Hermaphrodite

Children” presents two case studies of parents of intersexed children. These case studies are intended to elucidate challenges doctors face with respect to parents’ acceptance of “the medical decision of sex assignment.”<sup>25</sup> Understanding these challenges, the authors suggest, will help doctors help parents achieve “a feeling of complete conviction that they have either a son or a daughter.”<sup>26</sup>

One family, the authors report, is white and upper middle class (the father is a “junior executive in a large company”).<sup>27</sup> The other family is described as a large and uneducated family of Mexican descent (the father is a “migrant farm worker”). Both “Kitty West” and “Mary Torres,” as the respective children were called, were born with genitalia that appeared more masculine than feminine. On learning that their children were girls and not boys, as they were first announced, both families responded with “extreme shock.” Once informed of the situation, however, the parents’ reactions diverged; it is the difference in their response that is of most interest to the authors.

The Wests, as the authors tell it, “wanted to understand the defect and have it corrected.”<sup>28</sup> Mr. West found pride in the knowledge of their child’s disorder; Mrs. West looks forward to the genital surgery, repeatedly asking how soon it can be performed.<sup>29</sup> The authors write approvingly of the gender-appropriate behavior the Wests display in interacting with their child and of the mother’s reports of their on-and-half-year-old daughter’s “flirtatiousness.” The authors do concede that the question of whether any doubts or conflicts (e.g., over the parents’ original wish to have a boy) “will complicate Kitty’s eventual satisfactory sexual identity as a female is too early to tell.”<sup>30</sup> The implication is that Kitty may become a lesbian due to the “conflicts and doubts” of her parents. Here the entanglement of “proper” gender, sex, and sexuality is particularly evident.<sup>31</sup>

The Torreses’ response to the birth of their daughter differed markedly from that of the Wests. Rather than join the doctors as partners in the treatment of their daughter, they were unsatisfied with the “medical assurance that according to the best medical knowledge the baby was a girl.’ That the physicians did not demonstrate perfect confidence in their own diagnosis “fit in with the parent’s philosophy that there are many things which only God can know and perhaps the physicians made a mistake.” In sum, the authors relate, the Torreses “coped with the Intersex problem ... by accepting the ambiguity of the situation and ... actively implement[ed] it by giving the baby a neuter name (the name of a warlike tribe).”<sup>32</sup>

A the account of the case studies makes clear, the aim of “Divergent Ways of Coping with Hermaphrodite Children” is ultimately to foster in clinicians an appreciation of and sensitivity to cultural differences that can affect parents’ acceptance of physician recommendations with respect to children’s sex assignment. The Wests’ “faith in medical science” – a product of their education and social milieu – indicates that they can be brought in as full partners in their child’s treatment. The superstition harbored by the Torres family, on the other hand, disposes them to be suspicious of doctor’s recommendations. The case study of the Torres family notes that Mary eventually does undergo cosmetic genital surgery. Had the doctors been absolutely certain of their diagnosis from the outset and

conveyed that certainty in strong terms, perhaps Mary might not have had to wait until she was twelve to receive normalizing genital surgery. Had her parents not “accepted the ambiguity.” Perhaps she would have had a clearer gender identity than the psychological tests indicate.<sup>33</sup>

The clear argument of Bing and Rudikoff’s essay is this: For doctors to succeed in the work of sex assignment, as they promised to succeed in the case of the West family, cultural “differences” such as those that distinguish the Torres family from the West family must be taken into account. Rather than seek to understand how they might support parents in the “coping” they purport to address, the author’s aim appears to be much more narrowly confined to understanding how doctors can be most effective in overcoming obstacles (such as cultural “difference”) in order to effect the surgical and social outcomes doctors have determined to be appropriate.

The medical protocols doctors employ in treating intersex children were first outlined by John Money, the psychologist credited with creating the framework for the management of intersexed infants. For Money, the origin of an individual’s gender identity cannot be located in the innate characteristics that distinguish male from female. Gender identity is a function of socialization.<sup>34</sup> When parents dress the child announced to be a boy in blue and give him toys associated with masculine behavior, they are promoting his masculine sexual identity. For parents who unequivocally see their child as *either* male *or* female, social imperatives ensure that their comportment toward the child will result in an unambiguous gender identity. The problem with intersexed children, as Money saw it, was that ambiguous genitalia would promote doubt and confusion on the part of parents and so on the child him- or herself.<sup>35</sup> Corrective genital surgery was then understood as necessary for the successful assimilation of the child into a world divided into men and women, boys and girls.

Almost forty years after Money’s theories were first advanced, the rationale for the surgical assignment of gender remains largely unchanged. The Intersex Society of North America estimates that every day in this country, five children receive normalizing genital surgery.<sup>36</sup> That fact might not seem so remarkable, but for the revelation that the famous case that served as definitive proof of Money’s theory has been revealed to be a sham. “The Case of John/Joan,” or, as it may come to be known, “the true story of John/Joan/” has been recounted everywhere from *Oprah* to NPR.<sup>37</sup> It is the story of a boy, an identical twin, who at the age of eight months was injured as doctors performed a routine circumcision. Under Money’s counsel and supervision, “John” underwent sex change surgery and was reported to have been successfully raised as “Joan.” A medical calamity was stunningly redeemed, and in 1972, just five years after the surgery, Money published, with his colleague Anke Ehrhardt, *Man and Woman, Boy and Girl*, the book that widely publicized the case and promoted a conception of gender as a product of “social construction.”

But while the medical community and the general public – alerted by a story in *Time* magazine – were captivated by Money’s tale of “the boy who became a girl,” Joan’s family was struggling to maintain the fiction that their daughter was a “normal” girl. While her twin brother recognized her as his sister, according to him,

“she never acted the part ... When I say there was nothing feminine about Joan ... I mean there was *nothing* feminine. She walked like a guy. She talked about guy things, didn’t [care] about cleaning house, getting married, wearing makeup ... We both wanted to play with guys, build forts and have snowball fights and play army.”<sup>38</sup> Joan’s parents’ reports are similar: from tearing at lacy dresses her mother made for her as a child to flushing down the toilet estrogen pills her father demanded she take at puberty, Joan displayed an intense resistance to taking up her assigned role as a girl. None of these details appeared in Money’s book, however, or in subsequent follow-up reports that claimed that Joan’s “behavior is so normally that of an active little girl, and so clearly different by contrast from the boyish ways of her twin brother, that it offers nothing to stimulate conjectures.”<sup>39</sup> When she was fourteen and her father told her what had happened to her, Joan asked for a sex change. She took hormones, underwent mastectomy, had penile reconstruction, and called himself David. And what of the subsequent reports in the medical literature? Like so many children who have been the objects of studies of gender and sexual identity, Joan was “lost to follow-up” and no further reports of the case of Joan/John appeared in the literature.<sup>40</sup>

As presented by popular programs, the “problem” of the John/Joan case is the question that motivated Money’s prolonged experiment, namely, whether gender is “natural” or “socially constructed.” As Oprah tells it, the moral of the story is that “boys *will* be boys,” that no amount of good intentions, surgical intervention, or social conditioning will change what is “biological fact.” Despite the efforts made by Joan’s parents, his teachers, the doctors at home in Canada who were treating him, or the team at Johns Hopkins to whom he and his family made annual visits, he simply would not be a girl.

As the details of Money’s suppression of data are revealed, and as his refusals to comment on the case become more conspicuous with each call that he do so, the story also raises questions of a specifically ethical nature. But these are matters that are subordinated to the “taught” they reveal about sex. While, in popular discourse, the pendulum swings from “nurture” back to “nature”, the management of intersex children – for which the Johan/Joan case served as cornerstone – remains intact, if not unchallenged.<sup>41</sup>

In her groundbreaking 1990 *Signs* article, Suzanne Kessler uncovers how the advancement of medical technology in the second half of the twentieth century allowed doctors to make determinations about an infant’s “true sex” based on chromosomal and hormonal data.<sup>42</sup> Nevertheless, she writes,

Physicians who handle the cases of intersexed infants consider several factors beside biological ones in determining, assigning, and announcing the gender of a particular infant. Indeed, biological factors are often preempted in their deliberations by such cultural factors as the “correct” length of the penis and the capacity of the vagina.<sup>43</sup>

These concerns help to explain the preponderance of intersexed infants assigned female. As one doctor put it, “you can make a hole but you can’t build a pole,”<sup>44</sup> or at least you can’t build a pole up to culturally acceptable specifications. While Kessler’s observation might appear remarkable – doctors putting more stock in cultural understandings of gender than in “scientific” determinations of sex – it appears less so when one takes into account the enormous influence Money’s theory of gender wielded, and continues to wield, in the medical community. If, as he and his colleagues proposed, first in 1955, and then so sensationally in 1972 with the case of John/Joan, gender was utterly pliable until the age of eighteen months, then it would follow that doctors could make sex determinations with impunity. Despite the fact of a clear XY karyotype and the presence of tested, for example, an unusually small penis, or in clinical terms, a “micropenis,” could constitute grounds for clinical castration and a female sex assignment. Likewise, if a female child is born with a clitoris that is judged to be “too big,” then “clitoral reduction” is indicated, based on the understanding that parents who are raising unambiguously gendered children, must, as one physician put it, “go home and do their job as child rearers with it very clear whether it’s a boy or a girl.”<sup>45</sup>

### **Whose Decision? Whose Choice?**

Money and those who have followed him recognize that parents play a crucial role in the healthy development of gender identity. But when it comes to making decisions regarding their children’s health, parents appear in the medical literature in the background, “stagehands”<sup>46</sup> to the “production” that features, in the first act, the doctors with the children in their consulting rooms and surgical theaters, and in the second act, in what is explicitly marked (for the doctors at least) as the children’s convincing performance of gender.

That conception of intersex management is changing to some extent. In current discussions, there is an increasing tendency to speak not of the “doctors’ decisions,” but rather of the “parents’ decisions” to perform corrective genital surgery and gender reassignment. A radio program produced by a Boston Public Radio station featured the work of biologist Anne Fausto-Sterling, whose *Sexing the Body* had just been published. A young surgeon called in to respond to Fausto-Sterling’s argument against corrective genital surgery to claim, “It’s the *parents* who want the surgery done.” Another radio program produced by the BBC featured a woman who recounted the devastating effects of surgery to reduce the size of her enlarged clitoris. On the heels of her testimony, a prominent surgeon explained, “This [ambiguous genitalia] is very distressing to the family, and surgery is available to make that appearance more acceptable.”<sup>47</sup> These surgeons’ statements are representative of the confusing attribution of “the decision” and “the choice” when speaking about the prospect of corrective genital surgery or gender reassignment.

### **Carol and Jim’s Story**

Even the most informed decisions reveal the ambivalent nature of consent and choice. Carol and Jim already had two children, Alex and Bobbie, when Sammy was born in the late 1990s. They were on their way to the hospital when they decided that their third child would be named Samuel or Samantha. They joke now about how their older children had unisex nicknames (short for Alexander and Barbara), but this was the first time that they had picked out a male name and its feminine equivalent. In retrospect Carol reflects that God had prepared them for what would happen.

In the birthing room, darkened for the mother’s comfort, Sammy was pronounced a girl and nursed soon after birth. It was in the middle of the night, and after an hour, when all seemed well, the doctor and birthing assistant were sent home. When Carol got up for the first time to use the bathroom, her husband joined the remaining medical resident to bathe the baby and conduct a more thorough exam. Both Jim and the resident noticed a “puffiness” in the baby’s genital area, and together considered the possibility that Sammy was actually a boy. The resident told Jim that the swelling could be caused by any number of things, but that he would call the doctor back in. Jim should not tell Carol anything for the moment.

After some consultation, the doctor recommended discharging Carol and Jim so they could recover with Sammy at home. He was concerned that the genital swelling could be a sign of CAH, but, because Carol and Jim were experienced parents, he trusted them to keep a close eye on their baby for the next twenty-four hours and to go directly to the emergency room if the baby showed any signs of distress. In the meantime, a medical team would be assembled in the city children’s hospital and they should bring Sammy in for tests. Carol remembers that when they began the tests,

*They wouldn’t tell us anything. It was all whispers and stuff like that. We had this feeling that they were leaning towards boy. They ordered an ultrasound as the doctor did the ultrasound we both said, okay, “It’s going to be a Samuel. It’s going to be a Samuel,” but then we heard them say, “Oh, there’s the cervix.”*

Genetic tests revealed that Sammy had a rare “mosaic” chromosomal pattern, but with a predominance of X chromosomes. She had a vagina and uterus, as well as a descended gonad that appeared to be composed of testicular tissue. It was removed for fear that it would develop a malignancy. The other, lodged in her abdomen, appeared to be an ovary, but contained no follicles.

Of those few days, Jim recounts,

*There was a lot of buzz going around. They were bringing in different interns and everybody was poking in during different rounds at different times. You always saw one of the doctors and somebody you hadn’t seen before. So, we were like, “Okay, this definitely isn’t something normal because everybody wants to see and come back*

*and take a look.” ... They’re kind of prepping us with words like “surgery” and “we’re going to have to take that out.” We knew they would have to do some cutting sooner or later.*

Having been informed, in no uncertain terms, that their child was a girl, Carol and Jim agreed to the removal of the remaining gonad in her abdomen, the repositioning of her urethra, and clitoral reduction.

Carol and Jim were not uninformed in these decisions. When the doctors began discussing surgery, Jim went on the Internet. The doctors at the hospital disapproved of Jim’s pursuit of information; according to him, they “really tried to steer you away from doing any research on your own. They were afraid that you were going to uncover something that they didn’t warn you about yet.” When the surgeon came and told them what he planned to do, Jim went back online and began a correspondence with a physician in Canada. He returned to the surgeon and told him that he had decided that the surgery he had proposed was too experimental. The surgeon, according to Jim was “peeved,” but relented, warning them that he didn’t want to wait “until puberty, because they’re old enough to remember this.” Carol and Jim believe that some of these decisions are properly Sammy’s, and when the time comes they will help her understand why the surgery to move her vagina and practice dilation are necessary.

Carol’s and Jim’s religious beliefs dictate that there are girls, and boys, men and women. There is nothing “in-between.” They regard homosexuality as an unqualified wrong. Still Carol wonders, remarking on the aggressive behavior of their fearless and willful youngest child, so unlike her older siblings who are “very much a girl and a boy,” whether Sammy will grow up to desire women, to feel more like a boy than a the girl she is being raised to be. They watch Sammy closely when she plays with dolls and trucks, but, just two years old, she prefers the infamously gender-nonspecific Teletubbies. There are moments when Carol wonders whether “they made the right decision,” but most of the time expresses confidence that the judgments she and her husband have made are sound.

Through it all, they retain their sense of humor. Carol and Jim joke that Bobbie wanted a sister, but didn’t get her order in fast enough. Jim, Carol reports with a wry smile, wanted one of each. And Carol herself remembers that she always wondered, “What sort of people would give birth to a hermaphrodite? Oh, any sort of people, really: Me.”

### III. DEPENDENCY WORKERS AND *HABITUS*

When Carol remembers asking, “What sort of people would give birth to a hermaphrodite?” she points to a shift that has occurred in her understanding of the world and the rules that govern it. Before the birth of her third child, she took for granted the clear division of the world into male and female. Now that she knows

“the truth,” that variation occurs, and occurs with some frequency, she has had to confront a tension between the settled expectations that had ordered her understanding and her child’s daily and insistent contradiction of those expectations.

Despite this contradiction, the expectations that organize Carol and Jim’s world – what Bourdieu would call their *habitus* – remain largely intact. In the *Logic of Practice*, Bourdieu defines *habitus* as

*Systems of durable, transposable dispositions, structured structures predisposed to function as structuring structures, that is as principles which generate and organize practices and representations that can be objectively adapted to their outcomes without presupposing a conscious aiming at ends or an express mastery of the operations necessary in order to attain them.*<sup>48</sup>

*Habitus* is only imprecisely understood in terms of “culture,” the more or less fixed assumptions that ground a person’s understanding of the world and her place within it. As Bourdieu describes it, this understanding is not, for the most part, a reflected or explicit understanding. But while Carol and Jim can no longer take for granted the “fact” of sexual difference, they continue to abide by its rules. A “structured structure,” sexual difference itself “structures” the social order in which they move and make sense of the world. Carol and Jim maintain the secret of Sammy’s mosaic chromosomal pattern from all but a few members of their immediate families because they know that others’ ignorance or cruelty could harm Sammy. The rules that shape *habitus* dictate all too clearly what could happen in the secret were revealed. Carol and Jim, like Mary ten years before them, like Ruby almost thirty years earlier, maintain their silence for their child’s protection.

But do they do so only for the children’s sake? Bourdieu’s analysis suggests that the *habitus* in which they move and make sense of the world, in turn, moves and makes sense of *them*, not only as men and women, but as parents. It is not only that the silence protects them from a kind of guilt by association: “*What sort of people would give birth to a hermaphrodite?*” But, as the doctors made clear to them all: What sort of *parents* would subject their child to life as a hermaphrodite? The challenge for Carol and Jim, for Mary and for Ruby – the job of any parent – is not only to protect one’s charge, but also to accommodate her to the world in which she lives. If, in the case of intersexed children, cosmetic genital surgery is presented to parents as a necessary adjustment, it is only too easy to understand why parents would consent to its performance.

For Kittay, the development of a “transparent self” provides dependency workers with an attunement, or identification, with their charges. But in the case of parents of intersexed children, this identification is discouraged. Parents are not given the chance to imagine their children’s lives in any way except as in need of immediate correction. Despite the fact that doctors know, for instance, that later surgeries are less dangerous and more likely to produce desirable results – both with respect to appearance and the preservation of sensation – they nevertheless promote early surgery. Children, they claim, will experience less trauma if they are spared

memories of the removal of gonads or the excision of phallic tissue. Doctors understate the eventual necessity of painful vaginal dilation in the case of the (majority of) children assigned female. The likely prospect of additional surgeries or other traumatic procedures in subsequent years generally also goes unmentioned, as does the option of delaying surgery until the child is older. If, as the experiences of the parents I interviewed suggest, decisions were not made *for* parents, they could be understood to have been made *through* them: Parents are not simple instruments of doctors’ agendas; at the same time, their decisions cannot be regarded as products of an uncompromised agency. Similarly, doctors’ failure to present a complete picture to parents may be seen, not as a conscious and deliberate effort to mislead parents for the sake of the maintenance of the binary structure of gender, but as a function of habitus, which functions, as Bourdieu understands it, to reproduce itself.

The very fact of intersex, that is, the material evidence that sex is not an either/or proposition, but rather exists on a continuum, poses a threat to the current construction of habitus – a threat that is managed by the prevention of the very possibility of posing questions about it:

The *habitus* is a principle of the selective perception of indices tending to confirm and reinforce it rather than transform it, a matrix generating responses adapted in advance to all objective conditions identical to or homologous with the (past) conditions of its production; it adjusts itself to a probable future which it anticipates and helps to bring about because it reads it directly in the present of the presumed world, the only one it can even know.<sup>49</sup>

The dispositions that motivate the practices associated with corrective genital surgery must be very narrowly concerned with the reinforcement of “the present of the presumed world.” Consider doctors’ resistance to reconsidering standard practices despite the revelation of the true story of John/Joan and the increasing publication of critical narratives by intersexed adults. Consider the insistence with which doctors promote surgical “treatments” that are similar to many of the practices known in developing countries as “female circumcision” or clitorrectomy.<sup>50</sup> In a recent statement, the American Academy of Pediatrics (AAP) declared that “[t]he birth of a child with ambiguous genitalia constitutes a social emergency.”<sup>51</sup> If the AAP declines to elaborate on the nature of this emergency, it is perhaps because there is little question of the grave threat that the revelation of intersex poses to the existing social order.

The clouding of the transparent self in the case of parents of intersexed children is a function of habitus. Parents, unwilling to harm their children, nonetheless have a stake in its maintenance. At the same time, Kittay’s analysis indicates the presence of an imperative – one that is itself a product of habitus – acting on the dependency worker to develop a transparent self capable of being attuned to what one’s charge may experience, and further, to act for that charge in a way that respects and works to ensure the future agency of that child. While, as Kittay writes, many forms of dependency may be regarded as “natural” and “inevitable,” the ways that

dependency is regarded and understood, and the ways that dependency work is conceived, are neither natural nor inevitable. The normative force of Kittay’s conception of the transparent self demonstrates how very embedded the concept is in habitus. But the habitus itself functions to cloud the transparent self. In the space of this contradiction, we may, or perhaps, following Kittay, we must ask: *What if* parents claimed their rights as dependency workers to secure the future autonomy of their children? *What if* parents opted to understand the decision to perform cosmetic genital surgery as the child’s, that is, to forgo immediate corrective surgery? Understanding the management of intersex as a function of habitus suggests the radical potential of a dependency critique. If parents of intersexed children were to work to identify with their children as intersexed individuals, if doctors were to use their considerable authority to promote acceptance of genital variation instead of erasure, the prevailing habitus would undergo genuine transformation. Not only would such a positive identification lead to improved relationships between parents and children, it would also work against the conservative principles of habitus to effect social change.

#### NOTES

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<sup>1</sup> See, e.g., essays by Martha Coventry, Howard Devore, D. Cameron, Kim, Tamara Alexander, Hale Hawbecker, and Angela Moreno in *Intersex in the Age of Ethics*, ed. Alice Domerat Dreger (Hagerstown, MD: University Publishing Group, 1999), 71-82; 91-116; 137-140; Peter Hegarty and Cheryl Chase, “Intersex Activism, Feminism and Psychology: Opening a Dialogue on Theory, Research and Clinical Practice,” *Feminism & Psychology* 10, no. 1 (2000): 117-32.

<sup>2</sup> All uncited quotations are taken from transcripts of interviews conducted by the author.

<sup>3</sup> Eva Feder Kittay, *Love’s Labor: Essays on Women, Equality and Dependency* (New York: Routledge, 1999), x, 42. See also Martha Albertson Fineman, *The Neutered Mother, the Sexual Family and Other Twentieth Century Tragedies* (New York: Routledge, 1995), 162.

<sup>4</sup> The names of parents and their children have been changed to protect their privacy. The parents from the seven families I interviewed live in nearly every region of the United

States, with the exception of one mother, who lives in a Westernized country outside the United States.

<sup>5</sup> Congenital Adrenal Hyperplasia (CAH) is a genetic condition associated with a deficiency in the enzyme 21-hydroxylase, involved in making the steroid hormones cortisol and aldosterone. Girls and boys with the “salt-losing variety” of CAH (such as Ruby’s daughters) require regular doses of the steroid cortisol, which they cannot produce on their own, as well as of a salt-retaining hormone. Without such regular treatment, children will experience crises similar to the one that brought both of Ruby’s daughters so close to death. Girls with CAH may have genital ambiguity, but boys do not. For discussion of the variety of Intersex conditions, as well as data concerning the frequency with which they occur, see Anne Fausto-Sterling, *Sexing the Body: Gender Politics and the Construction of Sexuality* (New York: Basic, 2000), 51-54. See also the website of the Intersex Society of North America at [www.isna.org](http://www.isna.org).

<sup>6</sup> Sara Ruddick, *Maternal Thinking* (New York: Beacon, 1989), cited in Kittay, *Love’s Labor*, 33.

<sup>7</sup> Kittay, *Love’s Labor*, 51.

<sup>8</sup> Kittay, *Love’s Labor*, 31. Original emphasis.

<sup>9</sup> Kittay, *Love’s Labor*, 44.

<sup>10</sup> Kittay, *Love’s Labor*, 45.

<sup>11</sup> Perhaps for this reason, many parents of children with ambiguous genitalia, including many of those with girl children with Congenital Adrenal Hyperplasia, resist the association of the term *intersex* with their children (see postings at [www.congenitaladrenal-hyperplasia.org](http://www.congenitaladrenal-hyperplasia.org)) As used in the medical literature, however, the term *intersex* designates any “defect in the normal processes of sexual maturation that results in abnormality in ... the karyotype, the internal and external sexual organs, the gonads and the secondary sex characteristics which appear at puberty.” See Sarah Creighton, “Surgery for Intersex.” *Journal of the Royal Society of Medicine*, 94 (May 2001): 218-20, 218. Resistance to the term *intersex* can also be understood as an effort, made by parents and by intersex individuals alike, to deny their difference and “fit in” to the categories given by society. Bourdieu’s analysis, in the concluding section of this chapter, makes sense of this resistance.

<sup>12</sup> Kittay, *Love’s Labor*, 35.

<sup>13</sup> Kittay, *Love’s Labor*, 34.

<sup>14</sup> Kittay, *Love’s Labor*, 34.

<sup>15</sup> Jessica had a form of Androgen Insensitivity Syndrome (AIS), a condition in which a fetus with a normal (46XY) male karyotype is unable to absorb androgens in utero. In its “complete” form, AIS would result in a child with typical feminine external genitalia and undescended testicles. In its “partial” form, the body can absorb some androgens, and at puberty an enlargement of the clitoris can result.

<sup>16</sup> The use of term *clitorectomy* is controversial. Western doctors today do not refer to “clitorectomy,” but instead to “clitoral recession,” apparently to distinguish current practices from those that are now decades old. However, review of the older literature reveals that concern for the retention of erotic sensation was not absent, as some practitioners now suggest. In a chapter published in 1956, Hampson, Money, and Hampson write that “[p]artial amputation of an enlarged phallus in a girl is an operation approached with hesitation by many surgeons, in the fear that serious loss of sensitivity may ensue. Studies ... indicate that these women have subsequently been erotically responsive and able to experience orgasm.” See Joan G. Hampson, John Money, and John L. Hampson,

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“Hermaphroditism: Recommendations Concerning Case Management,” *Journal of Clinical Endocrinology and Metabolism* 4(1956): 547-56, 551.

Insistence on the more euphemistic term *clitoral recession* appears calculated not only to place distance between past and current practices, but also an effort to distinguish “medical” (beneficent, scientific, modern) practices from “cultural” (ignorant, primitive, uncivilized) practices that occur in “other countries.” On interrogation, the distinction is credible neither linguistically nor practically. The suffix “-ectomy” simply means “to cut,” not to completely excise. “Primitive” genital surgeries are not able to excise the clitoris in its entirety, because the structure is too deep and thereby inaccessible to the instruments used. Philosopher Diana Meyers proposes the term *genital cutting* to circumvent the euphemistic terminology to characterize both “medical” and “cultural” practices. See Diana Tietjens Meyers, “Feminism and Women’s Autonomy: The Challenge of Female Genital Cutting,” *Metaphilosophy* 31, no. 5 (October 2000): 470.

<sup>17</sup> See Suzanne J. Kessler, “The Medical Construction of Gender: Case Management of Intersexed Infants,” *Signs: Journal of Women in Culture and Society* 16, no.1 (1990): 18-21. Reproduced in *Lessons from the Intersexed* (New Brunswick, N.J.: Rutgers University Press, 1998), 25-27. It is also noteworthy that penises are deemed unworthy if they are not of sufficient length to penetrate a vagina. Surgery is also indicated if the position of the urinary meatus will not permit a boy to urinate in a standing position. Genital surgery is conducted on those assigned female with an eye not to performance, but to appearance. While neither is concerned with the sensate experience of the individuals, the emphasis on masculine “performance” (in sexual intercourse and in urination) and on feminine “appearance” is consonant with conventional conceptions of proper gender roles.

<sup>18</sup> Of her examination of approximately one hundred letters written by mothers of children with ambiguous genitalia, Suzanne Kessler notes that parents’ accounts of their children’s surgery focus “disproportionately on how the genitals look rather than on what the children might be experiencing or how her genitals might function in the future” (Kessler, *Lessons from the Intersexed*, 98). The recent accounts produced over the course of a year from a Web forum for parents of children with CAH ([www.congenitaladrenal-hyperplasia.org](http://www.congenitaladrenal-hyperplasia.org)) manifest a similar concern with the appearance of the genitals, rather than with the experience of the child.

<sup>19</sup> Kittay, *Love’s Labor*, 51.

<sup>20</sup> Kessler, *Lessons from the Intersexed*, 101. 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 suggested “[c]ontrary to conventional wisdom, it is not inevitable that such [men] must ‘recognize that [they] are incomplete, physically defective and ... must live apart.’” See Kenneth Kipnis and Milton Diamond, “Pediatric Ethics and the Surgical Assignment of Sex,” in *Ethics in the Age of Intersex*, ed. Alice Domerat Dreger (Hagerstown, MD.: University Publishing Group, 1999), 181.

<sup>21</sup> Kessler, *Lessons from the Intersexed*, 101-02.

<sup>22</sup> Kessler, *Lessons from the Intersexed*, 103.

<sup>23</sup> Kessler, *Lessons from the Intersexed*, 103.

<sup>24</sup> Kittay, *Love’s Labor*, 71.

<sup>25</sup> Elizabeth Bind and Esselyn Rudikoff, “Divergent Ways of Coping with Hermaphrodite Children,” *Medical Aspects of Human Sexuality* (December 1970): 77.

<sup>26</sup> John Money, “Psychosexual Differentiation,” in *Sex Research, New Developments*, ed. John Money (New York: Holdt, Rinehart and Winston, 1965), cited in Bing and Rudikoff, “Coping with Hermaphrodite Children,” 77.

<sup>27</sup> Bing and Rudikoff, “Coping with Hermaphrodite Children,” 77.

<sup>28</sup> Bing and Rudikoff, “Coping with Hermaphrodite Children,” 80.

<sup>29</sup> Bing and Rudikoff, “Coping with Hermaphrodite Children,” 83.

<sup>30</sup> Bing and Rudikoff, “Coping with Hermaphrodite Children,” 88.

<sup>31</sup> When doctors discuss gender reassignment with parents of intersexed children, anecdotal evidence suggests that doctors promote surgeries, in part, by invoking the specter of homosexuality. If the parents consent to the surgery, their children will be “proper” boys or girls, that is, they will be heterosexual boys and girls. Cheryl Chase has discussed the (unsubstantiated) assurances that doctors provide that the surgeries will result in happy men and women who will marry and have children (by adoption, if the intersex condition is associated with infertility) (see, e.g., Hegarty and Chase, “Intersex Activism,” 126-27). See also Kessler’s discussion of the heterosexual standard doctors employ in making assignment decisions in *Lessons from the Intersexed*, 26 (also in “Medical Construction,” 20), and Fausto-Sterling, *Sexing the Body*, 71-73. As a threat (lest parents resist surgery) and as reassurance (to confirm the importance of the surgery), homosexuality figures prominently in the management of intersex.

<sup>32</sup> Bing and Rudikoff, “Coping with Hermaphrodite Children,” 80.

<sup>33</sup> Bing and Rudikoff, “Coping with Hermaphrodite Children,” 88.

<sup>34</sup> This theory of gender socialization was initially regarded as promising by feminists such as Kessler and McKenna, who saw in it a way beyond repressive traditional beliefs about women’s essential nature. See Suzanne J. Kessler and Wendy McKenna, *Gender: An Ethnomethodological Approach* (New York: Wiley-Interscience, 1978; Chicago: University of Chicago Press, 1985). Money’s own recognition of this fact is reflected, as Cheryl Chase has observed (private conversation), in his tongue-in-cheek inclusion of an entry in the index of *Man and Woman, Boy and Girl* for “Woman’s liberation, quotable material,” which cites most of the contents of the book. See John Money and Anke A. Ehrhardt, *Man and Woman, Boy and Girl* (Baltimore, MD: Johns Hopkins University Press, 1982), 310.

<sup>35</sup> See, e.g., Money and Ehrhardt, *Man and Woman*, 16.

<sup>36</sup> [www.isna.org](http://www.isna.org). Anne Fausto-Sterling estimates the frequency of the occurrence of intersex to be 1.7 percent of live births, though cautions that the number “should be taken as an order of magnitude estimate rather than a precise count” (Fausto-Sterling, *Sexing the Body*, 51).

<sup>37</sup> See, e.g., “Why This Boy Was Raised as a Girl,” *Oprah Winfrey Show*. Air date February 9, 2000. *Fresh Air* with Terry Gross. Air date February 16, 2000.

<sup>38</sup> John Colapinto, “The True Story of John/Joan,” *Rolling Stone*, December 11, 1997, 65-66. Original emphasis.

<sup>39</sup> Quoted in Colapinto, “True Story,” 70.

<sup>40</sup> It was Milton Diamond, a biologist who had spent his entire career refuting Money’s theories, who finally located the twin and publicized the story in an article published with one of the members of John’s medical team in his native Canada. See Milton Diamond and Keith Sigmundson, “Sex Reassignment at Birth: Long-Term Review and Clinical Application,” *Archives of Pediatric and Adolescent Medicine* 15, no. 11 (May 1997): 298-304.

<sup>41</sup> In the wake of increasing skepticism concerning intersex management and explicit challenges to Money’s theory (in addition to Diamond and Sigmundson, see, e.g., William Reiner, “To Be Male or Female: That is the Question,” *Archives of Pediatric and Adolescent Medicine* 151 (1997): 224-25; “Sex Assignment in the Neonate with Intersex or Inadequate Genitalia,” *Archives of Pediatric and Adolescent Medicine* 151 (1997): 1044-45), Susan Bradley and colleagues in Canada report that a similar case of “ablation penis” had the desired result: The child, a normal 46XY male at birth, currently identifies as female. Bradley and her colleagues report that, consonant with Money’s theory, “the most plausible explanation of our patient’s differentiation of a female gender identity is that the sex of rearing as a female ... overrode any putative influences of a normal prenatal masculine sexual biology.” The authors speculate that the gender identity of their patient differed from that of Money for two reasons. One, the decision to reassign the child happened much earlier than in “John’s” case, and two, “that the parents of our patient, particularly the mother, had less ambivalence about the decision than the parents of [John].” See Susan J. Bradley, et al., “Experiment of Nature: Ablatio Penis at 2 Months, Sex Reassignment at 7 Months, and a Psychosexual Follow-Up in Young Adulthood.” *Pediatrics* 102, no. 1 (July 1998).

<sup>42</sup> For an extended treatment of the history of “hermaphroditism,” see Alice Dreger’s *Hermaphrodites and the Medical Invention of Sex* (Cambridge, Mass.: Harvard University Press, 1999).

<sup>43</sup> Susanne Kessler, “The Medical Construction of Gender,” 3; *Lessons from the Intersexed*, 12.

<sup>44</sup> Quoted in Melissa Hendricks, “Is It a Boy or a Girl?” *Johns Hopkins Magazine* 46, no. 6 (November 1993): 19-16, 15.

<sup>45</sup> Kessler, *Lessons from the Intersexed*, 16.

<sup>46</sup> Frye, *Politics of Reality*, 38, cited in Kittay, *Love’s Labor*, 38.

<sup>47</sup> “The Science and Culture of Gender,” May 24, 2000. *The Connection with Christopher Lydon*, broadcast on WBUR Boston, June, 2000. “Intersex Conditions” radio broadcast on the BBC December 11, 2001. Available from [info1.shtml](http://info1.shtml). See also Alice Dreger’s discussion of the experience of Tod Chambers, a bioethicist consulting on a case of intersex who was informed by the attending surgeon that surgical correction of ambiguous genitalia was “really for the benefit of the parents.” *ISNA News*, May 2001, 3. Available from [www.isna.org](http://www.isna.org).

<sup>48</sup> Pierre Bourdieu, *The Logic of Practice* (Stanford, Calif.: Stanford University Press, 1990), 53.

<sup>49</sup> Bourdieu, *Logic of Practice*, 64.

<sup>50</sup> Indeed, these practices are prohibited by federal law in the United States. It would appear that 18 U.S.C. § 116, entitled, “Female Genital Mutilation” (1996), would apply to surgeries performed on intersexed children. The law states that “whoever knowingly circumcises, excises, or infibulates the whole or any part of the labia majora or labia minora or clitoris of another person who has not attained the age of 18 years shall be fined under this title or imprisoned not more than 5 years, or both.” An exception is noted, however: “A surgical operation is not a violation of this section if the operation is ... *necessary to the health of the person on whom it is performed*, and is performed by a person licensed in the place of its performance as a medical practitioner.” In applying this exception, a subsection of the law clarifies that “no account shall be taken of the effect on the person on whom the operation is to be performed of any *belief on the part of that person, or any other person,*

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*that the operation is required as a matter of custom or ritual*” (emphasis added). That the very conventions of gender (as understood by Money and his colleagues) that explicitly motivate the surgeries could themselves be understood as “a matter of custom or ritual” is elided by the health exception written into the law.

<sup>51</sup> American Academy of Pediatrics, “Evaluation of the Newborn with Developmental Anomalies of the External Genitalia,” *Pediatrics* 106, no.1 (July 2000): 138.