

PROF. STEFAN TIMMERMANS (Orcid ID : 0000-0002-4751-2893)

Article type : Original Article

## Gender Destinies: Assigning Gender in Disorders of Sex Development-Intersex Clinics

Stefan Timmermans<sup>1</sup>, Ashelee Yang<sup>1</sup>, Melissa Gardner<sup>2</sup>, Catherine E. Keegan<sup>3</sup>, Beverly M. Yashar<sup>4</sup>, Patricia Y. Fechner<sup>5</sup>, Margaret Schnorhavorian<sup>6</sup>, Eric Vilain<sup>7</sup>, Laura A. Siminoff<sup>8</sup>, David E. Sandberg<sup>2</sup>

1 Department of Sociology-UCLA, Los Angeles, USA

2 Department of Pediatrics & Communicable Diseases, University of Michigan, USA

3 Department of Pediatric Genetics, University of Michigan, USA

4 Department of Human Genetics, University of Michigan, USA

5 Department of Pediatrics, Seattle Children's Hospital, Seattle, USA

6 Department of Urology, Seattle Children's Hospital, Seattle, USA

7 Children's Research Institute, Children's National Medical Center, Washington, DC 20010

8 College of Public Health, Temple University, Philadelphia, USA

### Abstract

Based on audio recordings of consultations in three U.S. pediatric multidisciplinary Disorders of Sex Development-Intersex clinics, we examine the process of gender assignment of children with “atypical” genitalia. Rather than fully determined by the presence of biological sex traits, the gender assignment discussion hinges on how clinician and parent collaboratively imagine

different aspects of what constitutes being a gendered person. They orient towards the potential

**This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the [Version of Record](#). Please cite this article as [doi: 10.1111/1467-9566.12974](https://doi.org/10.1111/1467-9566.12974)**

This article is protected by copyright. All rights reserved

for sexual intimacy, fertility, gender dysphoria, stigma, and gonadal cancer risk. While these futures remain inherently uncertain, clinicians and parents plan to mobilize gender socialization and medical interventions to render their choice of gender a self-fulfilling prophecy. Gender destinies capture that the child always had a specific, innate gender awaiting discovery, and presumes a project for medical and social monitoring, intervention, correction, and optimization.

Keywords: stigma, future imageries, gender, uncertainty, decision-making, socialization

Parents often feel unsettled when they find out that the biological sex characteristics of their newborn child look “ambiguous” (Gough et al., 2008; Zeiler & Wickstrom, 2009). Depending on definitional criteria, the incidence of what are called intersex or, in medical circles, disorders of sex development (DSD)<sup>1</sup> is estimated at 1 in 4,500-5,000 births (Lee et al., 2016). When a baby is born with intersex traits, parents and health care professionals face the decision of assigning a social gender category with little conclusive guidance from biological sex characteristics (Davis, 2015; Karkazis, 2008). This article examines how providers and parents approach intersex bodies to align embodiment with a binary system of sex, gender, and sexuality in light of the child’s imagined future.

The biomedical field of intersexuality has been sensitized by decades of activism and highly publicized media narratives that gender assignment can go wrong (Colapinto, 2000; Davis, 2015): when children with DSD grow up they may experience gender dysphoria (dissatisfaction with the assigned gender) and social stigma. Intersex activists have taken the medical profession to task for locking in the assigned gender with hormonal treatments and unnecessary and irreversible cosmetic surgeries, increasingly framing genital surgery not as a medical but as a human rights issue (Turner, 1999). Subsequently, some intersex activists and health care professionals developed a new nomenclature of Disorders of Sex Development with principles of care for the conditions that required medical intervention (Lee et al., 2006). While this collaboration and nomenclature proved controversial (e.g., Davis, 2015), accompanying documents acknowledge that an initial gender should be assigned to a child with DSD, but that initial assignment is more likely “incorrect” for DSD patients than for the general population

This article is protected by copyright. All rights reserved

(Consortium on the Management of Disorders of Sex Development, 2006). The challenge facing parents and clinicians contemplating gender assignment of a child born with intersex traits is that it is impossible to infer an infant's gender identity (how the child will identify with the assigned gender) from biological characteristics (Davis, 2015; Karkazis, 2008; Kessler, 1990; Preves, 2002).

Clinicians and parents, as surrogate decision makers of a child with “atypical” or “ambiguous” genitalia, aim to discover sex and infer gender soon after birth, striving for harmonization between gender identity and sex traits (Davis, 2015; Karkazis, 2008; Kessler, 1990; Preves, 2002). Parents generally harbor deep anxieties about what the future of a child with a DSD may look like, and these fears influence gender assignments (Davis, 2015; Feder, 2009; Gough et al., 2008; Karkazis, 2008; Kessler, 1998; Preves, 2002). Clinicians not only have more scientific data and experience to inform gender assignments, but also can marshal this information strategically to make certain decisions seem more appropriate than others (Timmermans et al., 2018), putting a distinct biomedical spin on gender.

Several intersex scholars have noted that normative gender expectations inform gender assignment. Comparing intersex and trans medical experiences, for instance, Davis, Dewey, and Murphy (2016) argue that health care providers are gender gatekeepers who authoritatively validate the construction of heteronormative bodies based on gender expectations. Similarly, Karkazis asserts that gender assignment for infants with intersex traits “is not so much an innate feature as something variously imagined and enacted” (Karkazis, 2008). She points to folk rules that buttress binary genders, noting that decision-making is suffused with cultural assumptions of gendered embodiment and sexuality. Danon argues that “socio-medical timeframes aim to control the future existence of intersex bodies, to enforce the dimorphic soma-gender order in the first two years of babies' lives, and to predict intersex patients' future social experiences, interactions, and relationships.” (Danon, 2018b). Building upon this work, we examine the specific projections that result in gender assignment as feminine or masculine during clinic visits.

Imagined gender-typical behavior has played a critical role in how institutions police gender ambiguity (Brubaker, 2016; Sweeting et al., 2017; Westbrook & Schilt, 2014). Such gender imaginaries may justify early cosmetic and often irreversible surgical interventions that have been the target of intersex advocacy (Davis, 2015). Rather than creating spaces and discourses

for gender variance (Meadow, 2011; Rahilly, 2015), these gender imaginaries then validate medical interventions that reinforce and normalize gender binaries and also pathologize intersex embodiments (Foucault, 1978).

To examine the role of biomedical gender expectations in gender assignment, we draw upon the scholarship of prognostication (Christakis, 1999), foretelling a patient's future based on current observations. Social scientists have been interested in how conjuring a particular future mobilizes people in the present (Tavory & Eliasoph, 2013). Even if the prognostic imaginary is based on faulty information, speculative scenarios, and root decision-making, actions are real in their consequences, leading to self-fulfilling prophecies. Tavory and Eliasoph (2013) emphasize how future anticipations fit into people's individual and collective trajectories. People situating themselves within various timeframes and drawing upon cultural repertoires may disagree about which future matters. Mische (2009) further distinguishes between the reach of future scenarios (short, middle, or long term), their breadth (range of possibilities), clarity of the future, the inevitability of future scenarios, the control people have over the future, and the social consequences of action or the way a future self will reflect back on an action taken now. These aspects circumscribe the extent to which people feel they have agency to implement a desired future or whether they have little option but to resign themselves to what's to come.

Based on audio recordings of consultations in three pediatric US Disorders of Sex Development (DSD) clinics, our contribution is twofold. First, we examine a controversial high stakes manifestation of medical professionals' cultural authority in the realm of gender. We argue that physicians patrolling the boundary between male and female categories skew the process of gender assignment to privilege gender manifestations that fit a biomedical frame. For instance, clinicians are more comfortable considering the possibility of gender dysphoria than the social stigma of "ambiguous" sex traits. Critical in the gender assignment decision is the sense of agency and responsibility clinicians provide parents to align sex with gender, and modify sex if future problems ensue. Clinicians' primary involvement in gender assignment then puts a distinct biomedical spin on the ontology of gender.

Second, drawing from medical sociology and social science scholarship on the importance of prognostic imaginaries for understanding medical decision-making, we develop the notion of *gender destinies*. We take issue with literatures that locate gender assignments primarily in

observed biological traits. Instead, we show that through clinical conversations, these traits are mobilized to project a normalized gender future for the child. Gender destinies capture that gender is simultaneously *natural*, in the sense that the child always had a specific, innate gender awaiting discovery, and *constructed*, in ways that render the assigned gender a project for medical and social monitoring, intervention, correction, and optimization. The term does not imply that gender is make-believe, but that for children with intersex traits gender is, quite literally, made real. The biomedical gender imaginaries combined with the idea that the child is destined for a gender provide a medical rationale that absolves clinician and parents from making the “wrong” choice.

## **Methods**

The analysis is based on audio-recordings of multiple visits between specialist healthcare providers and a total of 61 caregivers of 31 patients that occurred during regular DSD clinic appointments at three pediatric U.S. academic medical centers (A-B-C followed by a case-number). The research was part of a Patient-Centered Outcomes Research Institute (PCORI)-funded research project approved at each participating institution's IRB in which caregivers of 13 children gained access to a web-based Decision Support Tool (DST); 18 families were seen at clinic prior to the DST's creation. The DST advised parents about the difference between elective and urgent surgery, described the kinds of surgeries, and gave the parents a list of issues to consider when discussing surgery. Comparison of the transcripts from Phase 1 (prior to introduction of the DST) with those from Phase 2 (involving parent access to the DST), however, did not reveal systematic differences in the qualities of the clinician-caregiver communication. While this methodology has the advantage of observing gender assignment as it unfolds over time and is not subject to recall bias, a limitation of this study is that researchers did not observe the interactions in person.

The clinics relied on multidisciplinary teams including a geneticist, urological surgeon, endocrinologist, psychiatrist or psychologist, a coordinating nurse, social worker, and genetic counselor. The structure of clinical interactions differed between institutions: at two centers (A-C), families met with all or most specialty healthcare team providers simultaneously over the course of 1-2 hours; at the third center, families typically met with each provider, or a small

subset (2) of providers, serially over the course of several hours. Several of the clinicians in each site had professional contacts with the intersex advocacy movement.

At the time of the first audio-recording in clinic, caregivers ranged in age from 18 – 65 years ( $m = 33.5 \pm 9.3$ ). Ninety percent of caregivers were biological parents (30 biological mothers, 25 biological fathers, 6 grandparents). The majority of caregivers were women (57.4%), non-Hispanic (83.6%), and White (78.9%). The median highest educational level earned was High School or equivalent degree (48.0%). Patients included 14 infants and young children being reared as boys, 16 as girls, and one child whose gender of rearing remained undetermined during the course of the study. Patient age at the time of the first recording ranged from 0 – 5.5 years ( $m=1.0 \pm 1.5$ ). All but two of the children with gender assignment discussions were infants less than one year of age.

The audio recordings were transcribed by a professional transcription service. We coded the transcripts following the principles of abductive analysis (Tavory & Timmermans, 2014) to distinguish the components of gender assignment discussions and to map the course of decision-making. Abductive analysis is a sequential data analysis approach that aims to code data in light of an existing literature in order to make theoretical contributions. Abduction refers to a creative inferential process aimed at producing new theories based on surprising research findings. The process of qualitative data analysis began with reading the transcripts iteratively in light of the social science literature on intersex, gender, and patient-doctor interaction. Two coders independently reviewed all cases to identify all decisions about gender assignment and once complete, grouped interactions by the parents' initial inclination towards gender assignment. They reconciled all discrepant codes.

## **Results**

Discussion of gender assignment is not always on the agenda in DSD clinics. In about half of the families (15 out of 31), parents and clinicians did not discuss gender assignment. Patients may have presented with “ambiguous” genitalia, but their gender was not a pending concern. The parents came into the DSD clinic with a firm opinion about the patient's gender and DSD clinicians agreed by using the same gender pronouns that parents did.

In the sixteen cases where gender (re)assignment was addressed, the scope of the discussion

varied. The iconic instance where the agenda of the meeting was to decide about assigning a gender, occurred only in six instances. An example of an endocrinologist: “Right, the baby's karyotype is XY, and most XY individuals have testes. So, we're thinking it's very likely that your baby has testes. So, then the question becomes, should you continue to raise your baby as a girl or as a boy, and is that a decision you wanna make today or is it something that you wanna think about and wait until we get some more labs back?” (C12) In the other cases, the question was whether the assigned gender was appropriate in light of the sex characteristics. At issue is a variant of this Mom's query: “So, are they sure it's a girl?” (B4) The biomedical investigation may either lead to confirmation of the assigned gender, or it may introduce findings that reopen or change a previous decision.

Furthermore, some infants had life-threatening health concerns and gender assignment was not the most pressing issue. Thus, in a family where parents had three prior unsuccessful pregnancies, the father emphasized that the health of the baby was more critical than gender assignment: “We didn't get to hear any of our other babies cry. The medical fears in me overtook the fears of the genital thing” (B2). The fetus was identified prenatally as a girl on ultrasound. At birth the hospital staff put a bow on the baby's head to signify the female gender, even though the external genitals looked “ambiguous.” The parents and health care providers decided to re-assign a male gender at 21 days, largely based on karyotyping results. While the parents worried whether they made the right decision, they were delighted that the child was healthy.

Although gender assignments are often presented as a singular choice, salient in these data is how the diversity of disorders and children's presentations are treated as components which can gradually be put into a coherent puzzle that invoke one rather than another gender destiny. We organize the analysis by examining how gender destinies originate from expectations grounded in the pregnancy and delivery experience, followed by results of tests and observations in the DSD clinic. We then examine how specific gender imaginaries consolidate or change the child's gender destiny: clinicians advance the notion that sex traits can be modified now or in the future to align with gender identity and avoid gender dysphoria and social stigma. Reassured that they have some agency over the process, parents and clinicians then pick the “appropriate” gender based on the child's imagined fertility, sexual intimacy, cancer risk, and anticipated wishes.

## Past Expectations

The visit to the DSD clinic is never the beginning of gender assignment but inevitably a phase, albeit an often significant one, in an ongoing process. By the time parents reach the clinic, they may have settled upon a gender based on previous interactions with health care providers (Danon, 2018b). Prenatal ultrasound, chromosomal results from amniocentesis, or even maternal intuitions of how this pregnancy feels like a boy or girl inform parents about the child's presumed sex traits during pregnancy (Crissman et al., 2011). Twenty-eight out of 31 parents learned about the child's sex prenatally. Only two parents opted not to know, and for one of those the hospital staff still knew the child's karyotype (the remaining child was adopted from abroad). For instance, a father explained that his wife "had a very strong feeling that we were having a girl at the very beginning, and actually that changed throughout the pregnancy. She became more and more sure that we were having a boy." (C11)

Since most births take place under medical supervision, hospital staff examined the newborn soon after delivery to announce a gender based on visible sex characteristics, which may be inconsistent with the previous prenatal announcements. Five parents received a different gender announcement at birth from what they had been told prenatally and chose to go with the later assignment as they acknowledged that prenatal ultrasound can be unreliable (in three additional cases, prenatal ultrasound tests alternated between male and female). A mother recalled: "the ultrasounds throughout the pregnancy that seemed to be the most prevalent of the sex genitalia by the 18th week ultrasound, they were like, 'Girl,'— no questions." But then when the baby was born, the father, who worked as a nurse, reported: "when the baby came out I was like, "Wait a minute is that a girl?" And they were like, "No, it looks like it might be a boy." (B3).

Some children spent time in the NICU, or their pediatrician noted genital ambiguity. These health professionals reassigned gender from the gender announced at birth in three more children and documented ambiguities in three additional children.

Gender assignments prior to the DSD consultation are further socially and bureaucratically anchored with birth announcements to family and friends and by designating a sex on the birth certificate (Zeiler & Wickstrom, 2009). Thus, one Latino family waiting for a definitive gender assignment still treated the baby as a girl "Because the birth certificate thing happened. You know they have to do that within ten days. And we were trying to hold them off and then we had

to say something on Thursday. We had to give them a name.” (A1). Two young parents reported that “everyone bought them girl clothes” after an ultrasound told them that their child was a girl for whom “everything looked normal.” (B10).

These gender pronouncements at earlier time points generate *path dependency* (Shostak et al., 2008) of how the findings in the DSD clinic will be received. Path dependency explains how decisions in the past limit the choices in the present. Such dependency was striking in a situation in which the prenatal ultrasound and the genitalia at birth suggested that the parents were having a girl (B9). A surgeon repairing a hernia noted testicles and no sign of a uterus. The child visited the DSD clinic at age 2. Karyotyping<sup>2</sup> showed that the child had XY chromosomes. These findings raised consideration of gender reassignment but the parents were reluctant to even consider that possibility. The endocrinologist admitted that two years of raising the child as a girl would be difficult to change. “We have the diagnosis already. Also, it comes back to you as a family. Say we know that she has XY. However, XY does not mean she has to be boy. So, your family will decide. So, she will be a girl or you want to raise her as a boy. From what I know that you’re pretty much set you want to continue raising her as a girl, right?”

Based on these earlier experiences, parents enter DSD team interactions with the understanding that their child has been destined for a particular binary sex and gender: in spite of ambiguous genitalia, the child is perceived to be innately masculine or feminine and the remaining question is which side of the binary. DSD clinicians do not enter a neutral domain of decision-making with parents but one with preexisting gender and sex trait trajectories and these previous predictions, announcements, and assignments create impediments to change. Past expectations are not insurmountable: parents and clinicians did reassign gender and considered it in other cases. This step depended on how the medical staff linked the child’s biological sex traits to a biomedicalized future of a boy or a girl.

### Present Findings

The immediate task of the multidisciplinary DSD team is to assess the child’s biological sex traits in order to come to a diagnosis since the same configuration of reproductive anatomy can be caused by multiple conditions. This involves history taking, a physical examination which included detailed description of the external genitalia, chromosomal karyotyping (and in some

cases genetic testing), imaging of the internal reproductive ducts, and measuring sex and adrenal hormones during the child's critical first months of life. The cumulative evidence from such testing and predictions regarding the capacity of the gonads to produce sex hormones form the basis of recommendations shared with the parents. A genetic counselor explained the clinic's purpose to the parents of an older child with a 46,XY karyotype raised as a girl: "We also want to know too to, sort of, help us pinpoint what's her diagnosis because the diagnosis can help us with what kind of care and management she's going to need." (B1).

This diagnostic work occasionally informed gender (re)assignment directly by making one sex more likely than others. Thus, in a child diagnosed with a mosaic genetic pattern, with one cell line indicative of a Turner syndrome variant, the genetic counselor explained that Turner syndrome is associated with girls, but this particular variant goes with a boy: "Right. So, when we use the term Turner syndrome, Turner syndrome is used to describe girls who have only, like, those 45 X cells. So, they have – they're missing this other chromosome... So, we wouldn't say [child] has Turner syndrome. Right? Cause he's a boy. But he has some of these cells that can cause some of the features of Turner syndrome. Okay? So, that's why that term comes into play." (B5). This was a unique instance in which the DSD diagnosis implied that the child *is* indeed a boy or a girl.

More typically, the diagnostic work only indirectly impacted gender assignment. Across the three sites, the health care providers impressed that no single piece of biomedical data determines gender: "the tests just give information, they don't tell us what to do." (A1). "So, you should never believe that the physical difference at birth determines the happiness. Because it doesn't." (B2) "the important thing to know about this is that whether you're XX or XY doesn't necessarily dictate what your gender identity is." (C15). Implicit in the discussion of the size, texture, and form of external genitalia and the presence, composition, and functionality of internal genitalia is a theory of how physical, psychological, and social aspects of sex and gender open --or foreclose-- opportunities for future health and wellbeing. Parents and clinicians orient to different aspects of these futures and they weigh them differently. Gender assignment then becomes a quest to find the correct destiny for the child in light of future opportunities.

Anticipating the Future

This article is protected by copyright. All rights reserved

Drawing from clinical findings, parents and clinicians raised issues about the child's future, in the process making the case for one gender. Parents drove these conversations in nine of the consultations, meaning that they strongly argued for one gender, and sifted through the findings to bolster their preferred choice, looking for medical help to fulfill the child's gender destiny. Parents did not simply impose their preferred choice on the biomedical findings but they were motivated by two kinds of fear: anxiety about *social stigma* because the child with DSD would grow up different and the fear that the child would *reject the assigned gender* at a later age. Clinicians, in turn, offered normalizing biomedical interventions and gender socialization as a means to allay these fears. This did not address social stigma but was more successful in neutralizing concerns about gender dysphoria. Still, the possibility of medical recourse empowered parents and clinicians to align sex markers in favor of a specific gender assignment.

*Gender assignment, sex alignment*

The message communicated systematically across consultations was that whatever decision parents made, health care providers could help the decision “stick” through surgical and hormonal interventions. Clinicians seamlessly moved from diagnosis into treatment possibilities. While some surgeries would be more complicated than others and may come with drawbacks, no gender option was off the table because of surgical limitations. Gender assignment was thus not only presented as a binary choice but aligning gender and sex characteristics was always a possibility, even if “normal” results could not be assured. In a family of young parents (18 and 19 years old) where the father himself had undergone hypospadias repair<sup>3</sup> at age six, a surgeon summarized a review of the choices with:

So, I would say could we go down the path of a girl, could we go down the path of a boy – from a surgeon's point of view, I mean, they both have pros and cons, but they're both possible. And then the other aspect to consider is, whether you go down the path of male or female – the surgery issue is one issue, but the questions that you asked about – if you choose one path, then gonads will have to come out, and she'll have to be on lifelong estrogen replacement. ... And then the other path is you don't have to take hormone replacement because what she will produce is most likely gonna be testosterone. And so, if she is a boy then that's the correct hormone. (B10)

Note how the surgeon tips the “correct” decision by using female pronouns. Despite attempts to decouple the two decisions, the issue that traveled with gender assignment was whether and when to do genital surgery. The implied advantage of reconstructive surgery and gonad removal was that genitalia and gender of rearing could be aligned. Yet, the disadvantage was that this would lock in a decision. The same surgeon explained: “So, like, removing tissue – that’s something you cannot go back and undo.” Surgeons were aware of this issue because their practice contained grown-ups expressing dissatisfaction with genital surgery conducted early in life, and because of engagement with the intersex advocacy community.

### *Gender dysphoria*

Although the DSD staff raised the possibility of future gender dysphoria, they noted that it was difficult to predict and there was scant data on its causes. A psychologist admitted: “we don’t know what predicts gender identity or gender dysphoria in any kid, so.” (C11). The message for parents was that gender dysphoria was indeed a possibility but not necessarily tied to a specific DSD condition. Even if dysphoria was more likely among children with some DSD conditions, the gender of rearing mattered most: “We know with some conditions there is a chance that children will not identify with their sex of rearing [sic], or the sex that they were assigned [sic]. *Usually kids however they’re raised, that is how they identify with.* But we know with some of these conditions those differences in hormones do lead them to sorta feeling differently than how they were initially assigned. And that’s something we’re still learning a lot about.” (B9). The take-home point for parents is that *gender of rearing* strongly predicts the gender the child will identify with, in effect neutralizing the importance of gender dysphoria as a consideration in gender assignment. Parents received the message this way. A father whose child was initially assigned a male gender but for whom the discovery of a uterus in the NICU changed the gender assignment to female, noted after a psychologist explained to him that genitals do not determine gender identification: “Well, I already have ideas about what is most important in considering surgery, ... [Gender assignment]’s not as much of a concern now” (B8).

The only explicit association between DSD and gender dysphoria came in a discussion of gender assignment of a child diagnosed with 46,XX CAH (Congenital Adrenal Hyperplasia).<sup>4</sup> This condition can present along a spectrum of masculinized female genitalia; in this particular

case, genital appearance resembled that of a typical male (i.e., Prader scale score of 5/5 in which a higher score indicates more virilization of the genitalia). The parents were set on assigning a female gender and the geneticist cautioned them with: “So, CAH cases of Prader 4 and 5 are more likely than, than 1 to 3 to have, later on, some what’s called gender dysphoria. Meaning that they’re not as at ease with their gender than as the general population. It could be up to ten percent. It’s small. But it’s not zero” (A2). Note how this statement was weakened with guesstimates and a conditional presentation.

Some parents nevertheless expressed deep concerns about making the “wrong choice” or “wrong decision.” Those concerns could be allayed with the promise of future medical interventions. The staff emphasized that they could do genital surgeries when the child was older or hormonally suppress puberty in the case of pubertal changes discordant with the child’s gender identity. While they broached gender dysphoria, clinicians did *not* discuss that these early genital surgeries may also produce suffering, social alienation, and trauma later in life (Danon, 2018a; Davis, 2015).

### *Social Stigma*

A different fear was that once a choice was made, the child would still look atypical and be vulnerable to stigmatization. Except for three parents who downplayed the issue, parents vividly anticipated stigmatizing encounters if their child had ambiguous genitalia, if the child’s gender was reassigned, or if they reared their child in the “wrong” gender. Parents imagined bullying and lack of understanding from other people, including their family, friends, and people in the child’s life. The mother of an adopted child with XYY karyotype contemplating hypospadias repair stated:

The scenarios I picture are, you know, I played the game. Kids played the game. You know of peeking when somebody’s peeing and ... someone looking at him and saying, you don’t have a wiener or whatever kids would say. And so and then him being like, wait, what? And, and maybe that’s already happened and he just doesn’t care. But my fear is him being like, oh, gosh, they’re right, like I don’t look like that. Because, again, the peer – I think the peer influence is so much stronger. (B12).

In all these cases, the anticipated stigma greatly influenced their decision to assign a specific gender or to opt for surgical interventions by raising fear of difference and hope for normalcy (Adams et al., 2009).

One of the most striking cases where fear of social stigma drove decisions involved a child who developed an enlarged clitoris at six months of age. Her mother scheduled the appointment at age three to surgically reduce the clitoris, but the staff was unwilling to go that route until they understood its cause. They considered the enlarged clitoris cosmetic and temporary.

Complicating the issue was that the patient's karyotype came back 46,XY and that she had a uterus and testes. The mother, however, focused solely on the anticipated social implications of raising a girl with an enlarged clitoris. She refused to send her child to school out of fear of being singled out in the bathroom: "She's gonna need assistance and somebody gonna, 'Oh wow, look at this' or go talk to somebody else about it. No. I don't want my daughter going through that." Even though her husband did not see an issue, the mother refused to confide in a teacher: "If I have to homeschool that's what I'm gonna do. I don't want her to start school like that." (B11). Other parents earlier in the process really wanted a resolution in order to announce their baby's gender: "But I just, my thought I just, you know I hate if, you know people, you know we're in a small town. So, then you got someone knows about it and someone gets talking about it. And then, as she goes through school, you know, people talking. Oh, yeah, you're the one, you know. So, you know you worry about that kinda stuff. But just cause kids are brutal sometimes." (C15).

Clinicians' approach to social stigma was different from how they addressed gender dysphoria: they tried to convince parents that such fears were unfounded by exposing their hypothetical nature. A psychologist, for instance, told the story of a grandmother focused on the bullying her grandson would face when taking showers in high school. When he asked the grandmother if she ever had taken a shower in high school, she had to admit that she never had. The same psychologist said to a different family: "Anxiety's not a great guide for decision-making," (B8) implying that the fears underlying the imagined scenarios also reflected the parents' own discomfort with gender ambiguity.

But care providers were not unified in their take on social stigma: some brought up the potential of stigma or at least of looking and being "normal" as a reason for gender assignment combined with surgery. And indeed, even if this link was not always made explicitly, clinicians'

This article is protected by copyright. All rights reserved

presentation of surgery-hormone therapy as ways of making genitalia look and function in a more gender-typical manner sends parents the message that these interventions could also avoid stigma and therefore should be done sooner rather than later (Sanders et al., 2008).

The future presented in the clinic thus reinforces medical interventions as the solution to problems of embodied intersex differences for self and society. Even if the success of the medical interventions remains unclear, the core issue is that parents and clinicians feel they have a measure of control over the process and outcomes (Mische, 2009). Biological sex is presented as relatively plastic: external and internal sex traits can be removed, brought down, enlarged, shortened, or sculpted; while hormonal processes of development during puberty can be supplemented or suppressed. Clinicians present surgery and hormone therapies not simply as sex-normalizing but as sex-gender realignment techniques.

These messages give parents *agency* over the future in spite of lingering unknowns. Yet, it is an agency filtered and granted by clinician's cultural authority that saddles parents with the responsibility to fulfill their child's gender destiny. Health care providers suggest to parents that normalness is within reach, now and in the future, regardless of what gender they pick, absolving parents from making the wrong choice. The option of waiting things out becomes consequently less attractive: why not chose a gender and do surgery if there are few drawbacks, and problems can be fixed later? While the promise of continued medical problem-solving if issues arise in the future is reassuring, it does not tell parents and clinicians which gender to pick. Considering that parents come in with strong opinions of their child's gender destiny, these messages reinforce that their original aspirations are attainable.

### *Boy or girl?*

Parents and clinicians sift through DSD diagnostic findings to imagine gender-specific futures centered around biomedical sensibilities. With Tavory and Eliasoph (2013), we can think of these gendered futures as a temporal landscape of naturalized expectations that growing children experience in gendered and heteronormative ways. Blending in as boy or girl, preserving fertility, or having sexual intercourse are unquestioned projections, even though not every person, regardless of DSD, will experience them. Still, parents and clinicians steer the

decision in the hope of conserving at least the potential of these naturalized gender-typical futures, mobilizing these imaginaries to fulfill the child's gender destiny.

*Fertility:* Both parents and DSD providers marshaled the potential for fertility as evidence for a particular gender assignment. Thus, in a consultation where the geneticist tried to convince parents not to schedule surgery, he mentioned in passing the potential for fertility with a female gender assignment. The mother interrupted: "Right that is my biggest thing." (A2). Health care providers also mentioned the possibility of fertility to convince parents to reassign their child's gender from a girl to a boy. An endocrinologist stated: "But her sex of rearing [sic] we think would be better as a male, there's the potential for fertility as a male." In several cases, future fertility was the main argument in favor of a particular gender (C12). Fertility, however, could not be guaranteed. Leaving gonads only allowed for the *possibility* of fertility (Davis, 2015; Karkazis, 2008).

*Sexual Intimacy:* Potential for penetrative sexual activity for both men and women, and for men to pee standing up, were less decisive indicators of a particular gender destiny, but it was discussed as an added benefit for picking one gender. This concern was mentioned more by health care providers than by parents. Surgeons warned that reducing the clitoris could affect sexual pleasure. Generally, the message was that shape and size of genitals does not guarantee sexual bliss, but that satisfaction with genitalia should be monitored as the child grew up and to respond with love and support if problems arose.

Dad: This is gonna be kind of a weird question coming from her father but based on the physical exam that-that we're gonna do later, will you guys be able to tell us the likelihood of her having a normal sex life? Is that something you'll be able to sort of predict or --

Endocrinologist: Well I think that she's going to be most likely able to have that but if she needs help in terms of maybe some repair we can *offer* that to her when she's older.

Dad: Okay. Okay.

Gynecologist: Yeah and that's a really complex question so, as a gynecologist, I see lots of people you know, have normal sex lives, and may have anatomy or you know in different ways that you wouldn't expect but they have very healthy normal sex lives and then other gals who, you know everything seems sort of typical but they don't have a normal sex life for a variety of reasons. So, you know I think the most important thing going forward is that

she feels comfortable in her own skin that she feels loved and supported and that as she grows older that she gets into healthy relationships. (C1)

Surgeons also offered interventions at a later point if needed for sexual intimacy: “If [the vagina] remains too small we would just do a little something like that to make it a little bit bigger.

That’s all that she would need. That would be all she would need on the outside to be able to have sex.” (B1). Similarly, boys with chordee (downward curvature of the penis) could undergo surgery at a later date if sexual pleasure was an issue. While parents may have perceived these conversations as indicative of a heteronormative future, clinicians were careful to keep the child’s sexual orientation unspecified by focusing narrowly on issues of access and satisfaction.

*Cancer Risk:* The gendered future parents and clinicians agreed should be avoided is one where there is an increased risk for cancer due to undescended testes. Once the risk of cancer was more than minimal, health care providers and parents agreed on surgical removal of gonads without further questioning. Even when health care providers tried to assure parents that the cancer risk of leaving the gonads in place was relatively low (and this topic remains unsettled (Kathrins & Kolon, 2016)), parents still seized upon the small risk to press their case for a specific gender (B12). The prospect of cancer then worked as a gender consolidator.

*Child’s decision:* A final set of future imaginaries that influenced decision-making was the voice of the older child. DSD staff repeatedly reminded parents that gender of rearing does not need to lead to surgical interventions but that they had time to solicit their child’s input. Thus, when parents requested the removal of two descended testes in their daughter with “atypical” genitalia to avoid masculinization at puberty, the endocrinologist suggested that they could suppress puberty hormonally “Until she’s old enough to make the decision that she wants them taken out” (C2). A gynecologist advised against clitoral reduction on similar grounds: “So that’s really for you guys to kind of look at her and see is she uncomfortable with that? Is it something that’s you know bothering her and as kids get older they’re pretty good at wording how they feel.” (B1).

Some parents were receptive to the argument that the child should participate in treatment decisions, other parents, however, cited the social stigma potential as a reason to decide now. For example, in a discussion of gonad removal, a genetic counselor suggested waiting until the child had a say in the decision:

This article is protected by copyright. All rights reserved

“maybe we let [child] grow for a while and mature and get older until she can more participate in the decision of her gender identity. And then decide if she wants to have these gonads out or not. Because if let’s just say, um, [child] grows up and decides she identifies more as a boy, then those testes would, you know not necessarily need to come out. So that’s sort of where I think a lot of the management discussions need to be at today. Because how to raise your child gender-wise is a big decision, you know.” (B9).

But the parents decided that they wanted the testicles surgically removed, in part because they wanted their daughter to fit in. They would be supportive no matter what gender the child chooses later. The mom explained, “everyone’s pretty much on the same page. You know she’s still [Name]. We’re still gonna love her just the same. And this is just something that she’s gonna have to have lots a love and support to get through in her older years.” This mother sums up a common rationale for finalizing a gender assignment decision: sustained love and, if necessary, additional medical interventions make the gender parents and clinicians choose an attainable destiny for their children.

## **Conclusion**

The biomedical field of DSD has been under sustained criticism for the last decades by intersex activists for its paternalistic legacy in which clinicians locked gender assignment in with unnecessary and irreversible surgeries, and cultivated a culture of shame and secrecy (Chase, 2013; Davis, 2015). The possibility of gender dysphoria and the continued stigmatization of genital differences has upped the ante for gender assignment, rendering making the “right” choice even more consequential. Parents come to the DSD clinic with expectations of their child’s gender grounded in intuitions, prenatal testing, the presentation of genitalia at birth, and clinical judgments. Shifting these path-dependent trajectories is possible with the promise that the child may aspire to gender-typical presentation and may avoid the stigma of being ambiguously gendered. The specific biomedical sex findings matter and can complicate gender assignments, but clinicians emphasize that the findings do not determine gender. Parents and clinicians facilitate a gender assignment consensus when surgery and hormonal treatment combined with consistent gender rearing give them agency to render the present decision a self-fulfilling prophesy. They single out iconic medicalized indicators of gender typicality as

prognostic reference points. They imagine the child's optimal future as one where gender ambiguity is erased and parental love and medical support will allow the child to blend in as a healthy and happy boy or girl.

A consequence of the medicalized grounds of gender assignment is that social stigma of "atypical" genitalia rather than gender dysphoria constitutes the major anticipated risk. Gender dysphoria is presented as inherently uncertain but manageable. Parents feel that they can be there for their children if they express unhappiness with the gender of rearing and clinicians promise surgical or hormonal fixes if problems occur. Parents are motivated by the avoidance of anticipated social stigma related to the look and functioning of genitalia, normalization of their child's gender difference, and the achievement of gender-conforming life markers. Parents view the biomedical treatments as a means to avoid stigma by allowing the child to pass as gender-typical and erase the signs of difference. Clinicians argue that genital surgery may not be indicated for functional reasons now and that waiting to allow the child to express a choice has merit but these admonitions are overshadowed by their general emphasis on the plasticity of sex traits and the normalizing power of rearing the child consistently in a gender. At the same time, the gender imaginaries combined with the sense that the child has been destined for a specific gender provide a medical rationale for gender assignment that absolves clinicians and parents from the appearance of picking the "wrong" gender.

Gender destinies constitute an interactional mechanism through which clinicians in dialogue with parents leverage their medical expertise to extend their cultural authority of what is valid and true about sex and gender. Gender destinies not only achieve temporal alignment of past expectations, current findings, and anticipated futures but also conjoin sex characteristics with traditional social and institutional gender norms. The notion of gender destinies highlights that gender assignment is not a fate about to happen but actively made as a decision of lining up biomarkers and futures. It is something that was waiting in the child but requires cultivation with biomedical nurturing and parental socialization. Parents gain control over their child's destiny with medical help.

When gender destinies are formulated and acted upon in biomedical settings, this irreversible medicalization of gender comes with risks: the process of forecasting based on idealized gendered reference points is without guarantees. Fertility, sexual functioning, cancer

prevention, happiness, and social acceptance are all aspirational. Paradoxically, the only certainty is that surgically removing genital tissue from infants is irreversible. Even the long-term success of surgeries is unknown: current testimonies are based on past surgical techniques that have changed dramatically and it may take decades before the problems and advantages of current techniques are known. What is done in the present will also generate strong path-dependencies for the future, fueling the hope for fulfillment, but potentially becoming a source of future resentment, decision regret (Lorenzo et al., 2014), and trauma (Danon, 2018a; Davis, 2015). Critical voices of those who already experienced these futures, intersex adults, are left out of the decision-making process. Parents and clinicians hope that by securing a gender with surgeries and hormonal interventions, they create a self-fulfilling prophecy that the assigned gender will stick as a natural destiny. Instead, they may craft the conditions for continued biomedical surveillance and interventions. With the gender assignment decision, parents and clinicians then imbue the child with a profoundly modern destiny: gender remains a naturalized binary category that nevertheless needs to be biomedically and socially achieved.

#### Acknowledgments

We thank Tanya Stivers, Pamela Prickett, and Abigail Saguy for helpful comments on earlier drafts.

Address for correspondence: Stefan Timmermans, Department of Sociology-UCLA, Los Angeles, CA 90095. E-mail: [Stefan@soc.ucla.edu](mailto:Stefan@soc.ucla.edu)

#### References

Adams, V., Murphy, M. and Clarke, A. (2009) Anticipation, Technoscience, Life, Affect, Temporality, *Subjectivity*, 28, 246-265.

This article is protected by copyright. All rights reserved

- Brubaker, R. (2016) *Trans: Gender and Race in an Age of Unsettled Identities*, Princeton, NJ: Princeton University Press.
- Chase, C. (2013) What is the Agenda of the Intersex Patient Advocacy Movement?, *The Endocrinologist*, 13, 240-242.
- Christakis, N.A. (1999) *Death Foretold: Prophecy and Prognosis in Medical Care*, Chicago: University of Chicago Press.
- Colapinto, J. (2000) *As Nature Made Him: The Boy Who Was Raised as a Girl*, New York: Harper Collins.
- Consortium on the Management of Disorders of Sex Development (2006) *Clinical Guidelines for the Management of Disorders of Sex Development in Childhood*: Intersex Society of North America.
- Crissman, H.P., Warner, L., Gardner, M., Carr, M., Schast, A., Quittner, A.L., Kogan, B. and Sandberg, D.E. (2011) Children with disorders of sex development: A qualitative study of early parental experience, *Int J Pediatr Endocrinol*, 2011, 1, 10.
- Danon, L.M. (2018a) Comparing contemporary medical treatment practices aimed at intersex/DSD bodies in Israel and Germany, *Sociol Health Illn*.
- Danon, L.M. (2018b) Time matters for intersex bodies: Between socio-medical time and somatic time, *Social Science & Medicine*, 208, 89-97.
- Davis, G. (2015) *Contesting Intersex: The Dubious Diagnosis*, New York: New York University Press.
- Davis, G., Dewey, J.M. and Murphy, E.L. (2016) Giving Sex: Deconstructing Intersex and Trans Medicalization Practices, *Gender & Society*, 30, 3, 490-514.
- Feder, E.K. (2009) Imperatives of Normality: From "Intersex" to "Disorders of Sex Development", *GLQ*, 15, 2, 225-247.
- Foucault, M. (1978) *The History of Sexuality: An Introduction*, New York: Vintage Books.
- Gough, B., Weyman, N., Alderson, J., Butler, G. and Stoner, M. (2008) 'They did not have a word': the parental quest to locate a 'true sex' for their intersex children, *Psychology & Health*, 23, 4, 493-507.
- Karkazis, K. (2008) *Fixing Sex: Intersex, Medical Authority, and Lived Experience*, Durham, NC: Duke University Press.

- Kathrins, M. and Kolon, T.F. (2016) Malignancy in Disorders of Sex Development, *Translational Andrology and Urology*, 5, 5, 794-798.
- Kessler, S.J. (1990) The Medical Construction of Gender - Case-Management of Intersexed Infants, *Signs*, 16, 1, 3-26.
- Kessler, S.J. (1998) *Lessons from the Intersexed*, New Brunswick, NJ: Rutgers University Press.
- Lee, P.A., Houk, C.P., Ahmed, F.S. and Hughes, I.A. (2006) Consensus Statement on the Management of Intersex Disorders, *Pediatrics*, 118, e488-e500.
- Lee, P.A., Nordenstrom, A., Houk, C.P., Ahmed, S.F., Auchus, R., Baratz, A., Baratz Dalke, K., Liao, L.M., Lin-Su, K., Looijenga, L.H., 3rd, Mazur, T., Meyer-Bahlburg, H.F., Mouriquand, P., Quigley, C.A., Sandberg, D.E., Vilain, E., Witchel, S. and Global, D.S.D.U.C. (2016) Global Disorders of Sex Development Update since 2006: Perceptions, Approach and Care, *Hormone Research in Paediatrics*, 85, 3, 158-180.
- Lorenzo, A.J., Pippi Salle, J.L., Zlateska, B., Koyle, M.A., Bagli, D.J. and Braga, L.H. (2014) Decisional regret after distal hypospadias repair: single institution prospective analysis of factors associated with subsequent parental remorse or distress, *J Urol*, 191, 5 Suppl, 1558-63.
- Meadow, T. (2011) 'Deep down where the music plays': How parents account for childhood gender variance, *Sexualities*, 14, 6, 725-747.
- Mische, A. (2009) Projects and Possibilities: Researching Futures in Action, *Sociological Forum*, 24, 3, 694-704.
- Preves, S.E. (2002) Sexing the intersexed: An analysis of sociocultural responses to intersexuality, *Signs*, 27, 2, 523-556.
- Rahilly, E.P. (2015) THE GENDER BINARY MEETS THE GENDER-VARIANT CHILD: Parents' Negotiations with Childhood Gender Variance, *Gender & Society*, 29, 3, 338-361.
- Sanders, C., Carter, B. and Goodacre, L. (2008) Parents' narratives about their experiences of their child's reconstructive genital surgeries for ambiguous genitalia, *J Clin Nurs*, 17, 23, 3187-95.
- Shostak, S., Conrad, P. and Horwitz, A. (2008) Sequencing and Its Consequences: Path Dependence and the Relationships between Genetics and Medicalization, *American*

- Journal of Sociology*, 114, S1, S287-S316.
- Sweeting, H., Maycock, M.W., Walker, L. and Hunt, K. (2017) Public challenge and endorsement of sex category ambiguity in online debate: 'The sooner people stop thinking that gender is a matter of choice the better', *Sociol Health Illn*, 39, 3, 380-396.
- Tavory, I. and Eliasoph, N. (2013) Coordinating Futures: Toward a Theory of Anticipation, *American Journal of Sociology*, 118, 4, 908-942.
- Tavory, I. and Timmermans, S. (2014) *Abductive Analysis: Theorizing Qualitative Research*, Chicago: University of Chicago Press.
- Timmermans, S., Yang, A., Gardner, M., Keegan, C., Yashar, B.M., Fechner, P.Y., Scnorhavorian, M., Vilain, E., Siminoff, L.A. and Sandberg, D.E. (2018) Does Patient-Centered Care Change Genital Surgery Decisions? The Strategic Use of Clinical Uncertainty in Disorders of Sex Development Clinics, *Journal of Health and Social Behavior*, 58, 4, 520-535.
- Turner, S.S. (1999) Intersex identities - Locating new intersections of sex and gender, *Gender & Society*, 13, 4, 457-479.
- Westbrook, L. and Schilt, K. (2014) DOING GENDER, DETERMINING GENDER: Transgender People, Gender Panics, and the Maintenance of the Sex/Gender/Sexuality System, *Gender & Society*, 28, 1, 32-57.
- Zeiler, K. and Wickstrom, A. (2009) Why do 'we' perform surgery on newborn intersexed children? The phenomenology of the parental experience of having a child with intersex anatomies, *Feminist Theory*, 10, 3, 359-377.

---

<sup>1</sup> Most terms in this field are controversial, including the umbrella notion of “disorders of sex development” (see Davis 2015). Because we examine gender assignments from a biomedical perspective, we will use terms as used by clinicians and parents in our data. However, to keep the argument understandable, we noted when clinicians mixed up “gender of rearing” with “sex of rearing.” Sex refers to the biological differences between male and female bodies, while gender refers to the social classification as masculine or feminine.

<sup>2</sup> Chromosomal karyotyping is a test that examines the chromosomes for abnormalities.

<sup>3</sup> Hypospadias is a common congenital condition of the urethra where the urinary opening is not at the head of the penis. Surgical repair extends the urinary channel to the end of the penis.

<sup>4</sup> 46,XX,CAH means that the child had 46 chromosomes, the sex chromosomes were both X, and the test showed congenital adrenal hyperplasia, a recessive autosomal disease that may affect sex traits. 46,XY means 46 chromosomes, with a Y chromosome.

Author Manuscript