

VOICES: Normalizing Intersex

A Study Guide*

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The stories references in this study guide can be downloaded for free. Please see the [Normalizing Intersex volume of VOICES 2016](#)

Art Frank has written a short reflection piece on learning from narratives for NIB. Please see our website to [download](#) the piece.

General Questions:

1. What is the value of using narrative to learn about intersex?
2. How should we listen to the stories collected here? Does your response change if you are listening as a friend or family member of the individual? How might you listen as a prospective parent? What about as a medical provider?
3. It was common practice for medical providers to keep the diagnosis from intersex people and they often encouraged parents to do the same, as many physicians believed that withholding such information would protect the development of their patient's gender identity. What do these narratives suggest about the effects of these practices?
4. Many of the individuals who shared their stories in this symposium found comfort in connecting with others who had shared their experiences, as well as with the larger intersex community. What barriers to forming these types of connections might exist, and how might these barriers be minimized?

*Created to accompany VOICES: Stories from the Pages of NIB 2016 from the original narrative symposium in *Narrative Inquiry in Bioethics* Volume 5 Issue 2, 2015.

Story Questions:

The Truth in Writing

Amanda

1. Amanda was a medical student when she wrote her narrative, and as she explains, her interest in transgender medicine was shaped by her personal experience with intersex and her desire to help others facing similar challenges and concerns. How are Amanda's motivations similar to or different from those whose pursuit of their careers is shaped by disability, chronic illness, serious injury, or disease?
2. Amanda writes that keeping a journal is a way "to help sort through [her] feelings and experiences related to a newly discovered sexuality and changing gender identity." If you were to describe your own thoughts and feelings in a journal after reading this symposium, what would you write?

When Doctors Get It Wrong

Konrad Blair

1. Konrad Blair describes the apology he received from the university hospital that treated him as representing hope for himself and future patients. If apology was this powerful to him, might it be to others as well? Why might some doctors be reluctant to issue a formal apology?
2. Several months after the publication of his narrative, Konrad Blair asked to meet with one of the editors of this volume. He had no regrets about the publication of his narrative, but he wanted the editor to understand that he no longer believed that the apology he had received was genuine. The apology changed his life, he affirmed, but he had come to understand that the apology did not guarantee that children born intersex in the hospital where he had experienced so much suffering would not receive the same treatment he had. Konrad Blair argued that if the apology had been truly heartfelt, hospital physicians would no longer allow what had happened to him to happen to other children within its walls. Knowing something of this postscript to the apology, does your response to the narrative change in any way? What value, if any, would Konrad Blair's physicians find in knowing how his view of the apology had changed?

Solving the Jigsaw Puzzle

Peggy Cadet

1. It was difficult for Peggy Cadet to put together the scattered pieces of her medical history and make sense of the gaps in the information she had been provided. Do you view such gaps as a burden for patients? To whom does the responsibility for providing patients full information about their conditions fall?

2. Peggy Cadet learned as a young adult that her perception of her father's expectations—in particular, how she “should” understand her body and her identity—did not in fact reflect his true views, which were less fixed than she had thought. What can account for the difference between her father's later revelations and her experience of the doctor's direction of her care?

Game Change

Maximo Cortez

1. In 2013, federal and state lawsuits were filed in the case of “MC” [note: This child was not Maximo Cortez], a child adopted as a toddler in South Carolina. M.C. was born with atypical sex anatomy and surgically assigned female while M.C. was a ward of the state. Eight years old at the time the lawsuit was filed by his adoptive parents on his behalf, M.C. had rejected his assignment, and identified as a boy. Evidence presented by his attorneys indicates that there was no medical necessity for surgery; at the time of surgery, the couple who became his parents had expressed their willingness to adopt M.C. with his anatomy intact. What do you think could have motivated doctors to pursue normalizing intervention? Do you think that the state's insistence that similar surgeries be performed on five-year-old Maximo Cortez could have been similarly motivated?
2. Maximo Cortez's narrative could suggest that experience of medical treatment of individuals with intersex varies based upon class and educational background. Do the narratives assembled suggest that these factors play a role in medical decision-making and treatment?

Navigating Intersex Healthcare: My Odyssey

Cynthia

1. Cynthia explains in her narrative that her father was a practicing physician. In what ways might her father's professional experience have been an advantage? Are there any ways in which you think it made Cynthia's path more difficult?
2. As a young adult, Cynthia was aware of her parents' concern that she have a normal sex life, something that played an important role in her decision to undergo vaginoplasty in her early 20's. And yet, discussions of sex and sexual desire were avoided by her parents and, it appears, by her physicians as well. It may not be a surprise that there is a high value attached to having a “normal sex life,” nor that sex and sexuality remain a difficult topic of conversation in this cultural context. Could Cynthia's experience be considered a consequence of this difficulty? Can you imagine conversations that might have helped her?

The Secret Inside Me

Diana Garcia

1. On learning the truth of her condition through Internet research, Diana Garcia remembers asking, “Why would they tell a child he or she had cancer or leukemia but they couldn’t tell an 18-year-old woman the truth about androgen insensitivity syndrome (AIS)?” Why do you think Diana Garcia’s doctors lied to her? The consequences of the lies physicians told her had lasting effects, as she recounts.
2. Imagine that Diana Garcia had not had access to the Internet, and had never learned about AIS. In introductory ethics classes, students are often asked of such situations, whether they think someone would have been better off not knowing. Is this the right question to ask of Diana Garcia’s story; in other words, are there other questions that might be posed about the situation to investigate the ethical problems ethicists might identify?

Finding My Compass

Laura Inter

1. Laura Inter describes the confusing and humiliating process of undergoing a medical exam as a young teen—an appointment she had sought to find answers to questions about her body that had provoked anxiety and depression. How do you think the examining physician might have described her experience? What about the physician’s colleague (or medical student) who was present during the exam, whom Laura Inter remembers was sitting, silently, taking notes?
2. As with many of the other narratives in the symposium, the onus of learning about one’s diagnosis and connecting with similarly situated others fell on Laura Inter. Do medical providers have any responsibility to help patients understand their diagnoses and/or connect with others who might share their experience as patients?

Still I Rise

Lynnell Stephani Long

1. Lynnell Stephani Long describes herself as being one of the only black intersex advocates in the 1990s and early 2000s. Although, as she notes, there are far more visible advocates of color now, most intersex support groups and advocacy organizations remain predominantly white and middle class. What impact could this lack of racial and class diversity in support groups have on the support available to individuals and families who are marginalized by race, culture, or class?

2. Lynnell Stephani Long was treated much of her life at a teaching hospital, where patient care also serves as a classroom for medical students at different stages of their professional and educational development. She writes that she still has “flashbacks standing in front of the graph board, naked, while strangers walked in and out of the room.” Do accounts of experiences such as these suggest any unique challenges or concerns posed by teaching and learning with respect to the care of children, teens, and adults with intersex anatomies? Do the ways that intersex is understood as a “problem” for individuals and/or families figure into these challenges or concerns?

The Son They Never Had Pidgeon Pagonis

1. In 1996, the Canadian Medical Association published an award-winning essay by a medical student arguing that girls and women with Androgen Insensitivity Syndrome (AIS) should not be told the truth of their condition. The article reflected the standard of care at the time, which is to say, physicians generally thought it would benefit their patients to remain ignorant of their conditions. In response to the letters written by women with AIS who criticized the essay, the editor of the journal defended the journal’s selection because the medical student had made a “coherent” argument. He claimed, furthermore that, “...had the essay not appeared neither would [the letters criticizing the essay], and physicians would have been deprived of an excellent debate about a rare (and rarely publicized) medical condition.”¹ How do you think Pidgeon Pagonis might have responded to the journal editor’s view of the “coherence” of the argument?
2. Pidgeon Pagonis describes an awkward moment when, at eleven, Pidgeon Pagonis was asked to consent to vaginoplasty. This consent was noted in the patient record in Pidgeon Pagonis’s essay. How would you describe the consent process in this case? What similarities and differences do you see between the process described by Pidgeon Pagonis and those of other contributors whose surgical interventions were allowed by their parents?

A Changed Life: Becoming True to Who I Am Jay Kyle Peterson

1. How might you explain Jay Kyle Peterson’s experience of “relief” upon learning of his diagnosis?

¹ http://www.collectionscanada.gc.ca/eppp-archive/100/201/300/cdn_medical_association/cmaj/vol-154/1829e.htm

2. Jay Kyle Peterson's narrative suggests that an intersex diagnosis affects the entire family and not only the individual with intersex. In this respect, the effect of such a diagnosis is much like the revelation of any number of serious illnesses or disabilities in a child. Is there anything medical providers can or should do to preemptively address familial challenges that might surface with an intersex diagnosis?

Standing Up

Emily Quinn

1. Emily Quinn writes, "Having a doctor that understands your body, your variation, your medical needs, is the greatest possible gift to a patient." What might prevent doctors from forming such relationships to their patients with intersex traits?
2. Many people view access to medical care as a human right. And yet, Emily Quinn describes herself as "incredibly lucky" for having been spared an intervention that is regarded by many physicians as the "standard of care," which is, in other words, the care that any physician would be expected to provide in comparable circumstances. How does Emily's Quinn's story call into question whether medical care—a "right"—can be more harmful than helpful?

Dwelling in the Gaps

Galen Sanderlin

1. Galen Sanderlin identifies as a trauma survivor, and explains that this has left Galen Sanderlin with "a hard time trusting." How might this lack of trust interfere with a patient's medical care? What might a physician meeting Galen Sanderlin for the first time do to begin building Galen Sanderlin's trust?

XY/XO

Lianne Simon

1. Throughout her young adulthood, the divergence between Lianne Simon's experience of her sexual identity and the views and expectations of others created enormous tension in her life. These differences account, in part, for the acute vulnerability she describes, including the repeated threat of sexual violence. What connection, if any, do you see between this vulnerability and Lianne Simon's chromosomal difference? If college-aged Lianne Simon disclosed these instances of intimate violence to a medical provider, how would you expect that provider to respond? What could be recommended for her in the short and long term?

2. Religious teachings that ignore the natural fact of intersex anatomies fly in the face of well-established medical evidence. The importance of sensitivity to diverse religious convictions is widely acknowledged in medical ethical literature, while discussions of medical treatment for intersex are scarce. Do you think the needs of patients with intersex could vary depending on their family's religious observance? What is the responsibility of a medical provider to be aware of a patient's (or patient's family's) religious convictions? How might medical providers account for or accommodate these differences in their medical practice?

It's a Human Rights Issue

Daniela Truffer

1. Daniela Truffer identifies normalizing surgeries as "intersex genital mutilation." The acronym, IGM, intentionally refers to genital surgeries prevalent in much of Africa, the Middle East, and South Asia that critics of these practices refer to collectively as FGM, or female genital mutilation. There are differences between the two practices of genital surgery; in one case, surgery is performed only in children identified as "abnormal," whereas in the other, all members of the society are expected to participate in a rite celebrated as initiation into one's culture and society. Western physicians have discouraged comparisons between these practices as a fallacy of false analogy (comparing apples to oranges). Does Daniela Truffer's essay suggest that we should reconsider this comparison? In what ways might that comparison provide insight into the motivations—by family, medical providers, and perhaps even "society,"—for normalizing surgery for intersex?
2. Daniela Truffer claims that intersex genital mutilation (IGM) is an issue of human rights. Because physicians cannot agree that normalizing practices constitute IGM, she believes that a legislative solution might hold the only real chance of repairing the harms already caused by the standard of care, as well as preventing such harms in the future. In the US, a 1996 law prohibits unnecessary genital surgery (18 U.S.C. § 116 "Female Genital Mutilation") but no challenges to the standard of care have been made on the basis of this law. How effective do you think legal prohibition might be? Do you agree with Daniela Truffer that legislation may be the only hope for change in the near term?

Promoting Health and Social Progress by Accepting and Depathologizing Benign Intersex Traits

Hida Vilorio

1. When introduced in 2005, the term, "Disorders of Sex Development" seemed to many, both within and outside of medicine, to be a progressive leap from the use of the previous nomenclature based on the misleading and damaging "hermaphroditism" (which included the terms, "female

- pseudo-hermaphroditism," "male pseudo-hermaphroditism," and "true hermaphroditism"). Why does the term "disorder" in the context of atypical sex anatomy still provoke discomfort or anger? What alternatives might there be?
2. Hida Viloria writes, "I reject the term 'DSD', which I find as insulting as when my father referred to my lesbianism as a 'psychosexual disorder.'" She continues, "I use 'intersex' exclusively, and ask others to use it to refer to me, because I find being described solely as an acronym depicting sexual difference dehumanizing, stigmatizing, and hurtful." What is the value of physicians respecting their patient's terminological preferences? How does terminology play a role in perception for the patient, the family, the medical community, and the public at large?

Removing the Mask: Hopeless Isolation to Intersex Advocacy

Alexandra von Klan

1. Alexandra von Klan describes her experiences with three physicians whom she identifies as Doctor A, Doctor B, and Doctor C. What do you think each of the doctors could learn from one another?
2. When Alexandra von Klan described her "deflated or non-existent libido" to Doctor C, she was comforted learning "that 98% of her female patients have similar complaints." Would you say this physician's response and recommendations that involved seeing a "sex therapist," and "investing in erotic films" to stimulate arousal were successful and appropriate? Why or why not?

Standing at the Intersections: Navigating Life as a Black Intersex Man

Sean Saifa Wall

1. While there are similarities with Sean Saifa Wall's narratives and the other narratives that appear in this symposium, the author maintains that his experience "navigating life as a black intersex man" is different. How would you characterize these differences, and how might physicians be sensitive to them?
2. Sean Saifa Wall writes: "I charge the police state and the medical community with state-sanctioned violence: Each targets non-normative bodies—the former through incarceration and execution, and the latter by means of surgical and hormonal intervention." How would you respond to this charge if he were your patient?

"Normalizing" Intersex Didn't Feel Normal or Honest to Me

Karen Walsh

1. Why would Karen Walsh experience “gratitude” upon discovering a medical journal article in which she appeared as a case?
2. Karen Walsh expresses in her narrative that providers’ lack of concern about her quality of life is “frustrating beyond belief.” She asks: “Why doesn’t my health and [quality of life] as an adult matter to Medicine? Why do I have to fight and inveigle doctors to help me with my health and [quality of life]?” Do you believe quality of life to a priority in medical practice?

Invisible Harm

Kimberly Zieselman

1. After learning the truth about her diagnosis, Kimberly Zieselman wrote a letter to the teaching hospital that treated her as a young woman. She requested that the hospital acknowledge the harm she suffered while in its care, “and most importantly, [provide] evidence of [their] improved care and practices.” They responded by acknowledging her “unsatisfactory experience” and informed her “that too much time had passed to take further action.” Imagine that you were newly employed at that hospital, and received the letter. What do you think your response would be? How would you hope the hospital that employed you would respond?
2. Kimberly Zieselman writes: “Although I appear to be a DSD patient “success story,” in fact, I have suffered and am unsatisfied with the way I was treated as a young patient in the 1980’s, and the continued lack of appropriate care for intersex people even today.” How would you describe the “success story” to which she refers? How would you define a success story in intersex medical care after reading her narrative?

Michael’s Story or the Paradox of Normalcy

Michael Kreuzer

1. Michael Kreuzer observes that in the case of so many chronic medical conditions, medical providers appreciate the importance of patient advocacy groups. He asks “why is this not the case when it comes to DSD/intersex?” Do any of the narratives provide clues as to why DSD/intersex patient advocacy groups do not enjoy the sort of respect among physicians that other patient advocacy groups do?
2. Various diagnoses that may fall under the category of DSD or intersex occupy, as Michael Kreuzer recounts, a marginal place in medical education, something that may be explained by the relative rarity of

DSD/intersex. Do the narratives suggest any arguments for increasing attention to intersex anatomies in medical education?