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Kavya Sukumar/MEDILL
Mugsie Pike appeals to the medical community, "Let the children grow up and decide their gender."

When a child is born neither boy nor girl: Straddling the gender divide

by **KAVYA SUKUMAR**
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Crixx Haligowski was giving birth in a midwife clinic in rural Philippines, when he first heard about intersex people. The doctors told him (then her) that he was not fully female.

This did not come as a surprise to Haligowski. He was born with genitalia that are not clearly male or female. But what he did not know was that he had a narrower alignment of pelvic bones, usually found in men -- the kind that would make natural childbirth impossible.

Like Haligowski, an estimated one in 1,500 babies is born intersex. The term is used to describe conditions in which a person is not clearly male or female. Not all intersex people are born with atypical genitalia. Sometimes the differences may be at chromosomal or gonadal (ovaries and testes) levels.

In the medical community, the term intersex has been discarded in favor of a more neutral sounding "disorders of sex development" or DSD.

David E. Sandberg, a pediatric psychologist at the University of Michigan who has worked extensively with children with DSD, explained the reason for this shift.

"DSD is an umbrella term that covers any range of medical conditions associated with atypical development of sex," Sandberg said. "Whereas when you say intersex, it has a sense of identity associated with it."

Haligowski, who now lives in Chicago, has a condition called congenital adrenal hyperplasia or CAH, which is the most prevalent intersex condition. CAH affects the adrenal glands, which are located above the kidneys and produce various hormones including cortisol and androgen. CAH occurs when one of the enzymes needed for making these hormones is deficient.

Having too much or too little of these hormones affects how a baby's genitals develop. CAH can take different

forms based on a variety of conditions and may not always result in intersex conditions.

Halogowski was born with what is known as classic CAH, which is usually associated with visibly atypical genitalia. But he was not diagnosed.

Halogowski had already been in labor for more than two days by the time the doctors realized that his pelvis could not accommodate the child. The midwife clinic he was at didn't have facilities to do a cesarean.

"The doctor had to put ... one of those wood[en] vices and literally break my pelvis bone. It was a nightmare," Halogowski recalled this incident which happened 20 years ago, with a shudder.

Stories of medical nightmares like this are not uncommon in the intersex community. Some of them involve delay in diagnosis and sometimes misdiagnosis. Another problem intersex people encounter is the difficulty in getting their medical records. But the single biggest issue has been that of surgical sex assignment on babies born with ambiguous genitalia.

An elective surgery or a medical necessity?

When Alex McCorry was born in rural Indiana, the doctors told his parents that he was a boy.

"But a few hours later they changed their mind and said I was a girl," McCorry said. "I didn't know what happened and my mother would never tell me more."

McCorry was given a girly name, which he later changed to Alex, and was raised a girl. But McCorry did not feel at ease in the feminine role.

"I was forced into dresses all the time," McCorry recalled about his childhood. "And I had this beautiful long blonde curly hair which I would go out and get tangled up in the weeds and everything. So my mother got tired of having to brush all that crap out of my hair, she let me cut it short."

"I would tear my dresses and stain my dresses and everything else till she let me wear blue jeans," he added with a laugh.

McCorry did not find out more about what happened to him at birth, until he was 40.

Unhappy with his female gender role, McCorry was considering going through a gender reassignment process to become a transgender man. During a pre-evaluation examination, a doctor discovered that he was born with atypical genitalia.

McCorry found out that the doctors had surgically removed his penis and converted his genitalia to conform to a female one.

Surgeries, like the one done on McCorry, were once standard medical procedure for children born with genitalia that are not strictly male or female. This has changed in the recent past, said Dr. Mary Fallat, speaking for the American Pediatric Surgical Association. Fallat is a professor of surgery at University of Louisville, Kentucky, and a practicing pediatric surgeon.

"The medical community has changed the way they approach children that have genitalia that is not obviously one sex or the other. The rhetoric has changed," she said.

According to her, children born with unusual looking genitalia are transferred to a tertiary care center for multi-disciplinary care. A team of doctors including endocrinologists, pediatric surgeons and geneticists evaluate the child and decide on further treatment, she said.

Veronica Drantz, a biologist and a founder of a support group called Intersex Chicago, said she feels that the approach has not changed enough.

"I got involved with intersex rights advocacy when I found out that they are carving up babies to meet some twisted idea of normal and this carving up continues even today," said Drantz, who is not intersex. "The medical community has been way too enthusiastic in equating difference with disorder. Just because people are different, just because there are in minority, just because their numbers are small, doesn't mean that there is something wrong with them or that it needs to be fixed."

Activist Anne Tamar-Mattis raises a question on the ethics of this practice.

Tamar-Mattis is the founder of Advocates for Informed Choice, a California-based organization for legal advocacy of rights of children born with DSD.

“It is questionable whether adults should be allowed to decide on cosmetic procedures for children,” Tamar-Mattis said. “This irreversible physical treatment is not done for health needs. It is purely done to correct the way it looks.”

Sometimes surgery is a medical necessity for children born with DSD, said Sandberg, the pediatric psychologist.

“Sometimes there are issues like repeated urinary infections. Sometimes there are more severe problems that may require surgeries to fix this.”

Fallat points out that these days surgery is recommended only when it is required for health reasons and not for aesthetic reasons.

“There is also a question of informed consent,” Drantz points out. The surgery is irreversible and may have serious side effects. “The parents often do not fully understand what they are getting into,” she said.

His surgery, McCorry said, robbed him of any sensation in his genitals. “I was left with a useless flap of skin. The nerves were cut and there is no feeling at all.”

“Growing up, I went through all these years of sexual dysfunction because there is no feeling there. The few times I was able to ask a doctor about it, they told me it was probably all in my head,” McCorry said.

There is also the possibility of assigning the wrong gender. McCorry can attest to this.

“The moral of my story was that ‘The doctors decided you are a girl, so start acting like one,’” he said.

Sandberg agrees that the risks of the surgery often far outweigh the benefits. But he cautions that there may be a bigger picture.

“We have people who have had surgeries come out and be vocal about how it was wrong for them,” he said. “It doesn’t follow from that argument, that by not doing surgery there are no problems.”

Fallat points out the deficiency in quality and quantity of data available on the condition.

“Because we lack the ability to look at large numbers of people with different kind of [DSD], we are at a disadvantage when trying to look at the big picture,” she said. “I am a doctor who is trying to educate herself, so that I can take care of my patients in the best possible way. We just don’t know yet, what the right recipe is or if there is one.”

Despite these grey areas, there is consensus among the doctors, activists and members of the intersex community on the need to avoid unnecessary surgery.

“The recommendation is to hold off any irreversible changes till the child is grown up and able to decide for themselves,” Tamar-Mattis said.

So what is the recommended approach when a child is born with atypical sex?

Drantz is a proponent of letting things work themselves out.

“Leave them alone!” she said. “Do not try to fix something that is not a problem in the first place. We are all not ‘Adams or Eves.’ We are not in that story.”

Boy or girl or both?

A hands-off approach may not always work. How do you explain to a 5-year-old child that they are neither a boy nor a girl?

“We need to assign a working gender identity no later than when the child is 18 months old,” Sandberg said. “But

what is important is that everyone involved must understand that this assignment is not rigid. It may change as the child grows up.”

Not everybody agrees. Drantz questions the need for gender.

“We try to fit people into molds we are comfortable with,” she said. “We want them to be in neatly labeled boxes. Why can’t they be both? Who is to say that I can only be a woman?”

Some members of the intersex community echo Drantz’s reasoning.

“Why can’t I just be an intersex person and just take the hormone that is required to keep my body healthy?” Haligowski asked.

Haligowski has over the years come to terms with his sexuality and has picked a predominantly male gender identity. But he still acknowledges both his sides.

“My girlfriend calls me her ‘wifband.’ Some days I am such a husband and some days a wife,” he said.

While people like McCorry and Haligowski picked one gender, some people like Mugsie Pike prefer a middle road.

Pike embraces both the male and female identities equally and prefers the pronoun ‘they’ over a he or she.

“Gender is not black or white. It should not be rigidly defined,” they said. Pike, however, agrees that this may not be a concept that young children may understand. “A working gender identity is important for a child growing up. But there should be room for change.”

How do you decide the gender of a newborn baby?

Sandberg says that this decision is based on a number of factors including results of clinical observation, medical diagnosis and to some extent parents’ intuition.

“We make our best effort,” Sandberg said. “But there is no guarantee that this assignment will hold through their lifespan.”

“We certainly have gaps in what we know. We need to focus our efforts on improving this area of decision making,” he added.

To tell or not to tell

Yet another facet of this already complicated issue is the secrecy and shame associated with the condition.

“All of us are a little weird in some ways,” Drantz said. “Some of us will never discover the weird genes that we have. But when the difference is some sexual way, we are ostracized.”

Rogers Park resident Mugsie Pike, unlike Haligowski or McCorry, was born with a form of CAH called non-classic form. There were no tell-tale signs like ambiguous genitalia.

When “they” were in high school, Pike was prescribed birth control pills to combat acne. But their body reacted in unexpected ways. Doctors soon diagnosed Pike’s CAH. But Pike was not told.

“The doctors did not give me an inaccurate diagnosis. But they never told me it was an intersex condition,” Pike recalled.

When Pike read about CAH, they felt it explained their symptoms. Pike underwent treatment for three years before they confirmed their CAH self-diagnosis.

“[The doctors] are taught that it is emotionally traumatizing for the patient to be told that you are the ‘other.’ It was traumatizing for me not to be told that,” Pike said.

“Nobody is going to come out ‘normal’ after being systemically lied to,” Pike said. “One of the biggest problems with being intersex is isolation and invisibility. It is hard not to feel like a freak of nature.”

Sandberg, who has worked with a large number of parents of intersex babies, agrees.

“When parents first learn about their child’s condition, the initial reaction is to protect the child and the family against stigma,” he said.

Secrecy and shame extends to obtaining medical records.

“A lot of individuals have been lied to about their medical history. It is difficult to get their medical records,” Tamar-Mattis said. Advocates for Informed Choice, the organization founded by Tamar-Mattis, helps to educate intersex people and medical providers about HIPAA (guidelines for medical organizations on sharing patients’ medical information) and other privacy regulations.

The secrecy and stigma associated with the condition have led to misinformation and ignorance about DSD.

“When parents hear about DSD, they often do not know anything about it,” Sandberg said. “They know about rarer conditions like cystic fibrosis, which affects only one in 30,000 people. But DSD, which affects nearly 1 percent of the population, is alien to them.”

Information and education is the way to deal with the stigma, Sandberg said.

“It is never a question of if, but of when and how to tell the children about their condition,” he said.

Over the last decade, things have been improving for the gender variant community. Activists agree that society has been more accepting of those who do not strictly conform to the gender binary. But there is more to be done.

“They may not be clearly male or female,” Drantz said. “But they are clearly human. We must not forget that.”

Sandberg said, “It will benefit us all if we acknowledge that gender is more of a continuum and not a dichotomy.”



*Kavya Sukumar/MEDILL
Criss Haligowski talks about living with DSD.*



Kavya Sukumar/MEDILL
Alex McCorry talks about sex-reassignment surgery.



Kavya Sukumar/MEDILL
Mugsie Pike, a Rogers park resident, talks about "their" intersex diagnosis.

What is in a name?

Picking a name for your child can be hard enough as it is. The difficulty increases exponentially when the baby has no clear sex.

"When you hear a name, people jump to conclusions," Alex McCorry said.

It usually conveys gender and perhaps even ethnicity and age. When you are not clearly one sex or the other, how do you choose a name?

McCorry was born intersex but raised female and was given a girly name.

"I did not want that. So I chose to go with Alex," he said. Alex is not short for Alexander, he is quick to point out.

"I was still figuring out my gender identity," he said. "Alex just went with that."

McCorry refuses to tell what his birth name was. "That is not me anymore."

McCorry's mother, however, still refuses to call him Alex. "She still thinks I am her daughter," McCorry said.

Crixs Haligowski had a similar dilemma. He wanted a name that would convey his gender ambiguity. Just gender-neutrality was not enough for him.

"I consider myself the 'x' gender," he said. "I picked a common gender neutral name and changed the spelling to include an 'x,'" he said of his unusual spelling.

Mugsie Pike was raised female. "I was just lucky to have a gender neutral name to start with," Pike said. "I may have picked another one if it weren't neutral. I will never know."

Should parents choose a gender-neutral name? David Sandberg, who is a pediatric psychologist who works with intersex children, says that is not a good idea.

“I would discourage selecting an androgynous name like Logan, Jamie, etc., if the motivation is to hedge against later gender change,” Sandberg said.

McCorry has, since his name change, settled on a predominantly male identity and is now considering changing his name to Alexander.