TIM HOFF: Welcome to the first episode of the new Ethics Talk Author Interview Series from the American Medical Association Journal of Ethics. I'm your host, Tim Hoff. This new series provides an alternative format for accessing the interesting and important work being done by journal contributors each month. Joining me for this episode is Nat Mulkey, an MD candidate who works closely with faculty on LGBTQI+ curricula in undergraduate medical education at Boston University School of Medicine in Massachusetts, and Dr Carl Streed, an Assistant Professor at Boston University School of Medicine and Research Lead in the Center for Transgender Medicine and Surgery at Boston Medical Center. They, along with Dr Barbara Chubak, are the authors of the article A Call to Update Standard of Care for Children with Differences in Sex Development in the July 2020 issue of the journal, Illness, Invisibility and Measurability. Nat and Dr Streed, thank you so much for joining me today.

DR CARL STREED: Thanks for having us.

NAT MULKEY: Yeah, thanks for having us. [music fades out]

HOFF: To begin with, what is the key ethical argument being made in your article this month?

STREED: The main focus of the article really is to, is rooted in the basic premises of ethics, and I think the first one really obviously is primum non nocere. So, first do no harm. There’ve been years of outcry from the intersex community that early surgeries done without their consent or significant input have really harmed them physically and psychologically. This has been highlighted by multiple organizations, patient advocacy organizations, professional societies calling for deferral of these procedures. This article really highlights that well. I really quite simply want to say that these procedures violate our first ethical principles as clinicians and have been and continue to hurt and harm intersex individuals.

HOFF: What’s the most important thing for health professions students and trainees to take from your article?

MULKEY: So, in general, medicine is, it’s not static; it’s evolving. And as clinicians, we need to evolve to meet the needs of the patients we serve in the communities at large. So, students and trainees need to be prepared to relearn how we care for intersex individuals, also termed “differences of sex development.” As more hospitals correctly defer surgical interventions, as we mention in our article on these children, official standards of care need to change as well. And more so, they actually, there needs to be some more support organized for individuals who have already been harmed.

HOFF: Great. Thank you. And finally, if you could add one more important point to your article, what would that be?
STREED: Nat, if you want to go first?

MULKEY: Yeah. So, this information, for a while, this information has been available in that and information about intersex individuals’ own bodies and treatments has been withheld from them, and this really violates their own autonomy. And thanks to patient advocacy groups like interACT, advocates for intersex youth, and the Intersex Justice Project, health care is becoming more transparent for these individuals. And that’s, and we just want to acknowledge those two organizations who have done huge, their huge efforts are really what can be attributed to the deferral of a lot of these procedures in some large children’s hospitals.

HOFF: Great. Thanks. Dr Streed?

STREED: I absolutely agree. I kind of, really trying to gain additional, essentially reclaim, patient autonomy is a large part of what these organizations do. As Nat rightly put, for too long, have we been treating these differences in sex development as a shameful condition, and that shame has really pushed a lot of people out of being able to even talk with other folks who have similar conditions or similar experiences. So, these organizations have done a remarkable job of bringing people together and really trying to break down that shame to, again, allow people to have full autonomy of their lives. So, again, while the article really focuses on a large part of like do no harm, we also are trying to return autonomy to our patients and remove the shame that has unfortunately been placed there since the mid-20th century. [theme music returns]

HOFF: That was Nat Mulkey and Dr Carl Streed, authors, along with Dr Barbara Chubak, of a call to update standard of care for children with differences in sex development. Thank you both for joining me this month.

STREED: Thanks again for having us.

MULKEY: Thank you.

HOFF: To read the full article, along with the rest of the July 2020 issue of the journal, please visit our site, JournalOfEthics.org. Let us know what you think of this new series on Twitter or Facebook @JournalOfEthics. And we’ll be back soon with another episode of Ethics Talk from the American Medical Association Journal of Ethics. Talk to you then.