

Big gaps in transgender research: A team at UCSF is working to change that

The number of transgender children has grown, but the depth of data on transgender treatments hasn't

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SAN FRANCISCO — Sixteen years ago, a middle-aged clinical psychologist mustered up the courage to walk into an endocrinologist's office in Bryn Mawr, Pennsylvania, to ask the doctor for hormones to begin transitioning from male to female.

The physician was brusque and offered no help. “She said, ‘I don't do that,’” recalled Erica Anderson, who now works with transgender patients at the UC San Francisco Child and Adolescent Gender Clinic. “I left the office feeling like a leper.”

In recent years, Anderson and others in the field agree, attitudes toward transgender rights have changed dramatically among medical professionals and the general public. But they also concur that there is still surprisingly little data on the impacts of transgender treatments, particularly when it comes to children.

Researchers at UCSF Benioff Children's Hospital clinic are working to change this. Since 2015, they have been conducting a study that will involve nearly 300 young patients ages 8 to 18 to understand the long-term effects of transgender treatments. These include puberty-blocking hormones, which give patients more time to explore their gender identity, and testosterone and estrogen.

With the help of Children's Hospital Los Angeles, Boston Children's Hospital and Lurie Children's Hospital of Chicago, patients across the country are being monitored extensively during the first two years of their treatments.

The number of adults, adolescents and children who openly identify as transgender has grown in recent years. Today, roughly 150,000 kids in the U.S. ages 13 to 17 identify as transgender, making up 0.7 percent of that age group, according to the Williams Institute, a think tank at UCLA School of Law.

Previous research out of the Netherlands tracked transgender patients 12 and older. But the UCSF study is the first one to include children under 12 and rigorously assess transgender patients' psychological and physical health.

“Parents will say to us, ‘What do you really know about the long-term effects of puberty blockers? Who has really studied the children for 20 years?’” said Diane Ehrensaft, a clinical psychologist and the UCSF clinic's mental health director. “And we say, ‘That's what we plan to do.’”

The clinic uses the “gender affirmative model.” It allows transgender individuals — people whose gender identity does not align with their biological sex — and “gender-expansive” individuals, who do not conform to either the male or female gender, to freely express their gender identity.

Clinics like this one are a relatively new phenomenon.

“There was so much strong gender policing growing up,” said Anderson, now 66. “If you were interested in the things that the other sex was interested in as a boy, you were a sissy. If you were a girl, you were a tomboy. And I was never a sissy.”

Ehrensaft said one of the UCSF clinic’s goals is to allow the patient to express their “authentic gender, which lies between your ears, not between your legs.”

The clinic’s patients can start puberty blockers and testosterone or estrogen according to their pubertal stage, rather than their age. The stages are based on physical changes such as pubic hair growth and the beginning of menstruation.

This is unlike the “Dutch model,” which specifies treatments that are strictly based on a patient’s age. Children can take puberty blockers only if they’re 12 or older, and adolescents need to be at least 16 to start taking testosterone or estrogen.

Developed at Amsterdam’s Center for Expertise on Gender Dysphoria, the model served as the basis for the first-ever study on the long-term outcomes of transgender care. Dr. Annelou de Vries, a psychiatrist at the center, followed 55 transgender youth from before they started treatment to one year after receiving reassignment surgery, which can include the removal of breasts and construction of a vaginal cavity. In 2014, the lab published a study showing significant improvement in the patients’ psychological health.

Although they call the study a step forward, members of the UCSF team see gaps in the research that need to be filled.

Patients enrolled in the UCSF clinic’s study complete a litany of forms and an extensive interview by a physician every six months for two years. They also have follow-up appointments with their doctors to track their physical transition throughout the study.

As was done in the Dutch study, Ehrensaft said, the UCSF team is monitoring the patients’ mental health. But the current study, she said, has “widened the lens on what we’re looking at in terms of gender health.” And it will be the first to track transgender youth “receiving medical interventions based on stages, not ages,” Ehrensaft said.

Ukiah resident Jennifer Bilstein, the mother of 16-year-old Jacob, a transgender boy receiving treatment at the UCSF clinic, calls the research essential.

The study will “help people to look at things from a different perspective instead of utilizing the views that everybody grew up with 50 years ago,” she said.

Kimberly Richman, whose 9-year-old expressed a desire to transition from female to male last summer, thinks the clinic’s care is life-changing. Allowing the transition to start at a young age is “much more proactive and healthy and safe than waiting until they are adults and have a breaking point,” said the San Francisco resident.

Not all medical professionals agree.

In a 2017 paper in *The New Atlantis*, a conservative journal, Dr. Paul McHugh called puberty blockers both unnecessary and harmful.

As the former chief of psychiatry at Johns Hopkins Hospital, McHugh has worked with transgender patients since the 1970s. His philosophy is to encourage patients to postpone medical decisions until medical teams have ruled out other factors that could be influencing the patient’s desire to transition.

“There is an epidemic, particularly of male-to-female transgender patients,” he said in an interview. “That worries me, and I think that should worry everyone in America.”

But Dr. Johanna Olson-Kennedy, a physician at Children's Hospital in Los Angeles and lead principal investigator in the UCSF study, strongly disagrees.

"I have a fundamental problem with the way autonomy is stripped from trans people," she said. "It's frustrating to me the idea that someone else could know your gender better than you do."