

Chase, Cheryl (b. 1956)

by Linda Rapp

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A portrait of Cheryl Chase by Phyllis Christopher. Image courtesy Cheryl Chase.

Activist Cheryl Chase has given a voice to the intersexed and has led efforts to educate both medical professionals and parents of intersexed children so that medically unnecessary surgeries may be avoided and that intersexed people may have happier and healthier lives. Her efforts in this cause earned her the International Gay and Lesbian Human Rights Commission's Felipa de Souza Award in 2000.

When Chase was born on August 14, 1956, no one shouted, "It's a boy!" or "It's a girl!" The child had ambiguous genitalia, including what Chase describes as "a little nubbin." Doctors sedated Chase's mother for three days while deciding what to tell her. The belated verdict was that the child was a boy, who was christened Charlie Sullivan. (Chase adopted her current surname when she was in her thirties.)

Exploratory surgery eighteen months later revealed that the child had both a uterus and ovotestes, an organ containing both ovarian and testicular tissue, and was, in the terminology of the time, a hermaphrodite.

Doctors recommended a drastic solution: the "nubbin"--a large clitoris--should be completely removed surgically, and the parents should discard all photos of the youngster as a boy, secure a new birth certificate indicating that the child's sex was female, and move away from their hometown in New Jersey to a place where no one would know that their child, previously regarded as a son, was in fact a daughter.

"The doctors promised my parents if they did that, I'd grow up normal, happy, heterosexual, and give them grandchildren," stated Chase.

The Sullivans relied on the doctors' advice, and a clitorectomy was performed.

When Chase was ten years old, her parents told her that her clitoris had been removed, but, she stated in a 2000 interview, "they explained it all in terms that I had no understanding of" and emphasized that as a result of the surgery she was just fine. At the same time, however, they also underscored that she should tell no one about the operation.

The same year Chase's parents took her to a psychiatrist who never addressed the issue of her intersexuality but instead gave her "a plastic toy called 'The Visible Woman,' which had abdominal organs that you could replace with pregnant ones" in an apparent attempt "to prepare [her] for a future role as wife and mother."

At nineteen, Chase, who had been told by her child psychiatrist that she was "medically famous," resolved to discover the truth about her medical history and asked her gynecologist to obtain her records. He subsequently claimed that "the hospital had ignored his request and he couldn't understand why" and sent her on an errand of her own to the hospital records department of New York City, where employees refused to release her own records to her. Chase later learned that the records had been sent to her gynecologist not once, but twice.

"I think that he lied to me because he saw how distressed I already was," she stated. "He didn't want what was going to happen to me to happen in his office."

Chase next asked her childhood psychiatrist to obtain the records, but the woman was dismissive, saying, "You don't need them."

Chase moved to San Francisco two years later. When she requested help from her female gynecologist there, she finally found out the truth about her intersexed condition.

The news came as a shock to Chase, who "had understood [that she] was a lesbian from quite a young age." In San Francisco in the 1970s, she said, "lesbian separatism was popular, and men were supposed to be evil. In that context I wasn't about to explain to another lesbian that I didn't have a clitoris because I had been a boy for a year and a half!"

Chase returned east to study at the Massachusetts Institute of Technology, where she earned a degree in mathematics. She next studied Japanese at Harvard University and then moved to Japan, where she founded a very successful high-tech company.

Despite her professional success, Chase felt extremely depressed, and so she volunteered for a telephone counseling service, hoping to find fulfillment by being of assistance to others. In the course of her training, she told her story to the organization's professional therapist, but, said Chase, she "couldn't even deal with the fact that I was a lesbian," let alone intersexed.

After seeing another therapist who was likewise unhelpful, Chase contemplated suicide and imagined cutting her throat in the office of the doctor who had performed the clitorectomy.

Chase, then 35, returned to the United States to talk to her mother about the circumstances of her surgery. Her mother, however, was not forthcoming. She insisted that she had had nothing to do with the decision about the operation, which in any event, she declared, had not been painful and had had no effect on her daughter's life--despite abundant evidence to the contrary. As an afterthought, though, she mentioned that following the operation, Chase, who had previously been quite verbal, "forgot" all the words that she knew and did not speak again for six months.

Chase's mother--now deceased, as is her father--ended contact with her after the emotionally difficult conversation.

Chase decided that she needed to learn more about intersexuality, and so she moved back to the United States, settling again in San Francisco. She began consulting doctors considered experts in the field but found that "they were shockingly ignorant."

Chase began telling her story to anyone who would listen, and in a year she found six other intersexed people. Her activism truly began shortly thereafter, in 1993, when, after reading some of the works of Anne Fausto-Sterling, a professor of biology and gender studies at Brown University, she wrote a letter to the editors of *The Sciences* magazine, inviting intersexed people to write to Cheryl Chase of the Intersex Society of North America (ISNA).

Until that time Chase had been known as Cheryl Sullivan, but she took on a new name as well as a new endeavor.

When Chase wrote her letter to the editors, she was the sole member of ISNA, but she soon began receiving

correspondence from people throughout the country who had had genital surgery as children. They were grateful for her initiative because most of them had felt isolated, not knowing that there were any others like them. By the year 2000, ISNA had a mailing list of approximately 1,500.

In the early 1990s, the issue of clitorectomies being performed on girls in Africa was receiving considerable press attention worldwide. Chase hoped that American feminists would take up the cause of intersexed people in the United States, and she met with Soraya Mire, a Somali filmmaker and herself a victim of genital mutilation, who promised to introduce her to feminist writer Alice Walker. Walker, however, refused a meeting and, stated Chase in 2000, "has never acknowledged that clitorectomy continues in the U.S."

As an intersexed person acknowledging that she had been subjected to genital surgery, Chase gave the community a face. By her activism, she also gave them a voice.

She used that voice to press for recognition that "intersex is a psychosocial problem" and that "intersexed people need professional mental health support, peer support, and an attitude that isn't shameful."

Since Chase had lived with the experience of silence, deceit, and secrecy, she knew only too well the shame that many intersexed people felt, but, she stated, "one of the things that I understood on that night when I contemplated suicide was that, as hard as it was for me to accept the body that I was born with, it was impossible for that body to have been shameful. It was my knowledge of the history of the gay and lesbian civil rights movement that brought me to understand that the shame was socially imposed, not intrinsic to my anatomy."

Chase has embraced the use of the term *queer* as a sexual identity, saying, "The value of the word 'queer' is that it talks about a difference that's stigmatized or transgressive without defining exactly what the difference is. . . . When intersexed people say 'my body's OK like this' and 'my identity is OK like this,' those are queer things to do and to think."

To foster communication among intersexed people, Chase established a web site for ISNA in 1995 and also applied for association with the National Organization for Rare Disorders (NORD). The application was denied because doctors on the board of directors of NORD concluded that ISNA's demand that genital surgery only be performed at the request of a well-informed patient--and thus never on a child--amounted to "experimental treatment."

In 1996 Chase attempted to persuade a group of doctors holding a symposium on pediatric genital surgery to include a panel of patients in their program. When the physicians declined to do so, ISNA organized their own workshop. Some doctors attended but were not receptive to the idea that the surgeries performed on the people when they were children had been harmful.

Frustrated by the response of the medical community, Chase and ISNA drew public attention to the cause of the intersexed by demonstrating outside the convention of the American Association of Pediatrics in Boston.

Also in 1996, Chase hosted a retreat for intersexed people at her farm in Sonoma, California. Eleven ISNA members attended and held frank discussions, which Chase recorded and edited in a 34-minute film entitled *Hermaphrodites Speak!* (1996).

The participants described the emotional and physical toll of their surgeries--a profound sense of isolation growing up not knowing anyone else like them, a feeling of empowerment when they met others and began to speak out, and anger toward the surgeons whose actions had put them through such ordeals and left them with impaired sexual function.

Reviewers B. J. Rye and Richard Humpartzoomian hailed the film as "an important educational experience in the context of learning about variations in human sexuality. . . . Hermaphrodites Speak! is a critical, empathetic learning experience," especially for students who will become healthcare providers and policy makers.

Chase has been an advocate for the intersexed not just in the United States but also internationally. In 1998 she submitted a 10,000-word amicus curiae brief to the Supreme Court of Colombia, which was considering the case of a six-year-old intersexed boy on whom doctors were proposing to perform an operation to turn him into a girl. The following year the court, relying heavily on Chase's brief, issued a landmark ruling creating human rights protection for the intersexed.

Because of her writing and speaking, Chase gained both attention and, ultimately, respect from the medical community. In May 2000 the Lawson Wilkins Pediatric Endocrine Society, an organization for specialists in children's hormones, invited her to give a speech at their symposium. Her forums have also included radio and television shows, such as *Fresh Air* on NPR and *Dateline* on NBC.

To help educate medical and mental health professionals as well as families with intersexed children, Chase made the film *The Child with an Intersex Condition: Total Patient Care* in 2003. The twenty-minute video "outlines the problems with many current practices and provides guidelines for a new standard of care that is more advanced scientifically and ethically."

ISNA calls for lifelong care for the physical, mental health, and social needs of the intersexed patient, who, the organization stresses, is the child, not the parents. Gender assignment of an infant is both a legal and a social necessity, and parents should make the decision using their best judgment and taking into account the outcomes of patients with a similar presentation, but they should not have surgery performed. The choice of what, if any, surgery to have should be left to the patient when he or she is of an age and has sufficient accurate information to decide what is in his or her own best interests.

ISNA recommends counseling for both the patient and the family for the good emotional and mental health of all concerned. Peer support is likewise extremely valuable.

ISNA believes that honesty and openness are essential to the entire process. Children should be given information in an age-appropriate fashion, and facts should not be withheld or misrepresented. Medical practitioners and parents should let the child-patient know that he or she is somewhat different physically from most other people but should not treat the difference as a cause for feeling shame. Raising the awareness of both medical professionals and the public at large about intersexuality is an important goal for ISNA as the organization works to counter myths and social stigma that have been attached to the intersexed condition.

Articles by Chase have appeared in numerous journals, and she also contributed to the collection of essays edited by Stanlie M. James and Claire C. Robertson, *Genital Cutting and Transnational Sisterhood: Disputing U.S. Polemics* (2002). J. Steven Svoboda declares that "Chase's closing essay is the book's standout piece."

In it, Chase observes that it has been difficult to enlist the support of feminists to her cause "because intersexuality undermines the stability of the category 'woman' that undergirds much first-world feminist discourse." She also reiterates the need for protection of the rights of intersexed children so that they may eventually make their own decisions regarding their sexual identity and expression: "Cutting intersex genitals becomes yet another hidden mechanism for imposing normalcy upon unruly flesh, a means of containing the potential anarchy of desires and identifications within oppressive heteronormative structures."

As the Executive Director of ISNA, Chase is a tireless advocate for the rights of the interesexed to have

appropriate medical treatment and to enjoy dignity as members of society.

Since 2001 Chase has been the life partner of Robin Mathias, a healthcare industry analyst who specializes in the detection of fraud and abuse. The couple wed in San Francisco in 2004 during the brief period when same-sex marriage was declared legal there. They reside on a farm in Sonoma.

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