

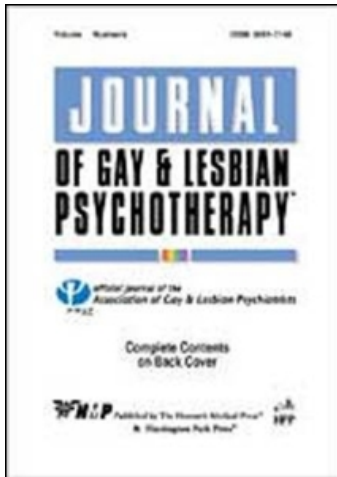
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An Interview with Cheryl Chase

Vernon A. Rosario, MD, PhD

INTRODUCTION

Cheryl Chase, the founder and current Executive Director of the Intersex Society of North America (ISNA), is an internationally recognized leader in intersex activism. She brings a passion to this work fueled by a painful intersex history. Chase had a tumultuous childhood and adolescence marked by tomboyism, social isolation, and unhappiness. She was kept in the dark about her early medical treatment. She underwent a mysterious abdominal surgery at age eight, followed by annual pediatric endocrinological check-ups until age twelve when she began menstruating. She was seen by a child psychiatrist between the ages of ten and eleven because of her disruptive behavior. At nineteen she began seeking information about her medical history only to be stonewalled by her parents and doctors. It was after much perseverance that she learned that she had been declared a boy at birth but this had later been reversed. Doctors then performed a clitoroplasty, which effectively removed her phallus. Histology of her gonads had ultimately shown that she had ovotestes, a condition still labeled with the misleading and archaic term “true hermaphroditism.”

The decades of shame, depression, and anger she suffered were redirected into social activism in 1993 when she started a support network for intersexed individuals. In its first years, ISNA was at once an international support group and a brash activist group in the style of AIDS and Queer activism of that time. Chase and ISNA were instrumental in

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bringing the plight of intersexed people to broader public attention in the 1990s. ISNA has focused its mission on raising public awareness about intersex conditions and educating medical professionals in order to provide better care for intersexed individuals from birth throughout the life cycle.

The following interview with Chase was conducted on November 17, 2003 after Chase had taken a year's break from the executive directorship of ISNA. She again became Director in January 2004. The interviewer, Vernon Rosario, was on the board of ISNA and Chair of its Medical Advisory Board at the time.

JGLP: It has been almost a year since you stepped down from the directorship of the Intersex Society of North America (ISNA). What do you see as the great advances that you and the organization have made, and what do you see as pressing issues that remain?

C. Chase: I think the most important advance is that intersex is much more visible now than when I started. When I began looking for information in the early 90s about intersex or people who had intersex conditions, there was not any way to find a person who had an intersex condition with whom to talk. The information you found in books was very medical and insisted that after "some physical interventions" the intersexuality would be gone. [The information] treated intersexuality as something that was fascinating for freak value or for what it might help us learn about "real" men and women, rather than [being written] out of any concern about the people with an intersex condition. That is quite changed now, there are lots of people with intersex conditions who are visible and whose stories are available. There are ways for families and people with intersex conditions to find other people with whom they can talk.

The biggest challenge is that there are lots of constituencies that have an investment in what intersex means as a concept and what intersex bodies mean. These constituencies are quite divorced from the welfare of people who have intersex bodies. People in queer theory have ideas about what the existence of intersexuality means for their studies of sex and gender and further aspirations for a kinder, more gentle future. People in gay activism have an agenda about what intersex bodies mean. Parents of intersex children are another. When their intersex child is born, it causes the parents to have many disturbing thoughts about sex and gender in general and specifically about their own gender and sexuality that are not really connected to the welfare or the experience of the intersex child. What that means is that when people hear the word

“intersex,” they immediately jump to all kinds of complicated ideas, inventing identities for intersex people, or imagining that if we did not perform surgery on intersex children we would be forced to change our social fabric in a really fundamental way. Those kinds of thoughts interfere with the ability of people who are trying to improve the well-being of intersex people and their families to focus on much smaller and accomplishable goals.

JGLP: A preliminary question, then, is what *you* define as intersex and where would *you* draw the boundaries?

C. Chase: When you say “boundaries,” that raises a red flag for me. People think of sex as a discrete and binary category, but actually there are many dimensions of sex. To put it mathematically, it is a multidimensional space rather than a single dimensional space. It is not an “atomic variable.” For most people, all of those factors that go into making up the sex that we think of a person being are pretty concordant. A man is likely to have masculine looking genitals and masculine behavior; and if we were to do some medical examinations, we would find that he has XY chromosomes; and if we looked at his face, he has a certain kind of facial structure, hairline, and pattern of hair on his body. And we could make similar generalizations for women. For most individuals, it is pretty easy to look at all those factors and they pretty much line up, and we say, “that’s a man” or “that’s a woman.” Whenever some of those factors do not line up, there is a discordance between the factors. Then, *that* is what *I* call intersex.

JGLP: But by that definition, we could include people with gender discordant psychological factors, like transsexuals.

C. Chase: I do not think it is important to come up with a definition that divides everyone in the world into categories. The work of the ISNA is not to define who is intersex, rather it is to end the shame and secrecy and unwanted genital surgeries that are the fate of most people who are identified as intersex when they are children.

JGLP: Earlier you were criticizing the ways in which some feminists have taken intersex. One way would be to generalize intersex: no one expresses maleness or femaleness in a Platonic ideal way; therefore, everybody is intersex. This dilutes the possibility of accomplishing ISNA’s mission.

C. Chase: It does dilute that work; therefore, I am not very interested in coming up with definitions that people can use as a litmus test to

determine if any particular individual is intersexed or not. That is a hopeless and pretty useless game. Rather, there is a system by which children who are identified as intersexed are usually harmed and that system involves thinking of anatomical sexual discordance as something that is shameful, that has to be kept secret, and that has to be hidden with cosmetic surgeries that are frequently harmful. The mission of the intersex advocacy movement is to end that system of harmful treatment.

JGLP: Would you say that under your guidance, ISNA's mission changed over the last decade?

C. Chase: No! I think the focus of how it was going to be accomplished changed. When I originally formed ISNA, I thought it would be pretty easy to get people who had been treated for intersex conditions and who had been harmed by that treatment to come together and cooperate in supporting each other and changing the system. I found that to be really difficult and ultimately I realized that if it is a human rights issue, we should invite people who care about human rights to do that work, regardless of what their own status or history is. I also found that trying to create a definition that determines who is intersexed and who is not, leads to incredible arguments and factiousness. It is just not useful.

JGLP: I think what you are referring to is the challenge of convincing people with intersex diagnoses that they are intersexed. I think one of the lingering feelings among intersex people and certainly in the academic community, is that ISNA is about promoting intersex as an identity: that people are neither male nor female or that intersex people, in particular, are neither male nor female and they should claim their intersex identity. There was the "Hermaphrodites with Attitude" slogan that seemed to be the message in the early days of ISNA. But that has been strongly rejected by various intersex groups, while being embraced by certain feminists with a different theoretical agenda.

C. Chase: The rhetoric that you saw in the early days of ISNA—about claiming hermaphrodite identity—was not meant to be a serious identity but was about taking terms that had been applied to us by doctors without our involvement in that process. They had been incredibly stigmatizing to the point of causing many people to have suicidal thoughts. "Hermaphrodites with Attitude" was about taking away the power of those terms to hurt by using them in a facetious way, and confronting the doctors who imagined that intersex status was so unthinkably freakish that no one could stand to claim it. It is true that I said earlier that so many people have an investment in what intersex means and they jump

immediately to identity. That supports the medical argument that we have to normalize these intersex bodies otherwise people would be stuck with an intersex identity, which would be an untenable way to live. That has led ISNA and many other groups, including doctors, to try to think of another term for all these sexual discordances that would not have all this baggage. But the problem is that any term that refers to all those sexual discordances is going to have that baggage. It refers to sex and sexual anatomy and people think of that as being intimately connected with identity.

JGLP: Having been to several intersex support group meetings for people with Androgen Insensitivity Syndrome (AIS), hypospadias, and Congenital Adrenal Hyperplasia (CAH), I sensed a strong rejection of the intersex label largely because the members see “intersex” in terms of gender identity. How do you think ISNA should proceed with these individual groups?

C. Chase: It is difficult. I am not certain what the answer is. I think part of what is going on is that intersex conditions are so strongly stigmatized that the individual groups have a motivation to embrace the narrowest technically diagnostic label available and not find common cause with other people who have been treated under the same medical model. That is something about which we need to figure out how to educate people. [Note: In 2005, ISNA began to use the term “disorders of sex development” (DSD)]¹.

JGLP: I have also been surprised by the degree to which individuals affected—or their parents—are enthusiastic about surgical interventions, support research and advances in surgery, and are quite hostile to what they view as ISNA’s interference in the development of science.

C. Chase: ISNA is not against surgery. I think that many people with intersex conditions, if they had not been subjected to surgery, would choose certain kinds of surgery later, and they have a right to have the best surgery we can provide. That comes from research and from polishing technique. It is really difficult to polish surgical techniques if you do not communicate with patients after the surgery has been done. The AIS support group is one that has come out strongly against early surgeries but not later ones, and that matches ISNA’s position.

JGLP: How do you feel about diagnosis, prenatal treatment of intersex conditions, and attempts to prevent intersex conditions?

C. Chase: I do not think that having an intersex condition is something that is going to make your child happier. If I were having a child, I would prefer that the child not have to deal with an intersex condition, and if I had a way to reduce the likelihood that my child might have an intersex condition, I would certainly pursue that for my child. At the same time, I think that a lot of people who might take advantage of prenatal diagnosis or interventions do not have a good idea of what it means to live with an intersex condition. They might choose abortion or highly risky interventions when that would not be their choice if they better understood what the child's life would be like.

JGLP: Returning to feminist appropriations of intersex, Suzanne Kessler in *Lessons From the Intersexed* (New Brunswick, NJ: Rutgers UP, 1998) proposes that intersex will help break down the gender divide. How do you feel about that?

C. Chase: Among the humanities scholars who have taken an interest in intersex, Kessler is one of the early ones to actually be willing to listen to us and be helpful. She has been helpful in many ways, and we are grateful for that. However, I find the idea that intersex is a tool we can use or a bit of an evidence we can use to create a society that has no sexes or genders to be ludicrous. I think that humans, like other primates, evolved to have sex differences in a way that is important to us and there are many ways that we get pleasure out of this. It is not realistic to think that we could eliminate sex or gender. I suspect that's something that is wired into us at a biological level. Nor would we like a world without sex or gender. It would be good to be less rigid about people who do not conform, so that we certainly will have ideas about what men usually are like and what women usually are like. However, when we encounter people who differ from those ideas we should not feel that that is wrong, sinful, sick, or something that should be prohibited or corrected.

JGLP: Let me push you further on this: What is the socially progressive, political message of ISNA? What does intersex politics say about changing the future?

C. Chase: I think a lot of people in women's studies imagine that the existence of intersex people is a justification for creating a future that is radically different. What I like to remind them is that intersex people have not been subjected to such an intense and harmful medicalization for very long. The ways intersex people are treated by doctors—with shame and secrecy and unwanted genital surgeries—only became widespread in the 1960s. What that means is that there are lots of intersex

people now who were not treated that way. It also means that in the early part of the 20th century, most intersex people were *not* medicalized. They made their way, for better or worse, in a world that was much more rigid about sex and gender than the one we live in today. So, radical social restructuring is not required in order for us to make the world an easier place for intersex people to live in.

JGLP: Also in poor countries there are not the resources for such medical interventions, and they often have extremely conservative gender constructs.

There seems to be a widespread misperception that the intersex politics of ISNA is about ending sex reassignment in cases like the David Reimer (John/Joan) case.²

C. Chase: This is related to the idea that intersex is an identity. People who believe they are sympathetic and that they are listening to us, are not listening and instead jump right to, "Sex reassignment is terrible and we have to end those." They are thinking only of cases in which intersex people grow up to reject the sex they were assigned and then transition. But that ignores the vast majority of intersex people who may feel harmed by having been shamed, lied to, and subjected to unwanted surgeries, but do not reject the sex to which they were originally assigned. Most intersex people were assigned female and most intersex people grow up to be women. So when people who intend to listen sympathetically equate intersex only with sex reassignment, they make it hard for us to be heard about what really happens to intersex people.

People also seem to have some motivation to take the kinds of harm that we are talking about and turn them into something much more extreme. So when we talked about unwanted genital surgeries the other night here in your house, one of your guests said, "Yes, and they do it without the parents' permission!" And that is just not true. It was true in the past at a time when doctors did many things without permission. But now they get permission. I just do not think that the permission is very informed or that the parents have the right to give that permission for the child. Even with regard to genital surgery, when we say that someone had genital surgery and now their function is impaired, very often a recounting of that in the media or in women's studies is turned into, "This person had genital surgery and now they have *zero* sexual function!" People who study sex know that zero sexual function is correlated with coma. People who are not in a coma usually have some level of sexual function, even if it is greatly impaired.

JGLP: Eric Vilain's research on early sexually dimorphic gene expression received a lot of publicity recently.³ There is also a large body of research looking at sex differences in the brain and in various psychological measures. Do you have any hypotheses about what intersex may teach us about this and sexed behavior and sexuality?

C. Chase: I think that one of the glaring errors of thought in women's studies, queer theory, and gay activist movement is that they decide that sex and gender are completely independent, and in particular, that sexual orientation and gendered expression are completely independent. That is contradicted by our experience. When we think that we recognize that someone is a gay man or a lesbian—when our gaydar works—it is not because we are able to see the sexual desire of the stranger. What we are seeing is something about their gendered expression. The reason that gaydar works is that there is some loose correlation between gendered expression and sexual orientation. I use “correlation” in the mathematical sense, meaning that they do not always line up. I am not saying that all gay men look feminine or that all lesbians look masculine, but rather that when you see a man who looks feminine, we suspect he might be gay and for good reason, because many gay men are feminine and vice versa. When you look at intersex people and think about them according to their etiology—the biological cause of their intersexuality—there also seems to be a correlation between sexual orientation and gendered expression. In my experience, people who have been exposed to higher levels of virilizing hormones during gestation (and have functional androgen receptors) are more likely to be attracted to women, more likely to be more masculine in their behavior than other women, and more likely to ultimately express that they have a masculine identity and prefer to live as a man. This means, for example, that lesbianism is quite common among intersex people assigned female.

JGLP: That's been one of the most controversial things in psychological studies of women with CAH: whether it affects sexual orientation. Numerous studies have found that gendered behavior is affected leading to increased male-typical behavior, but studies have been less consistent in associating female CAH with lesbianism.

C. Chase: I suspect that there is something wrong with the studies that do not find a high level of lesbian outcomes in CAH women because the CAH women I have met are extremely likely to be lesbian. One counterargument that could be made is that there is a sample bias in the women that I see: Only the CAH women who talk to ISNA or Cheryl Chase are more likely to be lesbians. But I have met a lot of women with complete

AIS and I can only recall two who were lesbians and the rest, the vast majority, were heterosexual. That makes me think that sample bias is not the answer because it is hard for me to imagine why of the women with CAH only the lesbians would talk to ISNA, while of the women with complete AIS only the heterosexuals would talk to ISNA.

JGLP: What do you think are the most pressing issues for intersex men?
C. Chase: From my experience, intersex men often are more hesitant to talk about what has happened to them or be public about it. I am not certain that the issues are fundamentally different. I think whether someone has been raised as a boy or a girl and whether they live as a man or a woman, being treated as if who you are is shameful, having your medical history and the history of your own body kept secret from you, and being subjected to surgeries that you would not have chosen yourself, are things that take away from the quality of your life.

JGLP: From my experience the Hypospadias and Epispadias Association (HEA) is undergoing an internal debate about intersex that is driven in part by Howard Devore's claiming an intersex identity. What struck me most at the 2003 HEA meeting was the huge amount of shame, guilt, and psychiatric consequences members associated with their hypospadias. All these seem like issues with which ISNA is in tune.

C. Chase: I think that it is presumptuous to tell anyone what their identity should be. I do not think it should be part of any liberal agenda to tell anyone that their identity should be determined by their anatomy. I do not understand why that is a position that is attractive to people in queer theory or women's studies: that intersex people's identity should be determined by their anatomy. I would strongly second your observation that the men with hypospadias are affected by shame and guilt. Doctors have tried to prevent those emotional consequences with surgery and secrecy and that program does not work. So we need to help doctors understand that shame and guilt are not prevented by surgery and secrecy but rather by psychosocial approaches including openness and professional support and introduction to peers: Particularly hypospadias, since it is so common yet it is so secret that many men with hypospadias imagine it is impossible to meet someone else who has it.

JGLP: The issues of "unwanted" surgery are very difficult when you look case by case. My sense is that doctors are becoming more conservative about what they will operate on. And they claim that none of the surgeries is just cosmetic or just to normalize the clitoris, but is about

addressing larger problems of sexual functioning like increasing vaginal depth, or vaginal introitus problems, or urinary outlet problems.

C. Chase: A lot of those doctors are seriously uninformed about actual human sexual function. They have not read the most basic literature about observations of human sexual function and they have not done much introspection about their own sexual function. So they equate sexual function purely with penile-vaginal penetration to the hilt. One woman I know who was subjected to unwanted medical attention because of her short vagina told me that when she ultimately did have sex with a man she discovered that his penis was remarkably responsive to all kinds of stimulation whether it involved a vagina or not, and she felt like she had been totally cheated by years of so much attention from doctors who insisted that unless her vagina was in a certain position, and of a certain depth and a certain capacity, that she would never be able to have sex with a man. Likewise we know that doctors frequently have much more stringent ideas of what constitutes a cosmetically acceptable clitoris than other people do.

For example, a colleague of mine who is a pediatric endocrinologist relates this story: A young woman who is a patient of his came to the clinic and she said that she was troubled by her short stature. She did indeed have an endocrine condition that led her to have short stature. When she was examined by one of his colleagues who was a woman, the woman came out the examination room and was very disturbed by the large size of this patient's clitoris. She said, "Oh my gosh, we need to do something, she needs a referral to surgery,"—like on the spot, with extreme urgency. My friend said, "Just a minute; come back into the examination room and be quiet while I talk to the patient."

He talks to the patient and asks her a little bit about her sexual experience and concerns and the woman expressed no concerns about the size of her clitoris, only her stature. He asked, "Is there anything else that's disturbing you?" She seemed a little hesitant, but he drew her out and ultimately she said, "yeah there is something." He asked if it was about sex. And she said "yeah." And he could see the woman pediatric endocrinologist's antenna going up, "Yes, yes, now we're going to learn that she's disturbed about the size of her clitoris!" Instead, the patient says, "I'm wondering if I can get pregnant." He discovers that she has been having vaginal sex with her boyfriend and she did not know whether she was capable of getting pregnant, and she was wondering if she could get pregnant accidentally. And he asks if there is anything else, and there is not. She leaves the room and he tries to explain to his colleague that this patient is having sex. She is not aware that her clitoris is larger than oth-

ers, and as far as we know, neither is her boyfriend. She has a concern about whether she is going to get pregnant and about her short stature, and it is too late for us to do anything about her stature. She is not bothered by her clitoris, so you should not be either. You should not create that anxiety in her.

JGLP: You will be coming back as executive director of ISNA in January 2004. In the intervening time it has formed a Medical Advisory Board, of which I am Chair. What other kind of projects do you want to see ISNA develop?

C. Chase: I am really excited about the MAB and I would like to see ISNA try to narrow its focus to work on medical reform. I think that is the area where we can do the most good. And by narrowing our focus to that we can work more effectively. We can try to avoid the morass of arguments about intersex as an identity.

JGLP: Any parting thoughts?

C. Chase: I would like to say something about “natural.” I hate the word “natural.” I do not think that appeals to the natural as a justification are useful. We look around the world and we see certain things. One of the things we see is that some people are born intersex. The world does not assign any value to the fact that they are born intersex. We have to decide as a culture what value to assign it. I think that usually when people decide to call something natural, it is a hidden appeal to religion. It means that God wanted it to be that way. I do not think that those kinds of arguments are very helpful in deciding how we as a culture want to treat people who are born with sexual anomalies.

JGLP: Can you give me an example of how people use natural and unnatural in relation to intersex?

C. Chase: I think a lot of doctors think it to be unnatural and therefore needing to be eliminated. I think that a lot of people who think they are making a progressive argument want to label intersex as natural, perhaps not just because they see it in the world, but because they like to use that as an argument that it should be free of intervention. But I don't think that natural or unnatural are very useful categories. I think that we need to talk to people who have intersex conditions and see what their experience of various interventions and kinds of care have been and use that information to help us improve how we care for intersex people in the future.

JGLP: One problem I have seen in terms of terminology is the place of the word “pathology”: Is intersex a pathology or is it normal? Is it something that shouldn’t be under medical purview like homosexuality was in the *DSM-II* or is it a disorder?

C. Chase: I think that most intersex presentations are caused by underlying disorders. So when you see someone who was born with a large clitoris or extreme hypospadias, or even mild hypospadias, it is reason to suspect that they could have a disorder that could make them sick. Therefore, we should investigate further to uncover the disorder and provide appropriate treatment for the disorder. But I don’t think that unusual genital appearance in itself is pathological. I do know that being born with a large clitoris might be a sign that the baby has CAH and that CAH may make the baby very sick or even cause the baby’s death; and those are not things that anyone would want. A lot of times doctors have a hard time separating those aspects, so when we say that we don’t think that girls born with a large clitoris should have clitoral surgery in infancy, they say, “But without treatment those babies would die!” Because they cannot separate their idea of giving cortisone to a baby with CAH from performing surgery to remove parts of her clitoris. But ISNA certainly is in favor of providing medical care for intersex disorders. When a child has gonadal dysgenesis, we know that they are at some risk of developing gonadal cancer, and that is certainly something we would not want to see happen in a child and warrants careful observation and perhaps even removal of the testes.

NOTES

1. Further information on the new Disorders of sex development nomenclature and clinical guidelines for management of DSD are available at <http://www.dsdguidelines.org>.

2. See John Colapinto, *As Nature Made Him: The Boy Who was Raised as a Girl* (New York: Harper Collins) and Milton Diamond and Keith Sigmundson (1997), Sex reassignment at birth: Long-term review and clinical implications, *Archives Pediatric & Adolescent Medicine*, 151: 298-304.

3. Dewing P., Shi T., Horvath S., Vilain E. (2003), Sexually dimorphic gene expression in mouse brain precedes gonadal differentiation, *Molecular Brain Research*, 118: 82-90.