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"Cindy," a 48-year-old Bloomington resident who is intersexed, is pictured at age 8. At that age, she did not know about her condition. She describes herself as having grown up as a "girly girl," drawn to dolls and frilly dresses. Courtesy photo

Pink or blue?

For intersexed people, biology doesn't provide a clear answer

by Dann Denny
Hoosier Times

June 19, 2005 BLOOMINGTON, IN –

When "Cindy" learned in 1992 that she was not fully female, she was dumbfounded - and angry with God.

"I asked God, 'Why me?' " said Cindy, who requested that her full name not be used for this story. "I told him that when I die, we're going to have a long talk about this."

Today, Cindy knows she is among 4,500 to 23,000 Americans (estimates vary from 1 in 13,000 to 1 in 65,000 live births) who are "intersexed," meaning they were born with some degree of sexual ambiguity at birth.

The ambiguity ranges from having a slight deviation from the normal male or female physiology to having both sets of fully developed

male and female external genitalia.

Cindy was born with the complete form of androgen insensitivity syndrome, which caused her to be born with male (XY) sex chromosomes and testicles inside her body - but female external genitalia.

Based on estimates that one in every 20,000 babies is born with some form of AIS, there are about 312 residents in Indiana - and six in Monroe County - with the disorder.

Not a tomboy

As a child, Cindy was a self-described "girly girl," instinctively drawn to dolls and frilly dresses. She continued feeling unequivocally female until she was diagnosed as being intersexed at age 34, thrusting her into a vortex of confusion and self-doubt.

"I always believed I was a girl and never wanted to be anything other than a girl," she said. "But after the diagnosis, I looked at myself in the mirror and wondered which gender I was supposed to be. Should I stop wearing dresses, makeup and jewelry?"

Today Cindy is 48, and a full-time staff member in Indiana University's College of Arts and Sciences. She's a 6-foot-tall blonde with broad shoulders; a bright smile; and a rosy-cheeked face that glows with good health.

She has female breasts, and a clitoris; but no uterus, cervix, ovaries, or fallopian tubes. Her vagina is short, about half the length of an average woman's.

Cindy was born with testicles, but because she is insensitive to masculinizing hormones called androgens, those testicles did not descend or fully develop.

"Technically, I'm intersexed," she said, saying she prefers that term to hermaphrodite. "I'm not 100 percent female, and I'm not 100 percent male. I'm in the middle biologically."

A misdiagnosis

Cindy and her parents first suspected something was wrong with her during adolescence when she failed to undergo puberty or have a menstrual cycle.

At age 17, a specialist gave her a battery of tests. He found she had non-functional ovaries and no uterus, thus preventing her from ever having children.

"I was devastated," she said. "As a young teen I had imagined getting married, having kids and pursuing the typical American dream."

The specialist also ran genetic and chromosomal studies, which he said indicated no further abnormalities. Looking back, Cindy feels the specialist knew the truth about her intersexed condition, but lied about it.

"I came from a very low-income, unemployed family with poorly educated parents," she said. "I don't think he felt my parents and I could understand all the ramifications of my condition."

A correct diagnosis

As young woman, Cindy never questioned her sexual identity. She felt utterly comfortable as a female - routinely donning earrings, dresses and makeup.

But knowing she had no uterus left her perplexed about her health care.

"I would read articles in the paper suggesting women have regular pap smears or mammograms," she said. "I wondered whether those recommendations applied to me."

So Cindy met with Bloomington gynecologist Andy Stafford, who diagnosed her as being intersexed.

"I will always be indebted to him for his honesty and sensitivity," said Cindy. "He took several hours out of his busy schedule to explain it to me in his office."

Later, Cindy visited a gynecologist / endocrinologist at IUPUI, who strongly suggested she have her underdeveloped testicles removed.

She said Cindy was playing Russian roulette, pointing out that if non-functional testicles are left inside a person's body, there's a 30 percent chance they will become cancerous by the time the person reaches 50.

After having her testicles removed, Cindy saw a Bloomington counselor who helped her process the sudden revelation that her sexual identity fell somewhere between male and female.

"She helped me realize I was born to be a woman, but just took a different path to get there than the average woman," she said. "I decided I would not give in to the disorder by becoming a butch, masculine-looking woman."

Sexual orientation

Though Cindy is in a committed relationship with another woman, she said her partner (who is chromosomally a female) is "butch," while Cindy (who is chromosomally a male) is thoroughly feminine.

"I do the cooking and cleaning," she said. "She does the yard work and cleans the gutters, we make it work for us."

Stephanie Sanders, associate director of the Kinsey Institute, said the incidence of homosexuality or bisexuality is no greater among intersexed individuals than the general population.

But Sanders adds that with many intersexed people, the issue of sexual orientation becomes murky.

"If a person with male chromosomes and female external genitalia is attracted to females, is that person heterosexual or homosexual?" she asked. "It's a difficult question."

At peace

Since Cindy became a national board member of the AIS Support Group-USA a year ago, she has felt more comfortable talking about her condition with friends, relatives and colleagues.

"I'm not ashamed about being born with AIS," she said. "And I've come to realize that this is not a big deal compared to some things - such as life-threatening illnesses."

But Cindy said many intersexed individuals still live in shame, and will go to their graves carrying their secret.

"That's tragic," she said. "When we're ashamed of ourselves, we perpetuate the shame."

---------- *Below is the second related story* ---------

Surgery on babies to assign a sex now discouraged

by Dann Denny
Hoosier Times

June 19, 2005 BLOOMINGTON, IN –

Most people with androgen insensitivity syndrome have the "complete" form of the disorder.

But 1 of 10 with AIS have the "partial" form, which tends to cause more severe abnormalities - such as being born with both male and female external genitalia.

This can create confusion for parents, who often wonder whether they should raise the baby as a girl or boy and whether they should have doctors remove either the male or female sex organs.

A Bloomington woman with AIS has strong opinions about both issues.

"My view is that no surgery should be performed on a child until that child is able to make the decision for him or herself," said "Cindy," a 48-year-old IU employee who asked to remain unidentified for this story. "If you want to know what sex your child is, wait until the child is old enough to tell you."

Stephanie Sanders, associate director of the Kinsey Institute, said most people in the medical community now agree with Cindy.

"Up until recently, the conventional wisdom was that whether it was medically necessary to perform surgery, it was important socially to assign a child a distinct sex and to alter the genitals to conform with that sex," she said. "Increasingly, however, that conventional wisdom is being challenged, largely because of a number of intersexed people who feel the surgical choice that had been made on their behalf was the wrong choice."

Sanders said most experts now feel parents of a partial AIS infant should assign it a male or female name and raise it accordingly - gradually

unfolding the truth to the child about its sexual ambiguity.

"Ethically it's not right to hide the truth from the child," Sanders said. "When the child becomes old enough to understand, the child should be given the facts. And at the appropriate age, the child should be allowed to decide how it may want to alter its genitalia."

Sanders feels Americans can learn something from a small village in the Dominican Republic where it's common for babies to be born with an intersexed condition called "5 alpha- reductase deficiency."

Infants with this condition lack an enzyme that affects how the genitals develop.

"A genetic male with this syndrome has ambiguous genitals at birth that are not completely masculinized," she said. "He is treated more like a girl until he reaches puberty at about age 12, when his penis begins to elongate and he begins to look more like a boy. From that point on he's treated more like a boy."

Sanders said the villagers call this condition "guevo doce," meaning "testes at 12" - and that it's so common that some families have several children with this condition.

"They accept it as a third type of gender," Sanders said. "Perhaps we should educate people in this country that some people are born with ambiguous genitals, and that we should see it as a wonder of nature rather than a negative."

Though Bloomington obstetrician/gynecologist Bob Wrenn has never seen an intersexed patient during his 30 years of practice, he feels any genital surgery should ultimately be the child's choice.

"I think it's important to always be honest with the child," he said. "And when the child becomes old enough to decide, he or she should be allowed to make the decision concerning surgery, unless surgery is needed prior to that due to health concerns."

But not all doctors - or parents - agree with Wrenn.

Sanders said some people feel that not surgically altering a child with ambiguous genitalia is like not fixing a birth defect.

"They would say it may cause the child to be ridiculed at school when other students notice the abnormality in the locker room," she said.

But Cindy says such thinking is flawed, citing an intersexed woman she knows whose parents had her external male genitalia surgically removed when she was an infant.

"Today, that woman cannot experience a normal, healthy sex life with her mate," said Cindy. "The surgery robbed her of her sexual function."

Cindy is involved in a national AIS support group that has nearly 300 members, most of whom were born with the disorder. She said a handful of them did not learn their parents had authorized the surgical removal of their genitalia until they were older.

"I suspect there are some people living today who have no idea their parents removed a portion of their male or female sex organs at birth," she

said. "They may live their whole lives without ever learning the truth."

AIS is hereditary

AIS is usually inherited from a recessive gene carried by the mother. A third of AIS individuals have the disorder due to a spontaneous genetic mutation.

A mother with the recessive AIS gene has a one in four chance of passing it along to her child.

"If a woman has one or more female relatives who can't have children, she might ask them why," said Cindy. "If she doesn't get a satisfactory answer, she should undergo some chromosomal and hormonal testing to see if she is carrying the AIS gene or some other intersex condition."

Marriage issues

Cindy has some questions about the U.S. Congress and the Indiana State Legislature's definition of marriage as only a union between a man and a woman.

"They don't specify what constitutes a man or a woman," she said. "Is it our chromosomes? Our genitals? Our birth certificate? Who do these politicians think that I should marry?"

Cindy said a recent bill proposed in the United Kingdom defined a woman as someone who has - or used to have - the ability to give birth to a child.

"But what about a person like me who looks, feels and acts like a woman but has male gonads and no uterus?" she asked. "What if we used the same definition for males, then any man who can't have an erection - without Viagra - is not a man? I doubt that bill would become law!"