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Adventures in Child-Rearing: The Sexual Life
of a Child Growing Up With Down Syndrome

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Abstract

The sexual development of one child with Down syndrome is detailed from his infancy through his adolescence. This paper confronts society's often-held notion that a person labeled with mental retardation is asexual, amoral, or immoral, and incapable of learning how to make reasoned decisions about his own sexual behavior. It is written by and from the perspective of his mother, a disabled disability advocate and a former special education teacher, but includes references to others who have had an impact on the choices that might have affected his sexual development. Her son is quoted both from notes she has taken throughout his life and his memories in response to hearing the draft of this article read aloud at the age of nearly nineteen.

As the single, adoptive parent of an adult child labeled with Down syndrome, I have noted since his infancy that friends, family, and society have questioned his right and capability to be a sexual being. This pervasive questioning has made me hesitate to raise my son as I would if he did not have his disability. I have always disagreed with those who believe that he could not make reasoned decisions about his sexuality believing that he could make such decisions if given adequate education and support. I believe that sexuality is an integral ingredient to making us human and one of life's greatest joys and so I have tried to give my son the tools to make sexual decisions safely. I am committed to enabling my son to experience life to its fullest, including responsible, consensual, sexual behavior. This paper discusses the choices I have made in raising my son to be the sexual being he has become and the responses we received. My son is now nineteen and some common life experiences for people with disabilities have changed for the better over time, but too much remains the same.

Infancy

My son arrived in my life when he was four months old. He was born with Down syndrome and the effects of prenatal cocaine exposure and, subsequently, was diagnosed with failure to thrive. When he came to live with me, he did not explore his body as is common for most infants. He had a flat affect and responded very little if at all to being rocked, cuddled, or spoken to. He did not turn his head to avoid a cloth over his face, or reach for objects, or grasp fingers. He did not resolve discomfort by sucking on his fingers, a bottle, or crying. One of the very first activities he seemed to take enjoyment in was wiggling. His nickname to this day is wiggle-butt. When dressed and lying on his stomach he would wiggle his body back and forth with obvious enjoyment. Teachers in his early intervention classes as well as his pediatrician discouraged me from encouraging and delighting in his pleasure, but I continued without apology.

Unlike many babies, when his diapers were removed, my son rarely reached for his genitals: he would prefer to be on his tummy and wiggle. As his mother, I found this lack of interest peculiar and worrisome. I decided he needed some help to discover he had a penis he could reach. I did this with considerable guilt and trepidation since I had never read of any child needing this help. My son showed no interest in exploring his body and continued to prefer to wiggle, even with my encouragement.

I made little attempt to discourage his wiggling, even with its obvious masturbatory effect, until he was four years old and attending a preschool where it was disruptive. I could not effectively teach him to make good choices about when and where to wiggle until elementary school. He still engages in it occasionally now, but wiggles only in private and stops if accidentally discovered.

Once my son became potty trained he discovered masturbation and the desire to be always naked. No diapers meant freedom - from clothing and from the thick padding between his legs. I could not decide whether to dress him in clothing that would make it easier to dress himself independently or quite the opposite. Masturbation became a favorite activity. He needed to learn how to dress and undress himself and I wanted to encourage his self-discovery and pleasure, but could not make him understand that there were places where it was appropriate to be naked or to masturbate and others where it was not. I chose to dress him in easy-to-remove clothing at home and thick, cotton corduroy, difficult to remove overalls when we went out. This encouraged nudity and masturbation at home and essentially eliminated it elsewhere.

People with Down syndrome are often characterized as extremely affectionate - and my son is no exception. This was not a concern of mine until he was about four years old. He wanted to kiss and hug everyone he met, but his hugging began to seem more and more like groping and his kissing became

excessive. Some people did not take an offense at his occasional groping, but others were appalled. Many people could not accept that this was developmentally appropriate for him even if it was no longer appropriate for his peers. I tried to discourage his affection and groping, without discouraging his friendliness, but he could not learn where to draw the line. Initially, there were few successful attempts at modifying his behavior. I tried to teach him to greet someone with a handshake and to ask before kissing, but this simply evolved into a longer handshake-hug-kiss greeting.

My mother was a square dancer and when she danced she wore billowing slips under her skirts. When we visited her, my son loved to wear these slips. It was very amusing to see a four-year-old wearing a bright red slip that encased all except his head. Little did anyone know that his interest in wearing this petticoat would last ten years and in time require strict rules about when and where he could wear it. He seemed unable to appreciate that he could be teased for wearing this red slip. He and I frequently argued about whether he could wear this slip outside to play or to school. "I need it!" he would say. He loved to stand and twirl in it. His interest in female attire was not limited to this red slip, but also included a desire to wear clothes with feminine colors and silky textures and dangling earrings and hair barrettes. I wished I could allow him to wear whatever he wanted wherever he wanted without hesitation, but feared an attack on his self-esteem.

When he was about three or four years old, I began to worry that I was seeing signs of gender confusion because when he saw someone very obviously dressed as a man or a woman, he could not consistently identify their gender based on their clothes. He viewed people by their role in society, rather than their gender - mommies, daddies, children, babies. He knew he was Mommy's boy, since I called him that, but was unclear how this differed from being a girl except he knew he had a penis.

Much to my consternation, this confusion inspired him to ask countless persons if they had a penis or a vagina. "You have penis?" he would ask. As this confusion continued, it was hard to tell whether my son was slow in learning how to decipher a person's sex, was not bound by conventional rules of what a man or a woman looks like, or was questioning the constancy of his own gender. I wondered whether he understood that all men had penises and all women had vaginas and if this confusion had anything to do with seeing transgendered and cross-dressing men when he was young at Gay Pride Parades. I did not observe his friends without disabilities having similar confusion and many of them also grew up having gender-ambiguous lifestyles and single moms and knowing transgendered people.

Early Childhood

Until my son was ten, I made no determined effort to dissuade him from wearing his beloved square-dance slip, or

discourage his interest in girl's toys or with playing largely with girls. I saw his gender ambiguity as a sign that I had been successful in raising my son without gender stereotypes. Each Halloween, I made him an elaborate paper-mache turtle, hand-sewed devil's horns and tails, or decorated Thomas the Train costumes and each Halloween he wanted a store-bought Cinderella or Barbie costume.

Finally, I discovered a possible solution - he could be Dracula and wear makeup and a long cape. This was surprisingly effective. With encouragement, he began to wear the cape instead of the slip in his day-to-day play. It was more appropriate for a ten-year-old boy to twirl about in a Dracula cape than a square-dance slip and yet both seemed to give him the same pleasure. And both caused the same argument about wearing it to school. "I need it!" he would say of the cape. Learning to play with boy toys, playing boy games, and being interested in male peers required more effort. I enlisted the help of a young adult male with Down syndrome to spend time with my son. This backfired as the young adult took his cues from my son, not me.

For example, one day I left the two of them in K-Mart to look at sports equipment with strict instructions to stay put while I looked for another item. When I returned a few minutes later they had disappeared to the TV area and were sitting on the floor watching cartoons. It took over an hour to find them at which point my calm, collected child said, "We not lost Mommy, we here!"

I also found college-aged girls with boyfriends to take my son to sporting events and play outdoor games. This also proved ineffective. He fell in love with the girls who showered him with attention and grew jealous of the boyfriends who drew their attention away. He would tell their boyfriends: "You no marry Jennifer; I marry Jennifer when I be a man."

In conflict, I found it necessary to tell him that his playing with girl toys was babyish and refused to purchase Barbie dolls for him. I insisted he watch me play with boy toys purchased for him, even if he chose not to join in. He became marginally more interested. He would show cursory interest in Lego building and running train sets for a few minutes and then switch to looking at picture books or dancing to music. Had he been a child without a disability, I doubt I would have gone to this length to encourage his masculinity. However, I felt that my son needed to exhibit mainstream male behavior as much as possible so that gender-inappropriate behavior would not interfere with others accepting his disability.

Throughout his life, but especially as a young child, I was gravely concerned with my son's personal and sexual safety. His easy affection, naivete, and willingness to go anywhere with anyone were a source of constant anxiety for me. He could not differentiate between good and bad strangers. He learned that there were people who hurt with guns, fists, and loud voices, but I could not teach him that people could also be bad when they offered you candy, hugs, or motorcycle rides.

To my son, the world was very black and white and he could not understand the subtleties in-between.

My son at nineteen now understands these subtleties better, but I am still certain that he could easily be convinced by anyone that his instinct of danger is wrong. When I asked him whether he would go to the mall in a car with a stranger who drove-by on our street, he said, "No, I don't know them yet." And when I asked, "What if I weren't home, and they said that I had been in an accident and they would take you to me," he said, "I say yes, let's go." Then I asked, "Would you let someone in the house you didn't know?" He replied, "Maybe, but I be careful."

Middle Childhood

A pivotal influence on my child's understanding of himself as a sexual male was Corky Thatcher. Corky was the teenage boy in an ABC Television series "Life Goes On" who also had Down syndrome. My son wanted to be like Corky. Until Corky, he had rarely seen anyone like himself in typical sexual and social situations on television or in other media. When I asked him what he liked about the TV show, he told me, "Corky a nice guy. He happy and has Down syndrome like me. Corky go on a date, and has a girlfriend. He want to take driving lessons; he gets angry at his mom and dad when they say no - maybe later. His parents are happy. He has friends at school."

The depiction of Corky was controversial to parents of children with Down syndrome. The actor who played sixteen-year-old Corky was in his twenties and compared to most Down syndrome children was exceptionally high functioning. Many parents felt that this portrayal put undue stress upon their children who would never be able to read or write or communicate as well as Corky. Corky also dated and tried to learn to drive, a thought that frightened most parents I knew. I most strenuously disagreed with this position. We idolize Michael Jordan for basketball, Mark Spitz for swimming, and Michelle Kwan for ice-skating: most children will never achieve their successes and yet parents are excited when their children choose these professionals as idols. Why not idolize Chris Burke in the role of Corky Thatcher and aim to be high functioning like Corky?

My son was very social in his school environment, but he was the only boy with Down syndrome in his classes. As much as I tried to make everything in his life as normal as possible, while celebrating his Down syndrome, he still seemed to have some underlying sense of himself as sexually androgynous. I do not know whether this was a consequence of his upbringing or how much he was affected by the conventional idea that people with cognitive disabilities are asexual or forced into asexual behavior. I have discussed sexuality and sexual behavior with other parents of children with Down syndrome, both on-line and in-person. I find it very disturbing that parents often believe that they can exert control over their children's sexuality by isolating them from particular experiences.

In a recent discussion with a parent of four children, the youngest of which was 21 and had Down syndrome, she told me without hesitation that her son would never be allowed to date because he might get some ideas about sex. He might want to be a part of a sexual relationship and get a girl pregnant. As I tried to initiate further discussion with her, she made it clear she did not want to discuss it and physically moved away from me. In another discussion with a mother of a young teenage girl, she said that she was considering sterilization believing incorrectly that this would not only eliminate the possibility of her getting pregnant, but would also end her sexual desires. I can remember to this day the first time I was aware my son had an erection from looking at a girl and my feeling of unqualified joy.

I am not entirely surprised that parents feel this way. Being sexual when you have a disability has many differences and complications. Usually, when a person meets someone at work, school, or play that they want to get to know better it is a simple matter of making a connection and arranging a mutually convenient time to see each other again. People with disabilities like Down syndrome may need permission to have a visitor to their home, need to arrange for transportation when it suits their care provider, need authorization from a guardian to have an overnight visitor, need help with pregnancy and disease prevention, and may require education and counseling to understand how to have a relationship that does not negatively affect their work performance or membership in the community. (Fairbairn et al. 1995; Hingsburger, 1990; Shakespeare et al., 1996)

I also understand how frightening the potential of sexual abuse can be for families of children with disabilities. It is well documented that people with disabilities experience a higher rate of sexual abuse than people without disabilities (Fairbairn et al., 1995; Nosek, 1995; Nosek & Howland, 1998; Senn, 1988; Sobsey, 1994; Wilgosh, 1990). People with disabilities are not encouraged to be knowledgeable about sexuality or to be sexual and it is my opinion that this increases their risk of sexual abuse.

In their research with sexual offenders, Longo and Gochenour (1981) found that abusers look for the most vulnerable people to abuse - and who is more vulnerable than someone with a disability, uneducated and inexperienced about responsible, consensual sexual behavior and wanting the affection that a perpetrator may utilize to initiate abuse? I do not think that I put my son at greater risk by encouraging his sexuality; instead I think that I protect him.

When my pre-pubescent child began to express interest in sex, I thought it would be easiest for him to understand that adults have sex, but children do not. I looked for material he could look at as a non-reader about the changes his body was ready to go through and initially found few that were remotely helpful. The sexuality education books he would find interesting and understandable were designed for three to five-year-olds (Baird, 1990; Blank, 1983; Mayle, 1973.) Books

that discussed puberty used words he could not read or understand (Bourgeois & Wolfish 1994, Madaras 1998; Mayle, 1975). I pointed out positive male role models in the gentlemen he saw in various movies and television programs and he took this very much to heart. Portraying an exaggerated male gender identity he would pull out my chair, hold up my coat to help me put it on, and, much to my chagrin - like knights of old - kiss my hand. In a young child this was cute, but it was important that he learned a more contemporary role. He is still often complimented on his Sir Galahad-like manners, but hand kissing has become a rare occurrence.

Adolescence

The first sign I saw of my son having real interest in a particular person as a sex object was his interest in the belly button of Baby Spice of the Spice Girls. Slowly, his fascination with Baby Spice's belly button expanded to the belly buttons of his peers. Interest in girls was clearly moving into a different direction and we began to discuss his role in a sexual relationship. My son quickly put together two things I had taught him in an unexpected way: when do boys become men and when can people have sex? It seemed simple when I taught him at a young age that he would be a man when he turned eighteen. It seemed equally simple that children do not have sex; only adults have sex. But, my son now looked forward to the day he turned eighteen as the day he became a man and the day he could have sex.

Due to my son's ever-expanding interests, I renewed my search for a good book to help him understand the changes his body and his emotions were going through. I found "It's Perfectly Normal: Changing Bodies, Sex, and Sexual Health" by Robie Harris (1996). From the cartoon illustrations in this book he could glean some information independently, especially after we had read and discussed the book together. Finding sexuality education materials for people who cannot read, or read well, that are not designed for institutional use continues to be very difficult. I continued to search for material that was age-appropriate, required no reading, was attractive, and encouraged responsible sexual behavior.

My son and I often watched people at the mall. As he progressed through puberty, he became an avid girl-watcher. We would discuss the characteristics in girls he found attractive while I shared with him my values around attractiveness, public behavior, dating, sexual expression, and life in general. One day I pointed out a girl that was similar in age to him who also had Down syndrome. I was mortified at his response to my assertion that she might be girlfriend material. He completely rejected the notion saying, "No way Mom, she can't be my girlfriend." Expecting to hear something I really did not want to hear, I asked why. His response was unexpected and logical: "I need to date girls who drive." Driving in American society is a teenage right of passage into freedom from parental control, especially for boys. Few people with Down syndrome can learn to drive competently due to

common characteristics including slow reaction time. Of those people with Down syndrome who do drive, most seem to have learned in their twenties.

As he neared sixteen, I chose to tell my son it was his Down syndrome that prevented him from learning to drive rather than detail the specific reasons. Obviously, he understood that if he were going to be dating without his mom as a chauffeur, his date needed to be able to drive. Partly, because of his response to this girl, I reconsidered my thoughts on why I told him he could not learn to drive. I began to tell him he was not ready to learn how to drive rather than he would never drive. Now, he nagged me and nagged me about when he would be ready and finally when he was eighteen and a half, I relented and began to give him lessons in a parking lot. I decided I thought it was important that he know how to drive - versus be a driver. He needed to be able to handle a car should he be in an emergency where ability to drive would be the only way out of a crisis situation. It also became increasingly obvious to me that to my son being able to say, "I know how to drive" represented far more to his ego than simply being able to move a car from point a to point b.

My son took to driving like a duck to water, although he has never been out of the parking lot marked for driver's education or allowed to exceed seven miles an hour. Unlike myself, who was clueless at his age about what to do behind the wheel of a car, he required no instruction at all. He put the key in the ignition, changed gears, pulled out, signaled, turned, stopped, and parked on request. Today, he accepts for the moment that he will probably never drive on the street. Now I just need to figure out what to do with his desire to have a red Ferrari.

One incident stands out in my mind as demonstrative of how our society denies people with Down syndrome their sexuality. I watched a video with my son we rented called "Artemisia" (Merlet, 1998) about the female Renaissance artist and the first woman to paint nudes. It had many scenes with female and male nudity that I thought were appropriate for my son and would allow him the opportunity to view the female body tastefully. It had one scene that happened in a bordello that I was unprepared to discuss with him and during that scene we went to the kitchen to make popcorn. Later, he told a respite care worker about watching the movie and she reported me to Social Services. Two social workers came to the house and suggested that I was subjecting my son to too much sexual stimulation. I eventually convinced them that I was presenting him with considerably less stimulation than his peers without disabilities were experiencing and explained that unlike his peers, my son cannot independently purchase sexually oriented magazines, surf the internet for pornographic sites, or even discuss sexual feelings and ideas fluently as boys his age often do and yet he still needs age-appropriate sexuality information. "Artemesia" provided him some of the visual information that my words could not provide and yet was

presented in the context of art.

David Hingsburger, a Canadian sex counselor, has developed two excellent videos - "Hand Made Love" (1995) and "Under Cover Dick" (1996) - designed primarily for men with cognitive disabilities. These videos were the second sex education materials I found to be really helpful to my son. Hingsburger recommends offering the viewer privacy in watching these videos in the accompanying manual, but my son and I watched the videos together the first time. I wanted him to understand that what he saw in them was nothing to be embarrassed about and to feel comfortable talking to me about what he saw. I also felt it was important to watch his response to the videos in the event he found them distressing. "Hand Made Love" is a video that teaches men how to masturbate. My son wanted to know whether I also masturbated and was clearly surprised when I said I did. It was obvious he thought either that moms did not masturbate or women did not. He then did something very similar to when he found out I had a vagina - he began asking whether people he knew masturbated, name by name. By these questions, it seems clear to me that he does not benefit by the same kinds of experiences as his peers. I am unaware if he has ever had the opportunity to talk openly with his friends about sexuality and its impact on his life prior to his sex education class in school at age seventeen. I continue to be surprised that my son and I keep having an open dialog about sexuality when most parents of teenagers have only brief discussions if at all, whether or not their children are disabled.

When I asked my son's pediatrician about his potential fertility, he insisted that the only way to know whether he was fertile was to test him. Conventional wisdom is that men with Down syndrome are infertile, but this belief might be as much from lack of opportunity to have sexual intercourse, due to same-sex segregation in institutions, as from infertility. He would have to ejaculate in order to test his fertility. Since I had no idea how to explain to him what he needed to do to be tested, I felt that he needed to know how to use a condom. "Under Cover Dick" was about how to put on a condom. His pediatrician had already volunteered to help him learn how to put on a condom and so he checked out what he had learned by watching the video and gave him a supply of multicolored condoms to practice with at home.

Soon after this visit with the pediatrician, I received a distraught phone call from a teacher. She was upset that I allowed my young adult child to carry a condom in his wallet. She believed he was much too young to engage in sexual behavior. I agreed with this teacher and I told her that my son was committed to abstinence until his eighteenth birthday and I did not think he would break that commitment, but my fear was that he would be pressured to have sex and not be prepared to engage in it safely.

Many researchers have noted that people with disabilities are often coerced into sex (Baladerian, 1991; Nosek, 1995; Nosek & Howland, 1998; Reynolds, 1997; Sobsey 1994; Sobsey &

Doe 1991; Turnbull et al. 1994; Wilgosh, 1993). I taught him that he must always use a condom during sex - no excuses, no exceptions. She was relieved, but still not convinced that keeping a condom in his wallet was prudent. The summer before his eighteenth birthday my son went to summer camp. When he returned home from his adventure, he flooded me with memories. A few days later he sheepishly came to me and told me he had something to tell me. He told me apologetically that he had not told me the truth about camp. I asked him what had he lied about. He replied, "I got kissed by a girl while we were swimming and it felt good." I gave him a hug and told him that I was pleased. He told me it was bad because he was not eighteen and I reassured him that it was OK. I tried to explain that kissing was not sex and that he was free to kiss whomever he pleased within reason and mutual consent. That evening after he went to bed I called everyone I knew that I thought would appreciate that my son had his first kiss.

Eighteen and Beyond

I looked forward to my child's birthday with a combination of dread and excitement. He was becoming more interested in his peers as sexual partners. He was keen to share this interest with them, but also was clear that he could not have sex until he was eighteen. With his immature understanding, he continued to believe that kissing was sex. He would tell his friends he wanted to kiss them, but they would have to wait until his birthday. Try as I might, I could not stop his fixation on this day as the magical time when all things would change. I considered several solutions to the potential disaster of his birthday. I planned to have his birthday party two months early to coincide with my university graduation. I hoped that this would prevent the birthday party itself being the site of the transforming moment when he changed into a man. My budding adult remained resolute that he would not be a man until the actual date of his birthday.

Thankfully, by chance, we had the opportunity to spend his birthday week at Disneyland. This eliminated any interest in sex. The focus of his life was seeing Mickey Mouse. He was still excited to see young girls dress in their skimpy summer attire, but sex was far from his mind. This behavior illustrates one of the greatest difficulties that I have had in understanding my son's sense of himself as a person. One moment he interacts with his world as a typical eighteen-year-old, and the next moment his behavior is more typical of a three, eight, or twelve-year old. How can I prepare my son to be an adult who consents to sexual activity when he is only partly able to comprehend its full potential?

One more recent concern regarding my son and his sexuality has been his announcement that he was gay. He had told friends his age that he was gay and wanted to get married to his male friends. Two girls his age came to the house and told me he had repeatedly said this and that it was causing some of his friends to avoid him. I was very distressed by this announcement, which took me by complete surprise, and

also upset that his friends were avoiding him. If he were gay that would be OK by me, but if he were not I did not want him to be ostracized for making such comments since he did not fully understand the consequences of making them. We discussed his announcement at length, and during this conversation he said, "All the good men are gay, and I want to be like Uncle Jim." At this point it became clear to me that he had made this decision after overhearing others and me commenting on gay men. ("Uncle Jim" was a gay man who was my best friend and who also acted as a parent figure to my son until his death.) Through more discussion, I explored how he wanted to be like Uncle Jim and discovered that it had nothing to do with sex. He simply wanted to be like Uncle Jim and Jim just happened to be gay. When I asked him if he wanted to kiss men, he said, "No, I want to kiss girls."

My son has just turned nineteen. His childhood is over and his adulthood has begun. When he first arrived in my life, it was a different world for people with Down syndrome. At that time, my desire for him to someday be a lover, a husband, and a father was unheard-of.

We recently watched a film titled "I am Sam" (2002) in which the main character has a cognitive disability similar to that of my son. Sam works in a coffee shop for a competitive wage, lives independently in a neat but lived in apartment, and raises a bright, inquisitive six-year-old daughter. This story line would have been unthinkable nineteen years ago and yet, with all this change, Sam had no romantic interests. The mother of his child is a homeless woman from a one-night-stand who disappeared from his life right after the child's birth. Sam may be the father of his child, but he is still depicted as an asexual, CHILD-LIKE, man. When Sam's lawyer begins to develop a romantic interest in him, Sam is clueless. This movie could have made the same points about the complexities people with disabilities face in their ADULT lives had Sam raised his daughter with her mother, but such a plot line would have raised questions about the SEXUAL RIGHTS of disabled people that American society is still largely unwilling to consider.

Recently, Sieker and Steutel (2002) proposed "that sexual interaction between people who are moderately mentally retarded and between individuals with mild mental retardation in relatively complex situations is only morally permissible under adult supervision that is both moral and paternalistic." This point of view is all too common and it does not acknowledge that people with disabilities who have impaired intellectual functioning can learn to make reasoned decisions about their sexual values and their behaviors.

If you ask my son what it means to be eighteen, he will tell you, "I be a man now." When I last asked him what it means to be a man he said, "I need a get a job to get money in a office. I need to live in my own house. I need a lot of money to have a house. I look sexy. I need be nice to my girl friend, kissing and moving my body and wear condoms. I need be responsible and have a good attitude. I want kids. I be a good

dad, but first I get married. I can drink beer and wine, but not too much and no smoking. Eat healthy food to keep me healthy."

In 1988 I wrote an article for college about my son's psychosexual development. At the end of this article, I wrote: "Every day of his life has been part of his learning to be a sexually responsive human being, and at the appropriate time, I hope a sexually active one." It is still my fervent hope that this will be true as I believe my son has both demonstrated his right to be sexual through his ability to make reasoned decisions regarding consensual sexual behavior and BECAUSE it is his desire to be a sexually active adult.

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