

Disability community decries 'Ashley treatment'

- 9-year-old disabled girl's growth was deliberately stunted
- Parents say action was taken to improve child's quality of life
- Case has triggered wide debate and a protest at the AMA

By Elizabeth Cohen
(CNN)

(CNN) -- David is a young man with severe cerebral palsy. He can't walk, he can't talk, he can't sit up by himself, but he can blog. This week, David blogged about Ashley.

"Ashley's parents have committed the ultimate betrayal," he writes. "They have treated their daughter as less than human, not worthy of dignity.... What strikes me about 'the Ashley treatment' and has brought me to tears is that the very people in all of society whom this child should trust have betrayed her."

Everyone on the Internet, it seems, has an opinion about what Ashley's parents did to her. Ashley, 9, has a condition called static encephalopathy, which means an unchanging brain injury of unknown origin. She's in a permanent infant-like state -- can't hold her head up, speak or roll over on her own. (Read a Q&A with the ethicist who helped decide on Ashley's treatment.)

When Ashley was 6 years old, her parents and doctors agreed to have her uterus and breast buds removed so she'll never reach puberty. She was given estrogen treatments and will never be more than 4 feet 5 inches and 75 pounds. Like the Terri Schiavo story before her, Ashley and her story have a lot to say about what it means to be disabled, what it means to be different and what it means to be human.

Feminist groups and disability activists protested Thursday in front of the American Medical Association headquarters in Chicago, demanding that the AMA officially condemn Ashley's doctors for performing the procedures.

Ashley's parents speak publicly only through their blog. On it, they explain why they did what they did: Ashley will be more comfortable at a smaller size; large breasts would have made lying down difficult; it will be easier to include her in family gatherings if she is lighter and easier to carry around.

Some of the most vociferous critics of what Ashley's parents call "the Ashley treatment" have been other parents of disabled children.

"My son is 11....doesn't walk, doesn't talk, etc., etc.," writes one mom. "He's hard to carry. He's not going to get easier to carry.... And still, I don't understand. I don't understand removing healthy tissue and functioning organs.... Growing is not a sin or a disease -- it's what kids' bodies do, even disabled bodies."

"Don't get me wrong -- caring for a 5 feet something, 110-plus pound adult with physical disabilities is no walk in the park," blogs another mom. "I've got the trashed lumbar discs to prove that. But I am truly just sick to my stomach to imagine that it's acceptable medical practice in any case to surgically stunt a child's growth.... Using their logic, why not just perform quadruple amputations? I mean, really, she's not going to use her arms and legs."

Many others have been supportive of Ashley's doctors and parents. On CNN.com, for example, one person wrote, "No one objects to surgery to remove a cancer or hormone treatments to treat a variety of ailments. No one objects to pain medication for palliative care. Why would anyone object to surgery or hormones to improve the quality of life and care for a severely mentally disabled child?"

In the end, as in the Schiavo case, it comes down to who speaks for Ashley, a girl who cannot speak for herself. A CNN.com reader who is supportive of Ashley's parents wrote: "Nobody is stopping to think how a little girl with the mentality of an infant would treat bodily processes such as puberty and menstruation -- a process that scares even the most normal of our children."

But others think they're in a position to understand what Ashley wants. "Ashley is human. I am human," writes David on his blog. "Ashley is me. I am Ashley. And you are Ashley, too."

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