

The Irreversible Disabling of a Child

The “Ashley Treatment”

Rev. Gerald D. Coleman, S.S.

A recent survey of clinics in the United States that offer embryo screening indicates that 3 percent, or four clinics surveyed, reported that they have provided the costly and complicated procedure to help families *create* children with a disability.¹ These “made-to-order” babies with genetic defects are created to make them like their parents, for example, deaf or dwarfed.² These “deformer babies” are the results of deliberate acts of maiming children either in the womb or after birth.

The controversial growth attenuation therapy for a severely disabled girl named Ashley is also about intentional and deliberate medical acts of crippling. Because of her severe mental and physical disabilities, Ashley’s parents, professional people who want to remain anonymous, decided to stunt her growth, sterilize her by way of a hysterectomy, and remove her breast buds and appendix.

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¹S. Baruch, D. Kaufman, and K. L. Hudson, “Genetic Testing of Embryos: Practices and Perspectives of U.S. IVF Clinics,” *Fertility and Sterility* (published online September 20, 2006).

²See John F. Kavanaugh, “Autonomous Individualism,” *America* 196.2 (January 15, 2007): 8; and Lindsey Tanner, “Designer Disabilities?” *Monterey County Herald*, December 22, 2006, A1.

Does crippling children amount to a fundamental violation of their dignity and the oath of physicians to first do no harm? In answering these questions one must confront a moral quandary. The way we formulate the dilemma, the picture we draw of its salient features, largely determines the conclusions we reach and the choices we make.³ In the cases of deformer babies and disabled children like Ashley, how should we view them? What are the elements in the accounts that the participants give? What elements are left out? Which values do they consider and which do they ignore? Whose picture is correct? While some accounts focus, for example, on the violation of the rights of a child, others claim that the central moral issue is to alleviate suffering for the persons involved.

One's approach to the story is critical. Do we make judgments from the point of view of the sanctity of human life, the celebration of difference, the rights of an individual, the commitment of parents, or the priorities of society? It is intellectually important to try to view the events as the major participants view them.

Ashley

Ashley is ten years old and the oldest of three children. Her brother and sister are not disabled. Ashley had a normal birth, but shortly afterward she evidenced eating problems and developmental delays, and her mental and motor faculties did not develop. Over the years neurologists, geneticists, and other specialists conducted a host of traditional and experimental tests but could not determine a cause. Eventually, Ashley was diagnosed with static encephalopathy, a condition that left her in an infant state, and whose symptoms are described in detail below. At six-and-a-half years of age, Ashley showed early signs of prepubescence, including pubic hair and initial breast growth (not uncommon in children with brain dysfunctions).

Ashley's disability renders her virtually unaware of her condition. She is likely to live a long life, but significant improvement in her cognitive and mental development was judged doubtful by her physicians. Some commentators have since remarked that there was potential for growth and development in Ashley that her doctors underestimated.

Static encephalopathy is a rare and severe brain condition. Persons with SE cannot walk, talk, move, or swallow food, and it is unclear whether they can recognize others, including parents and siblings. Those who suffer from SE usually have been diagnosed as having the awareness of a three-month-old baby. Analyses of Ashley's condition consistently maintain that the origin of her SE is unknown. It must be kept in mind, however, that while the origin of Ashley's general brain dysfunction is not known, the leading cause of SE is consumption of alcohol during pregnancy.⁴ As many

³ See James M. Gustafson, "Mongolism, Parental Desires, and the Right to Life," in *Bioethics: Basic Writings on Key Ethical Questions That Surround the Major Modern Biological Possibilities and Problems*, 3rd ed., ed. Thomas A. Shannon (Mahwah, NJ: Paulist Press, 1987), 107–133.

⁴ See Fetal Alcohol Syndrome Support, Training, Advocacy, and Resources, "Static Encephalopathy," Fasstar Enterprises (n.d.), <http://www.come-over.to/fasstar/static.htm>.

as one hundred babies are born each day in the United States who, “because of prenatal exposure to alcohol, sustain a considerable amount of damage [that interferes] with their ability to succeed in life.”⁵ When a fetus is exposed to alcohol in the womb, any and all areas of the developing brain are at risk of sustaining damage.

SE results in permanent and unchanging brain damage. The effects on development depend on the part of the brain involved and the severity of the damage. Developmental problems may include a range of disabilities, such as cerebral palsy, learning disabilities, mental retardation, autism, speech delays, attention deficits, hearing and vision impairments, and oral motor problems. They may also include pervasive development disorder (PDD), which is characterized by impairments in social interaction, imaginative activity, receptive and expressive language skills, and nonverbal communication skills and by repetitive and stereotyped mannerisms.⁶

Some commentators conclude that Ashley’s condition sealed her into an “infant state,” because she evidences all the signs of SE.⁷ She is alert, startles easily, and smiles, but does not maintain eye contact. She cannot walk or talk, keep her head up, roll over, or sit up by herself. She is fed medically by a tube. She is helpless and cries out when bothered by such things as falling off her pillow or feeling a hair land on her face. Her parents call her “pillow angel” because she stays where she is placed, usually on a pillow.

In July 2004, when Ashley was six-and-a-half years old, she underwent what is now called the “Ashley treatment”—her doctors, Daniel Gunther and Douglas Diekema, prefer the term “growth-attenuation therapy”—performed at Children’s Hospital in Seattle. The treatment refers to the series of surgeries and medical procedures that were performed on her, including growth attenuation through high-dose estrogen therapy over the past two years,⁸ a prophylactic hysterectomy to eliminate her menstrual cycle and associated discomfort, removal of breast buds to prevent the development of large breasts, and an appendectomy to prevent possible rupture of the appendix later in her life. Ashley was hospitalized for four days and was given aggressive pain control. Her discomfort appeared minimal, and her incisions healed in less than a month.

⁵ Ibid.

⁶ See “What is Pervasive Developmental Disorder” (n.d.), A Step Ahead Program, <http://www.asapprogram.org/pdd.html>.

⁷ One of Ashley’s physicians, Dr. Douglas S. Diekema, who also served as bioethicist on this case, dismisses this label and similar designations (“being frozen as a little girl”) because “that was not the intent of the parents.” Interview by Amy Burkholder, *CNN News*, January 11, 2007, <http://www.cnn.com/2007/HEALTH/01/11/ashley.ethicist/index.html>.

⁸ Gunther and Diekema rarely spoke about the wide-ranging negative influences of estrogen on the immune system, neuroprotection, hair follicle physiology, or negative effects on aging. See sources cited in American Association on Intellectual and Developmental Disabilities Board of Directors, “Unjustifiable Non-therapy: A Response to Gunther & Diekema (2006) and to the Issue of Growth Attenuation for Young People on the Basis of Disability,” position statement, footnotes 3–5, http://aamr.iserver.net/Policies/board_positions/growth.shtml.

Stunting her growth keeps Ashley's height at about four-and-a-half feet and her weight between sixty-five and seventy pounds, a 20 percent height reduction and a 40 percent weight reduction. She has a bone age of fifteen years. The growth reduction reduces the risk of bedsores and other conditions that can afflict bedridden persons, such as skin sores and ulcerations, pneumonia, and bladder infections. Four reasons were given for the removal of her breast buds: to prevent her from growing large breasts, to inhibit breast cancer, to avert possible sexual abuse, and to minimize discomfort when she is lying down. Large breasts and breast cancer are common in Ashley's family. The hysterectomy was performed to eliminate her menstrual cycle, possible uterine cancer, and possible pregnancy should she be the victim of a sexual attack. Her ovaries were kept to maintain her natural hormones.

Since age six, Ashley has been enrolled in a special school where she functions at the level of an infant. She spends most of the time lying on her back kicking her arms and legs, or watching television.

Ashley's Parents

Ashley's parents are Seattle area residents. When Ashley began to show signs of early puberty, they took "the long-term view" by initiating the Ashley treatment. Determined to personally care for Ashley and keep her out of residential care, their stated objective was to "uphold her dignity."⁹ They consistently defend their decision, saying that they were acting out of love and compassion in order "to improve our daughter's quality of life and not to convenience her caregivers."¹⁰

On a Web site they created, her parents write that "Ashley's biggest challenges are discomfort and boredom. . . . [The treatment] goes right to the heart of these challenges and we strongly believe that it will mitigate them in a significant way. . . . A nine-and-a-half-year-old body is more appropriate and provides her more dignity than a fully grown female body." They maintain that the benefits of this treatment far outweigh its burdens. For these reasons, they testify that their decision was an easy one. In reply to objections that the treatment "interferes with nature," her father writes, "Medicine is all about interfering with nature . . . Why give antibiotics for infections? Even an act as basic as cutting hair or trimming nails is interfering with nature."¹¹

⁹Sam Howe Verhovek, "The Ashley Treatment," *Los Angeles Times*, January 7, 2007, B2.

¹⁰Nancy Gibbs, "Pillow Angel Ethics," *Time*, January 7, 2007, <http://www.time.com/time/nation/article/0,8599,1574851,00.html>.

¹¹Ashley's parents, "The 'Ashley Treatment': Toward a Better Quality of Life for 'Pillow Angels,'" Ashley Treatment blog, posted January 12, 2007, updated March 25, 2007, <http://ashleytreatment.spaces.live.com/blog>. Ashley's parents set up an e-mail address that has generated more than twenty-five hundred e-mails, more than fifteen hundred in the first forty-eight hours. The blog prompted more than 1.6 million responses, more than 1 million in the first forty-eight hours. Google News reports that between January 5 and 8, 2007, the Ashley case topped their health section with more than four hundred articles worldwide. *Larry King Live* devoted an entire show to Ashley on January 12, 2007. Critics of the Ashley Treatment blog maintain that the outspokenness of the parents has been an attempt to make Ashley's treatment appear normal.

Ashley's parents write that "we are currently near the limits of our ability to lift Ashley." They adapted a double baby stroller to wheel her around the home. Their fear was that a day would come when it would be impossible for them to lift, move, or bathe their daughter or take her on family outings. Her treatment would "benefit her physical and mental well-being" by enabling her parents to take her on frequent trips and expose her to activities and social gatherings. They want to keep Ashley involved in typical family life and activities that provide her with "needed comfort, closeness, security and love." Again, they consistently maintain that their goal was "to improve our daughter's quality of life and not to convenience her caregivers."¹²

Ashley's parents' reason for keeping her breasts small was that they felt large breasts "would only be a source of discomfort to her," since the harness straps that hold her upright go across her chest.¹³ They affirmed that "the God we know wants Ashley to have a good quality of life. . . . The God we know wants us to actively share our experience and learning with the rest of the world to help all Pillow Angels and other special-needs children in reaping the benefits of the Ashley treatment." They hope that the treatment becomes "well-accepted and available . . . [even though] it is not for all disabled kids."

A capsule of their feelings toward Ashley is found on their blog:

Sometimes she seems to be watching TV intently. She loves music and often gets in [a] celebration mode of vocalizing, kicking, and choreographing/conducting with her hands when she really likes a song. (Andrea Boccelli is her favorite—we call him her boyfriend.) She rarely makes eye contact even when it is clear that she is aware of a person's presence next to her. Ashley goes to school in a classroom for special needs children, which provides her with daily bus trips, activities customized for her, and a high level of attention by her teachers and therapists. . . . She calms at the sounds of family voices.

Ashley's Physicians

Daniel F. Gunther, M.D., M.A., was a Seattle pediatric endocrinologist and associate professor of pediatrics at Seattle Children's Hospital and Regional Medical Center until his recent death. He was the primary physician overseeing Ashley's treatment and continued to monitor her condition every three months. Douglas S. Diekema, M.D., M.P.H., is director of education at Treuman Katz Center for Pediatric

¹²Gibbs, "Pillow Angel Ethics." Ashley's parents write in their blog that "we tried hard and found it impossible to find qualified, trustworthy, and affordable care providers." See also "Treatment Keeps Girl Child-Sized," *BBC News*, January 4, 2007, <http://news.bbc.co.uk/1/hi/world/americas/6229799.stm>.

¹³Ashley's parents, Ashley Treatment blog. See also "Pillow Angel Parents Deserve Credit, Not Blame," *Scientific America* editorial comments, SCIAM blog, posted January 4, 2007, http://blog.sciam.com/index.php?title=title_5&more=1&c=1&tb=1&pb=1. Since Ashley was treated, several couples have contacted Gunther and Diekema about treatment for their disabled children.

¹⁴For more information on the Treuman Katz Center for Pediatric Bioethics at Seattle Children's Hospital, see <http://bioethics.seattlechildrens.org>.

Bioethics in Seattle.¹⁴ He chairs the bioethics committee of the American Academy of Pediatrics and led the ethics committee at Children's Hospital through its deliberations on Ashley's case. Gunther and Diekema described the Ashley treatment in the October 2006 issue of *Archives of Pediatrics & Adolescent Medicine*.¹⁵ Diekema testified that Ashley suffered no harm from the surgery and that the treatment was motivated by "the girl's best interest."

The ethics committee of Children's Hospital includes physicians, nurses, social workers, chaplains, and local community members.¹⁶ On May 5, 2004, Gunther presented the committee with what was essentially a cost-benefit analysis. He argued that the Ashley treatment held both medical and emotional benefits and few burdens. The benefits included easy movement; better circulation, digestion and muscle conditioning; fewer bed sores and infections; and avoidance of the trauma of menstruation. In addition, her parents could continue to lift, bathe, and dress her without assistance.

While the ethics committee was initially hesitant and struggled with trying to understand what troubles might lie ahead, they came to see the benefits involved and concluded that their decision "was not a difficult ethical dilemma." Although there were some risks involved in administering high-dose estrogen, Gunther argued that there was only a "small risk of a blood clot." Diekema later said that the committee did not take a vote, but reached a unanimous consensus. Richard Molteni, the hospital's medical director, said that there was no need to consult an institutional review board because Ashley's case was not an experiment and the hospital was acting in Ashley's best interest.¹⁷

Diekema summarized the argument: "I felt we were doing the right thing for this little girl, but that didn't keep me from feeling a bit of unease. . . . And that's as it should be. Humility is important in a case like this." Gunther added, "If we did not use therapies available because they could be misused, we'd be practicing very little medicine."¹⁸ He said he would never want this option for growth attenuation to become an obligation.¹⁹

¹⁵Daniel F. Gunther and Douglas S. Diekema, "Attenuating Growth in Children with Profound Developmental Disability: A New Approach to an Old Dilemma," *Archives of Pediatrics and Adolescent Medicine* 160.10 (October 2006): 1013–1017.

¹⁶There have been some discrepancies in the reported number of committee members, which has ranged from twenty to forty. The committee was criticized by disability groups for not including in its membership, especially in this case, representation from the disability community.

¹⁷Lindsey Tanner, "Outrage over Girl's Surgery," *Monterey County Herald*, January 12, 2007, A2.

¹⁸Gibbs, "Pillow Angel Ethics."

¹⁹Estrogen treatments to curb growth have been in use since the early 1970s. Despite ethical concerns, it has often been standard clinical practice to remove the uterus of a profoundly retarded girl to reduce fears associated with menstruation and the risk of cancer.

One legal issue arose regarding the right to sterilize a disabled person. After legal consultation, the judgment was reached that disability law, which is intended to protect women with mild disabilities who choose to become pregnant, did not apply to Ashley because of the severity of her disability, which makes voluntary reproduction impossible. Gunther further argued that the sterilization was only the side effect of her treatment.

A number of physicians responded to the Gunther and Diekema article. George Dvorsky, a member of the board of directors of the Institute for Ethics and Emerging Technologies, said,

If the concern has something to do with the girl's dignity being violated, then I have to protest by arguing that the girl lacks the cognitive capacity to experience any sense of indignity. Nor do I believe this is something demeaning or undignified to humanity in general; the treatments will endow her with a body that more closely matches her cognitive state—both in terms of physical size and bodily functioning. The estrogen treatment is not what is grotesque here. Rather, it is the prospect of having a full-grown and fertile woman endowed with the mind of a baby.²⁰

In an editorial in the same issue of *Archives of Pediatric and Adolescent Medicine*, pediatricians Jeffrey Brosco, M.D., and Chris Feudtner, M.D., concluded that Gunther and Diekema's efforts were ill advised. They wrote, "In the end, what might be most distressing about attempts to shorten children with profound disabilities and thus lighten the load on their parents is not only that it might not work or [might] cause undesired adverse effects or be misused; . . . more distressing is how this solution fails to situate the plight of these parents . . . in the larger context of a society failure to provide adequate social support."²¹

Dr. Benjamin Wilfond, head of the Treuman Katz Center for Pediatric Bioethics in Seattle, "said the decision Ashley's parents made is not unlike parents choosing to have a child with a cleft palate undergo surgery or to give children medication for attention deficit disorder to help them in school. 'There are lots of things we do to make children interact socially, and this fits into that category.'" Dr. Lainie Ross, an associate director at the MacLean Center for Clinical Medical Ethics at the University of Chicago Comer Children's Hospital, agreed: "We have to look at what's best for the child. Ashley's parents should be commended for what they did, and we shouldn't be judging them for it."²²

²⁰George Dvorsky, "Helping Families Care for the Helpless," Sentient Developments blog, posted November 6, 2006, http://sentientdevelopments.blogspot.com/2006/11/helping-families-care-for-helpless_06.html.

²¹Jeffrey P. Brosco and Chris Feudtner, "Growth Attenuation: A Diminutive Solution to a Daunting Problem," *Archives of Pediatric and Adolescent Medicine* 160.10 (October 2006): 1077–1078.

²²Cherie Black, "Controversy Rages around Stunting Girl's Growth," *Seattle Post-Intelligencer*, January 5, 2007, http://seattlepi.nwsourc.com/local/298552_stunted05.html.

Societal Conversations

Visceral comments on the Internet in response to Ashley parents' Web site referred to the treatment as "Frankenstein-esque," "despicable," and "grotesque."²³ Other comments blamed media headlines for fooling people into thinking that the case "was about some demented parents who wanted to keep an otherwise normal child small."²⁴

More considered opinions came from the professional community. Calling the Ashley treatment "a medical experiment," Steven Taylor, director of Syracuse University's Center on Human Policy, wrote, "It is unethical and unacceptable to perform intrusive and invasive medical procedures on a person or child with a disability simply to make the person easier to care for."²⁵ Others described the treatment as a "pharmacological solution for a social failure" to adequately care for persons with disabilities. Dr. Joel Frader, a medical ethicist at Chicago's Children's Memorial Hospital, agreed, "As a society, we do a pretty rotten job of helping caregivers provide what's necessary for these patients."²⁶ Brosco and Feudtner also insisted that "more funds for home-based services, not more medication, is what is called for."²⁷ The most vociferous critics were parents of disabled children. One parent wrote, "Growing is not a sin or a disease. It's what kids' bodies do, even disabled bodies."²⁸

Critical responses came from the disability community.²⁹ The board of directors of the American Association on Intellectual and Developmental Disabilities charged that the treatment "reveals that [Gunther and Diekema] were unable to recognize ... potential for growth and development" in Ashley. The board insisted that there is "gross underestimation" of the cognitive capabilities of children with severe motor impairments.³⁰ They asserted that Ashley's body was "altered irreversibly" without independent analysis from, for example, social workers and legal counsel with explicit expertise in disability rights and autonomy.

²³ Caroline Davies, "Ashley the Pillow Angel: Love or Madness," *Telegraph* (U.K.), January 5, 2007, <http://www.telegraph.co.uk/news/main.jhtml?xml=/news/2007/01/05/wash05.xml>.

²⁴ Ashley's parents, Ashley Treatment blog.

²⁵ Cited in Tanner, "Outrage over Girl's Surgery," A2.

²⁶ Associated Press, "Surgery to Stunt Girl's Growth Sparks Debate," MSNBC News, January 5, 2007, <http://www.msnbc.msn.com/id/16473471/>.

²⁷ Brosco and Feudtner, "Growth Attenuation," 1077–1078.

²⁸ Elizabeth Cohen, "Disability Community Decries 'Ashley Treatment,'" CNN News, January 12, 2007, <http://www.cnn.com/2007/HEALTH/01/11/ashley.outcry/index.html>.

²⁹ Those deploring the Ashley treatment as a "medical fix" are carefully watching the direction that Britain is taking. The Royal College of Obstetricians and Gynecology has proposed that doctors openly consider allowing euthanasia of the sickest infants: "A very disabled child can mean a disabled family. ... [We need to] think more radically about non-resuscitation, withdrawal of treatment decisions ... and active euthanasia, as they are ways of widening the management options available to the sickest of newborns." Sarah-Kate Templeton, "Doctors: Let Us Kill Disabled Babies," *Times Online*, November 5, 2006, <http://www.timesonline.co.uk/tol/news/uk/article625477.ece>.

³⁰ Board of Directors of the AAIDD, "Unjustifiable Non-therapy."

Feminist Response in Disability Activism (FRIDA) demanded accountability from the American Medical Association, which permitted the publication of the Gunther and Diekema article in the *Archives of Pediatric and Adolescent Medicine*. They demanded that the AMA issue a formal statement condemning the growth attenuation procedures.³¹

Self Advocates Becoming Empowered (SABE), a national self-advocacy organization, expressed anger, sadness, and outrage about the treatment and those who participated in its implementation. Citing its mission statement, which ensures “that people with disabilities are treated as equals,” the SABE statement said, “Just because someone has a disability does not mean they should be denied the basic human right to grow and mature like everyone else. The selfish actions taken by Ashley’s parents put other people with disabilities at risk of being denied their human and civil rights.”³²

Youth members of ADAPT, a national disability rights organization, reacted with “shock and outrage” to the Ashley treatment.³³ Their statement quotes a young woman who objected to those who “think it is acceptable to surgically and hormonally manipulate Ashley because the reality of her adulthood as a person with a disability is too ‘grotesque’ . . . Her parents and doctors are physically reinforcing the disrespectful attitude held by many that people with disabilities are all ‘childlike,’ and can be treated like property or science experiments.” The statement goes on to say, “Ashley has now become a modern day symbol of the long and dishonorable tradition of sterilizing people with disabilities.”³⁴

ADAPT emphasized that people with disabilities are not medical problems to be cured but persons who deserve sensitive care to “age naturally and live lives of quality.” Disability groups empathized with parents who face difficult issues raising children with physical and mental disabilities, but the groups hold as “non-negotiable the principle that personal and physical autonomy of all people with disabilities be regarded as sacrosanct.”³⁵ These groups frequently cite the U.N. General Assembly’s adoption of the “Convention on the Rights of Persons with Disabilities.” Article 17 reads, “Every person with disabilities has a right to respect for his or her physical and mental integrity on an equal basis with others.”³⁶

³¹“Feminist Response in Disability Activism Demands Ethics and Accountability from the AMA,” FRIDA statement, January 10, 2007, Katrina Disability Information, <http://www.katrina-disability.info/ashleystatements>.

³²“Self Advocates Becoming Empowered: Statement on ‘Ashley X,’” SABE USA statement, n.d., <http://www.sabeusa.org/ashleyx.html>.

³³“ADAPT Youth Appalled at Parents Surgically Keeping Disabled Daughter Childlike,” ADAPT statement, January 5, 2007, <http://www.adapt.org/adaptpr/index.php?mode=A&id=253;&sort=D>.

³⁴It is important to point out that for over two decades less invasive means have been available to suppress menstruation when medically indicated.

³⁵“Modify the System, Not the Person,” Disability Rights Education and Defense Foundation statement, January 7, 2007, <http://dredf.org/news/ashley.shtml>.

L'Arche Canada issued a statement on January 15, 2007, indicating that the Ashley case does not exist in isolation and that it raises profound ethical and social problems.³⁷ Citing a "slippery slope" argument, L'Arche fears that the Ashley treatment has set a medical precedent: "The implications of condoning the permanent infantilization of a person with a disability are of grave concern with regard to the safety and respect for the dignity of other people born with significant disabilities."³⁸

Many other disability groups issued similar statements, adding that unchecked professional freedom leads to overuse of procedures whose long-term efficacy is unknown or demonstrably injurious.³⁹ These groups have judged that Ashley's best interest has not been respected, since it is virtually impossible to predict what an incompetent minor might want.⁴⁰ Calling the Ashley treatment "a new low in the medical ethical treatment of people with disabilities," the Canadian Association for Community Living called the treatment "a profoundly misguided, unethical decision on the part of all those involved."⁴¹ It concluded that Ashley has suffered three-fold discrimination—as a person with a disability, a girl, and a child.

United Cerebral Palsy (UCP) and The Arc, an advocacy group for people with intellectual and developmental disabilities, issued a joint statement affirming their commitment "to working together to ensure that all-encompassing and infantilizing interventions... are not promoted by our public policies." The statement summarizes well the concerns of disability organizations: "We believe that loving parents who are caregivers are not granted special dispensation to sanction irreparable and

³⁶General Assembly, Sixtieth Session, *Convention on the Rights of Persons with Disabilities* (A/RES/61/106), December 13, 2006, <http://www.un.org/disabilities/convention/>.

³⁷L'Arche (for "ark," a symbol of refuge) was founded by Jean Vanier and now operates homes and day care programs in 120 communities in Europe, Africa, Asia, Central America, and North and South America. The International Federation of L'Arche Communities collaborates with several national organizations to help create awareness of the special contribution that people with disabilities can make to society, and to sensitize the public to the isolation suffered by those who are marginalized. See L'Arche Canada Web site, <http://www.larche.ca>, and Jean Vanier, *Befriending the Stranger* (Grand Rapids, MI: Eerdmans, 2006).

³⁸L'Arche Canada, "L'Arche Canada Questions Ethics Used to Justify 'Ashley Treatment,'" press release, January 15, 2007, <http://larche.ca/en/home/news/?id=86>.

³⁹These groups include MindFreedom International, the Disability Education and Defense Fund, the Beach Center on Disability, the Canadian Association for Community Living, Inclusion International, and the online magazine for disability activists *Ragged Edge*.

⁴⁰The *Code of Medical Ethics* of the American Medical Association states, "If there is no reasonable basis on which to interpret how a patient would have decided, the decision should be based on the best interest of the patient, or the outcome that would best promote the patient's well-being" (E-8081, "Surrogate Decision Making").

⁴¹Canadian Association for Community Living, "Hormone Treatment Dehumanizing," press release, January 5, 2007, <http://www.newswire.ca/en/releases/archive/January2007/05/c3613.html>. It is estimated that there are more than fifty-four million Americans with disabilities.

irreversible surgeries to alter their son or daughter's physical being primarily for their own convenience and comfort."⁴²

A different response came from over two thousand people who sent e-mails to Ashley's parents through their Web site.⁴³ Some writers with disabled children lamented the fact that they had not had access to the Ashley treatment and eventually placed their children in institutions. Referring to her daughter, one such parent wrote, "I feel I have failed her." Some expressed deep empathy for Ashley's parents and judged that they did the right thing, because Ashley could remain a child, stay at home, interact with her family, receive education, and grow in a loving environment. One writer mourned a brother who, several decades ago, had been considered "retarded" and "defective" and was "warehoused" in a state hospital. Some called their children "precious" and "beautiful." They found the Ashley treatment an "amazing solution." They considered Ashley's parents self-sacrificing and "brave" while criticizing parents who do not live with a disabled child as clueless and "ignorant."

In response to remarks that the removal of Ashley's uterus and breast buds was not called for, a medical practitioner wrote, "I have had to do too many ultrasounds on females of all ages that have been raped by evil, sick people. That has been the most pitiful experience for these disabled females I have known." The practitioner offered Ashley's parents "sincere respect." Another person wrote that she knew of an institutionalized woman who was sexually assaulted by an employee, became pregnant, and "has no idea she has a daughter."

Responding to the photographs of Ashley on the parents' Web site, many joined her parents in calling her an "angel" and a child who shows "the face of God," like other disabled children who are "given to us as gifts from God." Ashley will now live "a dignified life" because of her treatment. In this vein, one writer compared the parental attention Ashley receives to the way older children and adults with severe disabilities are "shunned in the public eye." One mother described how her disabled daughter became scared when she had her menstrual period and "made terrible messes." Ashley, on the other hand, has been saved from all these problems, a singular gift since she would never be able to understand what was happening to her body. There would be less worry about her becoming a "victim of someone's abnormal desires and her inability to understand sexually."

A common refrain in these remarks concerned the lack of adequate "financial, community, [and] governmental support to allow . . . these individuals to stay home." The overall supportive responses claimed that the decision of Ashley's parents and physicians was a "true act of heroism" that would provide Ashley with "decades of a vastly improved quality of life." The Ashley treatment was labeled "brilliant," an act of love done in Ashley's best interest.

⁴²"UCP and The Arc Issue Joint Statement on 'Ashley Treatment,'" United Cerebral Palsy press release, January 26, 2007, http://www.ucp.org/ucp_generaldoc.cfm/1/9/10020/10020-10020/7108.

⁴³Ashley's parents, Ashley Treatment blog.

One writer summarized the sentiments of the advocates: "I commend you, salute you, bless you from my entire heart and ... almost envy you ... your spiritual strength, the God you know and understand, the love in your family, your unselfish thoughts and actions, your willingness, priorities and purpose in life. ... Your other children will witness unconditional, endless love."

Ethical Reflections

Ashley's inability to give consent allowed her parents and physicians, with the approbation of the ethics committee of Seattle Children's Hospital, to assume consent and perform the treatment. They ruled in favor of growth attenuation, a prophylactic hysterectomy, breast bud removal, and an appendectomy.

This parental decision was made in consultation with and supported by Drs. Gunther and Dickema. It was based on several perceived benefits for Ashley: to keep her weight and height low; to eliminate her menstrual cycle and prevent pregnancy and uterine cancer; to keep her from growing large breasts; to help avoid future internal ruptures; to reduce the risks of bed and skin sores, ulcerations, pneumonia, and bladder infections; to avert possible sexual abuse; and to enable better circulation, digestion, and muscle conditioning. These reasons were aimed at Ashley's best interest.

No matter how well-intentioned Ashley's parents were, I believe, based on the available evidence, that the treatment was ill advised and dismissive of Ashley's inherent dignity. Several ethical points lead to this judgment.

First, Ashley's parents, along with many advocates, judge that they acted out of love and compassion. Their expressed goal was to "uphold her dignity" and "improve Ashley's quality of life." They insist that the treatment was not done "to convenience her caregivers"—who are her parents and both of Ashley's grandmothers—but they also admit that all four caregivers found Ashley's increasing weight "difficult to manage." They note, too, that at her smaller size, Ashley could continue to be bathed (lying down) in a normal bathtub and be moved around the house in the double stroller they use, which she would otherwise have soon outgrown.⁴⁴ It is not evident that Ashley's parents expended adequate effort to address these problems in less drastic ways, and it seems facile to say simply that it was "impossible to find qualified, trustworthy, and affordable care providers."

Was convenience a driving force in the Ashley treatment? It seems so. This is a legitimate question in light of the admission of Ashley's parents that they were "near the limits of [their] ability to lift Ashley." Is it possible that they had reached their limits and decided to alter Ashley to make her care more convenient and comfortable? It seems so. Not looking beyond their present situation, they found justifications for what they did. Their desires superseded any moral claim of their disabled daughter.

The Ashley treatment was the subjugation of a noncompetent child by the imposition of drastic physical alterations on the child for the convenience of her family and caregivers. Such intrusive and invasive medical procedures are unethical and

⁴⁴Ibid.

unacceptable. Ashley was incapable of expressing her desires and was wholly dependent on her parents to advocate her best interest. However, it was the best interest of the parents that held the moral claim. The remarks of University of Pennsylvania bioethicist Arthur Caplan are accurate and on target. He finds the treatment “troubling and questionable,” for it does not directly benefit Ashley. The motive of the parents might be logical and the agreement of the medical team might be understandable, but “the Peter Pan option is morally wrong.”⁴⁵

Second, the parents wrote that they could not find adequate help for Ashley, and available help was too costly. This problem must be situated in the context of society. When a disabled child is born, the child should not be the sole responsibility of the family—a point made by some advocates, many organizations for the disabled, and the parents themselves. A just and humane society makes itself neighbor to a disabled person and the family. We share the burden of care. Local and federal funds are inadequate for assisting the families of disabled children, and this lack of resources must be confronted. “Inclusion” requires that necessary supports be provided for disabled people and their caretakers.⁴⁶

Third, the testimonies of Gunther and Diekema indicate that they, like Ashley’s parents, believed they were acting in Ashley’s best interest. But they also felt an obligation to acquiesce to the desires of the parents. The emotional and medical benefits they saw in the treatment were weighed as benefits primarily for the parents and secondarily for Ashley.

Burdens were weighed in terms of the risks of the surgeries rather than present or future risks to the dignity of Ashley. Diekema “felt we were doing the right thing for this little girl.” The inability of the physicians to uphold a dignified life for Ashley urged them to agree with her parent’s desires. They saw no need to seek the counsel of a disability social worker or counselor. The physicians recognized the moral autonomy of the parents alone and did not interfere. They believed that conscientious parents were the moral supreme court.⁴⁷ The principals were the parents. Ashley had no rights.

Self-determination (autonomy) has long been a hallmark of an American sense of liberty. The Ashley case is an alarming example of parents presuming to hold absolute determination over their disabled child. The deliberation on the part of the parents, physicians, and the ethics committee rose out of a conviction (even though Gunther expressed “a bit of unease”) that for Ashley’s good and the good

⁴⁵ Arthur Caplan, “Is ‘Peter Pan’ Treatment a Moral Choice?” commentary, MSNBC News, January 5, 2007, <http://www.msnbc.msn.com/id/16472931/>. Arthur Caplan, Ph.D., is the Emmanuel and Robert Hart Professor of Bioethics at the University of Pennsylvania Center for Bioethics.

⁴⁶ Diocese of Pittsburgh Multicultural Education Committee, “Terminology,” <http://www.diopitt.org/education/multiculturalte.htm#INCLUSION>.

⁴⁷ This was the same judgment reached by James Gustafson in the Johns Hopkins case. See Gustafson, “Mongolism, Parental Desires, and the Right to Life.”

of her parents, family, and future caregivers, the treatment was justified because Ashley was disabled. As Dvorsky shockingly opined, Ashley would not experience any indignity, because of her lack of cognitive capacity. According to this view, her dignity depends on her ability for cognition, maturation, and social awareness.

Fourth, the testimonies of Ashley's parents do not give evidence that Ashley's inherent dignity was considered. A child with static encephalopathy, while disabled, has intrinsic value and sustains the rights of a human being. All children have claims on parents and society, even when meeting these claims is costly, distressing, and burdensome. All human beings lay a claim on us which is not conditioned by their mental, emotional, or physical attributes. The fact that an infant cannot articulate his or her dignity is irrelevant. The intrinsic value and the rights of a human being are not qualified by a person's intelligence or physical capacities.

The intrinsic dignity of human beings is the fundamental basis of morality.⁴⁸ Disability and suffering do not lessen or eliminate human dignity. Intrinsic dignity remains no matter what a person's mental, physical, or social situation might be.⁴⁹ Conceptions of human dignity that are based on subjectivity, social worth, or freedom and control must be rejected.

Attributed dignity is overly emphasized in our society. It is based on value, worth, power, prestige, function, productivity, and self-control. Attributed dignity is not comparable to intrinsic human dignity. To be a person is to have intrinsic dignity. Persons who are vulnerable too often have their dignity called into question. As the testimonies of people in the disabled community and their supporters witness, society must never permit this to occur. Treating another person with respect for that person's intrinsic dignity is to make that person an equal in the most radical way possible.

Fifth, intrinsic dignity must be the pathway to understanding quality of life. Ashley's parents and physicians often repeat that their goal was to improve her "quality of life" rather than accommodate the parents and caregivers. Dvorsky goes so far as to claim that Ashley is unable to "experience any sense of indignity" since she lacks "cognitive capacity." Attributed dignity (cognitive capacity) is thus equated with inherent dignity. This analysis only considers objective criteria. The moral argument amounts to a judgment that since Ashley lacks any ability for interpersonal relationships, she has no inherent dignity.

⁴⁸See Daniel P. Sulmasy, *The Rebirth of the Clinic: An Introduction to Spirituality in Health Care* (Washington, D.C.: Georgetown University Press, 2006), 24–43.

⁴⁹This ethos is radically different from the one advocated by Joseph Fletcher, who refers to a defective fetus as "subhuman life." Fletcher's arguments extend to the lifting of restraints against euthanasia for defective infants. See Joseph Fletcher, "Ethics and Euthanasia," *American Journal of Nursing* 73.4 (April 1973): 670–675, and "Indications of Humanhood: A Tentative Profile of Man," *Hastings Center Report* 2.5 (November 1972): 1–4.

⁵⁰International Theological Commission, "Communion and Stewardship: Human Persons Created in the Image of God," *Origins* 34.15 (September 23, 2004): 233, 235–248.

All quality-of-life assessments must begin with the acknowledgment that every person is made in the image of God and is of invaluable worth.⁵⁰ No matter how limited, fragile, elderly, or ill, the person must be valued as sacred, a possessor of inherent dignity. The sacredness of human life must never be forfeited. The term “value of life” must never be substituted for “quality of life.” The main participants caring for Ashley did not consider *her* quality of life and inherent dignity. They gave primary importance to their own assessment of quality of life in terms of present and future convenience. A case can be made that the Ashley treatment amounts to a form of child abuse.⁵¹

When parents consent to subject a child to experimentation, they cannot do so on the grounds of the presumed and merely hypothetical consent of the child. Presumed consent is what an emergency room doctor relies on when attending to the injury of a mortally wounded patient. Theories of presumed consent based on what a child might want are weak, and easily become equated with manipulation.⁵²

The issue here is *proxy* consent. This means that Ashley’s parents as the consenting parties bore the obligation of representing Ashley’s best interest, which they did not do. The treatment was de facto a medical experiment, since its long-term adverse consequences are not known. The canons for consent in experimentation on human subjects are very stringent.⁵³ There is no evidence that Diekema and Gunther, the ethics committee of Seattle Children’s Hospital, or the hospital’s medical director took them into account.

Negative eugenics translates as the right of others to place a “restriction” on persons who have unwanted characteristics.⁵⁴ The Ashley case is an example of negative eugenics. One segment of the treatment was aimed at remedying possible pregnancy by direct sterilization. This surgery was interpreted by the parents and physicians as therapeutic. It was not. It was mutilation.⁵⁵ The ethics committee sought legal counsel about the right of the parents and physicians to sterilize a disabled individual. Although they argued that the sterilization was only indirect, the direct intent in removing her uterus was to prevent future involuntary reproduction. They concluded that since Ashley would never be able to reproduce voluntarily, the direct sterilization was

⁵¹ Department of Health and Human Services, “Child Abuse and Neglect Prevention and Treatment” in *Bioethics*, ed. Shannon, 149–168.

⁵² Benedict Ashley, O.P., and Kevin O’Rourke, O.P., *Health Care Ethics*, 4th ed. (Washington, DC: Georgetown University Press, 1997), 350.

⁵³ See Tom L. Beauchamp and James F. Childress, *Principles of Biomedical Ethics*, 5th ed. (New York: Oxford University Press, 2001), ch. 3, and Shannon, ed., *Bioethics*, part 4.

⁵⁴ Pat Milmoie McCarrick and Mary Carrington Coutts, “Scope Note 28: Eugenics,” National Reference Center for Bioethics Literature, Georgetown University, June 1995, <http://bioethics.georgetown.edu/publications/scopenotes/sn28.htm#intro>. Positive eugenics generally refers to encouraging the “best and brightest” to have more offspring. Liberal eugenics is interpreted as the state encouraging a broad range of enhancement technologies.

⁵⁵ The *Catechism of the Catholic Church* states, “Directly intended . . . mutilations . . . performed on innocent persons are against the moral law” (n. 2297).

simply a by-product of treatment. On the contrary, the directly intended sterilization was performed on an innocent child and represents an immoral act.

Ashley's father argued that every part of the treatment was as natural as using antibiotics for infections. Prescribing antibiotics, he claimed, was not inferring with nature, and neither is direct sterilization. This argument is fallacious because it fails to recognize the difference between curing and destroying. Antibiotics assist nature. A direct sterilization destroys it. Precisely because the surgery (direct sterilization) eliminates a future possibility (involuntary pregnancy), it remains ethically unacceptable.

The ethical principles of totality and integrity (the basic physical capacities that define human personhood are never sacrificed except to preserve life itself) and stewardship (one's self and nature are respected and used rightly) indicate that children are to be accepted by their parents as a gift to be loved for who they uniquely are. Children are not objects to be manipulated to meet the hopes and expectations of their parents.⁵⁶

A Catholic Response

In 1992, the Pontifical Council for Health Pastoral Care sponsored its seventh international conference, titled "Your Members Are the Body of Christ: Persons with Disabilities and Society."⁵⁷ This gathering was notable because the Catholic Church had seldom in the past fully acknowledged disabled persons.⁵⁸ In the early centuries, the Church's attitude was paternalistic and emphasized caretaking rather than including the disabled as persons with gifts to contribute. The 1992 conference insisted that all mentally and developmentally challenged persons be seen and named as God's special children.⁵⁹

In "Welcome and Justice for Persons with Disabilities," the U.S. Conference of Catholic Bishops encourages disabled persons and their parents or legal guardians to ask for the sacraments and participate in the Church as well as they possibly can. Pastors are to actively involve disabled persons in the life of the parish. As God's

⁵⁶ See Ashley and O'Rourke, *Health Care Ethics*, 4th ed., 66, 219, 316–323.

⁵⁷ Ruth C. Lindecker, "The Vatican and the Disabled: What's Next?" *America* 168.13 (April 17, 1993): 10–12.

⁵⁸ Walter F. Sullivan, "The Sacraments, Canon Law and the Rights of Disabled Persons," *America* 154.15 (April 19, 1986): 321–324.

⁵⁹ U.S. Conference of Catholic Bishops, "Pastoral Statement on People with Disabilities" (November 16, 1978), National Catholic Partnership on Disability, http://www.ncpd.org/pastoral_statement_1978.htm.

⁶⁰ U.S. Conference of Catholic Bishops, "Welcome and Justice for Persons with Disabilities: A Framework of Access and Inclusion" (1998), <http://www.usccb.org/doctrine/disabilities.htm>.

⁶¹ John P. Beal, James A. Coriden, and Thomas J. Green, *New Commentary on the Code of Canon Law* (New York: Paulist Press, 2000), canon 839, p. 1016. Canon 868 teaches that even the most severely disabled child may be baptized.

special children, those with disabilities contribute a wondrous gift to the Church.⁶⁰ Book IV, part I, of the new *Code of Canon Law* includes disabled persons among the “Christian faithful,” not a segregated segment.⁶¹ Canon 208 reads, “From their rebirth in Christ, there exists among all the Christian faithful a true equality regarding dignity and the action by which they all cooperate in the building up of the Body of Christ according to each one’s own condition and function.”

This understanding of disabled persons as God’s special children is radically different from the consideration of Ashley as a “pillow angel.” A special child is a subject and a gift; a pillow angel is an object and a task. In 2000, John Paul II addressed the social justice issue facing disabled persons and their caregivers: “For parents . . . it is important to know that society accepts responsibility for [the disabled] . . . so that they can see their disabled sons and daughters entrusted to the concerned attention of a community prepared to care for them with respect and love.”⁶²

The guidelines set forth in “Welcome and Justice for Persons with Disabilities” present sound principles of justice and inclusion and offer a helpful framework for assessing the Ashley case:

1. We are a single flock. . . . There can be no separate Church for persons with disabilities.
2. Each person is created in God’s image, yet there are variations in individual abilities. Positive recognition of these differences discourages discrimination and enhances the unity of the Body of Christ.
3. Our defense of life and rejection of the culture of death requires that we acknowledge the dignity and positive contributions of our brothers and sisters with disabilities. We unequivocally oppose negative attitudes toward disability which often lead to abortion, medical rationing, and euthanasia.
4. Defense of the right to life implies the defense of all other rights which enable the individual with the disability to achieve the fullest measure of personal development of which he or she is capable.
5. Parish liturgical celebrations and catechetical programs should be accessible to persons with disabilities and open to their full, active, and conscious participation.
6. Costs must never be the controlling consideration limiting the welcome offered to those with disabilities.
7. We must recognize and appreciate the contribution persons with disabilities can make to the Church’s spiritual life.
8. We welcome qualified individuals with disabilities to ordination, to consecrated life, and to full-time professional service in the Church.
9. Often families are not prepared for the birth of a child with a disability or the development of impairments. Our pastoral response is to become informed about disabilities and to offer ongoing support to the family and welcome to the child.

⁶² John Paul II, “Address on the Jubilee of the Disabled” (December 3, 2000), National Catholic Partnership on Disability, http://www.ncpd.org/jubilee_of_disabled.htm.

10. Evangelization efforts are most effective when promoted by diocesan staff and parish committees which include persons with disabilities.⁶³

Ashley's Legacy

The Ashley case represents the intentional medical crippling of a disabled child. Ashley was deliberately stunted in growth and mutilated by sterilization and the removal of her breast buds and appendix. Her human dignity was violated by her parents, physicians, and those who supported the treatment. She was viewed as less than fully human. Her physicians and the ethics committee of Seattle Children's Hospital gave sole attention to her disabled body, with no apparent acknowledgment of her inherent dignity. Her father and others went so far as to compare the treatment to cutting someone's hair or treating a cleft palate.

The ethical deliberations supporting the series of surgeries and medications were faulty and slipshod. Her physicians believed, for example, that the sterilization was only a side-effect of the treatment. On the contrary, it was a directly intended surgical procedure. This is medical and moral malfeasance. Ashley was seen as a medical problem to be solved rather than a disabled child to be cared for. Her parents spiritualized and authenticated this attitude by stating more than once that "the God we know" approved their decision and the physicians' actions.

Parents with disabled children must be given greater societal and governmental assistance through the provision of more home-based services. Such help would allow disabled children to remain at home, would support their parents and families, and would reduce institutionalization. Such awareness and assistance would also extend our knowledge of and respect for the inherent dignity of all persons with disabilities. Perhaps this will be Ashley's lasting contribution and legacy.

⁶³ There is no clear evidence that Ashley's parents are Catholic. However, they often wrote that they "spoke to their God" about the Ashley treatment. These principles can be adapted to any societal or religious context.