

2011

Growth Attenuation, Sterilization, and Cochlear Implants: Ethical, Legal and Social Themes

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**GROWTH ATTENUATION, STERILIZATION, AND COCHLEAR
IMPLANTS: ETHICAL, LEGAL AND SOCIAL THEMES**

PROFESSIONAL DISSERTATION

SUBMITTED TO THE FACULTY

OF

**THE SCHOOL OF PROFESSIONAL PSYCHOLOGY
WRIGHT STATE UNIVERSITY**

BY

Jenna Nicole Mercadante, Psy.M.

**IN PARTIAL FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE
OF
DOCTOR OF PSYCHOLOGY**

Dayton, Ohio

September, 2012

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June 11, 2011

I HEREBY RECOMMEND THAT THE DISSERTATION PREPARED UNDER MY SUPERVISION BY **JENNA MERCADANTE, PSY.M.**, ENTITLED **GROWTH ATTENUATION, STERILIZATION, AND COCHLEAR IMPLANTS: AN ANALYSIS OF ETHICAL, LEGAL AND SOCIAL THEMES** BE ACCEPTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF DOCTOR OF PSYCHOLOGY.

Leon VandeCreek, Ph.D., ABPP
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Abstract

Individuals with disabilities have been the subject of invasive medical procedures throughout history, violating their bodily rights and integrity. Because of a history of abuse, medical procedures performed on individuals with disabilities, especially those who cannot consent, require close scrutiny and analysis. This paper explores three controversial medical procedures performed on individuals with disabilities, which include sterilization, cochlear implants, and growth attenuation. Embedded in each medical procedure mentioned above are social, legal, ethical, and psychological variables that influenced the emergence of each procedure and the receptiveness of society. This project explores each of these variables in detail as it relates to growth attenuation, sterilization, and cochlear implants, with a focus on similar themes surrounding each medical procedure. These themes will then be applied to growth attenuation, a more recent procedure, to search for parallels and to anticipate future directions of the debate and use of the procedure.

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Chapter 1

Summary of the Problem

Throughout history, individuals with disabilities have been defined as objects of shame, fear, pity, or ridicule. At one time, it was not uncommon for Americans with disabilities to have been incarcerated, sometimes for life, in state institutions and nursing homes. Laws have prohibited people with certain disabilities from marrying, or even from appearing in public. Some persons with disabilities have been subjected to extensive medical procedures to “cure” their disability. Individuals with disabilities living in our society must grapple with forming their own identity within an able-bodied Western culture that views disability as “abnormal.” Stereotypes, internalized oppression, and material disadvantages are several of the barriers that affect the lives and identities of disabled individuals.

Medical procedures performed on people with disabilities can never exist independently of the history of discrimination, oppression, and stigma. The most famous widely publicized example is that of Jack Kevorkian, also known as “Dr. Death,” who was imprisoned in 1999 for the physician-assisted suicide of Thomas Youk. Thomas Youk was diagnosed with Lou Gehrig’s disease and contacted Dr. Kevorkian to assist him in ending his life. Although proponents of physician-assisted suicide, or “mercy killing,” stated it was Mr. Youk’s right to end his own life, disability rights activists contended that Mr. Youk was in an emotional and social

crisis as a result of a society that is rejecting of disability (Seigel, 2008). Although not on the same scale as physician-assisted suicide in terms of media attention, other medical procedures performed on people with disabilities are subjects of debate as well.

The procedure of growth attenuation calls attention to one of the most recent medical procedures performed on people with disabilities. Growth attenuation is a treatment originally performed on tall adolescent females to prevent further growth. The surgery involves administering high doses of estrogen to stunt a patient's growth. Several years ago, the procedure was performed on Ashley X, a 6-year-old girl with a severe disability. Growth attenuation reportedly had not been performed on a person with a disability before and the event caused widespread outrage about the child's rights and pity for her parent's plight. Ashley's story made national news, and to disability rights advocates she became an example of alteration of a person's body to help her to fit into a discriminatory society.

Another treatment of great debate among families, doctors, and disability advocates is involuntary sterilization of people with disabilities. Sterilization renders an individual permanently incapable of reproduction. In the early part of the 20th century, sterilization was performed for the alleged prevention and treatment of mental disorders and "handicap," and eugenically as prevention of these (Dolan, 2007). After World War II, involuntary sterilization lost much of its support due to the Nazi eugenics program of research and practice. Even in cases in which the individual in question was capable of providing consent, his or her rights were often neglected and the procedure was performed without consideration of autonomy and rights of the

person to make decisions about his or her own body. Moreover, the decision was made in the context of a society that believed that people with disabilities may “transmit” the disability to their offspring and therefore should not be parents (Field & Sanchez, 1999).

In the Deaf community, no medical procedure causes more debate than cochlear implants. A cochlear implant is a device that provides direct electrical stimulation to the auditory nerve in the inner ear. In the last two decades, these implants have been offered as treatment options not only for adults who have lost their hearing as a result of an accident or disease in later life, but also for children who became Deaf as infants or who were born Deaf. An increasing number of operations are being conducted on children as young as two years old to install these implants in order to allow the children to begin hearing and learning spoken language (Sparrow, 2005). Throughout the 1980s and the early 1990s, Deaf people mobilized to protest the use of cochlear implants. In particular, they objected to the choice being made on behalf of young children to insert the implant. These critics reject the very idea of trying to find a “cure” for Deafness and have compared it to genocide. The cochlear implant controversy therefore involves questions about the nature of disability and the definition of “normal” bodies. Moreover, the controversy raises arguments about the nature and significance of culture in defining normality and the rights of members of minority cultures (Sparrow, 2005).

Embedded in each medical procedure mentioned above are social, legal, ethical, and psychological variables that influenced the emergence of each procedure and the receptiveness of society. This project explores each of these variables in

detail as it relates to growth attenuation, sterilization, and cochlear implants, with a focus on similar themes surrounding each medical procedure. Sterilization and cochlear implants have been available for many years and as such may be considered “mature” procedures. Growth attenuation is a much newer procedure, especially as it is applied to children with disabilities and as such has not yet received full review and analysis. These themes will then be applied to growth attenuation to search for parallels and to anticipate future directions of the debate and use of the procedure. Clinicians need to be aware of issues and biases surrounding these medical procedures because in many cases they may be a consultant in a situation where a controversial procedure is considered.

Chapter 2 explores the background information important to understanding the history of treatment of people with disabilities. Also in this chapter, the current models for conceptualizing disability are discussed, especially as they relate to medical procedures. The next three chapters focus on each medical procedure in detail: growth attenuation, sterilization, and cochlear implants. Another chapter will be devoted to the exploration of similar themes surrounding each procedure, with an emphasis on how the themes are likely to play out with growth attenuation. Finally, implications and limitations of this analysis will be discussed.

Chapter 2

Background Information

This chapter focuses on the models of understanding disability, specifically the moral, medical, and social models. Models of disability are tools for defining impairment and for providing a basis upon which society can devise strategies for meeting the needs of disabled people and their caregivers. Models provide us with a useful framework to gain an understanding of disability issues, and of the perspective held by those who created and applied the models. Perhaps, most importantly, models of disability exert a powerful influence on the public perception of disability and the public's response to people with disabilities. Consequently, models of disability have the capacity to shape the self-identity of those with disabilities (Conrad, 2004).

In addition, the history of the Independent Living Movement is discussed. Because the Independent Living Movement was the most significant event in the acquisition of disability rights, a brief history of the movement is provided as it relates to the emergence of different perceptions of disability in America.

Models of Disability

Models of disability provide a framework for understanding the way in which people with impairments experience disability. They also provide a reference for society as laws, regulations, and structures are developed that impact the lives of disabled people.

The moral model is historically the oldest model of disability and asserts that individuals are responsible for their own disability. The model implies that disability is the sign of moral flaws of the individual or his or her family and that anyone with a disability has done wrong or is being punished by God (Edwards, 2009). For the individual with a disability and his or her family and friends, this model is particularly burdensome. This model has been associated with shame on the entire family of a member with a disability. In response, some families have hidden away the disabled family member, keeping him or her out of school and excluded from any chance at having a meaningful role in society. Even in less extreme circumstances, this model has resulted in general social ostracism and self-hatred (Kaplan, 2000).

With the emergence of advanced medical science, the medical model arose, which views illness or disability as a medical defect requiring a cure. The medical model views disability as the result of a physical condition, as intrinsic to the individual, and as a condition that may reduce the individual's quality of life and causes clear disadvantages to the individual. The medical model assumes that autonomy and self-sufficiency are defining elements of the “normal” human condition. This is the standard against which the lives of individuals with disabilities are typically measured (Koch, 2001). People with a disability whose autonomy and self-sufficiency are limited are assumed to have a decreased quality of life. The medical model of disability is often cited by disability rights groups when evaluating the costs and benefits of invasive medical procedures because the model is used to justify large investments in medical procedures, technologies, and research (Koch, 2001).

In contrast, the more recently proposed social model of disability, created by disability rights advocates, asserts that systemic barriers, negative attitudes, and exclusion by society are the ultimate factors defining in a particular society who is disabled and who is not. Proponents of the social model of disability assert that a physically dependent or interdependent life is no less full than one that is autonomous and independent. If differences do exist, they are due to social prejudice and indifference. The debate between the social model of disability and the medical model of disability reflects different views on personhood and humanness (Koch, 2001).

The social model of disability stems from social constructivist theories, which posit that constructs such as quality of life and disability act not to describe already established realities, but rather actively shape the social world in which we live (Potter, 1996). Reinders (2000) discussed how disability is socially constructed as “dependency,” “unhappiness,” and “loss,” which serves to politically marginalize or morally exclude individuals in a society that privileges autonomy, independence, and prosperity. The concept of disability is seen as a social construction in that the limitations and disadvantages experienced have nothing to do with the disability but are only social constructions, and therefore unwarranted (Smart & Smart, 2006). Disability is constructed as a “burden,” not just personally but in the public arena as well. When disability is seen as a public burden, society then places it on an agenda to become eliminated, to coincide with utilitarian ethics, which claims to protect the greatest good for the greatest number of people (Clapton, 2003). In his article on bioethics, Clapton (2003) described how people with disabilities are often construed as the “not good” and as the “other” who deviate from the “good” norm. This

construction privileges a particular understanding of personhood as the “norm,” usually a male characterized by independence, rationality, and reason (Davis, 2000). The concept of the “other” implies difference, which is based on a relation of domination in which *different from* implies a status of being *less than* (Bradiotti, 1994). Disability then becomes viewed as a disastrous situation and a problem to be fixed (Clapton, 2003).

Persons with disabilities seen as the “other” are subjected to professional decisions from powerful disciplines such as medicine, science, law, and moral philosophy that construct social identities based on labels, limitation, and loss (Asch, 1998). This understanding of the “other” is then augmented by traditional medical ethical frameworks based upon perspectivism (reality is known only in terms of the perspectives seen by individuals or groups at particular moments), and principlism, which emphasizes autonomy, justice, respect for persons, beneficence and nonmaleficence (Beauchamp & Childress, 2001). Medical ethics often reduces the status of people with disabilities to that of an object requiring control, rather than recognizing the value of subjectivity and one’s unique way of being human (Clapton, 2003). Individuals with a disability have historically been the subject of misunderstanding, inattention, prejudice, and outright bias in the delivery of health care and other human services. Medical decisions made by professionals are not independent of the historically intense devaluation of individuals with disabilities (Longmore, 1995).

There is a discrepancy between the values of disabled people and nondisabled people, particularly in the views of some health care professionals, ethicists, and

health policy analysts. The latter group is composed of the people that make treatment decisions and health care access decisions regarding people with disabilities (Longmore, 1995). Because disability is the battleground for many bioethical issues, one might assume that individuals with disabilities would be dominant stakeholders. Not surprisingly, this is not the case (Wolbring, 2003).

Wright (1988) has asserted that health care providers view individuals with disabilities as “unfortunate” despite the observation that most people with disabilities do not view themselves that way. Wright (1988) studied how persons with physical disabilities at a rehabilitation center rated themselves as at least *average* in how fortunate they were, whereas they were rated *below average* by staff and doctors. Wright (1988) explained this difference as non-disabled peoples’ tendency to label individuals with disabilities by a single stigmatizing label (i.e., paraplegia, chronic pain, etc.) which is perceived as creating a diminished quality of life. Quality of life is not a construct that exists independently but is actively constructed by society, politics, and culture. Discussion of treatment choices often revolves around the medical model view of quality of life (Longmore, 1995). Because of this emphasis, appropriate treatment is often denied because of discrimination and prejudice.

Most healthcare professionals have frequent contact with disabled citizens. As most disabled people have acquired impairments, contact with healthcare services and physicians inevitably occurs around the time of onset, potentially a vulnerable transitional time (Telford et al., 2006). Time of onset is when most families are at their most vulnerable state and are experiencing feelings of fear, confusion, and sadness. Not surprisingly, families look to the doctors that are assisting them for

advice and guidance. How physicians view disability influences how they describe the person's disability to parents and how they predict the person's quality of life. Disabled people can become defined by their impairments and thereby be excluded from decisions and research related to them. The focus then shifts to seeking causes and solutions to the problem of disability (Shakespeare, 2006).

Rather than investing in medical procedures, technology, and research, disability rights groups assert that adaptation of the disabled person's environment would be cheaper and more attainable. Some disability rights groups see the medical model of disability as a civil rights issue, and criticize charitable or medical initiatives that use it in their portrayal of disabled people, because it promotes a negative, disempowered image of people with disabilities, rather than casting disability as a political, social and environmental problem (Crow, 1996). Viewing disability from the medical model assumes that individuals with disabilities should be "fixed" and treatment decisions and quality of life judgments should fall on medical professionals. Subscribing to the medical model then implies that treatment decisions remain with people other than the individual with the disability.

History of Independent Living Movement

The 1960's civil rights movement was the first catalyst for people with disabilities to realize that they could claim the rights of the majority. The independent living movement emerged from the same philosophy as the civil rights movement, with the idea that people with disabilities should have the same civil rights, options, and control over choices in their own lives as people without disabilities. The movement, which introduced the social model of disability, stresses that barriers to

inclusion in the social environment prevent full participation in life by persons with disabilities. The environment (e.g., architectural barriers, inaccessible homes, etc.) is seen as the obstacle, not the individual (Barton, 2009). Next, deinstitutionalization moved people with disabilities out of institutions into their communities.

Deinstitutionalization arose from the principle of “normalization” proposed by Wolfensberger in 1972 that asserted people with disabilities should live in the most “normal” setting as possible. The independent living paradigm was developed by DeJong in the late 1970’s, which proposed a shift from the medical model to the independent living model, parallel to the social model of disability, which values individual empowerment (DeJong, 1979). The goal was for society to recognize that people with disabilities are not “defective” or “broken,” needing a “cure.” The actual problem was in attitudinal and social barriers that people with disabilities encountered. The independent living movement caused a shift from the medical model to a more respectful stance by viewing people with disabilities as able to make their own decisions and increase participation in the community. For the first time, disability was not a “tragedy,” but a common experience in life that did not inherently diminish quality of life (Barton, 2009).

In 1973, the Rehabilitation Act prohibited discrimination in federal programs and services to receive funding. Section 504 of the Act states “No otherwise qualified handicapped individual in the United States, shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving federal financial assistance.” Present Nixon at first vetoed this bill and

prevented it from becoming law. After much protesting by disability rights advocates, congress overrode the veto and the Rehabilitation Act became law (Barton, 2009). Amendments to the Rehabilitation Act were implemented in 1978 and 1983, allowing for consumer-controlled centers for independent living and an advocacy program for consumers of rehabilitation and independent living services. In 1990, the Americans with Disabilities Act (ADA), closely modeled after the Civil Rights Act, provided civil rights protections for people with disabilities. ADA is only two decades old. Even with the independent living movement, it was not until 1990 when the Americans with Disabilities Act was signed into law that the first regulation passed requiring wheelchair lifts on public buses, demonstrating the resistance of legislation to adhere to the needs of people with disabilities (this law took 20 years to implement and finally was approved in 1990).

Recently in 2008, the President signed the Americans with Disabilities Act Amendments Act. The Act makes important changes to the definition of the term "disability." The effect of these changes is to make it easier for an individual seeking protection under the ADA to establish that he or she has a disability within the meaning of the ADA. The basic definition of a disability under the ADA is a "physical or mental impairment that substantially limits one or more major life activities." In past cases, the Supreme Court has interpreted the "substantially limits" language of the definition very narrowly, but the new Americans with Disabilities Act clarifies that the "substantially limits" language should be construed more broadly (U.S. Equal Employment Opportunity Commission, n.d.).

Current Status of Models

Disability rights activists have dedicated their lives to acquiring equal rights for individuals with disabilities and their families. In spite of the legislative achievements of people with disabilities, general social and attitudinal barriers still very much exist. The medical model of disability, based on modern science and technologies, is still prevalent, and is especially salient when new medical procedures are introduced to people with disabilities as a “cure” or a solution for a “burden.” Although the medical model diminished the prevalence and influence of the moral model of disability and reflected a shift in thinking for the majority, the moral model is still prevalent today in some cultures and social classes. In some minority groups, where information is unavailable or insufficient, the moral model of disability is still the primary framework for conceptualizing disability. In many countries that are heavily based on a religious philosophy, the moral model is also the primary mode of viewing disability (Devlieger, 2005).

Chapter 3

Sterilization

As mentioned above, sterilization renders an individual permanently incapable of reproduction. Relevant to this project is when the mentally retarded individual in question is incapable of providing informed consent. This is likely to occur in moderate to severe cases of retardation in which the individual cannot understand the procedure or make a voluntary choice.

The Past

In the case of *Buck vs. Bell* (1927), the U.S. Supreme Court upheld a Virginia statute that provided for the eugenic sterilization for people considered “genetically unfit.” Carrie Buck, the plaintiff, did not consent to sterilization but was subjected to the treatment because the court found her “feeble-minded” and “promiscuous.” Buck’s lawyers argued unsuccessfully that sterilization ran counter to the 14th Amendment (prohibiting states from depriving any person of his or her life, liberty or prosperity without due process of law and denying any person equal protection of the law) and 5th Amendment (protecting against abuse of the government in legal proceedings). The effect of *Buck v. Bell* was to legitimize eugenic sterilization laws in the United States. The law affirmed eugenics theory, the proposition that tendencies to crime, poverty, mental illness, and moral failings are inherited in predictable patterns. The social costs of those conditions could be erased,

the eugenicists argued, and Carrie Buck's case went to court to establish a constitutional precedent and ratify the practice of eugenic sterilization (Lombardo, 2003). Virginia's sterilization statute was used as precedence for similar laws in 30 states, under which an estimated 65,000 “feeble-minded” Americans were sterilized without their own consent or that of a family member (Micklos, 2004). Virginia contested that the court met the minimum requirements of due process. Thus, states would claim that they met the required procedural protections of sterilization while still maintaining an active sterilization program (Field & Sanchez, 1999).

The idea that the state or other authority should involve itself with reproduction originated with the ideas of Galton in Britain (Galton, 1869) and Davenport in the United States (Davenport, 1911). The word “eugenics” refers to the idea that society should use the education and the power of the state to encourage procreation by the fittest and discourage procreation by the unfit to facilitate better breeding. Eugenics stemmed from the thinking that American immigrants between 1890 and 1920 were poor because of a genetic defect, not because of lack of opportunity, low wages, and inadequate housing (Dolan, 2007). Under the concept of "social responsibility," involuntary sterilizations, genetic manipulation, race segregation and imprisonment were justified in order to save America from the high cost of treating defective individuals, who were considered to be responsible for the nation's social ills (Center for Individual Freedom, 2002).

The eugenics movement in the United States arose in the wake of three intersecting developments: a belief in scientific management and rational planning, the pressures of economic instability, and the arrival of the progressive era (Allen,

1989). Eugenacists argued that the birth of defective persons caused a massive social burden and that the state had the right to control procreation among persons whose offspring would be dependent on the public purse. Thus, financial motivation was a core component in the argument for sterilization. There was concern that the quality of the population was declining and was a major obstacle to economic growth and success (Heidenheimer & Elvander, 1980). There was also concern with elements of the population that were simply incapable of meeting the challenges presented by an industrial society. If these individuals could not adjust, then the question of their welfare and reproduction became a pressing issue for the state. Thus, they believed that sterilization could contribute to efficient social management. This view is based on the philosophy of placing the needs of society above those of individual groups for the benefit of social progress (Ohlander, 1991).

The view by some health care professionals and legal representatives that it was unethical to make a decision about the bodily integrity of another was overshadowed by the force of the eugenics movement. Nonetheless, by the late 1930s, the study of eugenics began to lose its appeal in America. Increasingly, independent scientists began refuting eugenicists' claims. Moreover, the federal ban on birth control was lifted in 1938, allowing for less invasive measures to prevent pregnancy. After World War II, public opinion about eugenics and sterilization programs became more negative in the light of the connection with the genocidal policies of Nazi Germany. The Committee of the American Neurological Association for the Investigation of Eugenic Sterilization reported that sterilizations were being performed on individuals whose disability did not warrant sterilization. The

Committee recommended that eugenic sterilization be entirely voluntary because contrary to popular fears, mental disease in America was not increasing (Myerson, Ayer, Putnam, Keeler, Alexander, 1936). By 1939, financial support had declined and the Eugenics Record's Office was forced to close its doors. However, involuntary sterilizations continued in this country through the late 1970s with the last reportedly occurring in 1981 (Center for Individual Freedom, 2002). Sterilization laws remained on the books in some states for much longer after that, though they were rarely if ever used.

Current Legal Practices

Forced, or involuntary sterilization has been banned in all states. Currently, state laws dictate the rules surrounding sterilization. Voluntary sterilization in the United States is considered legal for contraceptive purposes if the person in question consents. Individuals who are not competent to make decisions cannot be sterilized without consent from a parent or guardian and is not considered involuntary, but non-consensual (Rivet, 1990). Advocates of human rights and individual autonomy contested that parents should not be permitted to make these decisions about the well-being of their disabled child, and as a result, judicial approval was necessary when caregivers or guardians requested sterilization for their child (Rivet, 1990). Parental decisions to sterilize or institutionalize a minor are subject to judicial review in a majority of states. Such reviews are consistent with those (e.g., Oullette, 2006) who have contended that third party oversight is appropriate when the interests of the parent differ from the interests of the child and when the health care decision is highly invasive and/or potentially abusive.

State laws vary on whether and how sterilization can be approved in cases where the person in question is an incompetent adult because the U.S. Supreme Court has not yet spelled out a constitutional rule that must be followed (Field & Sanchez, 1999). Most states allow non-consensual sterilization of individuals who cannot consent for themselves, but most require that courts oversee this decision. Judicial permission to sterilize is required because of the potential conflict of interest (between the patient and the person requesting sterilization) and the historic abuses of the procedure.

In contrast to Carrie Buck's case, more recent procedural protections are more sophisticated. The newer statutes still allow sterilization without the patient's consent, but only in carefully limited circumstances and they require clear and convincing evidence that the patient is incapable of consent and that sterilization is in her best interests (Field & Sanchez, 1999). For example, the Supreme Court in Washington requires that all less drastic means of contraception have proven unworkable and the person being sterilized will likely be unable to care for a child in the future to prove the procedure is in the best interest of the individual.

The Washington Supreme Court has established a set of procedures it requires for granting non-consensual sterilization (Field & Sanchez, 1999). These include: the petition must be reviewed in an official court proceeding, the patient must be represented by a disinterested third party, the court must receive independent and comprehensive medical, psychological, and social evaluations of the patient, and the court must attempt to elicit the patient's view about being sterilized. Obviously, in more severe cases of mental retardation, the last procedure would not be possible.

Other states require that notice be given to the subject of the sterilization request and that he or she be given a chance to testify or appeal the court's order. The courts also require the appointment of a guardian and possible legal counsel in addition to expert evaluations by disinterested medical professionals. If the patient is found capable of consenting to the procedure, then the procedure can end (Field & Sanchez, 1999).

Several variables are taken into consideration when a court is asked to make a decision whether to authorize a sterilization request. These variables may vary from state to state. California, for example, has criteria that must be established beyond a reasonable doubt (Field & Sanchez, 1999). These include: the person is incapable of giving consent, the individual is fertile and capable of reproduction, the person is capable of engaging in (and likely to engage in) sexual activity, all less invasive contraceptive methods are unworkable, the person has not made a knowing objection to the sterilization, and the person's disability renders her permanently incapable of caring for a child or would pose a risk to the life of the individual. In addition, the criteria note that sterilization should not be utilized if there are foreseeable advances in medical science that are less invasive.

In some states, old sterilization laws that permitted the procedure involuntarily were repealed but never replaced by newer legislation. The void in laws is usually filled by judicial decisions. Without legislative guidance, however, many judges are reluctant to grant petitions to sterilize persons alleged to be retarded. Many judges and advocates for persons with disabilities consider it inappropriate for third-party decision makers to apply their own best interest standards instead of standards created by legislatures (Field & Sanchez, 1999).

In summary, individuals with mental retardation and developmental disabilities are still vulnerable to involuntary sterilization, although with procedural safeguards. Sterilization requests almost always state that the procedure benefits the mentally retarded person in question. However, society's interest is still noticeable in the equation, such as the need to prevent the birth of disabled offspring if the disability is hereditary (Field & Sanchez, 1999).

Ethics

In Western society, value is placed on an individual's bodily rights and one's right to make decisions about his or her body. When one cannot make decisions, there are principles that help guide the decision making process for the third party in an attempt to prevent a violation of the person's rights. Two principles form the foundation for the debate over whether to approve of sterilization for mentally retarded individuals deemed incompetent, which are the best interest principle and substituted judgment (Dolan, 2007). Once society's interests were discarded as paramount after the eugenics movement, the person's best interest was used to justify courts' decisions (Field & Sanchez, 1999). The best interest principle is based on ideas such as quality of life, least restrictive alternative for living arrangements, inclusion in community life, expressed wish of parents, and burden of care. The best interest principle typically is patient-centered and suggests that society should try to make decisions that appear to be the best for the child, not necessarily for the parents and others. The court will hear expert testimony about whether the procedure is in the subject's best interest, often based on the criteria mentioned above. The purpose of the best interest analysis is to protect legally incompetent people from exploitation

(Field & Sanchez, 1999). In some instances, then, parents can be found to be biased in serving their own interests rather than the interests of a child, and sometimes decisions about whose needs take precedence should be made by the courts. Whether or not an intervention is in the patient's best interest depends on a prediction about how it affects his or her life (Deikema, 2003).

Some courts have challenged the notion of best interest and have used the ethical concept of substituted judgment, where the court decides not what is best for the individual, but how the individual would have decided (Dolan, 2007). Proponents of substituted judgment state it better protects the rights of the individual.

Brady (2001), writing from a disability rights perspective, examined the current legal and medical reasoning surrounding requests of sterilization of women with disabilities. Most decisions for sterilization are based on the medical model, viewing a disability as a personal tragedy that must be dealt with in a compassionate and protective manner (Brady, 2001). If disability is viewed as a tragedy to be eliminated, then the ethical principle of "do no harm" is consistent with the procedure. However, the principle of do no harm does not account for social and attitudinal variables affecting the sterilization requests. Brady (2001) stated that present-day sterilization requests are related to social values, notions of worth, and assumptions about women with disabilities rather than to the best interest of the person. Dolan (2007) stated that sterilization decisions should be placed under the utmost scrutiny to discriminate between the true interest of the individual and the interest of society. Moreover, neither of the ethical criteria mentioned above can eliminate the value systems of the court, experts, and third-parties involved.

It is generally accepted that in sterilization the interests of the person should be central. It is questionable whether the rights of the person should be the sole determinant of the sterilization decision, however (Field & Sanchez, 1999). Other's interests, such as those of society and parents, could be relevant as well. For example, parents may want to reduce their own caretaking responsibilities by sterilizing their mentally incompetent child. One may argue that the potential grandparents in the case may have actual responsibility for the potential child so their opinion should carry more weight than in a typical case. The state could have an interest in avoiding financial burdens, including providing parental training, family support if the mother keeps the child, and foster care if the child is removed from the home. Most courts, however, state that only the needs of the person should be considered rather than those of the taxpayer, the government, and the parents (Field & Sanchez, 1999).

Parental Opinions

Many studies have explored parental attitudes towards sterilization. Studies conducted before sterilization of persons with intellectual disabilities was banned in most jurisdictions found that up to 80% of parents and service workers approved of sterilization of persons with intellectual disabilities as a form of birth control (Alcorn, 1974; Whitecraft & Jones, 1974; Wolfe, 1997; Wolf & Zarfes 1982). In 1982, Passer, Rauh, Chamberlain, McGrath, and Burket reported that 85% of caregivers in their study favored a state statute that would enable sterilization under certain circumstances and limitations. They found that few caregivers supported an extremely permissive or restrictive position; most wanted sterilization permitted under certain circumstances and with specific safeguards to prevent abuse of the procedure, such as

judicial review. Caregivers preferred that these types of decisions should be made on a case-by-case basis.

Current Status of Sterilization

Currently, no good estimates are available of the number of sterilizations performed on individuals who are unable to consent. One can assume, however, that sterilization requests are few in light of the numerous contraceptive methods that are available. Sterilization rates have decreased in the general population in the past decade because of the availability of other, less invasive, procedures. The average five-year rate of female sterilization found in the United States is 6.5%, which is greater than in any other country, likely because of the historical popularity of the procedure (Egenderhealth, 2002). This percentage includes both involuntary and voluntary sterilizations.

Chapter 4

Cochlear Implants

A cochlear implant is an electronic device that restores partial hearing to a Deaf individual; it is appropriate for individuals with severe hearing loss. It is surgically implanted in the inner ear and activated by a device worn outside the ear. Cochlear implants were first approved for marketing in 1984. More than 30,000 individuals worldwide have received cochlear implants; 14,000 of those individuals are in the U.S. The current average cost for cochlear implants is more than \$40,000. The device is most effective when implanted on a child who was born Deaf. The younger the child when the surgery is completed, the greater the benefit achieved in the areas of speech perception and speech and language development (American Speech Language Hearing Association, n.d.). However, cochlear implants are particularly controversial when the implantation is on a child, because the child cannot consent to the procedure. Moreover, often Deaf children are born to hearing parents, making the parental choice of cochlear implants vulnerable to bias. In the following paragraphs, the word Deaf is capitalized to reference a self-defined cultural group in the United States, with a common history and language.

Is Deafness a Disability?

The conflict concerning cochlear implants centers around the definition of disability and debates between medical and social explanations of Deafness (Kermit,

2009). To explore the impact of cochlear implants on Deaf individuals, one must first understand Deaf culture and its impact on this debate. The experiences stemming from being unable to hear in a hearing world are central to the cultural identity of the Deaf. Yet, being unable to hear is not sufficient for membership in the Deaf culture. One must also use Sign and participate in the cultural institutions of the Deaf. Because 90 percent of Deaf children are born to hearing parents, Deaf culture cannot rely on cultural transmission in which culture is passed from one generation to the next within the family (Grodin & Lane, 1997). Instead, cultural transmission of Deaf culture occurs primarily in the other cultural institutions of the Deaf, and through contact with cultural role models other than parents. Children who are born without hearing or who lose their hearing at an early age are *potential* members of Deaf culture only (Tucker, 1998).

There are social as well as a biological aspects to Deafness (Sparrow, 2005). Deafness is not seen as a disability by many individuals in the Deaf culture, as they assert it is possible to have a productive life without hearing or speaking language. At the heart of the Deaf community's objection to cochlear implant technology is the claim that Deaf people constitute a minority culture rather than merely a group of people who share a disability (Sparrow, 2005). Because cochlear implants have the potential to ameliorate or eliminate ramifications of Deafness, Deaf culturists oppose them, and view efforts to "cure" Deafness or ameliorate its effects as an immoral means of killing Deaf culture (Tucker, 1998). According to this view, the search for a cure for Deafness represents the desire of a majority culture to impose its language and values on the Deaf rather than modify its institutions to take account of the

perspectives and needs of members of another culture (Sparrow, 2005). Disability rights activists assert that many of the “disadvantages” faced by people who are Deaf turn out to have social and institutional causes and could be rectified by changes in the way society is organized. For example, the replacement of all telephones with teletext machines would go a long way towards making the majority culture more responsive to the needs of Deaf individuals (Sparrow, 2005). According to the medical model, on the other hand, Deafness is a disability, and thus something to be altered and repaired. Proponents of the medical explanation of Deafness state that even though all socially created barriers that Deaf people face could be alleviated, the physical hearing impairment would still be there. That is, Deaf people are still missing one of the critical five senses. Deaf people are thus disabled (Johnston, 2005). From this perspective, the bioethical implication for cochlear implants is that a parent should not refrain from implanting a Deaf child, as this will mean maintaining the child’s disability instead of easing it (Kermit, 2009). Tucker (1998) predicted that people with disabilities may not be provided accommodations in the future if they refuse treatment that could have alleviated their disability and prevented the need for such accommodations. Individuals in the Deaf community reject this view, stating that the linguistic and cultural values of Deaf individuals are diminished and no acknowledgement is made of the value of life that Deaf people live (Hyde & Power, 2005). A medical/technical attempt to ease or cure impairments such as a lack of hearing should not cause much controversy according to a medical model. In fact, these attempts to cure deafness are in line with the best medical and ethical traditions to try to ease or cure disease, and until the implant was invented, nothing could be

done to help those whose hearing impairments were so severe that ordinary hearing aids were of no use. On the other hand, critics (e.g., Stokoe, 2005) of the medical model contend that Deaf people do, in fact, constitute a linguistic minority. The sign languages Deaf people use are as fully fledged and natural as spoken languages are. It would thus seem possible to question cochlear implantation and perhaps even argue that implantation is a form of forced normalization. If one can argue that prelingual Deaf children belong in some way to a signed language and its culture, attempts to alter this belonging by means of surgery could be ethically questionable (Kermit, 2009).

Ethics

Legally and ethically, it is widely accepted that parents can provide consent for medical treatment of their children (Hyde & Power, 2005). Informed consent has its beginnings in respect for autonomy of the individual making the decision and must involve accurate presentation of the information. Informed consent in this case includes educating parents on the risks and the benefits of the procedure. Although Deafness is not life threatening, cochlear implants are considered a “benefit.” If hearing is perceived as “good,” then the benefit should outweigh the risk. However, parents’ “informed consent” to the procedure usually only provides them with information from a medical point of view and neglects the richness of the Deaf culture (Hyde & Power, 2005). It is this balance between benefit and risk that is at the heart of the informed consent debate about cochlear implantation. Lane and Grodin (1997) argued that implants are a threat to the Deaf culture and parents may not understand what is in the best interest of their Deaf child. Hyde and Power (1995)

stated that parents should be provided information on the cultural characteristics associated with being Deaf. However, the current practice of informed consent for medical decisions operates within a medical model and does not fully account for wider social issues. From a medical standpoint, it is impossible to deny parents the right to make the cochlear implant decisions. Thus, we come back to the question of who defines disability and what is a reasonable medical treatment for someone with a disability.

Hyde and Power (2005) noted how there are inequities in access to cochlear implants. For example, in the United States, the rate of implantation is 5 times higher in white and Asian American children than in Hispanic children and 10 times higher than in African American children. Moreover, implanted children are far more likely to come from higher socio-economic areas. Most interestingly, children with other disabilities in addition to Deafness are less likely to be implanted than a child born only Deaf.

Parental Decisions

There are truly difficult questions about the rights of hearing parents to choose a cultural identity for their Deaf child, which may substantially reduce the opportunities available in later life (Davis, 2001). These questions are especially urgent in the case of Deaf parents making a decision about bringing up their child without an implant, because without the implant it is highly unlikely that their child will be able to learn the spoken language of the majority culture in later life, and is therefore likely to be severely restricted in ability to participate in it (Sparrow, 2005). The danger with existing cochlear implants is that they risk depriving such children of

full membership of *any* culture. It is widely acknowledged that the majority of persons who receive the implant will remain Deaf to some extent (Grodin & Lane, 1997). In the bioethical context of cochlear implantation, it is important to note that the ability to hear with an implant is by no means an automatic effect of surgery. The ability to understand and interpret sounds comes only as a result of training and habilitation and the outcomes vary. Many implanted children achieve a good hearing capacity, though there are still no documented cases in which an implanted child has achieved normal hearing (Sparrow, 2005).

Historically, attempts to teach Deaf children to overcome their hearing impairments and acquire a spoken language have not been very successful (Kermit, 2009). On the contrary, the identification of spoken language acquisition as Deaf education's primary objective turned out to have some problematic repercussions. Learning a spoken language was time consuming and this time was spent at the expense of the time used to teach other subjects. As a result, Deaf children often left school without having completed an ordinary education according to a normal curriculum. In addition, as most teachers in the Deaf school taught in spoken language, the students often had to strive more to understand what was said, than to understand the curriculum's content. For many Deaf students the result of repeated experiences of striving to understand the curriculum led to feelings of defeat when understanding proved difficult and led to the formation of self images as flawed and unauthentic persons. Reduced accessibility to the labor market and a career, due to poor education, effectively reinforces this image of Deaf people as less capable (Kermit 2006).

A significant percentage of early childhood implantees are unable to communicate effectively even with those close to them, without the benefit of Sign, lip reading, or other hearing aids. Moreover, ease of communication in a signed language removes the incentive for the child to learn to speak and for this reason communicating with the child in Sign, and the child's own use of Sign, may sometimes be discouraged. Implantees will likely not function as well as those who grow up with either English or Sign as their first language. Existing implants fall substantially short of guaranteeing that implantees will be able to participate fully in hearing interaction (Sparrow, 2005). If the child's attempt to learn to hear and speak with the aid of the implant fails, then he or she will have been deprived of the early contact and experience with Sign that allows those who learn it from birth to use it as a natural language. The child may grow up unable to use any language fluently and suffer a host of cognitive, developmental, and educational problems that flow from this (Sparrow, 2005).

Legal

Legally, there are no restrictions on parental choice of cochlear implants. Unlike sterilization, the choice to utilize cochlear implants is not legally regulated because it is considered to be a less invasive procedure. The general rule is that unless a particular medical decision regarding a child can be characterized as medical neglect, parental decisions about children's health care have no legal limitation (Oulette, 2006). A parent's right to make medical decisions for a child is protected by the Due Process Clause of the 14th Amendment (Oulette, 2006). Parental decisions for medical interventions are subject to very few legal restrictions. Unless clear data

demonstrate that the parent is unfit, the state generally will not insert itself into the private realm of the family to question the parents' decision making regarding their child. Prohibition of a medical decision applies only when a procedure is deemed destructive and medically inappropriate under any circumstances (Oullette, 2006). Restraint on parental choice is only justified when the state's interests outweigh the parents' constitutional right to make a medical decision for their child.

Chapter 5

Growth Attenuation

The most recent medical procedure that is receiving attention in the literature is growth attenuation. To understand the procedure and the conflicts surrounding the debate, the story of Ashley X will be presented. Ashley X has a diagnosis of static encephalopathy, which is defined as permanent or unchanging brain damage, resulting in profound mental retardation. She is unable to sit up, roll over, grasp objects, or speak. Her mental age is between 3 and 6 months, and the chance of improvement is non-existent. She is dependent in all activities of daily living, has a feeding tube, and is non-ambulatory. Like a 3-month-old child, Ashley is aware of her environment, responds to music, and constantly kicks her arms and legs when she is excited. Her parents refer to her as their “pillow angel,” because she lays in the same position on her pillow until her parents move her (Anonymous, 2007).

When doctors predicted she would mature to five foot six, and 160 pounds, Ashley’s parents began to worry about not being able to care for her when she got older. Ashley’s parents and her doctors developed a plan to attenuate her growth by using high dosages of estrogen. The effect of this medication is an acceleration of the closure of one’s growth plates and results in a stunting in growth. Her parents concluded that it would be easier to take care of her if they could accelerate the closure of her growth plates to stop her growth at four foot six, 65 pounds. High doses

of estrogen in girls cause the menstrual cycle to begin, which can be controlled with a hysterectomy. Ashley also underwent a hysterectomy to eliminate the menstrual cycle and breast bud removal to avoid development of large breasts and discomfort (Anonymous, 2007). Ashley's parents argued that a hysterectomy would allow her to avoid the menstrual cycle and the discomforts commonly associated with it, eliminate the possibility of pregnancy, and eliminate the possibility of uterine cancer. Ashley's parents stated that removing her breast buds was necessary because Ashley would not have children, making the ability to breastfeed unnecessary. Her parents also feared large breasts would "sexualize" Ashley, possibly leading to her becoming the victim of abuse (Anonymous, 2007). Ashley's parents and physicians met with an institutional ethics committee and reached the decision that growth attenuation and a hysterectomy were ethically appropriate in this case (Gunther & Diekema, 2006).

Ashley's parents argued that the best quality of life for her was in their home as opposed to an out-of-home placement. They believed keeping Ashley at home where they could always provide her with the love and care she needed would maximize her quality of life. Ashley's parents were also concerned that once she reached puberty and grew to her full potential, the burden of lifting, transferring, feeding, and bathing her would become too great. They feared Ashley would become too large for a wheel chair and would suffer from skin breakdowns and infections.

In May of 2007, the "Investigative Report Regarding the 'Ashley Treatment'" was released by the Washington Protection & Advocacy System (WPAS). WPAS also found that Ashley's sterilization was a violation of Washington state law because no court order was sought before the sterilization was performed. Moreover, they noted

that Ashley was never represented by a third-party mediator, a requirement for sterilization cases in the state of Washington (Maupin, 2011). The report stated that the mastectomy and estrogen therapy should also have been questioned because of her inability to consent. WPAS found that each step of the treatment Ashley should have been mediated by a "disinterested third party," who would advocate for Ashley, before the procedure was initiated (Maupin, 2011).

Ethics

As mentioned in Chapter 1, the "Ashley treatment" has caused a good deal of controversy since it came to light in 2007. Ashley's parents and her physicians found themselves the target of scrutiny, as have other parents who have elected this procedure since the time of Ashley's case (Newsom, 2007). Some have criticized Ashley's parents for altering their daughter's body for their own benefit. Critics have argued that Ashley's rights were violated and the surgery was not in her best interest. In their defense, Liao, Savulescu, and Sheehan (2007) stated that if society believes this surgery is undignified, then society must be prepared to provide caregivers with enough assistance and support so that parents will not consider taking such a step. As Kirschner, Brashler, and Savage (2007) stated, "this appalling lack of support (for parents) lies at the center of this debate and cannot be ignored or fixed with medical interventions such as surgery or drugs" (p. 3). Ashley's case presents several broad issues regarding growth attenuation, including ethical issues, stress of caregiving, and quality of life. Several ethics scholars and commentators have identified the ethical issues that are raised by growth attenuation, which are similar to those documented about sterilization. For example, Edwards (2007) listed some of the objections to the

growth attenuation of Ashley X. The first objection is that Ashley's rights have been violated. Proponents of the surgery state that one cannot possess rights if he or she is not capable of exercising competent and intentional decision-making and action (Deikema, 2003). Disability advocates are concerned that the "Ashley treatment" might represent a return to the eugenics movement and be an affront to human dignity (Cohen, 2007). Turnbull et al. (2006) stated that proponents of growth attenuation propose that it enhances functionality in the disabled person, but actually results in an alteration of the person's very self. Not only may it cause adverse side effects or be misused, it fails to address the real problem: a society failing to provide adequate services and social support to the parents (Brosco, 2006).

The second objection is that the surgery is a medical response to a social problem. This latter position is most often associated with disability advocates, who believe that if Ashley's parents had adequate support or social services, they would not have needed such an invasive surgery. Disability rights activists operate from the premise that all individual and institutional behaviors toward people with disabilities, including health care decisions, are shaped by historically deep-seated cultural assumptions about disability (Longmore, 1995). For individuals with disabilities, prejudice and discrimination found in the broader society are more of an obstacle than are medical impairments or functional limitations (Smart & Smart, 2006). When societal barriers are ignored in research, policies, and practice, the larger social context of disability is not considered. Ethical decisions, which often have been assumed to be free from prejudice, are consequently made from biased perspectives which hold negative views of people with disabilities (Wolbring, 2003). Medical

decisions for individuals with disabilities are based on the relief of suffering, while neglecting the nature and cause of one's distress. Drastic medical decisions may be perceived as the result of a compromised quality of life, when the real problem is actually inadequate supports for living (Gill, 2004).

The third objection is that Ashley's best interests are not enhanced by the interventions. In making medical decisions, surrogate decision-makers for incompetent persons are expected to use a best interest standard, weighing the proposed burdens and benefits of each decision. The phrase "best interest" was important in the decision-making process by the hospital ethics board that reviewed her parents' request for surgery. Ashley's parents asserted that it was in Ashley's best interest to have the surgery because she would experience serious discomfort if she continued to grow. Her parents also stated that her quality of life would improve by having the surgery, and therefore the surgery was in her best interest.

The fourth objection is that Ashley's treatment was completed as a convenience for her caregivers. In other words, growth attenuation was performed for the benefit of the parents, not for the benefit of Ashley. In contrast, Deikma (2003) argued that parental interests are an especially important issue when the individual in question is, and always will be, unable to understand. Considering one's best interest in isolation is not plausible because caregivers must balance their needs also (Ross, 1998). Kirschner, Brashler, and Savage (2007) stated that the family's opinions should carry significant weight because they are the ones most affected by this decision. For example, it is difficult to separate Ashley's needs from her parents' needs, considering that her care is determined by her family's ability to take care of

her 24 hours a day, 7 days a week (Kirschner et al., 2007). Those bearing the responsibility to act as surrogates for those who cannot speak for themselves must recognize that the disabled have historically been subjects of misunderstanding, inattention, judgment, and bias in the health care system. In addition, caregivers are not immune to a society that overtly and covertly discriminates against mentally retarded individuals. However, Nelson (2007) stated that history should not strip responsible surrogates of their ability to exercise a developmentally disabled person's right to give consent to treatment.

The final, and perhaps the strongest, objection to growth attenuation is the fear that the case will set an objectionable precedent. The surgery may provide justification for interventions that involve surgically administered radical changes in bodily constitution to disabled individuals (Edwards, 2007). Proponents of the surgery stated that Ashley's case is exceptional because of the severity and nature of her disability and the vast majority of retarded children would not benefit from her type of surgery (Newson, 2007). The eugenics movement with sterilization in the first half of the 20th century is now considered both immoral and unethical by most people. However, these circumstances did not prevent these invasive medical procedures from occurring again (Sandburg, 2007). Ethical factors in the decision to employ high-dose estrogen treatment to attenuate growth in a profoundly impaired individual included past abuses against this population justified by the benefits to society and caretakers, rather than the individual (Sandburg, 2007). Ouellette (2006) asserted that the removal of Ashley's uterus was arguably subject to mandatory court review in Washington State and the absence of a legal review was consistent with existing legal

paradigms. Not Dead Yet, a disability rights advocacy organization, decried a ban on the growth attenuation procedure. They asserted that the ethics committees consulted in this case were not a substitute for due process in the legal system.

Stress of Care

Caregivers of disabled children are under significant amounts of stress. Rearing a child with severe mental retardation puts extra physical, financial, and mental burdens on parents, especially when the child reaches puberty (Rimmerman, 1991). Lifelong care giving for a disabled child is associated with poor emotional and physical health in caregivers. They report back pain, migraine headaches, and stomach/intestinal ulcers. Quine and Pahl (1985) hypothesized that the more severe the disability, the higher the level of stress in the parents. However, they found no significant differences in stress levels of parents with children who have severe and profound retardation in comparison to caring for children with mild and moderate retardation. Researchers did find that when they assessed for multiple impairments, such as the child's mobility, speech, behavior, quality of social interaction, physical disorders, and psychiatric disorders, there was a significantly greater amount of stress on the caregivers. In other words, children with several impairments were more of a burden on parents. Their study also showed the stress levels of parents were higher when they had children who needed more assistance (i.e., bathing) than children who needed less assistance. The difference in these groups became significant when the burden included dressing and undressing, and nighttime disturbances. They concluded that high levels of stress in parents result from a multiplicity of impairments in the child, behavior problems, and adversity in the family. Although

severity of disability was not related to stress level, it was related to the consideration of medical procedures. Passer, Rauh, Chamberlain, McGrath, and Burket (1984) found that the more severe the disability, the greater the likelihood the caregivers considered sterilization of their child.

Leonard et al. (1993) posited that parents who are the most distressed are those who spend the most hours doing caregiving tasks and care for children who are older with multiple disabilities. There are even more physical and emotional demands on the family when the child grows up (Turnbull, et al., 1986). The question of what will become of disabled children when parents can no longer provide care is a major concern to parents (Mulcahey & Warren, 1984). The longer a child with severe disabilities remains at home with the family, the deeper the guilt feelings about separation become (Bromley & Blancher, 1989). Murphy et al. (2007) stated that caregivers expressed concern about what would happen to their child if the child outlived the parents. They were also angry about the absence of structured community programs for their children when they can no longer attend special needs schools. Some parents strongly value care facilities because of serious behavioral problems that are too difficult to deal with in the home (LaPorte & Meg, 2006). Tausig (1985) found that in younger individuals, behavior problems were the most notable factor in a parental decision to place the child out of the home. In older individuals, it was burden of care. Rimmerman and Duvdevani (1996) showed how decisions for out-of-home placement are predicted by parents' inability to cope with the burden of special care for their severely disabled child. Parents of disabled children face a monumental decision regarding placement. Do they keep their child at home and face the burdens

of care, or do they place the child out-of-home and face feelings of guilt?

Quality of Life

Quality of life (QOL) is a complex, multi-faceted construct, influenced by both personal and environmental factors. It has the same components for all people with both subjective and objective components and is enhanced by self-determination, resources, purpose in life, and a sense of belonging (Schalock, 2005). Measurement of QOL involves the degree to which people have life experiences that they value, reflects the domains that contribute to a full and interconnected life, and considers the contexts of physical, social and cultural environments that are important to people (Schalock, 2005). The conceptualization, measurement, and application of the QOL construct require a systemic perspective that integrates the micro (individual or family), the meso (organization and services delivery network), and macrosystems (society and culture) in which individuals and families live. The importance of the system's perspective is that it allows us to better understand the predictors of quality that extend beyond the person to the family, organization, and service delivery systems (Schalock, 2005). Literature has shown that the following dimensions are included in quality of life: social relationships and interaction, psychological well-being and personal satisfaction, employment, self-determination, autonomy and personal choice, recreation and leisure, personal competence, community adjustment and independent living skills, residential environment, community integration, normalization, individual and demographic indications, personal development and fulfillment, social acceptance, social status, physical and material well-being, and civic responsibility (Petry et al., 2005). In regard to quality of life in the severely

disabled population, Petry et al. (2005) found that physical well being, material well being, social well being, emotional well being, and development and activities were mentioned the most by parents and direct support staff.

The literature on quality of life in disabled individuals living in the home is limited. Seltzer and Krauss (2001) proposed several reasons for this. First, public expenditures target adults who live in out-of-home residential settings. Family support programs account for only 3% of the public expenditures for individuals with mental retardation. The second reason is the privacy of family life compared to life in a residential setting with many staff and other residents. Seltzer and Kraus (2001) found that relationships between a disabled child and parents are extremely close. In fact, closeness with family members is of vital importance for the maintenance of health, social functioning, and psychological well-being. Clearly, close family relationships lead to a higher quality of life in individuals who are disabled. The downside is that those living with families have smaller social support networks composed mostly of family members, while individuals living in the community have larger support networks that include staff and other residents.

Families are encouraged to keep young children at home until they reach late adolescence or adulthood (Taylor, Lakin, & Hill, 1989). The principle of normalization suggests that adolescents and young adults should make a transition to independent or semi-independent community living (Turnbull, Turnbull, Bronicki, Summers, & Roeder-Gordon, 1989). Although the concept of normalization encourages disabled individuals to move to community residencies, home-based care is still very common among disabled individuals of all ages (Seltzer & Kraus, 2001).

Even with the commonality of home-based care, however, funding is sorely lacking in assistance for parents with children living at home. Medical care is reported as a serious problem for adults living at home with mental retardation (Seltzer & Kraus, 2001). There are increased levels of unmet service needs at home and parents report they are upset over the lack of services their son or daughter has received.

Blancher and Baker (1994) demonstrated that most caregivers felt that their children received better services at the placement facility than they received when they were living at home. The list of services believed to be better in the placement facility included recreation, physical therapy, nutrition, school, speech therapy, and medical needs. According to Schwartz (2005), there is a tendency to place adults with mental retardation in out-of-home settings rather than keep them at home. Although more caregivers are looking into out-of-home placement, Schwartz acknowledged that this is the most difficult time of the caregiver's life. Schwartz (2005) found that 71% of parents claimed that the choice for out-of-home placement was made to improve quality of life. One item on the survey asked how family life would be if the son or daughter were still at home; 58% said it would be more difficult. Only one parent said that life would be better. It is also important to note that most parents frequently visited the facility where their son or daughter was placed. In other words, placement out of the home did not mean placement out of the family (Schwartz, 2005). Unfortunately, because quality of life is difficult to measure in the severely disabled population, few studies have attempted to measure quality of life in the home compared to out-of-home. Although there is abundant literature on ethical and social concepts regarding growth attenuation, no literature addresses caregiver perceptions

of the factors relevant to the treatment. Caregivers should give a unique voice in the growth attenuation debate, and yet they are not represented in the literature.

Chapter 6

Relevant Themes

The previous chapters described the relevant factors surrounding each procedure. The next several paragraphs explore common themes present in each individual controversial procedure. This will help facilitate the question: What will become of growth attenuation in the future? Because of the novelty and controversial nature of the procedure, what might happen next, based on past occurrences, warrants individual attention. In addition to similarities, differences will be discussed throughout to explore the unique variables shaping each procedure.

Medical Capability

The most striking similarity among the procedures is the *capability to perform* that procedure. Certainly, the 20th century showed the most medical advancements of any other century. In the 1930's, the first artificial pacemaker was invented. The 40's saw the first kidney dialysis machine. The 50's provided us with the first artificial hip and the first artificial heart valve. The first soft contact lenses and cochlear implants were developed in the 1970's. Before these medical advancements, each ailment was considered a part of life. Medical advancement in this country is considered most successful when there is a focus on "cure" rather than "living with." And that is understandable. After all, who would want to live with heart problems when there is the capability of having an artificial heart? Without the medical capability to perform

sterilization, growth attention, and cochlear implants, this discussion would not be relevant. As medical advancements continue, bioethical questions continue to arise. It seems, then, we as a society are moving faster medically or technically than we are able to determine if the procedure is morally admissible and under what circumstances.

Financial Motivation

In addition to the capability to perform a corrective procedure, the argument of financial gain is present in each procedure, with sterilization and growth attenuation in particular. Sterilization gained momentum during the Great Depression, with the argument that eliminating the unfit would save society money. It was believed that sterilization would use fewer public funds than if these individuals grew up to be dependent on the public's purse. Certainly with growth attenuation, in the current economic recession with funding cuts to group homes and mental retardation facilities, one can wonder whether growth attenuation will gain momentum. If there is a lack of financial assistance to out-of-home placements, then parents are left with caring for their disabled child in the home.

Individual Rights

Each of the above procedures has a component of *individual rights*. Common to these situations, the person's rights are balanced with the rights of society and the rights of caregivers. Western society values personal autonomy and individualism. In our modern world, which is becoming more global and boundless, people are able to make more autonomous decisions about where, how and with whom to live their lives and what cultural practices to exercise. Social constructionist theory views autonomy

as a moral value that results from a socially constructed network of meanings and practices of a particular society and culture (Schneewind, 1998). As a sociocultural construction, autonomy is not an inherent trait, but is more culturally and historically relative (Chirkov, 2006). Thus, a social construction viewpoint would argue that autonomy is not universal or a natural human tendency. Hofstede (1997) defined individualism as the system of cultural representations and practices where priority is given to the individual's needs, goals, and preferences, rather than to the group's needs, goals and preferences. Thus, individualism is seen as a pattern of cultural values, meanings, and practices that has been constructed through the history of human civilizations in order to provide people with guiding rules and standards for decision making in their behaviors. Without guiding rules and standards, we would have no means to question the controversial procedures mentioned above.

Individualism is one of several systems of cultural values (versus collectivism) which is distributed among various societies, ethnic groups and countries. In fact, autonomy is one of the components of individualism (Lukes, 1973). Given this information, it is no surprise that the concept of individual rights arises when deciding whether it is ethical to sterilize or stunt the growth of a person who is mentally retarded. The discussion of whether a person with severe mental retardation has rights is beyond the scope of this paper. More pertinent, though, is the realization that if our culture did not value the abstract concepts of individualism and autonomy, then it seems the debate over these medical procedures would not exist. For example, in collectivist cultures, the rights of the individual would not take precedence over the rights of society.

The concept of individualism gives rise to the ethical principle of individual rights. There are some differences between the three types of cases regarding the concept of individual rights. First, in the case of sterilization, the rights of the individual are weighed against the rights of society. If a woman who is mentally retarded cannot take care of her child, then the responsibility falls on society to pick up the slack and provide for the child. In the case of growth attenuation, Ashley's parents wished to exercise their right to keep their child at home. However, Ashley's parents were criticized for putting their own needs above those of Ashley. Thus, the question is, whose rights take precedence? One might state that if Ashley cannot make a decision for herself, then she is not an autonomous individual and thus her parent's rights should take precedence. However, given the past abuses against individuals with disabilities, society has taken more notice of possible decisions where the individual's rights have been violated.

Cochlear implants add another interesting element to the issue of rights when the child is too young to consent to the implants (the issue of consent will be described below). In the case of cochlear implants, the parents are exercising their rights as parents to make the best decision for their child who is too young to consent. As mentioned above, society, particularly the courts, will not intervene in parental care unless there is clear evidence of potential neglect or abuse. Because cochlear implants are a minimally invasive procedure and society values ablistic individuals, court approval is not necessary to explore the best interest of the child. After years of abuse of the sterilization procedure, the courts stepped in to regulate the practice in most states. Revealed was the knowledge that most disabilities could not be

“transmitted” to children and many people with disabilities could care for a child. Given this, one may hypothesize that eventually society will intervene regarding growth attenuation because like sterilization, it is a permanent alteration of the individual’s body.

In addition, growth attenuation and sterilization are both preventative procedures. That is, an invasive medical procedure is being performed without medical necessity. Cochlear implants, on the other hand, are considered a “cure” for an already present problem. It is widely assumed, at least by the medical model, that a “cure” for a disability would be in the individual’s best interest, likely accounting for the lack of regulations on the procedure. For a procedure that permanently alters one’s body without medical necessity, safeguards may be implemented to protect the child’s rights.

Consent and the Best Interest Principle

In the case of the three examples described, the individual in question typically cannot consent, which adds another element to the issue of individual rights. When an individual cannot consent, one may argue that he or she does not have rights, or that his or her rights are weighed against those of other parties. Each case similarly has the component of a third party making the decision for the individual in question. In sterilization, a third party must decide if the procedure is in the individual’s best interest. Because growth attenuation is only performed on individuals with a severe developmental disability and early in life, the parents must decide if this procedure is in the best interest of their child and in their best interest as the caretakers before the adult size and weight are even known. Because most parents

with Deaf children are hearing, they face a tough decision when considering cochlear implants. Their child cannot consent at such a young age, leaving parents to determine if the implants are in their child's best interest. As mentioned previously, best interest is an interesting concept applicable to many debates regarding vulnerable groups and covers a wide range of issues related to well-being. In each of the types of cases presented here, the person in question cannot consent, leaving others (e.g., courts, parents, doctors) to decide if the procedure is in the person's best interest. In cases of sterilization and growth attenuation of individuals with severe disabilities, the person in question will likely never be able to consent to the procedure. In the case of cochlear implants, the child will likely be able to consent when she or he reaches adult age. However, the cochlear device must be implanted at a young age for optimal hearing results. In growth attenuation, Ashley's parents asserted that they wanted to keep her at home to improve her quality of life, suggesting they are of the opinion that her best interests are served in the home. Others may argue that out-of-home placement would be beneficial to Ashley in improving her quality of life. Parents deciding for cochlear implants must decide whether it is in the child's best interest to grow up without the implants in the Deaf culture or with the implants, attempting to integrate with the majority culture. Parents with Deaf children may argue it is in their child's best interest to grow up in a hearing culture. In contrast, disability rights advocates argue that Deaf culture is the appropriate place for the child, rather than attempting to adjust to the hearing norm. Because in this society parents have the right to make medical decisions for their child, the courts will only intervene if the procedure is considered highly invasive or abusive. Growth

attenuation is a new procedure for individuals with severe disabilities and the procedure is quite invasive and similar in some respects to involuntary sterilization. Thus far, a disinterested third party, such as the courts, is not yet required. One might assume that in the future there will be limitations on the procedure to determine if it is in the child's best interest.

In cases such as Ashley's, an ethics committee met to decide if the procedure was in Ashley's best interest and the committee agreed that growth attenuation was in her best interest. Sterilization cases now must have court approval to determine if the procedure will benefit the individual in question and if the procedure is necessary given that less invasive options have not worked. Best interest determinations are generally made by considering a number of factors related to the circumstances of the child and the circumstances and capacity of the child's potential caregiver(s), with the child's ultimate safety and well-being as the paramount concern. In these cases, the people making the best-interest decision are part of a culture that views disability as an ailment needing a cure, not a socially constructed phenomenon. Disability rights activists criticize ethics committees that do not include people with disabilities. One option may be to assure that a disability rights representative is present during the decision-making process to ensure the procedure is in the individual's best interest and to educate parents on the social aspects of disability.

Parental Care

As discussed at length in chapter 4, parents of children with disabilities are under a significant amount of stress. Parents often are lacking in resources to take care of their disabled child, and must make decisions within a culture that does not

provide enough for people with disabilities. Moreover, they must make medical decisions in a culture that very much views disability as a medical problem to be eliminated. As mentioned previously, doctors continually under-evaluate quality of life in people with disabilities. This means that medical procedures are seen as a “fix” or “cure,” rather than focusing on “living with.” The first people parents have contact with regarding their child’s disability are members of the health care system, such as doctors and nurses. Given this information, it is not surprising that parents are consenting to these procedures with the opinion that it will improve their child’s quality of life. It is difficult to view a child’s disability from a social model when you do not have the resources, or education, to do so. Although disability rights advocates have paved the way for accessible transportation and facilities, society is still a long way from providing individuals with disabilities the resources they and their families need. Maybe if Ashley’s parents had been provided with in-home care assistance, or if parents of Deaf children were provided more resources on Deaf culture before deciding on cochlear implants, some of the difficulties of these decisions could be avoided. Each of the medical procedures described above has had the same objection by disability rights activists: these procedures are medical responses to a social problem.

State/Federal Guidelines

Given all of this information, what will happen to growth attenuation in the future? Many parents sympathized with the plight of Ashley’s parents due to the severity of her disability. When sterilization first began, it had no restrictions related to severity of disability. Arising at the time of the eugenics movement when bias

against disability was more prevalent even than today, involuntary sterilization faced few objections. After the heinousness of WWII, society began to recognize that sterilizing people against their will simply to prevent transmission of the disability was morally wrong and scientifically incorrect. Safeguards were then put into place and criteria were developed to prevent abuse of the procedure, especially for individuals who could not consent. The appropriateness of Cochlear implants, arising in the 70's, is still heavily debated, but currently no legal/ethical guidelines are in place, in part because the procedure is less invasive than the others mentioned. The cochlear implant is mostly related to the debate on whether Deafness is viewed as primarily a social or biological phenomenon. Because growth attenuation is a relatively new procedure, there are no state or federal statutes regulating the procedure. At most, an ethics review board at the hospital is asked to review and to approve the procedure because of the potential for abuse; however, there is no disability representation to advocate for a social perspective of disability. It is possible society has learned from past abuses and the procedure will remain for whom it was intended: children with severe/profound disabilities who are non-ambulatory. Even so, one might find it hard to imagine the growth of every child with a severe/profound disability as stunted. Based on past abuses of medical procedures against people with disabilities, the public may benefit from clear guidelines on circumstances in which growth attenuation can be performed on a child who cannot consent.

Factors such as caregiver stress and lack of resources led to this drastic decision. With the lack of resources provided to parents currently, it is difficult to

imagine a parent that *is not* stressed or concerned about a child's quality of life, suggesting this procedure may gain popularity. Guidelines have been developed only when there has been enormous public pressure from advocacy groups, or from courts, or from legislators. With sterilization, for example, cases such as for Carrie Bucks clearly illustrated how sterilization can be abused. So far, little of this has occurred for growth attenuation. It took years for guidelines and ethical frameworks to be developed for sterilization and yet there are still claims that the procedure is abused. We now know that sterilization was wrong, based on scientific evidence that disability could not be transmitted to offspring. Because growth attenuation is a new procedure, there is relatively little scientific information on side effects and unforeseen risks.

Court Involvement

An opposing argument might state that in cases of children without disabilities, parents make medical decisions that do not require review. Given this, what triggers the need to have the courts involved in cases where a decision is being made for a child with a severe cognitive disability? Courts are hesitant to impinge on the family domain; rather, they leave medical decisions to the caregivers except in very unusual situations. One might ask why Ashley's case should need a court review. To answer this question, we must step back to the basic question, which asks if Ashley has rights regarding care of her own body, and if she does, do her rights outweigh those of her parents who believe it would be best to care for her at home? Again, the debate on the extent of the rights of a person with a severe disability is beyond the scope of this paper. Even without the answer to whether she has rights,

one might argue that growth attenuation needs court review because of the invasiveness of the procedure for a non-medical cause, past history of abuse against individuals with disabilities, and because she cannot consent. To pursue a different line of thinking, assume that Ashley is non-ambulatory but possesses the cognitive capability to consent to the procedure. Should this circumstance require court review? In cases of sterilization, court review would still be necessary to explore her reasoning for the procedure and to make sure this is the least restrictive alternative, even if she can consent. Given this information, inability to consent is not necessarily a reason in itself for court review of a medical procedure. In addition, individuals in society frequently undergo invasive procedures, which alter their bodies, such as plastic surgery, without court approval. Thus, it is reasonably safe to argue that procedural guidelines are especially needed in cases of highly invasive procedures with individuals with severe disabilities where there is high potential for biases in those making the request.

Future Directions

The purpose of this paper was not to imply that parents of children with disabilities are poor decision makers or do not have their child's best interest in mind. Exactly the opposite is true. Parents face the most difficult decisions of their life when deciding on treatment options for their child. The striking point remains, as mentioned several times in this paper, that societal viewpoints of disability as a "burden to be removed" remain. Not having the resources and assistance they need, parents are forced to make medical decisions in an ultimately flawed system.

Although there was no state law in Washington that required a court order to

perform growth attenuation, the Washington Protection and Advocacy System stated Ashley's case should have required court approval. At the very least, the sterilization portion of the procedure violated Washington state law that requires court approval and a disinterested third party to represent the individual. Groups like the Washington Protection and Advocacy System will be imperative in pushing state legislatures to develop statutes for growth attenuation. Before guidelines are developed regarding growth attenuation, a minority of interested parties will likely have to pressure legislatures about the importance of having a statute developed. Interested parties may include disability rights advocates, medical professionals, courts, psychologists, and ethicists. Without pressure from numerous parties, control over growth attenuation will remain within the hospital setting without procedural safeguards to monitor the procedure.

Parents of children with disabilities may seek therapy to help support them while they make these difficult decisions for their child. Thus, clinicians may be requested to provide psychological services to a conflicted parent deciding on a medical procedure for a disabled child. Psychologists, especially those working in primary care settings, may be consulted about life-altering medical decisions. Knowledge of the issues surrounding these procedures will allow us to educate parents on all of the options available to them. Parents are not the only individuals who would benefit from awareness of pertinent disability issues; psychologists may use this information to educate other professionals as well. Psychologists are in a unique position to serve as allies to individuals with disabilities and have the ability to use their power in advocacy for underrepresented minority groups and to facilitate

dialogues on negative perceptions of disability in the health care field. Knowledge of models of disability and the issues surrounding each medical procedure helps us not only provide nonbiased services to parents, but can make important contributions to the medical profession by educating on the debate surrounding each procedure.

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