



Devaluing People with Disabilities

Medical Procedures that Violate Civil Rights

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Authors

David Carlson, Cindy Smith, Nachama Wilker

Contributors

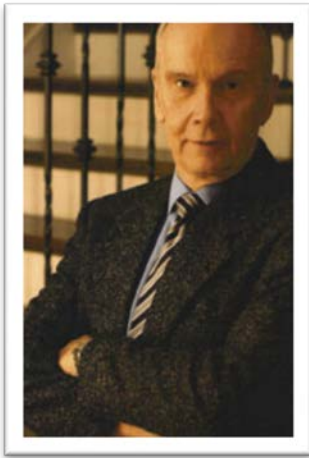
National Disability Rights Network: Cindy Smith, Nachama Wilker, Curtis Decker, Eric Buehlmann, Zachary Martin, Jane Hudson, David Card

Disability Rights Washington: David Carlson, Andrea Kadlec

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A Letter from the Executive Director

Right now, somewhere in America, parents or guardians are sitting down with a doctor to discuss withholding life sustaining medical treatment in situations where there is no terminal disease or removing their child's sex organs, breasts buds, and stunting growth with hormone treatments. The latter practice, commonly called the Ashley Treatment after the first known child to undergo this procedure, is the latest and most disgraceful point on the long continuum of ways our society devalues and violates the rights of people with disabilities.

These conversations happen because the persons being considered are viewed as having little value as they are. They are considered not as fully human, endowed with inalienable rights of liberty, privacy and the right to be left alone—solely because they were born with a disability.

The thought of doctors and parents, together, deciding to remove the body parts and stunt the growth of a child based on assumptions about their awareness and quality of life is shocking and disgusting. In one case that stunningly illustrates the assumptions made about these “burdensome” people, a jury in Oregon awarded parents \$3 million because their child was born with Down syndrome after pre-natal testing failed to identify the disability. It was called a “wrongful birth.” The reality that this has happened—and is happening--in the United States is anathema to the core values that we as Americans say we hold. That it is happening to those unable to use their own voice is even worse. The National Disability Rights Network—in an effort to shed some light on this barbaric practice and thrust the medical community that supports it into the 21st century—has released this report called *Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights*.

In my more than 30 years as a disability rights attorney and advocate, I often think that I have seen every type of discrimination and harm inflicted on people with disabilities. Unfortunately, humanity still finds a way to surprise and shock even me.

While many people find the Ashley Treatment to be eugenics, not medicine, others in the medical community, doctors, medical ethicists, hospitals, and even some parents of children with disabilities argue that no harm has been done because the individuals are believed to be too disabled to know, in their minds justifying the practice of making medical decisions that violate civil rights.

My question is why?

Every person is born with civil and human rights and an inherent dignity. The presence of a disability does not change that fact. Yet, every day people with disabilities have to fight to be recognized as a whole person.

Yes, we have made many positive advancements like the Americans with Disabilities Act and the movement to end institutionalization. However, when something like the Ashley Treatment is permitted, even encouraged, it is a slippery slope toward a world where people with disabilities have no value, no rights, and no dignity.

Curt Decker



Executive Director

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Executive Summary

Five years ago, news broke worldwide that a six-year-old child with developmental and physical disabilities, Ashley, was given growth attenuation treatment via estrogen and had her uterus and breast buds removed. The intent of the treatment was to keep her permanently small. The child's parents and doctors claimed that this set of procedures was in her best interest for numerous reasons, including that it would make it easier to care for her at home. Supporters of the treatment claim that this is the most personal of family decisions and there is no need for external judicial review of the decisions made by the family.

People with disabilities and advocates in the disability rights movement, however, assert that all individuals, regardless of their disability status, have individual rights that cannot be ignored. Decisions like those made in this case are the most personal of "personal rights," not "family rights." Every individual person has the right to bodily integrity, clearly recognized in our legal tradition, through the constitutional rights of liberty and privacy and the common law right to be left alone unless the individual chooses to have their body disturbed in some way. Individuals with disabilities, no matter the nature or severity of their disability, are no different. The Constitution and antidiscrimination laws make it clear, all people, including people with disabilities, are entitled to equal treatment under the law.

Anne's Story¹

Ashley's treatment ignited a firestorm of press, articles in scientific and other ethics journals, blog posts, websites, position papers from disability activists, and an investigation by Disability Rights Washington (the Washington Protection and Advocacy agency). The Disability Rights Washington investigation resulted in an agreement with the hospital where the procedure was performed where the hospital acknowledged that Ashley's rights had been violated and agreed to a number of required safeguards for children with disabilities, including a requirement for a court order if such procedures were considered in the future, and the inclusion of a person who has a disability, or an understanding of disability from a civil rights perspective, on their ethics committee.

I did live the experience. I lived it not as a parent or caregiver but as a bed-ridden growth-attenuated child. My life story is the reverse of Ashley's... Given that Ashley's surgery is irreversible; I can only offer sympathy to her and her parents. For her sake, I hope she does not understand what has happened to her; but I'm afraid she probably does. As one who knows what it's like to be infantilized because I was the size of a 4-year-old at age 18, I don't recommend it.

-Anne McDonald

The controversy sparked deliberations in the media that focused on who was right and how we as a society can and should make decisions about individuals with disabilities, especially children. Many articles claimed that no harm had come to Ashley because her intellectual functioning would not allow her to ever understand what had been done

to her. In many of these discussions, the rights of children were blended with the rights of their parents. However, when a parent seeks to permanently and potentially unnecessarily alter a child's body through invasive and irreversible procedures, this blended view of rights is inappropriate, as a potential or actual conflict of interest may exist. In these situations, it is imperative that the child's rights be untangled from those of their parents. When the child in question has a disability, the questions become even more complex.

Since Ashley's treatment, her parents report that they have been contacted by thousands of families interested in the treatment and they believe that at least a hundred children have undergone the same treatment.² A recent Guardian article published in March of 2012 reported on a ten year old girl who underwent a similar set of procedures and a seven year old boy who had his growth attenuated.³

The procedures Ashley and the others received were not conceived in a vacuum. The United States has a shameful history of how it has treated children and adults with disabilities dating back more than one hundred years and continuing today.⁴ This history has involved not only abuse, neglect, discriminatory segregation in institutions, and exclusion from receiving an education, but it has also included eugenic sterilization as an attempt to prevent the genes of individuals with disabilities from being passed onto future generations.⁵ Such actions reinforce social attitudes that devalue the lives of people with disabilities, supporting assumptions about their ability to participate in community life and their overall worth to society.

Gail's Story⁶

In recent years, new types of assistive and medical technology and procedures have emerged that allow people with disabilities, even those with the most significant disabilities, to live longer lives and improve their quality of life to live outside of institutions in their own homes in the community. The legacy of eugenics however, and the basic discriminatory structures that underlie it, are still powerful factors in medical decision making by some doctors and surrogate decision makers for people with disabilities. These technologies and procedures have not only been used to enhance quality of life, but they have also been used, at times, to reinforce social policies that devalue people with disabilities and keep them separate from community life. In fact, there are times, as this report will describe where physicians recommend and family or other surrogate decision makers decide to not provide a needed transplant, to withhold medical treatment including hydration and nutrition of individuals

Sarah was given the same diagnosis that Ashley had – the same microcephaly and cerebral palsy and even the 9-month-old expected age range - years before Ashley got her diagnosis. I think a lot happened to Ashley before her parents even had a chance to know her. These decisions were made for her before they could see her as a whole person. I didn't really *know* any of my children by the time they were six. They couldn't articulate what they would become. We don't expect this of our children without disabilities. Why did Ashley have to hold up to a different standard?

- Gail Lainhart-Rivas, Sarah's mother

without a terminal condition, or to sterilize people all on the basis of their disabilities. Applied in these ways, medical decision making and procedures are discriminatory and deny basic constitutional rights to individuals with disabilities including the rights to liberty, privacy, and other statutory and common law rights.

Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights provides a crucial, but missing, link in the discussion about how society can and should make medical decisions that uphold the rights and inherent dignity of people with disabilities.

Anne's Story⁷

The report puts individuals with disabilities at the center of this discourse. It reviews the facts of Ashley X, as a case study for a larger discussion and presents a continuum of common experiences and treatment of individuals with disabilities within a context of medical decision making. The report explores the potential and actual conflict of interest that medical decision making may present between a parent and his or her child. It describes the vital role that the legal system has in ensuring that the civil and human rights of individuals with disabilities are protected. The report discusses how the deprivation of these rights is harm within and of itself and that all individuals have substantive rights regardless of the severity of their disability. It goes on to outline how discrimination inherently causes harm to both the person who experiences the discriminatory conduct and society as a whole. Finally, the report presents a series of recommendations for how the legal and medical systems at the local, state, and national level, including protection and advocacy agencies, ethics committees, institutional review boards, and the courts can perform critical “watchdog” functions to ensure that the human and civil rights of individuals with disabilities are protected.

My life changed when I was offered a means of communication. At the age of 16, I was taught to spell by pointing to letters on an alphabet board. Two years later, I used spelling to instruct the lawyers who fought the habeas corpus action that enabled me to leave the institution in which I'd lived for 14 years. In the ultimate Catch-22, the hospital doctors told the Supreme Court that my small stature was evidence of my profound mental retardation. I've learned the hard way that not everything doctors say should be taken at face value.

-Anne McDonald

Evolution of Civil and Human Rights Protections for Individuals with Disabilities

The United States has a shameful history of how it has treated many minority groups by not recognizing their human and civil rights including their inherent right to bodily integrity and their dignity as fellow humans. Historically, society has viewed individuals with disabilities as defective and in need of fixing.⁸ This view is frequently referred to as the medical model of disability, and is traditionally how society has viewed individuals with disabilities.⁹ To many who have been trained in or held a medical view of disability, the presence of an impairment implied that an individual is unable and incapable of fully participating in society. By adopting the medical model of disability, “society has historically imposed attitudinal and institutional barriers that subject individuals with disabilities to lives of unjust dependency, segregation, isolation and exclusion.”¹⁰

When you have a disability, you have to fight for the right to grow up. It's not given to you.
-Thomas

The medical model of disability led the United States to take the stance that individuals with disabilities should remain out of sight and out of mind.¹¹ That belief led to the institutionalization of a large number of individuals with disabilities.¹² Although many individuals with disabilities remain institutionalized today, that number has been declining over the last twenty years.¹³ According to State of the States on Developmental Disabilities (2011), the number of individuals with developmental disabilities served by public and

private institutions has steadily decreased from 171,900 to 92,300 between 1990 and 2009.¹⁴ State laws codified the medical model of disability by declaring that individuals with disabilities were “unfit for citizenship”; requiring the sterilization of the “feebleminded”; permitting school districts to exclude children with disabilities when school officials determined that it was too much of a burden or “inexpedient” to serve them or because they produced a “nauseating” effect on others; requiring individuals with disabilities to be placed in institutions because they were considered to be “a menace to society.”¹⁵

One example of the prevalence of the medical model was in the early 1920s when approximately thirty states legally sanctioned the forced or coerced sterilization of individuals with disabilities as part of their efforts to improve society’s genetics and avoid the burden of supporting the offspring of individuals with disabilities.¹⁶ These policies led to more than 60,000 individuals with disabilities being involuntarily sterilized.¹⁷ In 1927, the rationale for sanctioning this eugenic policy was formally adopted by the U.S. Supreme Court in *Buck v. Bell*.¹⁸ Justice Oliver Wendell Holmes wrote one of the Court’s most shameful opinions, which reads:

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of

waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind...Three generations of imbeciles are enough.¹⁹

Involuntary eugenic sterilization continued in the United States until the 1970s. North Carolina, for example, used its eugenic sterilization statute from 1929 until 1974 to sterilize upwards of 7,600 people.²⁰ Subsequently, the state recognized how wrong it had been to engage in eugenic sterilizations for nearly half a century and established a commission to determine the amount of money that should be paid to the living victims of its eugenic sterilization policy, for their loss of reproductive potential and the psychological trauma caused by the state's actions.²¹ It was recently proposed that the victims would receive \$50,000.²²

In 1978, the U.S. Department of Health, Education, and Welfare (now known as the U.S. Department of Health and Human Services and U.S. Department of Education) issued regulations prohibiting the use of federal funds to sterilize individuals under the age of twenty-one, mentally incompetent individuals of any age, and

*Everybody has a right to
their whole body.*
-Heidi

individuals of any age living in institutions.²³ The failure of the U.S. Supreme Court to directly reconsider the constitutionality of sterilization statutes pertaining to individuals with disabilities following its subsequent decision to outlaw compulsory sterilization of prisoners has forced state and lower federal courts to make their own determinations in light of the unclear nature of whether *Buck v. Bell* is still the applicable legal precedent.²⁴ Some states continue to have processes for forcing certain individuals to submit to sterilization against their will.²⁵ There continues to be litigation about whether sterilization is in the best interest of certain individuals with disabilities as evidenced by examples as recently as 2008 in Illinois and 2012 in Massachusetts.²⁶

Around the same time that the U.S. Department of Health, Education, and Welfare restricted the use of sterilization by recipients of federal funds, in 1977, Bogdan and Biklen published "*Handicapism*," a journal article that described "a paradigm through which to understand the social experience of individuals with disabilities."²⁷ Bogdan and Biklen defined "handicapism" as having parallels to racism and sexism, and specifically as a "set of assumptions and practices that promote the differential and unequal treatment of people because of apparent or assumed physical, mental or behavioral differences."²⁸ Although, the term handicap is no longer used, discrimination based on disability is often referred to as ableism today.

During this time, the legal system also started to formally recognize that simply doing what parents, guardians and care providers deemed was in the best interest of an individual with a disability may conflict with the expressed interests of the individual and was often based on incorrect assumptions about the person's disability.²⁹ Many courts began to describe ways to adequately consider the individual right of the person with a disability in cases where the treatment proposed by parents, guardians and care providers was thought to be in the best interest of the individual, but was not actually

appropriate given the expressed interest of the individual or his or her rights as a person separate from those of the family.³⁰

In 1990, the U.S. government took the first comprehensive step to combat discrimination based on disability and move from a medical model of disability to a model that recognizes the civil and human rights of individuals with disabilities when the Americans with Disabilities Act (ADA) was signed into law.³¹ The ADA defines a person with a disability as a person with a “physical or mental impairment that substantially limits one or more of the major life activities of such individual.”³² The ADA acknowledges the civil and human rights of all individuals with disabilities regardless of the type or severity of a person’s disability. Civil and human rights are explicitly recognized as universal by the ADA, and are not provided on a sliding scale of protection.

All individuals have substantive rights and the only means of adequately protecting those substantive rights is to respect each individual’s right to procedural due process

In order to remedy the discrimination experienced by people with disabilities, Congress defined the concept of an “accommodation.”³³ An accommodation or modification is a change to a rule, practice, or environment that allows people with disabilities equal access to services, public places, and employment.³⁴ This mechanism of providing equal access to community life and opportunities through alternative means of access codifies the simple truth that treating everyone the same is not the same as treating everyone equally.

Assumptions about the limits of people with disabilities as well as discrimination against them are harmful to the individuals who live everyday under its weight.³⁵ Testifying before Congress during the consideration of the ADA, Judith

Heumann told of the lasting harm caused by ableism when she said, “In the past disability has been a cause of shame. This forced acceptance of second-class citizenship has stripped us as disabled people of pride and dignity...This stigma scars for life.”³⁶ Congress recognized the importance of challenging the widespread discrimination against people with disabilities when, in passing the ADA, it found that:

historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;³⁷

individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion, the discriminatory effects of architectural, transportation, and communication barriers, overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria,

segregation, and relegation to lesser services, programs, activities, benefits, jobs, or other opportunities; and

the Nation's proper goals regarding individuals with disabilities are to assure equality of opportunity, full participation, independent living, and economic self-sufficiency for such individuals.³⁸

The ADA was enacted to end discrimination on the basis of disability. When the ADA was amended in 2008, these finding statements were retained by Congress demonstrating their continued relevance to recognizing widespread discriminatory attitudes toward people with disabilities within society. Two of the purposes of the ADA in 1990, and reaffirmed in 2008, are to provide “a clear and comprehensive national mandate for the elimination of discrimination”³⁹ and “clear, strong, consistent, enforceable standards addressing discrimination.”⁴⁰ Regardless of the type or severity of a person’s disability, the ADA clearly supports that discrimination inherently causes harm to both the person who experiences the discriminatory conduct and society as a whole. The deprivation of this statutory right is harm within and of itself.

Passage of the ADA also reflected a shift in the view of individuals with disabilities from a largely medical model to a social model of disability that recognizes the civil and human rights of individuals with disabilities. The social model of disability does not view individuals with disabilities as needing to have their impairments “fixed” but instead views disability as a natural and normal part of the human experience. In viewing disability through this model, it is evident that disability is socially constructed by the physical characteristics of the human made environment; cultural attitudes and social behaviors; and institutional rules, policies and practices.⁴¹ Instead of focusing on “fixing” the person with a disability, the social model of disability focuses on taking effective and meaningful steps to modify the environment by eliminating attitudinal and institutional barriers that interfere with the opportunity of all individuals regardless of differing ability to fully participate in society.⁴²

The global community also strongly recognizes the need to protect the rights of individuals with disabilities. In 2008, the Convention on the Rights of Persons with Disabilities (CRPD), the first international human rights treaty focused specifically on the rights of individuals with disabilities, entered into legal force, and to date 112 nations have ratified the treaty.⁴³ The United States signed the treaty in July 2009, expressing the intent under international law to uphold the general purpose of the treaty.⁴⁴ It is anticipated that the United States Senate will soon begin consideration for ratifying the CRPD to enable the United States to join the majority of nations in recognizing disability rights as universal human rights. Since 2008, the CRPD has become critical to individuals with disabilities living in many nations without strong domestic disability rights legislation.

Numerous provisions of the CRPD recognize both the importance of protecting individuals with disabilities from exploitation and abuse,⁴⁵ and the need to ensure the protection of women and children with disabilities.⁴⁶ Specifically, the CRPD states that women and girls with disabilities must be allowed the full and equal enjoyment of all

human rights and fundamental freedoms, and be ensured full development, advancement, and empowerment in order to enjoy such rights.⁴⁷ The CRPD further requires that children with disabilities be entitled to all human rights and fundamental freedoms “on an equal basis with other children.”⁴⁸

Other provisions in the CRPD require that individuals with disabilities have the “right to respect for his or her physical and mental integrity on an equal basis with others,”⁴⁹ be “free from exploitation, violence, and abuse, including their gender-based aspects,”⁵⁰ not “be subjected without his or her consent to medical or scientific experimentation,”⁵¹ and that the existences of a disability shall not justify the deprivation of the right to liberty.⁵² Individuals with disabilities must also have the same right to legal capacity as others, and measures to support the exercise of the right to legal capacity, such as guardianships, be free of a conflict of interest or undue influence.⁵³

Stories from Wisconsin⁵⁴

A thirteen year old child who lived in a group home in Wisconsin died when his parents and doctors agreed to not treat him for a cold. Although, he had developmental and physical disabilities, he was not terminally ill or in a persistent vegetative state. The people who provided daily support to him at the group home took him to the doctor when he caught a cold, and the doctor prescribed an antibiotic. Once the parents discovered the group home provider had sought treatment for the child's cold, they informed the provider that they had an arrangement with the child's primary physician and they were in agreement that the next time he got sick, they would let the infection progress into pneumonia and then not treat the pneumonia, so that the child would die. The provider refused to implement the plan and continued the antibiotics. The parents then had the child removed from the group home and transported to the local university hospital in order to remove not just the antibiotics, but also nutrition and hydration. The child died a few days later.

At the same university hospital, there were allegations that a doctor attempted to unduly influence the family of a 72 year old patient with a developmental disability to deny that patient life-sustaining treatment. The family reported that the patient's doctor informed them that the patient would have a very poor quality of life and that life-sustaining medical treatment should no longer be used. Initially, the family agreed with the plan, but when the patient woke the next morning and requested to eat, the family changed their minds. The family requested that treatment and nutrition be resumed, but the family reported initially that they received resistance from the doctor who eventually relented and began treatment again and sent the patient back to live at a nursing home to recuperate.

Even with existing national and international protections, individuals with disabilities continue to experience pervasive discrimination on the basis of disability. While attitudinal barriers are beginning to evolve from a medical to social model of disability within and outside of the medical community, there are still large areas where this shift has not occurred. The continued reliance on the medical model instead of a social

model of disability devalues the lives of individuals with disabilities. This devaluing can be seen starting with some pre- and post-natal counseling, medical procedures such as the Ashley Treatment, the withholding of medical treatment and do not resuscitate orders, and continuing with segregation of individuals with disabilities in housing, employment, and education.

The purpose of this report is to add a critical, but missing, piece of the discussion regarding medical decision making and individuals with disabilities. To date, the majority of the discussion has failed to acknowledge and account for the civil and human rights that every person has, as a result of being human, regardless of their disability status or the severity of their disability. This report is focused on the views of individuals with disabilities and the impact the medical model of disability has on them. Reliance on the medical model has resulted in individuals with disabilities being devalued, and their civil and human rights being violated. The presence of a disability has been used to deny access to due process protections in regards to medical decision making in general and in situations where there is a potential or actual conflict of interest between individuals with disabilities and their parents or caregivers.

The case study of Ashley is an important starting point for this report because it highlights how persons with the most significant disabilities are devalued. The medical procedures performed on Ashley would not be acceptable for the purposes for which they were performed, if Ashley had not been a child with significant disabilities.

Parents and Professionals Often Make Medical Decisions for Individuals with Disabilities Without Representing the Individual's Interests: A Case Study: Ashley X

In October 2006, the story of Ashley first became known to the public when an article titled *"Attenuating Growth in Children with Profound Developmental Disabilities"* was published in the Archives of Pediatric and Adolescent Medicine.⁵⁵ The article, written by Gunther and Diekema (2006), was a case study that described a recently developed protocol to attenuate the growth of a child with a developmental disability using high-dose estrogen.⁵⁶ The medical procedures included a hysterectomy, breast bud removal and appendectomy, in addition to the administration of estrogen for the purpose of growth attenuation.⁵⁷ The combination of these medical procedures has become known as the "Ashley Treatment."⁵⁸ The Ashley Treatment cost under \$40,000 and was fully covered by the family's insurance.⁵⁹

My communication device opened up the world for me. . . My doctor was surprised that I could think.
-Sharon

Five years ago, at the age of nine, Ashley was described as having "static encephalopathy of unknown etiology".⁶⁰ She was described by her parents as being unable to:

keep her head up, roll or change her sleeping position, hold a toy, or sit up by herself, let alone walk or talk. She is tube fed and depends on her caregivers in every way. We call her our Pillow Angel since she is so sweet and stays right where we place her - usually on a pillow.⁶¹

Ashley is expected to have a normal life expectancy, is in stable health and has intellectual and physical disabilities.⁶² She is reported to be alert and aware of her environment and to startle easily.⁶³ In addition, Ashley is reported to be constantly moving her arms and legs and at times to appear to be watching TV intently.⁶⁴ She also is reported to love music, discerns particular singers, and demonstrates this by vocalizing, kicking and conducting with her hands.⁶⁵

Published Perspective of Ashley's Parents

Since the publication of the article titled *Attenuating Growth in Children with Profound Developmental Disabilities*, Ashley's parents published a blog on January 2, 2007 that they continue to maintain.⁶⁶ On their blog, Ashley's parents discussed some of their reasons for seeking the procedures for their daughter including:

A fundamental and universal misconception about the treatment is that it is intended to convenience the caregiver; rather, the central purpose is to improve Ashley's quality of life. Ashley's biggest challenges are discomfort and boredom; all other considerations in this discussion take a back seat

to these central challenges. The Ashley Treatment goes right to the heart of these challenges and we strongly believe that it will mitigate them in a significant way and provide Ashley with lifelong benefits.⁶⁷

Furthermore, as reported by Ashley's doctors, Ashley's parents had concerns about the effects of puberty which Ashley started at age six and a half, including her growth, the onset of menses, fertility, and breast development.⁶⁸ Ashley's parents believed that a hysterectomy would protect her from the possibility of pregnancy, prevent her from the discomfort of menstrual cramps, and prevent her from having to deal with monthly bleeding that would not be of any perceived value to Ashley and would be difficult for her to understand.⁶⁹ In addition, according to the parents, all of the available options to alleviate each of their concerns were accompanied by the possibility of long-term side effects and the need to administer medication on a regular basis.⁷⁰

Ashley's parents have stated that their reasons for seeking this set of procedures was not to reduce the work associated with caring for Ashley or for their convenience, but to make "it more possible to include her in the typical family life and activities that provide her with the needed comfort, closeness, security, meal time, car trips, snuggles, etc."⁷¹ Ashley's parents acknowledge that they have "tried hard and found it impossible to find qualified, trustworthy, and affordable care providers."⁷² Furthermore, Ashley's parents stated that Ashley will not need breasts or a uterus because she will not be bearing children and the removal of both would protect her from pregnancy if she were to be abused, and removal of her breast buds would help to keep her from being sexualized by a caregiver.⁷³ Ashley's parents discuss concerns for her welfare on their blog, and stated that they undertook these procedures because they believed they were in the best interest of Ashley.⁷⁴

To put our decision process in perspective, it is not uncommon for parents with children who have cancer or birth defects to pursue significantly more intrusive treatment (chemo or radiation therapy) or more involved surgery (extensive plastic surgery face reconstruction), than what the Ashley Treatment entails. We strongly believe that the benefits that we're seeking for Ashley are not any less worthy than these other unfortunate situations entail.⁷⁵

In regards to dignity, Ashley's parents state, "If people have concerns about Ashley's dignity, she will retain more dignity in a body that is healthier, more of a comfort to her, and more suited to her state of development."⁷⁶ Lastly, the parents state:

In our opinion, only parents and caregivers of Pillow Angels are in a position to fully relate to this topic. Unless you are living the experience, you are speculating and you have no clue what it is like to be the bedridden child or her caregiver. Furthermore, in the case of the female aspects of the treatment, women are in a better position to relate to these aspects and the benefits for which they are intended.⁷⁷

Completely absent from these statements is any recognition that their perspective might be in conflict with Ashley's civil rights. As described in the last section, all individuals

no matter the nature of their disability have civil and human rights that are separate from their parents, guardians or caregivers. Individuals with disabilities have rights that can create an actual or perceived conflict of interest with their parents or guardians.

Carmen's Story

In 2008, the mother of a 22-year old daughter ("Carmen") who has an intellectual disability went to an obstetrician/gynecologist (OB/GYN) seeking involuntary sterilization for her daughter. The mother complained that Carmen, who had one kidney removed already, had a history of kidney infections which had arisen from Carmen's poor hygienic care for her menstrual periods, which the mother described as heavy and painful and led to frequent urinary tract infections. The mother reported that Carmen's nephrologist opined that Carmen was at risk of death if she got another urinary tract infection. The OB/GYN accepted the Mother's report and agreed to perform a partial hysterectomy before even conducting an examination on Carmen.

The North Dakota Protection & Advocacy Project (ND P&A) met with Carmen's mother and doctor but could not convince them to recognize Carmen's rights. The ND P&A took the matter to guardianship court and represented Carmen at a trial. Carmen's mother and the OB/GYN testified resolutely in support of sterilization. The ND P&A called as a witness a nurse employed by Carmen's care provider, who testified that the log of Carmen's care showed Carmen did not have heavy menses, did not have abnormally painful menses, did not have urinary tract infections, did not have unhygienic care of her menses (as she got assistance from a paid provider), had not received advice from a nephrologist to get a hysterectomy, was terrified of an OB/GYN examination, and did not want sterilization. The court forbade the operation.

Growth Attenuation, Sterilization and Other Unnecessary Medical Procedures Continue to Violate the Civil Rights of Individuals with Disabilities

Despite constant advances in medical and surgical technologies and procedures, assistive technology, and other services and supports that have allowed people with disabilities to live longer lives, improve their quality of life, and ease the delivery of supports, the use of the Ashley Treatment has continued since the publication of *“Attenuating Growth in Children with Profound Developmental Disabilities.”* The continued use of the Ashley Treatment reflects attitudinal biases within the medical model of disability that devalues members of the disability community. This is especially evident with regard to medical decision making which may lead to individuals with disabilities having their civil and human rights violated by being discriminated against by hospitals, medical establishments and other medical entities.

A Parent's Perspective

Ashley's parent's blog recognizes the role that medical advancements have played in allowing children with disabilities to survive and live longer lives.⁷⁸ The blog includes a one page summary titled “The ‘Ashley Treatment’ for the wellbeing of ‘Pillow Angels.’⁷⁹ The summary refers to ‘Permanently Unabled’ children who we [the parents] affectionately call ‘Pillow Angels’ that they believe:

- Form a new category of disability, survival was made possible through recent medical advancements
- Constitute less than 1% of children with disability, they are the most vulnerable of society
- Are profoundly dependent on their caregivers & profoundly precious to their families

When I heard about the Ashley Treatment – and in all the talking I did, I never seemed to really get this point across – but because of all the things Ashley's parents were told, and the fact that the Ashley Treatment had been recommended, it was like a slap in the face to me. For years, we had been going to Children's and for years we had been talking with the doctors about our triumphs. Sarah now uses a communication device, and she is obviously much farther along than a 9-month old. What did the doctors think about my child? Did they not see these victories in all these years of follow up?

I just felt like they couldn't share in our joy. Every organism is on this Earth for some reason. I think that Sarah is a million times more beautiful than so many people that I meet. She has more hobbies than most people I meet. She brings so much more to life than so many around us. I didn't know why they [the doctors] couldn't see that potential, or that personage of her.

I think the parents should have been able to go home and just let the diagnosis percolate, and then meet other parents of children with that diagnosis. Just like parents of kids in a car accident can look at books that show you how to get from here to there, Ashley's parents should have had an opportunity to meet people who were already down the road, and not have been put into a box of fear.

- Gail Lainhart-Rivas

- Their quality of life is much richer under their family's loving care, versus getting "warehoused in institutions"
- The overwhelming majority of their families & caregivers believe that increased weight & size is their worst enemy
- An extreme condition that calls for individualized options in the hands of parents to help their children.⁸⁰

In addition, Ashley's parents' blog includes two stories originally published by The Guardian of children named Erica and Tom who have undergone the Ashley Treatment.⁸¹

Gail's Story⁸²

Erica is reported to have a disability as a result of shaken baby syndrome⁸³ and was subsequently placed with foster parents, who then decided to adopt her.⁸⁴ Erica's parents have taken in more than eighty children, most of them with disabilities, and her mom has worked in an institution and daycare settings. Erica's parents report that she can convey pleasure, distress and fear.⁸⁵ Erica responds to a video by smiling and laughing despite being reported to be unable to sit, roll over, hold her head up for more than a few seconds, walk, talk or eat.⁸⁶ Erica is fed through a feeding tube, cannot control her bladder or bowels and uses a wheelchair.⁸⁷ Erica is reported as having a normal life expectancy.⁸⁸ Erica is fourteen years old, but her parents report that growth attenuation procedures have resulted in her living in the body of a nine-year-old.⁸⁹

As medical procedures are made available to us, they are supposed to improve one's life. Who is to say that 10 years down the road they would have come up with something that Ashley really could have used to be a woman, or be more whole, or express herself and her awareness. Maybe she could let her voice be known. There is just not a way to gauge if she was aware at age six or not. They just don't know. And she was six. A 'normal' six-year-old cannot articulate all of their wishes or wants or desires. Why were we expecting that of Ashley at that time? She was just getting to the age where her own expression could have been discovered with augmentative communication or adaptive technologies. Her parents should have been encouraged to not act out of fear but seek out communication to find out what was going on in her head and help her be heard.

- Gail Lainhart-Rivas

Erica underwent growth attenuation, a breast-bud removal, and a hysterectomy.⁹⁰ Erica's parents, when asked why they chose to adopt Erica, stated:

Maybe it was the whole dependence thing I thrive on, because she was always going to need me. The satisfaction of being able to make her happy. It wasn't hard to love her like our own because we loved many babies like our own. We weren't thinking down the road. But as Erica grew bigger, they became increasingly worried about her future. Sometimes she is fussy around me like a baby if I'm not holding her. She lies in our laps and sucks her thumb. If she was 50lb heavier we probably couldn't do that. Even with a 70lb child, putting her in the bathtub is

difficult. We can pick her up and put her on the couch. She's not light, but it's manageable. If she weighed 140 or 150lbs, there's no way....We assumed we would take care of her as long as we could but we were older parents. The thought of having to let her go into an institution was very hard. I've worked with disabled adults. I know first hand the pain of parents who can no longer care for them in their homes." She recalls the moment she first learned of the Ashley treatment, from her grown son who had heard about it on the radio. It was, she says, like a "miracle."⁹¹

Erica's parents were informed by the gynecologist that they did not need to apply for a court order to have the hysterectomy, and report that no one questioned them about the need for a court order during the medical procedures.⁹² The hysterectomy and breast-bud removal were paid for by health insurance.⁹³ Erica and her parents did have to appear before a hospital ethics committee, who informed them they would like to setup a protocol for the Ashley Treatment.⁹⁴

Tom is the first boy publicly known to have undergone growth attenuation treatment.⁹⁵ Tom was born in Vietnam and now lives in a European country the Guardian chose to withhold.⁹⁶ He is 12 years old, has severe cerebral palsy, and is expected to have a normal life expectancy.⁹⁷ The severity of Tom's disabilities became known to his adoptive family when he was 2 years old.⁹⁸ Tom is reported to have an intellectual disability, be unable to sit, walk, eat or talk and has potentially fatal seizures from epilepsy.⁹⁹ He began to undergo growth attenuation treatment at the age of 8.¹⁰⁰ The main concerns of Tom's family when considering growth attenuation treatment included whether the treatment would result in Tom experiencing more seizures or Tom developing breast buds because of the use of estrogen.¹⁰¹ The endocrinologist that treated Tom stated that if breast bud growth were to occur that they could be removed.¹⁰² Tom's parents also believed that if Tom were to undergo puberty that it may be upsetting to him because he would not understand it.¹⁰³

They think because you have a disability that you are not so important.
- Heidi

Tom's mother stated:

If you had an eight-year-old who had cancer, you wouldn't ask, do we give her chemotherapy? You just do it. Every medical treatment is playing God. It is interfering with nature. This is to do with respecting a human being who needs help.¹⁰⁴

Tom's mother had been told that the procedure would not normally be undertaken without hospital ethic committee's approval, but she does not know whether it was obtained.¹⁰⁵ Tom's mother stated:

If the people who cried out the loudest in a negative way had any clue what it is to care for a child like Tom, like Ashley, they would not say the horrible things they have accused Ashley's family of...¹⁰⁶

In its reporting, the Guardian states that it has been able to confirm that at least twelve children have undergone the Ashley Treatment.¹⁰⁷ The Guardian reporter believes that more than 100 children have undergone hormone treatments to keep them small.¹⁰⁸

Anne's Story¹⁰⁹

When adults decide during a young child's life that something is impossible for that child and then close off the potential for that child, they limit the child's possibility to develop in whatever way turns out to be appropriate for her or him. No child knows whether she or he will wish to become a biological or adoptive parent at age two or six or even twelve. But when adults foreclose the possibility of biological parenthood, they violate the child's right to bodily integrity and with it the child's ability to determine her or his own future regardless of their capacity.

One eloquent summary of the Ashley Treatment demonstrates the profound impact of ableism within society.¹¹⁰

Many of the arguments in favour of the Ashley treatment come dangerously close to the core of the problem with it: they position people with disabilities as less than human... Ashley and the other children who are subjected to this treatment because they live in a world where people with disabilities are undervalued and their parents fear their capacity to care for them and move through public spaces with them. Their approach to this problem focuses on violating their integrity, rather than confronting the society around them to demand full rights and access for people with disabilities. Keeping people in a forcible state of underdevelopment for convenience would be condemned if procedures of this nature were performed on non-disabled children, and rightfully so – it would be viewed as an utter violation of humanity. Disabled children are not, apparently, accorded the same respect. The Ashley treatment is never ethically permissible, except under a framework that truly believes that disabled people are not human.¹¹¹

At the age of 19, I attended school for the first time, eventually graduating from university with majors in philosophy of science and fine arts. "Annie's Coming Out," the book about my experiences that I wrote with my teacher, was made into a movie (Best Film, Australian Film Institute Awards, 1984)... Unlike Ashley, I'm now an ordinary height and weight -- but I don't get left out, nonetheless. Though I still can't walk, talk or feed myself, I'm an enthusiastic traveler. My size has never got in the way, though my hip flask of Bundy rum often causes alarm at airport security. I love New York for its galleries, its shops and its theaters; hearing Placido Domingo at the Met was one of the highlights of my life. Interestingly, Ashley is also reported as enjoying opera -- maybe it goes with the turf.

- Anne McDonald

Withholding Life Sustaining Treatment

In addition to the continuing provision of unnecessary treatment such as the Ashley

Treatment, NDRN and the Protection and Advocacy agencies continue to have cases and hear stories that perpetuate the stereotype that the lives of individuals with disabilities are either worth less, or not worth living. The Protection and Advocacy agencies and media have documented situations where individuals with disabilities have had basic life sustaining treatment withheld from them that would not be contemplated by the medical community for individuals without disabilities.

Amelia's Story

For example, Disability Rights Washington (DRW), the Protection and Advocacy agency for Washington State, was working with a young man who has intellectual and psychiatric disabilities. In addition to the underlying disabilities, the young man had acquired significant neurological damage due to psychiatric medications that had been prescribed to him. The client had been admitted to a hospital and then later discharged to a nursing home to address medication side effects. When DRW staff checked in with his mother who was the legal guardian to see how he was progressing, she indicated that her son had been authorized hospice services. DRW staff visited the nursing home and determined the client had been put on hospice care due to a diagnosis of "debility NOS (not otherwise specified)". Due to the "debility NOS" diagnosis, nutrition was withheld and the client was essentially being allowed to starve to death.

When the DRW investigator visited the young man he was moaning and the DRW investigator inquired whether this could be because the client was hungry, but was told by the nursing home staff that the moans were caused by the young man's pain and that he was purportedly "catatonic." However, upon review, it was evident that he was fully conscious as the DRW investigator asked the client, in front of nursing staff, to follow his pen with his eyes as the investigator moved the pen back and forth across the young man's field of vision, and he did as requested. DRW advocated for a change in the plan of care to provide appropriate rehabilitative services and ensure that he was able to receive appropriate nutrition. Hospice care was removed and a new treatment program was initiated, in which nursing home staff actively encouraged him to eat. The young man gained weight and physical abilities and was, according to the treating physician, a "medical miracle."

Amelia Rivera, a 3-year-old girl with developmental and intellectual disabilities, was denied a life-saving kidney transplant in January 2012 because of her disability.

Amelia's doctor informed her parents that he would not recommend the surgery because Amelia is "mentally retarded." He also voiced concerns that if the operation were performed, Amelia, because of her disability, would not be able to adhere to the medication protocol required of individuals who receive organ transplants.

Amelia's parents turned to social media to tell their story. After receiving more than 37,000 signers to an online petition and sparking a media firestorm, the hospital issued a statement saying they do not disqualify transplant patients on the basis of intellectual disability and that Amelia would be evaluated for a transplant using the same process as all other patients. The hospital also apologized.

In another example, a corporate guardianship had been established for a 40 year old North Dakota man named “Waldo”, who had a personality disorder, alcohol dependency, and end stage liver disease. Waldo had frequent cycles through the state mental hospital, the state alcohol treatment facility, county jail, and freedom in the community. Waldo admitted he needed a guardian during his frequent episodes of active alcohol dependence. Waldo’s guardian got tired of his cycles and decided Waldo had no realistic hope for improvement and success at self-supported independent living. The guardian concluded that Waldo’s prospects were poor with end stage liver disease. The guardian put a “no code” on Waldo. Waldo objected.

The North Dakota Protection & Advocacy Project (ND P&A) tried to convince the guardian to respect Waldo’s wishes and drop the no code. The guardian felt strongly that it was doing the only sensible thing. The guardian refused to honor Waldo’s

*There is no such thing
as being too disabled.
The doctors told my
parents that I would be a
vegetable and would not
be able to do anything in
life. If they could see me
now.
-Ken*

wishes, which Waldo expressed most earnestly when sober. The ND P&A represented Waldo in guardianship court to remove the guardian’s authority to impose any restrictions on a full code for Waldo. Under this arrangement, the guardian would have to make a motion to the court with notice to Waldo and an opportunity for a hearing before the court would decide whether to impose any restrictions on the full code. After consulting a lawyer, the guardian agreed to settle the case fully in Waldo’s favor.

In a third example, the Rhode Island Disability Law Center (RI DLC), the Protection and Advocacy agency for Rhode Island, represented a 78 year old man with intellectual and other disabilities in a “petition for instructions” – a substituted judgment procedure to determine his wishes regarding

surgery for colon cancer. Pursuant to state practice, the petition was brought by the state developmental disability agency after his residential providers advised the state agency of the man’s need for treatment. In reviewing the client’s records, it became clear that without surgery he would die within a year. Although the client was non-verbal, the staff at his residence were convinced that the client still enjoyed his life and would not want to forego surgery. In meeting with the consulting surgeon in preparation for his testimony on the petition, the surgeon opined that there was no reason to prolong the client’s life due to his significant disabilities. Fortunately, the RI DLC was able to persuade the surgeon that the client could still enjoy life. The surgeon subsequently testified that the benefits of the surgery outweighed the risks. Surgery was ordered and performed and the client was able to enjoy life for another two years.

In a fourth example, an individual’s provider contacted the Ohio Legal Rights Service (OLRS) (the Ohio Protection and Advocacy agency) because the individual had been admitted to palliative care at a nearby hospital and there were concerns that his rights were being violated. Despite the fact that the individual had no guardian or power of

attorney and was still competent, the hospital had been deferring to his family on important decisions and had been refusing to communicate with the individual (either through his communication device or other method). The hospital, based on the family's decision, decided to stop providing him food or water or nutrients because medical professionals determined it could aggravate his existing health condition. It appears, however, that he, because of his communication impairment, was not consulted about such an important decision. Finally, there were concerns that he would not be discharged back to his home but rather a hospice unit in a nursing facility.

OLRS staff visited the individual several times in the hospital and confirmed that the hospital staff and doctors had not been communicating with him effectively. OLRS explained to him in detail exactly what was going on and subsequently wrote a letter to the hospital's risk management informing them of their concerns, asking for a second opinion on his inability to eat food or drink water without causing further harm to himself, etc. It appears the hospital began communicating with him after OLRS involvement. The hospital began affirmatively asking if he wanted food or water, rather than waiting for him to independently demand it himself. Also, a second opinion was obtained which confirmed the earlier opinion. Eventually his sister was appointed his guardian. She moved him to a nursing facility with hospice unit although he preferred to go back to his home.

In a fifth case, Equip for Equality (EFE), the Illinois Protection and Advocacy agency, provided assistance on behalf of a 51-year-old female with severe physical impairments. EFE received a call from a nursing home administrator stating that the client's guardian, who lived in a different state and had not seen the client in years, was demanding that the nursing home not follow the doctor's advice to run more tests or provide further medical treatment for the woman who was bleeding internally. EFE provided the nursing home with information about emergency guardianship in cases of wards being abused or neglected. Using this information, the nursing home was able to get the State appointed as emergency guardian, and as a result, the woman was provided with life-saving treatment.

In a final example, when John Smith was only 20 years old, doctors decided that the best treatment option was to let him die. John was admitted to the hospital on June 11, 2010, for treatment of an infected Stage IV decubitus ulcer (wound) and osteomyelitis, an underlying bone infection. The doctors initially planned to treat John's bone infection with intravenous (IV) antibiotics. However, after admission, John's doctors decided that, due to the severity of his wound, and his physical and intellectual disabilities, the benefits of treatment did not outweigh the risks. The doctors felt that John was not a candidate for surgery or IV antibiotics, and discharged John with the plan to withhold supplemental fluids and nutrition, and to allow him to slowly waste away in a long-term care facility.

Because there was no place to discharge John to at the time, John lingered in the hospital, where he did not receive food and water or treatment for his wound or bone infection. The nursing staff and residential provider expressed grave concerns about John's deteriorating condition; however, his doctors steadfastly refused to order supplemental amounts of fluids or nutrition, stating that John's conditions were not

treatable and that he was dying. In July 2010, John's doctor issued a "Do Not Resuscitate Order." The attending physicians discharge summary implies that the treatment decisions were, at least in part, based on John's disabilities. At the time of his hospitalization, John was a ward of the state. Pursuant to D.C. law, medical decisions should be made in coordination with the court-appointed Guardian *ad Litem* and legal custodian which was the Child and Family Services Agency (CFSA). The records obtained by University Legal Services (Washington, D.C. Protection and Advocacy agency) do not contain sufficient evidence to indicate whether John's attending physician presented the Guardian *ad Litem* or CFSA with detailed information regarding all available treatment options or even discussed the potential benefits that administration of supplemental fluid and nutrition could have John.

On August 2, 2010, after almost two months of hospitalization without aggressive treatment, or supplemental fluids or nourishment, John was discharged back to his apartment, in the community. John was frail, malnourished, and weighed only 89 pounds, amounting to a 25 pound weight loss during the course of his hospital stay and his wound had tripled in size. John required two subsequent hospitalizations at another hospital; both times requiring further treatment at a skilled nursing facilities. The second hospital provided aggressive treatment and the doctors stabilized his conditions by providing IV antibiotics and aggressive wound treatment. He responded well to this therapy and was discharged back to his home in the community. John continues to respond very well to treatment and his wound continues to heal. Despite his ordeal, and contrary to the hospital doctors' medical opinion that he was dying, he continues to live in the community.

Early Reaction of the Public, Self-Advocates, and the Disability Movement

Since the publication of the article by Gunther and Diekema (2006) and Ashley's parent's blog, hundreds of articles, editorials and interviews have been published or broadcast regarding the Ashley Treatment worldwide, and two public symposia and a workgroup were convened in Seattle, Washington (Workgroup) to discuss the ethics of using growth attenuation and to develop practical guidance for healthcare professionals. The Workgroup made a specific decision to only focus on the ethical questions of growth attenuation and not the other medical procedures that constitute the Ashley Treatment. Ultimately, the Workgroup was unable to come to agreement about the ethics of growth attenuation but instead reached a moral compromise that if growth attenuation were to be considered for children with significant disabilities, the discussion needed to be focused on the specific child and circumstances, and that individuals with disabilities should be part of the decision making process.

Numerous national and state organizations for people with disabilities issued statements and took action in reaction to the Ashley Treatment after it became public. Grassroots activists with disabilities picked up on the article shortly after it became public. Once Ashley's parents published their blog, however, the national disability grassroots group ADAPT and the anti-euthanasia group Not Dead Yet joined forces with the Chicago-based group Feminist Response in Disability Activism (FRIDA) to take direct action. ADAPT's youth advocates issued a statement in which they "expressed shock and outrage on behalf of the entire national membership of ADAPT at the news."¹¹²

FRIDA built on ADAPT's statement to organize a direct action campaign against the American Medical Association (AMA), demanding a meeting with the AMA leadership to review the ableism inherent in the Ashley Treatment and a commitment to viewing the Treatment as unethical. FRIDA galvanized women with disabilities across the country to view this and similar issues of bodily intervention as a problem with unique gender ramifications. They saw the focus on Ashley's female-identified body parts as a devaluing of women with disabilities as a whole. The group won dialogue with AMA leadership on the gender and bioethics angle after taking over the AMA lobby and generating media pressure.¹¹³

Self-Advocates Becoming Empowered (SABE) also spoke out against the procedure:

Members of Self Advocates Becoming Empowered feel angry, sad, and outraged with the decision made by doctors, Ashley's parents, hospital administrators, and the American Medical Association that violated Ashley's civil rights. SABE feels that if Ashley did not have a disability that this never would have happened. Just because someone has a disability does not mean they should be denied the basic human right to grow and mature like everyone else. The selfish actions taken by Ashley's parents put other people with disabilities at risk of being denied their human and civil rights.

The National Council on Independent Living passed a resolution condemning the Ashley Treatment and affirming the right to bodily integrity, based on the language of the UN Convention on the Rights of Persons with Disabilities.¹¹⁴

The Arc and United Cerebral Palsy issued a Joint Statement on the Ashley X Treatment which rejected the treatment as unacceptable, given the individual rights of children with disabilities to grow up. They stated, “We believe that loving parents who are caregivers are not granted special dispensation to sanction irreparable and irreversible surgeries to alter their son or daughter’s physical being primarily for their own convenience or comfort.”¹¹⁵

The Disability Rights Education and Defense Fund similarly recognized the difficult position the parents were in, but insisted that the individual rights of the child took precedence when it issued its reaction to the Ashley treatment which stated, “We deeply empathize with parents who face difficult issues raising children with significant physical and intellectual disabilities. However, we hold as non-negotiable the principle that personal and physical autonomy of all people with disabilities be regarded as sacrosanct.”¹¹⁶

The oldest multidisciplinary group of professionals who treat individuals with intellectual and developmental disabilities, the American Association of Intellectual and Developmental Disabilities (AAIDD), also denounced the Ashley Treatment, and called it “bad medicine.”¹¹⁷ AAIDD went on to describe:

we see an enormous potential for abuse here, and given the well-documented history of mistreatment, neglect and devaluation of this population, we are stunned and outraged by the very fact that the relative merits of growth attenuation could, in 2006, be a topic for serious debate ... and it distorts the concept of treatment and devalues the patient’s personhood.¹¹⁸

AAIDD rejected the use of the Ashley Treatment outright and stressed the need for clinicians to focus on the rights of the child with a disability, not simply the preferences of the child’s parents when it stated:

[G]rowth attenuation of children should not be included as an option. Under our law, parents are vested with the responsibility of making health care decisions for their minor children, but parental prerogatives are not absolute. Children have their own distinct rights and protections afforded them as individuals established in ethical principles and legal statutes. These rights should be of central relevance in the current situations, yet they did not seem to receive the attention they deserve.¹¹⁹

Perspectives of Individuals with Disabilities (2012)

Despite the discussion in much of the published literature to date that parents and caregivers are in the best position to make decisions on behalf of children with significant disabilities, the National Disability Rights Network and Disability Rights Washington find that individuals with disabilities are in a better position to represent the position of individuals with disabilities in regards to medical decision making.

The first hospital to perform the Ashley Treatment agreed that additional input from a person with a disability or a civil rights perspective on behalf of individuals with disabilities was necessary, and subsequently added a person with a disability onto its ethics committee to provide more insight on disability related considerations. An article in the American Journal of Physical Medicine and Rehabilitation agreed that this approach is “critical,” but also astutely pointed out that this proposal alone cannot be seen as a simple fix to this complicated problem because although “[s]omebody who has a lived experience of disability may be able to authentically represent a different perspective than the professionals who typically sit on hospital ethics committees[,] not everybody with a disability thinks alike or holds the same opinion.”¹²⁰

What can, however, be brought to the table is a deeper understanding, acceptance, and commitment to the reality that each person with a disability is entitled to have his or her civil and human rights protected. Even after the hospital where the Ashley treatment was performed admitted that her rights had been violated, many in the medical and bioethics community still argue that no harm was done to her based on their belief of her limited cognitive abilities. Individuals with developmental and communication disabilities regularly have decisions made for them based on a perception that they are not self aware when in fact, the perception is incorrect or there really is no way to know. Due process protections are needed to safeguard the civil and human rights implicated by the Ashley Treatment or other unnecessary medical procedures or when necessary procedures are withheld. Procedural due process protections are especially important where there is a perceived or actual conflict between the desires of parents, guardians or caregivers and the civil and human rights of individuals with disabilities. Regardless of the severity or type of disability, individuals with disabilities must have the opportunity to have their voices heard in the discussion of the impact of medical decision making on their lives. Although, every person with a disability is unique, the right to have civil and human rights recognized through due process protections is universal.

In the process of developing this report, NDRN and DRW convened five separate expert panels¹²¹ in the spring of 2012 to discuss the use of these medical procedures on individuals with disabilities, and more broadly the relationship between medical professionals, medical decision making and individuals with disabilities. One of the expert panels was convened via conference call and the other expert groups met in-person in Seattle and Washington, D.C. The experts in the in-person panels discussed their reaction to the Ashley Treatment and more broadly medical procedures using a guided set of questions to facilitate ongoing discussion.¹²²

The expert panels were comprised of people with cognitive, developmental and physical disabilities including communication disorders. The panelists are experts in their experience in living with disabilities as well as their own experience as people who could and have been affected by the decisions made in regards to the use of these medical procedures. No one person can speak on behalf of “people with disabilities”, but the individuals gathered were all people with developmental disabilities who live with people questioning their daily decisions and know what it is like to have professionals and family members make incorrect assumptions about their abilities and what is in their “best interest.” While no one can speak *for* Ashley and others who have had unnecessary procedures performed or necessary procedures withheld, the individuals we gathered certainly have lived similar experiences that others without developmental disabilities cannot ever truly understand from a firsthand perspective. Their shared perspectives are offered so that those who lack these experiences can learn a bit more about what it is like to have your autonomy and right to personal integrity at risk on a regular basis.

In both Seattle, and Washington, the groups were split by gender to facilitate discussion of sensitive topics like sexuality, gender discrimination and reproductive and parenting rights.

In Seattle, eight males and eight females participated in the expert panels that had a range of disabilities, a number of whom could be characterized as having significant disabilities. Group participants were recruited from around the state through several self advocacy organizations with which DRW has collaborated with in coalitions. The participants provided consent to video recording. Accessible travel, space, and eating logistics were implemented. The Expert Panel Discussion Guide was established and reviewed at the beginning of each panel, with time spent in reviewing the release of information, the purpose of the panels, and intended accessibility and participant comfort. The female panelists went first, for a three hour period which encompassed still photo shots, a framework of the discussion and video recording of the group discussion, with individual interviews afterwards for those who had additional comments. The female participants were provided lunch at the end of the panel and debriefed. For the male participants, the same three hour format was replicated. Lunch was provided beforehand. Support staff who needed to be in the room for purposes of accessibility were advised, at the beginning of each panel, to refrain from providing input or influencing participant answers in anyway, and staff did not intervene in anyway during either panel discussion.

In Washington, six males and four females participated in the expert panels that had a range of disabilities. Participants were recruited from self advocacy organizations in DC and Maryland. All but one of the participants agreed to video recording.¹²³ Accessible travel, space, and eating logistics were implemented. The Expert Panel Discussion Guide was established and reviewed at the beginning of each panel, with time spent in reviewing the release of information, the purpose of the panel, and intended accessibility and participant comfort. The female panelists met for a 2.5 hour period which encompassed a framework of the discussion and video recording of the group discussion. The female participants were provided light refreshments during the

discussion. For the male participants, the same 2.5 hour format was replicated, and the panels met simultaneously. Participants of both groups were given a modest Target gift card for the time and valuable input.

All of the expert panels of individuals with disabilities expressed outrage that these types of medical procedures would be performed on a child such as Ashley. This outrage stands in stark contrast to the Workgroup of professionals convened in Seattle described in the previous section who generally agreed that children with disabilities deserve dignity and respect; however they did not universally view the use of growth attenuation as a negative expression about disability or a representation of injustice.¹²⁴ Individuals with disabilities focused on Ashley's human and civil rights, and that those rights include the right to dignity and respect.

As stated by one participant, "this is no longer just about what happened. This turned into a civil rights issue as soon as they did the procedure. I want to do what I can to prevent this from happening to anyone." (Corinna).

Comments from other participants were:

"We want to make sure something like this never happens again." (John)

"Children with disabilities have rights and...the procedures performed on Ashley were unethical and unconstitutional." (Ken).

When asked why they were participating in these discussions of personal issues, one participant who is now married and living independently said, "This is really important to me, as a woman, because my mother said that if this treatment were available when I was little, she might have considered it for me." (Corinna).

"As a mother, whatever my daughter needs, I should accept. I want Ashley to have her own experience." (Evan).

Another participant stated that "Parents do have rights ... but not the right to do ANYTHING to their children. Ashley is not just an extension of her parents. Ashley is herself." (Joelle).

Other participants went a step further and suggested that the parents should face criminal penalties for their decision, and most certainly the doctors should face criminal penalties. One participant stated "first off it should be against the law. I thought that parents were supposed to make the right decisions. I don't think they did." (Robert).

In addition to framing the issue as a civil and human rights issue, multiple participants related the discussion back to the shameful history the United States has in regards to eugenics movement. One participant stated "I thought that our country fought a World War to end experimenting on humans...." (Matt). "As medical science advances, as a person with a disability, I worry about the things that we could be subjected too." (Matt).

Both male and female participants believed that parents and medical professionals should not unnecessarily change or alter the bodies that people were given by birth, and that everyone should be given the opportunity to grow into who they were going to be in regards to both body and mind and become independent to the degree they can be from their parents. “Everyone has a right to their own individual bodies” was strongly supported by the majority of participants who echoed similar statements.

As stated by two participants: “everyone has the right to their whole body.” (Heidi), and if parents are going to have children, “you should let that child grow up.” (Nikila).

“Extensive care should be taken with what we do to alter or change someone’s body. Whether people liked it or not, this is her body.” (Joelle).

One participant posed a question to Ashley’s parents; “I would say to her parents, ‘Why don’t you put yourself in her place? Would you want somebody to take away your body parts, or to take away your ability to become a woman?’” (Eric).

Similar statements were echoed that the significance of disability or age of the individual should not be factors in deciding whether to pursue the Ashley Treatment. This is in stark contrast to Gunther and Diekema (2006) who argued that the fear of being infantilized by society would not be an issue for Ashley because she has a significant intellectual disability.¹²⁵ Gunther and Diekema (2006) argued that the smaller size may present an opportunity for a child with a significant intellectual disability because adults may be more likely to interact with her in a developmentally appropriate manner.¹²⁶ In sharp contrast, one participant stated “It doesn’t matter what someone’s age is. There should be a choice about what happens to someone’s body.” (John). The groups pointed out that at the age of six, parents cannot know what their children will want for themselves when they grow-up.

As one participant stated, “the way that they messed her up. They think she has a mind of a three year old but they don’t know that... and the doctors, they don’t know either.” (Thelma).

“They made their decisions before they could know. It is a long time for them to teach her things. There is just no way that they can know for sure when she is six what she can’t become.” (Heidi).

“Ashley should have had a chance and what she wants in her life.” (Evan).

Another participant stated, “that this was done to a child is particularly offensive to me, that they didn’t want her to grow up, and that the hospital allowed the parents to do this. They supported infantilization so this little girl could never become a woman. The medical structure wants to keep us all children.” (Joelle).

Another participant stated that, “There is no such thing as being too disabled. The doctors told my parents that I would be a vegetable and would not be able to do anything in life. If they could see me now.” (Ken).

Almost all of the participants echoed similar statements: “I understand wanting to protect your child but, what happens when you are not around.” (Matt).

The infantilization and need for protection made in Ken’s statement was echoed by other participants particularly in regards to discussions around sexuality and reproductive rights. Many of the participants spoke in frustration of being viewed as asexual. As one participant stated, “they took her adulthood away.” (Jonathan).

“When you have a disability, you have to fight for the right to grow up. It isn’t given to you.”(Thomas). Thomas went on to state:

It took a long time for people to accept me in adult conversation. Even when I was older than them and I started talking about sex, they would stop me and treat me like I was a child. When you have a disability, you have to fight for the right to grow up. It’s not given to you. Your family members, they treat you like little children. And then they talk against us when we do get outraged when we throw it around but they set it up that way in order to be heard.

Another common extension of the infantilizing theme that was echoed by many members of the expert panels included the fact that girls, regardless of disability status, look forward to becoming women. The female participants echoed strong opinions on this topic. “It can be a tough road to becoming a woman, but there are some beautiful things about being a woman.” (Sarah).

“They (her parents) took away her rights of choosing. They left her with no rights to have children.” (Thelma).

Heidi also shared a story regarding her daughter who had problems with her kidneys, which impacted her daughter’s ability to grow. Heidi shared that her daughter used to get angry “when people would ask her if she was a midget. She wanted to wear heels, she wanted to grow.” In the same vein, concerns about sexual assault were also viewed by participants as being related to infantilizing or parents being overprotective. Women, regardless of their size, intellectual abilities or reproductive capacity, can be sexually assaulted.

“A lot of times parents get scared at the idea of their child with a disability having sex so they say – well you could get raped. Anybody could get raped. That doesn’t have anything to do with your disability. You have a right to having a family.” (Thomas).

Many of the participants believed that these medical procedures would not have been undertaken if Ashley did not have a significant disability. “This would have never happened if this little girl didn’t have a disability. Just imagine the outrage of the media and people if they had done this happened to ‘normal’ girl.” (Ken).

“I bet if they had another girl without disabilities that they ain’t going to cut out her uterus.”(Heidi).

Although, Ashley's parents have stated that their decision to have their daughter undergo these procedures was not for their convenience, many of the individuals with disabilities on the expert panel did not accept the parents' assertion that their convenience was not a factor. "Of course it's more convenient to say what you think in a way that is understood. It's more convenient when you understand what people are saying to you. But really, that's the heart of this whole case. I care much less about what was convenient for Ashley's parents, than I do about what is convenient for Ashley." (Joelle).

There was a strong sense that the parents were misinformed about what life was going to be like with a disability and how, in the future, assistive technology, and various support services might be available to help. Many of the participants discussed what information parents should have access to prior to contemplating a medical procedure. As one participant stated, "There is such a fear factor that parents of people with developmental disabilities have. People in the community are scared of us. It would be different if people in the community had a different idea about people with disabilities. The fear factor plays into what people are thinking." (John).

"Instead of stopping Ashley's growth to make it easier for her to move around, Ashley should have been provided with assistive technology and other supports and services to help with her mobility issues." (Heidi).

"Parents need to know that people with disabilities can work, live, and contribute to the communities." "I thought that is why we have wheelchairs and other devices." (Ken).

It doesn't make any sense [for the parents to say they did this to make it easier to take her places] because that is why they made wheelchairs and crutches to get around. They want to make it easier for themselves.
-Thelma

"It doesn't make any sense [for the parents to say they did this to make it easier to take her places] because that is why they made wheelchairs and crutches to get around. They want to make it easier for themselves." (Thelma).

"[The parents] were thinking about themselves." (Thomas). In addition, specific to Ashley, many of the participants contemplated how Ashley's parents would explain the medical procedures to her when she grew-up. "As she gets older she might be affected mentally, she is going to wonder why she don't have breasts. What are her parents going to tell her? That's horrible. Are they going to lie?" (Thomas).

In regards to the hospital's actions and the failure to provide adequate due process protections, one participant stated, "Hands down the hospital should not have done the surgery without a court order, and they knew that. The family took the shortcut and they

really should have gone through the court system so Ashley's voice would have been heard, instead of taking a legal shortcut to get what they wanted." (John).

Ashley deserved to have someone to say, "What are we doing?" This isn't right. The hospital should know her rights." (Robert).

More generally, beyond the case study of Ashley X, participants agreed that individuals with disabilities need advocates to represent their interests and should have powers of attorney so that their medical decisions are respected. "There is a way the kid can still be in the conversation and be part of the choice, and parents can learn from that." (Eric).

In addition, besides using the judicial system as a mechanism to protect the civil and human rights of individuals with disabilities, the experts with disabilities generally agreed that when other mechanisms such as ethics committees and institutional review boards are used they should be inclusive of individuals with disabilities by either modifying or eliminating specific education requirements for participation or by including several individuals with different disabilities on the committees and boards. Even the American Medical Association (AMA) acknowledges problems with ethics committees and identified that many see ethics committees as a way of avoiding the legal system, and the AMA's Council on Ethics and Judicial Affairs drafted a report on the use of ethics consultations to, in part, address what it saw as a "need for alternatives to judicial forums."¹²⁷ One participant stated that, "sometimes you need to force people to do the right thing. Make a law that you must have people with disabilities on committees making decisions about people with disabilities." (Matt).

More broadly in regards to medical decision making and the relationship between medical professionals and individuals with disabilities, the participants discussed the power dynamics that exist between medical professionals and individuals with disabilities. Almost all of the participants echoed similar statements regarding how medical professionals do not listen to and respect individuals with disabilities. "I want to be respected." (April).

"They think because you have a disability that you are not so important." (Heidi)

"Or that you don't have a mind of your own." (Thelma).

Participants generally agreed that doctors need to listen to them and respect their opinions. Thelma shared a story that illustrates the power dynamics and lack of respect for individuals with disabilities:

Doctors were making assumptions about what I could understand. One time at [a local hospital] seeing a new doctor. He took one look at me and asked where was my big book. Aren't you from a nursing home or group home? I told him that I am not from no group home or nursing home. I speak for myself....Nurses make assumptions too. A nurse looked at me

with an aid and she said – if you have an aid, she has to be with you. I look at her and say I don't think so. She doesn't know anything about me.

Heidi shared another poignant example:

Doctors want to give me shots so that I don't get pregnant because they say that I won't remember. But I don't like shots. I want to take the pills. They say, no you won't remember, you won't remember, we have to do this. I didn't like it. I had to tell a friend. She went with me to tell him that I will remember and every day I put my pills in a box. He didn't give me a choice. I felt like he thought I was stupid. I didn't like it.

Many of the experts with disabilities shared experiences that they felt that they were not listened to by their doctors, and instead were being used as experiments. One participant discussed that this perception is the direct result of the medical model of disability. "Doctors are trained to be academic. They are trained to think about what the disability is, not what the person can do. Very few doctors have positive examples when they explain diagnoses to new parents. Many of them are not even aware of the lives people with disabilities – even severe disabilities – are living." (John).

Another participant shared that when she received a communication device that it opened opportunities for her, "my communication device opened up the world for me. . . My doctor was surprised that I could think." (Sharon).

Another participant suggested that all doctors while in medical school should take a class on disabilities taught by a person with a disability. "Doctors need to come and sit with people with disabilities...They (doctors) think they know about us... but it is like they are window shopping at our lives." (Thomas).

Medical Procedures Violate the Civil Rights of Individuals with Disabilities: Due Process Protections Required

All citizens of the United States have the same Constitutional, statutory, and common law rights.¹²⁸ This includes adults and children with intellectual and developmental disabilities.¹²⁹ Congress has explicitly recognized that “disability is a natural part of the human experience and does not diminish the right of individuals with developmental disabilities to live independently, to exert control and choice over their own lives, and to fully participate in and contribute to their communities through full integration and inclusion in the economic, political, social, cultural, and educational mainstream of United States society.”¹³⁰ Additionally, Congress has recognized that discrimination based on disability is harmful and must be eliminated.¹³¹

As referenced above, the global community recognizes the need to eliminate discrimination against people with disabilities.¹³² Numerous international conventions recognize the importance of protecting certain people such as children, women, and those with disabilities from discriminatory exploitation and abuse. Despite the broad, cross-cultural, international community that has adopted standards which recognize the importance of legal and social protections for all individuals especially those with disabilities, many resist individual legal protections for children with disabilities.

Medical procedures and medical decision making that involve withholding necessary treatment or providing unnecessary treatment, based upon the disability of an individual must be reviewed by the legal and judicial system. Courts are necessary because they are the arbitrators of society’s most complicated issues when multiple parties do not agree on the final outcome. When dealing with cases as diverse as where to draw the line with potentially torturous interrogation of alleged criminals to authorizing medical treatment without the consent of a patient who is not competent to make a decision, courts have explicitly acknowledged that “we cannot escape the demands of judging or of making the difficult appraisals inherent in determining whether constitutional rights have been violated. We are here impelled to the conclusion, from all of the facts presented, that the bounds of due process have been exceeded.”¹³³ In order to carry out this heavy responsibility, courts learn about new factual scenarios and apply them to established legal principles to discern what decision should be made. Thus as medicine evolves, so will the courts’ decision making processes adapt to the ever changing factual scenarios that are presented, while remaining true to the spirit of the established rights vested in the individuals before them. As discussed more fully below, all individuals have substantive rights and the only means of adequately protecting those substantive rights is to respect each individual’s right to procedural due process. This process is at the heart of all decision making which impacts substantive rights and the rights of individuals with disabilities should be no different.

While not always able to rise above the medical model, the courts still represent the strongest established avenue for society to protect civil rights.

Some states’ sterilization laws are controlled by judicial precedent whereas others are the result of legislative enactments. As one example, Connecticut’s sterilization statute, Conn. Gen. Stat. § 45a-691, requires that a person must be 18 years of age and be

able to give informed consent to be able to undergo sterilization. Whenever a person is unable to give informed consent, the probate court has jurisdiction to determine whether sterilization shall be permitted.

Mary's Story

"Mary" is a thirty-two year old woman who has schizophrenia and/or schizoaffective disorder and bipolar mood disorder. She is pregnant and has been pregnant two other times. On the first occasion she had an abortion, and on the second occasion, she gave birth to a boy who is in the custody of her parents. At some point in the time period between her abortion and the birth of her son, Mary suffered a psychotic break, and has since that time been hospitalized numerous times for mental illness. The Massachusetts Department of Mental Health filed a petition seeking to have Mary's parents appointed as temporary guardians for purposes of consenting to an abortion. A probate judge appointed counsel for Mary and conducted a hearing. At the hearing Mary was asked about an abortion and replied that she "wouldn't do that." Mary also stated that she is "very Catholic," does not believe in abortion, and would never have an abortion. Based on "several and substantial delusional beliefs," the judge found Mary incompetent to make a decision about an abortion.

The judge appointed a guardian ad litem (GAL) to investigate the issue of substituted judgment. After investigating the facts and Mary's desires, the GAL concluded on a substituted judgment analysis that Mary would decide against an abortion if she were competent. Without conducting a hearing, the judge concluded to the contrary. The judge reasoned instead that if Mary were competent, she "would not choose to be delusional." and therefore would opt for an abortion. The judge ordered that Mary's parents be appointed as co-guardians and that Mary could be "coaxed, bribed, or even enticed . . . by ruse" into a hospital where she would be sedated and an abortion performed. Additionally without notice, the judge directed that any medical facility that performed the abortion also sterilize Mary at the same time "to avoid this painful situation from recurring in the future."

The decision was appealed and because the appeal was from a final order, the case was transferred to a panel of the court. The panel reversed the order requiring sterilization of Mary stating, "No party requested this measure, none of the attendant procedural requirements has been met, and the judge appears to have simply produced the requirement out of thin air." The appeals court also vacated the order for an abortion and making the parents co-guardians and remanded the case for a proper evidentiary inquiry and decision on the issue of substituted judgment.

Upon an application for sterilization, there is a two tier process: 1) determination of whether the person is able to give informed consent. If the evidence shows that the person is able to give informed consent, the analysis ends here and the court will make an order that the person is able to give consent to the procedure. The person can then choose to go forward with the procedure or not. 2) If the person is found not able to

give informed consent, the court engages in a best interest analysis. Like many states the legal standard applied requires a multipronged test be proven, in Connecticut's case the analysis involves eight criteria that have to be satisfied.

A Story from Pennsylvania

Upon application for sterilization a hearing is noticed within 30 days of the application. Notice is given to respondent, parents of respondent, siblings, guardians, if any, and the P&A.

The evidence that the court looks at to determine informed consent and best interest is from those interested parties that are noticed (parents, guardians, P&A, care-givers, medical providers, etc.) and from written reports, signed under penalty of false statement, from an interdisciplinary team of at least three impartial members appointed by the court from a panel of physicians, psychologists, educators, social and residential workers, who have personally observed or examined the respondent at some time over a one year period. These reports must contain specific information regarding whether the person is able to give informed consent and the specifics of informed consent which the respondent lacks. The panelists must also answer the eight best interest criteria.

The problems that the Connecticut Office of Protection and Advocacy for Persons with Disabilities (the Connecticut Protection and Advocacy agency) have experienced involve panelists who have not completed the reports accurately or whose opinion may be based on false or biased assumptions about individuals with disabilities. They also experience problems with the probate court judges who sometimes ignore the findings of the panelists and engage in their own analysis which are sometimes based on false assumptions about individuals with disabilities. Judges sometimes ignore the strict statutory requirements in making their

In re D.L.H., the Pennsylvania Supreme Court addressed whether a guardian has the right to refuse life-preserving treatment for a person who does not have an end-stage medical condition or is not in a permanent vegetative state. The lawsuit involves a resident of Ebensburg Center who was hospitalized with aspiration pneumonia. If he was placed on a ventilator to stabilize him, the doctors expected him to make a full recovery. The man's parents, who were his guardians, refused to authorize placing him on a ventilator. The Department of Public Welfare disagreed with the guardian's decision, and he was placed on a ventilator. Within a few weeks, the man recovered and was removed from the ventilator. In the interim, the Orphans' Court denied the guardians' petition for authority to withhold life-preserving treatment. The Superior Court affirmed, and the Supreme Court agreed to hear the guardians' appeal. The Disability Rights Network of Pennsylvania (the Pennsylvania Protection and Advocacy agency) submitted an amicus brief on behalf of itself, The Arc of Pennsylvania, Achieva, the Pennsylvania Developmental Disabilities Council, Vision for Equality, and Not Dead Yet. The Pennsylvania Supreme Court ruled that guardians cannot authorize doctors to withhold treatment necessary to preserve the life of persons in their care who do not have end-stage medical conditions or who are not permanently unconscious.

determinations. For example, even after finding that an individual is able to give informed consent, the judge engages in a “best interest” analysis and then orders sterilization. There are also problems with court-appointed counsel who engage in best interest analysis, instead of advocating for what the client wants or who blatantly side with the guardian or parent who has applied for sterilization.

Some have expressed concern that a rights perspective does not make significant distinctions based on individual circumstances. Yet, the sole purpose for having a legal and judicial system is to implement the rule of law in individual factual situations. The rule of law is a principle which describes a commitment to resolving disagreements through specific procedures prescribed by a set of laws that apply to each member of the society, not the individual whim of those with power.¹³⁴ The rule of law is not a novel concept to the United States or the other countries following an English legal tradition.¹³⁵ The United Nations has adopted the concept of the rule of law as a core principle and acknowledges that “[p]romoting the rule of law at the national and international levels is at the heart of the United Nations’ mission.”¹³⁶

Each and every person in the United States has certain rights, not just those who make a threshold showing sufficient intellectual ability.

As important as it is, the concept of the rule of law is often overlooked by the general public, as well as people who routinely work closely with legal concepts.¹³⁷ Each and every person in the United States has certain rights, not just those who make a threshold showing sufficient intellectual ability.¹³⁸ When medical professionals and others fail to accept the rule of law, there is a dissonance between clinical practice and individual rights. Since individual rights are not, and should not be, limited for the convenience or preference of others, the only way to bring medical decision making and individual rights into harmony is

for the importance of individual rights to be recognized and for medical professionals and others involved in these decisions to contribute constructively to the legal processes in place to protect those rights.¹³⁹

Courts have the ability to respond to new medical procedures while simultaneously remaining true to the rule of law and established Constitutional, statutory and common law requirements.¹⁴⁰ Therefore, the specifics of a particular medical procedure are less important than the legal basis for proposing and ultimately authorizing the use of the procedure. As described below, hospitals, medical establishments, other medical entities, ethics committees, institutional review boards and individual medical professionals may be violating the Constitution, common law principles, and federal and state statutes and regulations by performing certain unnecessary, invasive, and irreversible medical procedures on individuals with disabilities or withholding necessary treatment because of their patients’ disabilities.¹⁴¹

Informed Consent

Consent is a longstanding concept in common law that informs whether a given medical procedure is lawful or whether it is an unlawful assault on the recipient of the procedure.¹⁴² The Constitutional right to liberty also underlies the doctrine of informed consent.¹⁴³ The United States Supreme Court recognizes that courts have often looked to the doctrine of informed consent to resolve many legal issues pertaining to delivery or withholding of medical treatment.¹⁴⁴ This can, of course, be complicated by the existence of an impairment which impacts the current ability of an individual to make informed decisions for him or herself.¹⁴⁵ There are some instances where someone such as a legal guardian is authorized to assist a patient in effectuating a patient's intent, and in some very limited circumstances, a legal guardian may be authorized to provide or withhold consent on behalf of the patient, even when the patient's intent is unknown.¹⁴⁶ Therefore, when an individual cannot provide consent to certain procedures, it is necessary for a court to rule on what should be done, which then triggers Constitutional protections since the court proceedings and resulting decision are state actions.

There are a couple of tests a court may apply when reviewing the actions of an individual requesting to authorize or withhold consent on behalf of another. The court will first look to see if the decision maker is looking at the least intrusive way to assist the individual by following his or her "expressed interest."¹⁴⁷ Expressed interests can be determined, either by the current words and actions of an individual, or by their past words and actions. The first and easiest way to gauge an individual's expressed interest is when an individual can explicitly state his or her preferences.¹⁴⁸ In those instances, the guardian should seek to effectuate the ward's stated preference or intent in a manner consistent with the guardian's other duties relative to health, safety, and finances.¹⁴⁹ When the individual currently lacks capacity to state his or her preferences, the guardian should give significant weight to the ward's implied preferences, as ascertained by residual capacity to form preferences as well as the individual's historic preferences.¹⁵⁰ When the individual cannot make his or her preferences known either explicitly or implicitly, then the guardian is often authorized to select the option, the guardian believes would provide the best direct benefit to the individual.¹⁵¹

In many jurisdictions, if a person is not competent to make a decision about end of life care, a court appointed guardian is often authorized to make a decision on behalf of the individual, but even then certain prerequisite conditions must be present such as a terminal condition or persistent nonresponsive state.¹⁵² At the same time, the guardian may be categorically prohibited from ever consenting to electroconvulsive therapy,¹⁵³ the administration of involuntary antipsychotic medication;¹⁵⁴ involuntary sterilization;¹⁵⁵ and other invasive and irreparable procedures.¹⁵⁶ If such procedures are sought, only an order from the court would be sufficient before medical professionals could proceed.¹⁵⁷

Parents, like court appointed guardians, have the right to make certain treatment decisions regarding their minor children, but there are limits on the decisions they are allowed to make for their children. The need for such limitations is highlighted where there is a potential or actual conflict of interest between the parents and child.¹⁵⁸ The

United States Supreme Court has ruled that “the state has a wide range of power for limiting parental freedom and authority in things affecting the child’s welfare.”¹⁵⁹ This is especially true when the parents seek unnecessary medical procedures on their minor children.¹⁶⁰ State courts and legislatures also limit parental authority to consent to a variety of treatments including involuntary inpatient psychiatric care,¹⁶¹ the administration of electroconvulsive therapy in non-emergency life-saving situations,¹⁶² psychosurgery,¹⁶³ abortions for mature minors,¹⁶⁴ sterilization,¹⁶⁵ and other similar invasive medical treatments.¹⁶⁶

Serious concerns about parental decision making for treatment of their children with disabilities arose in the 1980s with the case of Baby Doe and related cases in which parents and doctors elected to not provide life sustaining treatment to infants with curable medical conditions due to the presence of a permanent, non-curable disability.¹⁶⁷ At that time, pursuant to Public Law 98-457 (Child Abuse Amendments of 1984), the United States Commission on Civil Rights issued a report which not only highlighted the harm that results from discriminatory withholding of treatment and nutrition to children with disabilities, the committee also offered a number of solutions including additional access authority and funding for the Protection and Advocacy System so they could provide independent oversight and advocacy to children with disabilities who may be subject to the discriminatory withholding of treatment.¹⁶⁸

There is also a need to address issues of forced sterilization which are often sought on their own, or may be pursued in conjunction with the battery of procedures known as the Ashley Treatment. Many states have addressed the issue of parental consent for sterilization of children with intellectual disabilities.¹⁶⁹ Courts do not afford parents their typical deference and instead insist that they obtain court approval prior to involuntary sterilization.¹⁷⁰ In these cases not only are parents precluded from providing consent, “[t]here is a *heavy* presumption against sterilization of an individual incapable of informed consent that must be overcome.”¹⁷¹ Similarly, in cases involving the combination of medical procedures that create the Ashley Treatment, parents should be precluded from giving consent. Just as when sterilization is performed as a separate procedure, courts should appoint guardians *ad litem* to represent the child’s interests when withholding necessary treatment or providing unnecessary treatment is contemplated, because the individual rights of the child may be in conflict with the parents, and the child may not be able to articulate where those rights diverge without the help of an advocate dedicated solely to the child.¹⁷²

Violations of the Fourteenth Amendment

The Fourteenth Amendment of the United States Constitution declares that no state shall “deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.”¹⁷³

Fundamental Rights of Liberty and Privacy

The right to liberty includes, among other things, the right to avoid unnecessary medical procedures and treatment that impact personal procreation choices;¹⁷⁴ the administration of involuntary antipsychotic medications;¹⁷⁵ the right to receive or refuse

life-sustaining care;¹⁷⁶ and to right to be free from involuntary sterilization.¹⁷⁷ As the United States Supreme Court stated:

These matters, involving the most intimate and personal choices a person may make in a lifetime, choices central to personal dignity and autonomy, are central to the liberty protected by the Fourteenth Amendment. At the heart of liberty is the right to define one's own concept of existence, of meaning, of the universe, and of the mystery of human life. Beliefs about these matters could not define the attributes of personhood were they formed under compulsion of the State.¹⁷⁸

The United States Supreme Court has extended its interpretation of substantive due process to include rights and freedoms, such as the right to privacy, that are not specifically mentioned in the United States Constitution but that derive from existing rights. The right to privacy protects individuals from state intrusion into decisions about contraception,¹⁷⁹ abortions,¹⁸⁰ and sterilization.¹⁸¹ The Court looks at any infringement of this fundamental right with strict scrutiny.¹⁸² The state must show that its decision has met the high burden of proving that the state's actions are the product of a compelling state interest¹⁸³ and narrowly tailored so as to avoid infringing on the fundamental rights of the individual as much as possible.¹⁸⁴ If the state fails to meet this burden, it cannot act in a way that infringes on an individual's rights; this includes using the power of its courts to authorize an involuntary sterilization or the provision or withholding of other procedures which impacts the fundamental rights of an individual.¹⁸⁵

When looking at whether to use the legal system as a mechanism to authorize the use of the unnecessary medical procedures such as the Ashley Treatment or withholding of necessary care such as nutrition, hydration, or antibiotics, the legal system would examine whether infringement on the liberty and privacy of the individuals being given unnecessary treatment or denied necessary treatment is sufficiently tailored to apply to only those individuals for whom the state has a compelling state interest in forcing to undergo or forgo such procedures. The initial question posed by the Ashley Treatment is whether the state has a compelling interest in sterilizing and otherwise manipulating the bodies of children with significant disabilities. Although *Buck v. Bell* has not been overruled, it must be recognized that the involuntary state sterilization statutes have been abandoned and explicit eugenic motivations have, in most instances, been repudiated. It is, therefore, likely that the state does not have a sufficient compelling reason to force children to undergo any set of procedures which requires unnecessary sterilization, and no state interest has ever been articulated to support the removal or breast buds or growth attenuation as individual procedures.

Equal Protection Under the Law

The Fourteenth Amendment of the United States Constitution also provides that no state shall "deny to any person within its jurisdiction the equal protection of the laws."¹⁸⁶ This means that individuals may not be treated differently by the state merely because they are members of one group and not another group.¹⁸⁷ In short, "all persons similarly situated should be treated alike."¹⁸⁸ Just as a state's actions must pass strict

scrutiny if it seeks to limit a fundamental right of liberty or privacy, it, too, must satisfy strict scrutiny if it seeks to limit a fundamental right of one group of people and not another group.¹⁸⁹ For example, the United States Supreme Court examined the equal protection arguments of prisoners who were involuntarily sterilized and found that “[w]e are dealing here with legislation which involves one of the basic civil rights of man. Marriage and procreation are fundamental to the very existence and survival of the race. The power to sterilize, if exercised, may have subtle far reaching and devastating effects.”¹⁹⁰

Even if the rights at issue are not fundamental rights, the equal protection clause still applies, but the level of judicial scrutiny depends on the group of people being treated differently by the state.¹⁹¹ Actions against certain groups that have historically experienced discrimination, such as racial, religious, or national groups are *per se* suspect.¹⁹² Distinctions based on these group classifications are analyzed with strict scrutiny regardless of the issue.¹⁹³ Women, and in this case more appropriately girls, are not one of the groups that require the use of the highest level of analysis, strict scrutiny, but they are afforded an intermediate, heightened level of scrutiny by the judicial system.¹⁹⁴ Therefore, all state actions that treat males and females differently must be “substantially related to a sufficiently important governmental interest.”¹⁹⁵ Differing legal treatment of people with disabilities is analyzed using a third test, which is the default “rational basis” test for equal protection.¹⁹⁶ The rational basis requires that the state action be rationally related to a legitimate state interest.¹⁹⁷ Therefore, the state would need to show that treating individuals with intellectual disabilities differently from those without disabilities is not based on “irrational prejudice.”¹⁹⁸ In addition, the fact that some have suggested using the Ashley Treatment on more male than female children so as to avoid the fundamental right to avoid involuntary sterilization may result in the court applying the heightened level of scrutiny described above for disparate treatment resulting from sexual classification.

Violations of Anti-Discrimination Laws

Statutory Prohibition of Disability-Based Discrimination

Federal statutes also protect people with disabilities from discrimination based on their disabilities. The Rehabilitation Act provides that recipients of federal funds may not discriminate against individuals with disabilities.¹⁹⁹ The Americans with Disabilities Act and its implementing regulations give a similar directive preventing discriminating against individuals with disabilities by state government entities and businesses that are open to the public.²⁰⁰ It is, therefore, difficult to conceive of a hospital or doctor’s office in the United States that is not covered by one or more of these antidiscrimination laws.

As an example of the protection provided, Title II of the Americans With Disabilities Act, which covers state operated services, declares that “no qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity, or be *subjected to discrimination* by any such entity.”²⁰¹ To establish a violation of the ADA, an individual must show that he or she: “(1) is a ‘qualified individual with a disability’; (2) was ...discriminated against by the public entity; and (3) such ... discrimination was by

reason of his disability.”²⁰² The same standard applies for Section 504 of the Rehabilitation Act.²⁰³

There is no doubt that the people diagnosed with intellectual and physical disabilities who are considered for the set of procedures that are part of the Ashley Treatment satisfy the first prong of this test, as they have disabilities which affect their major life functioning and are "qualified individuals with disabilities" who are protected from discrimination by any medical facility that receives federal funds, is operated by a state or local government, or is open to the public.

The second and third prongs look at whether the person with a disability experiences discrimination and whether the discriminatory act was taken as the result of the individual's disability. Congress recognized that “[d]iscrimination against people with disabilities results from actions or inactions that discriminate by effect as well as by intent or design. Discrimination also includes harms resulting from the ... application of standards, criteria, practices or procedures that are based on thoughtlessness or indifference—that discrimination resulting from benign neglect.”²⁰⁴ During the passage of the ADA, it was explicitly noted that discrimination against people with disabilities persists in the provision of medical treatment and involuntary sterilization.²⁰⁵

One court found that in passing the ADA, Congress recognized that:

individuals with disabilities are a discrete and insular minority who have been faced with restrictions and limitations, subjected to a history of purposeful unequal treatment, and relegated to a position of political powerlessness in our society, based on characteristics that are beyond the control of such individuals and resulting from stereotypic assumptions not truly indicative of the individual ability of such individuals to participate in, and contribute to, society.... This sweeping language—most noticeably Congress's analogizing the plight of the disabled to that of “discrete and insular minorit[ies]” like racial minorities,—strongly suggests that § 12132 should not be construed to allow the creation of spheres in which public entities may discriminate on the basis of an individual's disability.²⁰⁶

To that end, the antidiscrimination statutes prohibit services from being provided in a manner which treats individuals with disabilities as second class citizens.²⁰⁷ Unfortunately, the provision of unnecessary medical procedures such as the Ashley Treatment or withholding of necessary treatment does just that. This discriminatory “second class” status is affixed to individuals purely because of their disability status. Parents do not seek out such procedures to more easily care for children who do not have disabilities. Many would never consider removing the breasts and uterus, halting the growth, subjecting an individual to other unnecessary non-therapeutic interventions, or deny life sustaining treatment to an individual who did not have a disability, but would if the person did have a disability.²⁰⁸ These federal antidiscrimination statutes are, therefore, violated when such medical procedures are used in discriminatory ways to treat individuals with disabilities as second class citizens simply because they have disabilities. The discrimination stemming from a violation of these rights is not trivial,

and regardless of any additional physical harm incurred as a result of the invasive procedures, the discrimination alone constitutes irreparable harm.²⁰⁹

As described above, these procedures also violate fundamental constitutional rights. Those constitutional rights and the substantive statutory antidiscrimination rights described in this section both call for procedural due process. The United States Supreme Court held the ADA applies to state judicial proceedings.²¹⁰ As such, the ADA provides protections for individuals with disabilities who have matters that must be decided before a court. Therefore, a person's limited ability to participate in a hearing due to the severity of her/his disability should not be a valid basis for denying due process protections.

There is, therefore, an affirmative obligation on the part of state and local government, under the ADA, to reasonably accommodate²¹¹ a person with a disability for whom such procedures are sought.²¹² While the obligation to provide reasonable accommodations is not unlimited,²¹³ even where there is no reasonable accommodation available that would make the hearing accessible to the individual that does not justify a denial of a hearing for the individual.

There are a number of cases recognizing that where fundamental rights are at stake for people with intellectual disabilities, regardless of the severity of their disabilities, procedural due process protections must be afforded.²¹⁴ While these cases do not include ADA claims, they do specifically address discrimination based on severity of developmental disabilities in the context of the amount of due process protections to be afforded such individuals in the context of the hearings related to the deprivation of fundamental rights such as civil commitment or sterilization. Given that that the ADA has been construed to apply a higher standard than the rational basis test²¹⁵ for denial of rights based on disability,²¹⁶ it stands to reason that Title II of the ADA is applicable in such cases and would further limit any argument that procedural due process should not be provided, particularly in a case that involves fundamental constitutional rights, such as in the case of providing unnecessary treatment or withholding necessary treatment.

Moreover, the ADA regulations specifically prohibit discrimination against "any class of individuals with disabilities."²¹⁷ This includes people with intellectual disabilities, even severe intellectual disabilities. As the United States Supreme Court noted, the ADA was enacted to remedy the long-standing history of denial of access to the courts, which the Court acknowledged specifically included the denial of court access for people with developmental disabilities.²¹⁸

Finally, as a remedial statute, the ADA must be broadly construed to effectuate its purpose.²¹⁹ As discussed above, the sole purpose of the ADA is to end discrimination against people with disabilities. Therefore, the ADA must be interpreted broadly to effectuate this purpose, which includes prohibiting discrimination against people with intellectual disabilities which impairs their ability to voice their intent in hospitals, medical establishments and other medical entities' about the appropriateness of certain treatments as well as to have accommodations and representation to access a hearing

on whether they should be subjected to involuntary growth attenuation procedures, sterilization or other unnecessary procedures, or be denied life sustaining treatment simply because they have a disability. To do otherwise would contravene the intent and purpose of the ADA.

These federal laws establish the mere minimum level of protection that must be provided to people with disabilities. State and municipal governments, can and do provide additional, more stringent antidiscrimination protections for people with disabilities within their borders. Therefore, it is important for patients, parents, guardians, legal and medical practitioners, and policy makers in each state to understand any heightened protections for people with disabilities in their jurisdictions.

Recommendations

Hospitals, Medical Establishments and Other Medical Entities

Hospitals, medical establishments and other medical entities' reliance on ethics committees and consultations are insufficient protections of patient's legal rights and they must, therefore, establish and implement due process protections to ensure the civil rights of a person with a disability are protected when growth attenuation treatment, sterilization, or other elective or unnecessary medical procedures are performed based on the presence of a disability, and there is a perceived or actual conflict between the desires of parents or guardians and the civil and human rights of a person with a disability. These due process procedures must also be in place for instances of withholding necessary medical treatment including but not limited to nutrition, hydration or antibiotics.

Include at least one person on the ethics committee that has a disability or experience advocating for people with disabilities from a civil rights perspective.

Create a workgroup of appropriate organizations including the American Academy of Pediatrics, the Children's Hospital Association, the American Medical Association, the American Association of Clinical Endocrinologists, the American Hospital Association, the American Association of Intellectual and Developmental Disabilities, the National Disability Rights Network and other organizations advocating for the civil rights of people with a disability, and disability self-advocacy groups to provide technical assistance to their respective memberships on the impact of growth attenuation treatment, sterilization, or instances of withholding necessary medical treatment including, but not limited to, nutrition, hydration or antibiotics or providing unnecessary medical treatment based on the presence of a disability.

The Joint Commission on Accreditation of Healthcare Organizations

Decertify any hospitals, medical establishments or other medical entities not in compliance with these recommendations, existing sterilization and other relevant civil rights statutes and regulations covering people with disabilities. Publish a list of decertified hospitals, medical establishments and other medical entities on the Commission's website.

Insurance Companies

Refuse to pay for any growth attenuation treatment, sterilization where the individual has not consented, or other unnecessary medical procedures that are perceived or actually create a conflict between the desires of the parents and the civil and human rights of a person with a disability until sufficient due process protections to protect the civil and human rights of a person with a disability have been followed.

State Legislatures

Enact legislation, or amend existing statutes and regulations, to establish due process protections concerning the use of sterilization, growth attenuation treatment, or other elective or unnecessary medical procedures based on the presence of a disability when there is a perceived or an actual conflict between the desires of parents or guardians

and the civil and human rights of a person with a disability.

Enact legislation, or amend existing statutes and regulations, to establish due process protections for instances of withholding necessary medical treatment including but not limited to nutrition, hydration or antibiotics.

Require a guardian *ad litem* who zealously represents the interests of the person with a disability using the substituted judgment standard²²⁰ when possible, who does not waive any substantive rights of the child when a perceived or an actual conflict is present and provide the guardian with access to all necessary information to protect the civil and human rights of the person with a disability.

U.S. Department of Health and Human Services

Coordinate a summit of medical organizations, including the American Academy of Pediatrics, the Children's Hospital Association, the American Medical Association, the American Association of Clinical Endocrinologists, the American Hospital Association, the American Association of Intellectual and Developmental Disabilities, and the National Disability Rights Network and other organizations advocating for the civil rights of people with a disabilities, and disability self-advocacy groups to discuss the impact of medical decision making on, as well as due process protections for, people with disabilities.

Ensure that hospitals, medical establishments and other medical entities adhere to the required due process protections to protect the civil and human rights of people with disabilities when performing growth attenuation treatment, where the individual has not provided consent to receive sterilization, or other unnecessary medical procedures based on the presence of a disability when there is a perceived or an actual conflict between the desires of parents or guardians and the civil and human rights of a person with a disability. These due process procedures must also be in place for instances of withholding necessary medical treatment including but not limited to nutrition, hydration or antibiotics.

Withhold all federal funds from hospitals, medical establishments and other medical entities not in compliance with required due process protections and other relevant civil rights statutes and regulations.

Amend the Federal Sterilization Regulations codified at 42 C.F.R 50.201 *et. seq.* to prohibit recipients of federal funds from providing sterilization where the individual has not consented, or growth attenuation treatment based on a person's disability, or arranging for such procedures.

Amend the Federal Policy for the Protection of Human Subjects Regulations codified at 45 C.F.R. 46 *et. seq.* to require institutions engaged in human subjects research to require that disability be a factor considered when determining the membership of the Institutional Review Board (IRB). Require the inclusion of at least one person with a disability or experience advocating for people with disabilities from a civil rights perspective on the IRB, when it is reviewing research that includes subjects who are

individuals with disabilities.

Establish a federal interagency coordinating council to bring together resources and develop a central repository of information for parents or guardians of children with disabilities on such topics as assistive technology, community living, medical and rehabilitation devices and equipment, and additional services and supports available to assist in meeting the needs of people with disabilities.

Congress

Provide additional fiscal resources to Protection and Advocacy agencies, Legal Services funded entities and other legal entities to monitor hospitals, medical establishments and other medical entities, train provider groups, and investigate potential violations of the civil and human rights of individuals with disabilities in regards to due process protections.

Enact legislation to withhold federal funds from hospitals, medical establishments and other medical entities not in compliance with required due process protections and other relevant civil rights statutes and regulations.

Appendix A

Ashley's Treatment Discussion Group Outline

Time: Total - approximately 2 hours

Breakdown:

- | | |
|--------------------------------|---------------|
| 1. Settle-in and Introductions | 3-5 minutes |
| 2. Purpose of the discussion | 3-5 minutes |
| 3. Group discussion 1 | 40minutes |
| 4. Break | 10-15 minutes |
| 5. Group discussion 2 | 40 minutes |
| 6. Wrap-up | 10 15 minutes |

Purpose of the Discussion (3-5 minutes)

Ensuring Respectful and Courteous Discussion

1. To talk about what Ashley's Treatment is and what it means for people with disabilities
2. To hear the concerns of advocates
3. To talk about ways advocates can make sure people with disabilities have their rights protected
4. Confidentiality and disclosure, and that it's safe to share difficult content

Group Discussion #1 (40 minutes)

Ashley's Treatment

1. Who is Ashley?

Interventions:

1. Growth-attenuation
 - a) Treatment with high-dose estrogen to stop growth and speed up maturation of growth plates in a young child.
2. Combined with:
 - a) Hysterectomy – removal of uterus
 - b) Removal of breast buds

Reason for giving treatment

1. The parents say keeping the child permanently small will make care easier
 - a) Easier to lift
 - b) Easier to take places
 - c) Easier to participate in family activities
 - d) Easier to provide care for her
2. The parents say giving Ashley a hysterectomy will
 - a) Prevent cancer later in life
 - b) Prevent having to deal with menses, puberty, or pregnancy
 - c) Prevent likelihood of sexual assault

3. The parents say removing Ashley's breast buds will
 - a) Provide more physical comfort
 - b) Make care easier
 - c) Prevent cancer

Discussion Questions (reactions)

Some people think that because this treatment makes it easier to care for the child, it benefits both the parents and the child.

What do you think about this?

Some people think that this process increases the length of time a child could live with and enjoy their family.

Do you think this is true? Why or why not?

What do parents need to know about children with disabilities?

A reason for this treatment was to keep Ashley from getting pregnant.

What do you think about this? Is it okay to take this away from someone (male or female)?

People have argued keeping Ashley small was not necessary because there is assistive technology available for mobility purposes. Others say assistive technology is not affordable or available.

What do you think?

Some people have said that keeping Ashley short would not affect potential jobs, spouses, sports or cars because of the significance of her disability. They said marriage would be meaningless for Ashley.

What do you think about this?

One of the stated reasons for the Ashley treatment was to de-sexualize Ashley, to make her less of a victim of possible sexual abuse or assault.

Do you think this is true? There are no studies or data that we know of that indicates this treatment actually would reduce the risk of abuse or assault.

Group Discussion #2 (40 minutes)

Reason for giving treatment

1. Children's Hospital did the surgery because
 - a) The parents asked for it
 - b) The doctors thought it was okay
 - c) An ethics committee said it was okay
 - d) The parents' attorney said they didn't need a court order
 - e) The right policies were not in place to make sure Ashley's rights were protected.

Disability Rights Washington and Seattle Children's Hospital

2. Children's Hospital broke the law.
 - a) The law says that before a child has forced sterilization, (Ashley's hysterectomy) a court order has to be done.
3. Children's Hospital is working closely with Disability Rights Washington.
 - a) Make a policy, to protect children with developmental disabilities.
 - b) Have a court order before
 - (1) Doctors take out a child's uterus
 - (2) Doctors try to stop the child's growth
 - c) Children's Hospital will let Disability Rights Washington know
 - (1) when there is a request to take away someone's uterus
 - (2) when there is a request to stop someone's growth
4. Children's Hospital will include a disability advocate on their Ethics Committee, so that there is always a disability rights' voice when these types of decisions are being talked about.

Discussion Questions (reactions)

Have you had experiences with medical professional (doctors) not listening to patients?

How can advocates be involved in medical decisions made by doctors and hospitals?

What do doctors need to know about people with disabilities?

Often, an age equivalent is assigned to children with developmental disabilities, as in the case of Ashley, where experts said she would never have more awareness than a 3-month old. **Have you had experiences where you were assigned an age that is lower than your real age?**

Have people made decisions for you that you could have handled, because it was thought you weren't capable of understanding?

How has your awareness of yourself changed as you have become an adult? Do you think it's possible to not be aware of this?

Much of the debate around the Ashley treatment has come from the medical community. **How can people with disabilities inform this debate differently? Why is this important?**

Review boards or ethics panels have been encouraged to have an individual with a disability to review possible procedures like the Ashley treatment. This often becomes a physician or other professional with a disability.

Do you think it makes a difference what kind of disability someone has, or how much education someone has, when thinking about these procedures? Why or why not?

Do you think it makes a difference whether this treatment is done in males or females? (Some have said it is better to do this to males, because there is less red tape/legal issues without the hysterectomy)

What's Next? (10-15 minutes)

Appendix B: Expert Panel Participants List

Women's Expert Panel - Washington, DC

1. Naketa Bell
2. April Edwards
3. Thelma Greene
4. Heidi Case

Men's Expert Panel - Washington, DC

1. Matt Rice
2. James Miller
3. Robert Kennedy
4. Thomas Magnum
5. Ken Capone
6. Jonathon Herring

Men's Expert Panel - Seattle, Washington

1. Mike Raymond
2. John Lemus
3. Dale Colin
4. Eric Mattes
5. George Adams

Women's Expert Panel - Seattle, Washington

1. Joelle Brouner
2. Vicky Foster
3. Sara McQueed
4. Sharon Jodock-King
5. Corinna Fale
6. Evan Abadinas

Appendix C – Expert Panel Reviewers List

NDRN and DRW convened a fifth expert workgroup comprised of professionals who study and practice disability law, medical and legal ethics, human rights, and self-advocacy. The expert workgroup was convened on April 24, 2012, (with some individual calls with experts not able to participate in the group call) for the purpose of providing an interdisciplinary professional perspective on the report. The expert workgroup was not asked to reach collective agreement on the report contents or recommendations, but instead to provide input on the draft report from their areas of expertise. In addition, the participants in this expert workgroup were not asked to endorse the report or the recommendations when providing comments.

1. **Adrienne Asch**, Director, Center for Ethics at Yeshiva University; Professor of Epidemiology and Population Health; Professor of Family and Social Medicine, Albert Einstein College of Medicine; and Edward and Robin Milstein Professor of Bioethics, Yeshiva University
2. **Samuel Bagenstos**, Professor of Law, University of Michigan Law School and former Principal Deputy Assistant Attorney General for Civil Rights, Department of Justice
3. ***Deborah Dorfman**, Attorney, Center for Public Representation
4. **Rebecca Dresser**, Daniel Noyes Kirby Professor and Professor of Ethics in Medicine, Washington University Law School
5. **Debjani Mukherjee**, Director, Donnelley Ethics Program, Rehabilitation Institute of Chicago; Assistant Director of Graduate Studies, Medical Humanities & Bioethics; and Assistant Professor of Physical Medicine & Rehabilitation, and of Medical Humanities & Bioethics, Northwestern University Feinberg School of Medicine
6. **Melissa A. Parisi**, Chief, Intellectual and Developmental Disabilities Branch, Center for Developmental Biology and Perinatal Medicine, *Eunice Kennedy Shriver* National Institute of Child Health and Human Development
7. ***Michael Perlin**, Professor of Law; Director, Mental Disability Law Program; Director, International Mental Disability Law Reform Project, Justice Action Center, New York Law School
8. **Anna Stubbefield**, Associate Professor and Chair, Department of Philosophy, Rutgers University-Newark
9. **Anita J. Tarzian**, Associate Professor, Family & Community Health, University of Maryland School of Nursing Program Coordinator; Maryland Health Care Ethics Committee Network; Law & Health Care Program, University of Maryland School of Law
10. ***Steve Taylor**, Centennial Professor of Disability Studies, Director, Center on Human Policy, Syracuse University
11. ***Madeleine Will**, Vice President of Public Policy, National Down Syndrome Society

***NDRN thanks the individuals above for also endorsing this report. In addition NDRN appreciates the endorsement of the report by the National Association of Councils on Developmental Disabilities. NDRN would also like to thank Mary Nell Clark, Managing Attorney at University Legal Services in Washington, DC and the Glover Park Group.**

End Notes

¹ Anne McDonald, *The Other Story from a Pillow Angel: Been There, Done That, Preferred to Grow*, SEATTLE POST INTELLIGENCE, June 16, 2007, *available at* <http://www.seattlepi.com/local/opinion/article/The-other-story-from-a-Pillow-Angel-1240555.php#ixzz1uBhDuehY>.

² Ed Pilkington, *The Ashley treatment: Her Life is as Good as We Can Possibly Make It*, THE GUARDIAN, Mar. 15, 2012, *available at* <http://www.guardian.co.uk/society/2012/mar/15/ashley-treatment-email-exchange>.

³ Karen McVeigh, The 'Ashley treatment': Erica's Story, THE GUARDIAN, Mar. 16, 2012, *available at* <http://www.guardian.co.uk/society/2012/mar/16/ashley-treatment-ericas-story>. Karen McVeigh, Growth Attenuation Treatment: Tom, The First Boy to Undergo Procedure, THE GUARDIAN, Mar. 16, 2012, *available at* <http://www.guardian.co.uk/society/2012/mar/16/growth-attenuation-treatment-toms-story>.

⁴ Michael G. Silver, *Eugenics and Compulsory Sterilization Laws: Providing Redress for the Victims of a Shameful Era in United States History*, 72 GEO. WASH. L. REV. 862, 862 (2004).

⁵ *Id.*

⁶ Interview with Gail Lainhart-Rivas, Parent in Seattle, Wash. (May 4, 2012).

⁷ McDonald, *supra* note 1.

⁸ Robert Silverstein, *Emerging Disability Policy Framework: A Guidepost For Analyzing Public Policy*, 85 IOWA L. REV. 1691, 1695 (2000).

⁹ *Id.*

¹⁰ *Id.* at 1695.

¹¹ Robert Silverstein, Center for the Study and Advancement of Disability policy, Using Emerging Disability Policy Framework to Understand the Influence of IDEA (2005), www.disabilitypolicycenter.org.

¹² David Braddock, Richard Hemp, Mary C. Rizzolo, Laura Haffer, & Emily Shea Tanis, THE STATE OF STATE IN DEVELOPMENTAL DISABILITIES 51 (Colo. U. ed., 2011)(1977).

¹³ *Id.*

¹⁴ *Id.*

¹⁵ Silverstein, *supra* note 11.

¹⁶ Silver, *supra*, note 4.

¹⁷ Silver, *supra* note 4 at 862.

¹⁸ *Buck v. Bell*, 274 U.S. 200 (1927).

¹⁹ *Id.* at 207.

²⁰ Kim Severson, *Payment Set for Those Sterilized in Program*, N.Y. TIMES, Jan. 10, 2012, *available at* <http://www.nytimes.com/2012/01/11/us/north-carolina-sterilization-victims-get-restitution-decision.html>.

²¹ *Id.*

²² *Id.*

²³ Silver, *supra*, note 4.

²⁴ *Id.* at 862

²⁵ See *In re Hayes*, 93 Wash.2d 228 (1980).

²⁶ See *In re Estate of K.E.J.*, 382 Ill. App. 3d 401, 1st Dist. 2008; *Guardianship of Mary Moe*, No. 12-P-18, see http://msnbcmedia.msn.com/i/MSNBC/Sections/NEWS/z-pdf-archive/120119_mary_moe.pdf

²⁷ Robert Bogdan & Douglas Biklen, *Handicapism*, SOCIAL POLICY, 14, 14 (1977).

²⁸ *Id.*

²⁹ See *infra* note 153.

³⁰ *Id.*

³¹ Americans with Disabilities Act, 42 U.S.C. §§ 12101-12213 (2000).

³² *Id.* at § 12102(2).

³³ *Id.* at § 12111(9).

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- ³⁴ *Id.*
- ³⁵ See *Cupolo v. Bay Area Rapid Transit*, 5 F. Supp.2d 1078, 1084 (N.D. Cal. 1997).
- ³⁶ Testimony before House Subcommittee on Select Education and Senate Subcommittee on the Handicapped, S.Hrng. 100–926, September 27, 1988, p. 74. Others also testified to the degradation and stripping of basic human dignity that discrimination causes. See e.g. Testimony of Charles Sabatier before 324 House Subcommittee on Select Education, Ser. No. 100–109, October 24, 1988, p. 36.; Testimony of Emeka Nwojke before 42 House Subcommittee on Select Education, Ser. No. 100–109, October 24, 1988, p. 36.
- ³⁷ *Supra* note 31 at § 12101(2).
- ³⁸ *Id.* at § 12101(8),(9).
- ³⁹ *Id.* at § 12101(b)(1).
- ⁴⁰ *Id.* at § 12101(b)(2).
- ⁴¹ Silverstein, *supra* note 8 at 1695.
- ⁴² *Id.*
- ⁴³ Convention on the Rights of Persons with Disabilities (CRPD) (adopted New York, Dec. 2006, entered into force May 2008 upon ratification by the 20th nation).
- ⁴⁴ Under international law, a nation is not legally bound to the specific provisions of a treaty until the nation ratifies the treaty through the proper domestic legal process of the nation, but see, *In re Mark C.H.*, 906 N.Y.S.2d 419, 433 (Sur. 2010) (ruling under the Vienna Convention on the Law of Treaties (art. 18, May 23, 1969, 1155 U.N.T.S. 331), the US is obligated to "refrain from acts which would defeat [the Disability Convention's] object and purpose.").
- ⁴⁵ *Supra* note 43, see e.g. Art. 10 - Right to life, Art. 12 - Equal recognition before the law of individuals with disabilities, Art. 14 - Liberty and security of persons with disabilities, Art. 15 Freedom from torture or cruel, inhuman or degrading treatment or punishment, and Art. 16 – Freedom from exploitation, violence and abuse.
- ⁴⁶ *Id.* Arts. 6 and 7 (women and child with disabilities respectively).
- ⁴⁷ See *id.* at Art. 6.
- ⁴⁸ See *id.* at Art. 7(1) and (2).
- ⁴⁹ *Supra* note 43 at Art. 17.
- ⁵⁰ *Supra* note 43 at Art. 16(1).
- ⁵¹ *Supra* note 43 at Art.15(1).
- ⁵² *Supra* note 43 at Art.15(1)(b).
- ⁵³ *Supra* note 43 at Art.12(1) and (4).
- ⁵⁴ Jason Stein, *Group sues UW Hospital over policy on withholding treatment from disabled patients*, WISCONSIN STATE JOURNAL (May 14, 2009), available at <http://www.disabilityrightswi.org/archives/320>.
- ⁵⁵ Daniel F. Gunther & Douglas S. Diekema, *Attenuating Growth in Children With Profound Developmental Disability: A New Approach To An Old Dilemma*, 160 ARCHIVES OF PEDIATRICS AND ADOLESCENT MEDICINE, 1013, 1013-17 (2006).
- ⁵⁶ *Id.*
- ⁵⁷ *Id.* Gunther and Diekema fail to mention anything about the breast bud removal as being part of the treatment, yet the Children's Hospital Ethics Committee described the protocol in its ethics opinion regarding this intervention to include a mastectomy. See Special CHRMC Ethics Committee Meeting/Consultation (May, 2004) available at http://www.disabilityrightswa.org/home/Exhibits_K_T_InvestigativeReportRegardingtheAshleyTreatment.pdf. Further, as reported by Ashley's parents on their blog as well as by the surgeon involved, Ashley's breast buds were in fact removed as part of the intervention. See <http://pillowangel.org/AT-Summary.pdf>.
- ⁵⁸ Ashley treatment as term of art coined by Ashley's parents. Ashley's Mom and Dad, *The "Ashley Treatment": Towards a Better Quality of Life for "Pillow Angels"* (Mar. 17, 2012), <http://pillowangel.org/Ashley%20Treatment.pdf>.
- ⁵⁹ Pilkington, *supra* note 2.
- ⁶⁰ Gunther, *supra* note 55.

61 *Id.*
62 *Id.*
63 *Id.*
64 *Id.*
65 *Id.*
66 Ashley's Mom and Dad, *supra* note 58 at 4.
67 *Id.* at 4.
68 Douglas S. Diekema & Norman Fost, *Ashley Revisited: A Response to the Critics*. 10, THE AM. J.
OF BIOETHICS, 30, 30-42 (2010).
69 *Id.* at 31.
70 *Id.*
71 Ashley's Mom and Dad, *supra* note 58 at 4.
72 *Id.* at 8.
73 *Id.*
74 *Id.*
75 *Id.* at 11.
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77 *Id.* at 13.
78 <http://pillowangel.org/AT-Summary.pdf>
79 *Id.*
80 *Id.*
81 McVeigh, *supra* note 3.
82 Lainhart-Rivas, *supra* note 6.
83 McVeigh, *supra* note 3.
84 *Id.*
85 *Id.*
86 *Id.*
87 *Id.*
88 *Id.*
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99 *Id.*
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104 *Id.*
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106 *Id.*
107 Ed Pilkington and Karen McVeigh, '*Ashley treatment*' on the rise amid concerns from disability
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<http://www.guardian.co.uk/society/2012/mar/15/ashley-treatment-rise-amid-concerns>.
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109 McDonald, *supra* note 1.

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- ¹¹⁰ S.E. Smith, *Is the Ashley treatment right? Ask yourself if disabled people are human*, THE GUARDIAN, Mar. 16, 2012, available at <http://www.guardian.co.uk/commentisfree/2012/mar/16/ashley-treatment-disabled-people>.
- ¹¹¹ *Id.*
- ¹¹² ADAPT, *ADAPT Youth Appalled at Parents Surgically Keeping Disabled Daughter Childlike* (Jan. 5, 2007) available at <http://adaptold.adapt.org/adaptpr/index.php?mode=P&id=254>.
- ¹¹³ See http://fridanow.blogspot.com/2007_02_01_archive.html.
- ¹¹⁴ On file with author.
- ¹¹⁵ UCP & The Arc, *Joint Statement on "Ashley's Treatment"* (01/26/2007), available at http://affnet.ucp.org/ucp_generaldoc.cfm/1/9/10020/10020-10020/7108.
- ¹¹⁶ Disability Rights Education and Defense Fund, *Modify the System, Not the Person* (January 7, 2007), available at <http://dredf.org/news/ashley.shtml>
- ¹¹⁷ Hank Bersani, Jr., David A. Rotholz, Steven M. Eidelman, Joannea L. Pierson, Valerie J. Bradley, Sharon C. Gomez, Susan M. Haverkamp, Eayne P. Silverman, Mark H. Yager, Diane Morin, Michael L. Wehmeyer, Bernard J. Carabello, M. Doreen Croser, *Unjustifiable Non-Therapy: Response to the Issue of Growth Attenuation of Young People on the Basis of Disability*, 45 Intellectual and Developmental Disabilities 351, 353 (2007).
- ¹¹⁸ *Id.*
- ¹¹⁹ *Id.*
- ¹²⁰ Kristi L. Kirschner, MD, Rebecca Brashler, LCSW, Teresa A. Savage, PhD, RN, *Ashley X*, AM. J. OF PHYSICAL MEDICINE & REHABILITATION, 1023, 1023-29 (2007).
- ¹²¹ See *supra* Appendices B and C for List of Expert Panel members.
- ¹²² See *supra* Appendix A for Expert Panel Discussion Guide.
- ¹²³ The video camera was manually operated for this group discussion with the camera not pointed toward the individual who refused to be video recorded.
- ¹²⁴ Benjamin S. Wilfond, Paul Steven Miller, Carolyn Korfiatis, Douglas S. Diekema, Denise M. Dudzinski, Sara Goering, and the Seattle Growth Attenuation and Ethics Working Group, *Navigating Growth Attenuation in Children with Profound Disabilities: Children's Interests, Family Decision-Making, and Community Concerns*, 40 HASTINGS CENTER REPORT 27, 31-35 (2010).
- ¹²⁵ Gunther, *supra* note 55 at 1016.
- ¹²⁶ *Id.*
- ¹²⁷ American Medical Association Council on Ethical and Judicial Affairs, "CEJA Report 3 – I-97 Ethics Consultation" (1997).
- ¹²⁸ Individuals who cannot speak or who were unconscious also are to be afforded constitutional due process protections when their liberty, privacy, or other constitutional rights are at stake. *In re Grant*, 109 Wash.2d 545, 553, 747 P. 2d 445, 449 (1987). The *Grant* Court held that life sustaining treatment of terminally ill individual with developmental disability could be withheld stating that court found that "[a]n incompetent's right to refuse treatment should be equal to a competent's right to do so." *Id.*; *In re Hamlin*, 102 Wash.2d. 810, 816, 689 P. 2d 1372, 1376 (1984) "An incompetent patient does not lose his right to consent to termination of life supporting care by virtue of his incompetency." *Id.* citing *In re Colyer*, 99 Wash.2d 114, 124, 660 P.2d 738; *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, cert. denied, 429 U.S. 922, 97 S. Ct. 319, 50 L.Ed.2d 289 (1976); *Superintendent of Belchertown State Sch. v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977); *Leach v. Akron Gen. Med. Ctr.*, 68 Ohio Misc. 1, 426 N.E.2d 809 (1980); *Severns v. Wilmington Med. Ctr., Inc.*, 421 A.2d 1334 (Del.1980), *decision on remand*, 425 A.2d 156 (Del.Ch.1980); *John F. Kennedy Mem. Hosp., Inc. v. Blutworth*, 452 So.2d 921 (Fla.1984); *In re P.V.W.*, 424 So.2d 1015 (La.1982).
- ¹²⁹ U.S. Const. amend. I; U.S. Const. amend. XIV; the Developmental Disabilities Assistance and Bill of Rights Act, 42 U.S.C. § 15001, *et seq.*
- ¹³⁰ 42 U.S.C. § 15001(a)(1).
- ¹³¹ Americans with Disabilities Act, *supra* note 31.
- ¹³² Convention on the Rights of Persons with Disabilities, *supra* note 43.

¹³³ *Haynes v. Wash.*, 373 U.S. 503, 515, 83 S. Ct. 1336, 1344, 10 L. Ed. 2d 513 (1963) (criminal interrogation); *Matter of Moe*, 385 Mass. 555, 558, 432 N.E.2d 712, 716 (1982) (sterilization of a woman with an intellectual disability).

¹³⁴ See e.g., “[I]n America *the law is king*. For as in absolute governments the king is law, so in free countries the law *ought* to be king; and there ought to be no other.” Thomas Paine, *Common Sense*, in Nelson F. Adkins, ed, *Common Sense and Other Political Writings* 3, 32 (Liberal Arts, 1953). *Marbury v. Madison*, 1 Cranch 137, 5 U.S. 137 (1803) (holding that the constitution is the supreme law of the land and controls even the actions of the various branches of government).

¹³⁵ The concept of law as the sovereign controlling decision maker is at least as old as Aristotle. Antonin Scalia: The Rule of Law as a Law of Rules, 56 U. Chi. L. Rev. 1175, 1175-81 (1989)

¹³⁶ The United Nations defines the rule of law as a principle of governance in which all persons, institutions and entities, public and private, including the State itself, are accountable to laws that are publicly promulgated, equally enforced and independently adjudicated, and which are consistent with international human rights norms and standards. It requires, as well, measures to ensure adherence to the principles of supremacy of law, equality before the law, accountability to the law, fairness in the application of the law, separation of powers, participation in decision-making, legal certainty, avoidance of arbitrariness and procedural and legal transparency. U.N. SECRETARY-GENERAL, REPORT S/2004/616 ON THE RULE OF LAW AND TRANSITIONAL JUSTICE IN CONFLICT AND POST-CONFLICT SOCIETIES (2004), <http://www.un.org/en/ruleoflaw/>.

¹³⁷ E.g., Benjamin S. Wilfond, Paul Steven Miller, Carolyn Korfiatis, Douglas S. Diekema, Denise M. Dudzinski, Sara Goering, and the Seattle Growth Attenuation and Ethics Working Group, *Navigating Growth Attenuation in Children with Profound Disabilities: Children's Interests, Family Decision-Making, and Community Concerns*, 40 HASTINGS CENTER REPORT 27 (2010) (citing the involvement of judicial safeguards to resolve disputes as onerous); see also David B. Allen, Michael Kappy, Douglas Diekema, Norman Fost, *Growth Attenuation Therapy: Principles for Practice*, 123 PEDIATRICS 1556, 1559 (2009) (“In the Ashley case, a disability rights group persuaded the Seattle Children’s Hospital to agree that they would never begin such treatment without review by a court. Apart from political considerations, it is difficult to discern a principled basis for such an extraordinary restriction for a treatment that incurs such low medical risk.”).

¹³⁸ See Merle Spriggs, *Ashley’s Interests Were Not Violated Because She Does Not Have Necessary Interests*, 10 THE AMERICAN JOURNAL OF BIOETHICS, 52-54 (2010) (proposing that dignity and rights do not affix to a person with significant intellectual disabilities).

¹³⁹ Many who have written about the Ashley Treatment or the individual procedures that make up the treatment focus on the medical or philosophical considerations, but spend little to no time seriously considering the existing legal rights of the individual child. See e.g., Benjamin S. Wilfond, Paul Steven Miller, Carolyn Korfiatis, Douglas S. Diekema, Denise M. Dudzinski, Sara Goering, and the Seattle Growth Attenuation and Ethics Working Group, *Navigating Growth Attenuation in Children with Profound Disabilities: Children's Interests, Family Decision-Making, and Community Concerns*, 40 HASTINGS CENTER REPORT 27 (2010); David B. Allen, Michael Kappy, Douglas Diekema, Norman Fost, *Growth Attenuation Therapy: Principles for Practice*, 123 PEDIATRICS 1556, 1559 (2009); Merle Spriggs, *Ashley’s Interests Were Not Violated Because She Does Not Have Necessary Interests*, 10 THE AMERICAN JOURNAL OF BIOETHICS, 52-54 (2010); Peter Singer, A Convenient Truth, NEW YORK TIMES (Jan. 26, 2007).

¹⁴⁰ Antonin Scalia, *The Rule of Law as a Law of Rules*, 56 U. Chi. L. Rev. 1175, 1175-81 (1989).

¹⁴¹ David R. Carlson, Deborah A. Dorfman, *WPAS Investigative Report into the “Ashley Treatment”*, 16-21 (2007), <http://www.disabilityrightswa.org/home/ashley-treatment-investigation>.

¹⁴² *Cruzan by Cruzan v. Dir., Missouri Dept. of Health*, 497 U.S. 261, 269, 110 S. Ct. 2841, 2846, 111 L. Ed. 2d 224 (1990) (“At common law, even the touching of one person by another without consent and without legal justification was a battery.”, citing *W. Keeton, D. Dobbs, R. Keeton, & D. Owen, PROSSER AND KEETON ON LAW OF TORTS* § 9, pp. 39-42 (5th ed. 1984).

¹⁴³ *Cruzan*, 497 U.S. at 278 (guardians of individual with significant disabilities brought declaratory judgment action seeking judicial sanction of their wish to terminate artificial hydration and nutrition for individual).

¹⁴⁴ *Cruzan*, 497 U.S. at 272.

¹⁴⁵ *Cruzan* 497 U.S. at, 271-77 (discussing the various ways in which the common law right to bodily integrity and to be free from assault is addressed by different states when a patient is no longer competent to provide informed consent) *citing*, *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728, 370 N.E.2d 417 (1977) (applying substituted judgment to make decision impacting the right of privacy and the right of informed consent to permit the withholding of chemotherapy for a man with an intellectual disability); *In re Eichner*, 52 N.Y.2d 363, 380, 438 N.Y.S.2d 266, 420 N.E.2d 64, cert. denied, 454 U.S. 858, 102 S.Ct. 309, 70 L.Ed.2d 153 (1981) (others allowed to exercise right to remove respirator based on clear and convincing evidence of patient's past wishes); *In re Conroy*, 98 N.J. 321, 361-368, 486 A.2d 1209 (1985) (the right of self-determination should not be lost merely because an individual is unable to sense a violation of it and can be exercised by another if there is clear evidence of how the patient would have exercised his rights and in certain situations under best interest standard); *In re Westchester County Medical Center on behalf of O'Connor*, 72 N.Y.2d 517,530, 534 N.Y.S.2d 886, 531 N.E.2d 607 (1988) (refusal to accept surrogate decision maker's decision where there is less than a clear expression of the patient's wishes); *Conservatorship of Drabick*, 200 Cal.App.3d 185, 208, 245 Cal.Rptr. 840, 854-855 cert. denied, 488 U.S. 958, 109 S.Ct. 399, 102 L.Ed.2d 387 (1988) (upholding state statutory authorization of terminating life support based on medical advice and best interests); *In re Conservatorship of Torres*, 357 N.W.2d 332 (Minn.1984) (upholding state constitutional and statutory authority remove life support based on best interests); *In re Estate of Longeway*, 133 Ill.2d 33, 45-47, 139 Ill.Dec. 780, 549, 549 N.E.2d 292, 298 (1989) (state statute impacts informed consent and authorizes guardian to withhold life sustaining treatment based on "quality of life" if the patient is terminally ill or in an irreversible coma); *McConnell v. Beverly Enterprises-Connecticut, Inc.*, 209 Conn. 692, 705, 553 A.2d 596, 603 (1989) (upholding state statute which "provid[es] functional guidelines for the exercise of the common law and constitutional rights of self-determination"; attending physician authorized to remove life sustaining treatment if terminal condition, consent of family is given, and considers expressed wishes of patient).

¹⁴⁶ *Id.*

¹⁴⁷ See e.g., *In re Eichner*, 52 N.Y.2d 363, 380, 438 N.Y.S.2d 266, 420 N.E.2d 64, cert. denied, 454 U.S. 858, 102 S.Ct. 309, 70 L.Ed.2d 153 (1981) (others allowed to exercise right to remove respirator based on clear and convincing evidence of patient's past wishes); *In re Conroy*, 98 N.J. 321, 361-368, 486 A.2d 1209 (1985) (the right of self-determination should not be lost merely because an individual is unable to sense a violation of it and can be exercised by another if there is clear evidence of how the patient would have exercised his rights and in certain situations under best interest standard); *In re Westchester County Medical Center on behalf of O'Connor*, 72 N.Y.2d 517,530, 534 N.Y.S.2d 886, 531 N.E.2d 607 (1988) (refusal to accept surrogate decision maker's decision where there is less than a clear expression of the patient's wishes).

¹⁴⁸ See e.g., RCW 11.92.140 (providing in part: "The court...may authorize the guardian to take any action, or to apply funds not required for the incapacitated person's own maintenance and support, in any fashion the court approves as being in keeping with the incapacitated person's wishes so far as they can be ascertained...").

¹⁴⁹ See e.g., RCW 11.88.005.

¹⁵⁰ See Certified Professional Guardian Standard of Practice Regulations (hereinafter "CPG Reg.") 401.7 provides in part: "the guardian shall acknowledge the residual capacity of the incapacitated person to participate in or make some decisions."; CPG Reg. 402.1 provides in part: "the guardian shall make reasonable efforts to ascertain (he incapacitated person's historic preferences and shall give significant weight to such preferences".

¹⁵¹ *In re Guardianship of Lamb*, 173 Wash. 2d 173, 265 P.3d 876 (2011). See also, CPG Reg. 406.5.4 provides in part: "...the guardian shall...Consider the incapacitated person's ability to gain the benefits of specific decisions."; CPG Reg. 406.3 provides in part: "The guardian shall manage the estate with the primary goal of providing for the needs of the incapacitated person."; CPG Reg. 401 provides in part: "The independence and self-reliance of the incapacitated person shall be maximized to the greatest extent...."

¹⁵² *In re Colyer*, 99 Wash.2d 114, 128, 660 P.2d 738. It is important to note, however, that the *Colyer* court did not preclude judicial intervention after the appointment of a guardian, if necessary. *Id.* at 132. If judicial intervention subsequent to the guardianship appointment is required, however, a guardian ad litem would again be appointed to protect the interests of the incompetent in that proceeding. The guardian ad litem's function in this context would be to discover all of the facts relevant to the decision to withdraw life sustaining treatment and present them to the court. *Internal citations omitted. Id.* See also *In re Estate of Longeway*, 133 Ill.2d 33, 45-47, 139 Ill.Dec. 780, 549, 549 N.E.2d 292, 298 (1989) (state statute impacts informed consent and authorizes guardian to withhold life sustaining treatment based on "quality of life" if the patient is terminally ill or in an irreversible coma); *McConnell v. Beverly Enterprises-Connecticut, Inc.*, 209 Conn. 692, 705, 553 A.2d 596, 603 (1989) (upholding state statute which "provid[es] functional guidelines for the exercise of the common law and constitutional rights of self-determination"; attending physician authorized to remove life sustaining treatment if terminal condition, consent of family is given, and considers expressed wishes of patient).

¹⁵³ RCW 11.92.043(5) (a); see also RCW 71.05.217(7).

¹⁵⁴ RCW 11.92.043(5); see also RCW 71.05.215, RCW 71.05.217(7).

¹⁵⁵ See *Hayes*, 93 Wash.2d 228; *In re KM*, 62 Wash. App. 811 (1991).

¹⁵⁶ RCW 11.92.043(5).

¹⁵⁷ See *id.* (requiring a guardian, standby guardian or limited guardian who believes that psychiatric or other mental health procedures that restrict physical freedom of movement or other rights as set forth in RCW 71.05.370, to seek a court order for such treatment unless the court has previously authorized such treatment within the past 30 days following a full hearing where the individual for whom the treatment has been sought has been afforded full procedural due process protections including representation by an attorney and a full hearing held.)

¹⁵⁸ See *Hayes*, 93 Wash.2d at 236 (stating that "of great significance" in case where parent sought to sterilize child with a developmental disability was the fact that in such cases the parents' interest in obtaining the sterilization cannot be presumed to be the same as the minor for whom the sterilization is sought); see also *Koome*, 84 Wash.2d at 904 (holding that the constitutional rights of children are "[p]rima facie coextensive with those of adults.").

¹⁵⁹ *Prince*, 321 U.S. at 167.

¹⁶⁰ *Parham*, 442 U.S. at 585.

¹⁶¹ *Id.* at 584; *T.B. v. Fairfax Hosp. Wash.*, 129 Wash.2d 439, 452-53 (1996).

¹⁶² *In re A.M.P.*, 303 Ill. App.3d 907, 914-15, 708 N.E.2d 1235, 1240-41 (1999); RCW 71.34.355(9) (requiring a court order following a full hearing and procedural due process protections afforded the child before the child can be treated with ECT in non-emergency situations).

¹⁶³ RCW 71.34.355(10) (affording the rights of children "not to every have psychosurgery performed on him or her under any circumstances.")

¹⁶⁴ *State v. Koome*, 84 Wash.2d 901, 909-10 (1975).

¹⁶⁵ *Hayes*, 93 Wash.2d 228 (1980); *K.M.*, 62 Wash. App. 811 (1991); *In re Mary Moe*, 432 N.E. 2d 712, 716-17 (Mass. 1982); *In re Rebecca D. Nilsson*, 471 N.Y. Supp.2d 439 (1983).

¹⁶⁶ See e.g., *State v. Baxter*, 134 Wash. App. 587, 141 P.3d 92 (2006). The *Baxter* court stated that a father's right to make religiously based decisions for his children does not allow him to perform a circumcision on his eight year old son with a hunting knife. The court pointed out that "[b]oth corporal punishment and religious practice are grounded in the parents' beliefs as to the best interests of the child, and as parental control over the child's upbringing does not justify cutting the child as punishment, it does not justify cutting the child as a religious exercise." *Id.* at 602.

¹⁶⁷ UNITED STATES COMMISSION ON CIVIL RIGHTS, MEDICAL DISCRIMINATION AGAINST CHILDREN WITH DISABILITIES (1989), <http://www.eric.ed.gov/PDFS/ED326018.pdf>.

¹⁶⁸ *Id.* at 142-147.

¹⁶⁹ See e.g., *P.S. by Harbin v. W.S.*, 452 N.E.2d 969 (Ind.,1983); *In re C.D.M.*, 627 P.2d 607 (Alaska 1981); *In re A.W.*, 637 P.2d 366 (Colo.1981); *In re Grady*, 85 N.J. 235, 426 A.2d 467(1981); *In re Eberhardy*, 102 Wis.2d 539, 307 N.W.2d 881(1981); *In re Sallmaier*, 85 Misc.2d 295, 378 N.Y.S.2d

989 (1976); *In re Terwilliger*, 304 Pa. Super. 553, 450 A.2d 1376 (1982); *In re Penny N.*, 120 N.H. 269, 414 A.2d 541 (1980); *Hayes*, 93 Wash.2d 228; *K.M.*, 62 Wash. App. 811.

¹⁷⁰ *Id.*

¹⁷¹ See *Hayes*, 93 Wash.2d 228; *K.M.*, 62 Wash. App. 811

¹⁷² *Id.* See also *Infra* notes 210-220 and accompanying text.

¹⁷³ U.S. Const. amend. XIV, § 1.

¹⁷⁴ *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942).

¹⁷⁵ *Harper v. Washington*, 494 U.S. 210, 221-22 (1990) (the right to refuse psychiatric medication).

¹⁷⁶ *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 278 (1990) (the right to refuse life sustaining treatment).

¹⁷⁷ *Skinner*, 316 U.S. at 541.

¹⁷⁸ *Planned Parenthood of Southeastern Pa. v. Casey*, 505 U.S. 833, 851, 112 S.Ct. 2791, 120 L.Ed.2d 674 (1992),

¹⁷⁹ *Griswold v. Connecticut*, 382 U.S. 478, 485 (1965) (Court found state law criminalizing the use of contraceptive unconstitutional because it infringed upon marital privacy rights); *Eisenstadt v. Baird*, 405 U.S. 438, 454-55 (1972) (extending the right to privacy in making decisions regarding contraception to unmarried individuals).

¹⁸⁰ *Roe v. Wade*, 410 U.S. 113, 153 (1973) (women have the right to privacy to decide whether to have an abortion); see also *Planned Parenthood of Southeastern Pennsylvania v. Casey*, 505 U.S. 833, 849 (1992).

¹⁸¹ *In re Guardianship of Moe*, 81 Mass. App. Ct. 136, 139, 960 N.E.2d 350, 354 (2012) (“Because sterilization is the deprivation of the right to procreate, it is axiomatic that an incompetent person must be given adequate notice of the proceedings, an opportunity to be heard in the trial court on the issue of the ability to give informed consent, a determination on the issue of substituted judgment if no such ability is found, and the right to appeal.”); *Hayes*, 93 Wash.2d 228, 237, (1980) (holding, in relevant part, that although involuntary sterilization of an individual with a developmental disability may, in rare instances, be in the best interests of the individual, “the court must exercise care to protect the individual’s right to privacy....”); see also *K.M.*, 62 Wash. App. 811, 818 (1991) (holding individuals with developmental disabilities must have an effective independent advocate when sterilization is contemplated); *In re Mary Moe*, 432 N.E. 2d 712, 716-17 (Mass. 1982) (Court held that “sterilization is an extraordinary and highly intrusive form of medical treatment that irreversibly extinguishes the ward’s fundamental right of procreative choice”).

¹⁸² *Roe v. Wade*, 410 U.S. 113, 155 (1973), citing *Kramer v. Union Free School District*, 395 U.S. 621, 627, 89 S.Ct. 1886, 1890, 23 L.Ed.2d 583 (1969); *Shapiro v. Thompson*, 394 U.S. 618, 634, 89 S.Ct. 1322, 1331, 22 L.Ed.2d 600 (1969); *Sherbert v. Verner*, 374 U.S. 398, 406, 83 S.Ct. 1790, 1795, 10 L.Ed.2d 965 (1963).

¹⁸³ *Roe v. Wade*, 410 U.S. 113, 155 (1973), quoting *Kramer v. Union Free School District*, 395 U.S. 621, 627, 89 S.Ct. 1886, 1890, 23 L.Ed.2d 583 (1969); *Shapiro v. Thompson*, 394 U.S. 618, 634, 89 S.Ct. 1322, 1331, 22 L.Ed.2d 600 (1969); *Sherbert v. Verner*, 374 U.S. 398, 406, 83 S.Ct. 1790, 1795, 10 L.Ed.2d 965 (1963).

¹⁸⁴ *Roe v. Wade*, at 155, citing *Griswold v. Connecticut*, 381 U.S., at 485, 85 S.Ct., at 1682; *Aptheker v. Secretary of State*, 378 U.S. 500, 508, 84 S.Ct. 1659, 1664, 12 L.Ed.2d 992 (1964); *Cantwell v. Connecticut*, 310 U.S. 296, 307-308, 60 S.Ct. 900, 904-905, 84 L.Ed. 1213 (1940); see *156 *Eisenstadt v. Baird*, 405 U.S., at 460, 463-464, 92 S.Ct., at 1042, 1043-1044 (White, J., concurring in result).

¹⁸⁵ See *id.*

¹⁸⁶ *United States v. Carolene Products Co.*, 304 U.S. 144, 152, 58 S. Ct. 778, 783, 82 L. Ed. 1234 (1938).

¹⁸⁷ *Skinner*, 316 U.S. 535; *Carolene Products*, 304 U.S. 144.

¹⁸⁸ *Cleburne v. Cleburne Living Center*, 473 U.S. 432, 439, 105 S.Ct. 3249 (1985).

¹⁸⁹ *Carolene Products*, 304 U.S. 144.

¹⁹⁰ *Skinner*, 316 U.S. 535

¹⁹¹ *Carolene Products*, 304 U.S. 144..

¹⁹² *Id.*

¹⁹³ *Id.*

¹⁹⁴ *Cleburne Living Center*, 473 U.S. 432.

¹⁹⁵ *Id.* citing *Mississippi University for Women v. Hogan*, 458 U.S. 718, 102 S.Ct. 3331, 73 L.Ed.2d 1090 (1982); *Craig v. Boren*, 429 U.S. 190, 97 S.Ct. 451, 50 L.Ed.2d 397 (1976).

¹⁹⁶ *Cleburne Living Center*, 473 U.S. at 432.

¹⁹⁷ *Id.* at 450.

¹⁹⁸ *Id.*

¹⁹⁹ 29 U.S.C. § 701.

²⁰⁰ 42 U.S.C. § 12132 (state and local government services may not discriminate against people with disabilities); 42 U.S.C. § 12182 (places of public accommodation may not discriminate against people with disabilities).

²⁰¹ 42 U.S.C. § 12132. See also “A public entity may not, directly or through contractual or other arrangements, utilize criteria or other methods of administration: (i) that have the effect of subjecting qualified individuals with disabilities to discrimination on the basis of disability;. . . .” 28 C.F.R. § 35.130(b)(3); 28 C.F.R. § 41.51(b)(3)(i); 45 C.F.R. § 84.4(b)(4).

²⁰² *Weinreich v. Los Angeles County Metro. Transp. Auth.*, 114 F.3d 976, 978 (9th Cir. 1997) (emphasis omitted).

²⁰³ See 29 U.S.C. § 794. The rights and obligations created pursuant to the Rehabilitation Act and the Americans with Disabilities Act are very similar. Therefore, where there is no substantive difference between the provisions of the acts, they are interpreted as consistent with one another. *E.g. M.R. v. Dreyfus, et al.*, 663 F.3d 1100 (9th Cir. 2011)..

²⁰⁴ H.R. Rep. No. 101-485, at 29, as reprinted in 1990 U.S.C.C.A.N. 303, 310-11.

²⁰⁵ H.R. Rep. No. 101-485, at 31, as reprinted in 1990 U.S.C.C.A.N. 303, 312, , (quoting U.S. COMMISSION ON CIVIL RIGHTS, ACCOMMODATING THE SPECTRUM OF INDIVIDUAL ABILITIES, p. 159). See also, Testimony before Senate Subcommittee on the Handicapped, S. Hrng. 101–156, May 10, 1989, p. 100. Robert Burgdorf, Jr., Professor of Law at the District of Columbia School of Law, testified “... it makes no sense to bar discrimination against people with disabilities in theaters, restaurants, or places of entertainment but not in regard to such important things as doctor's offices. It makes no sense for a law to say that people with disabilities cannot be discriminated against if they want to buy a pastrami sandwich at the local deli but that they can be discriminated against next door at the pharmacy where they need to fill a prescription. There is no sense to that distinction.” *Id.*

²⁰⁶ *Bay Area Addiction Research & Treatment, Inc. v. City of Antioch*, 179 F.3d 725, 731-32 (9th Cir. 1999) (internal citations omitted).

²⁰⁷ *Swenson v. Lincoln County Sch. Dist. No. 2*, 260 F. Supp. 2d 1136, 1146-47 (D. Wyo. 2003) (holding it is discriminatory for a school to treat a student with a disability as a “second-class citizen”).

²⁰⁸ Lest individuals attempt to rationalize discriminatory action based on disability, they should take note of the well articulated testimony before Congress by Arlene Mayerson of the Disability Rights Education and Defense Fund during deliberation of the ADA in which she pointed out that “The discriminatory nature of policies and practices that exclude and segregate disabled people has been obscured by the unchallenged equation of disability with incapacity and by the gloss of “good intentions.” The innate biological and physical ‘inferiority’ of disabled people is considered self-evident.” Testimony before House Subcommittees on Select Education and Employment Opportunities, Ser. No. 101–51, September 13, 1989, pp. 78–79.

²⁰⁹ See *Cupolo v. Bay Area Rapid Transit*, 5 F. Supp.2d 1078, 1084 (N.D. Cal. 1997). Additional support is provided in the Congressional testimony of Judith Heumann who highlighted the harm caused by the propensity to treat people with disabilities as second class citizens in her testimony to Congress while it considered passage of the ADA that: “In the past disability has been a cause of shame. This forced acceptance of second-class citizenship has stripped us as disabled people of pride and dignity ... This stigma scars for life.” Testimony before House Subcommittee on Select Education and Senate Subcommittee on the Handicapped, S.Hrng. 100–926, September 27, 1988, p. 74. Others also testified to the degradation and stripping of basic human dignity that discrimination

causes. See e.g. Testimony of Charles Sabatier before 324 House Subcommittee on Select Education, Ser. No. 100–109, October 24, 1988, p. 36.; Testimony of Emeka Nwojke before 42 House Subcommittee on Select Education, Ser. No. 100–109, October 24, 1988, p. 36.

²¹⁰ *Tennessee v. Lane*, 541 U.S. 509, 124 S. Ct. 1978, 158 L. Ed. 2d 820 (2004).

²¹¹ *Id.* at 533.

²¹² Although *Lane* involved plaintiffs with physical disabilities, there is nothing in the *Lane* decision, Title II of the ADA, its implementing regulations, and the DOJ interpretive guidance to the regulations, to suggest that the right to access to the court is not equally applicable to people with mental, developmental or intellectual disabilities or to limit access based on severity of disability.

²¹³ *Lane*, 541 U.S. at 532-533.

²¹⁴ In *Conservatorship of Valerie N.*, 40 Cal.3d 143 (1985), the California Supreme Court held that individuals with developmental disabilities, including those who have conservators, have a due process right to be free from involuntary sterilization. In response to *Valerie N.*, the California Legislature enacted (Prob. Code § 1950, *et seq.*) In doing so, the Legislature intended to ensure that “no individual shall be sterilized solely by reason of a developmental disability and that no individual who knowingly opposes sterilization be sterilized involuntarily.” (Prob. Code § 1950.) The Legislature also expanded the due process requirements established by *Valerie N.* by requiring a higher burden of proof to justify the involuntary sterilization of an individual with a developmental disability by a conservator in order to ensure heightened protection of individuals with developmental disabilities from sterilization by their conservators; *In re Hop*, 29 Cal. 3d 82, 93-94 (1981) (holding that individuals with intellectual disabilities for whom civil commitment is sought are “entitled to the same congeries of rights including the right to a jury trial on demand as individuals with mental illness. In doing so, this Court explicitly rejected the argument made by the Respondent that “[p]ersons who are so low functioning that they cannot in any way object could not assist in any hearing on their behalf anyway.”) *People v. Wilkinson*, 185 Cal. App. 4th 543 (5th Div. 2010) (Court rejected the state’s assertion that a person with an intellectual disability could be barred from filing an appeal because of their intellectual disability. The Court stated that if adopted, such a rule would “effectively be precluding appellate review in all cases finding that an individual to be mentally retarded. Such a result hardly comports with the concept of due process.”); *People v. Alvas*, 221 Cal. App. 3rd 1459, 1463 (1990)(commitment of man with an intellectual disability reversed and remanded for retrial where he was denied his right to an advisement of his right to a jury trial in violation his rights under the Constitution to equal protection and due process.); *People v. Bailee*, 144 Cal. App. 4th 841 (2006) (holding that individuals with intellectual disabilities should not be afforded a different and lesser demanding standard of proof of dangerousness than others for whom commitment is sought based upon his or her dangerousness. *Cf. Heller v. Doe*, *Heller v. Doe*, 509 U.S. 312 (1993), the US Supreme Court addressed the issue of whether a person with an intellectual disability could be provided different and lesser due process protections in the context of civil commitment than for people with psychiatric disabilities. The court, in upholding the different standards for commitment, using a rational basis analysis, found that the differences in the standards for the commitment were rationally based because of the differences in conditions and treatment of those conditions; *In the Matter of GM*, 203 P. 3d 818 (upholding less protective commitment standards for people with intellectual standards than for people with mental illness); *People v. Barrett*, 181 Cal. App. 4th 196 (2009) *rev. granted* 229 P. 3d 11 (2010)(holding that persons with an intellectual disabilities committed under California’s commitment statute for people with intellectual disabilities are not entitled to an advisement of her a right to a jury trial concluding that people with “mental retardation” are incompetent to understand their rights and have “subaverage general intellectual functioning.” Review of this case is currently pending before the California Supreme Court).

²¹⁵ The Supreme Court has ruled that developmental disability is subject only to a rational basis review under a constitutional equal protection analysis. *Cleburne v. Cleburne Living Center, Inc.*, 473 U.S. 432, 447 (1985).

²¹⁶ *Board of Trustees of University of Alabama v. Garrett*, 531 U.S. 356, 373 (2001) (“The ADA also forbids “utilizing standards, criteria, or methods of administration” that disparately impact the

disabled, without regard to whether such conduct has a rational basis.”); *Lavia v. Pennsylvania Dept. of Corrections*, 224 F. 3d 190, 200 (3d Cir. 2000)((citations omitted).

²¹⁷ 28 C.F.R. §§ 35.130(b)(1)(iv) & (8), 41.51(b)(1)(iv) (prohibiting the provision of different or separate aid, benefits, or services to “any class of handicapped persons”).

²¹⁸ *Lane*, 541 U.S. at 527 (noting in relevant part, the extensive history of courts’ “failure to permit testimony of adults with developmental disabilities in abuse cases,...”); *see also Randolph v. Rodgers*, 170 3d 850 (8th Cir. 1999) (Title II of the ADA applies to the rights of prisoners to have “meaningful access” to a prison’s disciplinary process “even if [the inmate] was capable of limited participation.”).

²¹⁹ *Barden v. City of Sacramento*, 292 3d 1073, 1077 (9th Cir. 2002) *quoting Hanson v. Med. Board*, 279 F. 3d 1167, 1172 (*quoting Arnold v. United Parcel Serv., Inc.*, 136 F. 3d 854, 861 (1st Cir. 1998)(alteration in the original) (“the Act must be construed ‘broadly in order to effectively implement the ADA’s fundamental purpose of ‘provid[ing] a clear and comprehensive mandate for the elimination of discrimination against individuals with disabilities.’”)

²²⁰ Different states use slightly different definitions of substituted judgment but the most common form of substituted judgment is based on language from Section 314(a) of the Uniform Guardianship and Protective Proceedings Act (“Uniform Act”): A guardian, in making decisions, shall consider the expressed desires and personal values of the ward to the extent known to the guardian. Unif. Guardianship & Protective Proc. Act 314 (a) cmt. (1997), 8A, U.L.A. 370 (2003).

National Disability Rights Network

900 Second Street, NE, Suite 211

Washington, DC 20002

Tel: 202.408.9514 • Fax:202.408.9520 • TTY:202.408.9521

www.ndrn.org