

Investigative Report Regarding the “Ashley Treatment”

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Washington Protection and Advocacy System is a
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*Consistent with a national trend among protection and advocacy agencies, the Washington Protection and Advocacy System will change its name to Disability Rights Washington effective June 1, 2007.

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Executive Summary

- The Washington Protection and Advocacy System (WPAS) is the federally mandated protection and advocacy (P&A) agency for the state of Washington. The P&As, which exist in every state and territory, are “watchdog” agencies with legal authority under federal statutes to investigate allegations of abuse and neglect of persons with disabilities and to advocate for their legal and human rights.
- Pursuant to its federal authority, WPAS initiated its investigation of what happened to Ashley in regards to her “Ashley Treatment” after publication of a medical journal article describing the medical interventions provided to a young child with developmental disabilities and suggesting it might be appropriate for others. WPAS also received numerous complaints after widespread media coverage of the situation.
- Ashley is a girl with developmental disabilities who was six years old at the time the interventions began. The intervention included surgical removal of her uterus and breast buds, as well as high-dosage hormone therapy to limit her growth and physical sexual development.
- The Washington Supreme Court has ruled that when a parent or anyone else seeks to sterilize an incompetent individual with a developmental disability, the individual must be afforded due process and a multi-factored test must be proven by clear and convincing evidence before a court can authorize the sterilization.
- The “Ashley Treatment” was conducted by physicians at Children’s Hospital, at the request of Ashley’s parents and after review by the Hospital’s Ethics Committee. There was, however, no court order sought or obtained before the sterilization portion of the “Ashley Treatment” was performed.
- **FINDINGS:** The sterilization portion of the “Ashley Treatment” was conducted in violation of Washington State law, resulting in violation of Ashley’s constitutional and common law rights.
 - The Washington Supreme Court has held that a court order is required when parents seek to sterilize their minor or adult children with developmental disabilities, and that the individual must be zealously represented by a disinterested third party in an adversarial proceeding to determine whether the sterilization is in the individual’s best interests.
 - Courts have also limited parental authority to consent to other types of medical interventions that are highly invasive and/or irreversible, particularly when the interest of the parent may not be identical to the interest of the child. Thus, the other aspects of the “Ashley Treatment” – surgical breast bud removal and hormone treatments – should also require independent court evaluation and sanction before being performed on any person with a developmental disability.
 - The implementation of the “Ashley Treatment” also raises discrimination issues because, if not for the individual’s developmental disabilities, the interventions would not be sought. Such discrimination against individuals

because of their disabilities is expressly forbidden by state and federal law.

- The violations appear to have occurred as a result of:
 - a lack of policies at Children’s Hospital regarding the sterilization of minors with developmental disabilities;
 - an opinion of Ashley’s parents’ counsel that no court order was required. This legal opinion was not supported by Washington law;
 - reliance upon that opinion by doctors at Children’s Hospital and the mistaken belief that the opinion of Ashley’s parents’ counsel constituted a “court review;” and
 - insufficient internal controls at Children’s Hospital to ensure that Ashley’s independent legal interests were protected.

- As a result of the WPAS investigation, Children’s Hospital has agreed to take the following corrective actions:
 - Develop and implement a policy to prohibit sterilizations of persons with developmental disabilities without a court order. The policy will assure that all appeal periods and appeals, if any, are exhausted before any procedures are performed;
 - Improve internal controls and oversight to insure that no sterilizations can take place without the necessary court order; and
 - Give notice to WPAS of requested sterilization of persons with developmental disabilities so that it can continue to act as a watchdog on behalf of individuals with disabilities.

- Additionally, Children’s Hospital has also agreed to take the following additional steps to protect the rights of children with developmental disabilities for whom the “Ashley Treatment” or other growth-limiting interventions are sought:
 - Develop and implement a policy to prohibit growth-limiting medical interventions on persons with developmental disabilities without a court order. The policy will ensure that all appeal periods and appeals, if any, are exhausted before any procedures are performed;
 - Give notice to WPAS of requested “Ashley Treatment” and other growth-limiting interventions of persons with developmental disabilities so that it can continue to act as a watchdog on behalf of individuals with disabilities; and improve internal controls and oversight to assure that no such procedures can take place without the necessary court order. To the extent that it is medically viable, the policy will include provisions to monitor the prescriptions for high dosages of hormones that the Hospital’s pharmacy has been asked to fill; and
 - Include a disability rights advocate on the Hospital’s Ethics Committee. The Committee will also bring in experts in particular relevant areas as it relates to medical care and interventions for individuals with developmental disabilities, as appropriate.

- **NEXT STEPS:** In order to continue advocating for the rights of people with developmental disabilities for whom sterilization or growth-limiting interventions may be contemplated, WPAS will:
 - work with Children’s Hospital in ways identified in Section V of this Report and monitor the implementation of the Agreement between Children’s and WPAS;
 - conduct outreach to courts and guardians *ad litem* to advise them of WPAS’s availability to provide technical assistance to guardians *ad litem* and/or representation for children with disabilities for whom a court order is being sought to perform a sterilization, the “Ashley Treatment,” or other growth-limiting medical interventions;
 - provide technical assistance to other P&As and disability rights related organizations throughout the country who wish to address issues related to sterilization, the “Ashley Treatment,” or other growth-limiting interventions for children with disabilities, and conduct activities similar to those WPAS is doing in Washington State;
 - participate in opportunities to educate the public on legal and other issues related to sterilization, the “Ashley Treatment,” or other growth-limiting interventions for children with disabilities, from the perspective of the disability community;
 - promote the availability of WPAS’s advocacy services to obtain assistive technology to facilitate mobility and ease of providing personal care where funding is required by law; and
 - widely disseminate this report to various organizations and agencies in an attempt to draw attention to the need to take proactive measures to protect individuals with developmental disabilities.

WPAS will also collaborate with our partners in the disability community to:

- identify and promote the best candidates who have a “disability perspective” for participation in hospital ethics committees around the state;
- conduct outreach to hospitals throughout the state to encourage them to adopt policies similar to the ones being developed for Children’s;
- develop a strategy for reaching and educating doctors who may be considering providing high doses of hormones for the purpose of growth attenuation of individuals with developmental disabilities on an outpatient basis in their offices and without the involvement of any hospital;
- create and disseminate educational materials and make presentations to train doctors, medical students, members of hospital ethics committees, judges, guardians *ad litem*, lawyers, law students, people with disabilities and parents of people with disabilities on legal and other issues related to sterilization, the “Ashley Treatment,” and other growth-limiting medical interventions for children with developmental disabilities from the perspective of members of the disability community;

- work with agencies involved in certification, accreditation, and licensing of hospitals and health care providers to assure that standards, criteria and requirements related to the provision of sterilization, the “Ashley Treatment,” and other growth-limiting medical interventions for children with disabilities are clear, consistent with the law, and communicated to those who need to know;
- work with health insurance companies operating in Washington State and around the country to assure that their policies for reimbursing costs of the “Ashley Treatment” and other growth-limiting medical interventions for individuals with developmental disabilities are clear, consistent with the law, and communicated to those who need to know;
- work with the disability community in Washington State and around the country to identify and advocate other ways to restrict the performance of the “Ashley Treatment” and related growth-limiting medical interventions for children with disabilities to the furthest extent possible;
- to the extent necessary, seek the means necessary to accomplish the above in a timely manner; and
- work with people on every side of the debate to join together to improve the services and supports for children with disabilities and their families.

Washington Protection and Advocacy System & the National Disability Rights Network

WPAS is a private non-profit advocacy agency that is federally mandated to provide protection and advocacy services to individuals with disabilities in the state of Washington pursuant to the Developmental Disabilities Assistance and Bill of Rights (DD) Act, 42 U.S.C. § 15041, *et seq.*, the Protection and Advocacy for Individuals with Mental Illnesses Act, 42 U.S.C. § 10801, *et seq.*, the Protection and Advocacy for Individual Rights Act, 29 U.S.C. §794e, and the regulations promulgated thereto, as well as section 71A.10.080 of the Revised Code of Washington.

Over 60 percent of the members of WPAS's Board of Directors, Disability Advisory Council, and Mental Health Advisory Council have disabilities or are family members of people with disabilities. These groups provide ongoing guidance to WPAS regarding where it should direct its advocacy. WPAS's advocacy takes many forms, including information and referral services to thousands each year, policy and systemic reform advocacy in the state capital and around the state, as well as impact litigation including class actions and other individual and group legal representation to assist tens of thousands of people with disabilities in Washington.¹

WPAS is a member of the National Disability Rights Network (NDRN).² As one of the 57 federally mandated Protection & Advocacy ("P&A") Systems throughout the United States and its territories, WPAS receives most of its funding from the federal government.³ Federal law requires that each state, district, and territory have a P&A dedicated to advocate for and protect the rights of people with disabilities.⁴ The Appendix (App. 1, Ex. A) contains a list of contacts from other state P&As who have expressed a willingness to share information about applicable state law in their state related to sterilization and the growth-limiting medical interventions, such as the "Ashley Treatment," for children with developmental disabilities.⁵

In addition to general advocacy authority, Congress gave P&As such as WPAS the specific authority to investigate incidents of alleged abuse⁶ and neglect,⁷ as those terms

¹ See <http://www.wpas-rights.org>.

² See <http://ndrn.org/aboutus/history.htm>.

³ *Id.*

⁴ 42 U.S.C. § 15043 (a) (1).

⁵ Contacts for State Legal Requirements Regarding Ashley Treatment (attached as Exhibit A).

⁶ Under the DD Act implementing regulations, the term "abuse" is defined as, any act or failure to act which was performed, or which was failed to be performed, knowingly, recklessly, or intentionally, and which caused, or may have caused, injury or death to an individual with developmental disabilities, and includes such acts as: verbal, nonverbal, mental, and emotional harassment; rape or sexual assault; striking; the use of excessive force when placing an individual in bodily restraints; the use of bodily or chemical restraints which is not in compliance with Federal and State laws and regulations or any other practice which is likely to cause immediate physical or psychological harm or result in long term harm if such practices continue. 45 C.F.R. § 1386.19.

⁷ The term "neglect" is defined by the DD Act regulations as,

are defined by the P&A Acts. In establishing this duty, the federal government also gave WPAS the legal authority to conduct a full investigation⁸ when WPAS has probable cause to believe a person with a developmental disability has been or may have been abused or neglected.⁹ Federal statutes, regulations, and case law describe the authority of P&As to gain access to information that would otherwise be unavailable to most investigators and advocates.¹⁰

I. Introduction

In October of 2006, the Archives of Pediatric and Adolescent Medicine published an article by endocrinologist, Daniel F. Gunther, M.D., M.A and medical ethicist, Douglas S. Diekema, M.D., M.P.H., entitled “Attenuating Growth in Children with Profound Developmental Disability.”¹¹ The article described a case report of a recently developed protocol¹² to attenuate the growth of a child with a developmental disability and remove

a negligent act or omission by an individual responsible for providing treatment or habilitation services which caused or may have caused injury or death to an individual with developmental disabilities or which placed an individual with developmental disabilities at risk of injury or death, and includes acts or omissions such as failure to establish or carry out an appropriate individual program or treatment plan (including discharge plan); provide adequate nutrition, clothing, or health care to an individual with developmental disabilities; provide a safe environment which also includes failure to maintain adequate numbers of trained staff. 45 C.F.R. § 1386.19.

⁸ 42 U.S.C. § 15043 (a)(2)(B); Courts have consistently held that P & A systems have the federal statutory authority to conduct full investigations into allegations of abuse and neglect of individuals with disabilities or probable cause beliefs that the abuse and neglect occurred in both public and private institutions and facilities, such as Seattle Children’s Hospital. *Iowa Protection and Advocacy Services, Inc. v. Gerard Treatment Programs, L.L.C.*, 152 F. Supp.2d 1150 (N.D. Iowa 2001); modified preliminary injunction issued at 2001 WL 34008485 (N.D. Iowa July 17, 2001); permanent injunction issued on June 14, 2002 (unpublished); *Wisconsin Coalition for Advocacy, Inc. v. Czaplowski*, 131 F. Supp.2d 1039 (E.D.WI 2001).

⁹ 42 U.S.C. § 15043 (a)(2)(B); The DD Act regulations define “probable cause” as, a reasonable ground for belief that an individual with developmental disabilities has been, or may be subject to abuse or neglect. The individual making such determination may base the decision on reasonable inferences drawn from his or her experience or training regarding similar incidents, conditions or problems that are usually associated with abuse and neglect. 45 C.F.R. §1386.19.

Further, courts have specifically held that a P & A is the final arbiter of probable cause. *Arizona Center for Disability Law v. Allen*, 197 F.R.D. 689, 693 (D. Az. 2000).

¹⁰ See e.g., 45 C.F.R. § 1386.22, which provides access to numerous records including, investigative reports prepared by other agencies or the facility under investigation, care providers’ personnel records, all other documents in the possession of the facility under investigation related to the allegation of abuse and neglect, including but not limited to hand written notes, electronic files, photographs or video or audio tapes.

¹¹ Daniel F. Gunther, Douglas S. Diekema, *Attenuating Growth in Children With Profound Developmental Disability*, 160 Archives of Pediatrics & Adolescent Medicine 1013 (2006).

¹² The Gunther and Diekema article fails to mention anything about the breast bud removal as being part of the protocol described therein, yet as discussed more fully below in Section IV.B.2, 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) (see Exhibit M). Further, as reported by the Ashley’s parents on their website as well as by the surgeon involved, Ashley’s breast buds were in fact removed as part of the intervention. Ashley’s Mom and Dad,

her uterus. The child was later identified by her parents as “Ashley.”¹³ The collection of interventions began when Ashley was only six years old and included a hysterectomy, high-dosage hormone therapy, and removal of her breast buds.¹⁴ This intervention was developed for the purpose of providing parents the option of preventing their children with developmental disabilities from reaching full adult stature and physical sexual development.¹⁵ This set of medical interventions is now commonly referred to by the media and Ashley’s parents as the “Ashley Treatment.”¹⁶ Some of Ashley’s doctors and her parents have proposed that similar medical interventions could be performed on other children with disabilities similar to Ashley’s disabilities.¹⁷

Since the publication of the Gunther and Diekema article and the extensive discussion of the medical intervention by Ashley’s parents on their internet “blog,” hundreds of articles, editorials, and interviews have been published or broadcast about the administration of hormones and surgical procedures performed on Ashley.¹⁸ The intervention has generated great controversy as to whether the removal of Ashley’s uterus and breast buds and the administration with high doses of hormones in order to attenuate her growth and limit her physical sexual development was ethical. There was, however, virtually no discussion as to whether the set of interventions was done legally.

After reviewing press reports about Ashley and the “Ashley Treatment” with which she was treated, as well as receiving a number of complaints about this case, WPAS determined that it had probable cause to believe that Ashley may have been abused, as specifically defined by the implementing regulations of the DD Act,¹⁹ as a result of

The “Ashley Treatment”, Towards a Better Quality of Life for “Pillow Angels,” 3 (Jan. 7, 2007), at <http://pillowangel.org/Ashley%20Treatment%20v6-3%20photos.pdf>. (see Exhibit B).

¹³ Ashley’s Mom and Dad, *The “Ashley Treatment”, Towards a Better Quality of Life for “Pillow Angels,”* 3 (Jan. 7, 2007), at <http://pillowangel.org/Ashley%20Treatment%20v6-3%20photos.pdf>. (see Exhibit B).

¹⁴ *Id.* at 3-4.

¹⁵ Special CHRMC Ethics Committee Meeting/Consultation (May, 2004) (unpublished minutes, attached as Exhibit M); Ashley’s Mom and Dad, *The “Ashley Treatment”, Towards a Better Quality of Life for “Pillow Angels,”* (Jan. 7, 2007), at <http://pillowangel.org/Ashley%20Treatment%20v6-3%20photos.pdf>. (see Exhibit B).

¹⁶ *The “Ashley Treatment”,* at <http://Ashleytreatment.spaces.live.com>; See *infra* note 18.

¹⁷ Daniel F. Gunther, Douglas S. Diekema, *Attenuating Growth in Children With Profound Developmental Disability*, 160 *Archives of Pediatrics & Adolescent Medicine* 1013 (2006); Ashley’s Mom and Dad, *The “Ashley Treatment”, Towards a Better Quality of Life for “Pillow Angels,”* (Jan. 7, 2007), at <http://pillowangel.org/Ashley%20Treatment%20v6-3%20photos.pdf>. (see Exhibit B).

¹⁸ See e.g., Geoff Adams-Spink, *Campaign to prevent Ashley case*, BBC News Website, January 17, 2007, at <http://news.bbc.co.uk/go/pr/fr/-/1/hi/health/6267929.stm>; Cherie Black, *Controversy rages around stunting girl’s growth*, *Seattle Post-Intelligencer*, January 5, 2007; Michael Cook, *The Ashley experiment should never be repeated*, *The Sydney Morning Herald*, January 15, 2007; Editorial Staff, *Brain-damaged nine-year-old girl’s medical treatment fires ethical debate*, *The Times of India Online*, at <http://timesofindia.indiatimes.com>; Sam Howe, *Parents halt growth of severely disabled girl*, *The Seattle Times*, January 4, 2007; Several CNN interviews at

<http://transcripts.cnn.com/TRANSCRIPTS/0701/04/ng.01.html>,
<http://transcripts.cnn.com/TRANSCRIPTS/0701/09/pzn.01.html>, and

<http://transcripts.cnn.com/TRANSCRIPTS/0701/12/kl.01.html>; and Joseph Shapiro, *Parent’s Plan to Stunt Girl’s Growth Sparks Debate*, *National Public Radio-All Things Considered*, January 5, 2007, at

<http://www.npr.org/templates/story/story.php?storyId=6730813>

¹⁹ See 45 C.F.R. § 1386.19; *supra* note 6.

receiving the “Ashley Treatment.” WPAS, therefore, pursuant to its probable cause authority under the DD Act, initiated an investigation into Ashley’s case. The purpose of WPAS’s investigation was to determine whether, as a result of having this treatment, Ashley was abused or neglected, as defined under the DD Act, and whether her civil rights as guaranteed by the United States and Washington State Constitutions and other relevant state law were violated. It is important to note that although the ethical and legal issues that the “Ashley Treatment” raises are of a broad systemic nature, the purpose of this investigation and the scope of this report was to determine whether Ashley’s rights were violated and whether she was abused or neglected as defined by the DD Act.

II. Methodology of Investigation

In January 2007, after WPAS received information about the interventions performed on Ashley and numerous written and oral complaints from members of the general public and disability advocates who were concerned about the use of such invasive and irreparable procedures on Ashley, WPAS staff determined that WPAS had probable cause to believe that Ashley may have been abused or neglected as a result of the imposition of the sterilization, breast bud removal, and the administration of high-dosage hormone therapy. WPAS, therefore, invoked its probable cause authority pursuant to 42 U.S.C §§ 15043 (a)(2)(B) and initiated an investigation on January 6, 2007 to determine whether in receiving this treatment, Ashley was abused, neglected, or otherwise had her legal rights violated.²⁰ As discussed more fully below, in conducting its investigation, WPAS, pursuant to its federal authority, requested and reviewed documents, interviewed witnesses, conducted legal research, and consulted with medical experts.

A. Documents Requested and Reviewed

As part of its investigation, WPAS made comprehensive document and information requests of Children’s Hospital. These requests included:

- The number of people with developmental disabilities who have received or are scheduled to receive any procedure that is considered or could be considered part of the “Ashley Treatment;”
- All documents describing the process utilized by any treatment professional at Children’s Hospital considering the authorization of any portion of the “Ashley Treatment” for people with developmental disabilities;

²⁰ Letter from David Carlson, Associate Director of Legal Advocacy, WPAS, to Lisa Brandenburg, Interim Executive Director, UWMC (January 8, 2007) (attached as Exhibit C); Letter from David Carlson, Associate Director of Legal Advocacy, WPAS, to Jodi Long, Associate General Counsel, Children’s Hospital (January 10, 2007) (attached as Exhibit D).

- All documents describing the process utilized by any ethics committee considering authorization of any portion of the “Ashley Treatment” for people with developmental disabilities;
- All policies governing procedures resulting in the sterilization of people who lack capacity to provide informed consent;
- All court orders obtained granting Children’s Hospital and/or its treating professionals the authority to sterilize people who lack the capacity to provide informed consent;
- A copy of the minutes from the ethics committee meeting in which the initial provision of the “Ashley Treatment” was considered;
- Information as to the total cost of the entire “Ashley Treatment” for Ashley and who paid for the “treatment;” and
- Information as to whether any disciplinary action has been taken against any individual involved in providing the “Ashley Treatment” to Ashley or whether any sanctions have been imposed on any such individuals, whether through letters of reprimand, suspension, licensing complaints and violations, or any other type of action.

Children’s Hospital provided WPAS with written responses to the questions posed in WPAS’s requests for information, as well as relevant documents.²¹ Specifically, Children’s Hospital provided copies of a policy for the operation of a standing committee to review future requests for growth attenuation and sterilization of children, the mission statement of its current ethics committee, Children’s informed consent policy, its proposed policy regarding the sterilization of minors, as well as the minutes of the meeting in which the ethics committee considered the proposed “Ashley Treatment.”²² In addition to providing written responses, Children’s Hospital entered into a written agreement with WPAS to take specific corrective actions and systemic reform to ensure that the protection of the rights for children with developmental disabilities for whom

²¹ Letter from Jeffery Sconyers, General Counsel, Seattle Children’s Hospital and Regional Medical Center to David Carlson, Associate Director of Legal Advocacy, Washington Protection and Advocacy System (January 22, 2007) (attached as Exhibit F).

²² Children’s Hospital and Regional Medical Center Growth Attenuation/Sterilization Review Subcommittee (attached as Exhibit G); The Mission Statement for the Ethics Committee of the Children’s Hospital & Regional Medical Center (attached as Exhibit H); Legally Authorized Person for Informed Consent Decision Making When a Patient is a Minor (attached as Exhibit I); Letter from Jeffery Sconyers General Counsel, Seattle Children’s Hospital and Regional Medical Center to Deborah A. Dorfman, Director of Legal Advocacy, and David Carlson, Associate Director of Legal Advocacy, Washington Protection and Advocacy System (January 23, 2007) (attached as Exhibit J); Children’s Hospital & Regional Medical Center Sterilization of Minors Policy (attached as Exhibit K); Special CHRMC Ethics Committee Meeting/Consultation (May, 2004) (unpublished minutes, attached as Exhibit L).

sterilization or other interventions involving the manipulation of potential for normed maturation²³ are sought.²⁴

While the surgical procedures were conducted at Children's Hospital, which is not operated by the University of Washington, the doctors involved are employees of the University of Washington School of Medicine ("UWSM").²⁵ WPAS, therefore, also requested and obtained information from the University of Washington about the informed consent policies that govern UWSM faculty practicing at the University of Washington's hospitals.²⁶

B. Witnesses Interviewed

WPAS interviewed the endocrinologist who facilitated the growth attenuation treatment.²⁷ WPAS also interviewed the surgeon who preformed the hysterectomy and breast removal on Ashley.²⁸ These doctors provided WPAS with information about the collection of medical interventions provided to Ashley, and their understanding of the final Ethics Committee recommendations and legal authorization process in regards to the proposed interventions.²⁹

C. Medical Expert Consultation

In order to assist with the investigation, WPAS retained a medical expert Scott Stiefel, M.D. of the University of Utah Neuropsychiatric Clinic in Salt Lake City. Dr. Stiefel is a pediatrician and psychiatrist with an expertise in the area of treating children with developmental disabilities.³⁰ Dr. Stiefel provided WPAS with medical expert consultation throughout the investigation, negotiation of corrective actions taken by Children's, and the development of this report.

A list and copy of pertinent records provided to and reviewed by WPAS during this investigation follow hereto as Appendix I. A list of pertinent federal and state statutory,

²³ The medical profession has developed growth charts that have been statistically normed for children with specific conditions (e.g. individuals with Down Syndrome or children who are born premature) to assist in predicting potential growth. See Christine Cronk, Allen C. Crocker, Siegfried M. Pueschel, Alice M. Shea, Elaine Zackai, Gary Pickens, and Robert B. Reed, *Growth Charts for Children With Down Syndrome: 1 Month to 18 Years of Age*, 81 *Pediatrics* 102 (1988); R.J. Kuczmarski, C. Ogden, L. Grummer-Strawn, et al., *CDC Growth Charts: United States. Advance Data Report No. 314. Vital and Health Statistics of the Centers for Disease Control and Prevention, National Center for Health Statistics* (2000).

²⁴ Agreement Between Children's Hospital and Regional Medical Center and Washington Protection and Advocacy System (Disability Rights Washington) Promoting Protection of Individuals With Developmental Disabilities (attached as Exhibit T); See also *infra* Section V.

²⁵ Daniel F. Gunther, Douglas S. Diekema, *Attenuating Growth in Children With Profound Developmental Disability*, 160 *Archives of Pediatrics & Adolescent Medicine* 1013 (2006).

²⁶ *Persons Not Capable of Providing Informed Consent*, UW Medicine Informed Consent Manual (2001-2004) (attached as Exhibit E).

²⁷ Interview with endocrinologist (February 12, 2007).

²⁸ Interview with surgeon, (February 14, 2007).

²⁹ Interview with endocrinologist (February 12, 2007); Interview with surgeon (February 14, 2007).

³⁰ Curriculum Vitae of Scott Stiefel, MD, attached as Exhibit S.

regulatory, and case law reviewed and referenced in this report follows hereto as Appendix II.

III. Facts

A. Ashley's Parents Wanted to Keep Her Childlike

On January 2, 2007, the parents of a nine-year-old child with a developmental disability named Ashley created a "blog" which they posted on the internet to describe the unique medical interventions they sought for their daughter.³¹ On their website, the parents describe Ashley as a child with a cognitive disability resulting from static encephalopathy and they refer to her as their "Pillow Angel."³² The parents' blog recounts that when Ashley was six years old, the parents requested the assistance of Ashley's doctors to prevent Ashley from reaching full adult size and developing sexually.³³ What follows is a summary of some of the information that Ashley's parents presented on their website as to why they pursued the "Ashley Treatment" for Ashley.

Ashley's parents wrote that they wanted to prevent her from growing and developing sexually to address "Ashley's biggest challenges discomfort and boredom...."³⁴ Ashley's parent's claim that this collection of procedures help "pillow angels" by making them smaller and lighter, and thus more comfortable when laying down and more easily repositioned by one person.³⁵ Although, the parents maintain that this procedure was not intended to ease their work as Ashley's primary supports, they wrote that keeping Ashley small, helped make "it more possible to include her in the typical family life and activities that provide her with needed comfort, closeness, security and love: meal time, car trips, snuggles, etc."³⁶

Ashley's parents point out that this procedure also helps little girls avoid the eventual discomfort of menstruation and breasts.³⁷ The parents claim that removing Ashley's

³¹ *The "Ashley Treatment"* at <http://ashleytreatment.spaces.live.com>.

³² "We call her our "Pillow Angel" since she is so sweet and stays right where we place her—usually on a pillow." *Id.* Ashley parents go on to define "Pillow Angel" as an [a]ffectionate nickname for Ashley X, now generally refers to people with a cognitive and mental developmental level that will never exceed that of a 6-month old child as well as associated extreme physical limitations, so they will never be able to walk or talk or in some cases even hold up their head or change position in bed. Pillow Angels are entirely dependent on their caregivers. *Id.*

³³ *Id.*

³⁴ Ashley's Mom and Dad, *The "Ashley Treatment", Towards a Better Quality of Life for "Pillow Angels,"* 3 (2007), at <http://pillowangel.org/Ashley%20Treatment%20v6-3%20photos.pdf>. (see Exhibit B).

³⁵ *Id.* at 4.

³⁶ *Id.*

³⁷ *Id.* at 3-4; The American Academy of Pediatrics policy on sterilization of minors states that "[t]he inconvenience of problems dealing with normal menstrual bleeding is generally an inappropriate indication for surgical sterilization. Abnormal menses (e.g., excessive flow or bleeding for many days each cycle) should be treated as it would be for a patient without mental disability." American Academy of Pediatrics, Committee on Bioethics, Policy Statement, Sterilization of Minors With Developmental Disabilities, 104 Pediatrics 337 (Aug. 1999), reaffirmed Oct. 2006, 119 Pediatrics 405 (Feb. 2007), at <http://www.aap.org/policy/re9849.html>.

uterus was not for the purpose of sterilization, yet they state that one of the benefits was “avoiding any possibility of pregnancy, which to [their] astonishment does occur to disabled women who are abused.”³⁸ They go on to write that Ashley does not need a uterus or breasts because she will not be bearing children or breastfeeding.³⁹ Besides avoiding the discomfort of breasts, the parent’s also wanted to remove Ashley’s breasts in order to avoid a possibility of fibrocystic or cancerous growths at a later age.⁴⁰ Additionally, the original version of their web page stated that if Ashley were allowed to develop, she would have “[l]arge breasts [that] could ‘sexualize’ Ashley towards her caregiver, especially when they are touched while she is being moved or handled, inviting the possibility of abuse.”⁴¹

Ashley’s parents obtained the assistance of doctors to administer high doses of hormones to attenuate Ashley’s growth and had her uterus and breast buds removed.⁴² As stated by Ashley’s parents and her doctors, to their knowledge, this was the first time that these procedures and interventions had been combined to achieve the goal of keeping a person with a developmental disability from fully developing.⁴³

Doctors employed by the University of Washington performed the surgical procedures to remove Ashley’s uterus and breast buds at Children’s Hospital and Regional Medical Center (“Children’s Hospital”) which is a private hospital in Seattle, Washington.⁴⁴

B. Ashley’s Parents Sought Children’s Hospital Ethics Committee Opinions and Recommendations Regarding the “Ashley Treatment”

Before conducting the procedures at Children’s Hospital, Ashley’s family and doctors explained why they desired the proposed interventions to the Children’s Hospital Ethics

³⁸ Ashley’s Mom and Dad, *The “Ashley Treatment”, Towards a Better Quality of Life for “Pillow Angels,”* 8 (Jan. 7, 2007), at <http://pillowangel.org/Ashley%20Treatment%20v6-3%20photos.pdf> (see Exhibit B); The American Academy of pediatrics policy on the sterilization of minors also states that

[m]any who care for persons with developmental disabilities are understandably concerned about the sexual exploitation of those for whom they have responsibility. Although sterilization of vulnerable girls usually will prevent conception and pregnancy, it will not substitute for the establishment and enforcement of a safe environment that minimizes the chance for exploitation, nor will it prevent exposure to sexually transmitted diseases. American Academy of Pediatrics, Committee on Bioethics, Policy Statement, Sterilization of Minors With Developmental Disabilities, 104 Pediatrics 337, P 13 (Aug. 1999), reaffirmed Oct. 2006, 119 Pediatrics 405 (Feb. 2007), <http://www.aap.org/policy/re9849.html>.

³⁹ Ashley’s Mom and Dad, *The “Ashley Treatment”, Towards a Better Quality of Life for “Pillow Angels,”* 8 (2007), at <http://pillowangel.org/Ashley%20Treatment%20v6-3%20photos.pdf>.

⁴⁰ *Id.* at 9.

⁴¹ *Id.*

⁴² Ashley’s Mom and Dad, *The “Ashley Treatment”, Towards a Better Quality of Life for “Pillow Angels,”* 4 (2007), at <http://pillowangel.org/Ashley%20Treatment%20v6-3%20photos.pdf> (see Exhibit B).

⁴³ *Id.*; Daniel F. Gunther, Douglas S. Diekema, *Attenuating Growth in Children With Profound Developmental Disability*, 160 Archives of Pediatrics & Adolescent Medicine 1013 (2006).

⁴⁴ Daniel F. Gunther, Douglas S. Diekema, *Attenuating Growth in Children With Profound Developmental Disability*, 160 Archives of Pediatrics & Adolescent Medicine 1013 (2006).

Committee.⁴⁵ Because the “Ashley Treatment” was a new and unique application of this collection of medical procedures, there was no established procedure or specific policy about whether it would be appropriate to conduct this set of interventions. Ashley’s parents and doctors, therefore, asked Children’s Hospital’s Ethics Committee to provide its opinion and make recommendations regarding the proposed interventions.⁴⁶ The Ethics Committee at Children’s Hospital is comprised of a multidisciplinary group of providers and community members with training in medical ethics and one of Children’s Hospital’s lawyers.⁴⁷ This Committee provides non-binding recommendations to practitioners and family members looking for guidance regarding procedures or practices that appear to raise ethical concerns.⁴⁸

In 2004, the Children’s Hospital Ethics Committee convened to provide an opinion and make recommendations as to whether Ashley’s life would be substantially improved by the “proposed aggressive intervention (both surgical and pharmacologic) to limit her linear growth and sexual development.”⁴⁹ Ashley’s parents presented their rationale for seeking the collection of interventions and the physicians explained the aggressive surgical and pharmacological intervention the parents sought.⁵⁰

After hearing the proposal and conducting private deliberations, “the consensus of the Committee members was that the potential long term benefit to Ashley herself outweighed the risks; and that the procedures/interventions would improve her quality of life, facilitate home care, and avoid institutionalization in the foreseeable future.”⁵¹ The committee orally presented its recommendation to the family and the doctors present.⁵² The Committee, although finding that the proposed interventions were medically ethical, informed Ashley’s parents that it did not have the authority to determine whether the sterilization portion of the proposed set of procedures was legally permissible.⁵³ For that reason, the Ethics Committee advised the parents to retain an attorney in order to obtain a “court review” of the proposed sterilization “so they could meet the Washington State case law sterilization procedures.”⁵⁴

⁴⁵ Special CHRMC Ethics Committee Meeting/Consultation (May, 2004) at 1 (see Exhibit L).

⁴⁶ The Mission Statement for the Ethics Committee of the Children’s Hospital & Regional Medical Center (see Exhibit H).

⁴⁷ *Id.*

⁴⁸ *Id.*

⁴⁹ CHRMC Ethics Committee Meeting/Consultation (May 5, 2004) at 1 (see Exhibit M); see also, Daniel F. Gunther, Douglas S. Diekema, *Attenuating Growth in Children With Profound Developmental Disability*, 160 Archives of Pediatrics & Adolescent Medicine 1013 (2006).

⁵⁰ Special CHRMC Ethics Committee Meeting/Consultation (May 5, 2004) at 2 (see Exhibit L).

⁵¹ Special CHRMC Ethics Committee Meeting/Consultation (May 5, 2004) at 3 (see Exhibit L).

⁵² Interview with endocrinologist (February 12, 2007).

⁵³ See *id.*; Special CHRMC Ethics Committee Meeting/Consultation (May, 2004) (see Exhibit M). This recommendation conforms to the general advice provided by the American Academy of Pediatrics policy on the sterilization of minors which states that “[w]hen the involved parties believe surgical sterilization to be the best option, application to the courts may provide the only lawful means to accomplish that goal. Physicians and surgeons should be familiar with the law that applies to the jurisdictions where they practice.” American Academy of Pediatrics, Committee on Bioethics, Policy Statement, Sterilization of Minors With Developmental Disabilities, 104 Pediatrics 337, P 13 (Aug. 1999), reaffirmed Oct. 2006, 119 Pediatrics 405 (Feb. 2007), at <http://www.aap.org/policy/re9849.html>.

⁵⁴ Special CHRMC Ethics Committee Meeting/Consultation (May, 2004) at p. 3 (see Exhibit L).

C. No Court Order Was Sought or Obtained to Authorize the Treatment, Including the Hysterectomy

Following the Ethics Committee meeting, Ashley's parent's consulted with an attorney, Larry Jones, who has experience advocating for parents of children with developmental disabilities.⁵⁵ The parents' attorney wrote a letter to Ashley's father informing him that while courts have ruled that parents cannot consent to the sterilization of children with cognitive disabilities without a court order, he did not think Ashley's parents needed to get a court order in Ashley's case.⁵⁶ The parents' attorney opined that because sterilization was not the sole purpose of the treatment, there is an exception to the rule that a court order is necessary before the sterilization of a minor with a developmental disability can proceed.⁵⁷ As discussed below in Section IV.B.1., the legal opinion offered by the parents' attorney is not supported by a reasonable interpretation of pertinent law. A copy of the letter from the parents' attorney was provided to Ashley's doctors by Ashley's father.⁵⁸ The surgeon also received a copy of the Ethics Committee's written recommendation.⁵⁹ Although the Ethics Committee stated that a "court review" was necessary before the proposed procedure could proceed, the doctors reported to WPAS during interviews that they relied upon the opinion of the parents' attorney whom they have stated to WPAS staff, they believed to be well versed in disability law.⁶⁰ The surgeon subsequently stated to WPAS staff during an interview that at the time the parents presented him a letter from their attorney, he believed the letter satisfied the requirement for "court review."⁶¹ Before beginning the surgery, however, the surgeon reported that he also contacted the doctor serving as the Medical Director of Children's Hospital at the time of the "Ashley Treatment" was performed to confirm his understanding that the requirement for a "court review" had been satisfied and get final approval to proceed with the hysterectomy.⁶² The surgeon reported to WPAS that he received final approval from Children's Hospital's Medical Director, and proceeded with the hysterectomy and breast bud removal without a court order authorizing the sterilization or any other part of the "Ashley Treatment."⁶³

⁵⁵ See <http://www.seattledisabilitylaw.com/welcome.html>;

Larry Jones became a lawyer because his daughter Wendy had severe intellectual disabilities. For a quarter century, he has used the Americans with Disabilities Act and its predecessor statute to promote the integration and equal treatment of people with severe disabilities in our society. In 1984 his efforts on behalf of persons with mental retardation were recognized when he was chosen national Volunteer of the Year by The Arc of the United States. Larry has a Ph.D. in Ethics and Society from the Divinity School of the University of Chicago (1975) and a J.D. from the University of Washington (1989). *Id.*

⁵⁶ Letter from Larry Jones, Ph.D., J.D., to Ashley's Dad (June 10, 2004) (attached as Exhibit O).

⁵⁷ *Id.*

⁵⁸ Interview with endocrinologist (February 12, 2007); Interview with surgeon (February 14, 2007).

⁵⁹ Interview with surgeon (February 14, 2007).

⁶⁰ *Id.*

⁶¹ *Id.*

⁶² Interview with surgeon, (February 14, 2007). The former Medical Director was not interviewed regarding his involvement in the referenced telephone conversation.

⁶³ *Id.*

D. Insurance and Billing

Ashley's parents report in their internet blog that the growth attenuation treatment, hysterectomy, and mastectomy were all paid for entirely by insurance.⁶⁴ Ashley's parents also report on their website that the estimated cost to implement the "Ashley Treatment" that was carried out at Children's Hospital was approximately \$30,000.⁶⁵ Children's Hospital confirmed that a private insurer authorized payment for the surgical procedures conducted at the hospital.⁶⁶ Children's Hospital also provided WPAS with copies of billing for these surgical procedures, which amounted to \$26,389 before adjustments.⁶⁷ The precise total cost for these procedures is unknown, but based upon review of these billing statements, these costs do not include billing by the surgeon, the anesthesiologist, the endocrinologist, or the cost of any evaluation, follow-up care, and hormone treatment.

E. Disciplinary and Corrective Action

As part of its investigation, WPAS staff inquired as to whether Children's Hospital had taken any disciplinary action against the doctors or anyone else for proceeding with sterilization and breast bud removal procedures on Ashley without a court order.⁶⁸ Children's Hospital, through its attorneys, informed WPAS counsel that no such action had been taken, because the hospital did not feel it was warranted.⁶⁹ The Hospital, through its counsel, did, however, state that it believed that a systemic failure had occurred and that appropriate corrective action would be taken to prevent its occurrence in the future.⁷⁰

IV. Relevant Legal Requirements

The United States and Washington Constitutions recognize the individual liberty and privacy interests of children,⁷¹ as well as parents' liberty and privacy interests in raising their children, which includes making decisions in regards to their healthcare.⁷² The following section discusses these legal issues in the context of what happened to Ashley specifically and implementation of the "Ashley Treatment" on children with developmental disabilities in the future. Specifically, the following section will first set forth a discussion of the constitutional rights to privacy and liberty generally, followed by

⁶⁴ <http://ashleytreatment.spaces.live.com/>

⁶⁵ *Id.*

⁶⁶ Children's Hospital Billing Report for Ashley Treatment, see Exhibit R.

⁶⁷ *Id.*

⁶⁸ See Letter from Deborah Dorfman, Director of Legal Advocacy and Associate Executive Director, WPAS, to Jodi Long, Associate General Counsel, Children's Hospital, and Jeffrey Sconyers, General Counsel, Children's Hospital, dated March 27, 2007, attached as Exhibit P.

⁶⁹ See Letter from Jodi Long, Associate General Counsel, Children's Hospital, to Deborah Dorfman, Director of Legal Advocacy and Associate Executive Director, WPAS, dated April 5, 2007, attached hereto as Exhibit Q.

⁷⁰ See *id.*

⁷¹ See e.g., *Parham v. J.R.*, 442 U.S. 584, 600 (1979) (recognizing the liberty interests children have in being free from involuntary civil commitment for psychiatric care); *In re Hayes*, 93 Wn.2d 228, 234 (1980).

⁷² *Troxel v. Granville*, 530 U.S. 57, 66-67 (2000), *Parham v. J.R.*, 442 U.S. 584, 604 (1979).

a discussion of these rights in the context of making healthcare decisions for individuals who lack the competency to make their own treatment decisions, and what legal protections must be afforded such individuals in this area. Finally, this section will address what legal protections should have been afforded Ashley before she was given the “Ashley Treatment.”

A. Constitutional Rights: Privacy and Liberty Interests

1. Privacy and Liberty Interests Generally

All citizens of the United States have constitutional rights, including adults and children with developmental disabilities.⁷³ These rights include, but are not limited to, the substantive due process liberty and privacy rights protected by the Fourteenth Amendment. Courts have found, for example, that there is a constitutionally protected liberty interest in making personal procreation choices.⁷⁴ Similarly, the courts have also found constitutionally protected liberty interests in the rights to be free from involuntary invasive medical procedures and treatment, such as involuntary civil commitment,⁷⁵ the administration of involuntary treatment with antipsychotic medications,⁷⁶ the right to refuse life-sustaining care,⁷⁷ and involuntary sterilization,⁷⁸ among many other protected liberty interests. Courts have also found that there is a constitutionally protected privacy right derived from the penumbras of the Fourteenth Amendment to make decisions about contraception,⁷⁹ abortions,⁸⁰ and the right to be free from involuntary sterilization.⁸¹

⁷³ U.S. Const. Amend. I; U.S. Const. Amend. XIV. Such rights are equally afforded people with developmental disabilities and cannot be taken away just because they have a disability. RCW 71A.10.030.

⁷⁴ *Skinner v. Oklahoma*, 316 U.S. 535, 541 (1942).

⁷⁵ *Addington v. Texas*, 441 U.S. 418, 427 (1979).

⁷⁶ *Harper v. Washington*, 494 U.S. 210, 221-22 (1990) (the right to refuse psychiatric medication).

⁷⁷ *Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 278 (1990) (the right to refuse life sustaining treatment).

⁷⁸ *Skinner*, 316 U.S. at 541.

⁷⁹ *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. Barid*, 405 U.S. 438, 454-55 (1972) (extending the right to privacy in making decisions regarding contraception to unmarried individuals).

⁸⁰ *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).

⁸¹ *In re Hayes*, 93 Wn.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....”) (attached as Exhibit M); see also *In re K.M.*, 62 Wn. App. 811, 818 (1991) (holding individuals with developmental disabilities must have an effective independent advocate when sterilization is contemplated)(attached as Exhibit N); *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”).

Washington courts have also held that such liberty and privacy rights exist under the Washington State Constitution. For example, the Washington Supreme Court has held that individuals have a privacy right under the Washington Constitution to make decisions about abortion,⁸² to refuse end-of-life treatment that serves only to prolong the dying process for terminally ill patients,⁸³ and protection against involuntary sterilization,⁸⁴ among many other rights.

2. Legal Requirements Regarding Treatment Decisions for Adults Who Are Not Competent To Give Informed Consent and for Minors

Under Washington State law, competent adults have the legal right to refuse treatment and make treatment decisions under the informed consent statute.⁸⁵ The question of how decisions should be made in regards to medical treatment of an individual who is not competent to make such decisions for him or herself, however, depends upon the specific situation. For example, in the case of making end-of-life treatment decisions for a person who is incompetent to do so, the Washington Supreme Court has held that a court need not be involved before such a decision can be made.⁸⁶ Rather, in such cases, the court has held that it is for the legislature to establish guidelines and held that, in Washington, a guardian of the person appointed by a court following the full due process procedures required for appointment of a guardian under Washington State law,⁸⁷ can make these end-of-life treatment decisions.⁸⁸

In other situations involving healthcare decisions to be made on behalf of an individual who lacks the capacity to do so, however, the Washington Supreme Court and Washington State Legislature have determined that even guardians cannot make certain decisions, and judicial intervention is required before these medical treatments can be provided or procedures be performed. Such is the case for highly invasive and irreversible treatments such as electro convulsive therapy (ECT),⁸⁹ the administration of involuntary antipsychotic medication,⁹⁰ involuntary sterilization,⁹¹ and other similar

⁸² *State v. Koome*, 84 Wn.2d 901, 909-10, 530 P.2d 260, 266 (1975).

⁸³ *In re Colyer*, 99 Wn.2d 114, 120, 660 P. 2d 738, 742 (1983).

⁸⁴ *Hayes*, 93 Wn.2d at 238; See discussion *infra* notes 99-119 and accompanying text.

⁸⁵ See RCW 7.70.050.

⁸⁶ *Colyer*, 99 Wn.2d at 128. 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.*

⁸⁷ RCW 11.88.030 *et seq.*

⁸⁸ *Colyer*, 99 Wn.2d at 128.

⁸⁹ RCW 11.92.043(5) (a); see also RCW 71.05.217(7).

⁹⁰ RCW 11.92.043(5); see also RCW 71.05.215, RCW 71.05.217(7).

⁹¹ See *Hayes*, 93 Wn.2d 228; *In re KM*, 62 Wn. App. 811 (1991).

treatments.⁹² As discussed in more detail in this section below, in such cases, a court order is a pre-requisite to such treatment.⁹³

Parents also have the right to make treatment decisions regarding their minor children except in certain circumstances, as described below. The U.S. Supreme Court has held that parents have constitutional liberty and privacy interests in the right to make decisions as to how to raise their children, including making decisions about what medical procedures and treatment they should receive.⁹⁴ Washington State law and the Washington Constitution also afford parents these rights.⁹⁵

Although they have greater rights than guardians of adults, the rights of parents to make treatment and other decisions for their minor children, however, are not unfettered. “[T]he state has a wide range of power for limiting parental freedom and authority in things affecting the child’s welfare.”⁹⁶ Parents generally have the right to make medical decisions for their minor children and provide informed consent for various procedures; however, courts have limited this authority when parents seek highly invasive and/or irreversible medical treatment of their minor children.⁹⁷ Courts and the Washington State Legislature, for example, have held that parents do not have the authority to consent to medical treatment in cases involving involuntary inpatient psychiatric care,⁹⁸ the administration of electro convulsive therapy in non-emergency life-saving

⁹² RCW 11.92.043(5).

⁹³ 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.)

⁹⁴ See *e.g.*, *Meyer v. Nebraska*, 262 U.S. 390, 403 (1923) (finding parents had the right to teach their children German despite a law forbidding the instruction of any language other than English); *Pierce v. Society of the Sisters of the Holy Names of Jesus and Mary*, 268 U.S. 510, 534-35 (1925) (finding parents can choose to send children to private school instead of public school); *Prince v. Commonwealth of Massachusetts*, 321 U.S. 158, 167 (1944) (finding that although parents have the right to guide the upbringing and religion of their children, states may limit parental rights when a child’s welfare is at issue); *Parham v. J.R.*, 442 U.S. 584, 585 (1979). Parents “retain plenary authority to seek such care for their children, subject to an independent medical judgment.” *Id.* citing *cf. Pierce v. Society of Sisters*, 268 U.S. 510 (1925); *Wisconsin v. Yoder*, 406 U.S. 205 (1972); *Prince v. Massachusetts*, 321 U.S. 158 (1944); *Meyer v. Nebraska*, 262 U.S. 390 (1923); *Planned Parenthood of Central Missouri v. Danforth*, 428 U.S. 52 (1972) distinguished. Pp. 2503-2505.

⁹⁵ *In re Smith*, 137 Wn.2d 1, 969 P.2d 21 (1998); See RCW 7.70.065; see also RCW 71.34.010 (purpose of Washington children’s mental health treatment laws in relevant part “to assure the ability of parents to exercise reasonable, compassionate care and control of their minor when there is a medical necessity for treatment with out the requirement of filing a petition” with the court to obtain such mental health care); RCW 71.34.600 (authorizing parents, without the consent of the minor, to bring their children to an evaluation and treatment facility or other licensed inpatient treatment facility to request that a licensed and qualified mental health professional “determine whether the child has a mental disorder and is in need of inpatient treatment” for such a disorder); RCW 71.34.650 (authorizing parents, without consent of the minor, to bring their child to a qualified outpatient mental health treatment provider “to determine whether the child has a mental disorder and is in need of outpatient treatment”).

⁹⁶ *Prince*, 321 U.S. at 167.

⁹⁷ *Parham*, 442 U.S. at 585.

⁹⁸ *Id.* at 584; *T.B. v. Fairfax Hosp. Wash.*, 129 Wn.2d 439, 452-53 (1996).

situations,⁹⁹ psychosurgery,¹⁰⁰ abortions for mature minors,¹⁰¹ sterilization,¹⁰² and other similar invasive medical treatments,¹⁰³ particularly where the interest of the parent may not be the same as those of the child.¹⁰⁴

Like a number of other states,¹⁰⁵ the Washington State Supreme Court has addressed the question of whether a parent can provide consent for the sterilization of a minor due to a developmental disability and has held that the constitution requires court review and approval before a minor can be sterilized.¹⁰⁶ In *In re Hayes*, the Washington State Supreme Court held that a parent of a child with a developmental disability did not have the authority to consent to sterilization on behalf of her minor daughter.¹⁰⁷ The court found that unlike other medical procedures, parental consent is inadequate in cases involving sterilization of a child because involuntary sterilization imposes significantly on the child's fundamental liberty and privacy interests.¹⁰⁸ Thus, the court held that the child must be represented by a disinterested third party such as a guardian *ad litem*¹⁰⁹ or an attorney in an adversarial hearing to determine whether the sterilization of the minor is legally warranted.¹¹⁰

⁹⁹ *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).

¹⁰⁰ RCW 71.34.355(10) (affording the rights of children "not to every have psychosurgery performed on him or her under any circumstances.")

¹⁰¹ *State v. Koome*, 84 Wn.2d 901, 909-10 (1975).

¹⁰² *Hayes*, 93 Wn.2d 228 (1980); *K.M.*, 62 Wn. 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).

¹⁰³ See e.g., *State v. Baxter*, 134 Wn. 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.

¹⁰⁴ See *Hayes*, 93 Wn.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 Wn.2d at 904 (holding that the constitutional rights of children are "[p]rima facie coextensive with those of adults.").

¹⁰⁵ Many states reached the same conclusion that trial courts have the authority to decide if a minor with a cognitive disability can be sterilized without the need for statutes granting the trial court subject matter jurisdiction over this specific issue. 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).

¹⁰⁶ See *Hayes*, 93 Wn.2d 228; *KM*, 62 Wn. App. 811.

¹⁰⁷ *Hayes*, 93 Wn.2d at 236-37.

¹⁰⁸ *Id.* at 236.

¹⁰⁹ "[A] guardian ad litem is any person who is appointed by the court to represent the best interest of the child... or to assist the court in determining the best interest of the child...." Washington Superior Court Guardian Ad Litem Rules, 2.

¹¹⁰ *Hayes*, 93 Wn.2d at 237.

The *Hayes* Court also set forth the specific analysis that must be used in determining whether a court will authorize the sterilization of an individual with a developmental disability.¹¹¹ The *Hayes* Court specifically held that “[t]here is a *heavy* presumption against sterilization of an individual incapable of informed consent that must be overcome”¹¹² by proving *all* of the following conditions by a clear, cogent, and convincing standard (*emphasis added*):¹¹³

1. the child is incapable of making his or her own decision about sterilization;
2. the child is unlikely to develop sufficiently to make an informed judgment about sterilization in the foreseeable future;
3. the child is physically capable of procreation;
4. the child is likely to engage in sexual activity at the present or in the near future under circumstances likely to result in pregnancy;
5. the child is permanently incapable of caring for a child;
6. all less drastic contraceptive methods, including supervision, education and training, have been proved unworkable or inapplicable;
7. the proposed method of sterilization entails the least invasion of the body of the individual;
8. reversible sterilization procedure or other less drastic contraceptive method will not be available shortly; and
9. science is not on the threshold of an advance in the treatment of the child’s disability.¹¹⁴

The court went on to point out that not only is the strong presumption against sterilization very difficult to overcome, but the age of the child can make it “difficult or impossible” to prove each requirement.¹¹⁵ In *Hayes*, the court stated that since the child was still only sixteen-years-old, it was not possible to prove many of the required points listed above because of the uncertainties of the child’s future development.¹¹⁶ Here, the “Ashley Treatment” was performed on a six-year old child; therefore, getting court approval for these incredibly invasive procedures that result in irreparable harm to fundamental liberty and privacy interests of such a young child would likely be quite difficult.

¹¹¹ *Id.*

¹¹² *Hayes*, 93 Wn.2d at 239.

¹¹³ Requiring a clear cogent and convincing evidentiary standard “is the equivalent of saying that the ultimate fact in issue must be shown by evidence to be ‘highly probable.’” *In re Sego*, 82 Wn.2d 736, 739 (1973), citing, *Supove v. Densmoor*, 225 Or. 365, 358 P.2d 510 (1961); see also *State v. Blubaugh*, 80 Wn.2d 28, 491 P.2d 646 (1971). The clear cogent and convincing standard differs from the lower standard of “[p]reponderance of the evidence [which] means evidence that is more probably true than not true.” *Sego*, 82 Wn.2d at 739, citing, *Presnell v. Safeway Stores, Inc.*, 60 Wn.2d 671, 374 P.2d 939 (1962).

¹¹⁴ *Hayes*, 93 Wn.2d at 238-39.

¹¹⁵ *Id.* at 239.

¹¹⁶ *Id.*

In *In re K.M.*, the Washington Court of Appeals clarified the requirement for a court order and ruled that in order to afford individuals in this situation adequate procedural due process, the appointed guardian *ad litem* must zealously advocate to protect the rights of the child.¹¹⁷ Like Ashley, K.M. was a minor diagnosed with static encephalopathy and had a cognitive disability that prevented her from understanding and consenting to sexual activity.¹¹⁸ K.M.'s parents sought a court order authorizing doctors to sterilize their daughter.¹¹⁹ K.M.'s parents and doctors testified that sterilization was in K.M. best interest.¹²⁰ The court appointed a guardian *ad litem* for K.M.¹²¹ Without cross examining the parents and doctors, the guardian *ad litem* waived many of K.M.'s rights and agreed that sterilization was in K.M.'s best interest.¹²² The trial court ruled that the appointment of a guardian *ad litem* satisfied due process and authorized K.M.'s sterilization.¹²³ Prior to the sterilization, K.M.'s case was appealed to the Washington Court of Appeals.¹²⁴ The appellate court ruled that the mere appointment of a guardian *ad litem* who failed to zealously advocate for K. M. was a "meaningless gesture" and did not protect her due process rights.¹²⁵ The Court of Appeals held that when a trial court observes a guardian *ad litem* is not zealously advocating for the rights of the child, the court is obligated to appoint a lawyer to represent the child.¹²⁶

B. Was A Court Order Required Before the "Ashley Treatment" Was Implemented for Ashley?

The "Ashley Treatment" is unique and, to the knowledge of the authors of this report, the only time that such an intervention has been implemented.¹²⁷ As discussed directly

¹¹⁷The court in K.M.'s case was very clear that the child needed an impartial and effective advocate. *K.M.*, 62 Wn. App. at 815-16, citing *In re Quesnell*, 83 Wn.2d 224, 236-38 (1973).

[T]he guardian *ad litem* is appointed for the benefit of and to protect the rights and best interests of the alleged incompetent to whom he is assigned. For these purposes, it is essential that he act as an advocate in behalf of the accused. ...[I]t is the duty of the guardian *ad litem* to submit to the court all relevant defenses or legal claims the client may have, investigate actively any charges, consult meaningfully with the client, and explain the legal consequences of the proceedings... If these affirmative efforts to provide protection for the fundamental rights of the alleged incompetent are not observed, the appointment of the guardian *ad litem* can become a "mere formality" and a meaningless gesture. The nonadversary guardian *ad litem* necessarily does not afford realization of constitutional and statutory guarantees in regard to the assistance of counsel. *Id.*

¹¹⁸ *Id.* at 813.

¹¹⁹ *Id.* at 812.

¹²⁰ *Id.* at 813-14

¹²¹ *K.M.*, 62 Wn. App. at 813.

¹²² *Id.* at 814-15.

¹²³ *Id.* at 814.

¹²⁴ *Id.*

¹²⁵ *Id.* at 816.

¹²⁶ *K.M.*, 62 Wn. App. at 818; an attorney must be appointed "in order to ensure a thorough adversary exploration of the issues." *Id.*

¹²⁷ Ashley's Mom and Dad, *The "Ashley Treatment", Towards a Better Quality of Life for "Pillow Angels,"* 4 (Jan. 7, 2007), at <http://pillowangel.org/Ashley%20Treatment%20v6-3%20photos.pdf>. (see Exhibit B).

above in Section A, the Washington Supreme Court has clearly stated that the sterilization of incompetent individuals with developmental disabilities cannot be done without court approval and other due process requirements being satisfied. There is, however, no case law or statutes that address what to do when parents want their child to undergo growth-limiting medical interventions such as breast bud removal and the administration of hormones for the purpose of limiting the growth of children with developmental disabilities. For the reasons discussed more fully above in Section IV.A.1.b, as well as below in Section IV.B.2.b, decisions of the United States Supreme Court and Washington Supreme Court in *Hayes*, and other cases finding that individuals have a protected liberty and privacy interest in being free from invasive and irreversible medical treatments, support the argument that the due process and privacy protections afforded a minor in the case where sterilization is sought should be extended to the implementation of the “Ashley Treatment” as a whole, as well as to other growth-limiting medical interventions that may be contemplated for individuals with developmental disabilities.

Due to the highly invasive and irreversible nature of the “Ashley Treatment” and other growth-limiting interventions for individuals with developmental disabilities, a court order from a court of competent jurisdiction should be required in order to protect the privacy and liberty interests of children for whom such interventions are sought.¹²⁸ Additionally, before a court rules on whether to authorize such an intervention, the court should first fully review the matter and full procedural due process protections should be afforded the individual for whom the intervention is sought.¹²⁹ Below we will address what due process should be required for the “Ashley Treatment” as a whole. For the purposes of analysis here, we will discuss the hysterectomy first, and follow with a discussion of due process requirements in regard to the breast bud removal and the administration of high doses of hormones, both in the context of the “Ashley Treatment” as a whole.

1. The Hysterectomy

Washington law clearly states that a court order is required when parents seek to sterilize their minor or adult children with developmental disabilities for whom they are legal guardian whether the sterilization is being sought as part of the “Ashley Treatment” or alone. As discussed above in Section III.C, Ashley’s parents’ attorney wrote in his legal opinion letter to the parents (attached hereto as Exhibit N), that no court order was necessary to proceed with the interventions proposed in Ashley’s case; including the hysterectomy.

Under *Hayes*, there can be no doubt that the sterilization portion of the “Ashley Treatment” required a court order authorizing the procedure following a full court

¹²⁸ An outright ban of this procedure by a legislature or court, at least at this time, is highly unlikely as to do so would likely be considered unconstitutional. See *Conservatorship of Valerie N., Mildred G., as Conservator v. Valerie N.*, 40 Cal. 3d 143,168, 707 P. 2d. 760, 777(1985) (finding that California state statute outright banning all sterilizations of incompetent individuals with developmental disabilities unconstitutional).

¹²⁹ See discussion *supra* notes 99-119 and accompanying text.

hearing where legal representation, through an attorney or a guardian *ad litem*, was provided to represent Ashley's interests at the hearing. In his letter to Ashley's parents, the parents' attorney asserts that the requirements in *Hayes* do not apply in Ashley's case.¹³⁰ He goes on to attempt to distinguish the situation in the *K.M.* case from Ashley's case by saying, in relevant part, "the facts in that case are radically different: that young woman is able to testify and can understand how hard it is to raise a child-unlike Ashley, who does not know what a child is and cannot talk."¹³¹

This assertion is entirely inconsistent with the ruling in *Hayes* and *K.M.*, as well as other relevant Washington Supreme Court cases.¹³² Contrary to the arguments made by the parents' attorney, nowhere in *Hayes* or *K.M.* does the court say that the due process and privacy rights of minors with developmental disabilities for whom sterilization is sought are greater for an individual who can speak than for one who cannot.¹³³ To the contrary, the *Hayes* Court specifically held that "in *any* proceedings to determine whether an order for sterilization should issue, the retarded person must be represented, as here, by a disinterested guardian *ad litem*."¹³⁴

The unsupported argument of the parents' attorney asserts that the extent of the constitutional rights to be afforded an individual with a developmental disability for whom sterilization is sought should be determined as though the amount of constitutional rights and corresponding due process procedures were on a sliding scale in correlation to the severity of an individual's disability. The amount and scope of an individual's due process and privacy rights is not on a sliding scale. The court in *In re Colyer* specifically held otherwise when holding that incompetent individuals had constitutional interests in refusing end-of-life treatment when they were terminally ill.¹³⁵ There, the Washington Supreme Court specifically held a woman in a chronic vegetative state had a constitutional right to privacy in not being given end-of-life treatment that would only prolong the dying process.¹³⁶ Other courts have also held that 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.¹³⁷

¹³⁰ Letter from Larry Jones, Ph.D., J.D., to Ashley's Dad (June 10, 2004), see Exhibit O at 2.

¹³¹ *Id.* at 3.

¹³² See e.g. *Hayes* 93 Wn.2d at 237; *K.M.*, 62 Wn. App. at 815-17; *Quesnell*, 83 Wn.2d at 235-38.

¹³³ See *Hayes*, 93 Wn.2d 228; *K.M.*, 62 Wn. App. 811.

¹³⁴ *Hayes* 93 Wn.2d at 237 (emphasis added).

¹³⁵ *In re Colyer*, 99 Wn.2d 114, 660 P.2d 738 (1983);

¹³⁶ *Colyer*, 99 Wn.2d at 120. The fact that Ms. Colyer could, at one time before in a chronic vegetative state, speak and Ashley could never speak is irrelevant to the analysis because the same constitutional protections are afforded to the patient in either situation. *Id.* In other cases involving sterilizations of individuals with developmental disabilities or other invasive and/or irreversible treatments, courts have not reduced the amount of due process afforded to the individual for whom sterilization was sought on the basis of the severity of their disability. See e.g., *K.M.*, 62 Wn. App. at 816 (finding an a guardian *ad litem* for an adolescent girl with cognitive limitations described by the court as being similar to those of a six-year old needed to advocate for the protection of the girl's rights and was not permitted to waive those rights just because the guardian *ad litem* agreed with the parents plan for sterilization).

¹³⁷ *In re Grant*, 109 Wn.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

2. Breast Bud Removal and Hormone Therapy as Part of the “Ashley Treatment”

Just as individual constitutional liberty and privacy rights are affected by the invasive and irreversible procedures, in such as involuntary psychosurgery, ECT, antipsychotic medications, and sterilization, the portions of the “Ashley Treatment” that involve breast bud removal and the administration of high doses of hormones also impose on the constitutional rights of the individuals for whom such interventions are sought. These treatments are highly invasive and irreversible, particularly when implemented together as the “Ashley Treatment.” Additionally, these procedures, along with the hysterectomy, affect an individual’s common law right to be free from bodily invasion.¹³⁸

It is the opinion of WPAS’s attorneys that a court would probably find that, like sterilization, the removal of a child’s breast buds and administration of high doses of hormones for the purpose of implementing the “Ashley Treatment” would be considered by a court to pose a similarly significant imposition on the child’s liberty and privacy rights and, thus, would require that the child be afforded procedural due process protections, including a court review and approval, as well as representation by a guardian *ad litem*, as in the case of involuntary sterilization.

3. Discrimination Against Individuals Based Upon Their Disabilities

The implementation of the “Ashley Treatment” and sterilizations on individuals with developmental disabilities also raises discrimination issues because, if not for their developmental disabilities, this set of interventions would not be sought. Discrimination against individuals because of their disabilities is expressly forbidden by state and federal law.¹³⁹ If individuals such as Ashley are denied their full constitutional protections to liberty and privacy because of the severity of their disabilities, such a denial would not only be unconstitutional but also in violation of state and federal anti-discrimination laws.

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 Wn.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 Colyer*, 99 Wn.2d at 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).

¹³⁸ See *Grant*, 109 Wn.2d at 553, 747 P.2d. at 449; *In re Ingram*, 102 Wn.2d 827, 836, 689 P.2d 1363, 1368 (1984).

¹³⁹ Title II of the Americans with Disabilities Act, 42 U.S.C. § 12132; Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. §794; and the Washington Law Against Discrimination, RCW 49.60.030.

V. Corrective Actions and Other Systemic Reforms to Protect the Legal Rights of Individuals with Developmental Disabilities for Whom Sterilization and Growth-limiting Interventions are Sought

In Ashley's case, the legal procedures required for the hysterectomy as required by *Hayes* were not followed.¹⁴⁰ As a result of a number of communication and other institutional breakdowns and misunderstandings at Children's Hospital, and the legal advice the parents received from the attorney they retained, no court order was ever sought, and there was no opportunity for Ashley to have her legal rights represented in this case, as there was no opportunity for any party to present or rebut evidence to prove each of the court mandated requirements for sterilization.¹⁴¹

In order to ensure that a court order is obtained before a sterilization or growth-limiting medical intervention is performed on an individual with a developmental disability, Children's Hospital has entered into an agreement¹⁴² with WPAS to take the following steps:

A. Implementation of Policy and Procedure on Growth-Limiting Medical Interventions

Children's will develop, adopt, and implement a policy prohibiting growth-limiting medical interventions for individuals with developmental disabilities unless Children's has received a valid order from a court of competent jurisdiction, not subject to appeal, authorizing such intervention in a given specific case. In the event Children's does receive such an order providing legal authorization for one or more growth-limiting medical interventions for an individual with a developmental disability, Children's will in addition forward to its Ethics Committee for consideration any proposed use of such interventions. The Ethics Committee will review the proposed use and issue a report setting forth its recommendations regarding such interventions.

For purposes of this policy prohibiting growth-limiting medical interventions for individuals with developmental disabilities without a court order, the term "developmental disability" will have the definition set forth in federal law, 42 U.S.C. §15002(8)(A). A "growth-limiting medical intervention" means any medical intervention, including surgery or drug therapy, that alters or is intended to alter a patient's potential for normed physical maturation. The policy will apply whenever a growth-limiting medical intervention for an individual with a developmental disability is sought by a parent, guardian, or other third party. In developing its policy, Children's will consult closely with WPAS. Children's will adopt its policy as soon as possible after this consultation, and expects to adopt it by September 1, 2007.

¹⁴⁰ See discussion *supra* notes 104-114 and accompanying text.

¹⁴¹ See *Hayes*, 93 Wn.2d at 238-39; *supra* text accompanying note 112 detailing the nine points that must be proven by clear cogent and convincing evidence before a sterilization may take place.

¹⁴² Agreement Between Children's Hospital and Regional Medical Center and Washington Protection and Advocacy System (Disability Rights Washington) Promoting Protection of Individuals With Developmental Disabilities (see Exhibit T).

In developing its policy prohibiting growth-limiting medical interventions for individuals with developmental disabilities without a court order, Children's will include, to the extent feasible, the design and implementation of appropriate forcing functions within computer systems to prevent scheduling of breast bud removal surgery unless the requirements of Children's policy have been met. In addition, to the extent that Children's determines it is consistent with good clinical care to do so, and possible using Children's computer systems, Children's will design and implement forcing functions whereby any request made of Children's pharmacy to fill prescriptions for designated high dosages of hormone drug therapies will be monitored and reviewed by appropriate designated Children's clinical leaders for compliance with the policy prohibiting growth-limiting medical interventions for individuals with developmental disabilities without a court order. Children's pharmacy will not fill the prescription until it determines that it does not violate this policy.

To the extent permitted under federal and state laws regarding the privacy of health information, Children's will inform WPAS when it receives notice that a court order permitting growth-limiting medical intervention for an individual with a developmental disability has been entered. Children's will consult closely with WPAS to develop a procedure for providing this information.

B. Corrective Actions

Children's will take corrective actions to assure that in any future case involving the sterilization of an individual with a developmentally disability, a valid court order not subject to appeal is in place. These corrective actions will include design and implementation of appropriate forcing functions within computer systems to prevent scheduling any such procedure unless the requirements of Children's policies have been met. Children's will also undertake educational activities to inform members of its medical staff and employees about a) the legal requirements in the state of Washington for court review and order before sterilization of a developmentally disabled individual; b) Children's policy prohibiting growth-limiting medical interventions for individuals with developmental disabilities without court order; and c) bioethical considerations in limiting the physical growth of individuals with developmental disabilities.

C. No Sterilizations Without Court Order

Children's acknowledges that prior to performing surgery intended to sterilize an individual with a developmental disability, Washington law requires a valid court order permitting the procedure. Children's will adopt and implement a policy barring any sterilization without a court order except in emergency situations, and will require that all applicable appeals or appeal periods have concluded before proceeding with any non-emergency sterilization. In developing its policy, Children's will consult closely with WPAS. Children's will adopt its policy as soon as possible after this consultation, and expects to adopt it by September 1, 2007.

To the extent permitted under federal and state laws regarding the privacy of health information, Children's will inform WPAS when it receives notice that a court order permitting sterilization for a developmentally disabled individual has been entered. Children's will consult closely with WPAS to develop a procedure for providing this information.

D. Ethics Committee Membership

Children's believes it will benefit from adding to its Ethics Committee one or more individuals who can advocate for individuals with developmental disabilities. Within 60 days of receiving from WPAS its recommendation of one or more individuals to serve in this capacity, Children's will appoint an individual as a member of the Ethics Committee who can serve as this advocate. Children's will adopt and implement a policy requiring appointment of one or more such individuals to its Ethics Committee, and will consult closely with WPAS in developing its policy and making any such appointment. In addition, Children's will encourage and authorize the Ethics Committee to bring in appropriate internal and external experts for consultation and discussion with the Committee whenever it considers issues affecting individuals with developmental disabilities. If WPAS chooses to make recommendations regarding other categories of professionals who it believes should be considered for membership on the Ethics Committee, Children's will consider such recommendations carefully and consult closely with WPAS regarding them.

VI. Conclusion

As set forth above, the rights of six-year old Ashley were violated in the initial use of the "Ashley Treatment." Ashley's parents and doctors proceeded with a plan to keep her small by administering high levels of hormones and removing her uterus and breast buds without first obtaining a court order. The failure to obtain court approval before sterilizing Ashley was in clear violation of the Constitution and Washington law. Had court review been sought even on the issue of the sterilization, the court could have examined whether the "Ashley Treatment," in its entirety, should be authorized, as a guardian *ad litem*, whose appointment the law requires in sterilization cases, would have likely learned of the interrelationship between the sterilization and the rest of the growth attenuation plan when investigating the merits of the proposed sterilization. Because a court order for the hysterectomy was never sought, there was no opportunity to examine the legality of the sterilization, or the "Ashley Treatment" as a whole.

As acknowledged in *Hayes* and *K.M.*, it cannot be assumed that parents, guardians, or doctors have identical interests as the child for whom the sterilization is sought.¹⁴³ By including the required court review with full due process protections as required by *Hayes* and *K.M.*, and approval for the "Ashley Treatment" as a whole in hospital policies, hospitals and doctors can ensure that their patients have someone advocating for the child and can hopefully avoid unintentionally violating their patients' civil rights.

¹⁴³ *Hayes*, 93 Wn.2d at 236; *KM*, 62 Wn. App. at 817.

For all the reasons detailed in this report, judicial review of proposed procedures like the “Ashley Treatment” is absolutely necessary. Guaranteeing procedural due process for all people facing the “Ashley Treatment” or other growth-limiting medical interventions will not, however, answer the question of whether the “Ashley Treatment” *should* be done. While arguments in favor of autonomy and personal freedom and independence can be presented to courts considering authorization of the “Ashley Treatment” in the future, court is not the only forum for discussing issues relating to the “Ashley Treatment,” including whether it should be pursued in the future and what steps should and can be done to ensure that the individuals for whom such intervention is sought have their legal rights adequately protected.

It will never be known if a court would have authorized the original “Ashley Treatment” in Ashley’s case. Likewise, it is not known whether a court will ever authorize similar procedures in the future. That does not, however, prevent continuing dialogue in regards to how society values and respects people with developmental disabilities and their rights. Unfortunately, the problems faced by Ashley and her family are all too common across this country. Fears about inadequate and unsafe care, supports, and services available in the community are not unfounded. With that being said, many people with disabilities and their advocates have worked to promote the independent living movement; at the same time, there have been concerted efforts to improve conditions of care in community and institutional settings.

Through the lessons learned in this report and the discourse sparked in the media over the “Ashley Treatment,” it is possible for people on every side of the debate to join together in advocating for mutually agreeable solutions to the concerns we all have about the state of our social service delivery system. As always, WPAS will be involved in efforts to increase and improve the level and quality of services for people with disabilities. WPAS understands that issues raised in Ashley’s case go beyond Ashley and Children’s Hospital specifically, and WPAS intends to address these larger concerns. To that end, WPAS intends to be involved in education and advocacy efforts with law and medical students, judges, guardians *ad litem*, other hospitals and medical professionals, insurance companies, and agencies involved in certification, accreditation, and licensing of hospitals and health care providers, among others around the various issues raised by the “Ashley Treatment” and sterilization of individuals with developmental disabilities (see “Next Steps” listed in Executive Summary).

VII. Appendices

Appendix I: Documents

Contacts for State Legal Requirements Regarding Ashley Treatment	Exhibit A
Ashley's Mom and Dad, <i>The "Ashley Treatment", Towards a Better Quality of Life for "Pillow Angels,"</i> (2007)	Exhibit B
Letter from David Carlson, Associate Director of Legal Advocacy, WPAS, to Lisa Brandenburg, Interim Executive Director, UWMC (January 8, 2007)	Exhibit C
Letter from David Carlson, Associate Director of Legal Advocacy, WPAS, to Jodi Long, Associate General Counsel, Children's Hospital (January 10, 2007)	Exhibit D
<i>Persons Not Capable of Providing Informed Consent</i> , UW Medicine Informed Consent Manual (2001-2004)	Exhibit E
Letter from Jeffery Sconyers, General Counsel, Seattle Children's Hospital and Regional Medical Center to David Carlson, Associate Director of Legal Advocacy, Washington Protection and Advocacy System (January 22, 2007)	Exhibit F
Children's Hospital and Regional Medical Center Growth Attenuation/Sterilization Review Subcommittee	Exhibit G
The Mission Statement for the Ethics Committee of the Children's Hospital & Regional Medical Center	Exhibit H
Legally Authorized Person for Informed Consent Decision Making When a Patient is a Minor	Exhibit I
Letter from Jeffery Sconyers General Counsel, Seattle Children's Hospital and Regional Medical Center to Deborah A. Dorfman, Director of Legal Advocacy, and David Carlson, Associate Director of Legal Advocacy, Washington Protection and Advocacy System (January 23, 2007)	Exhibit J
Children's Hospital & Regional Medical Center Sterilization of Minors Policy	Exhibit K
Special CHRMC Ethics Committee Meeting/Consultation (May, 2004)	Exhibit L

<i>In re Hayes</i> , 93 Wn. 2d 536, 237, (1980)	Exhibit M
<i>In re K.M.</i> , 62 Wn. App. 811, 818 (1991)	Exhibit N
Letter from Larry Jones, Ph.D., J.D., to Ashley's Dad (June 10, 2004)	Exhibit O
Letter from Deborah A. Dorfman, Director of Legal Advocacy & Associate Executive Director, WPAS, to Jodi Long, Associate General Counsel, and Jeffrey Sconyers, General Counsel, Children's Hospital (March 27, 2007)	Exhibit P
Letter from Jodi Long, Associate General Counsel, Seattle Children's Hospital and Regional Medical Center to Deborah A. Dorfman, Director of Legal Advocacy, Washington Protection and Advocacy System (January 23, 2007)	Exhibit Q
Children's Hospital Billing Report	Exhibit R
Curriculum Vitae of Scott Stiefel	Exhibit S
Agreement Between Children's Hospital and Regional Medical Center and Washington Protection and Advocacy System (Disability Rights Washington) Promoting Protection of Individuals With Developmental Disabilities	Exhibit T

Appendix II: Legal Authorities

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<i>Eisenstadt v. Barid</i> , 405 U.S. 438 (1972)	16
<i>Griswold v. Connecticut</i> , 382 U.S. 478 (1965)	16
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