

# WASHINGTON PROTECTION & ADVOCACY SYSTEM

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## The following is an excerpt from the Investigative Report Regarding the “Ashley Treatment”

### 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.

To view the complete Investigative Report Regarding the “Ashley Treatment”, please see [www.DisabilityRightsWA.org](http://www.DisabilityRightsWA.org). To receive this document in an alternative format, please contact DRW Administrator Jessica McDanel at 206-324-1521 or TTY 206-957-0728.