

Devaluing People with Disabilities

Medical Procedures that Violate Civil Rights

Contributors

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

Disability Rights Washington: David Carlson, Andrea Kadlec

Executive Summary

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

Anne's Story¹

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

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

-Anne McDonald

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

The controversy sparked deliberations in the media that focused on who was right and how we as a society can and should make decisions about individuals with disabilities, especially children. Many articles claimed that no harm had come to Ashley because her intellectual functioning would not allow her to ever understand what had been done to her. In many of these discussions, the rights of children were blended with the rights of their parents. However, when a parent seeks to permanently and potentially unnecessarily alter a child's body through invasive and irreversible procedures, this blended view of rights is inappropriate, as a potential or actual conflict of interest may exist. In these situations, it is imperative that the child's rights be untangled from those of their parents. When the child in question has a disability, the questions become even more complex.

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

Gail's Story^{iv}

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

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

- Gail Lainhart-Rivas, Sarah's mother

participate in community life and their overall worth to society.

In recent years, new types of medical technology and procedures have emerged that allow people with disabilities, even those with the most significant disabilities, to live longer lives and improve their quality of life to live outside of institutions in their own homes in the community. The legacy of eugenics however, and the basic discriminatory structures that underlie it, are still powerful factors in medical decision making by some doctors and surrogate decision makers for people with disabilities. Not only have these technologies and procedures been used to enhance quality of life, they have at times been used to reinforce social policies that devalue people with disabilities and keep them separate from community life. In fact, there are times, as this report will describe where physicians recommend and family or other surrogate decision makers decide to not provide a needed transplant, to withhold medical treatment including hydration and nutrition of individuals without a terminal condition, or to sterilize people all on the basis of their disabilities. Applied in these ways, medical decision making and procedures are discriminatory and deny basic constitutional rights to individuals with disabilities including the rights to liberty, privacy, and other statutory and common law rights.

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

Anne's Story^{vii}

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

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

-Anne McDonald

functions to ensure that the human and civil rights of individuals with disabilities are protected.

Recommendations

Hospitals, Medical Establishments and Other Medical Entities

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

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

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

The Joint Commission on Accreditation of Healthcare Organizations

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

Insurance Companies

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

State Legislatures

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

Enact legislation, or amend existing statutes and regulations, to establish due process protections for instances of withholding necessary medical treatment including but not limited to nutrition, hydration or antibiotics or providing unnecessary medical treatment based on the presence of a disability.

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

U.S. Department of Health and Human Services

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

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

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

Amend the Federal Sterilization Regulations codified at 42 C.F.R 50.201 *et. seq.* to prohibit recipients of federal funds from providing sterilization where the individual has

not consented, or growth attenuation treatment based on a person's disability, or arranging for such procedures.

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

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

Congress

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

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

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

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

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

^{iv} Interview with Gail Lainhart-Rivas, Parent in Seattle, Wash. (May 4, 2012).

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

^{vi} *Id.*

^{vii} McDonald, *supra* note 1.

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