The Ashley Treatment: Furthering the Anthropology of Disability

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Questions regarding access to and the use of medical and surgical treatment for people with disabilities revisit themes central to medical anthropology. The “Ashley Treatment” is named after a nine-year-old girl, Ashley, who has extreme physical and cognitive disabilities. The Treatment refers to extensive medical and surgical procedures that are claimed to improve quality of life and prevent future medical problems. The Treatment has stimulated lively public debate on disability, medicalization, and caregiving. We illustrate how the Ashley Treatment emphasizes the importance of medical anthropological research on the construction of personhood and childhood disability, agency and autonomy, and the rights of representation and control, as well as the ethics of invasive procedures, hormone therapy, and body modification surgery.

Key Words: bioethics; child; disability; quality of life; surgical intervention

Persons living with disabilities have been one of the last groups served by international conventions and the associated recognition and protection of rights. In recent years, however, the United Nations has debated, negotiated, and finally passed the Convention on the Rights of Persons with
Disabilities. This adoption marked an important moment in the global super-
structure that molds local jurisdiction, organizations, and everyday practice. There have been dramatic changes that have anticipated and followed this, including ideational and governmental, local and global. These changes have been reflected in increased awareness of the ways in which disability and impairment are regarded as if intrinsic to the person rather than an artifact of social structure and environment, and a growing concern with how physical and cultural barriers block access, social inclusion, and capacity. Yet policymakers routinely relegate social research into the lives of persons with disabilities, and the decisions that are made in their names, to one side, the scholarship often as liminal as the subjects of inquiry. The result is poor appreciation of how political philosophy and social and economic circumstance—as much as culture—pattern how people live with differences. Recent public debates about treatments for people with disabilities that were generally performed in the name of normalization bring home this point.

Not all surgery normalizes; sometimes its aim is the reverse. The Ashley Treatment is one such example. Ashley was born in Washington state in 1997. She has severe development disabilities from static encephalopathy of unknown etiology and is described as having a cognitive and mental age of approximately three months. She cannot walk, talk, hold up her head, or change position, and she is fed through a gastrostomy (feeding) tube. Her parents nicknamed her “Pillow Angel,” according to the blog that they maintain (The “Ashley Treatment” 2007) because “she is so sweet and stays right where we place her—usually on a pillow.” They have extended this term to include any person with extreme physical limitations and profound cognitive limitations that will never exceed those of a six-month-old infant. Pillow Angels are entirely dependent on their caregivers.

The Ashley Treatment refers to a constellation of medical procedures that Ashley underwent, including appendectomy, hysterectomy, breast bud removal, and, most controversially, growth attenuation, which was performed with the expressed intentions of improving her quality of life and preventing future medical problems. The treatment was requested by Ashley’s parents and was approved by an ethics committee at Seattle Children’s Hospital. Treatment began when Ashley was six years, with surgery in July 2004 and estrogen therapy (to reduce height gain) completed in late 2006. Ashley’s case was published in the *Archives of Pediatric and Adolescent Medicine* in October 2006 (Gunther and Diekema 2006), and with an accompanying editorial, the public debate began. Ashley’s parents began their blog in January 2007 to address misconceptions in the media and to advocate the use of the Treatment for other Pillow Angels.

The debate concerning the Ashley Treatment draws on popular notions of ethics, moral responsibility, social policy, and parents’ responsibilities
in caring for children and on disability advocacy and rights discourse. Scholars such as Paul Hunt (1966), Lennard Davis (1995), David Mitchell and Sharon Snyder (1997), Mike Oliver (1990, 1996) and Tom Shakespeare (2006, 2007) have argued cogently of the social construction of disability. Exclusion, disadvantage, and social discrimination, they argue, are produced by “ableist ideologies” regarding normative bodies and normative bodily capacities that lead to systematic oversights of the physical and social environment. Medical anthropologists have shared this view, although they have also acknowledged the interplay of impairment, motivation and self-esteem, and external factors—social and physical structures and attitudes—to create the experience of disability (e.g., Murphy 1987; Ablon 1999; Shuttleworth and Kasnitz 2004). The Ashley Treatment grounds these academic arguments and the implicit questions relating to ethics and values, knowledge and power.

PROPRIETORS AND OPPONENTS OF THE TREATMENT

Surgical and hormonal interventions to address difference are becoming increasingly routine but are contested in some instances because of the value judgments implied in relation to body function and appearance. They include gastrostomy tube insertion for adults and children who cannot ingest, cochlear implants for deaf children, limb lengthening surgical procedures for children with dwarfism, and hormone therapy for various intersex conditions. The Ashley Treatment is not so different other than the number of procedures and body parts involved. It has, however, provoked extensive controversy, as argued through Internet media (blog sites, listserves, etc.).

Some critics accuse Ashley’s parents of desiring to keep her a child forever. Articles in the print and Web-based media draw on such images through reference to the “Peter Pan treatment...permanently freezing a person into childhood” (Caplan 2007). Critics argue that the Treatment violates Ashley’s human dignity, and treats her and by extension, all people with disabilities, as less than human. Her parents have been criticized for their use of the term “Pillow Angel,” for characterizing Ashley as innocent, passive, one-dimensional, without desire, and less than human. Most critics have objected to the removal of healthy organs or body parts, describing the Treatment as unnatural and unnecessary overall but also, most fervently, have objected to the perceived intent of the Treatment to make the parents’ lives easier, a matter of convenience. Bloggers also express their general fear of a “slippery slope” that would lead to similar interventions extended to people with less-severe disabilities, echoing anxiety about eugenics and recalling past histories of the forced sterilization of women with cognitive
impairment. There is concern too, in the public debate, that the hospital ethics committee that approved the Treatment had not included a representative from the disability community and suggestions that children in Ashley’s position should have an advocate from outside the family. Indeed, the Children’s Hospital acknowledged in May 2007 that it had contravened state law by performing Ashley’s hysterectomy without a court order or review by a panel including persons with disabilities. There is general agreement among most critics that the Treatment is a “technological solution to a social problem” (Brosco and Feudtner 2006), that of insufficient funding for the care of people such as Ashley.

Many people have responded to critics who misunderstand the Treatment as preventing any adult development. In their blog, Ashley’s parents point out that Ashley’s ovaries were not removed, so she has normal hormonal cycles; others reiterate that the purpose of the surgical and hormonal treatments was to prevent unnecessary suffering, including in association with menstruation. At the same time, those specifically supporting the Treatment or rejecting the standpoint of its opponents argue that the parents should make such decisions for their child. Ashley’s parents and their supporters see reduced impairment as the consequence of the surgery and, therefore, (presumed) decreased discomfort and increased social interaction. As they see it, those opposing the Treatment are guilty of using norms and values of healthiness, well-being, quality of life, and capacity applicable to non-disabled people, not to those who have severe cognitive and physical disabilities. The debate touches on themes central to medical anthropology, including what we consider to be natural or unnatural and social versus medical solutions to various health-related problems, how personhood is constructed, ideas of autonomy and agency, and ideas about dignity and “quality” of life. These are questions that have received meager attention, and much more anthropology needs to be done to help clarify the ethical and political issues such cases raise.

Disability provokes strong emotional and visceral reactions, and the vehemence, invective, and content of debates about the Ashley Treatment echo earlier debates related to medical interventions and the project of normalization. They are also reminiscent of debates on genetic research, prenatal diagnosis, transplant surgery, and life support, the latter frequently explored in public debates and by anthropologists with reference to the case of Karen Ann Quinlan (e.g., in Lock 2002, 2007).

Both critics and supporters of the Ashley Treatment often begin with a basic sense of what is known in bioethics as the “yuck factor” or “repugnance” (Kass 1997). This reaction stems partly from the disruption of normal systems of classification, from Ashley’s liminal position, and from the sense that the Treatment crosses some boundary between normal and
abnormal. Ashley is a maturing girl with what people see as the mind of an infant, so she disrupts normal classification in one way. Yet, contradictorily, the Treatment is disruptive because it intercepts “normal” growth patterns to prevent gender-appropriate and age-related normal processes. Ashley is neither adult nor child, before or after Treatment. But her liminality is made more monstrous in critics’ eyes by the surgeries and medical programs designed to make her less, not more, normal. Ashley becomes a “celebrity freak” of sorts, a grotesque body produced through technology to suit others (Douglas 1966; Yuan 1996).

A particular aspect of the Ashley Treatment, again pointing to the need for further ethnographic enquiry and anthropological analysis, was the removal of her uterus and breast buds to protect her, it was argued, from the discomfort associated with menstruation and the risks of sexual assault and unwanted pregnancy, as well as the potential threat of cancer. These surgical acts are situated in a wider discourse related to diverse culturally sanctioned and contestable surgeries: breast reduction or augmentation, circumcision and infibulation, hysterectomy and caesarean section. Sex assignment surgery is arguably an especially useful comparison with the Ashley Treatment in terms of attitudes to child and parents. As Gerschick (2006: 1264) observed, in terms of being recognized as appropriately gendered, people with disabilities are “in an asymmetrical power relationship with their temporarily able-bodied counterparts.” Their bodies “operate socially as canvases on which gender is displayed [and] make them vulnerable to being denied recognition as men and women” (Gerschick 2006: 1264).

EMERGING RESEARCH AGENDAS

People with profound disabilities challenge our perceptions of the body and human dignity and may not fit into our current models of disability. Ideas of liminality move our understanding of ability and disability beyond the medical to support the social model of disability. However, the Ashley Treatment challenges the dominance of an exclusively social paradigm and provides evidence for an integrated model informed by new research on the experiences of children with profound and multiple disabilities and their families and caregivers within diverse social, cultural, and economic contexts.

While most research on disability and writing about disability in academic settings comes from the industrialized political “North,” world wide, most people with disabilities live in resource-poor settings. Media attention surrounding the Ashley Treatment, however, spread the story around the globe, as a quick Web search illustrates. In consequence, families in many different countries who are struggling with the difficulties associated with
caring with few resources for children with profound impairments have sought this medical intervention for their severely disabled children, seeing in it perhaps a combination of reducing their burden of care and increasing their child’s quality of life, and the “proper” way to care for such children, a growing trend and a normal procedure in the United States.

The Ashley case highlights other gaps in anthropological enquiry. While Ashley’s story and the Ashley Treatment are first “about” disability, they are also very much about the medicalization of any bodily condition and the role of doctors in normalizing. While Ashley’s parents may have made the decision to proceed, the panoply of treatments that constituted Ashley’s Treatment—a toolbox of surgeries and medications—were not theirs to recommend and choose. The more muted ethical debate in this case, as in many, is one about the provision of information, the nature of informed consent, the right to give consent, and the framing of choice and outcome. This is a question that extends across much of medical anthropology’s territory. Fundamentally it is (again) a question of power and knowledge.

The case is also about body modification across cultures and historic periods. It is axiomatic that bodies are all modified in some deliberate way in any culture, time, and place, either temporarily (e.g., cutting one’s hair), permanently for symbolic and/or decorative reasons (e.g., tattooing, body piercing, scarification), medical procedures (surgery and/or chemicals), or by effecting structural or systemic changes through exercise and nutrition. The bodies of persons with disabilities may be especially likely to experience modification through medical treatments, prosthetics, and other enabling devices, but only in societies where there are such options and access to them.

The case is also about children: the labor and duties of care, ideas of childhood and adulthood, and rights and responsibilities. While the story raises questions of caregiving for children with profound, severe, and multiple disabilities, it also raises questions about all children. Medical anthropologists have given considerable attention to infant care and infectious disease, and so, early diagnosis and treatment, resort to help seeking, home care, and so on, as reflected in the literature on primary health care, malaria, diarrheal disease, and acute respiratory disease. In contrast, we have spent little time on questions relating to children with chronic conditions, ongoing health problems, and various disabilities. Such children have been generally marginalized within disability theory and undertheorized and understudied within anthropology as a whole, although they occupy important positions at the intersection of the individual and the social, the biological, and the cultural.

Cases like Ashley’s raise uncomfortable questions about the role of anthropologists, not just in identifying the unfolding research questions but also importantly in public debates, as public intellectuals. Several
medical anthropologists have turned to this path, including in relation to ethics, Margaret Lock (2002, 2007), making clear their own ethical standpoints and uneasiness in the face of various medical and bodily dramas played out in individual, local, and global arenas. All of us are concerned, because of our avocation, with questions of access to medical care, profiteering from medical services, the (lack of) agency of the disempowered, and rights of representation and control.

The social model of disability, as elucidated by anthropologists (e.g., Ablon 1984, 1999; Ingstad and Whyte 1995, 2007) and other social scientists and disability studies writers, has much to say about how different societies include or exclude people with disabilities instead of focusing on changing people with disabilities to fit into a “normal ideal” (Davis 1995: 154). The discourse surrounding the Ashley Treatment provides an opportunity to reexamine current models of disability and the place of children with profound and multiple disabilities within not only disability studies but within anthropology and other fields as well. Concurrently, it allows us to revisit dilemmas of interventions, both social and medical. How do we understand the short-term decisions in Ashley’s story as something other than “human rights abuses”? Changing society takes time; all parents are faced with and must regularly make decisions about their children’s current and future lives now. Parents may not see any way of changing society enough to match the benefits of medical interventions. In the context of an ungenerous world and persistent poor health and suffering, the social model may need to be combined with other approaches: medical and therapeutic interventions and social and political action. As we are well aware, access to medical advice and care, built environments, and social attitudes vary considerably within and between countries. Anthropology’s mandate is to explore diversity in experience and to relate this to social structures, values, and power. There is much to be done.

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