

THE ASSAULT ON ASHLEY

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The mutilation of this girl named Ashley should come as no surprise. By now the entire disability community is familiar with what happened to Ashley, *the justification on the grounds of convenience for the parents/caretakers* and the defense of these procedures *on the basis of diminished citizenship* by Peter Singer in the NY Times. Part of the outrage that some of us feel is simply that others are not outraged at all. This should give us pause. The uncomfortable question I would like to pose is simply this: to what extent are we complicit in this lack of outrage from the media and the general public?

There are two issues worth exploring here that I believe the disability community has avoided up to now. The first is our failure to develop an ethical grounding that would confront the utilitarian ethics of both this hospital committee (and most others like it) and the so-called ethicists like Peter Singer who never seems to wear out his welcome with the liberal media including both the NY Times and the New York Review of Books. In fact posing a difficult ethical problem to either Singer or to a hospital ethics committee guarantees no sure ethical response at all. We should wonder why.

The second issue that I believe needs to be confronted is to what extent do we in human services contribute to a view of individuals with intellectual and /or cognitive disabilities that allows some to so freely disparage them and render them less than equal under the law.

The two issues that dominated media discussion of Ashley's plight revolved around the justification for making it "convenient" for Ashley's parents to raise her and the Singer argument that whatever dignity Ashley possessed was extrinsic to her and conferred by others—in this case her parents. Both the acceptance of the family's convenience and the argument over the existence of Ashley's dignity are the antithesis of the beliefs held by the disability community. We hold that equality under the law is not subject to review or analysis. Not so the field of ethics.

Ethical theory is dominated by a branch of ethics called utilitarian ethics. They have over the last several decades carved out an exception to full equality based on what they consider *personhood*. By defining personhood as characterized by consciousness and intelligence they have created a lesser species of human being—not entitled to the same rights as those without these disabilities. Unfortunately, this distinction has made its way into the public consciousness and indeed into judicial decision-making.

So the question that needs to be posed here is where is the academic arm of the disability community and why have we not mounted a challenge to these invidious distinctions. We have historically reacted too late or fumbled our responses to serious ethical and legal issues over the years. While the left and the right carved up the ethical debate on Terri Schiavo the disability community was silenced by the media. Our friends on the left abandoned any of our cherished principles and the right to life movement, just like with the "baby doe" issue, captured our side of this debate. In the end, the person with the

biggest personal and fiscal conflict of interest, Terri Schiavo's former husband, became the darling of the media. With the exception of Not Dead Yet, the disability community has been effectively sidelined.

Contemporary human services may very well play right into the hands of those who hold these utilitarian views. We still routinely strip individuals of their constitutional rights under the imposition of guardianship. We still utilize IQ tests and IQ scores to define a person with intellectual disabilities. We routinely create programs that collect groups of individuals and present them to the wider community doing activities that are non--outcome producing and culturally inappropriate for others without disabilities. We do all of this with Medicaid financing and document it with mounds of paper. We buy into the assumption of incompetence rather than structure our organized support to promote assisted competence. We do not promote the very idea of freedom that emanates from our idea of equality. In fact, it can be argued that the very congregate organization of so much of human services is done for the convenience of those who provide "care giving."

These are not small indignities. They make it less likely that our voice will be heard regarding the inherent dignity of individuals with disabilities. We simply can't have it both ways: selective outrage over notorious issues and silence over the everyday indignities that are imposed by typical human services. We cannot counter ideas of reduced equality and personhood without a coherent ethical as well as legal theory to support it. We cannot object to decision-making based on someone else's convenience while we essentially do the same on a different scale. Our responses then result in a form of moral ambiguity that muddle rather than illuminate the discussion and debate over Ashley and others with similar disabilities.