



STATEMENT ON "THE ASHLEY X TREATMENT" January 26, 2007

The decision by the parents of a young girl with disabilities to medically restrict her physical growth and maturation, now known as "The Ashley Treatment," has sparked renewed debate of the rights of people with intellectual and developmental disabilities.

We believe that loving parents who are caregivers are not granted special dispensation to sanction irreparable and irreversible surgeries to alter their son or daughter's physical being primarily for their own convenience or comfort. In this case, the decision drastically altered Ashley's life. The ethics panel that approved the decision to perform these medical procedures on Ashley provided insufficient counsel to the family and the doctors, since they failed to account for Ashley's fundamental rights as a person with intellectual and developmental disabilities. In published accounts of the ethics review, consideration of Ashley and her stake in her own civil and human rights was absent. No child with a significant disability would have been similarly treated without legal charges against the parents and physicians.

For decades we have worked to ensure that people with intellectual and developmental disabilities have the same civil and human rights that others enjoy, and that they have the same respect and dignity that all persons receive. Too often, people with intellectual and developmental disabilities are treated as perpetual children. As advocates, we are acutely aware of the profound difficulties parents of sons and daughters with disabilities face, and we know that most of us need support and information so that we may provide the best possible care and nurturance to our children as they grow and become adults.

We remain committed to working together to ensure that all-encompassing and infantilizing interventions such as this are not promoted by our public policies. We work to ensure that communities are aware of the needs of all children and adults who live with significant disabilities, and of the concerns of their families. By learning to include, respect, and value people with the most significant disabilities, we can improve all of our communities.

It is vital that families who are overwhelmed by their care-giving responsibilities can access affordable, appropriate supports and that young persons with disabilities have access to meaningful self-advocacy supports and training. The "Ashley Treatment" has strengthened our collective will to foster improved communication and a better understanding of disability issues among physicians, ethicists, and policymakers. We are certain that decisions and policies are strengthened by the participation of people with disabilities, their families, and their advocates.