



ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES
RESEARCH, EDUCATION, SERVICE

AUCD Statement of Principles: Medical Interventions

The Association of University Centers on Disabilities (AUCD), located in Silver Spring, MD, promotes and supports a national network of interdisciplinary centers on disabilities. The members of AUCD represent every U.S. state and territory and include 67 University Centers for Excellence in Developmental Disabilities (UCEDD), 34 Interdisciplinary Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Programs and 21 Developmental Disabilities Research Centers (DDRC). Together, these organizations advance policy and practice through research, education, leadership and services for and with individuals with developmental and other disabilities, their families and communities, in support of independence, productivity and satisfying quality of life.

This past year, the issue of using medical interventions to ease the stress of long term care giving and improve the quality of life of people with severe disabilities, was raised in relation to a young girl named Ashley. Ashley is a child who is unable to communicate more than her basic needs and who requires 24-hour care due to the severity of her physical disability. The intensity of her care needs is not likely to change as she matures. Concerned about Ashley's comfort and their ability to continue to care for her at home, Ashley's parents consulted with their physicians and with their support, elected to treat Ashley with hormones to limit her skeletal growth and the surgical removal of her breast buds and uterus to prevent sexual maturation.

These interventions - of which some have never been used before - raise issues and questions that are worthy of discussion. The following Statement of Principles was developed by AUCD after careful consideration of questions that appear below.

1. Benefit to the Individual: What specific benefit is achieved by the individual who is to receive these interventions? Who are the main beneficiaries of these interventions (the individual, the family, the community, the political system)? And what is the risk of these interventions (pain, anxiety, financial pressures).

Principle 1: AUCD does not support invasive, irreversible medical procedures that are designed for the primary purpose of easing the stress of long term caretaking and improving the quality of life for a child unless there is a clear connection to outcomes that will benefit the individual with a disability and only after the benefit to the individual is deemed to outweigh the risks. A procedure may also benefit the family and the community, by reducing stress on the family or reducing the costs of care to a community, but these benefits should be secondary, not primary, in considering the appropriateness of the intervention.

2. Evaluation of Treatments: Many treatments available seem intuitively beneficial, though in fact, there may be little evidence to support this perspective. In addition, there may be no information about the long-term effects of a treatment. How do we assess the usefulness or ethical nature of an intervention when we have no or incomplete data on outcomes? Should we only support those interventions that are "evidence-based"?

Principle 2: AUCD does not recommend invasive, irreversible medical interventions unless there is scientific evidence to support the potential for a positive outcome for the individual. Medical procedures that lack a scientific basis should be viewed with skepticism and approached with extreme caution. As physicians and scientists, we recognize that some interventions may lack long-term data to support their current use, but future research may indicate their efficacy. To maximize the potential for future positive outcomes for individuals with significant disabilities, we support more research to develop a larger knowledge base.

3. The role of the family: What are the roles of families and professionals in decision making of this nature? What is the role of the individual with a disability in this decision making process if the severity of the disability or the person's age precludes a full understanding of the intervention and/or the other options available? If a treatment is new, do we consider an ethics committee adequate to ensure an individual's civil rights?

Principle 3: AUCD recognizes and supports the role of families in decision-making that affects sons and daughters with disabilities and their siblings. At the same time, AUCD feels that to balance the role of the family with the rights of the individual, it is essential to involve an advocate for the child and/or Ethics Committee members when a potentially life-altering irreversible decision is considered. If an Ethics Committee participates in this decision making, it should consult a full range of people related to the patient or his/her treatment or who bring relevant expertise to the table. They may include, but are not limited to: individuals with disabilities, family members, health care providers, an ethicist, an attorney, an advocate for the specific individual and an advocate for the family. If the individual with a disability can, in any fashion, participate in the decision under consideration, AUCD supports his/her involvement.

4. Alternative solutions and access: Many families, individuals with disabilities and professionals do not know what alternative treatments are available and might be useful. How can this information be made more universally available? Even if they have this knowledge, given the differences in resources between communities and/or the lack of funding available to families, how do we make sure these treatments are accessible?

Principle 4: AUCD believes that the need for invasive medical interventions is tremendously reduced when families can obtain the information, services and supports they need to care for family members with severe disabilities at home. Information about alternatives to these invasive procedures must be made universally available to the families and professionals who care for these individuals. States must reconsider where they allocate funds for individuals with disabilities. In lieu of the present situation, where the majority of dollars are spent on institutional care, most dollars should be directed to develop community services and provided to families or individuals with disabilities. This would ensure access to resources and supports that would significantly reduce the need for drastic interventions.

5. Knowledge of lifespan changes: Families who first learn that they have a child with a severe disability may hold the same biases and misunderstandings about disability as the culture in which they live. Professionals sometimes support these biases with labels that imply the child will not mature. Irrespective of the degree of disability, there are lifespan changes occurring with maturation that will affect the child's behavior and relationship with the family. How can families be helped to make decisions for their child in light of these maturational changes?

Principle 5: AUCD supports families having access to other families with a lifespan perspective on disability in order to weigh the consequence of their decisions. In addition, professionals counseling these families may need to broaden their own understanding of the maturation process of children with severe disabilities and how it impacts the child's relationships in order to counter myths and biases that may influence decision making.

Based on the above principles, AUCD recognizes that - given the present state of services and supports available to families and individuals with disabilities in the community - families may opt for invasive medical interventions for their loved ones. We honor their work and recognize the complexity of each situation. We believe that each family's request must be considered on an individual basis, that families must be allowed to make their decisions out of the public eye, and that the principles stated above must be followed to the greatest degree possible.

*This statement was approved by the AUCD Board of Directors, February 2008.
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AUCD Medical Intervention Work Group, 2007-2008

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