



AMERICAN ACADEMY OF PEDIATRICS

Joint Policy Statement

Principles of Treatment of Disabled Infants

Discrimination of any type against any individual with a disability/disabilities, regardless of the nature or severity of the disability, is morally and legally indefensible.

Throughout their lives, all disabled individuals have the same rights as other citizens, including access to such major societal activities as health care, education, and employment.

These rights for all disabled persons must be recognized at birth.

NEED FOR INFORMATION

There is a need for professional education and dissemination of updated information which will improve decision-making about disabled individuals, especially newborns. To this end, it is imperative to educate all persons involved in the decision-making process. Parents should be given information on available resources to assist in the care of their disabled infant. Society should be informed about the value and worth of disabled persons. Professional organizations, advocacy groups, the government, and individual care givers should educate and inform the general public on the care, need, value, and worth of disabled infants.

MEDICAL CARE

When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not available, arrangements should be made to transfer the infant to an appropriate medical facility. Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are

irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.

It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.

In cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.

GOVERNMENT AND COMMUNITY SUPPORT

Once a decision to treat an infant has been made, government and private agencies must be prepared to allocate adequate resources for appropriate services as needed to child and family for as long as needed. Services should be individualized, community-based, and coordinated.

The Federal Government has an historical and legitimate role in protecting the rights of its citizens. Among these rights is the enforcement of all applicable federal statutes established to prevent and remedy discrimination against individuals with disabilities, including those afforded by Section 504 of the Rehabilitation Act. States also have legitimate roles in protecting the rights of their citizens

and an obligation to enforce all applicable state laws.

SIGNATORIES

AMERICAN ACADEMY OF PEDIATRICS (AAP)
PAUL F. WEHRLE, PRESIDENT

ASSOCIATION FOR RETARDED CITIZENS (ARC)
Joseph A. Buonomo, Past President

THE NATIONAL ASSOCIATION OF CHILDREN'S
HOSPITALS AND RELATED INSTITUTIONS, INC
(NACHRI)
Robert H. Sweeney, President

SPINA BIFIDA ASSOCIATION OF AMERICA
Kent Smith, Executive Director

THE ASSOCIATION FOR PERSONS WITH
SEVERE HANDICAPS (TASH)
H. D. Fredericks, President

AMERICAN ASSOCIATION ON MENTAL DEFICIENCY
(AAMD)
Herbert Grossman, President

AMERICAN ASSOCIATION OF UNIVERSITY
AFFILIATED PROGRAMS FOR PERSONS WITH
DEVELOPMENTAL DISABILITIES (AAUAP)
Alfred Healy, President

AMERICAN COALITION OF CITIZENS WITH
DISABILITIES, INC (ACCD)
Eunice K. Fiorito, Past President

NATIONAL DOWN'S SYNDROME CONGRESS
Thomas J. O'Neill, President

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