The Arc

American Association on Intellectual and Developmental Disabilities

POSITION STATEMENT

HEALTH, MENTAL HEALTH, VISION, AND DENTAL CARE

Children and adults with intellectual and/or developmental disabilities[1] deserve dependable, affordable high quality health, mental health, vision and dental services in the community. They also need access to comprehensive public or private health insurance to obtain those services without regard to the nature or severity of their disability or health status.

ISSUE

Many persons with intellectual and/or developmental disabilities face substantial challenges, sometimes life-threatening barriers, when attempting to access timely and appropriate health, mental health and dental services wherever they live. These challenges and barriers include an inability to obtain routine and preventative health, mental health and dental services; limited access to specialists; and health, mental health and dental service providers who deny or limit services to people because of inappropriate biases, inadequate training, malpractice coverage or inadequate levels of compensation for their services. Individuals with complex and chronic conditions also often lack individualized care coordination.

Many communities lack sufficient numbers of health, mental health and dental service providers with training and experience in serving persons with intellectual and/or developmental disabilities. Even when service providers are available in a community, many people with intellectual and/or developmental disabilities lack public or private insurance to make those services accessible and affordable to them.

POSITION

All people with intellectual and/or developmental disabilities deserve access to appropriate, affordable, timely, effective and comprehensive medical, mental health and dental services throughout their lives.

People with intellectual and/or developmental disabilities should have universal access to comprehensive, affordable, quality health, mental health and dental coverage. Mental health plans must cover treatment for mental illness on the same terms and conditions as all other medical diagnoses.

People with intellectual and/or developmental disabilities must not experience disability-related discrimination in decisions to provide, delay, deny or limit medical, mental health or dental treatments. Protections must be in place to assure that an individual's medical, mental health and dental condition(s) and personal welfare are the only justifiable basis for making medical decisions. A person with a disability should have an equal opportunity to receive life sustaining treatments including organ transplants. People with intellectual and/or developmental disabilities deserve access to health, mental health and dental professionals who have received specialized training to understand and respond to their needs.

Reimbursement rates for health services provided to people with intellectual and/or developmental disabilities must reflect the true cost of providing those services, including the costs of treating more complex health, mental health and dental needs, and the greater amounts of time often required to understand and respond to those needs, so that reimbursement rates do not provide disincentives for services needed by persons with intellectual and/or developmental disabilities.

Health, mental health and dental service providers for persons with intellectual and/or developmental disabilities must meet the highest standards of quality, including a comprehensive approach to treatment, disease prevention, and health maintenance.

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[1] "People with intellectual disabilities and/or developmental disabilities" refers to those defined by the AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

In all matters of health, mental health, and dental services, individuals with intellectual and/or developmental disabilities have basic rights that must be protected, including information and appropriate accommodations to assure informed consent[2] that allows an individual, or under appropriate legal conditions, an advocate serving as guardian, health care power of attorney or surrogate decision-maker[3], to accept or refuse health-related services based on:

- Sufficient information to understand the risks, demands, potential for significant pain and benefits of any procedure for which consent is sought provided in ways that accommodate reading, language, learning and other limitations that are common among persons with intellectual and/or developmental disabilities;
- Opportunities to ask questions and receive answers about the proposed treatment in understandable and understood language;
- Full understanding that declining treatment will not affect access to other services that the person is receiving or might otherwise receive;
- Protection from coercion or deceit to accept or decline a particular treatment;
- Reasonable efforts when a guardian, health care power of attorney or surrogate decision-maker is involved to monitor, honor and accommodate indications of "implied assent" to treatment; and
- Having specific expressed desires regarding the use of life-sustaining treatments communicated in written or oral form and recorded in an advance directive by individual with intellectual and/or related developmental disabilities, as appropriate to their understanding of the nature, implications and reversibility of their decision.

If an individual is unable to make his/her own medical decisions about life-sustaining and other treatments and does not have an advance directive[4], an advocate acting as guardian, health care power of attorney, or surrogate decision-maker should:

a) Agree to make these decisions on a timely basis;

b) Commit to the informed consent or assent of the individual to the degree possible;

c) Have a limited role in decisions involving the refusal of medical treatments, or nutrition and hydration when such refusal will result in the death of the individual due to circumstances in which the person's condition is terminal, death is imminent, and any continuation or provision of treatment, nutrition and/or hydration would only serve to prolong dying;

d) Aggressively advocate for medical care and treatment to relieve pain, isolation, fear, and physical discomfort; and

e) Be prohibited from requesting any growth attenuation treatments to modify a child's typical development.

Providers of health, mental health, and dental services for persons with intellectual and/or developmental disabilities must follow practices regarding health information and records consistent with the guarantees of confidentiality contained in the Health Insurance Portability and Accountability Act (HIPAA).

See: Medicaid

Adopted: Board of Directors, The Arc of the United States
August 4, 2008

Board of Directors, AAIDD
August 18, 2008

Congress of Delegates, The Arc of the United States
November 8, 2008

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[2] Informed consent: voluntary, non-coerced agreement to accept a health care treatment. (Midwest Bioethics Center & University of Missouri-Kansas City, Institute for Human Development, Bioethics Forum, Fall 1996).

[3] Surrogate decision-maker: a person who makes health care decisions for a patient who cannot make his or her own decisions. (Midwest Bioethics Center & University of Missouri-Kansas City, Institute for Human Development, Bioethics Forum, Fall 1996). People who have such authority under state laws include the parent of a minor child, the guardian/conservator of an incapacitated adult, or surrogate decision-makers designated under a health care consent law. All decision-making by a surrogate decision-maker must be consistent with the principles of informed consent and must always be consistent with the best interests of the individual).

[4] Advance Directive: an individual's written or oral preferences regarding life-sustaining medical treatment decisions. (Ethics Manual, American College of Physicians, 1998).