

The Delaware Developmental Disabilities Council supports the views and position of the National Arc Organization as our position on Health for people with disabilities.

Health

All people, including people with intellectual and/or developmental disabilities¹ (I/DD), should have timely access to high quality, comprehensive, accessible, affordable, appropriate health care that meets their individual needs, maximizes health, well-being and function, and increases independence and community participation.

The health care system must be aligned to principles of nondiscrimination, comprehensiveness, continuity, appropriateness, and equity. Both comprehensive public and private health insurance must provide for necessary health care without regard to the nature or severity of disability, pre-existing conditions, or other health status.

ISSUE

Health can be understood broadly as a state of complete physical, mental, and social well-being, not merely the absence of disease or disability. The term “health care” encompasses physical, mental, behavioral, vision, hearing, oral and dental health care, substance abuse and addiction services, and services and supports that assist in attaining, maintaining, and improving skills, function, and community participation.

The current health care system is fragmented and does not provide uniform access to a comprehensive array of health services and supports.

While many people encounter difficulty in finding affordable, high quality health care, people with I/DD face additional barriers, sometimes life-threatening, when attempting to access timely, appropriate health services in their communities. These barriers include:

- **Access.** Underinvestment in public health and wellness targeted to people with I/DD results in preventable health care disparities and poorer health outcomes. Inadequate training, lack of coordinated care, and inadequate levels of reimbursement are some of the factors that create programmatic barriers while inaccessible clinical settings and diagnostic and medical equipment, along with translation and interpretation challenges, create physical barriers.
- **Discrimination.** Health care providers sometimes provide inadequate or inappropriate interventions and treatments or deny appropriate care for people with I/DD because of professional ignorance as well as personal and/or societal bias. State statutory liability damage limits discriminate against people with severe and/or life-long disabilities because they fail to provide sufficient compensation.
- **Affordability.** People with I/DD are more likely to live in poverty and cannot afford cost-sharing. For cost containment purposes, many public and private health care plans limit access to specialists and critical services. Even when services are available in a community, many people with I/DD lack adequate public or private insurance to pay for them.
- **Communication and personal decision making.** People with I/DD may have difficulties communicating their needs and making health care decisions without support. Their decisions may not be respected and implemented by health care providers and, where applicable, surrogate decision makers². People have not been ensured access to all necessary supports and information required to understand a health care decision and communicate their choices.

POSITION

- Important elements of this Health Position Statement include timely access, nondiscrimination, affordability, and communication and personal decision-making, including surrogate decision making. These elements are described more fully below:

Access

- Wellness, prevention, health promotion, and a robust public health infrastructure are essential components of health care.
- Health care providers for persons with I/DD must meet the highest standards of quality, including a comprehensive approach to treatment, disease prevention, and health maintenance.
- People with I/DD deserve access to health care providers who have received specialized training to understand and respond to their needs. This access should be provided in the community.
- People with I/DD need access to effective strategies to manage their care including care coordination, referral processes, transition assistance, and health promotion efforts.
- Data collection and the assessment of health outcomes must include disability status. Public health initiatives must support the goal of reducing health care disparities for people with disabilities and improving health and function.
- The health care system must be fully accessible with respect to facilities and equipment, as well as communication needs and related accommodations such as sufficient time, explanations, translators, and interpreters when necessary.

Nondiscrimination

- People with I/DD must not experience disability-related discrimination in decisions to provide, delay, deny, or limit health care interventions or treatments. Protections must be in place to assure that an individual's health and well-being 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 cancer therapy and transplantation. Physician assisted suicide is never acceptable.
- Health plans must cover treatment for mental illness on the same terms and conditions as all other medical diagnoses.
- Providers of health care services for persons with I/DD must follow practices regarding health information and records consistent with the guarantees of confidentiality contained in the Health Insurance Portability and Accountability Act (HIPAA).

- Treatments for persons with I/DD that are proposed primarily for the convenience of the caregiver (such as medical procedures that interfere with typical growth and development) must be denied.

Affordability

- People with I/DD should have universal access to comprehensive, affordable, quality health care.
- Efforts to contain health care costs should not create obstacles to care for people with I/DD by making needed services or treatments unaffordable or otherwise unavailable. The medical need for care must be determined on an individualized basis.
- Payment methodologies for health services provided to people with I/DD should compensate for the true cost of providing those services. This includes the costs of treating more complex health needs, and the greater amounts of time often required to understand and respond to those needs. Payment methodologies should not create disincentives to the provision of timely and appropriate services to persons with I/DD.

Communication and Personal Decision-Making

- In all matters of health, individuals with I/DD have basic rights that must be protected, including the right to information and appropriate accommodations to assure informed consent³ that allows an individual, or under appropriate legal conditions, a guardian, a health care power of attorney, or a surrogate decision-maker of the individual's choice 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 I/DD;
 - Opportunities to ask questions and receive answers about the proposed treatment in understandable and understood language;
 - Full disclosure that declining treatment may affect access to other treatments or 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 directive⁴ by individuals with I/DD, as appropriate to their understanding of the nature, implications, and reversibility of their decision. Advance directives of people with I/DD should be honored.

Surrogate Decision-Making

Individuals may temporarily or permanently lack the capacity to make some or all health care decisions. This lack of capacity may not be global, and the individual should always be assisted in making those decisions which they can and in participating in all other decisions as much as they are able. When an individual has been determined to lack capacity to make health care decisions and does not have an advance directive such as a “Living Will,” or a health care power of attorney, a surrogate decision-maker should be identified to make these decisions, whenever possible before a crisis arises. 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 should be consistent with the principles expressed in the sections above regarding health care and informed consent. Surrogate decision-makers must follow the expressed wishes of the individual. When the individual’s wishes are not knowable, the surrogate must follow the person’s probable wishes, taking into account the person’s known values, and, as a fall back, act in the person’s best interests. In decisions involving the refusal of medical treatments, or nutrition and hydration, when such refusal will result in the death of the individual, the legal authority of the surrogate decision-maker should be limited to those situations in which all three of the following conditions exist: (1) the person’s condition is terminal, (2) death is imminent, and (3) any continuation or provision of treatment, nutrition and/or hydration would only serve to prolong dying. However, in such situations,

people with I/DD must be provided appropriate palliative care, including medical treatment to relieve pain, sustenance as medically indicated, and care designed to relieve isolation, fear, and physical discomfort

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1“People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18,” as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) manual, Intellectual Disability: Definition, Classification, and Systems of Supports and the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM IV), published by the American Psychiatric Association (APA). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care. (II) Receptive and expressive language. (III) Learning. (IV) Mobility. (V) Self-direction. (VI) Capacity for independent living. (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated”, as defined by the Developmental Disabilities Assistance and Bill of Rights Act 2000. In everyday language, people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

2Surrogate decision-maker: a person who makes health care decisions for a person who is unable to make decisions about personal health care. A surrogate decision maker may be an appointed

agent under a durable power of attorney for health care or a court-appointed guardian with authority to make health care decisions. If there is no appointed surrogate, normal custom and practice, as well as the law in most states, permits health care practitioners to turn to next of kin as default surrogate decision makers. A growing number of states also authorize a close friend to act as default surrogate. All surrogates have an obligation to follow the expressed wishes of the adult person. If the individual's wishes are not known, the surrogate must follow the person's probable wishes, taking into account the person's known values, and as a fall back to act in the person's best interests. (Charlie Sabatino and Erica Wood, Commission on Law and Aging, American Bar Association. Presentation at the National Aging and Law Conference, December 2010, <http://new.abanet.org/aging/Pages/CLE.aspx>)

3 Informed consent has three elements: capacity of the consent-giver, information supplied to the consent-giver, and voluntary action by the consent-giver.

4 Advance directive: Written advance directives include living wills and the durable power of attorney for health care. Living wills enable individuals to describe the treatment they would like to receive in the event that decision-making capacity is lost. The latter enables a patient to appoint a surrogate to make decisions if the patient becomes unable to do so (Ethics Manual, American College of Physicians, 2012).

