

Self-Determination

People with intellectual and/or developmental disabilities¹ (I/DD) have the same right to, and responsibilities that accompany, self-determination as everyone else. They are entitled to opportunities, respectful support, and the authority to exert control in their lives, to direct their services, and to act on their own behalf.

Issue

Historically, many individuals with I/DD have been denied their right to self-determination. They have not had the opportunity or the supports to make choices and decisions about important aspects of their lives. Instead, they have often been overprotected and involuntarily segregated, with others making decisions about key elements of their lives. For many, the absence of the dignity of risk and opportunities to make choices has impeded people with I/DD from exercising their right of self-determination and has inhibited their ability to become contributing, valued, and respected members of their communities, living lives of their own choosing.

Position

People with I/DD have the same right to self-determination as all people and are entitled to the freedom, authority, and supports to exercise control over their lives. People with I/DD must understand that they can direct and influence circumstances that are important to them. This right to self-determination exists regardless of guardianship status.

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) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). "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.

Family members, friends, and other allies play a critical role in promoting self-determination by providing supports and working collaboratively to achieve the individual's goals. Families, friends, and other allies should understand, recognize, and promote the rights and responsibilities of self-determination and respect the limitations on their own authority. Service providers, educators, and substitute decision-makers must recognize and respect the individual's right to self-determination and the limitations on their authority.

To this end, people with I/DD must be able:

In their personal lives to:

- lead in decision-making and problem-solving about all aspects of their lives and have the supports they want to make decisions;
- advocate for themselves with the assurance that their desires, interests, and preferences will be respected and honored;
- choose their own supporters, friends, and allies;
- direct their own supports and services and allocate available resources;
- hire, train, manage, and fire their own staff;
- acquire additional skills to assist in determining the course of their lives;
- use adaptive communications devices and other assistive technology; and
- take risks to achieve the lives they desire.

In their community lives to:

- participate fully and meaningfully in the community;
- receive the necessary supports and assistance to vote and exercise other rights as citizens.
- become valued members and leaders of the community;
- serve as active members and leaders of community boards, advisory councils, and other organizations;
- take leadership roles in setting the policy direction for the self-determination movement; and
- have representation and meaningful involvement in policy-making at the federal, state, and local levels.

Recognition of the right to self-determination must be a priority. The principles of self-determination and opportunities to promote self-determination must be incorporated into conferences, publications, advocacy, training, services, policies, and research in the I/DD community.

Laws, regulations, policies, procedures, and funding systems should be regularly reviewed and revised to remove barriers and to promote self-determination. People with I/DD must be involved in this process at all levels.

Adopted:

AAIDD Board of Directors
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The Arc Board of Directors
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