

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 must have opportunities, respectful support, and the authority to exert control in their lives, to self-direct their services to the extent they choose, and to advocate on their own behalf.

Issue

Many individuals with intellectual and/or developmental disabilities have not had the opportunity or the support to make choices and decisions about important aspects of their lives. Instead, they are often overprotected and involuntarily segregated, with others making decisions about key elements of their lives. Many individuals with I/DD have not had the experiences that would enable them to learn decision-making skills, take more personal control in their lives, and make choices. The lack of such learning opportunities has impeded people with I/DD from becoming participating, valued, and respected members of their communities, living lives of their own choosing.

Position

People with intellectual and/or developmental disabilities have the same right to self-determination as all people and must have the freedom, authority, and support to exercise control over their lives. To this end, they must:

In their personal lives have:

- opportunities to advocate for themselves with the assurance that their desires, interests, and preferences will be respected and honored.
- opportunities to acquire and use skills and knowledge which better enable them to exercise choice.
- the right to take risks.
- the right to choose their own allies.
- the lead in decision-making about all aspects of their lives.
- the option to self-direct their own supports and services and allocate available resources.
- the choice and support necessary to hire, train, manage, and fire their own staff.

In their community lives have:

- the right to receive the necessary support and assistance to vote.
- opportunities to be supported to become active, valued members and leaders of community boards, advisory councils, and other organizations.

- opportunities to take leadership roles in setting the policy direction for the self-determination movement.
- the right to representation and meaningful involvement in policy-making at the federal, state, and local levels.

Self-determination is a priority for The Arc. The Arc will ensure that the principles of self-determination are incorporated into its conferences, publications, advocacy, training, services, policies, and research.

Further, The Arc will work with federal and state agencies to ensure regular review and revision of laws, regulations, policies, procedures, and funding systems to remove barriers, and to promote self-determination. People with intellectual and/or developmental disabilities must be involved in this process at all levels.

Families, substitute decision-makers, and service providers should be educated and supported in understanding self-determination, responsibilities to the individual, and the limits to their authority.

¹ "People with intellectual and/or developmental disabilities" refers to those defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) classification and the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM IV), published by the American Psychiatric Association (APA). 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.

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