

POSITION STATEMENTS

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SELF-DETERMINATION

People with intellectual and/or developmental disabilities¹ (IDD) 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 IDD 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 IDD 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 IDD 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 IDD must understand that they can direct and influence circumstances that are important to them. This right to self-determination exists regardless of guardianship status.

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.

¹ Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as "The DD Act", are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

The acronym "IDD" is used to describe a group that includes either people with both ID and another DD or a group that includes people with ID or another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

To this end, people with IDD 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 IDD community.

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

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