

# POSITION STATEMENTS

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## ADVOCACY

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Advocacy is acting with or on behalf of an individual or group to resolve an issue, obtain a needed support or service, or promote a change in the practices, policies, or behaviors of government agencies, businesses, and others. Advocacy is essential for promoting and protecting the civil and human rights of people with intellectual and/or developmental disabilities<sup>1</sup> (IDD). All advocacy efforts by, with, and on behalf of people with IDD must be centered around the views, needs, expressed interests, and leadership of self-advocates.

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## ISSUE

People with IDD often do not have access to the supports or opportunities they need to exercise their civil and human rights due to ableism and social, systemic, and institutional discrimination. Strong advocacy is necessary to support the full inclusion and participation of people with IDD in the community. Effective advocacy is also required to prevent and address abuse, neglect, discrimination, implicit and explicit bias, and any exploitation that people with IDD may experience.

## POSITION

To achieve their goals, advocates must be able to interact directly with those responsible for policies and practices that affect their lives, including public officials, private and government-funded support system leaders, other advocates, business leaders, and the general public. Self-advocates are people with lived experiences as people with IDD. Advocacy efforts should be led by self-advocates, sharing their stories, views, and expressed interests. Organizational advocacy efforts must be inclusive and accessible to all, regardless of age, gender identity and expression, race and ethnicity, sexual orientation and sexuality, communication and expression, culture, faith or religion, location, economic status, immigration and legal residency status, familial status, support need, or disability.

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<sup>1</sup> 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.

Advocates include individuals with and without IDD, family members, groups, and organizations that promote the human rights of people with IDD and support their full inclusion in the community. It is important that:

- Advocates have tools and information to understand political, legal, and disability services systems.
- People with IDD and families have resources to educate and empower them to be a force for change.
- People with IDD and their families have support to effectively navigate service delivery systems.
- Advocates understand the issues that people with IDD face and get to know the people they are advocating for.
- Advocates facilitate opportunities and support the empowerment of people with IDD to advocate for themselves.
- Advocates who need support get the support they need; supporters should respond to their support needs and provide education, as needed.
- Advocates are not threatened or retaliated against for their advocacy.
- Advocacy efforts involve whole communities, not just people with IDD.

Advocacy is critical for supporting the needs of an individual as well as for broader systemic change. Advocacy helps ensure the full exercise, enjoyment, and enforcement of human and civil rights for people with IDD. Advocacy is important to ensure marginalized groups have access to culturally responsive services and supports. Advocacy also is vital to influencing laws and policies to improve systems of support and services, both for those who currently receive services and for generations to come.

Advocacy can happen informally and formally. For example, informal advocacy can take place through educational activities, personal conversations, and social media posts. Examples of formal advocacy can include sending letters, individual or group meetings, public testimony, rallies, education forums, town halls, meetings with legislators and other policymakers, and litigation.

In certain situations, individuals with IDD need legal advocacy. There are federally mandated Protection and Advocacy (P&A) systems in each state that advocate for and protect the rights of people with disabilities, along with other forms of public legal assistance. Any form of public legal assistance must be available and accessible to people with IDD and must:

- Be able to respond to issues concerning any stage of life;
- Be independent of conflicts of interest, undue influence, and government control;
- Be adequately funded and staffed;
- Provide advocacy on behalf of clients even when a formal complaint has not been filed;

- Be subject to appropriate oversight to assure their quality, cost effectiveness, efficiency, and high standards;
- Be informed by data collection and available research on the needs and rights of people with IDD; and
- Be able to deliver multiple advocacy strategies, such as information and referral, mediation, legal action, legislative and regulatory solutions, and appeals for unfavorable decisions.

All advocacy efforts must follow the lead of self-advocates, sharing their stories, views, and expressed interests.

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