

POSITION STATEMENTS

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SELF-ADVOCACY AND LEADERSHIP

People with intellectual and/or developmental disabilities¹ (IDD) have the right to advocate and/or be supported to act as self-advocates. Self-advocates exercise their rights as citizens by communicating for and representing themselves and others, with whatever supports they need. Self-advocates must have a meaningful role in decision-making in all areas of their daily lives and in public policy decisions that affect people with IDD.

ISSUE

People with IDD have been isolated and segregated from their communities, and presumed incompetent, resulting in loss and denial of basic human rights and discrimination in almost all areas of personal and community life. Through self-advocacy, people with IDD will have more impact on their own situations and on the public policies that affect them.

The self-advocacy movement has been critically important in supporting people with IDD to learn about self-advocacy skills and other topics, including:

- Civil rights, including the right to vote, the right to integrated services and supports, and self-determination;
- Self-confidence and development of leadership skills;
- Successful story-telling;
- Public speaking;
- Problem-solving techniques;
- Participation in group decision-making; and
- Involvement on boards and task forces and with policymakers at the local, state, and national level.

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.

There are many ways for people with IDD to act as advocates, including individual self-advocacy for the individual services and supports that they or another person with IDD needs, as well as policy advocacy for the funding, services, and rights that impact people with IDD at the local, state, and national level.

POSITION

People with IDD must have the right to advocate for themselves and others. People with IDD have the right to speak or act on their own behalf and alongside other people with disabilities, whether the issue is individual or related to broader public policy. Recognizing these rights in a respectful partnership between people with and without disabilities can lead to better outcomes and better lives for everyone.

Self-advocates provide important knowledge, experience, and skills that individuals, organizations, and government agencies need in order to effectively support the needs of and enhance the lives of people with IDD. To promote this participation, it is critical to acknowledge the important role that self-advocates play in developing leadership skills and increasing people's pride, influence, and opportunities. To achieve this partnership between self-advocates and their support persons or organizations, the following must occur:

- People with IDD must have the power to make informed decisions about their own lives and the services they receive, including those who need support and those who have legally-appointed guardians.
- People with IDD have access to necessary accommodations and supports in order to meaningfully participate in meetings, conferences, task forces, boards, and other forums when issues and policies that are important to them are discussed (“Nothing about us without us” principle). These accommodations include but are not limited to:
 - › Extra time planned for meetings to ensure the participation of each person;
 - › Enhanced and alternative communication methods, such as communication devices, sign language, or interpreters;
 - › Availability of technology supports and access through technology to ensure participation;
 - › Materials provided ahead of the meeting for review;
 - › Meeting materials written in plain language;
 - › Support from direct support professionals, when needed; and
 - › Funding for transportation and travel-related costs, including support staff.
- When communicating with or about people with IDD, it is important to respect the way that people with disabilities prefer to be identified. In most circumstances, person-first language is most appropriate, e.g. person with IDD. However, some people with IDD prefer identity-first language, e.g. autistic person. In addition, people's self-identified pronouns for gender identity must be respected.
- Policy development must include self-advocates and be regularly evaluated to ensure that self-advocates are actively and meaningfully participating.
- Families, advocacy organizations, service providers, and government agencies must work

with self-advocates to increase public awareness of the importance of the self-advocacy movement.

- Self-advocacy organizations and individual self-advocates must be supported to develop and sustain the self-advocacy movement, including mentoring youth and young adults with IDD to become self-advocates.
- Foundations and federal, state, and local funding agencies must promote self-advocacy as a key matter of policy. These entities must provide enough money and resources to make sure that (1) people with IDD have accessible information, training, and education in self-advocacy, and (2) providers have the information they need to deliver person-centered services that address self-advocate-led trends in policy and design.
- Children and youth with IDD must be supported by families, schools, direct service providers, and other entities to learn self-advocacy skills and put these skills into practice. Children and youth with IDD should have opportunities to use advocacy skills in educational planning, including Individualized Education Programs (IEPs), transition plans, and all decision-making.
- Adults with IDD can be effectively supported by peers, self-advocates, families, direct service providers, and other entities to learn self-advocacy skills and put them into practice. In order to continually use these skills, adults with IDD should have opportunities to use self-advocacy skills in service planning and daily decision-making.
- Self-advocates must be afforded the same dignity of risk that all people have to make informed decisions and learn from any mistakes that impact themselves and others in the community.
- Self-advocates must be included on boards and other advisory bodies for disability advocacy organizations, service providers, and agencies who serve people with IDD, as well as encouraged to meaningfully provide input on the policies, programs, and evaluation methods of those organizations and agencies.

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