

SELF-ADVOCACY

People with intellectual and/or developmental disabilities¹ (I/DD) must have the right to and be supported to act as self-advocates. Self-advocates exercise their rights as citizens by communicating for and representing themselves, with supports in doing so, as necessary. This means they have a say in decision-making in all areas of their daily lives and in public policy decisions that affect them.

ISSUE

Historically, people with I/DD have experienced powerlessness and isolation resulting in loss and denial of basic human rights, segregation, and discrimination in almost all areas of personal and community life.

Before self-advocacy groups existed, only a small number of people with I/DD received education and support from people who had experiences like their own. Without these groups they did not have a way to learn about important self-advocacy skills or topics like:

- Their rights and responsibilities as citizens, such as the right to vote;
- Development of leadership and assertiveness skills;
- Confidence in their own abilities;
- Using their expertise as people living with disabilities;
- Development of public speaking skills and problem-solving techniques, and involvement in group decision-making; and
- Involvement on boards and task forces and with policymakers at the local, state, and national level.

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.

Without self-advocacy skills, people with I/DD have little impact on their own situations or on public policy that affects them.

POSITION

People with intellectual and/or developmental disabilities have the right to advocate for themselves. This means they have the right to speak or act on their own behalf or on behalf of other people with disabilities, whether the issue is personal (e.g., housing, work, friends) or related to public policy. Recognizing these rights in a respectful partnership between people with and without disabilities can lead to better outcomes and better lives in the community for everyone.

Self-advocates provide important knowledge, experience, and skills that individuals, organizations, and government agencies need in order to effectively support the needs and dreams of people with I/DD. To promote this participation, it is critical to acknowledge the important role that self-advocacy groups 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 I/DD must have the power to make day-to-day decisions about their own lives and the services they receive free from the manipulation of others. Service providers and government agencies can offer significant supports in making sure informed decision making is in the hands of the self-advocate.
- People with I/DD should be provided accommodations or supports in order to have a visible, respected, and meaningful place in meetings, conferences, task forces, or other forums when issues and policies that are important to them are discussed ("Nothing about us without us" principle). These accommodations may include, but not be limited to:
 - Extra time planned for meetings to accommodate the unique communication and participation needs of each person;
 - Enhanced and alternative communication methods with easy-to-use formats;
 - Communication devices, sign language or other similar accommodations;
 - Supporting people to serve as "translators"; and
 - Appropriate transportation and funding.
- Respectful communication is important when talking to or about people with I/DD. This includes using people first language whenever talking directly to someone with disabilities, or describing their lives, and speaking to them in a way that takes into account their unique communication abilities.

- Policy development by any entity at a local, state, or national level must include self-advocates in matters of governance, and periodically evaluate the effectiveness of that inclusion.
- People who provide direct support and disability advocates should work actively with people with I/DD to develop and sustain self-advocacy organizations and individual participants in their states and communities.
- Families, advocacy organizations, service providers, and government agencies must also work with self-advocates to increase public awareness of the importance of the self-advocacy movement and the need to support it.
- 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 I/DD have accessible information, training, and education in self-advocacy and (2) providers have the information they need to deliver services that match the self-advocate-led trends in policy and design.
- Families, schools, direct service providers, and other agencies must have the support they need to make sure that children and youth have the chance to learn self-advocacy skills and put them into practice. They should have opportunities to use those skills in educational planning (including Individualized Education Plans or IEPs and transition plans) and all decision-making.
- Self-advocates, families, direct service providers, and other agencies must have the support they need to make sure that adults with I/DD have the chance to learn self-advocacy skills and put them into practice. They should have opportunities to use those skills in service planning and all decision-making.

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