



For people with intellectual
and developmental disabilities



Position Statement Self-Advocacy

People with intellectual and/or developmental disabilities¹ must be able to act as self-advocates; that is, to exercise their rights of basic personhood and citizenship by speaking and standing up for themselves. This means people must have a voice in decision-making in all areas of their daily life and in public policy decisions affecting them.

Issue

The history of people with intellectual and/or developmental disabilities is one of acute powerlessness, characterized by nearly complete isolation from decisions profoundly affecting people's lives. This powerlessness and isolation has resulted in loss and denial of basic human rights, segregation, and rampant discrimination in almost all areas of personal and civic life.

Before the advent of self-advocacy groups, only a limited number of people with intellectual and/or developmental disabilities received education and support from people who have had experiences like their own. Without these groups, people did not have a place where they could learn about their rights and responsibilities, develop leadership skills and confidence about their abilities, practice public speaking, analyze issues, learn about voting and group decision-making, exercise problem-solving techniques, and develop assertiveness skills. Thus, they had little impact on either their own situations or on public policy that affects them.

Position

Because they know their own circumstances best, people with intellectual and/or developmental disabilities, as individuals and as groups, have the right to self-advocate. 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 be personal (e.g., housing, work, friends) or related to public policy. All entities, public and private, must recognize and respect these rights.

Self-advocacy contributes to the knowledge, experience, and wisdom that individuals, organizations, and government entities must have in order to respond effectively to the needs and aspirations of people with intellectual and/or developmental disabilities. People must therefore have opportunities to participate in all matters pertaining to learning, planning, advocacy, policymaking, and governing. To promote this participation, all concerned

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must support the important and continually growing role that self-advocacy groups play in developing leadership and increasing people's pride, influence, and opportunities. The following must occur to ensure individual and group self-advocacy:

- People with intellectual and/or developmental disabilities must have the power to make day-to-day decisions about their lives and their supports. Service providers and government agencies must be held accountable for making that happen;
- People with intellectual and/or developmental disabilities must be provided a visible and respected place in meetings, conferences, task forces, or other forums when issues and policies important to them are discussed (“Nothing about us without us” principle”);
- Communication with and about people with intellectual and/or developmental disabilities must be respectful. This includes using people first language both to address them and to describe their lives and speaking to them in a way that acknowledges their unique communication abilities;
- Service providers must include self-advocates in matters of governance and periodically evaluate the effectiveness of that inclusion;
- Service providers and disability

advocates must work actively with people with intellectual and/or developmental disabilities to develop and sustain self-advocacy organizations and individual participants in their states and communities;

- Families, advocacy organizations, service providers and government agencies must work with self-advocates to heighten public awareness of the importance of the self-advocacy movement and the need to support it;
- Resources must be available to ensure that self-advocates have the accommodations and supports necessary to speak for themselves and participate in meetings. These include enhanced and alternative communication methods with easy-to-use formats, mentors to serve as informants and “translators,” and appropriate transportation and funding;
- Federal and state funding agencies should promote self-advocacy as a key matter of policy and provide sufficient monetary and other resources to ensure that (1) service recipients (people with intellectual and/or developmental disabilities) have accessible and needed information, training, and education in this area and (2) providers have the consultation and technical assistance necessary to deliver services that match the evolving trends in policy and design; and

- Families, schools, and other entities must have the support they need to ensure that, both in and out of school, children and youth have the chance to learn and practice self-advocacy skills. They should have opportunities to use those skills in educational planning and decision-making.

¹“People with intellectual disabilities and/or developmental disabilities” refers to those defined by the AAIDD classification and DSM IV.

Adopted:

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