



“Nothing About Us Without Us”

Best Practices for Supporting Statewide Self-Advocacy Organizations

*NACDD’s Self-Advocacy Committee, in collaboration with self-advocates from across the country, leaders of national disability organizations and State and Territorial Developmental Disability Councils, has developed a list of best and promising practices that we believe will result in the growth and sustainability of effective self-advocacy organizations. It is the opinion of its developers that these practices should be implemented to the greatest extent possible in advocacy organizations of all size and scope. **

1. People with intellectual and developmental disabilities should participate in all decisions of the organization, including but not limited to being a member, being a leader and helping to define its vision, mission and activities.
2. Use people first and plain language. People first language puts the person first not the disability. Plain language uses the clearest words possible to describe actions, objects and people. Organizations must also respect that the meaning of words change and use language that best meets the needs of its members. For example, some advocates may choose to refer to themselves as “Autistic self-advocates.”
3. Maintain a diverse membership by including people of all ages, including youth and people with different religions, race, ethnicity, and sexual orientation in learning and practicing leadership.
4. Support access for all people, including access to buildings, printed materials, transportation, and other areas of life to make sure all people with intellectual and developmental have the chance to be fully included and have meaningful participation in self-advocacy activities.
5. Recognize that advocacy is practiced in many different ways and all have value. Self-advocacy can be talking about disability to help others understand or working on policies and laws that make changes to help people with intellectual and developmental

disabilities and their families.

6. People with intellectual and developmental disabilities develop job descriptions and roles and responsibilities to choose and/or hire staff to support self-advocacy organizations. People with intellectual and developmental disabilities have the training and support they need to also serve as the statewide self-advocacy organization staff, which could include paid staff and leadership positions.
7. Work to become an independent organization with money to support the work of the organization. Some self-advocacy organizations may choose to become a non-profit organization.
8. Share information and provide skill building opportunities to people with intellectual and developmental disabilities to work on key policy issues that support the mission of the self-advocacy organization.
9. When possible, work together with other groups both disability and non-disability, which share the same issues and concerns.
10. Use current technology, such as social media, to help people learn about the work of self-advocacy organizations, increase membership and share information.

* This document is available in Word and accessible PDF versions so self-advocates and Self-Advocacy organizations can change its content to fit the unique needs of their state.

Created June of 2015