

National Core Indicators™ Data Highlight



What can states learn from NCI™ results about people's involvement in self-advocacy activities?

In the 2017-2018 National Core Indicators In-Person Survey, 24% of respondents said they had the opportunity to participate in a self-advocacy meeting. This means that they either participated or had been given the opportunity to participate and said no. State results during that cycle ranged from a high of 45% to a low of 12%. Those who reported having the opportunity to participate in self-advocacy meetings were significantly more likely to have had at least some input in critical life choices such as choosing their home, their housemates, their staff, their schedule, what to buy with spending money and what to do in their free-time.

Why does it matter? The mission of self-advocacy organizations is to help people with intellectual and developmental disabilities (I/DD) to speak for themselves, to understand their rights, and to make important decisions about their lives. Self-Advocates Becoming Empowered (SABE)'s mission captures this aim: "To ensure that people with disabilities are treated as equals and that they are given the same decisions, choices, rights, responsibilities, and chances to speak up to empower themselves; opportunities to make new friends, and to learn from their mistakes." If states aim to support more people to self-direct, to be active participants in their individual plans, and to be involved in civic life, participation in self-advocacy organizations is one way to develop the necessary skills. Self-advocates can also provide much needed feedback and comments on key program documents, bulletins, and pending policy changes.

Questions to ask: Does your state or local organization provide resources to support self-advocacy organizations? Are families aware of the positive benefits of involving their family members in self-advocacy organizations? Are young people with I/DD introduced to self-advocacy organizations as part of their transition from school to adulthood? How does your state agency encourage or motivate providers of services to support people to attend self-advocacy meetings? How do the disability coalitions in your state assure they include self-advocacy organizations? When testimony is needed for legislative, regulatory or Medicaid program changes, how does your state seek out self-advocacy organizations for input? Does your state or local agency assure a self-advocacy agencies have membership on state advisory and/or quality committees?

Want to know more?

- The Arc. *Position Paper on Self-Advocacy*. www.thearc.org/who-we-are/position-statements/rights/self-advocacy
- Human Services Research Institute. *The Riot* (newsletters written by self-advocates, and self-advocacy resources). www.theriotrocks.org
- Institute on Community Integration, Self-Advocacy On Line, University of Minnesota. <https://ici.umn.edu/products/view/559>
- Institute for Human Development, University of Missouri-Kansas City; and Institute on Disability and Human Development, University of Illinois at Chicago (2012). *Advising Through Self-Determination — An Information Guide for Advisors*. <https://www.nasddds.org/self-advocacy/advising-through-self-determination-an-information-guide-for-advisors>
- Self-Advocates Becoming Empowered (SABE). www.sabeusa.org.
- Self-Advocacy Resource and Technical Assistance Center (funded by the Administration on Community Living). <http://selfadvocacyinfo.org/>

