

SSA National Disability Forum

Financial Independence: Directing the Management of One's Social Security Benefits

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AAIDD/The Arc Joint Position Statements

- Every two years, the American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc of the United States co-develop important policies in their Joint Position Statements, which are found on their websites
- AAIDD/ The Arc Position Statements focus on the current disability issues that are challenging the country, and point the way to the improved outcomes and modern supports that people with ID and their families need and want
- The powerful Joint Position Statements of AAIDD and The Arc add an essential voice to national policy debates that are critical to people with ID, their families, and our shared future

Joint Position Statement: *Autonomy, Decision-Making Supports, and Guardianship (2016)*

GUIDING PRINCIPLES:

All individuals with I/DD must

- ❖ Be recognized as a person before the law
- ❖ Have legal capacity as all individuals
- ❖ Experience respect and support for personal autonomy, liberty, freedom, and dignity
- ❖ Be presumed as competent to make decisions for himself or herself
- ❖ Receive the preparation, opportunities, and decision-making supports to develop as a decision-maker

Autonomy, Decision-Making Supports, and Guardianship, cont.

INTRODUCTION:

“All individuals with intellectual and/or developmental disabilities (I/DD) have the right to recognition as persons before the law and to enjoy legal capacity on an equal basis with individuals who do not have disabilities in all aspects of life (United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), 2006). The personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.”

Autonomy, Decision-Making Supports, and Guardianship, cont.

SELECTED ISSUES:

- Current trends presume the decision-making capacity of individuals with I/DD and the **preservation of legal capacity as a priority** for all people needing assistance with decision-making.
- Like their peers without disabilities, individuals with I/DD must be **presumed competent**; they must also be **assisted to develop** as decision-makers through education, supports, and life experience. Communication challenges should not be misinterpreted as lack of competency to make decisions.
- Individuals with I/DD should have access to supports and experiences **to learn** decision-making skills from an early age and **throughout their lifetimes** in educational and adult life service systems.

Selected Issues, cont.

- **Less restrictive means of decision-making supports** (e.g., health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship as an option is considered.
- All people, with and without disabilities, have a **variety of formal and informal processes** available to enact their decisions and preferences, including healthcare proxies and advance directives.

Autonomy, Decision-Making Supports, and Guardianship, cont.

POSITION:

*The primary goals in assisting individuals with I/DD should be to assure and provide supports for their personal autonomy and **ensure equality of opportunity, full participation, independent living, and economic self-sufficiency** (Americans with Disabilities Act, 1990, section 12101 (a)(7); Individuals with Disabilities Education Act, 2004, section 1400 (c)(1)). Each individual adult and emancipated minor is legally presumed competent to make decisions for himself or herself and should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime. All people with I/DD can participate in their own affairs with supports, assistance, and guidance from others, such as family and friends. People with I/DD should be aware of and have access to decision-making supports for their preferred alternatives.*

References

- <http://aaid.org/news-policy/policy/position-statements/autonomy-decision-making-supports-and-guardianship#.Wql-nwh3RY>
- <https://www.thearc.org/who-we-are/position-statements/rights/Autonomy-Decision-Making-Supports-and-Guardianship>
- Luckasson, R., Ford, M., McMillan, E., Misilo, F., & Nygren, M. (2017). Intellectual disability policy as developed, expressed, and evaluated in AAIDD/The Arc joint statements: The role of organization position statements. *Special Issue on Disability Policy in a Time of Change, Intellectual & Developmental Disabilities*, 55(4), 269-275.
- Schalock, R.L., Borthwick-Duffy, S., Bradley, V.J., Buntinx, W.H.E., Coulter, D.L., Craig, E.M., Gomez, S.C., Lachapelle, Y., Luckasson, R., Reeve, A., Shogren, K.A., Snell, M.E., Spreat, S., Tasse, M.J., Thompson, J.R., Verdugo-Alonso, M.A., Wehmeyer, M., & Yeager, M.H. (2010). *Intellectual disability: Definition, classification, and systems of supports* (11th ed.). Washington, DC: American Association on Intellectual and Developmental Disabilities.