

## Intellectual Disability Policy as Developed, Expressed, and Evaluated in AAIDD/The Arc Joint Statements: The Role of Organization Position Statements

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### Abstract

The American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc of the United States (The Arc) have a long history of joined efforts to develop, express, and evaluate disability policies. These efforts have resulted in a series of formal statements on critical issues such as education, healthcare, human rights, and criminal justice. Their joint efforts further important policy goals including providing clear strong communication about important policy values and directions, promulgating key principles of high quality supports and services, affirming best professional practices, and emphasizing personal outcomes. In addition, the joint efforts (a) affirm important aspects of organization identity; (b) enhance the organizations' abilities to assure the input of a wide variety of perspectives; (c) engage members' expanded ranges of experiences and talents; (d) multiply staff and leadership resources; (e) increase communication strength and avenues; and (f) establish processes for timely review and revision of policies as critical disability issues arise or change, and new opportunities for policy integration and advancement occur. This article describes the processes used to develop, express, and evaluate the position statements; summarizes the policy content of several joint statements; and discusses the role of these organization position statements.

**Key Words:** *intellectual disability; policy; professional organization; position statement*

### Introduction and Overview

This Special Issue on *Disability Policy in a Time of Change* acknowledges the many ways in which policies affecting people with intellectual disability and developmental disabilities (IDD) are made across multiple situations, including legal cases, rulings, statutes, treaties, regulations and guidelines, and multiple and varied approaches by organizations and systems to implement and evaluate services and supports. Professional organizations play a critical role in shaping and advancing disability policy. Their policy efforts take many forms including (a) submitting *amicus curiae* briefs to the U.S. Supreme Court and others; (b) establishing public policy goals for each Congress; (c) commenting on draft legislation, proposed rulemaking, and other federal activities; (d) participating in the work of the Consortium for Citizens with Disabilities (CCD); (e) contributing

to the popular press and social media on disability issues; and (f) sponsoring educational activities, such as the annual Disability Policy Seminar. Additionally, the American Association on Intellectual and Developmental Disabilities (AAIDD) and The Arc of the United States (The Arc) engage in an important type of education and communication about policy through their joint position statements.

This article focuses on these joint position statements promulgated by AAIDD and The Arc. We describe the processes used to develop, express, and evaluate the joint position statements; summarize the policy content of four joint statements; and discuss the role of these organization position statements. It is important to note that in addition to these joint activities, each organization also occasionally promulgates independent position statements that reflect their unique mission and membership.

## **The Processes Used to Develop, Express, and Evaluate the Position Statements**

Every 2 years The Arc and AAIDD establish the process and timeline for both analyzing current policy challenges or opportunities and reviewing their current joint position statements. The detailed steps of the process are slightly different for the two organizations because of their different structures, but the basic steps are the same. First, extensive input is solicited from each organization's leadership and members. Then the suggestions are analyzed and the revision of specific statements is prioritized. Workgroups of experts are established that include members of both organizations, and the workgroups begin studying and drafting progressive iterations of the position statements. After the members of the expert workgroup have accepted a draft position statement, an overall policy committee reviews and provides additional input. Multiple discussions and drafts later, a final draft of the proposed position statement is submitted to the partner organizations for their internal processes and votes or approvals. Through this process, the views of both organizations are incorporated into the statements, assuring that the statements reflect wide input and timely analysis of cutting edge policy issues in order to contribute to positive change.

## **The Policy Content of the Joint Statements**

The websites of both organizations prominently display all of the joint position statements. On The Arc website, they are found under “Who We Are” (Arc, 2016; <http://www.thearc.org/who-we-are/position-statements>) and on the AAIDD website they are found under “News & Policy” (AAIDD, 2017; <https://aaidd.org/news-policy/policy/position-statements#.WOT6So61ubc>).

The large number and variety of position statements reflect the wide range of issues that directly affect the lives of people with IDD and their families. Currently, more than 30 joint position statements are posted. Broad categories include aging, community living, education and early childhood services, employment and economic wellbeing, health, housing, causes, justice, protections, self-determination, supports, and transportation. Some titles of individual statements include Research; Early Childhood Services; Op-

portunities for Financial Asset Building; Health; Addressing the Causes and Effects of Intellectual and Developmental Disabilities; Criminal Justice System; Autonomy, Decision-Making Supports, and Guardianship; Human and Civil Rights; Advocacy; Inclusion; Sexuality; Spirituality; and Behavioral Supports.

For the purposes of this article, we summarize four of the recently promulgated or revised position statements. Initial attention is given to the statement on Autonomy, Decision-Making Supports, and Guardianship (AAIDD, The Arc, 2016b) in order to exemplify the structure and level of detail of the statements. In addition, briefer summaries of Opportunities for Financial Asset Building (AAIDD, The Arc, 2016c), Addressing the Causes and Effects of Intellectual and Developmental Disabilities (AAIDD, The Arc, 2016a), and Human and Civil Rights (AAIDD, The Arc, 2015) are provided.

## **Autonomy, Decision-Making Supports, and Guardianship**

The position statement on Autonomy, Decision-Making Supports, and Guardianship (AAIDD, The Arc, 2016b) provides an example of how the position statements are organized. The statement includes an introduction, identification of the main issues, and specification of what the organizations' position is, and then provides further clarification of important system issues, guardian responsibilities, and oversight matters.

This position statement also provides an example of how a statement evolves over time to capture modern thinking on an important topic. The title of the earlier statement was simply “Guardianship,” which reflected an earlier presumption that many, if not most, people with IDD were totally incapacitated and would require legally appointed guardians to make all decisions for them. The current iteration of the statement, however, represents a significant policy advance from previous statements in that the presumption of incapacity and guardianship is now replaced by a presumption of personal autonomy. The statement clarifies the presumption by noting that,

All individuals with intellectual and/or developmental disabilities (IDD) 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 [UNCRPD], 2006). The personal autonomy, liberty, freedom, and dignity of each individual with IDD 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 IDD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime. (AAIDD, The Arc, 2016b, “Statement,” para. 1)

The statement includes approximately 10 issues that should be addressed, including the following:

- Current trends presume the decision-making capacity of individuals with IDD and the preservation of legal capacity as a priority for all people needing assistance with decision making.
- Like their peers without disabilities, individuals with IDD 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 IDD 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.
- Families should have access to information about all options for assisting their family member to make decisions over the life course.
- 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.
- 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. (“Terminology for guardianship and guardians differs by state and can include tutor, conservator, curator, or other comparable terms.”)

- Where judges and lawyers lack knowledge about people with IDD and their human rights, poor advocacy and tragic legal outcomes often result. Financial incentives frequently benefit professionals and guardianship corporations, often to the detriment of individuals with IDD and their families.
- Serving in the dual roles of guardian and paid service provider or paid advocate creates a conflict of interest or the appearance of a conflict of interest. Such conflicts must be mitigated or avoided.
- Some statutory privacy measures have made it more difficult for those assisting other individuals to have access to their records, make decisions, or both. Thus, to obtain or modify needed medical care, services, and supports, an individual with IDD may be adjudicated to be incompetent and subjected to guardianship. This result conflicts with the legal presumption of competence and with principles of autonomy, decision-making supports, presumption of competence, and the use of less restrictive alternatives.

The appointment of a guardian is a serious matter for three reasons: (1) it limits an individual’s autonomy, that is, the individual’s agency over how to live and from whom to receive supports to carry out that choice; (2) it transfers the individual’s rights of autonomy to another individual or entity, a guardian; and (3) many individuals with IDD experience guardianship as stigmatizing and inconsistent with their exercise of adult roles and responsibilities. (AAIDD, The Arc, 2016b, “Issue,” para. 1)

The position of the organizations is indicated in this way:

The primary goals in assisting individuals with IDD 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 IDD can participate in their own affairs with supports, assistance, and guidance from others, such as family and friends. People with IDD should be aware of and have access to decision-making supports for their preferred alternatives.

- If legal limitations on autonomy are necessary, then National Guardianship Association or equivalent standards that are consistent with the values expressed in this position statement should be followed. If any restrictions on autonomy are legally imposed, each individual has the right to the least restrictive alternative, due process protections, periodic review, ongoing training and supports to enhance autonomy and reduce reliance on approaches that restrict individual rights, and the right to ultimately seek to restore rights and terminate the restriction when possible.
- Information and training about less restrictive alternatives to guardianship should be available to people with IDD, their family members, attorneys, judges, and other professionals.
- If the use of a guardianship becomes necessary, it should be limited to the fewest restrictions necessary for the shortest amount of time and tailored to the individual's specific capacities and needs.
- Strict monitoring must be in place to promote and protect the autonomy, liberty, freedom, dignity, and preferences of each individual even when placed under guardianship.
- Regardless of their guardianship status, all individuals with IDD should be afforded opportunities to participate to the maximum extent possible in making and

executing decisions about themselves. Guardians should engage individuals in the decision-making process, ensuring that their preferences and desires are known, considered, and achieved to the fullest extent possible.

- Regardless of their guardianship status, all individuals with IDD retain their fundamental civil and human rights (such as the right to vote and the right to make decisions related to sexual activity, marriage and divorce, birth control, and sterilization) unless the specific right is explicitly limited by court order. (AAIDD, The Arc, 2016b, "Position," para. 1)

Finally, important systems issues, guardian responsibilities, and oversight are specified in the position statement.

As can be seen from this example of a joint position statement, great care is taken to indicate the values behind the position statement and enough detail of the issues to capture contemporary thinking on current issues, communicate meaningful future directions, provide specific policy guidance to decision makers, and affirm important aspects of organization identity.

### Opportunities for Financial Asset Building

The joint position statement on Opportunities for Financial Asset Building (AAIDD, The Arc, 2016c). includes the common sections of an introduction, identification of the main issues, and specification of what the organizations' position is. Here, the values and goals are expressed as,

People with intellectual and/or developmental disabilities (IDD) must have the same opportunities to advance their economic and personal freedom by earning and saving money to enhance their physical, social, emotional, and financial well-being and the right to exercise choice in investment and spending decisions as their peers who do not have disabilities. ("Statement," para. 1)

The major issue identified is that:

often, people with IDD face greater economic inequalities than their peers without disabilities. People with IDD also typically have not

had adequate supports for full participation in financial life and decision-making, including earnings, saving, budgeting, spending, investments, and estate planning. (AAIDD, The Arc, 2016c, “Issue,” para. 1)

Furthermore, receipt of government benefits can cause people with disabilities to lose essential financial supports. Policies should encourage financial independence, productivity, and self-determination but often promote the opposite by preventing people from planning and saving, which then results in lifelong poverty for people with IDD. At the same time, families of people with IDD provide supports to them across the lifespan, but as a result also face financial insecurity through inadequate policies.

Thus, AAIDD and The Arc assert their position that people with IDD and their families should have equal access to economic self-security, including opportunities to save money and build financial assets to maintain or improve their basic economic and social status, strengthen their financial security, and save for retirement through education, financial literacy, employment, home ownership, and asset development. (AAIDD, The Arc, 2016c, “Position,” para. 1) The position statement goes on to specify particular policies and programs that would address improved opportunities for economic well-being and asset building for individuals and their families.

### **Addressing the Causes and Effects of Intellectual and Developmental Disabilities**

This joint position statement was previously named simply “Prevention.” But, as the personal empowerment and pride of people with IDD became more recognized, many were concerned that readers of a statement entitled “Prevention” might erroneously think that the organizations were calling for the prevention of people rather than the elimination of the causes of disability. Thus, the name of the statement was changed and the introduction clarified:

According to the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and other federal legislation, “disability is a natural part of the human experience...” Prevention activities do not diminish the value of individ-

uals with intellectual and/or other developmental disabilities (IDD), but rather strive to maximize independence and enhance their quality of life for people with IDD. The Nation must continue to investigate the causes, avoid those that are preventable, and limit negative effects of conditions that cause IDD through basic, applied, and clinical research, public awareness, education, advocacy, early intervention, and appropriate supports. (AAIDD, The Arc, 2016a; “Statement,” para. 1)

The statement identifies recent knowledge about biomedical causes of disability, preventive health care options, and the consequence of exposure to environmental hazards. It goes on to identify quality of life factors such as access to comprehensive health care, including mental health, habilitative supports, dental services, therapies, education, and assistive technology. The statement emphasizes that the Nation must investigate the causes, avoid those that are preventable, and limit the negative effects of conditions that cause IDD through prevention programs, policies, and practices and must include research and public health efforts.

### **Human and Civil Rights**

The organizations introduce the position statement on human and civil rights by stating that “the human and civil rights of all people with intellectual and/or developmental disabilities must be honored, protected, communicated, enforced and thus be central to all advocacy on their behalf” (AAIDD, The Arc, 2015; “Statement”). Furthermore,

All people with intellectual and/or developmental disabilities are entitled to human and civil rights. Given that all people with intellectual and/or developmental disabilities are complex human beings with varying attributes and living circumstances, and many experience multiple risk factors for human and civil rights violations, we emphasize that all are entitled to human and civil rights regardless of age, gender, race/ethnicity, sexual orientation, cultural, linguistic, geographic, and spiritual diversity, economic status, severity of disability, intensity of needed supports, or other factors that expose them to increased risk of rights violations. (AAIDD, The Arc, 2015, “Position,” para. 1)

Rights referenced in the statement include the rights to “autonomy, dignity, family, justice, life, liberty, equality, self-determination, community participation, property, health, well-being, access to voting, and equality of opportunity and others recognized by law or international declarations, conventions, or standards” (AAIDD, The Arc, 2015; “Issue,” para. 1). The statement emphasizes that “all people with intellectual and/or developmental disabilities must have the right to supports they need to exercise and ensure their human and civil rights. Local, state, federal, and international governments must strongly enforce all human and civil rights” (AAIDD, The Arc, 2015; “Position,” para. 2).

The statement goes on to address the following issues: (a) history of discrimination; (b) exclusion from meaningful choices; (c) exclusion from participation in employment, housing, voting, transportation, and other programs, activities, and services provided by the public and private sectors of society; (d) attitudes of devaluation and fear; (e) unfounded beliefs that people with IDD cannot or do not contribute to society; (f) failure to provide the supports wanted and needed for full community participation, equal opportunity, independent living, and economic self-sufficiency; (g) overprotection; (h) denial of the means of economic self-sufficiency; (i) forced impoverishment; (j) prejudice; and (k) other factors that expose people to increased risk of rights violations.

### **The Role of Organizational Position Statements**

Organizational position statements play a significant role in disability policy in a time of change because they (a) provide strong communication about policy values and directions that are critical for individuals and their families, (b) promulgate key principles of high quality supports and services, (c) affirm best professional practices, and (d) emphasize the direct link between public policies and personal outcomes for people with IDD. In addition, the statements (a) affirm important aspects of organization identity; (b) enhance the organizations’ abilities to assure the input of a wide variety of perspectives; (c) engage members’ expanded ranges of experiences and talents; (d) multiply staff and leadership resources; (e) increase communication strength and avenues; and (f) establish processes for timely review and revision

of policies as critical disability issues arise or change, and new opportunities for policy integration and advancement occur.

In the case of the AAIDD and The Arc joint statements discussed in this article, one can see how intimately connected the position statements are to the identity of the two organizations. Both organizations recruit national experts to the statement workgroups. The organizations invest considerable resources in the development, dissemination, and evaluation of the position statements. They display the statements prominently on their websites and use the statements to frame policy discussions and guide their policy efforts. Both organizations use broad processes to include as many stakeholders and as much expertise as possible in the development of their statements, thus assuring up-to-date accurate content. The collaboration of staff and volunteer leadership from both organizations allows a maximization of resources. The communication streams of each organization include some outlets and audiences not covered by the other so their joint communication efforts enhance the ability of both organizations to achieve more coverage for their position statements. And, the systematic biennial process for review and development assures timely consideration of important policy issues.

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