



# POSITION STATEMENT



## ADVOCACY

**Advocacy on the individual or systems level is acting with or on behalf of an individual or group to resolve an issue, obtain a needed support or service or promote a change in the practices, policies and/or behaviors of third parties. Advocacy is essential for promoting and protecting the civil and human rights of people with intellectual and/or developmental disabilities<sup>1</sup> and for establishing, maintaining or improving their quality of life.**

### ISSUE

Without strong advocacy at all levels, people with intellectual and/or developmental disabilities may not have access to needed supports as well as opportunities to exercise inherent civil and human rights. Additionally, strong advocacy may be required to prevent and/or address abuse, neglect and exploitation that people with intellectual and/or developmental disabilities may experience. Persons with intellectual and/or developmental disabilities may need the support of advocates to become effective self-advocates.

### POSITION

Advocacy is vital in improving and sustaining quality of life for persons with intellectual and/or developmental disabilities. To be effective, advocacy must take place at both the individual and system levels. Advocacy can be aimed at public officials, support systems and the general public.

#### **Individuals**

Advocates, including self-advocates, should be trained and knowledgeable about the rights and dignity of children and adults as set forth in the position statements of The Arc.

Advocates must communicate effectively with individuals they assist, encouraging them to express and act on their thoughts, choices and feelings about issues and proposed solutions to problems. The advocate and the individual must be able to understand each other. The advocate should exercise great care to ensure that the person with intellectual and/or developmental disabilities fully understands the benefits and risks of any decision. When making decisions, individuals should be encouraged to consult with the important people in their lives.

Advocates have an ethical obligation to represent the desires and needs of the person they represent, regardless of their own personal opinions on matters under consideration.

Self-advocates should:

- Know about, understand and assert their rights;
- Obtain support to be effective self-advocates;

---

<sup>1</sup> "People with intellectual disabilities and/or developmental disabilities" refers to those defined by the AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

- Practice self-determination and advocacy;
- Learn and develop the skills necessary to advocate for one's self;
- Practice self-protection;
- Obtain needed services; and
- Fully participate in their community.

In certain circumstances, parents, other legal representatives or other supporters may need to be involved in making decisions with and on behalf of the individual. At such times, advocates must represent the interests of the individual. Advocates must be careful to recognize and set aside their own personal desires or points of view that may conflict with those of the individual for whom they are advocating. If there is a conflict of interest, the advocate should withdraw from the decision-making.

## **Systems**

Systems change advocacy can provide tremendous benefit for people with intellectual and/or developmental disabilities.

The goal of systems advocacy is to enhance public awareness of the rights, strengths, needs, and interests of people with intellectual and/or developmental disabilities and influence law and policy to improve public and private systems of support and services. Family members and self-advocates should play a meaningful role in systems change. Agencies providing supports to individuals should also advocate for system change that will improve the quality of life for all individuals, whether supported by the agency or not.

Individuals should have access to Protection and Advocacy systems and other entities mandated by state and federal laws that:

- Have the flexibility to respond to issues raised at any time during an individual's life;
- Are independent of conflicts of interest, undue influence and government control;
- Are adequately funded and staffed;
- Provide advocacy on their behalf even though a formal complaint has not been filed;
- Have appropriate government or other oversight of quality, cost effectiveness, efficiency, and high standards to ensure the health, safety and well-being of individuals being served;
- Use multiple advocacy strategies, such as information and referral, mediation, legal action, and legislative and regulatory solutions; and
- Provide means for appealing unfavorable decisions.

Adopted: Board of Directors, AAIDD  
July 18, 2010

Board of Directors, The Arc of the United States  
August 23, 2010

Congress of Delegates  
November 6, 2010



# POSITION STATEMENT



## BEHAVIORAL SUPPORTS

**A full and active life supported by caring relationships can reduce the occurrence of challenging behaviors in people with intellectual and/or developmental disabilities<sup>1</sup>. However, if such behaviors occur, people with intellectual and/or developmental disabilities and those who support them must have access to positive behavioral supports that focus on improved quality of life as well as reductions in the behaviors.**

### ISSUE

People with intellectual and/or developmental disabilities need supportive and caring relationships in order to develop full and active lives. Historically, people with intellectual and/or developmental disabilities across the age span have frequently been subjected to aversive procedures (i.e., electric shock, cold water sprays and deprivations like withholding food or visitation with friends and family) that may cause physical pain, discomfort and/or psychological harm. Children and adults with intellectual and/or developmental disabilities are frequently subjected to physical restraint, including the use of life-threatening prone restraint and seclusion for long periods of time.

Research indicates that aversive procedures such as deprivation, physical restraint and seclusion do not reduce challenging behaviors, and in fact can inhibit the development of appropriate skills and behaviors. These practices are dangerous, dehumanizing, result in a loss of dignity, and are unacceptable in a civilized society.

### POSITION

Research-based positive behavioral supports should be readily available in natural settings including the family home. Families, caregivers, educators, direct support personnel, and other professionals and paraprofessionals should be provided with training and support in implementing effective positive behavioral interventions and supports in all environments.

Behavioral supports should be individually designed and positive, emphasize learning, offer choice and social integration, be culturally appropriate, and include modifying environments as needed.

The Arc and AAIDD are opposed to all aversive procedures, such as electric shock, deprivation, seclusion and isolation. Interventions must not withhold essential food and drink, cause physical and/or psychological pain or result in humiliation or discomfort. Physical restraints should only be used as a last resort to eliminate the danger of physical injury to self or others.

The following factors should be considered in developing a positive behavioral intervention plan:

- The circumstances and environment in which the behavior occurred;
- The perspectives of the individual, his or her family and their social/cultural background and values;
- The contributing factors, such as physical or medical conditions, social and environmental influences;
- The completeness and accuracy of any data which has been collected about the behavior;
- The nature, extent, and frequency of the perceived challenging behavior; and

---

<sup>1</sup> "People with intellectual and/or developmental disabilities" refers to those defined by AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

- The function of the behavior, especially what the person may be trying to communicate.

Further, any positive behavioral interventions must also include consideration of:

- The potential secondary effects and risks associated with the intervention;
- The legal, social and ethical implications;
- The ease and practicality of implementation; and
- The consistency with values of the individual's culture.

Positive behavioral supports should be:

- Designed in a person-centered process involving the individual;
- Developed within the broader context of providing quality medical, psychological, educational, and facilitative services;
- Based on a functional analysis of the behavior and the circumstances under which it occurred, a thorough assessment of each individual's unique abilities and contributions, and an understanding of how previous interventions worked;
- Provided through a least restrictive strategy and described in a written plan;
- Grounded in evidence-based procedures that will:
  - prevent challenging behaviors;
  - teach new skills that may replace challenging behaviors;
  - prevent the on-going reward of a challenging behavior;
  - reinforce positive behavior;
  - ensure safety (when necessary); and
  - provide systemic information on the effectiveness of the support.
- Used in a humane and caring manner respecting individual dignity;
- Implemented in positive, socially supportive and culturally appropriate environments, including the home;
- Carried out by individuals (i.e., staff, family members and others) who have been trained and are qualified to effectively apply positive, non-aversive approaches;
- Include adaptations to the environment and reinforcers that people with intellectual and/or developmental disabilities and their families identify as positive; and
- Monitored continuously and systematically to ensure appropriate implementation and that the support is consistent with individual needs, positive in its methods, successful in achieving established goals, and changed in a timely fashion if success is not evident or occurring at an appropriate rate.

Adopted: Board of Directors, AAIDD  
July 18, 2010

Board of Directors, The Arc of the United States  
August 23, 2010

Congress of Delegates  
November 6, 2010



# POSITION STATEMENT



## INDIVIDUAL SUPPORTS

**Individual supports, such as assistive technology and personal assistance, make it possible for all people with intellectual and/or developmental disabilities<sup>1</sup> to function in daily life.**

### ISSUE

Our constituents frequently are unable to perform unassisted in basic areas of everyday life such as communicating, interacting with others, completing daily living routines, and moving in and around the home and community. All too often, individual supports are denied because of restrictive criteria such as age, disability label, severity of the disability, problem behavior, motor or sensory limitations, or test scores.

### POSITION

Our constituents must receive the supports necessary to lead a meaningful life in the community. These supports should be available based upon functional needs, not eligibility criteria such as diagnosis or income. Common areas of individual support include:

- **Communication.** People learn to communicate in many ways, such as personalized gestures and sounds, picture symbols, manual signs, and spoken language. Support must be available to help improve an individual's communication and social interactions as well as reduce challenging behaviors.
- **Assistive technology.** People must have access to devices, services, and training that improve independence, mobility, communication, environmental control, and self-determination. Designers, manufacturers, service providers, educators and our constituents with their families should be educated about the benefits of technology.

- **Personal assistance.** Adults (and parents of children under 21) should be able to hire and fire personal assistants to help them perform everyday activities, make decisions, and exercise control over their lives. Supports must be individually planned and applied according to the principles of person-centered planning, self-determination and individual outcomes, and team collaboration. The individual supports must be independently and regularly monitored for quality, safety, and effectiveness.

Adopted: Board of Directors, AAIDD  
July 18, 2010

Board of Directors, The Arc  
August 23, 2010

Congress of Delegates, The Arc of the United States  
November 6, 2010

---

<sup>1</sup> "People with intellectual disabilities and/or developmental disabilities" refers to those defined by the AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.



# POSITION STATEMENT



## PREVENTION

**The nation must continue to investigate the causes, reduce the incidence and limit the consequences of intellectual and/or developmental disabilities<sup>1</sup> through education, clinical and applied research, advocacy, and appropriate supports. Prevention activities do not diminish the value of any individual, but rather strive to maximize independence and enhance quality of life for people with intellectual and/or developmental disabilities.**

## ISSUE

Knowledge about biomedical causes of disability, preventative healthcare options and the consequence of exposure to environmental hazards is increasing rapidly, yet practical application of this information is lacking. In addition, when individuals with intellectual and/or developmental disabilities do not receive adequate therapies, education, healthcare, and access to assistive technology, preventable secondary conditions can occur. The incidence of conditions such as depression, obesity and related disease, is higher among people with intellectual and/or developmental disabilities. These conditions are also associated with living or spending time in institutional and segregated environments.

## POSITION

The nation must reduce the incidence and limit the consequences of intellectual and/or developmental disabilities through prevention programs which must include:

- Research into the causes of intellectual and developmental disabilities;
- Information and care before, during and following birth, including frequent physical/developmental checks, referral to community resources and genetic counseling if appropriate;
- Programs to ensure that pregnant women, infants and children receive adequate nutrition;
- Expansion of newborn screening and early childhood developmental screening programs to identify conditions that require specialized medical treatment at birth or soon after, and to provide for timely referral to early intervention services;
- Immunizations of children for preventable contagious diseases that are associated with intellectual and/or developmental disabilities;

---

<sup>1</sup> "People with intellectual disabilities and/or developmental disabilities" refers to those defined by AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

- Programs to reduce the effects of poverty upon children's health and development;
- Continued research into and application of promising interventions, best practices and community-based supports that maximize independence and enhance quality of life for individuals with intellectual and/or developmental disabilities;
- Dissemination of knowledge about research-based best practices; and
- Appropriate funding for interventions, preventative health care, therapies, educational services, community-based supports, and assistive technology to maximize independence and lessen the development of preventable secondary conditions.

**Community awareness and advocacy must include:**

- Education of professionals and the public on the risks of prenatal and childhood exposure to agents that may harm brain development, such as alcohol, drugs, tobacco, bisphenol A(BPA) and environmental hazards such as lead and mercury. In addition, professionals, families and self-advocates should be made aware that individuals with intellectual and/or developmental disabilities who experience compromised health or limited access to healthcare may be uniquely vulnerable to environmental hazards;
- Promotion of folic acid supplementation among women of child bearing age, with emphasis in communities where the incidence of neural tube defects is higher;
- Efforts to prevent accidental childhood injuries, through programs to promote the use of car seats, seatbelts and bicycle helmets;
- Programs and education to reduce the incidence of disabilities resulting from child abuse, particularly Shaken Baby Syndrome;
- Proactive efforts to prevent health disparities and the development of secondary conditions in persons with intellectual and/or developmental disabilities;
- Elimination of and protection against environmental hazards known to cause or contribute to intellectual and/or developmental disabilities, such as lead and mercury; and
- Enforcement of existing public policy designed to prevent intellectual and/or development disabilities.

Adopted: Board of Directors, AAIDD  
July 18, 2010

Board of Directors, The Arc of the United States  
August 23, 2010

Congress of Delegates  
November 6, 2010



# POSITION STATEMENT



## RESEARCH

**Basic and applied research<sup>1</sup> on the causes, challenges and treatment of intellectual and developmental disabilities<sup>2</sup>, as well as research on interventions and services which could improve the lives of people with intellectual and/or developmental disabilities, must be adequately financed, well designed, focused on relevant topics, conducted with the highest ethical standards, presented in formats accessible to multiple audiences, and have a positive impact on people's lives.**

### ISSUE

Government and private funding is insufficient to support the broad research agenda that includes issues most important to people with intellectual and/or developmental disabilities and their families. Through basic and applied research, scientists and researchers can learn about causes of intellectual and/or developmental disabilities, address its preventable causes, improve the quality of life of people with intellectual and/or developmental disabilities and their families, and address policy and service-delivery enhancements. Researchers can identify the most promising educational, social and clinical interventions that help people live meaningful lives.

Historically, most people with intellectual and/or developmental disabilities and their families have not had input into the design, methodology, dissemination, use, and evaluation of research. Moreover, most research results have not been presented in ways which are accessible, understandable and useful for multiple audiences, including people with intellectual and/or developmental disabilities and their families.

Few groups are more vulnerable to potential exploitation in research than individuals with intellectual and/or developmental disabilities. Without comprehensive, clear policies, standards and safeguards in place to protect them, people with intellectual and/or developmental disabilities may be subject to exploitation and harm.

### POSITION

To make applied and basic research related to intellectual and/or developmental disabilities a national priority, the following must occur:

- Government and private entities must provide adequate funding to support research;

---

<sup>1</sup> Basic research refers to the study and research of pure science that is meant to increase the scientific knowledge base. Applied research refers to scientific study and research that seeks to solve practical problems and develop innovative approaches.

<sup>2</sup> "People with intellectual disabilities and/or developmental disabilities" refers to those defined by AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.



- Advocacy, service provider and professional organizations, government agencies, the research community, and people with intellectual and/or developmental disabilities and their families must work together in defining, evaluating, and promoting a research agenda;
- Results of research must be available in multiple formats, easily accessible and understandable for a wide audience, including people with intellectual and/or developmental disabilities and their families;
- Stringent scientific and ethical standards must be enforced to ensure efficient and effective use of limited research funds and to prevent exploitation or harm of people with intellectual and/or developmental disabilities and members of their families; and
- For all basic and applied research involving persons with intellectual and/or developmental disabilities:
  - Specific procedures must be implemented to ensure their full voluntary, informed, initial, and ongoing agreement to participate;
  - All research must be conducted by qualified researchers, in adequately monitored settings and reviewed for potential risk and benefit by qualified, competent scientific review boards;
  - No research may be conducted exclusively on persons with intellectual and/or developmental disabilities unless there is reasonable likelihood that the treatment would address unique intellectual and/or developmental disabilities medical issues or apply differentially to them; and
  - Persons with intellectual and/or developmental disabilities should not be excluded from research that might benefit them as members of the general population.

Entities involved in conducting and financing basic and applied research should ensure that policies and standards with specific guidelines and safeguards are in effect to protect persons with intellectual and/or developmental disabilities and their families.

The Arc and AAIDD are committed to identifying and promoting research-based best practices, setting high standards for direct services and measuring outcomes across all three levels of the organization (local, state and national).

Adopted: Board of Directors, AAIDD  
July 18, 2010

Board of Directors, The Arc of the United States  
August 23, 2010

Congress of Delegates  
November 6, 2010



## POSITION STATEMENT



### SPIRITUALITY

**People with intellectual and/or developmental disabilities<sup>1</sup> have the right to choose their own expressions of spirituality, to practice those beliefs and expressions and to participate in the faith community of their choice or other spiritual activities. They also have a right to choose not to participate in religious or spiritual activity.**

#### ISSUE

Spiritual or religious activities are seldom recognized as an important aspect of life or included in individual planning for people with intellectual and/or developmental disabilities. Some individuals may need assistance to participate in their chosen spiritual activities or faith communities.

Individuals with intellectual and/or developmental disabilities and their families also face a mixed response from faith-based communities, even though many faith communities have established model programs and strategies for including people with disabilities. Spiritual resources and faith communities are an underused resource in the community for people to exercise choice, develop relationships and social networks, demonstrate respect for cultural and family backgrounds, and serve others.

#### POSITION

Spirituality, spiritual growth and religious expression that respect a person's history, tradition and current preferences are rights that must be honored by service systems and faith-based communities, as should the choice not to participate.

- Spirituality is an important part of human experience that may be expressed both through religious practice and through other spiritual activities which carry personal meaning and reflect the person's values;
- Supports and accommodations, such as transportation and easy-to-read materials, must be provided as needed to facilitate the individual's full participation in spiritual or religious activities of her/his choice;

---

<sup>1</sup> "People with intellectual disabilities and/or developmental disabilities" refers to those defined by AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

- Supports and programs should be age-appropriate and inclusive;
- Faith communities should be encouraged to build their capacity to support and welcome individuals with intellectual and/or developmental disabilities and their families, and should be assisted in such efforts;
- Self-advocates, families, advocacy organizations, service providers, and faith communities should work together to develop training and other resources on the inclusion and support of people with intellectual and/or developmental disabilities and their families; and
- People with intellectual and/or developmental disabilities bring their own unique spiritual gifts and benefits to spiritual and religious communities, just as people without disabilities do.

Adopted: Board of Directors, AAIDD  
July 18, 2010

Board of Directors, The Arc of the United States  
August 23, 2010

Congress of Delegates  
November 6, 2010



# POSITION STATEMENT



## SUPPORT COORDINATION

**Support coordination is critical for finding and coordinating the necessary services, supports and resources within the community that are required by children and adults with intellectual and/or developmental disabilities<sup>1</sup> and their families.**

### ISSUE

People with intellectual and/or developmental disabilities and their families often have a hard time finding and coordinating the services, supports and resources they need to ensure a high quality of life and full inclusion in the community. Service systems can be complex, challenging to navigate and are often critically underfunded. Determining funding sources for necessary services can be extremely difficult.

In many areas of the country, resources for support coordination, also referred to as service coordination, are limited or have restrictive financial or diagnostic eligibility criteria. Some support coordinators have large “caseloads” with more people than they can fully serve. There may be high staff turnover. Support Coordinators may not be aware of universal and natural support systems that are available to all citizens.

### POSITION

People with intellectual and/or developmental disabilities and their families must have ongoing access to effective, responsive, affordable, reliable, and culturally appropriate individual service coordination as needed.

As support coordinators help design, coordinate, and monitor supports and services, they must:

- Follow the wishes and needs of each individual through a person-centered planning process;
- Enable people to explore a full range of options, to include provider options, then identify and access appropriate services and supports;
- Develop formal and informal supports (i.e., circles of support) around the individual rather than try to fit the person into existing services because of availability. Informal supports are natural supports such as family, friends, co-workers, and neighbors;

---

<sup>1</sup> “People with intellectual disabilities and/or developmental disabilities” refers to those defined by AAIDD classification and DSM IV. In everyday language they are frequently referred to as people with cognitive, intellectual and/or developmental disabilities although the professional and legal definitions of those terms both include others and exclude some defined by DSM IV.

- Represent and advocate for the interests, preferences and dreams of the individual and, when appropriate, the family;
- Assist individuals and families in independently coordinating their own supports and services if they so desire, and in hiring someone of their choice;
- Be free from conflicts of interest;
- Support the development and expression of self-determination and self-advocacy; and
- Share information about desired supports and services as well as system gaps with funders so that systems become more responsive to people's desires and needs.

Support coordination must be funded at a level that supports an appropriate caseload. Support coordinators must be provided with ongoing skills development; opportunities to build capacity through peer networks; and equipped with up to date, unbiased knowledge of community resources.

Adopted: Board of Directors, AAIDD  
July 18, 2010

Board of Directors, The Arc of the United States  
August 23, 2010

Congress of Delegates  
November 6, 2010