

Position Statements

of the

American Association on Intellectual and Developmental Disabilities (AAIDD)

Position statements are those formal documents created by the Association or created jointly with national partner organizations.

In addition, the Association from time to time endorses the positions, declarations, and reports of other organizations

This booklet contains AAIDD's position statements as of **June 15, 2020**.

As position statements are routinely reviewed and updated; the most current statements can be found on the AAIDD website: www.aidd.org



Abbreviations and Acronyms

AAIDD	American Association on Intellectual and Developmental Disabilities
AADMD	American Academy of Developmental Medicine and Dentistry
ANCOR	American Network of Community Options and Resources
ASA	Autism Society of America
ASAN	Autistic Self Advocacy Network
APSE	Association of People Supporting Employment First
AUCD	Association of University Centers on Disabilities
ID	Intellectual Disability
IDD	Intellectual and Developmental Disabilities
DD	Developmental Disabilities
NADSP	National Association of Direct Support Professionals
NACDD	National Association of Councils on Developmental Disabilities
NDRN	National Disability Rights Network
SBA	Spina Bifida Association
TASH	
The Arc	The Arc of the United States
TSA	Tuberous Sclerosis Alliance
UCP	United Cerebral Palsy
USICD	United States International Council on Disabilities

Table of Contents

Position Statements of the AAIDD

Addressing the Causes and Effects of Intellectual and Developmental Disabilities (AAIDD, The Arc, 2016).....	4	Growth Attenuation (AAIDD, 2020)	40
Aging (AAIDD, The Arc, 2014).....	6	Guidelines to Professional Conduct (AAIDD, 2020).....	42
Autonomy, Decision-Making Supports, and Guardianship (AAIDD, The Arc, 2016)	8	Health, Mental Health, Vision, and Dental Care (AAIDD, The Arc, 2012).....	43
Aversive Procedures (AAIDD, 2020)	12	Housing (AAIDD, The Arc, 2012).....	46
Behavioral Supports (AAIDD, The Arc, 2015)	13	Human and Civil Rights (AAIDD, The Arc, 2015).....	48
Caring at the End of Life (AAIDD, 2020)	15	Inclusion (AAIDD, The Arc, 2014)	50
Community Living and Participation (AAIDD, AUCD, 2016) ...	18	Individual Supports (AAIDD, The Arc, 2011).....	52
Criminal Justice (AAIDD, The Arc, 2014).....	21	Long Term Supports and Services (AAIDD, The Arc, 2020) ...	53
Direct Support Professional (DSP) Workforce (AAIDD, NADSP, 2016).....	23	Opportunities for Financial Asset Building (AAIDD, The Arc, 2016).....	56
Diversity and Inclusion (AAIDD, 2017)	25	Protection (AAIDD, The Arc, 2015).....	58
Early Intervention (AAIDD, The Arc, 2013).....	26	Quality of Life (AAIDD, The Arc, 2015)	60
Education (AAIDD, The Arc, 2018).....	28	Research (AAIDD, The Arc, 2010)	61
Electric Shock (AAIDD, 2019).....	32	Self Determination (AAIDD, The Arc, 2018)	63
Employment (AAIDD, The Arc, 2017)	33	Self-Advocacy and Leadership (AAIDD, The Arc, 2020).....	65
Environmental Health (AAIDD, 2020).....	35	Sexuality (AAIDD, The Arc, 2013)	67
Facilitated Communication and Rapid Prompting Method (AAIDD, 2019).....	37	Spirituality (AAIDD, The Arc, 2015)	69
Family Support (AAIDD, The Arc, 2020)	38	Support Coordination (AAIDD, The Arc, 2015).....	70
		Transportation (AAIDD, The Arc, 2020).....	71

Positions, Declarations, and Reports of Other Organizations Endorsed by the AAIDD

Communication Bill of Rights (2019).....	74	Must Be Addressed in Health Care Reform.....	79
Community Living and Participation for People with Intellectual and Developmental Disabilities: What the Research Tells Us (2015)	75	My Thinker’s Not Working: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports (2012)	79
The Community Imperative (2019)	76	The Rights of People with Cognitive Disabilities to Technology and Information Access (2013)	80
Core Competencies on Disability for Health Care Education (2018)	78	Toronto Declaration on Building Knowledge, Policy, and Practice in Aging and Disability (2012).....	81
Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights (2012).....	78	Universal Civil and Human Rights of People with the Most Significant Developmental Disabilities (2020).....	82
Including Individuals with Intellectual/Developmental Disabilities and Co-Occurring Mental Illness: Challenges that			

Addressing the Causes and Effects of Intellectual and Developmental Disabilities

Joint Position Statement of AAIDD and The Arc, 2016

Statement

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 individuals with intellectual and developmental disabilities (IDD)*, but rather strive to maximize the independence and enhance 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.

Issue

Knowledge about biomedical causes of disability, preventive health care options, and the consequence of exposure to environmental hazards is increasing rapidly, yet practical application of this information is lacking. Supporting the prevention of IDD and valuing the lives, diversity, and contributions of persons with IDD are compatible positions.

Despite dramatic advances in our Nation’s view of disability and supports and services for individuals with disabilities, quality of life remains elusive for far too many persons with IDD. When individuals with IDD do not receive adequate, comprehensive health care, including access to mental health, habilitative and dental health services across the lifespan, therapies, education, and access to assistive technology, preventable secondary conditions can occur.

Position

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 which must include:

Research

- Research on the conditions that cause IDD, including, but not limited to, biomedical causes of disability, preventive health care options, and the consequence of exposure to environmental hazards.

Public Health Programs

- 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, such as programs to promote the use of car seats, seatbelts, and bicycle and other sports helmets;
- Compliance with state laws on immunizations of children for preventable contagious diseases associated with IDD to achieve public health objectives and optimal health outcomes;
- Encouragement of immunizations for women of child-bearing age for preventable contagious diseases that are associated with IDD;
- Programs to ensure that prospective parents and pregnant women have coverage for and access to comprehensive prenatal care to support the best possible birth outcomes. In the case of mothers with IDD, such care must meet the mother’s disability and communication needs;
- Disability sensitive information and supports for post-natal care for mothers with IDD;
- Programs to ensure that pregnant women (including those with IDD), infants, and children receive adequate nutrition and healthcare;
- Information and care before, during, and following birth, including frequent physical/developmental checks, and referral to community resources, if appropriate;
- Programs to ensure that children who live in poverty have access to adequate health and development support;
- 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, polychlorinated biphenyls (PCBs) and environmental hazards such as lead and mercury. In addition, professionals, families, and self-advocates should be made aware that individuals with IDD who experience compromised health or limited access to healthcare may be uniquely vulnerable to environmental hazards;
- Reduced exposure to and protection against infectious agents and environmental hazards known to cause or contribute to IDD, such as insect-borne diseases like the

Addressing the Causes and Effects of Intellectual and Developmental Disabilities, continued

Zika virus, and lead, mercury, and polychlorinated biphenyls (PCBs), as well as improved workplace safety initiatives;

- Programs and education to reduce the incidence of disabilities resulting from child abuse, particularly Shaken Baby Syndrome;
- 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. Such programs should be modeled on the highly successful efforts to prevent IDD resulting from PKU and hypothyroidism; and
- Enforcement of existing public policies designed to prevent IDD.

Quality of Life

Investigating the causes, avoiding those that are preventable, and limiting negative effects of conditions that cause IDD will contribute to individual and family quality of life. It is also imperative that individuals with IDD engage in person-centered and self-directed services and supports that are appropriate and affordable in order to improve quality of life, as well as to address secondary conditions through the following:

- Appropriate funding for interventions, preventive health care, habilitation services, educational services, community-based supports, and assistive technology to maximize independence and lessen the development of preventable secondary conditions in people with IDD who often are at greater risk for health problems that can be prevented;
- Proactive efforts in policy development and program design to identify and prevent health disparities and the development of secondary conditions in persons with IDD;
- 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 IDD; and
- Dissemination of knowledge about research-based best practices.

Adopted:

AAIDD Board of Directors, March 16, 2016

The Arc Board of Directors, April 10, 2016

Chapters of The Arc, October 28, 2016

*

Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as “The DD Act,” are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

The acronym “IDD” is used to describe a group that includes either people with both ID *and* another DD or a group that includes people with ID *or* another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

Aging

Joint Position Statement of AAIDD and The Arc, 2014

Statement

People with intellectual and developmental disabilities (IDD)* who are 55 years of age or older have a right to the same opportunities to enjoy full lives as other older people. They are entitled to full access to community supports, including support from those agencies that serve all older people.

Issue

For the first time in history, Americans living in the 21st century will experience millions of people with IDD living into their “senior” years. These Americans with disabilities want to enjoy their older years in the same manner as other people their age. Unfortunately, the discrimination that older people often experience in accessing community activities, housing, services, and supports and in enjoying all aspects of community life as they age, is experienced to a much greater degree by people with IDD as they age.

Like other older Americans, people with IDD may require greater levels of support to allow them to live full, active and healthy lives in their communities as independently and as long as possible. Unfortunately, many older people with IDD lack basic housing supports, as well as the specialized services needed to enable them to live more independently. They also lack the access to the health care services they need as they grow older, particularly access to preventative services and to ongoing habilitation and rehabilitation services.

Additionally, family members of people with IDD often lack information about and access to resources to enable them to support the person who is growing older. Many people with disabilities see no future for themselves as they grow older, other than one inside the walls of a nursing home or other institutional setting.

These problems are compounded by the fact that many community-based services for senior citizens are not prepared to meet the special needs of older adults with IDD. Likewise, many disability-based organizations have historically not planned for the challenges faced by older people with IDD and are not prepared to address these unique needs, including providing education and training on mitigating the risk of elder abuse and neglect for a potentially more vulnerable population of older people. In addition, a disconcerting trend is occurring. More and more aging individuals with disabilities are becoming caregivers for their even older parents.

Position

As they age, people with IDD must have every opportunity to be recognized as respected members of the community. Community services and supports that are geared to older community members must accommodate the supports needed by those who have also experienced lifelong disabilities. People with IDD who are aging should:

- Be afforded the same rights, dignity, respect, and opportunities as other older people in their communities;
- Be empowered, together with their families if asked, to advocate for themselves;
- Be free from discrimination on the basis of disability and/or aging;
- Have access to appropriate community-based social services, transportation, legal services, and other services;
- Have access to a full array of affordable housing services appropriate to their age and physical and mental condition;
- Have access to a full array of health care services appropriate to their age and physical and mental condition, including preventive health care, ongoing habilitation and rehabilitation services for as long as they are needed, including appropriate end-of-life care;
- Receive the supports they need to live, work, play, and retire when, where, and how they prefer, including supports for family members who can assist them in the pursuit of a quality and self-determined aging experience;
- Be free from the fear of inappropriate institutionalization;
- Be free from the fear of elder abuse and neglect by family members, providers or community members; and
- Have access to financial supports that will provide them with retirement opportunities like those that are available to other older people who no longer work.

Aging, continued

Adopted:

AAIDD Board of Directors, August 18, 2008

The Arc Board of Directors, August 4, 2008

The Arc Congress of Delegates, November 8, 2008

Reviewed and extended without revision, 2014

*

Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

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Autonomy, Decision-Making Supports, and Guardianship

Joint Position Statement of AAIDD and The Arc, 2016

Statement

All individuals with intellectual and developmental disabilities (IDD)[1] 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 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.

Issue

- 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[2] as an option is considered.

- 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.

Position

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,

Autonomy, Decision-Making Supports, and Guardianship, continued

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.

Systems Issues

- States should provide systematic access to decision-making supports for all individuals with IDD.
- An individual (other than a family member) should not serve in dual roles as guardian and as paid advocate or paid service provider for an individual.
- An organization should avoid serving in dual roles as guardian and as paid advocate or paid service provider for an individual.
- Organizations that serve in dual roles of guardian and paid advocate or paid service provider must have written policies and organizational separations in place to mitigate conflicts of interest. These organizations should support efforts to develop independent guardianship organizations.
- Financial incentives that benefit professionals or guardianship corporations should never drive guardianship policy or result in expensive and unnecessary costs to individuals or their families.
- Appointment of a guardian of the person, the person's finances, or both, should be made only to the extent necessary for the legal protection and welfare of the individual and not for the convenience or preferences of the family, the service system, or others.
- Individuals with IDD must have access to all the accommodations and supports, including communication supports, they need to demonstrate their competency at initial evaluations for guardianship and at all periodic reviews of any guardianship.
- State laws should be reformed to prioritize less restrictive alternatives to full and plenary guardianship, including without limitation informal supports, supported decision-making, limited (and revocable) powers of attorney, health care proxies, trusts, and limited guardianships that are specifically tailored to the individual's capacities and needs. These alternatives should always be considered first. Use of these alternatives can help an individual who may have limited capacity to consent to satisfy statutory privacy or other requirements and to have records released to a person or entity designated as the individual's agent or provider of support and services. If used at all, any restrictions on the individual's rights and decision-making powers should be confined to those areas in which the individual demonstrates a

Autonomy, Decision-Making Supports, and Guardianship, continued

need for assistance that exceeds what can be provided through a less restrictive alternative.

- Laws should be reformed to require that less restrictive options are tried and found to be ineffective to ensure the individual's autonomy before full (plenary) guardianship is even considered. Alternatives and related procedures to change overly restrictive forms of any existing guardianship, including restoration of rights and termination of any guardianship, must be available under state law.
- Since guardianship represents a transfer of rights and the responsibility for exercising them, adequate safeguards must be in place to protect those rights. These safeguards include procedural due process (including without limitation the right to counsel representing the interests of the individual, impartial hearing, appeal, and burden and quantity of proof) must protect the individual's autonomy. The state must also ensure that the individual is informed and retains as much decision-making power as possible. The state should pay the costs of providing these due process protections and not impose the costs on families or on individuals with IDD.
- Members of the judiciary, attorneys, and other professionals need training and education on alternatives to guardianship for individuals with IDD, and they must zealously advocate for preserving the substantive and procedural rights of all individuals with IDD.
- If a guardian is to be appointed, the preferences and assent of the individual with IDD with respect to the identity and function of the proposed guardian should be considered.
- The appointment of a guardian should be appropriately time-limited in order to provide regular periodic review of the individual's current capabilities and functioning and whether a less restrictive alternative is now indicated. The reviews should include an independent professional assessment by a highly qualified examiner of the individual's functioning with necessary accommodations and communication supports. All costs of the review should be paid by the state and not imposed on individuals with IDD or their families.
- Guardianship should include a person-centered plan of teaching and/or supports for decision making so the individual with IDD will have opportunities to learn and practice the skills needed to be autonomous and to direct his or her own life. Understanding the nature and purpose of guardianship and understanding that most people with IDD can manage their own affairs with assistance and guidance should be part of transition planning in schools and of any curriculum or procedures that prepare the individual's person-centered plan for adulthood. Schools should not give legal advice to students and families, and should provide students and families with information about less restrictive alternatives to guardianship.
- The ultimate goal of any such curriculum or procedures should be to ensure the individual's autonomy to the maximum extent possible, individualize decision-making supports for the individual, and ensure that the individual has maximum access to equal opportunity, independent living, full participation, and economic self-sufficiency, each with supports that take into account the individual's capacities and needs.

Guardian Responsibilities

- Guardians should be knowledgeable about decision-making and other types of supports, services, and systems that can significantly affect the individual's autonomy, supports, and quality of life. Moreover, guardians must be committed to the individual's well-being and avoid any appearance or actual lack of commitment to the individual. They must know and understand the individual's needs and wishes and act in accordance with them whenever possible and whenever any action will not negatively affect the individual's health, safety, financial security, and other welfare. Family members are often preferable choices when a guardianship is ordered and the family members meet these standards of knowledge, they do not have conflicts of interest (other than also serving as a paid advocate or paid service provider), and the individual with IDD does not object to the family member's appointment as guardian.
- Guardians shall defer to the individual's preferences when decisions do not jeopardize the individual's health, safety, financial security, and other welfare.

Autonomy, Decision-Making Supports, and Guardianship, continued

Oversight

- States should adopt a set of minimum standards for all guardians and require training and technical assistance for all guardians.
- Professional guardians (those who both serve two or more people who are not related to each other and also receive fees for these services) should, at a minimum, be registered, and preferably licensed or certified by the state, either directly or through delegation to an appropriate independent professional organization. They should also have the appropriate education and skills. They should be independent from and not be receiving payment for providing other services to the individual.
- Guardians shall be legally accountable for all of their decisions and other actions with respect to the individual. Their decisions and other actions must be subject to the reporting and review procedures of the appropriate state court or other agency.

Adopted:

AAIDD Board of Directors, March 16, 2016

The Arc Board of Directors , April 10, 2016

The Arc Chapters , October 28, 2016

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[2] Terminology for guardianship and guardians differs by state and can include tutor, conservator, curator, or other comparable terms.

Aversive Procedures

Position Statement of AAIDD, 2020

Some people who have an intellectual or developmental disability continue to be subjected to inhumane forms of aversive procedures as a means of behavior support. The American Association on Intellectual and Developmental Disabilities (AAIDD) condemns such practices and urges their immediate elimination. The aversive procedures to be eliminated have some or all of the following characteristics:

1. Obvious signs of physical pain experienced by the individual.
2. Potential or actual physical side effects, including tissue damage, physical illness, severe stress, and/or death.
3. Dehumanization of the individual, through means such as social degradation, social isolation, verbal abuse, techniques inappropriate for the individual's age, and treatment out of proportion to the target behavior. Such dehumanization is equally unacceptable whether or not an individual has a disability.

This statement is intended to articulate important values and principles and to challenge the field of developmental disabilities to promote research activities leading to identification, testing, implementation, and dissemination of non-aversive alternatives to address severe behavioral disorders. Specific regulations regarding research, clinical practice, or individuals in making professional judgments are the province of regulatory agencies, funders, and certifying bodies.

Eliminating inhumane aversive procedures is a reflection of a growing concern for reducing actions by professionals and others that compromise the lives of people with an intellectual or developmental disability and their families. Positive behavior supports not only should reduce problem behaviors that pose functional barriers to successful life, but also enhance those behaviors that lead to self-determination, independence, productivity, and lifelong learning. Relationships between providers and self-advocate should foster the empowerment of the person, enhance choice, and promote the integration of people with intellectual disability or other developmental disabilities into community settings.

The AAIDD urges continuing research into humane and effective methods of positive behavior support.

Adopted :

AAIDD Board of Directors , July 11, 2012, and as

Revised and amended on January 29, 2020

See also related AAIDD position statements on the use of *positive behavioral supports* and *electric shock*.

Behavioral Supports

Joint Position Statement of AAIDD and The Arc, 2015

Statement

A full and active life supported by caring relationships can reduce the occurrence of challenging behaviors in people with intellectual and developmental disabilities (IDD).^{*} However, if such behaviors occur, people with IDD 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 IDD need supportive and caring relationships in order to develop full and active lives. Historically, people with IDD 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 IDD 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
- The function of the behavior, especially what the person may be trying to communicate.

Further, any positive behavioral inventions 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,

Behavioral Supports, continued

- 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 IDD 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:

AAIDD Board of Directors, July 18, 2010

The Board of Directors, August 23, 2010

Reviewed and extended without revision, 2015

*

Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as “The DD Act,” are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

The acronym “IDD” is used to describe a group that includes either people with both ID *and* another DD or a group that includes people with ID *or* another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

Caring at the End of Life

Position Statement of AAIDD, 2020

I. Purpose and Scope

A. There has been increase in awareness of end-of-life and palliative care issues in recent years for the general public, as well as for people with intellectual and developmental disabilities (IDD). Despite these changes, clinical experience, public attitudes, medical practice, and legal opinion concerning caring at the end of life vary significantly across the United States. It is important that appropriate and accurate information be available to support sound decision-making. Evidence exists to indicate that people with IDD are particularly at risk when caregivers do not have clear, consistent, and ethically sound guidelines. The foundations for such guidelines are discoverable through analyses of existing medical, ethical, legal, and policy deliberations. The purpose of this Position Statement is to identify these foundational principles and to enunciate policies to guide care at the end of life for persons with intellectual or developmental disabilities.

B. The end of life has been defined by some to be the last 6 months of life, although this time frame may provide an artificial timeline for anticipated death. For our purposes, end of life refers to a period in which death is soon anticipated in individuals with life-threatening or life-limiting conditions. Individuals are not at the end of life when they are living in a stable condition that requires significant life-sustaining treatment (such as a mechanical ventilator or a feeding tube) and wish to continue receiving such treatment. Individuals may be considered to be at the end of life when: (1) they have a condition that is progressive and irreversible, such as late-stage Alzheimer disease or terminal cancer, or (2) they have a condition or functional impairment whereby improvement or recovery is not expected, and withdrawal of life-sustaining treatment is under consideration. Life may come to an end suddenly and unpredictably (for example from a fatal injury), in which case the policies expressed here will ordinarily not apply, although some of the basic principles may pertain.

C. Discussions about caring at the end of life ideally should begin before the last 6 months of life. These discussions should include statements about what care the person would like to receive if he or she was in one of the end of life conditions described above. Identification of every possible situation is not feasible, so these discussions should be sufficiently general to cover most situations yet specific enough to provide practical guidance. Legal or other professional assistance will be helpful when developing living wills, health care proxies, durable powers of attorney for health care, and other such statements about personal preferences. These statements should be updated

periodically (perhaps every few years), taking into account medical advances, technological improvements, and changing perspectives during one's lifespan.

D. This Position Statement applies to people with IDD who are at the end of life as defined above. Such individuals may be of any age across the lifespan, from infancy to elderly. The Principles outlined below define the context in which caring should be provided to all such persons who are at the end of life. The Policies outlined below specify which interventions are deemed appropriate at the end of life and which are not.

II. Principles

A. AAIDD recognizes four major principles that form the basis for disability policy: (1) Dignity, (2) Respect for Autonomy, (3) Life, and (4) Equality. These principles are explained below and related to end of life care.

B. Dignity: All persons are equally valuable, with or without disability, and deserve respect consistent with human dignity. The value of a person's life is not related to the type, degree, or severity of disability. Inherent value must be distinguished from quality of life. Inherent value persists from birth to death, even though the quality of life may change as one approaches the end of life.

1. The quality of one's life must be assessed from a subjective viewpoint, that is, from the point of view of the person with a disability. Having a disability is not by itself a form of suffering. People without disability who fear becoming disabled must not assume that their feelings are shared by those who are living with a disability.
2. The mere presence of IDD, or likelihood of having a disability in the future, does not make a person's life less valuable.
3. Decisions about care at the end of life must be made respectfully, consistent with the principle of Dignity. Withdrawing or withholding care may be appropriate in some situations, although it should not itself imply a lack of respect for the importance of that person's life. Treatment should not be withdrawn or withheld only because a person has a disability.

C. Autonomy: Caregivers should always attempt, as much as possible, to discover the wishes and desires of the person with IDD and honor those wishes.

1. People generally express their preferences through verbal and/or nonverbal communication. Careful observation and interaction over time often clarifies what

Caring at the End of Life, continued

a person with IDD values as being important. Those who are closest to the person, such as family members, trusted caregivers, nurses, friends, and others, are best able to identify the person's preferences when he or she is unable to express them directly.

2. Individuals with IDD should be encouraged to express their preferences about care at the end of life before situations requiring decision-making occur, if possible. Many children, adolescents, and adults with IDD are capable of expressing their preferences about end of life care, and efforts should be made to discern their wishes. These preferences should be documented. Examples of such documentation may include living wills, personal vision statements, health care proxy instructions, and/or other indicators of one's wishes.
3. Decision-making capacity may vary in different situations. Health care providers must recognize that individuals with IDD whose legal competence is challenged nonetheless may have the capacity to express preferences about health care. These preferences should ordinarily be respected.
4. The principles of informed consent require that decision-makers have: (1) all of the information needed to make a decision, (2) the ability to assess the information adequately, and (3) freedom from undue influence by others. Caregivers must always seek to determine the uncoerced, authentic voice of the person with IDD and provide all of the information the person needs to express his or her preferences. Instructional strategies and/or training materials should be developed to assist individuals with IDD to access relevant information, analyze it effectively, and utilize it to assess options and make choices.
5. The process of self-determination helps individuals to apply the principle of autonomy in their lives and to identify their health care preferences clearly and effectively. Self-advocacy recognizes the autonomous, constitutional right of individuals with IDD to have their preferences respected.

D. Life: Caregivers should act to promote and protect the life of the person with IDD.

1. The best-interest standard should be the relevant basis for making decisions about treatment to promote and protect life. Normally the person determines what is in his or her best interest, and this takes precedence over all other determinations. When that is not possible, others may do so when they follow accepted legal procedures defined by state and federal laws and regulations.

2. In some situations, continued life may not be in the person's best interest. Existing law recognizes such situations as those in which: (1) life-sustaining treatment is clearly ineffective and would only prolong the process of dying and suffering with no prospect of reversing it; (2) the person is in an irreversible coma or permanent vegetative state (when those conditions are identified by qualified, expert neurological consultation); or (3) the treatment itself would impose excessive pain and suffering.
3. People for whom religion and spirituality are important, including people with IDD, may believe that forgiveness, reconciliation, peace or eternal life with God is more important than continued life on earth. This judgment about the person's religious or spiritual preferences should be made by the individual or his or her loved ones and should not be determined solely by health care providers.

E. Equality: Resources for caring at the end of life must be appropriate, sufficient, and available without discrimination.

1. There is a notable health disparity within the United States for people with IDD, particularly with regard to resources and health outcomes. Most individuals with IDD depend on public health care financing (Medicaid and Medicare), which may impact access to needed treatment.
2. Needed treatment should be available in the most appropriate context, taking into account the person's preferences and health care needs. People should not be required to live in a nursing home to get care that could be provided in a more natural setting, such as the person's home.
3. All needed treatment must be provided. Needed treatment may include, although is not limited to, provision of home health care, nursing, medications, nutrition, hydration, and social interaction. Hospice care at the end of life should be available when it is appropriate. Adequate pain relief is essential to alleviate and prevent suffering at the end of life. Spiritual or pastoral care should be provided when it is desired. Public and private health insurance should cover these needs.
4. Economic incentives for reducing the cost of health care, such as rationing or managed care, may influence providers to restrict or deny life-sustaining treatment for persons with IDD. Providers should treat all patients equally, regardless of the presence or absence of such disabilities, and provide whatever resources are needed in the particular context.

Caring at the End of Life, continued

F. Principles of Palliative Care: Guiding principles for the dying person.

1. Respect for the goals, likes, and choices.
2. Attendance to the medical, emotional, social, and spiritual needs.
3. Support for the family members.
4. Providing access to needed health care providers and settings.
5. Supports excellent care at the end of life.

III. Policy

A. Permissible treatment options at the end of life are the same for people with IDD as for everyone else. This reflects the Equality Principle.

1. The wishes of individuals who have clearly and competently expressed them should be honored by caregivers and health care providers, consistent with the Autonomy principle.
2. The presumption should always be in favor of treatment. This reflects the Life principle. This presumption may be overcome in the clearly specified situations enumerated in section II on Life, no. 2, above. As such, there are times in which aggressive treatments at end of life may provide needless discomfort and suffering, without the benefit of improved outcome and prolonged life. Withholding or withdrawal of nutrition, hydration, and other medical treatments may be allowed in these situations.
3. Individuals in a “minimally conscious state” are not at the end of life as defined above. Withholding or withdrawal of life-sustaining treatment (including nutrition and hydration) is not permissible unless the person has previously expressed a clear and competent preference regarding such withholding or withdrawal. AAIDD believes that determination of the person’s previously expressed preferences should follow the legal standard of “beyond a reasonable doubt” in this situation.
4. The legally determined next of kin (parent, spouse, etc.) or court-appointed guardian is authorized to make treatment decisions when the person is not able to make these decisions directly.
5. Judicial review is appropriate and necessary when application of this policy is unclear or in dispute among health care providers, family members, guardians,

friends, and other significant caregivers.

B. Physicians should always act in conformity with existing codes of medical ethics, existing state and federal laws, and their conscience. Physicians also need to be familiar with the medical and social issues related to individuals with IDD or use consultants with this type of expertise to guide their care.

1. Physician-assisted suicide (PAS) is opposed by the American Medical Association and is illegal in the vast majority of states. Physicians must not provide PAS to persons with IDD in states where it is illegal to do so. Where it is legal, physicians must follow the legally specified procedures in their jurisdiction. Application of those procedures must also be consistent with the principles outlined above. Even if it is legal, physicians cannot be compelled to provide PAS if it is against their conscience to do so.
2. Active voluntary euthanasia is different from PAS and is illegal everywhere in the United States. In PAS, a physician provides a fully competent person with the means to terminate his or her own life. In active voluntary euthanasia, the physician or some other agent terminates the person’s life directly. Active voluntary euthanasia is never permissible.
3. Individuals choosing PAS must be legally competent, when this procedure is legal. Surrogates cannot choose PAS for another person. Any attempt by another person (such as a parent or health care provider) to choose PAS for a person with IDD is not permissible.

C. Public policy should be developed to reflect the principles enumerated above.

Adopted:

AAIDD Board of Directors , July 11, 2012

Reviewed and extended without revision on January 29, 2020

References:

Botsford, A., & King, A. (2005). End-of-life care policies for people with an intellectual disability: Issues and strategies. *Journal of Disability Policy Studies*, 16, 22–30.

Friedman, S. L., & Helm, D. T. (Eds.). (2010). *End-of-life care for children and adults with intellectual and developmental disabilities*. Washington, DC: American Association on

Community Living and Participation

Joint Position Statement of AAIDD and AUCD, 2016

Statement

Community living is a major focus of national policy and related litigation (e.g. the Americans with Disabilities Act in 1990, the Supreme Court *Olmstead v. L.C.* decision in 1999, Workforce Innovation and Opportunity Act in 2014 and the Home and Community Based Services Final Rule in 2014). Increasingly public policy is promoting and requiring that federal funding be used to support people to live, work, and participate fully in their communities.

Community living and participation means being able to live where and with whom you choose; work and earn a living wage; participate in meaningful community activities based on personal interests; have relationships with friends, family and significant others; be physically and emotionally healthy; be able to worship where and with whom you choose (if desired); have opportunities to learn, grow and make informed choices; and carry out responsibilities of citizenship such as paying taxes and voting.

Of the estimated 6.2 million people in the United States with intellectual or developmental disabilities (IDD), most live with their families and many need and receive long term services and supports. When people live outside of their family home they have several options for community living including opportunities to live in apartments with individualized support, with one or two other people with support, with host families, and in small group homes with other people with disabilities and 24-hour support. Unfortunately, many people with IDD also may still live in large, segregated congregate places including large group homes (with 7 or more people living there), residential programs located on campuses, and state and private institutions, which could limit community inclusion.

The benefits of living in smaller community settings are well-documented. People who live in these environments have more choices and control over their lives, have more friendships, are engaged in their communities, are safer, and experience greater life satisfaction. The ability to live and thrive in individualized living situations and be in charge of their own home (e.g., staff schedule, what/when they eat, who visits and when) is possible for **all** persons regardless of need when the funding and supports are made available to them. That is, all people, regardless of the significance of their disability, can lead lives they control by being supported to experience the opportunities that community life offers and to choose how they will participate in their communities. All too often, many individuals with IDD are never afforded these opportunities and in many instances, there is systemic denial of choices due to constraints of service delivery

systems to provide such opportunities. Instead, low expectations sometimes held by professionals, families, community members, and others who touch the lives of people with IDD, result in perpetuated assumptions that people with IDD need and require 24-hour support, group employment, and group living. Approaches such as *Community First* and *Employment First* statewide initiatives emphasize an alignment of policies, funding, and practices to promote people with disabilities living, working, and contributing in their communities as the first option in the provision of services and supports.

Despite the evidence, there is a growing interest in many states by some advocates to move away from community living in favor of building new congregate programs that segregate people with IDD from their communities (e.g. working farms, campus models and gated neighborhoods). Often the interest and desire to create new congregate settings is in response to advocates' frustrations with: a) long waiting lists for community living, b) issues related to quality of community services, c) lack of options that are person-centered and able to meet the specific needs of each individual person, and d) staff who are not adequately prepared and not specifically trained to support people with certain types of significant needs. These concerns about community living are both real and significant, but the solution to return to building large, segregated, isolated living programs is not the answer to improving quality of life for people with IDD and could result in less positive outcomes. It is tempting to revert to institutional-type congregate settings when the resources or capacity to improve community living options are lacking. The alternative is to create and advocate for high quality community living options that are supported by federal and state governments. It is also important to make people aware of what is possible and what practices exist that result in quality community living. People with significant disabilities do, can, and should live in the community with the support they need and deserve. They have a fundamental right to do so.

Issues

Access to community services. Many people with disabilities experience access challenges to individualized community supports. There are many issues that create barriers for people with significant disabilities to live and work in the community. Some of these are:

- Nearly every state has significant waiting lists for Home and Community Based Services, the foremost funding source for community living. Recent data (2013) indicates an estimated 232,204 people in the U.S. are on waiting lists for community services.

Community Living and Participation, continued

- Many states have built systems that utilize group homes as a key way to support people in the community. When people find themselves in a situation where they need to live outside of their family home, they are often placed in an “open bed” versus being offered person-centered supports designed specifically to meet their needs. In many of these situations, people remain as isolated in these settings as they do in a large-scale institution. A process for creating and sustaining supports that make their living situation a home in a neighborhood is needed.
- In most states and communities, it is not unusual for people with IDD to transition from school to sheltered workshops or non-work day services with little opportunity to move out of those environments into supported or competitive employment. These assumptions place low expectations on people with IDD and both underestimate and undermine their potential achievement of supported or paid community employment.
- People with IDD do not have equal access to various forms of technology (e.g. communication devices, mobility devices, smart home, digital information) that could greatly increase their ability to live and work in the community.

Quality in community services. There is wide variability of quality within community residential, employment and other support models across the US.

- Ensuring the quality of community living is an on-going challenge in the United States. Federal requirements related to quality do not exist and each state develops, implements and monitors the quality of programs in different ways. This leads to wide variability in quality of services that often lack characteristics that are necessary to promote a self-determined, interdependent life for people with IDD.
- Many of the best practices that have evolved to promote community living and participation have not been brought to scale (e.g. individualized supported living, supported employment, technology, supported decision making). The best models are not disseminated broadly nor funded in ways that providers can fully implement. Sufficient, affordable models don’t exist for agencies that provide the best services to share their practices with others.

Funding for community services. The various funding mechanisms used to support community living and

employment are using antiquated models; the funding policies are not flexible, do not meet the needs of individuals, and over-rely on 24-hour staffing models.

- In the United States more money is spent *per person* on institutional and segregated services than is spent on community living and supported employment. \$260,970 was spent on institutional services per person (2013 state operated ICF/IID expenditure) compared with \$42,713 on community (2013 HCBS expenditure).
- About \$7,000 annually is spent per person on supported and integrated employment including both individual jobs and group supported jobs by state IDD agencies. For all day and employment services the annual expenditure is about \$13,000 per person. While an estimated \$947 million is spent in total by state IDD agencies on supported and integrated employment over \$7.2 billion is spent on sheltered or segregated employment and non-work day services. Integrated employment represents 13.5% of all spending for day and employment services (2014 expenditure data).
- The costs of archaic service models result in many people with IDD unnecessarily receiving 24-hour daily supports and they are therefore being over-served.
- Medicaid is a health care program based on a medical model of services and supports and often creates a lack of flexibility in funding systems. This can lead to the inability to readily respond and adapt in a timely manner, to the changing needs of each individual at any given point in time based on their unique context and individual characteristics.

Workforce challenges. The ability to meet the needs of people with IDD in the community, ensure quality of community services, and offer more flexible and individualized options requires a better compensated, stable, highly ethical and competent workforce.

- It is difficult for individuals, families and providers to find and keep direct support staff. The demand for workers far surpasses the number of qualified job seekers resulting in a significant personnel shortage.
- The direct support workforce is paid low wages (national estimated average is \$10.50 per hour) and consequently most direct support professionals work more than one job in order to pay their bills. This results in high levels of burnout and resignations and workers who are often chronically tired.
- Direct support professionals have demanding roles, both physically and psychologically, and as a consequence have one of the highest rates of workforce injury.

Community Living and Participation, continued

- The direct support workforce has few opportunities for training and professional development. Training requirements that do exist in states are not comprehensive nor do they ensure that direct support staff are trained to meet the needs of the people they support. This has resulted in diminished quality and a caretaking model of service instead of one that creates high expectations of people with IDD and supports them in learning, growing and developing new skills for community living and work.

Position

Everyone with an intellectual or developmental disability deserves to live in the community where they have the opportunity to experience vibrant lives that include work, friends, family, and high expectations for community contributions. Our systems to support people with IDD should promote individual growth and development through the provision of best practices in fully integrated community settings. It is essential to close institutions and at the same time create and support our existing communities to develop the capacity to support all people with IDD in their communities through individualized supports that:

- Ensure federal, state and local governments have an infrastructure in every existing community that results in people with IDD getting the support they need to live and work in their communities. This infrastructure should also focus on the need for community intervention and strongly encourage communities to take responsibility for full inclusion of people with IDD in all aspects of community life.
- Ensure a skilled, stable and fairly compensated workforce that adheres to high ethical standards to support people to live self-determined lives in the community.
- Promote public policy that provides incentives for states and local communities to expand access to individualized community living and employment. This funding should be spent on integrated inclusive community services and incentives provided to states and local governments to move away from segregated programs such as day programs, sheltered workshops and congregate living.
- Expand the availability and use of technology by people with IDD to further promote community living and employment.
- Expand opportunities for self-directed funding and services that put the individual with IDD in control of designing, implementing and monitoring their services and supports.

- Ensure there is an infrastructure and capacity in existing communities designed specifically to meet the support needs of people with complex health and behavioral challenges.
- Ensure community living supports are adequately funded and are of high quality.

Adopted:

American Association on Intellectual and Developmental Disabilities
Board of Directors
June 5, 2016

Association of University Centers on Disabilities
Board of Directors
June 23, 2016

Criminal Justice

Joint Position Statement of AAIDD and The Arc, 2014

Statement

People with intellectual and developmental disabilities (IDD)* have the right to justice and fair treatment in all areas of the criminal justice system, and must be afforded the supports and accommodations required to make justice and fair treatment a reality.

Issue

When individuals with IDD become involved in the criminal justice system as victims, witnesses, suspects, defendants, or incarcerated individuals, they face fear, prejudice, and lack of understanding. Attorneys, judges, law enforcement personnel (including school-based security officers), first responders, forensic evaluators, victim advocates, court personnel, correctional personnel, criminal justice policy-makers, and jurors may lack accurate and appropriate knowledge to apply standards of due process in a manner that provides justice for individuals with IDD. These individuals are:

- *Unrecognized as having a disability.* Individuals with IDD are frequently undiagnosed or misdiagnosed, especially by evaluators, including law enforcement personnel, who are not trained in assessment of individuals with intellectual disability and who do not recognize common characteristics such as individuals' attempts to hide their disability. Defendants with IDD are often denied a fair evaluation of whether they are entitled to legal protection as having IDD on the basis of false stereotypes about what individuals with IDD can and cannot understand or do.
- *Victimized at high rates.* Individuals with IDD are significantly more likely to be victimized (at least two times more likely for violent crimes and four to ten times for abuse and other crimes), yet their cases are rarely investigated or prosecuted because of discrimination, devaluation, prejudice that they are not worthy of protection, and mistaken stereotypes that none can be competent witnesses. Their victimization comes in many forms including violence, oppression, financial exploitation, sexual exploitation, and human trafficking;
- *Denied redress.* Individuals with IDD are subject to routine denial of opportunities for legal redress because of outdated and stereotyped views of their credibility, their competence to testify, or their need for advocacy, supports, and accommodations;
- *Denied due process.* Individuals with IDD are often denied due process and effective, knowledgeable advocacy and legal representation at each stage of the proceedings; and
- *Discriminated against in sentencing, confinement, and release.* Individuals with IDD are subject to abuse and exploitation when incarcerated and denied either alternatives to incarceration or appropriate habilitation programs that would address their intellectual disability,

and/or behavior, and help them return safely to the community. When incarcerated, individuals with IDD often serve extended time because they do not understand or cannot meet steps to reduce time and secure an earlier release.

When individuals with IDD or their families come into contact with the criminal justice system, they find few organized resources for information, training, technical assistance, referral, and supports. Moreover, people living with IDD who enter the criminal justice system encounter unique problems not faced by their nondisabled peers, such as:

- Failing to have their disability correctly identified by authorities who lack the expertise to discern the presence and nature of their disability (especially when the disability is denied by the person or somewhat hidden);
- Giving incriminating statements or false "confessions" because the individual is manipulated, coerced, misled, confused by either conventional or inappropriately used investigative techniques, or desires to please the questioner;
- Experiencing inappropriate assessments for competency to stand trial even when the individual cannot understand the criminal justice proceeding or is unable to assist their lawyer in their own defense;
- Being inappropriately placed in long-term institutions and subject to inappropriate one-size-fits-all "competency training" designed for people with other disabilities or no disabilities; and
- "Waiving" rights unknowingly when warnings such as *Miranda* are given without accommodating the person's IDD.

While the Supreme Court ruled in *Atkins v. Virginia*** that it is a violation of the Eighth Amendment ban on cruel and unusual punishment to execute people with intellectual disability, states continue to play a major role in applying the term and in deciding the process for consideration of a defendant's intellectual disability. Laws vary from state to state on how a defendant proves the presence of intellectual disability.

States also vary widely regarding whether it is the judge or jury who decides if the defendant has intellectual disability. States sometimes inappropriately appoint people who are not knowledgeable about intellectual disability to conduct "assessments" for intellectual disability or to offer "a diagnosis" that they are not professionally trained or qualified to provide. As a result, defendants may not have their intellectual disability correctly identified because of a state's unfair and inaccurate procedures. The Supreme Court ruled again in *Hall v. Florida**** in 2014, reaffirming the *Atkins* decision and denying states' use of strict IQ cutoffs to diagnose intellectual disability.

Criminal Justice, continued

Position

People with IDD must receive justice in the criminal justice system, whether as victims, witnesses, suspects, defendants, or incarcerated individuals.

As victims, witnesses, suspects, defendants, or incarcerated individuals, they must:

- Be protected by laws and policies that ensure their right to justice and fair treatment;
- Be treated fairly by personnel who are knowledgeable and trained about IDD, including all attorneys (prosecution and defense), judges, law enforcement personnel (including school-based security officers), first responders, forensic evaluators, victim advocates, court personnel, correctional personnel, criminal justice policy-makers, and jurors;
- Be informed about and have access to appropriate sentencing alternatives to incarceration, and be provided the supports and accommodations to enter alternatives;
- Receive supports and accommodations to effectively participate in all stages of legal proceedings for which they are competent;
- Have necessary supports and accommodations available so that their testimony is heard and fairly considered when they are victims;
- Have access to victim supports and compensation as appropriate;
- Have access to, and the right to present, expert evaluations and testimony by professionals with training, experience, and expertise in their disability;
- Have an advocate, in addition to their lawyer, who has specialized, disability-related expertise;
- Have their conversations with their advocate covered under, or treated similarly to, attorney-client privilege; and
- As a suspect, be protected from harm, self-incrimination, and exploitation at all stages of an investigation and prosecution, including when they are questioned, detained, and incarcerated.

When sentenced, individuals with IDD also must:

- Have available reasonable and appropriate supports, accommodations, treatment, and education, as well as alternatives to sentencing and incarceration that include community-based corrections; and
- Have access to well-trained probation and parole officers who will treat them fairly based on their individual disability and their need for the supports and accommodations necessary to re-enter society, including those that will enable people to re-establish Medicaid Waiver services, SSI, housing, education, and job supports.

When death penalty is an issue, individuals with intellectual disability also must:

- Continue to be exempt from the death penalty because existing case-by-case determinations of competence to stand trial, criminal responsibility, and mitigating factors at

sentencing have proved insufficient to protect the rights of individuals with intellectual disability;

- Have access to expert witnesses and professionals who are knowledgeable about, as well as trained and experienced in, intellectual disability and who can accurately determine the presence and effects of intellectual disability; and
- Have their intellectual disability determined by state procedures that are accurate and fair. Those state procedures must be consistent with the national standards on making an intellectual disability determination and ensure that people with intellectual disability are not executed.

Adopted:

Board of Directors, AAIDD
February 19, 2014

Board of Directors, The Arc of the United States
August 6, 2014

Congress of Delegates, The Arc of the United States
October 2, 2014

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The acronym “IDD” is used to describe a group that includes either people with both ID *and* another DD or a group that includes people with ID *or* another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

***Atkins v. Virginia*, 536 U.S. 304 (2002). The term “mental retardation” was used in the *Atkins* decision banning execution of people with intellectual disability (ID) and, though outdated, was still used in some state legal and criminal justice systems until the U.S. Supreme Court’s decision in *Hall v. Florida*. The outdated term has appeared, therefore, in many legal decisions and briefs, including *amicus* (“friend of the court”) briefs. The Arc and AAIDD support the modern terminology of ID and urge courts to follow the Supreme Court’s lead in adopting this modern terminology.

****Hall v. Florida*, ___ U.S. ___ (2014)

Direct Support Professional (DSP) Workforce

Joint Position Statement of AAIDD and NADSP, 2016

Statement

Individuals with intellectual and developmental disabilities (IDD) have long sought lives where they can be fully contributing and valued members of their communities. Federal regulations including the Americans with Disabilities Act (ADA), and more recently the Centers for Medicare and Medicaid Services (CMS) Home and Community Based Services (HCBS) Settings Rule and the US Department of Labor Workforce Innovation and Opportunity Act (WIOA) have set forth standards aimed at making inclusion and employment a reality. The availability of a qualified, competent, and stable Direct Support Workforce plays an important role in supporting people to accomplish these goals. To be successful, it is critical that Direct Support Professionals (DSPs) have the competence, confidence, and ethical decision-making skills with the guidance necessary to provide quality support, receive compensation that is commensurate with job responsibilities, and have access to a career path aligned with ongoing professional development.

Issues

The stability of the direct support workforce has been a long-standing issue across disability service systems. The field is plagued with high turnover at a time when demand for additional direct support professionals to support both disability and aging populations in the United States is peaking. It is estimated that nationally more than one million new direct support positions will need to be filled by 2022. This growing demand combined with limited availability of training and education and increased expectations and requirements make it essential that there be increased investment in this vital workforce.

The United States is at a critical juncture where workforce development, education, and disability service systems must implement strategies to increase the capacity and quality of the direct support workforce. Action is necessary if we are to provide the support people with IDD need to live and participate in their communities. Self-advocates and family-advocates have fought hard for decades to ensure that supports provided are person-centered, increase inclusion, and lead to valued lives for people with IDD. Researchers, practitioners, providers, and policy-makers have recommended recruitment, retention, and education strategies to address this critical workforce need, however, they have yet to be sufficiently funded or brought to scale. If the charge to address the workforce crisis is not acted upon, the entire disability service system is at risk of going back to

days of institutionalization, segregation, and stigmatization, turning the clock back on decades of advocacy and disregarding the voice of people with developmental disabilities across the country.

Low Wages

Wages paid to direct support professionals are comparable to those paid for entry level low wage positions in nearly all service industries. Insufficient wages affect workforce retention and the quality of support provided. There is a significant discrepancy between the job responsibilities and skill expectations required of DSPs and their low wages. Nearly half of direct support workers in the U.S. rely on public benefits. Others often work two to three jobs to support themselves and their families. Wages need to be increased. This, combined with other work related stressors, lead to DSP turnover which results in ineffective and inconsistent support for people with IDD.

Limited Training, Career Path and Credentialing Opportunities

The DSP role is complex because it is about supporting each individual in a person centered way within their unique context. The workforce must have the knowledge, skills, and ethical compass to perform a wide array of tasks that support people with intellectual and developmental disabilities be healthy, safe, valued, and participating members of their communities. To achieve this, it is important that DSPs receive sufficient, high-quality training and opportunities for paid professional development on an ongoing basis.

No federal minimum training requirements exist for DSPs. Career pathways that provide DSPs an opportunity to increase competency and professionalism are a recommended strategy to improve retention of the workforce and quality of support. The National Alliance for Direct Support Professionals (NADSP) and the Centers for Medicare and Medicaid Services (CMS) have identified nationally validated competencies for DSPs that recognize the knowledge, skills, and abilities need by DSPs to effectively support individuals with disabilities in the community. Several national organizations offer credential programs for DSPs who support people with IDD in varied roles. Despite the identification of required competencies, related credentialing and guidance^[1] from Medicaid about how to build training into HCBS reimbursement rates^[2], use of established competencies to set workforce development and training standards is not widespread.

Direct Support Professional (DSP) Workforce , continued

Ineffective Supervision and Organizational Support

DSPs are faced with fulfilling an increasing number of responsibilities in more autonomous situations. This will require that they be provided the professional development opportunities and have the support they need to ensure they are competent to provide support and be successful in their work. The supervision they receive is frequently inconsistent and ineffective. This can result from frontline supervision being the default career ladder for DSPs, often achieved without the requisite preparation necessary to succeed. It is important that supervisors are competent in critical skills to being an effective supervisor in long term services and supports for people with disabilities.

DSPs must be supported to effectively understand and utilize person-centered approaches designed to increase community inclusion for people with intellectual and developmental disabilities. Often systems and organizations promote these concepts but do not shift their organizational culture and practices to align with them. These changes may include increased use of technologies, flexible staffing patterns, and providing DSPs with the education and resources they need to make connections and build capacity within the community.

Position

Evidence-based practice must be widely implemented to increase the ability of individuals, families, and employers to recruit, retain, and ensure the competence of DSPs to improve the quality of life and outcomes of supports provided to people with IDD. A comprehensive approach to address the need to build capacity within the direct support workforce, which should include the following:

- Allocate federal and state funding at levels sufficient to provide living wages and the benefits necessary to attract and retain qualified DSPs in home and community based services.
- Provide credentialing opportunities, career pathways, and ongoing competency-based training and mentoring, embedded in public policy and sufficiently funded to create incentives for DSP participation.
- Ensure frontline supervisors are adequately trained and support to effectively recruit, retain, and support DSPs.
- Implement and evaluate the use of technologies as a universally-designed option for support while

simultaneously providing relief to the increased demand for support and support workers.

- Ensure DSPs have opportunities for needed training, mentoring, and professional development to effectively assist people with IDD to be fully included, valued, and participating members of their communities.

Adopted:

Board of Directors,
American Association on Intellectual and Developmental Disabilities
May 18, 2016

Board of Directors,
National Alliance of Direct Support Professionals
May 12, 2016

[1] Robbins, E., Dilla, B., Sedlezky, L., Sirek, A.J. (2013). *Coverage of Direct Service Workforce Continuing Education and Training within Medicaid Policy and Rate Setting: A Toolkit for State Medicaid Agencies*. The Lewin Group. <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/workforce/downloads/dsw-training-rates-toolkit.pdf>

[2] Centers for Medicare and Medicaid Services (2015). *Questions and Answers: Administrative Claiming Related to Training and Registry Costs*. <https://www.medicaid.gov/medicaid-chip-program-information/by-topics/financing-and-reimbursement/downloads/qa-training-registry-costs-071015.pdf>

Diversity and Inclusion

Position Statement of AAIDD, 2017

The core mission and principles of the AAIDD include the promotion and assurance of full human rights for persons with intellectual and developmental disabilities, the provision of accommodations needed to expand full participation in all aspects of life, and actions to enhance positive attitudes and public awareness of the contributions of people with intellectual and developmental disabilities.

In their joint position statement on Civil and Human Rights, AAIDD and the Arc of the US hold 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 holds that these fundamental civil and human rights are important to all people with disabilities and, indeed, to all people. Moreover, we recognize that the civil and human rights for people with intellectual and developmental disabilities are inherently connected to a society’s respect for diversity and the civil and human rights for all of its people. People with disabilities, along with groups marginalized according to race, ethnicity, sexual orientation, and linguistic, cultural and religious backgrounds are too often subject to negative attitudes, stereotypes, discrimination and violence.

We recognize that our advocacy for full human rights of people with intellectual and developmental disabilities and increased recognition of their contributions to our communities and societies must go hand in hand with honoring the same rights and contributions of diverse people of all racial and cultural backgrounds. There cannot be one without the other, for people with intellectual and developmental disabilities are represented in every racial, cultural, ethnic, and religious group in this country and around the world.

We are fully committed to our vision of a future where individuals and communities include and respect both difference and sameness, strengths and weaknesses, and the gifts of all who yearn for an equal and just society. We affirm the importance of recognizing our oneness as human beings amid diversity and condemn hatred and violence toward any individual or group who appears to be different. In every community, we support, celebrate and call for all Americans to uphold these truths and to remember who we are as “one nation, under God, with liberty and justice for all.” People with intellectual and developmental disabilities, their families, and friends have important gifts to bring to this common task. As professionals, we commit ourselves to joining and supporting them and others in this challenge and opportunity.

Adopted:

AAIDD Board of Directors
September 13, 2017

Early Intervention

Joint Position Statement of AAIDD and The Arc, 2013

Statement

All young children who are at-risk for or who have been identified with intellectual and developmental disabilities (IDD)* should have access to high-quality, affordable developmental services in natural environments. These services should build on the strengths of the child and family, address their needs, be responsive to their culture and personal priorities, and be delivered through research-based practices.

Issue

Access to and quality of intensive intervention for children with developmental delays and disabilities remains inadequate, despite a validated knowledge-base that establishes its critical importance. Early intervention services are inconsistent at the state and local level. Often such services are neither appropriate, nor well-timed, nor sufficient in intensity and quality to promote positive development or to prevent secondary conditions. Many children at risk for developmental disabilities due to environmental and/or biological factors are not identified in a timely fashion. Major barriers include inadequate funding and service systems which do not accommodate the needs of families.

Position

Early childhood services must be strengthened at the national, state, and local level. Screening and early identification must be readily available in the community and widely publicized through awareness campaigns and local child-find initiatives. Early childhood services should enhance the overall well-being and development of children who have or are “at risk” for developmental disabilities. Early childhood services should also provide family support that:

- Responds to families’ strengths and needs;
- Is delivered in a family-centered way;
- Improves family quality of life; and
- Assists family members in carrying out appropriate therapeutic practices in the home.

Children with, or at risk for, developmental disabilities must be identified and served as early as possible. Clear evidence has established that:

- Earlier is typically better when providing early childhood services and supports; and
- Providing services to children who are at-risk for developmental delay is a sound developmental and fiscal investment.

Measurable, cost-effective, and sound intervention will advance the development of children and support their health, well-being, and community participation. Substantial research and successful experience have established that early childhood services should:

- Be delivered in natural settings and, to the maximum extent possible, with same-aged peers who do not have disabilities; and
- Maximize opportunities for children to experience family, school, and community participation.

Families are the constant in children’s lives, and the primary source of lifelong support and early learning. Families should be supported in making informed decisions and in partnering effectively with professionals to achieve positive outcomes. Research and practical experience have established that:

- Families must have full access to the best available research, family wisdom and professional expertise to enable them to make informed decisions;
- Family partnerships with professionals which are based on mutual respect and trust are effective and contribute to family quality of life outcomes; and
- Children who are either in foster care or adoptive homes must be particularly targeted for screening for at-risk issues.

Children and families must have access to a system of evidence-based services which is:

Community-based and coordinated;

- Responsive to individual and cultural differences;
- Provided by supportive and skilled personnel;
- Directed towards:
 - seamless transitions between early intervention and public education;
 - community inclusion; and
 - measurable benefits for children and their families.

Research and successful practical experience have established that:

- When early childhood services are provided in natural environments, both children and families will experience increased community inclusion during early childhood and across the life span;
- State-of-the-art service coordination will enhance the access of children and families to support and services from multiple agencies and community resources; and
- Ongoing monitoring and evaluation of services will ensure measurable outcomes, equity and effectiveness.

Diversity and Inclusion, continued

The Arc of the United States and the American Association on Intellectual and Developmental Disabilities supports universal access to high quality, research-based, family-centered early childhood services for all children, between birth and five years at risk for development.

Adopted:

Board of Directors, AAIDD
August 18, 2008

Board of Directors, The Arc of the United States
August 4, 2008

Congress of Delegates, The Arc of the United States
November 8, 2008

Reviewed and extended without revision, 2013

*

Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as “The DD Act,” are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

The acronym “IDD” is used to describe a group that includes either people with both ID *and* another DD or a group that includes people with ID *or* another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

Education

Joint Position Statement of AAIDD and The Arc, 2018

Statement

All children and youth with intellectual and/or developmental disabilities (IDD)^[i] must receive a free appropriate public education that includes fair evaluation, ambitious goals, challenging objectives, the right to progress, individualized supports and services, high quality instruction, and access to the general education curriculum in age-appropriate inclusive settings. These are essential for achieving the nation's four policy goals of equality of opportunity, full participation, independent living, and economic self-sufficiency (the four policy goals). Parents and families must be supported as essential partners in the education and transition to adult life of their sons and daughters.

Issue

People with IDD continue to face numerous barriers in their education. Lifelong education is essential for all individuals with IDD to achieve the four policy goals of the Individuals with Disabilities Education Act (IDEA) and to pursue opportunities for rich lives and contribute to the public good. "Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities." (IDEA, Individuals with Disabilities Education Act).

Many students with IDD remain segregated in self-contained classrooms or separate schools, with few or no opportunities for academic achievement or social engagement in inclusive settings. Students with IDD frequently do not have appropriately ambitious^[ii] and personalized goals, challenging objectives, high quality instruction, individualized transition planning, and related services and supports necessary to engage as full members of their school learning communities. Consequently, many students with IDD leave school unprepared for further education, employment, and independent living in the community.

Many schools have policies and practices that push youth with IDD out of school and into the juvenile justice system (known as the "school to prison pipeline"). Further, many of those in detention facilities with qualifying disabilities are not provided special education and related services.

Many parents, families, and students themselves are excluded from systemic participation as essential partners in

the evaluation of the student's strengths and limitations, as well as the development and implementation of their Individualized Education Programs (IEPs).

Administrators, educators, and support staff too often lack sufficient training and knowledge about the legal rights, learning needs, and abilities of these students. School districts struggle to identify, recruit, and retain qualified special education personnel. Paraprofessionals providing support in inclusive classrooms are often poorly paid and do not always receive or seek professional development relevant to students' learning needs.

Outdated, inaccurate beliefs about students with IDD persist, leading to low expectations, segregated classrooms, inappropriate disciplinary practices, and diminished accountability for these students. In some communities, an unexamined sole focus on student performance has led to an erroneous conclusion that students with IDD are "bringing down" test scores and are to blame when schools and school systems do not achieve adequate progress.

Position

To ensure students with IDD receive the education to which they are legally entitled, all those involved in the education of these students must work to fully implement our nation's civil rights and education laws and accomplish the following actions.

All Means All: Zero Reject

- Assure timely evaluation, identification, and provision of education and related services to all students with IDD, incorporating all aspects of the students' diversity, including age, gender, ethnicity, culture, language, socio-economic circumstances, sexual orientation, and family environment.
- Disciplinary actions (suspension, expulsion, segregation) and alternate placements should not exclude the student from access to appropriate education and related services.

Non-Discriminatory and Comprehensive Eligibility Evaluations and Appropriate Assessments

- Assure that the needs of the individual are considered fairly and comprehensively, including cognitive, emotional, functional, and developmental needs, as well as all areas of suspected disability and mental health needs.

Education , continued

- Assure that multiple assessments, including those that identify a student’s strengths and abilities, are used and that IQ is not the sole measure of human functioning, nor does IQ alone determine placement or access to the general curriculum.
- Exercise clinical judgment that is built upon respect for the person and emerges from specialized training and experience in IDD, specific knowledge of the person and his/her environments, extensive data, and use of critical thinking skills.
- Assure that any predictions about a student’s potential learning are evidence-based and founded in high expectations for further education, employment, and independent living.
- Assure that all educators implement appropriately ambitious goals and challenging objectives and use measurements of progress that are aligned to the unique ways that students with IDD learn. Develop adaptations for assessment and grading, when necessary, that accurately capture the strengths and limitations of students with IDD.

High Expectations and Free Appropriate Public Education (FAPE)

- Develop and implement IEPs with high expectations that include appropriately ambitious personalized goals and challenging objectives and that build on a student’s strengths; meet the student’s learning, employment, and independent living needs; and offer related services and supplementary services necessary and likely, based on evidence, to ensure the student will make progress toward achieving the nation’s four policy goals.
- Ensure that all students have access to the general education curriculum. General education includes the academic curriculum, extracurricular activities, and other school activities.
- Incorporate evidence-based, peer-reviewed instructional strategies and interventions, provided by professionally qualified teachers, related services personnel, and other staff, all of whom receive the training, preparation, and supports they need to be effective professionals.
- Ensure that a range of appropriate technology options are made available in a timely and culturally and linguistically appropriate manner to all students who could benefit from them, and that the necessary training for use of the technology is provided immediately and consistently.

Autonomy, Self-Determination, and Decision-Making Supports

- Incorporate and support the development of autonomy, self-determination, self-advocacy, and leadership skills

throughout students’ educational experiences, including meaningful participation in the student’s IEP.

- Assure that school policy and semi-annual in-service training emphasizes autonomy, self-determination, and decision-making supports, and that teachers and other non-lawyers do not give families legal advice related to guardianship.

Inclusion and the Least Restrictive Environment (LRE)

- To the maximum extent appropriate, every student has a right to be educated in their inclusive neighborhood school and in the general education curriculum in that school. Any exception should be rare and considered only when education in the general education classroom cannot be satisfactorily achieved. Each student has a right to the related services, supplementary aids and services, accommodations, and modifications needed to learn alongside students without disabilities.
- Assure that the student is integrated in academic and social aspects of the general curriculum.
- Include an explicit written plan to achieve more integration in both academic and social aspects of the general curriculum when the student is currently in a restricted setting.
- Foster the development of peer relationships and membership in the school community to create a receptive, welcoming atmosphere, including extracurricular activities and school trips.
- Avoid the long-term costs of segregating students with IDD, including the reduced opportunities for learning, employment, independent living, and social engagement.
- Ensure that all teachers and related services personnel are trained, prepared, and supported to teach and support students effectively in the general education curriculum and in inclusive settings.

Safe and Supportive Education Environments

- Ensure safe school environments that provide mental health supports and protection against bullying.
- Ensure that all students with IDD have effective culturally and linguistically appropriate communication systems and technology that reduces the need to use behavior to communicate and maximize educational engagement.
- Assure development and ongoing use of school-wide and system-wide intervention models, including school-wide positive behavioral supports and using the principles of universal design for learning (UDL) in designing curricula, materials, instruction, and assessments to create maximum access to learning environments for students with diverse abilities and learning styles.

Education , continued

- Avoid harsh policies and procedures, such as “zero tolerance”, that lead to exclusion, injury, loss of education, or involvement with the criminal justice system by implementing school-wide positive behavior support that includes students with disabilities to prevent or eliminate such situations. Assure appropriate evaluations and IEPs, and avoid the criminalization of behaviors that are the manifestation of the student’s disabilities.
- Prohibit the use of mechanical or chemical restraint, isolation, or aversives. Emergency, time-limited, monitored restraint may be used only by trained personnel and only when the student's behavior presents an imminent danger of serious physical harm to the student or others and less restrictive interventions are insufficient to mitigate the imminent danger of serious physical harm. Physical restraint which restricts airflow, including prone restraint, and mechanical restraint must be prohibited.
- Ensure that supports and strategies are planned and implemented to successfully reintegrate a student who has been restrained or secluded back into the school or classroom environment.
- Assure that students are not disciplined for the manifestation of their disabilities.
- Assure safe school transportation for all students with disabilities, provided by trained and monitored drivers with background checks, in order to avoid abuse and maltreatment of students. Schools must assure the sufficient allocation of transportation resources such that transportation is not used to justify early departures, late arrivals, or excessive travel times.

School Choice

- Charter schools and private schools that accept public funds through a voucher or voucher-like system must comply with IDEA, the Americans with Disabilities Act (ADA), and Section 504 of the Rehabilitation Act (Section 504). Specifically, they must provide zero reject and free appropriate public education in the least restrictive environment, including nondiscriminatory evaluation, individualized appropriate education plan, access to the general curriculum (academic, extracurricular, and other school activities), procedural safeguards, and parent participation.
- Ensure that school choice efforts do not diminish the resources and effectiveness of public school systems in which they operate.

Family and Student Participation

- Ensure the meaningful participation of students, families, and their chosen advisors in the evaluation of

students and the design and monitoring of the students’ IEPs.

- Assure that parents with special needs, including those with disabilities or language or cultural differences, receive the information, supports, services, and full ADA/504 rights to effectively exercise their rights to partner in the education of their children.
- Expeditiously connect students and families with information, resources, and training that help them understand and exercise their rights under the IDEA, Section 504, the ADA, Family Educational Rights and Privacy Act (FERPA), and the Every Student Succeeds Act (ESSA).
- Assure that school personnel provide timely explanations that are understandable and use functional descriptive language for special education and related services being proposed for the student.

Lifelong Education, Transition, and Post-Secondary Education

- Provide early intervention and preschool services to infants, toddlers, and preschool-age children with disabilities alongside their typical peers and provide transition planning for children to ensure access to the general education curriculum and full integration in neighborhood schools as they move to kindergarten or first grade.
- Develop and implement transition plans based on student strengths, preferences, and interests to facilitate each student’s successful movement from school to adult life, including postsecondary and vocational education, competitive integrated employment, independent living, and community participation.
- Develop an individualized postsecondary and/or pre-employment program, including choices and creative career exploration through apprenticeships and internships, in coordination with IDEA and the Workforce Innovation and Opportunity Act (WIOA).
- Ensure that all students receive meaningful evidence of their school achievements including diplomas.

System Capacity Development, Funding, Oversight, and Accountability

- Assure that the training, preparation, compensation, supports, and accountability systems needed to build a cadre of effective professional teachers, other education personnel such as school principals, related services personnel, paraprofessionals, and other staff are evidence-based and effective to meet the child’s specific needs.
- Assure a cadre of effective lay and legal advocates to assist families and individuals to exercise their rights.

Education , continued

- Increase active monitoring and enforcement through local, state, and federal agencies to ensure that the IDEA, ADA, Section 504, and state special education laws and mandates are met.
- Fulfill the federal commitment to fully fund the IDEA.
- Ensure that all students with disabilities, including those with the most significant cognitive disabilities, continue to be included in public school, district, and state level accountability systems. Ensure that states are not allowed to exempt more than 1% of students (that is, exempt only those students that the state determines have the most significant cognitive disabilities up to 1%) from their general accountability data.

- Adopted:

Board of Directors, American Association on Intellectual and Developmental Disabilities
February 14, 2018

Board of Directors, The Arc of the United States
April 22, 2018

Chapters of The Arc
November 9, 2018

The acronym “IDD” is used to describe a group that includes either people with both ID *and* another DD or a group that includes people with ID *or* another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

[\[ii\]](#) In March 2017, the U.S. Supreme Court issued a unanimous decision in *Endrew F. v. Douglas County School District RE-1* clarifying the test for determining whether school districts have met their obligation to provide a free appropriate public education (FAPE) to students with disabilities guaranteed by the Individuals with Disabilities Education Act. The Court ruled that a child’s educational program must be “appropriately ambitious in light of his circumstances,” a more demanding standard than the “merely more than de minimis” test applied by the Tenth Circuit.

[\[i\]](#)

Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as “The DD Act,” are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

Electric Shock

Position Statement of AAIDD, 2019

The American Association on Intellectual and Developmental Disabilities (AAIDD) condemns the use of contingent electric shock and calls for the immediate elimination and permanent discontinuation of the use of electric shock as an intervention for the behavior of people with intellectual and developmental disabilities (IDD).

This position is supported by international organizations focused on human rights. In April 2010, when asked if the use of electric shock with students with disabilities constituted torture, the United Nations (UN) Special Rapporteur on Torture said, "Yes . . . I have no doubts about it. It is inflicted in a situation where the victim is powerless." In March 2013, a report of the UN Special Rapporteur on Torture determined that the use of electric shock as an intervention for the behavior of students with disabilities violates the UN Convention Against Torture and other international standards and called for it to be discontinued.

AAIDD supports the United States Food and Drug Administration's intent to ban the use of electric skin shock devices "because they present an unreasonable and substantial risk to public health" and further agrees that "state-of-the-art behavioral treatments, such as positive behavioral support, and medications can enable health care providers to find alternative approaches for curbing self-injurious or aggressive behaviors" (FDA News Release, April 2016).

Aversive procedures, such as electric shock, may cause some or all of the following:

- Physical pain;
- Physical injury, tissue damage, physical illness, stress or trauma, and even death;
- Dehumanization and/or humiliation through physical, verbal, social or other means; and/or
- Temporary or permanent psychological or emotional harm.

Use of aversive procedures can also have serious negative effects on family members, individuals who provide supports to individuals with (IDD) and others who witness these events.

AAIDD promotes positive behavior support (PBS) as the most appropriate and effective way to support people with IDD who exhibit challenging behavior. Positive behavior support is a set of research-based strategies to increase an individual's quality of life and decrease challenging behavior. This is accomplished by teaching the person new skills and making changes in their environment that facilitate

success. PBS begins with the individual and those who are important to them identifying and addressing the function of their behavior. Careful attention is given to identifying the person's strengths, building social and communication skills, and making changes to the situations and settings in which challenging behavior occurs.

People with IDD, including people with the most significantly challenging behavior, deserve respectful, humane support which increases self-determination and recognizes the fundamental human dignity of all persons. Contingent electric shock and other forms of aversives are never appropriate, ethical, or justifiable. AAIDD condemns their use in the strongest possible terms.

Adopted:

Board of Directors, AAIDD
February 5, 2019.

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Employment

Joint Position Statement of AAIDD and The Arc, 2017

Statement

People with intellectual and developmental disabilities (IDD)* can be employed in the community alongside people without disabilities and earn competitive wages. They should be supported to make informed choices about their work and careers and have the resources to seek, obtain, and be successful in community employment.

Issue

Historically, the majority of people with IDD have been either unemployed or underemployed despite their ability, desire, and willingness to work in the community. Many have been placed in “prevocational” programs and “disability-only” workshops where they are paid below minimum wage and have little expectation of moving into jobs where they work alongside people without disabilities.

People often leave school with little community-based vocational experience or planning for transition from school to work or post-secondary education. Adult service agencies have struggled to move people into the workforce using personnel who often do not have proper training in best practices for either finding or supporting people in jobs. When employed, few people have opportunities to advance, explore new possibilities, or, in their later years, retire.

Barriers to employment include, first and foremost, low societal expectations that foster job discrimination. In addition, unrealistically low limits on assets and earnings make people fear losing vital public benefits if they work too many hours or earn too much. Systemically, public resources fund service hours rather than outcomes and are often neither sufficient nor flexible enough to allow collaboration and blending of employment funding streams. Lack of other services like transportation or of accommodations like assistive technology can also hinder success.

Position

People with IDD should have the supports necessary from individuals and systems to enable them to find and keep community jobs based on their preferences, interests, and strengths, work alongside people without disabilities, receive comparable wages, and be free from workplace discrimination. Requirements related to employment include:

- Opportunities for post-secondary education, including college and vocational training, to gain knowledge and skills to allow people to get better jobs.

- Ongoing planning to promote job advancement and career development.
- Fair and reasonable wages and benefits.
- Opportunities for self-employment and business ownership.
- Opportunities to work with and, in the case of people with IDD who own small businesses, employ people without disabilities.
- The ability to explore new directions over time and, at the appropriate time, retire.
- Opportunities to work and increase earnings and assets without losing eligibility for needed public benefits.

Best Practices

- Employment supports and services should use best practices, including assessing skills and interests, working with employers, matching jobs to skill sets and employer needs, providing individualized and ongoing job supports, designing reasonable job accommodations, integrating people into the workforce, building social skills necessary in the workplace, and securing necessary ancillary services such as transportation.
- People with IDD must have training and information on how to access supports needed to find and keep jobs.

School-to-Work Transition

- Transition planning should start early.
- Transition activities should foster individualized exploration of and experiences with community-based employment options that enable youth to make informed choices.
- Transition activities should include career assessments to identify students’ interests and preferences, exposure to post-secondary education and career opportunities, training to develop job-seeking and workplace skills, and participation in multiple on-the-job activities and experiences in paid and unpaid settings. Transition activities should not be limited to unpaid internships at pre-set community worksites.
- Students should leave high school with opportunities to

Employment , continued

pursue post-secondary education and/or with an appropriate job or an action plan for finding one.

Training of Staff and People with IDD

Staff of employment and school-to-work transition programs must receive training in best practices to help people find and keep jobs.

Along with ensuring appropriate on-the-job training, people with IDD should receive guidance, if needed, in acquiring the social skills necessary in the workplace.

- People with IDD must have training, including, if desired, driver's education, to allow them to travel in the community so they can get to jobs and enhance their independence.

Systems

For all people with IDD, publicly funded employment programs should first explore employment alongside people without disabilities at comparable wages, with comparable benefits, before considering other options in the community. Ancillary services like transportation and accommodations like assistive technology must be available to individuals and support agencies. Public policy should encourage employers to hire people with IDD.

Publicly funded employment programs should also:

- Be available to all people with IDD who wish to explore opportunities to work, regardless of the nature and extent of their disabilities.
- Enable people to make informed choices by providing individualized exploration of and experiences with community-based employment and by presenting all information needed to make informed choices in an understandable way.
- Provide sufficient resources to support people to work in the community and be flexible enough to foster collaboration and braiding of employment-related funds.
- Build infrastructure and supports needed to phase out the issuance of subminimum wage certificates, increase opportunities for competitive integrated employment, and put in place safeguards to protect the interests of any people affected by this shift.
- Measure and publicly report on outcomes on an ongoing basis.

Board of Directors, AAIDD
September 19, 2012

Board of Directors, The Arc
July 29, 2012

Congress of Delegates, The Arc
October 27, 2012

Reviewed and extended without revision, 2017

[i]

Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as "The DD Act," are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

The acronym "IDD" is used to describe a group that includes either people with both ID *and* another DD or a group that includes people with ID *or* another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

[ii] In March 2017, the U.S. Supreme Court issued a unanimous decision in *Endrew F. v. Douglas County School District RE-1* clarifying the test for determining whether school districts have met their obligation to provide a free appropriate public education (FAPE) to students with disabilities guaranteed by the Individuals with Disabilities Education Act. The Court ruled that a child's educational program must be "appropriately ambitious in light of his circumstances," a more demanding standard than the "merely more than de minimis" test applied by the Tenth Circuit.

Environmental Health

Position Statement of AAIDD, 2020

People with intellectual and developmental disabilities have the right to live, work, learn, worship, and play in environments that are healthy and safe.

Issue

Environmental health focuses on “all the physical, chemical, and biological factors external to a person, and all the related factors impacting behavior. It encompasses the assessment and control of those environmental factors that can potentially affect health. It is targeted towards preventing disease and creating health-supportive environments” [1]. Environmental exposures to chemicals play a key role in human growth and development, the maintenance of health, and the development of disability and disease [2,3,4]. The health impacts of contaminated homes, workplaces, and communities pose a greater risk for the developing fetus, children, and people who already have compromising health issues and are faced with health disparities. These individuals experience unique vulnerabilities. This includes individuals living with an intellectual or developmental disability. Advocacy around environmental health involves working to reduce the environmental hazards that contribute to intellectual and developmental disabilities and minimizing further risks to health for persons living with intellectual and developmental disabilities. The precautionary principle calls for “producers or manufacturers of products to demonstrate safety prior to potential exposure or to use the least harmful chemicals available” [5,6]. Research into links between environmental chemicals, development, and other environmental factors (e.g., genetics, nutrition, pharmaceuticals, and stress) is needed. Studies should also address the cumulative effects of ongoing exposures or chemicals that are stored in the body over time and their effect on development of individuals living with intellectual or developmental disability [6]. Policy decisions should be based on sound evidence when available and the precautionary principle when evidence is not yet available.

Position

Numerous pollutants in the environment, including contaminants such as lead, mercury, pesticides, carbon monoxide, radon, polychlorinated biphenyls (PCBs), brominated flame retardants, plastic monomers (bisphenol A), plastic additives (phthalates), solvents, and combustion-related air pollutants (polycyclic aromatic hydrocarbons, nitrogen dioxide, and fine particulate matter) can affect brain and nervous system development and function and contribute to adverse health outcomes and health disparities [2,5,7,8].

With regard to environmental health, our constituents must:

- Have the right to live in homes that are healthy and safe and do not increase risks to health.
- Have the right to safe and healthy food, air, and water.
- Have the right to a safe workplace that is free from recognized safety and health hazards [9].
- Have the right to work in settings that are in compliance with OSHA standards.
- Have the right to be informed of known workplace hazards and to be provided with training and equipment to minimize risks to health.
- Have the right to live, learn, worship, and play in communities that are healthy and safe and do not exacerbate health conditions.
- Have the same degree of protection as other citizens from environmental health hazards and equal access to the decision-making process to have a healthy environment in which to live, learn, and work.
- Have the right to be supported by organizations, agencies, and staff who are knowledgeable about the effects of environment on health and how to minimize risks.
- Have the right to be protected in community-based residential settings by regulations that incorporate standards for safe and healthy environments.
- Have the right and responsibility to be educated and empowered with knowledge about risks to health from the environment and to make decisions to decrease exposure.

With regard to developing fetus and children:

- Have the right to develop in an environment that is free from contaminants that can result in intellectual and developmental disabilities and environmental health challenges later in life.

Adopted by the AAIDD Board of Directors on July 11, 2012, and as revised and amended on April 8, 2020

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Environmental Health, continued

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9. U.S. Department of Labor, Occupational Safety & Health Administration. Worker rights under The OSH [Occupational Health and Safety] Act, 1970. <http://www.osha.gov/workers.html>

Facilitated Communication and Rapid Prompting Method

Position Statement of the AAIDD Board of Directors, 2019

The Board of Directors of the American Association on Intellectual and Developmental Disabilities (AAIDD) strongly endorses the right of people with intellectual and related developmental disabilities to self-determination and recognizes that having an independent mode of communication is essential for individual agency (e.g., taking actions, making choices, expressing preferences).

Based on the current scientific evidence, the Board does not support the use of Facilitated Communication (FC)¹ or the Rapid Prompting Method (RPM)² as modes of communication for people with disabilities. In the case of FC, there is no scientific evidence supporting its validity, and there is considerable evidence that the messages are authored by the facilitator rather than by the individual with a disability. In the case of RPM, there is a lack of scientific evidence for its validity, and concerns about message authorship similar to those for FC have been raised.

The Board of Directors concludes that rather than helping people express their thoughts, desires, and choices, FC and RPM have the potential to effectively take away people's voices. This is due to the risk of facilitator influence/authorship as well as the potential to displace efforts to access scientifically valid communication modes, such as those associated with the field of Augmentative and Alternative Communication (AAC)³.

¹ Facilitated Communication (FC) is a technique that involves a person with a disability pointing to letters, pictures, or objects on a keyboard or on a communication board, typically with physical support from a facilitator. This physical support usually occurs on the hand, wrist, elbow, or shoulder (Biklen, Winston Morton, Gold, Berrigan, & Swaminathan, 1992).

² Rapid Prompting Method (RPM) is a technique that involves a person with a disability pointing to letters from multiple choice options with the aid of sensory "prompts" which are intended to maintain attention on the task and extinguish sensory-motor preoccupations (Chen, Yoder, Ganzel, Goodwin, & Belmonte, 2012). RPM requires an instructor to elicit responses through intensive verbal, auditory, visual and/or tactile prompts to compete with the individual's self-stimulatory behavior (Learning RPM – Frequent Questions, n.d.).

³ Augmentative and Alternative Communication (AAC) is a set of tools and strategies used to solve every day communicative challenges (What is ACC?, n.d.). An AAC aid is

any device, either electronic or non-electronic, that is used to transmit or receive messages (Beukelman & Mirenda, 2005); aids range from communication boards to speech generating devices (Mirenda, 2003).

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Adopted:

Board of Directors, AAIDD
January 9, 2019

Family Support

Joint Position Statement of AAIDD and The Arc, 2020

Statement

Family support services* and other means of supporting families across the lifespan should be available to all families to strengthen their capacities to support family members with intellectual and developmental disabilities (IDD**) in achieving equal opportunity, independent living, full participation, and economic self-sufficiency. Family caregivers include, but are not limited to, parents (including those with IDD themselves), adoptive parents, foster parents, siblings, uncles, aunts, cousins, grandparents, grandchildren, and individuals who are in spousal-equivalent relationships.

Issue

The vast majority of people with IDD live in the family home and families are overwhelmingly the primary source of support for their family member with IDD. Changing demographics are resulting in even greater demands on these family caregivers. The aging baby boom generation of caregivers has unique need for family support, such as assistance in developing desired in-home support plans or transition plans to community living for their family member with IDD when they are no longer able to continue in their caregiving role. In addition, an increasing number of persons with IDD are becoming parents and may require more support navigating service systems for their own children.

State IDD service systems are increasingly being built around the expectation that adults with IDD will reside in the family home. This is not consistent with other national policies for vulnerable populations. Nor is it consistent with the vision of self-determination.

Unfortunately, the increasing reliance on families is not being met with commensurate support. A generation ago, families were discouraged from keeping their family members with IDD at home and encouraged to use costly publicly financed institutional placements. Today, they face the other extreme where they are expected to be willing and able to provide lifelong support to their family member with IDD in place of appropriate community supports, even in cases when residing in the family home may not be a good option for adults with IDD or the family caregivers.

There is no comprehensive family support system in the U.S. Instead, the vast majority of publicly provided family support services are funded through Medicaid home and community-based services (HCBS) waivers and some states provide limited family support using state general fund dollars. Consequently, beneficiaries of family support experience the same portability and mobility limitations as those receiving

other Medicaid HCBS. This affects families (including military families) who either have to relocate to another state and begin the application and waiting process anew or who have to forfeit personal or career opportunities in other states.

Relatively small proportions of federal and state funding for persons with IDD are committed to family support, despite increasing numbers of people with IDD living with family for longer periods. Consequently, though family support is often critical for avoiding more segregated placements in costly and inappropriate institutions for the family member with IDD, the needed supports are frequently insufficient or unavailable.

Position

Comprehensive, universally accessible family support must be provided in order to strengthen families socially, emotionally, physically, and financially. It must:

- Strengthen the caregiving efforts of families, with special emphasis on their emotional and physical health, financial and material needs, and parenting and family interaction;
- Enhance the quality of life of all family members, and increase their access to supports and services for themselves and their members with IDD;
- Create and provide meaningful support to parents with IDD designed to ensure maximum opportunity for family wellness and cohesion;
- Enable families to make informed choices regarding the nature of community supports for themselves and their members with disabilities, including the use of supported decision making for family members with IDD;
- Help families with minor members to stay intact, preventing any type of out-of-home placements for a minor child, particularly institutions or congregate settings;
- Ensure that all employed caregivers have access to comprehensive paid leave, including job protection and sufficient wage replacement;
- Provide information, resources, and support to families of people transitioning from institutional placements to community homes;
- Provide support for families navigating systems of care,

Family Support, continued

including early intervention, education, mental/behavioral health, and other systems;

- Provide information and support for siblings to better prepare them to be advocates and caregivers; and
- Ensure aging caregivers are able to provide care for their loved one as long as necessary and appropriate while honoring self-determination.

Policies of family support and public and private systems for supporting families must:

- Recognize that relying on families to provide lifelong care cannot be a substitute for creating a national solution to provide appropriate long term supports and services;
- Be addressed in conjunction with the HCBS waiting list and direct support professional (DSP) crisis for family members with IDD;
- Be prioritized for when the need is most acute, such as when caregivers first receive a disability diagnosis for their child; during service system transitions or personal crises; and at the end of life;
- Be provided in a manner that builds on the family's strengths;
- Be provided in ways that are sensitive to the family's cultural and linguistic backgrounds, immigration status, values, religion, LGBTQ+, and socio-economic status;
- Assist the individual and family to maximize self-determination of the individual with IDD;
- Assist parents with IDD in being self-determined in creating supports around their family;
- Be controlled, determined, and directed by the family itself, in partnership with those who provide the service;
- Be provided through best practices and state-of-the-art methods;
- Be available to all families regardless of whether the person with IDD resides in the family home or is presently receiving publicly funded services;
- Provide options for family members to be compensated for their time providing essential supports at home.

These choices should be available throughout the lifetime of a person with IDD and subject to change as the person's and family needs or wants change; and

- Be defined as a comprehensive system of policies, practices, and procedures for supporting families, and not just "family support" programs sponsored by a government or private-sector entity.

Adopted:

Board of Directors, AAIDD
February 12, 2020

Board of Directors, The Arc of the United States
pending

* Traditionally, government-sponsored family support has consisted of: 1) Cash assistance from federal, state, and local governmental sources that is provided: a) Over and above any other federal cash benefit or medical, educational, or welfare benefit programs (including those under any title of the Social Security Act, Individuals with Disabilities Education Act, and Developmental Disabilities Assistance and Bill of Rights Act); b) Because of the disability of a family member ; and c) To the family as the primary beneficiary of the family support program; 2) Information and emotional and instrumental support provided by: a) Professionals, including those in generic (non-disability)-and disability specializing professions and entities; b) Friends or members of the individual's family; and c) Entities that support families or parents, including parent-to-parent and community-based family resource centers, or 3) Any combination of the above. Specific examples of family support services are respite, counseling, cash assistance, training, support groups, minor home modifications, and information and referral.

**

Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as "The DD Act," are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

Growth Attenuation

Position Statement of the Board of Directors of AAIDD, 2020

Unjustifiable Non-therapy: There is not objective evidence in support of growth attenuation therapy* for young people with disabilities, as first described by Gunther & Diekema (2006). A statement from the Board of Directors of the American Association on Intellectual and Developmental Disabilities.

The Board of Directors for the American Association on Intellectual and Developmental Disabilities, the oldest multidisciplinary association in the United States representing professionals within the field of intellectual and developmental disabilities (IDD), has a strong interest in seeking and promoting effective, evidence-based approaches to support people with IDD. This organization does not consider growth attenuation therapy as one of those appropriate supports.

Background

In 2006, Gunther and Diekema¹ published a description of an intervention they termed “growth attenuation therapy” in which a six year old girl with profound and multiple disabilities received hormone therapy, a hysterectomy, and bilateral mastectomy with the goal of keeping her stature and physical features undeveloped by halting growth prior to reaching her full adult size. They stated that they found it “hard to imagine how being smaller would be disadvantageous to a person whose mental capacity will always remain that of a young child” (p. 1016). In stating that there will be no significant future improvement from her baseline, Gunther and Diekema revealed that they and their colleagues recognized little potential for growth and development of this young child. The abundant evidence that all children are able to learn and that the cognitive capabilities of children with severe motor impairments can be grossly underestimated were not mentioned, nor were issues of bias and discrimination considered.

Families, often the primary support providers, may face extraordinary challenges raising their children and may seek this intervention out of fear not being able to continue support their loved one at home. They fear that as their children with significant and complex

support needs grows, their physical care, transportation, and other personal support needs become more than the family can manage. These families look to medical professionals who have an obligation to “do no harm” to ensure that the risks of clinical interventions are outweighed by the anticipated benefits. To our knowledge, there have been no studies tracking intervention outcomes (e.g., medical complications, perceived individual and family wellbeing, impacts to the medical providers, or any other long-term effects). We do know, however, that high doses of estrogen and progesterone can increase risk of complications such as thrombosis² (blood clots). Further, surgical interventions such as hysterectomies and removal of breast buds introduce unnecessary risk inherently associated with surgery. Despite such concerns, this protocol has reportedly continued³ though it is controversial⁴ and not supported by evidence documenting either short- or long-term benefits on physical, social, or emotional wellbeing.

A legal investigation found that the surgical intervention described was not adequately considered by appropriate ethical review boards and was in direct violation of the laws of the State of Washington as court protections for the child, including the need for a court order for this extreme intervention, had not been pursued.⁵ Reports of hospital ethics committee reviews have not included full developmental evaluations or disability rights specialists. This is concerning and suggests that the ethics review committee did not fully consider the disability rights perspective on these issues, including a meaningful review of the child’s current and potential capacities as well as the longer-term impacts on outcomes, including social and community participation and quality of life.

Position

The AAIDD board issued an initial statement in 2007 strongly disagreeing with Gunther and Diekema’s clinical intervention because of both ethical concerns (e.g., lack of respect for her autonomy) and the lack of any evidence in support of the intervention or any positive impact on long-term outcomes. An updated statement from the AAIDD board in 2012 reiterated opposition to this intervention based on lack of evidence, the ethical challenges which continued to

Growth Attenuation, continued

exist, and the foundational premise of autonomy for the people with IDD. This current position statement was developed after a review of existing and available evidence, as well as social and ethical arguments. It concludes that the use of growth attenuation therapy remains an inappropriate application of a medical intervention to address societal problems related to a lack of effective systems of support for people with IDD who have extensive support needs as well as ongoing biases and discrimination directed towards people with complex support needs. A lack of available support (real or perceived) cannot be used to justify interventions for which there is no objective evidence for an improved quality of life for the person with IDD in the short- or long-term.

As individuals and as an organization, we endorse policies and actions that help families to rear their children with intellectual and other developmental disabilities at home, accessing meaningful systems of supports that build children’s capacities while addressing support needs. We applaud the efforts of the many families and support professionals who are engaged in providing extraordinary care to children with extensive support needs and who continue to meet those needs throughout their adult lives. We also recognize the many challenges faced by physicians as they weigh with families the benefits versus costs of various treatment options and struggle with the complex ethical concerns that can arise.

We believe it is impossible for medical professionals to support this intervention as treatment effects have not been adequately documented. It is therefore unacceptable to use an unproven, invasive, and permanent intervention under the simple assertion that it will be effective and will not lead to unintended negative consequences to the person and the family over time.

Based on the discussion above, the AAIDD Board of Directors does not support the use of growth attenuation “therapy.” We view Gunther and Diekema’s intervention as an unacceptable option that does not constitute evidence-based medicine but is a medical “solution” for a societal problem. Recognizing the intense and immediate needs of families who might seek this clinical intervention, the Board supports policy initiatives that more fully address the home,

community and educational support needs of children with IDD that enable families and young people with IDD to be empowered and have access to systems of supports that are evidence-based and promote physical, social, and emotional wellbeing.

Adopted:
AAIDD Board of Directors
June 10, 2020

*While we assert that this is not a supported intervention or therapy, the term growth attenuation therapy is used as it is consistent with what is described in other writings.

¹Gunther, D., & Diekema, D. (2006). Attenuating growth in children with profound developmental disability: A new approach to an old dilemma. *Archives of Pediatrics and Adolescent Medicine*, 160, 1013–1017.

²Parasuraman, S., & Goldhaber, S. (2006) Venous Thromboembolism in Children. *Circulation*, 113 (2), e12-e16.

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⁴Field, G. (2016) Should parents of severely disabled parents be allowed to stop their growth? *New York Times Magazine*. March 27, 2016. <https://www.nytimes.com/2016/03/27/magazine/should-parents-of-severely-disabled-children-be-allowed-to-stop-their-growth.html> (retrieved March 30, 2020)

⁵Washington Protection and Advocacy System (2007) <https://dredf.org/public-policy/ethics/investigative-report-regarding-the-ashley-treatment/> (Retrieved March 30, 2020)

Guidelines to Professional Conduct

Position Statement of AAIDD, 2020

Preamble

The American Association on Intellectual and Developmental Disabilities is a professional organization that advances the knowledge and skills of individuals in the field of intellectual disability and related developmental disabilities; strives to enhance the life opportunities of people with intellectual disability and their families; and promotes public policies, research, and services that advance individual choices and human rights. The Association has developed guidelines for professional conduct that offer a set of values, principles, and standards to guide practice.

Guidelines

1. The professional fosters effective communication first and foremost with the individual, using all possible alternative means of communication to ascertain their unique needs, values, and choices.
2. The professional objectively honors, respects, and upholds the unique needs, values, and choices expressed by the individual being served.
3. The professional communicates fully and honestly in the performance of their responsibilities and provides sufficient information to enable individuals being supported and others to make their own informed decisions to the best of their ability.
4. The professional protects the dignity, privacy, and confidentiality of individuals being supported and makes full disclosure about any limitations on their ability to guarantee full confidentiality.
5. The professional is alert to situations that may cause a conflict of interest or have the appearance of a conflict. When a real or potential conflict of interest arises, the practitioner not only acts in the best interest of individuals being supported, but also provides full disclosure.
6. The professional seeks to prevent, and promptly responds to, signs of abuse and exploitation whether it is physical, mental, sexual, or financial in nature.
7. The professional engages neither in a dual relationship in which there is a professional and a personal relationship with the individual nor conduct that is abusive/exploitive in a physical, mental, sexual, or financial manner.
8. The professional assumes responsibility and accountability for personal competence in evidence-based practice and professional standards of his/her respective field, continually striving to increase professional knowledge and skills and to apply them in practice.
9. The professional exercises professional judgment within the limits of their qualifications and collaborates with others, seeks counsel, or makes referrals as appropriate.
10. The professional fulfills commitments in good faith and in a timely manner.
11. The professional conducts his/her practice with honesty, integrity, and fairness.
12. The professional provides services in a culturally competent manner and does not discriminate against individuals on the basis of race, ethnicity, religion, sex, age, sexual orientation, gender identity, national origin, or disability.
13. The professional is diligent in being knowledgeable regarding changes and emerging trends in guiding philosophies within the field (e.g., self-determination, self-advocacy, inclusion), and ensures that his/her professional practices remain compatible.
14. The professional strives to use and educate others to use preferred terminology and people-first language, rather than perpetuate the use of outdated and offensive terms.
15. The professional maintains currency in research findings for evidenced-based practices and, when applicable, applies those findings to practice and where needed, advocates for inclusion of people with intellectual disability in the discussion of the application of such findings.

Adopted by the AAIDD Board of Directors on July 11, 2012, and as revised and amended on January 29, 2020.

Health, Mental Health, Vision, and Dental Care

Joint Position Statement of AAIDD and The Arc, 2012

Statement

All people, including people with intellectual and developmental disabilities (IDD)*, should have timely access to high quality, comprehensive, accessible, affordable, appropriate health care that meets their individual needs, maximizes health, well-being and function, and increases independence and community participation.

The health care system must be aligned to principles of nondiscrimination, comprehensiveness, continuity, appropriateness, and equity. Both comprehensive public and private health insurance must provide for necessary health care without regard to the nature or severity of disability, pre-existing conditions, or other health status.

Issue

Health can be understood broadly as a state of complete physical, mental, and social well-being, not merely the absence of disease or disability. The term “health care” encompasses physical, mental, behavioral, vision, hearing, oral and dental health care, substance abuse and addiction services, and services and supports that assist in attaining, maintaining, and improving skills, function, and community participation.

The current health care system is fragmented and does not provide uniform access to a comprehensive array of health services and supports.

While many people encounter difficulty in finding affordable, high quality health care, people with IDD face additional barriers, sometimes life-threatening, when attempting to access timely, appropriate health services in their communities. These barriers include:

- *Access* - Underinvestment in public health and wellness targeted to people with IDD results in preventable health care disparities and poorer health outcomes. Inadequate training, lack of coordinated care, and inadequate levels of reimbursement are some of the factors that create programmatic barriers while inaccessible clinical settings and diagnostic and medical equipment, along with translation and interpretation challenges, create physical barriers.
- *Discrimination* - Health care providers sometimes provide inadequate or inappropriate interventions and treatments or deny appropriate care for people with IDD because of professional ignorance as well as personal

and/or societal bias. State statutory liability damage limits discriminate against people with severe and/or life-long disabilities because they fail to provide sufficient compensation.

- *Affordability* - People with IDD are more likely to live in poverty and cannot afford cost-sharing. For cost containment purposes, many public and private health care plans limit access to specialists and critical services. Even when services are available in a community, many people with IDD lack adequate public or private insurance to pay for them.
- *Communication and personal decision making* - People with IDD may have difficulties communicating their needs and making health care decisions without support. Their decisions may not be respected and implemented by health care providers and, where applicable, surrogate decision makers**. People have not been ensured access to all necessary supports and information required to understand a health care decision and communicate their choices.

Position

Important elements of this Health Position Statement include timely access, nondiscrimination, affordability, and communication and personal decision-making, including surrogate decision-making. These elements are described more fully below:

Access

- Wellness, prevention, health promotion, and a robust public health infrastructure are essential components of health care.
- Health care providers for persons with IDD must meet the highest standards of quality, including a comprehensive approach to treatment, disease prevention, and health maintenance.
- People with IDD deserve access to health care providers who have received specialized training to understand and respond to their needs. This access should be provided in the community.
- People with IDD need access to effective strategies to manage their care including care coordination, referral processes, transition assistance, and health promotion efforts.

Health, Mental Health, Vision, and Dental Care, continued

- Data collection and the assessment of health outcomes must include disability status. Public health initiatives must support the goal of reducing health care disparities for people with disabilities and improving health and function.
- The health care system must be fully accessible with respect to facilities and equipment, as well as communication needs and related accommodations such as sufficient time, explanations, translators, and interpreters when necessary.

Nondiscrimination

- People with IDD must not experience disability-related discrimination in decisions to provide, delay, deny, or limit health care interventions or treatments. Protections must be in place to assure that an individual's health and well-being are the only justifiable basis for making medical decisions.
- A person with a disability should have an equal opportunity to receive life sustaining treatments including cancer therapy and transplantation. Physician assisted suicide is never acceptable.
- Health plans must cover treatment for mental illness on the same terms and conditions as all other medical diagnoses.
- Providers of health care services for persons with IDD must follow practices regarding health information and records consistent with the guarantees of confidentiality contained in the Health Insurance Portability and Accountability Act (HIPAA).
- Treatments for persons with IDD that are proposed primarily for the convenience of the caregiver (such as medical procedures that interfere with typical growth and development) must be denied.

Affordability

- People with IDD should have universal access to comprehensive, affordable, quality health care.
- Efforts to contain health care costs should not create obstacles to care for people with IDD by making needed services or treatments unaffordable or otherwise unavailable. The medical need for care must be determined on an individualized basis.
- Payment methodologies for health services provided to

people with IDD should compensate for the true cost of providing those services. This includes the costs of treating more complex health needs, and the greater amounts of time often required to understand and respond to those needs. Payment methodologies should not create disincentives to the provision of timely and appropriate services to persons with IDD.

Communication and Personal Decision-Making

In all matters of health, individuals with IDD have basic rights that must be protected, including the right to information and appropriate accommodations to assure informed consent*** that allows an individual, or under appropriate legal conditions, a guardian, a health care power of attorney, or a surrogate decision-maker of the individual's choice to accept or refuse health-related services based on:

- Sufficient information to understand the risks, demands, potential for significant pain, and benefits of any procedure for which consent is sought provided in ways that accommodate reading, language, learning, and other limitations that are common among persons with IDD;
- Opportunities to ask questions and receive answers about the proposed treatment in understandable and understood language;
- Full disclosure that declining treatment may affect access to other treatments or services that the person is receiving or might otherwise receive;
- Protection from coercion or deceit to accept or decline a particular treatment;
- Reasonable efforts when a guardian, health care power of attorney, or surrogate decision-maker is involved to monitor, honor, and accommodate indications of "implied assent" to treatment; and
- Having specific expressed desires regarding the use of life-sustaining treatments communicated in written or oral form and recorded in an advance directive**** by individuals with I/DD, as appropriate to their understanding of the nature, implications, and reversibility of their decision. Advance directives of people with I/DD should be honored.

Surrogate Decision-Making

Individuals may temporarily or permanently lack the capacity to make some or all health care decisions. This lack of capacity may not be global and the individual should always be assisted

Health, Mental Health, Vision, and Dental Care, continued

in making those decisions which they can and in participating in all other decisions as much as they are able. When an individual has been determined to lack capacity to make health care decisions and does not have an advance directive such as a "Living Will," or a health care power of attorney, a surrogate decision-maker should be identified to make these decisions, whenever possible before a crisis arises. People who have such authority under state laws include the parent of a minor child, the guardian/conservator of an incapacitated adult, or surrogate decision-makers designated under a health care consent law.

All decision-making by a surrogate decision-maker should be consistent with the principles expressed in the sections above regarding health care and informed consent. Surrogate decision-makers must follow the expressed wishes of the individual. When the individual's wishes are not knowable, the surrogate must follow the person's probable wishes, taking into account the person's known values, and, as a fall back, act in the person's best interests. In decisions involving the refusal of medical treatments, or nutrition and hydration, when such refusal will result in the death of the individual, the legal authority of the surrogate decision-maker should be limited to those situations in which all three of the following conditions exist: (1) the person's condition is terminal, (2) death is imminent, and (3) any continuation or provision of treatment, nutrition and/or hydration would only serve to prolong dying. However, in such situations, people with IDD must be provided appropriate palliative care, including medical treatment to relieve pain, sustenance as medically indicated, and care designed to relieve isolation, fear, and physical discomfort.

Adopted:

Board of Directors, AAIDD
February 20, 2013

Board of Directors, The Arc
July 29, 2012

Congress of Delegates, The Arc
October 27, 2012

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****Surrogate decision-maker:** a person who makes health care decisions for a person who is unable to make decisions about personal health care. A surrogate decision maker may be an appointed agent under a durable power of attorney for health care or a court-appointed guardian with authority to make health care decisions. If there is no appointed surrogate, normal custom and practice, as well as the law in most states, permits health care practitioners to turn to next of kin as default surrogate decision makers. A growing number of states also authorize a close friend to act as default surrogate. All surrogates have an obligation to follow the expressed wishes of the adult person. If the individual's wishes are not known, the surrogate must follow the person's probable wishes, taking into account the person's known values, and as a fall back to act in the person's best interests. (Charlie Sabatino and Erica Wood, Commission on Law and Aging, American Bar Association. Presentation at the National Aging and Law Conference, December 2010.

*****Informed consent** has three elements: capacity of the consent-giver, information supplied to the consent-giver, and voluntary action by the consent-giver.

******Advance directive:** Written advance directives include living wills and the durable power of attorney for health care. Living wills enable individuals to describe the treatment they would like to receive in the event that decision-making capacity is lost. The latter enables a patient to appoint a surrogate to make decisions if the patient becomes unable to do so (Ethics Manual, American College of Physicians, 2012.)

Housing

Joint Position Statement of AAIDD and The Arc, 2012

Statement

People with intellectual and developmental disabilities (IDD) *, like all Americans, have a right to live in their own homes, in the community. Children and youth belong with families. Adults should control where and with whom they live, including having opportunities to rent or buy their own homes, and must have the freedom to choose their daily routines and activities.

Issue

People with IDD face a housing crisis with many contributing factors, such as a serious lack of safe, affordable, accessible and integrated housing, and significant housing-related discrimination. Outmoded public policy and programs which unnecessarily segregate people with IDD, as well as lack of coordination among funding systems, also pose major barriers.

Historically, families with a child with a disability had to either place their child in an institution, or manage without any supports or services at home. Institutions create an isolated, unnatural way of life that is inappropriate and unnecessary, while consuming a disproportionate share of limited public resources. As people with IDD have left institutions or their family homes, they frequently have been placed in group homes, often larger than family-sized, typically owned or leased by provider agencies. People in those settings may have little control over where and with whom they live, the services they receive, or the routines of daily life.

The recognition that people with IDD belong in the community has led to a growing demand for community-based housing. This demand is fueled by persons choosing to leave institutional settings, by young adults educated in inclusive schools, and by adults with IDD who live with elderly parents.

However, people with IDD are among the nation's poorest citizens. For many, Social Security and Supplemental Security Income benefits, which are often far lower than typical rents, are their primary or sole source of income; beneficiaries are generally priced out of rental markets across the country.

Affordable housing programs are drastically underfunded, with long waiting lists. In addition, Medicaid, the principal source of funding for services and supports for people with IDD, typically does not allow funds to be used for rent or other community-based housing-related costs.

These factors pose major barriers to community living, making it difficult for people to move from segregated facilities into the community, and putting many people with IDD at risk of unnecessary institutionalization or homelessness.

Position

People with IDD have the right to live in safe, accessible, affordable housing in the community.

- People must have freedom, authority, and support to exercise control over their housing, including choice of where and with whom they live, privacy within their homes, access to flexible supports and services when and where they choose, choice in their daily routines and activities, freedom to come and go as they please, and housing that reflects their personal preferences and styles. Providers should honor individual choices and preferences.
- Housing should afford people with IDD the opportunity to interact with people without disabilities to the fullest extent possible.
- The health and safety of people with IDD must be safeguarded wherever they live, but should always be balanced with the right to take risks and exercise choice and control.
- To ensure that people with IDD can make informed decisions about where and with whom they live, they and their families must be given understandable information about the benefits of living in the community, have the chance to visit or have other experiences in community settings, have opportunities to meet other people with disabilities who are living in the community, and have any questions or concerns addressed.
- All children and youth need a home with a family that provides an atmosphere of love, security, and safety.
- Adults with IDD should receive the supports they need to transition out of the family home when they wish to do so.
- Housing for people with IDD must be coordinated with home and community-based support systems, including transportation services, and should ensure access to other typical public resources.

Housing, continued

- There must be adequate funding of services to support people to live in the community. Funding must be stable and not subject to arbitrary limits or cuts. People with IDD must not be subjected to unnecessary institutionalization or removal from their homes and communities due to state budget cuts.
- Public policy should promote small, typical living situations for people with IDD. Information about innovative housing models that promote independence should be widely disseminated.
- Housing for people with disabilities should be scattered within typical neighborhoods and communities, and should reflect the natural proportion of people with disabilities in the general population.
- Public funds must be shifted from restrictive institutional settings to community supports. Institutional settings and large congregate living arrangements are unnecessary and inappropriate for people with IDD, regardless of type or severity of disability.
- Affordable housing options must be available to people with IDD, including those with very low incomes. Affordable housing programs must be expanded and funded to eliminate long waiting lists. Public policies must ensure that people with IDD receive their fair share of all local, state, and national housing resources.
- Universal design and visitability** standards should be adopted for all new housing. New and significantly renovated multifamily housing should include fully accessible units in numbers that reflect the natural proportion of people with disabilities in the general population.
- People with IDD have the right to be free from housing discrimination, and there must be robust education, outreach, and enforcement of that right. People with I/DD must have opportunities comparable to those of people without disabilities to rent or buy their own homes.

Adopted:

Board of Directors, AAIDD
September 19, 2012

Board of Directors, The Arc
July 29, 2012

Congress of Delegates, The Arc
October 27, 2012

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**Universal design means buildings, products and environments that are inherently accessible to both people with and without disabilities. Visitability is a set of construction standards through which housing offers a few specific accessibility features making it possible for people with disabilities to visit friends, family and neighbors.

Human and Civil Rights

Joint Position Statement of AAIDD and The Arc, 2015

Statement

The human and civil rights of all people with intellectual and developmental disabilities (IDD)* must be honored, protected, communicated, enforced and thus be central to all advocacy on their behalf.

Issue

Today, as throughout history, the human and civil rights of people with IDD have been unjustifiably limited or denied based on a lack of understanding of their humanity. These rights include the right to autonomy, dignity, family, justice, life, liberty, equality, self-determination, community participation, property, health, well-being, access to voting, freedom from unwarranted and unjustifiably extensive guardianship, equality of opportunity and other rights recognized by law or international declarations, conventions, or standards.

Though freedom from discrimination is a basic human right accepted as part of the fundamental law of the land, advancing the human and civil rights of people with IDD presents particular challenges.

Many individuals, businesses, federal, state, and local government agencies and other entities remain unaware of or ignore the human and civil rights of people with IDD. As a result, people with IDD face unique challenges, including the following:

- A history of discrimination and exclusion from meaningful choice and participation in employment, housing, voting, transportation, and other programs, activities, and services provided by the public and private sectors of society;
- Social and cultural attitudes of devaluation and fear; Unfounded beliefs that people with intellectual and/or developmental disabilities cannot and/or do not contribute to society;
- Societal failure to provide the supports wanted and needed for full community participation, equal opportunity, independent living, and economic self sufficiency;

- Overprotection without freedom to exercise individual rights;
- Under-payment for labor and services and denial of the means of economic self-sufficiency;
- Forced impoverishment;
- Prejudice that views people with IDD as unworthy of progressive public policies and related public funding; and
- The presence of other factors that, in combination with IDD, expose them to increased risk of rights violations. These factors include: age; gender; race/ethnicity; sexual orientation; cultural, linguistic, geographic, or spiritual diversity; economic status; severity of disability; intensity of needed supports; and others.

Position

All people with IDD are entitled to human and civil rights. Given that all people with IDD 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.

These rights 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. 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.

Human and Civil Rights, continued

Adopted:

Board of Directors, AAIDD
September 21, 2009

Board of Directors, The Arc of the United States
October 29, 2009

Congress of Delegates, The Arc of the United States
November 14, 2009

Reviewed and extended without revision, 2015

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Inclusion

Joint Position Statement of AAIDD and The Arc, 2015

Statement

All people with intellectual and developmental disabilities (IDD)* benefit when fully included in community life.

Issue

Individuals with IDD often are not treated equally. They have been labeled by their disability and separated from the community. For many years they were relegated to sterile, dehumanizing institutions. Even as they have begun living in the community, they have experienced exclusion from its schools, jobs, and social life. Moreover, the services they receive frequently segregate, isolate, and focus on an individual's deficits rather than their strengths and lifestyle choices.

Position

All people benefit when persons with iDD are included in community life. People with disabilities should be welcomed and included in all aspects of our society. This includes public activities, programs and settings, and private establishments which are open and accessible to members of the general public. People with disabilities should receive the supports they need to participate actively in community life without having to wait.

Children should have the opportunity to:

- Live in a family home;
- Have access to the supports that they need;
- Grow up enjoying nurturing adult relationships both inside and outside a family home;
- Enjoy typical childhood relationships and friendships; Learn in their neighborhood school in a general education classroom that contains children of the same age without disabilities;
- Participate in the same activities as children without disabilities;

- Play and participate with all children in community recreation; and
- Participate fully in the religious observances, practices, events, and ceremonies of the family's choice.

Adults should have the opportunity to:

- Have relationships of their own choosing with individuals in the community, in addition to paid staff and/or immediate family;
- Live in a home where and with whom they choose;
- Have access to the supports that they need;
- Engage in meaningful work in an inclusive setting;
- Enjoy the same recreation and other leisure activities that are available to the general public; and
- Participate fully in the religious observances, practices, events, and ceremonies of the individual's choice.

Adopted:

Board of Directors, AAIDD
September 21, 2009

Board of Directors, The Arc of the United States
October 29, 2009

Congress of Delegates, The Arc of the United States
November 14, 2009

Reviewed and extended without revision, 2015

Inclusion, continued

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Individual Supports

Joint Position Statement of AAIDD and The Arc, 2011

Statement

Individual supports, such as assistive technology and personal assistance, make it possible for all people with intellectual and developmental disabilities (IDD)* 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
August 18, 2008

Board of Directors, The Arc of the United States
August 4, 2008

Congress of Delegates, The Arc of the United States
November 8, 2008

Reviewed and extended without revision, 2011

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Long-term Supports and Services

Joint Position Statement of AAIDD and The Arc, 2020

Statement

All people with intellectual and developmental disabilities (IDD*) have the right to full lives in communities of their choosing where they can live, learn, work, and enjoy life. To achieve this, people with IDD need access to comprehensive, person-centered and self-directed high quality long term supports and services (LTSS). Robust, reliable, and immediately accessible funding sources that include Medicaid are needed. There must be a flexible public policy framework that emphasizes self-direction, is well-funded, responsive, and nimble, and is developed with—and not for—people with IDD. Waiting lists for home and community-based supports and services must be eliminated.

Issue

A variety of barriers to ensuring that people with IDD receive the LTSS required to live their fullest life in communities of their choice continue to exist. These include:

- Insufficient Medicaid funding;
- Institutional bias in the Medicaid program;
- Continued and worsening crisis of unmet need; and
- Persistent and worsening workforce crisis.

Insufficient Medicaid Funding

Medicaid has been the major funding source for all LTSS for people with IDD for decades. Medicaid is also under constant political threat, creating anxiety, confusion, and compromising the well-being of people with IDD and their families.

The persistent lack of a system of comprehensive community LTSS is a crisis requiring immediate solutions. Individuals and families are forced to navigate a patchwork of systems of supports and services that are complex and frequently uncoordinated; are limited and often diminishing in scope and relevance; and, are difficult to access and offer no clear path to assistance. Medicaid is means-tested, is not portable across state lines, differs—often dramatically—from state to state, and does not meet the demand for community-based LTSS for people with IDD of all ages.

Many individuals and families experience extraordinary hardships due to a lack of services and supports. Many

people with IDD are living at home with a caregiver of retirement age. Family caregivers play a critical role in providing uncompensated supports and services. Many family caregivers are forced to leave employment to provide services that their family member may need because that is their only option. Relying on families to provide support cannot be a substitute for creating a systemic solution to ensure that everyone with IDD who needs LTSS receives them.

Institutional Bias of Medicaid

Making choices and self-directing one's life with the assistance they may need should be an expectation for all people. However, most individuals with IDD are not given opportunities or supports to make and/or execute choices and decisions, or their choices have been ignored. It is important that self-direction includes the ability to select and dismiss the people who provide supports and services, and to have control over funding. Ensuring the system of LTSS is self-determined and person-centered and directed is critical to having a system of individualized supports for people with IDD. Too often decisions about supports and services are based on availability and cost, not on the person's choices made independently of the self-interests of the funder and/or service provider. Many people either accept supports and services that are available but inappropriate and/or inadequate, or receive no supports at all.

While most LTSS for people with IDD are community-based, a Medicaid institutional bias, based in the antiquated medical model of care, continues to exist. This means that institutional services (such as nursing homes) are mandatory under federal law, while community-based supports and services are optional. In addition, in many states, existing Medicaid services fall short of meeting the full needs of people with IDD, requiring continued advocacy to ensure ease of access to necessary, community-based services and supports.

To become or remain eligible for vital Medicaid-funded LTSS, most people seeking services are forced to impoverish themselves and remain poor for a lifetime. Program changes designed primarily to reduce costs rather than improve or expand supports and services are emerging in greater numbers of managed care state LTSS systems. This shift has, in a number of states, resulted in greater barriers to accessing LTSS.

Continuing and Worsening Crisis of Unmet Need

Long-Term Supports and Services, continued

People waiting for LTSS is unacceptable. Individuals with IDD remain on waiting lists for years—in some states for a decade or more—after requesting and being determined eligible for necessary supports and services. If ongoing supports and services are not available to young adults with IDD transitioning out of the education system, educational gains are lost, as are opportunities to launch careers and achieve independence.

People with disabilities often must experience the death of a parent, a medical emergency, or other tragic event to obtain the supports they need. They are thus thrust into a new situation without planning at a time of crisis.

As people with IDD continue to seek supports in their communities, access to affordable housing in safe neighborhoods has emerged as an urgent need. Because Medicaid eligibility for individuals with IDD often requires them to impoverish themselves, even generally available affordable housing programs are frequently inaccessible to them.

Direct Support Professional Workforce Crisis

The quality and effectiveness of LTSS for people with IDD depends upon qualified providers of supports and services with adequate skills and training. Inadequate compensation hampers both recruitment and retention of direct support professionals (DSP). Insufficient funding to support livable wages for DSPs, and for training of DSPs and their supervisors, negatively impacts the quality of supports available to people with IDD, as well as the success that individuals have in living the life they choose in the community.

POSITION

A comprehensive system of LTSS must include the following:

- An LTSS system that is sustainable and enables all eligible individuals to obtain LTSS whenever needed;
- A system that includes private and public funding mechanisms for LTSS, as a shared, societal responsibility;
- Elimination of the need for individuals or their families to impoverish themselves to receive supports and services;
- Services which are portable and allow people who move from one state or political jurisdiction to another to receive uninterrupted, self-directed supports;
- Medicaid as a viable funding option for individuals who need LTSS and have no or limited access to private insurance options;
- Medicaid buy-in options that are available in all states to allow people to preserve their eligibility for Medicaid-financed supports while encouraging careers, savings, and wealth-building;
- Medicaid programs that enable people to participate fully in their communities, experience a quality of life they define, and achieve economic security and personal independence;
- Medicaid funds that are controlled, to the fullest extent possible, by the person;
- Medicaid funding that is redirected from institutional care to person-centered home and community-based supports that are delivered in natural community environments;
- Improvements to Medicaid to ensure access to self-directed and determined LTSS, consistently deliver better outcomes for more people with IDD, and eliminate waiting; and
- Medicaid service delivery system redesign that is transparent and involves meaningful input of all stakeholders.

Self-Direction

Access to adequate and appropriate supports and services needed to live in the community is a basic human right. To achieve this:

- Individuals must design and direct their own services, to the fullest extent they wish and with the assistance they want;
- Services must be person-centered and based on the unique needs and desires of the individual, accompanied by measured progress toward person-centered outcomes to which the person aspires;
- Individuals with IDD who wish to employ DSPs must have access to timely and relevant information, technical assistance, and training;
- Services must be delivered promptly to meet individual needs and desires in the most integrated setting, with flexible funding to meet changing circumstances; and

Long-Term Supports and Services, continued

- Outcome measures, defined in substantial part by the person, and outcomes consistent with state-defined value based reimbursement systems should be used to measure the individual and systems outcomes of LTSS in every state.

Continuing and Worsening Crisis of Unmet Need

- Individuals who are eligible for and want LTSS should not have to wait to receive services;
- Public systems must actively reach out to individuals and to families with un- and under-met needs to make them aware of the process for obtaining LTSS and must maintain transparency until waiting is eliminated;
- People must receive crucial supports that assist them while they wait for comprehensive community supports and services; and
- Until waiting is eliminated, states must develop systems to prioritize delivery of services to individuals who are waiting for services on the waiting list to ensure that those experiencing emergencies (loss of caregiver, imminent threat of institutionalization) receive person-centered and self-directed supports and services immediately.

Direct Support Professionals Workforce Crisis

- System funding must provide for living wages and benefits to DSPs;
- Wages, benefits, and professional development opportunities remain consistently insufficient and must improve to attract and retain the workforce needed to fully support people living in the community;
- Competency-based training must be available to DSPs that covers the essential knowledge, ethical principles and practices, and skills necessary to provide direct support;
- National, state, and local private and public entities must engage in policy initiatives to recruit, train, and retain a high quality DSP workforce;
- Federal and state quality assurance programs must incentivize DSP retention and competence as part of licensure, in order to recognize positive performance and to direct assistance to those programs with unacceptable performance; and

- States must utilize a Nation-wide system for criminal and related background checks, including a system for tracking people for whom abuse, neglect, and exploitation charges have been substantiated, for all public and private DSPs working in the state.

Adopted:

Board of Directors, AAIDD
February 12, 2020

Board of Directors, The Arc of the United States
pending

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Opportunities for Financial Asset Building

Joint Position Statement of AAIDD and The Arc, 2016

Statement

People with intellectual and developmental disabilities (IDD) [1] 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

Issue

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.

When people use government benefits, certain income-based and/or asset-limit eligibility policies put some people at risk of being denied for and/or losing critical supports such as Medicaid, Supplemental Security Income, and Social Security benefits if they earn or save very modest sums of money. While some savings are allowed through certain self-settled trusts and the ABL Act which accommodate SSI and Medicaid means-testing rules, these plans do not address the needs of everyone. Thus many people with disabilities cannot plan and save for future needs like others, contributing to ongoing economic inequalities often resulting in lifelong poverty. Public policy should encourage rather than inhibit planning for financial independence, productivity, and self-determination.

In addition, families are the largest group of providers of physical, material, and emotional supports for people with IDD across the life course. Families incur increasing amounts of out-of-pocket expenses due, in part, to the decreasing federal funds contributing to family support services[2] in the states. Many families are restricted to a single income or underemployment due to the necessity to provide medical care or supports to their family member with I/DD. This greater reliance on family support requires families to explore and invest in a variety of financial security strategies to ensure opportunities for self-directed options and family quality of life.[3]

Position

Individuals 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.

These opportunities should include the following:

- Access to Individual Development Accounts (matched savings accounts similar to a 401(k)) that enable a person to save for education, home ownership, or one's own business and/or employment;
- Ensuring that government assistance programs allow people to retain reasonable portions of their income for daily living expenses, and permit savings. Access to low-cost, user-friendly approaches such as ABL accounts (savings accounts that enable eligible individuals to save for disability related expenses), for people with disabilities of all ages, for acquiring, maintaining, and expending assets while remaining eligible for publicly financed services and benefits;
- Equity with other savings programs, such as catch-up provisions and reasonable increases and limits on contributions and maximum contributions;
- Ensuring incentives in the tax code for charitable gifts and special needs trusts (a legal vehicle that manages funds for the benefit of a person who needs some assistance in daily living); and
- Ensuring that tax rates for wealth accumulation by people with disabilities (such as special needs trusts) are not excessive.

Policy reforms must allow people with IDD to have opportunities to earn money and invest in their futures without risking the health care, benefits, and supports and services necessary to live a full life in their community.

On a personal level, people with IDD and their families should have opportunities to learn how to manage their money and spend it wisely through such means as:

- Supports for full participation in financial planning and decision-making, including earnings, saving, budgeting, spending, investments, including tax-deferred investments like IRAs and 401(k)s, and estate planning;

Opportunities for Financial Asset Building, continued

- Financial literacy education throughout the school years and, particularly, contemporary practices in financial literacy curricula in high schools and other educational settings;
- Inclusive adult and higher education and consultation/coaching in communities;
- Access to free information in user-friendly print and electronic formats (similar to materials produced by the Consumer Financial Protection Bureau); and
- Training for human services support and professional staff, advocates, bank/credit union and investment personnel, government officials (from service coordinators to Internal Revenue Service (IRS) staff) in how best to help people enhance their assets.

Adopted:

American Association on Intellectual and Developmental Disabilities
Board of Directors
March 16, 2016

The Arc of the United States
Board of Directors
April 10, 2016

Chapters of The Arc
October 28, 2016

[1]

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period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

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[2] From The Arc and AAIDD position statement on Family Support: <http://www.thearc.org/who-we-are/position-statements/life-in-the-community/family-support>

[3] Braddock, D., Hemp, R., Rizzolo, M.C., Tanis, E.S., Haffer, L., & Wu, J. (2015). *The State of the States in Intellectual and Developmental Disabilities: Emerging from the Great Recession*. American Association on Intellectual and Developmental Disabilities.

Protection

Joint Position Statement of AAIDD and The Arc, 2015

Statement

People with intellectual and developmental disabilities (IDD)* must be free from abuse, neglect, or any kind of mistreatment.

Issue

Abuse, neglect, mistreatment, exploitation, and maltreatment (collectively, “mistreatment”) of people with intellectual and/or developmental disabilities is all too common. Mistreatment often occurs where people are isolated.

Individuals living outside the family home, regardless of the size or location of the residence, are vulnerable to mistreatment.

Some families lack knowledge or access to appropriate professional or informal supports and services that would help them care for their family members appropriately. A few may, as a result, mistreat their family members. Many more families lack the support they need to help them protect their members from mistreatment by others. When families believe mistreatment has occurred, they often do not have the support to ensure an effective investigation or forceful prosecution after the finding of probable cause.

Federal and state laws may in fact be insufficient for this purpose. Ineffective professional practices among child and adult protective service agencies may add to the problem. Emergency responders and other professionals such as police, emergency room, and protective service workers need to be educated as to how to assist people with IDD to be safe without violating their rights. Finally, IDD may not have received any, much less enough, training on how to protect themselves from or report mistreatment.

Position

Protection of all people with IDD from mistreatment is a core concept of public policy in the United States and an ethical obligation of anyone involved in their lives. The efforts to keep people safe from mistreatment should be balanced with the dignity of risk.

All people with IDD should receive training, in ways they can understand, on their rights to exercise their human and civil rights and to be free of mistreatment. They should also learn about the nature of mistreatment and its likely sources. They should know how to avoid it, report it to the appropriate authorities, and give credible proof that it has occurred.

Whenever children or adults with IDD are removed from their families’ homes to protect them from mistreatment, they should be placed in small homes, integrated into the community, and not in institutions. Putting people with IDD in segregated settings is not an effective way to keep them safe. One of the best protections people with IDD can have is a wide, involved network of contacts and relationships and a consistent visible presence in their community.

Children

The law and culture in our country presumes that the birth, adoptive, or foster family is the best source of protection from harm for a child. To assure that families can indeed protect their children, the following should be both available and easy to access:

- Family support systems, services, and funding;
- Groups that provide information, referral, and direct services to parents and other family members; and
- Advocacy, law enforcement, and judicial systems that ensure effective investigation and forceful prosecution of suspects.

If the family is unable to protect its child for any reason, then federal, state, and local child protection systems, services, and funding should be available, accessible, appropriate, affordable, and accountable to the child and, as appropriate, the family.

Whenever a federal, state, or local government agency acts to protect a child, it must do so in ways that are least intrusive into the child’s and family’s rights to privacy. These entities must protect children from abuse.

Adults

The best protection for an adult needing such assistance usually comes from the person’s family, community, and friends. However, when necessary, adult protective agencies or advocacy groups should also provide the needed services. As with children, the full force of the law should be applied to protect the individual from mistreatment. The law, as applied, should recognize the right of all adults to make and follow through on choices that do not put their own physical, emotional, mental, and financial well-being at great risk.

Protection, continued

Adopted:

Board of Directors, AAIDD
September 21, 2009

Board of Directors, The Arc of the United States
October 29, 2009

Congress of Delegates, The Arc of the United States
November 14, 2009

Reviewed and extended without revision, 2015

*

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Quality of Life

Joint Position Statement of AAIDD and The Arc, 2015

Statement

People with intellectual and developmental disabilities (IDD)* must be able to live the lives they choose and have a good quality of life.

Issue

People with IDD often do not have the services, supports and personal relationships they want and need to lead a full life in the community. They may encounter attitudinal, public policy, service system, and other barriers that keep them from choosing where they live and work. Moreover, they often lack opportunities to participate in and contribute to their communities.

Position

People with IDD must have the opportunity to lead lives that offer them a meaningful quality of life. A meaningful quality of life exists for them when they:

- Receive, at all stages of their lives, the support, encouragement, opportunity, and resources to explore and define how they want to live and who is in their lives;
- Choose the services and supports they need and receive them anywhere in the country without waiting for an uncertain and extended length of time;
- Direct the services and supports they receive;
- Lead a life enriched by friends and family and have opportunities for intimate relationships based on informed consent and responsibilities;
- Experience life-long learning and develop decision-making skills;
- Work in a job that is meaningful to them;
- Enjoy the same rights and respect for their dignity and privacy, as do people without disabilities;
- Are fully informed about options, understand the risks associated with the options, and are allowed to take risks inherent in the options they choose; and
- Receive support to live in a healthy and safe environment.

Policies, regulations and funding must promote these desired

outcomes. In addition, public agencies, private organizations, and individuals providing services and supports must:

- Be accountable and responsible to individuals and their families;
- Continuously improve their efforts to support individuals;
- Be recognized when they make major contributions to the quality of life of individuals;
- Be replaced when they fail to defend or protect the people they serve or fail to enhance the quality of their lives;
- Participate in ongoing monitoring that is independent of the service provider; and
- Ensure training that will lead to desired outcomes and the satisfaction of the people served and their families.

Adopted:

Board of Directors, AAIDD
September 21, 2009

Board of Directors, The Arc of the United States
October 29, 2009

Congress of Delegates, The Arc of the United States
November 14, 2009

Reviewed and extended without revision, 2015

*

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Research

Joint Position Statement of AAIDD and The Arc, 2015

Statement

Basic and applied research* on the causes, challenges and treatment of intellectual and developmental disabilities (IDD) **, as well as research on interventions and services which could improve the lives of people with IDD, 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 IDD and their families. Through basic and applied research, scientists and researchers can learn about causes of IDD, address its preventable causes, improve the quality of life of people with IDD 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 IDD 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 IDD and their families.

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

Position

To make applied and basic research related to IDD a national priority, the following must occur:

- Government and private entities must provide adequate funding to support research;
- Advocacy, service provider and professional organizations, government agencies, the research community, and people with IDD 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 IDD 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 IDD and members of their families; and
- For all basic and applied research involving persons with IDD:
 - 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 IDD unless there is reasonable likelihood that the treatment would address unique IDD medical issues or apply differentially to them; and
 - Persons with IDD 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 IDD 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

Reviewed and extended without revision, 2015

Research, continued

* 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.

**

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Self Determination

Joint Position Statement of AAIDD and The Arc, 2018

Statement

People with intellectual and developmental disabilities (IDD) * have the same right to, and responsibilities that accompany, self-determination as everyone else. They are entitled to opportunities, respectful support, and the authority to exert control in their lives, to direct their services, and to act on their own behalf.

Issue

Historically, many individuals with IDD have been denied their right to self-determination. They have not had the opportunity or the supports to make choices and decisions about important aspects of their lives. Instead, they have often been overprotected and involuntarily segregated, with others making decisions about key elements of their lives. For many, the absence of the dignity of risk and opportunities to make choices has impeded people with IDD from exercising their right of self-determination and has inhibited their ability to become contributing, valued, and respected members of their communities, living lives of their own choosing.

Position

People with IDD have the same right to self-determination as all people and are entitled to the freedom, authority, and supports to exercise control over their lives. People with IDD must understand that they can direct and influence circumstances that are important to them. This right to self-determination exists regardless of guardianship status.

Family members, friends, and other allies play a critical role in promoting self-determination by providing supports and working collaboratively to achieve the individual's goals. Families, friends, and other allies should understand, recognize, and promote the rights and responsibilities of self-determination and respect the limitations on their own authority. Service providers, educators, and substitute decision-makers must recognize and respect the individual's right to self-determination and the limitations on their authority.

To this end, people with IDD must be able:

In their personal lives to:

- lead in decision-making and problem-solving about all aspects of their lives and have the supports they want to make decisions;

- advocate for themselves with the assurance that their desires, interests, and preferences will be respected and honored;
- choose their own supporters, friends, and allies;
- direct their own supports and services and allocate available resources;
- hire, train, manage, and fire their own staff;
- acquire additional skills to assist in determining the course of their lives;
- use adaptive communications devices and other assistive technology; and
- take risks to achieve the lives they desire.
 - In their community lives to:
- participate fully and meaningfully in the community;
- receive the necessary supports and assistance to vote and exercise other rights as citizens;
- become valued members and leaders of the community;
- serve as active members and leaders of community boards, advisory councils, and other organizations;
- take leadership roles in setting the policy direction for the self-determination movement; and
- have representation and meaningful involvement in policy-making at the federal, state, and local levels.

Recognition of the right to self-determination must be a priority. The principles of self-determination and opportunities to promote self-determination must be incorporated into conferences, publications, advocacy, training, services, policies, and research in the IDD community.

Laws, regulations, policies, procedures, and funding systems should be regularly reviewed and revised to remove barriers and to promote self-determination. People with IDD must be involved in this process at all levels.

Self Determination, continued

Adopted:

Board of Directors, AAIDD February 14, 2018

Board of Directors The Arc of the United States
April 22, 2018

Chapters of The Arc , November 9, 2018

*

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Self-Advocacy and Leadership

Joint Position Statement of AAIDD and The Arc, 2020

Statement

People with intellectual and developmental disabilities (IDD*) have the right to advocate and/or be supported to act as self-advocates. Self-advocates exercise their rights as citizens by communicating for and representing themselves and others, with whatever supports they need. Self-advocates must have a meaningful role in decision-making in all areas of their daily lives and in public policy decisions that affect people with IDD.

Issue

People with IDD have been isolated and segregated from their communities, and presumed incompetent, resulting in loss and denial of basic human rights and discrimination in almost all areas of personal and community life. Through self-advocacy, people with IDD will have more impact on their own situations and on the public policies that affect them.

The self-advocacy movement has been critically important in supporting people with IDD to learn about self-advocacy skills and other topics, including:

- Civil rights, including the right to vote, the right to integrated services and supports, and self-determination;
- Self-confidence and development of leadership skills;
- Successful story-telling;
- Public speaking;
- Problem-solving techniques;
- Participation in group decision-making; and
- Involvement on boards and task forces and with policymakers at the local, state, and national level.

There are many ways for people with IDD to act as advocates, including individual self-advocacy for the individual services and supports that they or another person with IDD needs, as well as policy advocacy for the funding, services, and rights that impact people with IDD at the local, state, and national level.

Position

People with IDD must have the right to advocate for themselves and others. People with IDD have the right to speak or act on their own behalf and alongside other people with disabilities, whether the issue is individual or related to broader public policy. Recognizing these rights in a respectful partnership between people with and without disabilities can lead to better outcomes and better lives for everyone.

Self-advocates provide important knowledge, experience, and skills that individuals, organizations, and government agencies need in order to effectively support the needs of and enhance the lives of people with IDD. To promote this participation, it is critical to acknowledge the important role that self-advocates play in developing leadership skills and increasing people's pride, influence, and opportunities. To achieve this partnership between self-advocates and their support persons or organizations, the following must occur:

- People with IDD must have the power to make informed decisions about their own lives and the services they receive, including those who need support and those who have legally-appointed guardians.
- People with IDD have access to necessary accommodations and supports in order to meaningfully participate in meetings, conferences, task forces, boards, and other forums when issues and policies that are important to them are discussed ("Nothing about us without us" principle). These accommodations include but are not limited to:
 - Extra time planned for meetings to ensure the participation of each person;
 - Enhanced and alternative communication methods, such as communication devices, sign language, or interpreters;
 - Availability of technology supports and access through technology to ensure participation;
 - Materials provided ahead of the meeting for review;
 - Meeting materials written in plain language;

Self-Advocacy and Leadership, continued

- Support from direct support professionals, when needed; and
- Funding for transportation and travel-related costs, including support staff.
- When communicating with or about people with IDD, it is important to respect the way that people with disabilities prefer to be identified. In most circumstances, person-first language is most appropriate, e.g. person with IDD. However, some people with IDD prefer identity-first language, e.g. autistic person. In addition, people’s self-identified pronouns for gender identity must be respected.
- Policy development must include self-advocates and be regularly evaluated to ensure that self-advocates are actively and meaningfully participating.
- Families, advocacy organizations, service providers, and government agencies must work with self-advocates to increase public awareness of the importance of the self-advocacy movement.
- Self-advocacy organizations and individual self-advocates must be supported to develop and sustain the self-advocacy movement, including mentoring youth and young adults with IDD to become self-advocates.
- Foundations and federal, state, and local funding agencies must promote self-advocacy as a key matter of policy. These entities must provide enough money and resources to make sure that (1) people with IDD have accessible information, training, and education in self-advocacy, and (2) providers have the information they need to deliver person-centered services that address self-advocate-led trends in policy and design.
- Children and youth with IDD must be supported by families, schools, direct service providers, and other entities to learn self-advocacy skills and put these skills into practice. Children and youth with IDD should have opportunities to use advocacy skills in educational planning, including Individualized Education Programs (IEPs), transition plans, and all decision-making.
- Adults with IDD can be effectively supported by peers, self-advocates, families, direct service providers, and other entities to learn self-advocacy skills and put them into practice. In order to continually use these skills,

adults with IDD should have opportunities to use self-advocacy skills in service planning and daily decision-making.

- Self-advocates must be afforded the same dignity of risk that all people have to make informed decisions and learn from any mistakes that impact themselves and others in the community.
- Self-advocates must be included on boards and other advisory bodies for disability advocacy organizations, service providers, and agencies who serve people with IDD, as well as encouraged to meaningfully provide input on the policies, programs, and evaluation methods of those organizations and agencies.

Adopted:

Board of Directors, AAIDD
February 12, 2020

Board of Directors, The Arc of the United States
pending

*

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Sexuality

Joint Position Statement of AAIDD and The Arc, 2013

Statement

People with intellectual disabilities and developmental disabilities (IDD)*, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected.

Issue

For decades, people with IDD have been thought to be asexual, having no need for loving and fulfilling relationships with others. Individual rights to sexuality, which is essential to human health and well-being, have been denied. This loss has negatively affected people with intellectual disabilities in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior. People with IDD frequently lack access to appropriate sex education in schools and other settings. At the same time, some individuals may engage in sexual activity as a result of poor options, manipulation, loneliness or physical force rather than as an expression of their sexuality.

Position

Every person has the right to exercise choices regarding sexual expression and social relationships. The presence of IDD, regardless of severity, does not, in itself, justify loss of rights related to sexuality.

All people have the right within interpersonal relationships to:

- Develop friendships and emotional and sexual relationships where they can love and be loved, and begin and end a relationship as they choose;
- Dignity and respect; and
- Privacy, confidentiality, and freedom of association.
- With respect to sexuality, individuals have a right to: Sexual expression and education, reflective of their own cultural, religious and moral values and of social responsibility;
- Individualized education and information to encourage informed decision-making, including education about such issues as reproduction, marriage and family life,

abstinence, safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases; and

- Protection from sexual harassment and from physical, sexual, and emotional abuse.
 - With respect to sexuality, individuals have a responsibility to consider the values, rights, and feelings of others.

With respect to the potential for having and raising children, individuals with IDD have the right to:

- Education and information about having and raising children that is individualized to reflect each person's unique ability to understand;
- Make their own decisions related to having and raising children with supports as necessary;
- Make their own decisions related to using birth control methods within the context of their personal or religious beliefs;
- Have control over their own bodies; and
- Be protected from sterilization solely because of their disability.

Adopted:

Board of Directors, AAIDD
August 18, 2008

Board of Directors, The Arc of the United States
August 4, 2008

Congress of Delegates, The Arc of the United States
November 8, 2008

Reviewed and extended without revision, 2013

Sexuality, continued

*

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Spirituality

Joint Position Statement of AAIDD and The Arc, 2015

Statement

People with intellectual and developmental disabilities (IDD)* 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 IDD. Some individuals may need assistance to participate in their chosen spiritual activities or faith communities.

Individuals with IDD 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;
- Supports and programs should be age-appropriate and inclusive;
- Faith communities should be encouraged to build their capacity to support and welcome individuals with IDD 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 IDD and their families; and
- People with IDD 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

Reviewed and extended without revision, 2015

*

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Support Coordination

Joint Position Statement of AAIDD and The Arc, 2015

Statement

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 developmental disabilities (IDD)* and their families.

Issue

People with IDD 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 IDD 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;
- 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

Reviewed and extended without revision, 2015

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Transportation

Joint Position Statement of AAIDD and The Arc, 2020

Statement

People with intellectual and developmental disabilities (IDD)* must have access to both public and private transportation to lead full, self-directed lives.

Issue

People with IDD lack sufficient access to reliable, accessible, and safe modes of public and private transportation. Every mode of transportation, including air, water, road, rail, and even pedestrian transportation, presents barriers for individuals with IDD. These barriers prevent people with IDD from meaningful participation in everyday activities that promote high quality community living experiences. In the U.S., millions of individuals with disabilities use public transit to maintain their autonomy and participate fully in society. For many, it is their only transit option. However, even where accessible public transportation exists, adults with IDD consider transportation options inadequate.

Federal and state legislation encourages economic self-sufficiency for people with all types of disabilities, which requires transportation. Inadequate transportation inhibits community involvement, including successful employment. Where there is available transportation, there is often little to no training available to support individuals with IDD to make full use of it. For those providing the transportation, there is insufficient training to understand and meet their customers' needs, including cultural competencies. Those living in rural areas often face the greatest challenge of all due to lack of public transportation, limited private transportation options, and long distances between destinations.

Position

Transportation industries, agencies, service providers, and advocacy organizations must ensure that:

- Transportation at comparable cost and service models is available to individuals of all abilities.
- When making decisions, planning, and testing transportation options and payment methods, individuals with IDD are involved in the process.
- Improved coordination maximizes existing transportation services.
- Public transportation is adequately funded, fully

financially and physically accessible, reliable to meet people's needs, and equipped to suit the physical, sensory, and cognitive needs of all people.

- As technological innovations emerge (such as virtual wayfinding, autonomous vehicles, and digital ticketing), transportation modalities are designed to be accessible, usable, and reliable, including such things as language access, visual cues, safety considerations, and audio and hands-free options to meet individuals' needs and preferences.
- Technological platforms that relay information from users with IDD to transportation providers utilize inclusive research design to ensure accessibility and ease of use.
- Travel training is available for users covering all modes of travel, prioritizing peer-to-peer training where possible.
- Appropriate disability awareness training is available for service and transportation providers.
- As smart city initiatives advance, they are developed for users of all abilities and needs. Data collection and migration tools include users with IDD in the design, to ensure inclusive smart cities.
- The unique challenges and lack of options within suburban and rural areas are addressed.
- Technology and service providers protect a user's privacy by ensuring data such as contacts, camera, photos and files, health and disability status, and locations visited is not shared, or used for commercial or tracking purposes, without permission of the individual. For any information to be accessed or shared, customers must opt-in, versus opting-out, and have clear explanations of with whom and what will be shared. In light of data management, people with IDD must have the opportunity to receive training on self-directed data management and use.
- At the same time, transportation navigation software allows an individual to share appropriate information with a third party, to enhance efficiency and safety – for example, confirming arrival and indicating off-route warnings, as directed by users.
- Innovative vehicles and transportation options do not create additional barriers, based on where vehicles are parked, stored, and operated.

Transportation, continued

- People with IDD have the option of owning, modifying, and operating vehicles and other transportation options of their choice at affordable costs.
- All vehicles, public and privately owned, meet applicable federal, state, and local safety requirements.
- Autonomous Vehicles (AVs) are fully accessible and universally designed to take into account all individuals' abilities and disabilities to safely access and operate. Regulation of AVs must consider the needs of people with IDD and avoid unnecessary licensing requirements that would restrict or eliminate access.

Adopted:

Board of Directors, AAIDD
February 12, 2020

Board of Directors, The Arc of the United States
pending

*

Intellectual Disability (ID) is a lifelong condition where significant limitations in both intellectual functioning and adaptive behavior emerge during the developmental period (before adulthood).

Developmental Disabilities (DD), first defined in 1975 federal legislation now known as "The DD Act," are a group of lifelong conditions that emerge during the developmental period and result in some level of functional limitation in learning, language, communication, cognition, behavior, socialization, or mobility. The most common DD conditions are intellectual disability, Down syndrome, autism, cerebral palsy, spina bifida, fetal alcohol syndrome, and fragile X syndrome.

The acronym "IDD" is used to describe a group that includes either people with both ID *and* another DD or a group that includes people with ID *or* another DD. The supports that people with IDD need to meet their goals vary in intensity from intermittent to pervasive.

Positions, Declarations, and Reports of Other Organizations Endorsed by the AAIDD

Communication Bill of Rights

*Position of the National Joint Committee for the Communication Needs of Persons with Severe Disabilities
(as updated 2016)*

Endorsed by the AAIDD Board of Directors July 10, 2019

All people with a disability of any extent or severity have a basic right to affect, through communication, the conditions of their existence. Beyond this general right, a number of specific communication rights should be ensured in all daily interactions and interventions involving persons who have severe disabilities. To participate fully in communication interactions, each person has these fundamental communication rights:

1. The right to interact socially, maintain social closeness, and build relationships
 2. The right to request desired objects, actions, events, and people
 3. The right to refuse or reject undesired objects, actions, events, or choices
 4. The right to express personal preferences and feelings
 5. The right to make choices from meaningful alternatives
 6. The right to make comments and share opinions
 7. The right to ask for and give information, including information about changes in routine and environment
 8. The right to be informed about people and events in one's life
 9. The right to access interventions and supports that improve communication
 10. The right to have communication acts acknowledged and responded to even when the desired outcome cannot be realized
 11. The right to have access to functioning AAC (augmentative and alternative communication) and other AT (assistive technology) services and devices at all times
 12. The right to access environmental contexts, interactions, and opportunities that promote participation as full communication partners with other people, including peers
 13. The right to be treated with dignity and addressed with respect and courtesy
 14. The right to be addressed directly and not be spoken for or talked about in the third person while present
- The right to have clear, meaningful, and culturally and linguistically appropriate communications

Cite as:

Brady, N.C., Bruce, S., Goldman, A., Erickson, K., Mineo, B., Ogletree, B.T., et al. (2016). Communication services and supports for individuals with severe disabilities: Guidance for assessment and intervention. *American Journal on Intellectual and Developmental Disabilities*, 121 (2), pp. 121-138. <https://doi.org/10.1352/1944-7558-121.2.121>

Community Living and Participation for People with Intellectual and Developmental Disabilities: What the Research Tells Us

A joint letter from AAIDD and AUCD issued on July 24, 2015 on the anniversary of the ADA

To: Interested Parties

From: The Association of University Centers on Disabilities (AUCD) and the American Association on Intellectual and Developmental Disabilities (AAIDD)

Re: Community Living and Participation for People with Intellectual and Developmental Disabilities

Date: July 24, 2015

Monday, July 26th is the 25th Anniversary of the signing of the Americans with Disabilities Act (ADA). As he signed the law on the south lawn of the White House, President George H. W. Bush, surrounded by people with disabilities and members of Congress, closed his remarks by stating, "Let the shameful wall of exclusion come tumbling down." Despite great advances in physical access and technology that have made schools, workplaces, and neighborhoods more accessible, there continue to be barriers to equal opportunity, full participation, independent living, and economic self-sufficiency for all people with disabilities.

AUCD supports and promotes a national network of university-based interdisciplinary programs to advance policies and practices that improve the health, education, social, and economic well-being of all people with developmental and other disabilities, their families, and their communities.

AAIDD is a national organization that promotes progressive policies, sound research, effective practices, and universal human rights for people with intellectual and developmental disabilities. Established in 1876, AAIDD is the oldest and largest professional society in the US concerned with intellectual and developmental disabilities.

On this 25th anniversary, we are releasing the attached paper, based on over 50 years of research, to describe how AUCD and AAIDD think the next 25 years of the ADA should translate into access, opportunity, and support for people with disabilities. This work has been shaped by two primary sources: the voices of people with disabilities themselves and the research evidence on achieving the best possible outcomes for people with disabilities. These sources, of course, have also been shaped by our national laws and policies, the most significant being the ADA.

On this 25th anniversary of the signing of the ADA, we hope this paper will provide direction for the road ahead, a road leading to greater access, better economic opportunities, and true equality throughout our country.

Andrew J. Imparato
Executive Director, AUCD

Margaret A. Nygren, EdD
Executive Director & CEO, AAIDD

The Community Imperative: A 2020 Vision

A statement drafted by volunteers in the field (2019)

Endorsed by the AAIDD Board of Directors September 11, 2019

1. Human Rights

- All people have basic human rights. These rights must be protected for all people, regardless of a person's abilities, characteristics, or limitations

- All people are born into the communities of their family, culture, and country, so

All people have the right to be a welcomed and valued member of the community in which they were born or in which they choose to live.

2. Community

- People with disabilities should be able to fully participate in the life of their community, and be included as valued members, neighbors, and friends

- All people regardless of ability have unique gifts that they can share with their neighbors and friends in the community, so

All community members should help and support one another in order for everyone's life to flourish.

3. Education

- Students with disabilities have a right to be educated together with their peers

- All students need supports regardless of their abilities and are able to accept and enjoy the company of their peers, including those with disabilities, with whom they will create a new world, so

Education should provide supports that meet the needs of all students and help them to develop their own skills and capacity to contribute to inclusive communities.

4. Health Care

- All people with disabilities should have access to the health care they need, including long term supports and services

- People with disabilities should receive high quality and affordable health care that supports healthy life in their community, so

The health care system must meet the individual needs of people with disabilities, and be high quality, accessible, and affordable for people with disabilities.

5. Employment and Economic Security

- All people with disabilities should receive the support they may need to find and maintain fulfilling employment that meets their needs for economic stability

- When people with disabilities are unable to be economically self-sustaining through employment, government programs should provide financial supports that do not create barriers for employment or economic security

All people with disabilities should be able to participate in the workforce to improve and sustain their economic security, advance their skills and interests, build relationships, and increase their independence; government programs should promote these same goals for people who are unable to be economically self-sustaining through work.

6. Supports and other Services

- All people with disabilities are able to choose what is best for them, with the help of individuals of their choosing

- People with disabilities should receive the services and supports they need without being forced into undesired situations or programs because no other options are available, so

All people with disabilities have the right to choose self-directed supports and services within their community that best support and advance their strengths and abilities and match their individual desires for happiness.

7. Community Accountability

- All children and adults with disabilities have the right to be free of neglect, mistreatment, restraint, seclusion, abuse, and discrimination whether in schools, service settings, or in public settings

- Communities and governments must support people with disabilities to be free of abuses and hold accountable all persons or entities who violate their rights, so

All people with disabilities must be able to rely on government agencies and other community resources to help safeguard their personal rights to safety and protect against discrimination, regardless of settings where the abuses or violations occur.

Therefore,

All who endorse this statement pledge to work in the decade of the 2020s to achieve the vision of a world in which all people regardless of their abilities are valued and productive members of their community and are welcomed as neighbors and friends.

Core Competencies on Disability for Health Care Education

Competencies developed by the Alliance for Disability in Health Care Education and the Ohio Disability and Health Program designed to integrate disability-related content and experiences into health care education and training programs (2018)

Endorsed by the AAIDD Board of Directors June 24, 2018

The Alliance for Disability in Health Care Education (the Alliance) and the Ohio Disability and Health Program have partnered to improve the disability training that health care students receive. The purpose of this project is to develop a consensus on the disability competencies required for health care providers to provide quality care to patients with disabilities and to have them integrated into health education curricula.

Competencies are abilities and attributes that are essential to effective health care delivery. Disability competencies, then, are the skills and attributes essential to providing quality health care to patients with disabilities. Health education programs are built around the core competencies of the profession. These competencies are designed to be cross-disability and interdisciplinary.

See the competencies at

<https://nisonger.osu.edu/education-training/ohio-disability-health-program/corecompetenciesondisability/>

Devaluing People with Disabilities: Medical Procedures that Violate Human Rights

Report of the National Disability Rights Network and Disability Rights Washington (2012)

Endorsed by AAIDD Board of Directors June 17, 2012

Devaluing People with Disabilities: Medical Procedures that Violate Civil Rights provides a crucial, but missing, link in the discussion about how society can and should make medical decisions that uphold the rights and inherent dignity of people with disabilities.

The report puts individuals with disabilities at the center of this discourse. It reviews the facts of Ashley X, as a case study for a larger discussion and presents a continuum of common experiences and treatment of individuals with disabilities within a context of medical decision making. The report explores the potential and actual conflict of interest that medical decision making may present between a parent and his or her child. It describes the vital role that the legal system has in ensuring that the civil and human rights of individuals with disabilities are protected. The report discusses how the deprivation of these rights is harm within and of itself and that all individuals have substantive rights regardless of the severity of their disability. It goes on to outline how discrimination inherently causes harm to both the person who experiences the discriminatory conduct and society as a whole. Finally, the report presents a series of recommendations for how the legal and medical systems at the local, state, and national level, including protection and advocacy agencies, ethics committees, institutional review boards, and the courts can perform critical “watchdog” functions to ensure that the human and civil rights of individuals with disabilities are protected.

See the report at

https://www.aaid.org/docs/default-source/policy/devaluing_people_with_disabilities.pdf

Including Individuals with Intellectual/ Developmental Disabilities and Co-Occurring Mental Illness: Challenges that Must Be Addressed in Health Care Reform

Position paper of NADD (October 2013)

Endorsed by AAIDD Board of Directors January 11, 2014

The NADD position recognizes the challenges that state policymakers face in responding to today's economic, political, and regulatory environments, and makes recommendations for state officials to address the continuing fiscal limitations resulting from the economic recession, respond to increasing numbers of people with co-occurring disorders waiting for services, and more effectively manage current service costs.

See the statement at

<https://www.aaid.org/docs/default-source/policy/including-individuals-with-intellectual-developmental-disabilities-and-co-occurring-mental-illness-challenges-that-must-be-addressed-in-health-care-reform.pdf>

My Thinker's Not Working: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports

Report of the National Task Group on Intellectual Disabilities and Dementia Practices (2012)

Endorsed by AAIDD Board of Directors August 15, 2012

The report of the National Task Group on Intellectual Disabilities and Dementia Practices, affiliated with the AADMD, provides a summary of the challenges facing the nation as we observe an increasing rate of dementia found in older people with intellectual disabilities. The Report offers recommendations for the various stakeholders in the field of intellectual disability.

See the report at

<https://www.aaid.org/docs/default-source/policy/ntgthinkerreport.pdf>

The Rights of People with Cognitive Disabilities to Technology and Information Access

A Declaration on equal rights of people with intellectual disability to technology and information access (2013)

Endorsed by the AAIDD Board of Directors February 20, 2013

Whereas

Twenty-eight million United States citizens have cognitive disabilities such as intellectual disability; severe, persistent mental illness; brain injury; stroke; and neurodegenerative disorders such as Alzheimer's disease;

People with cognitive disabilities must have access to commercially available devices and software that incorporate principles of universal design such as flexibility and ease of use for all;

People with cognitive disabilities are entitled to inclusion in our democratic society under federal laws such as the Americans with Disabilities Act (ADA), the Developmental Disabilities Assistance and Bill of Rights Act (DD Act), the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act, and under state and local laws;

The disruptive convergence of computing and communication technologies has substantially altered how people acquire, utilize, and disseminate knowledge and information;

Access to comprehensible information and usable communication technologies is necessary for all people in our society, particularly for people with cognitive disabilities, to promote self-determination and to engage meaningfully in major aspects of life such as education, health promotion, employment, recreation, and civic participation;

The vast majority of people with cognitive disabilities have limited or no access to comprehensible information and usable communication technologies;

Technology and information access by people with cognitive disabilities must be guided by standards and best practices, such as personalization and compatibility across devices and platforms, and through the application of innovations including automated and predictive technologies;

Security and privacy must be assured and managed to protect civil rights and personal dignity of people with cognitive disabilities;

Enhanced public and private funding is urgently required to allow people with cognitive disabilities to utilize technology and access information as a natural consequence of their rights to inclusion in our society;

Ensuring access to technology and information for the 28 million people with cognitive disabilities in the United States will create new markets and employment opportunities; decrease dependency on public services; reduce healthcare costs; and improve the independence, productivity, and quality of life of people with cognitive disabilities.

Therefore

We hereby affirm our commitment to equal rights of people with cognitive disabilities to technology and information access and we call for implementation of these rights with deliberate speed.

Toronto Declaration on Bridging Knowledge, Policy and Practice in Aging and Disability

Drafted by the Participants of Growing Older with a Disability (GOWD) Conference, a part of the Festival of International Conferences on Caregiving, Disability, Aging and Technology (FICCDAT) (2012)

This declaration builds upon the Barcelona Declaration on Bridging Knowledge in LongTerm Care and Support, March 5-7, 2009, the Graz Declaration on Disability and Ageing, 9th June, 2006, the Linz Declaration as well as United Nation's Conventions (in particular the United Nations Convention on the Rights of Persons with Disabilities and the United Nations 2002 Political Declaration from the Madrid World Assembly on Aging II) and international directives that recognize the human rights and the biopsychosocial approach to disability.

See the declaration at

https://www.aaid.org/docs/default-source/policy/toronto_declaration.pdf

Universal Civil and Human Rights of People with the Most Significant Developmental Disabilities

Position of ASAN, 2020

Endorsed by AAIDD Board of Directors, April 8, 2020

People with disabilities have the same civil and human rights as their peers without disabilities. Those rights are not modified, lessened, or “balanced” against other considerations because of their support needs. Every individual with a developmental disability, including those with the most significant intellectual disability, the most complex communication needs, and the most challenging behaviors, is a person with the right to:

- Self-determination, including setting their own goals and making decisions about all aspects of their lives;
- Community living, rather than residing in a segregated or institutional setting;
- Education that is inclusive and promotes academic, civic, and social knowledge and skills;
- Employment that is integrated and pays fair wages;
- Freedom from abuse, neglect, and exploitation, including freedom from restraint, seclusion, and aversive intervention;
- Nondiscrimination in and equitable access to any and all needed health care; and,
- Public policies that ensure their access to the same choices, opportunities, and experiences as people without disabilities.

The evidence is unambiguous that every person--even those with the most significant disabilities, who have complex medical, behavioral, or communication needs, or who need support 24 hours a day--can successfully learn, live, and work in the community. We also know that when people with disabilities are integrated and included in the community, they are safer, happier, gain more skills, and have a dramatically higher quality of life. We acknowledge that existing service systems may be inadequate--but we also know that practical solutions do exist to support people with the most intense needs to live full lives of meaning and purpose in their communities. The rightful focus of attention for all stakeholders must be on improving systems and scaling up high-quality community-based services, not a return to institutions.

Community living, inclusion, and self-determination are the rights of *all* people with disabilities. *All* means *all*. These rights are universal and apply equally and fully to all of humanity--including people with the most significant developmental disabilities, who have always been the last to be allowed their full rights. Civil and human rights are universal to all people and are not dependent on the level of support someone may require. Public policies, civil infrastructures, services, and supports for people with disabilities must be designed with this recognition. *All* means *all*.

