

# *Position Statements*

NOVEMBER 2018



*For people with intellectual  
and developmental disabilities*

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## *The Arc*

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities (I/DD) and their families. We encompass all ages and more than 100 different diagnoses including autism, Down syndrome, Fragile X syndrome, and various other developmental disabilities.

### *Strong National Presence*

With state and local chapters nationwide, The Arc is on the front lines to ensure that people with intellectual and developmental disabilities and their families have the support and services they need to be fully engaged in their communities. The Arc's federation of state and local chapters creates an impressive network of human service agencies working to ensure promotion and protection of civil rights at all levels. Our nationwide network of chapters provides a wide range of human services and other supports to people with I/DD and their family members, including individual and public policy advocacy and residential, educational, and vocational services that support people with I/DD to participate and be included in their communities. In addition, many of our chapters provide person-centered and financial planning, recreational activities, and other supports that meet the unique needs of people with I/DD and their families.

The Arc has a rich history spanning over 65 years and marked by many accomplishments. We continue to carry out our work on behalf of people with intellectual and developmental disabilities, as well as their parents and siblings, guided by our Mission Statement, Core Values and Guiding Principles, and Position Statements.

## *Mission Statement*

The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

## *Core Values*

### *People First*

The Arc believes that all people with intellectual and developmental disabilities are defined by their own strengths, abilities and inherent value, not by their disability.

### *Equity*

The Arc believes that people with intellectual and developmental disabilities are entitled to the respect, dignity, equality, safety, and security accorded to other members of society, and are equal before the law.

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## *Community*

The Arc believes that people with intellectual and developmental disabilities belong in the community and have fundamental moral, civil and constitutional rights to be fully included and actively participate in all aspects of society.

## *Self-determination*

The Arc believes in self-determination and self-advocacy. People with intellectual and developmental disabilities, with appropriate resources and supports, can make decisions about their own lives and must be heard on issues that affect their well-being.

## *Diversity*

The Arc believes that society in general and The Arc in particular benefit from the contributions of people with diverse personal characteristics (including but not limited to race, ethnicity, religion, age, geographic location, sexual orientation, gender and type of disability).

# *Guiding Principles*

## *Participatory Democracy*

The Arc acts to ensure that people with intellectual and developmental disabilities, their parents, siblings, family members and other concerned members of the public have meaningful opportunities to inform and guide the direction of the organization's advocacy, including determining policy and positions on important issues. The Arc strives for diversity in its leadership, as well as in all facets of the work of the organization.

## *Visionary Leadership*

The Arc leads by articulating a positive vision for the future of people with intellectual and developmental disabilities and catalyzes public and private support in realization of that vision through carefully planned and well-executed goals, strategies and actions.

## *Public Interest*

The Arc represents the public interest, supporting and acting with and on behalf of all people with intellectual and developmental disabilities and their families regardless of the type of disability or membership in The Arc.

## *Collaboration*

The Arc works with individuals, organizations and coalitions in a collaborative fashion. The Arc values and promotes effective partnerships between volunteer and staff leadership at all levels of the organization.

## *Transparency, Integrity and Excellence*

The Arc conducts its business with integrity, accountability, and open, honest and timely communication. The Arc is committed to quality and excellence in all it does.

# Position Statements

The Arc's position statements address critical issues related to human and civil rights, health care and treatment, and services and programs for children and adults with intellectual and developmental disabilities and their families.

Position statements are used to advance The Arc's public policy goals, as well as provide a platform for our state and local chapters to gain a national perspective for what The Arc stands for. They also serve to inform our constituency, stakeholders and the general public on the prevailing organizational view on key issues.

## *Creation of Position Statements*

The President of The Arc appoints the Policy and Positions Committee which considers development of new position statements and revision of existing position statements and which collaborates with the American Association on Intellectual and Developmental Disabilities (AAIDD).

New position statements and revisions of existing statements are developed through a process that provides substantial opportunity for input and participation by chapters of The Arc. Chapter comments are taken into consideration as the final drafts are developed for consideration by the Board of Directors of The Arc. After approval by the Board, final drafts are presented to the Chapters for adoption at The Arc's Annual Meeting. Once adopted, position statements remain in force until they are replaced or withdrawn. The Arc's bylaws require that the position statements be reviewed at least every six years.

Position statements are used to inform The Arc's public policy agenda, as well as to provide the national platform of positions of The Arc for use by chapters at all levels of The Arc in its work – national, state, and local. The statements also serve to inform our constituency, stakeholders, media, and the general public on the prevailing organizational view on key issues.

## *Of Note*

The Arc has many position statements which are written jointly with AAIDD; for each of those joint position statements, a notice is included on the statement in this document. In addition, each statement includes a last reviewed/revised date at the end of the statement (for example, Rev'd 2018).

The statements are organized in the following sections: *Quality of Life, Rights, Life in the Community, and Systems*.

2018



POSITION STATEMENTS:  
THE ARC OF THE UNITED STATES

*Policies Related  
to Quality of Life*

## Quality of Life Summary

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**The primary goal for all persons with intellectual and/or developmental disabilities<sup>1</sup> is to enjoy and maintain a good quality of life.**

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### Quality of Life

People with intellectual and/or developmental disabilities must be able to lead the life they choose so that they can have a quality of life that is meaningful to them.

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<sup>1</sup> “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

## Quality of Life

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**People with intellectual and/or developmental disabilities<sup>1</sup> must be able to lead the life they choose so that they can have a quality of life that is meaningful to them.**

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### *Issue*

People with intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities 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.

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Rev'd 2015

Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

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



POSITION STATEMENTS:  
THE ARC OF THE UNITED STATES

*Policies Related to Rights*

## *Rights Summary*

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**People with intellectual and/or developmental disabilities<sup>1</sup> have the same basic legal, civil, and human rights as other citizens. They may need accommodation, protection, and support to enable them to exercise these rights. Their rights should never be limited or restricted without due process.**

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### *Advocacy*

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

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

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

### *Criminal Justice System*

People with intellectual and/or developmental disabilities (I/DD) 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.

### *Human and Civil Rights*

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

## *Inclusion*

All people with intellectual and/or developmental disabilities benefit when fully included in community life.

## *Physician-Assisted Suicide*

Physician-assisted suicide must be prohibited for people with intellectual disability (ID) due to the inherent risk of undue influence.

## *Protection from Mistreatment*

People with intellectual and/or developmental disabilities must be free from abuse, neglect, or any kind of mistreatment.

## *Self-Advocacy*

People with intellectual and/or developmental disabilities (I/DD) must have the right to and be supported to act as self-advocates. Self-advocates exercise their rights as citizens by communicating for and representing themselves, with supports in doing so, as necessary. This means they have a say in decision-making in all areas of their daily lives and in public policy decisions that affect them.

## *Self-Determination*

People with intellectual and/or developmental disabilities (I/DD) 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.

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<sup>1</sup> “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

## Advocacy

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

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### Issue

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

### Position

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

### Individuals

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

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

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

Self-advocates should:

- Know about, understand and assert their rights;

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

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

### *Systems*

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

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

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

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

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Rev'd 2015

Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

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

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

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**All individuals with intellectual and/or developmental disabilities<sup>1</sup> (I/DD) have the right to recognition as persons before the law and to enjoy legal capacity on an equal basis with individuals who do not have disabilities in all aspects of life (United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), 2006). The personal autonomy, liberty, freedom, and dignity of each individual with I/DD must be respected and supported. Legally, each individual adult or emancipated minor is presumed competent to make decisions for himself or herself, and each individual with I/DD should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime.**

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### *Issue*

- Current trends presume the decision-making capacity of individuals with I/DD and the preservation of legal capacity as a priority for all people needing assistance with decision-making.
- Like their peers without disabilities, individuals with I/DD must be presumed competent; they must also be assisted to develop as decision-makers through education, supports, and life experience. Communication challenges should not be misinterpreted as lack of competency to make decisions.
- Individuals with I/DD should have access to supports and experiences to learn decision-making skills from an early age and throughout their lifetimes in educational and adult life service systems.
- 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<sup>2</sup> as an option is considered.



- Where judges and lawyers lack knowledge about people with I/DD 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 I/DD 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 I/DD 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 I/DD experience guardianship as stigmatizing and inconsistent with their exercise of adult roles and responsibilities.

## *Position*

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

- 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 I/DD, 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 I/DD 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 I/DD 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 I/DD.
- 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 I/DD 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

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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 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 I/DD.
- Members of the judiciary, attorneys, and other professionals need training and education on alternatives to guardianship for individuals with I/DD, and they must zealously advocate for preserving the substantive and procedural rights of all individuals with I/DD.
- If a guardian is to be appointed, the preferences and assent of the individual with I/DD 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 I/DD or their families.
- Guardianship should include a person-centered plan of teaching and/or supports for decision making so the individual with I/DD 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 I/DD 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 I/DD 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.

## 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.

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Rev'd 2016

Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

<sup>1</sup> "People with intellectual disability (ID)" refers to those with "significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18", as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). "People with developmental disabilities (DD)" refers to those with "a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated," as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

<sup>2</sup> Terminology for guardianship and guardians differs by state and can include tutor, conservator, curator, or other comparable terms.

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## Criminal Justice System

**People with intellectual and/or developmental disabilities<sup>1</sup> (I/DD) 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 intellectual and/or developmental disabilities (I/DD) 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 I/DD. These individuals are:

- **Unrecognized as having a disability.** Individuals with I/DD 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 I/DD are often denied a fair evaluation of whether they are entitled to legal protection as having I/DD on the basis of false stereotypes about what individuals with I/DD can and cannot understand or do;
- **Victimized at high rates.** Individuals with I/DD 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 I/DD 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 I/DD 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 I/DD 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 I/DD often serve extended time because they do not understand or cannot meet steps to reduce time and secure an earlier release.

When individuals with I/DD 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 I/DD 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 I/DD.

While the Supreme Court ruled in *Atkins v. Virginia*<sup>2</sup> 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*<sup>3</sup> in 2014, reaffirming the *Atkins* decision and denying states’ use of strict IQ cutoffs to diagnose intellectual disability.

## *Position*

People with intellectual and/or developmental disabilities 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 I/DD, 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 I/DD 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.

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Rev'd 2014

Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

<sup>1</sup> “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

<sup>2</sup> *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.

<sup>3</sup> *Hall v. Florida*, 134 S. Ct. 1986 (2014).

## *Human and Civil Rights*

**The human and civil rights of all people with intellectual and/or developmental disabilities<sup>1</sup> 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 intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities. As a result, people with intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities as unworthy of progressive public policies and related public funding; and



- The presence of other factors that, in combination with intellectual and/or developmental disabilities, 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 intellectual and/or developmental disabilities are entitled to human and civil rights. Given that all people with intellectual and/or developmental disabilities are complex human beings with varying attributes and living circumstances, and many experience multiple risk factors for human and civil rights violations, we emphasize that all are entitled to human and civil rights regardless of age, gender, race/ethnicity, sexual orientation, cultural, linguistic, geographic, and spiritual diversity, economic status, severity of disability, intensity of needed supports, or other factors that expose them to increased risk of rights violations.

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.

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Rev'd 2015

Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

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

## *Inclusion*

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**All people with intellectual and/or developmental disabilities<sup>1</sup> benefit when fully included in community life.**

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### *Issue*

Individuals with intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities 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.

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Rev'd 2015

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

## *Physician-Assisted Suicide*

**Physician-assisted suicide must be prohibited for people with intellectual disability<sup>1</sup> (ID) due to the inherent risk of undue influence.**

### *Issue*

Physician-assisted suicide occurs when a physician provides a medical means for death, usually a prescription for a lethal amount of medication that the patient takes on his or her own<sup>2</sup>. As the nation, individual states, and various interest groups consider the adoption of physician-assisted suicide policies, it is essential that people with ID have their rights and interests protected. Historical ignorance, prejudice, and discrimination against people with ID continue. Education of policy makers and society at large is critical.

Major problems that exist are:

- The documented history of denial of basic rights and medical care, including nutrition and hydration, places the lives of people with ID at extraordinary risk.
- Despite well-intended laws designed to protect people with ID, our constituents can be unduly influenced by authority figures such as doctors, health care workers, social workers, family, guardian/conservators, and friends, resulting in a lack of true informed consent.
- The current system of health services, particularly managed care, provides economic incentives for rationing health care, and can lead to the encouragement of physician-assisted suicide.
- Society often incorrectly perceives that people with ID, by definition, have a poor quality of life.

Public perception on this issue is sometimes confused with specific issues related to advance directives<sup>3</sup> and death with dignity.

### *Position*

We strongly oppose physician-assisted suicide for people with ID and believe it requires strong and absolute vigilance because:

- The death of any person with ID by way of physician-assisted suicide is never acceptable and should not be allowed by law under any circumstances;
- Laws and procedures, however strict, are not sufficient to protect people with ID from being coerced into ending their lives;

- When the person is seriously ill and in pain, the use of appropriate medical or palliative care to reduce and/or eliminate pain and discomfort can and must be provided.

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Rev'd 2017

<sup>1</sup> “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) *Manual, Intellectual Disability: Definition, Classification, and Systems of Supports*, and the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM IV)*, published by the American Psychiatric Association (APA). In everyday language people with ID are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

<sup>2</sup> Physician-assisted suicide: Occurs when a physician provides a medical means for death, usually a prescription for a lethal amount of medication that the patient takes on his or her own. (In euthanasia, the physician directly and intentionally administers a substance to cause death.) (Ethics Manual, American College of Physicians, 2012). The American College of Physicians does not support legalization of physician-assisted suicide or euthanasia. “After much consideration, the College concluded that making physician-assisted suicide legal raised serious ethical, clinical, and social concerns and that the practice might undermine patient trust; distract from reform in end-of-life care; and be used in vulnerable patients, including those who are poor, are disabled [sic], or are unable to speak for themselves or minority groups who have experienced discrimination.” The American Medical Association also opposes physician assisted suicide: “allowing physicians to participate in assisted suicide would cause more harm than good. Physician-assisted suicide is fundamentally incompatible with the physician’s role as healer, would be difficult or impossible to control, and would pose serious societal risks.” (Code of Ethics, American Medical Association, 1996). As of March of 2012, only two states, Oregon and Washington, specifically authorize physicians, in limited circumstances, to assist suicide. These states, however, do not allow for the practice to be used in situations where the person choosing to commit suicide lacks mental competence.

<sup>3</sup> See The Arc’s health care position statement regarding advanced directives.

## *Protection from Mistreatment*

**People with intellectual and/or developmental disabilities<sup>1</sup> 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 intellectual and/or developmental disabilities to be safe without violating their rights. Finally, individuals with intellectual and/or developmental disabilities may not have received any, much less enough, training on how to protect themselves from or report mistreatment.

### *Position*

Protection of all people with intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities 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 intellectual and or developmental disabilities in segregated settings is not an effective way to keep them safe. One of the best protections people with intellectual and/or developmental disabilities 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.

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Rev'd 2015

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## Self-Advocacy

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**People with intellectual and/or developmental disabilities<sup>1</sup> (I/DD) must have the right to and be supported to act as self-advocates. Self-advocates exercise their rights as citizens by communicating for and representing themselves, with supports in doing so, as necessary. This means they have a say in decision-making in all areas of their daily lives and in public policy decisions that affect them.**

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### Issue

Historically, people with I/DD have experienced powerlessness and isolation resulting in loss and denial of basic human rights, segregation, and discrimination in almost all areas of personal and community life.

Before self-advocacy groups existed, only a small number of people with I/DD received education and support from people who had experiences like their own. Without these groups they did not have a way to learn about important self-advocacy skills or topics like:

- Their rights and responsibilities as citizens, such as the right to vote;
- Development of leadership and assertiveness skills;
- Confidence in their own abilities;
- Using their expertise as people living with disabilities;
- Development of public speaking skills and problem-solving techniques, and involvement in group decision-making; and
- Involvement on boards and task forces and with policymakers at the local, state, and national level.

Without self-advocacy skills, people with I/DD have little impact on their own situations or on public policy that affects them.

### Position

People with intellectual and/or developmental disabilities have the right to advocate for themselves. This means they have the right to speak or act on their own behalf or on behalf of other people with disabilities, whether the issue is personal (*e.g.*, housing, work, friends) or related to public policy. Recognizing these rights in a respectful partnership between people with and without disabilities can lead to better outcomes and better lives in the community for everyone.



Self-advocates provide important knowledge, experience, and skills that individuals, organizations, and government agencies need in order to effectively support the needs and dreams of people with I/DD. To promote this participation, it is critical to acknowledge the important role that self-advocacy groups 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 I/DD must have the power to make day-to-day decisions about their own lives and the services they receive free from the manipulation of others. Service providers and government agencies can offer significant supports in making sure informed decision making is in the hands of the self-advocate.
- People with I/DD should be provided accommodations or supports in order to have a visible, respected, and meaningful place in meetings, conferences, task forces, or other forums when issues and policies that are important to them are discussed (“Nothing about us without us” principle). These accommodations may include, but not be limited to:
  - Extra time planned for meetings to accommodate the unique communication and participation needs of each person;
  - Enhanced and alternative communication methods with easy-to-use formats;
  - Communication devices, sign language or other similar accommodations;
  - Supporting people to serve as “translators”; and
  - Appropriate transportation and funding.
- Respectful communication is important when talking to or about people with I/DD. This includes using people first language whenever talking directly to someone with disabilities, or describing their lives, and speaking to them in a way that takes into account their unique communication abilities.
- Policy development by any entity at a local, state, or national level must include self-advocates in matters of governance, and periodically evaluate the effectiveness of that inclusion.
- People who provide direct support and disability advocates should work actively with people with I/DD to develop and sustain self-advocacy organizations and individual participants in their states and communities.
- Families, advocacy organizations, service providers, and government agencies must also work with self-advocates to increase public awareness of the importance of the self-advocacy movement and the need to support it.
- 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 I/DD have accessible information, training, and education in self-advocacy and (2) providers have the information they need to deliver services that match the self-advocate-led trends in policy and design.

- Families, schools, direct service providers, and other agencies must have the support they need to make sure that children and youth have the chance to learn self-advocacy skills and put them into practice. They should have opportunities to use those skills in educational planning (including Individualized Education Plans or IEPs and transition plans) and all decision-making.
- Self-advocates, families, direct service providers, and other agencies must have the support they need to make sure that adults with I/DD have the chance to learn self-advocacy skills and put them into practice. They should have opportunities to use those skills in service planning and all decision-making.

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Rev'd 2014

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<sup>1</sup> “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

## *Self-Determination*

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**People with intellectual and/or developmental disabilities<sup>1</sup> (I/DD) 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.**

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### *Issue*

Historically, many individuals with I/DD 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 I/DD 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 I/DD 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 I/DD 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 I/DD 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 I/DD community.

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

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Rev'd 2018

Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

<sup>1</sup> “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.



POSITION STATEMENTS:  
THE ARC OF THE UNITED STATES

*Policies Related  
to Life in the Community*

## *Life in the Community Summary*

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**All people, regardless of disability, deserve the opportunity for a full life in their community where they can live, learn, work, and play alongside each other through all stages of life. People with intellectual and/or developmental disabilities<sup>1</sup> need varying degrees of support to reach personal goals and establish a sense of satisfaction with their lives.**

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### *Aging*

People with intellectual and/or developmental disabilities 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.

### *Behavioral Supports*

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

### *Early Childhood Services*

All young children who are at-risk for or who have been identified with intellectual and/or developmental disabilities 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.

### *Education*

All children and youth with intellectual and/or developmental disabilities (I/DD) 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.

## *Employment*

People with intellectual and/or developmental disabilities (I/DD) 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.

## *Family Support*

Family support services and other means of supporting families should be available to all families to strengthen families' capacities to support family members with intellectual and/or developmental disabilities (I/DD) in achieving equal opportunity, independent living, full participation, and economic self-sufficiency.

## *Health*

All people, including people with intellectual and/or developmental disabilities (I/DD), 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.

## *Housing*

People with intellectual and/or developmental disabilities (I/DD), 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.

## *Individual Supports*

People with intellectual and/or developmental disabilities (I/DD) must have access to individual supports, such as assistive technology and personal assistance, to support their participation in daily life.

## *Opportunities for Financial Asset Building*

People with intellectual and/or developmental disabilities (I/DD) 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.



# *Parents with Intellectual and/or Developmental Disabilities*

The presence of an intellectual and/or developmental disability does not in itself preclude effective parenting; therefore, the rights of parenthood must not be denied individuals solely on the basis of intellectual and/or developmental disabilities. Parents with intellectual and/or developmental disabilities should have access to support as needed to perform parental roles just as they are supported in other valued social roles and activities.

## *Sexuality*

People with intellectual disabilities and/or developmental disabilities, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected.

## *Spirituality*

People with intellectual and/or developmental disabilities 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.

## *Transportation*

People with intellectual and/or developmental disabilities must have access to both public and private transportation to lead full, independent lives.

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## Aging

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**People with intellectual and/or developmental disabilities<sup>1</sup> 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.**

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### Issue

For the first time in history, Americans living in the 21st century will experience millions of people with intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities as they age.

Like other older Americans, people with intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities. Likewise, many disability-based organizations have historically not planned for the challenges faced by older people with intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities 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 intellectual and/or developmental disabilities 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.

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Rev'd 2013

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## *Behavioral Supports*

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

### *Issue*

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

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

### *Position*

Research-based positive behavioral supports should be readily available in natural settings including the family home. Families, caregivers, educators, direct support personnel, and other professionals and paraprofessionals should be provided with training and support in implementing effective positive behavioral interventions and supports in all environments. Behavioral supports should be individually designed and positive, emphasize learning, offer choice and social integration, be culturally appropriate, and include modifying environments as needed.

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

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

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

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

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

Positive behavioral supports should be:

- Designed in a person-centered process involving the individual;
- Developed within the broader context of providing quality medical, psychological, educational, and facilitative services;
- Based on a functional analysis of the behavior and the circumstances under which it occurred, a thorough assessment of each individual's unique abilities and contributions, and an understanding of how previous interventions worked;
- Provided through a least restrictive strategy and described in a written plan;
- Grounded in evidence-based procedures that will:
  - prevent challenging behaviors;
  - teach new skills that may replace challenging behaviors;
  - prevent the on-going reward of a challenging behavior;
  - reinforce positive behavior;
  - ensure safety (when necessary); and
  - provide systemic information on the effectiveness of the support.
- Used in a humane and caring manner respecting individual dignity;
- Implemented in positive, socially supportive and culturally appropriate environments, including the home;
- Carried out by individuals (i.e., staff, family members and others) who have been trained and are qualified to effectively apply positive, non-aversive approaches;
- Include adaptations to the environment and reinforcers that people with intellectual and/or developmental disabilities and their families identify as positive; and

- Monitored continuously and systematically to ensure appropriate implementation and that the support is consistent with individual needs, positive in its methods, successful in achieving established goals, and changed in a timely fashion if success is not evident or occurring at an appropriate rate.

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Rev'd 2015

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## Early Childhood Services

**All young children who are at-risk for or who have been identified with intellectual and/or developmental disabilities<sup>1</sup> 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.

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

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Rev'd 2013

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**Achieve with us.**<sup>®</sup>



## Education

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**All children and youth with intellectual and/or developmental disabilities<sup>1</sup> (I/DD) 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.**

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### Issue

People with I/DD continue to face numerous barriers in their education. Lifelong education is essential for all individuals with I/DD 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 I/DD 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 I/DD frequently do not have appropriately ambitious<sup>2</sup> 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 I/DD leave school unprepared for further education, employment, and independent living in the community.

Many schools have policies and practices that push youth with I/DD 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 I/DD 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 I/DD are “bringing down” test scores and are to blame when schools and school systems do not achieve adequate progress.

## *Position*

To ensure students with I/DD 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 I/DD, 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.
- 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 I/DD, 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 I/DD learn. Develop adaptations for assessment and grading, when necessary, that accurately capture the strengths and limitations of students with I/DD.

### ***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 I/DD, 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 I/DD 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.
- 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.

- 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.

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<sup>2</sup> 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.

## Employment

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**People with intellectual and/or developmental disabilities<sup>1</sup> (I/DD) 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.**

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### Issue

Historically, the majority of people with I/DD 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 I/DD 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.

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- Opportunities for self-employment and business ownership.
- Opportunities to work with and, in the case of people with I/DD 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 I/DD 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 pursue post-secondary education and/or with an appropriate job or an action plan for finding one.

### ***Training of Staff and People with I/DD***

- 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 I/DD should receive guidance, if needed, in acquiring the social skills necessary in the workplace.
- People with I/DD 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 I/DD, 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 I/DD.



Publicly funded employment programs should also:

- Be available to all people with I/DD 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.

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Rev'd 2017

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## Family Support

**Family support services<sup>1</sup> and other means of supporting families should be available to all families to strengthen families' capacities to support family members with intellectual and/or developmental disabilities<sup>2</sup> (I/DD) in achieving equal opportunity, independent living, full participation, and economic self-sufficiency.**

### Issue

Individuals with I/DD frequently require support to perform basic daily activities and to achieve the national goals of equal opportunity, full participation, independent living, and economic self-sufficiency. Families are overwhelmingly the primary and often the major source of support for their family member with I/DD. Nearly three quarters of people with I/DD live in the family home and, according to The Arc's Family and Individual Needs for Disability Supports (FINDS) survey, most of these family caregivers provide more than 40 hours of care per week (including 40% who provide more than 80 hours of care per week).

Changing demographics are placing even greater demands on this already limited service system. The aging of the baby boom generation is resulting in an increasing number of people with I/DD living with aging caregivers. These aging caregivers will have greater 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 I/DD when they are no longer able to continue in their caregiving role.

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 I/DD 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 I/DD in place of appropriate community supports, even in cases when residing in the family home may not be a good option for adult offspring with I/DD or themselves.

Our service system is increasingly being built around the expectation that adults with I/DD will reside in the family home. This is not consistent with other national policies for vulnerable populations.

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

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 mobility and portability limitations as those receiving other Medicaid HCBS. This problem is most acutely felt by military families who move frequently and have to begin the application and waiting process anew with each move between states.

Although family support has been a policy of the federal and state governments since the 1980s, families and individuals with I/DD increasingly are using their social capital to achieve the four national goals and attain quality of life outcomes, and are also benefitting from and seeking more policies, practices, and procedures of generic governmental and private-sector entities that support families. Families' reliance on social capital and these other means for supporting families have become important as supplements to, not replacements of, governmental-sponsored family support programs.

## *Position*

Comprehensive, universally accessible family support must be provided in order to:

- Assist families as they guide their member with a disability toward being self-determined individuals and achieving the nation's goals for people with disabilities as set out in federal legislation, namely, equal opportunity, economic productivity, independent living, and full participation;
- 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 I/DD;
- Recognize that relying on families to provide care cannot be a substitute for creating a national solution to provide appropriate long term supports and services;
- Enable families to make informed choices regarding the nature of supports for themselves and their members with disabilities, including the use of supported decision making for family members with I/DD; and
- Help families with minor members to stay intact, preventing any type of out-of-home placements for a minor child, particularly institutions.

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

- Be provided in a manner that builds on the family's strengths;
- Be provided in ways that are sensitive to the family's culture, religion, and socio-economic status;
- Assist the individual and family to maximize the self-determination of its member with I/DD;
- 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 family caregivers, including, but not limited to, parents (including those with I/DD themselves), adoptive parents, foster parents, siblings, uncles, aunts, cousins, grandparents, grandchildren, and individuals who are in spousal-equivalent relationships;
- Be available to all families regardless of whether the person with I/DD 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, while ensuring that such arrangements are mutually desired by the family caregiver and member with I/DD and do not impose inappropriate barriers under the guise of regulating medical services provided by paid family caregivers (such as requiring a nursing license to provide g-tube feeding or insulin shots as part of respite care); and
- Be defined as a system of policies, practices, and procedures for supporting families rather than as a “family support program” sponsored by a government or private-sector entity. Increasingly, these individualized supports should be available from generic (non-disability-specific) governmental and nongovernmental entities.

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<sup>1</sup> Traditionally, government-sponsored family support has consisted of the following types of support: 1) Cash assistance from federal, state, and local governmental sources that is provided: a) Over and above, to supplement but not to supplant, any other federal cash transfer or medical, educational, or welfare benefit programs (including without limitation 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 member of a family; and c) To the family as the primary beneficiary of the family support program, not to the member of the family who has a disability as the primary beneficiary; 2) Information and emotional and instrumental support provided by: a) Professionals, including those in disability-specializing professions and entities and those in generic, non-disability specializing professions and entities; b) Members of the family of the person with a disability or friends of the family or person; 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.

<sup>2</sup> “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

## Health

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**All people, including people with intellectual and/or developmental disabilities<sup>1</sup> (I/DD), 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.**

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## 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 I/DD 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 I/DD 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 I/DD 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 I/DD 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 I/DD lack adequate public or private insurance to pay for them.
- **Communication and personal decision making.** People with I/DD 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<sup>2</sup>. 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 I/DD must meet the highest standards of quality, including a comprehensive approach to treatment, disease prevention, and health maintenance.
- People with I/DD 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 I/DD need access to effective strategies to manage their care including care coordination, referral processes, transition assistance, and health promotion efforts.
- 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 I/DD 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 I/DD 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 I/DD 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 I/DD 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 I/DD 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 I/DD 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 I/DD.

### **Communication and Personal Decision-Making**

In all matters of health, individuals with I/DD have basic rights that must be protected, including the right to information and appropriate accommodations to assure informed consent<sup>3</sup> 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 I/DD;
- 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<sup>4</sup> and recorded in an advance directive<sup>4</sup> 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 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 I/DD 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.

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<sup>2</sup> 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, <http://new.abanet.org/aging/Pages/CLE.aspx>)

<sup>3</sup> Informed consent has three elements: capacity of the consent-giver, information supplied to the consent-giver, and voluntary action by the consent-giver.

<sup>4</sup> 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

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**People with intellectual and/or developmental disabilities<sup>1</sup> (I/DD), 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.**

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### Issue

People with I/DD 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 I/DD, 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 I/DD 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 I/DD 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 I/DD who live with elderly parents.

However, people with I/DD 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 I/DD, 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 I/DD at risk of unnecessary institutionalization or homelessness.

## Position

People with I/DD 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 I/DD the opportunity to interact with people without disabilities to the fullest extent possible.
- The health and safety of people with I/DD 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 I/DD 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 I/DD should receive the supports they need to transition out of the family home when they wish to do so.
- Housing for people with I/DD must be coordinated with home and community-based support systems, including transportation services, and should ensure access to other typical public resources.
- 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 I/DD 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 I/DD. 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 I/DD, regardless of type or severity of disability.
- Affordable housing options must be available to people with I/DD, 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 I/DD receive their fair share of all local, state, and national housing resources.

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- Universal design and visitability<sup>2</sup> 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 I/DD 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.

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Rev'd 2017

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<sup>1</sup> “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) Manual, *Intellectual Disability: Definition, Classification, and Systems of Supports*, and the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM IV)*, published by the American Psychiatric Association (APA). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care. (II) Receptive and expressive language. (III) Learning. (IV) Mobility. (V) Self-direction. (VI) Capacity for independent living. (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

<sup>2</sup> **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.

## Individual Supports

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**People with intellectual and/or developmental disabilities<sup>1</sup> (I/DD) must have access to individual supports, such as assistive technology and personal assistance, to support their participation in daily life.**

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### Issue

People with intellectual and/or developmental disabilities are often able to better perform basic tasks of everyday life such as communicating, interacting with others, completing daily living routines, and moving in and around their homes and communities when individual supports are provided when needed. 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. For many people, the opportunity to create individual supports is limited by the availability of funding due in some cases to waiting lists and the institutional bias in Medicaid.

### Position

People with intellectual and/or developmental disabilities must have access to the supports necessary to lead a meaningful life in the community. These supports should be provided based upon functional needs and choice. Supports should lead to opportunities for community involvement and development of individual interests.

Individual supports may include:

- **Personal assistance.** Adults with intellectual and/or developmental disabilities (and parents of minor children with I/DD) should be able to hire and fire personal assistants to help them perform everyday activities, make decisions, and exercise control over their lives.
- **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 enhance independence, mobility, communication, environmental control, and self-determination. The ways assistive technology can be used must be assessed throughout a person's life cycle and as needs change. Designers, manufacturers, service providers, educators, and people with I/DD and their families should be educated about the benefits of technology.

Supports must be individually planned and applied according to the principles of person-centered planning, self-determination and individual outcomes, flexible funding, and team collaboration. The individual supports must be independently and regularly monitored for quality, safety, and effectiveness.

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## *Opportunities for Financial Asset Building*

**People with intellectual and/or developmental disabilities<sup>1</sup> (I/DD) 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 I/DD face greater economic inequalities than their peers without disabilities. People with I/DD 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 ABLÉ 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 I/DD 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<sup>2</sup> 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.<sup>3</sup>

### *Position*

Individuals with I/DD 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 ABLE 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 I/DD 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 I/DD 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;
- 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.

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*Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.

<sup>2</sup> 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>

<sup>3</sup> 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*. Washington, DC: American Association on Intellectual and Developmental Disabilities (AAIDD).

## *Parents with Intellectual and/or Developmental Disabilities*

**The presence of an intellectual and/or developmental disability<sup>1</sup> does not in itself preclude effective parenting; therefore, the rights of parenthood must not be denied individuals solely on the basis of intellectual and/or developmental disabilities. Parents with intellectual and/or developmental disabilities should have access to support as needed to perform parental roles just as they are supported in other valued social roles and activities.**

### *Issue*

The history of discrimination toward individuals with intellectual and/or developmental disabilities includes the denial of rights and opportunities to have and to raise their own children. This history has included segregation and involuntary sterilization of adolescents and adults. After birth, infants have been removed immediately from parental care, and through legal provisions, parents have been denied the opportunity to raise their children in their home.

Examples of social and social service biases and discriminatory practices include:

- Presumption of incompetence, that is, a general belief that people with intellectual and/or developmental disabilities are unfit to be parents;
- Limited supports to parents with intellectual and/or developmental disabilities;
- Professional emphasis on limitations of parents with intellectual and/or developmental disabilities to the point of weakening parents' sense of competence and potential for success;
- Public resources primarily focused on crisis-driven support;
- Lack of trust of service providers or government officials by parents with intellectual and/or developmental disabilities based upon fears of losing their children and their vulnerability to arbitrary authority; and
- Disproportionate representation of parents with intellectual and/or developmental disabilities in child custody proceedings, where, their competence as parents is held to higher, less flexible and more frequently applied standards than those applied to other parents.

Despite research which documents the ability of many parents with intellectual and/or developmental disabilities to raise a child successfully with appropriate and effective supports, access to these supports continues to be limited, fragmented and

uncertain. Few specialized programs exist. Many family support and early intervention programs are not equipped to provide the intensive and ongoing supports that parents with intellectual and/or developmental disabilities and their children are likely to require.

## *Position*

All adults, when provided access to appropriate and effective supports as needed to fulfill the basic responsibilities of child rearing, are more likely to be effective in their roles as parents.

Parents with intellectual and/or developmental disabilities and their children deserve social and health supports that:

- Recognize the need of parents to be viewed as unique individuals able to learn and improve in their skills and to respond to the needs of their children;
- Distinguish the effects of the family's living conditions and economic status independently from assessing ability to perform a parenting role;
- Build a trusting relationship between the parents, child, and those who provide formal and informal supports to them;
- Recognize, include, and engage the informal supports of family members, neighbors, and their community members to assist parents and the family as a whole;
- Recognize that as the needs of children change, parenting skills must evolve and may require new forms of support for parents and children;
- Respond to the unique learning needs of parents with intellectual and/or developmental disabilities;
- Assist parents in becoming actively engaged in their children's school and community;
- Reflect the full range and multiple components of effective support programs including, as needed:
  - in-home visits to teach parenting skills;
  - assistance with daily living skills;
  - access to nutritional resources such as “ready to feed” formula;
  - child care, early intervention services, and counseling;
  - basic academic education for parents;
  - assistance in accessing public benefits as appropriate;
  - crisis intervention services, availability of intensive supports as needed, and volunteer mentoring programs; and
- Assure that access to parent supports and to the environments and programs in which parental participation is beneficial to the child and family are provided with proper consideration of Section 504 of the Rehabilitation Act, the Americans with Disabilities Act, and related accommodations.

The Arc of the United States and the American Association on Intellectual and Developmental Disabilities support adoption of the United Nation's Convention on the Rights of Persons with Disabilities. Article 23, “Respect for Home and the Family,”

Obligation 4 states that “Parties shall ensure that a child shall not be separated from his or her parent against their will, except when competent authorities subject to judicial review determine, in accordance with applicable laws and procedures, that such separation is necessary for the best interests of the child. In no case shall a child be separated from parents on the basis of a disability of either the child or one or both of the parents.”

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Rev'd 2013

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## Sexuality

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**People with intellectual disability and/or developmental disabilities<sup>1</sup>, like all people, have inherent sexual rights. These rights and needs must be affirmed, defended, and respected.**

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### Issue

For decades, people with intellectual disability and/or developmental disabilities 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 disability in gender identity, friendships, self-esteem, body image and awareness, emotional growth, and social behavior. People with intellectual or developmental disabilities 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 an intellectual or developmental disability, 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 intellectual or developmental disabilities 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.

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## *Spirituality*

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

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### *Issue*

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

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

### *Position*

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

- Spirituality is an important part of human experience that may be expressed both through religious practice and through other spiritual activities which carry personal meaning and reflect the person's values;
- Supports and accommodations, such as transportation and easy-to-read materials, must be provided as needed to facilitate the individual's full participation in spiritual or religious activities of her/his choice;
- Supports and programs should be age-appropriate and inclusive;
- Faith communities should be encouraged to build their capacity to support and welcome individuals with intellectual and/or developmental disabilities and their families, and should be assisted in such efforts;

- Self-advocates, families, advocacy organizations, service providers, and faith communities should work together to develop training and other resources on the inclusion and support of people with intellectual and/or developmental disabilities and their families; and
- People with intellectual and/or developmental disabilities bring their own unique spiritual gifts and benefits to spiritual and religious communities, just as people without disabilities do.

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Rev'd 2015

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## Transportation

**People with intellectual and/or developmental disabilities<sup>1</sup> must have access to both public and private transportation to lead full, independent lives.**

### Issue

Our constituents lack sufficient access to mass transit, paratransit, trains, ferries, airplanes, their own vehicles, and other modes of transportation to perform everyday activities. Even where accessible public transportation exists, adults with disabilities consider transportation inadequate. In the U.S., 24 million individuals with disabilities use public transit to maintain their independence and participate fully in society. For many, it is their only transit option.

Although federal and state legislation encourages more people with all types of disabilities to go to work, getting to work requires transportation. Inadequate transportation inhibits community involvement. Those living in rural areas often face the greatest challenge of all due to total lack of public transportation and long distances between destinations.

### Position

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

- There is increasing flexibility and growth in available transportation options throughout the U.S. for our constituents, including those in rural areas.
- Public transportation is adequately funded and available.
- Existing public transportation is accessible, available in a timely manner, and equipped to suit the physical, sensory, and/or cognitive needs of all people.
- Paratransit systems for those who need them must be available at comparable cost and funded as an alternative to mass transportation.
- Our constituents have the option of owning and operating their vehicles.

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POSITION STATEMENTS:  
THE ARC OF THE UNITED STATES

*Policies Related  
to Systems*

## *Systems Summary*

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**Systems are necessary to support people with intellectual and/or developmental disabilities<sup>1</sup> and their families to enable them to live their lives like other people. These support systems must be of high quality and focused on the people and their families, not the staff.**

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

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/or other developmental disabilities (I/DD), but rather strive to maximize the independence and enhance quality of life for people with I/DD. The Nation must continue to investigate the causes, avoid those that are preventable, and limit negative effects of conditions that cause I/DD through basic, applied, and clinical research, public awareness, education, advocacy, early intervention, and appropriate supports.

### *Long Term Supports and Services*

Individuals with intellectual and/or developmental disabilities (I/DD) deserve the opportunity for a full life in their community where they can live, learn, work, and socialize. To achieve this goal, they need a comprehensive, person-centered and directed, national system of appropriate high quality long-term supports and services (LTSS), with a reliable and immediately accessible funding source, including Medicaid, and a well-trained, fairly compensated workforce of providers and direct support professionals. Waiting must be eliminated.

### *Research*

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

## Support Coordination

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

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

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**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/or other developmental disabilities<sup>1</sup> (I/DD), but rather strive to maximize the independence and enhance quality of life for people with I/DD. The Nation must continue to investigate the causes, avoid those that are preventable, and limit negative effects of conditions that cause I/DD through basic, applied, and clinical research, public awareness, education, advocacy, early intervention, and appropriate supports.**

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### *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 I/DD and valuing the lives, diversity, and contributions of persons with I/DD 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 I/DD. When individuals with I/DD 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 I/DD through prevention programs, policies, and practices which must include:

#### ***Research***

- Research on the conditions that cause I/DD, 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 I/DD 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 I/DD;
- 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 I/DD, such care must meet the mother's disability and communication needs;
- Disability sensitive information and supports for post-natal care for mothers with I/DD;
- Programs to ensure that pregnant women (including those with I/DD), 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 I/DD 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 I/DD, such as insect-borne diseases like the 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 I/DD resulting from PKU and hypothyroidism; and
- Enforcement of existing public policies designed to prevent I/DD.

## Quality of Life

Investigating the causes, avoiding those that are preventable, and limiting negative effects of conditions that cause I/DD will contribute to individual and family quality of life. It is also imperative that individuals with I/DD 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 I/DD 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 I/DD;
- Continued research into and application of promising interventions, best practices, and community-based supports that maximize independence and enhance quality of life for individuals with intellectual and/or developmental disabilities; and
- Dissemination of knowledge about research-based best practices.

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## *Long Term Supports and Services*

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**Individuals with intellectual and/or developmental disabilities<sup>1</sup> (I/DD) deserve the opportunity for a full life in their community where they can live, learn, work, and socialize. To achieve this goal, they need a comprehensive, person-centered and directed, national system of appropriate high quality long-term supports and services (LTSS), with a reliable and immediately accessible funding source, including Medicaid, and a well-trained, fairly compensated workforce of providers and direct support professionals. Waiting must be eliminated.**

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### *Issue*

Many barriers remain to ensuring that people with I/DD receive the long term supports and services they require to live a full life in the community.

#### *National Crisis of Unmet Needs*

The lack of a comprehensive community long term supports and services system is a national crisis requiring immediate national solutions. The patchwork of limited private LTSS options and the current public program are not designed to address or capable of meeting the demand for community-based LTSS for people of all ages. Individuals and families are forced to navigate a complex, frequently uncoordinated system of care including state-specific publicly funded services, limited supports funded by private pay and charitable giving, and often no clear path to assistance. Many individuals and families experience extraordinary stress due to lack of supports and services. Family caregivers play a critical role in providing services and supports. Almost a million Americans with I/DD are living at home with a caregiver of retirement age. Relying on families to provide care cannot be a substitute for creating a national solution to ensure that everyone who needs LTSS receives them.

#### *Quality Supports and Services*

Many individuals with I/DD have not had the opportunity or the support to make choices and decisions about important aspects of their lives. Ensuring that our system of LTSS is based on principles of self-determination, person-centered planning, and individualized supports is critical to having a system that supports people with I/DD. Too often decisions about supports and services are based on availability and cost, not on a person-centered approach made independently of the self-interests of the funder and/or the provider of services. Many people either accept services and supports that are available, but inappropriate and/or inadequate, or receive no supports at all.

## ***Medicaid***

While Medicaid is the lifeline for individuals with I/DD, it falls short of meeting their needs. Medicaid has been the major funding source for all LTSS for people with I/DD. Today most LTSS for people with I/DD are community supports and services; however, the institutional bias remains in the Medicaid program. To become or remain eligible for vital Medicaid LTSS, most people seeking services are forced to impoverish themselves and remain poor for a lifetime. To make matters worse, both federal and state policy makers have attempted to scale down the growth of Medicaid through regulatory and eligibility changes, budget cuts, and program changes designed to reduce costs rather than improve or expand services and supports. Increasingly states are shifting the management of LTSS to managed care organizations — a process that may result in more barriers to needed services.

## ***Waiting Lists and Unmet Needs***

The prevalence of people waiting for services and supports is an unacceptable national crisis. Often a state will not even have a process for developing and monitoring a waiting list for Medicaid supports and services. Individuals with disabilities often have to experience the death of a parent, a medical emergency, or other tragic event to obtain the services from Medicaid that they need. They are thus thrust into a new situation without planning at a time of family crisis. Individuals with I/DD remain on waiting lists for years — in some states it can take a decade or more — after requesting necessary supports and services. If ongoing supports and services are not available to young adults with I/DD transitioning out of the education system, educational gains will be lost.

## ***Direct Support Professionals***

The quality and effectiveness of LTSS for persons with I/DD depend upon qualified providers of supports and services with necessary skills and training. Inadequate compensation hampers both recruitment and retention. Inadequate funding for training of direct support professionals (DSPs) and their supervisors, as well as lack of sufficient supervision, threatens health and safety.

# ***Position***

A comprehensive system of LTSS must include the following:

## ***National Solution***

- An LTSS system must enable anyone of any age and disability to obtain LTSS when needed;
- The system must include private and public financing mechanisms because the obligation to provide LTSS is not just a personal responsibility but a shared, societal responsibility;
- The system must be sustainable so that people can count on getting what they need when they need it; and
- Individuals or their families should not be required to impoverish themselves to receive the supports and services they need to live.

### ***Quality Supports and Services***

- It is not only a choice but also a basic civil right that individuals have adequate and appropriate supports and services needed for them to live in the community;
- Individuals must have opportunities to design and direct their own services to the extent that they wish and with the assistance they need;
- Plans must be person-centered and based on the unique needs of the individual and accompanied by measured progress toward person-centered outcomes and flexible funding to meet changing circumstances;
- Services must be delivered promptly in the most integrated setting and with sufficient quality and quantity to meet individual needs; and
- Effective quality monitoring programs to measure the individual and systems outcomes of LTSS need to be in place in every state.

### ***Medicaid***

- Medicaid must remain a viable option for individuals who need LTSS and have no access to private insurance options;
- Medicaid programs must enable people to participate fully in their communities, experience a high quality of life and, as adults, achieve economic security and personal independence;
- Medicaid programs should fund person-centered community supports and services with continuing efforts to redirect Medicaid funding from institutional care to home and community-based supports;
- Medicaid funding must be portable across states and other political jurisdictions;
- Medicaid funding must provide for living wages and decent fringe benefits to direct support workers;
- Medicaid reform must preserve the individual entitlement and not simply shift costs to individual beneficiaries or states and must preserve consumer protections such as minimal cost-sharing, appeals and grievance procedures, and independent assessments;
- Medicaid reform must address waiting lists and unmet needs and the quality of service providers and staff; and
- Medicaid service delivery system redesign must be transparent and involve meaningful input of all stakeholders.

### ***Waiting Lists and Unmet Needs***

Individuals who need LTSS should not have to wait to receive them. Because there is an absence of a national system of LTSS, where waiting exists at the state level:

- Public systems must actively reach out to individuals and to families with unmet 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 the availability of or enrollment in 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 supports and services immediately.

### ***Direct Support Professionals (DSPs)***

- Wages, benefits, and professional development opportunities must increase for DSPs so as 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 to individuals. DSPs must receive training in the philosophy of self-determination and the value of full inclusion and community participation of individuals;
- National, state, and local private and public entities must engage in policy initiatives to recruit, train, and retain a high quality direct support workforce;
- Individuals who wish to employ DSPs must have access to high quality information, technical assistance, and training;
- Federal and state quality assurance programs must assess and monitor DSP vacancy rates, recruitment and retention, and competence as part of licensure, in order to recognize positive performance and to direct assistance to those programs with unacceptable performance;
- States must utilize a system for criminal background checks for all public and private DSPs working in the state; and
- States must also develop and make available a list of individuals for whom abuse and neglect charges have been substantiated.

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Rev'd 2014

Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

<sup>1</sup> “People with intellectual disability (ID)” refers to those with “significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. This disability originates before age 18”, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, *Intellectual Disability: Definition, Classification, and Systems of Supports* (Schalock et al., 2010), and the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5)*, published by the American Psychiatric Association (APA, 2013). “People with developmental disabilities (DD)” refers to those with “a severe, chronic disability of an individual that- (i) is attributable to a mental or physical impairment or combination of mental and physical impairments; (ii) is manifested before the individual attains age 22; (iii) is likely to continue indefinitely; (iv) results in substantial functional limitations in 3 or more of the following areas of major life activity: (I) Self-care, (II) Receptive and expressive language, (III) Learning, (IV) Mobility, (V) Self-direction, (VI) Capacity for independent living, (VII) Economic self-sufficiency; and (v) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated,” as defined by the *Developmental Disabilities Assistance and Bill of Rights Act 2000*. In everyday language people with ID and/or DD are frequently referred to as people with cognitive, intellectual and/or developmental disabilities.



## Research

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

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### Issue

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

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

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

### Position

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

- Government and private entities must provide adequate funding to support research;
- Advocacy, service provider and professional organizations, government agencies, the research community, and people with intellectual and/or developmental disabilities and their families must work together in defining, evaluating, and promoting a research agenda;

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

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

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

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Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

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

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

## Support Coordination

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

### Issue

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

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

### Position

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

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

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

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Rev’d 2015

Joint Statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

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



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