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POSITION STATEMENTS

APRIL 2025

The Arc®

For people with intellectual
and developmental disabilities

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INTRODUCTION

The Arc

The Arc is the largest national community-based organization advocating for and serving people with intellectual and developmental disabilities (IDD) 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 IDD and their family members, including individual and public policy advocacy and residential, educational, and vocational services that support people with IDD 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 IDD and their families.

The Arc has a rich history spanning over 70 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, siblings, and families, 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

Human Dignity

People with IDD have human dignity. The lives of people with IDD have value.

Personhood

People with IDD have varying strengths, abilities, and interests. Each person is unique.

Choice

People with IDD can make decisions about their lives. People with IDD should be supported to do so as requested or needed.

Rights

People with IDD have human and civil rights, which must be protected.

Community

People with IDD are part of and contribute to the fabric of society. Everyone benefits when people with IDD are present and participate.

Support

People with IDD have differing support needs. Society must support people with IDD to achieve their full potential. Society should also help families who provide support for loved ones with IDD.

Equity

Society must remove barriers and correct injustices that limit opportunities for people with IDD. Extra action is needed to help people with IDD and their families, who face other forms of bias or discrimination.

Diversity

Human diversity is beautiful and powerful. We celebrate, honor, and seek to understand the differences in our identities and life experiences.

Guiding Principles

Advocacy First

The Arc is a disability rights organization. We work with and for people with IDD, their families, and our communities to achieve change. We use the power of advocacy to improve the lives of people with IDD.

Stronger Together

The Arc unites our chapters to advance the human rights and wellbeing of people with IDD and their families. The success of our advocacy depends on the strength of the chapter network. We are stronger together.

Quality and Excellence

The Arc provides programs and services that people with IDD and their families want and depend upon in their daily lives. We strive for quality and excellence in all we do.

Shared Leadership

The Arc actively engages people with IDD and their family members in leading and guiding our work. These voices are the most important. The strong partnership between volunteer, experts, and the people we serve is critical to our mission.

Consensus

The Arc leads by building consensus around a clear vision for the future of people with IDD. We unite and mobilize people behind goals and strategies that will make that vision a reality.

For All People with IDD

The Arc works with and for ALL people with IDD. While our work also helps all people with disabilities, our priority is people with IDD and their families.

Partnership

The Arc works in coalition with other disability, civil rights, and human services groups. We value joint effort and step up to provide leadership when needed.

Open and Accountable

The Arc is accountable to people with IDD, their families, donors, and the public. We are committed to honesty and transparency.

Identity and Language

The Arc respects the rights of people with IDD to decide if or when to self-identify and the language they use when doing so.

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.

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

Joint statements: The Arc has many position statements which are written jointly with the American Association on Intellectual and Developmental Disabilities (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.

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

Definitions: For each position statement, a footnote is included with a reader-friendly definition of intellectual disability, developmental disabilities, or both, depending on the statement However, for those readers who need the more detailed information, see the following:

"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" that manifest during the developmental period, as defined by the American Association on Intellectual and Developmental Disabilities (AAIDD) in its manual, Intellectual Disability: Definition, Diagnosis, Classification, and Systems of Supports, 12th Ed. (Schalock, Luckasson, and Tassé, 2021), and in the Diagnostic and Statistical Manual of Mental Disorders, 5th Ed. Technical Revision (DSM-5-TR) of the American Psychiatric Association (APA, 2021).

"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 Quality of Life

The Arc

QUALITY OF LIFE SUMMARY

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

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

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

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

QUALITY OF LIFE

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

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;

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- 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.

Reviewed/Revised 2021

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

POSITION STATEMENTS:
The Arc of The United States

Policies Related to Rights

The Arc.

RIGHTS SUMMARY

People with intellectual and/or developmental disabilities[1] 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.

ADVOCACY

Advocacy 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, or behaviors of government agencies, businesses, and others. Advocacy is essential for promoting and protecting the civil and human rights of people with intellectual and/or developmental disabilities (IDD). All advocacy efforts by, with, and on behalf of people with IDD must be centered around the views, needs, expressed interests, and leadership of self-advocates.

ANTI-RACISM

Racism is the systemic prejudice, discrimination, or antagonism directed towards a person or people based on their membership in a particular racial or ethnic group, typically one that is a minority or marginalized. Anti-racism means being committed to the daily work of identifying and disrupting racism in both its implicit and explicit manifestations. This includes looking at public policy work with an intersectional lens, considering the intentional or unintentional impact upon people of color with intellectual and/or developmental disabilities (IDD). It also includes partnering with all Black, Indigenous, and people of color with IDD because they are uniquely capable of providing the leadership required to truly address issues at the intersection of disability and racial justice.

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

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

AUTONOMY, DECISION-MAKING SUPPORTS, AND GUARDIANSHIP

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

CRIMINAL JUSTICE SYSTEM

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

HUMAN AND CIVIL RIGHTS

All people have human rights and are entitled to the protection and benefits of the civil rights laws of their country. This includes people with intellectual and/or developmental disabilities (IDD). They are entitled to exercise their rights and to have their human rights and civil rights respected. When their rights are violated, they are entitled to protection and rights restoration.

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 AND LEADERSHIP

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

SELF-DETERMINATION

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

ADVOCACY

Advocacy 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, or behaviors of government agencies, businesses, and others. Advocacy is essential for promoting and protecting the civil and human rights of people with intellectual and/or developmental disabilities[1] (IDD). All advocacy efforts by, with, and on behalf of people with IDD must be centered around the views, needs, expressed interests, and leadership of self-advocates.

ISSUE

People with IDD often do not have access to the supports or opportunities they need to exercise their civil and human rights due to ableism and social, systemic, and institutional discrimination. Strong advocacy is necessary to support the full inclusion and participation of people with IDD in the community. Effective advocacy is also required to prevent and address abuse, neglect, discrimination, implicit and explicit bias, and any exploitation that people with IDD may experience.

POSITION

To achieve their goals, advocates must be able to interact directly with those responsible for policies and practices that affect their lives, including public officials, private and government-funded support system leaders, other advocates, business leaders, and the general public. Self-advocates are people with lived experiences as people with IDD. Advocacy efforts should be led by self-advocates, sharing their stories, views, and expressed interests. Organizational advocacy efforts must be inclusive and accessible to all, regardless of age, gender identity and expression, race and ethnicity, sexual orientation and sexuality, communication and expression, culture, faith or religion, location, economic status, immigration and legal residency status, familial status, support need, or disability.

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Advocates include individuals with and without IDD, family members, groups, and organizations that promote the human rights of people with IDD and support their full inclusion in the community. It is important that:

- Advocates have tools and information to understand political, legal, and disability services systems.
- People with IDD and families have resources to educate and empower them to be a force for change.
- People with IDD and their families have support to effectively navigate service delivery systems.
- Advocates understand the issues that people with IDD face and get to know the people they are advocating for.
- Advocates facilitate opportunities and support the empowerment of people with IDD to advocate for themselves.
- Advocates who need support get the support they need; supporters should respond to their support needs and provide education, as needed.
- Advocates are not threatened or retaliated against for their advocacy.
- Advocacy efforts involve whole communities, not just people with IDD.

Advocacy is critical for supporting the needs of an individual as well as for broader systemic change. Advocacy helps ensure the full exercise, enjoyment, and enforcement of human and civil rights for people with IDD. Advocacy is important to ensure marginalized groups have access to culturally responsive services and supports. Advocacy also is vital to influencing laws and policies to improve systems of support and services, both for those who currently receive services and for generations to come.

Advocacy can happen informally and formally. For example, informal advocacy can take place through educational activities, personal conversations, and social media posts. Examples of formal advocacy can include sending letters, individual or group meetings, public testimony, rallies, education forums, town halls, meetings with legislators and other policymakers, and litigation.

In certain situations, individuals with IDD need legal advocacy. There are federally mandated Protection and Advocacy (P&A) systems in each state that advocate for and protect the rights of people with disabilities, along with other forms of public legal assistance. Any form of public legal assistance must be available and accessible to people with IDD and must:

- Be able to respond to issues concerning any stage of life;
- Be independent of conflicts of interest, undue influence, and government control;
- Be adequately funded and staffed;
- Provide advocacy on behalf of clients even when a formal complaint has not been filed;

- Be subject to appropriate oversight to assure their quality, cost effectiveness, efficiency, and high standards;
- Be informed by data collection and available research on the needs and rights of people with IDD; and
- Be able to deliver multiple advocacy strategies, such as information and referral, mediation, legal action, legislative and regulatory solutions, and appeals for unfavorable decisions.

All advocacy efforts must follow the lead of self-advocates, sharing their stories, views, and expressed interests.

Reviewed/Revised 2022
Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

ANTI-RACISM

Racism is the systemic prejudice, discrimination, or antagonism directed towards a person or people based on their membership in a particular racial or ethnic group, typically one that is a minority or marginalized. Anti-racism means being committed to the daily work of identifying and disrupting racism in both its implicit and explicit manifestations. This includes looking at public policy work with an intersectional lens, considering the intentional or unintentional impact upon people of color with intellectual and/or developmental disabilities[1] (IDD). It also includes partnering with all Black, Indigenous, and people of color with IDD because they are uniquely capable of providing the leadership required to truly address issues at the intersection of disability and racial justice.

ISSUE

Today, as throughout history, racism is embedded at the individual, institutional, and structural levels of society. To be anti-racist is to actively identify these embodiments and work to reverse and repair them. The first step in being anti-racist is acknowledging how biases can be intentional, unconscious, or unintentional. It is also critical to acknowledge that people with multiple marginalized identities experience complex challenges because of their intersectional identities. People of color with IDD face more profound challenges because of historical and current barriers. Some examples of these challenges include:

- **Inequity in Education:** Children of color are more likely than their White peers to be identified with a disability in schools with a majority White census but are substantially under-identified in schools that have high percentages of students of color. Additionally, Black students are more likely to be misdiagnosed or categorized with an intellectual disability or emotional disturbance, while more accurate diagnoses of learning disabilities,

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autism, or speech/language impairment remain unrecognized. Students of color are also more likely to be restrained and secluded. They are more likely to be placed in a restrictive classroom setting than their White peers.

- **Disproportionate interactions with the criminal legal system**: Law enforcement disproportionately interacts with people of color. People with disabilities are overrepresented amongst those who are injured or killed by law enforcement. The lack of a crisis response system that can serve people with IDD and people with co-occurring IDD and mental health disabilities contributes to these horrific instances. In schools, the presence of school resource officers and other law enforcement agents often lends to the unnecessary and harmful criminalization of students of color with disabilities, as early as elementary school. Threat assessment teams target those same students for behaviors related to their disabilities. These early interactions compound the likelihood that people of color with disabilities will be forced into the criminal legal system, contributing to the preschool to prison pipeline.

- **Systemic Health Inequities and Access to Health Care Services**: People of color experience far more barriers to quality health care and health insurance than White Americans, systemically leading to negative health outcomes. On average, communities of color experience a significantly higher incidence of chronic health conditions. People with IDD are already more likely to develop common health conditions such as high cholesterol, high blood pressure, cardiovascular disease, obesity, and diabetes; rates are even higher for people of color with IDD. Additionally, people of color have historically experienced a breakdown of trust with health care providers because of inequities in access and the provision of services. Studies have demonstrated that many health care providers carry implicit biases towards people of color, perhaps most shockingly demonstrated in the mortality and morbidity rates of Black mothers in childbirth. These mothers are more likely to develop a disability and are more likely to give birth to premature babies who, if they survive, often develop chronic complex medical conditions. A history of sterilization of people with disabilities, including a disproportionate number of people of color with disabilities, as well as illicit medical experimentation involving people of color, has increased distrust. Other systemic gaps, such as a lack of accessible transportation in Tribal and other areas, has kept people of color from getting the care they need.

- **Housing Discrimination:** Historically, many people with disabilities, especially those with the highest needs, were forced to live in large, congregate residential treatment institutions that isolated the residents from the rest of society. These facilities also discriminated on the basis of race and treated people of color with disabilities differently. People of color with disabilities continue to face the risk of institutionalization in the modern versions of these facilities and face housing discrimination when they seek homes in communities of their choosing. People of color have been excluded from housing through block-by-block segregation, restrictive covenants, redlining, and racially targeted subprime loans, along with other discriminatory practices. The current greater rates of housing insecurity for communities of color are a legacy of these practices, many of which continue to this day. They are compounded for people of color with disabilities who might also need wheelchair access or deaf-accessible housing. Black and Latino renters are more likely than any other group to face eviction.

- **Socioeconomic Inequalities:** People of color with IDD face compounded barriers to financial independence through employment discrimination, barriers to banking services, medical debt, geographic food deserts, and exposure to unsafe housing (such as lead poisoning), and environmental racism (such as disproportionate rates of asthma and lung disabilities for families of color living in high pollution areas). These historical factors all prevent people of color from building wealth and disproportionately impact the generational wealth of families of color, especially those with family members with IDD.

POSITION

To be anti-racist, all policy reform efforts must include the voices of and perspective of people of color with disabilities. Policy work then must move forward to enact necessary changes with and in support of the efforts of people of color and disability-led organizations. To do this work, policy and advocacy efforts must:

- Acknowledge the impacts that racism and the intersectional aspects of racism have had on existing systems.
- Acknowledge the role that all organizations, including our own, have in perpetuating racist systems and structures.
- Analyze and identify specifically racist structures and biases that impact people of color with IDD.
- Actively advocate in response to circumstances that have a significant impact on people of color with IDD.
- Engage people of color from diverse communities in ways that are culturally respectful and intentional, ensuring that they are present, heard, and supported at every level of leadership and in all federal policy work.
- Prioritize efforts to eliminate racist barriers, systems, and biases, including reversing the impacts of historical discrimination, while working towards collective access.
- Demonstrate a commitment to cross-disability solidarity by ensuring that each person, regardless of their disability, has an option to be a part of the disability justice movement.
- Support efforts of people of color with disabilities and the disability and racial justice movements.
- Examine internal priorities and efforts continually to ensure they are actively anti-racist.

Reviewed/Revised 2022

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

AUTONOMY, DECISION-MAKING SUPPORTS, AND GUARDIANSHIP

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

ISSUE

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

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

- All people, with and without disabilities, have a variety of formal and informal processes available to enact their decisions and preferences, including healthcare proxies and advance directives.
- Less restrictive means of decision-making supports (*e.g.*, health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship[2] as an option is considered.
- Where judges and lawyers lack knowledge about people with IDD and their human rights, poor advocacy and tragic legal outcomes often result. Financial incentives frequently benefit professionals and guardianship corporations, often to the detriment of individuals with IDD and their families.
- Serving in the dual roles of guardian and paid service provider or paid advocate creates a conflict of interest or the appearance of a conflict of interest. Such conflicts must be mitigated or avoided.
- Some statutory privacy measures have made it more difficult for those assisting other individuals to have access to their records, make decisions, or both. Thus, to obtain or modify needed medical care, services, and supports, an individual with IDD may be adjudicated to be incompetent and subjected to guardianship. This result conflicts with the legal presumption of competence and with principles of autonomy, decision-making supports, presumption of competence, and the use of less restrictive alternatives.

The appointment of a guardian is a serious matter for three reasons:

1) It limits an individual's autonomy, that is, the individual's agency over how to live and from whom to receive supports to carry out that choice;
2) It transfers the individual's rights of autonomy to another individual or entity, a guardian; and
3) Many individuals with IDD experience guardianship as stigmatizing and inconsistent with their exercise of adult roles and responsibilities.

POSITION

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

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

- If legal limitations on autonomy are necessary, then National Guardianship Association or equivalent standards that are consistent with the values expressed in this position statement should be followed. If any restrictions on autonomy are legally imposed, each individual has the right to the least restrictive alternative, due process protections, periodic review, ongoing training and supports to enhance autonomy and reduce reliance on approaches that restrict individual rights, and the right to ultimately seek to restore rights and terminate the restriction when possible.
- Information and training about less restrictive alternatives to guardianship should be available to people with IDD, their family members, attorneys, judges, and other professionals.
- If the use of a guardianship becomes necessary, it should be limited to the fewest restrictions necessary for the shortest amount of time and tailored to the individual's specific capacities and needs.
- Strict monitoring must be in place to promote and protect the autonomy, liberty, freedom, dignity, and preferences of each individual even when placed under guardianship.
- Regardless of their guardianship status, all individuals with IDD should be afforded opportunities to participate to the maximum extent possible in making and executing decisions about themselves. Guardians should engage individuals in the decision-making process, ensuring that their preferences and desires are known, considered, and achieved to the fullest extent possible.
- Regardless of their guardianship status, all individuals with IDD retain their fundamental civil and human rights (such as the right to vote and the right to make decisions related to sexual activity, marriage and divorce, birth control, and sterilization) unless the specific right is explicitly limited by court order.

Systems Issues

- States should provide systematic access to decision-making supports for all individuals with IDD.
- An individual (other than a family member) should not serve in dual roles as guardian and as paid advocate or paid service provider for an individual.
- An organization should avoid serving in dual roles as guardian and as paid advocate or paid service provider for an individual.
- Organizations that serve in dual roles of guardian and paid advocate or paid service provider must have written policies and organizational separations in place to mitigate conflicts of interest. These organizations should support efforts to develop independent guardianship organizations.
- Financial incentives that benefit professionals or guardianship corporations should never drive guardianship policy or result in expensive and unnecessary costs to individuals or their families.
- Appointment of a guardian of the person, the person's finances, or both, should be made only to the extent necessary for the legal protection and welfare of the individual and not for the convenience or preferences of the family, the service system, or others.
- Individuals with IDD must have access to all the accommodations and supports,

including communication supports, they need to demonstrate their competency at initial evaluations for guardianship and at all periodic reviews of any guardianship.

- State laws should be reformed to prioritize less restrictive alternatives to full and plenary guardianship, including without limitation informal supports, supported decision-making, limited (and revocable) powers of attorney, health care proxies, trusts, and limited guardianships that are specifically tailored to the individual's capacities and needs. These alternatives should always be considered first. Use of these alternatives can help an individual who may have limited capacity to consent to satisfy statutory privacy or other requirements and to have records released to a person or entity designated as the individual's agent or provider of support and services. If used at all, any restrictions on the individual's rights and decision-making powers should be confined to those areas in which the individual demonstrates a need for assistance that exceeds what can be provided through a less restrictive alternative.
- Laws should be reformed to require that less restrictive options are tried and found to be ineffective to ensure the individual's autonomy before full (plenary) guardianship is even considered. Alternatives and related procedures to change overly restrictive forms of any existing guardianship, including restoration of rights and termination of any guardianship, must be available under state law.
- Since guardianship represents a transfer of rights and the responsibility for exercising them, adequate safeguards must be in place to protect those rights. These safeguards include procedural due process (including without limitation the right to counsel representing the interests of the individual, impartial hearing, appeal, and burden and quantity of proof) must protect the individual's autonomy. The state must also ensure that the individual is informed and retains as much decision-making power as possible. The state should pay the costs of providing these due process protections and not impose the costs on families or on individuals with IDD.
- Members of the judiciary, attorneys, and other professionals need training and education on alternatives to guardianship for individuals with IDD, and they must zealously advocate for preserving the substantive and procedural rights of all individuals with IDD.
- If a guardian is to be appointed, the preferences and assent of the individual with IDD with respect to the identity and function of the proposed guardian should be considered.
- The appointment of a guardian should be appropriately time-limited in order to provide regular periodic review of the individual's current capabilities and functioning and whether a less restrictive alternative is now indicated. The reviews should include an independent professional assessment by a highly qualified examiner of the individual's functioning with necessary accommodations and communication supports. All costs of the review should be paid by the state and not imposed on individuals with IDD or their families.
- Guardianship should include a person-centered plan of teaching and/or supports for decision making so the individual with IDD will have opportunities to learn and practice the skills needed to be autonomous and to direct his or her own life. Understanding the nature and purpose of guardianship and understanding that most people with IDD can manage their own affairs with assistance and guidance should be part of transition planning in schools and of any curriculum or procedures that prepare the individual's person-centered plan for adulthood. Schools should not give legal advice to students and families, and

should provide students and families with information about less restrictive alternatives to guardianship.

- The ultimate goal of any such curriculum or procedures should be to ensure the individual's autonomy to the maximum extent possible, individualize decision-making supports for the individual, and ensure that the individual has maximum access to equal opportunity, independent living, full participation, and economic self-sufficiency, each with supports that take into account the individual's capacities and needs.

Guardian Responsibilities

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

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.

Reviewed/Revised 2021

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

CRIMINAL JUSTICE SYSTEM

People with intellectual and/or developmental disabilities[1] (IDD) have the right to justice and fair treatment in all areas of the criminal justice system, and must be afforded the supports and accommodations required to make justice and fair treatment a reality.

ISSUE

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

- **Unrecognized as having a disability.** Individuals with IDD are frequently undiagnosed or misdiagnosed, especially by evaluators, including law enforcement personnel, who are not trained in assessment of individuals with intellectual disability and who do not recognize common characteristics such as individuals' attempts to hide their disability. Defendants with IDD are often denied a fair evaluation of whether they are entitled to legal protection as having IDD on the basis of false stereotypes about what individuals with IDD can and cannot understand or do;
- **Victimized at high rates.** Individuals with IDD are significantly more likely to be victimized (at least two times more likely for violent crimes and four to ten times for abuse and other crimes), yet their cases are rarely investigated or prosecuted because of discrimination, devaluation, prejudice that they are not worthy of protection, and mistaken stereotypes that none can be competent witnesses. Their victimization comes in many forms including violence, oppression, financial exploitation, sexual exploitation, and human trafficking;

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

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

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

- **Denied redress.** Individuals with IDD are subject to routine denial of opportunities for legal redress because of outdated and stereotyped views of their credibility, their competence to testify, or their need for advocacy, supports, and accommodations;
- **Denied due process.** Individuals with IDD are often denied due process and effective, knowledgeable advocacy and legal representation at each stage of the proceedings; and
- **Discriminated against in sentencing, confinement, and release.** Individuals with IDD are subject to abuse and exploitation when incarcerated and denied either alternatives to incarceration or appropriate habilitation programs that would address their intellectual disability, and/or behavior, and help them return safely to the community. When incarcerated, individuals with IDD often serve extended time because they do not understand or cannot meet steps to reduce time and secure an earlier release.

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

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

While the Supreme Court ruled in *Atkins v. Virginia*[2] 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

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[2] *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.

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

When sentenced, individuals with IDD also must:

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

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[3] *Hall v. Florida,* 134 S. Ct. 1986 (2014).

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.

Reviewed/Revised 2021

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

HUMAN AND CIVIL RIGHTS

All people have human rights and are entitled to the protection and benefits of the civil rights laws of their country. This includes people with intellectual and/or developmental disabilities[1] (IDD). They are entitled to exercise their rights and to have their human rights and civil rights respected. When their rights are violated, they are entitled to protection and rights restoration.

ISSUE

Freedom from discrimination is a basic human right. Yet today, and historically, the human and civil rights of people with IDD have been unjustifiably denied or limited.

People with IDD form a diverse group, sharing the same characteristics found in society at large. People with IDD can be found among people of any age, gender identity and expression, race and ethnicity, sexual orientation and sexuality, communication and expression, culture, language, faith or religion, location, economic status, immigration and legal residency status, familial status, support need, and among people who have other disabilities.

Many identities and lived experiences, including IDD, are socially marginalized. Those with IDD who have additional marginalized identities – including those related to race, ethnicity, LGBTQ+[2] status, and poverty – are least likely to have their rights respected, protected, and enforced. Those at the intersection of multiple marginalized identities are most likely to experience oppression and violation of their human and civil rights.

People with IDD have the right to share in the benefits and riches of society and the world as well as the right to make their own contributions to their communities and society. They have often been denied these rights and opportunities.

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

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

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

[2] LGBTQ+ stands for lesbian, gay, bisexual, transgender, queer or questioning, and other expressions.

Human Rights

One of the purposes of the United Nations is to “reaffirm faith in fundamental human rights, in the dignity and worth of the human person …”, as stated in its 1945 charter. The UN’s Universal Declaration of Human Rights (1948) includes recognition of the inherent dignity and worth of, and equal and inalienable rights of, all members of the human family as the foundation of freedom, justice, and peace in the world. The Declaration, which the United States ratified in 1992, holds that human rights should be protected by law.

A number of UN covenants address human rights, most notably the right to individual autonomy and independence and the right to make one’s own choices. Other human rights noted in the Declaration and later covenants[3] include freedom from discrimination on the basis of disability; freedom from fear, torture, or inhuman or degrading treatment or punishment; and the right to accessibility and equality of opportunity for people with disabilities. They address self-determination, including control of own resources; availability of education for all; the right to work, fair wages, safe working conditions, and reasonable time off; and the right to be equal before the courts. Identified human rights are protected by civil rights laws of the various countries and enforced by governments, legal systems, and private actions.

Civil Rights

In the United States, civil rights are affirmed at the national level by the U.S. Constitution, the Bill of Rights, and the various civil rights laws. In practice, state and federal laws have failed to adequately protect or support people with disabilities and other marginalized identities. People with IDD, their families, and advocates filed numerous lawsuits, including class actions, over more than fifty years to enforce the rights of people with IDD at the state and federal levels.

In response, Congress has enacted many additional federal laws to establish, bolster, and further protect the civil rights of people with disabilities. Recent examples include Section 504 of the Rehabilitation Act, the Individuals with Disabilities Education Act (IDEA), the Civil Rights of Institutionalized Persons Act, the Americans with Disabilities Act (ADA) and its amendments, and provisions of the Affordable Care Act.

Regrettably, even with federal protections, people with IDD continue to face barriers to the full exercise and enjoyment of their human and civil rights, including:

- Discrimination in education, employment, housing, voting, transportation, and other programs and activities;
- Social and cultural attitudes of devaluation and fear;
- Prejudiced beliefs and implicit bias that promotes that people with IDD cannot and/or do not contribute to society or that they are unworthy of public funding;
- Societal failure to provide the supports wanted and needed for full community participation, equal opportunity, independent living, and economic self-sufficiency;
- Systems that value protection over freedom to exercise individual rights;
- Restraint, seclusion, use of aversives, and other forms of behavioral control masquerading as treatment;

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[3] The United States has not ratified all of these additional covenants or conventions.

- Reliance on prisons, jails, psychiatric, and other institutional facilities as a substitute for supporting people in successful community living;
- Barriers to economic independence that are built into existing programs, intentional or not;
- Underpayment for labor and services and denial of the means of economic self-sufficiency;
- Systemic barriers to culturally accessible and competent health care resulting in significant health disparities, including higher rates of treatable illness and death; and
- Legislation and regulations that restrict or limit access to voting or the ability to vote without undue barriers or hardship, including support to cast one's ballot.

POSITION

Human and civil rights are recognized by national or international laws, declarations, conventions, or standards. These rights include the right to life; liberty; equality; speech, assembly, and petition; dignity; self-determination; autonomy; family and reproduction; justice; community participation; property and finances; health; well-being; voting; equality of opportunity; choice; and bear arms. They also include freedom from unwarranted and unjustifiably extensive guardianship or conservatorship, restraints, seclusion, and aversive treatments.

People with IDD are richly diverse, sharing the same characteristics found in society at large. People with IDD can be found among people of any age, gender identity and expression, race and ethnicity, sexual orientation and sexuality, communication and expression, culture, language, faith or religion, location, economic status, immigration and legal residency status, familial status, support need, and among people who have other disabilities.

People with IDD have the same human rights as all people and are entitled to the same benefits and legal protection of their civil rights. They are entitled to exercise their rights and to have their human rights and civil rights respected. When their rights are violated, people with IDD are entitled to protection, rights restoration, and compensation for losses.

All people with intellectual and/or developmental disabilities have the right to accommodations, assistance, and 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.

Education of all key actors is important. It is imperative that responsible people, including law enforcement, educators, providers, direct support professionals, family members, and others are held accountable for negligent, deliberate, or unlawful harm to people with IDD caused by their actions or inactions. Harm can result from indifference and brutality. Both can result in severe consequences to people with IDD. One glaring example is the inhumane use of restraints, seclusion, and aversive treatments, which too often lead to death.

Policy makers must act to ensure that human rights are protected by law; that any gaps or failures in the law are corrected; and that laws are enforced by respectful and knowledgeable authorities.

Reviewed/Revised 2022

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

INCLUSION

All people with intellectual and/or developmental disabilities[1] benefit when fully included in community life.

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;

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

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

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- 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.

Reviewed/Revised 2021

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

PHYSICIAN-ASSISTED SUICIDE

Physician-assisted suicide must be prohibited for people with intellectual disability[1] (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.[2] 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.

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

[2] 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.

- 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[3] 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.

Reviewed/Revised 2023

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[3] See The Arc's health care position statement regarding advanced directives.

PROTECTION FROM MISTREATMENT

People with intellectual and/or developmental disabilities[1] 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

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

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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.

Reviewed/Revised 2021

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

SELF-ADVOCACY AND LEADERSHIP

People with intellectual and/or developmental disabilities[1] (IDD) have the right to advocate and/or be supported to act as self-advocates. Self-advocates exercise their rights as citizens by communicating for and representing themselves and others, with whatever supports they need. Self-advocates must have a meaningful role in decision-making in all areas of their daily lives and in public policy decisions that affect people with IDD.

ISSUE

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

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

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

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

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

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

POSITION

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

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

- People with IDD must have the power to make informed decisions about their own lives and the services they receive, including those who need support and those who have legally-appointed guardians.
- People with IDD have access to necessary accommodations and supports in order to meaningfully participate in meetings, conferences, task forces, boards, and other forums when issues and policies that are important to them are discussed ("Nothing about us without us" principle). These accommodations include but are not limited to:
    - Extra time planned for meetings to ensure the participation of each person;
    - Enhanced and alternative communication methods, such as communication devices, sign language, or interpreters;
    - Availability of technology supports and access through technology to ensure participation;
    - Materials provided ahead of the meeting for review;
    - Meeting materials written in plain language;
    - Support from direct support professionals, when needed; and
    - Funding for transportation and travel-related costs, including support staff.
- When communicating with or about people with IDD, it is important to respect the way that people with disabilities prefer to be identified. In most circumstances, person-first language is most appropriate, e.g. person with IDD. However, some people with IDD prefer identity-first language, e.g. autistic person. In addition, people's self-identified pronouns for gender identity must be respected.
- Policy development must include self-advocates and be regularly evaluated to ensure that self-advocates are actively and meaningfully participating.

- Families, advocacy organizations, service providers, and government agencies must work with self-advocates to increase public awareness of the importance of the self-advocacy movement.
- Self-advocacy organizations and individual self-advocates must be supported to develop and sustain the self-advocacy movement, including mentoring youth and young adults with IDD to become self-advocates.
- Foundations and federal, state, and local funding agencies must promote self-advocacy as a key matter of policy. These entities must provide enough money and resources to make sure that (1) people with IDD have accessible information, training, and education in self-advocacy, and (2) providers have the information they need to deliver person-centered services that address self-advocate-led trends in policy and design.
- Children and youth with IDD must be supported by families, schools, direct service providers, and other entities to learn self-advocacy skills and put these skills into practice. Children and youth with IDD should have opportunities to use advocacy skills in educational planning, including Individualized Education Programs (IEPs), transition plans, and all decision-making.
- Adults with IDD can be effectively supported by peers, self-advocates, families, direct service providers, and other entities to learn self-advocacy skills and put them into practice. In order to continually use these skills, adults with IDD should have opportunities to use self-advocacy skills in service planning and daily decision-making.
- Self-advocates must be afforded the same dignity of risk that all people have to make informed decisions and learn from any mistakes that impact themselves and others in the community.
- Self-advocates must be included on boards and other advisory bodies for disability advocacy organizations, service providers, and agencies who serve people with IDD, as well as encouraged to meaningfully provide input on the policies, programs, and evaluation methods of those organizations and agencies.

Reviewed/Revised 2020

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

SELF-DETERMINATION

People with intellectual and/or developmental disabilities[1] (IDD) have the same right to, and responsibilities that accompany, self-determination as everyone else. They are entitled to opportunities, respectful support, and the authority to exert control in their lives, to direct their services, and to act on their own behalf.

ISSUE

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

POSITION

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

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

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To this end, people with IDD must be able:

In their personal lives to:

- lead in decision-making and problem-solving about all aspects of their lives and have the supports they want to make decisions;
- advocate for themselves with the assurance that their desires, interests, and preferences will be respected and honored;
- choose their own supporters, friends, and allies;
- direct their own supports and services and allocate available resources;
- hire, train, manage, and fire their own staff;
- acquire additional skills to assist in determining the course of their lives;
- use adaptive communications devices and other assistive technology; and
- take risks to achieve the lives they desire.

In their community lives to:

- participate fully and meaningfully in the community;
- receive the necessary supports and assistance to vote and exercise other rights as citizens;
- become valued members and leaders of the community;
- serve as active members and leaders of community boards, advisory councils, and other organizations;
- take leadership roles in setting the policy direction for the self-determination movement; and
- have representation and meaningful involvement in policy-making at the federal, state, and local levels.

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

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

Reviewed/Revised 2023

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

POSITION STATEMENTS:
The Arc of The United States

Policies Related to Life in the Community

LIFE IN THE COMMUNITY SUMMARY

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[1] need varying degrees of support to reach personal goals and establish a sense of satisfaction with their lives.

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.

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EDUCATION

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

FAMILY SUPPORT

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

HEALTH

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

The health care system must be aligned to principles of nondiscrimination, comprehensiveness, continuity, appropriateness, and equity. Comprehensive public and private health insurance must provide for both individualized and appropriate health care without regard to the nature or complexity of disability, socioeconomic status, pre-existing conditions, other health status, race, ethnicity, or LGBTQIA+ status.

HOUSING

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

INDIVIDUAL SUPPORTS

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

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 (IDD) must have access to both public and private transportation to lead full, self-directed lives.

AGING

People with intellectual and/or developmental disabilities[1] who are 55 years of age or older have a right to the same opportunities to enjoy full lives as other older people. They are entitled to full access to community supports, including support from those agencies that serve all older people.

ISSUE

For the first time in history, Americans living in the 21st century will experience millions of people with 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.

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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.

Reviewed/Revised 2019

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

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.[1] 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.

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

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

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

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

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

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

Positive behavioral supports should be:

- Designed in a person-centered process involving the individual;
- Developed within the broader context of providing quality medical, psychological, educational, and facilitative services;
- Based on a functional analysis of the behavior and the circumstances under which it occurred, a thorough assessment of each individual's unique abilities and contributions, and an understanding of how previous interventions worked;
- Provided through a least restrictive strategy and described in a written plan;
- Grounded in evidence-based procedures that will:
  - prevent challenging behaviors;
  - teach new skills that may replace challenging behaviors;
  - prevent the on-going reward of a challenging behavior;
  - reinforce positive behavior;
  - ensure safety (when necessary); and
  - provide systemic information on the effectiveness of the support.

- Used in a humane and caring manner respecting individual dignity;
- Implemented in positive, socially supportive and culturally appropriate environments, 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.

Reviewed/Revised 2021

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

EARLY CHILDHOOD SERVICES

All young children who are at-risk for or who have been identified with intellectual and/or developmental disabilities[1] 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

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- 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.

Reviewed/Revised 2019
Joint statement with the American Association on Intellectual and Developmental Disabilities (AAIDD).

EDUCATION

All children and youth with intellectual and/or developmental disabilities[1] (IDD) must receive a free appropriate public education that includes fair evaluation, ambitious goals, challenging objectives, the right to progress, individualized supports and services, high quality instruction, and access to the general education curriculum in age-appropriate inclusive settings. These are essential for achieving the nation's four policy goals of equality of opportunity, full participation, independent living, and economic self-sufficiency (the four policy goals). Parents and families must be supported as essential partners in the education and transition to adult life of their sons and daughters.

ISSUE

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

Many students with IDD remain segregated in self-contained classrooms or separate schools, with few or no opportunities for academic achievement or social engagement in inclusive settings. Students with IDD frequently do not have appropriately ambitious[2] and personalized goals, challenging objectives, high quality instruction, individualized transition planning, and related services and supports necessary to engage as full members of their school learning communities. Consequently, many students with IDD leave school unprepared for further education, employment, and independent living in the community.

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

Many parents, families, and students themselves are excluded from systemic participation as essential partners in the evaluation of the student’s strengths and limitations, as well as the development and implementation of their Individualized Education Programs (IEPs).

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

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

POSITION

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

All Means All: Zero Reject

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

Non-Discriminatory and Comprehensive Eligibility Evaluations and Appropriate Assessments

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

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[2] 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.

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

High Expectations and Free Appropriate Public Education (FAPE)

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

Autonomy, Self-Determination, and Decision-Making Supports

- Incorporate and support the development of autonomy, self-determination, self-advocacy, and leadership skills throughout students' educational experiences, including meaningful participation in the student's IEP.
- Assure that school policy and semi-annual in-service training emphasizes autonomy, self-determination, and decision-making supports, and that teachers and other non-lawyers do not give families legal advice related to guardianship.

Inclusion and the Least Restrictive Environment (LRE)

- To the maximum extent appropriate, every student has a right to be educated in their inclusive neighborhood school and in the general education curriculum in that school. Any exception should be rare and considered only when education in the general education classroom cannot be satisfactorily achieved. Each student has a right to the related services, supplementary aids and services, accommodations, and modifications needed to learn alongside students without disabilities.

- Assure that the student is integrated in academic and social aspects of the general curriculum.
- Include an explicit written plan to achieve more integration in both academic and social aspects of the general curriculum when the student is currently in a restricted setting.
- Foster the development of peer relationships and membership in the school community to create a receptive, welcoming atmosphere, including extracurricular activities and school trips.
- Avoid the long-term costs of segregating students with IDD, including the reduced opportunities for learning, employment, independent living, and social engagement.
- Ensure that all teachers and related services personnel are trained, prepared, and supported to teach and support students effectively in the general education curriculum and in inclusive settings.

Safe and Supportive Education Environments

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

Reviewed/Revised 2023

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

EMPLOYMENT

People with intellectual and/or developmental disabilities[1] (IDD) can be employed in the community alongside people without disabilities and earn competitive wages. They should be supported to make informed choices about their work and careers and have the resources to seek, obtain, and be successful in community employment.

ISSUE

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

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

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

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

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

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

POSITION

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

- Opportunities for post-secondary education, including college and vocational training, to gain knowledge and skills to allow people to get better jobs.
- Ongoing planning to promote job advancement and career development.
- Fair and reasonable wages and benefits.
- Opportunities for self-employment and business ownership.
- Opportunities to work with and, in the case of people with IDD who own small businesses, employ people without disabilities.
- The ability to explore new directions over time and, at the appropriate time, retire.
- Opportunities to work and increase earnings and assets without losing eligibility for needed public benefits.

Best Practices

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

School-to-Work Transition

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

Training of Staff and People with IDD

- Staff of employment and school-to-work transition programs must receive training in best practices to help people find and keep jobs.
- Along with ensuring appropriate on-the-job training, people with IDD should receive guidance, if needed, in acquiring the social skills necessary in the workplace.

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

Systems

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

Publicly funded employment programs should also:

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

Reviewed/Revised 2023

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

FAMILY SUPPORT

Family support services[1] and other means of supporting families across the lifespan should be available to all families to strengthen their capacities to support family members with intellectual and/or developmental disabilities[2] (IDD) in achieving equal opportunity, independent living, full participation, and economic self-sufficiency. Family caregivers include, but are not limited to, parents (including those with IDD themselves), adoptive parents, foster parents, siblings, uncles, aunts, cousins, grandparents, grandchildren, and individuals who are in spousal-equivalent relationships.

ISSUE

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

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

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

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

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

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

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

There is no comprehensive family support system in the U.S. Instead, the vast majority of publicly provided family support services are funded through Medicaid home and community-based services (HCBS) waivers and some states provide limited family support using state general fund dollars. Consequently, beneficiaries of family support experience the same portability and mobility limitations as those receiving other Medicaid HCBS. This affects families (including military families) who either have to relocate to another state and begin the application and waiting process anew or who have to forfeit personal or career opportunities in other states.

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

POSITION

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

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

- Provide support for families navigating systems of care, including early intervention, education, mental/behavioral health, and other systems;
- Provide information and support for siblings to better prepare them to be advocates and caregivers; and
- Ensure aging caregivers are able to provide care for their loved one as long as necessary and appropriate while honoring self-determination.

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

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

Reviewed/Revised 2020

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

HEALTH

All people, including people with intellectual and/or developmental disabilities[1] (IDD), should have timely access to high quality, comprehensive, accessible, affordable, appropriate health care that meets their individual needs; maximizes their health, well-being, and function; and increases their independence and community participation.

The health care system must be aligned to principles of nondiscrimination, comprehensiveness, continuity, appropriateness, and equity. Comprehensive public and private health insurance must provide for both individualized and appropriate health care without regard to the nature or complexity of disability, socioeconomic status, pre-existing conditions, other health status, race, ethnicity, or LGBTQIA+ status.

ISSUE

Health is a state of physical, mental, and social well-being. The term “health care” encompasses services and supports that assist in attaining, maintaining, and improving skills, function, and community participation. Health care includes all aspects of physical, mental, and behavioral health including wellness, health promotion and preventative services, vision, hearing, oral and dental health care, substance use disorder and addiction services, medication management, pre-natal care, reproductive and sexual health, rehabilitation, pain management and palliative care.

People with IDD often experience a wide and varying range of health conditions leading to poorer health and shorter lifespans. The current health care system is fragmented and does not provide uniform access to a comprehensive array of health services and supports. Planning for health care services and emergency response to pandemics, natural disasters, and other situations resulting in urgent health care needs typically does not involve people with disabilities and advocates to ensure that care is inclusive and integrated. This lack of input and planning contributes to higher death rates in major public health and other emergencies.

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

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

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

While many people encounter difficulty in accessing affordable, high quality health care, people with IDD face additional barriers, sometimes life-threatening, when attempting to access timely, appropriate health services in their communities. People with IDD who have additional marginalized identities – including those related to their socioeconomic status, race, ethnicity, language, or LGBTQIA+ status, – may experience additional barriers resulting in even greater health disparities.

Policy makers must address the social determinants of health which are non-medical factors that significantly influence health outcomes. They encompass the conditions in which people are born, grow, work, live, and age; as well as the broader forces and systems that shape daily life including current and historical social, environmental, and economic exclusions. These social determinants play a crucial role in health equity, both positively and negatively affecting the health status of individuals and communities.

Finally, increasing reliance on technology for delivering and managing health care provides benefits such as easier access to providers or more comfortable settings for appointments. Some technology may also create barriers for people with IDD who may not have the knowledge, skills, or access to technology or the internet to navigate health care through telehealth and scheduling and patient management portals.

Major barriers to quality health care include:

Access

- Underinvestment in public health, health promotion, and wellness targeted to people with IDD results in disparities in preventable health care conditions and poorer health outcomes.
- Plain language explanations or materials are not routinely offered to help navigate a complex health care system.
- Inadequate training of health care practitioners, lack of coordinated care, and inadequate systems of reimbursement are some of the factors that create programmatic barriers.
- Inaccessible clinical settings and diagnostic and medical equipment, along with translation and interpretation challenges, create barriers to care.
- Timely access to health care providers can also be limited by geographic availability of providers, too few health care professionals willing to take public health insurance, and lack of transportation options.

Discrimination

- Health care providers sometimes provide inadequate or inappropriate interventions and treatments or deny appropriate care for people with IDD because of professional ignorance as well as ableism.
- Discrimination may take the form of refusing to see individuals with IDD, treating them differently, ignoring or not responding to individual's requests, wrongly attributing health care issues to the fact that they have IDD, deciding that appropriate treatment is not needed due to their IDD (i.e. diagnostic overshadowing), or not viewing people with IDD and their advocates as reliable communicators of health issues.

- Providers also may fail to follow federal and state non-discrimination laws and policies in providing health care to individuals with IDD.
- State statutory liability damage limits discriminate against people with severe and/or life-long disabilities because they fail to provide sufficient compensation.

Affordability

- People with IDD are more likely to live in poverty and be unable to afford public/private insurance premiums or out of pocket costs.
- For cost containment purposes, many public and private health care plans limit access to specialists, medications, durable medical equipment, therapy services, and other critical health services, creating access barriers and making these critical services unaffordable.
- Even when services are available in a community and providers are willing to accept patients with IDD, many people with IDD lack adequate public or private insurance to pay for them.

Communication and personal decision making

People with IDD may have difficulties communicating their health concerns and goals and making health care decisions without support.

- When making their own decisions about health care, many people may want or need support in making the decisions. **This is often referred to as supported decision making.**[2] Some states have added supported decision making to state laws to give formal recognition and make it clear that individuals have the right to make decisions in this way. Individuals often choose friends, family members, professionals, or other trusted advisors to be their supporters.
- When people are unable, for various reasons, to make their own decisions, state laws allow other people to make decisions for them instead. This is known as **surrogate decision making** and includes surrogates appointed in advance by the individual in an advance directive[3] such as a "living will" or through a health care power of attorney. If the person has not indicated who they want to make their decisions, state laws provide for default surrogates or guardians. There are standards that surrogates must follow in making these decisions.

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[2] "Supported decision making (SDM) is a tool that allows people with disabilities to retain their decision-making capacity by choosing supporters to help them make choices. A person using SDM selects trusted advisors, such as friends, family members, or professionals, to serve as supporters. The supporters agree to help the person with a disability understand, consider, and communicate decisions, giving the person with a disability the tools to make her own, informed, decisions." Supported Decision-Making: Frequently Asked Questions. https://www.aclu.org/wp-content/uploads/legal-documents/faq_about_supported_decision_making.pdf

[3] 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.)

However, often individuals' choices regarding health care decisions are not respected and implemented by health care providers and, where applicable, surrogate decision makers.[4] People have not been provided access to all necessary supports and information required to understand a health care decision and communicate their choices. People have been denied access to their chosen support person in medical settings. Medical practitioners who are unfamiliar with supported decision making may therefore limit or ignore an individual's choice in medical treatment. Further, health care facilities and settings are often not prepared to respect or meet the communication needs of the individual.

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, health promotion, and a robust public health infrastructure are essential components of health care.
- Health care providers for persons with IDD must meet the highest standards of quality, including a comprehensive approach to education, treatment, disease prevention, medication management, and health maintenance.
- Health care professional training must reflect inclusive health care best practices, including disability information, research, and clinical training.
- Health care providers must be adequately incentivized to provide inclusive care, including to those with IDD.
- Health care providers must be precluded, by policy, practice standards, and ethics frameworks, from limiting the number of patients with disabilities, including IDD, from being accepted into their practices.
- People with IDD require and must have access to effective strategies to manage their care including care management, referral processes, comprehensive transition from pediatrics to adult medicine, and health promotion efforts.

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[4] A surrogate decision maker is a person who makes health care decisions for an individual who is unable to make decisions about personal health care. A surrogate decision maker may be chosen by the individual in advance through an advance directive or by choosing an agent under a durable power of attorney for health care. A court-appointed guardian with authority to make health care decisions will also act as a surrogate decision maker. If there is no appointed surrogate, 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. Surrogates should include the individual in the decision making process as much as possible. 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. See Default Surrogate Decision Making, Pope, JD, PhD, Thaddeus, M., Mitchell Hamline School of Law, Reviewed/Revised Oct 2023, Merck Manual Consumer Version. https://www.merckmanuals.com/home/fundamentals/legal-and-ethical-issues/default-surrogate-decision-making

- Health surveillance and the assessment of health outcomes must include disability status. Public health initiatives must support the goal of reducing health care disparities and inequities for people with disabilities and improving health and function.
- The health care system must be fully accessible with respect to communications, facilities, equipment, and technology. It must provide necessary accommodations such as sufficient time, explanations, translators, and interpreters.

Nondiscrimination

- People with disabilities 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.
- Health professionals must provide all patients, including those with a disability, an equal opportunity to receive all necessary health care treatment including life sustaining treatments such as cancer therapy and transplantation.
- Health plans must cover treatment for mental health conditions on the same terms and conditions as all other medical diagnoses.
- Providers of health care services for persons with IDD must follow practices regarding health information and records consistent with the guarantees of confidentiality contained in the Health Insurance Portability and Accountability Act (HIPAA).
- Treatments for persons with IDD that are proposed primarily for the convenience of the caregiver (such as medical procedures that interfere with typical growth and development or inappropriate polypharmacy) must be denied.

Affordability

- All people including people with IDD must have universal access to comprehensive, integrated, affordable, high quality health care.
- Efforts to contain health care costs must not create obstacles to care for people with IDD by making needed services or treatments unaffordable or otherwise unavailable. The medical need for care must be determined on an individualized basis.
- Payment methodologies for health services provided to people with IDD must compensate for the true cost of providing accessible 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 must not create disincentives to the provision of timely and appropriate services to persons with IDD.

Communication and Personal Decision-Making

In all matters of health, individuals with IDD have basic rights that must be protected, including the right to information and appropriate accommodations to assure informed consent[5] that allows an individual to accept or refuse health-related services based on:

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

- 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 for communication needs and any cognitive limitations that persons with IDD may experience; and accommodate reading, language, learning, and other differences that are common among persons with IDD and/or distinct to the needs of the specific individual;
- 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, including protection from medical guidance toward or away from specific treatments solely on the basis of the individual's disability;

Some individuals may temporarily or permanently lack the capacity to make some or all health care decisions. This lack of capacity may not cover all necessary decisions in the individual's life. The individual should always be assisted in making those decisions which they can make and be assisted in participating as much as they are able in all other decisions. This assistance, including assistance in the form of supported decision making, must be respected and the decisions must be honored.

Surrogate Decision-Making

When a surrogate decision maker is involved and making decisions on behalf of the individual, people with IDD continue to have basic rights that must be protected. This includes the right to appropriate accommodations and information to assure informed consent that allows the surrogate acting on the individual's behalf (a guardian, a health care power of attorney, or other surrogate decision-maker of the individual's choice), under appropriate legal conditions, to accept or refuse health-related services.

Advance directives of people with IDD should be honored, including an individual's specific expressed desires regarding the use of life-sustaining treatments, communicated in written or oral form and recorded in an advance directive, as appropriate to their understanding of the nature, implications, and reversibility of their decision. Where a guardian, health care power of attorney, or other surrogate decision maker is involved, reasonable efforts must be made to monitor, honor, and accommodate indications of "implied assent" to treatment.

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, preferably before a crisis arises. If no surrogate has been appointed in advance, state law determines who will serve as the default surrogate decision maker. Generally, default surrogate authority under state laws includes the parent of a minor child, the guardian/conservator of an adult, or surrogate decision-makers designated under the state's 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 that refusal will result in the individual's death, the legal authority of the surrogate decision-maker should be limited to only those situations in which all three of the following conditions exist: (1) the person's condition is terminal, (2) death is imminent, and (3) any continuation or provision of treatment, nutrition and/or hydration would only serve to prolong dying. However, in such situations, people with IDD must be provided appropriate palliative care, including medical treatment to relieve pain, sustenance as medically indicated, and care designed to relieve isolation, fear, and physical discomfort.[6]

Reviewed/Revised 2024

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[6] See generally, discussion of Legal Standard for Making Medical Decisions, Default Surrogate Decision Making, Pope, JD, PhD, Thaddeus, M., Mitchell Hamline School of Law, Reviewed/Revised Oct 2023, Merck Manual Consumer Version

HOUSING

People with intellectual and/or developmental disabilities[1] (IDD), like all Americans, have a right to live in their own homes, in the community. Children and youth belong with families. Adults should control where and with whom they live, including having opportunities to rent or buy their own homes, and must have the freedom to choose their daily routines and activities.

ISSUE

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

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

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

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

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

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

POSITION

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

- People must have freedom, authority, and support to exercise control over their housing, including choice of where and with whom they live, privacy within their homes, access to flexible supports and services when and where they choose, choice in their daily routines and activities, freedom to come and go as they please, and housing that reflects their personal preferences and styles. Providers should honor individual choices and preferences.
- Housing should afford people with IDD the opportunity to interact with people without disabilities to the fullest extent possible.
- The health and safety of people with IDD must be safeguarded wherever they live, but should always be balanced with the right to take risks and exercise choice and control.
- To ensure that people with IDD can make informed decisions about where and with whom they live, they and their families must be given understandable information about the benefits of living in the community, have the chance to visit or have other experiences in community settings, have opportunities to meet other people with disabilities who are living in the community, and have any questions or concerns addressed.
- All children and youth need a home with a family that provides an atmosphere of love, security, and safety.
- Adults with IDD should receive the supports they need to transition out of the family home when they wish to do so.
- Housing for people with IDD must be coordinated with home and community-based support systems, including transportation services, and should ensure access to other typical public resources.
- There must be adequate funding of services to support people to live in the community. Funding must be stable and not subject to arbitrary limits or cuts. People with IDD must not be subjected to unnecessary institutionalization or removal from their homes and communities due to state budget cuts.
- Public policy should promote small, typical living situations for people with IDD. Information about innovative housing models that promote independence should be widely disseminated.
- Housing for people with disabilities should be scattered within typical neighborhoods and communities, and should reflect the natural proportion of people with disabilities in the general population.

- Public funds must be shifted from restrictive institutional settings to community supports. Institutional settings and large congregate living arrangements are unnecessary and inappropriate for people with IDD, regardless of type or severity of disability.
- Affordable housing options must be available to people with IDD, including those with very low incomes. Affordable housing programs must be expanded and funded to eliminate long waiting lists. Public policies must ensure that people with IDD receive their fair share of all local, state, and national housing resources.
- Universal design and visitability[2] standards should be adopted for all new housing. New and significantly renovated multifamily housing should include fully accessible units in numbers that reflect the natural proportion of people with disabilities in the general population.
- People with IDD have the right to be free from housing discrimination, and there must be robust education, outreach, and enforcement of that right. People with IDD must have opportunities comparable to those of people without disabilities to rent or buy their own homes.

Reviewed/Revised 2023

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

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[2] **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

People with intellectual and/or developmental disabilities[1] (IDD) must have access to individual supports, such as assistive technology and personal assistance, to support their participation in daily life.

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 IDD) 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

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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 IDD 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.

Reviewed/Revised 2023

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

OPPORTUNITIES FOR FINANCIAL ASSET BUILDING

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

ISSUE

Often, people with IDD face greater economic inequalities than their peers without disabilities. People with IDD also typically have not had adequate supports for full participation in financial life and decision-making, including earnings, saving, budgeting, spending, investments, and estate planning.

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

In addition, families are the largest group of providers of physical, material, and emotional supports for people with IDD across the life course. Families incur increasing amounts of out-of-pocket expenses due, in part, to the decreasing federal funds contributing to family support services[2] in the states. Many families are restricted to a single income or underemployment due to the necessity to provide medical care or supports to their family member with IDD. This

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greater reliance on family support requires families to explore and invest in a variety of financial security strategies to ensure opportunities for self-directed options and family quality of life.[3]

POSITION

Individuals with IDD and their families should have equal access to economic self-security, including opportunities to save money and build financial assets to maintain or improve their basic economic and social status, strengthen their financial security, and save for retirement through education, financial literacy, employment, home ownership, and asset development.

These opportunities should include the following:

- Access to Individual Development Accounts (matched savings accounts similar to a 401(k)) that enable a person to save for education, home ownership, or one's own business and/or employment;
- Ensuring that government assistance programs allow people to retain reasonable portions of their income for daily living expenses, and permit savings. Access to low-cost, user-friendly approaches such as 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 IDD to have opportunities to earn money and invest in their futures without risking the health care, benefits, and supports and services necessary to live a full life in their community.

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

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

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

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

- 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.

Reviewed/Revised 2021

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

PARENTS WITH INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

The presence of an intellectual and/or developmental disability[1] 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;

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- 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."

Reviewed/Revised 2019

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

SEXUALITY

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

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.

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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.

Reviewed/Revised 2021

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

SPIRITUALITY

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

ISSUE

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

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

POSITION

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

- Spirituality is an important part of human experience that may be expressed both through religious practice and through other spiritual activities which carry personal meaning and reflect the person's values;

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- 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.

Reviewed/Revised 2021

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

TRANSPORTATION

People with intellectual and/or developmental disabilities[1] (IDD) must have access to both public and private transportation to lead full, self-directed lives.

ISSUE

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

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

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POSITION

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

- Transportation at comparable cost and service models is available to individuals of all abilities.
- When making decisions, planning, and testing transportation options and payment methods, individuals with IDD are involved in the process.
- Improved coordination maximizes existing transportation services.
- Public transportation is adequately funded, fully financially and physically accessible, reliable to meet people's needs, and equipped to suit the physical, sensory, and cognitive needs of all people.
- As technological innovations emerge (such as virtual wayfinding, autonomous vehicles, and digital ticketing), transportation modalities are designed to be accessible, usable, and reliable, including such things as language access, visual cues, safety considerations, and audio and hands-free options to meet individuals' needs and preferences.
- Technological platforms that relay information from users with IDD to transportation providers utilize inclusive research design to ensure accessibility and ease of use.
- Travel training is available for users covering all modes of travel, prioritizing peer-to-peer training where possible.
- Appropriate disability awareness training is available for service and transportation providers.
- As smart city initiatives advance, they are developed for users of all abilities and needs. Data collection and migration tools include users with IDD in the design, to ensure inclusive smart cities.
- The unique challenges and lack of options within suburban and rural areas are addressed.
- Technology and service providers protect a user's privacy by ensuring data such as contacts, camera, photos and files, health and disability status, and locations visited is not shared, or used for commercial or tracking purposes, without permission of the individual. For any information to be accessed or shared, customers must opt-in, versus opting-out, and have clear explanations of with whom and what will be shared. In light of data management, people with IDD must have the opportunity to receive training on self-directed data management and use.
- At the same time, transportation navigation software allows an individual to share appropriate information with a third party, to enhance efficiency and safety – for example, confirming arrival and indicating off-route warnings, as directed by users.
- Innovative vehicles and transportation options do not create additional barriers, based on where vehicles are parked, stored, and operated.
- People with IDD have the option of owning, modifying, and operating vehicles and other transportation options of their choice at affordable costs.
- All vehicles, public and privately owned, meet applicable federal, state, and local safety requirements.

- Autonomous Vehicles (AVs) are fully accessible and universally designed to take into account all individuals' abilities and disabilities to safely access and operate. Regulation of AVs must consider the needs of people with IDD, and avoid unnecessary licensing requirements that would restrict or eliminate access.

Reviewed/Revised 2020

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

POSITION STATEMENTS:
The Arc of The United States

Policies Related to Systems

SYSTEMS SUMMARY

Systems are necessary to support people with intellectual and/or developmental disabilities[1] 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.

LONG TERM SUPPORTS AND SERVICES

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

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.

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

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

RESPONDING TO THE INTERRELATED CAUSES OF INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

Valuing the lives, diversity, and contributions of people with intellectual and/or developmental disabilities (IDD) AND advancing policies that mitigate the impact of psychoeducational, sociocultural, biomedical, and justice causes of IDD are compatible positions. 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 and in no way diminishes the rights of individuals to participate in or contribute to society."

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.

LONG TERM SUPPORTS AND SERVICES

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ISSUE

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

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

Insufficient Medicaid Funding

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

The persistent lack of a system of comprehensive community LTSS is a crisis requiring immediate solutions. Individuals and families are forced to navigate a patchwork of systems

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of supports and services that are complex and frequently uncoordinated; are limited and often diminishing in scope and relevance; and, are difficult to access and offer no clear path to assistance. Medicaid is means-tested, is not portable across state lines, differs—often dramatically—from state to state, and does not meet the demand for community-based LTSS for people with IDD of all ages.

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

Institutional Bias of Medicaid

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

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

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

Continuing and Worsening Crisis of Unmet Need

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

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

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

Direct Support Professional Workforce Crisis

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

POSITION

A comprehensive system of LTSS must include the following:

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

Self-Direction

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

- Individuals must design and direct their own services, to the fullest extent they wish and with the assistance they want;
- Services must be person-centered and based on the unique needs and desires of the individual, accompanied by measured progress toward person-centered outcomes to which the person aspires;
- Individuals with IDD who wish to employ DSPs must have access to timely and relevant information, technical assistance, and training;
- Services must be delivered promptly to meet individual needs and desires in the most integrated setting, with flexible funding to meet changing circumstances; and
- Outcome measures, defined in substantial part by the person, and outcomes consistent with state-defined value based reimbursement systems should be used to measure the individual and systems outcomes of LTSS in every state.

Continuing and Worsening Crisis of Unmet Need

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

Direct Support Professionals Workforce Crisis

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

including a system for tracking people for whom abuse, neglect, and exploitation charges have been substantiated, for all public and private DSPs working in the state.

Reviewed/Revised 2020

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

RESEARCH

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

ISSUE

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

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

Few groups are more vulnerable to potential exploitation in research than individuals with intellectual and/or developmental disabilities. Without comprehensive, clear policies, standards

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

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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).

Reviewed/Revised 2021

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

RESPONDING TO THE INTERRELATED CAUSES OF INTELLECTUAL AND/OR DEVELOPMENTAL DISABILITIES

Valuing the lives, diversity, and contributions of people with intellectual and/or developmental disabilities[1] (IDD) AND advancing policies that mitigate the impact of psychoeducational, sociocultural, biomedical, and justice causes of IDD are compatible positions. 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 and in no way diminishes the rights of individuals to participate in or contribute to society."

ISSUE

Knowledge about the psychoeducational, sociocultural, biomedical, and justice causes of IDD is increasing rapidly, yet the will, effort, and resources necessary for meaningful access to and application of the research lag behind. The four broad areas of causation are defined as follows:

1) Psychoeducational causes of IDD refer to limited opportunities in learning, adaptive behavior, and intellectual functioning. Examples might include lack of early intervention or lack of opportunities for necessary personal growth.

2) Sociocultural causes refer to limited opportunities to develop in the social context and through social interactions. Examples might include living in an impoverished environment, unstable living conditions, or experiencing social stigma.

3) Biomedical causes refer to problems in physical development or functioning. Examples might include biological conditions or limited brain development.

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4) Justice causes refer to damaging discrimination or denial of legal rights. Examples might include health disparities, social inequality, or denial of human rights.

Examples of Interrelated Causes of IDD

The four broad areas of possible causation are often interrelated, for example:

- IDD resulting from youth trauma may have biomedical (e.g., the injury), psychoeducational (e.g., the lack of access to appropriate education), sociocultural (e.g., the dangers in the neighborhood), and justice (e.g., the conditions of incarceration) aspects to the causation.
- IDD resulting from homelessness may have biomedical (e.g., malnutrition), psychoeducational (e.g., the lack of access to counseling), sociocultural (e.g., stigma), and justice (e.g., discriminatory denial of financial supports) aspects to the causation.
- IDD resulting from the effects of drugs and alcohol in the development and behavior of young children may have biomedical (e.g., prenatal exposure), psychoeducational (e.g., the lack of access to early education and counseling), sociocultural (e.g., social values), and justice (e.g., criminal charging and sentencing practices) causes of disability.
- IDD resulting from the effects of poverty on children may have biomedical (e.g., lack of prenatal care), psychoeducational (e.g., lack of access to parenting education and supports), sociocultural (e.g., access to stable housing), and justice (e.g., discriminatory loan practices) causes of disability.

POSITION

The nation must value the lives and contributions of individuals with IDD and their families, while also (a) researching the causes of IDD, (2) developing policies to support and enhance individuals' functioning, (c) providing supports, programs, and advanced practices to implement the policies and meet individual needs, and (d) eliminating the roadblocks currently found in values, research, policies, and supports.

Values

The underlying value for all efforts regarding causes of IDD must be respect for the individuals and their families. In addition, the values of autonomy, agency, person-centeredness, self-direction, diversity, and intersectionality must be integrated in a holistic way. Valuing the lives, diversity, and contributions of people with IDD AND advancing policies that mitigate the impact of psychoeducational, sociocultural, biomedical, and justice causes of disability are compatible positions.

Researching the Causes of IDD

- Research on causes of IDD should include research in the four broad areas of causation: psychoeducational, sociocultural, biomedical, and justice causes of disability. Research should be integrated among the four areas of causation, when appropriate, because causes are often complex and interwoven.
- Research must identify and use standard and rigorous definitions and develop greater quantification of causes of IDD, including data focus and prevalence.

- Research should include people with IDD in the development of research questions, design and implementation of the research, and dissemination of results.
- Research must assure that diversity, equity, and inclusion, including issues of intersectionality, are reflected in design and implementation.
- Research must be equitably funded to attain valued outcomes.
- Research must be broadly disseminated and accessible for maximum impact.

Developing Policies to Enhance Individuals' Functioning

- Policies addressing causes of IDD should also include the four broad areas of causation.
- Policies must enhance the autonomy and agency of people with IDD.
- Policies must be agile to respond to changing times and reflect new ways of supporting people with IDD toward equality of opportunity, full participation, independent living, and economic self-sufficiency.
- Policies must be informed by people with IDD and their families.

Providing Supports, Programs, and Advanced Practices

- Supports, programs, and advanced practices addressing causes of IDD should include the four broad areas of causation.
- Supports, programs, and advanced practices should address access to early intervention and inclusive special education; self-advocacy, self-determination, and leadership skills; physical and mental health services; dental and vision care; poverty reduction, adequate nutrition and stable housing; elimination of discrimination; employment; and a safe and healthy environment for all children, as well as other supports that improve health; increase access to education; promote diversity, equity, and inclusion; and promote a society that is fair and just for all.
- Supports, programs, and practices should include family supports that recognize the impact of life-long disability on family members and caregivers.
- Systemic advocacy is needed to assure development of and access to appropriate supports, programs, and advanced practices and should be supported with adequate resources.
- Supports, programs, and advanced practices require sufficient staff who are appropriately compensated, prepared, supported, and valued.

CONCLUSION

Respect for the individuals and their families must be the underlying value for all efforts regarding causes of IDD. People with IDD, their families, and the advocacy community supporting them must be a valued part of all discussions to address causes of IDD. Knowledge about the causes of IDD is continuing to develop. Currently, however, necessary actions are lagging behind the research. Meaningful actions, including promotion of research, strong policies, and advanced practices and supports, must keep pace with the developing knowledge.

Reviewed/Revised 2022

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

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[1] 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;

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- 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.

Reviewed/Revised 2021

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

The Arc®

For people with intellectual and developmental disabilities

1.800.433.5255

thearc.org

info@thearc.org