



*The Arc*<sup>TM</sup>

*New Mexico*



# Position Statements

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ON KEY ISSUES

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# Overview

The Arc of New Mexico'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 inform The Arc of New Mexico's public policy agenda, as well as to set its agenda for each year's legislative session. The statements also serve to inform our constituency, stakeholders, media, and the general public on the prevailing organizational view on key issues.

## ***How We Determine Position Statements***

The Public Policy Officer, working with the CEO of The Arc of New Mexico, develops position statements for our state chapter. Once developed, they are approved and published by the Board of Directors.

New position statements and revisions of existing statements are developed through a process that provides substantial opportunity for input and participation by staff of the Arc of New Mexico and its Board of Directors. After approval by the Board and once adopted, position statements remain in force until they are replaced or withdrawn. The Arc of New Mexico reviews position statements on a yearly basis and updates or revises the position statements as deemed necessary.



# Advocacy

## ADVOCACY

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

## ISSUE

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

## POSITION

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

## Individuals

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

Self-advocates should:

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

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



## SYSTEMS CHANGE

Systems change advocacy can provide tremendous benefit for people with intellectual and/or developmental disabilities. The goal of systems advocacy is to enhance public awareness of the rights, strengths, needs, and interests of people with intellectual and/or developmental disabilities and influence law and policy to improve public and private systems of support and services. Family members and self-advocates should play a meaningful role in systems change. Agencies providing supports to individuals should also advocate for system change that will improve the quality of life for all individuals, whether supported by the agency or not. Individuals should have access to Protection and Advocacy systems and other entities mandated by state and federal laws that:

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

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# Aging

## **AGING**

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

## **ISSUE**

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

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

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

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

## **POSITION**

As they age, people with intellectual and/or developmental disabilities must have every opportunity to be recognized as respected members of the community. Community services and



supports that are geared to older community members must accommodate the supports needed by those who have also experienced lifelong disabilities.

People with intellectual and/or developmental disabilities who are aging should:

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

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# Autonomy, Decision-Making Supports, and Guardianship

## DECISION MAKING

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.

## ISSUE

- Current trends presume the decision-making capacity of individuals with IDD and the preservation of legal capacity as a priority for all people needing assistance with decision-making.
- Like their peers without disabilities, individuals with IDD must be presumed competent; they must also be assisted to develop as decision-makers through education, supports, and life experience. Communication challenges should not be misinterpreted as lack of competency to make decisions.
- Individuals with IDD should have access to supports and experiences to learn decision-making skills from an early age and throughout their lifetimes in educational and adult life service systems.
- Families should have access to information about all options for assisting their family member to make decisions over the life course.
- All people, with and without disabilities, have a variety of formal and informal processes available to enact their decisions and preferences, including healthcare proxies and advance directives.
- Less restrictive means of decision-making supports (e.g., health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship 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 are legally presumed competent to make decisions for himself or herself and should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime. All people with IDD can participate in their own affairs with supports, assistance, and guidance from others, such as family and friends. People with IDD should be aware of and have access to decision-making supports for their preferred alternatives.

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



- Regardless of their guardianship status, all individuals with IDD should be afforded opportunities to participate to the maximum extent possible in making and executing decisions about themselves. Guardians should engage individuals in the decision-making process, ensuring that their preferences and desires are known, considered, and achieved to the fullest extent possible.
- Regardless of their guardianship status, all individuals with IDD retain their fundamental civil and human rights (such as the right to vote and the right to make decisions related to sexual activity, marriage and divorce, birth control, and sterilization) unless the specific right is explicitly limited by court order.

## 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.

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# Behavior Supports

## **BEHAVIORIAL 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.

## **ISSUE**

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

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

## **POSITION**

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

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

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

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

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



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

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

Positive behavioral supports should be:

- Designed in a person-centered process involving the individual;
- Developed within the broader context of providing quality medical, psychological, educational, and facilitative services;
- Based on a functional analysis of the behavior and the circumstances under which it occurred, a thorough assessment of each individual's unique abilities and contributions, and an understanding of how previous interventions worked;
- Provided through a least restrictive strategy and described in a written plan.

Grounded in evidence-based procedures that will:

- prevent challenging behaviors;
- teach new skills that may replace challenging behaviors;
- prevent the on-going reward of a challenging behavior;
- reinforce positive behavior;
- ensure safety (when necessary); and
- provide systemic information on the effectiveness of the support.

Used in a humane and caring manner respecting individual dignity:

- Implemented in positive, socially supportive and culturally appropriate environments, including the home;
- Carried out by individuals (i.e., staff, family members and others) who have been trained and are qualified to effectively apply positive, non-aversive approaches;
- Include adaptations to the environment and reinforcers that people with intellectual and/or developmental disabilities and their families identify as positive; and
- Monitored continuously and systematically to ensure appropriate implementation and that the support is consistent with individual needs, positive in its methods, successful in achieving established goals, and changed in a timely fashion if success is not evident or occurring at an appropriate rate.

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# Criminal Justice System

## 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.

## 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 policymakers, and jurors may lack accurate and appropriate knowledge to apply standards of due process in a manner that provides justice for individuals with IDD.

These individuals are:

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

When individuals with IDD or their families come into contact with the criminal justice system, they find few organized resources for information, training, technical assistance, referral, and supports. Moreover,



people living with IDD who enter the criminal justice system encounter unique problems not faced by their nondisabled peers, such as:

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

While the Supreme Court ruled in Atkins v. Virginia that it is a violation of the Eighth Amendment ban on cruel and unusual punishment to execute people with intellectual disability, states continue to play a major role in applying the term and in deciding the process for consideration of a defendant’s intellectual disability. Laws vary from state to state on how a defendant proves the presence of intellectual disability. States also vary widely regarding whether it is the judge or jury who decides if the defendant has an intellectual disability. States sometimes inappropriately appoint people who are not knowledgeable about intellectual disability to conduct “assessments” for intellectual disability or to offer “a diagnosis” that they are not professionally trained or qualified to provide. As a result, defendants may not have their intellectual disability correctly identified because of a state’s unfair and inaccurate procedures. The Supreme Court ruled again in Hall v. Florida in 2014, reaffirming the Atkins decision and denying states’ use of strict IQ cutoffs to diagnose intellectual disability.

## 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.

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

- Continue to be exempt from the death penalty because existing case-by-case determinations of competence to stand trial, criminal responsibility, and mitigating factors at sentencing have proved insufficient to protect the rights of individuals with intellectual disability;
- Have access to expert witnesses and professionals who are knowledgeable about, as well as trained and experienced in, intellectual disability and who can accurately determine the presence and effects of intellectual disability; and
- Have their intellectual disability determined by state procedures that are accurate and fair. Those state procedures must be consistent with the national standards on making an intellectual disability determination and ensure that people with intellectual disability are not executed.

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# Early Childhood Services

## 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.

### ISSUE

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

### POSITION

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

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

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

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

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

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

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

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

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

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

Research and successful practical experience have established that:

- When early childhood services are provided in natural environments, both children and families will experience increased community inclusion during early childhood and across the life span;
- State-of-the-art service coordination will enhance the access of children and families to

support and services from multiple agencies and community resources; and

- Ongoing monitoring and evaluation of services will ensure measurable outcomes, equity and effectiveness.

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

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# Education System

## THE EDUCATION SYSTEM

All children and youth with intellectual and/or developmental disabilities (IDD) must receive a free appropriate public education (FAPE) 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 the 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 and personalized goals, challenging objectives, high quality instruction, individualized transition planning, and related services and supports necessary to engage as full members of their school learning communities. Consequently, many students with IDD leave school unprepared for further education, employment, and independent living in the community.

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

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

Administrators, educators, and support staff too often lack sufficient training and knowledge about the legal rights, learning needs, and abilities of these students. School districts struggle to identify, recruit, and retain qualified special education personnel. Paraprofessionals providing support in inclusive classrooms are often poorly paid and do not always receive or seek professional development relevant to students' learning needs. Outdated, inaccurate beliefs about students with IDD persist, leading to low expectations, segregated classrooms, inappropriate disciplinary practices, and diminished accountability for these students. In some communities, an unexamined sole focus on student performance has led to an erroneous conclusion that students with IDD are "bringing down" test scores and are to blame when schools and school systems do not achieve adequate progress.

## **POSITION**

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

### **All Means All: Zero Reject**

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

### **Non-Discriminatory and Comprehensive Eligibility Evaluations and Appropriate Assessments**

- Assure that the needs of the individual are considered fairly and comprehensively, including cognitive, emotional, functional, and developmental needs, as well as all areas of suspected disability and mental health needs.
- 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 aversive. 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.
- Expediently connect students and families with information, resources, and training that help them understand and exercise their rights under the IDEA, Section 504, the ADA, Family Educational Rights and Privacy Act (FERPA), and the Every Student Succeeds Act (ESSA).
- Assure that school personnel provide timely explanations that are understandable and use functional descriptive language for special education and related services being proposed for the student.

#### **Lifelong Education, Transition, and Post-Secondary Education**

- Provide early intervention and preschool services to infants, toddlers, and preschool-age children with disabilities alongside their typical peers and provide transition planning for children to ensure access to the general education curriculum and full integration in neighborhood schools as they move to kindergarten or first grade.
- Develop and implement transition plans based on student strengths, preferences, and interests to facilitate each student's successful movement from school to adult life,

including postsecondary and vocational education, competitive integrated employment, independent living, and community participation.

- Develop an individualized postsecondary and/or pre-employment program, including choices and creative career exploration through apprenticeships and internships, in coordination with IDEA and the Workforce Innovation and Opportunity Act (WIOA).
- Ensure that all students receive meaningful evidence of their school achievements including diplomas.

### **System Capacity Development, Funding, Oversight, and Accountability**

- Assure that the training, preparation, compensation, supports, and accountability systems needed to build a cadre of effective professional teachers, other education personnel such as school principals, related services personnel, paraprofessionals, and other staff are evidence-based and effective to meet the child's specific needs.
- Assure a cadre of effective lay and legal advocates to assist families and individuals to exercise their rights.
- Increase active monitoring and enforcement through local, state, and federal agencies to ensure that the IDEA, ADA, Section 504, and state special education laws and mandates are met.
- Fulfill the federal commitment to fully fund the IDEA.
- Ensure that all students with disabilities, including those with the most significant cognitive disabilities, continue to be included in public school, district, and state level accountability systems. Ensure that states are not allowed to exempt more than 1% of students (that is, exempt only those students that the state determines have the most significant cognitive disabilities up to 1%) from their general accountability data.

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# Employment

## 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.

## ISSUE

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

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

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

## POSITION

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

- Opportunities for post-secondary education, including college and vocational training, to gain knowledge and skills to allow people to get better jobs.
- Ongoing planning to promote job advancement and career development.
- Fair and reasonable wages and benefits.
- Opportunities for self-employment and business ownership.

- Opportunities to work with and, in the case of people with IDD who own small businesses, employ people without disabilities.
- The ability to explore new directions over time and, at the appropriate time, retire.
- Opportunities to work and increase earnings and assets without losing eligibility for needed public benefits.

### **Best Practices**

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

### **School-to-Work Transition**

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

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# Family Support

## **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.

## **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.

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.

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# Health

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

## ISSUE

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

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

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

- **Access.** Underinvestment in public health and wellness targeted to people with IDD results in preventable health care disparities and poorer health outcomes. Inadequate training, lack of coordinated care, and inadequate levels of reimbursement are some of the factors that create programmatic barriers while inaccessible clinical settings and diagnostic and medical equipment, along with translation and interpretation challenges, create physical barriers.



- **Discrimination.** Health care providers sometimes provide inadequate or inappropriate interventions and treatments or deny appropriate care for people with IDD because of professional ignorance as well as personal and/or societal bias. State statutory liability damage limits discriminate against people with severe and/or life-long disabilities because they fail to provide sufficient compensation.
- **Affordability.** People with IDD are more likely to live in poverty and cannot afford cost-sharing. For cost containment purposes, many public and private health care plans limit access to specialists and critical services. Even when services are available in a community, many people with IDD lack adequate public or private insurance to pay for them.
- **Communication and personal decision making.** People with IDD may have difficulties communicating their needs and making health care decisions without support. Their decisions may not be respected and implemented by health care providers and, where applicable, surrogate decision makers. People have not been ensured access to all necessary supports and information required to understand a health care decision and communicate their choices.

## POSITION

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

### Access

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



- People with IDD need access to effective strategies to manage their care including care coordination, referral processes, transition assistance, and health promotion efforts.
- Data collection and the assessment of health outcomes must include disability status. Public health initiatives must support the goal of reducing health care disparities for people with disabilities and improving health and function.
- The health care system must be fully accessible with respect to facilities and equipment, as well as communication needs and related accommodations such as sufficient time, explanations, translators, and interpreters when necessary.

### **Nondiscrimination**

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



## **Affordability**

- People with IDD should have universal access to comprehensive, affordable, quality health care.
- Efforts to contain health care costs should not create obstacles to care for people with IDD by making needed services or treatments unaffordable or otherwise unavailable. The medical need for care must be determined on an individualized basis.
- Payment for health services provided to people with IDD should compensate for the true cost of providing those services. This includes the costs of treating more complex health needs, and the greater amounts of time often required to understand and respond to those needs. Payment methodologies should not create disincentives to the provision of timely and appropriate services to persons with IDD.

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

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

- Sufficient information to understand the risks, demands, potential for significant pain, and benefits of any procedure for which consent is sought provided in ways that accommodate reading, language, learning, and other limitations that are common among persons with IDD;

Opportunities to ask questions and receive answers about the proposed treatment in understandable and understood language;

- Full disclosure that declining treatment may affect access to other treatments or services that the person is receiving or might otherwise receive;
- Protection from coercion or deceit to accept or decline a particular treatment;





- Reasonable efforts when a guardian, health care power of attorney, or surrogate decision-maker is involved to monitor, honor, and accommodate indications of “implied assent” to treatment; and
- Having specific expressed desires regarding the use of life-sustaining treatments communicated in written or oral form and recorded in an advance directive by individuals with IDD, as appropriate to their understanding of the nature, implications, and reversibility of their decision. Advance directives of people with IDD should be honored.

### **Surrogate Decision-Making**

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

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

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# Housing

## 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.

## ISSUE

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

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

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

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

Affordable housing programs are drastically underfunded, with long waiting lists. In addition, Medicaid, the principal source of funding for services and supports for people with IDD, typically does not allow funds to be used for rent or other community-based housing-related costs. These factors pose major barriers to community living, making it difficult for people to move from segregated facilities into the community, and putting many people with IDD at risk of unnecessary institutionalization or homelessness.

## POSITION

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

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

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# Human and Civil Rights

## HUMAN AND CIVIL RIGHTS

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

## ISSUE

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

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

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

- A history of discrimination and exclusion from meaningful choice and participation in employment, housing, voting, transportation, and other programs, activities, and services provided by the public and private sectors of society;
- Social and cultural attitudes of devaluation and fear;
- Unfounded beliefs that people with intellectual and/or developmental disabilities cannot and/or do not contribute to society;

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

## **POSITION**

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

These rights include the rights to autonomy, dignity, family, justice, life, liberty, equality, self-determination, community participation, property, health, well-being, access to voting, and equality of opportunity and others recognized by law or international declarations, conventions, or standards. All people with intellectual and/or developmental disabilities must have the right to supports they need to exercise and ensure their human and civil rights. Local, state, federal, and international governments must strongly enforce all human and civil rights.

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# Inclusion

## **INCLUSION**

All people with intellectual and/or developmental disabilities (IDD) 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;
- Participate in the same activities as children without disabilities;
- Play and participate with all children in community recreation; and
- Participate fully in the religious observances, practices, events, and ceremonies of the family's choice.

Adults should have the opportunity to:

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





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# Individual Supports

## 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.

## 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 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.

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# Opportunities for Financial Asset Building

## **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 wellbeing 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 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 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.

## **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;
- 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.

# Protection From Mistreatment

## PROTECTION FROM MISTREATMENT

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

## ISSUE

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

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

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

Federal and state laws may in fact be insufficient for this purpose. Ineffective professional practices among child and adult protective service agencies may add to the problem. Emergency responders and other professionals such as police, emergency room, and protective service workers need to be

educated as to how to assist people with intellectual and/or developmental disabilities to be safe without violating their rights. Finally, individuals with intellectual and/or developmental disabilities may not have received any, much less enough, training on how to protect themselves from or report mistreatment.

## POSITION

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

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

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

### **Children**

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

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

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

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

### **Adults**

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



# Self-Advocacy and Leadership

## SELF-ADVOCACY & 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.

## ISSUE

People with IDD have historically 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 the right to self-determination;
- Self-confidence and development of leadership skills;
- Successful story-telling;
- Public speaking;
- Problem-solving techniques;
- Participation in group decision-making; and
- Involvement on boards and task forces and with policymakers at the local, state, and national level.

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

## POSITION

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

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

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

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# Sexuality

## SEXUALITY

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

## ISSUE

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

## POSITION

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

All people have the right within interpersonal relationships to:

- Develop friendships and emotional and sexual relationships where they can love and be loved, and begin and end a relationship as they choose;
- Dignity and respect; and
- Privacy, confidentiality, and freedom of association.

With respect to sexuality, individuals have a right to:

- Sexual expression and education, reflective of their own cultural, religious and moral values and of social responsibility;
- Individualized education and information to encourage informed decision-making,

including education about such issues as reproduction, marriage and family life, abstinence, safe sexual practices, sexual orientation, sexual abuse, and sexually transmitted diseases;

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

With respect to the potential for having and raising children, individuals with intellectual or developmental disabilities have the right to:

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

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# Spirituality

## **SPIRITUALITY**

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

## **ISSUES**

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

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

## **POSITION**

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

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

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

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# Transportation

## TRANSPORTATION

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

## ISSUE

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

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

## POSITION

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

- Transportation at comparable cost and service models is available to individuals of all abilities.
- When making decisions, planning, and testing transportation options and payment methods, individuals with IDD are involved in the process.
- Improved coordination maximizes existing transportation services.
- Public transportation is adequately funded, fully financially and physically accessible, reliable to meet people's needs, and equipped to suit the physical, sensory, and cognitive needs of all people.
- As technological innovations emerge (such as virtual wayfinding, autonomous vehicles, and digital ticketing), transportation modalities are designed to be accessible, usable, and reliable, including such



things as language access, visual cues, safety considerations, and audio and hands-free options to meet individuals' needs and preferences.

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

**Advocacy**

**Aging**

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

**Behavior Supports**

**Criminal Justice**

**Early Childhood**

**Education**

**Employment**

**Family Support**

**Health**

**Housing**

**Human and Civil Rights**

**Inclusion**

**Individual Supports**

**Opportunities for Financial Asset Building**

**Protection from Mistreatment**

**Self-Advocacy and Leadership**

**Sexuality**

**Spirituality**

**Transportation**