



POSITION STATEMENT



ADVOCACY

Advocacy is essential in maintaining or improving the quality of life for people with intellectual and/or developmental disabilities¹.

ISSUE

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.

Persons with intellectual and/or developmental disabilities may need the support of advocates to:

- Know about, understand and assert their rights;
- Practice self-determination;
- Learn and develop the skills necessary to advocate for one's self;
- Practice self-protection;
- Obtain needed services;
- Identify and overcome barriers to full participation in their community; and
- Be protected from mistreatment, abuse and neglect.

POSITION

Advocacy is vital in improving and sustaining quality of life for persons with intellectual and/or developmental disabilities. To be successful, advocacy must take place at both the individual and the system levels.

Individuals

Advocates should be trained and well grounded to become knowledgeable in basic principles of respect for the rights and dignity of children and adults as set forth in the position statements of The Arc.

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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. 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. In making decisions, people 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 the matter.

In certain circumstances, parents and other legal representatives may need to be involved in making decisions with and on behalf of the individual. At such times, advocates must represent the interest 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

It is desirable that agencies providing supports to individuals 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 mandated by state and federal laws that:

- Are free from government influence and control;
- Are free from conflict of interest;
- Are adequately funded and staffed;
- Provide advocacy on their behalf even though a formal complaint has not been filed;
- Have the capacity to bring together all other community resources available in pursuit of the appropriate remedies; and
- Use multiple advocacy strategies, such as information and referral, mediation, legal action, and legislative and regulatory solutions.

Adopted: Board of Directors, The Arc of the United States

Board of Directors, AAIDD
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Congress of Delegates, The Arc of the United States



POSITION STATEMENT



GUARDIANSHIP

Most people with intellectual and/or developmental disabilities¹ can manage their own affairs with assistance and guidance from others, such as family and friends. If guardianship² is necessary, it should be tailored to the person's needs. Strict monitoring must be in place to protect the best interests and preferences of each person.

ISSUE

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

- 1) It limits a person's autonomy, that is, the person's choice of how to live and from whom to receive support to carry out that choice; and
- 2) It transfers the person's rights of autonomy to another person, a guardian.

Some statutory privacy measures have made it more difficult for those assisting other persons to get access to their records and/or make decisions. Thus, to obtain and modify needed medical care, services, and supports, a person may be forced into a guardianship arrangement. This conflicts with The Arc's principles of presumption of competence and the use of alternatives.

Guardianship has been over-used by those who were unaware of less intrusive alternatives or who simply wanted to have their views prevail over the wishes of the individual. Frequently, lesser forms of legal intervention, such as limited guardianship and use of powers of attorney or advance directives, have been either overlooked, intentionally avoided, or unavailable. Even powers of attorney³ can pose risks to a person easily influenced by others. They are private contracts that have no monitoring by courts or third parties. They can also be overly comprehensive.

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² Terminology for guardians differs by state and can include tutor, conservator, curator, etc.

³ Terminology for Power of Attorney differs by the State and can include durable power of attorney, limited power of attorney, healthcare power of attorney, durable power of healthcare, etc. See Uniform Guardianship Act, Commissioners on Uniform Laws.

POSITION

The majority of people with intellectual and/or developmental disabilities can manage their own affairs with informal assistance and guidance from family, friends, and others. When necessary, people should be aware of and have access to preferred alternatives. If guardianship is essential, it should be used only to the extent necessary, with a presumption in favor of limited rather than full guardianship.

Systems Issues

- 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 society;
- State laws should be reformed to prefer less intrusive alternatives to full guardianship, including limited guardianship, limited (and revocable) power of attorney or health care proxy, specifically tailored to individual need. These alternatives should always be considered first. Use of these alternatives can help someone who may not be competent to satisfy statutory privacy requirements that records only be released to a competent adult or the person's agent. They can also satisfy other privacy rights laws. If used at all, these restrictions on the person's rights and decision-making powers should be confined to those areas in which the person clearly cannot understand the serious consequences of his or her choices or the person lacks foresight;
- Ways to change overly restrictive forms of existing 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, including due process and the right to counsel, must protect the person's autonomy. They must also ensure that the person is informed and retains as much decision-making power as possible;
- Members of the judiciary and attorneys need training on alternatives to guardianship for people with intellectual and developmental disabilities;
- Guardianship should include a plan of teaching or support so the person will have more opportunities to learn and practice the skills needed to direct his or her own life. Understanding what guardianship is and that most people with intellectual and/or developmental disabilities can manage their own affairs with assistance and guidance should be part of transition planning in schools that prepares the individual's person-centered plan for adulthood; and

- The ultimate goal should be to individualize the process to support the person's preferences and desire to fully partake in community life with appropriate services and supports.

Guardian Responsibilities

- Guardians should be knowledgeable about services, supports, and systems that could significantly affect the quality of life and choices of the person. Moreover, guardians must be committed to the well-being of the person. They must know and understand the person's needs and wishes and act in accordance with them whenever possible. Family members are preferable choices for guardianship when they meet these criteria; and
- Guardians shall defer to the person's preferences if the decision does not jeopardize the health, safety, or financial security of the individual.

Oversight

- States should adopt minimum standards for all guardians and require that training and technical assistance be made available;
- Professional guardians (those who serve two or more people who are not related to each other and receive fees) 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 person; and
- Guardians shall be accountable for their actions, whether financial or quality of life decisions, made on behalf of the person. Those actions must be reviewed periodically and subject to a court's reporting requirements.

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POSITION STATEMENT



HUMAN AND CIVIL RIGHTS

The human and civil rights of all people with intellectual and/or developmental disabilities¹ must be honored, protected, communicated, enforced and thus be central to all advocacy on their behalf.

ISSUE

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

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

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

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

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- 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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POSITION STATEMENT



INCLUSION

All people with intellectual and/or developmental disabilities¹ benefit when fully included in community life.

ISSUE

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

POSITION

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

Children should have the opportunity to:

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

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- 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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POSITION STATEMENT



OPPORTUNITIES FOR FINANCIAL ASSET BUILDING

People with intellectual and/or developmental disabilities¹ must have opportunities to advance their economic and personal freedom by earning and saving money to enhance their physical, social, emotional, and financial well-being.

ISSUE

People with intellectual and/or developmental disabilities are poorer than people without these challenges. Government policies put people at risk of 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 trusts which meet SSI and Medicaid rules, these plans do not address the needs of everyone. Thus people with disabilities cannot plan and save for future needs like everyone else. Many government requirements conflict with goals for increased independence, productivity, and self-determination for persons with intellectual and/or developmental disabilities.

POSITION

Individuals with intellectual and/or developmental disabilities and their families should have opportunities to save money to maintain or improve their basic economic and social status including employment, housing, and retirement.

These opportunities should include such policy reforms as:

- Tax incentives, including Earned Income Tax Credit, Child Tax Credit, medical expenses, and business tax incentives;
- Individual Development Accounts that would enable a person to save for education, home ownership, or one's own business and/or employment;
- Expansion of housing assistance through the U.S. Department of Housing and Urban Development Housing Choice Voucher program so people can secure housing while retaining reasonable portions of their income for other expenses and investments;

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- Access to low-cost, user-friendly approaches for acquiring, maintaining, and expending resources while remaining eligible for publicly financed services and benefits; and
- Tax rates for wealth accumulation by people with disabilities which are not excessive.

Policy reforms must allow people with intellectual and/or developmental disabilities to have opportunities to earn money and invest in their futures without risking the health care, benefits, and support services on which they depend. Public policy should encourage rather than inhibit planning for future independence, productivity, and self-determination.

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

- Transition curricula in high schools and other educational settings;
- Inclusive adult and higher education and consultation/coaching in communities;
- Knowledge of and access to free information in user-friendly print and electronic formats; and
- Training for human services support and professional staff, advocates, bank/credit union and investment personnel, government officials (from service coordinators to IRS staff) in how best to help people enhance their assets.

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POSITION STATEMENT



PROTECTION FROM MISTREATMENT

People with intellectual and/or developmental disabilities¹ 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

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mistreatment. They should also learn about the nature of mistreatment and its likely sources. They should know how to avoid it, report it to the appropriate authorities, and give credible proof that it has occurred.

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

Children

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

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

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

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

Adults

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

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POSITION STATEMENT



QUALITY OF LIFE

People with intellectual and/or developmental disabilities¹ must be able to lead the life they choose so that they can have a quality of life that is meaningful to them.

ISSUE

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

POSITION

People with intellectual and/or developmental disabilities must have the opportunity to lead lives that offer them a meaningful quality of life. A meaningful quality of life exists for them when they:

- Receive, at all stages of their lives, the support, encouragement, opportunity, and resources to explore and define how they want to live and who is in their lives;
- Choose the services and supports they need and receive them anywhere in the country without waiting for an uncertain and extended length of time;
- Direct the services and supports they receive;
- Lead a life enriched by friends and family and have opportunities for intimate relationships based on informed consent and responsibilities;
- Experience life-long learning and develop decision making skills;

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- Work in a job that is meaningful to them;
- Enjoy the same rights and respect for their dignity and privacy, as do people without disabilities;
- Are fully informed about options, understand the risks associated with the options, and are allowed to take risks inherent in the options they choose; and
- Receive support to live in a healthy and safe environment.

Policies, regulations and funding must promote these desired outcomes. In addition, public agencies, private organizations, and individuals providing services and supports must:

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

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