



For people with intellectual
and developmental disabilities



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.

Position

The majority of people with intellectual and/or developmental disabilities can manage their own affairs with informal assistance and

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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.

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

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

³Terminology 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.

Adopted:

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Congress of Delegates, The Arc of the United States
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