



STATE OF DELAWARE  
**STATE COUNCIL FOR PERSONS WITH DISABILITIES**  
MARGARET M. O'NEILL BUILDING  
410 FEDERAL STREET, SUITE 1  
DOVER, DE 19901

VOICE: (302) 739-3620  
TTY/TDD: (302) 739-3699  
FAX: (302) 739-6704

**MEMORANDUM**

DATE: May 18, 2016

TO: Delaware State Bar Association

FROM: Ms. Daniese McMullin-Powell, Chairperson  
State Council for Persons with Disabilities

RE: S.B. 230 (Supported Decision-Making)

The State Council for Persons with Disabilities (SCPD) has reviewed S.B. 230 which creates the option of a supported decision-making (SDM) agreement for adults who do not need a guardian but who need assistance in gathering information, making decisions, and communicating those decisions. SCPD endorses the proposed legislation since it enhances the scope of assistance available to individuals, with safeguards. In addition, AARP has endorsed S.B. 230 (see attached letter).

SCPD also coordinated the development of the attached 2015-2016 Legislative & Policy Agenda. The agenda, which includes SDM as one of the top ten (10) disability-related priorities, was supported by the following organizations: Developmental Disabilities Council; Governor's Advisory Council for Exceptional Citizens; Governor's Advisory Council on Aging & Adults with Physical Disabilities; Governor's Advisory Council to the Division of Developmental Disabilities Services; Autism Delaware; Community Legal Aid Society, Inc.; Delaware ADAPT; Delaware Association of Rehabilitation Facilities; Easter Seals; Endless Possibilities in the Community; Hearing Loss Association of Delaware; MS Society; National Alliance on Mental Illness-Delaware; Nemours/A.I. duPont Hospital for Children; People First; The Arc of Delaware; United Cerebral Palsy of Delaware; Division of Prevention and Behavioral Health Services; Division of Services for Aging and Adults with Physical Disabilities; Division for the Visually Impaired; and Division of Vocational Rehabilitation.

In recent years, the federal Administration on Aging and the Administration for Intellectual and Developmental Disabilities have promoted the availability of supported decision-making options. Their rationale is that both the elderly and individuals with disabilities may benefit from the availability of assistance which is respectful of their autonomy while offering a menu of supports from which they can choose.

Many national organizations are also promoting the availability of supported decision-making for persons with disabilities. For example, the national ARC and American Association on Intellectual and Developmental Disabilities (AAIDD) adopted the attached position statement in April, 2016, “Autonomy, Decision-Making Supports, and Guardianship”. The national position statement includes the following guidance:

- States should provide systemic access to decision-making supports for all individuals with IDD.
- Each individual...should receive the preparation, opportunities, and decision-making supports to develop as a decision-maker over the course of his or her lifetime. All persons with I/DD can participate in their own affairs with supports, assistance, and guidance from others, such as family and friends. People with I/DD should be aware of and have access to decision-making supports for their preferred alternatives.
- 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.

See also attached Joint ARC and AAIDD Position Statement, “Self Determination” (2011).

Representatives of the Department of Health & Social Services, Office of the Public Guardian, Disabilities Law Program, and multiple State Councils formed a workgroup to prepare enabling legislation resulting in S.B. 230. The legislation does not supplant guardianship, powers of attorney, or other options available to help individuals with disability-related limitations. Rather, as illustrated in the attached “Comparison of Decision Making Options in Delaware” chart, it is part of a continuum of tools and resources to facilitate decision-making.

In nutshell, the Department of Health & Social Services will publish a form which a “principal” can execute defining the scope of authorized assistance (lines 88-89 and 163). The “supporter” must also sign the form and agree to abide by its terms (lines 98-102). If authorized, the supporter assists the principal in understanding financial, healthcare, and other information (lines 113-114); obtaining information (lines 115-117); making appointments (lines 118-119); and helping organize and keep track of information (lines 120-121).

The bill includes many safeguards:

- A. The DHSS form must be used (lines 88-90).
- B. The form must be signed in the presence of 2 witnesses (line 91).
- C. The supporter and witnesses must not be disqualified based on potential conflicts of interest (lines 92-95 and 124-131).
- D. Supporters are barred from misusing their role or information (lines 132-137).

- E. Supporters must protect the confidentiality of information (lines 159-161).
- F. The principal can revoke the form agreement at any time (lines 105-106).

The supporter essentially assists and facilitates decision-making and implementation of a principal's decisions. The supporter is not a substitute decision-maker (lines 12-13).

Thank you for your consideration and please contact SCPD if you have any questions regarding our position or observations on the proposed legislation.

cc: Mr. Brian Hartman, Esq.  
Ms. Laura Waterland, Esq.  
Ms. Lexie McFassel, Esq.  
Mr. Tanner Polce  
Governor's Advisory Council for Exceptional Citizens  
Developmental Disabilities Council  
P&I/senate bills/SB 230 SDM DSBA 5-18-16

To the Members of the Senate Health and Human Development Committee:

AARP champions positive social change and delivers value through advocacy, information and service. We have approximately 38 million members nationwide. In Delaware, AARP has over 182,000 members, a number which reflects more than half of Delaware's age 50+ population. AARP believes that opportunities should not diminish with age, and that Delawareans should age with dignity and independence in their communities.

AARP supports passage of Senate Bill 230. We recognize that supported decision-making can serve as a less-restrictive alternative to guardianship in some cases, where individuals are able to make their own decisions, but may need assistance in specific areas like, managing finances, navigating appointments, selecting housing, and communicating decisions. We believe this bill will protect the ability of older adults who may have cognitive decline, as well as individuals with disabilities to remain independent and continue to be a part of their communities.

AARP supports Senate Bill 230, which makes it easier for Delaware's growing 50+ population to age successfully, with dignity and independence.

Sincerely,

Roberta J. Hemmerich  
AARP Volunteer  
34144 Pinewood Circle  
Lewes, DE 19958

John Walsh  
AARP Volunteer  
48 Colonial Lane  
Rehoboth, Delaware 19971

Robert Chin  
AARP Volunteer  
33722 Mulberry St., Frankford, DE 19945

---

For more information, contact:

Sheila Grant, AARP DE Associate State Director for Advocacy  
Phone: 302-561-8214 | Email: [sagrants@aarps.org](mailto:sagrants@aarps.org)

# 2015-2016 LEGISLATIVE & POLICY AGENDA



***Brought to you by:***

*Developmental Disabilities Council; Governor's Advisory Council for Exceptional Citizens; State Council for Persons with Disabilities; Governor's Advisory Council on Aging & Adults with Physical Disabilities; Governor's Advisory Council to the Division of Developmental Disabilities Services; Autism Delaware; Community Legal Aid Society, Inc.; Delaware ADAPT; Delaware Association of Rehabilitation Facilities; Easter Seals; Endless Possibilities in the Community; Hearing Loss Association of Delaware; MS Society; National Alliance on Mental Illness-Delaware; Nemours/A.I. duPont Hospital for Children; People First; The Arc of Delaware; United Cerebral Palsy of Delaware; Division of Prevention and Behavioral Health Services; Division of Services for Aging and Adults with Physical Disabilities; Division for the Visually Impaired; Division of Vocational Rehabilitation; Ms. Jamie Wolfe, Advocate; Mr. Timothy Brooks, Parent Advocate*

## **CMS RULE ON HOME AND COMMUNITY BASED SERVICES (HCBS)**

In January 2014, CMS released rules for Medicaid-funded long term services and supports provided in residential and non-residential home and community-based settings. CMS released the rules to provide opportunities for participants to engage in community life, have access to the community, control their personal resources, and seek employment and work in competitive settings. The purpose of the rule is to enhance the quality of HCBS, provide additional protections to HCBS program participants, and ensure that individuals receiving services through HCBS programs have full access to the benefits of community living. Delaware is developing its Transition Plan to meet the requirements of the CMS Rule. The disability community has collaborated with the State, and needs to continue those efforts to ensure the Plan meets the requirements of the CMS Rule and is designed to develop infrastructure, services and supports to ensure smooth transitions for all those impacted.....people with disabilities, families, providers and State agencies.

## **FAMILY SUPPORT WAIVER**

The Division of Developmental Disabilities Services (DDDS) is proposing to amend its current Home & Community Based Waiver to include individuals living at home receiving DDDS day services and future school graduates, and a set of additional services designed to meet the needs of families. The amended waiver would enable a new group of waiver eligible individuals living at home to participate in a flexible program of supports to assist them in achieving their personal goals. The expanded waiver would include these new services: Community Living Supports, such as Respite, Assistive Technology (not otherwise covered under the State Plan for individuals under 21), Specialized Medical Services not otherwise covered by Medicaid and Home and Vehicle modifications (some of these services have individual annual limits). In addition to the new services, individuals living at home will also be able to access current non-residential waiver services like Behavior Consultation, Nursing Consultation and day and employment services. In addition to those services, the Division intends to include a different type of day service called Community Participation, if current funding allows. The waiver will definitely enhance the lives of many individuals with disabilities and their families in the state. Should additional funding become available in a future budget, DDDS would also propose including Preventative and Restorative Dental Services (limited to \$1,500 per member per year).

## **ACCESSIBLE PARKING**

H.B. 200 adds provisions to Title 21 defining accessible parking spaces, incorporating federal standards for accessible parking spaces found in the ADA and adding additional requirements that enhance these standards and better reflect the needs of persons with disabilities in Delaware. Enhanced standards include wider spaces, required signage that parking in access aisles is prohibited, designated spaces for wheelchair/scooter users only and requirements for consistent signage. The legislation also requires that no accessible parking space shall be installed, resurfaced, restriped, or repainted until the county or municipality has issued a permit authorizing such action and has an inspection process for the construction or modification of the space to ensure

compliance. Finally, the legislation increases the penalty for illegally parking in an accessible space.

### **PERSONAL ATTENDANT SERVICES PROGRAM**

Continued funding is needed for the Community-Based Attendant Services Act (H.B. 30) which is mainly utilized by the Division of Services for Aging and Adults with Physical Disabilities (DSAAP) for personal attendant services (PAS). DSAAPD administers the attendant services program in collaboration with two non-profit contractors, Easter Seals and JEVS Human Services. Attendant services are subsidized to permit participants to engage in employment, attend school, or avoid institutionalization. The PAS program has enjoyed broad support from major disability organizations, the General Assembly and people that utilize the services. DSAAPD receives money from “tobacco” funds and general funds to serve participants. Providing such funding minimizes the likelihood of institutionalization and maximizes potential for independent living of individuals with disabilities. In addition, it enhances the continuum of community-based services offered and reduces barriers to participation in vocational, educational, social and other community-based activities. This is consistent with the Department’s efforts to rebalance its disproportionate spending of long term care dollars on institutional care given that the average per participant cost of attendant services is approximately \$13,126 vs. the average cost of a Delaware nursing home in 2015 which exceeds \$98,000.

### **SOURCE OF INCOME DISCRIMINATION LEGISLATION**

Legislation was introduced in the 147 General Assembly (H.B. 196) which would prohibit housing discrimination based on source of income by adding “source of income” as a protected class under the Delaware Fair Housing Act and the Landlord Tenant Code. A person may still take into account sufficiency of income and credit worthiness of a tenant or buyer, so long as any standards are applied neutrally without regard to the source of income. There is also an exception for landlords who are employees of a housing authority and are prohibited by their employer’s conflict of interest policy from renting to persons receiving housing assistance payments. This measure will prevent and address discrimination against those who receive part or all of their income from child support, government or private assistance programs, or any lawful occupation. The issue merits reintroduction of a bill with a revision which adds language specifying that landlords will not be compelled to participate in rental assistance programs, and that the bill is not meant to prevent landlords who do participate in housing programs from reserving a certain number of units for that purpose.

### **SOLITARY CONFINEMENT**

In Delaware, solitary confinement typically results in an inmate spending 24 hours daily in a small cell with the exception of 1 hour, 3 days per week, to shower and exercise. In August, 2015 the ACLU and CLASI filed federal litigation challenging the use of solitary confinement for inmates with a serious mental illness. On September 3, 2015 the Governor signed HJR 5 which authorizes the retention of an expert to analyze the use of solitary confinement in the Delaware prison system. A

report with findings and recommendations is due by December 31, 2015 which would likely result in remedial legislation. Earlier legislation (H.B. 36) which would have restricted use of solitary confinement for juveniles and individuals with a serious mental illness was tabled in committee in deference to acquiring the expert evaluation contemplated by HJR 5. Many states are limiting or eliminating use of solitary confinement for individuals with mental illness. Delaware's statutory and policy standards merit revision.

## **SUPPORTED DECISION MAKING**

This Bill would create the option of a Supportive Decision-Making Agreement for people who don't need a guardian but who need assistance in gathering information, making decisions and communicating those decisions. The bill allows those individuals to select and appoint one or more trusted friends or relatives or a paid provider to act as a supporter. The supporter can provide assistance and guidance on issues affecting the individual, such as coordinating health care and services and making health and service-related decisions, dealing with housing issues, daily living activities and routine financial matters. The supporter is not empowered to make decisions for the individual or to substitute their judgment. The bill includes safeguards such as limiting who can act as a supporter and requiring a written document with disinterested witnesses. The bill gives the supporter legal status to participate in the decision-making process by gathering information and assisting the individual in making and communicating decisions. Decisions communicated by the supporter must be honored, absent indicia of fraud, misrepresentation and undue influence. A Supported Decision-Making Agreement would not supplant options that are currently available (e.g. Power of Attorney, Guardianship).

## **ACCESSIBLE TAXIS**

Creation of accessible taxi service is needed in Delaware. According to the University of Delaware's Optimizing Accessible Taxi Service to Augment Traditional Public Transit Services in Delaware, in 2011, a total of 101 taxicabs were being operated in Delaware by 40 firms. None of the vehicles catalogued in Delaware's taxi fleet were capable of accommodating a motorized wheelchair. The report concluded, in part, that a new regulatory framework should be developed which implements universal design with the goal of providing every user with a superior passenger experience. The achievement of that goal will result in expansion of the market which will provide more business for providers and universal taxi accessibility for all Delaware's residents and visitors alike. The FY 2016 Grant-in-Aid Bill requires DeIDOT/DTC to administer an RFI for operating and managing a safe, affordable and reliable "taxi-style" service for paratransit customers.

## **DeIDOT TRANSIT REDESIGN**

In January 2015, Delaware's Department of Transportation/Delaware Transit Corporation (DTC) released its Transit Redesign Implementation Plan which outlined the way it plans to operate its state transit programs, particularly the Paratransit service. The rationale for such a change is the



cost of its statewide paratransit service and that the current model of serving customers regardless of location is not sustainable. In addition, DTC claims the service is not meeting the needs of the customers and the current model is jeopardizing DTC's ability to meet mandated legal requirements for ADA paratransit and could potentially impact future federal funding. Key changes include increases in the price of Paratransit fares (both "ADA" and "Demand-Response" fares) and changing Paratransit services where there are no established fixed routes. Through a coordinated advocacy effort, parts of the plans were delayed and there has been collaboration, but the community still fears for the long term impact on paratransit customers. Therefore, the community is requesting a structure to study the impact of these recommendations on the disability community in Delaware, examine what other states with similar issues are doing, and determine what other alternatives are available.

### **MEDICAID COVERAGE OF ADULT DENTAL CARE**

Tooth decay and gum disease are linked to depressed immune systems, heart disease, exacerbation of diabetes, and cancer. Most states include at least limited dental services in their Medicaid plans. Legislation (S.B. 142) has been introduced in the 148th General Assembly which expands Delaware's Public Assistance Code to provide preventative and urgent dental care to all eligible Medicaid recipients. Payments for preventative or urgent dental care treatments shall be subject to a \$10.00 recipient co-pay and the total amount of dental care assistance provided to an eligible recipient shall not exceed \$1,000.00 per year, except that an additional \$1,500.00 may be authorized on an emergency basis for urgent dental care treatments through a review process established by the State Dental Director [Begin Synopsis Here](#). This Act would become effective upon appropriation by the General Assembly of funds sufficient to accomplish the purposes of this Act. Two initiatives have expanded, or may expand, access to dental care to two Medicaid subpopulations: 1) effective January 1, 2015, one of two Medicaid Managed Care Organizations has included coverage of a single dental exam and cleaning annually in its services menu; and 2) the Delaware Department of Health and Social Services solicited \$2.4 million in its FY17 budget request to include Medicaid coverage of dental benefits for adults. The extension of dental care coverage to adult Medicaid beneficiaries qualifies as a top health care priority.

Bookstore Career Center AAIDD Community Newsletter Contact Us

LOG IN JOIN [Forgot Password](#)

Education Publications News & Policy SIS Intellectual Disability About AAIDD

9

|        |
|--------|
| News   |
| Policy |

Home / News & Policy / Policy / Position Statements / Autonomy, Decision-Making Supports, and Guardianship

# Autonomy, Decision-Making Supports, and Guardianship

Joint Position Statement of AAIDD and The Arc



## Statement

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

## Issue

- Current trends presume the decision-making capacity of individuals with I/DD and the preservation of legal capacity as a priority for all people needing assistance with decision-making.
- Like their peers without disabilities, individuals with I/DD must be presumed competent; they must also be assisted to develop as decision-makers through education, supports, and life experience.
- Communication challenges should not be misinterpreted as lack of competency to make decisions.
- Individuals with I/DD should have access to supports and experiences to learn decision-making skills from an early age and throughout their lifetimes in educational and adult life service systems.
- Families should have access to information about all options for assisting their family member to make decisions over the life course.
- All people, with and without disabilities, have a variety of formal and informal processes available to enact their decisions and preferences, including healthcare proxies and advance directives.
- Less restrictive means of decision-making supports (e.g., health-care proxies, advance directives, supported decision-making, powers of attorney, notarized statements, representation agreements, etc.) should be tried and found to be ineffective in ensuring the individual's decision-making capacity before use of guardianship as an option is considered.
- Where judges and lawyers lack knowledge about people with I/DD and their human rights, poor advocacy and tragic legal outcomes often result. Financial incentives frequently benefit professionals and guardianship corporations, often to the detriment of individuals with I/DD and their families.
- Serving in the dual roles of guardian and paid service provider or paid advocate creates a conflict of interest or the appearance of a conflict of interest. Such conflicts must be mitigated or avoided.
- Some statutory privacy measures have made it more difficult for those assisting other individuals to have access to their records, make decisions, or both. Thus, to obtain or modify needed medical care, services, and supports, an individual with I/DD may be adjudicated to be incompetent and subjected to guardianship. This result conflicts with the legal presumption of competence and with principles of autonomy, decision-making supports, presumption of competence, and the use of less restrictive alternatives.

The appointment of a guardian is a serious matter for three reasons: (1) It limits an individual's autonomy, that is, the individual's agency over how to live and from whom to receive supports to carry out that choice; (2) It transfers the Individual's rights of autonomy to another individual or entity, a guardian; and (3) Many individuals with I/DD experience guardianship as stigmatizing and inconsistent with their exercise of adult roles and responsibilities.

## Position

The primary goals in assisting individuals with I/DD should be to assure and provide supports for their personal autonomy and ensure equality of opportunity, full participation, independent living, and economic self-sufficiency (Americans with Disabilities Act, 1990, section 12101 (a)(7); Individuals with Disabilities Education Act, 2004, section 1400 (c)(1)). Each individual adult and emancipated minor is legally presumed competent to make decisions for himself or herself and should receive the preparation, opportunities, and decision-making

- The appointment of a guardian should be appropriately time-limited in order to provide regular periodic review of the individual's current capabilities and functioning and whether a less restrictive alternative is now indicated. The reviews should include an independent professional assessment by a highly qualified examiner of the individual's functioning with necessary accommodations and communication supports. All costs of the review should be paid by the state and not imposed on individuals with I/DD or their families.
- Guardianship should include a person-centered plan of teaching and/or supports for decision making so the individual with I/DD will have opportunities to learn and practice the skills needed to be autonomous and to direct his or her own life. Understanding the nature and purpose of guardianship and understanding that most people with I/DD can manage their own affairs with assistance and guidance should be part of transition planning in schools and of any curriculum or procedures that prepare the individual's person-centered plan for adulthood. Schools should not give legal advice to students and families, and should provide students and families with information about less restrictive alternatives to guardianship.
- The ultimate goal of any such curriculum or procedures should be to ensure the individual's autonomy to the maximum extent possible, individualize decision-making supports for the individual, and ensure that the individual has maximum access to equal opportunity, independent living, full participation, and economic self-sufficiency, each with supports that take into account the individual's capacities and needs.

#### Guardian Responsibilities

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

#### Oversight

- States should adopt a set of minimum standards for all guardians and require training and technical assistance for all guardians.
- Professional guardians (those who both serve two or more people who are not related to each other and also receive fees for these services) should, at a minimum, be registered, and preferably licensed or certified by the state, either directly or through delegation to an appropriate independent professional organization. They should also have the appropriate education and skills. They should be independent from and not be receiving payment for providing other services to the individual.
- Guardians shall be legally accountable for all of their decisions and other actions with respect to the individual. Their decisions and other actions must be subject to the reporting and review procedures of the appropriate state court or other agency.

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

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

supports to develop as a decision-maker over the course of his or her lifetime. All people with I/DD can participate in their own affairs with supports, assistance, and guidance from others, such as family and friends. People with I/DD should be aware of and have access to decision-making supports for their preferred alternatives.

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

#### Systems Issues

- States should provide systematic access to decision-making supports for all individuals with I/DD.
- An individual (other than a family member) should not serve in dual roles as guardian and as paid advocate or paid service provider for an individual.
- An organization should avoid serving in dual roles as guardian and as paid advocate or paid service provider for an individual.
- Organizations that serve in dual roles of guardian and paid advocate or paid service provider must have written policies and organizational separations in place to mitigate conflicts of interest. These organizations should support efforts to develop independent guardianship organizations.
- Financial incentives that benefit professionals or guardianship corporations should never drive guardianship policy or result in expensive and unnecessary costs to individuals or their families.
- Appointment of a guardian of the person, the person's finances, or both, should be made only to the extent necessary for the legal protection and welfare of the individual and not for the convenience or preferences of the family, the service system, or others.
- Individuals with I/DD must have access to all the accommodations and supports, including communication supports, they need to demonstrate their competency at initial evaluations for guardianship and at all periodic reviews of any guardianship.
- State laws should be reformed to prioritize less restrictive alternatives to full and plenary guardianship, including without limitation informal supports, supported decision-making, limited (and revocable) powers of attorney, health care proxies, trusts, and limited guardianships that are specifically tailored to the individual's capacities and needs. These alternatives should always be considered first. Use of these alternatives can help an individual who may have limited capacity to consent to satisfy statutory privacy or other requirements and to have records released to a person or entity designated as the individual's agent or provider of support and services. If used at all, any restrictions on the individual's rights and decision-making powers should be confined to those areas in which the individual demonstrates a need for assistance that exceeds what can be provided through a less restrictive alternative.
- Laws should be reformed to require that less restrictive options are tried and found to be ineffective to ensure the individual's autonomy before full (plenary) guardianship is even considered. Alternatives and related procedures to change overly restrictive forms of any existing guardianship, including restoration of rights and termination of any guardianship, must be available under state law.
- Since guardianship represents a transfer of rights and the responsibility for exercising them, adequate safeguards must be in place to protect those rights. These safeguards include procedural due process (including without limitation the right to counsel representing the interests of the individual, impartial hearing, appeal, and burden and quantity of proof) must protect the individual's autonomy. The state must also ensure that the individual is informed and retains as much decision-making power as possible. The state should pay the costs of providing these due process protections and not impose the costs on families or on individuals with I/DD.
- Members of the judiciary, attorneys, and other professionals need training and education on alternatives to guardianship for individuals with I/DD, and they must zealously advocate for preserving the substantive and procedural rights of all individuals with I/DD.
- If a guardian is to be appointed, the preferences and assent of the individual with I/DD with respect to the identity and function of the proposed guardian should be considered.



The Arc

For people with intellectual  
and developmental disabilities



## POSITION STATEMENT Self Determination

People with intellectual and/or developmental disabilities<sup>1</sup> have the same right to self-determination as all people. They must have opportunities and experiences that enable them to exert control in their lives and to advocate on their own behalf.

### *Issue*

Many of our constituents have not had the opportunity or the support to control choices and decisions about important aspects of their lives. Instead, they are often overprotected and involuntarily segregated. Many of these people have not had opportunities to learn the skills and have the experiences that would enable them to take more personal control and make choices. The lack of such learning opportunities and experiences has impeded the right of people with these disabilities to become participating, valued, and respected members of their communities. Furthermore, state monitoring and licensure policies and practices may be contrary to the principles of self-determination.

### *Position*

Our constituents, as Self Advocates, have the same right to self-determination as all people and must have the freedom, authority, and support to exercise control over their lives. To this end, they must:

In their personal lives have:

- opportunities to advocate for themselves with the assurance that their desires, interests, and preferences will be respected and honored.
- opportunities to acquire and use skills and knowledge which better enable them to exercise choice.
- the right to take risks.
- the right to choose their own allies.

The Arc  
1825 K Street, NW  
Suite 1200  
Washington, D.C. 20006  
Phone: 202.534.3700  
Toll free: 800.433.5255  
Fax: 202.534.3731  
[www.thearc.org](http://www.thearc.org)



- the lead in decision-making about all aspects of their lives.
- the option to self-direct their own supports and services and allocate available resources.
- the choice and support necessary to hire, train, manage, and fire their own staff.

- opportunities to take leadership roles in setting the policy direction for the self-determination movement.
- the right to representation and meaningful involvement in policy-making at the federal, state, and local levels.

In their community lives have:

- the right to receive the necessary support and assistance to vote.
- opportunities to be supported to become active, valued members and leaders of community boards, advisory councils, and other organizations.

"People with intellectual and/or developmental disabilities" refers to those defined by AIDD 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.

Adopted  
Congressional Delegation, The Arc of the United States  
2011

*Achieve with us.*

For more information on this and other topics, visit [www.thearc.org](http://www.thearc.org)

**ENDLESS POSSIBILITIES**  
**A COMPARISON OF DECISION MAKING OPTIONS IN DELAWARE**

| <b>Who Completes the Form</b>                | <b>Supportive Decision Making (Proposed)</b>                                                                                                                                           | <b>Surrogate Decision Making</b>                                                                                                 | <b>Advanced Health-Care Directive</b>                                                                                                                      | <b>Power of Attorney</b>                                                                                                                                  | <b>Guardianship</b>                                                                                                    |
|----------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------|
| The adult, two witnesses, and the Supporter. | Determination is made by the attending physician if patient lacks capacity, or stated by the patient if able.                                                                          | The adult, with or without medical or legal consultation.                                                                        | Legal document stating a person's preferences to guide future health care treatment if the adult loses decision-making capacity, and may appoint an agent. | The adult, with or without legal consultation.                                                                                                            | A petition and multiple forms must be filed by the person seeking guardianship with the Court of Chancery.             |
| <b>Type of Document</b>                      | Document executed and witnessed indicating what type of assistance is needed and what the supporter has permission to do.                                                              | Documented by the physician in the patient's health record as to who is designated by the patient, or who is available to serve. | All adults that have even a modest level of capacity, who are aware and able to understand the nature and effect of the document. (Testamentary capacity)  | Legal document appointing an agent to manage financial affairs on behalf of the adult prior to or when the adult loses capacity.                          | Court Order specifying the powers of the guardian and what, if any, rights are retained by the individual.             |
| <b>Intended Population</b>                   | Individuals who need help in gathering and assessing information, including those with physical disabilities, cognitive or intellectual disabilities, brain injuries, and the elderly. | Patients in the health care setting with or without decision making capacity.                                                    | All adults that have even a modest level of capacity, who are aware and able to understand the nature and effect of the document. (Testamentary capacity)  | All adults that have even a modest level of capacity, who are aware and able to understand the nature and effect of the document. (Testamentary capacity) | All individuals assessed by a physician to have no decision making capacity, or those at risk of harm or exploitation. |

|                                                 |                                                                                                                                                                                                                                   |                                                                                                                                                                                                                                          |                                                                                                                                                                             |                                                                                         |                                                                                                                                                                                                        |
|-------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Signatures required</b>                      | Document must be signed by the adult, two witnesses, and the appointed Supporter.                                                                                                                                                 | Confirmed in writing by the physician if patient lacks capacity, or by the physician and the witness if decision maker designated by patient.                                                                                            | Person and two witnesses meeting specific requirements.                                                                                                                     | Document must be signed, witnessed and notarized.                                       | Court Order signed by a Judicial Officer.                                                                                                                                                              |
| <b>Appointment of Authorized Representative</b> | Appoints an individual to gather information and assist in assessing information. Supporter does not have individual authority.                                                                                                   | A person may designate a surrogate decision maker by informing the health care provider in the presence of a witness, or if unable to do so, the health care provider may recognize an individual pursuant to the law. (16 Del.C. §2507) | Title 16, Chapter 25 provides a form which must be executed to set out the wishes of the person and appoint an agent who may act when the individual becomes incapacitated. | Title 12, Chapter 49A provides a statutory form and directions for appointing an agent. | The Court of Chancery appoints a guardian upon the petition. Title 12, Chapter 39.                                                                                                                     |
| <b>Role of Representative</b>                   | To provide support to the adult, including help in assessing information, options, responsibilities and consequences of the adult's life decisions, including those about health care, financial decisions, and support services. | To make decisions about health care in place of the individual.                                                                                                                                                                          | To make decisions about health care in place of the individual in conformance with their wishes.                                                                            | To make decisions in place of the individual about financial matters.                   | To assume all decision making in place of the individual, who retains not ability to make decisions for themselves. Authority extends to both person and property depending on the order of the Court. |
| <b>Termination of Power</b>                     | May be revoked by individual.                                                                                                                                                                                                     | A competent person may disqualify a surrogate in writing or by communicating with the care provider.                                                                                                                                     | May be revoked in writing or another means of effective communication the intent to revoke.                                                                                 | May be revoked by the individual.                                                       | The guardianship may be terminated upon petition to the Court of Chancery if the individual recovers capacity, or terminates upon death.                                                               |