

SUPPORTED DECISION- MAKING: AN ALTERNATIVE TO GUARDIANSHIP AND CONSERVATORSHIP

**A PROGRAM OF THE ARC OF MS
PRESENTED BY KIM DUFFY**



THE ARC OF MISSISSIPPI



- The Arc of Mississippi was founded in 1961 and is an affiliate of The Arc of the United States (www.arc.org). The Arc promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.

ATTORNEY BY TITLE, SOCIAL WORKER AT HEART

- Former Legal Service Attorney
 - with elderly and those with disabilities
 - Supervised the Ombudsman Program for Area Agency on Aging
- Former attorney with MS Center for Justice
- Currently attorney The Arc of MS Supported-Decision Making
- Mother of sons with extra challenges and needs

CIVIL RIGHTS ISSUE OF OUR DAY

“Supported decision making and providing powers of attorney are the options we should look to first – rather than reflexively choosing guardianship and stripping a person of every civil liberty.”

[American Civil Liberties Union](#)

Interdisciplinary Network of Guardianship Stakeholders (WINGS)

- **State Wings Pilots**

- In 2013 and again in 2015, the National Guardianship Network, with coordination by the ABA Commission on Law and Aging, sought and received support from the State Justice Institute, the Borchard Foundation Center on Law and Aging, and other sources, for start-up funds and technical assistance to pilot WINGS in selected states.

WINGS

- A project to support court-led partnerships in states to drive changes in guardianship policy and practice.
- **Mississippi**
- The Mississippi Administrative Office of the Courts convened WINGS in September 2015, with committees on reformed court procedures, capacity determinations, data, less restrictive options, monitoring and training.

MISSISSIPPI MOVING TOWARD REFORM

COMMISSION ON GUARDIANSHIP & CONSERVATORSHIP

On May 10, 2017, the Mississippi Commission on Guardianship and Conservatorship to begin work to develop recommendations to improve the way the courts protect children, vulnerable adults and estates.

MS WINGS

- **Interdisciplinary Workgroup:**
- **Focused on broader issues and includes non-attorneys and judges**
- **For example, CASA like program for guardianships**

“RIGHT TO LIFE, LIBERTY AND PROPERTY”

- The United States Constitution guarantees all citizens the right to life, liberty and property.
- **We get to decide:**
 - how, where and with whom we live
 - where we work
 - how, where and with whom we spend our free time

"LIFE, LIBERTY AND THE PURSUIT OF HAPPINESS"

Our founders also declared that we have certain “inalienable rights”. These are rights which our founding fathers declared have been given to all human beings by their Creator, and for which governments are created to protect.

[United States Declaration of Independence](#)

INALIENABLE RIGHTS

- Inalienable rights refer to rights that **cannot be surrendered**, sold or transferred to someone else, especially a natural right.
- Inalienable is defined as incapable of being surrendered or transferred - at least without one's consent.
- These rights **cannot be taken away except in punishment** of crime.
- **Governments are instituted to "secure,"** not grant or create, these rights.

WHAT ABOUT ME?

What if ...

I am elderly, have a disability or have impairment that effects my judgment or ability to make decisions ...

Do I still have "inalienable rights"?

WHAT ABOUT MISSISSIPPI?



UNITED STATES DEPARTMENT OF JUSTICE

- **On December 22, 2011, after a full investigation, the DOJ found Mississippi in violation of the Americans with Disabilities Act's (ADA) and the United States Supreme Court decision, *Olmstead v. L.C.*, 527 U.S. 581 (1999).**
- (www.ada.gov/olmstead/documents/miss_findings_letter.doc)

AMERICANS WITH DISABILITIES ACT FINDINGS

- (1) physical or mental disabilities in **no way diminish a person's right to fully participate in all aspects of society**, yet many people with physical or mental disabilities have been precluded from doing so because of discrimination; others who have a record of a disability or are regarded as having a disability also have been subjected to discrimination;
- (2) historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem;
- (3) discrimination against individuals with disabilities persists in such critical areas as employment, housing, public accommodations, education, transportation, communication, recreation, institutionalization, health services, voting, and access to public services;

PURPOSE OF ADA

- (1) to provide a clear and comprehensive national mandate for the **elimination of discrimination** against individuals with disabilities;
- (2) **to provide clear, strong, consistent, enforceable standards** addressing discrimination against individuals with disabilities;
- (3) to ensure that the **Federal Government plays a central role in enforcing the standards** established in this chapter on behalf of individuals with disabilities; and
- (4) to invoke the sweep of congressional authority, including **the power to enforce** the fourteenth amendment and to regulate commerce, in order to address the major areas of discrimination faced day-to-day by people with disabilities.

OLMSTEAD DECISION

- On June 22, 1999, the United States Supreme Court held in *Olmstead v. L.C.* that **unjustified segregation of persons with disabilities constitutes discrimination in violation of title II of the ADA. The Court held that public entities must provide community-based services to persons with disabilities** when (1) such services are appropriate; (2) the affected persons do not oppose community-based treatment; and (3) community-based services can be reasonably accommodated, taking into account the resources available to the public entity and the needs of others who are receiving disability services from the entity.

THE SUPREME COURT EXPLAINED THAT ITS HOLDING "REFLECTS TWO EVIDENT JUDGMENTS."

1. "Institutional placement of persons who can handle and benefit from community settings perpetuates unwarranted assumptions that persons so isolated are incapable of or unworthy of participating in community life."
2. "Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment."

WELL-MEANING BUT WITHOUT UNDERSTANDING

“Experience should teach us to be most on our guard to protect liberty when the Government’s purposes are beneficent. . . . ***The greatest dangers to liberty lurk in insidious encroachment by men of zeal, well-meaning but without understanding.***”

Olmstead v. U.S., 277 U.S. 438 (1928)

**The 14th Amendment to
United State Constitution provides
equal protection and due process of
law for all people.**



UNITED NATIONS CONVENTION ON THE RIGHTS OF INDIVIDUALS WITH DISABILITIES

- Preamble:
- (o) Considering that persons with disabilities should have the opportunity to be actively involved in decision-making processes about policies and programs, including those directly concerning them,

Article I Purpose

The purpose of the present Convention is to promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity.

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others

DOJ'S FINDINGS REGARDING GUARDIANSHIP

Approximately 160 individuals placed in Mississippi institutions **did not have an independent guardian or decision maker.** The director of the institution was either directly named as the guardian or was acting as guardian due to the absence of one.

RESPONSE TO THE FINDING

- The Arc decided to pay particular attention to this issue
- Other Arc's across the country had guardianship programs
- We were already working with individuals in the Bridge to Independence program

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- We initially looked at following a traditional guardianship model.
 - We researched what Arc's and other nonprofit or public guardianships were doing in other states and looked at various options.
 - We soon landed on the supported decision making model.

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- **Supported Decision-Making**
 - **VS**
 - **Substituted Decision-Making**

SUBSTITUTED DECISION-MAKING

- Another person makes decisions for the individual
- Individual may not have opportunity to decide who will provide support
- Individual loses legal capacity to act independently across entire domain

WHAT IS SUPPORTED DECISION MAKING?

- System of supporting an individual who is elderly or has a disability to make his or her own choices
- May include assistance with gathering information, understanding options, and communicating with third parties
- Level of support will vary with level of need or importance of decision

SUPPORTED DECISION-MAKING

- Individual makes own decisions (with support)
- Individual decides who will provide support
- Level of support may vary according to situation

HOW DOES SUPPORTED DECISION- MAKING HELP?

- Centers on the person in decision-making process
- Tailors support to amount needed
- Helps build decision-making experience and skills
- Requires supporters to commit to interactive process
- Holds supporters accountable to person

AUTONOMY *WITH* SUPPORT

- •Under guardianship model, autonomy of a person with cognitive or intellectual disability must be limited to protect the person from exploitation, manipulation, or “bad choices”
- •Early civil libertarian critiques focused on imposing guardianship only when a person is “truly unable” to make decisions independently
- •*Supported* decision-making acknowledges need for support while preserving autonomy

MEDICAID WAIVER REGULATIONS

- Regulations require person-centered planning process for HCBS – including for people in guardianship
- Settings regulations also require integration, including meaningful opportunities to make choices, arrange schedule

THE ARC'S SUPPORTED DECISION-MAKING PROGRAM

- Using person centered approach to assist individuals to have maximum input and control over where and how they want to live.
- We have gone to court and had some guardianships dissolved and had the individuals' rights restored.
- The Arc is acting in a supportive role to insure the individuals needs and wishes are in harmony with their plan of support. Using Durable Powers of Attorney and MS Uniform Health-Care Decisions Act

SUPPORTED DECISION-MAKING AGREEMENT

- Supported Decision-making is a process in which people that need support work in partnership with others to make life choices, such as with whom/where/how they live and by whom/where/how they receive needed services. The Arc of Mississippi is an organization devoted to protecting the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in decision-making throughout their lifetimes.
- To further promote this mission, **The Arc**, it's Executive Director and designated personnel of the organization, agree to work with the **Supported Person** through the Supported Decision-making process and to perform all duties in a person-centered manner respecting their rights and dignity. It is agreed that:

The Arc of Mississippi

Minimum Follow-up For Supported Decision Making / Advocacy

Supported Decision-Making is a process in which people work in partnership with supporters to decide on management, guidance, care and implementation of preferences.

The Arc of Mississippi is an organization devoted to protecting the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the decision-making throughout their lifetimes.

- Ⓞ Complete initial paperwork on each person to identify specific needs and/or concerns, i.e. intake form using the Personal Outcome Measurement (POM) process. POM is a method of guided interviews to 'discover' the real person behind the diagnosis; their preferences, dreams, and conditions in order to support them at their best.
- Ⓞ Determine best practices for individualized support; Supported Decision Making, Powers of Attorney, etc. Notify appropriate providers and services involved in the ongoing support of the person of any decisions made around Supported Decision Making and/or Powers of Attorney and provide copies for their files.
- Ⓞ Visit as needed to assure that needs are met.
- Ⓞ Phone contact quarterly or as appropriate. Contact pertains both to the person being supported as well as checking in with the providers or services supporting them.
- Ⓞ Ongoing contact with case manager, service coordinators and/or family members as needed.
- Ⓞ Attend planning meetings as scheduled, at least annual face-to-face. Planning meetings have different names such as Individualized Educational Plans, Service Plans, Employment Plans, Person Centered Plans, Habilitation Plans, etc. These are opportunities for all of those who provide planning or support to a person to come to the table together and assist the person in deciding what is important, what services they want, who they want in their life, defining goals, objectives, activities, or resolving conflict.
- Ⓞ Maintain and submit a quarterly report on each person to administration at The Arc of Mississippi or a representative Human Rights Committee of The Arc of Mississippi.

Achieve with us.

WHO WE SUPPORT


- Various individuals referred from SPOTT team - living in a variety of settings
- Hudspeth Regional Center – approximately 40 individuals that the Director had been the acting surrogate

WHAT ABOUT CAPACITY?

- Medical - diagnostic approach
- Legal – functional evaluation
- Proof of legal capacity relies heavily on medical evaluations of competency

IDENTIFYING ALTERNATIVES TO GUARDIANSHIP

Name of Individual: _____
 Name of person completing this form: _____
 Relationship to individual (*circle one*): Self Family Friend Guardian Other: _____
 How long have you known the individual? _____

<p>This checklist is a tool designed to be used as guidance in The Arc of Mississippi's Supported Decision-Making Program.</p> <p>It is designed to assist with identifying a person's ability to make decisions and manage key areas of the individual's life. It is intended to assist with exploring alternatives and less restrictive options to plenary or full guardianship.</p> <p>The questions listed below are <u>not</u> exhaustive and are <u>not</u> intended to provide a final determination of what a person should (or should not) do in their unique circumstances.</p>	LEAST RESTRICTIVE: Individual Makes Own Decisions "YES" If the answer is "YES," place a ✓ in the box. If the answer is "NO," go to next column. →	 Individual Needs Support With Making Decisions "NO" If there is an ALTERNATIVE that meets this need, list it below If NO Alternative meets this need, go to next column. →	MOST RESTRICTIVE: Individual has NO RIGHTS to Make Decisions "NO" Place a ✓ in the box and consider whether you need to address the need through one of the GUARDIANSHIP OPTIONS
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EMPLOYMENT

Can the person make and communicate choices in regard to employment?			
Can the person look for and find a job (<i>go to employment agency, respond to ads, use contacts</i>)?			

MONEY MANAGEMENT

Is the person able to manage their money (i.e. meet financial commitments, such as regular bills)?			
Is the person able to manage the monetary benefits he or she is supposed to receive?			
Is the person able to identify and resist financial exploitation?			

HEALTH & NUTRITION

Does the person make decisions about where, when, & what to eat?			
Can the person follow a prescribed diet and/or take medicines as directed?			
Does the person understand the need to maintain personal hygiene and dental care?			
Can the person make and communicate decisions regarding medical treatment, including understanding the consequences of not accepting treatment?			
Does the person understand health consequences associated with high risk behaviors (<i>substance abuse, overeating, high-risk sexual activities, etc.</i>)?			
Can the person alert others and seek medical help for serious health problems?			

STANDARDS OF CAPACITY

- Testamentary (Make a will or power of attorney):
 - Understand & appreciate nature & effect of act
 - Understand & recognize objects, persons and relationship to him
 - Capable of determining the disposition of property he/she wants
- Contractual:
 - Must understand the nature & effect of the transaction
 - Higher standard than testamentary capacity

HOW DO WE MOVE TO SUPPORTED DECISION-MAKING?

- Reforms across multiple systems:
- **Courts:** change laws to favor supported decision-making over guardianship
- **Support Professionals:** stop pushing guardianship
- **Service Systems:** ensure that people have access to decision-making supports
- **Third Parties:** make sure doctors, landlords, etc. understand SDM; provide certainty that acting consistently with SDM will result in enforceable contracts/health care decisions.

USE WHAT WE HAVE

- Durable Power of Attorney
- Mississippi Uniform Health-Care Decisions Act

DURABLE POWER OF ATTORNEY

- A written document in which a person gives another person the rights to make decisions for them.
- The “principal” person appoints another to be an “attorney-in-fact”.
- It creates a substitute decision-maker without the involvement of the court system.
- Unlike guardianship or conservatorship, it does not take away the rights or control of the person appointing the attorney-in-fact.

MISSISSIPPI UNIFORM HEALTH-CARE DECISIONS ACT

Advanced Directives:

“An individual’s ability to understand the significant benefits, risks, and alternatives to proposed health care and to make and communicate a health care decision.”

- *Section 41-41-223* of Uniform Health-Care Decisions Act of Mississippi

PRESUMPTION OF CAPACITY

- In Mississippi, an individual is presumed to have capacity to make a health-care decision, to give or revoke an advance-health directive, and to designate or disqualify a surrogate.
 - *Section 41-41-223* of Uniform Health-Care Decisions Act of Mississippi

HEALTH-CARE SURROGATE

- A third party or “surrogate” can make health care decisions for one who is unable to make decisions for herself, where no health-care agent has been appointed or is not available.
 - Section 41-41-211 of Uniform Health-Care Decisions Act of Mississippi

ORDER OF PRIORITY FOR SURROGATE DESIGNATED CLASSES

- Spouse, unless legally separated
- Adult child
- Parent
- Adult brother or sister
- An adult who has exhibited special care and concern for the patient, who is familiar with patient's personal values, and who is reasonably available to act.

DECLARATION OF SURROGACY

- If there is not a spouse, adult child, parent or adult brother or sister available to act as a surrogate, the next available surrogate is “*an adult who has exhibited special care and concern for the patient*”, pursuant to § 41-41-211(3).
- A Declaration of Surrogacy can be signed expressing the intention to serve in this role.

There will be circumstances when a guardianship is required.

But, it should be the last resort, not the first option.

And, it should be as limited as possible.

“For anyone who has been told you can’t do something, you can’t make your own decisions, I give you Jenny Hatch — the rock that starts the avalanche”

[The Washington Post \(quoting Jonathan Martinis\)](#)

- **Comments and Questions**