SUPPORTED DECISION-MAKING:
An alternative to guardianship and conservatorship

A PILOT 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

• Legal Service Attorney
  ◦ with elderly and those with disabilities
  ◦ Supervised the Ombudsman Program for Area Agency on Aging

• Attorney with MS Center for Justice

• Board of The Arc of MS/Gulf Coast Down Syndrome Society

• Mother of sons with special challenges and needs
"Life, Liberty and the Pursuit of Happiness"

Three examples of the "inalienable 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).

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.
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."
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.
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.
• 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.
THE ARC’S SUPPORTED DECISION-MAKING PROGRAM

• Pilot 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
“JUSTICE FOR JENNY”

Aug. 2, 2013 | “I’m so happy to go home today,” Jenny Hatch said through tears. “I deserve it.” She plans to return to the home of Jim Talbert and Kelly Morris, who employed her and were designated to be her temporary guardians for the next year, with the goal of ultimately helping her achieve more independence. (Steven Tulwin/For The Washington Post)

But for national experts on the rights of people with disabilities, several of whom testified on Hatch’s behalf, the case was about much more. It was about an individual’s right to choose how to live and the government’s
Case Study: Jenny Hatch

• Jenny lived with her friends, Jim & Kelly
• She worked at their thrift store, where she earned above the minimum wage
• After a bicycle accident, her mother tried to place her under guardianship, and force her to live in a group home setting and work in the group home’s sheltered workshop
• Jenny successfully fought for transition to SDM – she’s now back at her chosen home and making her own life decisions with the aid of her support network
Right to Choose Where, With Whom & How to Live

It was about an individual’s right to choose how to live and the government’s progress in providing the help needed to integrate even those with the most profound needs into the community.

In the end, Newport News Circuit Court Judge David F. Pugh said he believed that Hatch, who has an IQ of about 50, needed help to make decisions but that he had also taken into account her preferences. He designated Morris and Talbert her temporary guardians for the next year, with the goal of ultimately helping her achieve more independence. The temporary guardianship has ended.
Supported Decision-Making: An Agenda for Action

“It’s an important time to have this conversation. This generation of people with disabilities is the first to grow up with the rights and opportunities protected and promoted by the Americans with Disabilities Act (ADA). There is growing recognition that over-reliance on formal systems of substituted decision-making can hinder or prevent inclusion, self-determination and community integration, in violation of the ADA and other federal laws (Salzmann, L., 2010).”
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*
WE ALL MAKE DECISIONS WITH “SUPPORT”

- People get decision-making support from:
  - Doctors
  - Financial advisors, agents
  - Lawyers
  - Counselors
  - Informational materials (online or elsewhere)
  - Family and friends
  - Clergy
  - Support groups
EVEN THE PRESIDENT HAS ADVISORS TO HELP HIM MAKE DECISIONS
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 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
Supported Decision-Making

• Individual makes own decisions (with support)
• Individual decides who will provide support
• Level of support may vary according to situation
Isolating Effects of Guardianship

• Cannot make decisions without approval of guardian
• Become “disconnected” from decision process and fail to gain – or may even lose – decision-making skills
• May be “constructively isolated” from community due to inability to enter into contracts, find housing, see doctor, or go shopping without guardian. - Leslie Salzman

Isolating Effects of Guardianship

- Challenges and conflicts among family members require lengthy court process
- Elderly & persons with disabilities too often do not have legal representation, which makes a challenge improbable
- Crowded dockets and limited court oversight
- Even in states that have limited guardianship options, Courts often avoid limiting guardianships – even though they’re supposed to favor them – because they want guardians to have as much authority as possible
Public Guardianships: Special Problems

• Guardians with multiple wards may opt for “one size fits all” approach to decision-making

• Guardians do not have personal relationship with ward, may face communication barriers, may lack background information about ward’s preferences and personality

• M.P. case and ComCare in Tennessee
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
NEW MEDICAID WAIVER REGULATIONS

• Recent 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
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.
Texas is the first state to recognize Supported Decision-Making as alternative to Guardianship

Effective Sept. 1, 2015, there are significant changes to Texas Guardianship laws. For the first time, probate courts must consider alternatives to guardianship, and supports and services available to the proposed ward before a guardianship is created. Two new alternatives to appointing a guardian now exist: Designation of Guardian Before the Need Arises and Alternate Forms of Decision-Making Based on Person-Centered Planning; and Supported Decision Making Agreement. Tex. Est. Code §§ 1002.0015 & 1357.001.
Before Appointing a Guardian, the probate court must find by clear and convincing evidence that alternatives to guardianship and supports and services have been considered and determined not to be feasible. If the court grants a Limited guardianship, the court must specifically state whether the proposed ward lacks the capacity with or without supports and services to make personal decisions regarding residence. *Tex. Est. Code § 1101.101(a)(D) & (E)*;
(c). In addition, an Order for Full Guardian must specify that the ward does not have the capacity to make personal decisions regarding residence. *Tex. Est. Code § 1101.151(b)(5).*
Before appointing a guardian, the court must make a reasonable effort to consider the ward’s preference of the person to be appointed guardian regardless of whether the person was designated by the ward before the need arises. A guardian has the right to decide where the ward resides but may only place a ward in a more restrictive placement if the guardian provides notice to the court, the ward and any person who has requested notice and the court orders the placement after a hearing if the ward or another person objects to the proposed placement in a timely manner. *Tex. Est Code § 1151.051(e)*
The law now includes a new section on Supports and Services, defined as available formal and informal resources and assistance that enable an individual to:

Meet his/her needs for food, clothing, or shelter;
Care for his/her physical or mental health;
Manage his/her financial affairs; or
Make personal decisions regarding residence, voting, operating a motor vehicle, and marriage. *Tex. Est. Code § 1002.031*
BILL OF RIGHTS FOR PERSONS UNDER GUARDIANSHIP

Including the right of a ward to complain or raise concerns regarding the guardian or guardianship to the court, including living arrangements, retaliation by guardian, conflicts of interest between the guardian and service providers, or a violation of any of the Bill of Rights; to vote unless restricted by the court, and to petition the court and retain counsel of his/her choice who is certified, to represent ward’s interest in the termination or modification of guardianship, the appointment of a different guardian or other appropriate relief under the Bill of Rights, including transition to a supported decision-making agreement. Tex. Est. Code § 1151.35
START BY USING 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.
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
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.
Mississippi Uniform Health-Care Decisions Act

A model for Supported Decision-Making?
“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