

# Supporting Self-Determination: How States Can Make a Difference

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# Administration for Community Living

The Administration for Community Living was created around the fundamental principle that older adults and people of all ages with disabilities should be able to live where they choose, with the people they choose, and with the ability to participate fully in their communities.

By funding services and supports provided by networks of community-based organizations, and with investments in research, education, and innovation, ACL helps make this principle a reality for millions of Americans.

# American Bar Association Commission on Law and Aging

The Commission on Law and Aging is a collaborative and interdisciplinary entity that works to strengthen the legal rights, autonomy, quality of life, and quality of care of aging persons.


The Commission accomplishes its work through research, policy development, advocacy, education, training, and through assistance to lawyers, bar associations, and other groups working on issues of aging.




# American Bar Association

- One of the world's largest voluntary professional organizations
- Over 400,000 members and more than 3,500 entities.
- Committed to serving our members, improving the legal profession, eliminating bias and enhancing diversity, and advancing the rule of law throughout the United States and around the world.

# What We'll Discuss

- Overarching principles in decision supports and autonomy
  - Approaches to strengthen decisional capacity
    - Supported Decision Making
    - Financial
    - Healthcare
    - Other legal approaches
  - Grantee projects
  - WINGS and state-level actions
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# Overarching Principles

- Values and wishes
  - Self-determination
  - Person-directed
  - Decisional capacity is situational, not immutable
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# Supported Decision-Making: What is it?


Supports and services that help an adult with a disability make his or her own decisions, by using friends, family members, professionals, and other people he or she trusts: to help understand the issues and choices; ask questions; receive explanations in language he or she understands, and communicate his or her own decisions to others (Dinerstein, 2012; Blanck and Martinis, 2015).



# Supported Decision-Making: What Is it?

- Informal assistance – money management, doctor’s visits, relationship advice
- Supported decision-making agreements (legally recognized in at least 9 states)
- Pilot Programs
  - Supported Decision-Making New York, [sdmny.org](http://sdmny.org)
  - Center for Public Representation SDM Demonstration Project, [supporteddecisions.org](http://supporteddecisions.org)
  - In the Media
    - Jamie Beck of Indiana
    - Ryan King of Washington, D.C.

# Decision Supports and Less Restrictive Options than Guardianship


- Planning ahead
  - Self-determination
  - Legal options
  - Everyday, informal practices
  - Avoiding unnecessary guardianship
  - Facilitating opportunities for person with a guardian to exercise self-determination
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# Challenges in Implementing Decision Supports

- Financial
- Finding a trusted supporter(s)
- Recognition of supportive arrangements by financial institutions, health care providers, others




# Decision Supports for Financial Matters

- Representative Payees
  - Daily or regular money management
  - Financial power of attorney
  - Trusts
  - Joint ownerships
  - Protective Arrangements
  - Informal arrangements
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# Social Security Representative Payee Program

- Social Security Administration appoints a payee to manage benefits for beneficiaries it determines are “incapable” of managing their own benefits.
- Can a rep payee provide decision supports or is that counter to the definition of the payee’s responsibilities?
- Interdependence: When a family member serves as payee and the members live in the same household.


# Financial Power of Attorney

- Legal document delegating financial decision-making authority to a proxy, agent, surrogate, representative
    - Revocable at any time
    - Person must have capacity to appoint an agent
    - Lawyer not required but recommended
    - If “durable” can be used if the agent is incapacitated
  - Pros: Avoids guardianship, less/no court time or cost, allows the person to plan for the future, and to choose who may make decisions on his or her behalf
  - Cons: Risk of abuse and exploitation, lack of institutional/judicial monitoring
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# Money Management


- Direct deposit
  - Bill paying
  - Preparing checks for signature
  - Bank deposits, handling cash
  - Payroll for home attendants and other staff
  - Tax preparation
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# Other Decision-Making Supports

- Trusts
  - Joint Ownership
  - Protective Arrangements – a single court order about property or money:
    - Confirming someone is eligible for public benefits;
    - Managing money or property;
    - Sale, mortgage, lease, or other transfer of property;
    - Signing a contract;
    - Adding to or creating a trust;
    - Making or breaking a contract, trust, will, or other transaction.
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# Decision Supports for Healthcare and End-of-life Decisions

- Delegating decision-making authority (advance directive)
    - Healthcare Power of Attorney
    - Psychiatric Advance Directive (mental health care)
  - Preferences for end of life care
    - Living Will
    - Physician Orders for Life-Sustaining Treatment (POLST)
  - Substitute health care decision-making laws
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# Healthcare Powers of Attorney

- Legal document delegating decision-making authority to a healthcare proxy, representative, surrogate, or agent.
- Usually not effective until person is incapacitated, but some states provide for authority of healthcare power of attorney before incapacity.
- Best practices
  - Proxy should be familiar with the person's values and wishes
  - Should be able to make the same treatment preferences the person would choose
- Pros: Person chooses the agent, opportunity to think about and discuss wishes regarding medical treatment
- Cons: Can be misused, difficult to enforce, lack of monitoring

# End of life decisions

- Living Will or Advance Directive: Preferences regarding feeding tubes, ventilator support, and resuscitation
- The Conversation Starter Kit at [www.theconversationproject.org](http://www.theconversationproject.org)

# ACL Grantee Projects

- American Bar Association Commission on Law and Aging
  - State WINGS
- Volunteers of America Minnesota's Center for Excellence in Decision Making
  - Established a replicable statewide model based on Supported Decision-Making to promote safe and viable alternatives to guardianship and conservatorship in Minnesota.
- Stark County Eldercaring Coordination Program
  - Provides conflict mediation assistance to elders and families, expands its Court's Guardianship Visitor Program through partnerships with other court systems, and evaluates support systems to eliminate the need for guardianship.



Working Interdisciplinary Networks  
of Guardianship Stakeholders

# What is WINGS?

Court-  
Community  
Partnerships

Evaluation  
of “on the  
ground”  
practices

Ongoing  
forum



# Goals of WINGS

- **Identify** strengths and weaknesses in the state's current system of adult guardianship and less restrictive decision making options
- **Address** key policy and practice issues
- **Engage** in outreach, education and training
- **Serve** as ongoing problem solving mechanism
- **Open doors** to communication, understanding; break down silos; develop SYNERGY



**“Large scale social change comes from better cross-sector coordination rather than from the isolated intervention of individual organizations.”**

**--2011 article on *Collective Impact***



# WINGS Synergy

- *“When everyone is around a table, we can short-circuit problems.”*
- *“Advocates from every side bring forth good discussion.”*
- *“Things are easier when you get to know someone personally, triaging with those who come to the table.”*





# Key **WINGS** Stakeholders

- Judges; court staff
- Bar associations; legal services
- State unit on aging; AARP; aging advocates
- Disability rights agency, developmental disability councils; disability advocates
- Adult protective services
- Long-term care stakeholders; ombudsman; provider & hospital staff representatives
- State guardianship associations; public guardianship agency
- Professional & family guardians
- Social Security & VA representatives
- Self advocates

# 2016 ACL Elder Justice Innovation Grant Project

- Federal ACL funds to establish, encourage & enhance WINGS
- ACL grant to ABA Commission on Law and Aging, with National Center for State Courts
- Technical assistance, strategic planning, outcome measurement, infrastructure of resources; communication across states
- <http://ambar.org/wings>



## States with WINGS

- States funded before ACL project: MN, NY, OR, TX, UT, WA
- States funded by ACL project: AL, AK, FL, ID, IN, OR, UT
- States independently developed: “Wingish” – KY, MA, MO, MT, MD, NE, NV, NC, OH, PA, VA, WV, WI


<http://ambar.org/wings>



# WINGS Accomplishments

- AL – Resolution, judicial survey, town hall meetings
- AK – Changes in forms and probate rules; guardian education
- ID -- Complaint form; Bench card; Regional coordinator/monitors
- IN – Education & pilot on supported decision-making
- MD –New judicial rule on guardianship; guardian training
- MN – Annual summit
- NV – Consistent statewide court rules & forms
- NC – Report & data on restoration of rights
- OR – Less restrictive options survey; train the trainer curriculum; public education; data project
- UT – Funding for statewide visitor program
- ALL – SYNERGY; COLLECTIVE IMPACT

# Actions that States Can Take

- Court partnerships
  - Education
  - Funding (Older Americans Act, Section 721)
  - Stakeholder coalitions
  - WINGS
  - Offer resources and leadership to local partners/stakeholders
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# Resources

- ABA resources
  - ABA’s Toolkit for Health Care Advance Planning, [www.ambar.org/agingtoolkit](http://www.ambar.org/agingtoolkit)
  - WINGS Tools and Backgrounders:  
[https://www.americanbar.org/groups/law\\_aging/resources/wings-court-stakeholder-partnerships0/guardianship-reform-wings-background/](https://www.americanbar.org/groups/law_aging/resources/wings-court-stakeholder-partnerships0/guardianship-reform-wings-background/)
  - 2015 Assessment by National Center for State Courts
  - 2015 WINGS Replication Guide (to be updated in 2019)
  
- Consumer Financial Protection Bureau, Managing someone else’s money guides: <https://www.consumerfinance.gov/consumer-tools/managing-someone-elses-money/>
  
- Finding the Right Fit: Decision-Making Supports and Guardianship:  
<https://eji.courtllms.org/catalog/info/id:140?eType=EmailBlastContent&eld=78fc945e-be1f-4cdb-8474-cfd9b72ca056>.

# Be in Touch!

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