

# Compassion, not Control

Supporting Decision Making in Older Adults

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**2023 ALCA New England Pre Conference**

Boston-Needham Marriott, MA

October 4, 2023



Age-friendly  
University  
Global Network



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# DISCLOSURE

The content of this presentation does not relate to any product of a commercial interest.

There are no relevant financial relationships to disclose.

# Goals

Enhance practice

Use self-knowledge  
in service of others

Offer tools



# Objectives

Distinguish capacity from competency

Describe approach for examining limits on self-determination

Discuss least restrictive alternatives from ethical perspective

Discuss supported decision-making



**Caveats and  
Critical  
Concepts**



**Tremendous variation**



A person with **DEMENTIA**

A **PERSON** with dementia

**A PERSON**





**WHO a person is**  
**What a person CAN STILL DO**





**How do you know  
what you know?**

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## When head and heart disagree

Leave it to the bones?

Check your gut?



# Risk Tolerance

Slow lane | Fast lane

Game show winnings  
(Jeopardy)

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# **A one minute paired conversation**

Introduce yourselves

# Independence, Autonomy, Self-Efficacy



# Independence

Remaining independent =  
staying in one's own home

Accepting help at hand

Doing things alone

Having family, friends, and  
money as resources

Preserving physical and  
mental capacities

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# Fear of Dependency

> Fear of death

> Fear of illness

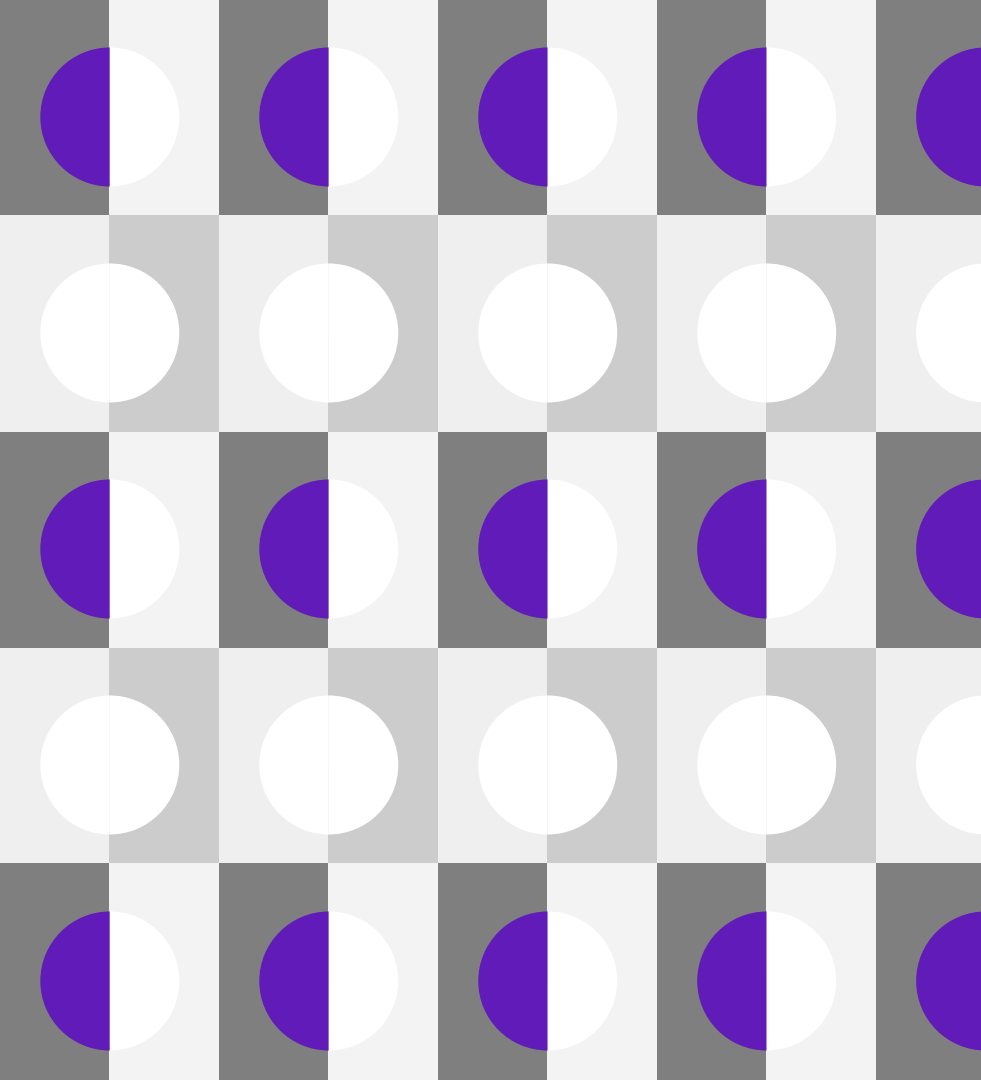
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**On being dependent**

**Fundamental  
task across  
the lifespan**





**Significant frailty and cognitive decline create greater reliance on others.**

**This need not threaten autonomy or sense of well-being**





# Autonomy



# *The right to be left alone*

Legal Doctrine







# Legal doctrine

**constitution intended to protect**

*“a great many foolish, unreasonable  
and even absurd ideas which do not  
conform...”*

--Warren Burger



# Autonomy

- To choose
- To self-determination
- To be responsible
  - Dignity of risk
- To fail
- To privacy





# Self-determination

Better health

Greater well-being

It's the law!



# Self-efficacy

*Belief* in one's ability to  
succeed in reaching  
favorable outcome

Not the ability itself

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# Self-efficacy

“I can do this”

“What I do makes a difference”

“I’m in charge” of my destiny





# Fears

Fear of loss of autonomy

Fear of becoming a burden

Fear of dependency

- > Fear of death

- > Fear of illness

**Fear**  
**Frustration**  
**Filial love**

Safety

Falls

Protection from exploitation

Fear of Decline

Access to medical care

Access to services



# Common Triggers

Treatment refusal

Non-adherence

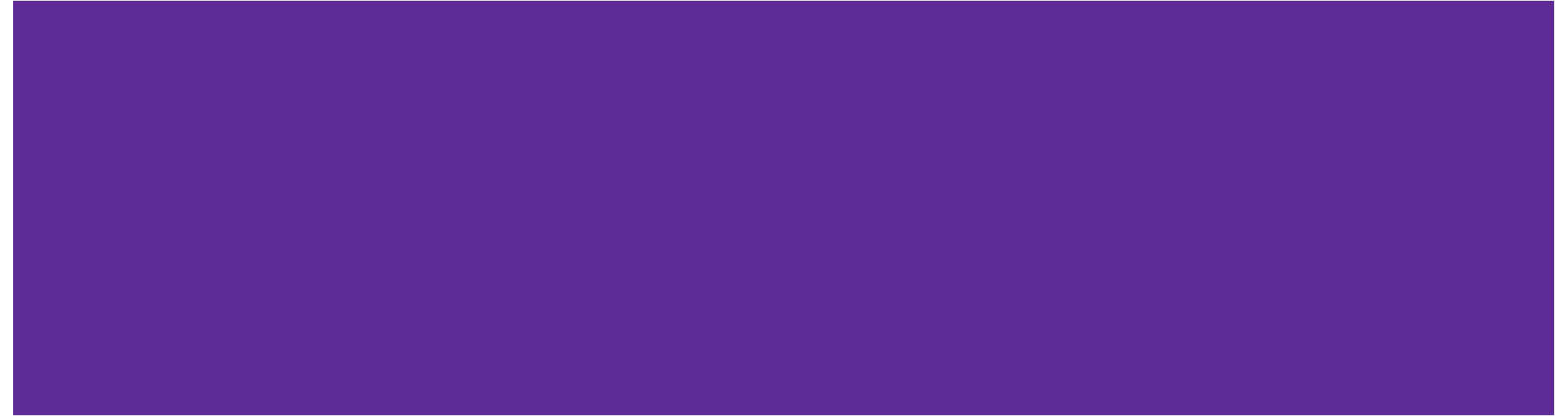
Abuse, neglect, exploitation

Lifestyle intolerance

Hospitalization

# Paired Conversation

Capacity and Competency: What's the difference?





# Competency v. Capacity

## **Competency**

a legal concept

## **Capacity**

a clinical concept

the ability to “do”  
something



# Capacity

Task specific, not global

Contextual

Capacity can fluctuate

Determining capacity in persons with complex impairments can be difficult



# Capacity

What decision needs to be made?

What is interfering with decision-making?

Is capacity likely to change?

Issues of undue influence?

# Key aspects of decisional capacity

## **Understanding**

Problem  
Alternatives  
Advantages &  
Disadvantages

## **Appreciating**

Personal deficits  
Potential impact  
of alternatives

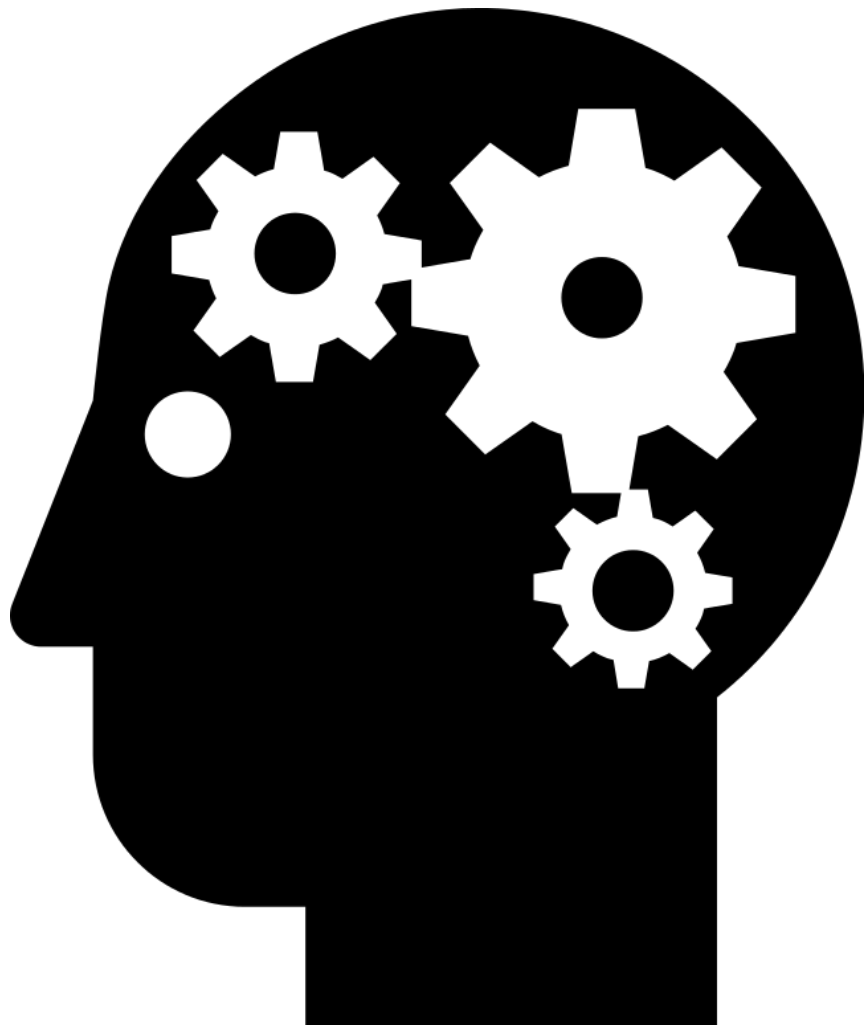
## **Reasoning**

Comparative &  
consequential  
reasoning

## **Expressing a choice**

Choice of how to  
solve an everyday  
problem

Logical  
consistency



## Types

### **Everyday**

Capacity to live alone

Managing medications

Managing finances

Driving capacity

### **Consent to treatment**

### **Testamentary**

**Conjugal (spousal)  
visits**

Research consent





## Testamentary capacity

Can a person leave his fortune to his cats?

(and win, when the will is contested?)



**Meet Pearl**



# Support for at-risk adults

Finding balance

Enhancing self-efficacy



# Think about...

## **Decision-making and thinking**

Nature and extent of impairments

Residual strengths

## **What a person can do, as well as can not do**

Self, financial, medical, civic, legal,  
home and community life

Will person use adaptive assistance

# SDM

Supported  
decision-making

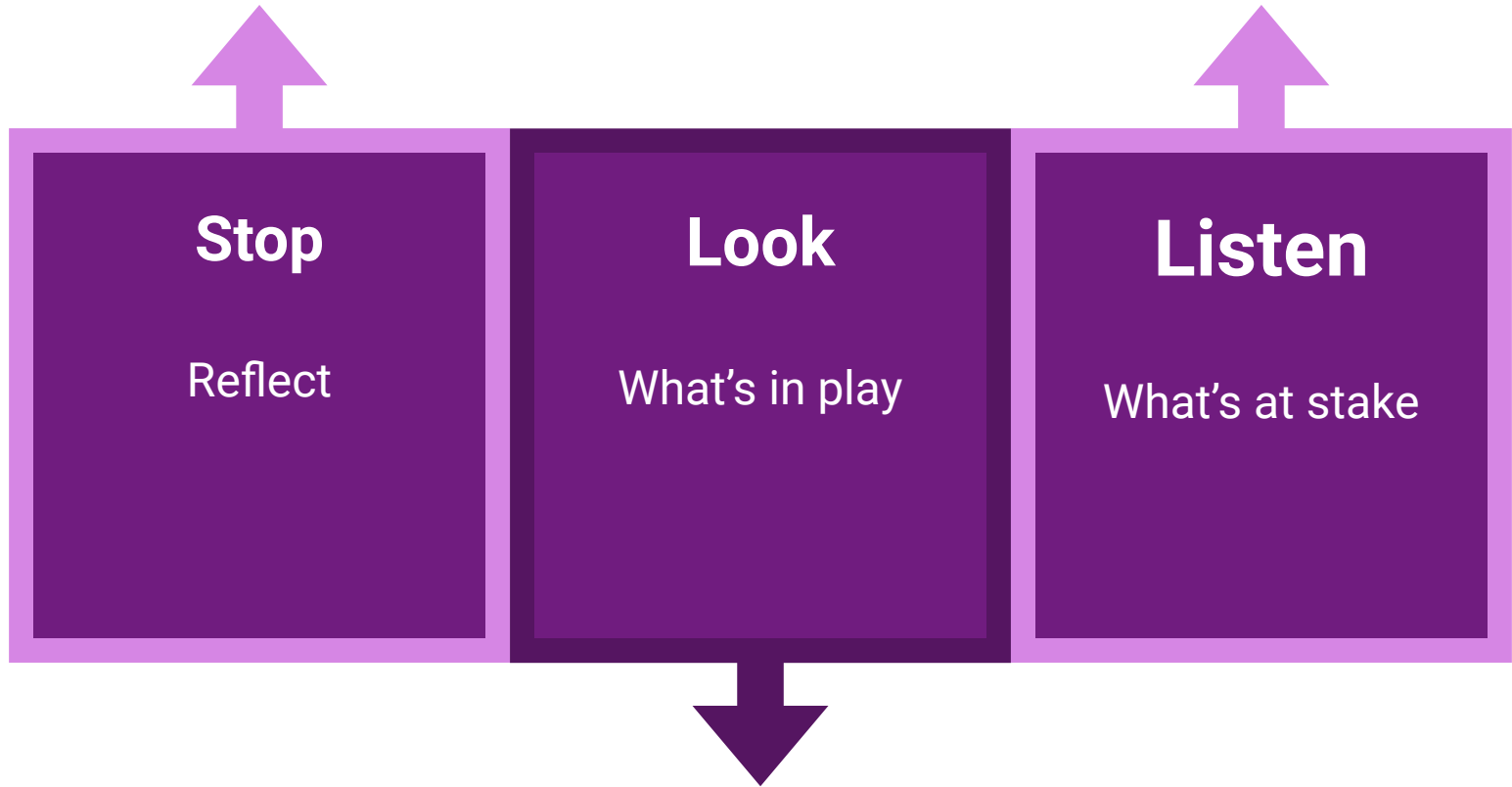
Starting point is NOT capacity

Starting point is preference,  
choice, formal  
decision-making

Amount and type of support  
critical

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# Supporting Decision-Making with Older Adults



# Alternatives to full guardianship

<b>Least Restrictive</b>	<b>Middle Ground</b>	<b>Most Restrictive</b>
Individual retains full independence and full decision-making power	Individual retains some --but not all-- decision making power	Guardian has full decision-making control over all areas of a person's life
No court involvement	Limited court involvement	Requires a court order





## Consider family mediation

- Family dynamics are complicated
- Late life transitions are complicated
- Simmering disputes often emerge into hostile conflict
- Everyone can express needs and feelings, then deal rationally with the problems
- Mediation can achieve positive conflict resolution outside of a courtroom

# In conclusion

**Lead with  
compassion  
not control**

**Find the balance**

**Try SDM**

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**Thanks**  
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