



How Can Consumer Direction Really Be Right For Everyone?

National Resource Center for Participant-
Directed Services (NRCPS)

Boston College

January 13, 2010

TA Call Outline

- Goals of Consumer Direction
- Research Results: Does Mental Illness Affect Consumer Direction of Community-Based Care?
- Concerns, Decisions, and Viewpoints
- Assessments and Representatives
- Common Sense Approaches and Interventions
- Additional Tools and Resources





Goals of Consumer Direction

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Director of Program Design and Implementation

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Goals of Consumer Direction

- Anyone desiring to consumer-direct should be given the opportunity
- Respect individual choice
- Facilitate empowerment, autonomy, and skills
- Develop strategies for success
- Leave competency for the legal system



Goals of Consumer Direction (continued)

- Assess capacity to determine level of support, not program eligibility
- Requires buy-in at all levels
- Consumer direction is easy in concept, but execution may more difficult
- Anything goes? No, not quite...





Does Mental Illness Affect Consumer Direction of Community-Based Care? *Lessons From the Arkansas Cash & Counseling Program*

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Dawn Loughlin, PhD

Study Authors: Ce Shen, PhD, Michael A. Smyer, PhD, Kevin J. Mahoney, PhD, Dawn M. Loughlin, PhD, Lori Simon-Rusinowitz, PhD and Ellen K. Mahoney, DNS,
The Gerontologist 48:93-104 (2008)

Study Highlights

- Participants with a mental health (MH) diagnosis had equal or better outcomes under Cash & Counseling (C&C) than in traditional services.
- Participants with a MH diagnosis who received agency services fared worst by large amounts when compared to participants without a MH diagnosis receiving agency services or C&C participants (with or without a MH diagnosis).



Study Highlights (continued)

- Results are consistent across diverse outcomes, including participants' satisfaction with paid caregivers' reliability, schedule, and performance; perceived quality of life; and the workers' attitudes and their relationship.
- If a client has mental illness and chooses to self-direct, it is better to be in C&C than in agency services.



Key Policy Points

- During the 5 year Arkansas C&C Demonstration (12/98 – 7/03), there were no reported instances of abuse by caregivers for either mentally ill or non-mentally ill participants.
- Representatives are an important program feature that can ensure that participants with mental illness are successful in the cash option.
- Participants with mental illness were significantly more likely to choose a representative.





Concerns, Decisions, and Viewpoints

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Potential Concerns

- Environment
 - Economic status
 - Incidents of abuse, neglect, or financial exploitation
 - Burden of providing caregiving and stress associated for family
- Behavior
 - History of noncompliance with medication or diet
 - Displaying behavior hurtful to others
 - Excessive alcohol consumption
 - Illegal drug use – misuse of prescription drugs
 - Lack of general well-being; inability to live with meaning and purpose



Potential Concerns (continued)

■ Medical

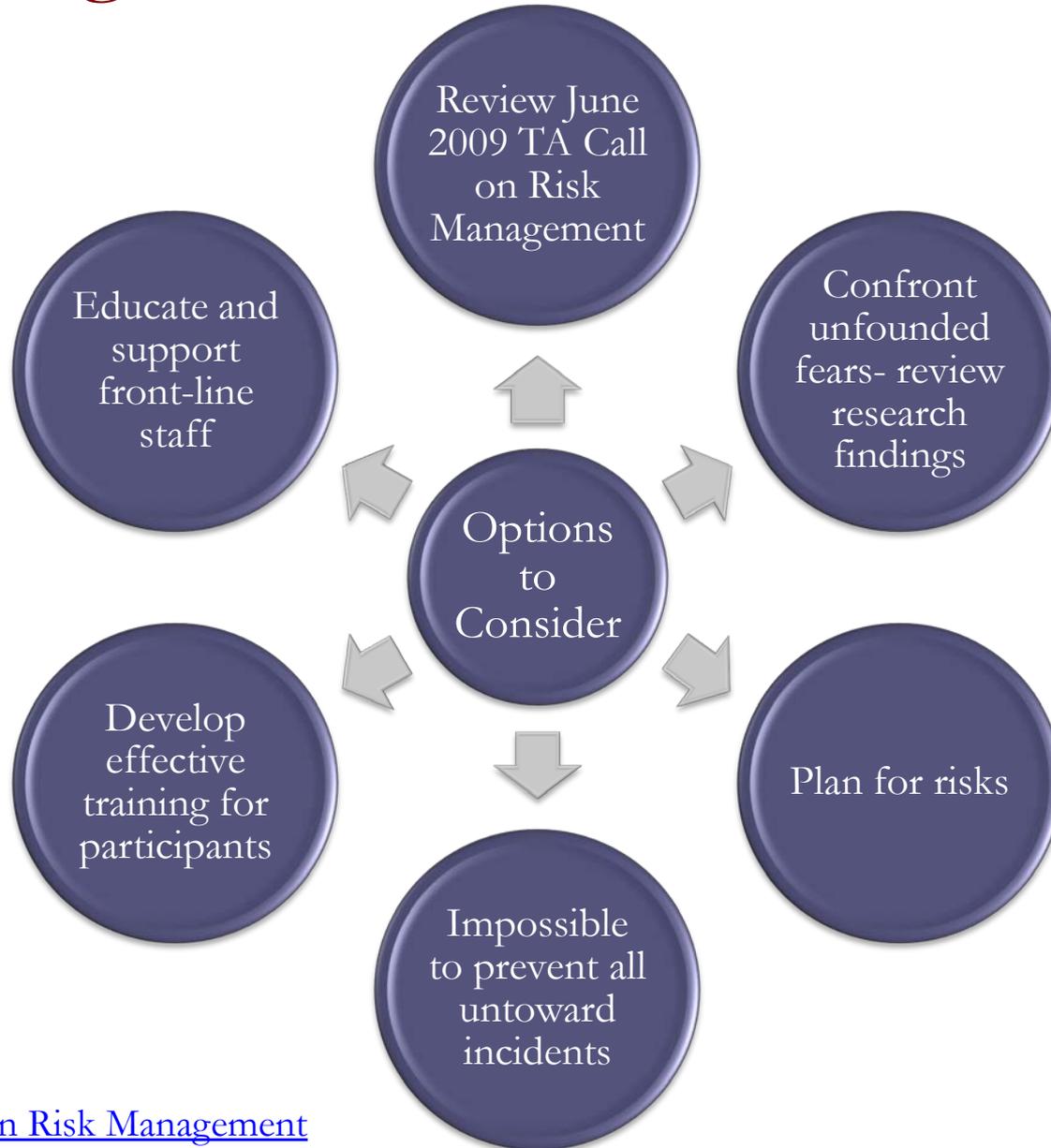
- ❑ Frequent hospitalizations over a short period of time or frequent visits to the emergency room
- ❑ Cognition issues or dementia
- ❑ Traumatic brain injury
- ❑ Mental health/illness diagnosis

■ Physical

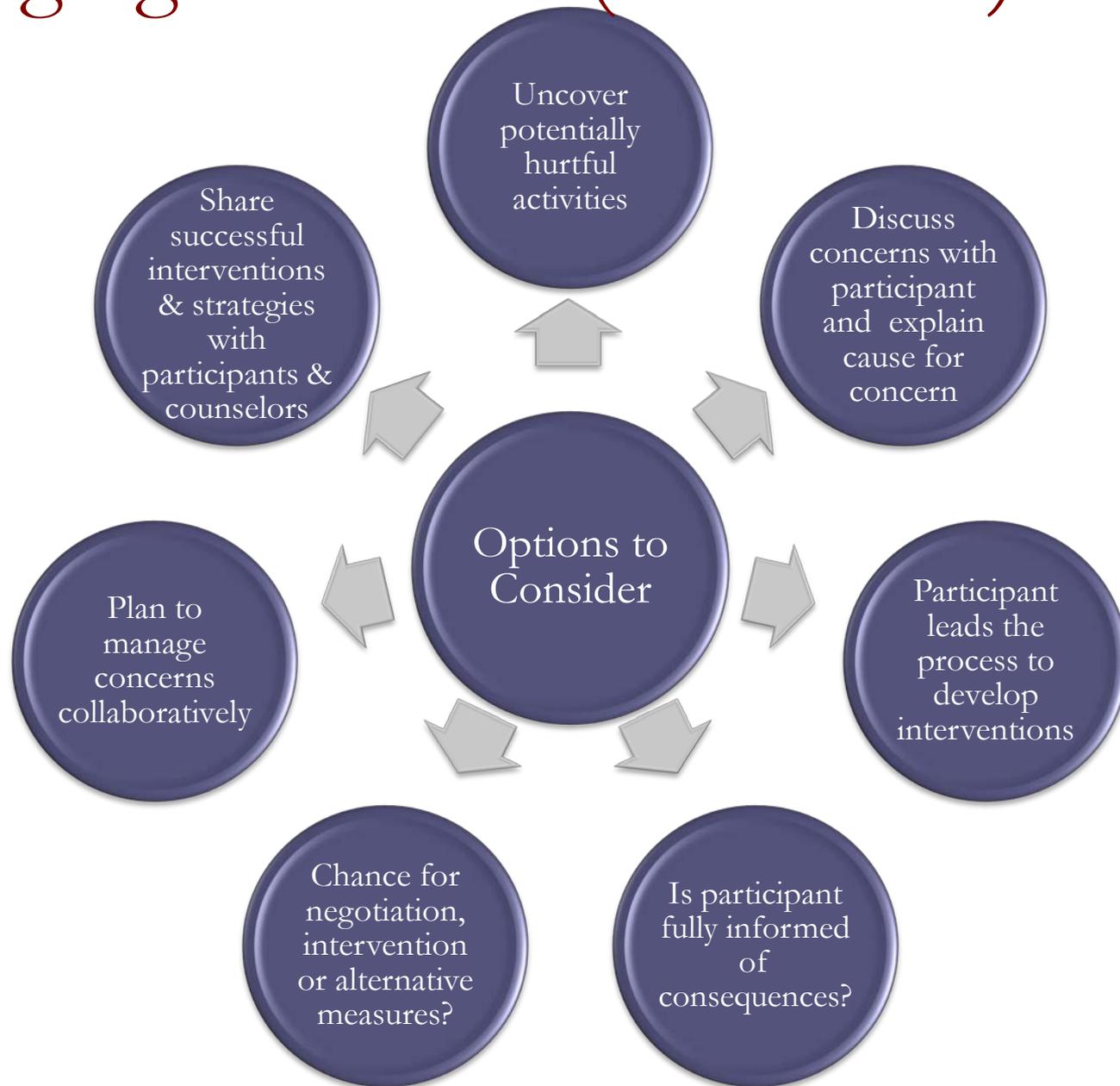
- ❑ Mobility/transferring issues
- ❑ Falls (preventable accidents)
- ❑ Physical inactivity or lack of exercise
- ❑ Poor nutrition



Managing Concerns



Managing Concerns (continued)



Competency Versus Capacity

Competency

Legal reference

Varies with decision being made

Varies with gender, culture, and economic status

Gray area even for courts

Tools/instruments to determine – validity still questioned

Capacity

Ability to make decisions

May be affected by overuse of alcohol or drugs dementia, psychiatric disorders, traumatic brain disorders, or poor judgment

May be established by informal observation or conversation

Caution about instruments/tools – uncover not determine eligibility

Decisions, Decisions, Decisions – Too Many for Some?

- Participant responsibilities can be complex
- Can be simplified to these key decisions:
 - Finding a person to hire
 - Telling the person when to come
 - Telling the person what to do
- Know support system is available and can be accessed:
 - Recruiting, hiring, managing, dismissing, problem-solving
 - Facilitating skills development (training, resources, information)
 - Managing individual budget and purchases
 - Payroll and employment taxes



Participant Viewpoint

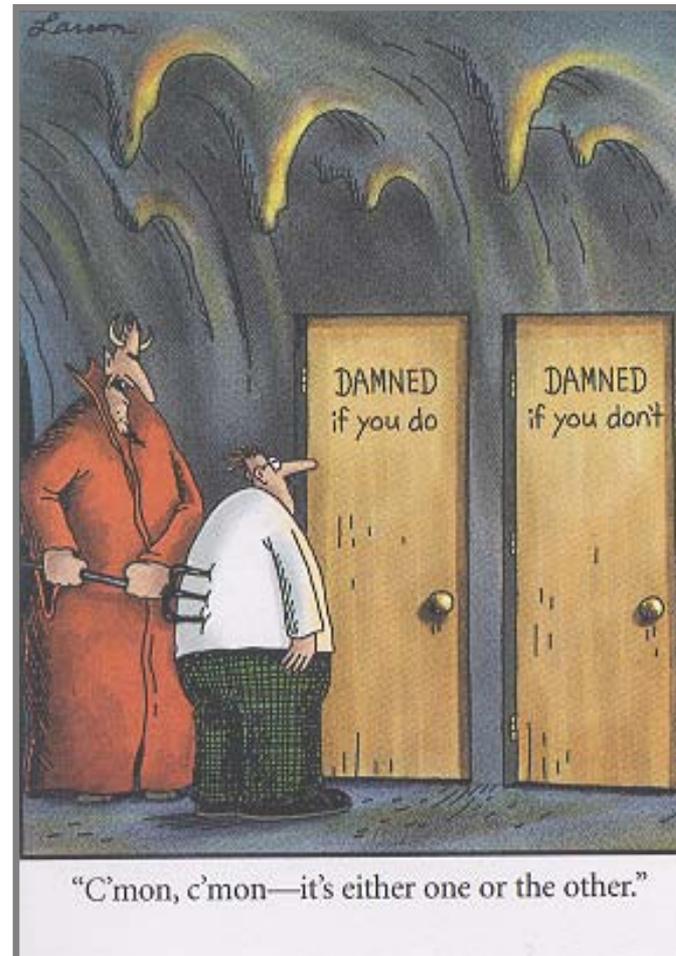


- I have a right to make personal decisions and make choices like everyone.
- I know what is best for me – not what is best for you.
- I don't want to have to answer to anyone.
- I'm not sure what to do?
- I have knowledge about how the program can improve – will you listen to me?



Counselor Viewpoint

- I am responsible for all outcomes.
- I have a moral and professional responsibility.
- I must comply with program policy.
- I will get into trouble.
- I will get sued.
- I must use my best judgment.
- I am on my own on this.
- If I err, I'll err on the safe side.



Administration Viewpoint

- I am accountable to the funder (and board, etc.) to protect participants.
- It will look bad in the community if something negative happens.
- Third party concerns will think the program is irresponsible.
- I can't create policy that covers each situation.
- How can I trust my staff to make the right decision?
- I will be sued and subject my organization to financial liability.



Viewpoints

Participant

- “I have a right to make choices.”

Counselor

- “I have a professional responsibility.”

Administration

- “I am accountable to the public.”





Assessments and Representatives

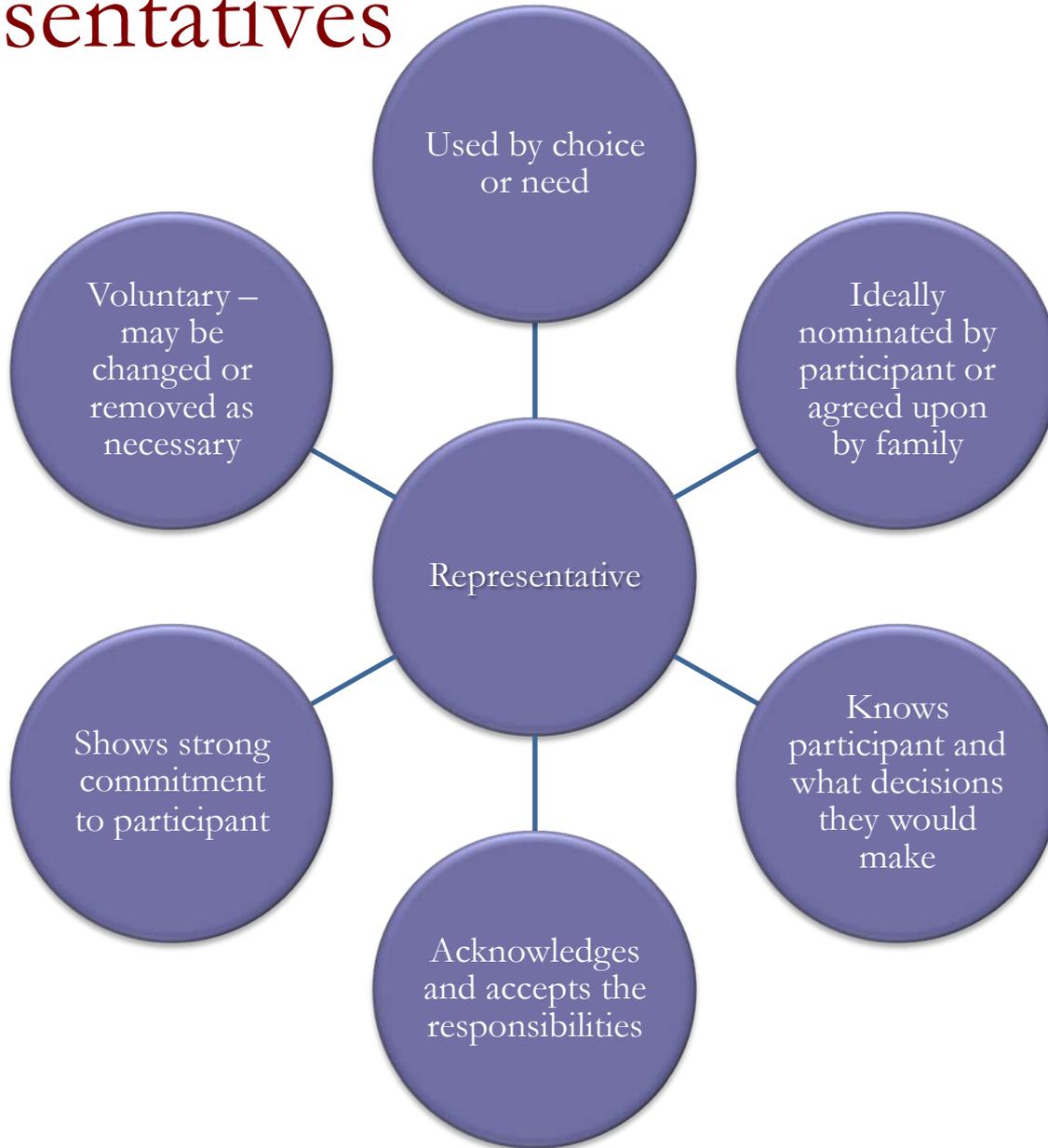
Sandy Barrett
NRCPS

Assessing Ability to Make Service Decisions

- Idea is not to screen out, but determine level of support needed
- Guide the participant toward understanding their ability to make service decisions
- Use a decision-tree to guide thinking
 - Make it simple: What do you need doing? Who will you hire to help you? When do you want help?
 - Go a little deeper: How will you train your worker? How will you tell them when they are doing work the way you want it done?
 - Can you ask for help: Do you know assistance is available? When will you call the counselor? Do you have someone who will help when you need it?



Representatives





Common Sense Approaches and Interventions

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Director of Program Design and Implementation

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Common Sense Approaches: Pre-Plan Because Tough Situations WILL Happen

- Develop protocol
 - Use advisory group with strong participant involvement – meet routinely
 - Pre-identify acceptable risks and unacceptable risks
 - Allow for systematic tiered review system
 - Discuss with Supervisor and Agency Director or Internal Review Committee
 - Create participant review/appeal process
 - Create Peer Counseling Network to discuss strategies, discuss common experiences and successful interventions
 - Create Peer Participant Network to provide support
 - Expect consistency and oversee the application of protocol
 - Train staff initially and periodically



Common Sense Approaches

- Assess situation (different than determining needs)
 - Starting point- ensure participant preferences are identified
 - Determine level of capacity of participant to make decisions about consumer-directed issues
 - Develop support strategies based on this determination
 - Recommend representatives
 - Involve family (but NOT before involving the participant)
 - Ensure service plan and budget meet needs
 - Increase communication/contact in “iffy” situations



Common Sense Approaches

- Participant is key
 - Honor the “dignity of risk”
 - Accept individual’s life-style and preferences
 - Ensure participant has lead role intervention
 - Is participant provided sufficient information about concern and given ample resources and opportunity to weigh consequences of concern?
 - Is participant provided sufficient and accessible tools and resources to be fully engaged and make informed decisions?
 - What additional supports or resource can be offered?



Common Sense Approaches

- Day-to-day counseling activity
 - ❑ Are personal values, cultural differences and personal opinions driving the situation?
 - ❑ Follow policy, involve peers, and supervisors
 - ❑ Is staff training in protocol and process?
 - ❑ Is staff expected to eliminate personal values and cultural difference?



Common Sense Approaches

- Apply interventions
 - ❑ What might prevent or reduce impact of concern?
 - ❑ Ensure participant understands the consequences of their actions or their lack of taking action
 - ❑ Increase level of supports
 - ❑ Obtain second opinion: peer case managers, peer participant network, supervisor, family, state supervisors, independent mediator, or arbitrator using neutral party
 - ❑ Recommend informal representative to assist with decision making
 - ❑ Appointment of informal representative or legal guardian



Apply Interventions (continued)

- Present alternatives to reduce and minimize risks
 - Add services to plan
 - Replace services in plan
- Provide participant skills training
- Provide worker skills training and educational opportunities
- Offer alternative assistive devices
- Discuss voluntary termination from program
 - Fully informed decision by participant

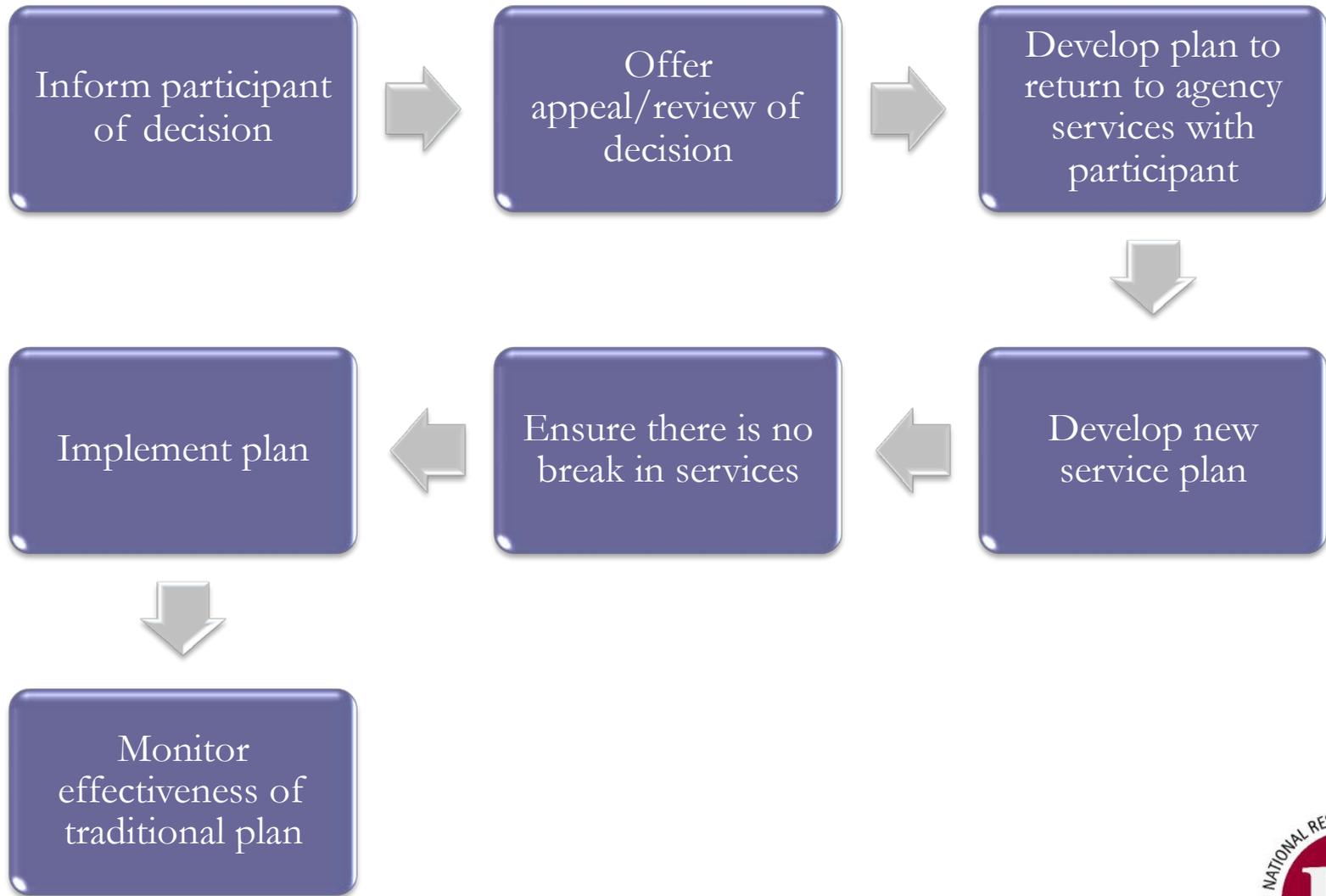


This is NOT Working...

- Marked deterioration of health due to poor choices
- Potentially harmful/hurtful to others due to poor choices
- Blatant misuse of funds after interventions are applied
- Substantiated report to Adult Protective Services after interventions are applied



Process



Remember....



*It's not about measuring competency or screening out —
it's about how to make consumer direction work.*



Tools and Resources

- NRCPPDS website- www.participantdirection.org
- Cash & Counseling website- www.cashandcounseling.org
- ADRC website- www.adrc-tae.org
- June 2009 TA Call on Risk Management- [Presentation](#)
- NRCPPDS [Insights & Publications](#)
- Does Mental Illness Affect Consumer Direction of Community-Based Care? Lessons from the Arkansas and New Jersey Cash & Counseling Programs- [Report](#)
- Is Consumer Direction Appropriate for Everyone Who Wants It? Experience from the Cash & Counseling Demonstration and Evaluation- [Report](#)
- Addressing Liability Issues in Consumer-Directed Personal Assistance Services (CDPAS)- [Report](#)
- [Self-Assessment Form](#)
- [Representative Screening Questionnaire](#)



Thank You!



Advancing choice and control for people living with disabilities

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