

February 4<sup>th</sup>, 2014

***Disability-Competent Care Webinar Roundtable Series:  
Training in Disability-Competent Care and Supports***

# Dignity of Risk



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**Dignity of Risk**



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## Overview

- This is the first session of an eight-part “Disability-Competent Care Webinar Roundtable Series”
- Each session will be interactive (e.g., polls and interactive chat functions), with 20 minutes of presenter-led discussion, followed by 40 minutes of presenter and participant discussions
- Video replay and slide presentation are available after each session at:

**<http://www.ResourcesForIntegratedCare.com/>**

# Disability-Competent Care Webinar Roundtable Series

## What We Will Explore in This Series

- Unique experiences of adults with disabilities and their needs and expectations
- Provision of specific components of Disability-Competent Care and supports
- Approaches to being person-centered in care and interactions based on the individuals' goals and preferences
- Achieving the Triple Aim goals of improving the health and participant experience of health care delivery while controlling costs in their work with adults with disabilities

# Agenda and Learning Objectives

## Agenda

- Introduction and context
- Description of dignity of risk
- Steps to facilitate the discussion
- Presentation of first-person stories
- Participation questions and discussion

## Learning Objectives

- Understand and respect the concept of dignity of risk
- How to engage a participant on informed risk-taking while respecting participant choice

# Introductions

## Presenters

Christopher Duff  
Executive Director  
Disability Practice Institute



Kathy Thurston  
Director of Care Coordination  
AXIS Healthcare



Mary Lou Breslin  
Co-Founder and Sr. Policy Advisor  
Disability Rights Education & Defense Fund



# Participant Expectations and Rights

- Concept of *Dignity of Risk* is closely tied to the concepts of self-determination and independence
- Adults with disabilities, like all of us, expect:
  1. Respect of their needs and priorities
  2. Information of their status and identification of options
  3. Providers who will partner with them to implement their decisions
- Our job is to:
  1. Listen
  2. Inform and educate
  3. Respect participant decisions

# Care Coordination and the Dignity of Risk

“**Dignity of Risk**” refers to the consumer’s right to make an informed choice to experience life and take advantage of opportunities for learning, developing competencies and independence and, in doing so, take a calculated risk. The concept means that all adults have the right to make their own choices about their health and care, even if health care professionals believe these choices endanger the person’s health or longevity.

## Role of the Care Coordinator

- Disability-competent care coordinators are charged with helping their participants identify their risks and make informed decisions

## Respect the Dignity of Risk

- Every person needs enough control within their lives to choose what they value and reject what they do not
- Health care professionals may try to move away from this when patients are elderly or have disabilities
- Follow-up and treatment plans must respect what is important to the person

# Care Coordination and the Dignity of Risk

## Facilitating this discussion

- Understand the person's basic requirement for happiness: what is important to them?
- Partner with the participant in order to reduce/manage risk within that context: what is important for them?
- Keep the person at the center of care and treatment planning

# Steps to Facilitate this Discussion

## 1. Understand the participant story

- Listen for their experience and perceptions
- Listen for their hopes and dreams
- Listen for their fears and strengths

# Steps to Facilitate this Discussion

## 2. Understand what is important to the participant

- What, if anything, would you like to be different in your day-to-day life?
- Why is that important to you?
- Is there someone in your life who supports / helps you?
- How can we be of help to you?
- Name one or two things you hope to accomplish

## Steps to Facilitate this Discussion

### 3. Develop a plan

- Consider what is important to the participant and find out how you can support them to address one or two identified life changes?
- Who do we include in their circle of support?
- How will we work together?

### 4. Implement the plan

# John: Living with the Dignity of Risk

## 1. Understand his story

- 56 year old male with severe arthritis, obesity
- Limited mobility
- Depression and anxiety
- Dependent with most ADLs; some IADL dependencies
- Good emotional support system, but lives alone and has no one close by
- Recurrent cellulitis and skin breakdown
- Recurrent UTIs and hospital admissions
- No longer able to bear weight or transfer out of bed to chair

# John: Living with the Dignity of Risk

## 2. Understand what is important to him

- It is very important that he remains in his own home
- He wants to stay out of the hospital
- He is anxious about going to medical appointments
- He does not want to discuss weight or the need for weight loss
- He is able to call for help if need be

## John: Living with the Dignity of Risk

### 3. Develop a plan

- Collaboration of his team\* to establish a realistic plan that addresses both what is important to and for him
- Plan focused on the areas that John wanted to change, staying out of the hospital, and respected John's choice to risk living alone and with inability to get out of bed
- Team has begun talking about life-sustaining treatment plans and factoring in John's desire to remain in his home

\*Team includes: John, primary care provider, CC, PCA provider, and John's sister

## John: Living with the Dignity of Risk

### 4. Implement the plan

- PCP, PCAs, family accepted and respected what was important to John
- PCP accepted and respected John's living with the risk of complications from immobility, obesity and living alone
- John agreed to work on some things that are important for him to prevent skin breakdown and manage UTIs at home

### Outcome

- No skin breakdown
- No hospital admissions for 12 months
- Remains in his own home with support of PCA, homemaking and emotional support from family and friends

# Jane: Living with the Dignity of Risk

## 1. Understand her story

- 38 year old female post CVA, new diagnosis of Type 2 diabetes
- Hypertension, major depression, chronic pain
- Independent with ADLs; some IADL dependencies
- Limited informal supports, at risk of isolation
- Jane does not want to do follow-up care or a prescribed treatment plan
- Jane does not believe that she has diabetes

## Jane: Living with the Dignity of Risk

### 2. Understand what is important to her

- Does not want to give up the few things that give her pleasure: soda and sweets
- Does not want to add another medication because she is on so many
- Very scared she is losing more of her independence
- As a result, she is not taking hypoglycemic agent, not checking blood glucose, and eating whatever she wants

## Jane: Living with the Dignity of Risk

### 3. Develop a plan

- Jane was willing to start working on a couple of things that were important for her health
- Collaboration of her team\* to establish a realistic plan that addresses both what is important to and for her
- Plan allows her to keep some of what is important to her while making small steps toward changing some things that are important for her
- Her team is all on the same page with this plan

\*Team includes: Jane, primary care provider, CC, home care nurse

## Jane: Living with the Dignity of Risk

### 4. Implement the plan

- Jane was willing to start working on a couple of things that were important for her health
- PCP accepted and respected what was important to Jane
- PCP accepted and respected Jane's living with the risk of complications from under-managed diabetes and elevated blood glucose levels

### Outcome:

- Checking her blood glucose 5 days/week
- Reduced intake of soda: weight loss, lowered HgbA1C
- Accepts that she has diabetes
- Reports feeling much better
- Still enjoying small amounts of soda and sweets

# Summary

## Participants

- Deserve the dignity and respect of determining their health care plans and related risks
- Need to understand these risks and make informed decisions

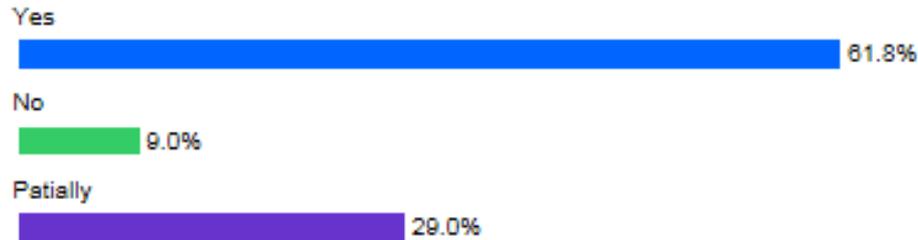
## Coordinators

- Listen, engage and respect
- Identify risks, develop mitigation strategies and create a plan in case harm should occur

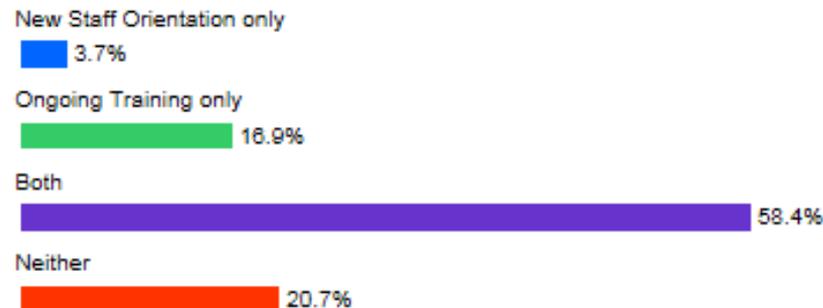
# Audience Questions and Discussion

## **Polling Questions Results:** These questions were posed to webinar participants at different points throughout the webinar

**Does your organization have policy to guide staff in communications with their individual participants?**

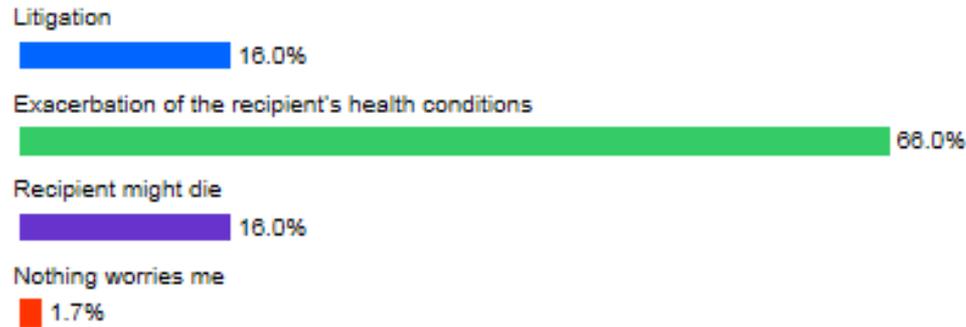


**Does your organization include the concepts of self-determination and dignity of risk in your new staff orientation or on-going training?**

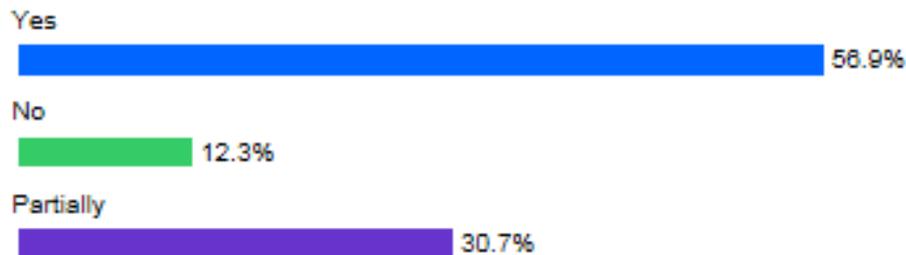


## Polling Questions Results: These questions were posed to webinar participants at different points throughout the webinar

### What aspect of the dignity of risk worries you and your colleagues the most?

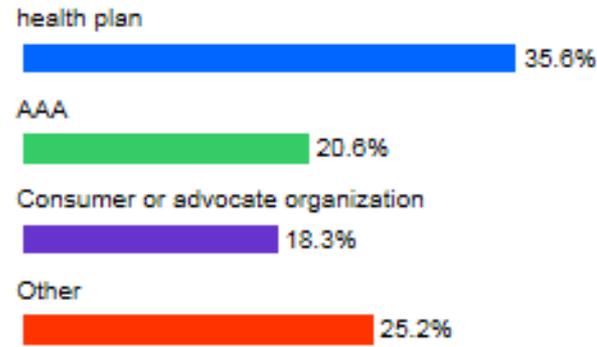


### Does your organization have a policy to guide staff in communications and interventions with their individual participants regarding risk?



## Polling Questions Results: These questions were posed to webinar participants at different points throughout the webinar

### What type of organization are you working within?



## Send Us Your Feedback

Help us diversify our series content and address current Disability-Competent Care training needs – your input is essential!

Please contact us with your suggestions at

[RIC@Lewin.com](mailto:RIC@Lewin.com)

### What We'd Like From You:

- How best to target future Disability-Competent Care webinars to health care providers and plans involved in all levels of the health care delivery process
- Feedback on these topics as well as ideas for other topics to explore in webinars and additional resources related to Disability-Competent Care

## Thank You for Attending



- For more information, contact:
  - Christopher Duff at [cduff@DPInstitute.org](mailto:cduff@DPInstitute.org)
  - Kathy Thurston at [kthurston@axishealth.org](mailto:kthurston@axishealth.org)
  - Mary Lou Breslin at [mlbreslin@dredf.org](mailto:mlbreslin@dredf.org)
  - Jessie Micholuk at [RIC@lewin.com](mailto:RIC@lewin.com)
  - Kerry Branick at [kerry.branick@cms.hhs.gov](mailto:kerry.branick@cms.hhs.gov)

## Resources and References

- “A Few Words About Dignity of Risk”
  - <http://www.health.state.nm.us/ddsd/meaningfullife/documents/AYMAFEWWORDSABOUTDIGNITYOFRISK.pdf>
- “Reflection on the Dignity of Risk”
  - <http://healthcareorganizationalethics.blogspot.com/2011/09/dignity-of-risk.html>
- “Managing Risk in Community Integration: Promoting the Dignity of Risk and Supporting Personal Choice”
  - [http://tucollaborative.org/pdfs/Toolkits\\_Monographs\\_Guidebooks/community\\_inclusion/Managing\\_Risk\\_in\\_CI.pdf](http://tucollaborative.org/pdfs/Toolkits_Monographs_Guidebooks/community_inclusion/Managing_Risk_in_CI.pdf)

# Resources for Integrated Care Website

We encourage you to explore [www.ResourcesforIntegratedCare.com](http://www.ResourcesforIntegratedCare.com) for a wide array of resources related to integrating care for Medicare-Medicaid enrollees:

## Resources

- Assessment tools
- Concept guides
- Topic-specific briefs
- Educational webinars

## Topic Areas

- Disability-Competent Care
- Self-Management Support
- Integrating Primary Care in Behavioral Health
- Care Coordination Workforce Development
- Navigation Services

## Stakeholders

- State Medicaid Agencies
- Health Plans
- Long-Term Services and Supports Providers
- Behavioral Health Providers

## Individuals with...

- Intellectual and developmental disabilities
- Physical disabilities
- Serious mental illness

Sign up for our [E-Alerts](#) to receive updates!

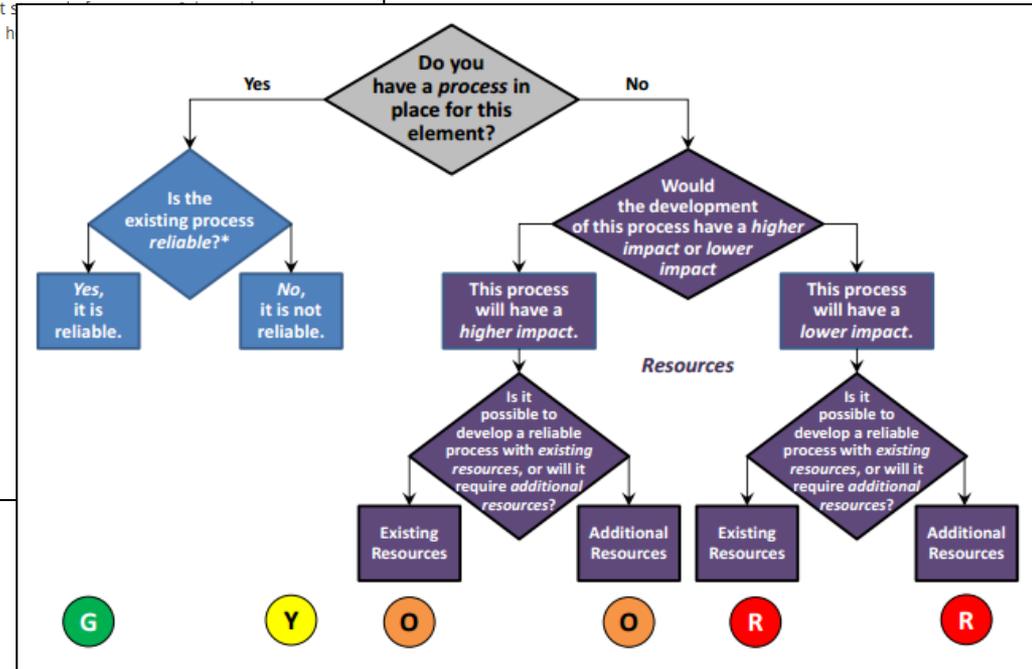
# Disability-Competent Care Self-Assessment Tool

Introduction	1. Relational-Based Care Management	2. Highly Responsive Primary Care	3. Comprehensive Long-Term Services and Supports	Appendix A	Results	Forum
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## 1. Relational-Based Care Management

Participant-centered care is based on the recognition that the participant is not merely a passive recipient of medical care, but rather the primary source for defining care goals and needs. This type of care requires cultivating a relationship with the participant, seeing him or her as a whole person with hopes and preferences, and recognizing that the participant is oftentimes the best person to make choices about the participant-centered planning of care goals and needs. This is also the concept of the dignity of risk, which holds that participants have the right to make choices even if they are inconsistent with the recommendation of the IDT.

- ▶ 1.1. Participant-Centered Practice
- ▶ 1.2. Eliminating Medical and Institutional Bias
- ▶ 1.3. Interdisciplinary Team
- ▶ 1.4. Assessment
- ▶ 1.5. Individualized Plan of Care
- ▶ 1.6. Individualized Plan of Care Oversight and Coordination
- ▶ 1.7. Transitions
- ▶ 1.8. Tailoring Services and Supports
- ▶ 1.9. Advance Directives
- ▶ 1.10. Allocation of Care Management and Services



Disability-Competent Care Self-Assessment Tool available online at:  
<http://www.ResourcesForIntegratedCare.com/>

## Next Webinar

Disability-Competent Care Webinar Roundtable Series:  
Training in Disability-Competent Care and Supports

### **Strategies to Stimulate and Support Participant Engagement**

Tuesday February 11<sup>th</sup>, 2014  
2:00-3:00PM EST