

June 3rd, 2015

Strategies for the Implementation of Disability-Competent Care

Dignity of Risk



Media Player

0:00

Participant line: (866) 812-0463
Participant Access Code: #358327

Q&A

Refresh Now

Submit

Slides

RESOURCES FOR INTEGRATED CARE
Resources for Plans and Providers for Medicare-Medicaid Integration

May 6th, 2015

Strategies for the Implementation of Disability-Competent Care

Disability-Competent Care; What Is It and Why Is It Important



www.ResourcesForIntegratedCare.com

If your slides are not advancing, please press F5



Overview of Webinar Series

Strategies for the Implementation of Disability-Competent Care

- This series takes a fresh look at topics that were presented in the previous two webinar series, which are available for viewing at <https://www.resourcesforintegratedcare.com/>
- We aim to provide participants with updated information and the opportunity to discuss topical questions with leading healthcare professionals and subject matter experts. We hope you come prepared with questions and comments for this discussion.
- The Lewin Group, under contract with the CMS Medicare-Medicaid Coordination Office, partnered with Christopher Duff and other disability practice experts to create the eight-part weekly webinar series, **Strategies for the Implementation of Disability-Competent Care**.

Introductions

Presenters

Christopher Duff
Disability Practice & Policy Consultant



Adam Burrows, MD
Medical Director, Upham's Corner PACE;
Senior Medical Director,
Commonwealth Care Alliance SCO



Karen Luken
Disability & Health Consultant



Webinar Agenda

- History and Context of self-determination
- Description of dignity of risk – from both the participant and providers perspective
- Steps to facilitate the discussion
- Discussion through use of a of first-person stories
- Audience questions

Historical Context of Self-Determination

Self-Determination is making choices and decisions based on personal preferences and interests, with a sense of personal goals and self-direction

- People with disability have the same right to, and responsibilities that accompany, self-determination as everyone else
- People must have opportunities, respectful support, and the authority to exert control in their lives
- Service systems have been geared towards ‘overprotection’, which is counter-productive to allowing for personal growth, informed choice and ‘dignity of risk’
- Tendency to “go overboard” to protect, comfort, keep safe and take care of and watch over
- People with disabilities may be ‘experience poor’ thereby commonly needing support to make decisions about important aspects of their lives

Participant Expectations and Rights

- Concept of *Dignity of Risk* is closely tied to the concepts of self-determination and independence
- Like all of us, adults with disabilities, 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 participant’s right to identify the need to be able 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

- **Participants:** Have a right to make choices about their health, and care, even if health care professionals believe these choices endanger the person’s health or longevity
- **DCC Providers:** Are charged with helping participants identify preference, need and risk which allows for informed decision making

Steps to Facilitate the Discussion

1. Understand the participant's story and perspective
2. Understand what is important to the participant
3. Develop a plan to support participants priorities and goals
4. Implement and monitor the plan to support participants priorities and goals

Camille: Living with Risk

1. Understand her story

- Late 30s, lives in an apartment with her cats
- Describes herself as an artist, advocate, and pet owner
- Close to mother and brother who live in other states; local friends and artists she stays in touch with via the internet
- Autism Spectrum Disorder, learning disability, hearing, vision, and thyroid problems
- On Medicaid with limited income; does not drive
- Experienced a significant increase in health problems over the past year; extended in-patient hospital stays and complicated out-patient plan of care
- Mobility has become challenging due to leg swelling, pain and weight gain

Camille: Living with Risk

2. Understand what is important to her

- Remains in her own apartment; has someone who will look after her pets when she is away; has a dependable way to get to medical appointments; has someone to call for help if she has an emergency; stays out of rehab and long term care facilities; has a primary care doctor she respects and who has some knowledge about disability and community resources

“I want to see someone who respects me and will be around for a while.”

Camille: Living with Risk

- 3. Develop a plan to support participants priorities and goals**
 - A realistic plan that addresses what is important *to* and *for* Camille
 - The DCC team is helping Camille explore additional social service resources and options. Camille identified other concerns:
 - “What happens as I get older and have other health problems”.
 - “What happens if medical costs go even higher?”
 - “Sometimes I have to choose between my “regular” disability services and other health care services, because Medicaid wouldn't pay for both. The system needs to realize people need more than one thing every day.”

Camille: Living with Risk

4. Implement and monitor the plan to support participants priorities and goals

- The DCC team accepted and respected what was important to Camille: living with the risk of complications from thyroid, limited mobility, obesity, and living alone
- Camille agreed to learn how to prevent leg swelling, skin breakdown, weight gain, and immobility

Camille: Living with Risk

■ Outcomes

- Leg swelling has decreased
- No hospital or facility admissions for eight months
- Remains in her own apartment/home with support of attendant
- Now receives some assistance with medication and medical supply costs
- Remains active with her artistic endeavors
- Friend is able to drive her to some medical appointments

Daughter / Mother: Supporting Choices and Dignity of Risk

Young adult with cerebral palsy, vision and mobility limitations, multiple medications

- College student requiring new primary care provider
- As she enters adulthood the daughter's choices or dignity of risk is not intended to be superseded by her parents and/or guardians who have power of attorney

Words of Advice:

- Be watchful of the tendency to assume medical fragility
- Be mindful that not every medical issue is an emergency just because I have a disability
- Teach and support me to learn about my health, including the benefits and risks of specific decisions
- Build a scaffold of support: respect, dignity, communication, independence, health and safety

Dignity of Risk – The Role of Providers

- Principle of informed consent
 - How we operationalize autonomy
 - Provider informs, educates, counsels
 - Individual makes informed decision, assumes risk
 - Capacity for informed consent implies capacity for informed refusal
- Key point
 - Individual assumes risk, not provider
- Key challenges
 - Not allowing beneficence to become intrusive, paternalistic
 - Broadening understanding of risk and safety
 - Role is to help individual mitigate risk, not necessarily eliminate it

Dignity of Risk – The Role of Providers

- Redefining success
 - Helping persons with disability achieve *their* goals
 - Achieving their goals may entail risk
 - May require assigning lower priority to medical goals
- Key point
 - Person-centered care means upending the institutional, professional paradigm
- Key challenges
 - Reconciling medical goals with person-centered goals
 - Redefining professional responsibility
 - Redefining quality

Dignity of Risk – Common Scenarios

- Living at home vs. living in an institution
 - 80-year-old woman who wants to live in the family homestead despite mobility impairment, obesity, multiple chronic medical conditions, inconsistent family support and a cluttered household
- Discharge from hospitals
 - 88-year-old woman hospitalized after falling from standing on a chair. Hospital physical therapist documents need for 24-hour supervision. Trauma surgeon prescribes hard cervical collar and wheelchair
- Eating vs. risk of aspiration
 - Hospital staff recommended a feeding tube for 72-year-old de-institutionalized woman with tardive dyskinesia because of aspiration risk

Summary

Participants:

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

Providers:

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

Audience Questions & Discussion

Next Webinar

“Stimulating and Supporting Participant Engagement”

Wednesday June 10th, 2015

Session VI will:

- Explore the concept of participant engagement, and focus on understanding the value in this.
- Discuss strategies for engaging participants in their health and life planning.

Please respond to our survey!

Thank You for Attending!



- For more information contact:
 - RIC@lewin.com
 - Gretchen Nye at gretchen.nye1@cms.hhs.gov
 - Christopher Duff at chrisduff2@gmail.com
 - Adam Burrows at aburrows@commonwealthcare.org
 - Karen Luken at karenluken@gmail.com
- Disability-Competent Care Self-Assessment Tool available online at:
<https://www.resourcesforintegratedcare.com/>

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
- National Gateway to Self-Determination
<http://www.ngsd.org/everyone/what-self-determination>
- The Arc
<http://www.thearc.org/>

Disability-Competent Care Self-Assessment Tool

1. Relational-Based Care Management

[Introduction](#)

[1. Relational-Based Care Management](#)

[2. Highly Responsive Primary Care](#)

[3. Comprehensive Long-Term Care](#)

[Appendix A](#)

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 steward of resources. Inherent in participant-centered planning is also the concept of the dignity of risk [1] which honors and respects the participant's choices even if they are inconsistent with the recommendation of the IDT.

[1] Dignity of risk means the right of individuals to choose to take some risk in engaging in life experiences, even if that choice would not be one that a health professional would choose (e.g. choosing to smoke).

-
- ▶ [1.1 Participant-Centered Practice](#)
 - ▶ [1.2 Eliminating Medical and Institutional Bias](#)
 - ▶ [1.3. Interdisciplinary Care Team \(ICT\)](#)
 - ▶ [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](#)
 - ▶ [1.11 Care Partners](#)
 - ▶ [1.12 Electronic Health Record](#)

Available at <https://www.resourcesforintegratedcare.com/>