

Wednesday February 15<sup>th</sup>, 2017

# Disability-Competent Participant Engagement

## DCC Pillars Webinar Series



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The screenshot shows the 'Resources for Integrated Care' webinar interface. The top navigation bar includes 'OPTIONS', 'WORKSPACE', and 'HELP'. The main content area displays the webinar title 'Introduction to Disabilities and Disability-Competent Care' and the date 'Wednesday February 8th, 2017'. Below the title is a section titled 'DCC Pillars Webinar Series' with three images showing people in a clinical setting. On the left side, there is a 'PARTICIPANTS' list with names like Angela George, Danielle Lewis, Jessie Micholuk, Todd Ruppel, and Christopher Duff. Below the participants list is a 'CHAT' section with a text input field labeled 'Type here' and a dropdown menu set to 'All'. A red circle highlights the 'Type here' input field. Another red circle highlights the download icon in the top right toolbar.

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# Introductions

- Christopher Duff
  - Disability Practice and Policy Consultant



# Disability-Competent Care Webinar Series Overview

The Lewin Group, under contract with the CMS Medicare-Medicaid Coordination Office, partnered with Christopher Duff and other disability practice experts to create the “Disability-Competent Care Webinar Series”.

- This is the second session of the seven-part series.
- Each session will be interactive, with 40 minutes of presenter-led discussion, followed by a 20 minute presenter/participant question and answer session
- Video replay and slide presentation are available after each session at:

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

## DCC Pillars – Webinar Series

1. Understanding the DCC Model
2. Participant Engagement
3. Access
4. Primary Care
5. Care Coordination
6. Behavioral Health
7. Long Term Services and Supports

# Agenda

1. Understanding the participant experience
  - Common barriers
  - Supporting the participant
2. Assessing participant needs
  - The care planning process
3. Developing a plan
  - Individualized Care Plan (ICP)
4. Leveraging support
  - Care partners and communication

# UNDERSTANDING THE PARTICIPANT EXPERIENCE

*“The best tool we have in working with persons with disabilities is the relationship we develop with them and their care partners.”*

*- Dr. Paul Johnson, Health Plan Medical Director*

## Understand the Participant's Perspective

- Participant engagement requires actively listening to both stories and experiences, as well as careful review of complete profile records, including:
  - Personal history
  - Social history
  - Health history



## Barriers to Care

Understand and consider the barriers participants may experience in accessing community participation and care. Common barriers include:

- **Attitudinal** – results in the participant not wanting to interact with the provider;
- **Access** – results in the participant being unable to obtain the necessary care;
- **Communication** – results in the participant being unable to hear, express or comprehend during interactions with the provider;
- **Programmatic** – results in the participant not knowing of available services or how to obtain the necessary care.

# Health Disparities

People with disabilities are more likely to:

- Experience worse outcomes and are less likely to receive the recommended care<sup>1</sup>
- Experience difficulties or delays in receiving the necessary health care
- Not have had recommended health screening tests<sup>2</sup> (e.g., **breast cancer, colorectal cancer and diabetes**)
- Not receive comprehensive preventive care (e.g., **BMI assessment, medication adherence and annual flu vaccine**)
- Not have had an annual dental visit
- Limited knowledge and access to sexual health information
- Have high blood pressure

**Sources:** 1) Office of the Assistant Secretary for Planning and Evaluation. (2016). Report to Congress: Social Risk Factors and Performance under Medicare's Value Based Purchasing Programs

2) Disability and Health. Healthy People 2020. Retrieved from <https://www.healthypeople.gov/2020/topics-objectives/topic/disability-and-health/ebrs>

## Social Factors

- Payers, including Medicare and Medicaid, are moving from traditional fee-for-service payment toward models that reward value over volume.
- Disability status and the health disparities are often associated with poorer performance on measures that are linked to payment in value-based purchasing programs.
- On many measures of focus (e.g., cancer screenings, vaccinations, diabetes management), the clinical interventions are straightforward but communications and service delivery for people with disabilities stretch the disability competence of most providers.
- Improving outcomes for people with disabilities will have a direct impact on revenue for many providers and plans.

**Source:** 3) National Academies of Sciences, Engineering, and Medicine. (2017). *Accounting for social risk factors in Medicare Payment*. Washington, DC: The National Academies Press. doi: 10.1722

## Work to Overcome Barriers

Participant engagement aims to address and remove barriers to health care for individuals with disabilities.

- Make the conversation participant-centered: their life, their needs and their goals. This helps build trust.
- Be aware of barriers that exist in the participant's environment. This is the first step in overcoming them.
- Perceived barriers may be different than those identified by the participant. Be open to learning about their perspective and share your perceptions.

## Assess Ability to Self-Manage

Utilization history is usually indicative of the participant's ability to self-manage their services and supports. Consider the following when assessing the participant's ability to manage their health and health care:

- Avoidable ER visits or hospitalizations;
- Stable home care;
- Active participation in required nursing and functional assessments;
- Active primary care relationship;
- Support (formal and informal) systems in place.

# Prepare the Participant to Direct their Care

Offer tips to help participants with directing their own care, such as:

- Don't accept hurtful or inappropriate interactions.
- Take a friend or assistant with you to take notes and provide support.
- Prior to the appointment, write down any questions for your provider.
- Call ahead to ask about wheelchair access or other accessibility concerns.
- Ask individuals you trust to find a good medical doctor.
- Ask about a specialist's experience or willingness to treat disabled people.
- Don't be "patient" with mistreatment.
- If you feel "patronized", ask the physician to treat you like any other adult.
- Expect your physician to be willing to learn about your disability.
- Insist that you understand the explanations about treatment.

**Source:** 4) Saxton, Marsha. Ph.d. (2011). Access to Medical Care: Training Tools for Health Care Providers, Disabled Patients and Advocates on Culturally Competent Care and Compliance with Disability Law. Retrieved from <https://worldinstituteondisabilityblog.files.wordpress.com/2016/01/access-to-medical-care-curriculum-pdf-format.pdf>

## Supporting the Participant

Each participant brings varying levels of ability and readiness to the assessment and care planning process. Take into account the participant's:

- Dependence on care management support;
- Ability to initiate interventions on their own;
- Ability to seek assistance when needed;
- Ability to understand and follow program procedures;
- Awareness of risks and ability to monitor / intervene appropriately;
- Level of health literacy.

# ASSESSING PARTICIPANT NEEDS

*Listen ... listen ... listen!*



## First Person Story

[Jim LeBrecht](#) was born with Spina Bifida. He grew up outside of New York City and went to college in Southern California. Jim moved to the east bay of Northern California to take a job with the Berkeley Repertory Theater as a sound engineer. He has recently opened his own business serving the film industry.



*Double Click*

# Understanding the Care Planning Process

The care planning process involves multiple steps and is designed to produce a comprehensive care plan. The care planning process includes the following steps:

1. **Assessment**
2. **Identification of needs and priorities**
3. Development of a care and service plan
4. Implementation and oversight
5. Evaluation and refinement

The care planning process spans across both participant engagement and care coordination. The first two steps (**assessment** and **identification of needs and priorities**) steps are discussed in greater detail while the remaining steps will be covered in care coordination - webinar five.

# 1. Assessment

Assessments are conducted by the interdisciplinary team (IDT), including a primary care practitioner, nurse, social worker, and mental health professional.

The initial assessment provides an opportunity to begin establishing a relationship with the participant by building the trust needed for successful, ongoing health care and care management.

Some helpful tips:

- A face-to-face assessment is preferable and can help identify additional care coordination needs.
- An in-home assessment can aid in better understanding the participant's living environment and needs.
- Involving the participant's family or friends in the assessment furthers their role as care partners.

## 2. Identification of Needs and Priorities

The role of the interdisciplinary care team (IDT) will vary based on the ability and readiness of each participant to assume responsibility for their own health and health care.

- Help the participant express their goals, hopes and priorities.
- Try to understand the participant's level of awareness and ability regarding their health and health care.

Actively engaging participants and proactively involving them in understanding the need for basic care outcomes<sup>1</sup> can lead to improved compliance and health. Outcomes can include:

- cancer screenings,
- preventive inoculations, and
- identification of chronic conditions.

**Source:** 5) Office of the Assistant Secretary for Planning and Evaluation. (2016). Report to Congress: Social Risk Factors and Performance under Medicare's Value Based Purchasing Programs, pg.186

# Comprehensive Assessment Components

- Participant strengths, goals, and priorities
- Demographic, contact, financial, and eligibility information
- Functional assessment
- Medical diagnoses and utilization history
- Behavioral health screening
- Communication needs
- Access needs
- Nutrition
- Health-related services and all current providers
- Long-term services and supports
- Home and community environment, safety, accessibility, and health risks
- Social and relational activities
- Formal, informal, and social supports
- Level of education attained, and employment / volunteer status
- Review of other assessments

## Including Other Disciplines

- Besides the IDT, participants with functional disabilities benefit from a rehabilitation assessment; it's helpful to include these professionals in the initial assessment process.
- Allow members of the care coordination team to review the assessment, as each discipline brings a different set of skills and knowledge.
- Identify additional expertise that may be needed to address all care needs (nutritionist, audiologist, and others).

## Tom's Story

- Traumatic brain injury in adolescence, with significant long-term functional and cognitive limitations.
- Bounced back and forth between rehabilitation centers, his mother's home and nursing homes.
- Goals:
  - Live with his mother
  - Coordinate his own care
  - Find a job
  - Build relationships
- Barriers:
  - Physical limitations and access in home
  - Impulsive and inappropriate behavior

# DEVELOPING A PLAN

*The Individualized Care Plan (ICP) addresses participant's needs and wants.*



## The Individualized Care Plan (ICP)

- The ICP is the guiding document that identifies all care, services, and supports for each participant.
- The ICP is referenced and revised over time to meet the needs and goals of the participant.
- The ICP addresses the participant's:
  - Life goals;
  - Care goals;
  - Specific action steps to meet the goals.

# Components of the ICP

- Components may include:
  - Care provided;
  - Support services provided;
  - Individuals providing care and support;
  - Schedules for services.
  
- The tailored nature of the ICP provides clarity and a sense of comfort to participants and their care partners by removing uncertainty.

## Additional Components of the ICP

- **Communication needs** of the participant: this document will serve as a reminder to all those interacting with the participant of any communication needs they may have.
- **Risk management plan:** this can take the form of an assessment of the living environment, counseling to manage stress, smoking cessation or others.
- **Emergency or crisis management plan:** a crisis can range from a caregiver suddenly being unavailable for needed care, a family crisis, a hospitalization or a behavioral health issue. This plan identifies what to do in a crisis.

## Tom's Story Continued: ICP

Actions taken to address Tom's personal situation:

- Initiated primary care relationship and met with specialists for assessments.
- Home assessment identified several modifications and provided in-home occupational therapy (OT) and physical therapy (PT) to increase self-sufficiency.
- Received independent living skills training focusing on instrumental activities of daily living (IADL's) to reduce dependency on his mother.
- Redesigned personal care assistance (PCA) support to include trips to local YMCA to workout.
- Worked to rebuild relationships with siblings and friends from school.

## ICP as a Living Document

- It is important that the IDT consistently ensures that the participants know they can accept, negotiate, modify, or appeal components of the ICP.
- Any changes brought to the ICP should be at the discretion of the participant.
- Ideally the ICP is electronic and available to the participant, as well as all involved authorized providers.

# LEVERAGING SUPPORT

*A person is not an island unto themselves; the benefit from trusting, supportive familial and peer relationships cannot be underestimated.*

## Care Partners

- Family and friends of the participant commonly function as informal care partners.
- It is important to clarify with each participant how they want to involve their care partners and what information can be shared.
- Some participants require support from individuals beyond their immediate family and close circle of friends. It is important to inquire and attend to the needs of the participant and their primary care partners so as to help them maintain healthy and supportive relationships.

# Communication between Care Partners and Providers

- A clear means of communication should be established between the providers and the identified care partner(s).
- Most care partners are not experienced in this role, thus information or training may help them in their support role.
- Understand which needs are being met through the care partners, and where gaps may exist.
- Improved communication can directly impact a participant's quality of care and the likelihood of receiving common clinical interventions / recommended care outcomes<sup>5</sup> which may include:
  - Annual Flu Vaccines
  - Cancer Screening
  - BMI Assessment
  - Diabetes Care

**Source:** 6) Centers for Medicare and Medicaid Services. Examining the Potential Effects of Socioeconomic Factors on Star Ratings, pg.24, September 8, 2015



# CONCLUSION

*Participant engagement is a key element for providing disability-competent care as this model revolves around person-centered care.*

## Key Takeaways

- Trust is the first step in establishing a successful relationship.
- Understanding the participants experiences of their health and health care is key to building this trust.
- Assessment is an iterative process, conducted through a discussion with the participant.
- Assessments and care plans are living documents.

# AUDIENCE QUESTIONS & DISCUSSION

## 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

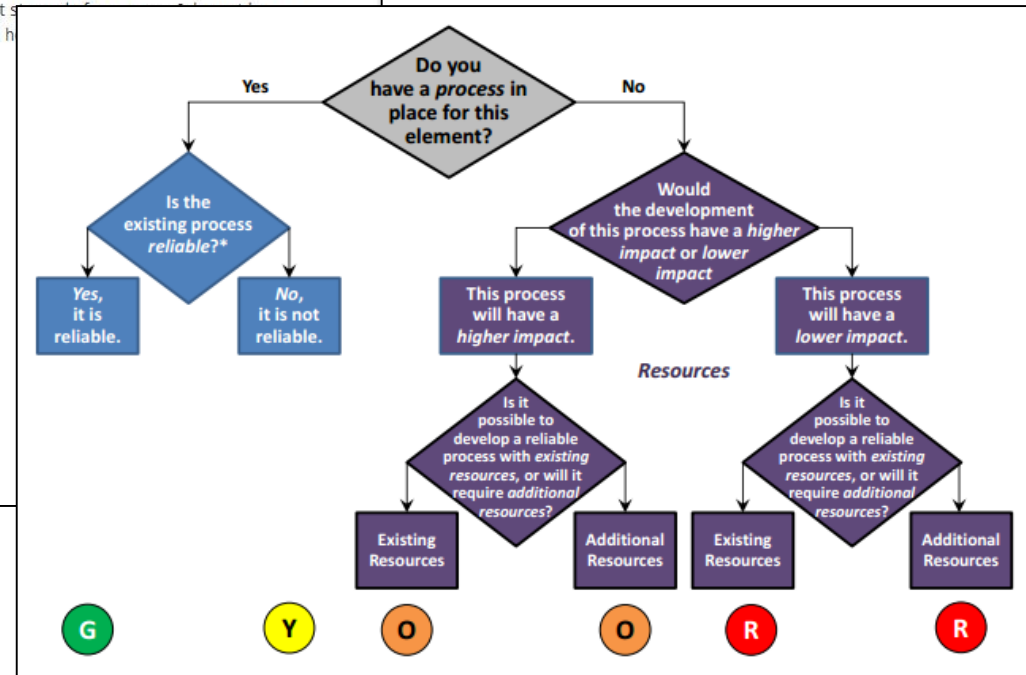
# Disability-Competent Care Self-Assessment Tool

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 source of information about their own needs. Participant-centered planning of care goals and needs 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 Series**

## **Disability-Competent Access**

**Wednesday February 22<sup>nd</sup>, 2017  
2:00-3:00PM EST**

# Thank You for Attending!



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