

Wednesday March 1st, 2017

Disability-Competent Primary Care

DCC Pillars Webinar Series



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The screenshot shows a webinar interface for "Resources for Integrated Care". 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 "Type here" input field. A red circle highlights the "Type here" input field, and another red circle highlights the download icon in the top right toolbar.

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Introductions

- Judith Chamberlain, MD, FAAFP
 - Sr. Medical Director, Aetna Medicaid

- 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 fourth 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:

<https://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. Delivery of Care
2. Preventive Care and Health Education
3. Cancer Screening
4. Sexual Health
5. Primary Care Network
6. Pain Assessment and Management

Primary Care and People with Disabilities

- Who are we talking about?
 - People with physical disabilities
 - People with intellectual disabilities
 - People with serious mental illness
- Some content pertains more to one subgroup than another.
- Many people fall into more than one subgroup.

Health Disparities

People with disabilities are more likely to:

- Experience worse outcomes and are less likely to receive the recommended care.¹
- Experience difficulties or delays in receiving the necessary health care.
- Not have had recommended health screening tests² (e.g., breast cancer, colorectal cancer and diabetes).
- Not receive comprehensive preventive care (e.g., BMI assessment, medication adherence and annual flu vaccine).
- Have limited knowledge and access to sexual health information.
- Have hypertension and poor nutrition.

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 dual eligibility for Medicare and Medicaid 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, BMI and others), the clinical interventions are straightforward but communications and service delivery for people with disabilities stretch the disability capacity of most providers.
- Improving outcomes for people with disabilities will have a direct impact on revenue for some plans and providers.

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

DELIVERY OF CARE

Disability-competent primary care is a participant-centered approach with the primary care provider functioning as part of the interdisciplinary care team (IDT).

Key Challenges in Primary Care

Primary Care Challenges	Disability-Competent Approaches to Mitigate Challenges
Episodic, discontinuous, poorly-integrated care delivery	<ul style="list-style-type: none"> ▪ Team-based ▪ Active provider-participant relationship; both sides are partnered for the delivery of health care ▪ Staff training
Avoidable utilization of emergency departments	<ul style="list-style-type: none"> ▪ 24/7 access to the care team supported by the participant's clinical record; informing decision making
Difficult to access physician offices/clinics for care; Poor physician reimbursement for home visits	<ul style="list-style-type: none"> ▪ Capacity for home visits and transfer of clinical decisions to the home or other care settings as necessary; full "picture" of needs
Traditional "disempowered role" of participant in the relationship with busy physicians and practices	<ul style="list-style-type: none"> ▪ Meaningful participant involvement in care management and care design
Fragmented relationships with specialists, hospital and institutional providers	<ul style="list-style-type: none"> ▪ Coherent and fully organized hospital, institutional and specialist network center (Fully Integrated System of Care (FISoC))

Pedro's Story

Pedro's story is an example of the absences of effective primary care.

- 27 year old from the Dominican Republic (DR) who sustained a spinal cord injury (SCI) ten years ago in the DR. Care in the DR was limited, so he moved to the Northeast US to be with extended family.
- Shortly after arriving, he was admitted to the emergency room with chronic respiratory insufficiency, constipation, multiple pressure ulcers, incontinence and a urinary tract infection (UTI).
- After an extended period of stabilization and rehabilitation, he was discharged to the nursing facility.
- His goal: live with his mother, manage his own care, find a job and build relationships.
- Barriers to achieving his goals include:
 - Physical limitations and access in his home
 - Impulsive and challenging behavior making relationships difficult.

Effective Primary Care

- Primary care for persons with disabilities involves maintaining health, preventing or managing common secondary complications, preventing avoidable hospitalizations and establishing transition protocols to mitigate difficult changes.
- Primary care is built on a strong provider-participant relationship that involves:
 - Active listening
 - Shared problem solving
 - Developing preventive strategies and a comprehensive care plan
- Effective primary care focuses on early diagnosis of treatable conditions, reducing hospitalizations and minimizing poor outcomes.

Annual Primary Care Visit

- The standard of care for all, including persons with disabilities, is at minimum an annual primary care visit which can include:
 - History and physical (H&P)
 - Medication review
 - Care plan review
 - Identification of prevention and health screening strategies
 - Review or discussion of advanced directives
- Participants with higher social risk factors (i.e., lower socio-economic status) are less likely to receive certain medical interventions which can lead to worse outcomes on quality measures in the Medical Advantage program.^{4, 5}

Sources: 4) 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. 183

5) Centers for Medicare and Medicaid Services. (2015). Examining the Potential Effects of Socioeconomic Factors on Star Ratings, pg. 16, 24

Tailoring Primary Care Resources

- Disability-competent primary care includes having additional or alternative delivery of services including:
 - Availability of a primary care provider (PCP) 24/7 for urgent consultation, diagnosis and treatment.
 - Accessible diagnostic tests either in-house or through referral, including x-ray and laboratory testing.
 - Home care if the participant's health status affects their ability to travel to a PCP.
 - Availability of behavioral health homes for people living with serious mental illness.

PREVENTIVE CARE AND HEALTH EDUCATION

The presence of a disability does not in and of itself make the participant sick or unwell. Health and wellness can coexist with disability and are as important to people with disabilities as to those without disabilities.

Managing the PCP Visit

Participants with disabilities commonly require additional accommodations, such as:

- Extended visits to allow for adequate time to complete the exam.
- Physically accessible waiting rooms and exam rooms.
- Accessible communication throughout the visit.
- Inclusion of family and care partners, as necessary.
- Empowerment of the person as much as their disability allows.

Tailoring Standard Care for Participants with Disabilities

- Traditional protocols and practices for the management of chronic conditions are applicable; however, they must be tailored to each participant to factor in their other needs, medications, functional status and available supports.
- Involving participants and their care partners can help with health promotion, self-care direction and education and make the experience more tailored.

Addressing Secondary Conditions

- It is important not to assume secondary conditions (e.g., physical decline, illness, pain, weight gain, etc.) are inevitable when living with a disability.
- Clinical protocols need to be in place for the identification and treatment of secondary conditions including:
 - Skin breakdown
 - Urinary tract infections
 - Upper respiratory infections
 - Bowel impaction
 - Depression and other behavioral health disorders

CANCER SCREENING

Research has demonstrated there are major disparities in access to cancer screenings due to disability status.⁶

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

Barriers to Screening

California Health Interview Survey found lower levels of common cancer screenings for participants (both men and women) with disabilities.

- Women are less likely to receive routine mammograms.
- Pap smears may be difficult for women with disabilities or may be skipped on the assumption of not being sexually active.
- Men are less likely to have or discuss routine prostate exams.
- Both men and women are less likely to receive recommended colonoscopies.
 - Colonoscopies (and the prep) and mammograms are often seen as less accessible due to physical or equipment barriers and are therefore avoided.

Source: 7) Breslau, E. S., Jeffery, D. D., Davis, W. W., Moser, R. P., Mcneel, T. S., & Hawley, S. (2009). Cancer screening practices among racially and ethnically diverse breast cancer survivors: results from the 2001 and 2003 California Health Interview Survey. *Journal of Cancer Survivorship*, 4(1), 1-14. doi:10.1007/s11764-009-0102-5

SEXUAL HEALTH

Persons with disabilities, especially women, are viewed by many as unable or uninterested in being sexual, thus there is a tendency to avoid the topic entirely. The result is a lack of information and unassessed or untreated needs .

Sexual Health Assessment

- Persons with disabilities have the same needs and desires as others, though commonly experience barriers in fulfilling these interests.
- It's important to incorporate a sexual health history and participant interest into the assessment process.
- Offer education, STI (sexually transmitted infection) testing and birth control.
- Common barriers to an active sexual life include erectile dysfunction, physical limitations and sensations.
- Be aware of prior and current sexual abuse, especially of girls and women with intellectual disabilities.

PRIMARY CARE NETWORK

The availability of primary care clinics and providers with accessible offices, and the experience, capacity and interest to serve persons with disabilities is limited.

Primary Care DCC Competency

- PCPs seldom receive education or training in serving persons with disabilities. Therefore, they develop competency through experience.
- Whether employing PCPs or contracting with external providers, extensive training and supports should be put into place.
- When engaging with external primary care practices, plans and provider organizations sometimes identify a lead or “champion” from within the practice.
 - A lead or “champion” will provide ongoing coaching to its practitioners and staff.

Building a Primary Care Network

Disability-competent PCPs are committed to partnering with and supporting persons living with disabilities. This includes being:

- Participant-centered and focusing on the long-term success of each participant.
- Responsive to the participant's medical and functional needs within the context of his or her goals and priorities.
- Accessible in practice and process.
- Collaborative and engaged with the Interdisciplinary Team (IDT).
- Involved in ongoing training and education by and for the population they serve.

Utilizing Primary Care Practices

- When engaging with a primary care practice, many organizations designate a lead or “champion” disability-competent PCP to provide ongoing coaching to the external practice.
- Helping practices to establish or strengthen their disability competency can improve the care received by participants. Strategies may include:
 - Offering a checklist on the physical elements of providing disability-competent care
 - Guidance for improved communication
 - Provider training programs
 - Procedure guidance for front-office and support staff

Accessibility

When choosing a PCP, participants benefit from the following information:

- A directory of PCPs that is routinely updated based on the provider's or practice's disability-competency.
- Accessibility of the practice such as the building, equipment and communication.
- Participants often benefit from hearing peer experiences when choosing a PCP.
- PCP's special areas of interest.

PAIN ASSESSMENT AND MANAGEMENT

Persons with disabilities may experience pain at greater rates than persons without disabilities and may have difficulty expressing it. This can be a direct result of their disability, functional limitations, and / or an acute situation.

Pain and Disability

- The experience of pain can be episodic (such as skin breakdown) and / or chronic (such as phantom pain, orthopedic joint stress or overuse).
- Pain is commonly a warning of the presence of a secondary condition, and may be resolved as the condition is addressed.
- Some participants with disabilities may have difficulty expressing or quantifying their pain.

Pain Assessment and Management

- The PCP should assess if the participant is experiencing pain during the initial and subsequent assessments.
 - Each experience of pain is personal, as is the cause and the impact on the participant's ability to function.
 - Beyond quantifying the level of pain; PCPs should understand, from the participant's perception, how the pain impacts their functioning, relationships and community participation.

Pain Management Plans

- The care plan includes a specific section used to treat and manage pain.
 - Identify strategies and steps to address ongoing pain and pain as it arises.
 - Developed alongside the participant and taking their input into account.
- If it becomes chronic or the initial course of treatment is insufficient, a pain specialist may need to be involved to develop a more comprehensive plan.

Pedro's Story – 5 years later

- Now 32 years old, he lives with his mother in subsidized housing and has personal care attendants.
- He is independent using his power wheelchair, and attends a weekly peer support group where he has several friends.
- His spasticity is well managed and he is now able to wear sneakers.
- He continues to have chronic skin ulcers, although mostly small and proactively managed.
- He continues with a tracheostomy tube, but is off the ventilator and his respiratory status is stable.
- His feeding tube has been removed.
- He describes himself as “stronger” and will be evaluated for a driving assessment.

CONCLUSION

Maintaining participant health and well-being is dependent upon having PCPs that can meet their needs in terms of availability, timeliness and disability competence.

Key Takeaways

- Primary care is an integral part of the IDT, but alone will not be effective in achieving the health outcomes and goals of the participant. Their expertise and experience is vital, in collaboration with the remainder of the team, participant and care partners.
- While the key functions and components of primary care are the same with most populations, persons with disabilities are commonly more complex and experience greater barriers to timely care, accessing needed services, and preventing avoidable secondary conditions.
- As Pedro's story shows, achieving health and life goals is a process requiring communication, collaboration and teamwork.

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

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

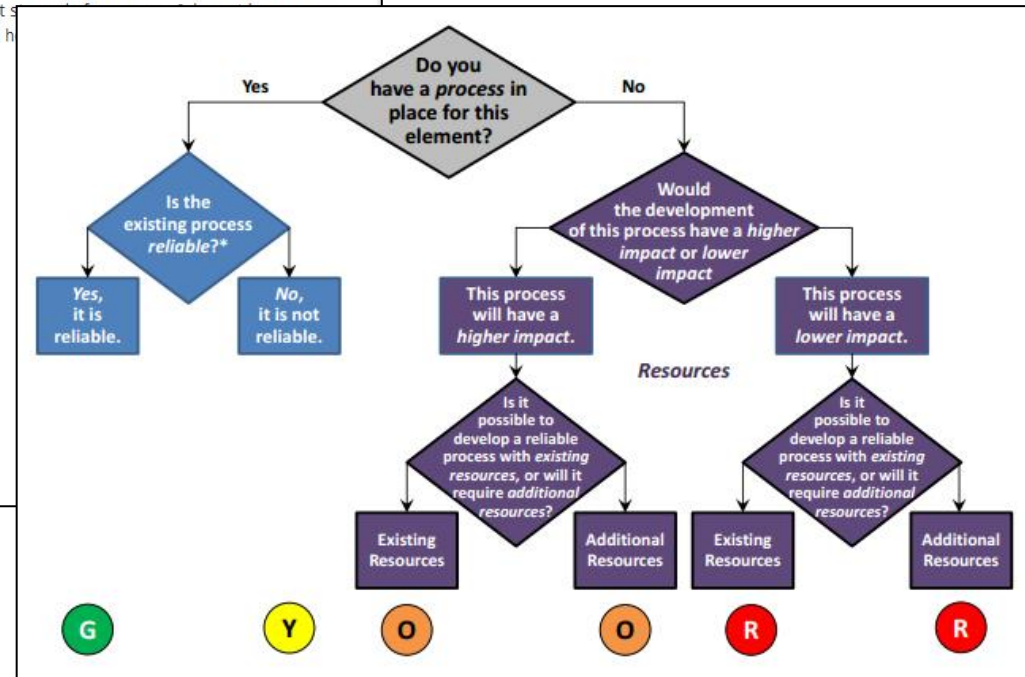
Disability-Competent Care Self-Assessment Tool

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 recognizes that 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:
<https://www.ResourcesForIntegratedCare.com/>

Next Webinar

Disability-Competent Care Webinar Series

Disability-Competent Care Coordination

Wednesday March 8th, 2017
2:00-3:00PM EST

Thank You for Attending!



- For more information contact:
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- Further information, including webinar resources, are available at:
<https://www.resourcesforintegratedcare.com>