

May 13th, 2015

Strategies for the Implementation of Disability-Competent Care

Understanding the Lived Experience of Disability



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Strategies for the Implementation of Disability-Competent Care

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



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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



June Isaacson Kailes

Disability Policy Consultant
Associate Director, Center for Disability
and Health Policy at Western University
of Health Sciences, California



Dennis Heaphy

Co-Founder of Disability Allies Advocating
for Change Together (DAART)



Webinar Agenda

Understanding and listening to the consumer experience is a precursor to improved outcomes. This webinar will:

- Introduce the experience of living with a disability
- Explore key barriers to accessing care:
 - Attitude
 - Communication
 - Equipment
 - Physical access
 - Navigation and coordination
- Audience questions

Importance of Hearing the Lived Experience of a Disability

Stories from the front lines of health care add an essential human dimension to a large body of research showing that people with disabilities experience both health and healthcare disparities and face specific, persistent barriers to care.

Videos available for download show the stunning lessons to be learned and important solutions that will improve healthcare for people with disabilities:

<http://dredf.org/healthcare-stories/>

Human Dimensions of the Lived Experience of a Disability

Alice Wong, a researcher in the San Francisco Bay area living with Spinal Muscular Atrophy, Type Two.

In this video, she speaks of her struggles with having her priorities and choices heard and respected as she seeks health care services.



Be Aware Of and Control Your Disability-Related Biases

Be aware of your disability-related beliefs, biases, prejudices, stereotypes, and fears, and understand:

- Where they come from
- How they can affect your ability to work effectively with people with disabilities
- How to contain them, so they don't interfere with your ability to provide effective care

Knowing Those You Are Serving

- Persons living with disabilities are a diverse group varying in age, gender, race, ethnicity, socioeconomic position, sexual orientation, and type of functional limitation.
- Disability-Competent Care requires that providers of health care understand their consumers':
 - Experience of being disabled
 - Disability itself (clinically)
 - Functional limitations due to the disability

Defining Disability

- Fourteen percent of adults in the U.S. have a disabling condition resulting in complex activity limitations. As a whole, they are:
 - More likely to live in poverty
 - More likely to experience material hardship
 - More likely to experience food insecurity, not getting needed medical or dental care, and not being able to pay rent, mortgage, and utility bills
 - Disproportionately represented in racial and ethnic minority groups
 - Growing in number as the population ages and with technological advancements in care

Key Barriers to Accessing Care

Availability & Awareness

- Ability to know and obtain needed services from health care system – this concept was explored in Webinar 1
 - Right care
 - Right place
 - Right time

Barriers to Accessing Care

- Attitude
- Communication
- Equipment
- Physical Access
- Navigation and coordination

Without Addressing Access...

Persons with disabilities can experience:

- Frustration
- Fatigue
- Failure
- Fear

Poor quality:

- Lack of care
- Delayed diagnosis
- Deteriorating health

Barriers in Accessing Care

Appropriate access to health care for people with disabilities involves addressing additional barriers:

- Attitude
- Communication
- Equipment access
- Physical access
- Navigational and coordination access

Attitude

“There is no reason for someone like you to be tested for AIDS”

“You don’t have to worry about osteoporosis because you can’t walk”

“It’s best you not have children”

“But this is an ambulatory care clinic”

“My, aren’t you cute”

“Getting a mammogram is hard for you so you can just skip it”

Communication

Two aspects of communication:

1. Engagement and listening
2. Using the right auxiliary aids and services to accommodate for limitations, including:
 - Auditory
 - Visual
 - Comprehension

Equipment Access

Attention needs to be given to barriers in the delivery of care. Pay particular attention to:

- Exam tables
- Transferring
- Scales
- Radiological devices

Physical Access

Attention needs to be given to accessing settings of care – from the micro to the macro

- Maneuvering within exam rooms
- Maneuvering within offices
- Accessing the office
- Accessing to the building in the community

People will need to know about the level of physical access that they should expect.

Navigational & Coordination Access

Consumers commonly need help navigating the multiple services, financial resources, settings, and providers of care:

- Knowing the service is available
- Knowing who provides the service
- Obtaining authorization for the service
- Ensuring accessibility to the service
- Arranging for the service

Navigational & Coordination Access

Quality, Service, & Accommodation Alerts (QSAs) ensure consumer specific accommodations from the moment an individual enters the healthcare delivery system. Can include:

- Schedule longer appointment
- Use lift for transfers
- Use life team for transfers
- Use hi/low table located in specific rooms
- Use accessible scale
- Use ASL interpreter
- Use assistive listening device

Many electronic health records are incorporating QSAs.

Attend to the Details

It is important to:

- Know how to document accommodation needs
- Incorporate accessibility into processes, procedures, protocols, policies, training, practice, and experience!
- Adopt a “Can Do” approach that incorporates flexibility and good problem solving skills

Summary

1. Recognize the complexities of living with disability
2. Be aware of disability related biases
3. Listen, learn and use information from participants and those who know them best
4. Attend to the details

Summary

“We are all faced with a series of great opportunities
brilliantly disguised as impossible situations.”

- Charles R. Swindoll

Audience Questions & Discussion

Next Webinar

“Integrating Behavioral Health Within Disability-Competent Care”

Wednesday, May 20th, 2015

Session III will:

- Explore the prevalence and importance of addressing participant behavioral health needs.
- Discuss strategies to facilitate timely communication and collaboration between behavioral health providers and disability-competent care teams.

Please respond to our survey!

Thank You for Attending!



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 - June Isaacson Kailes at jik@pacbell.net
 - Dennis Heaphy at dennis.heaphy@gmail.com
- Disability-Competent Care Self-Assessment Tool available online at:
<https://www.resourcesforintegratedcare.com/>

Resources & Reference Material

- Accessible health care briefs:
<http://www.cdihp.org/products.html>
- Accessible website design:
<http://www.washington.edu/doit/Brochures/Technology/universal.design.html>
- First-person stories of health care experiences:
<http://dredf.org/healthcare-stories/>

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).

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- ▶ **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**

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