LEADING HEALTHCARE PRACTICES AND TRAINING: DEFINING AND DELIVERING “DISABILITY-COMPETENT CARE”

Session IV: Providing Disability-Competent Primary Care

Presented to individuals working with persons with disabilities, particularly in a primary care context.

October 22nd, 2013
LEADING HEALTHCARE PRACTICES AND TRAINING: DEFINING AND DELIVERING “DISABILITY-COMPETENT CARE”

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Overview of Webinar Series

- This is a continuation of the 3-part webinar series presented in September
- The second part of this series will explore:
  
  I. “Disability-Competent Primary Care” 10/22/2013
  
  II. “The Individualized Plan of Care” 10/29/2013
  
  III. “Managing Transitions” 11/5/2013
  
  IV. “Flexible Long Term Services and Supports” 11/12/2013
- Each presentation is about 45 minutes with 15 minutes reserved for Q&A
- Webinars are recorded; video and PDFs are available for use after each session at:

  https://www.resourcesforintegratedcare.com/
Disability-Competent Care Webinar Series

What We Will Explore in This Series:

- The unique needs and expectations of individuals with disabilities
- Disability care competency
- Person-centered care and interactions
- Preparing to achieve the *Triple Aim* goals of improving the health and participant experience of health care delivery while controlling costs in all work with adults with disabilities

What We’d Like From You:

- How best to target future Disability-Competent Care webinars to specific groups of healthcare professionals involved in all levels of the healthcare delivery process
- Feedback on these topics as well as ideas for other topics to explore in these webinars and subsequent resources related to Disability-Competent Care
Introductions

Presenters

Chris Duff
   Executive Director
   Disability Practice Institute

Lynne Morishita
   Nurse Practitioner, Geriatric and Disability Health Consultant

Mary Glover, ANP-BC, MSN
   Executive Director,
   Commonwealth Community Care

June Isaacson Kailes
   Disability Policy Consultant
Webinar Agenda

- Lessons learned in obtaining primary care
- Primary care delivery redesigns that better serve adults with disabilities
- Primary care as part of an interdisciplinary care team
- Prevention of avoidable hospitalizations and episodes of illness
- Leading practices for managing common secondary complications of living with disability
- Audience questions
What I’ve Learned...

Health, chronic conditions, and disability can and do co-exist
What I’ve Learned...

- It is important to obtain, read, understand, maintain and share my medical record with providers
- Planning prevents poor performance
  - Prepare and do your homework
- Don’t just accept ‘you are getting older’ as a response
  - Seek further explanation
- I make my providers better by asking questions
What I’ve Learned...

Elements to consider when choosing a provider:

- Accessibility
  - Physical
  - Equipment
  - Communication
- Disability knowledge
- Relationship: confidence and trust
Accessibility

or...

or...

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Disability Knowledge

- Are they open to learning from me?
- Will they respect my skill sets and knowledge?

It is unrealistic to expect providers to know everything regarding your condition or disability.
Relationship

Will this relationship work for me?

- Partnership and respect
- Trust
- Personality fit
Pedro’s Story

- 27 year old Spanish speaking male from the Dominican Republic (DR) sustained a C6-7 spinal cord injury in 2003, while living in Puerto Rico
- Due to complex medical issues a nurse in the DR recommended Pedro come to US
- Pedro initially went to the emergency room for care. He was admitted with an indwelling catheter, tracheostomy for chronic respiratory insufficiency, constipation, multiple pressure ulcers, incontinence, and a UTI
- Pedro was discharged, though returned to the hospital soon thereafter with bilateral pneumonia
- He was transferred from inpatient to a rehab facility when conditions were stable
Pedro’s Story

The disability-competent care team first met Pedro at a local rehab facility where Pedro identified the following goals:

- Short-term - increased independence with self-care and transfers; desire to wear sneakers again which was impossible due to spasticity
- Long-term - driving, independent care, work, a girlfriend

Initial plans/interventions for discharge to the community:

- DME: hospital bed, air mattress, roho cushion, shower/commode
- Housing advocacy and referral for transportation
- Bladder management: intermittent catheterization regimen with meds to minimize incontinence
- Bowel program
- Teaching regarding respiratory management, “quad coughing”, etc.
- VNA for wound care
Pedro’s Care Plan

Medical:

- Home visits to follow up on bowel / bladder program, respiratory status, wound assessment, coordination of services such as VNA, specialists, obtain labs, update immunizations (no records available), teaching. Management of episodic issues such as UTI’s, changes in skin, respiratory exacerbations
- Referred to pulmonary / ENT to discuss removal of tracheostomy and pulmonary management
- Referred to rehab for consideration for botox injections to reduce spasticity

Social Service:

- Assistance with housing referral, financial benefits
Pedro’s Care

- **Urology**: UTIs; kidney stones treated; erectile dysfunction treated
- **ENT**: Failed attempt to decanulate resulting in respiratory distress and replacement of the trach tube; multiple laser procedures by ENT allowed for trach removal without success requiring a feeding tube because of a tracheal fisutula
- **Pulmonary**: stable management with secretion management
- **Personal Care Attendants and housing**
- **Team Physiatrist** effectively managed spasticity with botox injections; now able to wear sneakers!

All services coordinated by care team who accompanied Pedro to specialty visits when appropriate. Average of 10 visits per year by the care team
Pedro is now 32 years old; weighs 142 lb., up from 113 lb.

- Lives in accessible, subsidized housing with his mother, and employs personal care attendants
- He is independent with mobility using his power wheelchair, and attends a weekly peer support group
- Referred for ESL classes
- Continues to have chronic skin ulcers, though are mostly small and manageable
- Continues with a tracheostomy tube, but is off the ventilator and respiratory status is stable
- Feeding tube has been removed and eats without aspiration
- Describes himself as “stronger”
Systemic Barriers to Effective Primary Care

- Primary care is routinely ineffective or nonexistent - due to multiple / complex issues; requiring need for more physical space and accessible medical equipment
- Predictable array of secondary complications - causing functional decline, recurrent hospitalizations, poor outcomes and avoidable costs
- Reliable personal care and appropriate durable medical equipment are essential and must be accessible to and integrated with medical care
- Standard health plan network, contracting, benefit design, utilizations, management and care coordination strategies are at best irrelevant, and at worst dangerous
What’s Needed

- Interdisciplinary care team
- Community outreach and integration
- Person-centered approach to partnership
- Integration of hospital care and primary care teams to improve transitions
- Emphasis on long-term services and supports
  - Consumer-directed personal care
  - Flexible durable medical equipment (DME) benefit
The Interdisciplinary Care Team

- Nurse practitioners/physician assistants, registered nurses
- Physicians
- Social workers/behavioral health specialists
- Rehabilitation specialists: PT/OT
- DME specialists
- Administrative support staff
- Outside specialists and consultants
- Hospital team
- Health outreach workers
Routine Primary Care Procedures

- **PAP smears**
  Requires an accessible height-adjusted exam table for positioning, such as side-lying, and sometimes alternate place for exam, such as home, in bed

- **Mammograms**
  Requires adapted equipment, specialized chairs for positioning, extra space, extra time, increased tech support

- **Colonoscopy**
  Requires modified preps, increased home supports, pre-procedure hospital stay for support with prep

- **Weights**
  Requires wheelchair scales, hoyer lift scales, exam tables with capacity to weigh
Being Responsive

Presenting Situation:
65 year old woman with neuromyelitis with recent exacerbation resulting in ventilator dependency. She was recently discharged home after extensive inpatient stay. Family called to report a low oxygen saturation of 80%

Intervention:
- Nurse Practitioner (NP) made an urgent home visit, and was able to stabilize her status with suctioning and ambu bag breathing
- The NP obtained phone consultation with MD
- Contacted the respiratory company to obtain supplies, instructed her caretakers on additional interventions
- Contacted Support Services Coordinator to evaluate for more personal care attendant time
Some Unique Strategies: Designated Inpatient Unit

- Designated hospital floor for all member admissions to Boston Medical Center
- Designated hospitalist MD/NP/PA team
- Hospitalist serves as attending of record on the unit and as medical consultant or care coordinator when patients are off service
- Coordinate emergency department care and triage to most appropriate setting including SNF or home
- Daily communication with the outpatient team updating status and planning for discharge
- Coordinate direct admissions with the outpatient team as appropriate
- Integration of personal care attendants
Some Unique Strategies: Inpatient PCA Pilot

In-hospital PCA pilot to integrate PCAs into the hospital care system when appropriate to achieve the following goals:

- Improve personal care during hospitalizations
- Reduce strain on valuable hospital resources, specifically the nursing staff
- Reduce lengths of stay
- Improve transitions in and out of the hospital by allowing for the continuity of PCA care and support
- Promote autonomy, independence, and function to the maximal extent possible to all members in all settings
## Summary

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<thead>
<tr>
<th>Problem</th>
<th>Opportunity</th>
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<tbody>
<tr>
<td>1. Inadequate, discontinuous, unengaged Primary Care</td>
<td>- Team approach - RN/NP/SW/BH/PCP</td>
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<td>- Horizontal rather than vertical MD relationship</td>
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<td>2. Inappropriate dependence upon Emergency Rooms for sick/non-emergent issues</td>
<td>- 24/7 telephonic access to care team, supported by member’s clinical record to inform clinical triage and decision making</td>
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<td>3. Difficulty of getting to physician offices/clinics for care; Inability of physician to assess home environment</td>
<td>- Capacity for home visits and transfer of clinical decisions to the home or other care settings as necessary; full “picture” of needs</td>
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<td>4. Traditional “disempowered role” of member in the relationship with busy physicians</td>
<td>- Meaningful consumer involvement in care management and care design</td>
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## Summary Continued

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<td>5. Fragmented relationships with specialists, hospital and institutional providers</td>
<td>▪ Coherent and fully organized hospital, institutional and specialist network centered around the primary care physician and team</td>
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<td>6. Insurance company “rules” regarding benefit requirements and service authorization</td>
<td>▪ Fully empowered Primary Care Team able to order/authorize all needed services</td>
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<td>7. Lack of continuity and shared information among medical, behavioral health and long term care providers</td>
<td>▪ Fully integrated network of all providers and the Primary Care Team as the “hub” of the wheel to promote information sharing and care transitions</td>
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<td>8. Incoherent “picture” of totality of member’s medical, behavioral health and support service needs</td>
<td>▪ Fully integrated clinical record and state of the art data support</td>
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Audience Questions

Webinar Evaluation Survey
“Disability-Competent Care Planning: The Individualized Plan of Care”
Tuesday, October 29th, 2013
2:00 - 3:00PM Eastern

Session V will focus on:
- Exploring the Interdisciplinary Care Team and introducing the Care Planning Process
- Aligning care coordination resources with the unique needs of each participant

Targeted audience:
- Individuals who work with persons with disabilities, in particular those who support interdisciplinary care teams
“Managing Transitions”
Tuesday, November 5th, 2013
2:00 - 3:00PM Eastern

Session VI will focus on:

- Introducing the Transitional Care Model, and understanding the importance of managing transitions
- Understanding the need for managing non-medical transitions, including emotional, familial, social, vocational, financial, and housing.

Targeted audience:

- Individuals who work with persons with disabilities, in particular those working in long term care, inpatient and home care settings
“Flexible Long Term Services and Supports”
Tuesday, November 12th, 2013
2:00 - 3:00PM Eastern

Session VII will focus on:
- Integrating and coordinating all health care services and supports,
- Understanding the roles and responsibilities of the disability-competent interdisciplinary care team.

Targeted audience:
- Individuals who work with persons with disabilities, in particular home and community-based service providers.
Thank You for Attending

- For more information contact:
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- Disability-Competent Care Self-Assessment Tool available online at: https://www.resourcesforintegratedcare.com/
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

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