Providing Disability-Competent Care for an Aging Population

What is disability-competent care and why is it important?

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Disability Practice Institute
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November 13, 2013
The “Olmstead” Ruling of 1999

The US Supreme Court “Olmstead” decision held that it is against the law to keep people with disabilities in institutional settings against their will.


See: www.worksupport.com/resources/printView.cfm/376June 22, 1999
“Disability is now understood to be a human rights issue. People are disabled by society, not just by their bodies.”
- World Health Organization, November, 2012

“…Disability in America is not a minority issue
…Disability affects today or will affect tomorrow the lives of most Americans …”
- Institute of Medicine 2007, The Future of Disability

“Disability is not a static condition but rather a process of continuous adaptation to changes across the life course.”
- Debra Sheets, CIRRIE, Aging with Physical Disability in America, 2010
What do we mean by people with disabilities?

- Individuals* who need increasing levels of assistance with activities of daily living (ADLs) or instrumental activities of daily living (IADLs) to maintain or achieve wellness and live with maximum independence
- Persons with complex care needs, who require long-term supports and services to remain independent and in their homes
- Individuals who need expertise from an interdisciplinary team including mobility experts, home care aides, primary care clinicians; social workers; housing specialists; pharmacists, mental health and physical/occupational therapists, nutritionists and other specialists, to achieve their optimal function

*For the purposes of this presentation, adults 18 yo and over
A high percentage of people with disabilities have mental illness and other complications

Conservative figures suggest about 45 percent of individuals with severe disabilities suffer from depression. At best, depression and other emotional/mental health disabilities are undertreated. Other issues include hearing impairment, intellectual disabilities, and many other complex, compounding issues.

Source: Johnson and Wiener, Urban Institute, 2006
A home-visiting doctor on treating people with complex developmental and intellectual disabilities...

“Here is what I do on a daily basis:

- Primarily provide primary care and consultation services for individuals with severe developmental disabilities, the vast majority of whom have severe intellectual disability, often with physical disability as well.

- Most have severely limited means of communication resulting in the need to obtain information about their symptoms and medical history through others’ observations.

- Since many do not live in a family setting, those “others” may be a disparate collection of caregivers that observe the individual in a variety of settings and times of day. So any description obtained from one observer is not necessarily representative of what would be offered by another.

- Many individuals with intellectual disability also present behavioral challenges that often appear to be means of communicating that they perceive some distress.

- The underlying etiology for this distress may be physical and/or emotional discomfort related to medical illness and/or psychiatric issues….”
How many people are aging with disabilities?

Some 54 million people in the US are living with disabilities

- ≈75% people needing assistance from caregivers rely exclusively on unpaid (“informal”) caregivers.
- ≈ 35% of all older adults with “severe” (need assistance w/ ≥ 3 ADLs) disabilities were living alone

- Only 14.3% of “frail” older adults (need assistance w/ ≥ 1 IADL)
- Only 3.6% of older adults needing assistance with ≥ 3 ADLs

Source: A Profile of Frail Older Americans and Their Caregivers; Richard W. Johnson, Joshua M. Wiener, March 2006; based on 2002 data from Health and Retirement Survey (HRS)
http://www.urban.org/url.cfm?ID=311284&renderforprint

http://www.dpinstitute.org  Participants, Providers and Payers Partnering to Advance Disability-Competent Care
Aging with lifelong/long-term disabilities is different than aging and getting more frail....

- Total expenditures to provide disability-competent care ≈30% higher*
- Medicare and Medicaid-risk adjustment models don’t reflect difference
- Aging-related loss of muscle function lowers the threshold to serious and life threatening complications, to a far greater degree than in those aging without preexisting disabilities
- “Slippery slope” issues relating to advance directives are far more complex
- Inadequate SNF/NF staffing

*Source: Commonwealth Care Alliance, 2013
<table>
<thead>
<tr>
<th>Population</th>
<th>Medicare Risk Score</th>
<th>Total Medical Service Expenditures Including Long-Term-Care (LTC) Costs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frail elders aging up with lifelong disability++</td>
<td>2.90 (median age=71)</td>
<td>N=143 $5,832/month</td>
</tr>
<tr>
<td>Frail elders with acquired disabilities of age++</td>
<td>1.87 (median age=79)</td>
<td>N=3,946 $4,110/month</td>
</tr>
</tbody>
</table>

*Source: Commonwealth Care Alliance, 2013, based on Mass Medicaid Nursing Home Certifiable (NHC) criteria, and based on actuals 5.1.2012 – 4/30/13
++Meeting NHC criteria
**Some of the Specific Costs of Aging up with Disabilities vs with Acquired Disabilities of Aging**

<table>
<thead>
<tr>
<th>Population</th>
<th>Hospital Admissions/K/yr</th>
<th>Durable Medical Equipment Expenditures</th>
<th>Long-term In Home Support Care Costs/PMPM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frail elders aging up with lifelong disability++</td>
<td>796/k/yr</td>
<td>$761 per member per month (PMPM)</td>
<td>$2,473</td>
</tr>
<tr>
<td>Change in 1 year= 0.8 per person /yr</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Frail elders with acquired disabilities of age++</td>
<td>603/k/yr</td>
<td>$64/PMPM</td>
<td>$1,554</td>
</tr>
<tr>
<td>Change in 1 year=24% increase</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Source: Commonwealth Care Alliance, 2013, based on Mass Medicaid Nursing Home Certifiable (NHC) criteria, and based on actuals 5.1.2012 – 4/30/13
++Meeting NHC criteria

$2,473

$1,554
What does it mean to be disability-competent?

Being disability-competent means:

- Recognizing/treating each individual as a whole person, not as a diagnosis or condition, according to their choices
- Responding to each participant’s physical and clinical needs while considering emotional, social, intellectual and spiritual needs
- Respecting a individual’s “dignity of risk.” Their life, their choices.
- Integrating an individual’s Individualized Plan of Care (IPC) with all services and supports needed to realize the IPC
- Providing flexible, home-based primary care when needed
- Ensuring coordination between care management and home care

http://www.dpinstiute.org  Participants, Providers and Payers Partnering to Advance Disability-Competent Care
What is disability-competent care?

- Person/participant-driven. “Nothing about me without me.”
- Accessible*, team-based, and available in a “meaningful” way 24/7
- Incorporates all services and supports covered by Medicare and Medicaid
- Promotes integration of care/care coordination and services across all settings
- Enables individuals to function with maximum independence and self-sufficiency

*You can get to the care and the care can get to you

http://www.dpinststitute.org Participants, Providers and Payers Partnering to Advance Disability-Competent Care
Does disability-competent care look like this?
Or like this?
How about this?
ICF Model of Aging with Disability
(Lange, Requejo, Flynn, Rizzo, Valero-Cuevas, Baker, & Winstein, 2010)

Health Condition
Aging with Disability

Body Functions and Structures
- Sensorimotor
- Cognition

Activities
- Physical activities and exercise
- Feeding, grooming, working
- Mobility in the home and community

Participation
- Quality of life
- Standardized self-report measures of self-care, self-esteem, and mobility

Environmental Factors
Clinic, home, community, work, assistive technology

Personal Factors
Age, weight, height, gender, ethnicity, duration of impairment

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Disability-Competent Health System by Susan E Palsbo & June I. Kailes, 2006

Disability-Competency Check List:
1. Gate-opening standard operating procedures.
2. Disability-accessible providers.
3. Extended appointments.
4. Holistic services.
5. Manage the need, not the benefit.
6. Disability competency training.
7. Clinical competency support.
8. Assistive technology support.
10. Accessible websites.
11. Comprehensive information system that manages and supports care coordination and quality improvement.

Informed, motivated person with disability

Productive Interactions

Improved Outcomes & Independence

Source: Palsbo, Susan E and Kailes, June I. in Disability Studies Quarterly, 26(2), Spring 2006

“Commonwealth Community Care has a unique collaborative approach to administering care...these practitioners have very specialized knowledge in the field of adults with disabilities. The knowledge evolves from combining their smarts with a respect for the experience and know-how of consumers. It results in very powerful stuff. We stay out of hospitals. We stay home and away from emergency rooms visits. We do not feel alone. We do not feel misunderstood. We feel like participants in our own destiny. And this just builds on itself. The more ownership you feel in your care, the more invested you are in staying well...”

Liz Casey, Participant & Board Member
Best Practices in Disability-Competent Care: Commonwealth Community Care (CCC) & Independence Care System

Shared Elements

- Person-centered, comprehensive, interdisciplinary, team-based care/care coordination, driven by the participant, and guided by the participant’s Individualized Plan of Care (IPC)
- Care that addresses the whole person, including emotional, social, behavioral, and medical health
- A full range of home care services and supports, including personal care assistants and home health aides
- Expert assistance in wheeled mobility and other durable medical equipment, including assistive communications devices
- Pressure ulcer prevention and intervention
- Rehabilitation services to maintain optimal wellness and ability
- Prepaid, risk-adjusted, capitated financing via Medicare and Medicaid payments

http://www.dpinstute.org Participants, Providers and Payers Partnering to Advance Disability-Competent Care
Best Practices in Disability-Competent Care: Commonwealth Community Care (CCC)

- Boston-based Commonwealth Community Care (CCC/formerly BCMG), part of Commonwealth Care Alliance (CCA), is a specialized interdisciplinary primary care practice that for 25 years has been caring for younger individuals with complex needs.

- Today about 10% of the practice is comprised of individuals with a multiple, complex physical, intellectual, and developmental disabilities who have “aged up” in the system, including:
  - Carlos, age 66, with C5-level cervical spinal cord injury 43 years ago
  - Margaret, age 76, with cerebral palsy (CP) and spastic quadriplegia, who uses a tube for nutrition, and assisted ventilator support at night
  - Max, age 60, with a type of Duchenne Muscular Dystrophy and quadriplegia, who lives independently with a tracheostomy and assisted ventilation
  - André, age 68, with Spina Bifida, paraplegia, and slowly progressive renal failure, who has had multiple, recurrent kidney infections over decades

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Aging Up in CCC: April R.

- April, 73, born with cerebral palsy, who has spastic quadriplegia (functional loss in all extremities) and muscle spasticity in her pharynx, increasing her risk of aspiration.

- April lived in a state institution all her life – until she decided, at age 40, to transition to independent living in her own apartment supported by Medicaid funded PCA services, a specially adapted motorized wheelchair, and a communication assistive device.

- For almost 30 years, from ages 40 – 69, there were only a few complications that required hospitalization - e.g. aspiration pneumonia or other broncho-pulmonary infections.

- Age 69 marked a turning point, April was hospitalized repeatedly for complications that occurred with increasing frequency over the next four years culminating in a recent long ICU stay for intubation and assisted ventilation, nutrition via gastrotomy (“G”) tube, and weeks of convalescence in a Skilled Nursing Facility (SNF).
What have been the elements of disability-competent care for April in Commonwealth Community Care?

- Respect and appreciation for April as an individual.
- Assessments and care by an interdisciplinary team → Individualized Care Plan (IPC), based on April’s goals and choices.
- Always available (24/7) “meaningful” care based on April’s IPC
- Same-day responsiveness to new medical problems
- Continuity of care in every setting (home, hospital, rehab, and every combination), including management of transitions, and knowing where in the system April is, so she isn’t left to fend for herself.
- Access to experts in independent living/housing possibilities, home and community benefits, personal care assistance, and durable medical equipment, including options for wheeled mobility with proper custom cushions, and assistive communications devices.
- Collaborative, candid, clear advice on options for care
Best Practices in Disability-Competent Care: Independence Care System

- New York City-based Independence Care System (ICS) has operated a nonprofit managed long-term care (MLTC) plan for Medicaid and Dual eligible individuals for some 13 years.
- ICS is dedicated to supporting adults with physical disabilities and chronic conditions to live at home and participate fully in community life.

Photo courtesy of www.icsny.org
Independence Care System Best Practices include:

- **Expert wheelchair fitting, purchase, maintenance and repair**, including professional evaluation, home assessment, skilled wheelchair technicians, three vans for pick-up and delivery, timely repairs (in the home and in ICS’s repair shop), training, demonstration and loaner chairs, and self-help workshops in wheelchair maintenance.

- **Specialists in pressure ulcer prevention and intervention**, who assess all ICS members to identify those at risk (nearly 60% of members) and coordinate care. This program has reduced the percentage of ICS members who developed a pressure ulcer to 5%, compared to the average national pressure-ulcer prevalence rate for individuals requiring long-term care/home care of 28%.

- **Social/educational/artistic activities to combat isolation**, which have proven to be a first step for many members to becoming socially involved in activities beyond ICS.

- **Transportation services, including car services, and ambulette** companies found by ICS to have the safest equipment, best on-time records and greatest sensitivity to the needs of people with physical disabilities.

http://www.icsny.org
Best Practices in Disability-Competent Care: Independence Care System

Wound care management

- While >60% of ICS members are at risk of skin breakdown, fewer than 1% developed a new pressure ulcer in 2012.
- ICS established a Pressure Ulcer Prevention and Comprehensive Wound Management Program in 2003. Headed by a Certified Wound Care Nurse and expert in the field, the Program makes ICS unique among long-term care programs.
- ICS nurses assess every member at intake and every 180 days thereafter for their risk of developing a pressure ulcer, using the Braden Scale. They then administer the Skin Integrity Interventions form developed by ICS, which provides recommendations for specific actions that correspond to the Braden score.
- ICS’s social work care managers maintain regular contact with ICS members, involved relatives, and home care aides and make sure interventions are in place.
- ICS social workers appreciate the opportunities to teach members at risk of skin breakdown how serious a wound can be and what they can do to protect themselves.
- They advise about using skin inspection mirrors or skin barrier ointment; makes sure that the cushions on their wheelchairs are intact and still properly fitted; make referrals for pressure-relieving mattresses or wheelchair seating evaluations; recommend nutritional supplements; and refer for physical and occupational therapy.

Source: http://www.icsny.org/blog/staying-wound-free-with-ics/
Artists on Wheels Program
- Drawing and Painting from Life
- Crafts with Liz
- The R-tist and the Ideas U Know
- One Man’s Junk is Another Man’s Treasure
- Basic Jewelry Café
- Knitting and Crocheting Circle
- Music for Everyone

Health and Wellness
- Women’s Support Group
- Young Women’s Support Group
- Weight Watchers

Creative Writing Circle
Friday Night Hangout

ICS Social Programs
- Movies at ICS: Beasts of the Southern Wild Thursday, June 6th, 2013
- Stand-up Comedy DVD Night at the ICS Friday Night Hangout: Eddie Murphy Friday, June 7th, 2013
- Bingo at ICS Friday Night Hangout Friday, June 14th, 2013

View complete Calendar of ICS Social Programs

Special Events and Outings to NYC attractions
Some important web-based sources

**Disability Practice Institute**, [http://www.disabilitypracticeinstitute.org](http://www.disabilitypracticeinstitute.org)


The Disability Practice Institute worked collaboratively with partner organizations to develop tools, to help health plans and health systems evaluate their current ability to meet the needs of adults with functional limitations, and to identify areas for improvement; both can be found on the CMS website:

**Disability Competent Care Self-Assessment Tool**

**Disability-Competent Care Evaluation Grid**

**Ohio’s “Dual Demonstration” project:**
Memorandum of Understanding (MOU) between CMS and The State of Ohio Regarding a Federal-State Partnership to Test a Capitated Financial Alignment Model for Medicare-Medicaid Enrollees; Demonstration to Develop and Integrated Care Delivery System; this includes the Three-way contract consisting of a Federal-State partnership along with Integrated Care Delivery System Plans; From September 1, 2013 – December 31, 2016
“I used to try to explain that in fact I enjoy my life, that it's a great sensual pleasure to zoom by power chair on these delicious muggy streets, that I have no more reason to kill myself than most people. But it gets tedious. God didn't put me on this street to provide disability awareness training to the likes of them. ..

Are we ‘worse off’? I don't think so. Not in any meaningful sense. There are too many variables. For those of us with congenital conditions, disability shapes all we are. Those disabled later in life adapt. We take constraints that no one would choose and build rich and satisfying lives within them. We enjoy pleasures other people enjoy, and pleasures peculiarly our own. We have something the world needs.”

- Harriet McBryde Johnson, MPA, JD (July 8, 1957 – June 4, 2008)

Ms. Harriet McBryde Johnson - American author, attorney, and disability rights activist

http://www.dpinstitute.org  Participants, Providers and Payers Partnering to Advance Disability-Competent Care
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Sources and References


Chart on Slide XX from Palsbo, Susan E, PhD, Kailes, June I, Disability-Competent Health Systems. Disability Studies Quarterly. Spring 2006, 26:2 www.dsq-sds.org


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Palsbo, Susan, Mastal, Margaret, PhD, RN; ODOnnell, Lolita; PhD, RN

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