



Ensuring Person-Directed Principles when Integrating HCBS with Healthcare Systems

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Objectives

1. Articulate the benefits of providing person-directed care for individuals with serious illness, their families, and caregivers, through integrated health and community care systems.
2. Identify three focus areas to improve integration of person-directed care.
3. Promote implementation of an idea or experience discussed during this presentation.

Meet Mary

- 79 years old
- Multiple chronic conditions:
- Chronic Heart Failure (CHF)
- Kidney Disease
- Heart Disease
- Anemia
- Frequent Hospitalizations
- Frequent Emergency Room Visits
- Precarious Health Status
- “Non compliant” with medication or health instruction



Mary and Frank



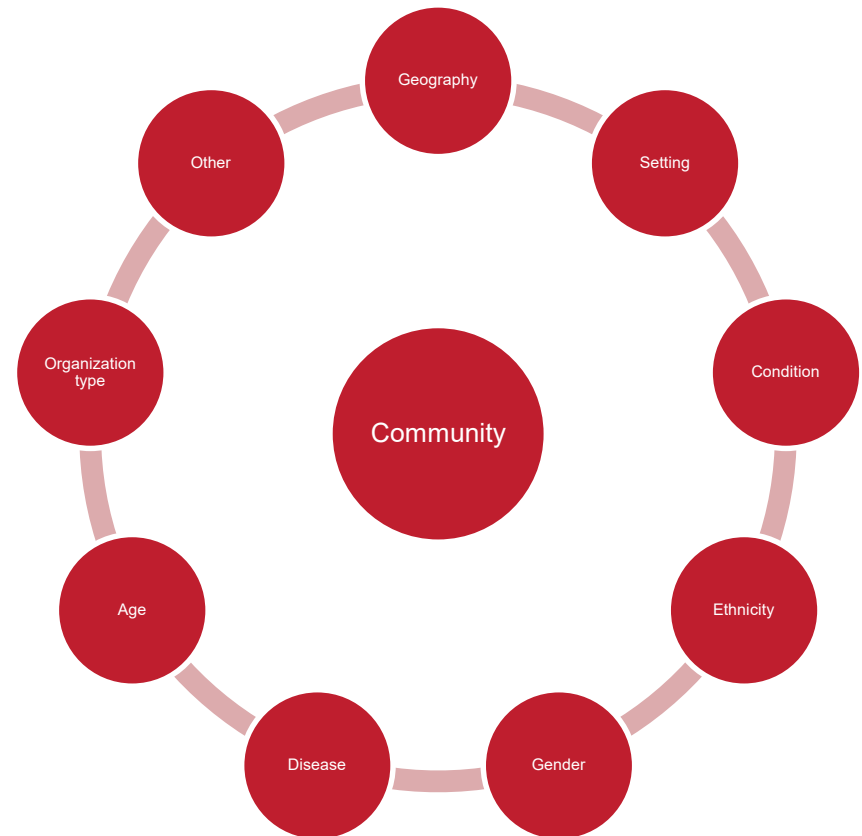
- Married 47 years
- Sole caregiver for Frank, her husband with severe dementia
- Can't leave Frank alone
- Struggle to pay for medicines
- Multiple doctors giving her varied instructions

Home and Community-Based Services

- Use of home and community-based services is growing - number of Medicaid beneficiaries using HCBS has expanded from 2.3 million in 2002 to 3.2 million in 2012 (KFF, 2013), with about 4.6 million enrollees receiving Medicaid HCBS in 2017 (KFF, 2019).
- Studies have shown the positive impact of HCBS on care efficiency and costs
 - Thomas and Mor (2013)
 - Berkowitz et al. (2018)
 - Weissert, Cready, and Pawelak (2005) review

Palliative Care as an Example of Person-Directed Care

- Defined by the person living with a serious illness
- A lens through which needs are assessed and met
- Palliative care relates to HCBS through...
- Care coordination
- Consumer choice and comfort
- Advanced care planning
- And more



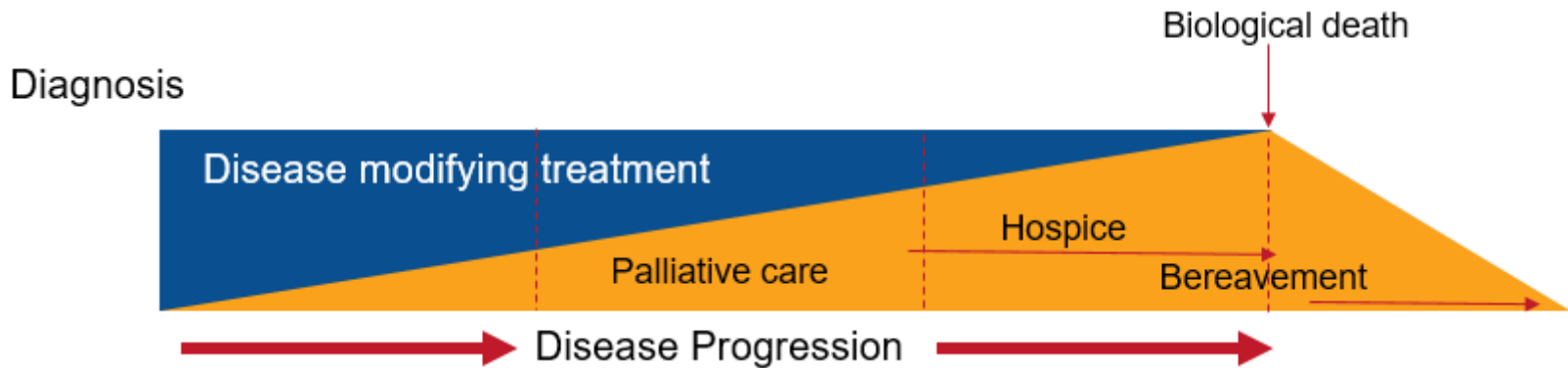
Palliative Care

- Palliative care:
- Is an interdisciplinary care delivery system designed for the person, their families, and caregivers
- Is beneficial at any stage of serious illness
- Anticipates, prevents, and manages physical, psychological, social, and spiritual suffering to optimize quality of life
- Is delivered in any care setting through the collaboration of many types of care providers
- Can improve quality of life for both the person and the family through early integration into the care plan

(National Consensus Project for Quality Palliative Care)

Palliative Care Key Concepts

- Person-directed and family-centered care
- Inclusive of all people living with a serious illness
- Can be incorporated into all disciplines and clinicians caring for people with a serious illness



Palliative Care

| Palliative Care and Outcomes | Study |
|--|--|
| Individuals live longer with higher QoL - More communication, symptoms & depression improved | Temel NEJM 2010 |
| Greater family satisfaction with quality of care - More communication, greater comfort, preferences met | Casarett Arch Int Med 2011 |
| Improved pain, symptoms and satisfaction with care - Symptom management and multidisciplinary team | Higginson JPSM 2003 El-Jawahri JSO 2011 |
| Lower costs per day - Goals of care changed | Morrison Arch Int M 2008 |
| Fewer hospitalizations, hospital days, readmissions and lower costs - Symptom management support to primary care providers; goals of care and advance care planning support to patients and families | Lukas JPM 2013 |
| Fewer ED visits and hospital admissions - Better symptoms with in-home PC | Brumley JPM 2003 |
| Fewer hospital admissions and inpatient deaths - Better symptoms with in-home PC | Brumley JAGS 2007 |
| Fewer 30-day readmissions - Support with home PC or hospice | Enguidanos JPM 2012 |

ACL's 13 Principles for Person-Directed Services and Supports During Serious Illness

1: Live with serious illness according to personal values and goals

2: Enable choice of services

3: Avoid discrimination

4: Enable choice of representative

5: Carry out person-directed planning and decision-making

6: Access to care coordination

7: Choose among services and supports

8: Deliver palliative care

9: Provide hospice care when chosen

10: Provide independent advocacy services

11: Educate and support providers

12: Support family caregivers

13: Address the concerns of older adults; people with disabilities, including those with developmental disabilities; and their family caregivers

National Perspectives and Recommendations: Implementing the 13 Principles

- Consulted with:
 - Consumer advocates
 - Health plans
 - Health and LTSS providers
 - Relevant literature
- Three key themes of recommendations:
 - Managing resources
 - Infrastructure and interoperability
 - Workforce and training

Managing Resources - Recommendations

- Timely access
- Culturally sensitive communication
- Building relationships with CBOs
- Integrated care models
- Use of palliative care and hospice benefits
- Support redirection of medical resources

ACL Resources – Managing Resources

- Business Acumen Initiative
 - Learning Collaboratives
 - Grants
- ElderCare Locator: eldercare.acl.gov/
- Centers for Independent Living:
<https://acl.gov/programs/aging-and-disability-networks/centers-independent-living>

ACL Resources – Managing Resources

- No Wrong Door Initiative – nwd.acl.gov
 - Resources to build networks:
<https://nwd.acl.gov/resources.html>
 - *National Key Elements* document:
<https://nwd.acl.gov/pdf/NWD-National-Elements.pdf>

ACL Resources – Managing Resources

- ACL - Diversity and Cultural Competency
 - Toolkit for Serving Diverse Communities
 - HRSA Cultural Competence Resources for Health Care Providers

Discussion Period – Managing Resources

- What challenges have you had in managing resources to ensure high quality care for people with serious illness?
- How have you been able to leverage/secure resources to ensure quality care for people with serious illness?

Infrastructure and Interoperability - Recommendations

- Expand the mental model of health care delivery to include CBOs
- Use data to identify those in need
- Standardize practices ([Clinical Practice Guidelines for Quality Palliative Care](#))
- Adopt technologies to improve connectivity and communication
- Improve access to real-time data and interoperability

ACL Resources – Infrastructure and Interoperability

- ACL data at AGID.acl.gov
- 2017: Evidence-Based Care Transitions Program
 - [AHRQ - Resources and Care Transitions Exchange](#)
- ACL [Oral Health webpage](#)
- [Aging and Disability Business Institute](#): Health IT Learning Collaborative
- [CMS – Data Element Library](#)

Discussion Period – Infrastructure and Interoperability

- How have you adapted new technologies to improve communication or share data?
- What challenges do you find, if any, in communication that are unique to serious illness?

Workforce and Training- Recommendations

- Expand team training
- Universal geriatric and palliative care education
- Cultural competency training
- Education on the benefits and services available
- Family caregivers are part of the team

ACL Resources – Workforce and Training

- Strengthening Aging and Disability Networks:
<https://acl.gov/programs/strengthening-aging-and-disability-networks>
 - Duals Demonstration Ombudsperson Technical Assistance
 - Diversity, Cultural Competency
- Brief from Resources for Integrated Care:
<https://acl.gov/news-and-events/announcements/resources-integrated-care-ric-briefs-community-health-workers>

ACL Resources – Workforce and Training

- National Family Caregiver Support Program:
<https://acl.gov/programs/support-caregivers>
- ACL resources for consumers about protecting rights and preventing abuse:
<https://acl.gov/programs/protecting-rights-and-preventing-abuse>

Discussion Period – Workforce and Training

- What education or competency do you think is most needed in your area?
- In your role, what can you do to address that need?

Recap

- ACL Document available for download:
[“Principles for Person-Directed Services and Supports During Serious Illness”](#)
- Resources for addressing elements of the 13 principles are available at ACL.gov
- **The National Center on Advancing Person-Centered Practices and Systems (NCAPPS)**
<https://ncapps.acl.gov/about-ncapps.html>

Thank You!

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