Person-Centered Planning and Programs that Promote Community Living

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Topics

• Overview of ACL
• Person-Centered Planning and the HCBS Settings Rule
• HCBS Settings Rule Implementation Challenges
• ACL Support of Person-Centered Planning, Practices and Systems
• Veteran Directed Care Program
• Person-Centered Planning Principles during Serious and Advanced Illness
• Conclusions

OVERVIEW OF ACL
What is ACL’s Purpose?

Mission
Maximize the independence, well-being, and health of older adults, people with disabilities across the lifespan, and their families and caregivers.

Vision
All people, regardless of age and disability, live with dignity, make their own choices, and participate fully in society.

Administration for Community Living
An operating division within the Department of Health and Human Services (created April 2012).
- Administration on Aging (administers Older Americans Act)
- Administration for Disability (administers the DD Act, Independent Living, etc.)
- National Institute on Disability, Independent Living, and Rehabilitation Research
- Center for Policy and Evaluation
- Center for Innovation and Partnership
- Center for Management and Budget
- Center for Regional Operations

Detailed Overview of ACL

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Person-Centered Planning and the HCBS Settings Rule

Person-Centered Thinking, Planning and Practice

- Person-Centered Thinking, Planning, and Practice is foundational to supporting people with disabilities and older adults to live full lives in community-based settings.
- Person-centered planning is different from care planning or patient centered medical care.
  - Focus is on individual goals, desires, values
  - In all aspects of the individual's life

Federal Policy Framework

- Generally focused on principles of person centeredness: values, preferences, goals
- A few specific requirements:
  - person decides where, when, and who in the planning process
  - Strategies for conflict negotiation
  - Includes goals, services, and supports
  - Conflict of Interest
  - Updates as needed
Person-Centered Requirements/Guidance in HHS Programs

- HCBS Final Rule (CMS)
- Long Term Care Rule (CMS)
- Managed Care Rule (CMS)
- ACA Section 2402(a) (HHS-Wide)
- Accountable Care Communities FOA (CMS)
- Person & Family Engagement Program (CMS)
- No Wrong Door (ACL)
- Mental Health Block Grants (SAMHSA)
- Certified Community Mental Health Clinics (SAMHSA)
- eLTSS Standards (ONC)

Focus on 2014 Medicaid HCBS Final Rule

- Effective March 17, 2014
- Addresses Medicaid HCBS requirements across: waivers, state plan services, Community First Choice, 1115 Demonstrations
- Requirements apply whether delivered under a fee for service or managed care delivery system
- States have until March 17, 2022 to achieve compliance with requirements for home and community-based settings in transition plans for existing programs.

Person Centered Planning in the Context of HCBS

- Individual Preferences
- Innovation & Use of Technology
- Flexibility in Scheduling
- Leveraging of Person and Paid Supports
Goal #1: HCBS Should Support Individuals to:

- Live in their own home with the people they choose to live with
- Enjoy the support and engagement of family and friends
- Get a job, volunteer, or retire but continue to engage
- Enjoy good health
- Be a meaningful part of and contribute to their community
- Achieve their personal potential for independence, inclusion and self-sufficiency

Goal #2: HCBS should be Focused on Preserving and Improving Social Determinants of Health among Beneficiaries

Social Determinants of Health as Cost Control
- Enlightened cost control strategy—not just for Medicaid, but health care system overall
- Increase efficiency while also improving health of enrollees
- Interventions for targeted populations have demonstrated cost savings, such as
  - Intensive care management for super-citizens
  - Coordinating access to and affordable housing for individuals who are veterans or homeless

Out with the Old, In with the New

- Old Ways of Thinking
  - Cyclical Dependency
  - Ineligibility
  - Determinations
  - “Payer of Last Resort”
  - Always Someone Else’s Responsibility, and Someone Else’s Fault
- A New Approach
  - Dignity of Risk
  - Presumption of full inclusion
  - Everyone has a shared responsibility and accountability from Day 1

“When patterns are broken, new worlds emerge.”
Tuli Kupferberg
Federal HCBS Setting Requirements

Is integrated in and supports access to the greater community
Provides opportunities to work, recreation, and social activities that are integrated and aligned with the individual's personal interests
Assures the individual receives services in the community to the same degree of access as individuals not receiving Medicaid HCBS
Assures the individual's rights of privacy, respect, and屏障from coercion and restraint
Facilitates individual choice regarding services and supports that are provided

**Additional Requirements for Provider-Controlled or Controlled Residential Settings**

Promoting Community Integration in HCBS

Access
• Availability of supports to allow a person to engage in the broader community for the maximum number of hours desired daily.
• Activities designed to maximize independence, autonomy and self-direction.

Variety
• Broad range of activities/offerings that are comparable to those in which individuals not receiving HCBS routinely engage.
• Access to both individualized and small-group activities, on and off site.

Quality
• Cultural competency
• Measurement focused on Increasing Community Access, Decreasing Social Isolation

Stakeholder Engagement: How
• Ongoing (from design to implementation to oversight)
• Robust and meaningful
• Responsive
• Transparent
• Timely notice of meetings & other opportunities for meaningful input
• Meetings at times convenient for all
HCBS Settings Rule
Implementation Challenges

Practices

• 28 approaches to Person Centered Planning
• Most states have person centered practices in the following areas:
  – Mental Health
  – Employment
  – Independent Living
  – Older Adults/Dementia
  – Intellectual and Developmental Disabilities

Common Approaches

– Essential Lifestyle Planning/Person Centered Thinking
– Motivational Interviewing
– Shared Decision Making
– Graphic Approaches (PATH, MAPS)
– State driven models
Interactions: Person-Centered Planning, Assessments, Service Authorization

- Distinct functions that are often conflated in practice
  - Person centered planning: driven by the person and reflects his/her perspective
  - Assessments: judgments made by professionals (e.g. diagnosis, functioning, service needs)
  - Service Authorizations: the final determination of what services are provided for what purpose

Status Quo Prevails

- People are often left with someone else’s plan:
  - Doing things they don’t want to do
  - With people they don’t want to be with
  - In places they don’t want to be

Implementation with Integrity: System Issues

- Funding/Reimbursement
- Capacity
- Community Integration
- Conflict-Free Case Management
- Person-Centered Planning
Current State of Practice

- Several states have committed, ongoing emphasis on person-centered planning in part or all of their HCBS programs.
- Most states have very small commitments
- Large state demand for TA (no central entity)
- No agreed upon practice standards or systems design requirements
- Little end user awareness of what to expect
- Little research on best practices, KSAs, systems design.

Potential Land-Mines (Threats) to HCBS Systems Change

- Budget Cuts
- View of HCBS as Family Respite
- New Legislative Proposals
- Resisting of Federal Regulations
- The Choice Argument

ACL Support of Person-Centered Planning, Practices and Systems
**ACL Vision for Person-Centered Systems**

- People know what to expect
- People who facilitate planning processes are competent
- Systems deliver services and supports in a manner consistent with person-centered values
- Quality measures are implemented for process fidelity, experience, and outcomes based on each person’s preferences and goals.
- Principles of continuous learning are applied throughout the system.
- Formalized and ongoing partnerships with people with disabilities and older adults in design and implementation.

**National Center on Advancing Person Centered Planning, Practices and Systems (NCAPPS)**

- Despite progress in HHS policy and programming, state programs continue to grapple with how to effectively implement person-centered thinking, planning, and practices in a manner consistent with the policy intentions.
- ACL and CMS seek to augment existing state efforts to implement HHS Person-centered policy and guidance by creating a National Center for Advancing Person-Centered Practices and Systems
- Contract awarded to HSRI September 2018

**NCAPPS Functions**

- Central clearinghouse for all stakeholders to access useful information through a centralized website.
- Provide effective TA to states on the full spectrum of needs related to implementing person-centered thinking, planning, and practices in their systems
- Assist states in creating the organizational culture, processes, payment incentives, policy, and practices at all levels of state systems to support Person-centered planning.
- Support state-to-state E-Learning communities of practice to facilitate the development and sharing of best practices across state systems.
- Support partnerships with people with disabilities and older adults in designing and implementing person-centered thinking, planning, and practices in systems.
Example of Person Centered Planning Results with Life Trajectory Tool
Completed with Person Supported: Robert

Vision for a GOOD Life
- Money, job or own business
- Healthy and fit
- Married (5 kids?)
- Volunteering
- Contribution to my community
- Living in my own home

Vision for what I DON'T Want
- Poverty, no savings
- Guardianship
- Institution/group home living
- Being lonely and isolated
- Frequent hospitalization
- Family separated from me
- No friends

Everyone wants a good life. The boxes on the right will help you think about what a good life means for you or your family member, and identifying what you know you don’t want.

Space around the arrow will help you think about current and needed experiences that influence the direction of your good life.

Adapted from

- Moving into “a home”
- Rely on paid supports
- Get married
- Retire in Florida
- Visit Puerto Rico
- Learn to play golf
- Play basketball
- Volunteer at Martha’s Table
- Work at Verizon Center
- Role in supporting systems change
- Efforts to improve access to employment & HCBS

THE VETERAN DIRECTED CARE PROGRAM
Key Elements of the Program

• In 2008, ACL began a partnership with the Veteran's Health Administration (VHA) to serve veterans of all ages at risk of nursing home placement through the Veteran Directed Care Program.

• Vision is a LTSS system that is person-centered and consumer-directed, and that helps people at risk of institutionalization to continue to live at home and engage in community life.

• The Program provides eligible veterans with opportunities to:
  – Self-direct their LTSS and continue living independently at home.
  – Manage their own flexible budgets
  – Decide what mix of goods and services best meet their needs
  – Hire and supervise their own workers.

• Through an options counselor, the Aging & Disability Network provides facilitated assessment and care/service planning, arranges fiscal management services, and provides ongoing counseling and support to veterans, their families, and caregivers.

Program Status

• As of April 2019, the Program is serving 2,166 Veterans across 37 States and the District of Columbia and Puerto Rico.

• 86 Veterans Affairs Medical Centers (VAMCs) have partnered with Aging and Disability Network Agencies (ADNAs) including State Units on Aging (SUAs), Aging & Disability Resource Centers (ADRCs), Area Agencies on Aging (AAAs) and Centers for Independent Living (CIL) to offer the program.

• The Program is available through the Veteran's Health Administration’s (VHA) Office of Geriatrics and Extended Care Services. VAMCs are responsible for determining eligibility and making referrals to ADNAs for VDC. Nearest VA location can be found here: https://www.va.gov/directory/guide/home.asp.

THE ROLE OF PCP DURING SERIOUS & ADVANCED ILLNESS
ACL’s Education and Work Related to Care During Serious and Advanced Illness

- Every person should be able to choose and control their health care and LTSS.
- The ability to choose is independent of age or disability and not diminished by illness, whether serious or advanced.
- One of our goals is to help ensure that when a person is very ill, they and their families do not face discrimination based on assumptions about age or disability.
- We also are promoting the voice of the individuals with serious or advanced illness within policy conversations.

ACL Education and Advocacy Activities

- A series of educational fact sheets on advanced illness services, which are targeted to older adults and their families and connect them to useful government resources and information.
- A video guide to advance care planning, designed for older adults.
- Support for a collection of resources on advance care planning and end-of-life care, designed for long-term care ombudsman programs.
- An ACL internal workgroup on serious and advanced illness to guide this work and coordinate with other HHS agencies.

Reasons for Principles:

- Few opportunities for consumer input in public discussions
- Right to make choices and control decisions, independent of age, disability, or illness
- Need to understand stakeholders’ thoughts on this topic and their language
- Inform ACL’s role and approach
Development Process for Principles

- Literature from and aging and disability perspectives 2010-2015
- 2-year consultation process with stakeholders
  - Engaged with individual stakeholders representing:
    - Older adults
    - People with disabilities
    - People with intellectual disabilities
    - People with dementia
  - Engagement activities focused on communities’ unique perspectives on:
    - Ideal services and supports for their constituents during serious illness.
    - What providers and payers should do

Conversation Findings:

- Person-directed approach that:
  - Informs individuals about their conditions
  - Honors choices
  - Manages symptoms
  - Provides emotional and spiritual supports
  - Avoids discrimination by age or disability

Additional Consultations

- 11/16 announced creation of principles with invitation for initial feedback
- Developed Principles based on literature and conversations
- 12/16 held Aging & Disability Stakeholder Dialogue
- 3/17 Blog and posted draft Principles on ACL.gov
  - Sent to our mailing list (50,000+) and social media
  - Asked stakeholders to publicize
  - 60 day comment period through May 2017
  - ~80 comments from individuals and organizations adding content to draft
- Principles Released 9/17
Concepts underlying Principles

- People need to be informed about their conditions and have the opportunity to express their preferences.
- Service providers should respect those preferences and place individual choices at the center of treatment decisions.
- Choices may be to accept or refuse treatment.
- Service providers should honor the individual's choices, help manage their symptoms, and provide needed emotional and spiritual supports to them and their families.

Summary of Principles

- People with disabilities often few chances to make choices
- Older adults often face loss of control
- Choices may not be honored
- Foundation of choice is person-directed services and supports
- Older adults and those with disabilities are the only ones who know how and where they want to live, given their own unique circumstances
- No one should make assumptions about “quality of life”

Summary

ACL has a:

- Broad range of programs designed to promote community living and engagement for older adults and people with disabilities of all ages. You have heard about 3 of them today.
- Strong commitment to person-centered planning across its programs and through its partnerships with other Federal agencies, state and local programs, and affiliated service providers
- Resources dedicated to promoting person-centered planning.
Links to Resources

- Principles for Person-directed Services and Supports during Serious Illness: At ACL, we believe that every person has the right to make choices and control their own decisions. This right is independent of age or disability or stage of illness. To help ensure that people who have serious illnesses are able to control their care and services, ACL will be using these principles to inform policy discussions and enhance existing programs and services related to serious illness among adults and individuals with disabilities.

- Promoting Community Living for Older Adults Who Need Long-term Services and Supports: This issue brief describes how states could provide home and community-based services to adults with disabilities and help them remain in their homes and communities. The special circumstances of older adults with dementia, who are at high risk for nursing home use, are also described.

- Community Living for American Indian, Alaskan Native, and Native Hawaiian Elders: The Administration for Community Living (ACL) is committed to assisting American Indian, Alaskan Native, and Native Hawaiian Elders to live with dignity and self-determination, while participating fully in their communities. This issue brief describes how states could provide home and community-based services to American Indian, Alaskan Native, and Native Hawaiian Elders, and shares some of the innovative programs that promote health and support community living for Elders.

- Opportunities to Improve Nutrition for Older Adults and Reduce Risk of Poor Health Outcomes: There are examples for states and others to consider when seeking to improve adults’ health and well-being through nutrition interventions for community-living older adults, and those experiencing hospitalization.

- Oral Health and Its Impact on Adults who are Older or Have Disabilities: Describes how a person’s overall health is related to their oral health and a number of options states have for expanding access to oral health.