Introducing the National Center on Advancing Person-Centered Practices and Systems

HCBS Conference
August 27, 2019
<table>
<thead>
<tr>
<th>Name</th>
<th>Position and Organization</th>
</tr>
</thead>
<tbody>
<tr>
<td>Shawn Terrell</td>
<td>Senior Policy Advisor, Administration for Community Living</td>
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<tr>
<td>Amanda Hill</td>
<td>Health Insurance Specialist, Division of Long Term Services and Supports, Centers for Medicare &amp; Medicaid Services</td>
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<tr>
<td>Nicole LeBlanc</td>
<td>NCAPPS PAL-Group Coordinator, Human Services Research Institute</td>
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<tr>
<td>Alixe Bonardi</td>
<td>NCAPPS Co-Director, Human Services Research Institute</td>
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<tr>
<td>Shannon Gadd</td>
<td>Commissioner, Kentucky Department for Aging and Independent Living</td>
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</tbody>
</table>
NCAPPS OVERVIEW
NCAPPS is for...

States, Tribes, and Territories

Systems for people with disabilities and older adults with long-term service and support needs, including

- Brain injury
- Intellectual and developmental disabilities
- Aging and disability
- Behavioral health
ACL/CMS Vision for Person-Centered Systems

- People know what to expect from process, services, and supports
- People who facilitate planning processes are qualified
- Systems are configured to deliver services and supports in a manner consistent with person-centered values
- People with lived experience drive change at all levels of the system
- 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
NCAPPS Approach

Apply person-centered principles in NCAPPS structure and processes

• Focus is on people in their cultural, social, and environmental contexts
• Listening and a commitment to act on what we hear
• Multiple points of engagement for everyone from the curious to the deeply committed
• Information and resources designed to foster creativity and critical thinking
• Practical application of these principles through technical assistance, and intergroup learning and exploration
What is person-centered thinking, planning, and practice?

**Person-centered thinking**
- A foundational principle requiring consistency in language, values, and actions
- The person and their loved ones are experts in their own lives
- Equal emphasis on quality of life, well-being, and informed choice

**Person-centered planning**
- A methodology that identifies and addresses the preferences and interests for a desired life and the supports (paid and unpaid) to achieve it
- Directed by the person, supported by others selected by the person

**Person-centered practices**
- Alignment of services and systems to ensure the person has access to the full benefits of community living
- Service delivery that facilitates the achievement of the person’s desired outcomes
NCAPPS Goals and Priorities

NCAPPS Goal: Promote systems change that makes person-centered principles not just an aspiration but a reality in the lives of people across the lifespan

Key Priorities:
• Participant and family engagement
• Cultural and linguistic competence
• Cross-system collaboration

...transforming how we think, plan, and practice
NCAPPS COMMUNITY: DIVERSE PERSPECTIVES – DRIVEN BY PARTICIPANT’S VOICE
Person-Centered Advisory and Leadership Group (PAL-Group)

• Majority are people with direct lived experience of navigating HCBS systems
• Building membership now with strong focus on diversity of perspectives, experiences, and backgrounds
• Promotes and actualizes participant engagement in all NCAPPS components and activities
• Meets twice per year with additional ad hoc meetings and communications
• As subject matter experts, members will contribute to webinars, resource development
To be person-centered means to function in a way that creates a culture where staff and providers presume competence, have high expectations and embrace the dignity of risk. Learning to “Let Go” is one thing we must strive for as a system. By doing this it will support people with disabilities to live the DREAM and experience life to the fullest.

NICOLE LEBLANC-PAL Coordinator
I have dedicated the rest of my life in service to the community that raised me, Pueblo Elders notably.

Joseph Ray
Person-Centeredness is more than just a philosophy to me. It is my passion, my mission and compass for my life.

Anntionete Morgan
NCAPPS Leadership Team

**Administration for Community Living (ACL):**
- Shawn Terrell
- Serena Lowe
- Thom Campbell
- Dana Fink
- Joseph Lugo

**Centers for Medicare & Medicaid Services (CMS):**
- Amanda Hill
- Melissa Harris

**Human Services Research Institute (HSRI):**
- Co-Directors - Alixe Bonardi and Bevin Croft
- PAL-Group Coordinator – Nicole LeBlanc
- Project Coordinator – Miso Kwak
- Senior Advisors - David Hughes, Valerie Bradley, Julie Bershadsky
- TA Leads - Yoshi Kardell, Jami Petner-Arrey, Teresita Camacho-Gonsalves
National Organization Partners

- National Association of State Head Injury Administrators (NASHIA)
- National Association of States United for Aging and Disabilities (NASUAD)
- National Association of State Directors of Developmental Disabilities Services (NASDDDS)
- National Association of State Mental Health Program Directors (NASMHPD)
- National Association of County Behavioral Health and Developmental Disabilities Directors (NACBHDD)
- National Association of Medicaid Directors (NAMD)
NCAPPS COMPONENTS
Our Website
ncapps.acl.gov
NCAPPS Webinars

• Delivered by national experts and people with lived experience
• Coordinated and hosted by HSRI
• Free and open to the public
• Topics derived from technical assistance and priorities identified by the PAL-Group
• All webinars have cc in English and Spanish, and are archived on our website ncapps.acl.gov
• Register at https://ncapps.acl.gov/webinars.html

July 2019
(Part One of a Four-Part Series):
Pieces of the Same Puzzle: The Role of Culture in Person-Centered Thinking, Planning, and Practice

August 2019
Considering Brain Injury: Why Being Brain Injury-Informed Is a Critical Component of Person-Centered Thinking, Planning, and Practice

September 2019
Building Person-Centered Practice into the System's Architecture: Strategies for Promoting Other Person-Centered Practices within Existing Agency Workflows
Learning Collaboratives

**Goal**: Promote peer-to-peer learning to accelerate improvement efforts

- Structured group work with support from subject matter experts
- 12-24 months duration, depending on topic and improvement framework
- Membership open to technical assistance recipients and other system stakeholders with expressed interest
Learning Collaborative Topics

• Person-Centered Thinking, Planning, and Practice for People with Brain Injury [FALL 2019]

• Beyond Compliance: Enhancing Person-Centered Thinking, Planning, and Practice in Alignment with the HCBS Final Rule [SPRING 2020]

• Tribal Adaptations to Person-Centered Thinking, Planning, and Practice [FALL 2020]

• In the Driver’s Seat: Realizing the Promise of Self-Direction [TBD]

• Amplifying the Voice of Lived Experience in Human Service Systems [TBD]
Communications

- Central mailing list to share NCAPPS news and resources
- Subscribe by sending an email to NCAPPS@acl.hhs.gov
- Working on developing a social media presence
Technical Assistance Overview

Goal: Support systems change efforts so the participant and family are at the center of thinking, planning, and practice

• Available to up to 15 States, Tribes, or Territories each year
• Up to 100 hours per year for three years
• Delivered by national experts based on a detailed technical assistance plan
Technical Assistance Domains & Examples

• **Practice** – selecting and developing training, setting practice guidelines, culturally and linguistically responsive approaches

• **Policy** – adopting requirements for person-centered planning, issuing policy guidance

• **Payment** – adjusting service parameters and rates, implementing alternative payment models, use of quality measures

• **Participant Engagement** – supporting participants to serve on oversight boards, incorporating feedback into program design, culturally and linguistically responsive engagement
Technical Assistance Expectations

1. Develop **concrete goals and objectives** based on one or more technical assistance domains (**practice, policy, payment, participant engagement**)

2. Create an **evaluation plan** for collecting, analyzing, and reporting whether and how each technical assistance goal will be met

3. Establish **strategies for meaningful participant and family engagement** in the technical assistance process and all systems change efforts
## Selected States and Lead Agencies

<table>
<thead>
<tr>
<th>State</th>
<th>Lead Agency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alabama</td>
<td>Alabama Department of Mental Health (DMH)</td>
</tr>
<tr>
<td>Colorado</td>
<td>Colorado Department of Health Care Policy and Financing (HCPF)</td>
</tr>
<tr>
<td>Connecticut</td>
<td>Connecticut Department of Rehabilitation Services (DORS) State Unit on Aging</td>
</tr>
<tr>
<td>Georgia</td>
<td>Georgia Department of Human Services (DHS) Division of Aging Services (DAS)</td>
</tr>
<tr>
<td>Hawaii</td>
<td>Hawaii Department of Human Services (DHS) Med-QUEST Division</td>
</tr>
<tr>
<td>Idaho</td>
<td>Idaho Department of Health and Welfare, Division of Medicaid</td>
</tr>
<tr>
<td>Kentucky</td>
<td>Kentucky Department for Aging and Independent Living (DAIL)</td>
</tr>
<tr>
<td>Montana</td>
<td>Montana Department of Public Health and Human Services (DPHHS) Senior and Long Term Care</td>
</tr>
<tr>
<td>North Dakota</td>
<td>North Dakota Department of Human Services (DHS)</td>
</tr>
<tr>
<td>Ohio</td>
<td>Ohio Department of Medicaid (ODM)</td>
</tr>
<tr>
<td>Oregon</td>
<td>Oregon Department of Human Services (DHS) Aging and People with Disabilities (APD)</td>
</tr>
<tr>
<td>Pennsylvania</td>
<td>Pennsylvania Department of Aging (DOA) Aging and Disability Resource Office</td>
</tr>
<tr>
<td>Texas</td>
<td>Medicaid and CHIP/ Policy and Program Development/ Texas Health and Human Services</td>
</tr>
<tr>
<td>Utah</td>
<td>Utah Division of Services for People with Disabilities (DSPD)</td>
</tr>
<tr>
<td>Virginia</td>
<td>Virginia Department for Aging and Rehabilitative Services (DARS)</td>
</tr>
</tbody>
</table>
### NCAPPS TA Applicant Populations of Focus

<table>
<thead>
<tr>
<th>Population</th>
<th>Number of Agencies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Older Adults with LTSS Needs</td>
<td>23</td>
</tr>
<tr>
<td>Intellectual and Developmental Disability</td>
<td>22</td>
</tr>
<tr>
<td>Physical Disability</td>
<td>21</td>
</tr>
<tr>
<td>Brain Injury</td>
<td>19</td>
</tr>
<tr>
<td>Behavioral Health</td>
<td>17</td>
</tr>
</tbody>
</table>

Note: Most agencies specified multiple populations of focus
## NCAPPS Applicant Goal Topics

<table>
<thead>
<tr>
<th>Goal Topic</th>
<th>Number With This as an Identified Goal</th>
</tr>
</thead>
<tbody>
<tr>
<td>Staff Training and Competencies</td>
<td>27</td>
</tr>
<tr>
<td>Participant Engagement</td>
<td>22</td>
</tr>
<tr>
<td>Measurement and Quality Improvement</td>
<td>21</td>
</tr>
<tr>
<td>Cross-System Consistency and Planning</td>
<td>17</td>
</tr>
<tr>
<td>Other Practice-Related Goals</td>
<td>10</td>
</tr>
<tr>
<td>Payment and Managed Care</td>
<td>9</td>
</tr>
<tr>
<td>Cultural and Linguistic Responsiveness</td>
<td>7</td>
</tr>
</tbody>
</table>

*Note: Each applicant identified two to four goals*
Kentucky Department for Aging and Independent Living

Shannon Gadd, Commissioner
History

• March 2009 – Universal Plan of Care
  • Single assessment tool across all programs
• March 2010 – Care Coordination
  • Single plan of care across all programs
• March 2014 – Independent Case Management
  • Vision of a single case manager of record
• September 2016 – HCB2 Implementation
  • Blended codes, rate changes
• February 2018 – Waiver Redesign begins
• June 2018 – New Leadership at DAIL
  • Vision of redesigning KY Guardianship
• February 2019 - Applied for NCAPPS
• August 2019 – Here and Now!
## Approximate Number of People with IDD in KY

<table>
<thead>
<tr>
<th>Age</th>
<th>Under 5</th>
<th>5-19</th>
<th>20-64</th>
<th>65</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total KY Population</td>
<td>282,367</td>
<td>863,837</td>
<td>2,614,936</td>
<td>573,227</td>
</tr>
<tr>
<td>(6.5%)</td>
<td>(19.5%)</td>
<td>(60.4%)</td>
<td>(13.3%)</td>
<td></td>
</tr>
<tr>
<td>Persons with IDD</td>
<td>4461</td>
<td>13,648</td>
<td>41,315</td>
<td>9,057</td>
</tr>
<tr>
<td>(1.58%)</td>
<td></td>
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</table>
## Procedure

### Practice Domain
- Develop person-centered thinking and planning training for staff/providers
- Create organizational change strategies for increasing person-centered practice

### Policy Domain
- Issue policy guidance to enhance case management processes to support person-centered planning
- Enhance provider requirements person-centered planning and services

### Participant Engagement Domain
- Meaningfully engage participants with direct lived experience in all facets of the design, refinement, implementation, and evaluation of person-centered thinking, planning, and practice

### Payment Domain
- Implement alternative payment models and strategies to incentivize person-centered organizational change
- Identify strategies for measuring outcomes for person-centered planning
Goal

Establish a foundation, culture, and strategic direction for planned system changes.

• Complete a self-assessment
• Use Charting the LifeCourse (CtLC) for visioning
• Identify strengths and opportunities for improvement
CHARTING the LifeCourse™

Charting the LifeCourse™ and LifeCourseTools.com is a project of the University of Missouri-Kansas City Institute for Human Development, Missouri’s University Center for Excellence in Developmental Disabilities Education, Research and Services (UCEDD).
National Community of Practice for Supporting Families

Project Goal
To build capacity through a community of practice across and within States to create policies, practices and systems to better assist and support families that include a member with I/DD across the lifespan.
What is Charting the LifeCourse??

Guiding Framework
- Guides thinking and problem-solve

Practices
- Specific Area (action, policy, procedure) to enhance or change

Tools
- Educational Resources
  Planning & Problem-solving
  Worksheets
Person and Family Level
Quality of Life Domains

Daily Life and Employment
(school/education, employment, volunteering, routines, life skills)

Community Living
(housing, living options, home adaptations and modifications, community access, transportation)

Social and Spirituality
(friends, relationships, leisure activities, personal networks, faith community)

Healthy Living
(medical, behavioral, nutrition, wellness, affordable care)

Safety and Security
(emergencies, well-being, legal rights and issues, guardianship options and alternatives)

Citizenship and Advocacy
(valued roles, making choices, setting goals, responsibility, leadership, peer support)
What We Have Learned:
Universal Framework for “All”

100%

• Early Childhood
• Children in Foster Care
• High School and College Students
• Aging
• Community Health Workers
• Managed Care Organizations
• Electronic Record Keeping Systems
• Support/Care Coordination
• Informational and Referral
Strategies for Universal Change

- Parent to Parent/Peer Support
- Family, Self-Advocacy & Sibling Networks
- Inclusive education with supports
- Adaptive equipment & Accommodations
- Information and Navigation Supports
- Universally designed and affordable homes
- Grocery carts for older kids
- EMT and Police knowledgeable and supportive
- Strong families and friends to share lives with
- Inclusive, accepting spiritual and recreational opportunities
Comprehensive, Integrated & Coordinated Systems Across Life Domains & Stages

- Pediatrician, Families and Friends, Faith based
- IDEA Part C, Parents as Teachers, Health, Headstart
- School, Special Education, Health, Recreation
- Vocational Rehab, Health, Employment, College, Military
- Disability Services, Health, Housing, College, Careers
- Retirement, Aging System, Health
Life Experiences = Life Outcomes

Experiences at age 5
Experiences at age 13
Experiences at age 80

What We Want
Friends, family, enough money, job I like, home, faith, vacations, health, choice, freedom

What We DON'T Want
DAIL’s Participant Engagement

• Learn from national experts about engaging participants
• Involve stakeholders and participants in ongoing strategic visioning process.
• Share visioning process with participant groups and broadly to build on shared understanding
## Services for Different Age Groups

<table>
<thead>
<tr>
<th>65+</th>
<th>25-64</th>
<th>5-18</th>
<th>Under 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Medicare, Medicaid-- ADRC, Senior</td>
<td>Guardianship (lifespan)</td>
<td>Public school (special Ed)</td>
<td>People 0-5</td>
</tr>
<tr>
<td>Transportation, Senior Citizens, Home</td>
<td>State personal careattendant program (run by AAAs, state, CILS)</td>
<td>Family resources (FRYSKI)</td>
<td>First Steps</td>
</tr>
<tr>
<td>and Community Waiver, Home delivered</td>
<td>Centers for Independent Living</td>
<td>Kentucky SPIN state parent information network (parent information)</td>
<td>Helping Hands (WIC)</td>
</tr>
<tr>
<td>Meals, Homecare Services (housekeeping),</td>
<td>State supported Treatment Providers Waivers</td>
<td>SNAP</td>
<td>Head Start</td>
</tr>
<tr>
<td>Long term ombudsmen (Older Americans</td>
<td>Food Stamps</td>
<td>Medicaid</td>
<td>Head Start</td>
</tr>
<tr>
<td>Act)</td>
<td>Parks and Recreations</td>
<td>Waivers</td>
<td></td>
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<tr>
<td>Hart Supported Living (grants for</td>
<td>Community Health</td>
<td>TBI trust fund</td>
<td></td>
</tr>
<tr>
<td>aging, Mental Health, or DD)</td>
<td>Centers</td>
<td>KY Afterschool Alliance</td>
<td></td>
</tr>
<tr>
<td>TBI Trust Fund, Mental Health and Aging</td>
<td>Community Actions Centers</td>
<td>Medicaid Transportation</td>
<td></td>
</tr>
<tr>
<td>Coalitions, Money follows the Person,</td>
<td>TBI Trust Fund</td>
<td>EPSDT</td>
<td></td>
</tr>
<tr>
<td>Heath and disease prevention, 211,</td>
<td></td>
<td>Impact and Impact +</td>
<td></td>
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<tr>
<td>Guardianship</td>
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Charting the LifeCourse Strategic Planning Trajectory

Going Well:
- Conflict Free Case Management
- Allies in Legislature
- Advocacy Groups: NAMI/BIAK/Counsel
- Final Rule

Vision for Person Centered System
- Trained Personnel - Professional
- Government Leadership - By 1
- Family Education - Advocacy - Amount
- Flexible - Adaptable to Individual Needs
- Conflict Free Case Manager
- Support Group Networks, Sibling
- Mentor Network - Peer Support
- Faith-Based Networks

What We Don’t Want
- Respect All Value Systems

Shortage of Provider
- of Money
- of Direct Support Parents
- of Caring tools given to next generation

Not Going Well:
- Communication between Agencies
- Territorialism - Silo
- Awareness of Possibilities
- Customer Service
<table>
<thead>
<tr>
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<th>Not Going Well</th>
</tr>
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<tr>
<td>• Conflict Free Case Management</td>
<td>• Shortage of providers</td>
</tr>
<tr>
<td>• Allies in Legislation</td>
<td>• Shortage of money</td>
</tr>
<tr>
<td>• Advocacy Groups</td>
<td>• Lack of communication between organizations</td>
</tr>
<tr>
<td>• Final Rule</td>
<td>• Territorial/Silos</td>
</tr>
<tr>
<td></td>
<td>• Lack of awareness of the possibilities</td>
</tr>
<tr>
<td></td>
<td>• Customer Service</td>
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</table>
“LifeCourse trajectory is how guardianship can support the person to take control of their lives”

“Liked hearing ideas, it makes you think differently”

“It’s a process that they can apply to all populations”

“Any group would believe in it and work towards that and thinking about the opportunities that they have instead of waiting for leaders to do it for them”
Next Steps

• Examine what other sister agencies are doing
• Fill in missing quilt squares
• Determine what is our “vision” for Kentucky
  – Trained professionals
  – Government leadership buy-in
  – Family education
  – Flexibility
  – Mentor network/peer support
  – Faith based networks
  – Respect all value systems
www.lifecoursetools.org

- Clear, Defined Path for an Improved User Experience
- Connect with the CtLC Network
- Access Training, Technical Assistance, and Partnership Opportunities
Questions?

Shannon Gadd, Commissioner
shannon.gadd@ky.gov

Marnie Mountjoy, Staff Assistant
marnie.mountjoy@ky.gov

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NCAPPS is funded and led by the Administration for Community Living and the Centers for Medicare & Medicaid Services and is administered by HSRI.

Thank you.
Stay in touch at https://ncapps.acl.gov