TODAY’S PRESENTERS

Shawn Terrell
Administration on Community Living (ACL)/Office of Policy Analysis and Development

Bevin Croft
Co-director
National Center on Advancing Person Centered Practices and Systems (NCAPPS)

Alix Bonardi
Co-director
National Center on Advancing Person Centered Practices and Systems (NCAPPS)
<table>
<thead>
<tr>
<th>Item</th>
<th>Agenda Item</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>01</strong></td>
<td>Person (and Family)-Centered Thinking, Planning, Practice</td>
</tr>
<tr>
<td></td>
<td>A brief overview of principles Person-Centered Thinking LifeCourse Framework</td>
</tr>
<tr>
<td><strong>02</strong></td>
<td>NCAPPS Overview and Components</td>
</tr>
<tr>
<td></td>
<td>Website and Listserv Webinars and Technical Resources Learning Collaboratives Technical Assistance</td>
</tr>
<tr>
<td><strong>03</strong></td>
<td>Thinking through Person (and Family)-Centered Respite supports</td>
</tr>
<tr>
<td></td>
<td>Resources How NCAPPS will be supporting systems to move to a culture of person-centered supports</td>
</tr>
<tr>
<td><strong>04</strong></td>
<td>Questions and discussion.</td>
</tr>
</tbody>
</table>
POLLING QUESTION #1

How person-centered are respite services that you offer?

1) We are VERY person-centered in how respite services are made available and delivered.

2) Almost there … respite is usually person centered, but there are times that resource limitations or policy mean that respite can’t be person-centered.

3) We have a way to go… we are still learning what it means for respite supports to be person-centered.
PERSON(AND FAMILY)-CENTERED THINKING, PLANNING, AND PRACTICE: BRIEFOVERVIEW
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
Person Centered Thinking helps discuss the Person’s Vision for their Good Life as demonstrated by LifeCourse Framework.
Example of Person Centered Planning Results with Life Trajectory Tool
Completed with Person Supported: Robert

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 past, current, and needed experiences that influence the direction of your good life.

Vision for a GOOD Life
- Money, job or own business
- Healthy and fit
- Staying active
- Married (5 kids?!) - Attending concerts
- Vacations to Puerto Rico
- Contribute 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

Adapted from
© 2015 UMKC Institute for Human Development, UCEDD | LIFECOURSETOOLS.COM
Identifying Integrated Strategies for Problem Solving and Exploring Options

- Focuses on Life Domains for our Trajectory
- We all need supports in these domains
- Helps identify supports we already have
- Helps us brainstorm on supports we need and how to get them

©TLCPCP 2016 www.learningcommunity.us
Polling Question #2

What areas of support are most relevant to a person’s experience in respite?

- Personal Strengths and Assets
- Relationship-Based
- Eligibility-Based
- Community-Based
- Technology-Based
- All of them
PERSON CENTERED THINKING
Introducing the Core Concept:

IMPORTANT TO AND IMPORTANT FOR AND THE BALANCE BETWEEN THEM
What is important to a person includes those things in life which help us to be satisfied, content, comforted, fulfilled, and happy.

It includes:

- People to be with /relationships
- Status and control
- Things to do and Places to go
- Rituals or routines
- Rhythm or pace of life
- Things to have
Important FOR

Health:
- Prevention of illness
- Treatment of illness / medical conditions
- Promotion of wellness (e.g.: diet, exercise)

Safety:
- Environment
- Well being ---- physical and emotional
- Free from Fear

What others see as necessary to help the person:
- Be valued
- Be a contributing member of their community

©TLCPCP 2016  www.learningcommunity.us
Health and Safety Dictate Lifestyle
All Choice
No Responsibility
Balance
What People Like and Admire about Ruth

• Such a “grandmother”
• A true lady
• Has the gift of gab—can hold a conversation with anyone!
• Always dressed so nicely—everything always matches, right down to socks and earrings
• Very liberal thinker for her age

Supports Ruth Needs to be Content, Healthy and Safe

• Needs people to ask frequently if she is warm enough and help her put on sweater/sweatshirt if she is not (she'll be cold when you're not)
• Must have assistance with her medications—knows them by color but you need to dole them out and keep track of times
• Needs assistance with bathing and dressing—will tell you what clothes she wants to wear for the day/event
• When bathing, no water on face—she will wash with cloth
• Must talk with daughter 2-3 times a week on the phone—will need you to dial for her
• Must see her doctor right away if she has cough, fever or is “off balance”—indications of systematic infection that will grow quickly!

What is Important to Ruth

• Living with her granddaughter and grandson-in-law
• Being warm and feeling safe with caregivers
• Having a “little pour” before bed (rum and tea)
• Being a part of whatever is going on at home—being in the middle of it!
• Sweets during the day!

People who Support her Best

• Like to chit chat
• Are timely and stay busy
• Polite and mannerly
• Have a witty and dry sense of humor
• Can be reassuring and help Ruth feel safe
Polling Question #3

What might be some challenges to achieve person-centered approaches in planning for respite?

1) Limited time to get to know the person’s personal preferences.

2) Need to prioritize health and safety (important ‘for’).

3) With family involvement, it is hard to know what is ‘person centered’.
NCAPPS OVERVIEW
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 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
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
“Person-centered planning ensures that people with disabilities are able to live the life they want.”

Robyn Powell, MA, JD
Lurie Institute for Disability Policy at The Heller School for Social Policy & Management, Brandeis University
PAL-Group Member
One of our most important rights as human beings and sovereign citizens is the right to pursue our goals, our dreams, our loves and the things that make us happy. This is something that all people want and need. It fulfills us and makes our lives more rich and valuable. Person-centered planning is a thoughtful, research-based and beautiful process which helps provide the foundation for people with disabilities to also experience the joys of a living a self-determined life. The work of NCAPPS is vital as a mechanism for the proliferation of best practices for person-centered planning throughout the nation and to provide people with disabilities, their families, and practitioners with the tools to make this all possible. The work of NCAPPS is some of the most timely and relevant work taking place in the disability community today.”

Kimberly R. Mills, Ph.D., BCBA-D
Senior Executive Director – Virgin Islands University Center for Excellence in Developmental Disabilities (VIUCEDD)
PAL-Group Member
I am passionate about the work of NCAPPS as many in my community (people with disabilities) have felt disempowered regarding decisions concerning their treatment, well-being, and quality of life and have not been given the necessary knowledge to make true informed choices about their care. Collaboration between providers and patients through person-centered planning is vitally important to best achieve a person’s desired outcomes and enhance one’s quality of life.”

Martha Barbone, Certified Peer Specialist
PAL-Group Member
NCAPPS Leadership Team

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

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

Human Services Research Institute (HSRI)
- Alixe Bonardi
- Bevin Croft
- Melissa Burnett
- Teresita Camacho-Gonsalves
- David Hughes
- Valerie Bradley
- Julie Bershadsky
- Yoshi Kardell
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)
Subject Matter Experts

• Georgetown National Center for Cultural Competence
• Support Development Associates
• University of Missouri Kansas City Institute for Human Development
• Independent Living Research Utilization and the National Center for Aging and Disability
• Mission Analytics
• Applied Self Direction

• Collective Insight
• Live & Learn, Inc.
• Lydia X.Z. Brown, JD
• Joe Caldwell, PhD
• Suzanne Crisp
• Dee O’Connor, PhD
• Janis Tondora, PsyD
...and others
NCAPPS COMPONENTS
NCAPPS Resources

Education and Awareness
- published articles and reports
- practical tools and frameworks
- recorded webinars and slides
- validated scales and measures

Technical Assistance and Training

Policy and Research
- person-centered planning resources
- links to partner orgs and related initiatives
- federal guidance on person-centered thinking, planning, and practice

Quality and Service Delivery
NCAPPS Webinars

- Delivered by national experts
- Coordinated and hosted by HSRI
- Free and open to the public
- Topics derived from technical assistance, Learning Collaboratives, and priorities identified by the PAL-Group
Listserv and 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

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

- 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
Learning Collaboratives

• Goal: Promote peer-to-peer learning
• Structured group work
• Topic-specific, for example
  • Expanding expectations of person-centered practices through participant and family engagement
  • Cultural and linguistic considerations
  • Aligning financing to support delivery of person-centered supports
• Membership open to technical assistance recipients and other system stakeholders with expressed interest
NCAPPS AND RESPITE
Discontent is the first necessity of progress.

-Thomas Edison
Discontent is the Engine of Change

- Anything you are happy with you want to stay the same
- You are only interested in change when there is discontent
  - But there are 2 kinds of discontent
    - Cynical
    - Optimistic
  - We have too much cynical and not enough optimistic
Any changes an organization makes to its practices, structure or rules that result in positive differences in the lives of people who use services or in your own work life.

Any changes an organization makes to its practices, structure or rules that result in positive differences in the lives of people.

Any change in practice, structure and rules made at the system level. These changes have an effect on many organizations, and therefore many peoples’ lives.
Person Centered Thinking, Planning, and Practice and Respite

Question to consider:

1. How to engage with and/or facilitate person-centered planning for respite?

2. How to ensure that the respite provider engages with the person according to his/her preferences and interests?

3. How can respite providers can engage in continuous learning and improvement?
How can Respite providers engage to advance person-centered practices?

https://ncapps.acl.gov

- NCAPPS – Resource page (INCLUDE reference to CtLC Respite resources)
- NCAPPS Listserve.
- NCAPPS TA and Learning Communities. If your state is engaged, make sure Respite community is at the table. If your state is not yet engaged, reach out!
- Provide (or develop) resources.
- Engage in an organizational culture change effort – start small, build knowledge and practices.
Thank you.
Stay in touch at https://ncapps.acl.gov

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