Person-Centered Planning and Positive Behavior Support

David A. Rotholz, University of South Carolina
Bevin Croft, Human Services Research Institute
Barbara Brent, National Association of State Directors of Developmental Disabilities Services
Why This Session?

- APBS, as represented by the Board of Directors values the IDD sector

- Board created ex-officio seat with specific focus on IDD and Home and Community Based Supports

- Focus is also on creating linkages with key national organizations with IDD, Community focus
APBS Board Focus on IDD

- I’ve been the first person in this ex-officio role
  - 3 years

- Collaboration is focused on presentations and areas of mutual interest.

- Collaboration has included: NASDDDS, AAIDD, CMS, ACL, multiple UCEDDs, national training expert, model treatment programs and now NCAPPS.
Our Collaborators

- Wonderful to have PCP as a focus of this session (and a few other sessions at the conference as well).

- Pleased to welcome NCAPPS to APBS!

- NASDDDS is a long-time collaborator and partner with APBS. It’s worth noting that NASDDDS has one position statement in their lengthy history as a national organization. It is on Positive Behavior Support as the recommended approach!
Introducing the National Center on Advancing Person Centered Practices and Systems

Bevin Croft, MPP, PhD
NCAPPS Co-Director
THE FOUNDATION: A BRIEF OVERVIEW OF NCAPPS
So... why are we talking about person-centered practices and systems?

Negative perspectives on disability has led to a ‘SYSTEMS focus’:

• Limitations define the person
• Disability supports are ‘services’ that people become eligible for, based on the extent of their ‘impairment’
• Overemphasis on problems
• Supports are driven by the needs of the system (structure, forms, professional rules and boundaries)

Person-centered approaches:

• Recognize person’s unique capabilities and contributions
• Identify strengths and preferences
• Recognize the challenges of disability in planning for a future life and identify supports
• A person-centered system of support builds capacity of each individual based on who they are
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

...transforming how we think, plan, and practice

**Key Priorities:**
- Participant and family engagement
- Cultural and linguistic competence
- Cross-system collaboration
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 approaches include 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 involves learning about a person’s 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
Working toward a vision, expressed by ACL/CMS, for person-centered systems

- **People know what to expect** from planning processes, services, and supports
- Plan facilitators are **well-qualified and well-supported**
- Systems 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** document implementation, experience, and outcomes based on each person’s preferences and goals
- Principles of **continuous learning** are applied throughout the system
Strong Partnerships: NCAPPS Team

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

**Centers for Medicare & Medicaid Services (CMS)**
- Amanda Hill
- Melissa Harris
- George Failla
- Jodie Sumeracki

**Human Services Research Institute (HSRI):**
- Co-Directors - Alixe Bonardi & Bevin Croft
- PAL-Group Coordinator – Nicole LeBlanc
- Project Coordinators – Miso Kwak & Connor Bailey
- Senior Advisors – David Hughes, Valerie Bradley, Julie Bershadsky, Jane Lawrence
- TA Leads
  - Yoshi Kardell
  - Jami Petner-Arrey
  - Teresita Camacho-Gonsalves
  - Alena Vazquez
National Partners & Subject Matter Experts

- National Association of State Head Injury Administrators (NASHIA)
- ADvancing States (formerly 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)
Person-Centered Advisory and Leadership Group (PAL-Group)

- Majority are people with direct lived experience of navigating HCBS systems
- Membership is in place with strong focus on diversity of perspectives, experiences, and backgrounds
- Promotes and produces participant engagement in all NCAPPS components and activities
- Meets twice per year with additional ad hoc meetings and communications
- As subject matter experts, members contribute to webinars, Learning Collaboratives, and 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-Group Coordinator
NCAPPS COMPONENTS
Technical Assistance

Goal: Support systems change efforts so the participant and their loved ones 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
Examples of State NCAPPS TA activities

- Work to **redesign the Transitional Living Program for individuals with brain injury**, ensuring it is person-centered
- Enhance **stakeholder engagement** in systems design and planning activities
- Develop **cross-agency teams** to establish common understanding of person-centered approaches, and align efforts
- Establish **quality metrics** that effectively measure person-centered approaches
- Develop an understanding of training needs and **develop a strategy to train workforce**, options counselors, and others in person-centered thinking, planning, and practice
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<tr>
<th>State</th>
<th>Lead Agency</th>
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<tr>
<td>Alabama</td>
<td>Alabama Department of Mental Health (DMH)</td>
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<td>Colorado</td>
<td>Colorado Department of Health Care Policy and Financing (HCPF)</td>
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<td>Connecticut</td>
<td>Connecticut Department of Aging and Disability Services (ADS)</td>
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<td>Georgia</td>
<td>Georgia Department of Human Services (DHS) Division of Aging Services (DAS)</td>
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<td>Hawaii</td>
<td>Hawaii Department of Human Services (DHS) Med-QUEST Division</td>
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<td>Idaho</td>
<td>Idaho Department of Health and Welfare, Division of Medicaid</td>
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<td>Kentucky</td>
<td>Kentucky Department for Aging and Independent Living (DAIL)</td>
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<td>Montana</td>
<td>Montana Department of Public Health and Human Services (DPHHS) Senior and Long Term Care</td>
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<td>North Dakota</td>
<td>North Dakota Department of Human Services (DHS)</td>
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<td>Ohio</td>
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<td>Oregon</td>
<td>Oregon Department of Human Services (DHS) Aging and People with Disabilities (APD)</td>
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<td>Pennsylvania</td>
<td>Pennsylvania Department of Aging (DOA) Aging and Disability Resource Office</td>
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<td>Texas</td>
<td>Medicaid and CHIP/ Policy and Program Development/ Texas Health and Human Services</td>
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<td>Utah</td>
<td>Utah Division of Services for People with Disabilities (DSPD)</td>
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<td>Virginia</td>
<td>Virginia Department for Aging and Rehabilitative Services (DARS)</td>
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Learning Collaboratives

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

• Structured group work with support from SMEs
• 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 – Currently Underway
• Beyond Compliance: Enhancing Person-Centered Thinking, Planning, and Practice in Alignment with the HCBS Final Rule
• Tribal Adaptations to Person-Centered Thinking, Planning, and Practice
• In the Driver’s Seat: Realizing the Promise of Self-Direction
• Amplifying the Voice of Lived Experience in Human Service Systems
NCAPPS Webinars Overview

- Delivered monthly by national experts, including people with lived experience
- Free and open to the public
- Topics derived from technical assistance and priorities identified by the PAL-Group
- All webinars have closed captioning in English and Spanish
- Slides, recordings, and other resources are archived on the website
- Access past webinars and register for upcoming webinars at https://ncapps.acl.gov/webinars.html
Past and Future NCAPPS Webinars

**July 2019:** 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:** Microboards 101: An Introduction to a Person-Centered Solution Offering Full Accountability, Active Community Support, and Lifelong Continuity of Care

**October 2019:** Cultural Competence: Implications for Person-Centered Thinking, Planning, and Practice

**November 2019:** Trauma-Informed Person-Centered Support

**December 2019:** Finding the Balance: Person-Centered Supports that Honor Safety and Dignity of Risk

**January 2020:** Meaningful Stakeholder Engagement: A Collaborative Approach to Programs for People with Intellectual and Development Disabilities and Their Families

**February 2020:** Building Capacity Using Family-Centered Approaches to Promote the Best Life for Young Children with Disabilities: An Innovative Family-to-Family Program
National Center on Advancing Person-Centered Practices and Systems

Transforming how we think, plan, and practice

Our Website
ncapps.acl.gov
STATE EXAMPLE

NORTH DAKOTA
North Dakota’s Technical Assistance Goals

- Orientation and strategic support for executive leadership
- Stakeholder engagement, with a focus on people who use supports and their loved ones
- Person-Centered Practices Self-Assessment for each agency Division
What’s a self-assessment?

A process for taking a look at how person-centered a system (division, department, agency, program) is

A foundation for an action plan for systems change

A tool to measure progress over time and see if we are getting the systems change outcomes we want
Person-Centered Practice Self-Assessment Domains

1. Leadership
2. Person-Centered Culture
3. Eligibility and Access
4. Person-Centered Service Planning
5. Finance
6. Workforce Capacity and Capability
7. Collaboration and Partnership
8. Quality and Innovation
Thank You.

NCAPPS is funded and led by the Administration for Community Living and the Centers for Medicare & Medicaid Services and is administered by HSRI.
The content and views expressed in this webinar are those of the presenters and do not necessarily reflect that of Centers for Medicare and Medicaid Services (CMS) or the Administration for Community Living (ACL).
Person Centered Planning in the Context of the Family and Community Life
Positive Behavior Support needs to be predicated on the basis that every person has the right to a good life in the community. Through a strong person centered plan (within the context of a person’s family and community) and a strong cultural belief in the good life”, positive behavior supports fit hand and glove.
The National Association of State Directors of Developmental Disabilities Services (NASDDDS) represents the nation's agencies in 50 states and the District of Columbia providing services to children and adults with intellectual and developmental disabilities and their families. NASDDDS promotes visionary leadership, systems innovation, and the development of national policies that support home and community-based services for individuals with disabilities and their families.
First Things First

- Consensus Definition of PBS for State I/DD agencies- through a workgroup composed of state I/DD agency leaders and the expertise of Drs. David Rotholz and Rachel Freeman

- NASDDDS first Position Statement
  - Announcing First Position Statement on the use of Positive Behavior Supports and Rejecting the use of Aversive Interventions

- While important and discussed for years—it was time to take a stand

- Since the time of the Rotholz/Mosely Study more states took formal moves against aversives of any kind. While not allowed, not all had in statute-hard to change, statutory changes take time—but changes moving fast!
Pressures for System Change!

But we can keep moving forward!

Demand for Service

Fee for service

Work Force

Budget

NASDDDS
National Association of State Directors of Developmental Disabilities Services
Where do people with I/DD receiving long term services and supports live?

Nursing Home, Psychiatric, 2%

Family Home, 57%

Has implications and considerations for pcp and pbs
What does it take to accomplish Transformational Change?

Efforts Underway to Build a Sustainable Future

• Supporting Families AND
• Developing Innovative Supports – Relationship based
• Expectations for Employment Outcomes
• Building on Technology
• Focusing on Person Centered Planning
• Investing in Peer Networks

All take understanding of PBS
Integrating Services and Supports-Person Centered Planning & Positive Behavior Supports-Point to the Right!

75%
People with I/DD not receiving formal DD services

25%
People with I/DD receiving formal DD services

100%
People with I/DD receiving integrated services and supports
Discovering WHO

Adapted from The Learning Community for Person Centered Practices and Helen Sanderson Associates

to learn more:
http://helensandersonassociates.co.uk/person-centred-practice/one-page-profiles/one-page-profile-templates/

Charting the LifeCourse Portfolio: Exploring

What Do People Like and Admire About Me?

• List positive strengths, talents and qualities.
• Ask family or others who know you well for input

What Is Important to Me?

• People, places & things important to you.
• Hobbies, possessions, rituals, routines, family culture.
• What do you value most?

What Are The Best Strategies To Support Me?

• Specific kinds of support that are helpful, and what is not.
• Support you need to create the best environment and outcomes in your life.
  • What is your preferred learning style?
  • What keeps you motivated?
  • How are you best encouraged?
Community of Practice for Supporting Families-Conversations for PCP and PBS (UMKC and NASDDDS)
What State I/DD Agencies are Learning: PBS and PCP Implementation Strategies Align With Where People Live and Work and State Context

- PBS and PCP training, partnerships and implementation models are becoming more nimble to support adults in their family’s home, community and at work. Nimble, flexible and how it works for all of us.

- States have unique funding, political, Medicaid structures and history. These impact how PCP and PBS roll out and we need to listen closely.


NASDDDS
National Association of State Directors of Developmental Disabilities Services
Positive Behavior Support Across the States
Pathways Forward

National PBS trends in state I/DD systems:

• States describe PBS implementation as a journey, identifying new opportunities with partnerships, continuous learning and a commitment to change—even, or especially-when times are difficult.

• States have purposeful intent to move systems from deficit-based decisions in policy & practice, such as modifications to behavior focused on prohibited practices and learned replacement skills toward strength and preference-based decisions, plans and actions to improve overall quality of life.

• More services showing up on family and individual peer to peer, consultative supports; not only crisis intervention or structured plans in the absence of a quality person centered plan.

NASDDDS
National Association of State Directors of Developmental Disabilities Services
We Continue to Learn

• There is no one “right” way. Every state has different “cultural considerations” in terms of politics, funding, geography and history

• People work and more day services are moving to the community. Implications?

• Dispersed staff-congregating less in one place

• Not all states choose BCBAs or one specific professional type to provide PBS-no right way and how do we support quality?

• No one way to write and implement a person centered plan-lots of methods, but no one way-how do we support quality?

• We believe in our partners-self advocates, families, providers, UCEDDS
Why it is so hard to be person-centered?

• It is inconvenient
  • It takes time – often more than we think we have
  • People chose priorities that we don’t agree with and after all, we “know best”
  • They might not make our deadlines
  • The person doesn’t want to follow our clinical or therapy protocols
  • People won’t fit within our schedule
  • We can’t use platitudes when we are communicating: we have learned to objectify people so that we can treat them without becoming emotionally exhausted – but we must be authentic.

• It’s hard because every person that interacts with the person must consistently listen, focus on how the person feels. They must be “in the moment.”

• And----families do not turnover
We are Committed to Continue the Effort

NASDDDS is committed to working with all partners to improve the lives of people with disabilities and their families-to listen, and to engage in quality person centered planning and positive behavior support.

Let me layout 70 years of evidence...our relationships with other people matter, and matter more than anything else in the world.”

George Vaillant, MD  Director of the Harvard Grant Study  2009  Positive Psychology News.

Thank you!

Barbara Brent
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www.nasddds.org
Questions FOR YOU

• Please discuss in small group and then we will discuss.

• Choose any/all of the questions to discuss based on your interest

• The 4 questions are on the next slide and in the handout
1. How can state/tribal/territory agencies integrate approaches like PBS into their efforts to achieve more person-centered systems?

2. In your experience, what are the biggest system-level barriers to implementing person-centered practices like Positive Behavior Supports? And what are your recommendations to overcome the barriers?

3. How well did you understand Person-Centered Planning at the start of this session?

4. Have you ever directly participated in a person-centered planning process that included a trained PCP facilitator?
Questions and Discussion