CHANGE HAPPENS AT THE RATE OF TRUST: USING PERSON CENTERED THINKING AND THE LIFECOURSE TOOLBOX TO DEVELOP TRUST AND ACHIEVE CHANGE
AGENDA

• Meet the Panel
• Setting the Stage
• National Leadership
  • NASDDDS
  • ACL
• What the States have: Accomplished, Learned and Next Opportunities
  • District of Columbia
  • Alabama
• Questions and Answers
MEET THE PANEL

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SETTING THE STAGE
WHY THIS PRESENTATION

• The motivation
• Diversity in approach
• Share innovative ideas
• Generate discussion
NATIONAL ROLE
Charting the LifeCourse
Supporting Families & Person Centered Planning- Barb Brent NASDDDS
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.

Project Outcome

• State and national consensus on a national framework and agenda for improving support for families with members with I/DD.
• Enhanced national and state policies, practices, and sustainable systems that result in improved supports to families.
• Enhanced capacity of states to replicate and sustain exemplary practices to support families and systems.
Trajectory towards Good Life

Vision of What I Don’t Want

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

Trajectory towards Life Outcomes

Trajectory towards things unwanted
Trajectory Across Life Transitions

Life Transitions And Disability System Transitions

- Getting New Diagnosis
- Leaving Early Childhood/enter school
- Transition planning
- Turning 18. Leaving school at 18 or 21
- Parents Turn 65 Medicare & SSDI
- Living Adult Life
- My parents have passed away, what do I do?
Trajectory Across Life Experiences

Chores and allowance

Dating & Heartaches

Birthday parties with friends

Learning to say “no”

Scouts, 4H, faith groups

Playing sports or an instrument

Summer jobs, babysitting

Making Mistakes

“Anticipatory Guidance for Life Experiences”
Connected Life Domains-planning

**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)
Family Life Experience Impacts Trajectory

- Biology: Likes, dislikes, skills, abilities
- Policy: Dreams, aspirations, house rules, cultural rules, expectations
- Environment: Neighborhood, socio-economic, education
- Social: Family and friend network, connection with community members

Family Cycle Impacts Member Life Cycle

Family Unit Impacts Individual Level Characteristics

Person Centered Supports
Person within Context of Family
(regardless of where they live or their age)
LifeCourse Integrated Supports STAR-for planning, problem solving and brainstorming

- Technology: i-pad/smart phone apps, remote monitoring, cognitive accessibility, Adaptive equipment
- Relationships: family, friends, neighbors, co-workers, church members, community members
- Community Based: school, businesses, church faith based, parks & rec, public transportation
- Eligibility Specific: SHS services, Special Ed, Medicaid, Voc Rehab, Food Stamps, Section 8
- Personal Strengths & Assets: resources, skills, abilities characteristics

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CT and MO has LifeCourse in ISPs

Learning Opportunities Quality Works, Inc
Initial and Annual Assessment

Consumer Name (first, middle, last name): 

Date of Birth: 

Instructions for use: Parts of this assessment are annual or initial assessment. Share with the adult members of their care team such social position in community. Answers should be recorded in full not when they need it or assessment the services needed a diary. A form used to other names. 

Initial Assessment  Annual Assessment

Contribution to staff or family: 

Community Living

Living Arrangement:
Do you like where you live and who you live with? Are there any modifications I needed to (bike, staff, team, etc)? Do you feel safe when you are at home? 

Transportation and Community Access:
Are there nearby places you like to go and how do you get there? What support do you need if any, to access your community? 

Is there anything you would like to learn how to do as a hobby or a special interest to you?

Social and Spirituality

Communication: 
Who are your family and friends that are most important to you and what do you enjoy doing together?

How do you communicate with your family and friends? (Verbal: Phone, letters, email, communication device) and by text, email, etc. How did you like that you could make more frequent contact?

Alighting for Life Course categories logos and graphics from the Museum Parks to Parks Resource Guide, and can be found at: https://www.museumsttoparks.org/resources
Indiana An Updated PCISP Approach

- LifeCourse Framework
  - Infused Throughout the Process
  - Focus on Holistic Planning
  - Emphasis on Supports Beyond Goods & Services
  - Tools Available to Individual, Family, and Case Manager to Use, As Desired
  - Promote more effective plan implementation through linking between PCP and ISP
  - Address elements of HCBS settings rule
Person-Centered: From Principles to Practice

Shawn Terrell, Administration for Community Living
Person Centered Thinking, Planning, and Practice is the foundation of HCBS
Person-Centered

- **Person-centered thinking** recognizes that people are experts in their own lives, everyone can express their preferences and live a full life in their own community that they and the people who care about them have good reasons to value.

- **Person-centered planning** identifies and addresses the preferences and interests that make up a desired life and the supports (paid and unpaid) needed to achieve it. It is directed by the person and supported by others selected by the person, who are independent of any service/support to be delivered in the plan.

- **Person-centered practice** is the alignment of service resources and systems that give people access to the full benefits of community living and delivers services in a way that facilitates achieving the person’s desired outcomes.
Person-Centered Requirements/Guidance in HHS Programs

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

• People know what to expect
• People who facilitate planning processes are competent
• Systems are configured to 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.
States Expressed Unmet TA Needs

State programs are seeking actionable support for implementing person-centered planning in their systems including:

• Operational definitions
• How to reconfigure systems to support person-centered planning and service delivery
• What training models are available and how to choose one most appropriate for a given state system
• How to structure payment systems to support person-centered planning
• How to select and implement structural, process, and outcome quality measures to effectively evaluate the impact person-centered planning has in state systems
National Center for Advancing Person-Centered Practices and Systems (NCAPPS)

• 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.
Questions to Ask in Developing Person-Centered Systems

• **Person-Centered Planning Facilitators:**
  – Training requirements?
  – Credential or competency demonstration?
  – Are there any specific tools or resources used to implement the process?
  – Is there any research on the approach?
  – Ongoing learning?

• **How are trainers supported?**
  – Train the trainer, private consultants?
Questions to Ask (cont.)

• How do providers know what is expected of them?
  – Clear descriptions of requirements?
  – Review processes?
  – Is there a focus on systems level changes?

• How do consumers know they are getting a qualified facilitator?
  – Consumer education on expectations?
Questions to Ask (cont.)

• How are programs reimbursing for person centered planning?
  – Part of Case Management, peer supports, independent?
  – Conflict of interest standards?
  – How are person centered planning functions differentiated from functional assessments and service authorizations?

• How does the process become a plan?
  – How does the plan introduce people to others?
  – How are goals linked to services and supports?
  – How are unpaid supports woven in to support goals?
Questions to Ask (cont.)

• **How are plans implemented?**
  – Do all providers and the person receive copies and know their responsibilities?

• **How are plans monitored?**
  – Consumer experience measures?
  – Review of goal achievement/progress?
  – IT systems development?
Additional HHS Work Forthcoming

• Review and revise the definition of person-centered practice standards
• Develop a set of core competencies of people performing PCP facilitation
• Develop a framework for PCP measure development
• Develop a research agenda
  – Help validate proposed competencies
  – Suggest areas for development of meaningful quality measures
• Make recommendations for systems characteristics that support PCP
• Develop and finalize an environmental scan of PCP in LTSS systems
Change Occurs at the Rate of Trust:
Person-Centered Planning Tools and LifeCourse Tools

August 30, 2018
District of Columbia

- Person-Centered Thinking
- Supporting Families Community of Practice
- Employment First: EFSLMP, Partners in Employment
- No Wrong Door LTSS Implementation Grant
- National CoP on Cultural & Linguistic Competency
- HCBS Transition Plan
Start with Why

The Golden Circle

Why is a purpose, cause or belief.

It is the very reason we invest in person-centered thinking.

http://www.ted.com/talks/simon_sinek_how_great_leaders_inspire_action
## Milestones of PCT Systems Change

<table>
<thead>
<tr>
<th>Year</th>
<th>Milestones</th>
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| 2012 | • Launched PCT initiative  
• PCT training for all DDA staff  
• * PCT train the trainer  
• * Changed new employee orientation |
| 2013 | • National Supporting Families Community of Practice  
• PCT Phase 2 training  
• * PCT coaching  
• * PCT training for families  
• * Stipend authority |
| 2014 | • Providers become person-centered organizations (PCO)  
• Families and self-advocates become PCT trainers  
• * Launch Family Support Council  
• * No Wrong Door Planning Grant |
| 2015 | • Changes to the waiver and implementing regulations  
• Guided conversations on employment & community integration at ISP  
• * Individualized Daily Schedules  
• * Training on Discovery |
| 2016 | • Launched DC PCT Learning Community  
• Development of PCT Mentor trainers  
• * PCT trainers across LTSS (DD, Medicaid, Behavioral Health & Aging)  
• * Changed Front Door to Developmental Disabilities Administration |
| 2017 | • New waiver and implementing regulations  
• New outcome-oriented ISP  
• * All big day programs become PCOs  
• * CLC CoP  
• * Charting the LifeCourse Ambassador training  
• * DDS becomes PCO |
| 2018 | • Streamlined front door to DDA & VR  
• New Individual & Family Supports waiver  
• * Self-direction amendments  
• * DC PCT Gathering & Celebration  
• * Outcome-oriented 6 month review  
• * Exec team PCT Coaching |
It Takes a Village

From individual to system change

Level 1 changes
- Change what we can change
- Team level
- Working Not Working
- Implementing Person Centred Practices

Level 2 changes
- Change what we can change
- Organisational level
- Working Not Working
- What we can change

Level 3 changes
- Change what we can change
- System level
- Working Not Working
- What we can’t change
PCT Training for Staff

Becoming a Person Centered Organization:

The Department on Disability Services,
The Developmental Disability Administration
We are Peer Trainers for People Planning Together.
Engaging Families
Providers Become PCOs

- Providers become person-centered organizations
Person-Centered Counseling, as articulated by ACL for a NWD system, includes the following functions:

- Confirm the need for/interest in person-centered counseling
- Support any immediate LTSS needs, conduct personal interview, and identify strengths and preferences
- Conduct comprehensive review of private resources, informal caregiver supports and screening for public programs
- Facilitate the development and implementation of the person-centered plan
DDS Executive Team Coaching
DC’s PCT Learning Community

Training

Person-Centered Counseling Training
People Planning Together Training
Families Planning Together Training

Learning

Professionals
People enrolled in LTSS and Families

Adapting

Service Delivery

Single-Loop Learning
The most common style of learning is just problem solving—improving the system as it exists.

Assumptions
Why We Do What We Do

Strategies and Techniques
What We Do

Results
What We Get

Double-Loop Learning
More than just fixing the problem, this style of learning questions the underlying assumptions, values and beliefs behind what we do.
Vision for a Person Centered LifeCourse System

What we don’t want

• When seeking services or supports, having to make multiple phone calls before we reach someone who can help, speaking with people who are annoyed with us for not understanding the "system," and having to share details about what we CAN’T do over and over again.
• Isolation from our communities and loneliness.
• Not having financial means to do things that make us happy.
• Services that create barriers between us and our families because professionals think they know best.

Obstacles

- Fiscal impact
- Bill stalls at Council
- Trust deficit
- Resistance to change
- Culture of compliance

Trajectory Worksheet: The Service System
Person and Family Centered Support Through the LifeCourse

Create through legislative a Family Support Council to advise govt’ agencies

Families and self-advocates at the table with govt’ & executive leadership embedded at SF CoP meetings

PCT & LifeCourse in waiver service definitions, regulations, monitoring & provider certification

Supported Decision-Making bill

Reframing the front door to DD agency and LTSS (NWD)

Legislative authority for an IFS waiver

Legislative authority for stipends for people with I/DD & families

PCT & LifeCourse become part of ISP format and process

DC Level 3 Changes
Changing the Front Door

• Person-Centered Planning starting at intake
  – *Like and Admire* to determine strengths
  – *Working/ Not Working* to identify LTSS needs
  – *Trajectory* to identify goals
  – *Integrated Supports Star* to match to supports
  – Start eligibility for public LTSS, only if needed
• Aligns with Initial ISP at DDA
• Guided conversation on employment leads to streamlined intake for Vocational Rehabilitation
PCT & LifeCourse in Planning

- 5 Required PCT Tools
  - Pre-populate from: PCT Tools section of MDCS
  - Timelines: Completed at ISP Meeting and Committed after meeting

What People Like and Admire about me

Reflects the person’s strengths

Communication: (What is the best way to communicate with me)

What is Important to me AND What is important for me

Reflects the person’s preferences

For a good match: Characteristics of the people who support me best

PERSONAL STRENGTHS & ASSETS
- Life experiences, personal resources, personality, skills, hobbies, special needs, education and learning

TECHNOLOGY
- Assistive devices

RELATIONSHIPS
- Family, friends, neighbors, businesses, community members, church members

COMMUNITY BASED
- School, recreation, transportation, businesses, churches, parks & recreation

INTEGRATED SUPPORTS

ELIGIBILITY SPECIFIC
- Developmental disability services, special education, Medicaid, Special Status, Services to People with Vocational Rehabilitation

DISTRICT OF COLUMBIA
DEPARTMENT OF DISABILITY SERVICES
PCT & LifeCourse in HCBS waiver

- Waiver renewal in November 2017
- Weekly open meetings with stakeholders
- New Services:
  - Significant limits to congregate day services – but allow facilities to remain as “launch and landing pads”
  - Peer to peer support for families (individual and small group)
  - Parenting Supports (peers and professionals; individual & small group)
  - Flexible Assistive Technology service
- Currently working on an amendment for self-direction + new Individual and Family Support waiver
Disability Services Reform Amendment Act

• Puts decision-making back in the hands of people with disabilities and their families by:
  – Formally recognizing Supported Decision-Making
  – Ending involuntary civil commitment of people with I/DD
ALABAMA
QUESTIONS???

Presenter contact info on Slide 3 and Bios on next slide
• Cathy Anderson—Cathy has more than 30 years of experience (government and consulting). She has held leadership roles in state agencies supporting people with intellectual and developmental disabilities and was responsible for the organization and management of statewide service systems. She is the former director of services for people with intellectual and developmental disabilities in Nebraska, Iowa, and the District of Columbia, and she also served as the Medicaid Director in Iowa. She is a past President of NASDDDS Board of Directors. Ms. Anderson has extensive experience in designing, visioning, revising and monitoring waiver programs both as a state employee and as a consultant. She initiated the District of Columbia’s Developmental Disabilities Administration’s work to become a Person-Centered Organization (PCO) and the administrations participation the Supporting Families Community of Practice work. She has provided training for states on the LifeCourse Took Kit and the compatibility with person-centered practice. She is also a key lead on PCG’s Person Centered Organization efforts.

• Barbara Brent—Barbara Brent, M.S., is the Director of State Policy for NASDDDS and the Co-Director of the CoP for Supporting Families Across the Lifespan. Barbara has more than 34 years of experience in publicly funded systems for children and adults with disabilities. She has worked in state and county government, as well as in the private sector in a variety of roles. Barbara served as the state director for the Arizona Division of Developmental Disabilities Services, overseeing the state’s acute/medical and long-term service and supports through a unique managed care system. Barbara was also the state I/DD director in Tennessee. Her primary areas of expertise are Medicaid, positive behavior support, supporting families, quality improvement, employment, autism and stakeholder engagement.

• Karen Coffey—Karen Coffey began her career in the field of Rehabilitation in 1994 as a Vocational Evaluator at the Opportunity Center Rehabilitation Facility. She has also worked as an Independent Living Specialist for the Alabama Department of Rehabilitation Services in Anniston, Alabama. Following this position, she took a position of Vocational Rehabilitation Counselor for the State of Alabama Independent Living (SAIL) Waiver and Homebound programs. In 2002, Ms. Coffey went to work in the SAIL state office in Montgomery as a Rehabilitation Specialist I. From 2006 to 2015 she was the SAIL Coordinator. She then took her current position of Director of System Management at the Alabama Department of Mental Health. Her primary responsibilities with ADMH/DDS are ensuring that the waivers are written and submitted to CMS routinely and as waiver amendments are done she provides oversight to the ADIDIS billing system. Other duties include assisting the Employment Coordinator in employment initiatives and serving as the Department’s facilitator for the Community of Practice; Supporting Families for the Lifetime. Ms. Coffey collaborates with the Alabama Medicaid Agency, the Alabama Departments of Senior Services, Public Health, the Governor’s Office on various projects and committees, and with various provider and state agencies throughout Alabama. Her home is originally Piedmont, Alabama where she still has family and friends.

• Erin Leveton—Erin is the Program Manager of the State Office of Policy, Planning & Innovation at the D.C. Department on Disability Services, working to achieve best practice in areas such as Supporting Families, Person Centered Thinking, Employment First, Community Life Engagement and Supported Decision-Making. Erin is D.C.’s Project Director for several federal grants to create systems change: No Wrong Door, Partners in Employment, and the National Community of Practice on Cultural and Linguistic Competence. Erin has nearly 30 years of experience working with people with disabilities, including more than 25 years doing legal services and policy work. Erin graduated with honors from George Washington University Law School; and magna cum laude, Phi Beta Kappa, from Binghamton University. Erin is a graduate of the National Leadership Institute on Developmental Disabilities and has been recognized by Georgetown University, Human Rights Action - Amnesty International as Outstanding Human Rights Practitioner for her work on behalf of people with disabilities in the Washington DC metropolitan area.

• Shawn Terrell—Shawn has been working in the long term services and supports (LTSS) arena for 18 years. Currently he is a Health Insurance Specialist at the Administration for Community Living, where his primary focus is on developing person-centered planning capacity and quality measurement and improvement in home and community based services (HCBS) systems. Shawn is engaged in a number of policy development and implementation activities including: behavioral health recovery, self-directed HCBS, managed LTSS, LTSS access, and Medicaid financing. He holds a Master’s Degree in Medical Anthropology/Health Services Administration and a Master’s Degree in Social Work.
THANK YOU!