# **Next Steps for the CoP**

Year 4 and 5

There is now a push to a Waiver
But please can you do us a favor?
Don't make a new form
Make "simple" the norm
And then we can sit back and savor.

Judy Berry William

Every family can run into trouble
But they never need live in a bubble
Just reach out your hand
To the folks in the land
Together, our efforts will double
– Laura Serinsky, Chicago, IL

Medicaid has many a rule.

Its funding is in a big pool.

With the economy slowing

And life expectancy growing

Think of it as a community tool.

- Sharon St. Aubin, Minot, ND

The waiting list's gone thru the sky
And the flexible funds have run dry
Court community now
Milk the Medicaid cow
Says Agosta of HSRI
– Susan Yuan, Burlington, VT

Should the money go here or should it go there? To this family or that family? Families everywhere? For 1 services, 2 services, 3 services, MORE? Oh, dividing up family support money's a chore. Please tell me the answer. Don't walk out that door!

Should we use a voucher a contract, a waiver? Please tell me the answer your wisdom I savor. Please do me just this one little favor. Tell me, is there enough money to meet every need? Perhaps not enough money, but resources? INDEED!

If we all work together,
that's our motto our creed.
We'll build our communities,
support families and each other.
Working alongside our sisters and brothers.
We'll achieve the vision.
It's so simple, yet true:
If we support families,
they'll support others too!

Patti Killingsworth, Jefferson City, MO



# Defining Supports to Families

**GOAL** 



#### Individual

Will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life

#### Families

Will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support the individual to achieve their goal



Recognizing that individuals exist within a family system

# DISCOVERY AND NAVIGATION

Knowledge & Skills

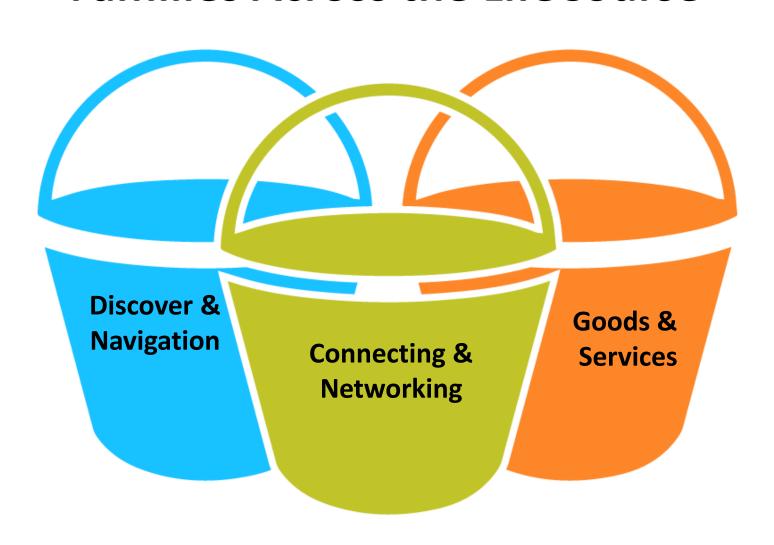
## CONNECTING & NETWEORKING

Mental Health & Self-Efficacy

## GOODS & SERVICES

Day-to-Day & Caregiving/Supports

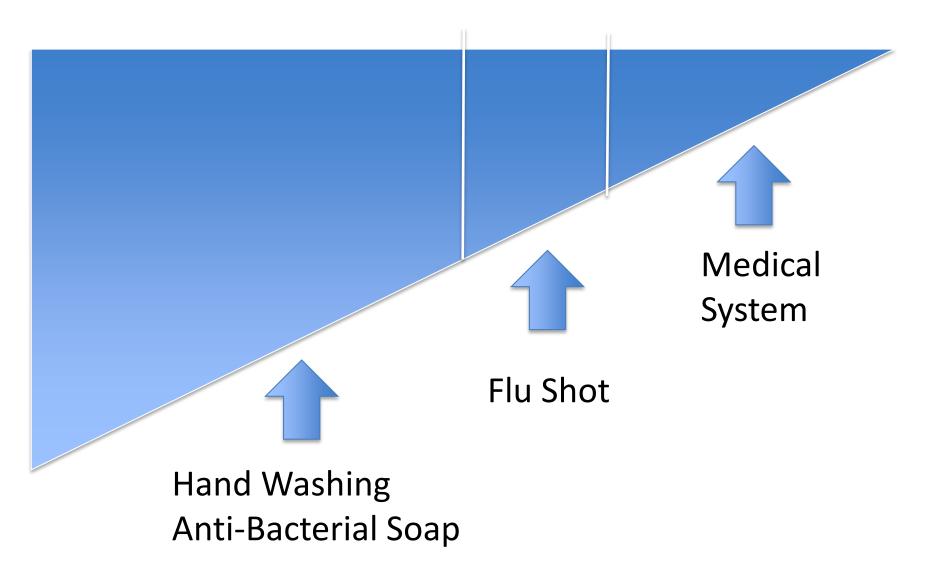
# Mapping Strategies for Supporting Families Across the LifeCourse



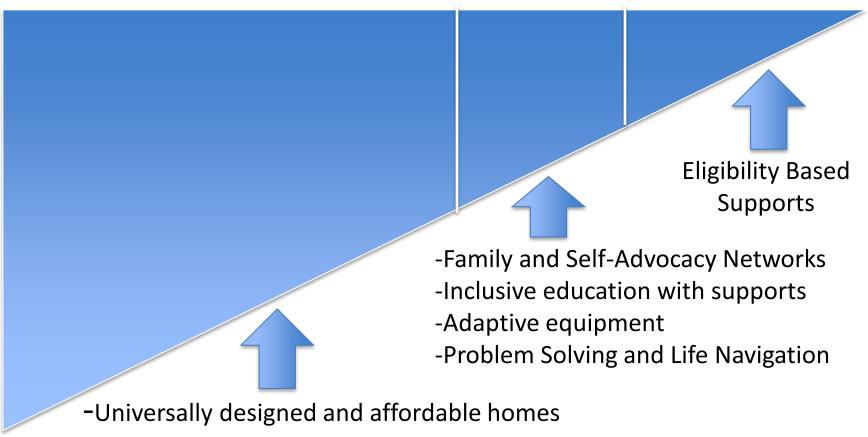
# Goods and Service Bucket: focused on Family and Caregivers

- Respite (ARCH National Respite Network)
- Training on Health and Wellness
- "Aging in Place" Aging Planning for the Future
- Paid Family Caregivers
- Partnering with Providers
- 55
- 55

## **ALL: Public Health Framework**



# Constructing Universal Strategies for Supporting Families Across the LifeCourse



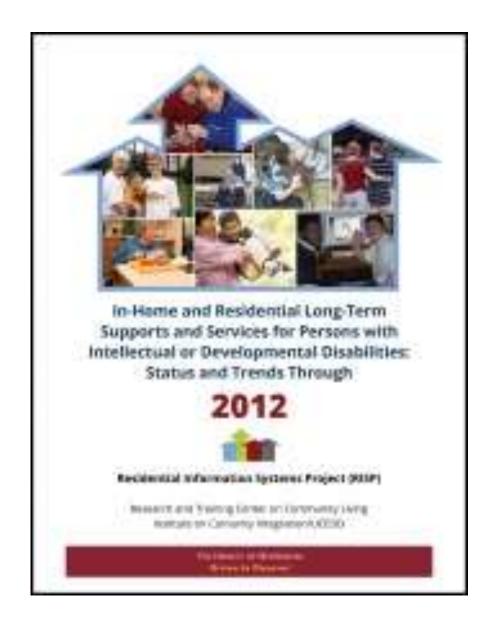
- -Grocery carts for older kids
- -EMT and Police knowledgeable and supportive
- -Strong families and friends to share lives with
- -Inclusive and accepting spiritual and recreational opportunities

# National and State Initiatives to Consider in Your Work to Support Families

#### **CMS HCBS Rules**

- Settings Rule
- Person Centered Rule

# Individual and Family Information Systems Project



## **National Core Indicators**

Draft:

Survey Focusing on "Family"

How can your state use this data to look at the outcomes of some of your work on Supporting Families?

# **National Family Support RRTC**

#### **Call for Promising Practices in Family Support**

Do you know of a successful local, state, or national program that supports family caregivers of individuals with disabilities and/or seniors? If so, tell us about it. The Family Support Research and Training Center is doing a national search to identify promising practices and programs. We will share what we learn with aging and disability advocates across the

country. <a href="https://www.surveymonkey.com/s/FamilySupp">https://www.surveymonkey.com/s/FamilySupp</a>
<a href="https://www.surveymonkey.com/s/FamilySupp">ortRRTC</a>

# CoP Partnering with ADRC/NWD

# Purpose for ADRC/No Wrong Door System

 To have Aging and Disability Resource Points of Entry serving Oklahomans as highly visible and trusted entities where Oklahomans of all incomes and ages can get information on the full range of long term support options and provides "No Wrong Door" access to public long term support programs and benefits.

# ADRC/NWD

- Public Outreach and Coordination with Key Referral Sources
- Person Centered Counseling
- Streamlined Access to Public LTSS Programs and
- State Governance and Administration

#### **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 than 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.







OK

TN



# **Specific Innovations**

- Information, Planning, and Navigational Supports
  - At all stages of life and across systems
  - Specific to LTSS DD Support Coordination and Person Centered Planning process
- Connecting Families to Peer Support
- Focusing on the Front Door of LTSS
- HCBS Waiver Services
- Goods and Services Specific to Families and Caregivers: Respite and Health & Wellness Supports

#### **Partners**

#### **No Wrong Door Focus Staff**

- AAA Options Counselors, Waiver Case Managers, Care Transitions Coaches
- Medicaid Agency Nurses Performing Functional Assessments; Transition Specialists; Waiver Case Managers
- CIL Independent Skills Specialists, Peer Counselors; MFP Transition Coordinators
- Community Action Agency Community Health Workers
- DD Agency Case Managers, Integrated Employment Counselors
- VAMC Benefits Counselors
- Nursing Facility/Hospitals Discharge Planners
- Community Mental Health Center Counselors, peer support specialists, Access center workers

#### **CoP on Supporting Families**

- DD agency
- UCEDD
- DD Council
- Family Networks
- Education
- And more, more...

# Who is in the occupation of Supporting Families?

# Person Centered Counseling Options Counseling

- PCC/OC is an important occupation that plays a key role in the No Wrong Door and ADRC systems.
- PCC/OC is the process of providing support to people with disabilities, including people with intellectual and developmental disabilities, and older adults in need of long-term services and support (LTSS) so they can get the right services at the right time in the right place.
- 24 million may need PCC each year; to meet demand, need ~51,000 FTE providing PCC in USA.

#### **LifeCourse Conversations**

- DD Support Coordinators
- Person Centered and Options Counselors
- Family Navigators
- Special Education Teachers
- Early Childhood Coordinators
- VR Counselors
- Etc.

# Target Focus: People with Disability 1 in 5 Americans with Disability

**9.4 million individuals** have difficulties with activities of daily living (eating, bathing, dressing)

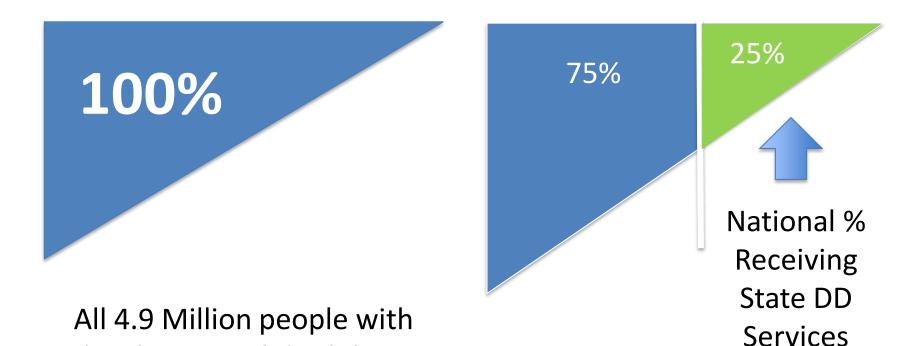
5 million required assistance

**15.5 million individuals** have difficulties with instrumental activities of daily living (housework, phone, meal preparation)

12 million required assistance

(Americans with Disabilities 2010, U.S. Census Bureau)

# Focusing on Person with Intellectual and Developmental Disabilities



developmental disabilities

<sup>\*\*</sup> Based on national definition of developmental disability with a prevalence rate of 1.49%

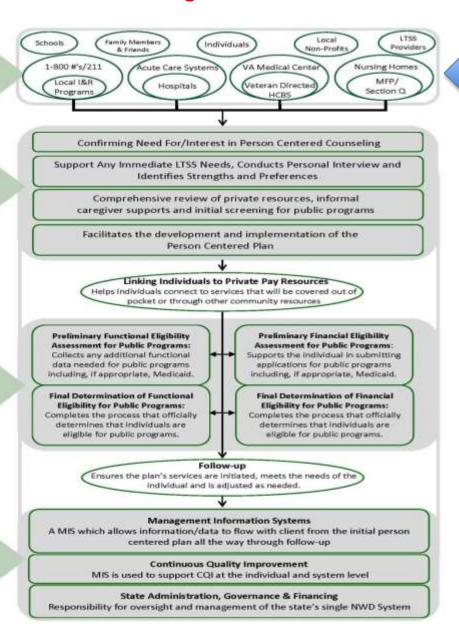
#### WHERE OUR WORK OVERLAPS

Sources of Referral to Person Centered Counseling

Person Centered Counseling

Streamlined Access to Public Programs

Administration of the NWD System



## Additional Sources of Referral

- State DD Agencies
- Vocational Rehabilitation
- Medical Homes or Health Homes, including Pediatric Offices
- Early Childhood Programs
- Schools and Colleges
- Family and Self-Advocacy
   Networks

Individuals with DD and their Families may have LIFE LONG Long Term Service Needs...

LTSS Family Members Schools Individuals Non-Profits Providers & Friends Sources of Referral 1-800 #'s/211 VA Medical Center Nursing Homes Acute Care Systems to Person Centered Local (&R MFP/ Veteran Directe Counseling Hospitals Section Q Programs Confirming Need For/Interest in Person Centered Counseling Support Any Immediate LTSS Needs, Conducts Personal Interview and Identifies Strengths and Preferences Person Centered Counseling Comprehensive review of private resources, informal caregiver supports and initial screening for public programs Facilitates the development and implementation of the Person Centered Plan Linking Individuals to Private Pay Resources Helps individuals connect to services that will be covered out of pocket or through other community resources **Preliminary Financial Eligibility Preliminary Functional Eligibility** Assessment for Public Programs: Assessment for Public Programs: Supports the individual in submitting Collects any additional functional data needed for public programs applications for public programs including, If appropriate, Medicaid. including, if appropriate, Medicald. Streamlined Access to Public Programs Final Determination of Functional Final Determination of Financial Eligibility for Public Programs: **Eligibility for Public Programs:** Completes the process that officially Completes the process that officially determines that individuals are determines that individuals are eligible for public programs. eligible for public programs. Follow-up Ensures the plan's services are initiated, meets the needs of the individual and is adjusted as needed. Management Information Systems A MIS which allows information/data to flow with client from the initial person centered plan all the way through follow-up Administration of Continuous Quality Improvement the NWD System MIS is used to support CQI at the individual and system level State Administration, Governance & Financing Responsibility for oversight and management of the state's single NWD System

Focus of
CoP Supports to
Families and
DD System:

- Support Coordination
- Person Centered
   Thinking, Planning,
   and Facilitation
- Family Navigation
- LifeCourse
   Framework and Tools
- Responding to new CMS HCBS rule
- Eligibility determination

Developmental Disability Field has been evolving from an institutional based to system to a person centered system for many years

LTSS Schools Family Members Individuals Non-Profits Providers & Friends Sources of Referral 1-800 #'s/211 VA Medical Center Acute Care Systems Nursing Homes to Person Centered Local (&R MFP/ Veteran Directe Counseling Hospitals Section Q Programs **HCBS** Confirming Need For/Interest in Person Centered Counseling Support Any Immediate LTSS Needs, Conducts Personal Interview and Identifies Strengths and Preferences Person Centered Counseling Comprehensive review of private resources, informal caregiver supports and initial screening for public programs Facilitates the development and implementation of the Person Centered Plan Linking Individuals to Private Pay Resources Helps individuals connect to services that will be covered out of pocket or through other community resources **Preliminary Financial Eligibility Preliminary Functional Eligibility** Assessment for Public Programs: Assessment for Public Programs: Collects any additional functional Supports the individual in submitting data needed for public programs applications for public programs including, if appropriate, Medicaid. including, if appropriate, Medicald. Streamlined Access to Public Programs Final Determination of Functional Final Determination of Financial Eligibility for Public Programs: **Eligibility for Public Programs:** Completes the process that officially Completes the process that officially determines that individuals are determines that individuals are eligible for public programs. eligible for public programs. Follow-up Ensures the plan's services are initiated, meets the needs of the individual and is adjusted as needed. Management Information Systems A MIS which allows information/data to flow with client from the initial person centered plan all the way through follow-up Administration of Continuous Quality Improvement the NWD System MIS is used to support CQI at the individual and system level

State Administration, Governance & Financing

Responsibility for oversight and management of the state's single NWD System

LifeCourse Tools focusing on Adapting, Accommodating and Integrating Supports:

- Own Strengths,
   Assets and Resources
- Technology
- Relationships
- Community
   Resources
- Eligibility Specific Services and Supports

Planning may require identifying, developing and adapting supports beyond private and public supports

centered plan all the way through follow-up

Continuous Quality Improvement

MIS is used to support CQI at the individual and system level

State Administration, Governance & Financing

Responsibility for oversight and management of the state's single NWD System

LTSS Family Members Schools Individuals & Friends Non-Profits Providers Sources of Referral 1-800 #'s/211 VA Medical Center Nursing Homes Acute Care Systems to Person Centered Local (&R MFP/ Veteran Directe Counseling Hospitals Section Q Programs Confirming Need For/Interest in Person Centered Counseling Support Any Immediate LTSS Needs, Conducts Personal Interview and Identifies Strengths and Preferences Person Centered Counseling Comprehensive review of private resources, informal caregiver supports and initial screening for public programs Facilitates the development and implementation of the Person Centered Plan Linking Individuals to Private Pay Resources Helps individuals connect to services that will be covered out of pocket or through other community resources **Preliminary Financial Eligi Preliminary Functional Eligibility** Assessment for Public Programs: Assessment for Public Pr Supports the individual Collects any additional functional data needed for public programs applications for put including, if appropriate, Medicaid. including, if appro Streamlined Access to Public Programs Final Dete of Financial **Final Determination of Functional** Eligibil Eligibility for Public Programs: ic Programs: Completes the process that officially ocess that officially determines that individuals are hat individuals are public programs. eligible for public programs. Follow-up Ensures the plan's services are initiated, meets the needs of the individual and is adjusted as needed. Management Information Systems A MIS which allows information/data to flow with client from the initial person

LifeCourse Tools focusing on Life Outcomes that include LTSS:

- Vision for Good Life
- Trajectory of Life Experiences
- Specific Vision for Life Domains
- One Page Profile
- Life Possibilities
- Life Experiences

Person with DD and families:

- Don't always know what they don't know
- May lack a vision for future
- Taught system only responses
- Only know traditional supports
- Tired and scared

Administration of the NWD System

# Ways to Work Together

- Utilize each others strengths and knowledge, such as Cross Training
- Focus on Integrating with DD systems initiatives, such as
  - Front Door of All Systems and connect to work of CoP
- Work on strategies together that balance the role and impact on family and with persons selfdetermination and needs
- Start early, pro-active supports not when they call in crisis

#### **ACL CoP** Pilot:

Using Integrated **Supports Star** to Guide Conversations around Comprehensive Review of Resources and teach about Linking with Resources

#### **Person Centered Counseling Competencies**

Confirms Need For/Interest in Person Centered Counseling

Support Any Immediate LTSS Needs, Conducts Personal Interview and Identifies Strengths and Preferences

Conducts comprehensive review of private resources, informal caregiver supports and screening for Public Programs

Facilitates the development and implementation of the Person Centered Plan

#### **Specialties**

Facilitates Transitions: Hospital Based Transition, Institutional Transition & Youth Transition, etc.

Serves Unique Populations: Individuals with Physical Disabilities, Seniors, Individuals with Intellectual/Developmental Disabilities or Alzheimer's Disease/Dementia, etc.

#### Links Individuals to Private Pay Resources

Helps individuals connect to services that will be covered out of pocket or through other community resources

#### Assists Individuals in Applying for LTSS Public Programs

Uses information from the person centered plan and any additional information as needed to help individuals apply for LTSS public program(s) relevant to person centered plan and helps individuals navigate through the entire eligibility process.

**Preliminary Functional Eligibility Assessment for Public Programs** 

Final Determination of Functional Eligibility for Public **Programs** 

**Preliminary Financial Eligibility** Assessment for Public Programs

Final Determination of Financial Eligibility for Public **Programs** 

#### Follow-up

Ensures services are activated, are meeting the needs of the individual and adjusted as necessary

Core Training: Required of all Person-Centered Counselors

Specialties: Duties to be performed by subsets of Counselors with specialized knowledge and experience

Duties that can be assigned to Person-Centered Counselors

at the discretion of the State

**ACL CoP** Pilot:

**Develop Cross-**Training Curriculum on Developmental Disability, Specifically focusing on Family and Transitioning to Adulthood

"People with I/DD often need help envisioning or finding a good life- whereas someone who is aging is trying to maintain their good life"

# MCH Home Visiting Programs funded by HRSA and ACF

Developmental Delay: Less than 50 percent of young children with developmental or behavioral disabilities are identified before they start school. Early identification has been shown to improve the developmental trajectories of children with such delays or a developmental disability. In 2014, 14 grantees (AL, AZ, CA, CO, CT, ID, IL, KS, LA, MS, ND, NE, NM, TN) reported screening rates of at least 75 percent, more than twice the national average of 31 percent in 2011-2012.

- **New Mexico**: At six months after enrollment or birth, 90 percent of children in the Home Visiting Program were screened for developmental delay. In comparison, the state-wide screening rate among children aged 10 months to five years in 2011-2012 was 38 percent.v
- Illinois: 87 percent of enrolled children aged 12 months were screened for developmental delay. In 2011-2012, the state-wide screening rate among children aged 10 months to five years was 34 percent.v
- Alabama: 83 percent of enrolled children were screened for developmental delay within six months of enrollment. The state-wide screening rate was 25 percent in 2011-2012.v

## **Education**

- Part C Early Childhood (Family Centered Plans and required transition plans)
- State Performance Indicators, especially Indicator 13
- Parent Training Information Centers

#### **IDEA Performance Indicator 13**

"Percent of youth with IEPs aged 16 and above with an IEP that includes appropriate measurable postsecondary goals that are annually updated and based upon an age appropriate transition assessment, transition services, including courses of study, that will reasonably enable the student to meet those postsecondary goals, and annual IEP goals related to the student's transition services needs. There also must be evidence that the student was invited to the IEP Team meeting where transition services are to be discussed and evidence that, if appropriate, a representative of any participating agency was invited to the IEP Team meeting with the prior consent of the parent or student who has reached the age of majority." (20 U.S.C. 1416(a)(3)(B))

Next steps.....

# WHAT ARE YOU GOING TO DO IN YOUR STATE??

# Discussion: Team Next Steps

What is your state going to go back and talk about and do differently based on what you heard over the last three days?

Your "a-ha" you are going to take action on.

Turn this into us.

## **Back in Your State: Team Work**

- Identify an "innovation" that you are working on and go through the "System Drivers" Activity and fill it out.....we will send everyone notes from your presentation.
- Continue to identify and share what you want to know from other states.....so we can use this on our calls or webinars.
- Talk about specific technical assistance you might want in year 4.