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

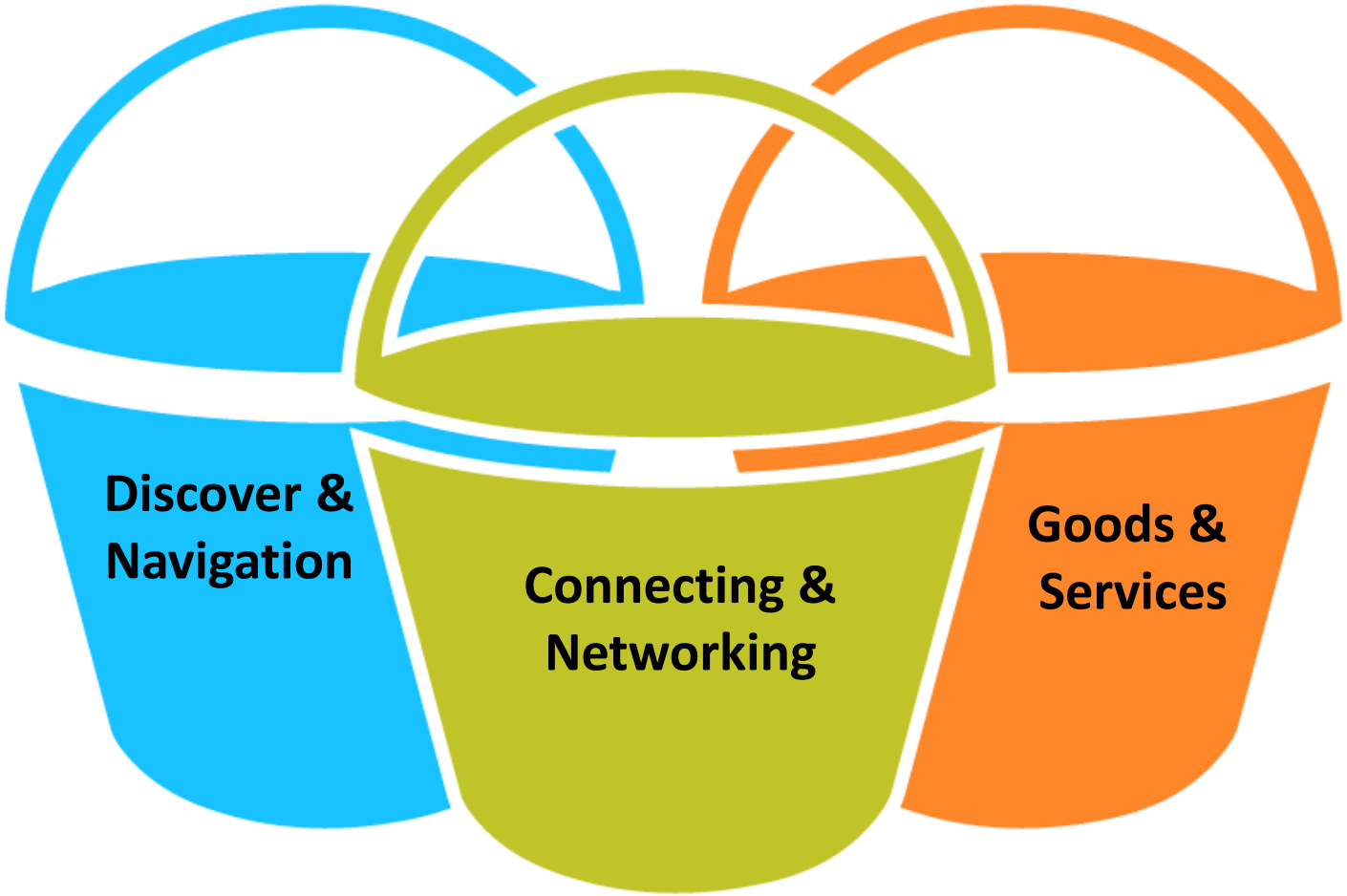
Individual
Will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life

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	CONNECTING & NETWEORKING	GOODS & SERVICES
Knowledge & Skills	Mental Health & Self-Efficacy	Day-to-Day & Caregiving/Supports

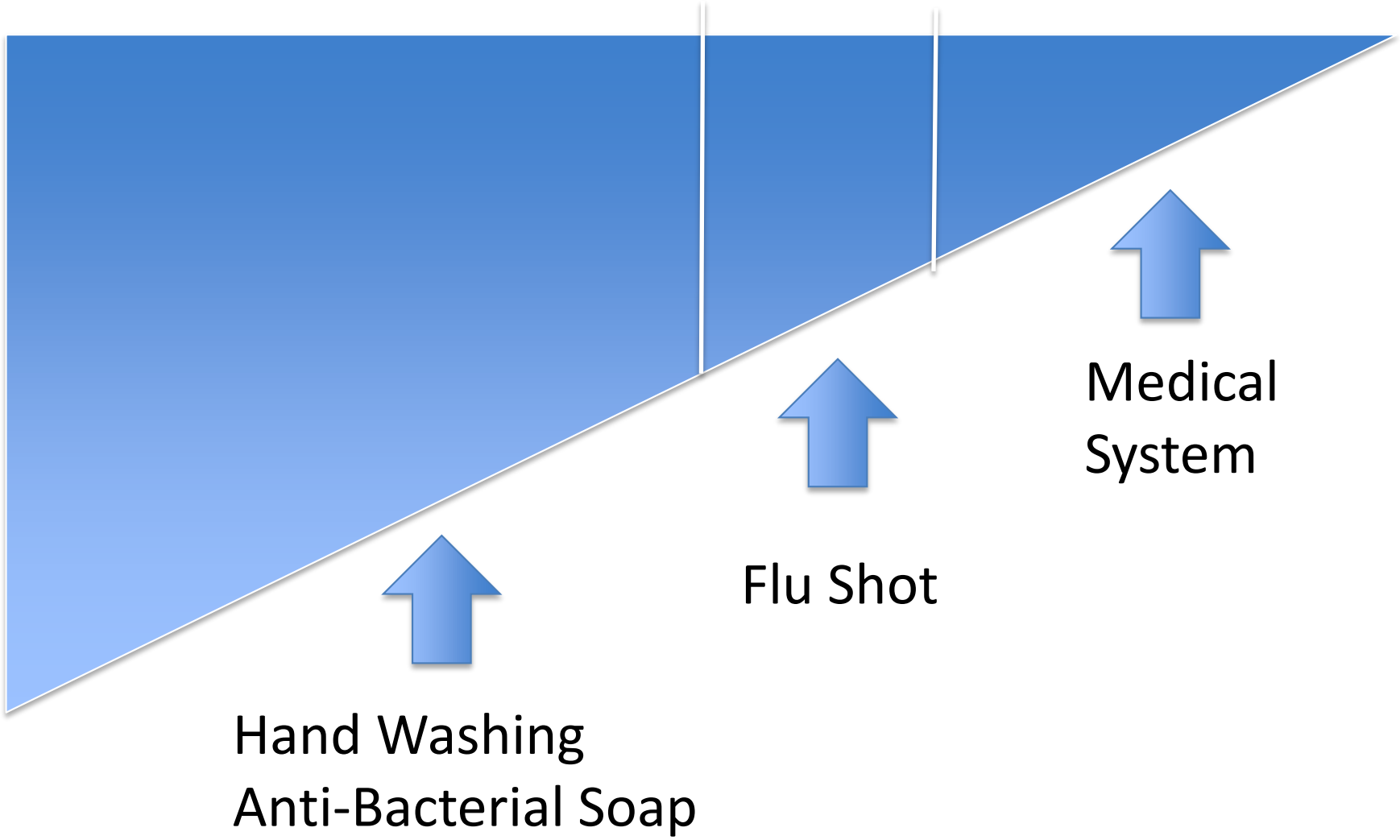
Mapping Strategies for Supporting Families Across the LifeCourse



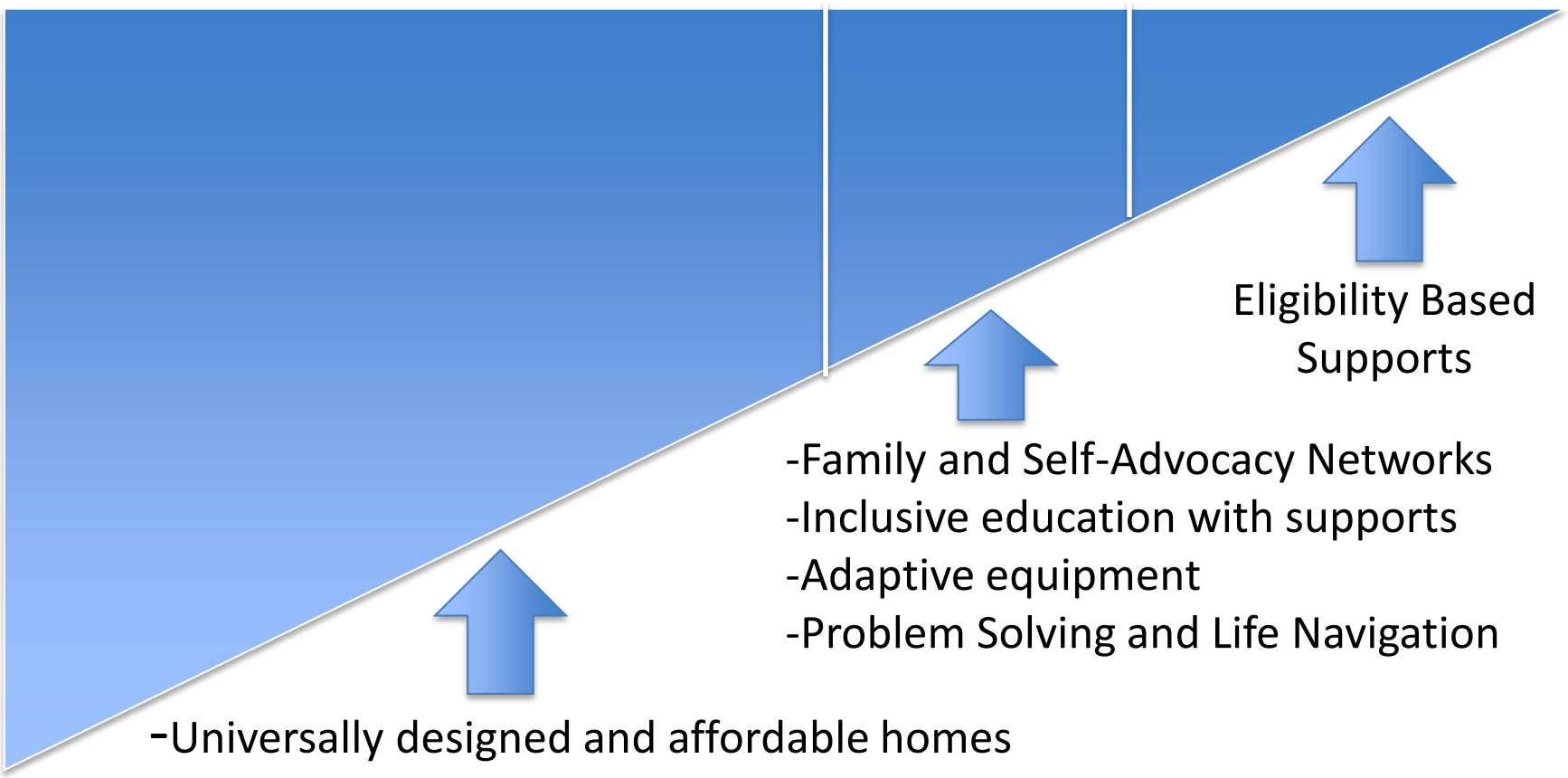
Goods and Service Bucket: focused on Family and Caregivers

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

ALL: Public Health Framework



Constructing Universal Strategies for Supporting Families Across the LifeCourse



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. https://www.surveymonkey.com/s/FamilySupportRRTC

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

SUPPORTING FAMILIES
of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

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.

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

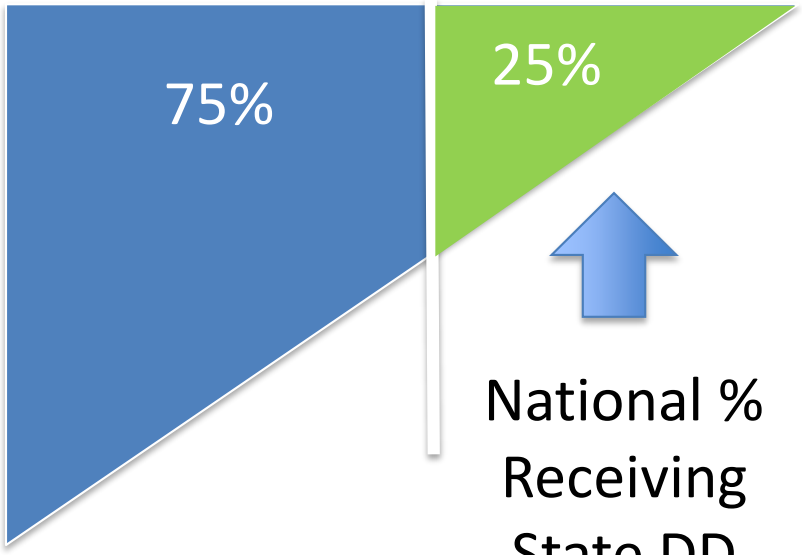
15.5 million individuals have difficulties with instrumental activities of daily living (housework, phone, meal preparation)

12 million required assistance

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

Focusing on Person with Intellectual and Developmental Disabilities

All 4.9 Million people with developmental disabilities

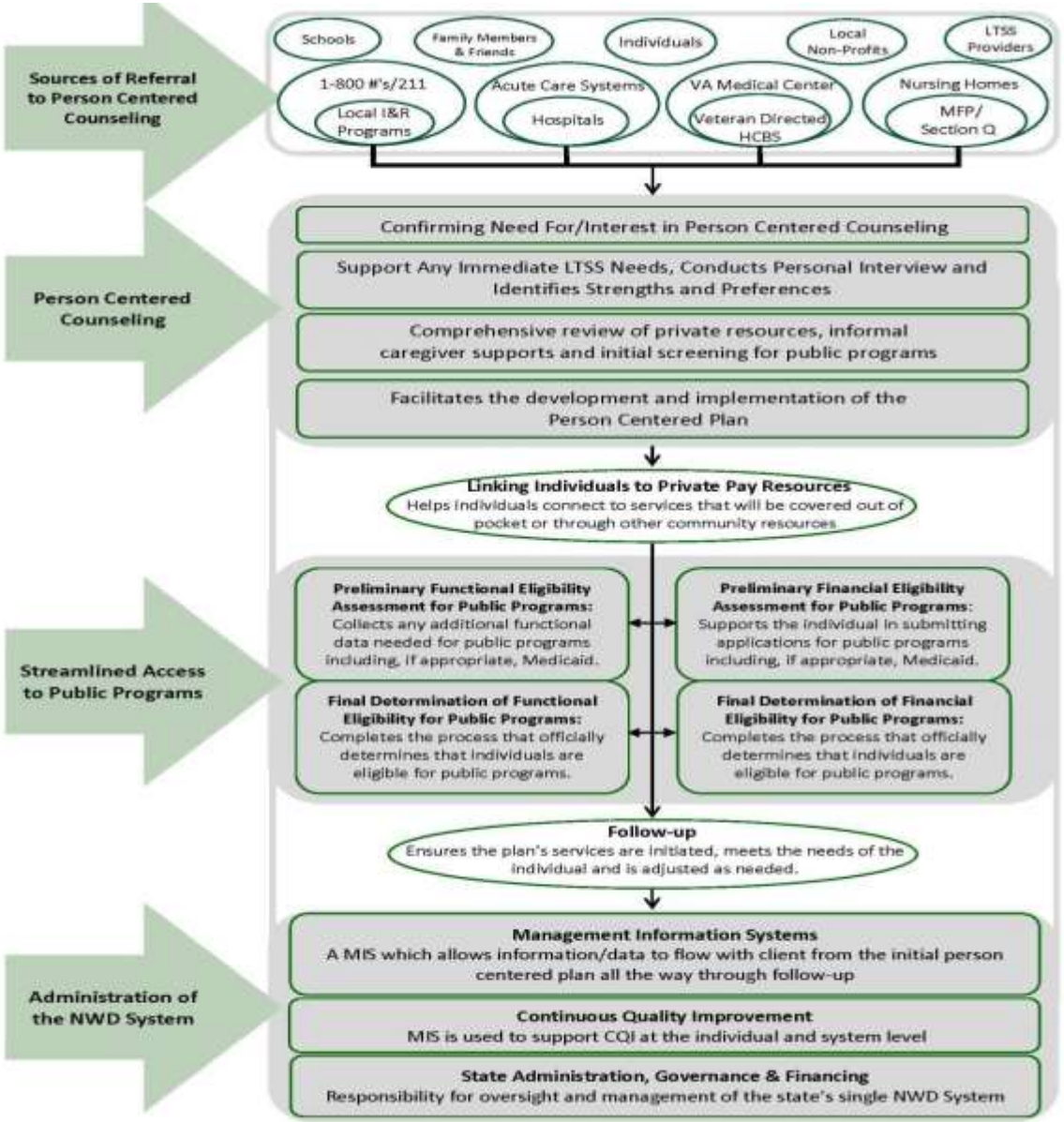


National % Receiving State DD Services

*** Based on national definition of developmental disability with a prevalence rate of 1.49%*

WHERE OUR WORK OVERLAPS

No Wrong Door SYSTEM

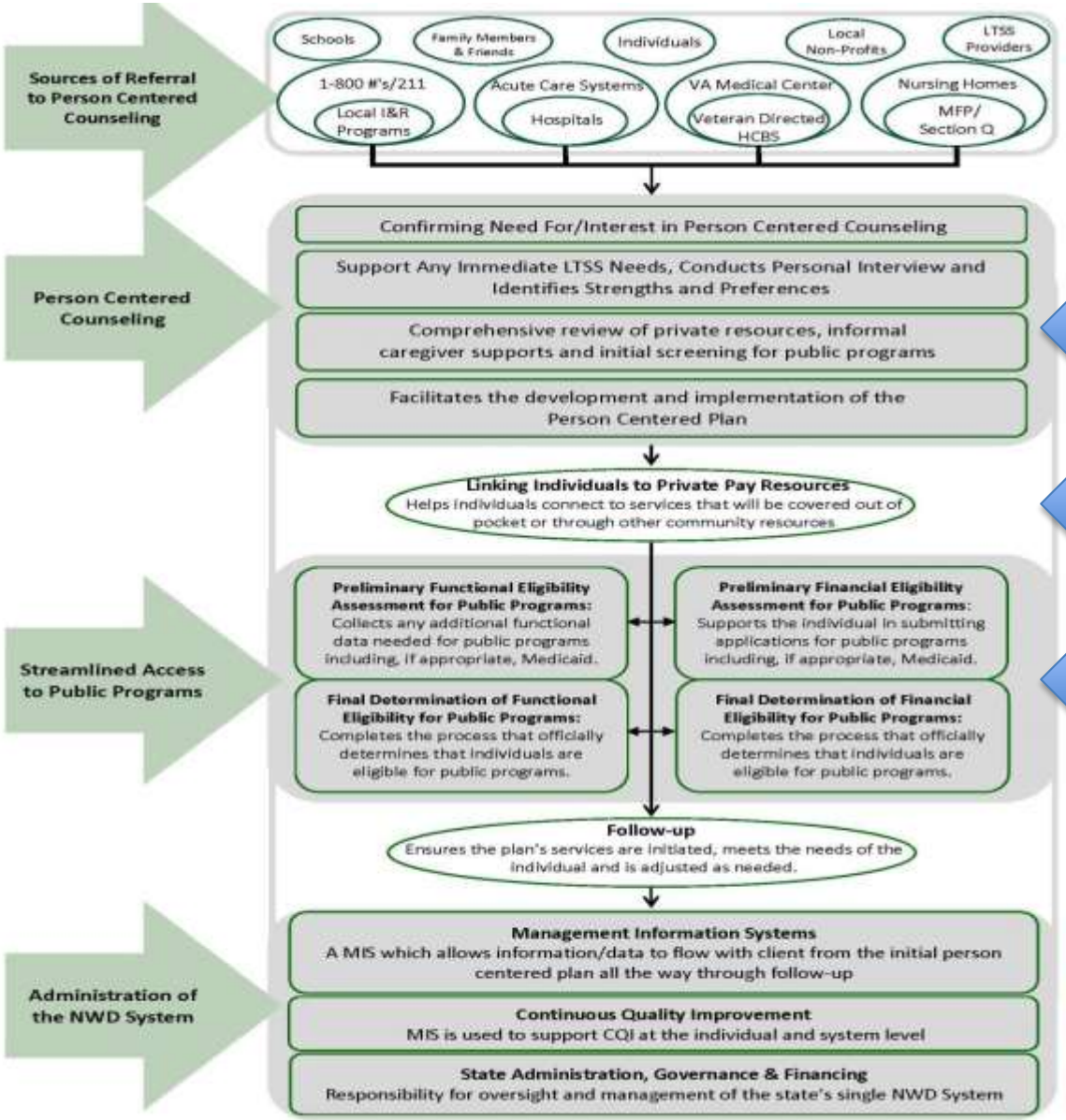


Additional Sources of Referral

- 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…

No Wrong Door SYSTEM

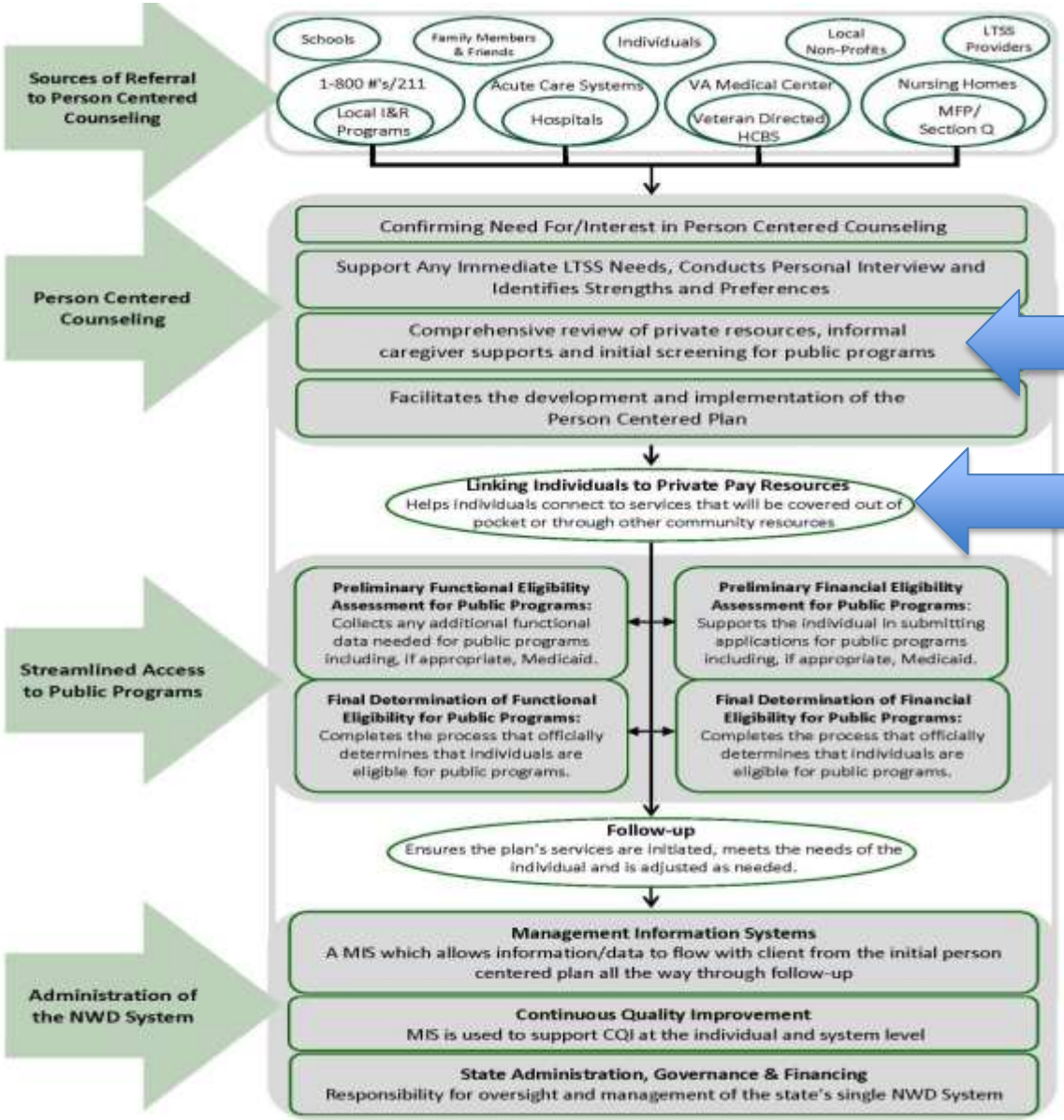


Focus of CoP Supports to Families and DD System:

- 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

No Wrong Door SYSTEM

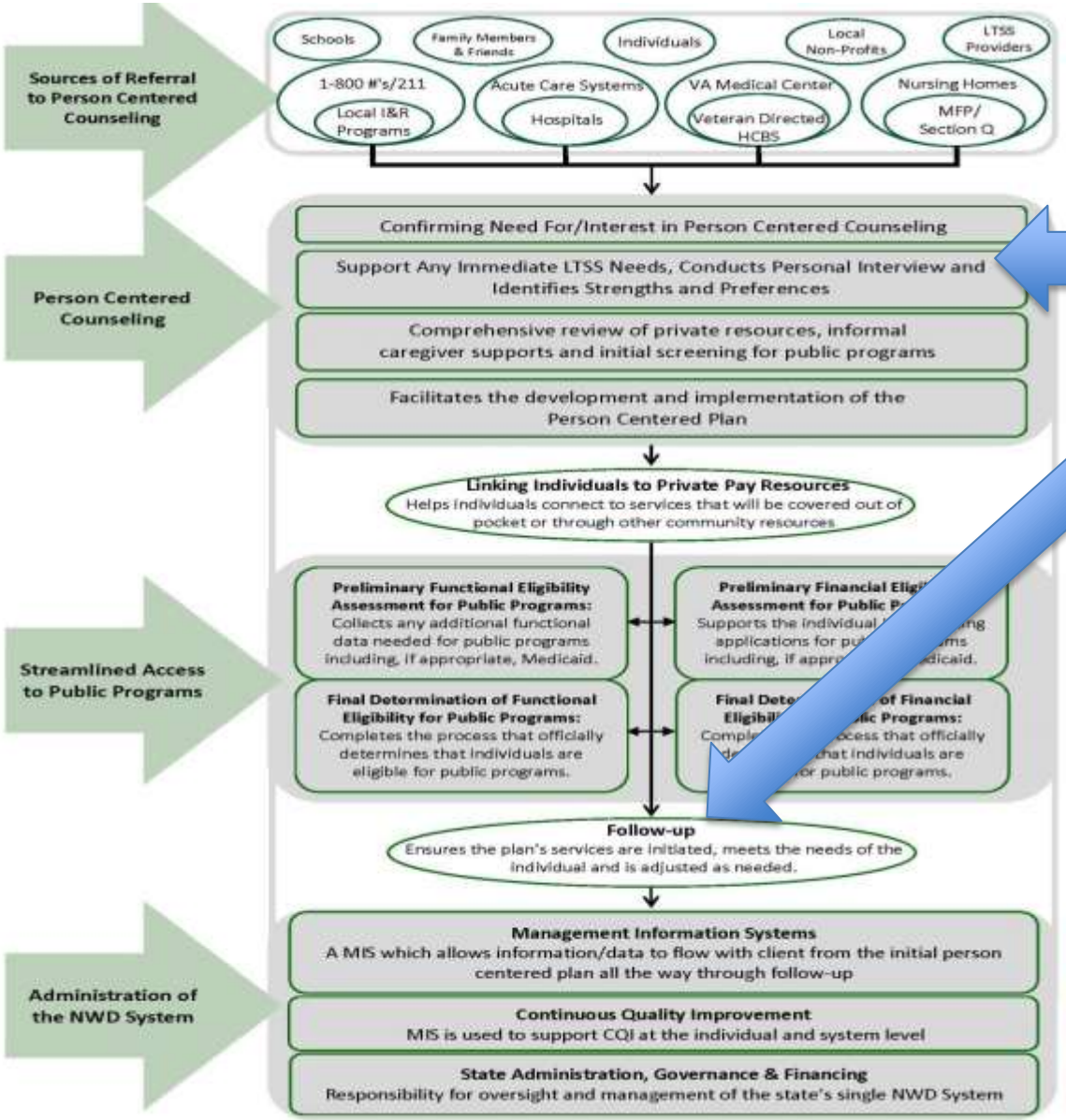


LifeCourse Tools focusing on Adapting, Accommodating and Integrating Supports:

- 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

No Wrong Door SYSTEM



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:

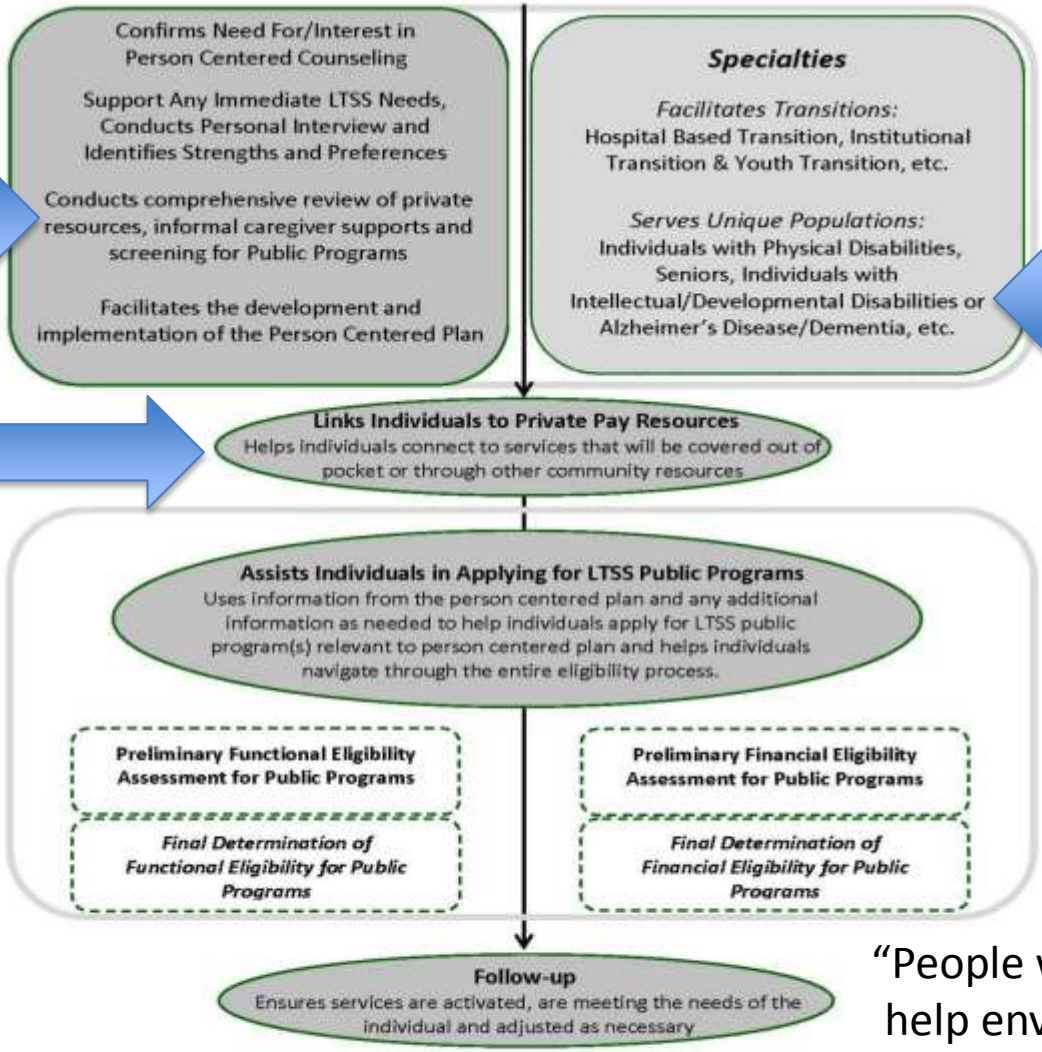
- *Don't always know what they don't know*
- *May lack a vision for future*
- *Taught system only responses*
- *Only know traditional supports*
- *Tired and scared*

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 self-determination and needs
- Start early, pro-active supports not when they call in crisis

Person Centered Counseling Competencies

ACL CoP Pilot: Using Integrated Supports Star to Guide Conversations around Comprehensive Review of Resources and teach about Linking with Resources



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.