Community of Practice
for Supporting Families of Individuals
with Intellectual & Developmental Disabilities

Our Learning from Six States in the Community of Practice

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HCBS Conference

Outcomes for Today

- Overview of the National Community of Practice on Supporting Families
- Introduce the framework for "reframing the conversation and solution finding" at all levels
- Share key areas of learning in States
- Discuss next steps and ways for others to get invovled

**Community of Practice
for Supporting Families of Individuals
with 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.

Funded by

ADMINISTRATION on INTELLECTUAL and DEVELOPMENTAL DISABILITIES

National Partners

**Community of Practice
for Supporting Families of Individuals
with Intellectual & Developmental Disabilities**

CT

DC

MO

OK

TN

WA

Type of Change that is Needed

Transitional Change

- "Retooling" the system and its practices to fit the new model
- Mergers, consolidations, reorganizations, revising systematic payment structures,
- creating new services, processes, systems and products to replace the traditional one

Transformation Change

- Fundamental reordering of thinking, beliefs, culture, relationships, and behavior
- Turns assumptions inside out and disrupts familiar rituals and structures
- Rejects command and control relationships in favor of co-creative partnerships

Creating Blue Space, Hanns Meissner, 2013

Long Term Goal
"Good Life for All"

The Individual will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life
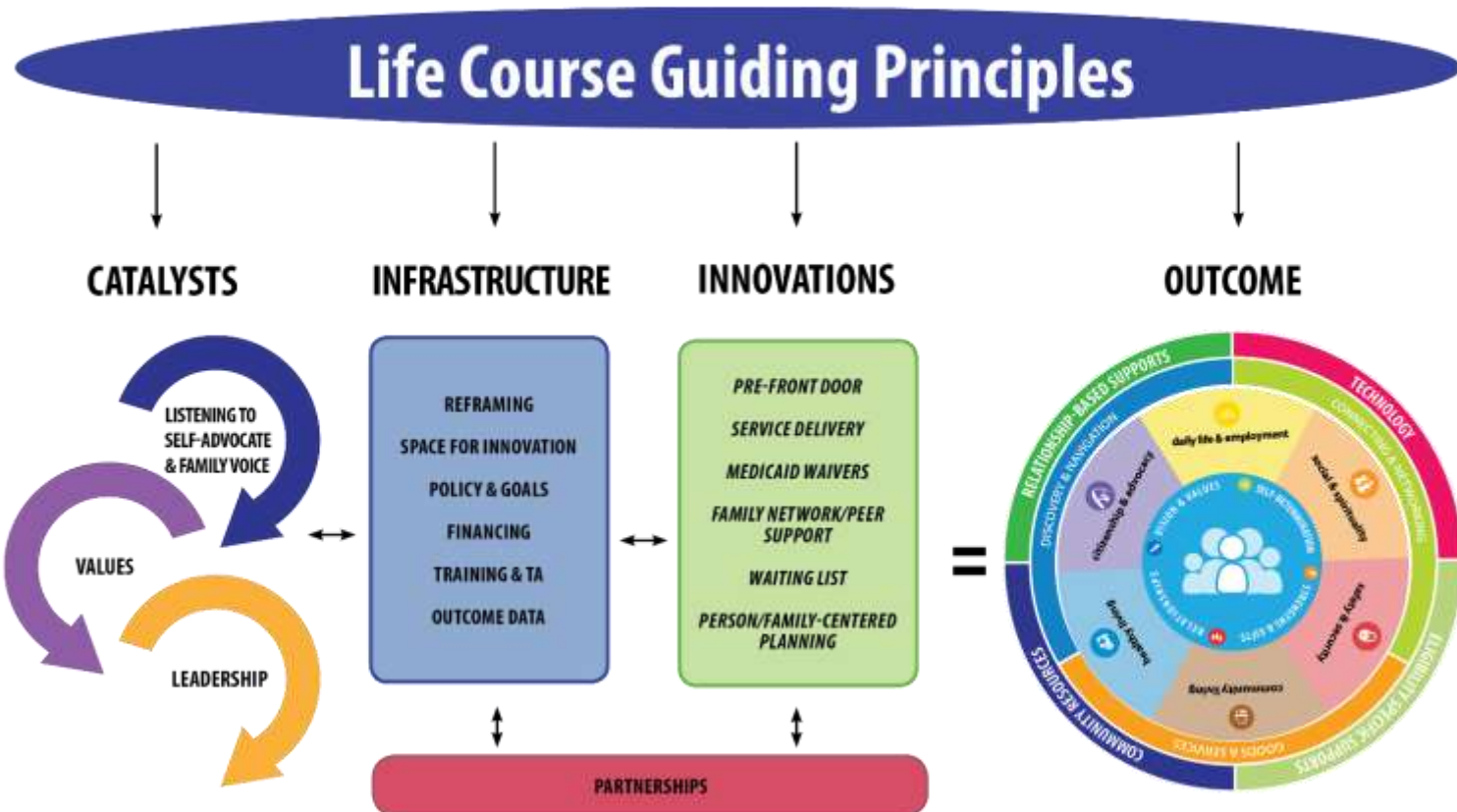
Families will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support the individual to achieve their goal

What have we learned? Reframing the Conversation at All Levels

REFRAMING OUR THINKING

Systems Change Framework

Life Course Guiding Principles

CATALYSTS

LISTENING TO SELF-ADVOCATE & FAMILY VOICE

VALUES

LEADERSHIP

INFRASTRUCTURE

- REFRAMING
- SPACE FOR INNOVATION
- POLICY & GOALS
- FINANCING
- TRAINING & TA
- OUTCOME DATA

PARTNERSHIPS

INNOVATIONS

- PRE-FRONT DOOR
- SERVICE DELIVERY
- MEDICAID WAIVERS
- FAMILY NETWORK/PEER SUPPORT
- WAITING LIST
- PERSON/FAMILY-CENTERED PLANNING

OUTCOME

Adapted from Hall et all, 2007

*Adapted from SELN Framework

Focusing on ALL

All 4.9 Million people with developmental disabilities

25%

75%
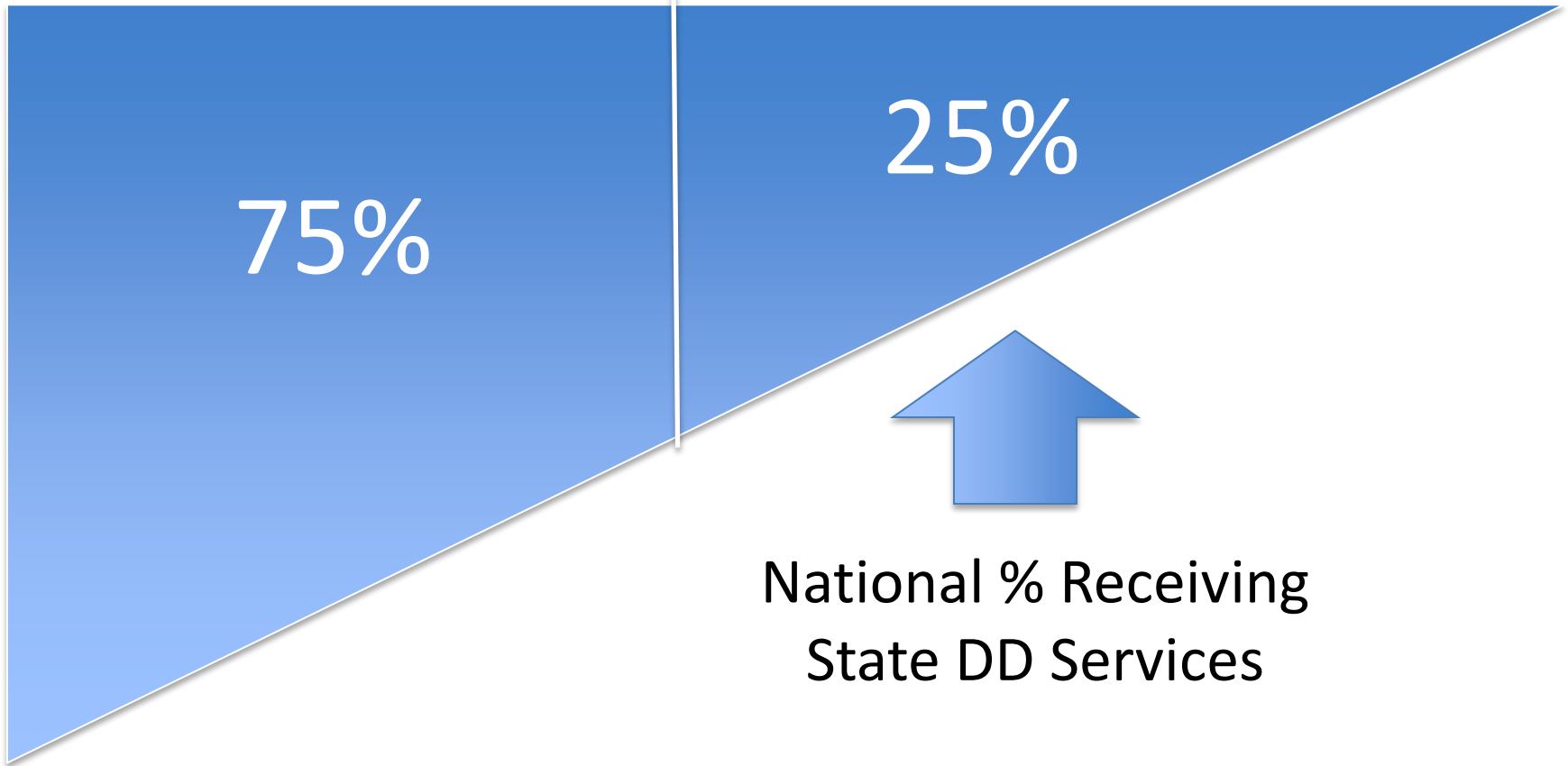
National % Receiving
State DD Services

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

The FAMILY is a SYSTEM!!
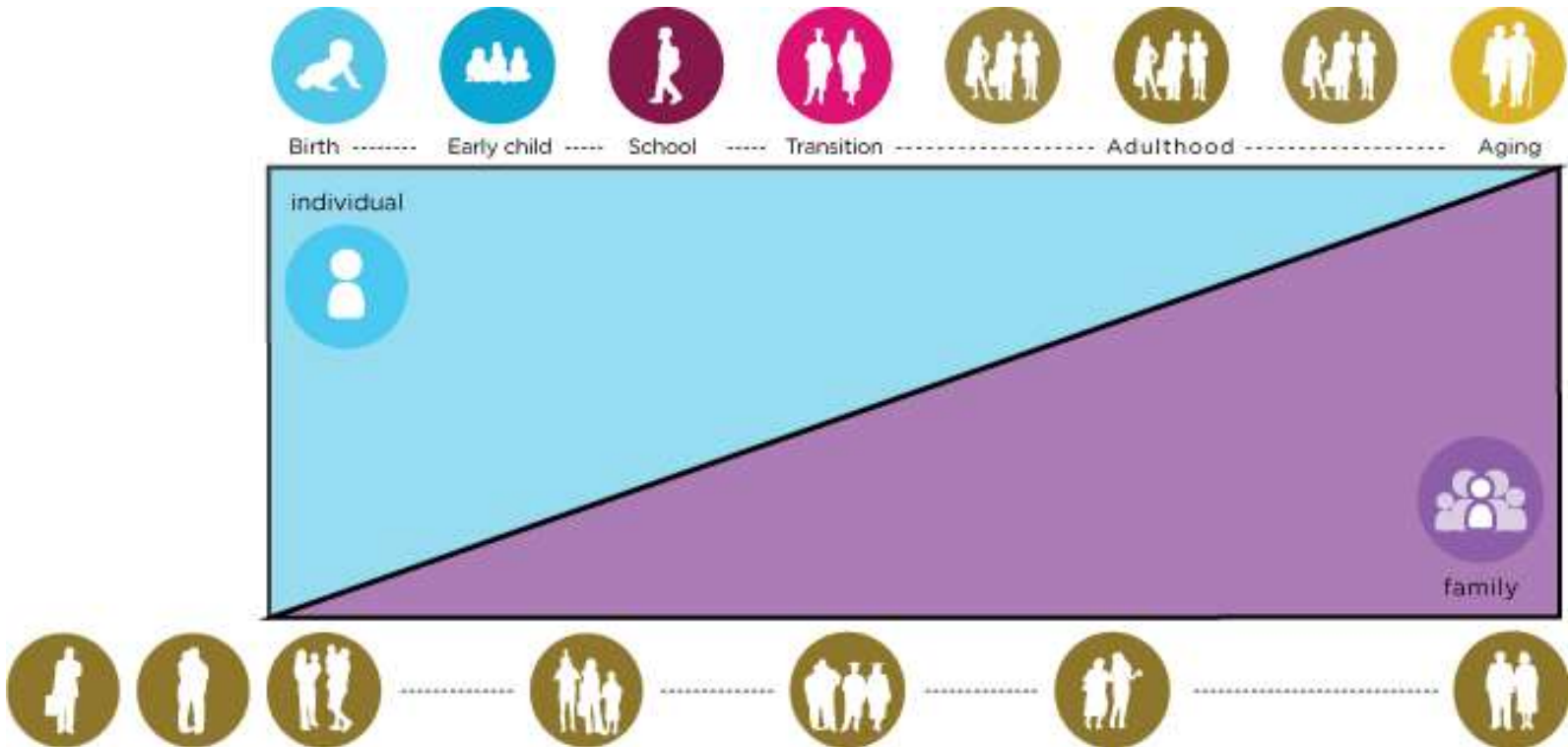
There are FAMILY CYCLES!!

INDIVIDUALS
live within
the context of
THEIR FAMILY

Reciprocal Roles of Family Members

	Caring About	Affection & Self-Esteem
		Repository of knowledge
		Lifetime commitment
	Caring For	Provider of day-to-day care
		Material/Financial
		Facilitator of inclusion and membership
		Advocate for support

Identifying What is Impacting Life's Trajectory

Vision for Good Life

Trajectory towards Outcomes

Vision of What I Don't Want

Trajectory towards things unwanted
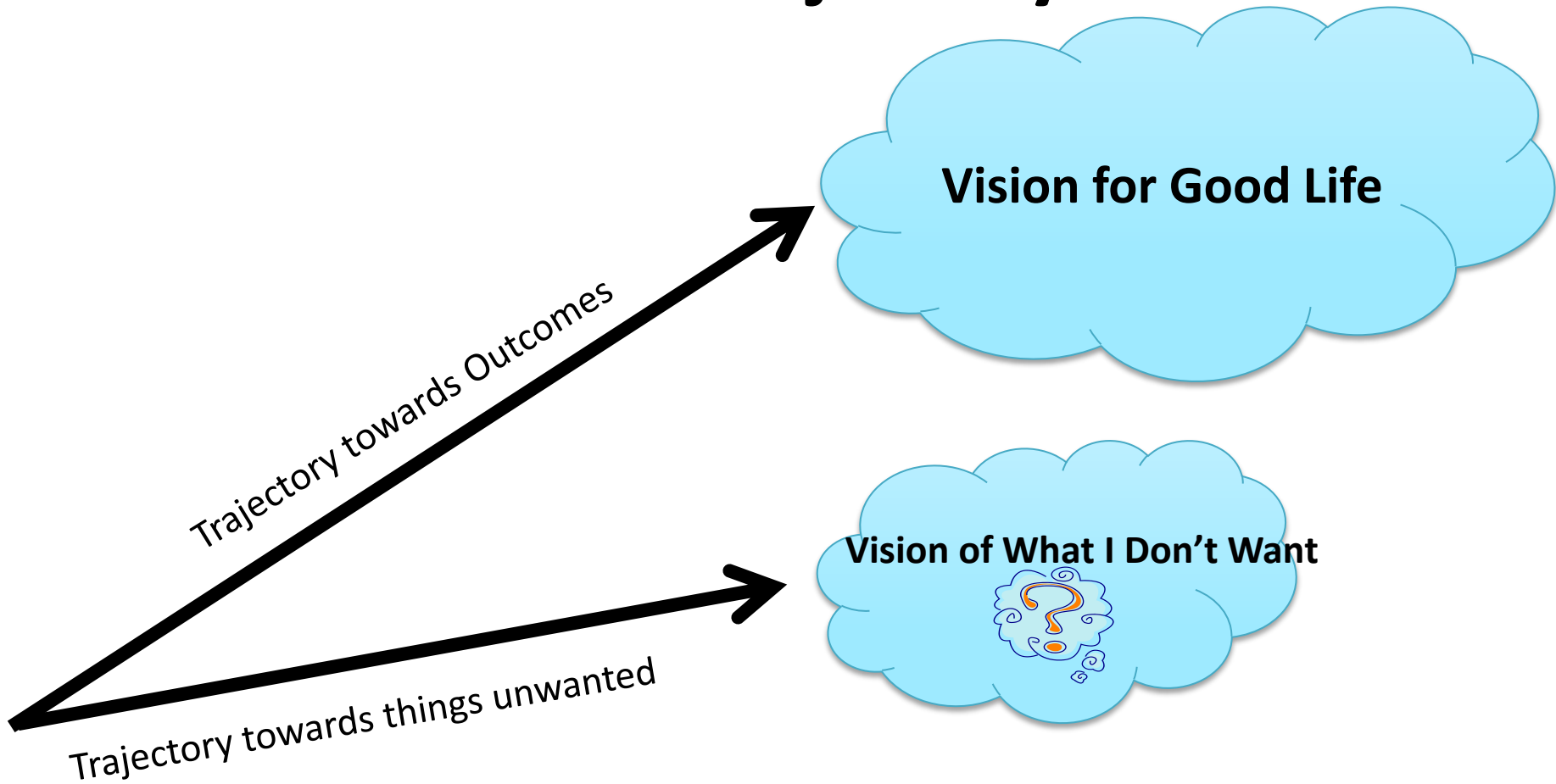
*Both in practice with individuals and
in policy changes for systems*

Thinking About All Life Stages

Birth---Early Child---School--Transition-----------Adulthood----------Aging

Both in practice with individuals and in policy changes for systems
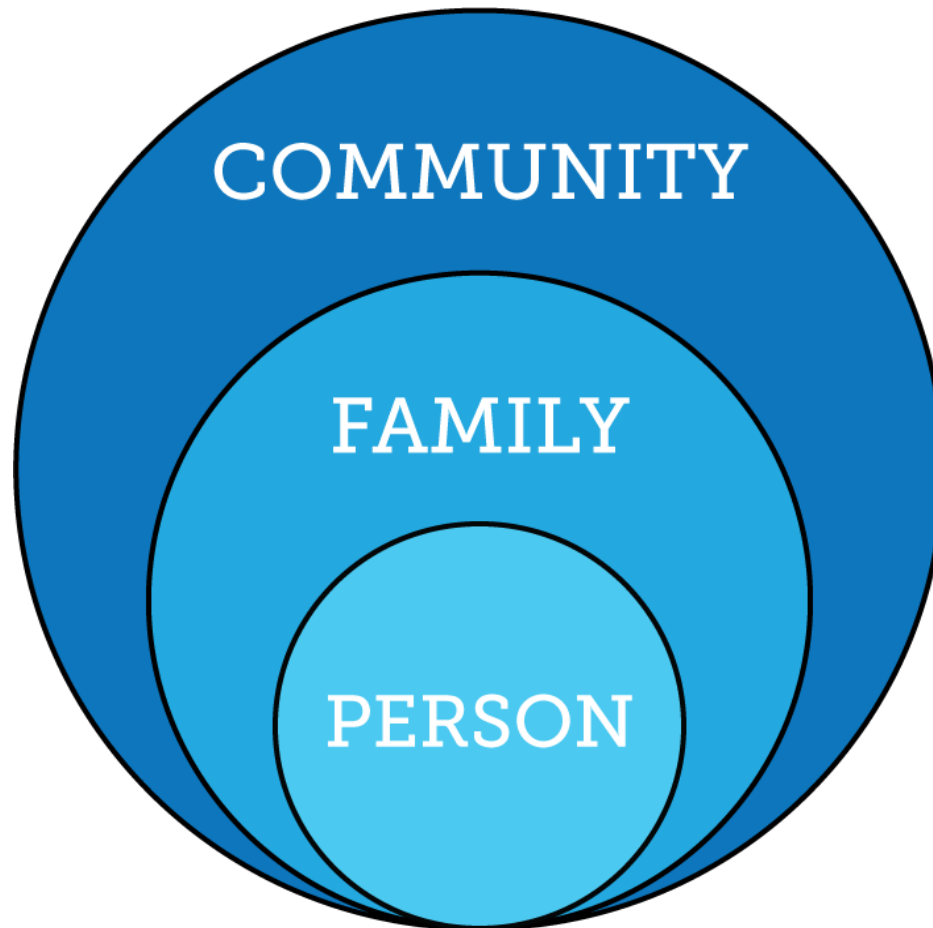
Bigger than Family Support:
Requires Organizing Culture, Policies and Practices
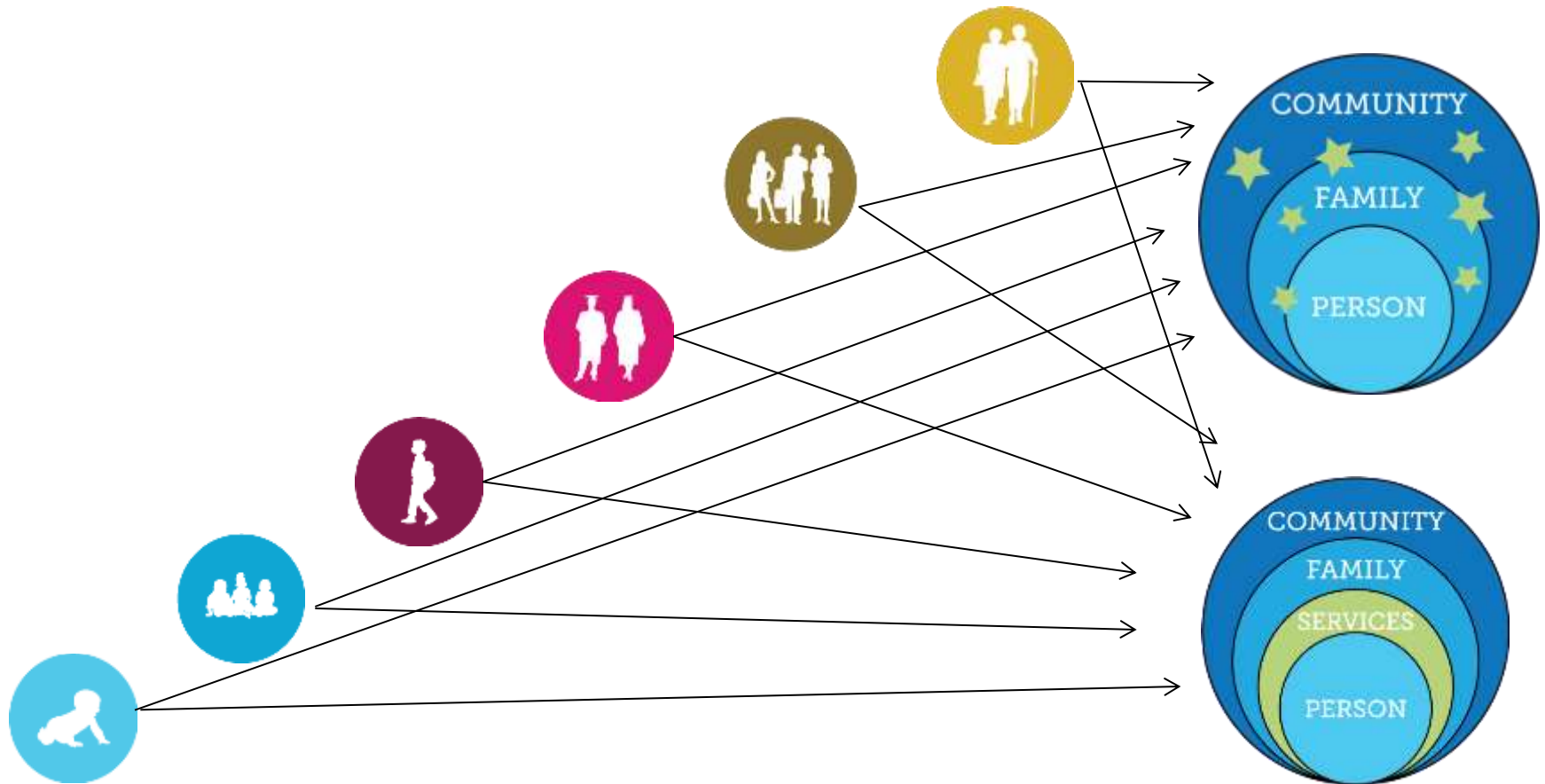
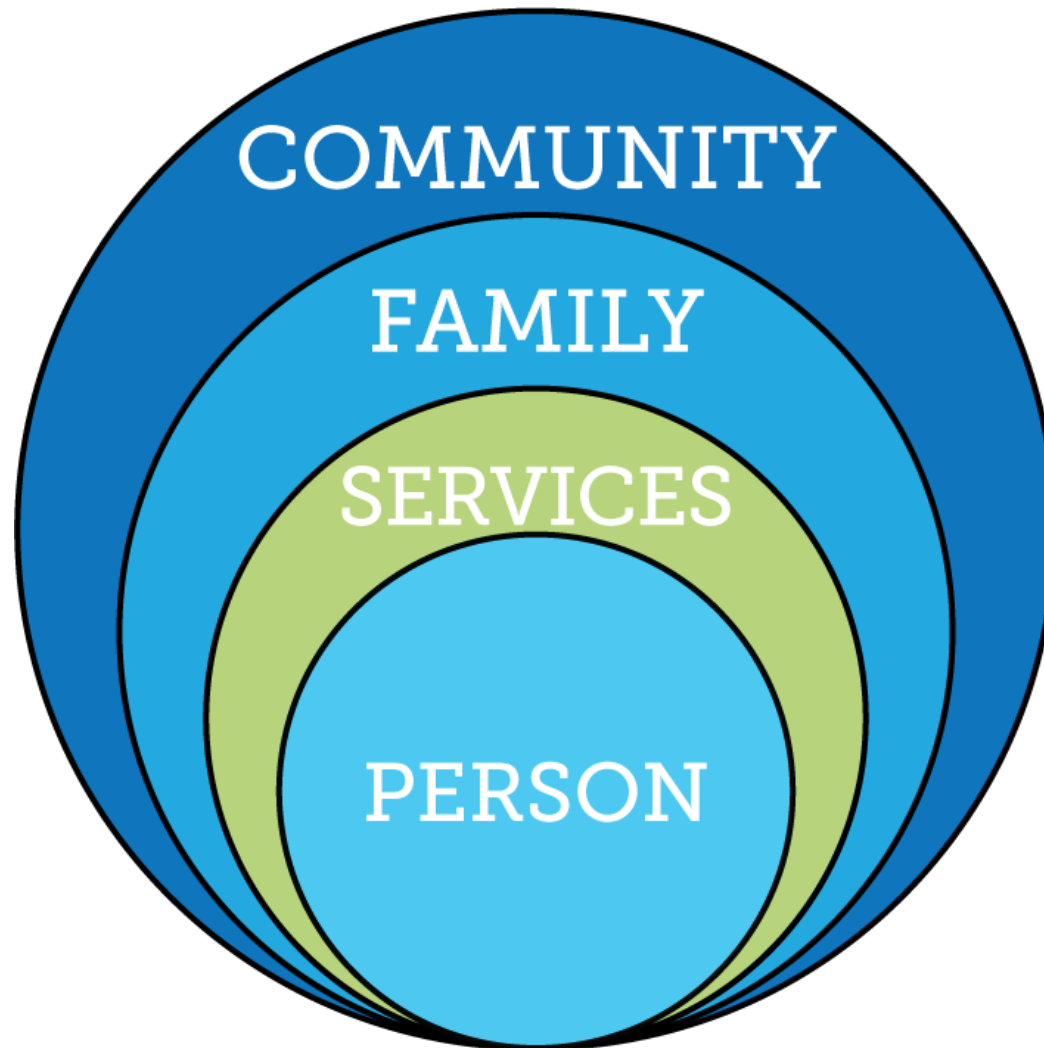Birth-----Early Child----School----Transition---Adulthood-----Aging

What have we learned? Reframing the Conversation at All Levels

REFRAMING OUR PRACTICES AND POLICIES

Supports should Enhance Real Lives

Current Support System
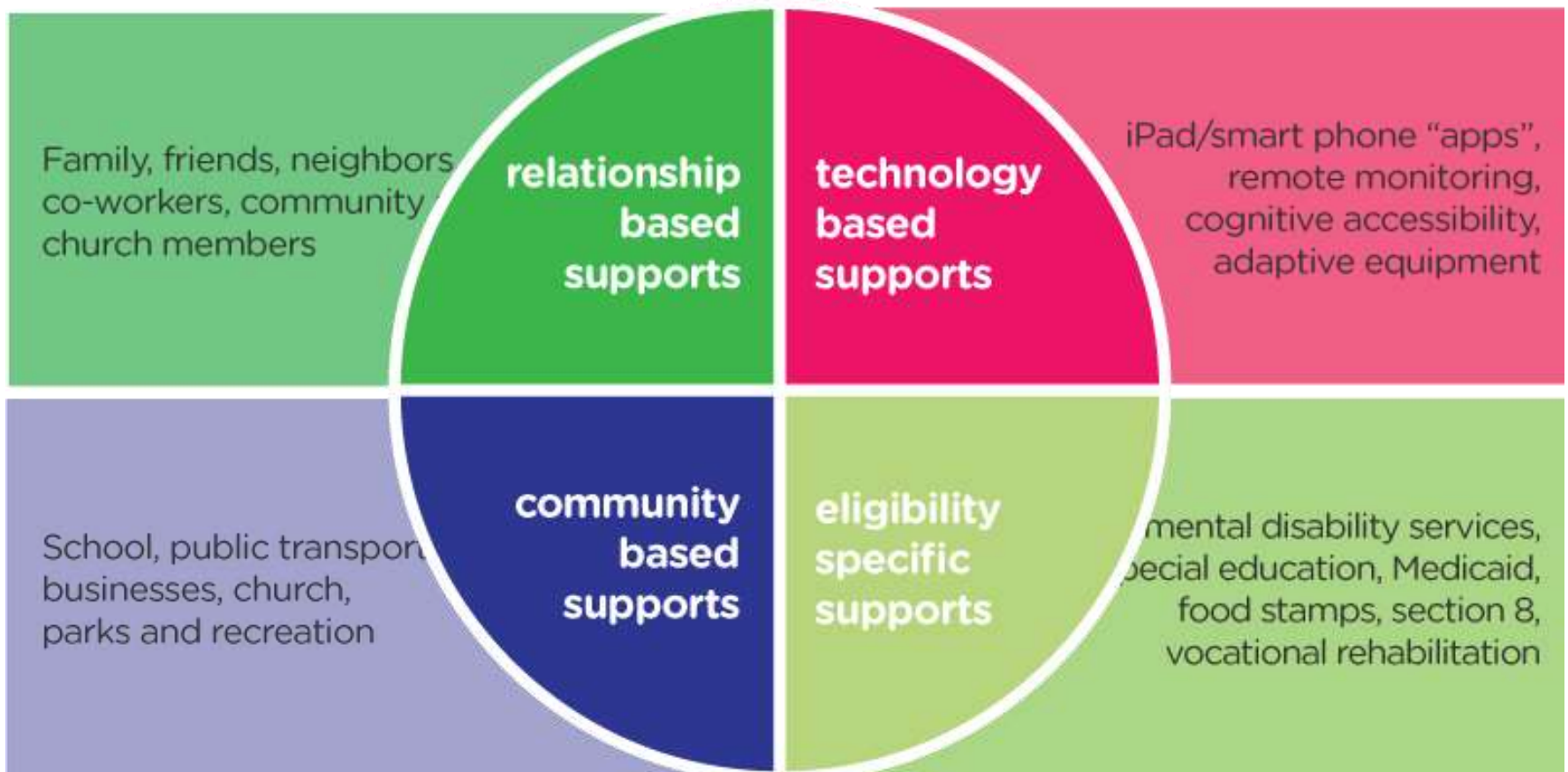
Real People, Real Lives with Integrated Supports

Thinking Across All Life Domains

Daily Life & Employment	What a person does as part of everyday life – school, employment, volunteering, routines, life skills	**Healthy Living**	Managing and accessing health care & staying well –medical, mental health, behavioral health, developmental, wellness & nutrition
Community Living	Where and how someone lives – housing and living options, community access, transportation, home adaptations & modifications	**Safety & Security**	Staying safe and secure – emergencies, well-being, guardianship options and alternatives, legal rights and issues
Social & Spirituality	Building friendships and relationships, leisure activities, personal networks, faith community	**Citizenship & Advocacy**	Building valued roles, making choices, setting goals, assuming responsibility and driving how one's own life is lived

Support Physical, Emotional, Intellectual and Financial Well-being

Discovery & Navigation: Knowledge & Skills	Connecting & Networking Mental Health & Self-efficacy	Day-to-Day Services Instrumental Supports
• Information on disability • Knowledge about best practices and values • Skills to navigate and access services • Ability to advocate for services and policy change	• Parent-to-Parent Support • Self-Advocacy Organizations • Family Organizations • Sib-shops • Support Groups • Professional Counseling • Non-disability community support	• Self/Family-Directed services • Transportation • Respite/Childcare • Adaptive equipment • Home modifications • Financial assistance • Cash Subsidies • Short/Long term planning • Caregiver supports & training

Identifying Integrated Strategies for Delivery Supports: *Not only DD Services*

Family, friends, neighbors co-workers, community church members

relationship based supports

technology based supports

iPad/smart phone "apps", remote monitoring, cognitive accessibility, adaptive equipment

School, public transport, businesses, church, parks and recreation

community based supports

eligibility specific supports

mental disability services, special education, Medicaid, food stamps, section 8, vocational rehabilitation

Inter-Agency Collaboration and Partnerships

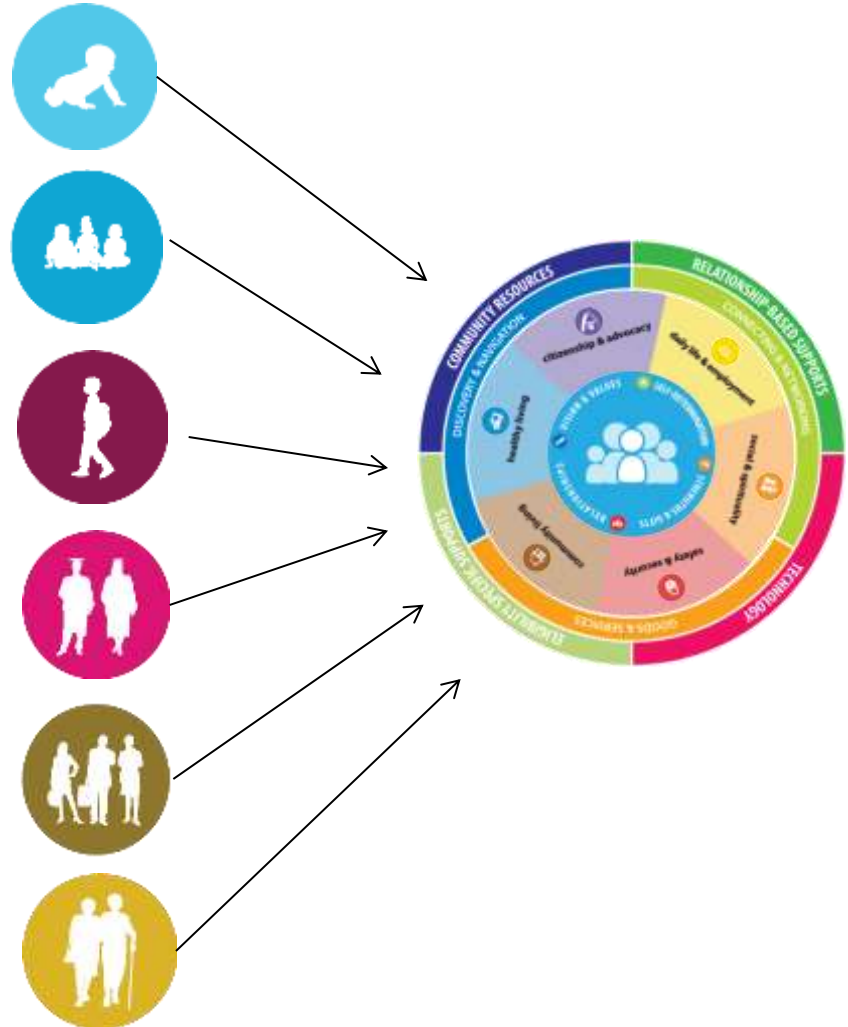Pediatrician, Families and Friends, Faithbased

IDEA Part C, Parents as Teachers, Health, Headstart

School, Special Education, Health, Recreation

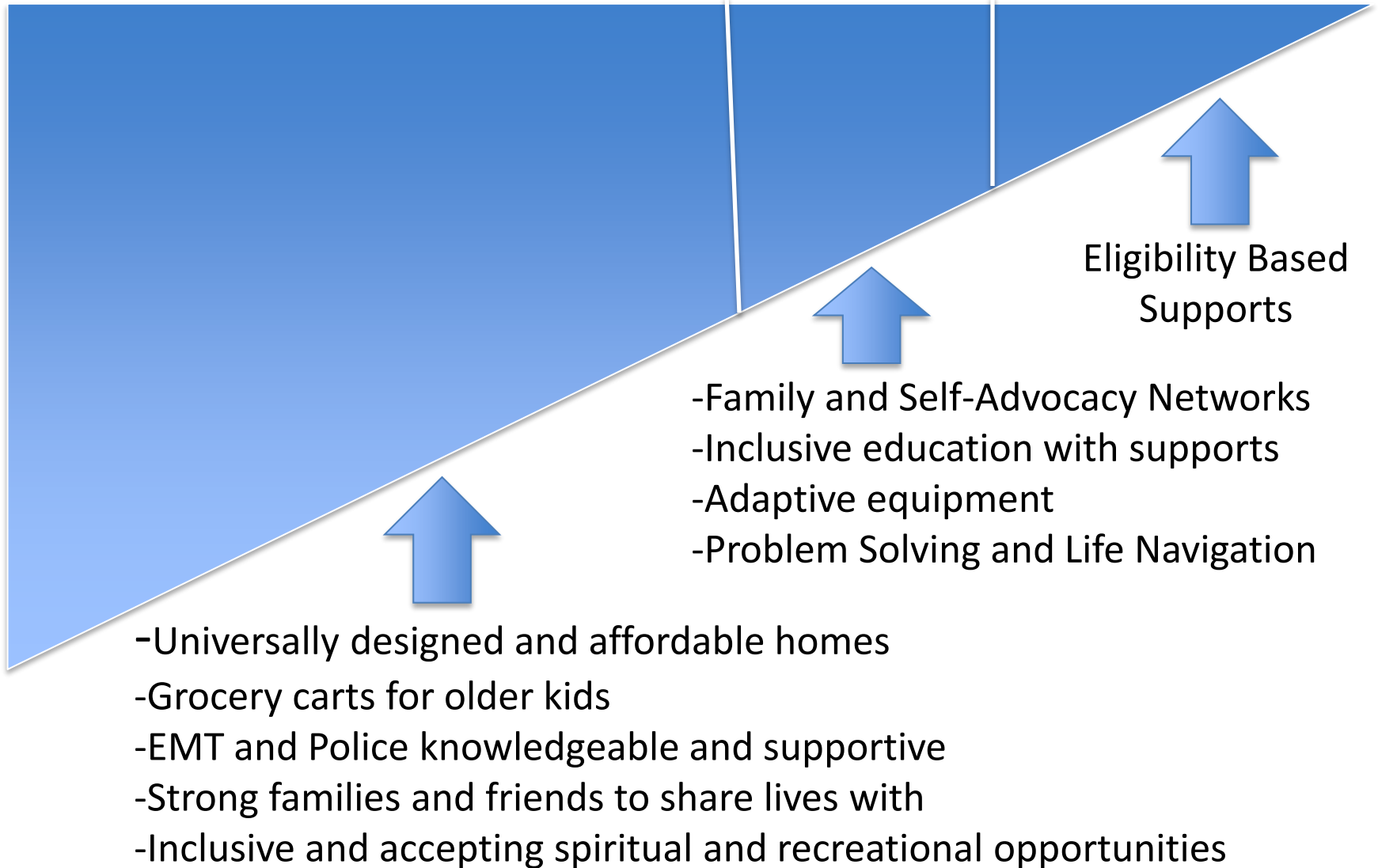Vocational Rehab, Health Employment, College, Military

Disability Services, Health, Housing, College, Careers
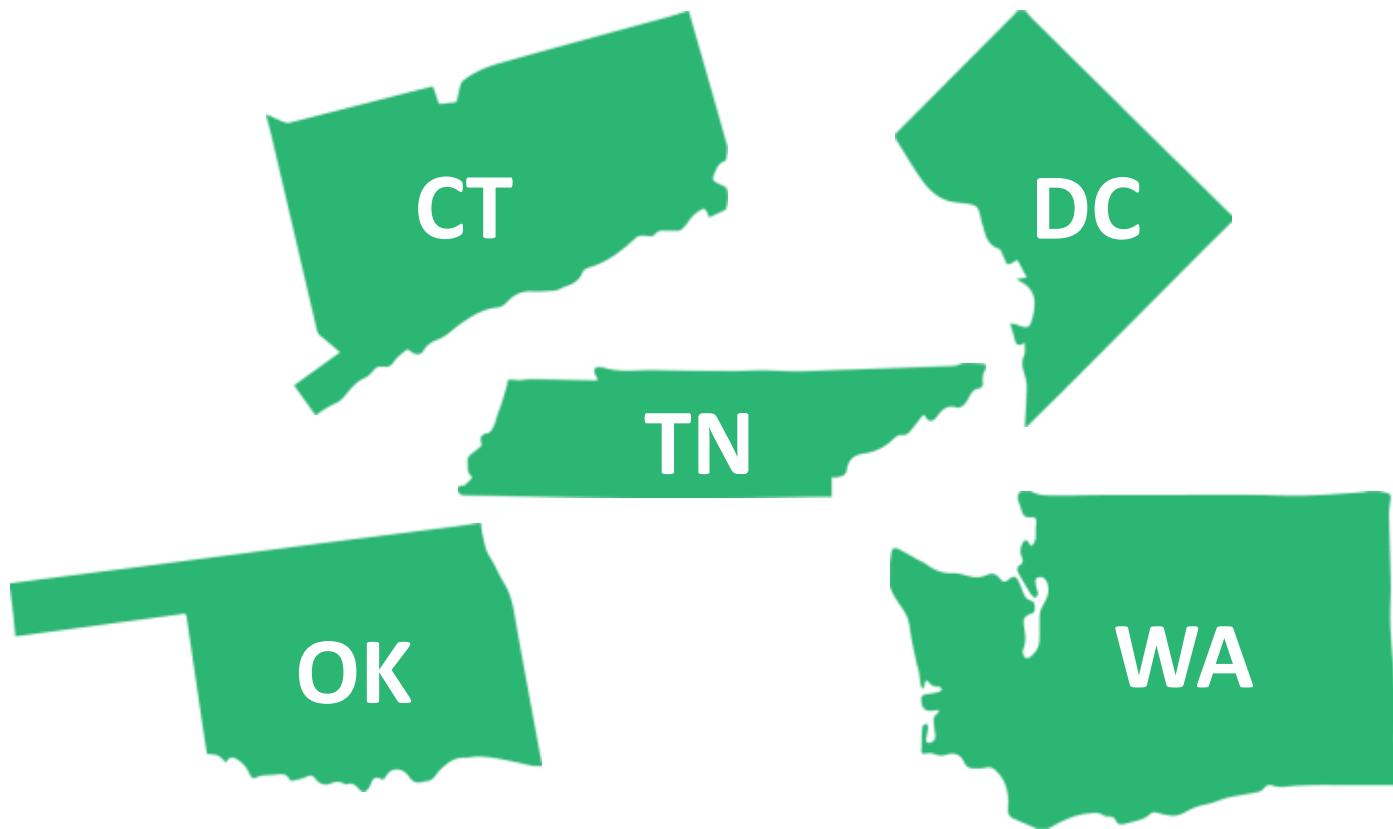
Retirement, Aging System, Health

Developing Innovative Strategies for Transformation within and outside DD

Eligibility Based Supports

-Family and Self-Advocacy Networks
-Inclusive education with supports
-Adaptive equipment
-Problem Solving and Life Navigation

-Universally designed and affordable homes
-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

What is happening in the CoP States?

CT   DC
TN
OK   WA

Community of Practice
for Supporting Families of Individuals
with Intellectual & Developmental Disabilities

Connecticut

- Two full time people in Central office to focus on systems change to support families
- Cross department life span team
- Creating Consistent Message
- Focusing on "community teams" with new partners
- Enhancing eligibility process to be more family friendly
- Supporting the development of Sibling Network

Connecticut

- Community Teams
  - Information Dissemination
  - Family Mentoring and Leadership
  - Training and Education
  - Self-Directed Services and In-Home Supports
  - Social Supports and Respite
  - Positive Behavior Supports
  - Person Centered Housing
  - Employment
  - Healthy Living
  - Technology

Connecticut

PROJECTS & ACTIVITIES

PERSONAL STRENGTHS & ASSETS
- Assets Planning
- Employment
- Micro-enterprise
- Benefits Counseling

RELATIONSHIP-BASED
- TYZE Online Services
- Person Centered Planning Succession Plan
- FSN Caregiver Supports
- Sibling Supports

COMMUNITY-BASED
- Direct-Hire Faith Communities
- MFP- Livable Communities
- Community Social Services

INTEGRATED SUPPORTS

ELIGIBILITY-BASED
- DDS Survey
- CoP Committee Publication
- DDS IP Process
- DDS News Hour
- DDS Social Pilot
- PBS Trainings, publications Website
- Housing website, housing policies & procedures

TECHNOLOGY-BASED
- Tech Handouts
- Tech Demonstration Sites-NEAT Smarthome
- Tech Idol Video
- Tech Consumer Positions

Connecticut

Community

Assistive Technology

Eligibility Services

DDS Services

Strengths & Assets Planning

Person Centered Planning

Connecticut

CONNECTICUT COMMUNITY OF PRACTICE FOR SUPPORTING FAMILIES

MISSION

To discover, design and deliver effective supports for families who have a family member with a disability.

FOUR YEAR VISION OF SUCCESS

360 degrees of support. Families feel surrounded by support. This can't be done by just shifting the buckets of money! It must be done by engaging with communities.

FAMILIES FEEL BETTER ABOUT THEIR LIVES BECAUSE THEY HAVE ACCESS TO:

- **MENTORING** to increase their Personal Power. Each individual in the family feels greater confidence in their individual role (parent, sibling, grandparent, self-advocate, etc.).
- **FAMILY GROUPS** to increase their Family's Power. Families feel more powerful because they are able to support one another through groups and community connections.
- **COMMUNITY COLLABORATION** to increase their Civic Power. Most family issues (health, safety, social, home, school, employment, etc.) are addressed in common ways in their communities just like any other citizen –unique needs are met as needed for only as long as needed.

VALUES

- **COMMUNITY**: Our job is to help people with disabilities be part of the larger world, not just the disability world. Community needs to be a central feature of all that we do.
- **LIFESPAN**. All of our work needs to be built upon a lifespan approach. We cannot do our work in isolated stages. Each lifespan stage is built upon what has occurred in a previous stage. We need to work together across all ages.
- **STRENGTHS AND COMMONALITIES:** A focus on scarcity of resources or on fears produces short term solutions to the challenges we face. The discovery and building upon commonalities, strengths and "what works" will lead us to better, more sustainable solutions for the long term.
- **INNOVATION**: Innovation is good. Sustainable innovation is better. Scalable innovation is best. We need to make sure proposed innovations will work for many, not just a targeted few.
- **TEAMS**: It takes a team to create solutions to the barriers we face in designing more effective supports for families. We need architects to help use and/or design creative support models. We need contractors who can help us transform the design models into everyday practices. We need workers who can make sure the contractors ideas are implemented properly so that the design is a well-made structure. Families and individuals also need to modify and adapt what we do in ways that meet their individual needs. We need you.

A COLLABORATION BETWEEN

CT Council on Developmental Disabilities
ct.gov/ctcdd

DDS

Connecticut Department of Developmental Services
ct.gov/dds

GET INVOLVED WITH THE COMMUNITY OF PRACTICE

CONTACT
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Robin.Wood@ct.gov

Molly Cole,
CT Council on Developmental Disabilities
800-653-1134
molly.cole@ct.gov

LEARN ABOUT THE NATIONAL CoP

VISIT
supportstofamilies.org

STRATEGIES TO SUPPORT REAL LIVES

RESOURCES & SERVICES ALONG THE LIFESPAN

District of Columbia

- Legacy system
  - Adults with Intellectual Disabilities only
  - Commitment to community based supports
  - Stalled at reforming the law

  - System Reform Initiatives
    - Employment First
    - Person Centered Thinking
    - Supporting Families CoP

District of Columbia

Examples of Levels of Change

- DDA
  - Stipends
  - Policy Review Committee
  - Regulatory change and waiver amendments
  - Plans for Parent to Parent Support
- DDC
  - Partners in Policy Making
- UCEDD
  - Web-based resource for families
- Quality Trust
  - Training and capacity building for families

Oklahoma

- Build on longstanding family involvement activities:
  - Strong involvement of Family Voices and UCEDD Family Leadership Advisory Council
  - Trained Family Advisory members on LifeCourse framework
  - Focused Annual Joining Forces Conference on LifeCourse and Supports to Families
  - Resulted in Rural Family Institutes using LifeCourse Framework for training workshops
- State DD System focusing on role of case managers working with families
- Blue Ribbon Task Force using LifeCourse framework to guide conversations and plan development

Oklahoma

- State DD System
  - Existing initiatives focused on person centered planning
  - Enhance role of case managers and intake workers support to families
- Governors Blue Ribbon Task Force using LifeCourse framework to guide conversations and plan development

Washington

Infused the lifecourse framework into existing "Informing Families, Building Trust" messaging efforts

Informing Families
Building Trust

informingfamilies.org
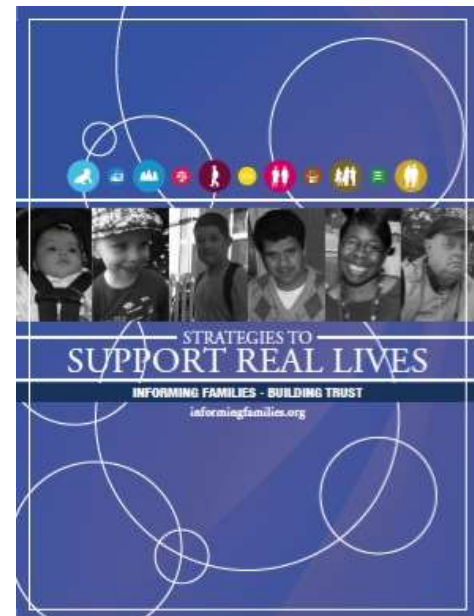
Washington

- Strong leadership and partnership of state DD Council with State DD system

- Recommendations made to integrating "supporting families" framework and specific services into the new states K Plan

- Exploring "a family component" into already strong use of NCI data to drive systems change

Washington

- Hosting focus groups based on a newly recognized need to "ask questions differently" and to target specific groups to guide ongoing systems activities:
    - Families on the "no paid services"
    - Aging Caregivers
    - Transition Age Families
    - Parents with Disabilities
    - Siblings

Tennessee

Three major focus areas:

- Tools for Re-Framing: Communication strategies, Information Dissemination

- Focus on the 'Front Door' to Services

- Target Activities for Those Waiting for services (7,000+ in TN)

Tennessee

Communication Tools for Reframing

(e-newsletter, magazine, folder, website, social media)

TENNESSEE **COUNCIL**
on developmental disabilities

DIDD
DEPARTMENT OF INTELLECTUAL
AND DEVELOPMENTAL DISABILITIES

A New Project in Tennessee:
Supporting Families of Individuals with
Intellectual & Developmental Disabilities
Issue #2

Families Teaching Families

One key concept in the "Supporting Families" framework is the importance of peer support, i.e. support provided directly through other families affected by disability.

Connecting and networking a family with other families who have members with

STRATEGIES TO
SUPPORT REAL LIVES
CONNECTING TO RESOURCES IN TENNESSEE

Tennessee

Leveraging Current Opportunities

- Previous experience with Person-Centered Practices Community of Practice
- On way to being 1st state DD system to achieve Council on Quality Leadership accreditation
- 3 major employment grants (Labor, DIDD, & Vanderbilt / UCEDD)
  - "TennesseeWorks": UCEDD grant, but also operates as an overarching stakeholder group
  - Gov.'s "Employment First Exec. Order", Employment First Task Force to plan strategies for increasing employment for Tennesseans w/ I/DD
  - Many CoP state team members are on leadership teams for employment grants
  - TennesseeWorks: family survey, community conversations, family coalitions

Tennessee

Building new opportunities

- Governor's Children's Cabinet
- University of TN Strengthening Families initiative – *policy seminar focused on educating policymakers about needs of all families*
- State Interagency Coordinating Council (for Early Intervention Services)
- New Parent-to-Parent Mentoring program through Dept. of Mental Health grant

Missouri

- DMH DDD contracted with UMKC-UCEDD and its Family to Family Resource Network on "supporting families" activities, such as:
  - Process consulting to key leadership on applying lifecourse framework to policy and practices
  - Training and technical assistance to Family Support Coordinators and other Statewide Leads
  - Establishment of new state DD intake procedures and capacity to seamlessly refer families to F2F for Information and Peer Support

Missouri

- DD Council and LifeCourse Framework
  - Long term partnership with UMKC and Family to Family Resource Network
  - Used LifeCourse Strategic Planning Tools to:
    - Organize Council Retreat
    - Map and Align projects, staff and efforts
  - Integrated LifeCourse and Supporting Families into Partners in Policymaking curriculum and alumnae weekend

Missouri

Development and Integration of LifeCourse Tools

Identifying Key Drivers and Indicators for Systems Transformation and Implementation
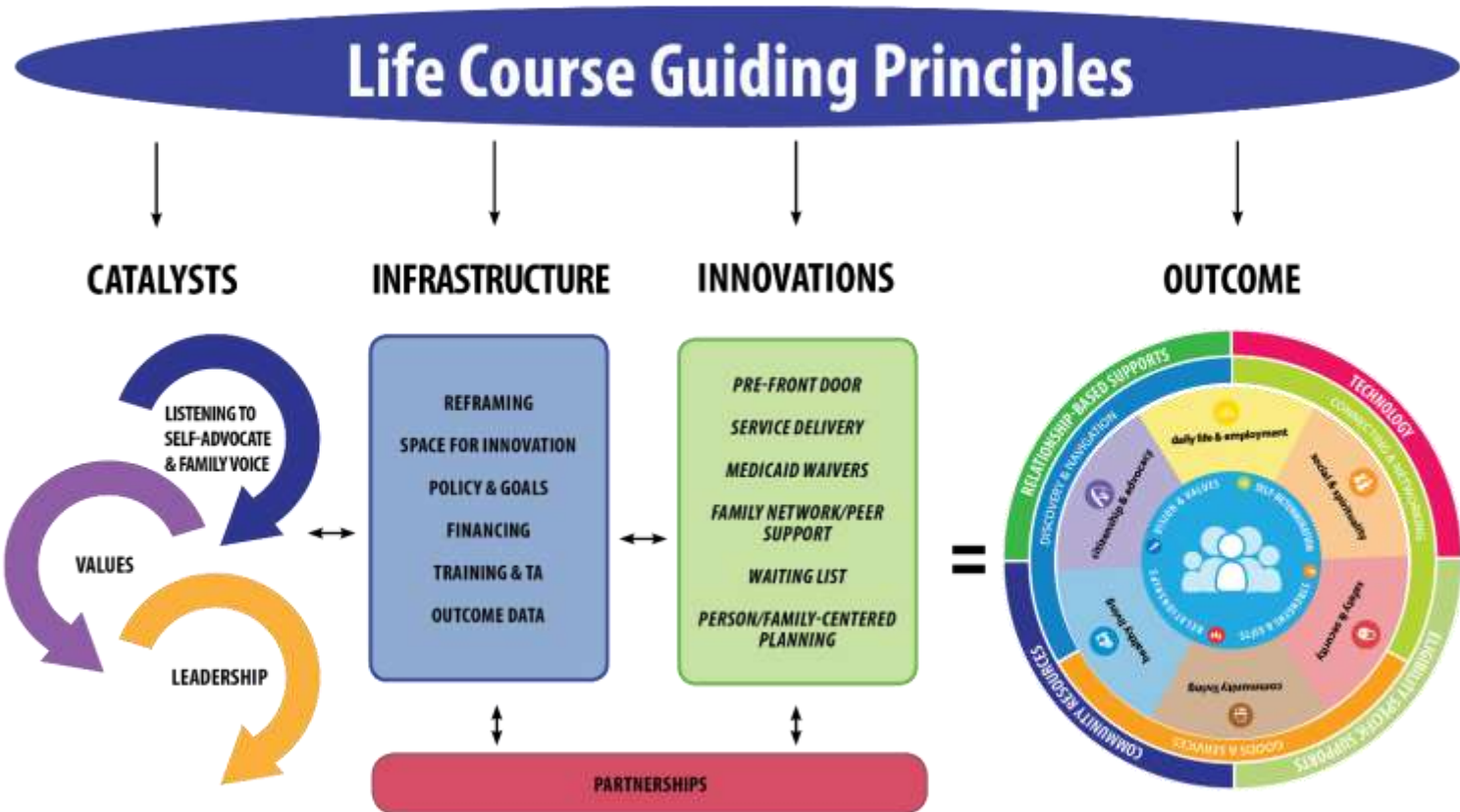
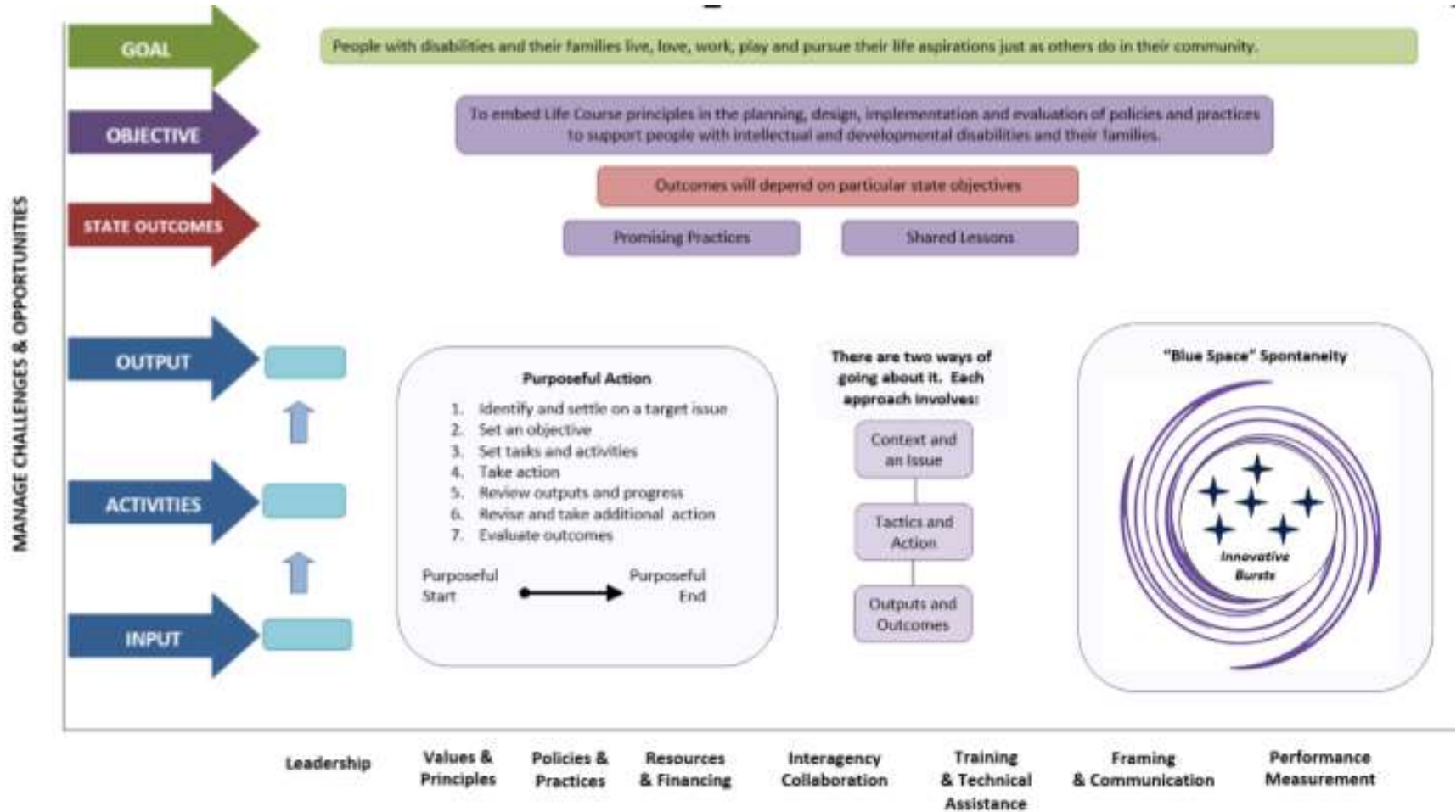Adapted from Hall et all, 2007

*Adapted from SELN Framework

Capturing Our Learning

Stages of Development

Active
Members engage in developing a practice

Coalescing
Members come together and recognize their potential

Dispersed
Members no longer engage very intensely, but the community is still alive as a force and a center of knowledge

Potential
People face similar situations without the benefit of a shared practice

Memorable
The community is no longer central, but people still remember it as a significant part of their identities

Typical Activities

Finding each other, discovering commonalities

Exploring connectedness, defining joint enterprise, negotiating community

Engaging in joint activities, creating artifacts, adapting to changing circumstances, renewing interest, commitment, and relationships

Staying in touch, communicating, holding reunions, calling for advice

Telling stories, preserving artifacts, collecting memorabilia

time

Capturing Our Learning

supportstofamilies.org

Questions, Reflections and Discussion

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