INNOVATIONS IN SUPPORTING FAMILIES

COMMUNITY OF PRACTICE FRAMEWORK FOR SYSTEMS CHANGE WEBINAR SERIES

LifeCourse in Action:

Informing Families in Washington State

1/26/2017

NASDDDS

UMKC
INSTITUTE FOR HUMAN DEVELOPMENT
A University Center for Excellence in Developmental Disabilities (UCEDD)

HSRI

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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.

ADMINISTRATION ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

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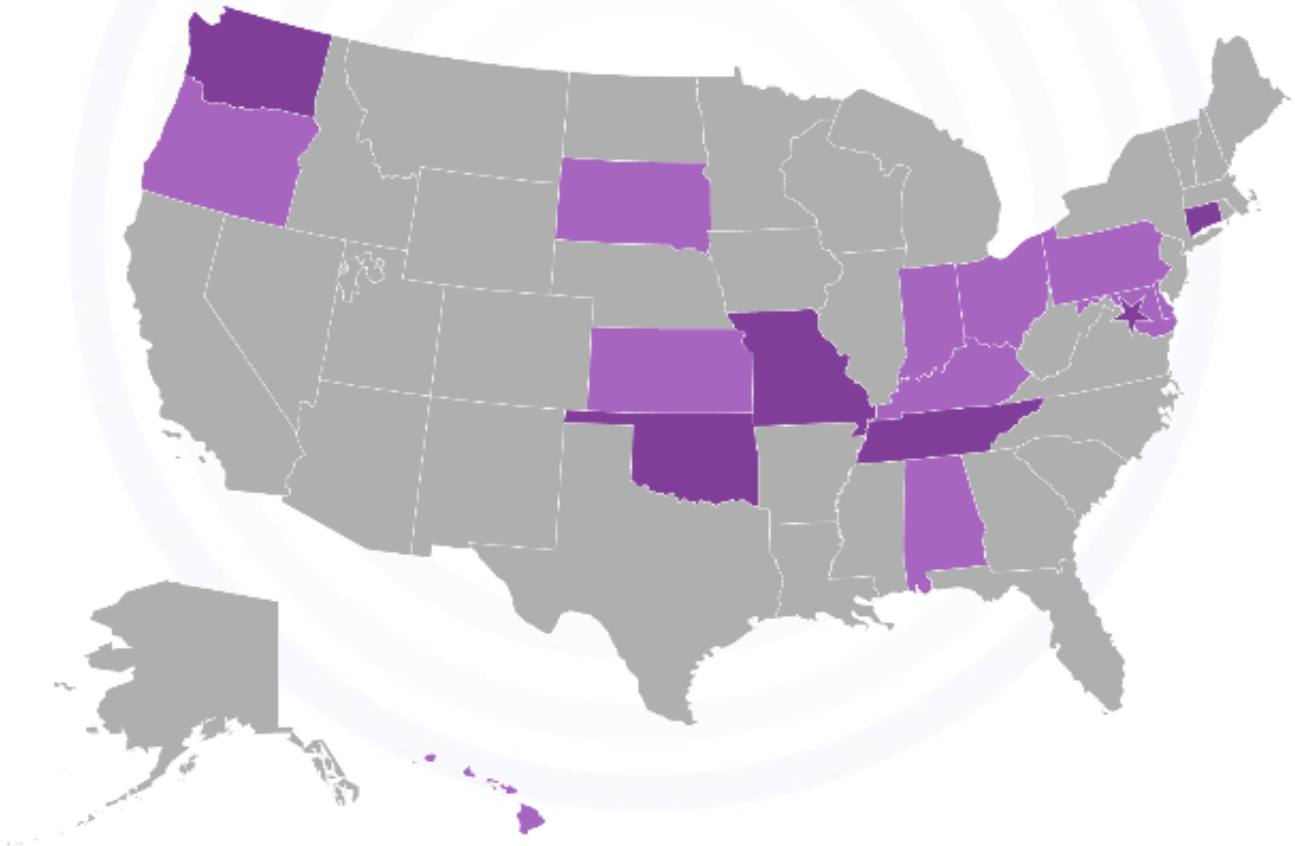
Community of Practice Expansion

11 new states July 2016



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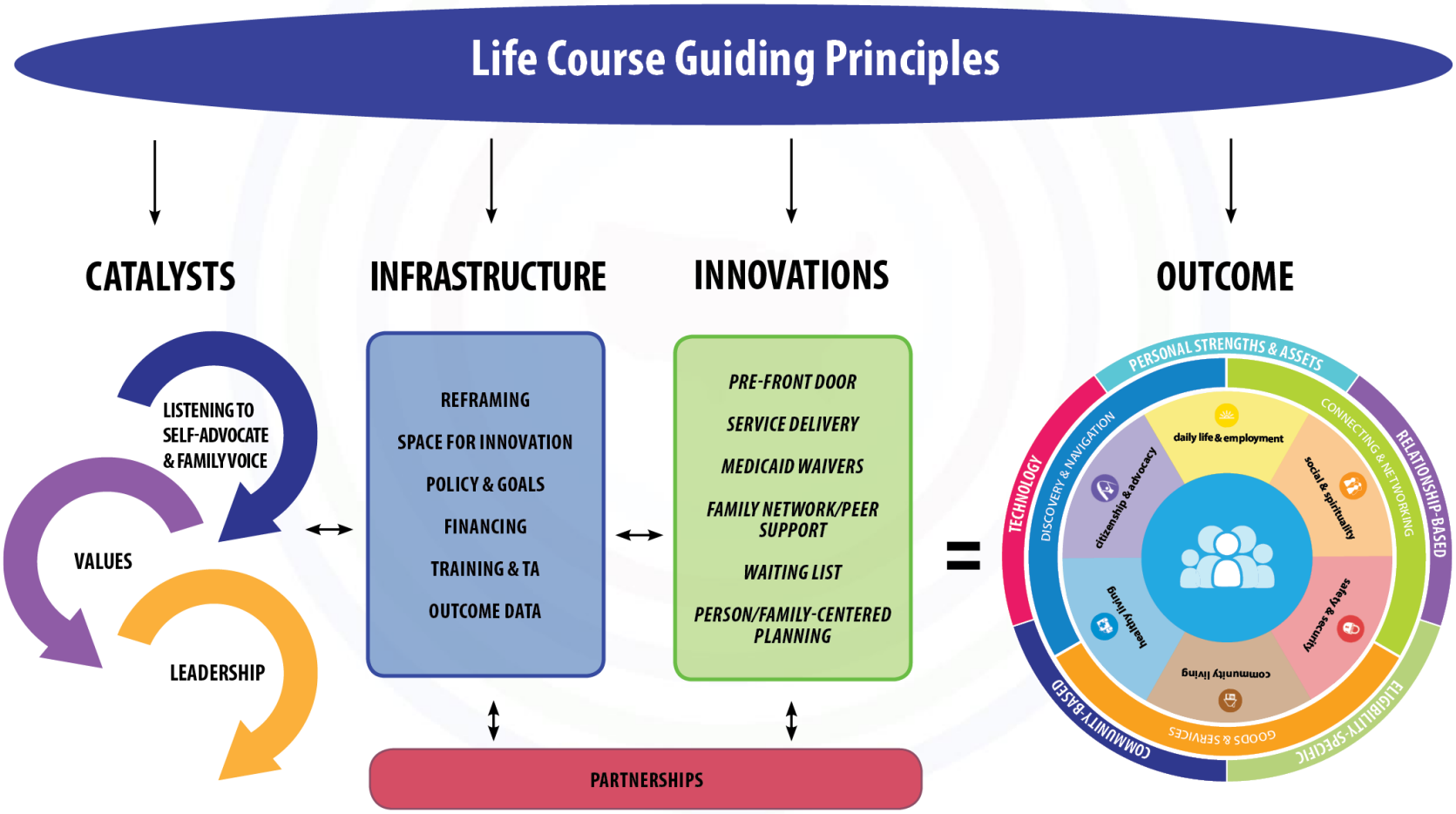
National CoP for Supporting Families Framework for Systems Change



Michelle "Sheli" Reynolds, PhD. UMKC Institute for Human Development, UCEDD. Revised June 2014. Adapted from Hall et all, 2007

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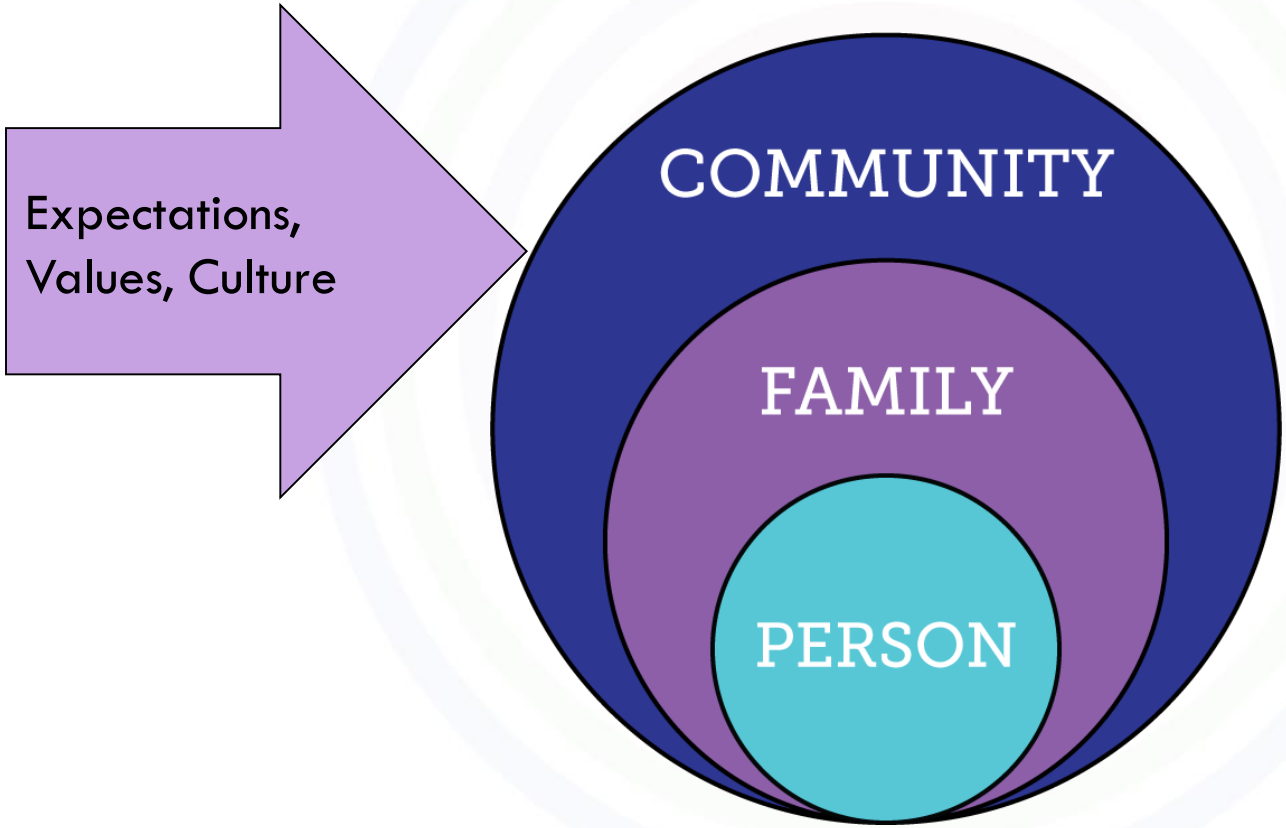
Current Reality of Supports



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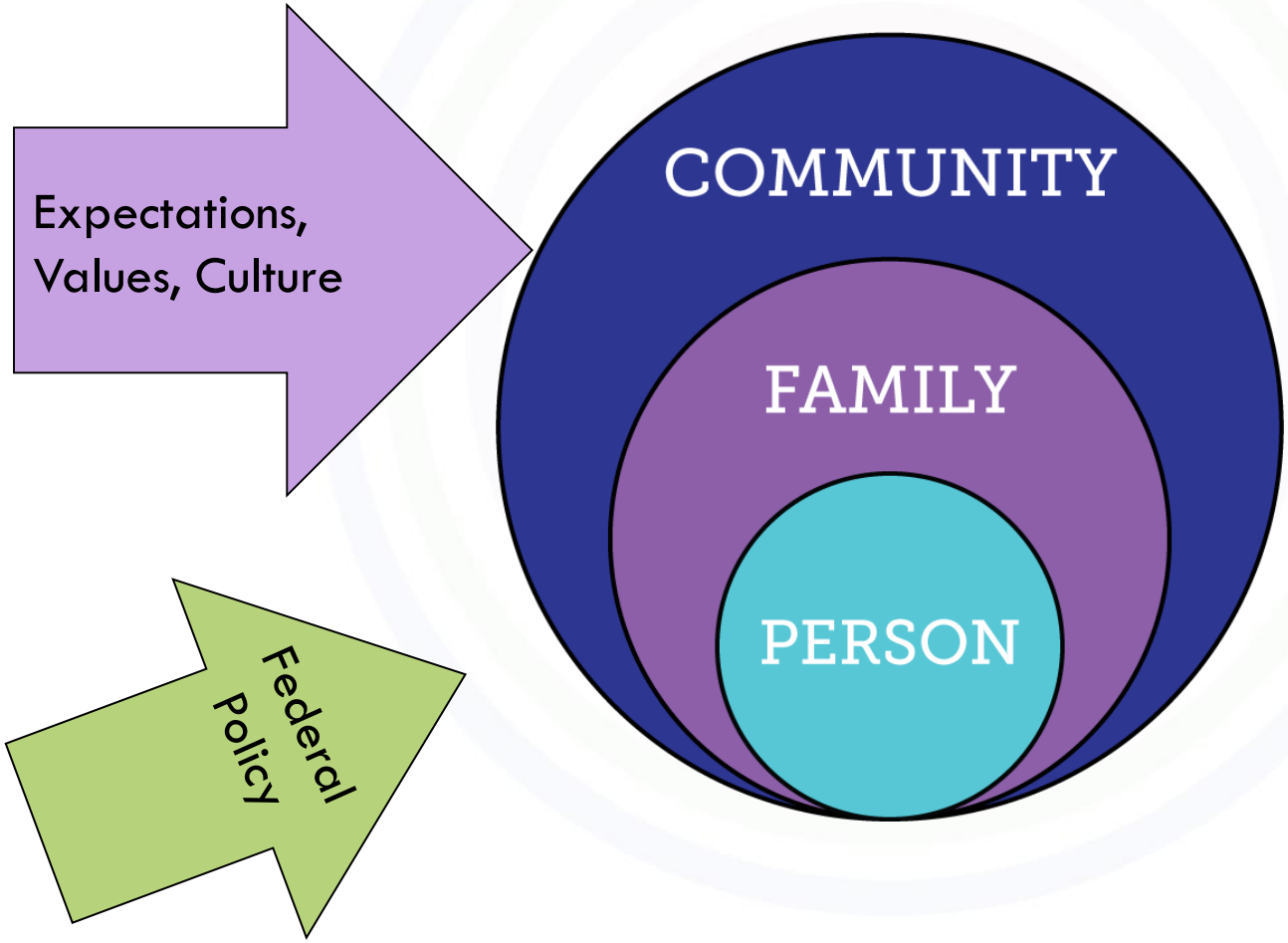

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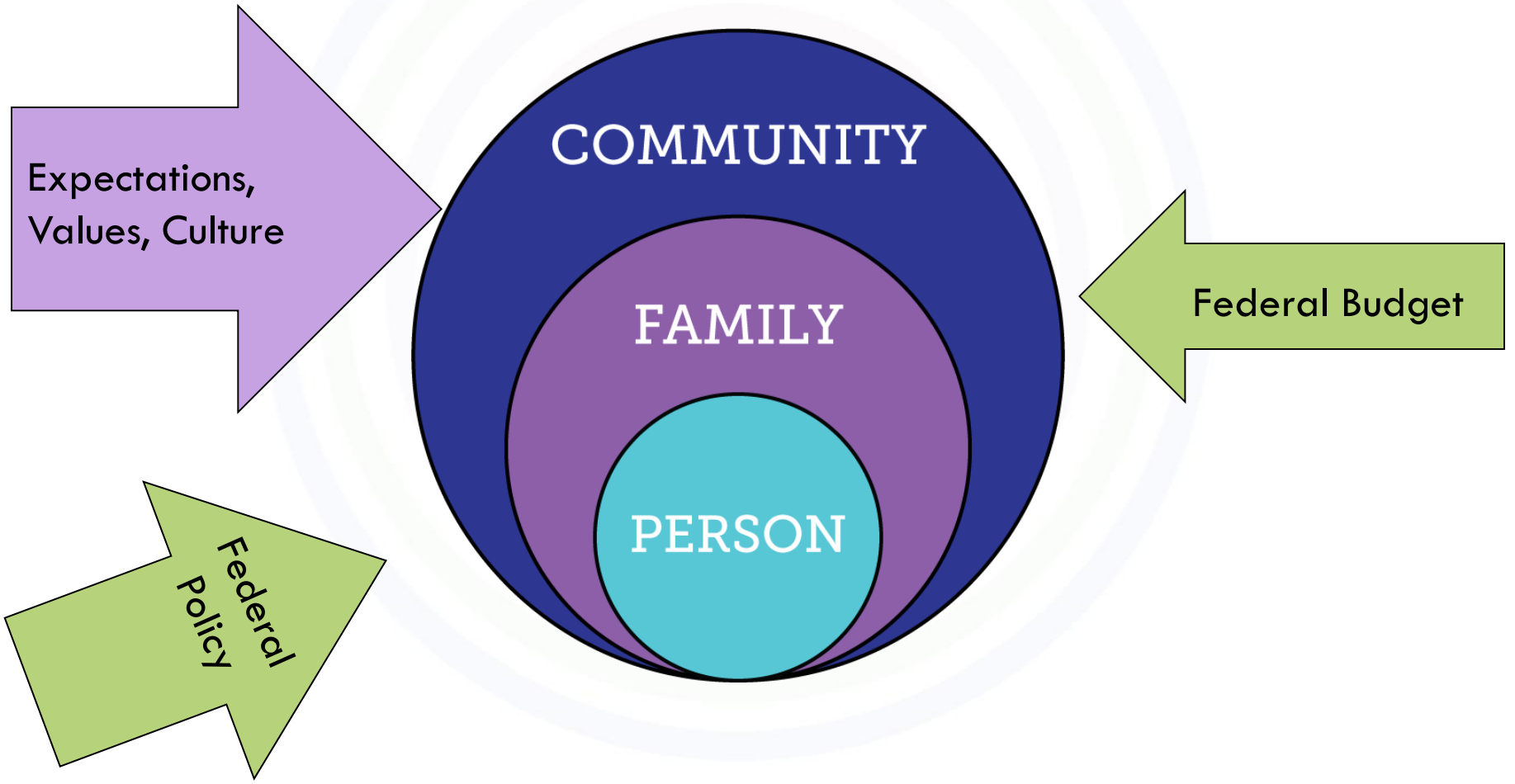

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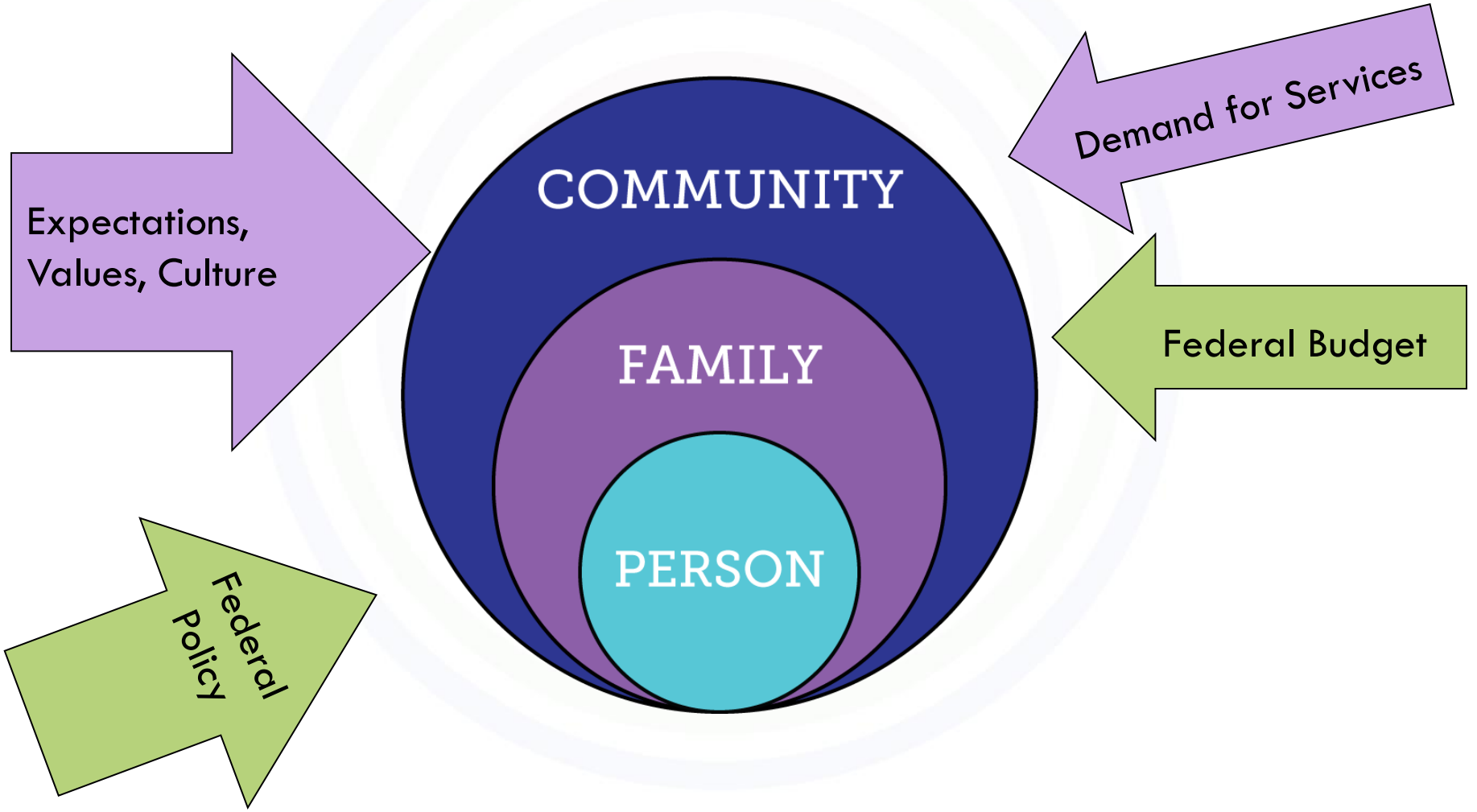

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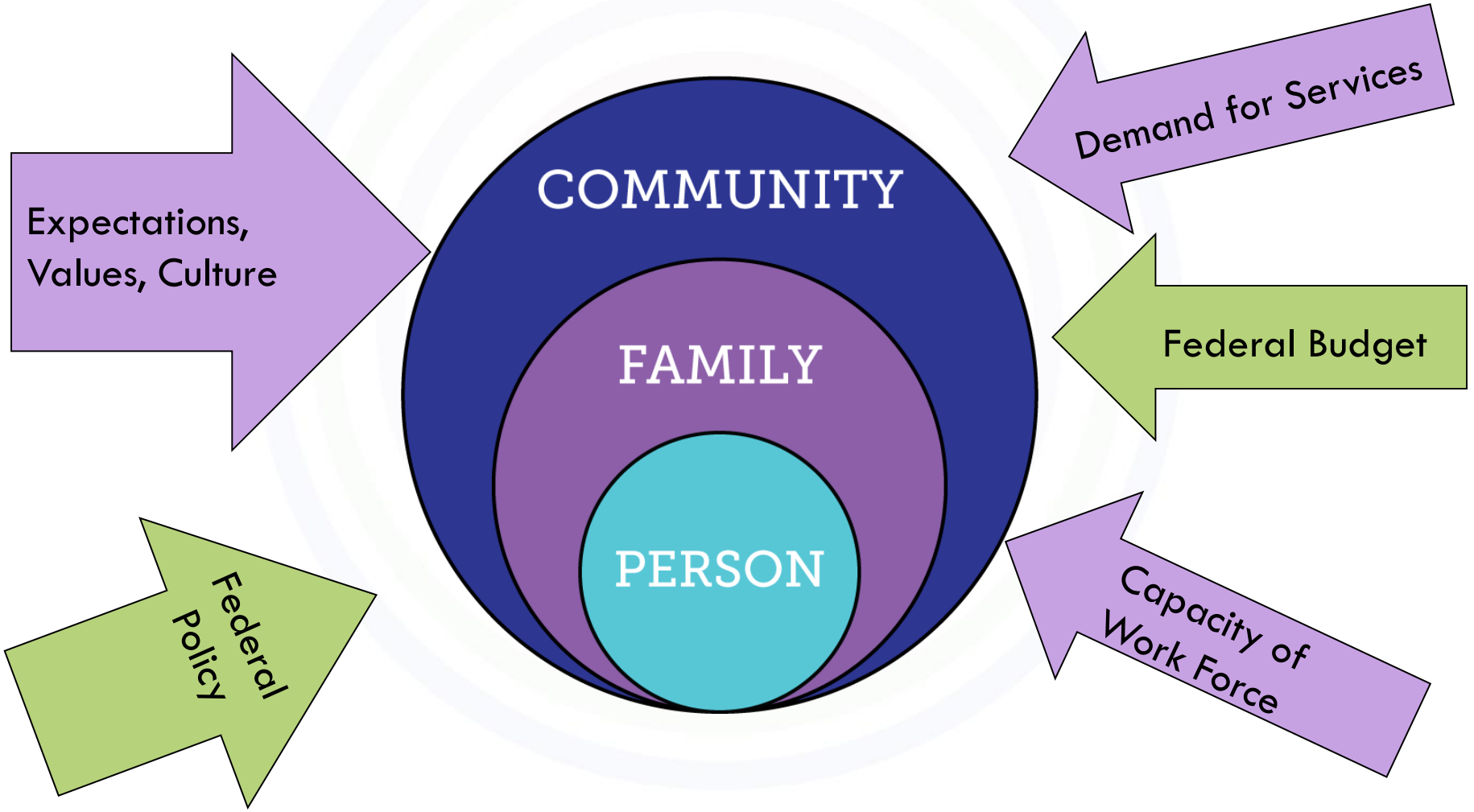

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Setting the Stage

Everyone exists with in the context of their family and community.

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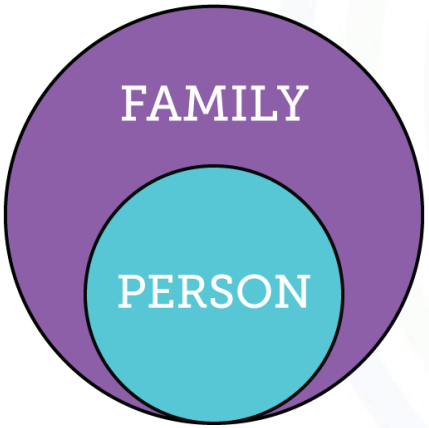

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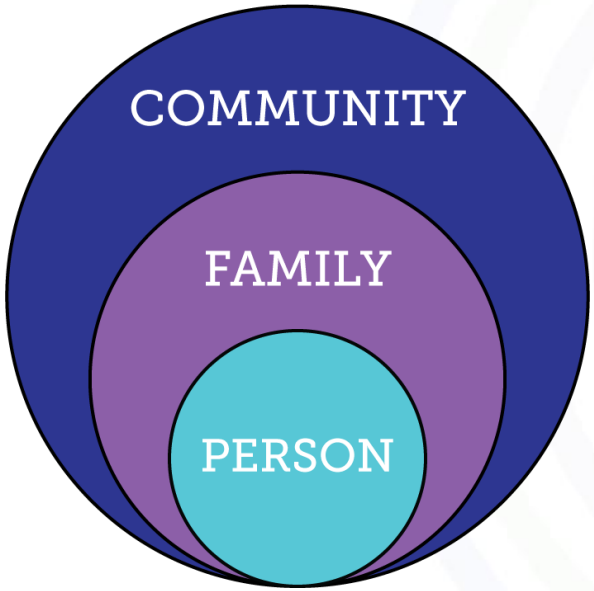

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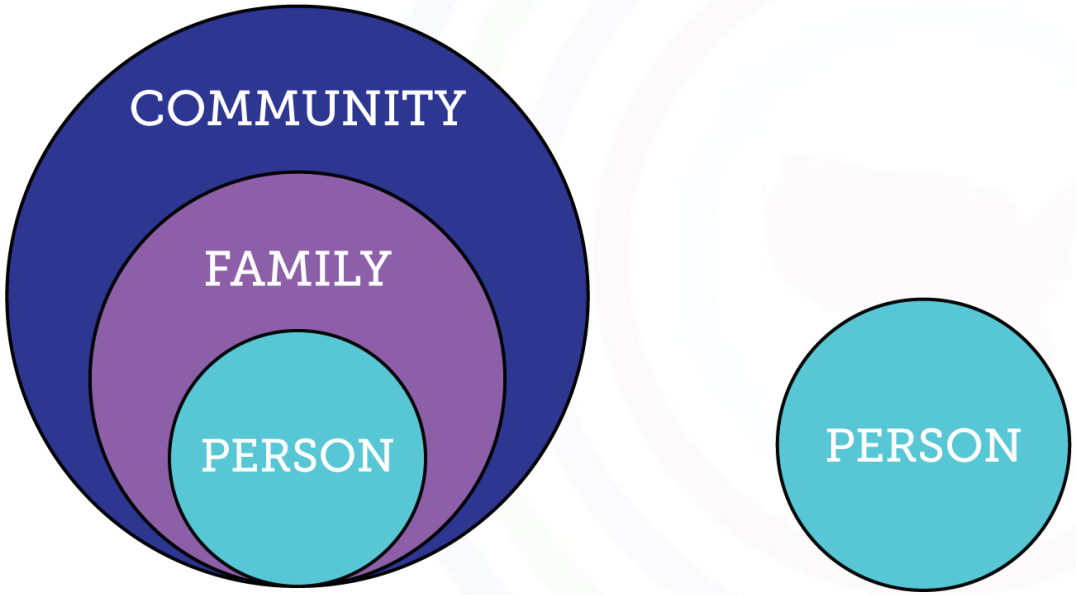

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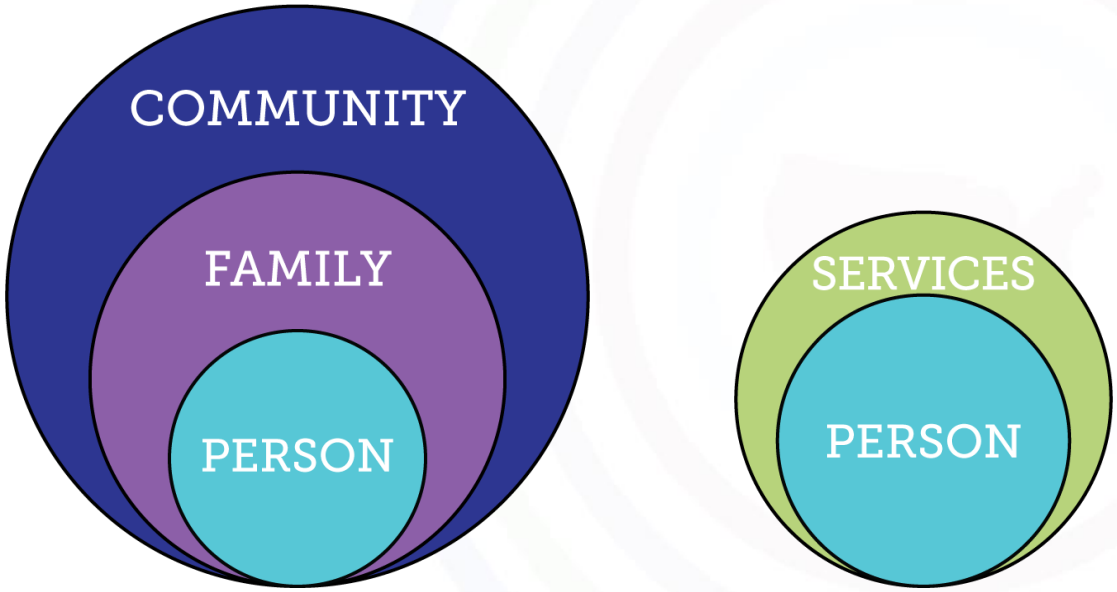
Setting the Stage

But, with the best of intentions….



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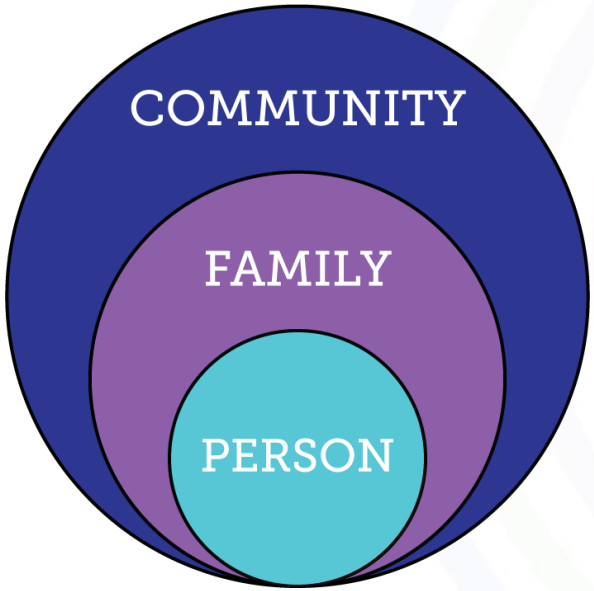

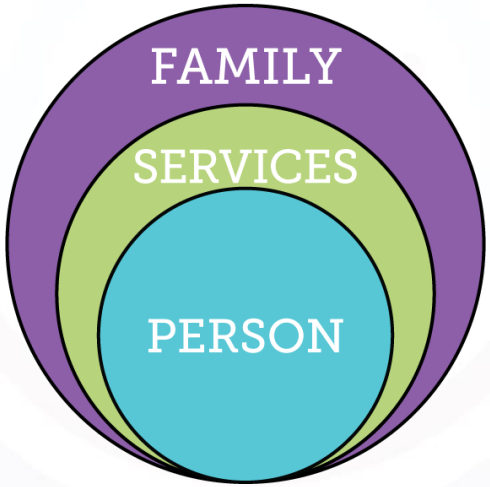

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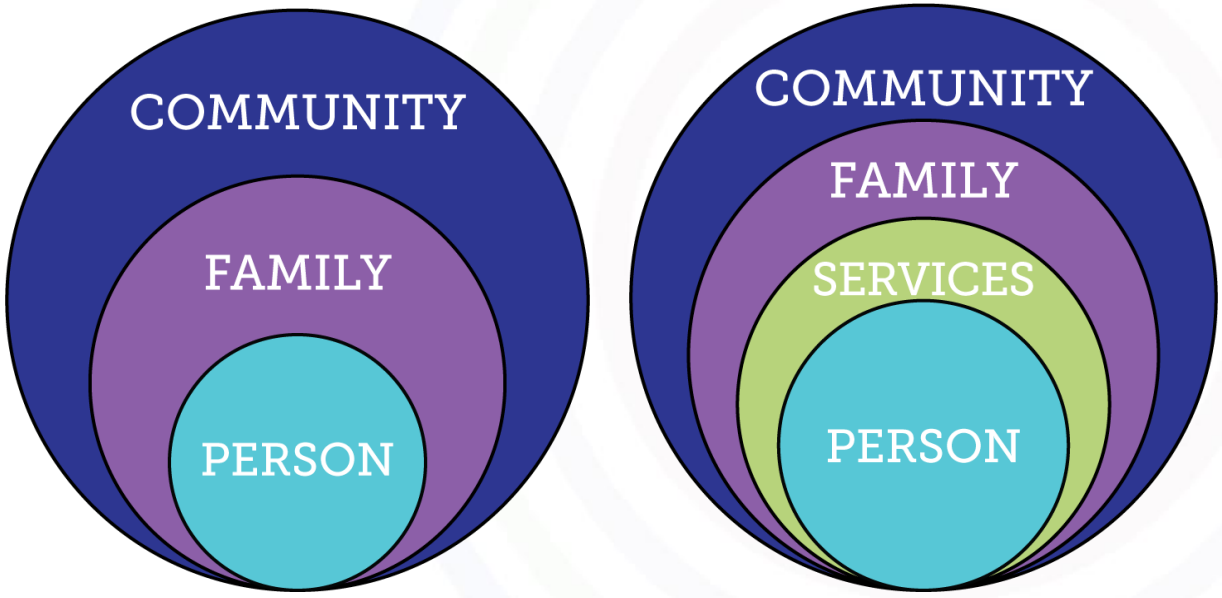

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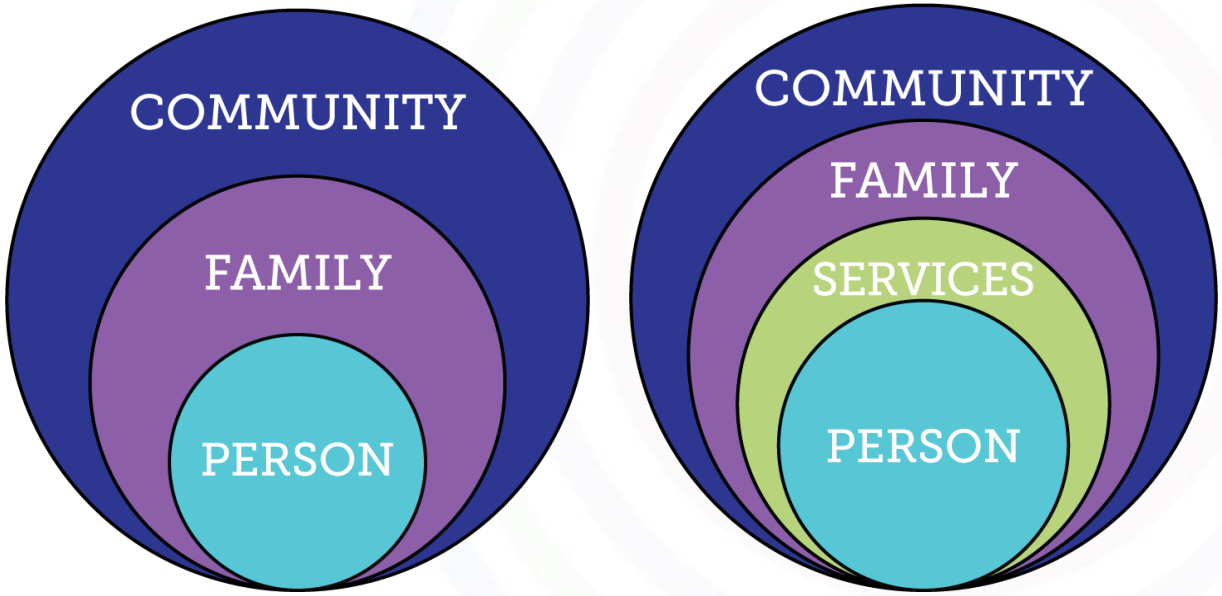
Setting the Stage

Our Vision…



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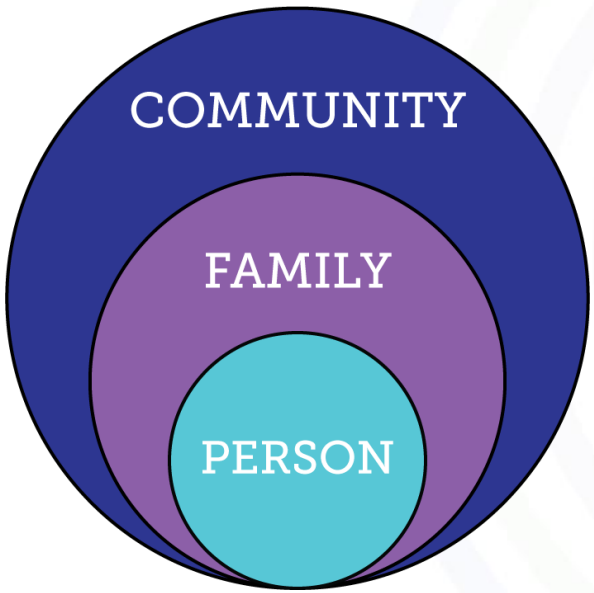
Setting the Stage

Integrated Services and Supports within context of person, family and community



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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

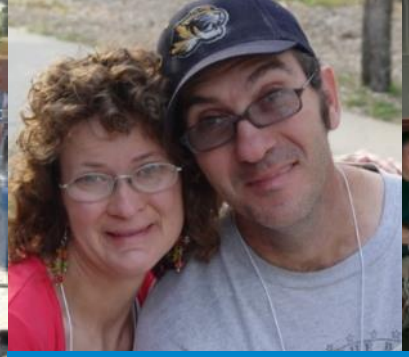
Transformational Change

- 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

The LifeCourse Framework

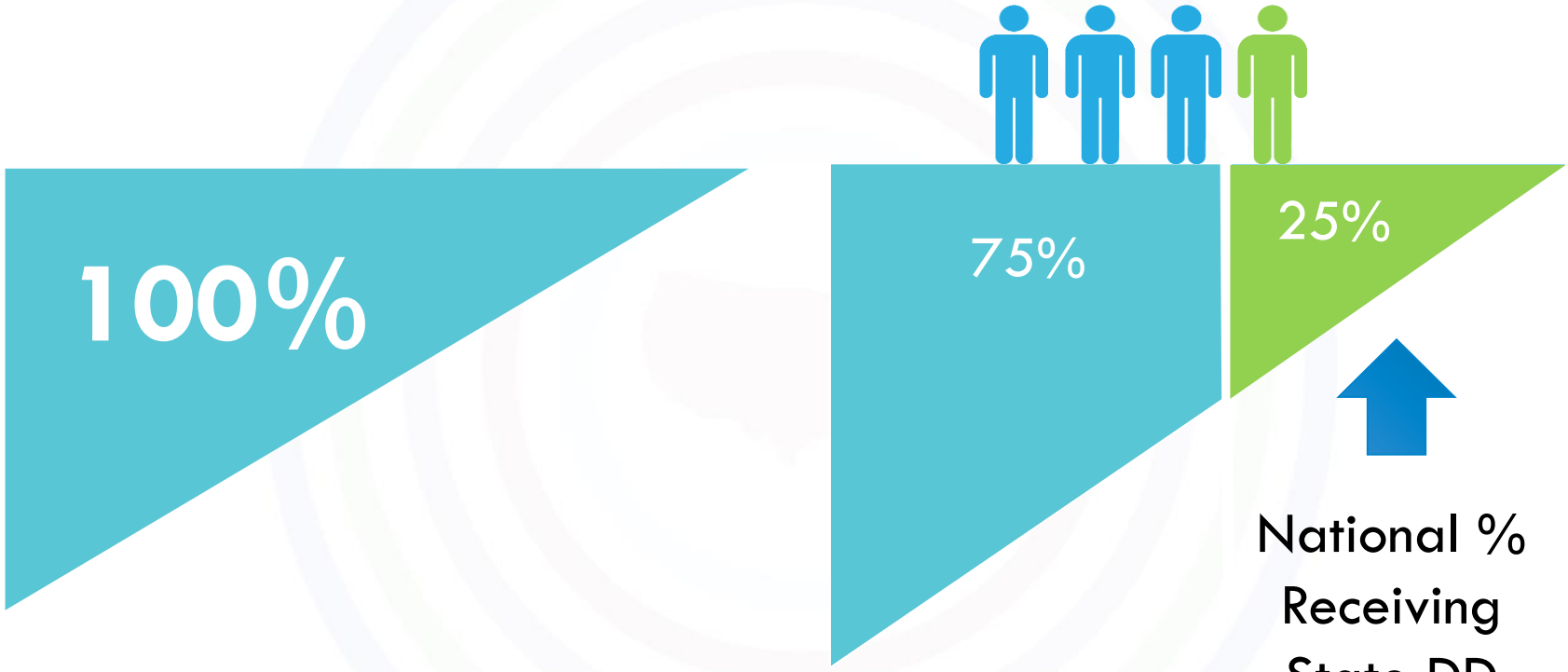
Introduction



All people
have the right to live,
love, work, play and
pursue their dreams
in their community.

Focus on "ALL"

1 in 4 Persons with I/DD Receive Formal State DD Services



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 1.55%*

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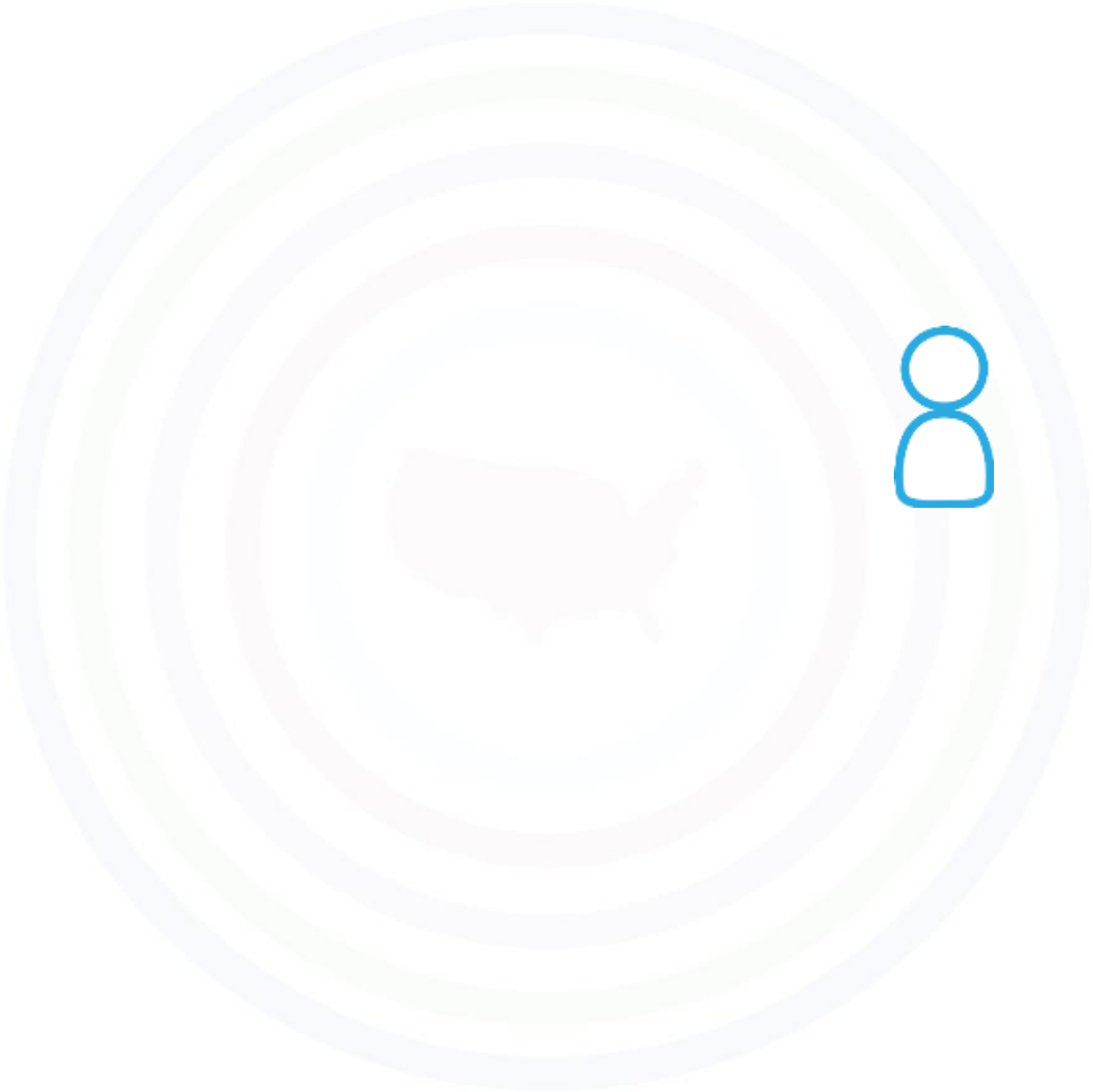

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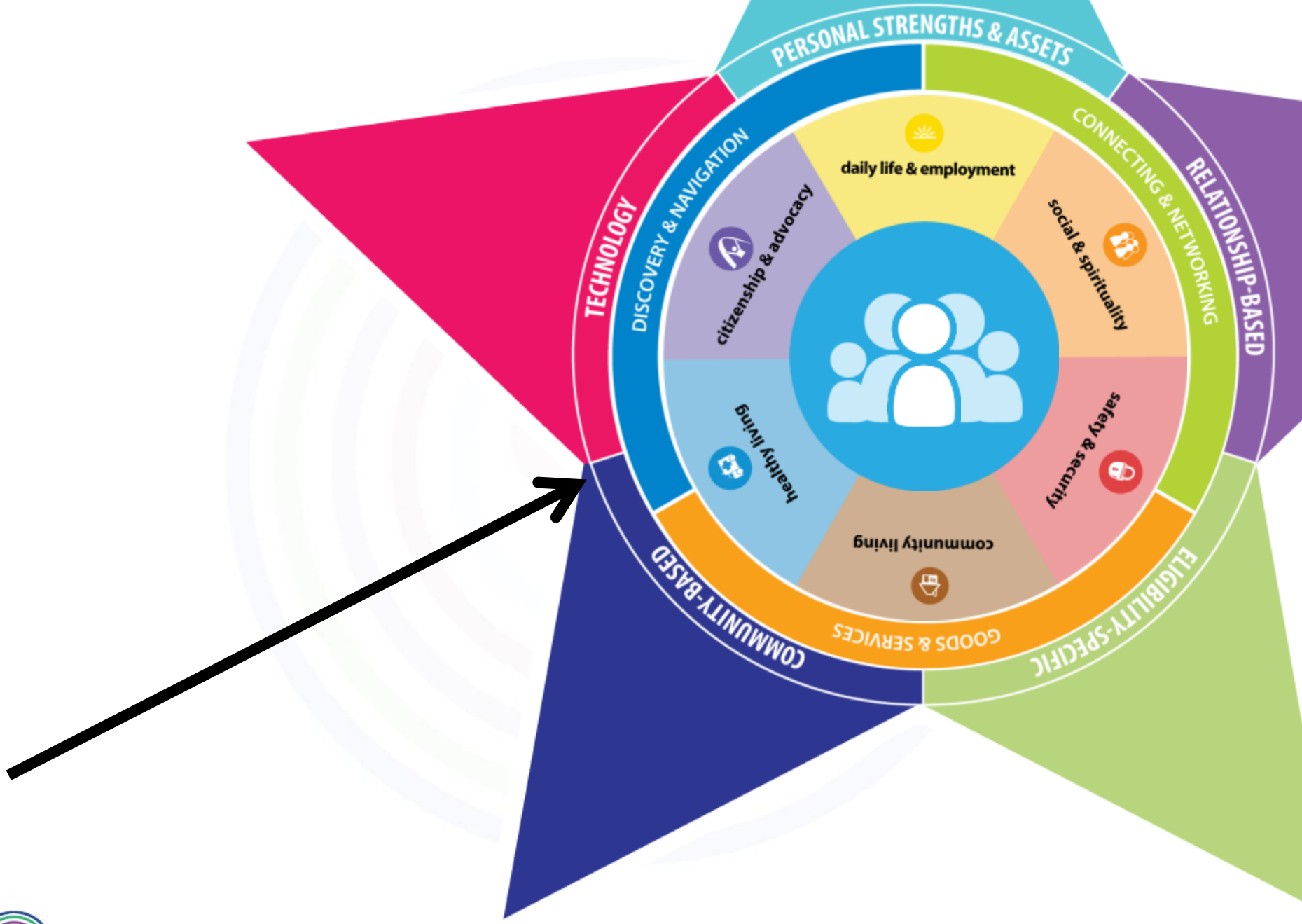

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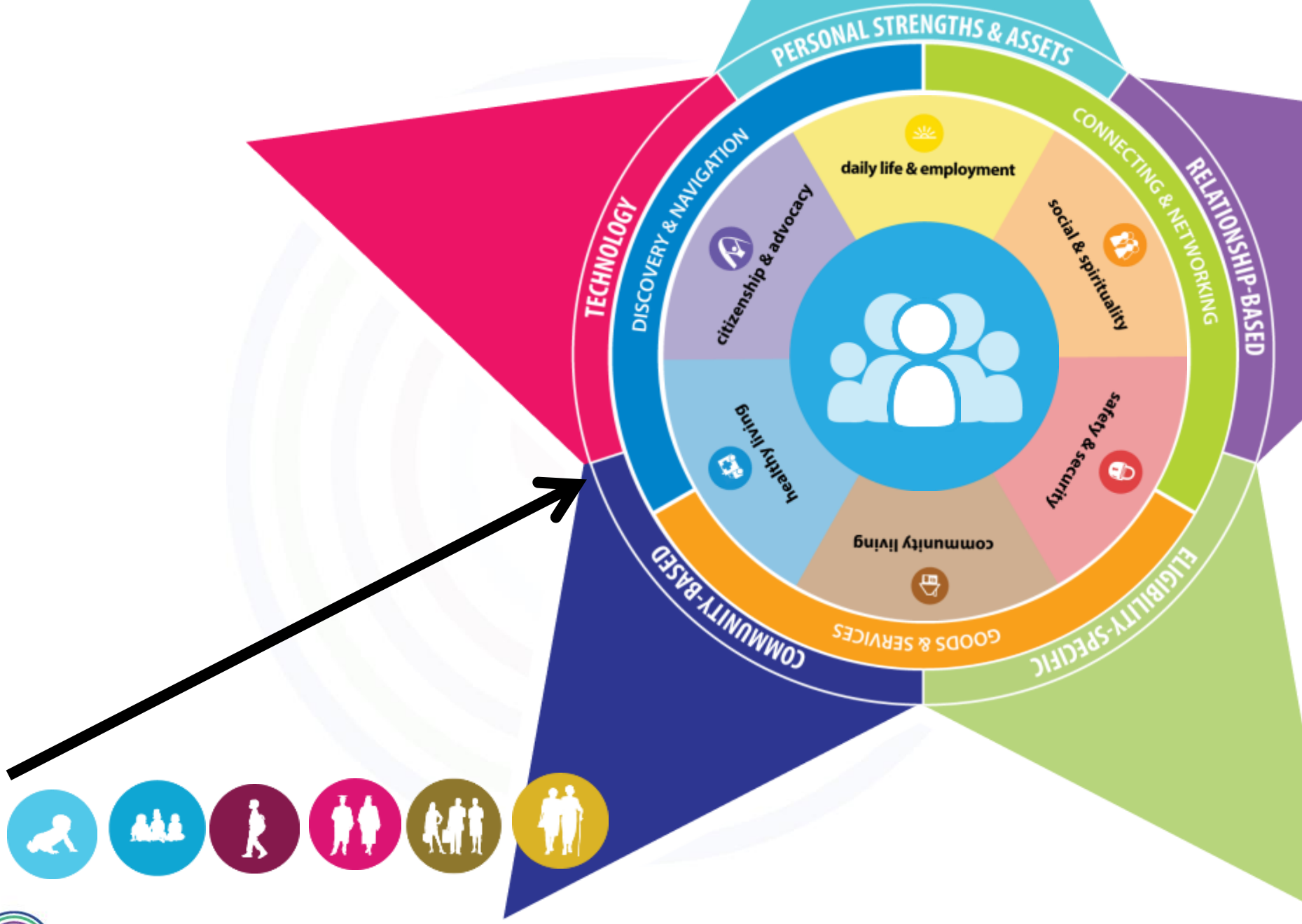

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Outcomes for Today's Webinar

1. Understand the principles of the LifeCourse framework,
2. See how the WA Community of Practice has been working to enhance supports to individuals with I/DD and their families at the systems level
3. Hear examples of how the LifeCourse framework is informing work at the regional level with families of diverse backgrounds
4. Watch how the LifeCourse is working at the county level to improve the lives of individuals with DD and their families

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Informing Families in Washington State

MEANINGFUL LIVES

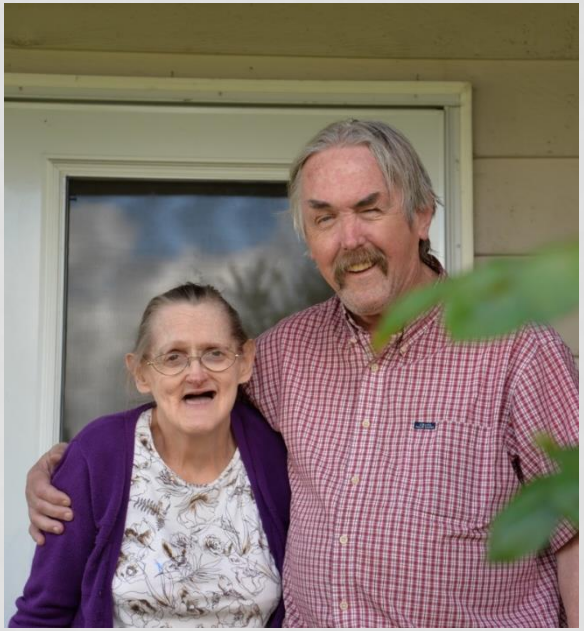
Over the Life Course

WASHINGTON STATE COMMUNITY OF PRACTICE
Ideas that Last

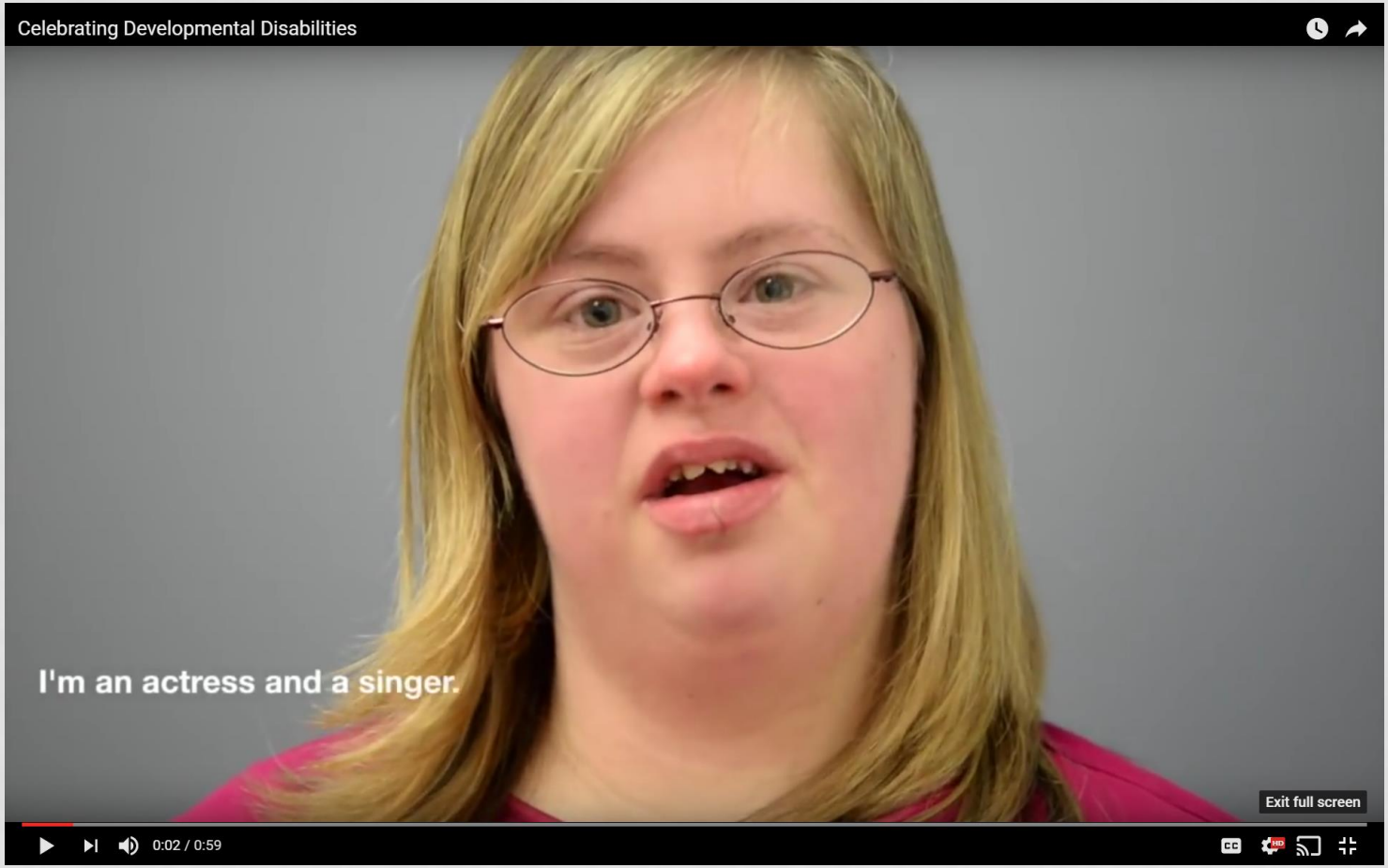
OUR CONTEXT

Washington selected five areas of focus:

1. Older individuals living at home with parents/families
2. Adult Siblings assuming support roles
3. Parents with intellectual and developmental disabilities
4. Front Door Entry
5. Starting difficult conversations



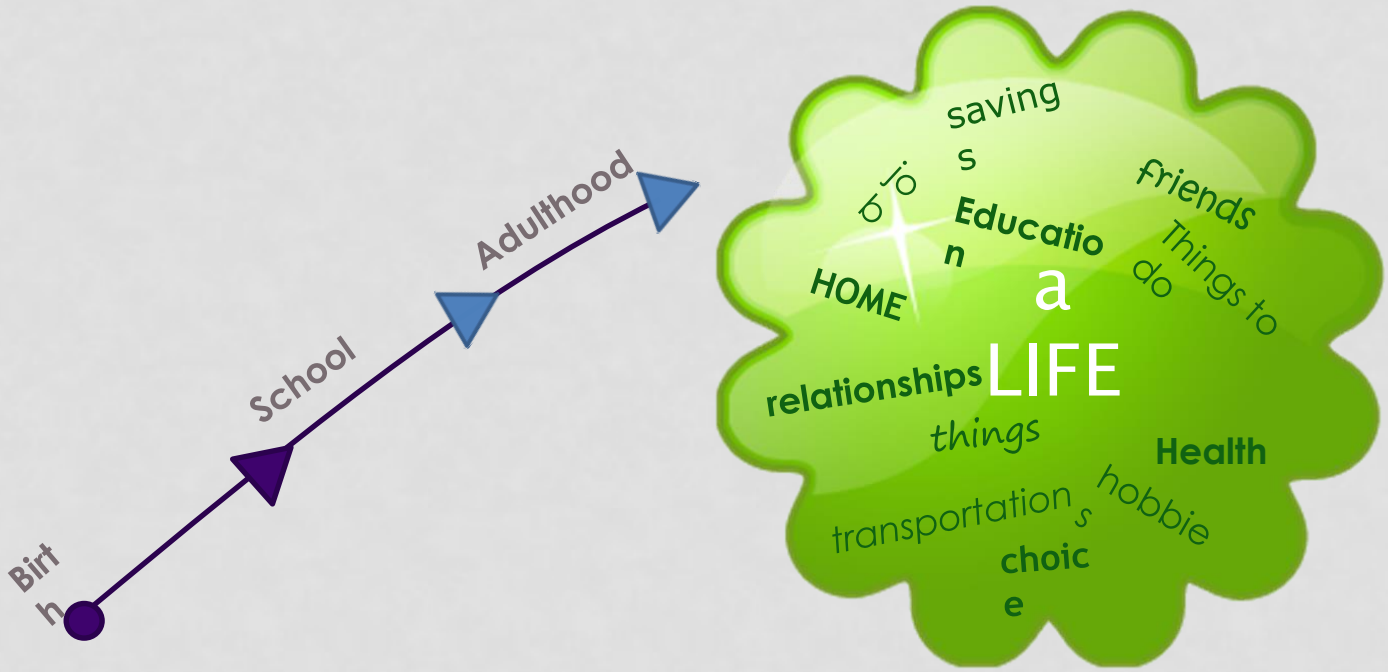
JUST LIKE YOU

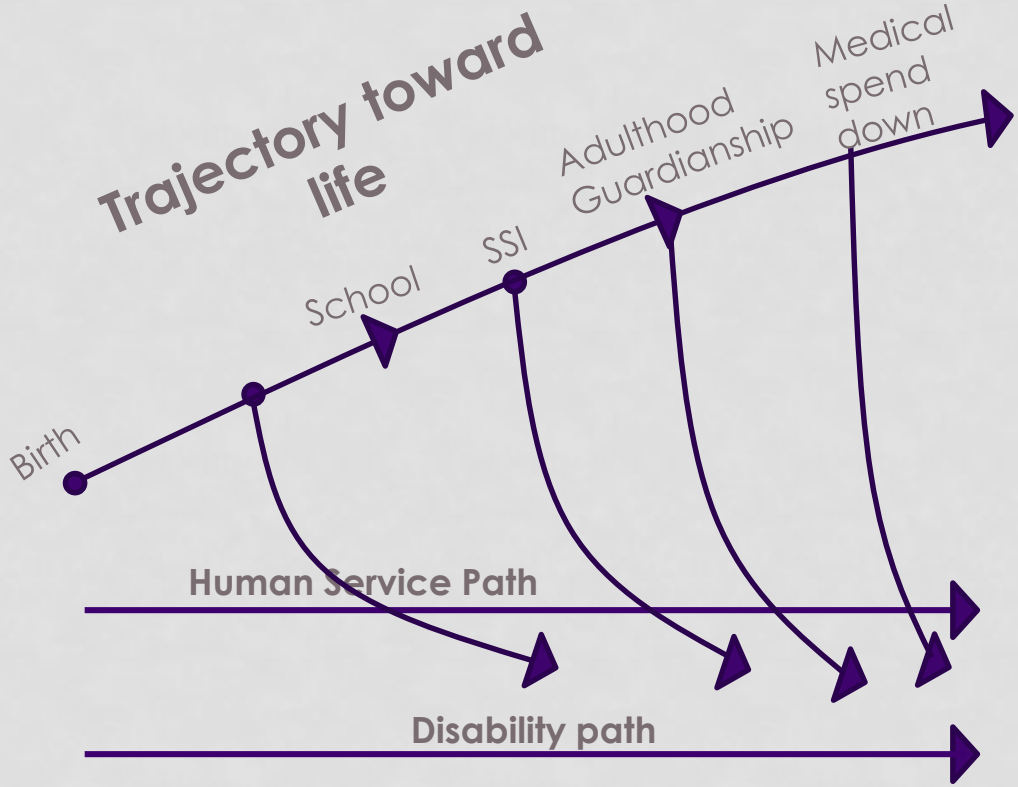


https://www.youtube.com/watch?v=0b5c4KUcAFI

VISION FOR PEOPLE

TRAJECTORY TOWARD A LIFE

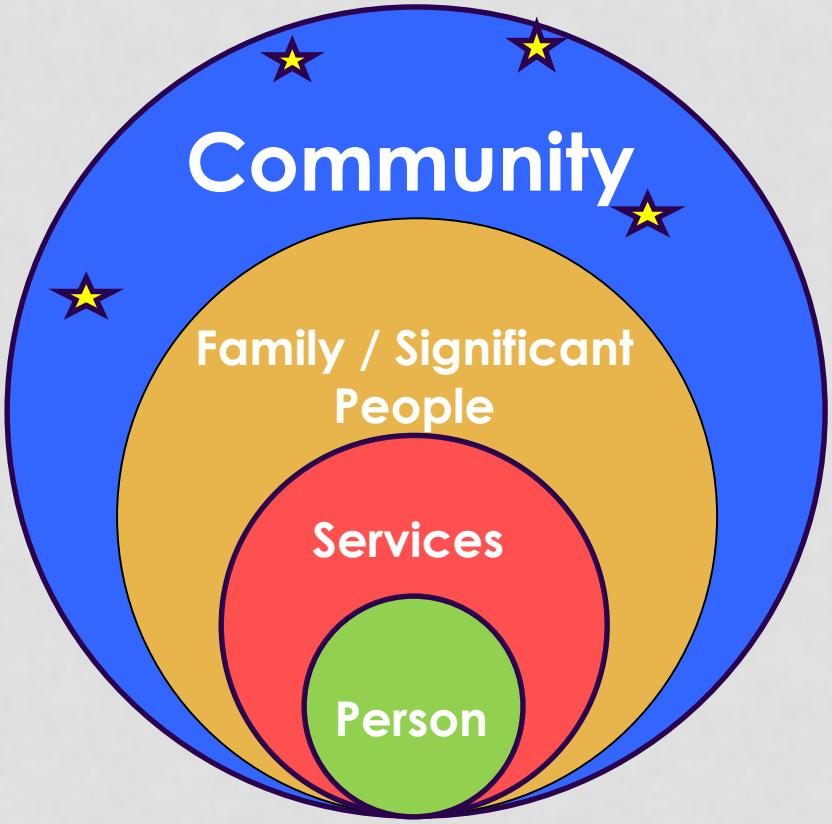



Trajectory toward life
Birth
School
SSI
Adulthood Guardianship
Medical spend down
Human Service Path
Disability path

a
Life

LABELED
WORLD

OLD MODEL

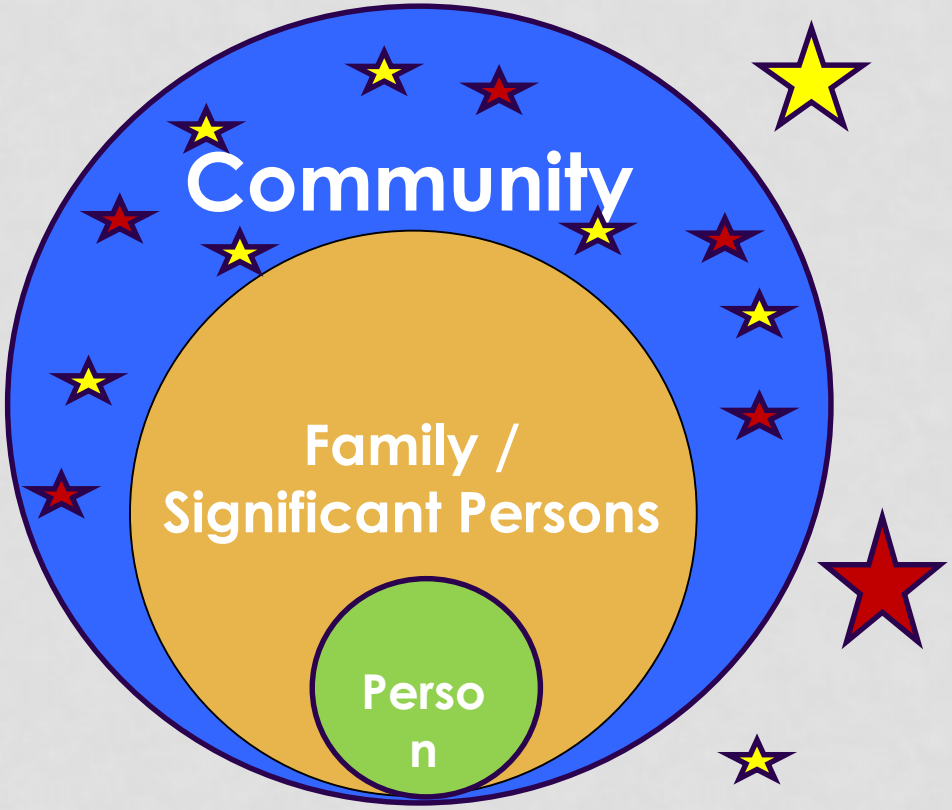


Services meet the person's needs...

Wall the person off…

Isolate from community.

COMMUNITY OF PRACTICE VISION



Supports a person might obtain

Services *for* a person

LIVING MEANINGFUL LIVES

- Just like you
- Across the life span
- Making it last

WINDOWS OF OPPORTUNITIES

Improving Supports

PERSON CENTERED PRACTICES and the DDA ASSESSMENT-CHANGING PRACTICE

DDA considered the release of the 2014 Centers for Medicare and Medicaid Services (CMS) standards for person centered practices a natural extension of long held values that have guided how we approach supporting individuals with disabilities and an opportunity to better align our assessment and planning processes with the LifeCourse principles.

LEGISLATIVE ACTION: HB 2746

- Directed the refinancing of Medicaid Personal Care using the 1915k Community First Choice Option.
- Enhanced 6% federal match created savings for service system reinvestment.

Washington State-Community First Choice

- A new Medicaid state plan option assists individuals to access:
  - Personal Care;
  - Skills Acquisition Training;
  - Back-up Systems;
  - Training on caregiver management; and
  - Assistive Technology.

LEGISLATIVE ACTION: SB 6387

Investment in Developmental Disabilities Services

- 4,000 more served by new Individual and Family Support waiver; and
- 1,000 more served by Basic Plus waiver by June 2017.

IFS Waiver

- The objective of the IFS Waiver is to supplement natural support systems and develop and implement supports and services to successfully maintain individuals in their family homes and communities.

Basic Plus Waiver

- The Basic Plus Waiver provides increased supports for individuals living in their family or own home and includes employment service.

WE'RE CHANGING THE CONVERSATION

At every level…

TO LIVE A MEANINGFUL LIVE

You need…

- Information you can access and understand.
- Time to plan, then engage.
- Technology for greater independence and connection.

INFORMING FAMILIES

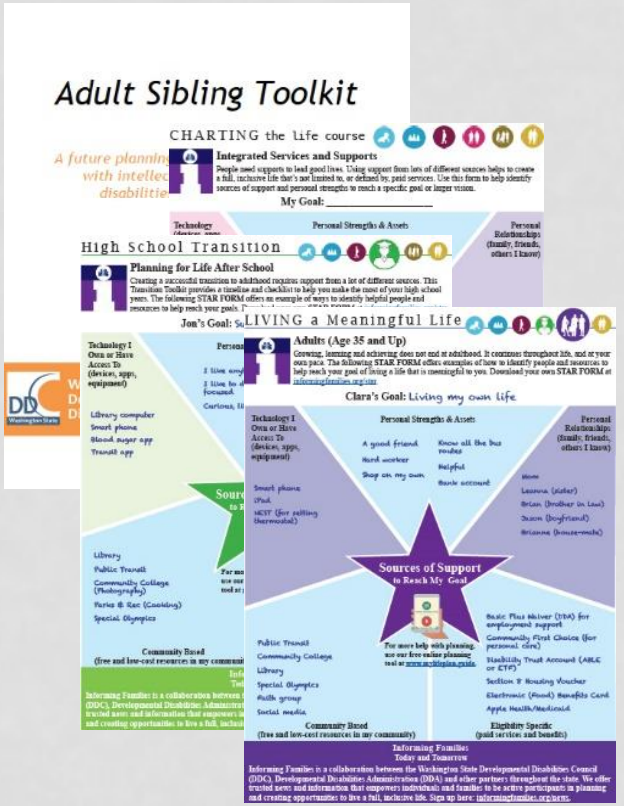
www.informingfamilies.org

PLANNING: IT'S ABOUT ME

- Person centered planning application
- One pagers on person centered planning
- Training DDA case resource mangers
- Making the annual assessment more person centered

TOOLS TO HELP PEOPLE

- Adult Sibling Tool Kit (online)
- Early Welcome Four Pager
- Transition from School to Adulthood Four Pager
- Living the Middle Years Four pager
- Community Connections Guidebook
- Local Community of Practice Workshops; Supporting Local Strategies

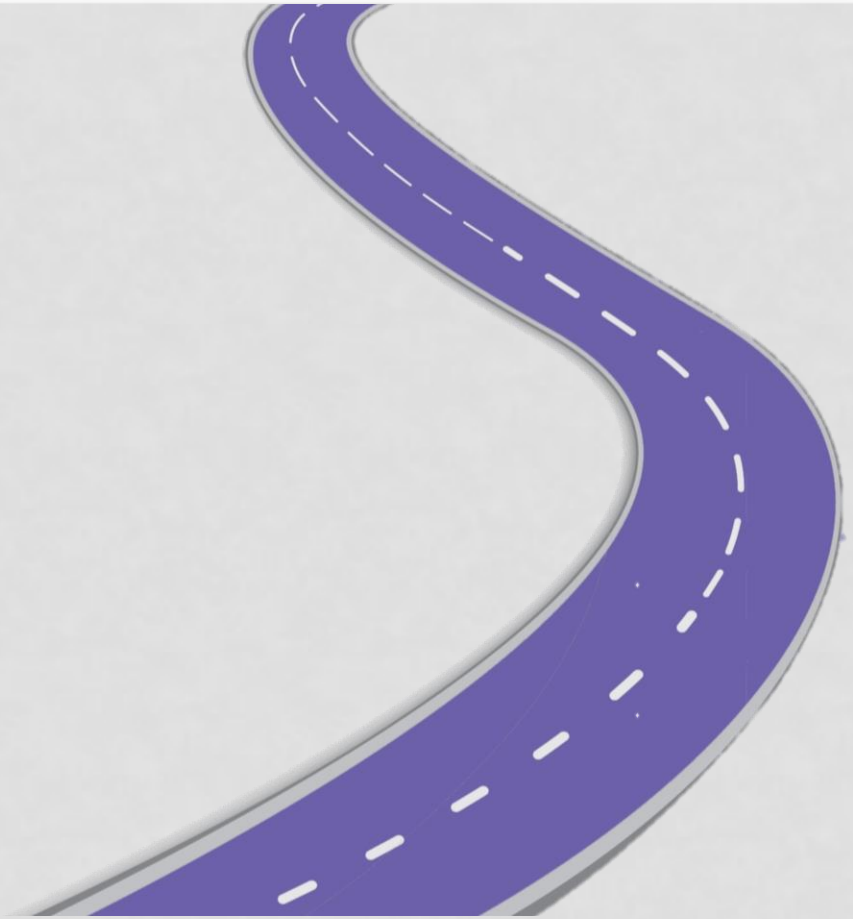


IMPORTANT CONVERSATIONS

Adults having important conversations with parents or families are important but hard to start. https://www.youtube.com/watch?v=REne9rXqSRY

MOVING FORWARD

- Informing People about supports and community resources
- Technology opening new doors or falling way behind
- Supported Housing: Planning and Consultation
- DDA assessment modernization



OPEN DOORS FOR MULTICULTURAL FAMILIES

WHO WE SERVE

Culturally & Linguistically Diverse families who have loved ones with developmental/intellectual disabilities & special health care needs

MISSION

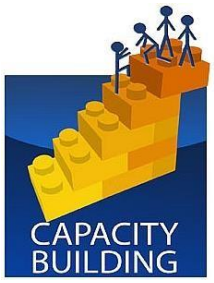
Equal access to culturally and linguistically appropriate information, resources & services

MULTICULTURAL PARENT TRAINING & INFORMATION CENTER PROGRAM

CLD youth & families:

➢**Increase knowledge** about transition & related services in their primary language

➢**Increase access** to culturally responsive transition related services



Service System & Professionals

➢**Increase capacity** to meet the need of CLD youth and their families

LIFE AFTER HIGH SCHOOL:

A GUIDE FOR CULTURALLY AND LINGUISTICALLY DIVERSE FAMILIES OF YOUTH WITH DISABILITIES

- Transition related info & resources in culturally sensitive manner
- Target Languages
  1. Spanish
  2. Somali
  3. Korean
  4. Russian
  5. Chinese
  6. Vietnamese
  7. Tagalog
  8. Arabic

FRAMEWORK APPLICATION

Concept of “Trajectory” and “Vision for future”

Concept of time

Role of family & community

FRAMEWORK APPLICATION: INTEGRATED SUPPORT & SERVICES

Integrated Support and Services

Throughout this manual, we will use the model below to help youth and families explore and organize different types of support. Everyone needs support in life, and using different types of supports and services helps us move toward the life we want. The tool below can help you and your family think about how to find and coordinate the right supports for your future. Types of support may include:

TECHNOLOGY BASED

iPad/smart phone apps, Assistive Technology, adaptive equipment

PERSONAL STRENGTHS & ASSETS

Life experiences, personal knowledge, person/family connections, personality, education, training

RELATIONSHIP BASED

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

INTEGRATED SUPPORTS

School, businesses, faith-based community, public transportation parks & recreation

COMMUNITY-BASED

Developmental Disability Administration (DDA), Division of Vocational Rehabilitation (DVR), Supplemental Security Income (SSI), Medicaid, Food Stamps, Section 8 Housing,

ELIGIBILITY-SPECIFIC

Access the LifeCourse framework and tools at www.lifecoursetools.com/

Meet Mickle and his Integrated Support System

TECHNOLOGY BASED

I use an iPad to set a timer, which tells me when I'm done with my work and activities

I fold pizza boxes at work. My **Assistive Technology,** a frame made with pipe, helps me count 10 pizza boxes!

I like to use gestures to communicate, but I have a **communication device** in case I want to use it for communication.

PERSONAL STRENGTHS & ASSETS

I'm friendly, happy and funny. I'm easygoing and get along with people. I have a good smile. I like helping people! I'm physically strong and active.

RELATIONSHIP BASED

Mom and Dad help me at home and in the community

My sisters are away for college, but they help me when they are home.

My supervisor and coworkers help me at work when I need help with my job

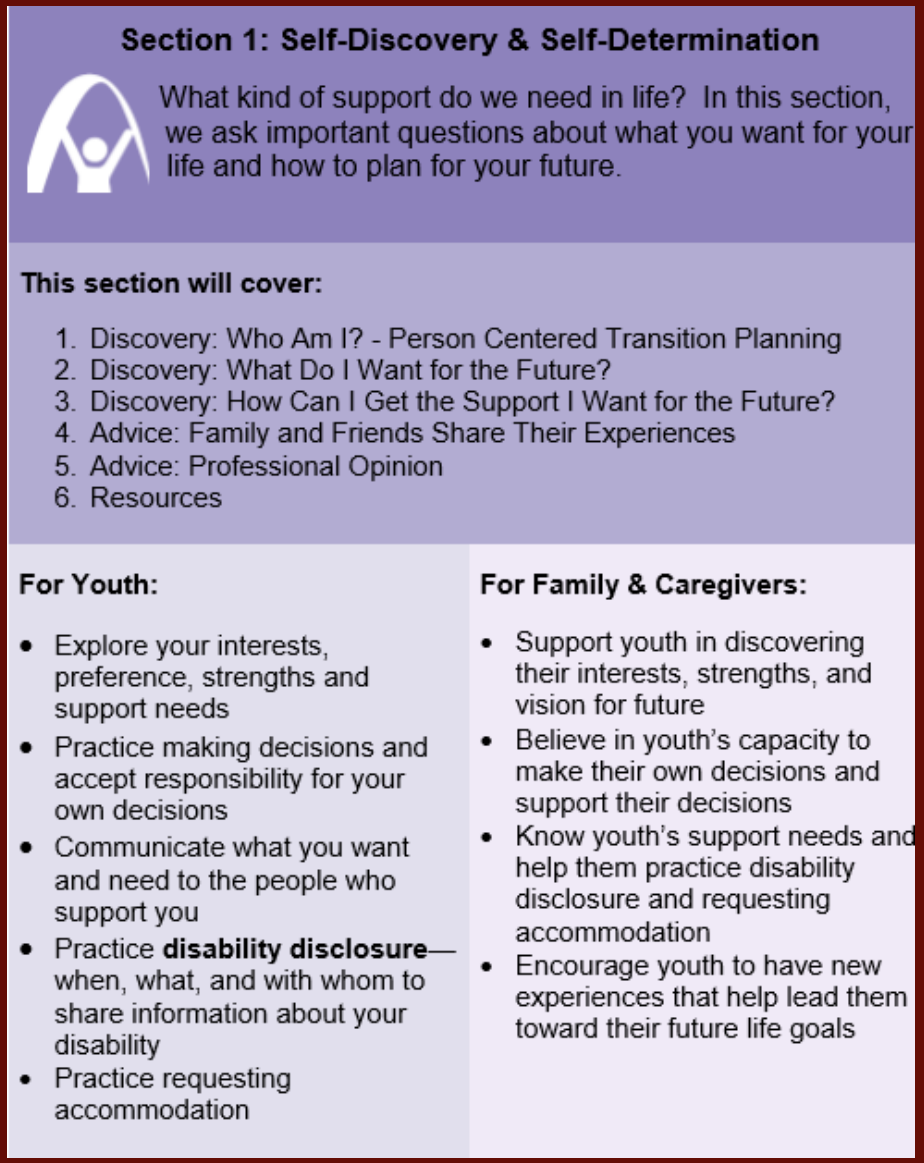
I attend church, and participate in Special Olympics and lots of events and activities through my local Community Center. I meet people there, and they help me when I need support!

COMMUNITY-BASED

My parents helped me apply for services which I qualify for as an adult with a disability. **DDA** funds a caregiver, who takes me to Special Olympics and other activities. **DVR** and my job coach helped me get my pizza job and learn job tasks. I take **Paratransit** service to my work all by myself!

ELIGIBILITY-SPECIFIC

FRAMEWORK APPLICATION: YOUTH VS. FAMILY ORIENTED?



Section 1: Self-Discovery & Self-Determination

What kind of support do we need in life? In this section, we ask important questions about what you want for your life and how to plan for your future.

This section will cover:

1. Discovery: Who Am I? - Person Centered Transition Planning
2. Discovery: What Do I Want for the Future?
3. Discovery: How Can I Get the Support I Want for the Future?
4. Advice: Family and Friends Share Their Experiences
5. Advice: Professional Opinion
6. Resources

For Youth:

- Explore your interests, preference, strengths and support needs
- Practice making decisions and accept responsibility for your own decisions
- Communicate what you want and need to the people who support you
- Practice **disability disclosure**—when, what, and with whom to share information about your disability
- Practice requesting accommodation

For Family & Caregivers:

- Support youth in discovering their interests, strengths, and vision for future
- Believe in youth's capacity to make their own decisions and support their decisions
- Know youth's support needs and help them practice disability disclosure and requesting accommodation
- Encourage youth to have new experiences that help lead them toward their future life goals

- Youth vs. Parents/Guardians, who should be the center of focus?
  - ➢Parents/Guardians continue to play active role in young adult's life in collectivistic culture
  - ➢Found the middle ground by starting each section addressing both youth & their families

CULTURALLY RESPONSIVE CONTENT

Discovery: Who Am I?

What is Person-Centered Planning?

Person-Centered Planning (PCP) is a planning process driven by a focus on the whole person (youth) with support from people who know him/her well. PCP offers a way to discover **who** the person is, **what** they want in life, and **how** to support the person.

Why is PCP important?

Family, friends, and teachers have offered support for youth at home, school, or in the community. However, when a young person becomes an adult, support from school and teachers will end. Young people will need to understand themselves and express their needs, with or without family's support. To learn more about **PCP** and how to get support with the planning process, check the resources page.

Meet Mickle and His Family

Mickle is 21 and graduating this year from his **transition program** with a job. He is a happy young adult and loves to observe people. Because of his autism, he has many support needs, particularly with communication. He communicates mostly through body language because he does not like assistive technologies.

When he was transitioning from elementary to middle school, he and his family started to do **PCP**. It helped them learn more about who Mickle is, what his strengths are, and what he loves to do. They identified the supports he needs and the family's goals and dreams for Mickle. Because they started PCP early, Mickle and his family were prepared for changes that come with transition. More information about resources for PCP is available in the resources page (p.16)

LESSONS LEARNED

What is Disability Disclosure?

When individuals with a disability become adults, there will be situations where they need to explain the disability. **Disability Disclosure** means that a person shares information about the disability to achieve a specific purpose. However, **Disability Disclosure** is a choice. An individual with a disability does not have to share personal information unless the disclosure is necessary.

Sometimes you need to talk about your disability to ask for support you need. Disability is not something bad or shameful. It's part of who I am. I have a choice about when and who to talk to about my disability—like at college or work. I recommend that people know how to disclose their disability because they might need an ***accommodation.*** *Without that support, it might be hard to be successful with your job or education.*

Accommodation is any arrangement an individual with a disability requires to achieve equal opportunity at school, work or in the community.

To learn more about **Disability Disclosure** and **accommodation**, please see the resources page (p.16).

Why is Disability Disclosure Important?

While youth with disabilities attend school, their families, teachers, and professionals understand their needs and arrange accommodations. However, when a youth leaves school and becomes an adult, accommodations are not automatic. Support will not be provided until he or she requests accommodation. It is very important to understand how to ask for accommodations.

Special Education teachers and Independent Living Centers can help youth and families understand **Disability Disclosure.** They can also help youth and families practice sharing personal information about a disability and requesting accommodations. More information about Independent Living Centers is available online and in the resources page (p.16).

CHALLENGES

- How much information?
  - Appendix section
- Terminology & Concepts
  - "self-advocacy"
  - "citizenship"
  - "self-determination"
  - "disability disclosure"
- Integrated Star vocabularies
  - Personal "assets" & other categories

UPCOMING PUBLICATIONS

School-based transition

- Student & Parental Rights
- What is Transition IEP & Services?
- What is Transition Program?
- Dispute Resolution

Daily Life

- Independent Living
- Employment
- College

Appendix

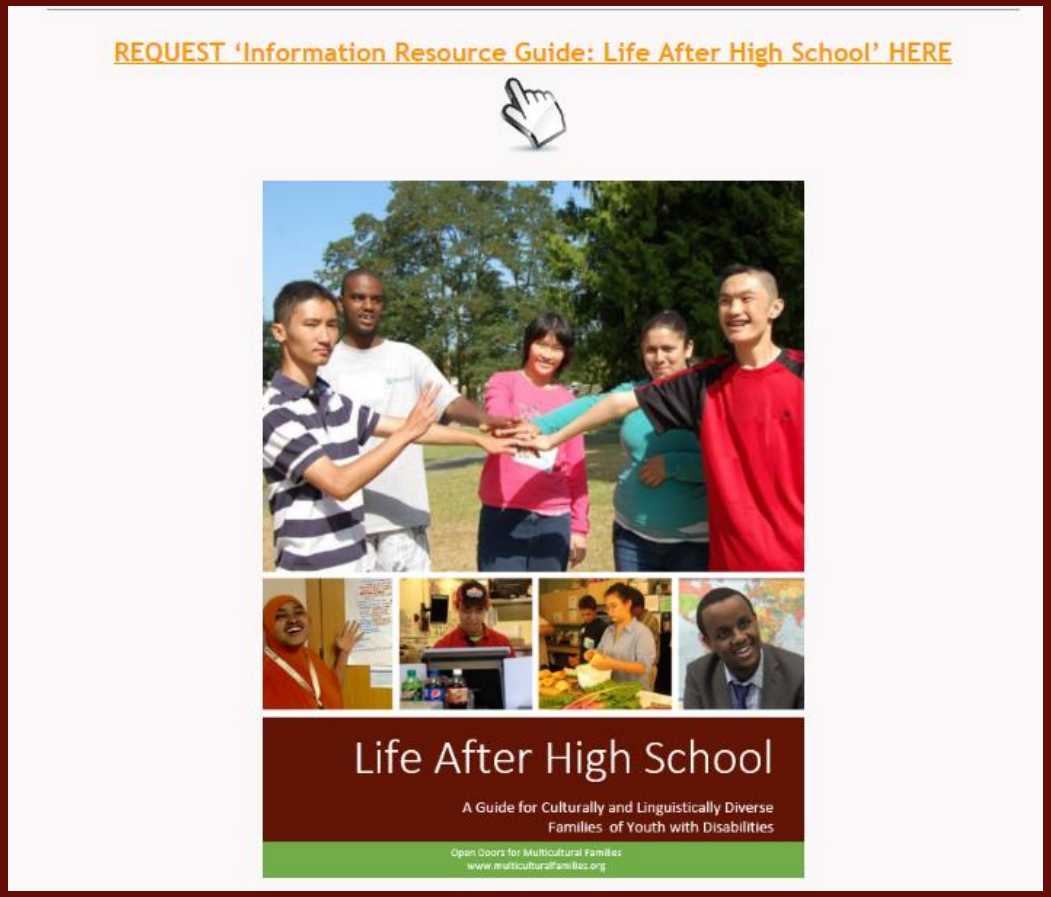
- Eligibility-based Services

FUTURE ACTIONS

(Image: Center for Change in Transition Services)

- Complete translation with quality assurance
- Glossary lists of translated terms
- Outreach throughout the WA state
- Capacity building

To Access, visit: www.multiculturalfamilies.org



Questions?

Program Coordinator: Miho Onaka (Japanese)

mihoo@multiculturalfamilies.org

Snohomish County Developmental Disabilities

January 26th, 2017

Tamra Bradford Program Manager

Snohomish County Human Services/Developmental Disabilities

425-388-7208 Tamra.Bradford@snoco.org

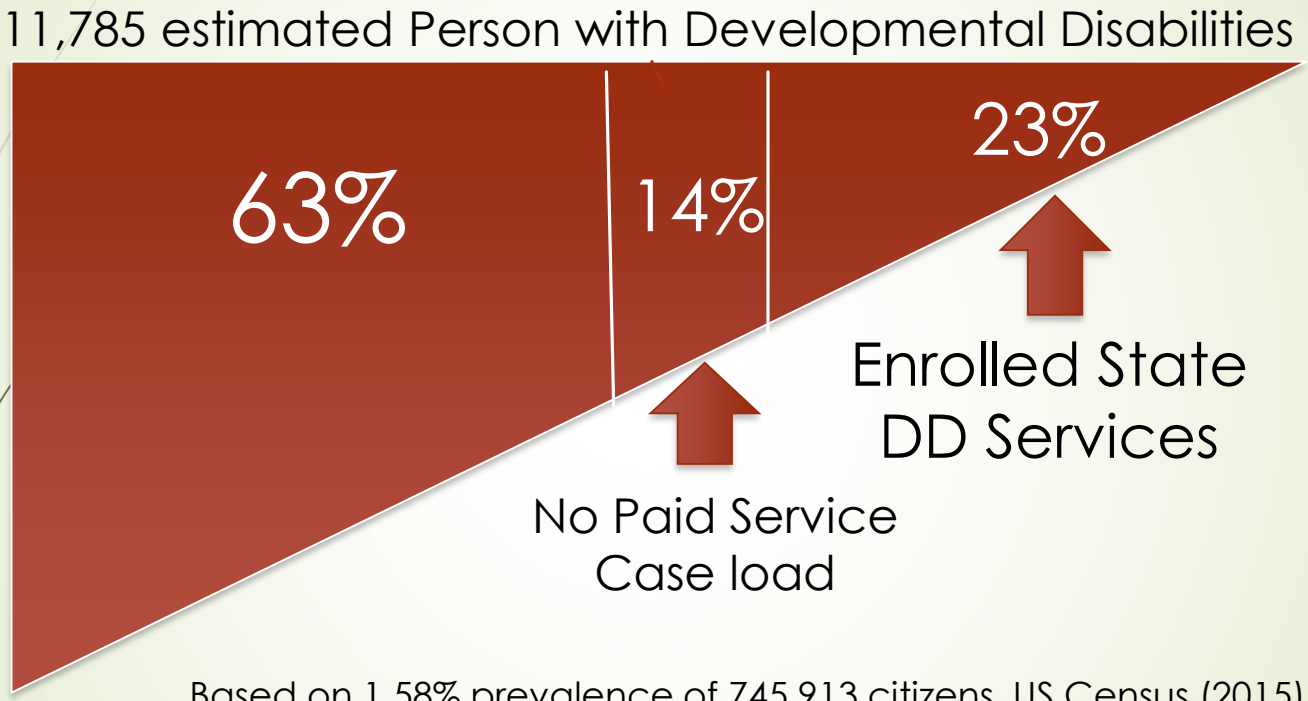
Snohomish County Developmental Disabilities website:

http://www.snohomishcountywa.gov/428/Developmental-Disabilities

Mission Statement

Foster inclusive communities that support people with developmental disabilities to fully participate in and contribute to all aspects of community life.

Snohomish County with I/DD



Based on 1.58% prevalence of 745,913 citizens, US Census (2015)
No paid service case load- 1,651
Enrolled in services, 2,726 paid DDA service

Think Across Life Stages and Generations

Age	0-5	6-18	19-64	65
WA Total Population	446,319 (6.4%)	1,150,667 (16.5%)	4,428,326 (63.5%)	948,428 (13.6%)
DD WA (1.58%)	7,096	18,295	70,410	15,080
Snohomish County	47,026 (6.3%)	127,642 (17.1%)	484,443 (64.9%)	87,334 (11.7%)
DD Sno. (1.58%)	747	2,029	7,702	1,388

Snohomish County - US Census (2015)

Charting The LifeCourse Presentation

April 15, 2015 by Michelle "Sheli" Reynolds, Ph.D.

300 people attended from across Snohomish County

- Self-Advocates
- Families
- State Developmental Disabilities Administration case managers
- Early intervention staff
- Residential and vocational providers
- Health care providers,
- Family support centers,
- Person Centered Planning Facilitators
- Teachers
- Recreation and Leisure programs
- General Community

Charting The LifeCourse Presentation

April 15, 2015 by Michelle "Sheli" Reynolds, Ph.D.

Learning Objectives:

- **Day 1**
- History of the disability service system and its effect on the current services and supports available.
- Significant and important role families play in their members with disabilities lives across the lifespan.
- An introduction to the LifeCourse framework
- Shared "real life" examples and strategies that can be used to impact the trajectory towards a "good life."

Charting The LifeCourse Presentation

April 15, 2015 by Michelle "Sheli" Reynolds, Ph.D.

Learning Objectives:

Day 2

Identified Levels of Change:

- Individual change
- Organizational changes
- System and Community Level Changes

Individual Level of Change

Individual Level Of Change:

Any change **You** make that results in a positive difference in the lives of people that use supports.

- Personal and Family member planning
- Use at work
- Change my thinking
- Advocacy

Framework Into Action

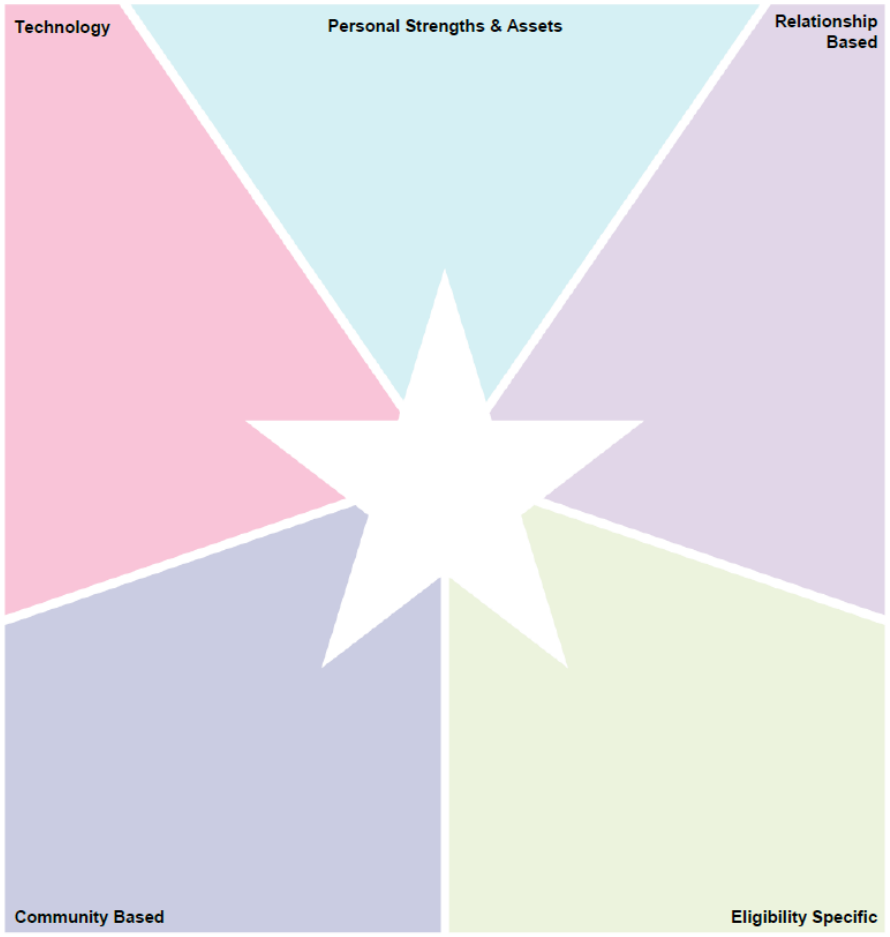
Charting the Life Course Group- Meets bi monthly to share best practices

- Includes: Families, school staff, advocacy groups, transition coordinators planning facilitators, employment support staff, early childhood providers and general community members
  - Successes
  - Challenges
- Charting The LifeCourse Training June 14, 2016 by Michelle "Sheli" Reynolds, Ph.D
  - 54 attended: family members, school administration and teachers, community leaders, DDA casemangers, Tribal, Community College, Northwest Justice Project, early head start, DVR staff, vocational agencies, early intervention staff, family support Centers, and County staff

CHARTING the life course

Integrated Services and Supports

People need supports to lead good lives. Using a combination of lots of different kinds of support helps to plot a trajectory toward an inclusive, quality, community life. This tool will help families and individuals think about how to work in partnership to support their vision for a good life.



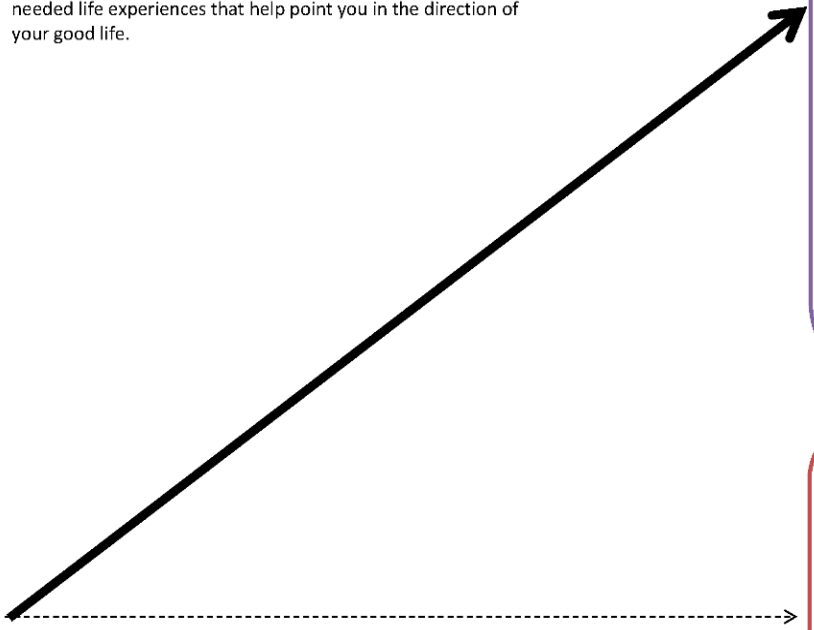
Access the LifeCourse framework and tools at lifecoursetools.com

Developed by Missouri Family to Family at the UMKC Institute for Human Development, UCEDD mofamilytofamily.org | MAY 2016

CHARTING the life course

Life Trajectory Worksheet: Family

Everyone wants a good life. The bubbles on the right will help you think about what a good life means for you or your family member, and identifying what you know you don't want. You can use the space around the arrows to think about current or needed life experiences that help point you in the direction of your good life.



VISION for a GOOD LIFE

What I DON'T Want

Developed by Missouri Family to Family at the UMKC Institute for Human Development, UCEDD | mofamilytofamily.org

May 2016

Organizational Level Change

Organizational Change:

Any changes an **Organization** makes to its practices, structure or rules that result in positive differences in the lives of many people who use services or employees.

- Advocate
- Incorporate into work/organizations
- Incorporate into schools
- Arc
- DDA specific

Framework Into Action

Front Door Model

Arc –Sibling support

Incorporate into resource materials

Organizational Level Change

- **Front Door Model**
  Charting The LifeCourse Philosophy and Tools

Partnerships

- The Arc of Snohomish County
- Snohomish County Developmental Disabilities
- Developmental Disabilities Administration
- Division of Vocational Rehabilitation
- Snohomish County School Districts

- Reframe the initial front door encounter to be more efficient, functional, individualized and person centered.
- Provide information, age specific resources and tools that support an individual to live an inclusive, quality, and community life.:

Target Audience: Birth to 3, Elementary School, Middle School, High School and Transition (18-21) and teachers and school staff.

2016 Presentations

- 8 School Districts
- 2 teacher trainings,
- Transition Kick Off- all school districts
- 2017- 4 school district presentations scheduled so far.

System Level of Change

Systems Change:

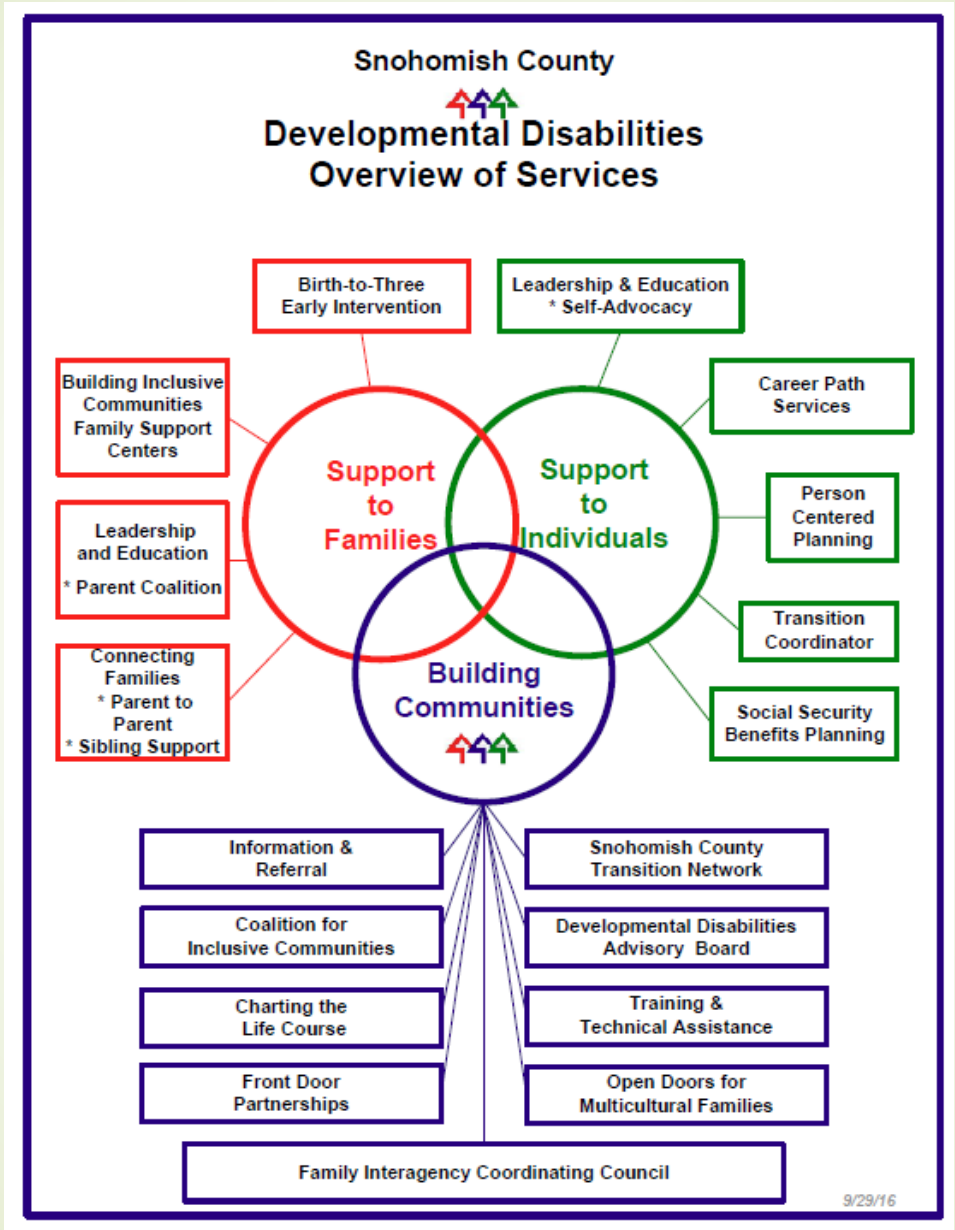
Any change in **Practice, Structure**, and **Rules** made at the **System** or **Community Level**. These changes have an effect on different systems, organization or the community level and therefore many people's lives

- Services
- Eligibility
- Policy
- Conversations for change

Framework Into Action

Outreach efforts

Incorporating into resource materials and daily work


Snohomish County
Developmental Disabilities
Overview of Services
Birth-to-Three
Early Intervention
Leadership & Education
* Self-Advocacy
Building Inclusive
Communities
Family Support
Centers
Career Path
Services
Support
to
Families
Support
to
Individuals
Leadership
and Education
* Parent Coalition
Person
Centered
Planning
Transition
Coordinator
Connecting
Families
* Parent to
Parent
* Sibling Support
Building
Communities
Social Security
Benefits Planning
Information &
Referral
Snohomish County
Transition Network
Coalition for
Inclusive Communities
Developmental Disabilities
Advisory Board
Charting the
Life Course
Training &
Technical Assistance
Front Door
Partnerships
Open Doors for
Multicultural Families
Family Interagency Coordinating Council
9/29/16

Q&A

LifeCourseTools.com

Innovations Webinar Series

Next webinar:

TBA

Archived webinars:

- Overview of the LifeCourse Framework
- Focusing on the Front Door of Long Term Services & Supports
- We're All in This Together: Uniting the Movements for a Good Life
- Reframing the Conversation at All Levels: Tools for Change
- Technology & Strategies for Supporting Families
- LifeCourse in Action: Implementation at all Levels in Missouri
- LifeCourse in Action: Reaching the All in Tennessee
- LifeCourse in Action: A Good Life for All in Oklahoma
- LifeCourse in Action: Scaling up the LifeCourse at Every Stage in Connecticut
- LifeCourse in Action: Vision for Supported Families in DC

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