


National Community of Practice:

Supporting Families who have Family Members with Developmental Disabilities Across the Lifespan



Mary Lee Fay
National Association of State Directors for
Developmental Disabilities

Michelle “Sheli” Reynolds, SIBLING, PhD
UMKC Institute for Human Development, UCEDD

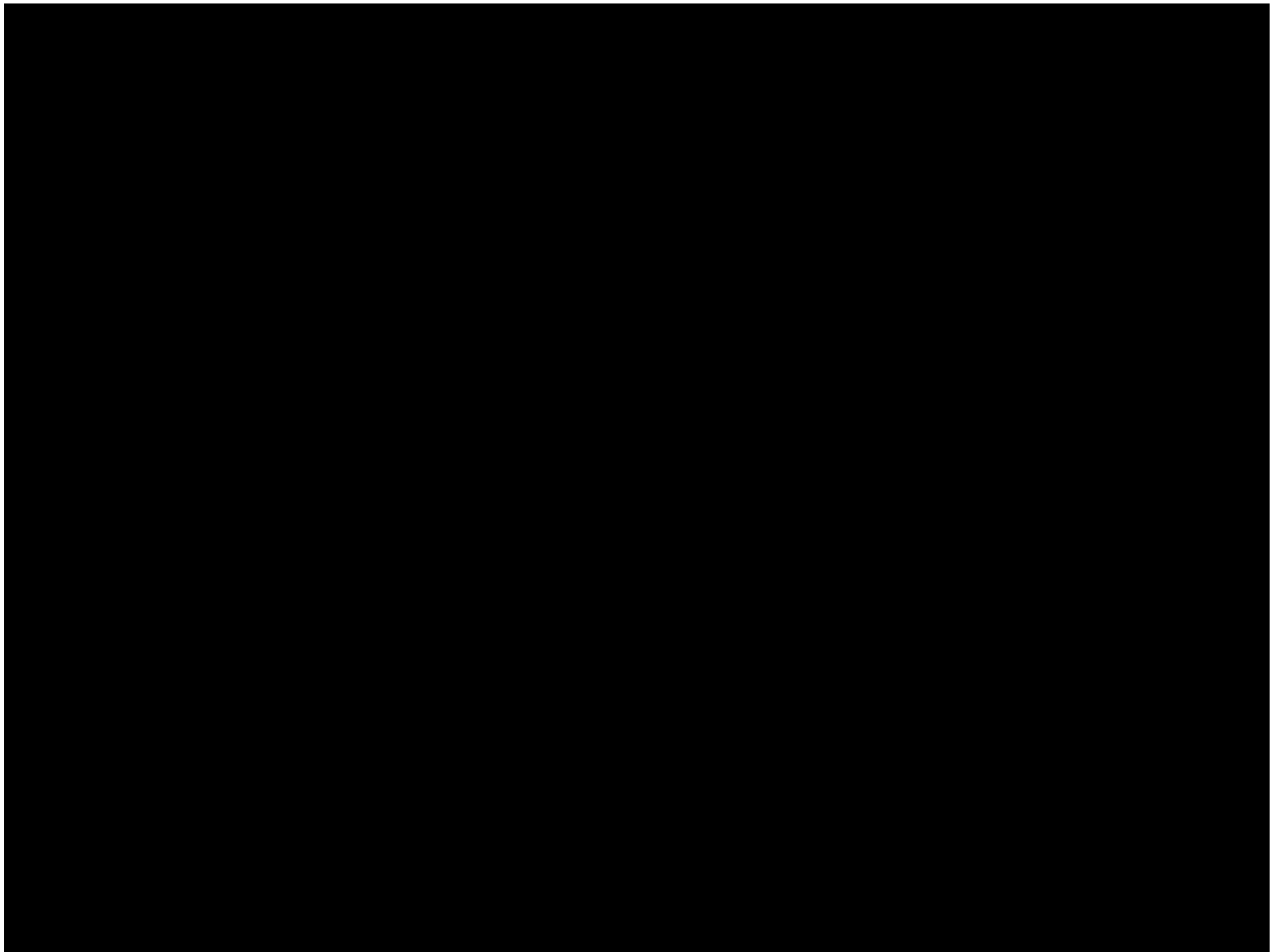
September 17, 2013

About the Community of Practice

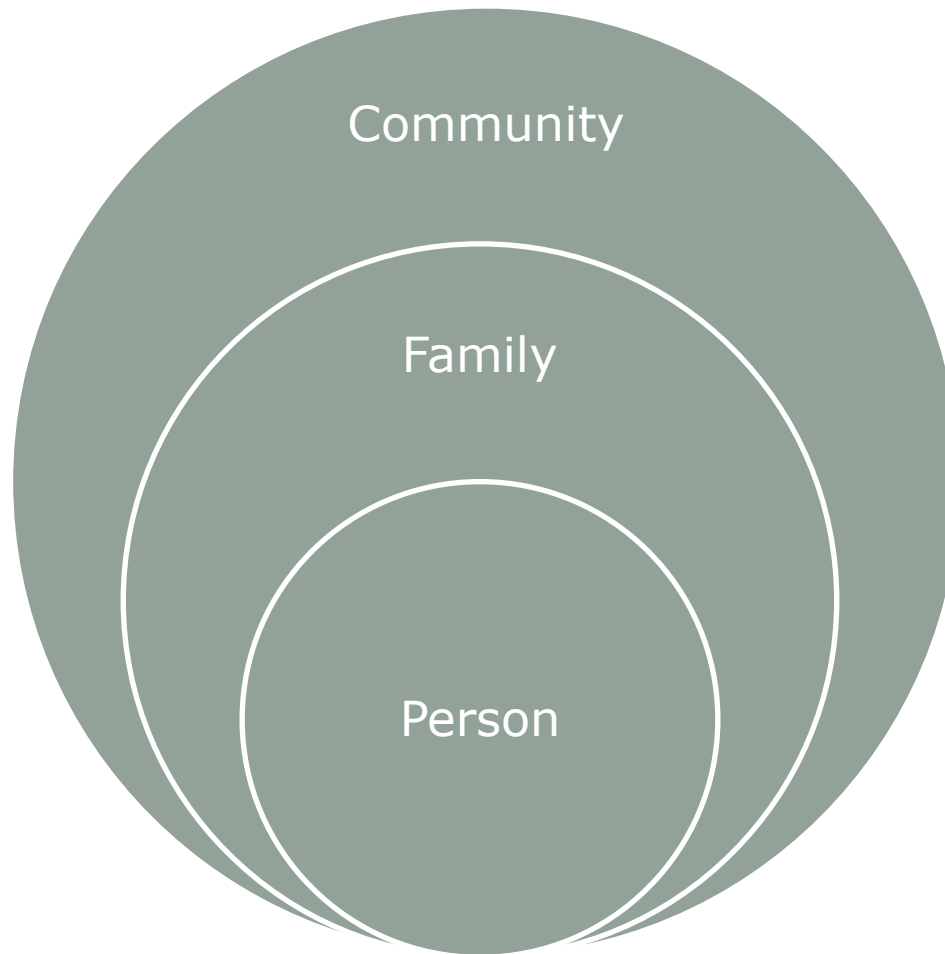
- ❑ National Initiative Funded by Administration on Intellectual and Developmental Disabilities
- ❑ Lead Organizations:
 - NASDDDS
 - UMKC-IHD
 - HSRI
 - National Association of Councils on DD
- ❑ Missouri serves as a demonstration
- ❑ 5 additional states will participate in CoP

Purpose of Community of Practice

- ❑ Develop National Framework for Supporting Families Across the Lifespan based on National Agenda on Supports to Family
- ❑ Provide technical assistance to 5 states and Missouri to:
 - Identify existing policy and practices that support the national framework
 - Learn from one another
 - Develop and/or implement policy and practices within the six states that support families



Real Lives, Real People

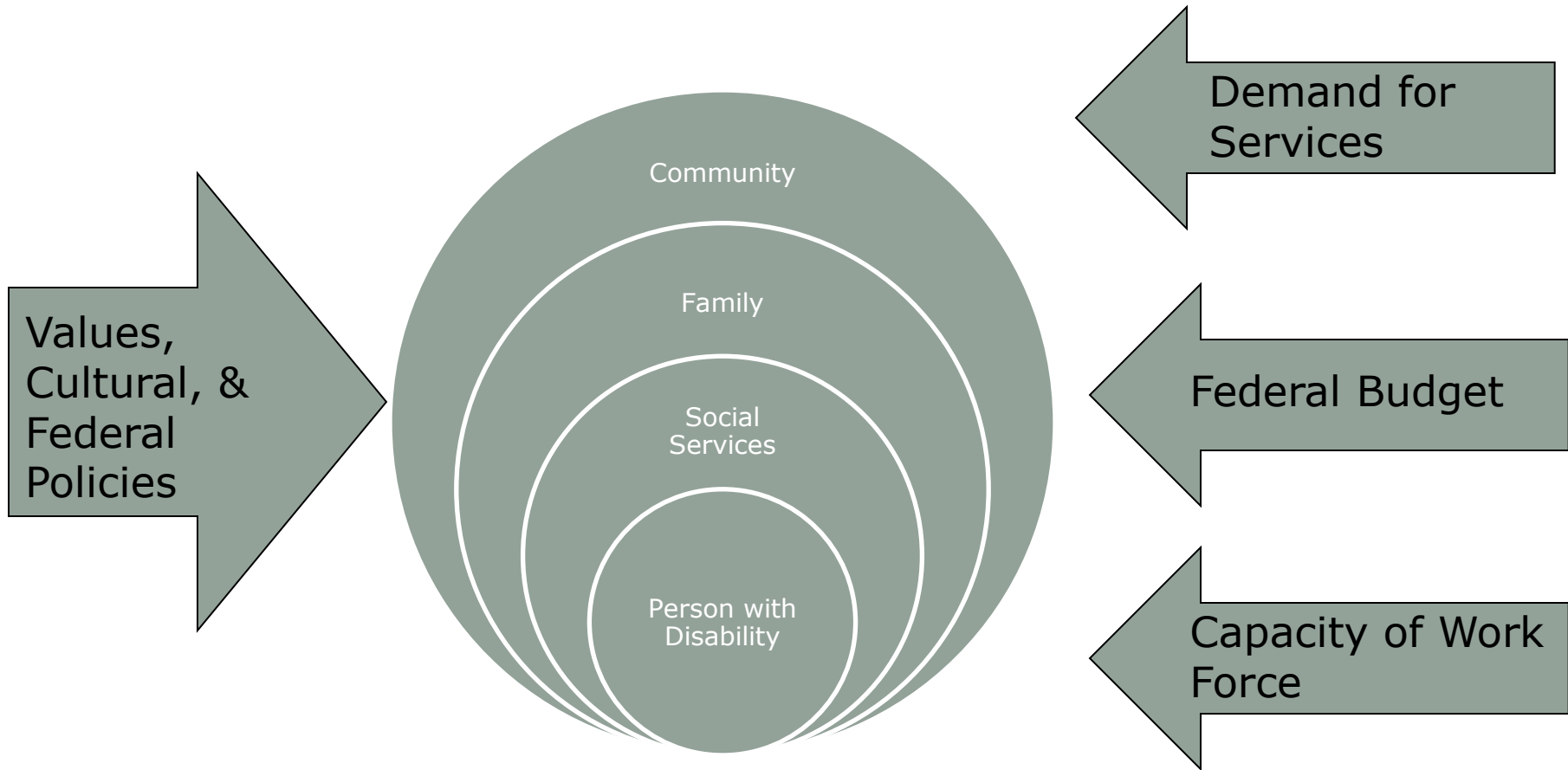


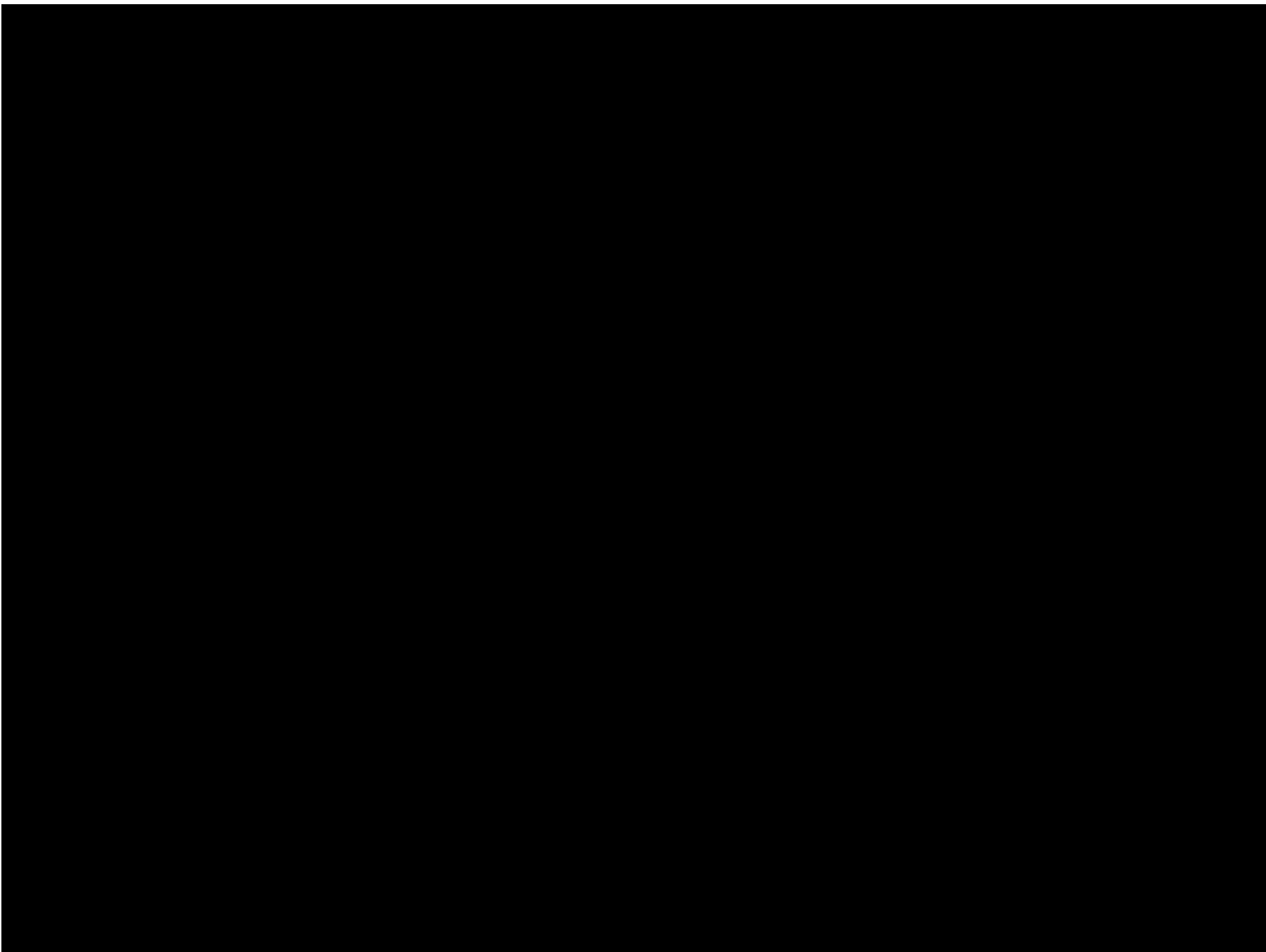


Disability Services



Other Forces Impact Services





National Agenda: Supporting Real Lives



My Experience

- ❑ Sibling of 30 year old brother with developmental disability
- ❑ Supporting Self-Advocacy Movement
- ❑ Focusing on policy and practices that support families



Charting a New Reality

***Charted
Traditional
or familiar***

***Slightly
Charted
Tried but not
norm***

***Uncharted
New or
unfamiliar***

***Unknown
Not yet
discovered***

- *Removes value judgments and blame*
- *Not a continuum, but current or historical options*
 - *Does not imply it is or isn't available*
- *Allows for comparison of where you are and where to go*

Why Uncharted Waters?

- ❑ **Journey:** Recognizing life is not static
- ❑ **Exploring:** identifying new options and possibilities
- ❑ **Navigating together:** Sharing responsibility
- ❑ **Our overall compass is “quality of life”**



New Vision for Family Support

***Families:**
will be supported in ways that maximizes their capacity, strengths and unique abilities
so they can best support, nurture, love and facilitate.....

Individual with Disability:
achievement of self-determination, interdependence, productivity, integration and inclusion in all facets of community life



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

Joining Forces for a New Vision

1950s Parent--Family
2007's Siblings

1960s State Service Systems
1980s Medicaid Waiver

1970s Self-Advocacy

2000s Community



Social Service Response to Family

Era	Understanding of Family	Disability Services
1800s-	Moral blame assigned to parents	Removal from Society
1900s	Child damaged families	Removal from Family
1950s	Burden of Caregiving	Specialized Therapeutic Congregate Services
1980s	Families seen as system Positive Coping	Community Group Residential Supports
1990s	Families support children to remain in their home for as long as possible	Family Support programs for children living at home

Social Service Response to Family

Era	Understanding of Family	Disability Services
2010s	Families adapt, accommodate and are resilient Recognize that there are additional emotional, physical and financial realities	-Family is a main constant in the lives of persons with disability -Families play significant role across the lifespan regardless of service provision -Families may need supports for the different roles they play in the lives of their family member

New Supports for Families

Chartered	New Charter
Defined by eligibility, services or programs available, or funding	Not a program or based on eligibility, it is needs defined by the families across the lifespan regardless of service provision
Caregiver or parent	Family is defined functionally; inclusive of siblings, parents with disabilities, grandparents
Tension between self-advocacy and family support	Enhances opportunities for self-advocacy and self-determination
Crisis, immediate response	Preventative, long-term planning
Supporting caregiver in order to decrease demand on long-term services	Creates a quality of life for person with DD and their family by supporting their many roles

What Do We Know About Family?

Caring About	Affection & Self-Esteem
	Repository of knowledge
	Lifetime commitment
Caring For	Provider of day-to-day care
	Material/Financial
	Facilitator of inclusion, recreation, spirituality & meaningful activities
	Advocate for support

Bigby & Fyffe (2012), Dally (1988), Turnbull et al (2011)

Where Do People with DD Live?

Total Persons with DD	4.7 Million	100%
Total Persons with DD Living in Homes in Community	4.17 Million	87%
Total Persons with DD Living in Residential	528,000	13%

**Lakin, C., Larson, S., Salmi, P. & Webster, A. (2010). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009. Institute on Community Integration, Minneapolis, MN.*

Who Provides Supports?

	Person with DD
Est. Number of Persons with DD	4.7 Million
Receiving Formal DD Services	1.2 Million (25%)
Supported by Family and other informal supports	3.5 Million (75%)

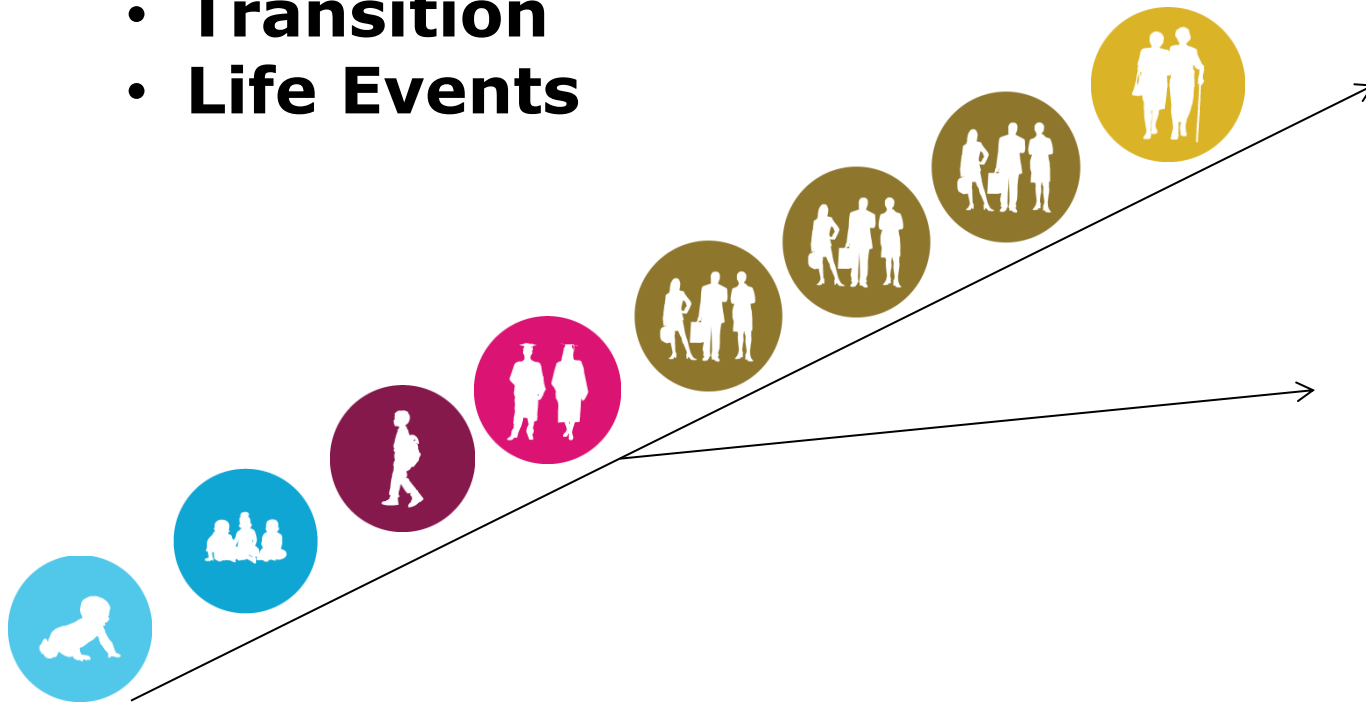
**Lakin, C., Larson, S., Salmi, P. & Webster, A. (2010). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2009. Institute on Community Integration, Minneapolis, MN.*

Vision for an Uncharted Life



LifeCourse Perspective

- **Trajectory**
- **Transition**
- **Life Events**



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

Uncharted with Supports



Charted





New Charter for Supports

DISCOVERY AND NAVIGATION

Information and
Training Supports

PEER SUPPORT NETWORKS

Emotional Supports

DAY-TO-DAY NEEDS

Supports for Role of
Daily Care/Support

Supporting Individuals and Families Across the Lifecourse

Information and Training Supports:

Knowledge and Skills

- Information on disability
- Knowledge about best practices and values
- Skills to navigate and access services
- Ability to advocate for services and policy change

Emotional Supports:

*Mental Health and
Self-efficacy*

Instrumental Supports:

Day-to-Day Needs

Supporting Individuals and Families Across the Lifecourse

**Information
and Training
Supports:**
*Knowledge
and Skills*

Emotional Supports:
*Mental Health and
Self-efficacy*

- Parent-to-Parent Support
- Self-Advocacy Organizations
- Family Organizations
- Sib-shops
- Support Groups
- Professional Counseling
- Non-disability community support

**Instrumental
Supports:**
Day-to-Day Needs

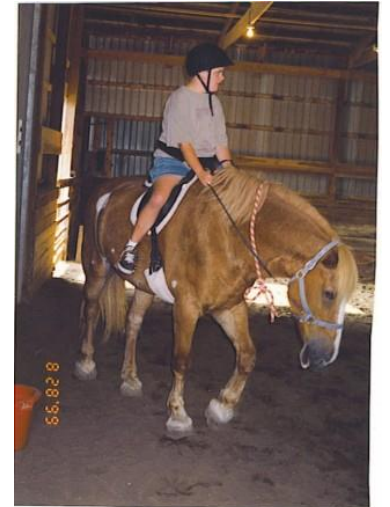
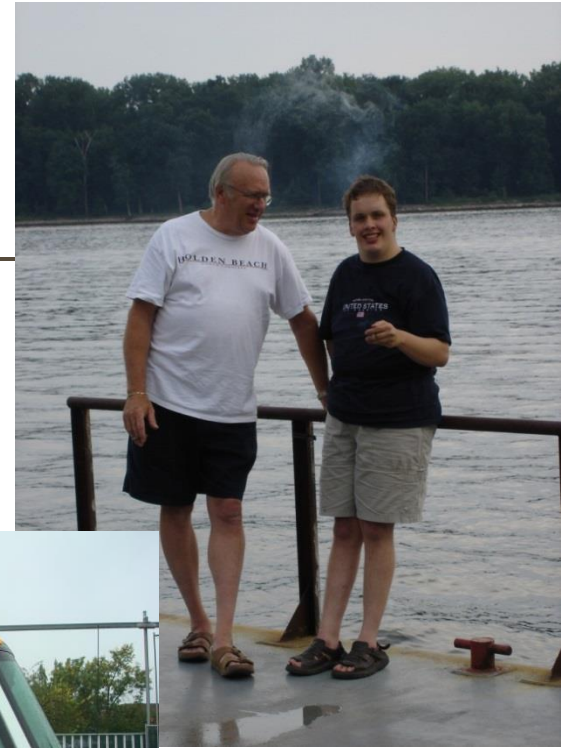
Supporting Individuals and Families Across the LifeCourse

**Information
and Training
Supports:**
*Knowledge and
Skills*

**Emotional
Supports:**
*Mental Health and
Self-efficacy*

Instrumental Supports:
Day-to-Day Needs

- Self/Family-Directed services
- Transportation
- Respite/Childcare
- Adaptive equipment
- Home modifications
- Financial assistance
- Cash Subsidies
- Short/Long term planning
- Caregiver Supports and training



National Agenda: Supporting Real Lives





Where will My Child Live?



Vision for the Future

Not Yet Discovered

- ?????

Uncharted

- Own home
- Shared Living Space
- Co-op
- Environmental Adaptations

Slightly Charted

- Independent Supported Living

Charted

- Training Centers
- Intermediate Care
- Group Homes





Who will Support My Child?



Vision for the Future

Not Yet Discovered

- ??????

Uncharted

- Remote Monitoring
- Assistive Technology
- Time banks
- Human-service coops

Slightly Charted

- Self-directed Services
- Respite
- Micro-boards

Charted

- Staff hired by Provider





What will my Child Do During the Day?



Vision for the Future

Not Yet Discovered

- ??????

Uncharted

- Micro-enterprise
- College/Tech Schools
- Career
- Military

Slightly Charted

- Supported Employment
- Volunteerism
- AmeriCorps/VISTA

Charted

- Sheltered Workshops
- Day Habilitation





What about our Quality of Life?



Vision for the Future

Not Yet Discovered/Uncharted

- Self-determination
- Emotional Well-being
- Personal Development
- Interpersonal Relationships
- Physical and Material Well-being
- Social Inclusion
- Rights



Slightly Charted

- Meaningful Roles
- Normalization

Charted

- Health and Safety
- Guardianship



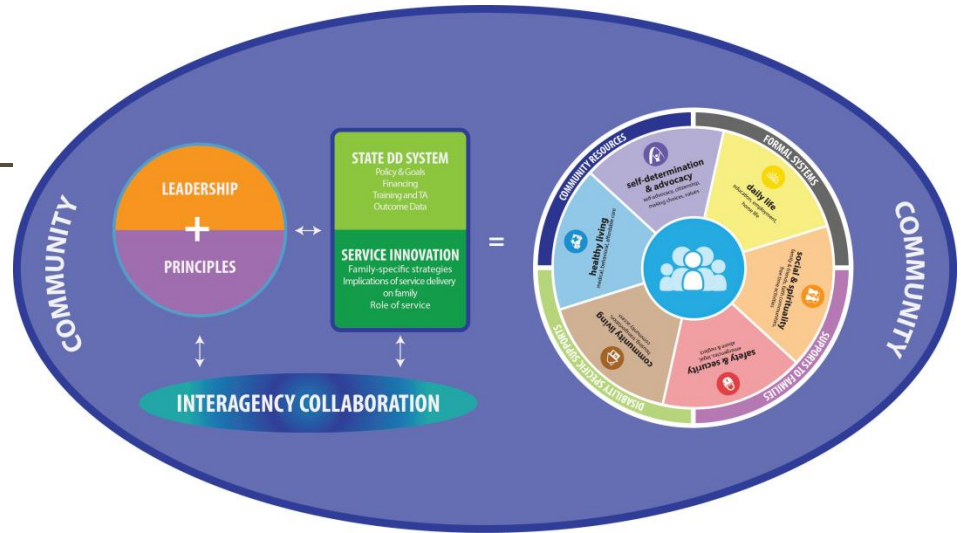
Vision for a Quality of Life



- Building own family and relationships
- Community connections provide quality assurance
- Fostering self-advocacy and self-determination skills leads to safety and protection
- Focusing on meaning of life beyond interventions and concrete day-to-day supports

Our Uncharted Life









Community of Practice

NATIONAL FRAMEWORK TO SUPPORT REAL LIVES

Re-evaluating current services – How many could we serve?

Type of Service	Cost per Person	Cost to Serve the Waiting List 122,870	People Served with \$5 M
ICF/MR	\$128,275 CT \$383,316	\$15,761,114,925	 39 CT 13
Non-family HCBS	\$70,133 CT \$140,199	\$8,617,241,710	 71 CT 36
Host Family	\$44,122 CT \$51,687	\$5,421,270,140	 113 CT 97
Own Family	\$25,072 CT \$30,390	\$3,080,596,640	 200 165

Data Source: Lakin, K.C. MSIS and NCI data from 4 states (1,240 Individuals)

NASDDDS

National Association of State Directors of Developmental Disabilities Services

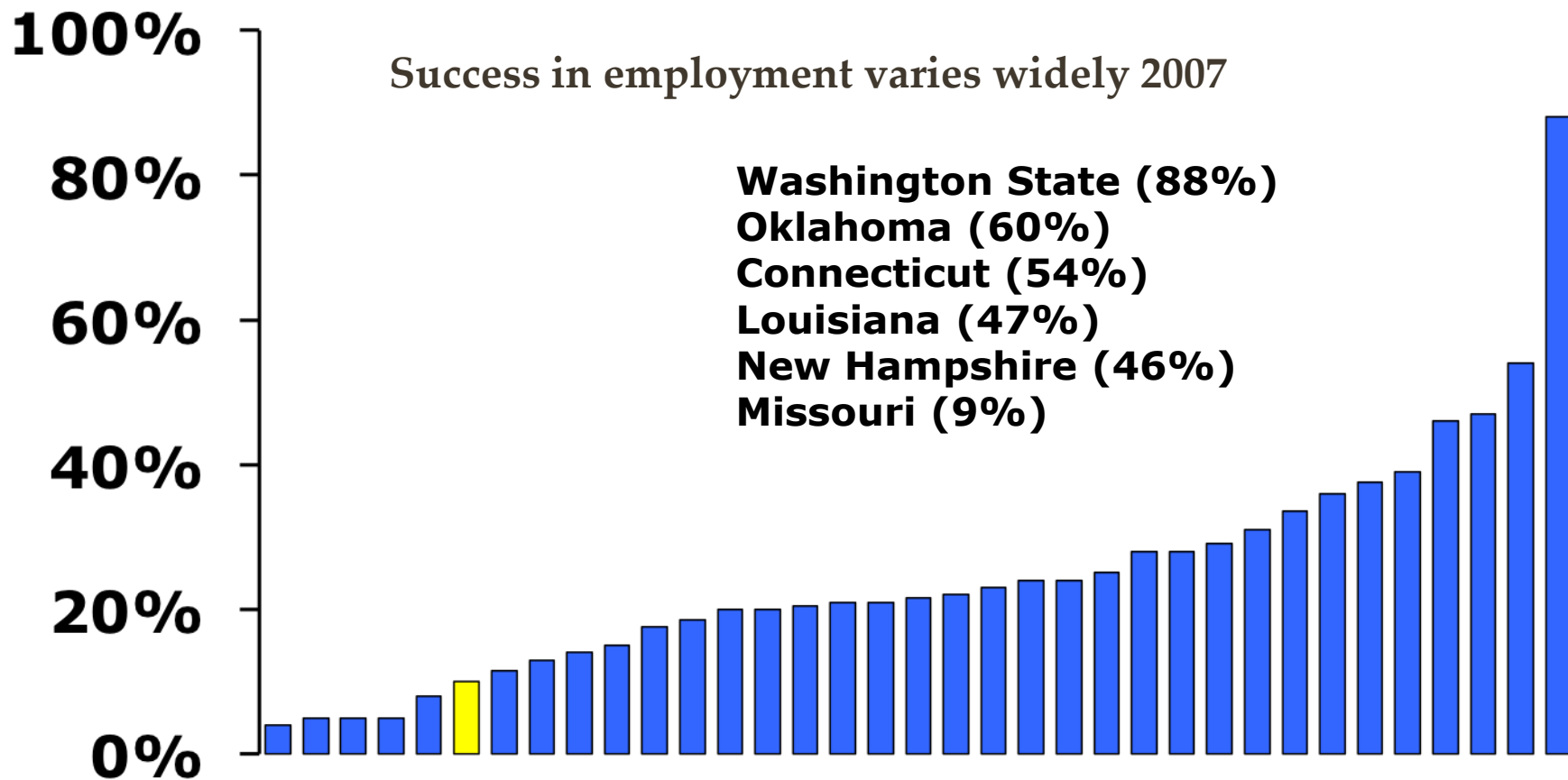
Thinking for the Long Term

Type of Service	Cost per Person	20 yrs. Cost	30 yrs. Cost
ICF/MR Institution	\$128,275	\$2,565,600	\$3,848,250
HCBS 24hr staffed Residential	\$70,133	\$1,402,660	\$2,103,990
Shared Living (Adult Foster Care)	\$44,122	\$882,440	\$1,323,660
Supports in Own or Family Home	\$25,072	\$502,440	\$752,160

NASDDDS

National Association of State Directors of Developmental Disabilities Services

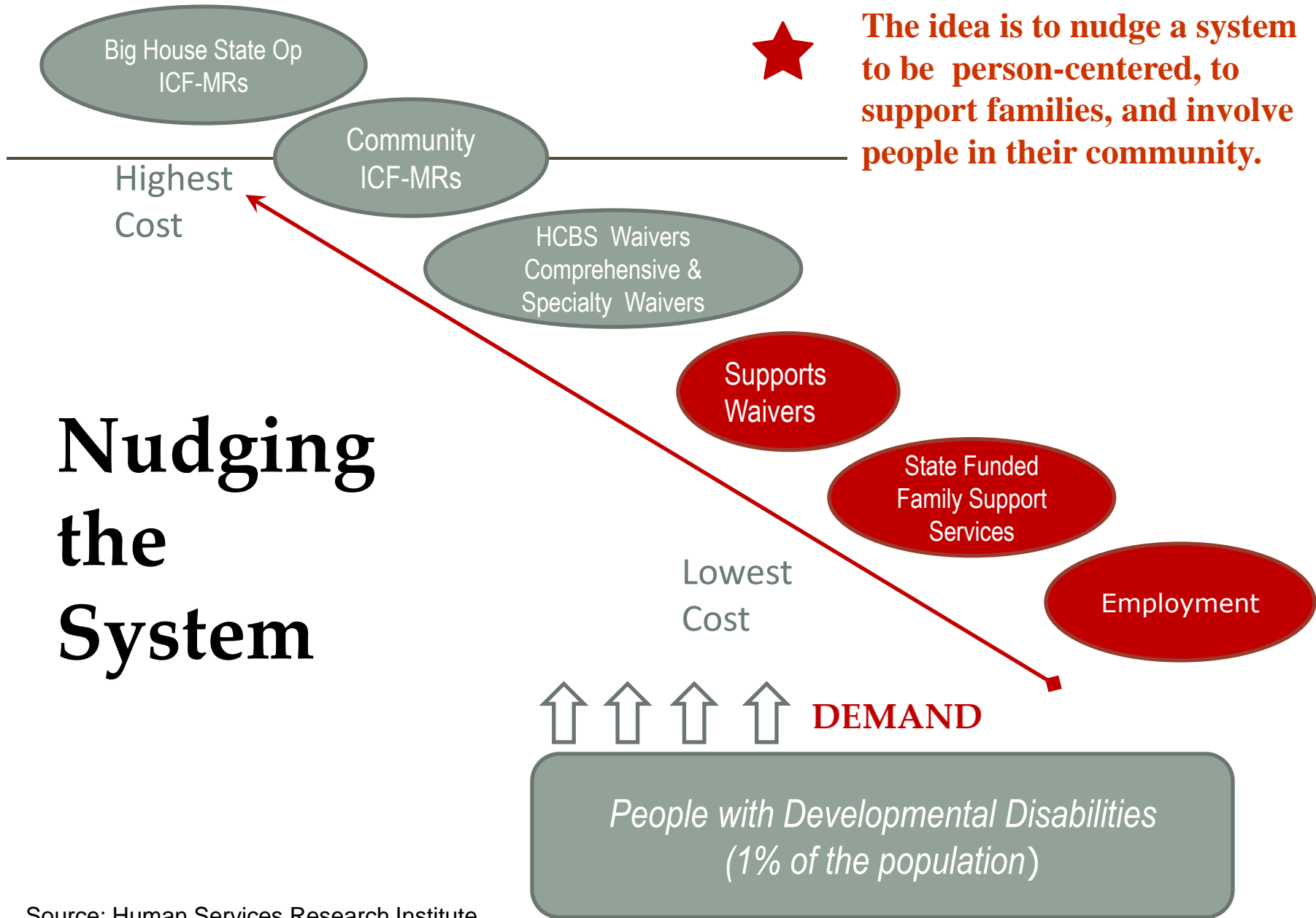
What People Do During Day



2009 -UMass Boston ICI ID/DD Agency Survey

NASDDDS

National Association of State Directors of Developmental Disabilities Services



Nudging the System

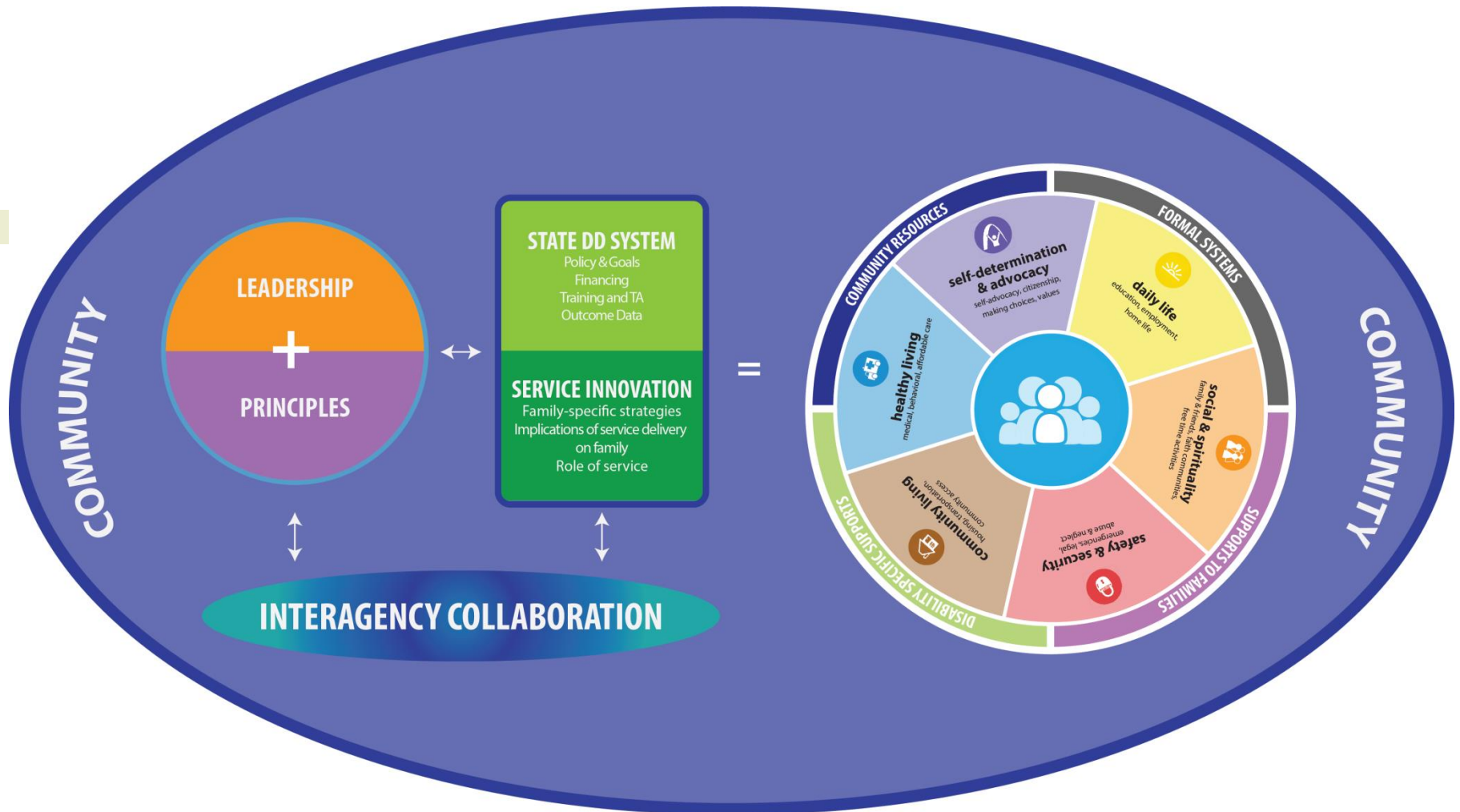
Does Everyone Have to Live with Their Family?

No.

It means we have to maximize the extent to which as many people as possible can live great lives without 24 hours of paid supports using RELATIONSHIP BASED OPTIONS.

- Family
- Extended Family
- Friends
- Shared Living
- Independently or with a friend
- Paid Companion

National CoP Framework





LEADERSHIP

PRINCIPLES

STATE DD SYSTEM

Policy & Goals

Financing

Training and TA

Outcome Data

SERVICE INNOVATION

Family-specific strategies

Implications of service delivery
on family

Role of service

INTERAGENCY COLLABORATION

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

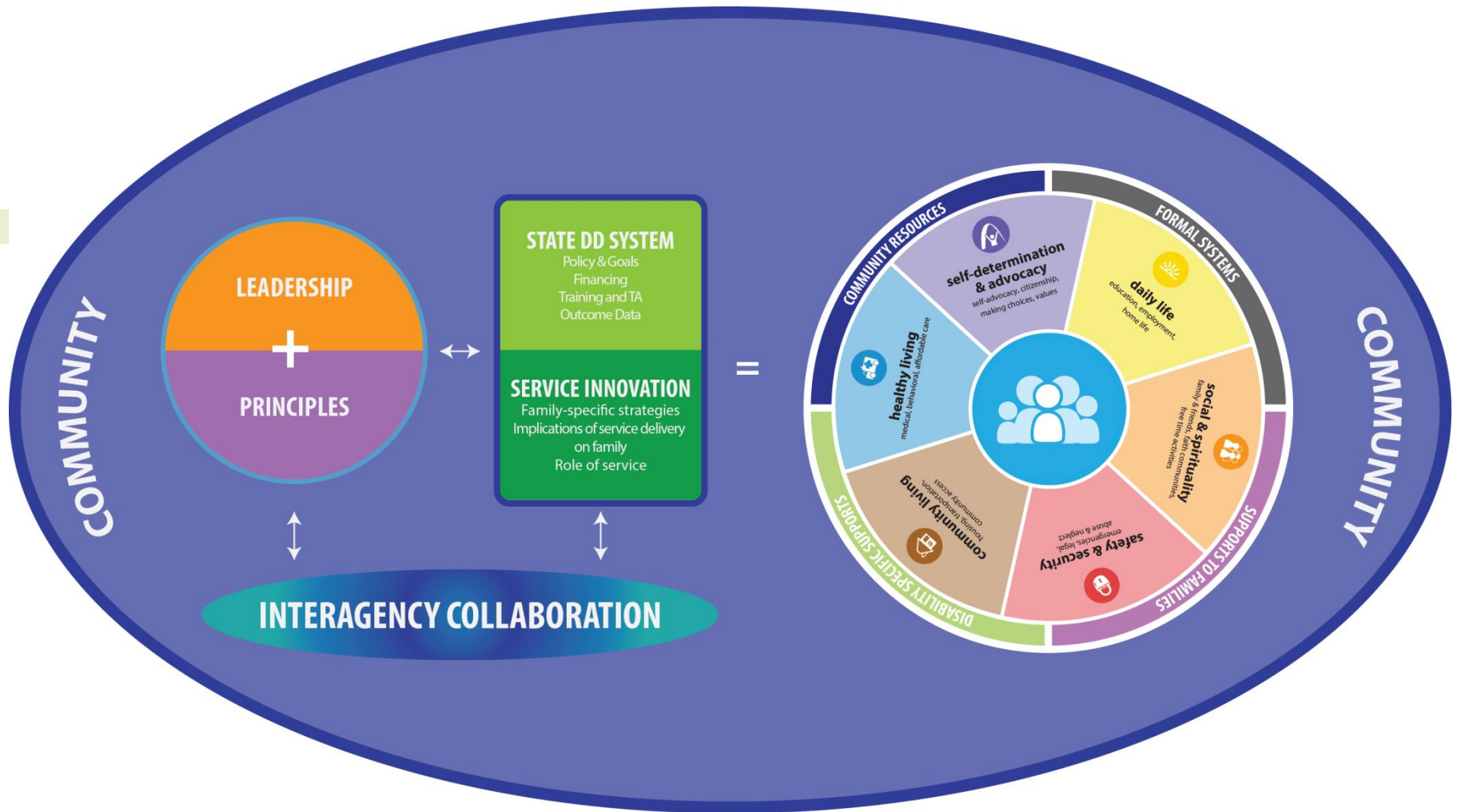


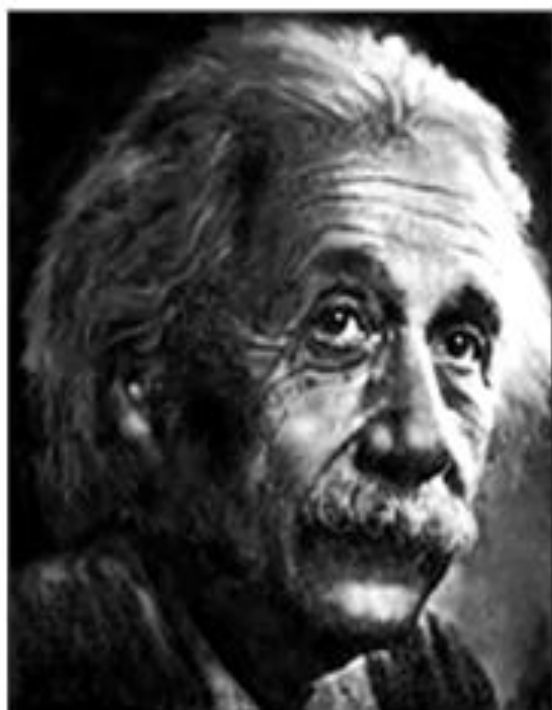
COMMUNITY

Communities embrace,
include, value, and
celebrate the diverse
cultures of all their
children, youth and
families.

COMMUNITY

National CoP Framework





*The significant problems
we face can not be solved
at the same level of
thinking we were at when
we created them.*

Albert Einstein