

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

What Do 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

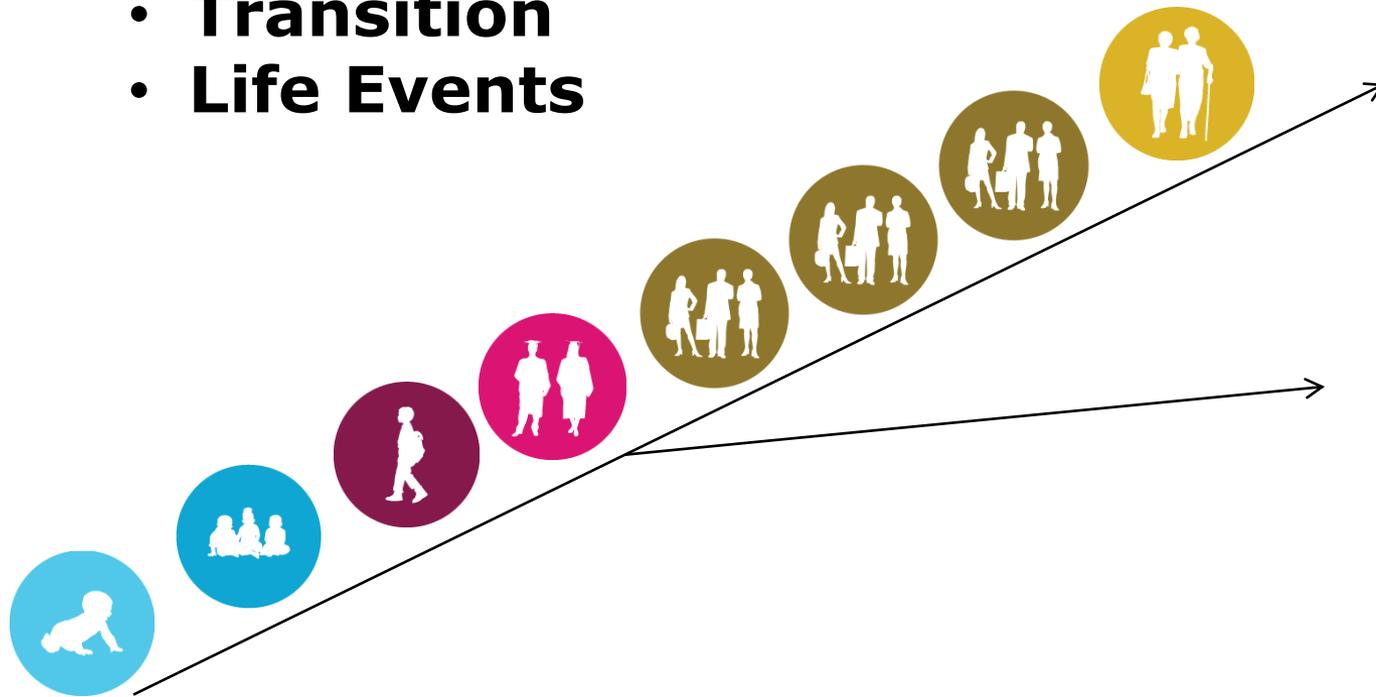
Bigby & Fyffe (2012), Dally (1988), Turnbull et al (2011)

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



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

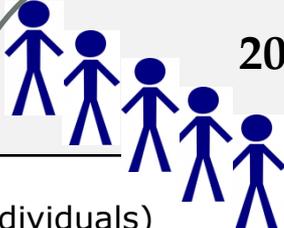
Does Everyone Have to Live with Their Family?

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

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	\$15,761,114,925	 39
Non-family HCBS	\$70,133	\$8,617,241,710	 71
Host Family	\$44,122	\$5,421,270,140	 113
Own Family	\$25,072	\$3,080,596,640	 200

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

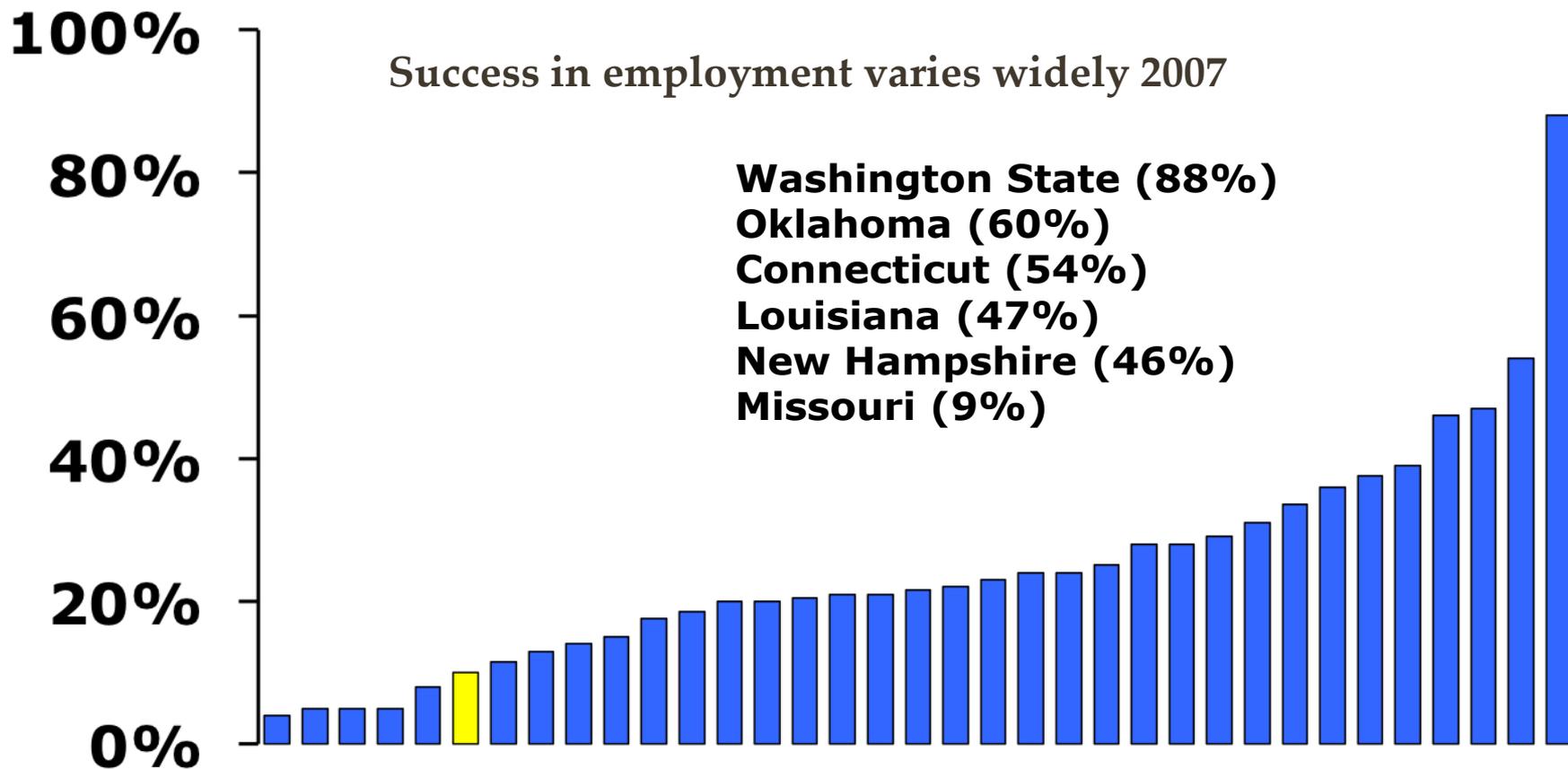
Thinking for the Long Term

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

INTERAGENCY COLLABORATION

Pediatrician, Families and Friends, Faithbased

IDEA Part C, Parents as Teachers, Health, Headstart

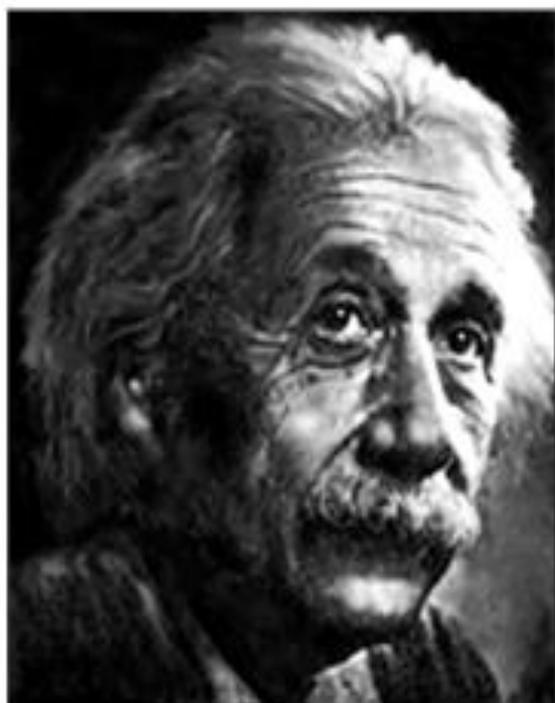
School, Special Education, Health, Recreation

Vocational Rehab, Health Employment, College, Military

Disability Services, Health, Housing, College, Careers

Retirement, Aging System, Health





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

Albert Einstein