



BUILDING SUSTAINABLE SYSTEMS

Collaboration Conference

Virginia Beach

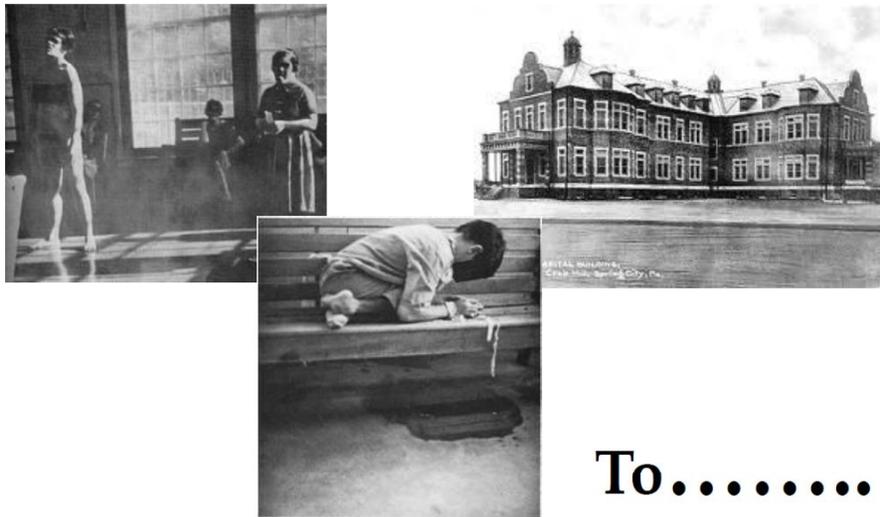
Oct. 4th, 2011

Nancy Thaler, Ex. Director NASDDDS

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We've Made the Leap from



To.....



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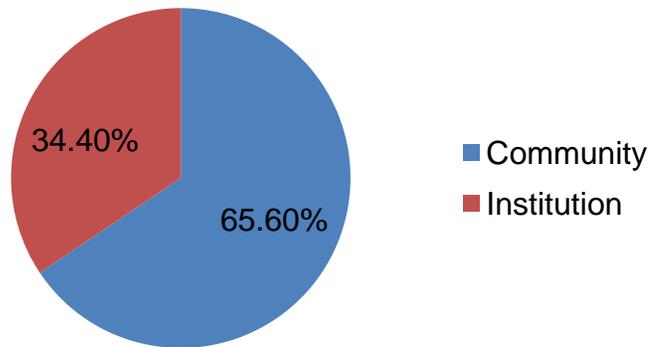
The World Needs Leaders Who...

- Make judgments knowing that ***everything is contextual*** and ***everything is changing***;
- Take actions knowing that ***everything depends on doing so in a timely fashion***;
- ***Can pair micromanagement with big-picture aspirations about the future.***

Excerpts from
The *Big Idea: The Wise Leader*
Ikujiro Nonaka and *Hiroataka Takeuchi*
HBR May 2011

Evidence of Change

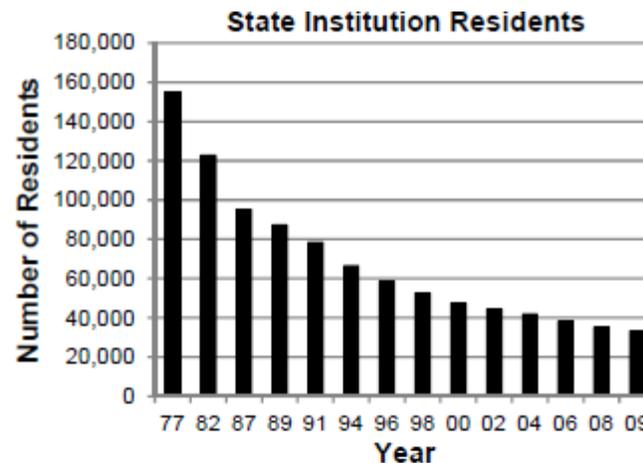
Institution/Community \$ Balance



No Public Institutions in 12 states

1. New Hampshire
2. D.C.
3. Vermont
4. Rhode Island
5. Maine
6. Alaska
7. New Mexico
8. West Virginia
9. Hawaii
10. Oregon
11. Michigan
12. Alabama – Nov.'11

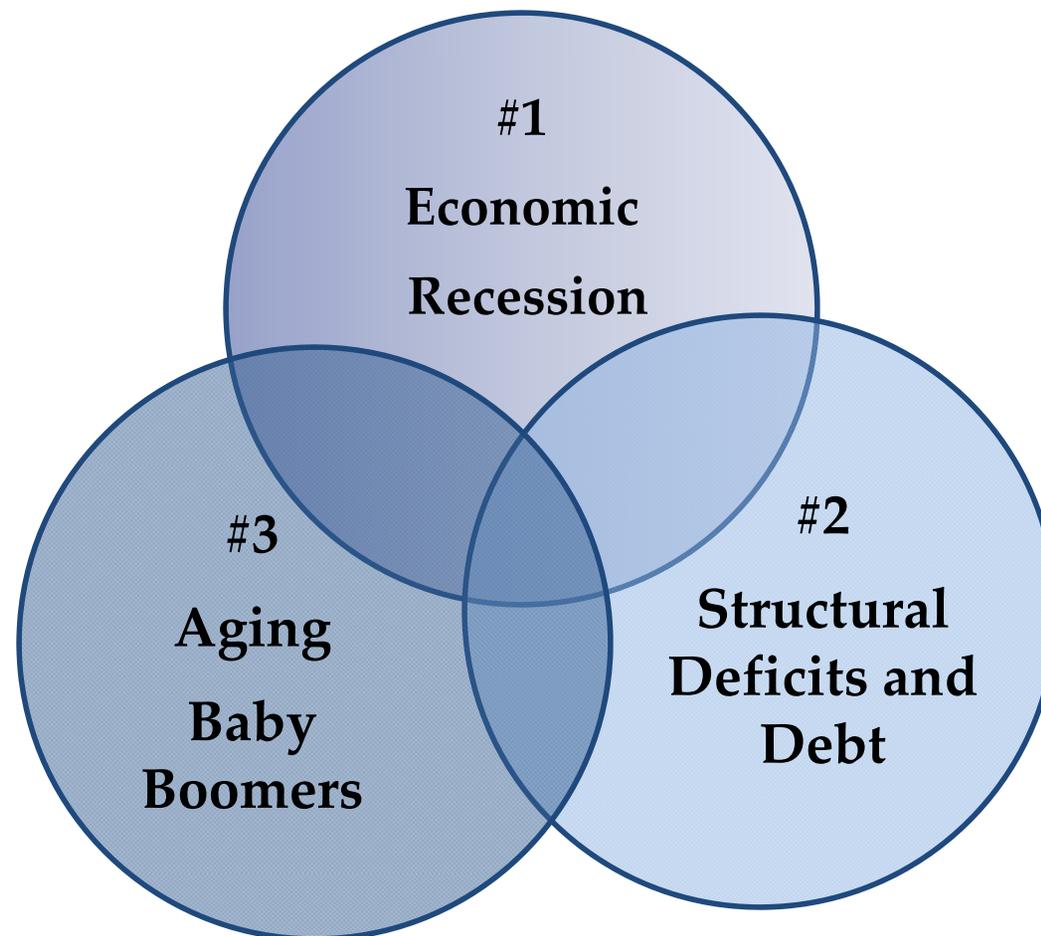
Declining Census



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Three Big Problems That will be With Us for Decades



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Problem No. 1

Economic Recession

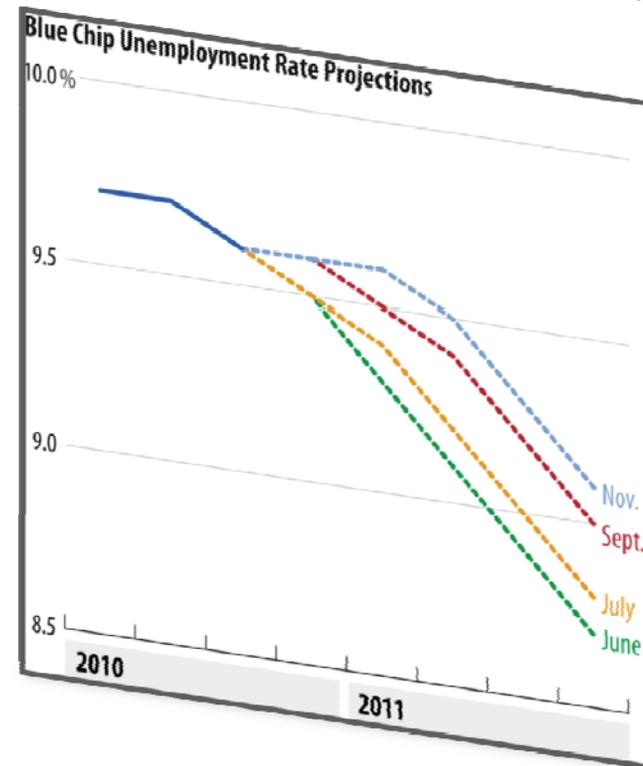
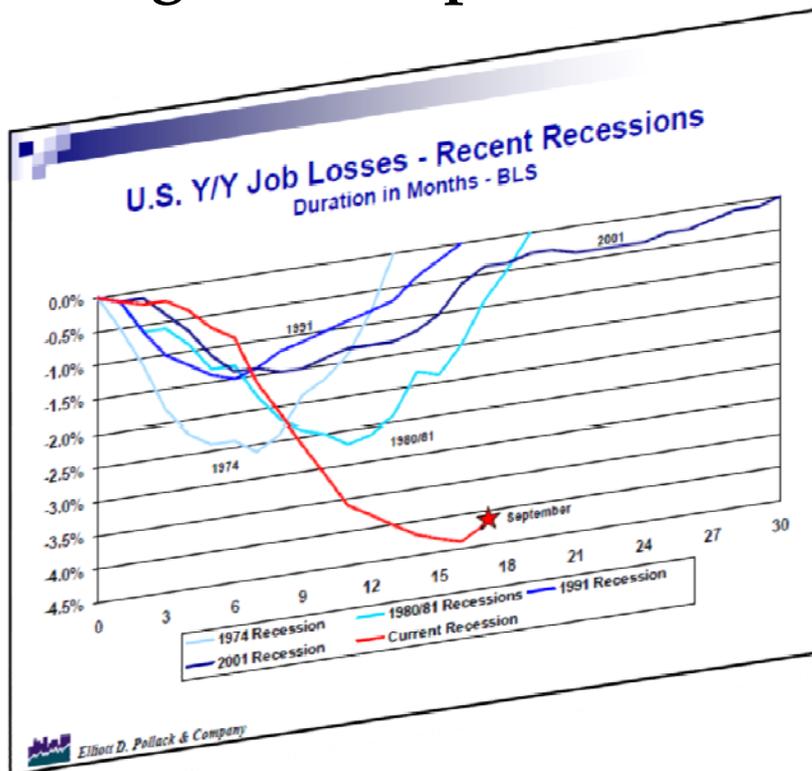
A Long and Deep Recession

August 2011

14. Million Unemployed

(9.1%)

<http://www.bls.gov/cps/>

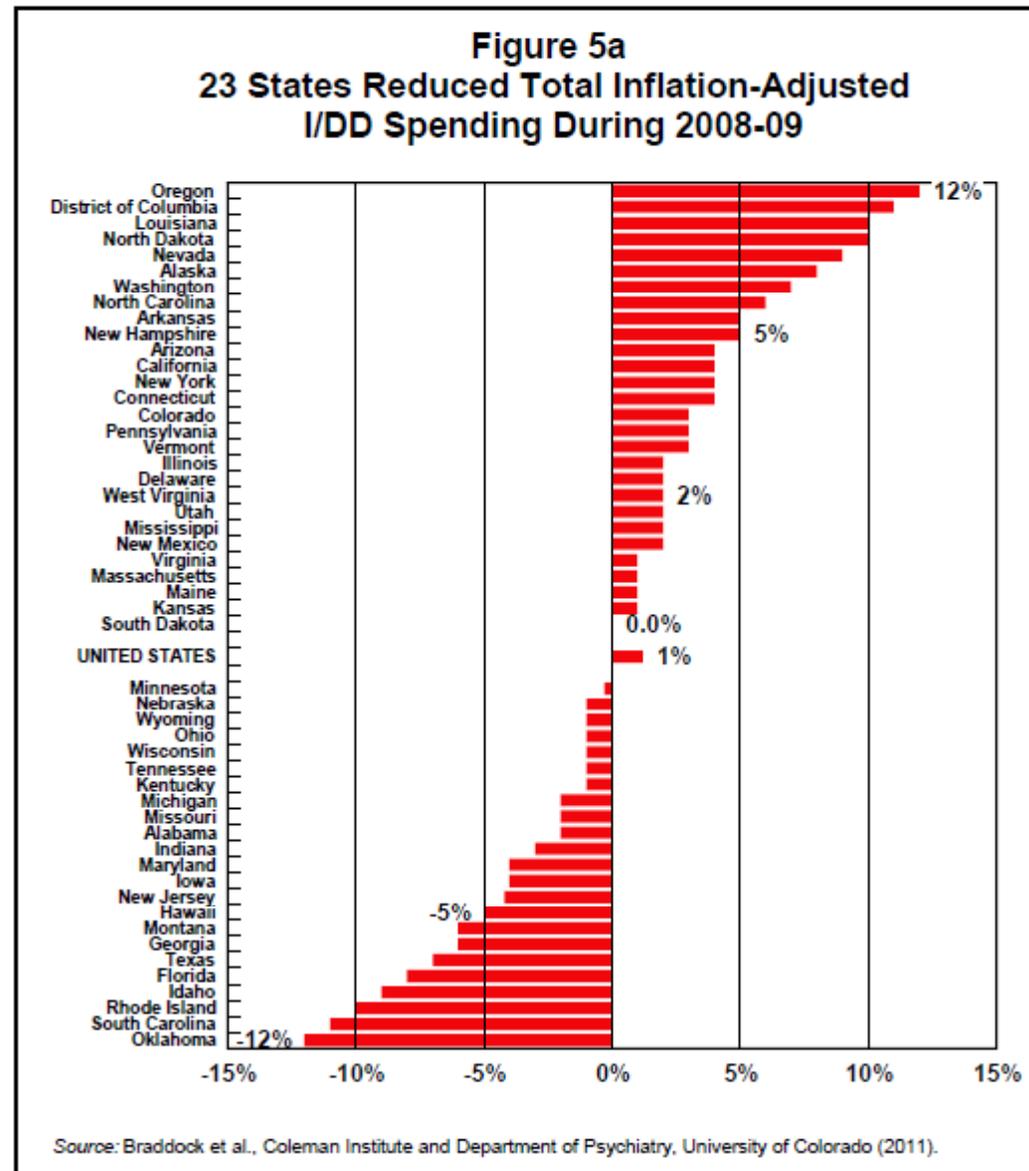


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Impact on State DD Systems and People

David Braddock
State of the States 2011



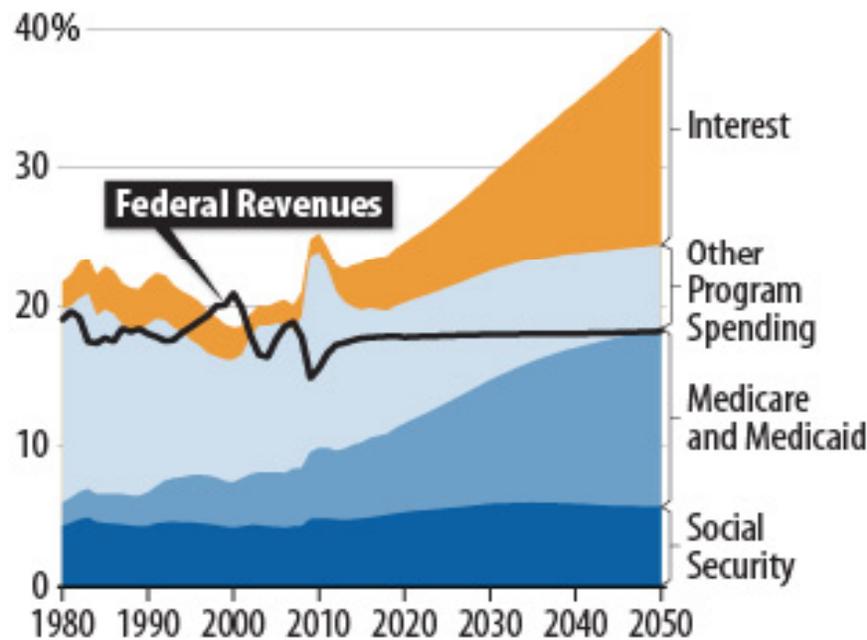
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Problem No. 2

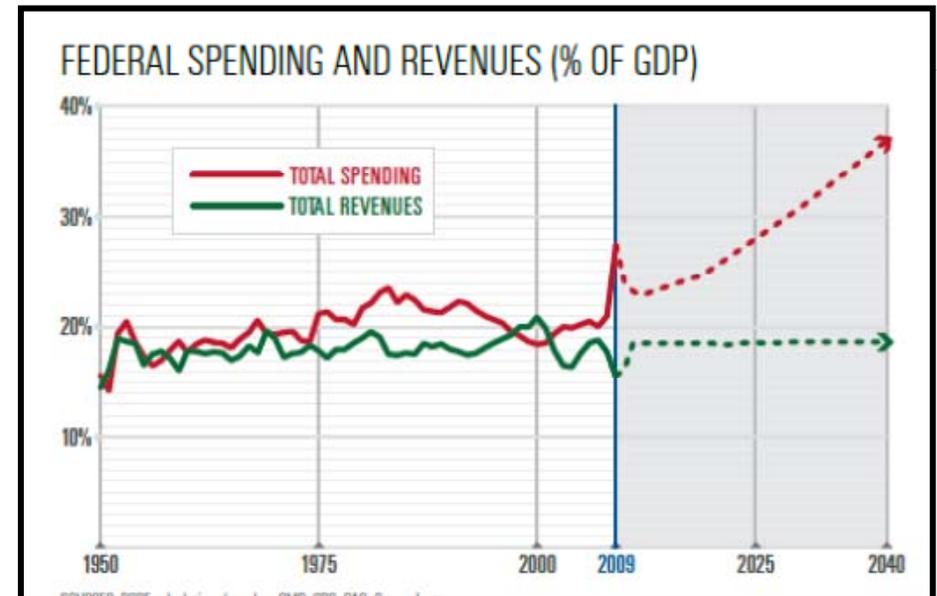
The National Structural Budget Deficit

We are spending more money than we are taking in.



Source: CBPP projections based on CBO data.

[Center on Budget and Policy Priorities | cbpp.org](http://cbpp.org)



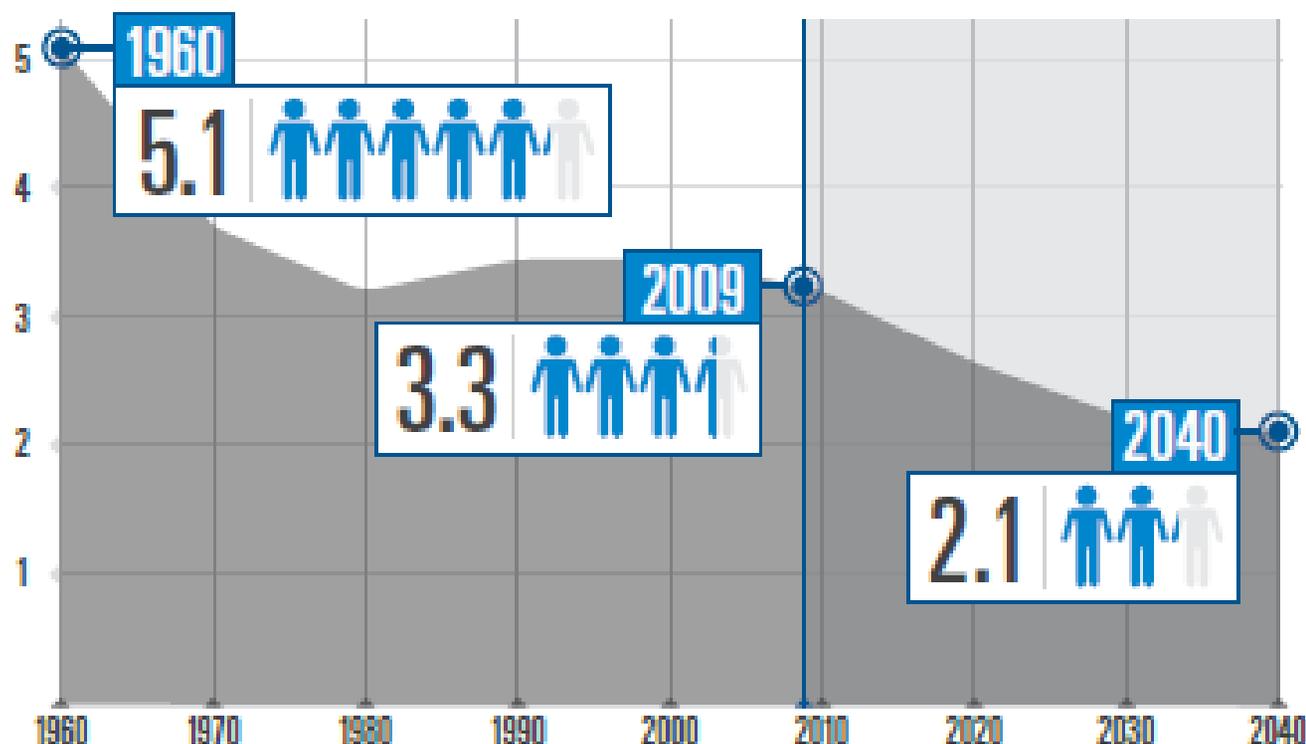
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Problem No. 3

Demographic Shift- Aging Baby Boomers

COVERED WORKERS PER SOCIAL SECURITY BENEFICIARY

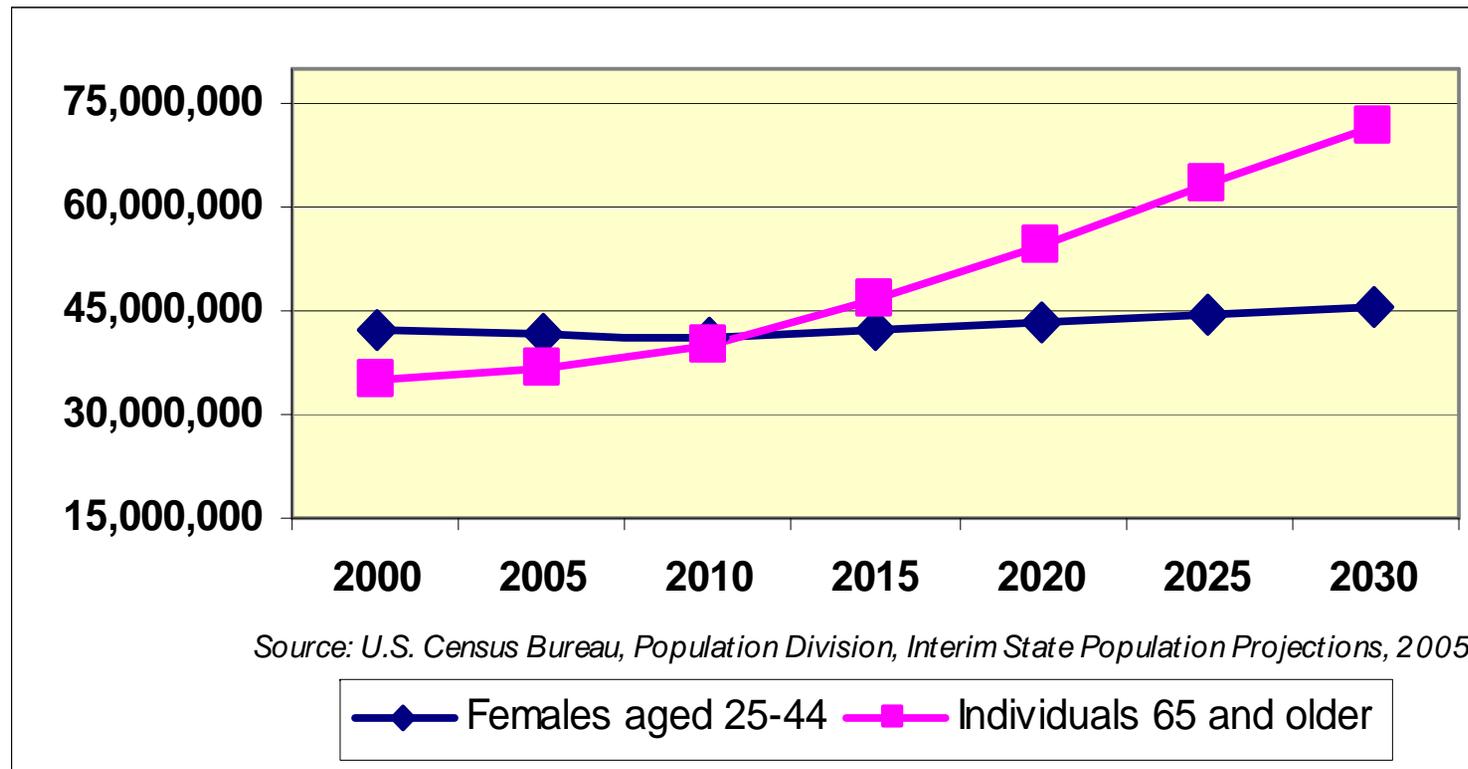


SOURCE: Social Security Administration

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Demographic Shift - Not Enough Workers to Take Care of the Baby Boomers



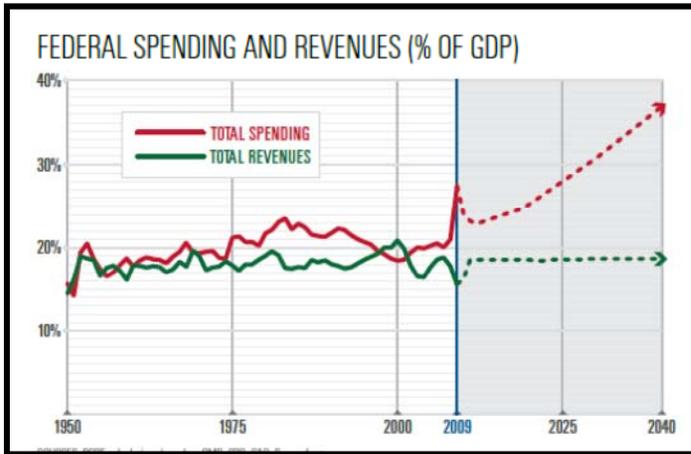
Larson, Edelstein, 2006

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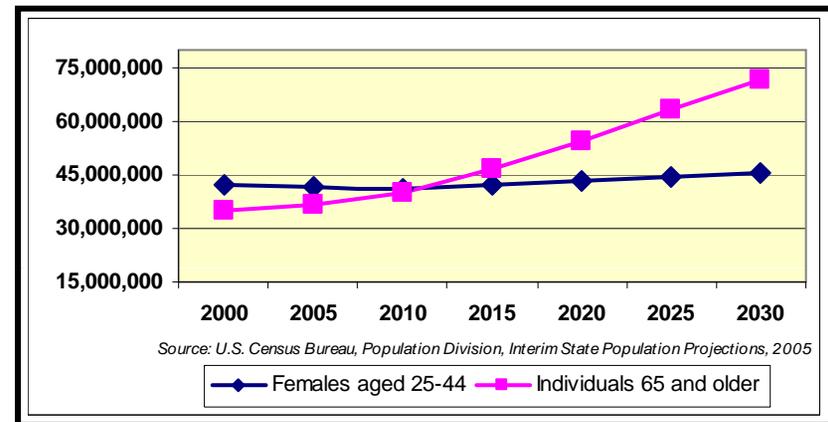
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Confronting Reality

Public funding growth will slow



Workforce will not keep pace with demand



Persons Waiting- Under reported	Residential Services Recipients	Growth Needed
122,870(Lakin) 240,000 (Kaiser)	439,515	28%

We have waiting lists

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WHAT STATES ARE DOING

Increasing Focus on Sustainability of the System

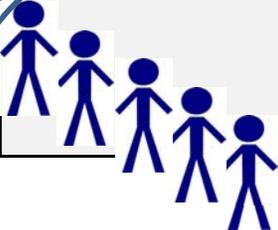
- What can we and future generations afford?
- What can we justify based on:
 - Relative costs of various options?
 - Resources spent in comparison with others in need?
 - Outcomes achieved for resources spent?

Source: Lakin U. of Minn.

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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)

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Thinking for the Long Term

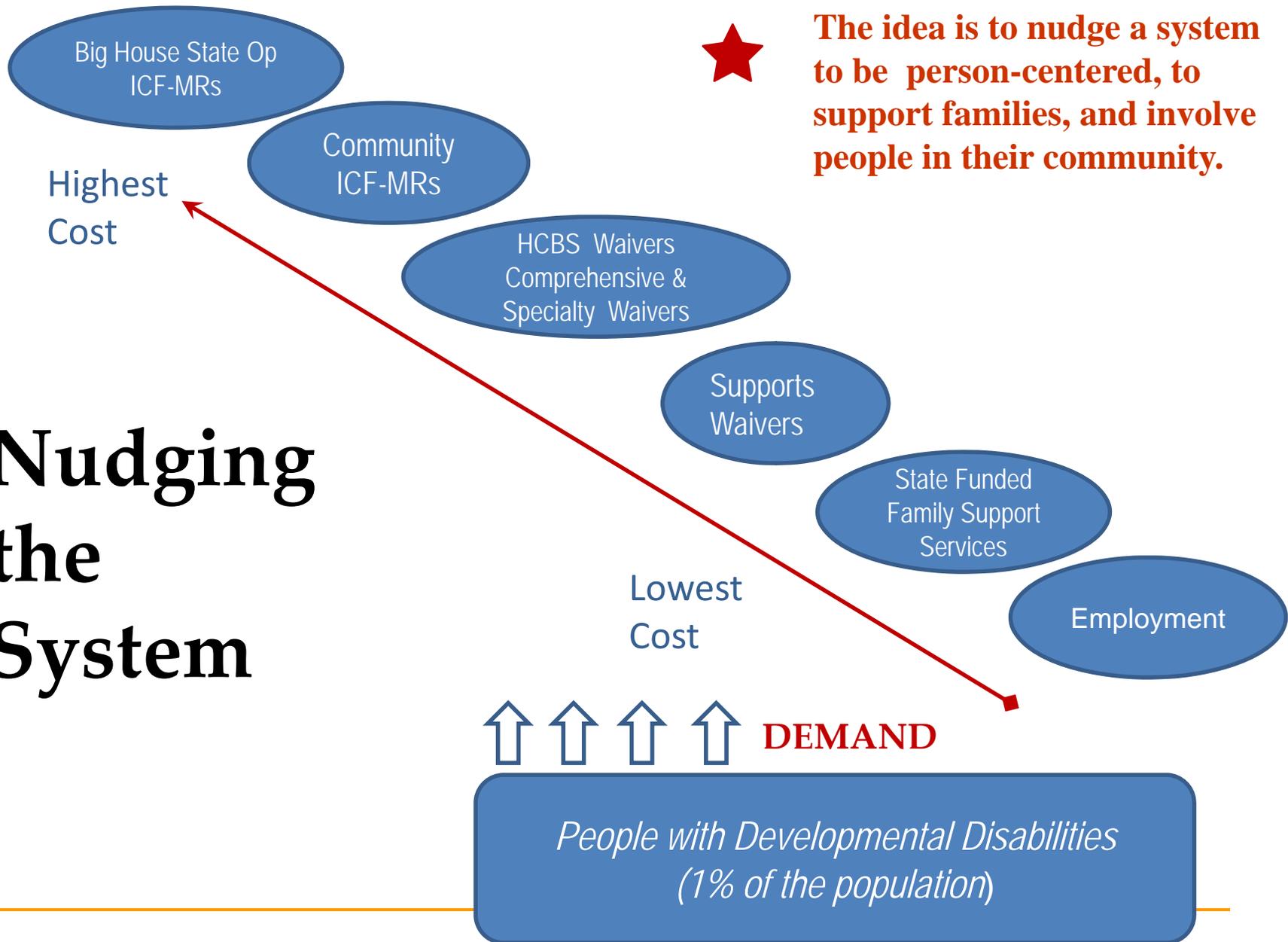
Type of Service	Cost per Person	20 yrs. Cost
ICF/MR Institution	\$128,275	\$2,565,600
HCBS 24hr staffed Residential	\$70,133	\$1,402,660
Shared Living (Adult Foster Care)	\$44,122	\$882,440
Supports in Own or Family Home	\$25,072	\$502,440

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

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Nudging the System



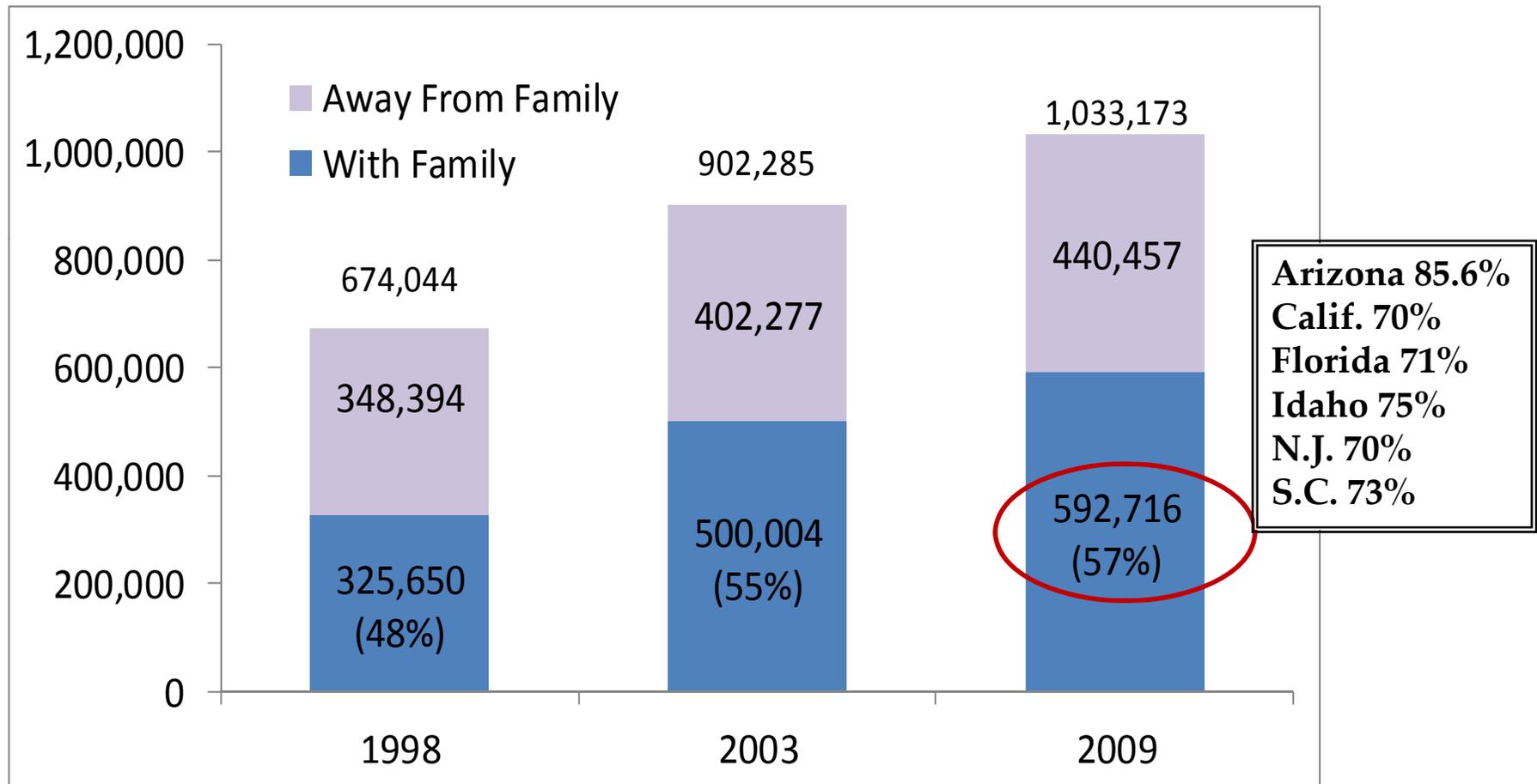
Conclusion

**Sustainability
depends on how
good we are at
supporting families
and getting people
jobs.**

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More and More, Families are Becoming the Primary Support



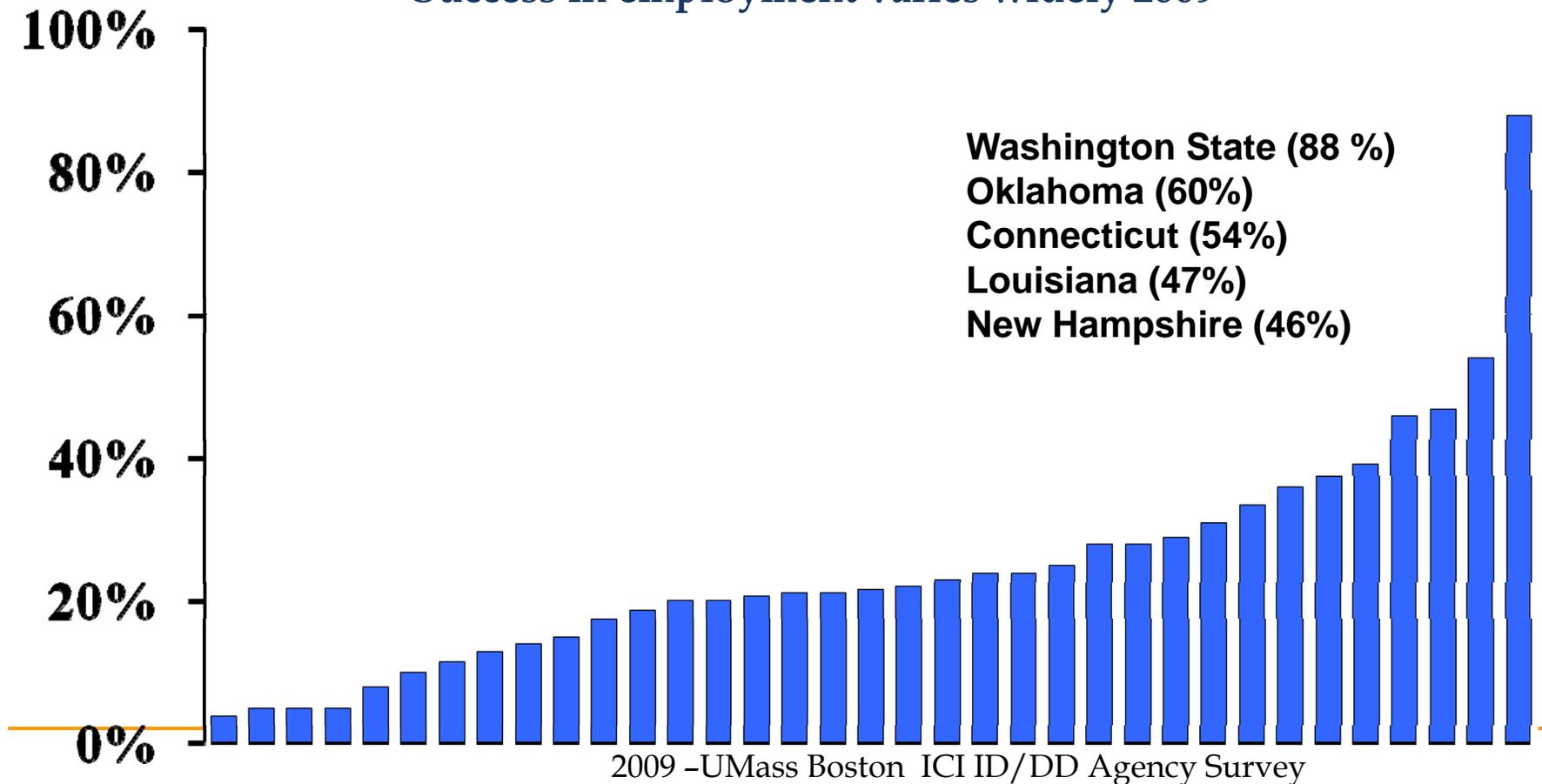
Charlie Lakin UMinn RTC on Community Living/ICI

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States are Focusing on Employment

Success in employment varies widely 2009



States are Promoting Employment

- **Adopting Employment First Policies**
- **Changing reimbursement systems**
- **Strengthening training programs**
- **Collaborating with other state employment programs**
- **Using data to measure performance**
- **Making room for innovation**

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Benefits of Employment

- ✓ **Get out of poverty**
 - ✓ **More independence**
 - ✓ **Make Friends**
 - ✓ **Make a contribution to the community**
 - ✓ **Positive image and valued role within the family and community**
 - ✓ **Opportunities for learning and expanding relationships**
-

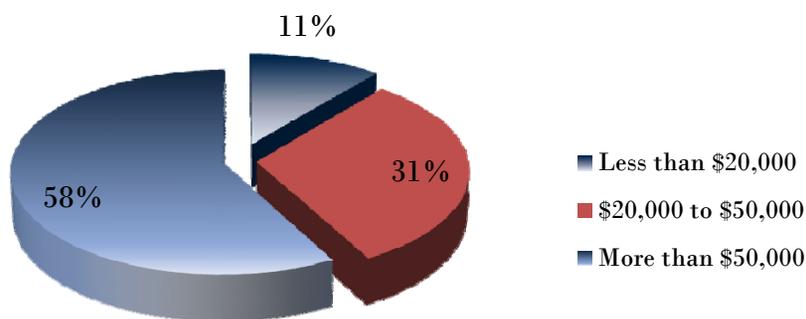
WHAT WE KNOW ABOUT INDIVIDUALS AND THEIR FAMILIES

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Total Household Income is Low

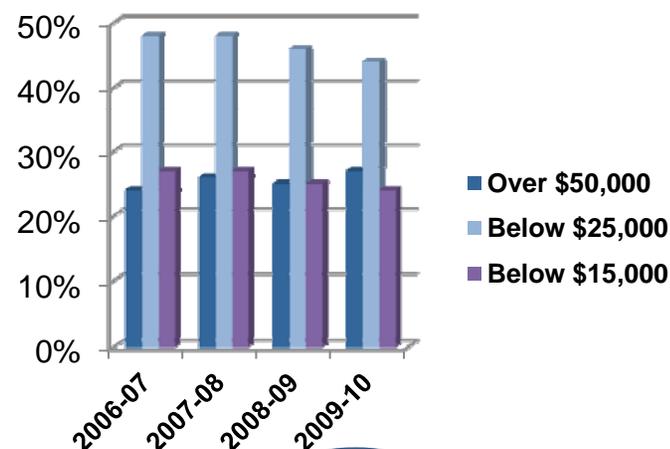
Household Income FAST



42% Annual Income less than \$50,000

FAST – PACER’s National Family Advocacy and Support Training Project

Household Income NCI



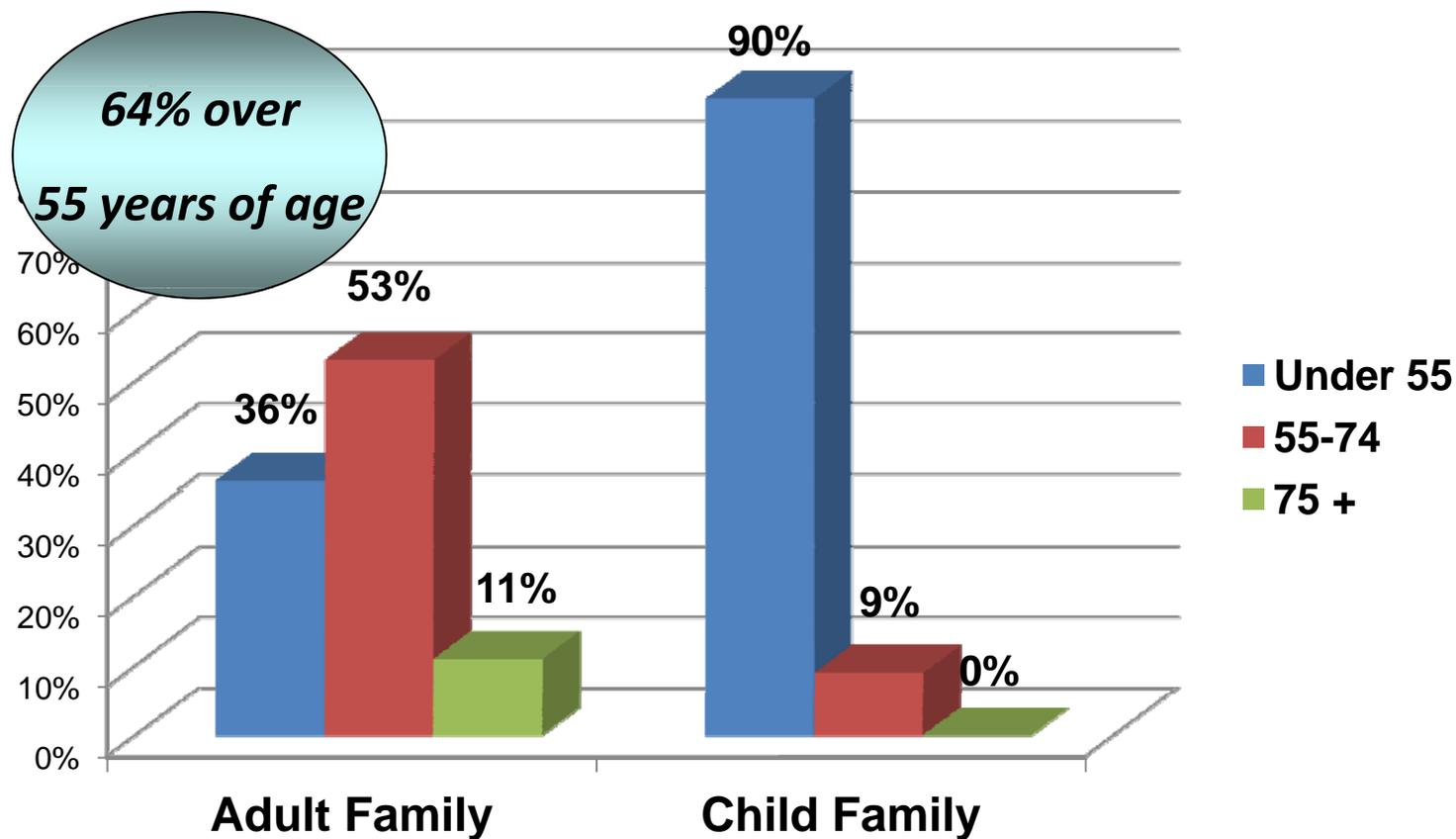
44% below \$25,000

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National Core Indicators**

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Family Caregivers are Aging



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Families Want to Know....

- **Access to information rated by over 50% of all families as very important**
- **Information needs**
 - **Helping person build lasting friendships (85%)**
 - **Advocating for person's rights (85%)**
 - **Developing skills for living alone (85%)**
 - **Obtaining medical care and health insurance (85%)**
 - **Preparing the person for work (85%)**

FAST Survey

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Summary: What We Know About Families

- ❖ Income is generally low in a large percentage of households
- ❖ Family caregivers of adults are 55 or older and getting older
- ❖ Families are thinking about the future
- ❖ Families want information
- ❖ Families need services they can rely on

WHAT SHOULD WE BE DOING FOR INDIVIDUALS AND THE FAMILIES THAT SUPPORT THEM?



Sustainability depends on
how well we support
families and get people
jobs

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Objective of Providing Support to Families

To support families, with all their complexity and diversity, in ways that maximizes their capacity, strengths and unique abilities **so they can best support, nurture, love and facilitate the achievement of self-determination, interdependence, productivity, integration and inclusion in all facets of community life for their family members.**

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About Families

- ❖ **Families are made up of parents; siblings; grandparents; aunts & uncles, cousins, other relatives.**
- ❖ **Families are complicated. They.....**
 - ❖ Help each other; they sacrifice for one other;
 - ❖ Hurt each other; they apologize and forgive;
 - ❖ Have fun and celebrate with each other
 - ❖ Have routines, customs and habits – they have their way of doing things
 - ❖ Have secrets and things they don't talk about
 - ❖ Have troubles, get tired and discouraged and then do the impossible
 - ❖ Commit abuse and take advantage of other families members
 - ❖ Are resourceful but they need some help
- ❖ **The family is the context for everything; personal outcomes will be influenced by the family**

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Charting a New Way to Think About Supporting Families

What we've been doing	How we need to change
Defining caregiver as the parent	Family is defined functionally; inclusive of siblings, parents , grandparents and other relatives
Tension between self-advocacy and family support	Family support enhances opportunities for self-advocacy and self-determination
Crisis intervention	Preventative, long-term planning
Supporting caregivers in order to decrease demand on long-term services	Create a quality of life for person with ID/DD and their family

Adapted from work by Michelle "Shelli" Reynolds, PhD
Director of Individual Advocacy and Family Support
University of Missouri- Kansas City, Institute for Human Development
University Center on Developmental Disabilities

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A New Way to Think About Supporting People and the Families They Live With

Instrumental Supports: *Day-to-Day Needs*

- **Person/family- centered planning**
- **Service Coordination**
- Habilitation/companion
- Personal assistance
- **Employment services**
- Respite
- Adaptive equipment
- **Home modifications**
- **Assistive Technology**
- Cash Subsidies
- Paying family caregivers
- **Financial planning/trusts**
- Health and wellness promotion

Emotional Supports: *Mental Health and Self-efficacy*

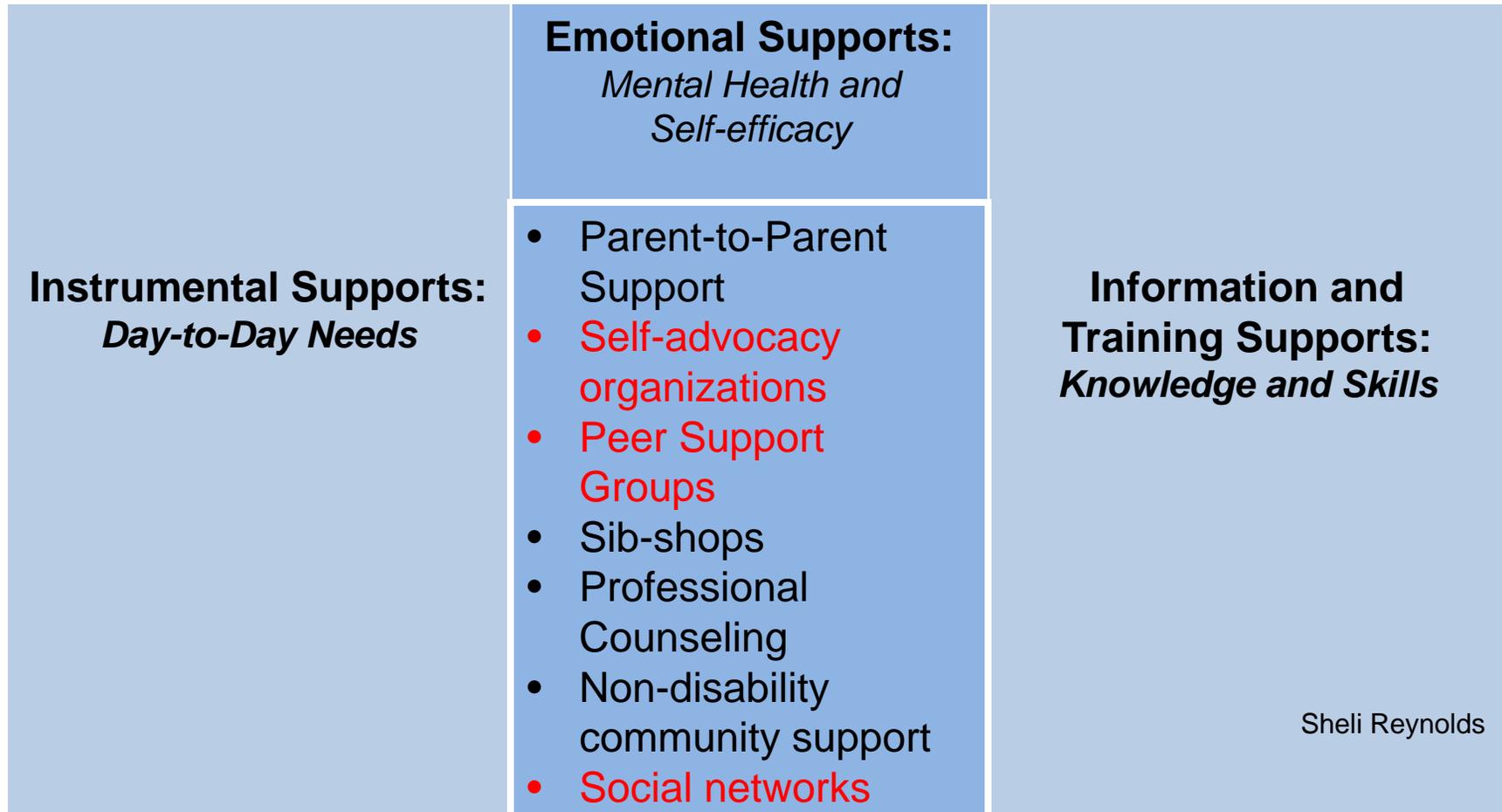
Information and Training Supports: *Knowledge and Skills*

Sheli Reynolds

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A New Way to Think About Supporting People and the Families They Live With



Sheli Reynolds

A New Way to Think about Supporting People and the Families They Live With

Instrumental Supports: <i>Day-to-Day Needs</i>	Emotional Supports: <i>Mental Health and Self-efficacy</i>	Information and Training Supports: <i>Knowledge and Skills</i> <ul style="list-style-type: none">• Information on disability• Information on benefits related to employment• Information @ generic supports• Knowledge @ best practices and values• Skills to navigate & access services• Ability to advocate for services & policy change• Technology trainer, guide and trouble shooter
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Sheli Reynolds

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Rethinking Supports to Individuals Families

- ❖ **Supporting individuals and the families they live with is not a program, it's our core mission**
- ❖ **Think about families broadly – grandparents, aunts, uncles, siblings, cousins and people who “are like family”**
- ❖ **The purpose of services is to benefit their family member**
- ❖ **More direct control by Individuals and families**
- ❖ **Pay family caregivers**
- ❖ **Services are important, information and training are critical, emotional supports holds things together**

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What is in the New Service Paradigm?

- ❖ **Support coordination – small ratios; training in family dynamics; conflict resolution; knowledge about employment; strong supervision**
- ❖ **Adapting Person-Centered Planning to Family-Centered Planning**
- ❖ **Customized services and new services: e.g. “family helpers; technology guides; home adapters**
- ❖ **Employment services and alternatives when people aren’t working**
- ❖ **Support Self Advocacy and Family Support Network infrastructure**

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What is in the New Service Paradigm?

- ❖ **Consumer direction; individual budgets**
- ❖ **Pay family care givers and peer supports**
- ❖ **24 hour help line/reliable crisis intervention as part of infrastructure**
 - ❖ Reduce service utilization
 - ❖ Protect people from abuse and neglect
 - ❖ Reduce caregiver burnout
- ❖ **Monitor health and wellness and assist with health care**
- ❖ **Family financial planning and succession planning for relative care giving**

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Questions

- **Does everyone has to live with their family to have a sustainable system?**

No. It means we have to maximize the extent to which as many people as possible can be supported without 24 paid supports.

Family

Extended Family

Friends

Shared Living

Independently or with a friend

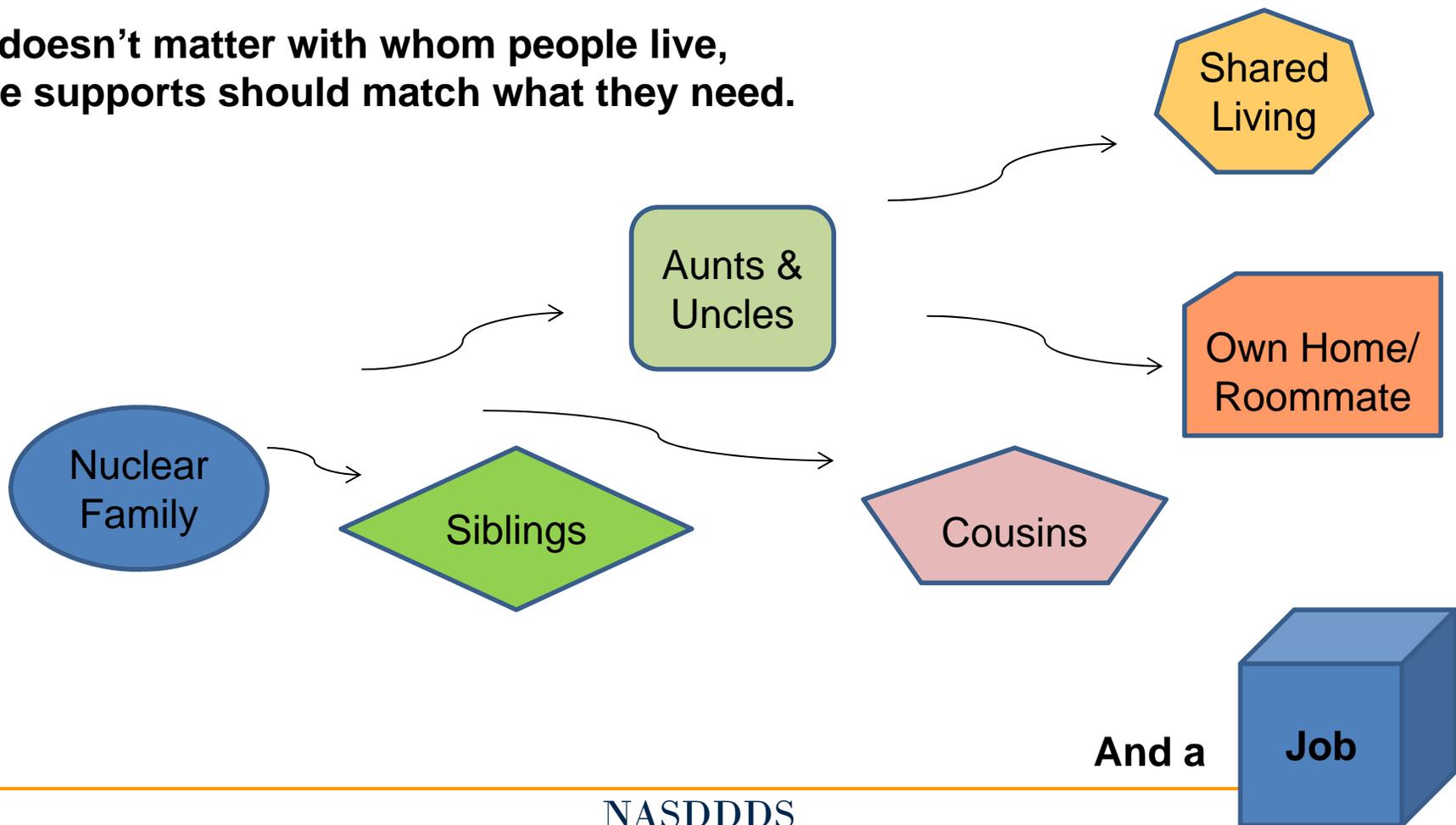
Etc.

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Supporting Individuals and the People They Live With

It doesn't matter with whom people live, the supports should match what they need.



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The Question is...

Not whether people who are disabled (and older) will be living with and relying on their families for support but

whether people and their families will struggle alone or have a great life because the supports are there for them and they are part of their community.

Nancy Thaler
Executive Director
National Association of State Directors of Developmental Disabilities Services
113 Oronoco Street
Alexandria, VA 22314
703-683-4202
nthaler@nasdds.org

